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Family-centred services for children affected by HIV and AIDS

Guest Editor: Linda Richter
Supplement Editors: Susan Kippax and Shirin Heidari

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EDITORIAL

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Visioning services for children affected by HIV and AIDS through a family lens

Linda Richter[1], Chris Beyrer[2], Susan Kippax[3] and Shirin Heidari*[4]

Abstract

The HIV epidemic continues to place a great burden on children, from loss of parents and income to severe disruptions of their homes and families. Underpinned by the understanding that a healthy family constitutes the foundation for a child's wellbeing, the importance of family-centred care and services for children is increasingly recognized. It is not enough to merely provide antiretrovirals: it is of pivotal importance that treatment and care for children are integrated into the broader context of family-support schemes. However, despite growing evidence of the benefits of family-centred services, reforms in favour of family-oriented HIV interventions have been slow to emerge. Treatment, prevention and care interventions often target individuals, and not families and communities.

For the first time, this supplement to the *Journal of the International AIDS Society* brings together in one place the rationale for family-centred services for children affected by HIV and AIDS and some of the available evidence for the effectiveness of doing so. We hope this constitutes a beginning of what could be a groundswell of interest in family-centred services for children affected by HIV and AIDS.

Children have borne a significant burden throughout the course of the HIV epidemic. Countless children have been infected with the virus as a result of failure in rollout of interventions that prevent vertical transmission. Globally, two million children under the age of 15 are estimated to be living with HIV [1].

In 2008, the coverage of prevention of mother to child transmission (PMTCT) programmes was around 45% in low- and middle-income countries, despite the relative ease and remarkable cost effectiveness of proven interventions to prevent this mode of transmission. Progress has been made in sub-Saharan Africa, with an average PMTCT coverage of 58%. However, in some regions of the world, especially in north Africa and in the Middle East, coverage is still sometimes less than 1% [1].

In addition, a small but noteworthy proportion of children are infected due to contaminated blood products and unsafe medical practices, an overlooked tragedy that is entirely preventable. The largest such outbreak was reported in Central China's Henan region and neighbouring provinces in the 1990s, where large-scale blood collection enterprises in these provinces cut corners, re-used collection equipment and generated a unique epidemic among adult donors. The children of this iatrogenic epidemic were affected by losing parents, and many perinatally infected infants were born as a secondary effect of this tragedy [2].

More recent HIV outbreaks due to iatrogenic transmission were reported in the central Asian states of Kazakhstan and Uzbekistan in 2006 and 2007. Due to official denial by the government, little is known about the Uzbek outbreak, although it is probably similar to the situation in Kazakhstan. The outbreaks were caused by the use of non-sterile medical equipment and unsafe blood in a corrupt scheme in which parents were persuaded to accept unnecessary blood transfusions for their children. In Kazakhstan, 119 children were confirmed to have been infected with HIV, of whom at least 10 had died by 2007 [3, 4].

Millions of children are additionally affected as AIDS erodes the families and communities in which they live. More than 15 million children have lost one or both parents to the disease. Consequently, children suffer the effects of increased poverty, family disruption, interrupted or prematurely terminated education, and additional work, including becoming caregivers. As AIDS continues to affect families, an increasing number of youth-headed households are emerging, with young people assuming the role of breadwinners for their younger siblings [1].

Further, children have to cope with the psychosocial distress caused not only by the presence of serious illnesses affecting family members, but also by

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*Correspondence: shirin.heidari@iasociety.org
[4]International AIDS Society, Geneva, Switzerland
Full list of author information is available at the end of the article

discrimination and social exclusion that often accompanies HIV and AIDS [5]. Existing community support mechanisms are eroded by stigmatization of HIV and AIDS and chronic dependency. Exhaustion of financial, social and emotional resources ultimately drives families into poverty and isolation, further exacerbating the health outcomes of family members [6].

Today, there is no question of the urgent need to prevent paediatric HIV and provide treatment to children. However, mere provision of antiretrovirals will not be sufficient; it is of pivotal importance that treatment and care for children are integrated into the broader context of family-support schemes.

The concept of family-centred care and services for children has been increasingly recognized and adopted with regard to other paediatric illnesses, in particular in high-income countries [7]. This philosophy is based on the understanding that a healthy family constitutes the foundation for a child's wellbeing. There is clear evidence showing that children's health outcomes are strongly dependent on those of their parents, caregivers and families. For example, studies show that maternal death and maternal HIV infection increase the risk of child death [8, 9].

Despite growing evidence of the benefits of family-centred services, reforms in favour of family-oriented HIV interventions have been slow to emerge. The field frequently adopts an individualistic, person-oriented framework, and treatment, prevention and care interventions often target individuals, rather than families and communities [10]. However, we now recognize that infections of individuals ultimately impact the structure of families and society, and that the loss of income of an HIV-infected parent, the burden of healthcare expenses, and the psychosocial stress associated with this disease transcends individuals.

Families, defined in an inclusive way, can and should play a central role in delivery of treatment, prevention and care for children, and family members should be involved in the decision making for any health-related intervention. This approach will be critical to meet the challenges of a growing epidemic, including among the most marginalized groups, many of whom have children.

Investing in programmes that target the entire family will undoubtedly have long-term benefits for our response to HIV. Families are the primary sources of behavioural patterns, and interventions involving the entire family may positively influence risk reduction and health-seeking behaviours, and may help to overcome disparities in access to treatment and healthcare observed between men and women [11,12].

Although progress in expanding access to treatment and support appears moderate, indications of change induce optimism: during recent years, donors have increasingly recognized the need for programmes that specifically target families. PMTCT-plus models have been developed to provide comprehensive care and treatment to HIV-infected, pregnant women and members of their families. Increasing numbers of home-based HIV counselling and testing and treatment programmes are being implemented and gaining ground [13,14].

The international community now needs to reshape its thinking and construct targeted approaches that build on the strengths of families and provide support in a framework for the benefit of the entire family.

The *Journal of the International AIDS Society* is pleased to launch this special issue, which we hope constitutes a beginning of what could be a groundswell of interest in family-centred services for children affected by HIV and AIDS. This is the first time that the rationale for family-centred services for children affected by HIV and AIDS and some of the available evidence for its effectiveness has been brought together in one place.

The articles in this issue have been solicited from the initiative, The Road to Vienna, led by the Coalition on Children Affected by AIDS (CCABA). This initiative, which brings together a number of foundations and other partners committed to the wellbeing of children, is striving to accelerate the generation of evidence on the feasibility and effectiveness of family-oriented programmes for children affected by HIV and AIDS, and to promote the implementation of sustainable and effective interventions.

This special issue of nine articles explores the various elements and dimensions of families affected by HIV and AIDS within a variety of contexts.

Beginning with an opening piece by Linda Richter, readers are introduced to the field of family-centred services. Richter presents historical highlights on emergence of this thinking, and provides a definition of the family in the context of the delivery of health services by offering an insight into the complex reality of children affected by HIV and AIDS.

Betancourt *et al* go on to review the evidence for family-centred models for prevention of vertical transmission, exploring the existing evidence and identifying areas for further research.

In a systematic review, Leeper *et al* present an analysis of the impact of family-centred HIV treatment models on children's health outcomes.

Men as fathers, oft-invisible elements of families, are addressed in two papers. Sherr explores the existing literature, covering a broad range of dimensions of HIV in relation to men, their sexuality, their desire for fatherhood and their paternal roles. In their complementary paper, Hosegood and Madhavan closely investigate how men can be successfully included in programmes for women and children in sub-Saharan Africa.

Exemplary cases from Ukraine, Zambia and India are presented in two articles by Beard *et al* and Solomon *et al.* These articles describes the role of families and implications for children of marginalized populations, such as drug users, female sex workers, and married men who have sex with men and women.

HIV interventions for youth, yet another area suffering from lack of exposure, is the focus of a review by Bhana *et al*. Describing the Collaborative HIV Prevention and Adolescent Mental Health Project, the authors present a model for meeting the needs of pre-adolescents and early adolescents in poverty-affected settings.

Lastly, Tomlinson provides us with a different angle, and examines research from the field of depression to draw lessons for family-centred approaches to children affected by HIV and AIDS.

By publishing this special issue, we hope to make an important contribution to the discourse targeting the broader public including community members, policy makers and academics. Readers have the opportunity to comment on individual articles by scrolling to the end of the article on the website. We would like to invite and encourage readers to contemplate the diverse aspects of this area and to engage with the editors and the authors in dialogue on this important and timely issue.

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Author details
[1]Child Youth Family & Social Development (CYFSD), Human Sciences Research Council, Durban, South Africa. [2]Department of Epidemiology, Bloomberg School of Public Health, The Johns Hopkins University, Baltimore, USA. [3]Social Policy Research Centre, University of New South Wales, Sydney, Australia. [4]International AIDS Society, Geneva, Switzerland.

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INTRODUCTION Open Access

An introduction to family-centred services for children affected by HIV and AIDS

Linda Richter*

Abstract

Family-centred services in the context of HIV/AIDS acknowledge a broad view of a "family system" and ideally include comprehensive treatment and care, community agencies and coordinated case management. The importance of family-centred care for children affected by HIV/AIDS has been recognized for some time. There is a clear confluence of changing social realities and the needs of children in families affected by HIV and AIDS, but a change of paradigm in rendering services to children through families, in both high-prevalence and concentrated epidemic settings, has been slow to emerge.

Despite a wide variety of model approaches, interventions, whether medical or psychosocial, still tend to target individuals rather than families. It has become clear that an individualistic approach to children affected by HIV and AIDS leads to confusion and misdirection of the global, national and local response. The almost exclusive focus on orphans, defined initially as a child who had lost one or both parents to AIDS, has occluded appreciation of the broader impact on children exposed to risk in other ways and the impact of the epidemic on families, communities and services for children. In addition, it led to narrowly focused, small-scale social welfare and case management approaches with little impact on government action, global and national policy, integration with health and education interventions, and increased funding.

National social protection programmes that strengthen families are now established in several countries hard hit by AIDS, and large-scale pilots are underway in others. These efforts are supported by international and national development agencies, increasingly by governments and, more recently, by UNAIDS and the global AIDS community.

There is no doubt that this is the beginning of a road and that there is still a long way to go, including basic research on families, family interventions, and effectiveness and costs of family-centred approaches. It is also clear that many of the institutions that are intended to serve families sometimes fail and frequently even combat non-traditional families.

The idea that health and social services for children should be family centred is not new, but it has yet to take hold in the area of greatest need for millions of children worldwide – those affected by HIV and AIDS and related risk factors, whether these be poverty and migration or injecting drug use.

Family-centred services for children, rooted in the consumer-led movements of the 1960s, emerged towards the end of the twentieth century, initially in the fields of paediatric and geriatric care. For example, research on the adverse effects of separating young children from their caregivers led to policies that welcomed family members to be with their children during hospitalization and to participate in their children's care, especially if the clinical regime depended on continued active engagement of the family in the children's treatment and rehabilitation. As awareness of the embeddedness of the wellbeing of all individuals in social relationships and networks grew, family-centred services began to be accepted as a model for intervention [1].

Advocates of family-centred services for children point out that the family is the basic unit of care for children, with primary responsibility for the delivery of services to children and the greatest influence on a child's health and wellbeing prior to, during and subsequent to interventions by health and social welfare professionals. These convictions have driven fundamental changes in health legislation and practice in both the United States and

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*Correspondence: lrichter@hsrc.ac.za
Child, Youth, Family and Social Development, Human Sciences Research Council, South Africa

elsewhere, according rights to families to be fully involved in the health and wellbeing of children [1,2].

The core concepts of family-centred care for children were first formally articulated in 1987 [3]. While more a philosophy than a set of prescribed practices, the most important concepts have been that:

1. Families are constant in the lives of children (and adults) while interventions through programmes and services are intermittent and generally short lived.
2. Families must be variously and inclusively defined.
3. Family-centred approaches are comprehensive and integrated.
4. Love and care within families, when recognized and reinforced, promote improved coping and wellness among children and adults.

Initial resistance by health professionals to the involvement of families in treatment were countered by evidence that revealed few, if any, ill effects of involving families, even in intensive care environments [4], as well as the many benefits of family participation. These include support for improved adherence, sensitive monitoring of changes in patient state, and extension of treatment and other services beyond the health facility [1,5].

Extensive experience of family-centred services has been gained, amongst others, in the care of children with chronic conditions [6], disabilities [7], child welfare [8], neonatology [9], and early interventions to promote the development of young children at risk [10].

Family-centred services and children affected by HIV and AIDS

The importance of family-centred care for children affected by HIV/AIDS has long been recognized in the United States [1,11-15]. Twenty years ago, Carol Levine observed, “AIDS threatens the intimacy and acceptance that ideally undergird family relationships, while at the same time making them all the more powerful and necessary” [16]. Family-centred services in the context of HIV/AIDS acknowledge a broad view of a “family system” and ideally include comprehensive medical treatment, community agencies and coordinated case management [17].

Levine [16] speaks of family members as “individuals who by birth, adoption, marriage, or declared commitment share deep, personal connections and are mutually entitled to receive and obligated to provide support of various kinds to the extent possible, especially in times of need”. The Task Force on AIDS and the Family concluded, “Families should be broadly defined to include, besides the traditional biological relationships, those committed relationships between individuals which fulfil the function of family” [18]. And, in 1994, the Global Programme on AIDS marked World AIDS Day under the banner, “AIDS and the Family”.

The World AIDS Day Newsletter [19] pointed out that “any group of people linked by feelings of trust, mutual support and common destiny may be seen as a family. The concept need not be limited to ties of blood, marriage, sexual partnership or adoption. In this light, religious congregations, workers’ associations, support groups of people with HIV/AIDS, gangs of street children, circles of drug injectors, collectives of sex workers … may all be regarded as families”.

Such definitions both respect traditional notions of family, as well as recognizing non-traditional forms of commitment arising from changes in reproductive biology, laws governing interpersonal obligations, acceptance of same-sex relationships, and deep association based on shared experience. In this sense, AIDS is a catalyst in expanding definitions of “family” to reflect the reality of contemporary life. More and more people live in non-traditional families, or “families of choice” [20], made up of some traditional family members, partners and friends [21].

There is a clear confluence of changing social realities and the needs of children in families affected by HIV and AIDS, but a change of paradigm in rendering services to children through families, in both high-prevalence and concentrated epidemic settings, has been slow to emerge. Rotheram *et al* [15] argue that the history of HIV, particularly in the United States, led to an individualistic focus that is proving hard to shift [22]. Despite a wide variety of model approaches, interventions, whether medical or psychosocial, tend to target individuals, not families [23-25].

Yet, when an individual is affected by HIV/AIDS, their family is inevitably affected [26,27]. Risk for infection is shared, as is apprehension about disclosure, stigmatization, ill-health and suffering, the costs and burdens of treatment, loss of income, and need for care and support. AIDS throws families into crisis, causing anxiety and stress wherever it occurs [28,29]. The full impact of HIV and AIDS, including its social and economic effects, is only appreciated when the family, and not only the individual, is the unit of analysis [30].

Children affected by HIV and AIDS

Early into the new millennium, it became clear that an individualistic approach to children affected by HIV and AIDS was leading to confusion, and misdirecting, rather than amplifying, the global, national and local response [31]. There was an almost exclusive focus on orphans, defined initially as a child who had lost one or both parents to AIDS, to draw attention to the large number of children being made vulnerable by AIDS [32]. But this definition, with its focus on parental death, occluded appreciation of the broader impact on children exposed to risk in other ways and the impact of the epidemic on families, communities and services for children [33]. In addition, it led to narrowly focused, small-scale social welfare and case management approaches with little impact on government action, global and national policy, integration with health and education interventions, and increased funding.

It was under these conditions that the Joint Learning Initiative on Children and AIDS (JLICA) was launched in 2006. The JLICA was modelled on the Joint Learning Initiative on Human Resources for Health [34], as an independent, collaborative, cross-sectoral and multidisciplinary initiative with a finite goal [35]. The aim of the JLICA was to gather evidence, including about best practices, stimulate innovative thinking, and facilitate communication across disciplines and stakeholders in order to generate a set of high-level recommendations for the global community, governments, and international and local organizations. JLICA organized its work under four learning groups directed at topics suggested by the widely endorsed Framework for the Protection, Care and Support of Orphans and Vulnerable Children Living in a World with HIV and AIDS [36]: Strengthening Families; Community Action; Expanding Services and Protecting Human Rights; and Social and Economic Policies.

Spanning two years, the learning groups worked in a wide variety of ways, including by commissioning papers and through meetings, live and electronic debates, and a learning collaborative. The JLICA's final report was hailed as setting a new agenda for children [37], calling attention to the importance of families and family strengthening through family-centred services, economic assistance and social protection, and community support. Apart from reports generated by JLICA (http://www.jlica.org), these arguments are set out in detail in Richter [38], Richter and Sherr [39], and Richter *et al* [40].

The death of a parent is an unspeakable loss for any child, an experience exacerbated by illness and suffering, potential loss of economic support, dislocation and separation from siblings. Adult deaths from AIDS continue to increase in the absence of antiretroviral treatment. But to focus only on orphans is to miss the bigger picture: 88% of so-called "orphaned" children have a surviving parent [38], and more than 90% of "orphans" live with close family [41,42]. Families were the first to respond to children affected by AIDS, both in the USA and in southern Africa [43,44], and have continued to be the vanguard of care and support for affected children.

Despite this, pitifully few resources and services are directed at bolstering and protecting this front line. Fewer than 15% of families caring for orphans and vulnerable children in 2007 were estimated to have received any assistance from external agencies [45]. It has taken equally long to recognize the role that communities play and the importance of strengthening these systems of care [46].

Surviving parents and families who take in children of relatives experience the stresses of increased dependency and, across the world, become poorer [47,48]. The death of working-age adults means the loss of jobs, livelihoods and skills, and additional care exacts heavy costs. The poorest families respond by cutting consumption: eating less and spending less on education and healthcare for other members of the family. All this critically affects the wellbeing of children [41,49].

The assumption that families are collapsing has led to a burgeoning of orphanages and other forms of institutional care drawing resources, even those intended to assist children affected by AIDS, away from families into expensive alternatives with known adverse effects on children's health and development [50]. While there is no question that families are under considerable strain, families are intimate social networks evolved for human care. As such, they continue to form, adapt and reconfigure, both throughout the family lifecycle and in response to external stressors [51,52]. Belsey [53] attests that it is the loss of family capital, in terms of resources, networks and reserves, that mediates the impact of HIV and AIDS on children and on the wider society. By his estimates, close to 60% of families in high-prevalence environments are directly affected by AIDS.

At its heart, AIDS can be thought of as a family disease. In high-prevalence environments, transmission occurs mainly in the family, between parents and children [54] and between partners and spouses [55]. Families are also on the front line of prevention [14], providing education and reinforcing risk reduction, especially among young people [56].

Levine [16] argues that the impact of AIDS on families, and the potential of families to be at the forefront of prevention, treatment and care, has not been fully appreciated, partly because people in high-risk groups, such as men who have sex with men, injecting drug users, sex workers, migrants and refugees, are inaccurately assumed to be isolated from family life. In concentrated epidemics, transmission from men who have sex with men (MSM), injecting drug users (IDUs) and sex workers spreads into families through concurrent heterosexual sex and sex with regular partners and spouses, and vertical transmission [57].

Among these extremely marginalized groups, families are also inevitably affected, whether in their roles as parents, spouses, partners, siblings, children or intimate others [58]. Despite the lack of attention to family factors in these populations, many MSM and IDUs are married [59], and most female sex workers have children and regular partners, in addition to clients. Families of these groups have been identified to be important for, among other things, prevention [60,61], disclosure [62,63], support [64], and treatment adherence [65].

The way forward

The JLICA made strong recommendations regarding strengthening families through social protection and income transfers, on the one hand, and family strengthening through family-centred services on the other.

Social protection for families affected by HIV/AIDS is part of a groundswell of provision and demand for increased protection against destitution and improved social security, including for the poorest families in the poorest parts of the world [38,39,49,66]. National programmes are established in several countries hard hit by AIDS, including South Africa, Botswana, Mozambique, Namibia and Lesotho, and large-scale pilots are underway in, among others, Malawi, Zambia and Kenya. These efforts are supported by international and national development agencies, increasingly by governments [66] and, more recently, by UNAIDS and the global AIDS community [67].

The second prong of the response – family strengthening through family-centred services for children affected by HIV and AIDS – has yet to receive similar levels of endorsement and commitment. In response, the Coalition on Children Affected by AIDS (see www.ccaba.org), a network of child-focused foundations advised by researchers and advocates, started The Road to Vienna, an initiative to explore the nature of family-centred services, evidence for their feasibility and effectiveness, barriers to their expansion, and their relevance to especially marginalized populations. The initiative began with a meeting in Nairobi in late September 2009, piggy backed onto the first African Conference on "Promoting Family-Based Care for Children in Africa", organized by the African Network for the Prevention and Protection against Child Abuse and Neglect and its partners. Ten presentations were made on various aspects of family-centred services, including applications to prevention of mother to child transmission, antiretroviral (ARV) treatment for children, early child development services, and depression; five of these presentations appear as papers in this special issue (Bentancourt *et al*, Leeper *et al*, Bhana *et al*, Tomlinson, and Hosegood and Madhavan).

A second meeting was convened in Geneva in February 2010, in partnership with the International AIDS Society, to consider family-centred services for children and families of people in especially marginalized groups (MSM, IDUs, sex workers, and people currently or recently incarcerated). Seven presentations were made, together with a panel discussion, with strong participation from people representing affected groups. Three of these presentations appear as papers in this special issue (Beard *et al*, Solomon *et al*, and Sherr). What became clear from this meeting is the almost complete lack of research in this area, and a strong desire by people in marginalized groups to receive services to support their families and legal reform to help them to be good parents.

The rationale and available evidence for family-centred services for children affected by AIDS has not been brought together before. While there are very few clinical trials on family-centred services, DeGennaro and Weitz [68] make the point that individual components of family-centred services have been shown to be effective. These include home-based models of HIV voluntary counselling and testing [69], risk reduction following couple's counselling and testing [70], response to ARV treatment and adherence [71,72], prevention of mother to child transmission (PMTCT) [73], and child nutrition and education benefits of adult ARV programmes [74].

There are also clear costs for not adopting family-centred approaches to children affected by HIV and AIDS. These are especially evident in PMTCT programmes. For example, partner participation in programmes has been found to be associated with higher acceptance of post-test counselling, increased couple communication about HIV prevention, and increased use of ARVs [75]. Narrow pharmacological approaches are a lost opportunity for PMTCT to be the gateway to family-based prevention, care and treatment [73].

A piecemeal approach, tackling only one aspect of a complex multifaceted problem, also has the disadvantage that early successes may be reversed because later stage factors were not considered [76]. For example, eliminating HIV transmission to children is critical, but it does not eliminate risks to the mortality, morbidity and developmental progress of exposed but uninfected children [77,78].

Conclusions

There are many different kinds of families, facing different kinds of challenges, and they will require different kinds of support. For example, Levine points out, "Because non-traditional families are more commonly socially and psychologically similar to the patient, having been deliberately formed around shared interests, they may be better equipped to respond to external pressures such as stigma, but not to the dependency and level of care occasioned by illness" [16]. But what seems unquestionable is that a family lens would significantly move forward our ability to understand contextual influences on HIV and AIDS prevention, treatment and care to ensure access by more people to services with better outcomes, and balance available resources across services, families and communities to achieve comprehensive and integrated care.

There is no doubt that this is the beginning of a road and that there is much to be done, including basic research on families, family interventions, and effectiveness and costs of family-centred approaches. It is also clear that many of the institutions that are intended to serve families (law, health care, social security and welfare, housing, work) sometimes fail and, importantly, frequently even combat non-traditional families. The latter may, at worst, be prosecuted for their lifestyle and lose custody of their children and, at least, be excluded from decisions about treatment, and be excluded from insurance benefits and/or home tenancy when a partner dies.

Competing interests

The author declares that they have no competing interest.

Author's contributions

LMR conceived the review, conducted the search for materials and wrote the paper.

Author information

LMR co-chaired Learning Group 1: Strengthening Families in the Joint Learning Initiative on Children and AIDS (JLICA) and is a member on the Committee of the Coalition on Children Affected by AIDS (CCABA). Executive Director, Child, Youth, Family and Social Development, Human Sciences Research Council, South Africa; Honorary Professor, Department of Psychology, University of KwaZulu-Natal, South Africa; Honorary Professor, Department of Paediatrics and Child Health, University of Witwatersrand, South Africa; Honorary Research Associate, University of Oxford, United Kingdom; Visiting Scholar, Harvard, University, United States.

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REVIEW **Open Access**

Family-centred approaches to the prevention of mother to child transmission of HIV

Theresa S Betancourt*[1], Elaine J Abrams[2], Ryan McBain[1] and Mary C Smith Fawzi[3]

Abstract

Background: Prevention of mother to child transmission (PMTCT) programmes have traditionally been narrow in scope, targeting biomedical interventions during the perinatal period, rather than considering HIV as a family disease. This limited focus restricts programmes' effectiveness, and the opportunity to broaden prevention measures has largely been overlooked.

Although prevention of vertical transmission is crucial, consideration of the family environment can enhance PMTCT. Family-centred approaches to HIV prevention and care present an important direction for preventing paediatric infections while improving overall family health. This paper reviews available literature on PMTCT programmatic models that have taken a broader or family-centred approach. We describe findings and barriers to the delivery of family-centred PMTCT and identify a number of promising new directions that may achieve more holistic services for children and families.

Methods: Literature on the effectiveness of family-centred PMTCT interventions available via PubMed, EMBASE and PsycINFO were searched from 1990 to the present. Four hundred and three abstracts were generated. These were narrowed to those describing or evaluating PMTCT models that target broader aspects of the family system before, during and/or after delivery of an infant at risk of acquiring HIV infection (N=14).

Results: The most common aspects of family-centred care incorporated by PMTCT studies and programme models included counselling, testing, and provision of antiretroviral treatment for infected pregnant women and their partners. Antiretroviral therapy was also commonly extended to other infected family members. Efforts to involve fathers in family-based PMTCT counselling, infant feeding counselling, and general decision making were less common, though promising. Also promising, but rare, were PMTCT programmes that use interventions to enrich family capacity and functioning; these include risk assessments for intimate partner violence, attention to mental health issues, and the integration of early childhood development services.

Conclusions: Despite barriers, numerous opportunities exist to expand PMTCT services to address the health needs of the entire family. Our review of models utilizing these approaches indicates that family-centred prevention measures can be effectively integrated within programmes. However, additional research is needed in order to more thoroughly evaluate their impact on PMTCT, as well as on broader family health outcomes.

Background

Many programmes that aim to prevent mother to child transmission of HIV (PMTCT) in resource-limited settings have tended to take a narrow focus, often providing targeted biomedical interventions during late pregnancy and delivery, and neglecting the impact of HIV on the health of both pregnant women and families. The narrow focus of PMTCT to date represents a lost opportunity to effectively combat the vertical transmission of HIV to children – a largely preventable infection given current scientific knowledge.

We argue that family-focused approaches would facilitate broader implementation of PMTCT programming, addressing the comprehensive needs of women, particularly those in need of treatment for their own health, as well as of children and other family members, over time. This paper reviews the literature on existing models of

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*Correspondence: theresa_betancourt@harvard.edu
[1]François-Xavier Bagnoud Center for Health and Human Rights, Harvard School of Public Health, Harvard University, USA
Full list of author information is available at the end of the article

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family-centred PMTCT, as well as barriers and challenges. We lay out a vision for family-centred approaches to PMTCT and point to a number of promising new directions for preventing mother to child transmission, and also for improving overall family health and functioning and enriching the developmental context for children born into HIV-affected households.

Family-centred care

Family-centred care has been defined in a number of ways. A useful definition comes from the American Academy of Pediatrics (AAP), which states: "In pediatrics, family-centered care is based on the understanding that the family is the child's primary source of strength and support" [1]. In this model, a number of core principles of family-centred care are outlined, including such elements as: (a) respect for each child and his or her family; (b) recognizing and building on family strengths; and (c) providing and/or ensuring formal and informal support (e.g., family-to-family support) for the child and parent(s) and/or guardian(s) during pregnancy, childbirth, infancy, childhood, adolescence, and young adulthood.

While the rubric outlined by the AAP does not perfectly translate to the context of PMTCT in resource-limited settings, one might think of these principles as a more general recognition of the need to assume a family-centred approach to the treatment and maintenance of child health and wellbeing, including in the framework of PMTCT programmes. This need has been increasingly acknowledged by international organizations like the World Health Organization (WHO), which recently outlined in its *PMTCT Strategic Vision 2010-2015* that "priority will be given to strengthening linkages between PMTCT and HIV care and treatment services for women, their children and other family members in order to support an effective continuum of care" [2].

Family-centred PMTCT models include all family members in the care paradigm and address the comprehensive health needs of all of the family members, particularly the mother and child. We propose that such an approach can facilitate the prevention of primary infection, prevention of unwanted pregnancies, ameliorate and protect the health status of the mother and child, and enrich the capacity and functioning of an HIV-affected household.

HIV is a family illness

A family-centred approach to PMTCT has the potential to enhance health outcomes for the mother and child, as well as other members within the household. A central issue is that HIV-affected families are at high risk for a broad range of negative health outcomes, which have cascading effects on the health of all family members [3].

For example, by offering HIV testing and treatment to other family members, pregnant women may be more likely to accept HIV testing and collect their results, adhere to PMTCT regimens, and disclose their HIV-positive status to their partners [4-6]. This may result in reduced risk of vertical transmission of HIV if more women accept HIV testing, are tested earlier, and initiate treatment during an earlier time of gestation. In addition, if through appropriate support and counselling a woman shares her test results with her partner, use of condoms and other prevention methods may reduce the risk of transmission among sero-discordant couples, as well as potentially prevent transmission in future pregnancies [7,8].

In the context of PMTCT efforts to date, family-centred care has not yet fulfilled its promising potential. Coverage of HIV testing among pregnant women in low- and middle-income countries is estimated at only 21% [9]. In fact, in many high HIV burden settings, it has been difficult to identify HIV-positive women before delivery or early in their gestation, when ART or PMTCT regimens can be optimized. Access to antenatal care is routinely insufficient: only 32% of pregnant women in developing countries receive four or more antenatal care visits, the minimum number of visits recommended by the United Nations Children's Fund (UNICEF) and WHO [10].

In addition, even if a woman accesses a PMTCT regimen in a timely manner, she may not have the capacity to effectively adhere to the regimen, particularly if she is afraid to disclose her HIV status due to fear of stigma and domestic violence, or if she is lacking appropriate social support. Transportation to clinic-based follow-up antenatal care presents another significant barrier.

Similar barriers also limit access to facility-based delivery and appropriate follow up for new mothers and infants: in sub-Saharan Africa, only 40% of births take place at health care facilities; in least developed countries, this figure is as low as 32% [10]. Moreover, very few data exist on access to postnatal care, but those that are available suggest substantial shortfalls in this area, with a median coverage of 24% [11].

Mothers who have not disclosed their HIV-positive status to their partners or other family members may have difficulty pursuing an alternative to breastfeeding. Although there are promising results when offering a recent three-drug antiretroviral regimen during breastfeeding, transmission through breastfeeding cannot be completely prevented using this regimen [12]. While breastfeeding increases the risk of vertical transmission, it also avoids the social isolation that alternative safe feeding methods may evoke [13,14].

Although prevention of HIV transmission from mother to child is imperative, programmes can also improve effectiveness by addressing the overall physical and mental health of the family unit. Heymann *et al* [15] propose that infection prevention alone is insufficient in ensuring overall family health, and argue that prevention of family illness and death plays a significant role in constructing stable child-support networks. The ensuing problems of children whose parents have died from HIV disease include depression, anxiety, school drop out and high-risk sexual behaviour, placing them at greater risk of acquiring HIV infection as they transition into adulthood [15].

Methods

Search strategy and article selection

Using a standard review methodology, we searched PubMed, PsycINFO, and EMBASE from 1990 to November 2009 for all published articles pertaining to family-centred approaches to PMTCT. Under the global search criteria of HIV and PMTCT, returns were limited to those that contained key words or text within a matrix of relevant terminology (e.g., "family-centred"+ intervention, "MTCT-Plus"). Sensitivity of searches was improved by using key words and the bibliographies of eligible studies identified in the early stages of the search. We also asked experts in the field who have relevant subject expertise to identify additional publications or promising family-centred PMTCT programme models.

Two team members screened each of the abstracts identified, compared resultant abstracts selected, and reached consensus in order to resolve discrepancies regarding the appropriateness of inclusion for review. We included studies or programme descriptions that contained components of family-centred PMTCT in at least one of three categories of HIV care:

1. Family services provided as a part of antenatal care (ANC), such as household HIV counselling and testing, PMTCT counselling, antenatal care delivered via home visits or clinic sessions, risk assessments for intimate partner violence, evaluation for mental health problems, antiretroviral therapy (ART) for mothers or other family members as indicated, and treatment or prevention services for other illnesses
2. Family services provided around the time of birth, such as antiretroviral prophylaxis at birth for HIV-positive women, hospital-based delivery, C-section and nutritional counselling related to exclusive breastfeeding or infant formula supplementation
3. Services provided for the family following the birth of a child, such as follow up of HIV-exposed infants, family planning, early childhood development intervention activities, household risk assessment and referral or treatment for mental health problems or intimate partner violence, family HIV education or poverty-reduction strategies.

Excluded articles included those that discussed only family planning as compared to family-centred PMTCT and care, articles that were principally theoretical in nature, or articles investigating only singular biomedical interventions to prevent vertical transmission during delivery. Tables 1-3 provide an overview of models that adopt one or more family-centred components outlined in the three categories (including study design, target group, intervention components, outcomes and limitations).

Results

Our initial search of PubMed, PsycINFO, and EMBASE yielded 403 articles. Forty-eight were excluded as they were reviews. Of the remaining studies of PMTCT models, we found that 15 included at least one component of family-centred services provided before, during or after the birth of a child at risk for mother to child transmission (MTCT). Twelve were family-centred PMTCT intervention models and three were qualitative studies investigating partner perspectives on involvement in PMTCT (for qualitative studies, see Table 4 [16-18]).

Of the 12 intervention models outlined in Tables 1-3, seven focused primarily on extending HIV counselling and testing to the partners of pregnant women attending ANC clinics (see Table 1 [4,6,19-23]). In some instances, uptake among partners was achieved by community outreach efforts [6], while in other contexts, women were simply encouraged to invite their partners [19]; in one hospital setting, an opt-out approach was assumed, meaning that testing and counselling were provided to partners unless they otherwise requested not to receive these services [21].

Across these studies, partner participation was associated with positive outcomes, such as greater use of antiretrovirals [19,22] and higher acceptance of post-test counselling among pregnant women [20], as well as increased spousal communication about HIV and sexual risk [4]. Moreover, when couples received pre- or post-test counselling together, greater use of alternative feeding methods [22] and greater acceptance of HIV testing [6] were observed among women. Partner participation was also often utilized as an entry point for the provision of additional PMTCT services to both male and female participants.

A second series of the studies we reviewed focused on expanding provision of antiretroviral therapy (ART) to partners and other family members (Table 2, [24,25]). One central finding in this category was high adherence and retention of ART among all participants – women, men and children – likely because of greater supports within the family unit.

A third category of studies and programme models reviewed delineated the successes and shortcomings of comprehensive PMTCT models involving numerous family members (Table 3, [26-29]). The MTCT-Plus Initiative was one of the few programmes actively seeking

Table 1. Family-centred PMTCT intervention models: Extension of HIV counselling and testing

Citation, country, sample size	Design	Target group	Family-centred PMTCT programme components	Outcomes	Study limitations
[4] Desgrees-Du-Lou *et al*, 2009; Côte d'Ivoire; 710 women	Prospective cohort	Families	Pregnant women were encouraged to suggest HIV testing to partners Free HIV counselling and testing were provided at the request of women's partners and relatives	Prenatal HIV counselling and testing of women was followed by increased spousal communication about HIV and sexual risks, irrespective of HIV status (p <0.01) This communication was associated with increased HIV testing in male partners (p <0.05; OR=4.03; 95% CI 1.50-10.82)	Study conducted among a population participating in a research programme offering routine and systematic prenatal HIV testing and counselling. Thus, the effect of counselling and testing is likely to be higher than in other community settings that do not provide systematic counselling and HIV testing
[22] Farquhar *et al*, 2004; Kenya; 2836 women and 308 men	Prospective cohort	Pregnant women and partners	Male partners were invited to voluntary counselling and testing (VCT) for HIV at an antenatal clinic Couples were offered post-test counselling Instruction was provided on contraceptive use, safe sex during pregnancy, and breastfeeding practices	Women whose partners came for VCT (10% of total) were 3 times more likely to return for nevirapine (p=0.02), and more than 3 times more likely to report taking maternal and administering infant doses of nevirapine (p=0.009) Couples post-test counselling was associated with an 8-fold increase in postpartum follow up and greater nevirapine utilization (p=0.03) Couples-counselled HIV+ women were more likely to use substitute feeding methods (p=0.03)	Women whose partners came to the clinic were a select group who may have differed from those whose partners did not come. These differences may have contributed to effects on uptake of interventions. Since 2001, the approach to PMTCT testing, and the method of drug delivery, has changed considerably
[21] Homsy *et al*, 2006; Uganda; 4462 women and 287 men	Cross-sectional	Pregnant/ delivering women and partners	At a rural hospital, opt-out PMTCT education, HIV testing and counselling was provided to pregnant women in antenatal care, as well as attending partners Opt-out intrapartum HIV counselling/treatment was offered to women and partners Couples could choose to attend post-test counselling together or individually	Using this opt-out approach, HIV counselling and treatment acceptance was 97% among women and 97% among accompanying partners in the antenatal care (ANC) ward, and 86% among women and 98% among partners in the maternity ward In ANC, only 51 couples (2.8% of all tested persons in ANC) were counselled together In the maternity ward, 130 couples (37% of all tested persons in maternity) were counselled together	Staffing shortages on evenings and weekends slowed intrapartum HIV counselling and testing uptake until additional labour was hired Given the short follow-up interval, the data did not allow inference as to the rate of hospital delivery among ANC-tested HIV+ women
[20] Kakimoto *et al*, 2007; Cambodia; 20,757 women and 3714 men	Prospective cohort	Pregnant women and partners	Partners participated in a "mother class" in which information on VCT, pregnancy, delivery and newborn care was provided VCT was extended to women and their partners, and pre- and post-test couples counselling was offered	85.1% of women accompanied by partners to the mother session accepted pre-test counselling, compared with only 18.7% of women who attended the session alone (p <0.001; OR=25.00; 95% CI 22.7-27/8) Acceptance of post-test counselling was also higher among accompanied women (p <0.005; OR=1.2; 95% CI 1.07-1.37)	Pregnant women were voluntary attendees at a health facility and not randomly selected at the community level
[23] Katz *et al*, 2009; Kenya; 2104 women and 313 men total	Prospective cohort	Pregnant women and partners	Women attending an antenatal clinic were asked to invite and return with their partners to receive couples or individual VCT Males' attitudes towards VCT were evaluated, as well as the correlates of accompanying partners and receiving couples' counselling	16% of men who were informed by their wives of the availability of HIV testing accompanied their partners to the antenatal clinic Among 296 couples in which both partners received testing, 39% were counselled as a couple and 57% of men returned for a follow-up visit 87% of men attended the clinic to receive an HIV test, and 11% because they wanted information on HIV or MTCT	The study was conducted in a public antenatal clinic serving an urban population. Therefore, it may not be applicable to other resource-limited settings, including rural communities

Continued overleaf

Table 1. Continued

Citation, country, sample size	Design	Target group	Family-centred PMTCT programme components	Outcomes	Study limitations
[19] Msuya *et al*, 2008; Tanzania; 2654 women and 332 men	Prospective cohort	Pregnant women and partners	Pregnant women invited their partners to attend antenatal clinics Partners who participated in VCT received HIV, syphilis, and herpes simplex virus 2 testing, as well as pre- and post-test counselling Couples were invited to a joint counselling session	12.5% of male partners came for HIV counselling and testing 91% of HIV+ women whose partners attended VCT took nevirapine during delivery, compared with 74% of women whose partners didn't attend (OR=3.45; 95% CI 1.00-12.00) These women were also more likely to choose not to breastfeed and adhere to a selected feeding method (OR=3.72; 95% CI 1.19-11.63) Women's intention to disclose test results was associated with partner participation (p <0.001; OR=5.15; 95% CI 2.18-12.16)	Low male participation may have been due to failure of women to inform partners of VCT availability The researchers had to rely on women's self reports that they invited their partners Males may also have gone elsewhere for testing
[6] Semrau *et al*, 2005; Zambia; 9409 women and 868 men	Prospective cohort	Pregnant women and partners	Within an ongoing study on breastfeeding method and postnatal HIV transmission, women and their partners were offered couples counselling in HIV testing/ PMTCT at antenatal clinics Partner involvement was promoted by community outreach	9.2% of women were accompanied by their partners for counselling Among women counselled as a couple, 96% agreed to HIV testing compared with 79% of women counselled alone (p < 0.0001). Disclosure inherent in couples counselling did not significantly increase likelihood of adverse social outcomes (e.g., intimate partner violence)	Adverse consequences of disclosure may have been underreported among women who did not disclose HIV status; thus, adverse outcomes may be overestimated by study

Table 2. Family-centred PMTCT intervention models: Extension of ART services

Citation, country, sample size	Design	Target group	Family-centred PMTCT programme components	Outcomes	Study limitations
[24] Byakika-Tusiime *et al*, 2009; Uganda; 177 individuals	Prospective cohort	Families	At one MTCT-Plus Initiative site in Uganda, treatment and therapy for mothers and HIV-infected family members was provided, including basic treatment of HIV-related opportunistic infections, as well as provision of antiretroviral therapy (ART)	In this family-centred model, near perfect adherence to ART was observed: mean adherence in studied groups ranged from 87.7% to 100% Among adults, depression was significantly associated with incomplete adherence (p=0.04; OR=0.32; 95% CI 0.11–0.93)	Information was not collected on the time gap between delivery and initiation of therapeutic treatment
[25] Tonwe-Gold *et al*, 2009; Côte d'Ivoire; 605 women and 582 infants	Prospective cohort	Families	Through the MTCT-Plus Initiative, HIV prevention and care for family members, including clinical ART services Involvement and support of partners and children	Among cohort of 568 women with a living spouse, 53% disclosed HIV status to their male partner Enrolment of HIV-positive male partners was low (12%) Retention of individuals on ART was high (2.5% index women, 5.5% index partners lost to follow up)	Non-disclosure rates to partners remained high, even in the context of ART access Limited access to children outside the ANC context

enrolment of family members into the programme. Overall, more than 67% of women enrolled a family member [27], primarily HIV-exposed infants born to the pregnant or postpartum woman; enrolment of other family members proved to be more challenging. At the sites in Abidjan, Cote d'Ivoire, it proved difficult to test older children within the family as they often lived with other families in rural communities. Table 3 contains detailed information pertaining to all study designs, outcomes and limitations.

Among the programme models identified in the literature review, two salient examples were the MTCT-Plus

Table 3. Family-centred PMTCT intervention models: Comprehensive Services

Citation, country, sample size	Design	Target group	Family-centred PMTCT programme components	Outcomes	Study limitations
[27] Abrams *et al*, 2007; 8 countries in sub-Saharan Africa and southeast Asia; roughly 12,000 individuals	Observational cohort	HIV-infected pregnant women and their families	As part of the MTCT-Plus Initiative, women receiving prevention of mother to child transmission (PMTCT) services were invited to enrol in MTCT-Plus, a comprehensive HIV care programme, along with their newborn infants, as well as HIV+ family and household members	More than 2/3 of index women enrolled their HIV-exposed baby or an HIV-infected family member Retention of participants was very high, with fewer than 600 adults leaving the programme, including 190 reported deaths More than 2000 infants, 90% of those who reached 18 months, were determined uninfected, and of the 761 infected children enrolled, 65% received highly active antiretroviral therapy (HAART)	The feasibility of linking the different services represented in this model may be hindered in other contexts by factors like resource constraints, human capacity and community preferences
[26] Geddes *et al*, 2008; South Africa; 2624 women	Prospective cohort	Families	PMTCT integrated into antenatal services Women were encouraged to bring partners for HIV counselling and testing Psychological services provided for discordant couples Cluster of differentiation 4 (CD4) counts measured to determine appropriate form of ART and mode of delivery Polymerase chain reaction (PCR) test given to HIV-exposed infants; HIV+ babies were enrolled in children's programme	During 18 months, 100% of women attending the clinic received counselling 91% of women and 25% of partners were tested for HIV In 338 cases of maternal HIV+, 70% of live births were by caesarean section and 98% of live babies were given nevirapine; 76% also received azidothymidine. Of the 81% of babies tested at 6 weeks (via PCR), 2.9% tested positive	May have been subject to selection bias – 11% of mothers lost to follow up Participants may have been socio-economically and educationally better off than others who attended public facilities
[28,29] Mermin, 2005; rural Uganda; more than 6000 family members	Prospective cohort	Families	VCT for HIV extended to more than 6000 family members of HIV+ individuals Distribution of cotrimoxazole prophylaxis and a home-based water purification systems Future support for additional home-based delivery of ART for more than 4000 individuals	>95% of family members accepted VCT; 35% of married HIV+ individuals discovered they were living with an HIV- spouse Cotrimoxazole prophylaxis taken by HIV+ individuals was associated with a 46% reduction in mortality The water purification system was associated with a 25% reduction in diarrhoea among persons with HIV	Data were acquired mainly from a 2005 conference abstract and therefore have not been subjected to peer review

Initiative [27] and the CDC-Uganda, Global AIDS Program [28,29]. Although the conceptual framework of the MTCT-Plus Initiative is described more thoroughly in the Discussion, a number of specific results achieved by this initiative are worth noting here.

For example, among pregnant women who also enrolled their infants into MTCT-Plus Initiative programmes within the first months of life, the majority received complex antiretroviral regimens: 47% received short-course regimens during pregnancy, 20% initiated highly active antiretroviral therapy (HAART), and 30% received single-dose nevirapine. Women initiating HAART during pregnancy also exhibited an excellent immunologic response with an average increase of 451 cells/mm^3 after 30 months on treatment. Overall retention in care for MTCT-Plus participants initiating ART was high: 82% for pregnant women, 86% for men, and 87% of non-pregnant women at 30 months of follow up [30]. In addition, the mortality rate for both adults and pregnant women was found to be much lower than that reported at publicly funded programmes [31,32].

We were also able to acquire more recent supplementary data, which further illuminate the potential of this model to improve overall family health: from January 2003 until April 2008, 16,457 individuals (9718 adults and 6739 children) enrolled in MTCT-Plus Initiative programmes in Cameroon, Cote d'Ivoire, Kenya, Mozambique, Rwanda, South Africa, Uganda, Zambia and Thailand. Overall, 4275 (45%) women enrolled during pregnancy and 3611 (37%) women enrolled during the postpartum period.

Additionally, 1569 male partners and 449 older children living with HIV infection were enrolled and able to access comprehensive HIV care and treatment services. More than 6000 women chose to enrol their newborn child into the follow-up programme, where a battery of

Table 4. Family-centred PMTCT intervention models: Qualitative assessments

Citation, country, sample size	Design	Target group	Family-centred PMTCT programme components	Outcomes	Study limitations
[18] Mlay *et al*, 2008; Tanzania; 18 women, 16 men, 11 counsellors	Cross-sectional	Women and men of childbearing age	Women and men were asked to identify their views concerning couples voluntary counselling and testing for HIV, couples' motivation to receive results together, and effective ways of counselling sero-discordant couples	Categories identified: community sensitization; male involvement; caring; resentment; abandonment/divorce; violence Recognition of a cultural belief that ANC is exclusively for women Many participants were unaware that sero-discordancy existed	This qualitative study may have been influenced by selective enrolment and should not be viewed as a representative sample
[17] Theuring *et al*, 2009; Tanzania; 124 men	Cross-sectional	Male partners	Assessment of male attitudes regarding partner involvement in ANC/PMTCT interventions Examination of barriers preventing regular programme attendance	Among the convenience sample of males interviewed, 99% expressed positive regard for joint counselling Among males who were having children, only 46% had attended ANC/ PMTCT services The primary external barrier to ANC/PMTCT services identified was "lack of knowledge and information"	Study sample of men included some individuals aged 50+ years, who are less likely to be involved in family planning
[16] Tijou Traoré *et al*, 2009; Côte d'Ivoire; 26 women and 10 men	Prospective cohort	Pregnant women and partners	Assessment of couples' decision-making process concerning infant feeding in the framework of a MTCT-Plus programme	Interviews showed that initial individual preferences were subject to conjugal negotiation, and conflicts were often resolved after revelation of HIV status to spouse Most women associated refraining from breastfeeding with an internal moral suffering; this feeling was reinforced by social pressures	Small scale of study is illustrative and not generally applicable Selective enrolment of participants who were receptive to study Attitudes may have been influenced by the project's biomedical model

services, including early infant diagnosis, opportunistic infection prophylaxis, growth monitoring and antiretroviral treatment, were provided. HIV infection status was determined in more than 70% of the exposed infants, an unusually high percentage compared with traditional PMTCT programmes; approximately 10% of exposed infants were found to be HIV infected.

A second exemplary model identified through the literature review process (namely, the CDC-Uganda, Global AIDS Program [28,29]) also demonstrated a number of impressive outcomes. This programme extended home-based voluntary counselling and testing (VCT) for HIV to 6000 family members of HIV-positive individuals. The acceptance rate exceeded 95%, and 35% of those who were HIV positive and married discovered that their spouse was HIV negative. In addition, 10% of the children under the age of five years had undiagnosed HIV.

Cotrimoxazole consumption by HIV-positive individuals was associated with a 46% reduction in mortality, and 30% to 70% lower incidence of malaria, diarrhoea and hospitalization. There was also a 63% reduction of mortality among HIV-negative children whose HIV-positive parents were taking cotrimoxazole; this finding was likely the result of reduced morbidity and mortality among the HIV-positive parents, since death of a parent was associated with a three-fold increase in risk of child mortality. Additional information the CDC programme is provided in the discussion.

Discussion

Barriers to effective family-centred PMTCT

In our review of published programme models/evaluations and synthesis of the available literature, a number of barriers have been identified in the implementation of PMTCT in low-resource settings, which have implications for developing effective family-centred PMTCT. These include: limited access to antenatal care and obstetric services [10,27,33]; lack of routine (opt-out) and rapid HIV testing [34-37]; poor access to CD4 monitoring [38,39]; limited access to ART, as well as to multi-drug prophylactic regimens for PMTCT [40-43]; limited testing of partners [19]; low access to paediatric testing and treatment for HIV [44,45]; and poor adherence, as well as retention in care after delivery [46].

Also problematic in the delivery of PMTCT is the lack of coordination and integration among services, such as HIV testing, counselling, and distribution of ARVs, as well as assimilation with maternal and child health services more generally [47]. In many low- and middle-income countries, services are too centralized to reach remote areas, presenting a key barrier to antenatal care and PMTCT services [48,49]. In addition, as in all of health care in these countries, there is a lack of human and material resources that impacts access to care [50].

As demonstrated in our review of programme models that targeted partners for HIV counselling and testing, social support from family members must also be considered in family-centred PMTCT approaches. Women with lower levels of family support have been found to be more likely to refuse HIV testing than their peers with higher family support [51]. In addition, fear of HIV-related stigma and fears about disclosure may lead others to avoid being tested [52]. Furthermore, gender inequalities manifested in the limited education and literacy of women, power dynamics in the household about decision making, and infant care and reproductive health decisions all present barriers to family planning services and pose a significant obstacle to the primary prevention of HIV transmission in women.

For these reasons, father involvement in PMTCT and family-based testing and care are critically important. For example, as noted earlier, women who acquire HIV may be at risk for violence or abuse if they disclose their HIV-positive status to their partners without appropriate supports and engagement of their partners. These dynamics can in turn impact adherence to treatment regimens, as well as the ability of mothers to implement safe infant feeding practices [53].

Addressing barriers by promoting a family-centred approach

1. The MTCT-Plus Initiative

Of the models of family-centred PMTCT reviewed for this paper, as mentioned previously, the MTCT-Plus Initiative [27], which operated at 13 sites in eight countries in sub-Saharan Africa and in Thailand, offered one of the most comprehensive models for family-focused care using PMTCT as an entry point (see Table 3, Abrams *et al*, ref [27]). This model uses an explicitly family-centred approach, which includes two critical components: (1) addressing the health needs of the mother as well as the infant; and (2) recognizing that women's families should also be brought into care [27].

Integration of PMTCT services with HIV treatment and care not only facilitates women's access to care for her own HIV disease, but also improves the quality of PMTCT care by offering complex regimens [27] and by enriching the support context around the HIV-positive mother, who serves as the index case for this family-centred model.

A comprehensive package of services is offered to all family members and includes medical care for HIV-positive adults and children, early infant diagnosis, patient education and counselling, reproductive health and family planning services, psychosocial support, adherence and retention promotion, and nutrition education and support, as well as community outreach. These services are supported by a multidisciplinary team that includes nurses, physicians, counsellors, social workers, pharmacists and community health workers [27].

Access to related services is encouraged, including identification of and treatment for tuberculosis, nutritional support, family planning, and malaria prevention programmes. In addition to the broader scope of services, by offering treatment to all family members, long-term continuity of care, as well as treatment adherence, are promoted. For example, follow up of HIV-exposed infants is supported through programmes that ensure the availability of early infant diagnosis and treatment for children found to be HIV infected [27] (detailed outcomes of this study are provided in the results section and the summary of the programme model in Table 3).

2. CDC-Uganda, Global AIDS Program

Using a home-based testing approach in rural Uganda, Mermin *et al* [28,29] evaluated several interventions that could be used to form a "preventive care package". Extension of VCT to 6000 family members of HIV-positive individuals was coupled with provision of cotrimoxazole for those found to be HIV positive, as well as the distribution of more basic health interventions like home-based water purification systems. This study presents strong evidence of the benefits of addressing the health status of all family members.

Although the intervention was not specific to PMTCT, such approaches are readily applicable to family-centred PMTCT and speak to the potential for family-based interventions to have strong uptake and a "cascade" of positive effects within the family system (see detailed outcomes of this study in the results section and programme model summary in Table 3).

Involving partners and other family members

One component of the family-centred approach that has been often overlooked in many programmes is the involvement of fathers and other members of the family in the prevention of vertical transmission. Our review indicates that father involvement has been credited with improved access to and retention of services, as well as improved health outcomes.

In the Ivory Coast, Tijou Traore *et al* [16] followed a cohort of HIV-positive women and their infants over a two-year period during a PMTCT project (see Table 4, Tijou Traore *et al*, ref [16]). When men knew that their spouse was HIV positive and involved in the PMTCT project, they played an active role in applying the advice received, particularly related to exclusive breastfeeding and early weaning [16].

In Uganda, recognizing that male partners tended not to accompany women to prenatal visits and were often unlikely to take time off work, The AIDS Service Organization made efforts to increase uptake of HIV testing by offering special sessions on Saturdays for men [54]. However, positive outcomes associated with this strategy were not systematically documented. This shortcoming is indicative of the broader need for the development of an empirical evidence base highlighting the efficacy of such adaptive approaches to intervention.

Another novel programme in Uganda utilized an opt-out framework in order to increase uptake of HIV testing among men involved in their partner's antenatal clinic visits and delivery (see Table 1, Homsy *et al*). They found high levels of uptake of HIV testing at ANC visits (97% for women and men) and during delivery (86% for women and 98% for men). In addition, they observed a 12% increase in detection of HIV infection [21].

A fourth study, in Kenya, found that women accompanied by their partner for HIV-VCT were three times more likely to return for antiretrovirals; couples post-test counselling was also associated with an eight-fold increase in postpartum follow up, as well as greater antiretroviral utilization [22] (see Table 1, Farquhar *et al*, ref [22]).

Overall, it appears that engaging men has important benefits that support the goals of family-centred PMTCT. However, experiences across studies indicate that it remains challenging. Many successful programmes have relatively low rates of male engagement. For example, the study by Homsy *et al* [21], just described, demonstrated good participation from men, but only from those who were actively engaged in the care of their partners: among the 605 women who were tested in their study, only 180 of the men accompanied them at the time of delivery (30%). However, continued efforts to increase the involvement of men in family-based HIV testing, as well as counselling about infant feeding and child development, are likely to contribute to the effectiveness of family-centred PMTCT programmes.

Going to scale via family-centred approaches to PMTCT

Family-centred PMTCT interventions have the potential to better engage families and to retain beneficiaries in care, thus creating a sound platform for the scale up of interventions. In fact, several national PMTCT programmes have utilized family-focused strategies to ensure successful scale up. For instance, Botswana is well known for its dramatic increase in PMTCT coverage: from 7% in 2000 to 83% by 2005. Family-centred components included integration of PMTCT with reproductive and child health services, psychosocial support for women, and ART for women's own clinical care [55].

Similar to the Botswana programme, the success of Thailand's PMTCT programme appears to be partially associated with its integration within a strong maternal and child health and public health programme, promoting close monitoring and follow-up care for women and HIV-exposed infants [56]. While both programmes demonstrate progressive models that integrate family-centred components of HIV care into existing systems, they could be further strengthened by extending services to additional family members.

Ongoing challenges and advancing the field

Despite emerging examples of the power of family-centred approaches to PMTCT, and despite consensus among organizations like UNICEF and WHO that more holistic approaches are needed [2,57], there remains a prevailing focus on simplified medical interventions to reduce transmission. In reality, only a handful of studies investigate family-centred approaches to PMTCT. Given this state of affairs, and despite a compelling conceptual basis, the evidence base to move this agenda forward requires much more attention.

As a whole, current family-centred approaches remain largely underdeveloped and underdocumented. As seen in our review of available models, there are few formal published evaluations of family-centred PMTCT models and almost no comparative research in this area. Furthermore, although discussed as important, no programs reviewed here included direct attention to intimate partner violence, mental health issues or the integration of nutritional and early childhood development services into family-centred care. Therefore, trials pertaining to the efficacy of family-centred care versus "segmented delivery of only ART or PMTCT" are nearly non-existent [58].

Conclusions

A paradigm shift is needed in PMTCT, which considers the needs of entire families, rather than placing a singular focus on preventing MTCT during pregnancy and delivery [15]. PMTCT represents an entry point for improving overall family health and functioning [27]. While family-centred models are relatively uncommon in the literature, those models that do exist show promising results.

These data speak to the prevailing perspective among stakeholders that a family-centred approach to HIV prevention and care is essential, compelling and far overdue, while also underscoring the continuing paucity of programmes and policies that actually work towards the realization of this ideal.

Competing interests

The authors declare that they have no competing interests.

Authors' contributions

TSB conceived the study, undertook research relevant to production of the manuscript, facilitated the screening process for study selection, and drafted or contributed to all parts of the manuscript. EJA helped to conceive the study, and undertook research relevant to production of the manuscript, in addition to editing and revising all parts. RM screened abstracts and studies for inclusion criteria, drafted the table of selected studies, and assisted in manuscript editing. MCSF helped to conceive the study and undertook research relevant to production of the manuscript, and drafted or contributed to all parts. All authors read and approved the final manuscript.

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Author details
[1]François-Xavier Bagnoud Center for Health and Human Rights, Harvard School of Public Health, Harvard University, USA. [2]International Center for HIV/AIDS Care and Treatment Programs, Mailman School of Public Health, Columbia University, USA. [3]Department of Global Health and Social Medicine, Harvard Medical School, Harvard University, USA.

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Author/Date	**Region**	**Cohort**	**Intake/referral**	**Location**	**Services**
Porricolo 2006 [12]*	Bronx, New York City, USA	26 mother-child dyads		Hospital-based outpatient HIV clinic	Comprehensive HIV care, including HAART
Sendzik 2008 + 2006 [20, 21]*	Brooklyn, USA	200+ clients	Clients may enrol if they have children at home, or are considering having children	Hospital-based HIV clinic	Comprehensive HIV care, including HAART Primary care for HIV+ and HIV- family members Ob/gyn nurse midwife Family nutritionist Family counsellors Educational and social activities
El-Sadr 2004 [17]*	12 programmes in 9 countries	981 HIV+ index women 276 HIV+ partners 48 HIV+ index neonates 53 HIV+ children 36 children on HAART	MTCT-Plus		Comprehensive HIV care, including HAART PMTCT
Van Griensven 2008 [28]	Kigali, Rwanda	2937 adults on HAART 315 children on HAART	Paediatric cohort: Children of HIV+ adult patients (90%) Orphans (10%) □□ PMTCT and in/outpatient services (<1%) Transfer from other ART programmes (<1%)	Community-based health centres	Primary health care Comprehensive HIV care, including HAART
Callaway 1997 [39]*	Columbus, Ohio, USA			Children's hospital-based outpatient clinic	Comprehensive HIV care, pre-HAART Primary care for HIV+ and HIV- family members Gynaecological care, including family planning Substance abuse and mental health interventions Nutritional assessment and support
Eley 2004 [22]	South Africa	80 children on HAART 3 mothers on HAART		Children's hospital-based HIV clinic	Comprehensive HIV care, including HAART Inpatient consultation service
Gibb 1997 [30]	London, UK	185 HIV+ children 112 HIV+ adults (24% fathers)	Children precipitate testing of parents	Children's hospital-based HIV clinic	Comprehensive HIV care, pre-HAART Terminal care services Family counselling Family planning service
Habibu 2006 [23] *	Kano, Nigeria	52 children on HAART 22 parents started on ART.		Specialist hospital-based HIV clinic	Comprehensive HIV care, including HAART Adherence nurse Social worker
Himid 1998 [56]	South London, UK	37 HIV+ mothers 47 HIV+ children	HIV+ mothers (pre-existing cohort) as index patients	Hospital-based outpatient clinic	Comprehensive HIV care, pre-HAART Social workers "Specialist health visitors" (paediatricians, midwives)
Ida 2006 [57]*	Brooklyn, USA	47 families	The Obstetrics clinics where HIV-positive pregnant women were identified Transfers from the Adolescent and Adult HIV clinic Family members of index positive paediatric and adult patients		Comprehensive HIV care, including HAART Full time adult providers & general paediatricians
Kabugo 2007 [32]*	Uganda	HIV+ index women (n = ?) HIV+ male partners (n = ?) HIV+ index neonates (n = ?) HIV+ children (n = ?)	MTCT-Plus	Hospital-based antenatal clinic	Comprehensive HIV care, including HAART PMTCT
Kiromera 2006 [36]*	Malawi	2 infants on HAART 111 parents on HAART (40% fathers)	MTCT-Plus	Hospital-initiated, community-based care	Comprehensive HIV care, including HAART PMTCT Education on appropriate infant feeding Supplementary feeding to HIV-affected families Supervised for adherence by treatment helpers selected among HIV+ clients
Luisama 2008 [24]*	Kinshasa, Democratic Republic of Congo	505 HIV+ children 393 children on HAART Caregivers (n=?)		Paediatric hospital-based HIV clinic	Comprehensive HIV care, including HAART
Marima 2006 [33]*	Kenya	Children on HAART (n = ?) Caregivers on HAART (n = ?)	Adult and paediatric patients refer each other		Comprehensive HIV care, including HAART Referrals to community-based organizations for nutritional support, home-based care, and economic support
Midturi 2008 [25]*	Baylor College of Medicine, Lilongwe, Malawi	56 HIV+ paediatric cases in family care 112 HIV+ paediatric controls in paediatric care			
Okubamichael 2007 [58] *	Lesotho		MTCT-Plus	Hospital-based antenatal clinic	Comprehensive HIV care, including HAART ART service at clinic run by medical officer 3x/week PMTCT Counselling on breastfeeding, postnatal/under-5 care
Reddi 2007 [26]	KwaZulu-Natal, South Africa	151 HIV+ children 68 HIV+ caregivers	Adult and paediatric patients refer each other	Hospital-based outpatient clinic	Comprehensive HIV care, including HAART Psychosocial support for adults and children

Author/Date	Region	Cohort	Intake/referral	Location	Services
Tonwe-Gold 2009 [27]	Yopougon and Abobo (Abidjan, Cote d'Ivoire)	605 HIV+ women 69 male partners 30 neonates (index pregnancy) 18 children	MTCT-Plus	Community-based antenatal clinics	Comprehensive HIV care, including HAART Cotrimozaxole prophylaxis Malaria treatment Psychological and social support Nutritional + infant feeding counselling and support, Referral to family planning and tuberculosis services Minimal fee for transport of patients to the clinic
van Kooten Niekerk 2006 [35]	Tygerberg, South Africa	274 HIV+ children 97 parents (14% fathers)	"Clinical suspicion" in paediatric inpatients The parents were identified through their children and with the input of the adult infectious diseases service	Hospital-based HIV clinic	Comprehensive HIV care, pre-HAART Antiretroviral therapy was given to limited numbers of children and parents, either through pharmaceutical trials, medical insurance, donations, or through the hospital Clinic operational on Tuesdays
Van Winghem 2008 [29]	Kenya	1205 HIV+ children 657 children on HAART HIV+ caregivers (n = ?)	Adult and paediatric HIV care cohort members as index patients – refer family members	1 hospital-based HIV clinic + 3 community-based health centres	Comprehensive HIV care, including HAART Primary care TB care Psychosocial support for adults Psychosocial support for children Nutritional support
Wamalume 2004 [59]*	Lusaka, Zambia	60 index women 19 partners 34 children "enrolled" (22 patients total on ART)	MTCT-plus Women tested at ANC/postnatal clinics, referred to primary health centre for HIV care	Community-based health centre	Comprehensive HIV care, including HAART INH prophylaxis against TB Nutrition supplements from the World Food Programme.
Yalala 2008 [31]*	Kinshasa, Democratic Republic of Congo	174 HIV+ index women 10 HIV+ index neonates 11 HIV+ male partners 2 HIV+ children	MTCT-Plus Women tested at ANC, referred to primary health centre for HIV care	Community-based health centre	Comprehensive HIV care, including HAART Primary care

* Indicates that this refers to a conference abstract, rather than a published journal article

Note: An empty table cell indicates none of that type of data were available in that publication

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REVIEW **Open Access**

Lessons learned from family-centred models of treatment for children living with HIV: current approaches and future directions

Sarah C Leeper*, Brian T Montague, Jennifer F Friedman and Timothy P Flanigan

Abstract

Background: Despite strong global interest in family-centred HIV care models, no reviews exist that detail the current approaches to family-centred care and their impact on the health of children with HIV. A systematic review of family-centred HIV care programmes was conducted in order to describe both programme components and paediatric cohort characteristics.

Methods: We searched online databases, including PubMed and the International AIDS Society abstract database, using systematic criteria. Data were extracted regarding programme setting, staffing, services available and enrolment methods, as well as cohort demographics and paediatric outcomes.

Results: The search yielded 25 publications and abstracts describing 22 separate cohorts. These contained between 43 and 657 children, and varied widely in terms of staffing, services provided, enrolment methods and cohort demographics. Data on clinical outcomes was limited, but generally positive. Excellent adherence, retention in care, and low mortality and/or loss to follow up were documented.

Conclusions: The family-centred model of care addresses many needs of infected patients and other household members. Major reported obstacles involved recruiting one or more types of family members into care, early diagnosis and treatment of infected children, preventing mortality during children's first six months of highly active antiretroviral therapy, and staffing and infrastructural limitations. Recommendations include: developing interventions to enrol hard-to-reach populations; identifying high-risk patients at treatment initiation and providing specialized care; and designing and implementing evidence-based care packages. Increased research on family-centred care, and better documentation of interventions and outcomes is also critical.

Background

Highly active antiretroviral therapy (HAART) has now been available for more than 10 years, profoundly changing the way we think about HIV, turning victims into survivors. Reliably robust results have been documented repeatedly in high- and low-income settings, with adults and with children [1,2]. Despite its long-standing record of proven efficacy, this treatment remains inaccessible to most children born with HIV in many low- and middle-income countries today.

In the five countries with the highest adult HIV prevalence worldwide, HIV is the single leading cause of under-five mortality, responsible for 41% to 56% of deaths [3]. One thousand children were born with HIV every day in 2007, due in part to the fact that only about 45% of all HIV-positive women worldwide have access to prevention of mother to child transmission (PMTCT) programmes [4]. Less than half of the children born with HIV in Africa are expected to survive until their second birthday [5].

With early diagnosis and treatment, however, their outlook improves substantially. For example, the Children with HIV Early Antiretroviral Therapy trial recently demonstrated a 76% reduction in mortality for children born with HIV when HAART was started within the first 12 weeks of life [6]. Among infected children of all ages, HAART initiation can decrease hospital admissions, incidence of pneumonia, and diarrhoea, can bring about "significant immunological reconstitution" and, in the

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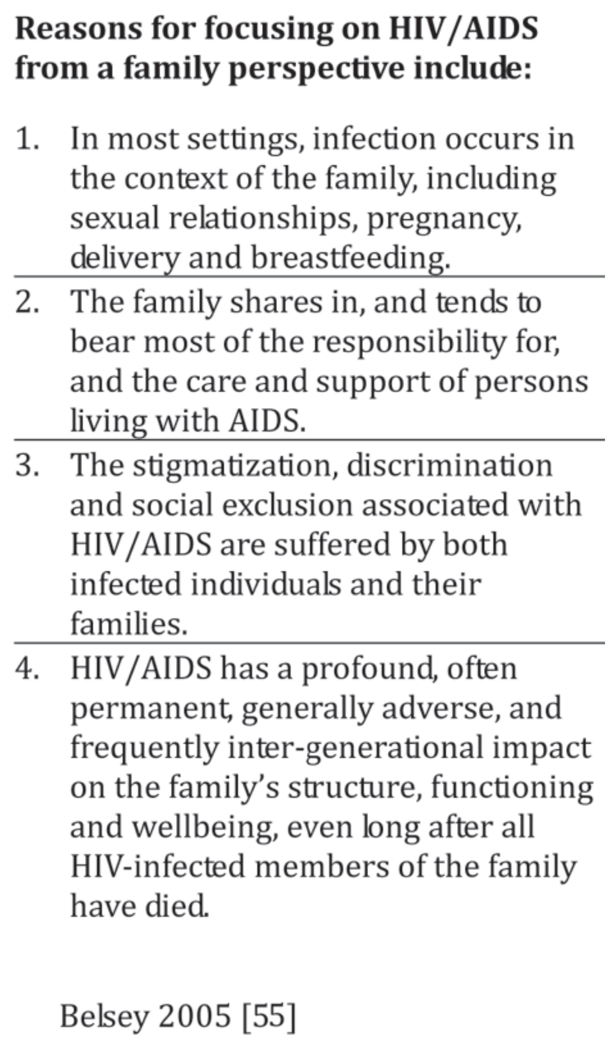
*Correspondence: Sarah_Leeper@brown.edu
Brown University Medical School, Providence, Rhode Island, USA

sub-Saharan African context, result in a probability of survival after one year of therapy of between 84% and 97% [1].

Children (infected and uninfected) also receive substantial indirect benefits when their parents are treated: decreases in malaria, diarrhoea, hospitalizations and mortality have been seen, as well as improvements in child nutritional status and school enrolment, and decreases in child labour [7-9]. In the context of HIV, family members have been shown to significantly impact the mental health, access to care, adherence and treatment outcomes of other family members [7,9-13]. However, only 38% of children and 43% of adults requiring antiretroviral therapy (ART) are currently able to access treatment [4]. Family-centred care models have emerged as a way to meet the clear and present need to test and treat more HIV-positive children and caregivers in a way that is mindful of intimate and dynamic family relationships (see Figure 1).



Reasons for focusing on HIV/AIDS from a family perspective include:

1. In most settings, infection occurs in the context of the family, including sexual relationships, pregnancy, delivery and breastfeeding.
2. The family shares in, and tends to bear most of the responsibility for, and the care and support of persons living with AIDS.
3. The stigmatization, discrimination and social exclusion associated with HIV/AIDS are suffered by both infected individuals and their families.
4. HIV/AIDS has a profound, often permanent, generally adverse, and frequently inter-generational impact on the family's structure, functioning and wellbeing, even long after all HIV-infected members of the family have died.

Belsey 2005 [55]

Figure 1. HIV/AIDS from a family perspective.

The concept of "family-centred care" was first formally defined in 1982 by the Association for the Care of Children's Health in response to a growing desire for a new approach to care for children with special health needs. It was based on a bio-psychosocial systems approach: the primary focus of health care is the client in the context of their family [14]. While the family was originally assumed to include healthy adults as caregivers for the child, definitions have evolved to meet the reality created through the vertical transmission of HIV. HIV family-centred care is now described simply as programmes where "adult and paediatric services are provided together in a single setting" [15].

While that is the working definition used in this paper, it is important to acknowledge that more ambitious definitions exist, which broaden the mandate of care providers beyond basic HIV services. For example, another definition is: "A comprehensive, coordinated care approach that addresses the needs of both adults and children in a family and attempts to meet their health and social care needs, either directly or indirectly through strategic partnerships and/or linkages and referrals with other service providers" [16].

There is currently no consensus as to what meeting "health and social care needs" means, as evidenced by the diversity of programmes reviewed in this paper. These myriad approaches illustrate the difficulty in drawing general conclusions about the efficacy of any given intervention, but also point to a broad global interest in exploring this care delivery model.

Objectives

The goal of this paper is to review existing literature on family-care models used to treat children and caregivers living with HIV. The features of the HIV/AIDS family-centred care programmes, as well as paediatric cohort characteristics, are described, including demographics, treatment outcomes, adherence and retention. Lessons learned and recommendations for future interventions and research will be identified. Although the health of families is a complex and interrelated system, the focus will be mainly on the impact of the family-care model on the health of children living with HIV.

Methods

The current study is a systematic review of English-language literature on family-centred HIV care programmes. Due to the low number of peer-reviewed publications on this topic, unpublished conference abstracts were also included. All relevant publication dating until August 2009 were identified by searching the PubMed database. The International AIDS Society (IAS) abstract search was used to identify abstracts, posters

Table 1. Paediatric cohort characteristics and outcomes

Author/ Date	# children on HAART	Age at initiation	Duration of follow up	CD4 at initiation	Adherence	Survival	Loss to Follow-Up
Abrams 2005 [18]	144		Median 19 months (Range 2 months – 12 years)				
Van Griensven 2008 [28]	332	Median 7.2 years (IQR 4.5-10.4)	Median 2.0 years (IQR 1.2-2.6)	Median 14% (IQR 9-18%)	49%: >95% adherence 46%: >80% adherence	98% survival at 12 months 8 deaths (2.6% mortality)	12 children (3.8%)
Eley 2004 [22]	80	Median 1.25 years (Range .003-12.0)			"Most": >85% adherence	7 deaths (8.8% mortality)	4 children (5%)
Habibu 2006 [23]*	52				>95% adherence		0 children
Lusiama 2004 [24]*	393	Median 7.5 (years) (IQR 4.3-10.5)	Median 21.9 months (IQR 7.5-25.9)	Median 12% (IQR 7-18%)		30 deaths (8% mortality)	44 children (9%)
Midturi 2008 [25]*	56	Mean 39.6 months	Mean 14.7 months		77.8% adherence	1.8% mortality	1.8%
Reddi 2007 [26]	151	Median 5.7 years (Range 0.3-15.4)	Median 8 months (IQR 3.5-13.5)	Median 7.4% (IQR 2.1-13.7%)	59.6%: no missed doses 29.8%: >95% adherence	90.9% survival at 12 months 13 deaths (8.6% mortality)	0 children
Tonwe-Gold 2009 [27]	43		Median 12 months (IQR 5.0-15.0)			2 deaths (4.9% mortality)	0 children
Van Winghem 2008 [29]	657	Median 5.5 years (IQR 3.2-8.7)	Median 1.36 years (IQR 0.6-2.2)			95.3% survival at 12 months 7 deaths (6.7% mortality)	67 children (10.2%)

* Indicates that this refers to a conference abstract, rather than a published journal article
Note: An empty table cell indicates none of that type of data were available in that publication

and presentations from the following conferences: 1st to 5th IAS Conferences on HIV Pathogenesis and Treatment (2001, 2003, 2005, 2007, 2009), and XIV to XVII International AIDS Conferences (2002, 2004, 2006, 2008).

The following search terms were used: ("famil*") + ("HIV" OR "AIDS" OR "HAART" OR "antiretroviral*"); also ("MTCT plus" OR "PMTCT plus"). Review of the citations within the articles found yielded additional articles. Final inclusion criteria included: (1) provision of treatment for HIV-positive adults and children in a single setting; and (2) a description of at least one of our measures of interest (services provided, cohort epidemiology, service uptake, testing, clinical/lab outcomes, adherence, retention, psychosocial support). Papers that did not address the treatment of HIV-positive children (such as publications on prevention of mother to child transmission or the follow up of HIV-exposed infants alone) were not included.

Data analysis primarily consisted of calculating ranges and measures of central tendency, when possible. Formal meta-analytic techniques could not be applied for a comparative analysis because of methodological and data collection discrepancies across studies.

Results

Twenty-five publications and abstracts met inclusion criteria (cited throughout). Papers were published between 1997 and 2009, describing cohorts primarily in Africa, the US and the UK. Publications that were part of the Mother to Child Transmission Plus Initiative (MTCT-Plus) were considered separately if they were determined to describe discrete patient groups across unique time periods [17], while reports containing aggregate data on the same patient populations were not considered unique cohorts [18,19]. Similarly, results from two reports by Sendzik [20,21] detailing the Program for AIDS Treatment and Health (PATH) in Brooklyn, New York, USA, were combined.

Twenty-two separate cohorts were identified. All documented programme characteristics, and eight provided paediatric outcomes data [22-29]. See Additional File 1 and Table 1 for additional cohort references.

Setting

Nineteen reports detailed the physical location where the patients were treated. A significant majority (n=11) were located in ambulatory HIV clinics affiliated with various hospitals: community, teaching, public, and paediatric. Gibb *et al* report that this decision "had the advantage … of being non-stigmatising (other paediatric outpatient clinics are held in parallel)" [30]. At Red Cross Children's Hospital in South Africa, the programme includes an inpatient consultation service, created to optimize the care of patients in the early stages of therapy who require hospitalization [22].

Five family-care programmes were based at government primary health centres. These locations were often conveniently located in settlements where families lived, and at the time of enrolment, were already offering a full range of primary care services for adults and children, including TB care. One drawback was that women who were tested at antenatal clinics and referred to these centres for care often failed to present for enrolment: in Kinshasa, Democratic Republic of the Congo, for example, only 27% of eligible women presented with their newborns [31].

Four family-care sites were located at antenatal or PMTCT clinics: three were hospital affiliated and one was community based. Although this facilitated maternal follow up, Tonwe-Gold theorized that the location "may have prevented a larger number of men from choosing to access the services provided" [27].

Staffing

Most programmes were staffed by a core multidisciplinary team, including doctors, nurses, social workers and/or counsellors. Some included gynaecologists, child life specialists, and/or nutritionists. However, to navigate the challenges of trained health care worker shortages, several programmes took more innovative approaches to staffing.

Programmes that were part of MTCT-Plus, supported by the International Center for AIDS Care and Treatment, assembled and trained multidisciplinary teams at each site. Personnel were trained using a specific MTCT-Plus curriculum focusing on the team as a whole [17]. In a separate intervention in Nigeria, Habibu *et al* trained paediatricians to manage both children and adults for HIV-related conditions and prescribe ART, instead of training adult physicians to treat children. However, they caution, "Staff motivation can be impacted by the complexity of managing both children and adults and the multiple needs of the family" [23].

Project sites in Rwanda and Kenya implemented task-shifting measures to varying degrees. In Kigali, Doctors Without Borders-supported clinics piloted "health center/nurse-based care". Nurses were trained to initiate and change antiretroviral (ARV) treatment, and perform routine follow up. They observed a gradual decrease in the need of physician time from one full-time physician per 1500 patients to one per 3000 patients as the programme matured. To avoid overloading the nurses, other tasks were taken over by "new or reinforced cadres in the health centers": receptionists, community support groups, and lab staff [28].

In Kenya, "rapid turnover of trained medical staff" was identified as a major challenge. Van Winghem *et al* propose training selected HIV-positive patients as peer educators and counsellors to take over those responsibilities from paid staff, as the volunteers "would be more likely to remain long-term with the program" [29].

Programme components

Programmes vary widely in terms of services provided (see Additional File 1). Some offer only comprehensive HIV care to children and adults, and others provide supplementary services, such as primary care for all family members (HIV positive and HIV negative), TB screening and isoniazid prophylaxis, reproductive health services, nutritional supplementation, play therapy for children, and terminal care services. Locations of the programmes determined to some extent which services were offered: antenatal clinic-based programmes were better equipped to offer PMTCT services [32], and paediatric hospital-based programmes were well positioned to mobilize inpatient consult teams [22].

Enrolment

Enrolment points varied widely, and included: antenatal clinics, PMTCT programmes, adult/adolescent HIV clinics, inpatient adult and paediatric wards, maternal and child health clinics, and subsequent use of "index patients" within the recruited cohort to identify HIV-positive family members. Many sites relied on a combination of the above techniques. The enrolment method often influenced the inclusion or exclusion or various demographic groups within the treatment cohort.

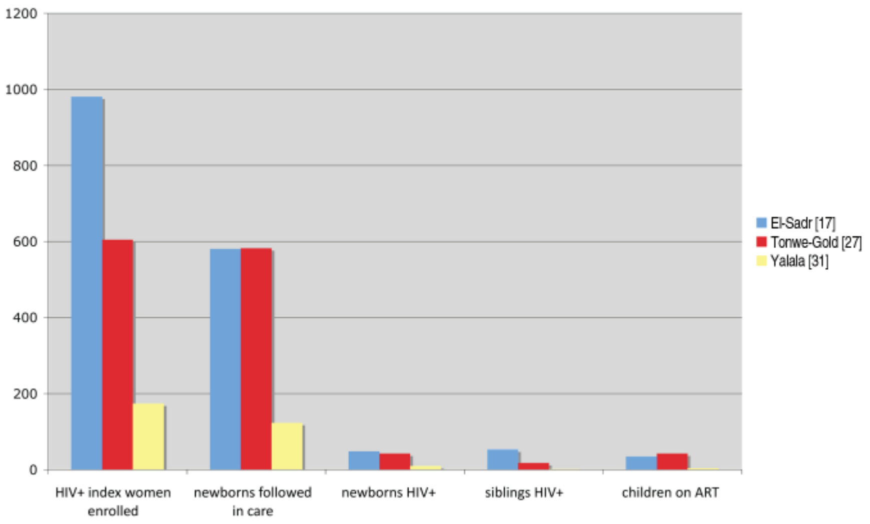
1. MTCT-Plus

A commonly used and well-documented strategy is MTCT-plus, a model of care that was developed from the MTCT-Plus Initiative [19]. Pregnant women are tested at antenatal or PMTCT clinics and, if HIV positive, referred to the family-care programme; they become the "index women". Upon enrolment, they are encouraged to bring children and male partners for testing and, if necessary, treatment and care. Although these programmes are extremely effective at recruiting HIV-positive women and supporting prevention of mother to child transmission, they have documented little success in recruiting HIV-positive children into care.

Figure 2 describes three MTCT-Plus cohorts: Tonwe-Gold in Cote d'Ivoire, Yalala in Kinshasa, Democratic Republic of Congo, and El-Sadr. , which describes a composite cohort from 12 programmes in nine countries [17,27,31]. Despite a combined total of 1760 index women reported by the three authors, together they document only 74 children on HAART.

The uptake of testing for previously born children of the index women is particularly low. Various theories are offered, including "the possibility that many of the children lived away from the mother's household with other relatives in distant communities". This may be exacerbated by low rates of disclosure to a male partner, as revealing a child to be HIV positive might by extension reveal the mother's status. Figure 2b describes the same three cohorts in terms of partner enrolment. Again, Tonwe-Gold's study is the only one to document how many living male partners are reported (n=568) [27].

(a) MTCT-Plus paediatric cohort



(b) MTCT-Plus male partner cohort

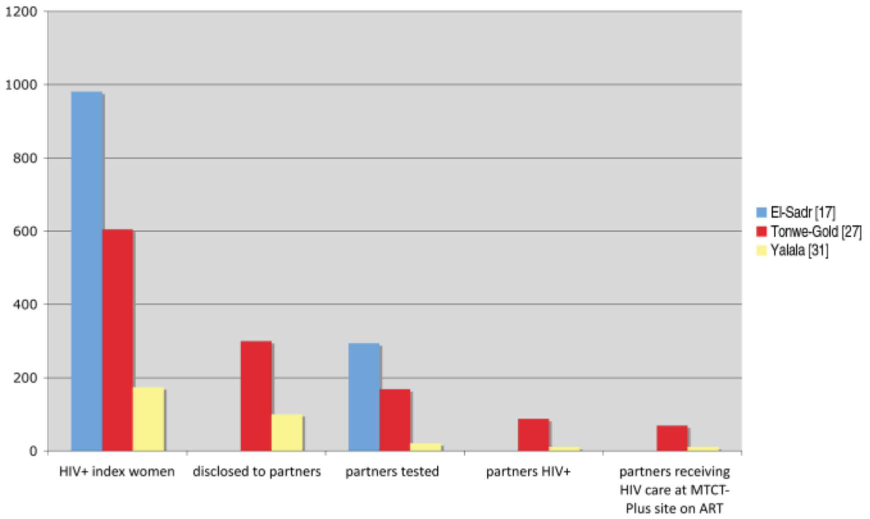


Figure 2. (a) MTCT-Plus paediatric cohorts. (b) MTCT-Plus male partner cohorts.

2. Other adult index patients

Other cohorts use adults (male and female) in their existing HAART cohorts as index patients to recruit other family members. Ninety percent of the children in a large Rwandan cohort were children of adult HIV-positive patients (299 out of 332) [28]. Some programmes used incentives to encourage parents to enrol children: Sinikithemba Clinic in Durban, South Africa, offered free paediatric care to children whose parents were enrolled, and referred family members were prioritized for treatment [26]. Adult patients in Kenya were allowed to enrol in care at an earlier WHO clinical stage if they had a child in care [29].

Some cohorts have seen increased paediatric referrals since implementing family-centred care (the proportion of patients at Family AIDS Care and Education Services in Kenya who are children has doubled from 5% to 10%), but others are struggling to recruit paediatric patients [33]. At five health facilities in South Africa, HIV-positive patients were given referral cards to pass along to family members. Despite the fact that 33% of these adults reported not knowing their children's HIV status, the referred population was primarily adult (mean age 34 years) [34].

Only two programmes described interventions specifically aimed at increasing paediatric enrolment:

developing a video for continuous playback in ART clinic waiting rooms encouraging parents in care to bring their children for testing [34]; and "in-depth counseling sessions … with the caregivers to discuss testing of children in detail" [28]. Outcome data on these interventions are not currently available.

3. Paediatric index patients

Some projects prioritize the recruitment of children, and rely on them to precipitate the diagnosis of adult family members. At Family Clinic for HIV at Tygerberg Academic Hospital in South Africa, the majority of infants and children living with HIV were identified through clinical suspicion based on hospitalization with "intercurrent disease or opportunistic infection". Parents were identified both through their children and with the input of the adult identification document service. However, the authors report "inadequate utilization by the parents, especially the fathers"; only 18% of potential parents attended the clinic [35].

In South London, UK, children were referred from a variety of sources, including paediatricians from district hospitals, social workers and general practitioners. The majority of parents had not been tested at the time their children first attended the HIV clinic, but in the five-year description of the programme, only 17% chose to remain untested. Again, the majority of adult patients who registered in care with their children were mothers (76%).

Paediatric characteristics and outcomes

Paediatric baseline characteristics and outcomes were available for nine programmes. Very little data was available on clinical, immunological or virological outcomes. However, most studies documented cohort size, follow-up time, age of cohort, and rates of adherence, retention in care and mortality.

Cohorts contained between 43 and 657 children, and approximately one-third served <100. Median follow-up time after HAART initiation was recorded for eight cohorts, and ranged from 6.7 months to more than two years. Eight cohorts report average patient age at HAART initiation: half had a median age >5 years old, and half <5 years old, with two <2 years. CD4 percentage at initiation was reported by only three studies, and ranged from 7.4% to 14%.

Adherence data was available for six cohorts, and was assessed by methods ranging from patient self-report to pharmacy refill. The lowest adherence rate achieved was 77.8%, and four cohorts reported >95% adherence for the majority of their patients. Families on ART in Malawi, who are supervised for adherence by treatment helpers selected among HIV-positive clients, achieved an adherence rate of 99.7% [36]. Byakika-Tusiime *et al* note "near perfect adherence to ART" in both mothers and children when treatment was provided to all eligible HIV-positive family members [37].

In a particularly striking case study of a family with six family members living with HIV, all of whom were started together on HAART in rural Kenya, "excellent outcomes" were achieved despite a family total of 49 individual pill or syrup administrations daily [38]. These assessments, though imprecise, compare favourably to those of similar cohorts [2].

Excellent attendance at scheduled clinic visits was documented in several cohorts. The Global HIV/AIDS Initiative Nigeria Project in Kano, Nigeria, reports that in nearly a year of managing 202 children and 90 parents, only two clients missed scheduled clinic appointments [23]. In fact, family-care patients seem to be more likely to attend scheduled visits: in 2007, adults in the Family Program at PATH (the HIV service of Brooklyn Hospital, New York) kept 74% of their medical visits, compared to 44% for PATH patients overall [20,21].

Loss-to-follow-up (LTF) rates were low in the majority of studies: 10 report <11% LTF, including Ida *et al*, who demonstrated >90% retention during a seven-year observation period. Three cohorts report zero patients lost to follow up. One study, by Niekerk *et al*, reports 52% LTF, although this should be interpreted in light of the fact that this was predominantly a pre-HAART era report, and only 22% of the children were receiving HAART through various clinical trials [35].

The probability of survival one year after HAART initiation was 90.9% to 98% [26,28,29], and overall mortality ranged from 1.8% to 8.8% [22,24,25,27]. Several studies highlighted a particularly vulnerable period shortly after the initiation of HAART: all of the deaths (n=7) reported by Eley took place within six weeks of HAART initiation, 70% of the deaths reported by Lusiama within three months, and all of the deaths (n=13) reported by Reddi within five months [26,36,39]. This finding is consistent with the experience of other paediatric HIV treatment programmes in resource-limited settings [2].

Three articles identified predictors of mortality and LTF in family care cohorts. Reddi *et al* report that HIV-positive caregivers showed a protective effect against mortality when compared with caregivers who were untested or HIV negative [26]. Lusiama *et al* compared children in the family care cohort both with and without participating family members, and found that the rate of deactivation/death was higher among children without a family member participating in the programme [24]. A three-year retrospective case-control-matched study of children on ART enrolled at the Baylor Center of Excellence family clinic in Lilongwe, Malawi, and children receiving routine paediatric ART revealed better outcomes in family clinic cases compared with controls regarding retention in care, death, LTF, stopped ART, and transfer to other ART sites [25].

Discussion

Limitations

Due to the emerging and evolving nature of the family-centred care model, no fixed definition exists to facilitate the classification of programmes as family-centred or not. Consequently, studies included in this review were chosen on the basis of self-identification. Additionally, no consistency across studies exists with regard to programme components or data collection, precluding rigourous comparison and evaluation. Given the low number of peer-reviewed publications on this topic, a significant number of conference abstracts were also included in order to provide a more complete picture of the work being done “on the ground”.

Challenges to care and management – lessons learned

Preliminary data from family-centred care sites suggest that this model can be an effective tool for recruiting HIV-positive women, preventing mother to child transmission, increasing paediatric and adult referrals, supporting patient adherence and clinic attendance, and improving paediatric clinical outcomes. The data also describe a number of challenges encountered by programmes in their efforts to provide comprehensive health care for the whole family.

The majority of programmes described here reported challenges in recruiting one or more types of family members: females, males and children. Those with robust paediatric cohorts often struggled to recruit parents, and those with large numbers of HIV-positive mothers in care had great difficulty recruiting male partners and children. Fathers were the least likely to access care in all scenarios: as Tonwe-Gold wryly observed, involving males in family services like MTCT-Plus “is known to be very taxing” [27].

Failure of HIV-positive females to disclose their status to male partners has been well documented: fear of accusations of infidelity, abandonment, discrimination, loss of economic support, and violence are often cited as primary reasons. These fears are not groundless. A review of 17 studies found that between 3.5% and 14.6% of women reported experiencing a violent reaction from a partner following disclosure; other negative outcomes included separation from partner, abuse by in-laws, or being forced to move away from home [40]. Low levels of disclosure may negatively affect not only the likelihood that fathers will enrol in care, but also that mothers will seek testing and treatment for their children.

Several studies described the failure of the “trickle-down” method of paediatric enrolment. The assumption that adults in care will refer their children for testing and treatment is not borne out by the clinical evidence and requires serious reconsideration.

Children living with extended family are made particularly vulnerable to exclusion from treatment. By 2010, it is estimated that 20 million children in sub-Saharan Africa – 12% of all children in the region – will have been orphaned by AIDS [41]. In Namibia, Tanzania and Zimbabwe, the United Nations Children’s Fund (UNICEF) reports that grandmothers are responsible for the care of 40% to 60% of orphaned children. According to Mudzingwa and Reddi, non-parental caregivers are significantly less likely to know their own status, and thus to be in care for HIV [26,42]. Therefore, family-care models that depend solely on adult index patients are likely to miss the substantial proportion of HIV-positive children who live with non-biological caregivers.

DeGennaro suggests that family-centred programmes are able to “locate infections at earlier disease stages”, and there is some tentative data to support their success in this endeavour [43]. Although age of enrolment is not an ideal surrogate for disease stage, it is the best indicator available, and there is likely to be some overlap between the two. Half of the family-centred HAART cohorts had a median paediatric cohort age of <5 years, whereas a review of paediatric antiretroviral cohorts in sub-Saharan Africa showed that only about ¼ of their cohorts had a median age of <5 years [1].

MTCT-Plus programmes have documented particularly strong results: in Uganda, less than 1% of HIV-exposed infants in the programme died before testing [32]. Abrams *et al* reported that in 2004, a remarkable 37% of the paediatric cohort at all MTCT-Plus sites worldwide was less than one year of age [19]. However, it is necessary to find ways to replicate this success with infants who have a greater risk of infection, such as those whose mothers did not participate in MTCT.

The frequency of paediatric deaths at the onset of HAART, documented by Reddi, Eley and Lusiama, reflects a much larger trend across paediatric HIV treatment models. Sutcliffe, in a comprehensive review of paediatric HIV cohorts in sub-Saharan Africa, reports that “most deaths occurred within 6 months of treatment, with several studies reporting a mean or median time to death of 57-182 days” [2]. Identifying high-risk patients at the onset of treatment is an urgent necessity, especially in family-centred care settings where family members receiving treatment at the same site are well-positioned to serve as allies in the care of the high-risk child.

Finally, many of the programmes reviewed here have structural difficulties that limit their ability to provide comprehensive paediatric and adult care. A survey of non-governmental organizations by DeGennaro reveals “lack of healthcare workers trained in pediatrics” as the most common reason for the failure to provide treatment to children with HIV [44]. This sentiment is echoed in surveys of barriers to paediatric care in Zambia [45], South Africa [46] and district hospitals throughout Africa [47]. In Malawi, Lesotho, Swaziland and Botswana, per capita numbers of paediatricians range from 0.2 to 2.5 per 100,000 children [48].

Even trained staff can be overwhelmed by the increased volume of patients, or may view the attention to paediatric care in addition to adult care as an unnecessary burden. Finally, the simple logistics of finding space for additional programming at already overcrowded clinics may be difficult. In a community-based government health clinic in Kenya, "There was limited physical capacity of the clinics to provide child-specific activities and rooms" [29].

Recommendations and interventions – a way forward

1. Goal 1: Expand patient recruitment efforts

New methods of patient recruitment must be incorporated into family-centred care provision if more children are to be diagnosed, and diagnosed at earlier stages of illness. A variety of opportunities present themselves, including: immunizations, postpartum care, sick/well baby clinics, and inpatient paediatric wards. These sites would allow identification of both symptomatic and asymptomatic children, and include children with non-biological caregivers who might otherwise be missed in a parent-centred care and recruitment model. Studies addressing the acceptability of such interventions have found that routine HIV counselling and testing could be successfully incorporated into immunization clinics, paediatric inpatient wards, malnutrition treatment programmes and paediatric emergency departments with high parental acceptance rates [49-52].

It is also important to develop thoughtful, context-specific interventions both to support adult HAART patients' referral of their partners and children, and to encourage the caregivers of paediatric HAART patients to be tested themselves. These efforts need to take into account the very real danger faced by many women worldwide when disclosing their status to a partner. Counsellors should be trained to identify women most at risk for negative outcomes, and provide additional support, including referral to domestic violence services when necessary [40].

Interventions that might support the positive participation of males in HIV testing and treatment include utilizing male health care workers and counsellors, and establishing "fathers' clinics" or similar male-centred activities as an opportunity for education and peer support [53].

2. Goal 2: Pay special attention to children during the first six months of HAART

While not specific to family-centred care, the unacceptably high risk of mortality for paediatric patients during the first six to 12 months of HAART needs to be addressed by all paediatric providers.

Integration of family-centred services may be useful in mitigating some of these risks. Incorporating therapeutic and supplementary feeding with HIV treatment programmes could support patients who are malnourished, and combining HIV care with TB screening and treatment might result in a lower TB incidence at baseline. Reddi *et al* recommend children identified as high risk at baseline be referred to paediatric inpatient wards or a local palliative (step-down) care centre for HAART initiation [26]. Other simple measures could include scheduling more frequent follow-up appointments after initiation, or treatment counsellor home visits. With the appropriate support, adult family members in care at the same treatment site could provide invaluable support and expertise during this treacherous time.

3. Goal 3: Develop comprehensive services

At this point, it is difficult to identify which components of a family-centred care programme might be the most crucial and efficacious. Tolle, in advocating for a package of primary health services for comprehensive family-centred HIV/AIDS care, acknowledges that "implementing (packages) will require substantial and long-term investments in infrastructure and human resources". However, in the short term, services packages may present "a framework around which a programme may construct its own particular model of care, providing those services for which it is able while finding a reference point for the development of its future capacities" [15].

Additionally, establishing a consensus as to which interventions define family-centred care would allow researchers not only to independently validate discrete interventions, but also to compare broadly the effects of a standardized set of interventions comprising "family-centred care" versus more traditional segmented adult and paediatric care.

For these reasons, we suggest here, in Table 2, a "wish list" of services, compiled from the recommendations of Tolle, Richter, DeGennaro, and DeBaets [15,43,47,54].

Conclusions

Family-centred care can be implemented in developed and developing world settings. Although data is currently limited, and additional research is urgently required, family-centred care produces good outcomes in terms of service uptake, clinical outcomes, adherence and retention.

Important considerations for future programming include building personnel and infrastructural capacity, innovating methods for testing hard-to-reach populations within the family, identifying and implementing specialized services for high-risk populations early in treatment, and providing a full range of comprehensive services for all family members. Additionally, more consistent documentation of programme experiences,

Table 2. Family-centred care "wish list"

HIV + TB care	Paediatric + adult primary care	Psychosocial/economic support	Administrative
• PMTCT • VCT, including viral diagnostic tests for early infant diagnosis • Opportunistic infection prophylaxis • HAART for adults and children • Regular TB screening, INH prophylaxis, and treatment	• Immunizations • Growth monitoring • Routine neurodevelopmental assessments • Nutritional supplementation and infant feeding support • Reproductive health services, including cervical screening and STD care • Family planning services • Insecticide-treated bed nets, malaria screening and treatment • Management of other endemic disease (e.g., helminths) • Management of chronic illness: cardiovascular disease, Type II diabetes, hyperlipidemia • Safe drinking water • Pain management and palliative care • Home health visits for pregnant mothers and young children	• Adherence counselling for adults and children • Psychosocial support for both HIV+ and HIV- caregivers, including substance abuse, mental health, and domestic violence education • Psychosocial support for children: social and educational activities • Early childhood development programmes • Subsidized patient transport to and from the clinic • Income assistance	• Follow up and patient tracking • A tight network of referrals and linkages with community-based organizations • Monitoring and evaluation systems

Tolle, Degennaro, DeBaets, and Richter [15,43,47,54]

and efforts to reach consensus around key definitions, would promote the development of understanding of how, and when, family-centred care is most effective.

Additional File

Additional File 1. Family-centred care programme data (Word document).

Competing interests

The authors declare that they have no competing interests.

Authors' contributions

SCL undertook the study concept and design, and analysis and interpretation of data. BTM, JFF and TPF were responsible for critical revision of the manuscript for important intellectual content. All authors have read the final manuscript and approved it for publication.

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REVIEW **Open Access**

Fathers and HIV: considerations for families

Lorraine Sherr*

Abstract

Background: Fathers are intricately bound up in all aspects of family life. This review examines fathers in the presence of HIV: from desire for a child, through conception issues, to a summary of the knowledge base on fathers within families affected by HIV.

Methods: A mixed-methods approach is used, given the scarcity of literature. A review is provided on paternal and male factors in relation to the desire for a child, HIV testing in pregnancy, fatherhood and conception, fatherhood and drug use, paternal support and disengagement, fatherhood and men who have sex with men (MSM), and paternal effects on child development in the presence of HIV. Literature-based reviews and systematic review techniques are used to access available data Primary data are reported on the issue of parenting for men who have sex with men.

Results: Men with HIV desire fatherhood. This is established in studies from numerous countries, although fatherhood desires may be lower for HIV-positive men than HIV-negative men. Couples do not always agree, and in some studies, male desires for a child are greater than those of their female partners. Despite reduced fertility, support and services, many proceed to parenting, whether in seroconcordant or serodiscordant relationships. There is growing knowledge about fertility options to reduce transmission risk to uninfected partners and to offspring.

Within the HIV field, there is limited research on fathering and fatherhood desires in a number of difficult-to-reach groups. There are, however, specific considerations for men who have sex with men and those affected by drug use. Conception in the presence of HIV needs to be managed and informed to reduce the risk of infection to partners and children. Further, paternal support plays a role in maternal management.

Conclusions: Strategies to improve HIV testing of fathers are needed. Paternal death has a negative impact on child development and paternal survival is protective. It is important to understand fathers and fathering and to approach childbirth from a family perspective.

Background

Fathers are intricately bound up in all aspects of family life. Family issues play a part in determining life roles, goals and social environment [1] . Yet within the HIV field, fatherhood is understudied. This is a shortcoming, given that HIV itself is predominantly a sexually transmitted infection, closely intertwined with human reproduction and intimate relationships. As fathers have input over the life course, from conception and birth attendance to child rearing, parenting and grandparenting, their absence in the literature is stark.

This paper discusses a variety of fathering issues in the presence of HIV infection. Motherhood and parenting are empty concepts if fathers are not consulted, and any sociological or psychological study of families will confirm the central roles that relationships and fathers play. The paper should be read in conjunction with the paper by Hosegood and Madhavan [2] in this *Journal of the International AIDS Society* supplement, which may provide some explanatory pathways for the absence of data on fathers and the underrepresentation of paternal insights and views within the literature.

Methods

The review focuses on seven topics, which, although not exhaustive, provides a synthesis of the existing literature. This takes the form of systematic reviews when there is a sufficient body of data and original empirical data.

The topic, desire for a child, is covered by summarizing the current literature on desire for a child and conducting a specific systematic search on studies looking at childhood desires among men. The coverage was based

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*Correspondence: sherr@pcps.ucl.ac.uk
University College London, Research Department of Infection and Population Health, London, UK

on a previous systematic review [3] updated and adjusted to focus on men using Pubmed, the Cochrane Database and Psychlit. The search used the key terms, "fertility desire", "pregnancy", "reproductive decision making", "reproductive intentions", "motherhood", "fatherhood", "fathers", "men", "males" and parenthood". Papers were then restricted to those which included mention of HIV and AIDS.

The topics of HIV testing in pregnancy, fatherhood and conception, fatherhood and drug use, paternal support and disengagement were summarized and reviewed based on a synthesis of published literature. For these topics, the paucity of data rendered a systematic review inappropriate.

The topic, fatherhood and men who have sex with men (MSM), was reviewed based on a synthesis of published literature and supplemented by original data from a survey of male HIV clinic attendees. This information was gathered in the UK. [4] . The published data from this study focused on heterosexual, HIV-positive men (n=32). For the purpose of this report, the data from 84 men who self-reported their sexuality as MSM" were included.

Questionnaire responses were gathered from consecutive male attendees at a London HIV clinic (n=168) in a study approved by the local ethics committee. One hundred and sixteen men agreed to participate (69.1% response rate). Of these, 84 (72.4%) self-reported their sexuality as MSM signed an informed consent form, were provided with information as to the purpose of the study, assured of anonymity and completed a detailed 17-item questionnaire. The questionnaire included an examination of background demographic issues, parenting experience, attitudes toward parenthood, information needs in relation to reproductive support and service provision, decision making and possibility of unprotected sex, and the meaning of fatherhood.

Questions were rated on Lickert-type or forced choice scales, derived from scales previously utilized in a study of maternal attitudes to parenting in the presence of HIV infection. The data was analysed using SPSS

The section, Fatherhood and child development, was based on the findings from the Joint Learning Initiative on Children and AIDS report [5]. A systematic review of child outcome, orphaning and HIV formed the basis of this report. Data on paternal death were extracted for this article.

Results

Desire for a child

For men, fertility, status and lineage considerations all contribute to fertility desires. Most men reside in pronatal societies. Antle *et al* [1] described the importance that parenting has to people living with HIV, who saw it as a joyous part of their lives. In a large US representative sample of HIV-positive males, 28-29% desired children in the future [6].

A systematic review [3] of pregnancy desires identified 29 studies exploring reproductive intentions among HIV-positive groups of people internationally. Twenty were studies of women only, seven explored views of men and women, and two examined the views of men exclusively.

Data on men who have sex with men and bisexual men are particularly elusive. Indeed, some studies on parenting desires conducted among HIV populations specifically exclude men who e have sex only with men [6,7] . Men continue to desire fatherhood in the presence of HIV, whether from the United Kingdom [4], South Africa [8,9], Brazil [10,11] or Uganda [12]. In one study in Uganda, men were more likely than women to desire children in the presence of HIV [13]. This was confirmed in a study in Nigeria [14], which also showed a desire for multiple children by men who were newly diagnosed and who had not disclosed their status. A USA study of 2864 people living with HIV showed that 59% of males expected to have a child in the future, but 20% of their female partners were not in agreement [6].

Yet when men and women with HIV are compared to HIV-negative groups, relatively lower fertility desires are reported. A study in Uganda showed a six-fold decrease in desire for children in the presence of HIV [12].

A systematic review of the terms, "pregnancy intentions in HIV" and "males/men", was carried out. The term, "pregnancy intentions", generated 1 122 studies, but when combined with HIV, this reduced to 66. When combined with "men and/or male", 28 studies remained. Hand sorting to meet inclusion criteria (male data, quantitative or qualitative methodology, pregnancy intention outcomes) revealed 14 relevant studies, 10 quantitative and four qualitative. These studies are summarized in Table 1.

Table 1 shows consistent reports of a desire for fatherhood, with one qualitative study noting that none had "extinguished" the desire for a child. Despite this desire, many studies report a lack of information, services, advice and support.

HIV testing in pregnancy

HIV testing in pregnancy has become a standard facility available within pregnancy care. Yet, historically, this has been focused on women, with few attempts to include partners, despite the fact that it is highly cost-effective to offer screening to male partners [16] to record discordancy and to reduce the possibility of transmission of HIV during pregnancy. Late HIV infection during pregnancy may result in undetected HIV, missed opportunities for antiretroviral treatment and an elevated chance of vertical transmission. Policy has been very slow

Table 1. Summary of studies looking at pregnancy and reproduction intentions among men with HIV

Study	Country	N	Gender (sexuality if given)	Fatherhood finding
Paiva *et al* 2003 [10]	Brazil	250	Men	43% desired children. Low support and input from health care and reproductive health providers.
Paiva *et al* 2007 [11]	Brazil	739	Women (533), men (206): bisexual and heterosexual	Desire for child (27.9%) more frequent among men than among women (50.1% versus 19.2%). Bisexual men more likely to desire biologic children. Male gender, younger age, having no children, living with 1-2 children, and being in a heterosexual partnership were independently associated with desire to have children.
Heys *et al* 2010 [12]	Uganda	421 (199 HIV+, 222 HIV-)	Men (36%) and women (64%): heterosexual	Odds ratio of wanting to stop childbearing was 6.25 times greater (p <0.01) for people living with HIV.
Sherr & Barry 2004 [4]	UK	32	Men (heterosexual)	59% said fatherhood gave meaning to their lives, high fertility desire, low support and access to health care input on reproduction.
Sherr & Barry 2003 [66]	UK	84	Men (MSM)	77.6% said there was no discussion with a doctor about becoming a parent. 68.2% felt they were not sufficiently informed.
Chen *et al* 2001 [6]	USA	1421	Men and women ** (M= bisexual or heterosexual, F= heterosexual)	59% of men expect to have a child. 20% of men who desire child have a partner who does not desire child.
Cooper *et al* 2009 [8]	South Africa	459	Men (174) and women (285): heterosexual	57% of men were open to possibility of having children. Intention associated with being male, having fewer children and ART treatment.
Nakayiwa *et al* 2006 [13]	Uganda	1092	Men (408) and women (604): heterosexual	Men 4 times more likely to want children than women.
Oladapo *et al* 2005 [14]	Nigeria	147	Men (52), women (95): heterosexual	71% of men intended to have a child (or more than one). Non-disclosure of HIV status to partner increased odds of child desire.
Panozzo *et al* 2003 [7]	Switzerland	114	Men (68) and women (46) **	38% expressed a desire for children, women more often than men.
Cooper *et al* 2007* [89]	South Africa	61	Men and women	Strong reproductive desires; treatment availability enhanced such desires.
Ko and Muecke 2005* [90]	Taiwan	8	Men and women	Optimism and high information seeking.
Smith and Mbakwem 2007* [91]	Nigeria	22	Men and women	Treatment enables reproductive goals for both men and women.
Ndlovu V *et al* 2009* [15]	Zimbabwe	15	Couples (men and women, at least 1 HIV+)	Treatment availability transformed intentions. None had extinguished intentions.

* = qualitative studies
** = studies which specifically excluded men who have sex with men exclusively

to change, despite the fact that testing women only is counterproductive, enhances stigma and leaves men out of the cycle of medical care [17].

Studies on couples testing show this approach to be viable. It results in reduced stigma, enhanced treatment uptake and reduced risk exposure in the event of discordancy [18,19,20]. Male partner testing is increased when women attending antenatal clinics are requested to invite their partners to attend [21,22]. Couple counselling has shown greater levels of disclosure and acceptance [21-22]. Women are more willing to accept HIV testing in pregnancy if their partners are tested at the same time [23] or even simply attend the clinic with them [24]. The converse is also true in that fear of negative responses from male partners is a disincentive to women testing [25,26]. Yet randomized, controlled trials show low uptake of couples testing, and innovation is needed to reach out more systematically to men [27].

It is also curious to note that HIV testing has been confined to antenatal care with no parallel provision in family planning [28], termination of pregnancy clinics [29] or well-men (or women) clinics. This probably reflects a focus on the infant and may be short sighted. Provision for men at multiple venues may be a more effective strategy.

Fatherhood and conception

Conceiving a baby is an issue of heightened concern in the presence of HIV. The advent of new therapies and the growing knowledge base has meant that parenting in the presence of HIV is a realistic option [30,31]. Attainment of fatherhood in the presence of HIV is affected by discordancy and by which partner is HIV positive. Interventions concentrate on reduction of viral load, which in turn reduces (but does not eliminate) risk of infection.

The key considerations relate to the risk of infection at the point of conception, reduced fertility as a result of HIV infection, prevention of infection to the infant, and access to support and services in the process of conception and pregnancy. Fertility care and treatment is well established as an HIV-associated service need. In 2001, 75% of fertility clinics surveyed in the UK had a policy of offering treatment to HIV-positive couples [32].

Reduced fertility and problems in conception have been reported in many couples who wish to have a baby, but who do not want to expose an uninfected partner to HIV [33]. Reduced motility of sperm has been noted in the presence of antiretroviral treatment [34,35]. Treatment access is often limited, with ethical and referral barriers reported. Infertility problems were confirmed in a Spanish study [36] with abnormal semen parameters in 83.4% of HIV-infected and 41.7% of HIV-uninfected partners of 130 HIV-positive women. In an African study, there was a high level of risk exposure for non-infected male partners of HIV-positive women desiring pregnancy [37].

Where the man is HIV positive, conception has been documented in the presence of semen washing and in timed unprotected sex. For HIV-positive men, there are four options [38]. Three remove the possibility of genetic parenting: donor sperm insemination (which reduces the risk of viral transmission), fostering and adoption. Sperm-washing techniques have been well described for a number of years and are based on the finding that HIV does not attach to live sperm [39-44]. The techniques require high-level technological provision and have been well established as effective, with minimal risks of infection to either the infant or the partner [45-47,30].

Strategies for harm reduction for couples with no access to treatment [49] try to limit exposure of the uninfected partner. The risk of transmission from an HIV-positive man to an HIV-negative woman in studies in the West is quoted as 0.1-0.3% per act of intercourse [49-51]. This may be elevated in the presence of co-infections. The risk of transmission from an HIV-positive woman to an uninfected man is somewhat lower.

Antiretroviral treatment may affect semen viral load. A review of 19 studies concluded that undetectable viral load in semen was possible with effective treatment, and was negatively influenced by poor adherence to treatment and the presence of other sexually transmitted infections [52]. Caution is consistently needed as studies have also established definitive viral shedding, even in the presence of full viral suppression [53-55]. A number of studies have attempted to evaluate the risk of infection to partners when conception is attempted. This varies by viral load, condom use outside of the fertility window and treatment status of the HIV-positive partner [56-59].

When the woman is HIV positive and the man is HIV negative, infection of her partner can be avoided by using artificial insemination techniques. When both partners are concordant for HIV, there is no risk of transmission, but there is potential for super infection with a different (and possibly drug-resistant) viral strain. To avoid this, artificial insemination procedures can be considered [38].

Fatherhood and men who have sex with men

Men who have sex with men (MSM) have traditionally fathered children in a number of ways, including having children in a previous or concurrent heterosexual relationship [60], forming a partnership with a woman [61], and using artificial insemination, semen donation or surrogate arrangements. They also become fathers by adoption and fostering children.

There has been a distinct lack of focus on the value of children for men who have sex with men (MSM) generally and HIV-positive, MSM specifically. A study in six US cities estimates that more than 7% of MSM and at least one-third of lesbians are parents [61]. Those men who do wish to become parents must overcome pressures of societal “norms” regarding who or what makes the best family. This is heightened for MSM, HIV-positive men, who, if they want to become parents, must overcome additional obstacles.

The thoughts and expectations of HIV-positive women have been researched, but those of men have been neglected. Prior to the HIV epidemic, Bigner and Jacobson (1989, 1992) investigated the value of children to MSM and heterosexual fathers. Comparisons between the two groups found that MSM fathers did not differ significantly in their desires to become parents, although their motivations for becoming parents were significantly different [62-64]. This was noted in differences on two motivational measures, namely tradition-continuity-security and social status.

A review of 23 empirical studies from 1978 to 2000 among children of lesbian mothers or MSM fathers (one Belgian/Dutch, one Danish, two British, and 18 North American) showed that the majority (20) reported on offspring of lesbian mothers, and three on MSM fathers. The study included 615 children with a wide age range who were contrasted with 387 controls on a series of measures. Children raised by lesbian mothers or MSM fathers did not systematically differ from other children on any of the seven outcome domains, including emotional functioning, sexual preference, stigma experience, and gender role behaviour [65].

Data on HIV-positive men in London were available for both heterosexual and MSM clinic attendees [4,66]. Of the 84 MSM, 77.6% had not had any discussion with a doctor or nurse about the possibility of becoming a parent, with 68.2% feeling insufficiently informed. Approximately one-third had considered having children. Four had had a child prior to HIV diagnosis. Only 4.7% felt that they were fully informed about the issue, and 77.6% had not had any discussion with healthcare professionals about becoming a parent. Few men (4.7%) had considered sperm washing and no men had undergone sperm washing.

Three men reported fathering as a result of an unplanned pregnancy and four men had been involved in a planned pregnancy. More than half of the men questioned said that they would not have unprotected sex in order to conceive, although 38.2% would consider artificial insemination, 2.9% would definitely consider adoption, and 10.6% would definitely consider fostering. More than 90% believed that they would experience some discrimination. Of the sample, 29.4 % believed that a child gave meaning to life, and 60% agreed with the statement that a baby would give them something to live for.

It is clear that significant proportions of HIV-positive MSM want children and would use a variety of routes to having a child if the opportunity was offered to them.

Fatherhood and drug use

In many countries, HIV infection among heterosexual groups is clustered around drug use as a risk factor. The issues surrounding fatherhood, HIV and drug use may have a direct effect on families. A study comparing drug-using fathers with a matched control group (n=224) noted that drug use contributed to compromised fathering [67] . These results may reflect a skewed group as the drug-user fathers in this study were recruited from methadone maintenance programmes and may thus reflect a group already motivated to address or control their drug use and in contact with services.

Despite this potential positive bias, there were significant negative effects impacting on economic resources to support family formation, patterns of pair bonding, patterns of procreation and parenting behavior. The opioid-dependent fathers displayed: constricted personal definitions of the fathering role; poorer relationships with biological mothers; less co-residence with their children; lower economic provision; less parenting involvement; lower self-esteem as a father; and lower parenting satisfaction ratings. The researchers point out that such compromised fathering in itself may cause psychological distress to the father, as well as impaired parenting experience to the child [68].

A study of the adolescent children of drug-using, HIV-positive fathers (n=505) found direct associations between paternal distress and adolescent distress [69]. In addition, they described several indirect pathways, such as the link between paternal distress and impaired paternal teaching of coping skills, adolescent substance use, and ultimately, adolescent distress. They also report on a direct link between paternal drug addiction and/or HIV and adolescent distress. These data suggest that both drug use and HIV impact directly on fathers, as well as on their ability to parent their children.

Fathers and support of HIV-positive mothers

Although an understudied area, fathers are generally involved in pregnancy and their support may be key in a number of outcomes [84]. Studies that overlook paternal involvement run the risk of missing a crucial element in family composition, family dynamics and decision pathways. Male involvement in feeding decisions has been associated with increased ease of uptake of exclusive breastfeeding [70,71,72].

On the other hand, lack of male involvement or fear of male negative reaction has been clearly associated with lowered uptake or avoidance of HIV prevention and protection measures [73,74]. Although many women fear negative reaction from partners when HIV-positive status is disclosed, studies have often recorded positive responses, such as support and financial assistance [75]. Disclosure patterns may often be culturally affected, and it is important to understand who the most desired disclosure contacts are [76].

Paternal disengagement

Within the HIV literature, there is a background echo, which may well be part of an ongoing myth, around paternal disengagement. Paternal disengagement is a concept that may need to be challenged in the absence of sound global data. Positive engagement in household life by men was reported in a longitudinal South African study. This positive engagement was often not supported or acknowledged [77].

There is good evidence that involving men and providing for risk reduction, particularly for men, can be effective. A systematic review of interventions for men and boys provided compelling evidence of the efficacy of such interventions, thus showing that interventions do exist and are effective and the barrier is one of reaching out to men rather, than the absence of effective tools to do so [78].

Yet there may be some variations and shifts in traditional roles, responsibilities and responses. HIV-positive mothers were interviewed in Uganda to explore paternal involvement, as well as paternal kin support and future placement plans [79]. They found that half had fathers who were already deceased, one-third had fathers who were alive but non-resident with their children, and only 16% were residing with their fathers and being

Table 2. Effect of paternal death on child outcome

Study	Design	Sample	Father findings
Thurman *et al* 2006 South Africa [92]	Comparison of orphan and non-orphan youth (age 14-18)	N=1694, 31% classified as orphan	Significantly more likely to have engaged in sex compared with non-orphans (49% vs. 39%). After adjusting for socio-demographic variables, orphans were nearly one and half times more likely than non-orphans to have had sex. Among sexually active youth, orphans reported younger age of sexual intercourse, with 23% of orphans having had sex by age 13 or younger compared with 15% of non-orphans.
Beegle *et al* 2009 [93]	Compared groups who lost a parent aged <15 and those who did not	N=718. Longitudinal study 1990-2004	On average, children who lose their mother before the age of 15 suffer a deficit of around 2cm in final attained height (mean 1.96; 95% CI 0.06-3.77) and 1 year of final attained schooling (mean 1.01; 95% CI 0.39-1.81). This effect was permanent. Father's death is a predictor of lower height and schooling as well.
Vreeman *et al* 2008, Kenya [94]	Association between ART adherence and parental death.	1516 0-14 year olds	33% had both parents living when they started ART. 21% father dead, 28% mother dead, and 18% both parents dead. The odds of ART non-adherence increased for children with both parents dead.
Birdthistle *et al* 2008, Zimbabwe [95]	Comparison between orphans and non-orphans (half experienced parental death).	839 adolescents	Increased sexual risk (HSV2 positive, HIV positive or ever pregnant) among maternal orphans (aOdds Ratio=3.6; 95% CI 1.7-7.8), double orphans (aOdds Ratio=2.4; 95% CI 1.2-4.9), and girls who lost their father before age 12 (aOdds Ratio=2.1; 95% CI 0.9-4.8) but not later (aOdds Ratio=0.8; 95% CI 0.3-2.2). Maternal and double orphans likely to initiate sex early, have had multiple partners, and least likely to use a condom at first sex and to have a regular sexual partner.
Hosegood *et al* 2007, Malawi Tanzania South Africa [96]	1988-2004 data from 3 DSS surveys	Incidence of orphanhood doubled over time	Increased orphan prevalence in 3 populations. Paternal death substantially higher than maternal death. Pattern of co-residence in non-orphans predictive of orphan pattern. 77% paternal orphans live with mother and 68% maternal orphans live with father.
Ford & Hosegood 2005 South Africa [97]	Effect of parental death on child mobility	39,163 children 0-17	Survival status and residency of both mother and father affected mobility. Fathers' death from AIDS was not significantly different from other causes of death.
Doring *et al* 2005 Brazil [98]	1998-2001 AIDS mortality and healthcare registry data, 1131 orphans identified, 75.4% participated	Survey data	70% had lost their father and 50% their mother, and 21% had lost both parents. At the time of the survey, 41% of the children lived with the mother, 25% lived with grandparents and 5% lived in institutions. In multivariate analysis, HIV positivity multiplied the child's chances of living in an institution by a factor of 4.6, losing a mother by 5.9, losing both parents by 3.7.
Watts *et al* 2005 Zimbabwe [99]	1998-2000 open cohort follow-up data		Paternal orphan incidence (20.2 per 1000 person years) higher than maternal (9.1 per 1000 person years) and maternal orphans lost fathers at a faster rate than paternal orphans lost their mothers. Paternal and maternal orphan incidence increased with age. Incidence of maternal orphanhood and double orphanhood among paternal orphans rose at 20% per annum. More new paternal and double orphans had left their baseline household. Mortality higher in orphans with the highest death rates observed amongst maternal orphans.
Nyamukapa *et al* 2005 Zimbabwe [100]	Stratified population survey at 12 sites (1998-2000)		Maternal orphans but not paternal or double orphans have lower primary school completion rates than non-orphans in rural Zimbabwe. Sustained high levels of primary school completion among paternal and double orphans, particularly for girls, result from increased residence in female-headed households and greater access to external resources. Low primary school completion among maternal orphans results from lack of support from fathers and stepmothers and ineligibility for welfare assistance due to residence in higher socio-economic status households.
Crampin *et al* 2003 Malawi [101]	1106 offspring of HIV-positive diagnosed adults in 1980s		Death of HIV-positive mothers, but not of HIV-negative mothers or of fathers, was associated with increased child mortality. Among survivors who were still resident in the district, neither maternal HIV status nor orphanhood was associated with stunting, being wasted, or reported ill-health.
Lindblade *et al* 2003 Kenya [102]	Compared non-orphaned children under 6 years with those who lost one or both parents	N=1190	7.9% lost one or both parents (6.4% father, 0.8% mother and 0.7% both parents). No difference between orphans and non-orphans regarding most of the key health indicators (prevalence of fever and malaria parasitaemia, history of illness, haemoglobin levels, height-for-Age z-scores), Weight-for-height z-scores in orphans were almost 0.3 standard deviations lower. This association was more pronounced among paternal orphans and those who had lost a parent more than 1 year ago.
Thorne *et al* 1998 European Collaborative Study [103]	Survey study	1123 children born to HIV-infected women, followed prospectively	70% children cared for by their mothers and/or fathers consistently in their first four years of life, by age 8 approximately 60% will have lived away from parents (i.e., with foster or adoptive parents, other relatives or in an institution), irrespective of child HIV status. Maternal injecting drug use, single parenthood and health status were the major reasons necessitating alternative care.
Kang *et al* 2008 Zimbabwe [104]	Comparison of orphan versus non-orphan girls	N=200	Maternal orphans were more likely to be in households headed by themselves or a sibling, to be sexually active, to have had a sexually transmitted infection, to have been pregnant, and to be infected with HIV. Paternal orphans were more likely to have ever been homeless and to be out of school.

Continued overleaf

Table 2. Continued

Study	Design	Sample	Father findings
Parikh *et al* 2007 South Africa [105]	Comparison of orphan and non-orphan children aged 9-16	N=174; 87 orphans , 87 non-orphans (13 maternal, 30 paternal, 26 double, 19 missing info)	No significant differences in most education, health and labour outcomes. Paternal orphans more likely to be behind in school. Recent mobility positive effect on school outcome.
Timaeus and Boler 2007 South Africa [106]	Household interviews over time waves	5477 reports on children 8-20 years. (approx. 13% maternal orphans, 26% paternal)	Paternal orphanhood and belonging to a different household from one's father resulted in slower progress at school. Absence of father also associated with household poverty (but did not explain falling behind at school).
Bhargava 2005 Ethiopia [107]	Comparison of Maternal AIDS orphan and other orphans	479 maternal AIDS deaths compared with 574 other maternal deaths	The presence of the father in the household did not significantly affect chances of school participation after maternal death. Presence of father in household positive and significant effects on scores on emotional adjustment. If father prepared meals, positive association with mean scores on 60 items of the Minnesota Multiphasic Personality Inventory.
Foster *et al* 1995 Zimbabwe [108]	570 households comparison of orphan and non-orphan household	81.8% paternal death, 13.6% maternal, 4.5% double	Paternal family caring in only 16% families.

CI = confidence interval; ART = antiretroviral therapy

supported by them. Furthermore, contrary to cultural norms, mothers indicated preference for placement with maternal, rather than paternal, kin.

Families with HIV-positive mothers were compared with families with HIV-negative mothers, and found significant increased paternal absence and disengagement in the families with HIV-positive mothers [80]. In the USA, disclosure of HIV status was seen as similar to other diseases, but fathers disclosed later than mothers [81]. This may reflect clinic practice, and fathers being overlooked or excluded, as much as father behaviour. For example, White reported, “There was HIV discordancy in more than one-fifth of the parents’ relationships. In over 46% of the relationships, the HIV status of the natural or birth father was not known because he was either untested or unavailable” [82]. Such a situation clearly indicates that including and reaching out to fathers is a specific strategy and may need a more family-oriented clinic approach to overcome such gaps.

Fathering an HIV-positive child can bring with it many stressors. Fathers of 31 HIV-positive children aged six to 18 years showed significantly elevated levels of both parenting and psychological distress compared with standardized norms [83]. These fathers requested a range of services, such as gender-specific support groups, assistance with child discipline, help with disease management, and support for future coping.

Fatherhood and child development

Research on child development has increasingly emphasized the importance of fathers [84]. The current era has seen a change in father roles, as well as a growth in understanding of such roles [85]. The literature on child development and paternal role in the presence of HIV is found in the “orphan” literature in studies that differentiate the gender of the deceased parent and explore the impact of paternal death on a variety of child outcomes.

Despite the fact that there is scant literature on the impact of HIV-positive fathers while they are alive, when they die, the ramifications are considerable. Although HIV is a key factor accounting for paternal death, there are other causes of mortality, such as violence, war, other illnesses and accidents. For example, more than a quarter of young South Africans reported that they had experienced a parental death [86]. Parental death in the HIV literature has been clouded by the fact that many studies do not differentiate between single parent death or dual parent death [87]. Furthermore, few disaggregate their data according to maternal or paternal death or proceed to analyze it separately. Those that do (n=17) provide clear insight into the impact of paternal death on child development.

The findings are summarized in Table 2. Father presence exerts a protective factor on a range of child outcomes and age at paternal loss is also important. Paternal death can affect economic environment, maternal mood, maternal health, access to treatment [88], access to schooling, migration from base families, and a number of other health and psychological outcomes. These findings are complex as the effects of paternal death have implications on maternal health and well-being, as well as on child outcomes.

Conclusions

This paper clearly indicates the crucial role of fathers in family life and structure. The piecemeal state of the literature is lamentable. Where there is good evidence, it is clear that fathers and fathering is a central aspect of the HIV epidemic. Fathers play an important role in the family and their assistance can be harnessed if there is sufficient effort. Fathers can support mothers in the difficulties around infant feeding, early weaning and potential HIV disclosure through feeding practices.

Gender studies often explore lack of attention and provision for women, but in terms of family knowledge and response, the HIV literature on men generally and fathers specifically has specific oversights. Within this, some of the marginalized and difficult-to-reach groups are particularly hard hit. Fatherhood in the presence of HIV infection of the father and drug use in developing and resource-constrained countries, and for MSM, is not fully understood. Yet the loss of a father severely impacts on multiple facets of child development. Fatherhood and paternal contribution to families need to move to centre stage.

Competing interests

The author declares that she has no competing interests.

Author's contributions

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REVIEW **Open Access**

Data availability on men's involvement in families in sub-Saharan Africa to inform family-centred programmes for children affected by HIV and AIDS

Victoria Hosegood*[1,2] and Sangeetha Madhavan[3,4]

Abstract

The Joint Learning Initiative on Children and AIDS recently recommended that programmes for children affected by HIV and AIDS in sub-Saharan Africa direct more support to families. Interest has grown in including men in such family-orientated interventions by researchers, policy makers, and community and non-governmental organizations. However, there is a lack of good quality data on men's involvement with children in the diverse settings in sub-Saharan Africa. In addition, limited research has examined their role in providing emotional, material support and protection for HIV- and AIDS-affected children and families.

In this paper, we describe the availability of data about men and families, in particular fathers, in ongoing sub-Saharan African surveys and longitudinal population cohorts. We discuss the conceptual and measurement issues associated with data collection on men's involvement in these types of studies. We consider the opportunities for improving the collection of data about men and families in household surveys and population cohorts in order to inform the design and evaluation of family-centred interventions for children affected by HIV and AIDS.

Introduction

The Joint Learning Initiative on Children and AIDS has recently recommended that families need to be more central in intervention programmes to support children affected by HIV and AIDS in sub-Saharan Africa [1]. The growing body of evidence about the unique contributions that biological and social fathers make to child health, welfare and other outcomes [2-4] has encouraged researchers [1,5-12], policy makers [13], and community and non-governmental organizations [14,15] to explore how men might be engaged in family-centred interventions.

Efforts to develop effective interventions that promote positive involvement by men in the care and support of children face a number of challenges. Although considerable experience has been built up about how to promote maternal involvement with children through interventions, far less is known about how to support the positive involvement by fathers and other men within families. Given the wide variation in family forms and family functioning that exist in sub-Saharan Africa, there are good reasons to anticipate that the levels and types of men's involvement will vary considerably, as will the ways in which this can be promoted and supported [16-18]. Within the region, differences also exist in severity of the HIV epidemic, the impacts on families and households, and the wider economic and political contexts [19].

The importance for family policy and programmes of comprehensive, appropriately conceptualized, reliable and valid data on men's involvement is illustrated by the experience of the United States. Detailed data on fathers has been collected by the National Study on Family Growth [20], the National Longitudinal Study of Youth [21], and the Fragile Families project [22,23]. These data have been used to inform the development of effective policies to support low-income (particularly African-American) fathers and their families [24]. In sub-Saharan Africa, the high cost of specialized family studies means there is a greater reliance on alternative sources of data about men and families [25].

In this paper, we consider the availability of empirical data about men's involvement with families in ongoing surveys and longitudinal population cohorts in sub-Saharan Africa. We focus particularly on the identification of men who are fathers and information about how they contribute to, and are involved with, their children. We highlight conceptual and methodological

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*Correspondence: vicky.hosegood@lshtm.ac.uk
[1]Centre for Population Studies, London School of Hygiene and Tropical Medicine, UK
Full list of author information is available at the end of the article

issues related to data collection, and suggest ways in which data might be improved to inform the design and evaluation of family-centred interventions that engage men in the support of children affected by HIV and AIDS.

We begin our paper by briefly reviewing the socio-demographic impact of HIV and AIDS on families and households and the evidence for men's involvement in affected families. We describe the types of data available about men and families, and discuss the conceptual and measurement issues associated with data collection. We highlight areas for strengthening the availability of data that can be used to inform and evaluate family-centred interventions for children affected by HIV and AIDS. Our paper complements another paper in this issue by Lorraine Sher, which discusses fathering in the context of HIV and AIDS.

Discussion

HIV impact on children and families

Families and the households in which they live are central in shaping the health, development and wellbeing of children [26,27]. In sub-Saharan Africa, the HIV epidemic has placed a severe burden on families over the past two decades, many of which have also faced a wide range of other concomitant social, economic and political adversities.

Recent review papers have examined the evidence for the socio-demographic impact of the HIV epidemic on families and households within the region with respect to living arrangements, fertility, mortality, migration, union formation, and household developmental lifecycles [28,29]. The cumulative impact of HIV and AIDS on families extends beyond the direct demographic and economic impacts of illness and death to encompass the effects on psychosocial wellbeing of indirect consequences of the HIV epidemic, including stigma, grief and family dispersal (for overviews see [1,19]).

The prevalence of all types of orphaning has risen substantially in sub-Saharan Africa, mirroring the increases in adult mortality since the start of the epidemic [30-32]. Empirical multi-country comparative studies using cross-sectional data have most consistently found orphans to be at risk of poorer education outcomes than non-orphans [33], whereas for other outcomes, including growth and malnutrition, the findings are more mixed [34].

The ability of many families to care for and support children has undoubtedly been threatened by the HIV epidemic. The published data and empirical literature, however, consistently show that most affected families and households in sub-Saharan Africa adapt and continue to provide for the needs of children [1]. The majority of orphans have a surviving parent, and most children affected by HIV and AIDS live with parents and other adult family members [30,31]. Multiple studies have shown that the proportion of child-headed households remains small, even in severely affected communities [31,35,36]. One aspect that has received less attention is the role of men in family responses to HIV/AIDS.

Men and families affected by HIV and AIDS in sub-Saharan Africa

Family formation remains strongly linked to childbearing and marriage, even though the domestic arrangements that result are heterogeneous and dynamic in different cultural, demographic, economic and political contexts [37]. These contextual factors influence the way in which family life is organized with respect to membership, roles and responsibilities, including parenting and child care [18,38]. Furthermore, although cultural and social norms specify normative behaviours of men in relation to their own biological children and other children in the family, specific circumstances (e.g., labour migration, extra-marital fertility, multi-partner fertility, divorce or maternal deaths) may lead men to establish new social and residential arrangements regarding children or take on new or modified roles and responsibilities.

Studies investigating family responses to the care and support of children affected by HIV and AIDS in sub-Saharan Africa have focused almost exclusively on the role of mothers, grandmothers and other female relatives. Where data are collected about fathers, the emphasis is typically on financial contributions. Few studies collect information about the family roles and responsibilities of men, other than those of biological fathers.

Despite, or perhaps because of, the limited amount of detailed data about men's involvement in other activities related to children, the findings bolster assumptions about the absence or limited involvement of men, particularly fathers. Assumptions about the involvement of non-resident fathers and other men have been challenged by findings from qualitative studies of men and families in southern Africa [18,39-42].

Re-examining data from an ethnographic study of households in rural South Africa that had experienced adult AIDS illness or deaths, Montgomery *et al* (2006) found that men were positively involved with their families and households in a wide range of ways, including caring for people who were ill, caring for children, undertaking domestic activities, and financially supporting immediate and extended family members. However, the involvement of men in these activities was not readily acknowledged by female respondents or men themselves, nor anticipated by interviewers.

Studies have also shown that men's involvement needs to be understood as part of a kinship network that seeks to meet the needs of children [16,38]. These networks include men; therefore, when biological fathers are unable to meet the needs of their children, their own fathers or brothers may step in and assist. In the context of HIV and AIDS, support to HIV-infected fathers who become ill includes assistance in fulfilling paternal roles and responsibilities [43].

The HIV epidemic has been most severe in southern Africa, where several distinctive family and household characteristics (albeit not unique or universal) have implications for the design of effective family-based interventions that engage fathers and other men. A combination of historical and contemporary social, historical, political and economic factors have resulted in high levels of residential separation of biological fathers and their children. Some of these factors, for example, the apartheid political system and its effects on labour migration, settlement and family separation, are specific to South Africa and neighbouring countries. Others, such as urbanization and increasing marital instability, are increasingly influencing men's experience of family life in other parts of the region.

In southern Africa, many households function as "stretched" residential units with family members "dispersed" between different households [44,45]. Low rates of marriage [46,47], together with cultural norms related to household formation and childbearing, also contribute to the social and residential separation of biological fathers from their children [41]. The majority of young children born to unmarried parents will live with their mothers [48,49].

Data about fathers and children available from survey and population cohorts

The most widely available sources of demographic data on families and households in the region are the Demographic and Health Surveys (DHS) conducted in most countries in the region [50]. Sources of detailed data on sub-national populations are the ongoing Demographic Surveillance Systems (DSS) conducted in several African countries [51]. In addition, there are several ongoing child cohorts and household panel studies that collect data on family structure, parenting, and experiences of HIV and AIDS [52-54]. Currently, surveys and population cohorts collect very limited data about men's involvement with children and families [55]. In this section, we describe commonalities in the available data on men and fathers. We also consider several conceptual and methodological issues related to the types of data needed to inform the design and evaluation of family-based interventions for children affected by HIV and AIDS.

Identity and characteristics of biological fathers

Information about the identity and survival status of children's biological fathers is collected by most household surveys and population cohorts. The identification specifically of biological fathers is not always clearly specified. While the identity of children's fathers is typically restricted to men who are listed in the household roster, most surveys collect information about paternal orphaning for all children in the household. This is usually done by simply asking a household respondent whether the father of each child is alive. Data on paternal orphanhood is used in research studies as a potential risk factor for health and welfare outcomes in children, but can also be used to estimate adult mortality [56].

Where fathers are co-resident household members, information commonly available includes his age, education, employment and marital status. The co-residential arrangements of children and their fathers are documented by surveys and cohorts. However, information about living fathers who are not members of the same household as their child is not usually available.

In household surveys and demographic surveillance systems, the primary sampling and enumeration unit is the household, rather than families. Therefore, specific questions must be asked to establish the identity, characteristics and involvement of fathers living in other households, questions that few large sub-Saharan African surveys or longitudinal studies ask at present. Engaging fathers is a challenge for all family interventions, particularly when fathers are not co-resident with their children, and it is important to understand the specific circumstances in which fathers live apart from their children.

Social fathers

It is important for family research and interventions that information about men's involvement with children is not restricted solely to biological fathers. The person fulfilling the role of father may not always be the child's biological father. Social fathers, a term that includes stepfathers and foster and adoptive fathers, are a common feature in sub-Saharan Africa social and cultural contexts [16,57]. In matrilineal societies, social fathering will often be the responsibility of a child's maternal uncle, even when his or her biological father is living. Men may take on a social fathering role for the children of new partners, for younger siblings or for grandchildren.

Fathering roles may also be performed by women, for example, in situations where children are raised by single mothers or grandmothers. The phenomenon of social fathering is exacerbated by high rates of labour migration, union instability and orphaning due to paternal AIDS deaths. Unfortunately, despite the strong justification that collecting data about social fathers provides a more complete picture of fathering and social protection, such information is seldom collected in sub-Saharan surveys or population cohorts.

Men's involvement in families of children affected by HIV and AIDS

The measurement of involvement by biological and social fathers has been the subject of considerable multi-disciplinary attention [3,4]. Central components of father involvement include paternal engagement, accessibility and responsibility, including economic contributions [58]. However, with the exception of specialized family studies, very limited data about men's involvement is collected by surveys and population cohorts.

Commentators have suggested that the lack of data collection is a reflection of the normative attitudes and stereotypes on the part of researchers and policy makers, who consider African fathers to have limited engagement with children [17]. Information about men's involvement is almost exclusively restricted to questions about biological fathers' co-residence and financial support. However, in South Africa, qualitative research has shown that co-residence of fathers with children is a poor indicator of men's involvement with children [59,60].

In surveys and cohorts, data about father involvement can potentially be collected from the perspective of the child or the father. Each adult man in the household can be asked about his involvement with each child in the household or with any child outside the household. For each child in the household, the type of involvement that his or her biological or social father has can be specifically documented. However, these approaches are rarely used in surveys.

Rather, the more commonly used method is to ask a household respondent to identify which person has "main" or "primary" responsibility for a child with respect to a specific activity, for example, care giving or payment of school fees. Should this person not be the child's father, any involvement by the father in these activities will be unrecorded. One exception is the National Income Dynamics Survey, a South African panel survey that has collected information about financial contributions by biological and social fathers to children within and outside study households [61].

Survey data about men's involvement with children and families in surveys could contribute greatly to the design and evaluation of interventions that seek to engage men in family- or school-based interventions. In longitudinal cohorts, information about father involvement can also be used as a screening tool to: identify children who lack positive support and protection by men within their families, for example, paternal orphans living without other male kin; or to identify positively involved men who may benefit from additional support, for example, co-residential fathers following the death of the child's mother. Routinely collecting data about father involvement with children affected by HIV and AIDS in longitudinal population cohorts may also provide a cost-effective approach to monitoring and evaluating family-based programmes.

How can data collection be improved?

The experience of fatherhood scholarship in developed countries has been that social surveys can be used to collect information about the kinds of activities that resident and non-resident fathers, as well as other men, engage in with respect to children of different ages [62]. However, enhancing the collection of family data in ongoing studies in sub-Saharan Africa requires a balance between the benefits of the additional family data and constraints due to the design and cost of large surveys and population cohorts. One of the benefits of population-based data is the ability to document the way families exist and function in the real world as opposed to the more controlled environment of intervention studies.

However, data collection in nationally representative household surveys and large population cohorts typically rely on proxy reporting. This has implications for data reliability and validity as proxy reporting may lead to selective bias in reports of men's involvement with children and families. For example, family respondents tend to under-report financial contributions by non-resident fathers [63,64].

Undoubtedly, a central challenge to improving data collection on men's involvement in sub-Saharan Africa, and most especially in southern Africa, is the extent of residential separation of men, children and families. The social and economic rationales for including resident and non-resident household members in household surveys has been recognized in the design of many surveys in countries with high levels of migration, for example, South Africa [49,65,66].

It is reasonably straightforward to ask whether each man is involved in activities related to each child in the household. Basic characteristics of these men are already collected as part of the survey. However, information about any contributions or involvement by men that are not listed on the household roster will have more value for research if it is linked with other data about the man, for example, the type of relationship he has with the child and the child's mother, and his socio-demographic characteristics. This data would usually need to be obtained from a proxy respondent.

Interviewing men themselves may also be a strategy in enhancing data on men's involvement. This option is particularly attractive in household surveys that already administer adult questionnaires, for example, to collect data on income or reproductive health. Sampling of men from the household roster would not include fathers or other involved men outside the household. Family studies have shown that it is possible to contact and interview "hard-to-reach" non-resident fathers, although this can be very resource intensive and subject to gatekeeping by household members, particularly mothers [67]. Were surveys to collect data on father involvement from proxy respondents and men themselves, it would be important to examine the reliability and validity of multiple sources of data [64].

In summary, data collection to support intervention research can be improved by: (i) collecting information about the identity and involvement of social and biological fathers within and outside the study household; (ii) extending data collection efforts to include non-resident fathers and other family members given the context of dispersed families and high levels of migration in sub-Saharan Africa; (iii) collecting information that reflects the inter-dependence of family members and the existence of multiple family environments providing care and support to children; (iv) assessing the reliability and validity of data about fathers and father involvement reported by proxy household respondents; and (v) collecting paternity histories.

Data to inform family-centred programmes for children affected by HIV and AIDS

Survey data about men's involvement with children and families in surveys could contribute greatly to the design and evaluation of interventions that seek to engage men in family- or school-based interventions. For the design and evaluation of family-centred programmes to support children affected by HIV and AIDS, there are several key indicators related to men's involvement with children and families that could feasibly be collected by many of the ongoing surveys and population cohorts in sub-Saharan Africa. These include:

For each child:

- Identity of biological father
- Identity of social father (e.g., stepfather, foster father, grandmother)
- Identity of mother's partner (if not in a fathering relationship with the child)
- HIV and AIDS experiences:
    - HIV infection (self, parent, other household member)
    - AIDS illness and mortality (parent, other household member)
- Child health, development and wellbeing indicators
- Biological and/or social fathers' involvement:
    - Co-residence with his child
    - Time spent with child, frequency of visits
    - Father's activities by type and time with child (care, meals, play)
    - Quality of relationship between father and child
    - Quality of relationship with child's biological mother
    - Quality of relationship with child's primary caregiver (if not mother or self)
    - Financial or material support for child by type and amount
    - Financial or material support for household by type and amount
- Involvement by other resident or non-resident men (not father of the child):
    - Financial or material support to child and household
    - Relationship of child to other men who contribute or are involved with child

For each biological or social father:

- Survival status of father (date of death, age at death)
- Place of residence
- Demographic characteristics (age, residential patterns, marital and partnership status, ethnicity, language, education)
- Social characteristics (relationship to other household members)
- Economic characteristics (employment status, income)
- Health (general health status, mental health, alcohol and drug use)
- Paternity history with identification of child's mother and survival status of mother

Conclusions

Family-based interventions can be used to support HIV- and AIDS-affected children and families in a range of different ways. These include: family-based HIV testing delivered at home; HIV prevention programmes that involve parents and children; family treatment support for HIV-infected children and adults, including case management and service delivery; and programmes to support families of HIV- and AIDS-affected children with financial assistance (for education, housing, food), counselling and medical care.

Successful interventions will be those that build on the strengths of family functioning by developing models based on a knowledge about how families provide care and support to children, and develop appropriate models of delivery suitable in varied social, economic and infrastructure contexts [68]. For example, interventions that recognise inter-household, as well as intra-household relationships and involvement, will be better able to support those children affected by HIV and AIDS whose families are dispersed and where the men that support them are not co-resident.

The development of culturally appropriate, safe and acceptable family-centred interventions that can successfully engage men in the support of HIV- and AIDS-affected households requires detailed family data. For example, programme delivery should consider men's presence patterns, recognising that non-resident fathers may not be able to participate in home- or school-based programmes. Data about men's paternity and partnership histories will assist in understanding barriers to increasing men's involvement.

The enrolment of fathers or other male relatives may sometimes be impossible or ill-advised, as in the case where these men are in prison or hospital, or have problems related to mental health, drugs or alcohol, or have physically or sexually assaulted members of their family [69]. This issue may be particularly pertinent in such countries as South Africa, where high rates of domestic violence and child sexual abuse have been reported [70].

Ongoing surveys and population cohort studies in sub-Saharan Africa are not only valuable sources of data on men and families, but could be used as tools for evaluating family-centred interventions. A recent systematic review by King *et al* (2009) identified no rigorously evaluated studies of health and welfare family interventions to improve the psychosocial wellbeing of children affected by HIV and AIDS in sub-Saharan Africa [71]. The urgent need for evaluation studies is another impetus to improve the availability of data about men and families, particularly in population and community cohorts whose longitudinal design makes them ideally suited as platforms for family intervention research.

Competing interests

The authors declare that they have not competing interests.

Authors' contributions

VH and SM drafted the manuscript and approved the final version.

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Author details

[1]Centre for Population Studies, London School of Hygiene and Tropical Medicine, UK. [2]Africa Centre for Health and Population Studies, University of KwaZulu-Natal, South Africa. [3]African American Studies Department, University of Maryland, USA. [4]Medical Research Council/Wits Rural Public Health and Health Transitions Research Unit, School of Public Health, University of the Witwatersrand, South Africa.

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Children of female sex workers and drug users: a review of vulnerability, resilience and family-centred models of care

Jennifer Beard*[1], Godfrey Biemba[1], Mohamad I Brooks[1], Jill Costello[1], Mark Ommerborn[1], Megan Bresnahan[2], David Flynn[2] and Jonathon L Simon[1]

Abstract

Background: Injection drug users and female sex workers are two of the populations most at risk for becoming infected with HIV in countries with concentrated epidemics. Many of the adults who fall into these categories are also parents, but little is known about the vulnerabilities faced by their children, their children's sources of resilience, or programmes providing services to these often fragile families. This review synthesizes evidence from disparate sources describing the vulnerabilities and resilience of the children of female sex workers and drug users, and documents some models of care that have been put in place to assist them.

Review: A large literature assessing the vulnerability and resilience of children of drug users and alcoholics in developed countries was found. Research on the situation of the children of sex workers is extremely limited. Children of drug users and sex workers can face unique risks, stigma and discrimination, but both child vulnerability and resilience are associated in the drug use literature with the physical and mental health of parents and family context. Family-centred interventions have been implemented in low- and middle-income contexts, but they tend to be small, piecemeal and struggling to meet demand; they are poorly documented, and most have not been formally evaluated. We present preliminary descriptive data from an organization working with pregnant and new mothers who are drug users in Ukraine and from an organization providing services to sex workers and their families in Zambia.

Conclusions: Because parents' drug use or sex work is often illegal and hidden, identifying their children can be difficult and may increase children's vulnerability and marginalization. Researchers and service providers, therefore, need to proceed with caution when attempting to reach these populations, but documentation and evaluation of current programmes should be prioritized.

Background

Female sex workers (FSWs) and injection drug users (IDUs) are often categorized as two of the four populations "most at risk" for becoming infected with HIV due to behaviours that heighten their vulnerability to the virus. According to the Joint United Nations Programme on HIV/AIDS (UNAIDS), the term, "most-at-risk populations" (MARP), refers to men who have sex with men, injection drug users, sex workers and their clients. These risk behaviours are believed to drive the HIV epidemics in western countries, former Soviet republics and Asia, where HIV is concentrated in specific populations [1].

Interventions for MARP tend to focus on the needs of adults, with the objective of reducing their risk for HIV through prevention, behaviour-change education and risk-reduction strategies. But, to date, little attention has been paid in the published literature to the vulnerabilities faced by their children or to interventions focused on keeping these potentially vulnerable families together, improving the wellbeing of both parents and children, and reducing the risk of both generations for becoming infected with or transmitting HIV.

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*Correspondence: jenbeard@bu.edu
[1]Center for Global Health and Development, Boston University, 801 Massachusetts Avenue, Boston, Massachusetts, USA
Full list of author information is available at the end of the article

This review aims to synthesize evidence from disparate sources (including research, advocacy and programmatic information) describing the vulnerabilities and sources of resilience of the children of female sex workers and drug users, and to document the two selected models of care in low-and middle-income countries that have been put in place to assist these groups. In the following sections, we analyze peer-reviewed and grey literature to begin to answer four research questions:

1. What are the vulnerabilities faced by the children of drug users and FSWs?
2. What are their sources of resilience?
3. Are there interventions that have focused on mitigating the vulnerability of children and addressing the needs of these families?
4. What do we know about the effectiveness or impact of these interventions?

While our original objective for this literature review was to focus specifically on the children of female sex workers and injection drug users in low- and middle-income countries, we found very little information specific to the children of IDUs. However, we did find a great deal of published work more broadly focused on drug and alcohol addiction in general. Likewise, we found that the most relevant literature on the children of drug users is from developed countries, and the United States in particular. As a result, we broadened our original scope in order to draw inferences from the global literature about the children of drug users of any type in low- and middle-income countries. By contrast, the literature on children of sex workers globally is limited, but the majority of the information we did find is focused on lower resource countries.

Synthesizing what is known about the types of vulnerability and resilience experienced by children of these groups, the types of assistance families need to minimize children's vulnerability, and the effectiveness of the interventions that exist is useful for several reasons. First, attention needs to be drawn to the reality that sex workers and drug users are often parents whose children potentially face vulnerabilities unique to their family situation. Second, understanding the needs of these children is necessary for creating relevant, evidence-based interventions focused on supporting their families. Finally, documenting the types of care that do exist and assessing their effectiveness is critical for scaling up and adapting successful interventions to new contexts.

Literature review methodology

This literature review utilized both electronic and manual search methods to locate relevant peer-reviewed articles and grey literature from all low- and middle-income countries. We expanded our inclusion criteria to all countries regardless of income level only after our search for sources from lower resource contexts turned up little useful information. The following online databases and search engines were searched to identify relevant studies: Ovid/Medline, PubMed, Child Development and Adolescent Studies, PsychInfo, Published International Literature on Traumatic Stress, Sociological Abstracts, Social Services Abstracts, Web of Science, Google Scholar, Popline/One Source, the New York Academy of Medicine Grey Literature Report, and Public Affairs Information Service Archive. Organizational websites and references of all relevant sources were searched manually.

Our search paired the terms "parent", "child", "youth", and "orphan" with the following, using various combinations: "most-at-risk populations", "risk factors", "vulnerability", "resilience", "HIV/AIDS", "commercial sex worker", "female sex worker", "prostitution", "drug user", "drug use", "substance abuse", "substance abusing parents", "addiction", "intervention", "child care", "education", "prevention", "child victims", "injection drug use", "child welfare", "parent-child", and "child of impaired parents".

We also contacted staff from relevant programmes to ask about interventions being implemented for children of sex workers and drug users. Correspondence and phone interviews with these key informants provided the most relevant information on interventions in low- and middle-income countries.

Terminology and definitions

This review faced a number of semantic challenges. First, the definition of "sex work" is profoundly unclear and runs a wide gamut of very different types of transactional sex, including but not limited to: brothel-based prostitutes; waitresses or bar girls who sell sexual favours within the establishments where they are employed; street walkers; dancing girls; caste-based *devadasis* in India; *kanjar* families in Pakistan; and courtesans or in *taiwaifs* South Asia who entertain men they call "husbands" and receive cash and other material gifts.

We looked at the children of sex workers who sometimes run the risk of entering the profession or being trafficked, but not at children who have been trafficked or who have entered prostitution through means other than "inheriting" it from their mothers. Nor did we examine the relationship between the children of FSWs and their fathers, who are often their mothers' clients (i.e., the fourth MARP category). For simplicity, we use the term, "female sex worker", to include all categories of women participating in transactional sex. We did not find information on the children of male sex workers.

As mentioned, the focus of this paper was shifted from the children of IDUs specifically to the children of drug users more generally to encompass the *drug use* or *substance abuse* literature, which includes research on the impact of all forms of parental drug use (including alcoholism) on children. While drug injection is specified in the literature on populations most at risk for HIV, we opted to include the more general drug use literature to inform our discussion of child vulnerability and resilience. But the intervention we describe later is specific to mothers who inject drugs.

Finally, we set out to look at the vulnerabilities and resilience of, and interventions for the children of drug users and sex workers, using search terms specific to each group. However, overlap between these two groups is common as drug use can create a gateway into sex work and vice versa [2-4]. We present information that is either generalizable across the two groups or distinct to each; however, we were not able to find data assessing the impact of "co-morbidity" on children whose parents are both drug users and sex workers.

Estimating the number of drug users and female sex workers who are parents

Estimating the number of people within most-at-risk populations who are parents is extremely difficult. Drug users and sex workers are often parents, although this fact has generally been ignored in the MARP literature.

As noted by the UNAIDS Reference Group for Estimates, Modelling and Projections, "estimating the numbers and associated prevalence for high risk populations is a fundamentally difficult exercise" [5], creating a gap that undermines the validity of national estimates of HIV prevalence in concentrated epidemics [6]. For instance, while the United Nations Office on Drugs and Crime estimates 18-38 million "problem drug users" and 11-25 million injection drug users worldwide [7], we could not find global estimates of the proportion of drug users who have children.

Some country-specific estimates of children living with drug users have been calculated based on national household data. For instance, almost half a million children in the United Kingdom live with parents who reported drug use and problem drinking in the past year [8]. Not surprisingly, similar estimates of the number of children affected by parental drug use are not available for countries without similarly sophisticated, national healthcare tracking systems.

Overall global estimates of the number of female sex workers also could not be found. A global estimate of 40 million is sometimes cited by activists, but we were unable to find the source of that estimate. Vandepitte *et al* provide prevalence estimates of sex workers in urban areas of sub-Saharan Africa (0.7%-4.3% of the population), Asia (0.2%-2.6%), former Soviet countries (0.1%-1.5%), eastern Europe (0.4%-1.4%), western Europe (0.1%-1.4%) and Latin America (0.2%-7.4%) [9]. But they admit that their method of arriving at these estimates is precarious at best (and most likely conservative) due to inconsistent definitions of what sex work entails.

Likewise, global estimates of the number of sex workers who have children or of the number of children whose mothers are sex workers could not be found. Total fertility rates of sex workers globally have also not been documented in the searchable literature. While HIV and other sexually transmitted infections can reduce female fertility [6], the increased frequency of coital acts among sex workers also increases their exposure to pregnancy, arguably rendering their fertility to be little different from that of the general population. A study from Kenya reported that the mean number of children per their 385 sex worker respondents was 3.4 (±2), making them comparable to the national mean of 3.2 [2].

Vietnam was the only country found to specify children of sex workers and drug users as vulnerable, along with children who have been trafficked, street children, and children who are themselves engaged in drug use and sex work. While the Ministry of Labour, Invalids and Social Affairs (MOLISA) is able to give estimates of the numbers of children who fall into the latter categories, it indicates that data is not available on children of sex workers or drug users [10].

Sources of vulnerability and resilience for children of drug users and sex workers

The children of drug users and sex workers can face unique risks, stigma and discrimination as a result of their parents' addictions or profession. However, this potential vulnerability can be ameliorated by potential sources of resilience connected to support networks, parent health, parent-child bonding, education, economic situation and other environmental factors [11]. Research on the children of drug users in general focuses on their vulnerability to numerous forms of deprivation and abuse. A review of key articles from the past two decades yields a relatively long list of possible negative outcomes for children, ranging from cognitive developmental delays to neglect and abuse as a result of prenatal and postnatal exposure to parental addiction. However, research findings on the determinants of these various risks tend to be inconclusive, with family and community support networks, parental physical and mental health, and other socio-economic and environmental factors mediating child development outcomes and resilience [11-23].

The primary limitation of these research findings on possible vulnerabilities faced by children of drug users is that they come almost solely from high-income countries. Arguably, the risks and sources of resilience faced by children of addicted parents are potentially similar in contexts where certain drugs are illegal, drug use is stigmatized, and rehabilitation and risk-reduction programmes are difficult to access, if available at all. Overall, though, the generalizability of the information to low- and middle-income countries is unknown. At best, these findings can be useful for establishing research questions to be answered in lower resource contexts.

The literature on the children of sex workers, by contrast, is very small and, with a few exceptions, largely qualitative and ethnographic. While some useful articles look at US-based sex worker populations, most of the relevant research focuses on south Asia and Kenya. Specific vulnerabilities documented as affecting children of sex workers include: separation from parents, sexual abuse, early sexual debut, introduction to sex work as adolescents, low school enrolment, psychosocial issues arising from witnessing their mothers' sexual interactions with clients, and social marginalization [2,3,24-29]. The research on sex workers and their families tends to have a particular focus on girls and their potential for sexual abuse, early sexual debut, witnessing adult sexual activity, grooming to enter the trade, and trafficking. Sex work is often handed on from parent to child as the family trade in some cases, or out of a real or perceived lack of other options [28,30].

Sources of potential resilience for children of sex workers are also dependent on a complex combination of economic, environmental and social factors. Pardeshi and Bhattacharya found that *devadasis* had strong family support in their native villages [27]. While many of these women sent their children to their village homes to live with extended family, they remained connected with their children and visited at least once a year. Women who kept their children with them reported their income, peers, and brothels organized around native villages as sources of support. In Kenya, the more educated a sex worker was, the more likely she was to prioritize education for her children [2].

Examples of family-centred interventions

Some interventions have been implemented in low- and middle-income countries to assist families of drug users and sex workers, but they tend to be small, piecemeal and struggling to meet demand. The few interventions directed at children of FSWs and drug users that we did find all started with a focus on adults, but expanded their services as parents sought care for their children. Family Health International, for instance, started providing healthcare to children of at-risk parents in Cote d'Ivoire as more parents started seeking care. Many of these parents had previously been unable to access support because their children do not fit the national definition of an orphan or vulnerable child.

MAMA+ for IDU

Most information about family-centred care models for children of drug users comes from developed countries [12-14,16,31,32]. As Zuckerman notes, an addicted mother's interest in her baby is often the "healthiest" part of her life. But this interest is a double-edged sword that can exacerbate feelings of failure as much as provide a positive impetus to begin methadone maintenance or enter a rehabilitation programme [13,33].

In the US, drug rehabilitation programmes traditionally focused on the needs of men and did not accommodate a mother's reluctance to leave her children in order to enter residential treatment programmes. This started to change in the United States in the 1990s with the development of outpatient, family-focused treatment integrating screening of mothers during pregnancy for addiction and drug rehabilitation counselling, with, for example, primary healthcare for mothers and their children, legal assistance, food assistance and housing [13].

The MAMA+ for IDU project in Ukraine is the single programme outside of developed western countries for which we were able to find solid, if limited, information on provision of services to children or families of IDUs. As can be seen in Table 1, the integrated, family-centred, "one-stop shopping" model of care offered by MAMA+ is similar to that pioneered in the United States by Zuckerman and others during the 1990s [13].

MAMA+ for IDU was piloted by HealthRight International in Ukraine with funding from the Open Society Institute as an extension of the *United States Agency for International Development* (USAID)-funded Prevention of Abandonment of Children Born to HIV-Positive Mothers programme (called MAMA+) offered to HIV-positive, pregnant women in Russia and Ukraine [34]. The original project set out to reduce the number of children abandoned by HIV-positive mothers through the establishment of networks of agencies and specialists to identify seropositive pregnant women and mothers. The programme identified the primary drivers of abandonment as lack of information on HIV/AIDS and prevention of vertical transmission; stigma and discrimination at medical and social institutions and by families; financial pressure and homelessness; unplanned pregnancy; and lack of social and peer support.

Thirty-five percent of MAMA+ clients were IDUs, but in the original incarnation of the intervention, their drug addiction was not taken into consideration as a risk factor requiring additional support. In order to adequately meet the needs of this substantial portion of their target group, MAMA+ conducted a six-month pilot intervention focused on providing drug-addicted women with drug and alcohol counselling, risk reduction, legal assistance and referrals [34].

The referral network was adapted to include harm reduction, drug-substitution therapy, and rehabilitation programmes. A drug and alcohol addiction consultant was hired, and new peer support groups started, focusing on the challenges created by dependence on illegal drugs. The comprehensive approach combined early identification

Table 1. MAMA+ for IDU, Ukraine

Service provider networks specializing in HIV & IDUs	Psychosocial support	Harm reduction
• Early identification of HIV+ pregnant women and mothers with young children • Identification of pregnant women at risk of abandoning infants • Comprehensive antenatal and post-delivery healthcare referrals • Referrals to harm-reduction services • Home visits • IDU team comprised of team coordinator, social workers, medical professional, drug and alcohol abuse consultant, psychologist and lawyer	• Psychological consultations • Peer network and peer support groups • Legal assistance • Material support • Child development consultations	• Drug and alcohol rehabilitation • Substitution therapy • Other (non-specified)

and enrolment with home visits, and provided material, psychological and legal support (Table 1). Within six months of launching the project, 25 HIV-positive IDU pregnant women and new mothers were benefiting from services, in addition to 27 children and 19 other family members.

TASINTA for children of sex workers

We found information on 18 organizations providing care for the children of sex workers in Bangladesh, Cote d'Ivoire, Kenya, India, Nepal, Vietnam and Zambia. The information available on the programmes was largely gleaned from Internet searching and correspondence and phone interviews with programme implementers. It is, therefore, limited in terms of programmatic detail, information about the population served, and effectiveness or long-term impact.

The interventions we found tend to provide multifaceted assistance to mothers and children across several categories, providing children with educational opportunities and a safe place to play, study, or sleep when their mothers are working. Likewise, the same programmes provide vocational training and alternative income-generation opportunities to mothers who want to leave sex work or reduce the number of clients they need to entertain in order to provide for their families. Other types of assistance provided include peer support, nutrition, housing and healthcare.

TASINTA (We Have Changed), started in Zambia in the 1990s, is the programme for which we were able to gather the most comprehensive information [personal communication, Nkandu Luo]. TASINTA started as a programme to help sex workers protect themselves from HIV, but input from the women themselves made it clear that a more broadly based, family-centred approach was necessary. A list of TASINTA's services to FSWs and their children is provided in Table 2.

TASINTA's partnership with residential care facilities to serve as a boarding school for children whose mothers have died may at first seem antithetical to the family-centred care model. However, it appears that TASINTA is redefining family beyond the bounds of biological relationships in the best interests of the child to include what Richter calls "long-term, mutually supportive relationships" [35].

After experimenting with reuniting orphans with extended family, TASINTA found that it was no longer able to monitor the care and safety of children and faced a situation where family members were selling the children into prostitution. Programme managers and clients working for the organization found themselves, not infrequently, searching for children and rescuing them: hence, the decision to place them in a residential environment they knew to be safe and where the children can remain close to adults they know and trust.

Conclusions

Methodological and ethical challenges

In order to understand the vulnerabilities faced by the families of drug users and sex workers and provide interventions designed specifically to mitigate risks and fulfill needs, identification of individuals or communities and analysis of their specific situation are necessary first steps. Yet conducting research among and even targeting the vulnerabilities faced by sex workers and drug users and their children is a methodologically and ethically challenging undertaking. Any attempt to document their needs or provide them with interventions must take care not to expose or further compromise fragile families frequently existing on the fringes of the law.

Table 2. TASINTA (We Have Changed), Zambia

Day care	Residential care	Rehabilitation & vocational training for mothers	Education & vocational training for children	Other services
• After-school drop-in centre	• Partnership with two institutions (Kasisi Orphanage and Hope House) to provide residential care and schooling for orphans	• Drop-in centre where mothers can learn alternative skills • Grants for small business start up • Sponsorship of higher education courses for women with secondary school education • Programme participants become trainers and employees	• Assistance with school fees • After-school drop-in centre • School-age orphans attend boarding school at Hope House	• Help women rent homes • Reunite women with children living with extended family • Partner with police and government to reduce exploitation and recruit women into programme

Because drug use and sex work are often illegal, those who engage in these activities are frequently referred to as "hidden" or "invisible" populations. While methodologies have been developed to reduce sampling bias, it is nearly impossible to obtain a truly random sample of such populations [5]. The very act of identifying families can also increase their vulnerability.

As noted by Family Health International, the usefulness of knowing the magnitude of vulnerable populations does not outweigh the guiding principle of public health to "do no harm" [36]: "The danger of a backlash exists not only at the individual but also at the population level, through the mere publication of information about the existence and size of a sub-population. Where there is a real possibility … leading to harm … it may be better to drop the whole exercise." In the case of sex workers and drug users and their children, caution must prevail in order to avoid the forced removal of children from parents, imprisonment or worse.

A case in point is the situation facing the families of drug users and sex workers in Vietnam. MOLISA's clear objective to highlight the needs of this hidden subset of extremely vulnerable children in the National Plan of Action for Children Affected by AIDS (NPA) (mentioned earlier) illustrates the complexity and possible danger of documentation and heightened attention. Despite what seem to be the good intentions to direct services to MARPs and their families, the NPA also notes contradictions between public health policy and a legal system that can increase vulnerability [10].

Identification of children whose parents use illegal drugs or sell sex may land parents in rehabilitation centres or prison, effectively leaving their dependent children to be incarcerated with their parents or placed in protection centres. These institutions are often impersonal, providing little in the way of care, and may not separate juvenile inmates from adults or offer HIV-prevention education or harm-reduction services. They may thus perpetuate the cycle of vulnerability [10,37]

The situation in Vietnam is an extreme but not anomalous example of the tension that can exist between drawing attention to vulnerable families in order to provide services and advocacy, and pushing an invisible population into a spotlight from which they have long shied away. Documenting the illegal behaviours of parents can lead to scrutiny from child welfare advocates and law enforcement, and indirectly lead to forced separation of children and parents. While such separation may reduce the immediate risks faced by an abused or neglected child, it can also do collateral damage to already fragile, but otherwise positive, family situations, leading to depression and self-blame on the part of the parent, causing distress among children and potentially jeopardizing child-parent attachment [13].

Programme documentation and evaluation

None of the interventions we found in lower resource countries have been evaluated for short-term effectiveness or longer-term impact. Indeed, the peer-reviewed and grey literature focused on the children of drug users and sex workers is silent on many issues of critical importance for reducing their vulnerabilities, including:

- Strategies for accessing these often hidden, hard-to-reach families, in particular children
- The type of interventions that are most effective
- Strategies for designing, implementing and scaling up interventions for children of parents whose behaviour is illegal and perceived to be immoral in many countries.

Responding to these critical challenges would facilitate more accurate targeting of interventions toward families in need. And building an empirical evidence base of what interventions work in varying contexts would allow programme planners and implementers to be more thoughtful in choosing interventions. The establishment and enforcement of global guidance on norms and country-specific regulations that acknowledge the needs of the families engaged in illegal or "immoral" activities is essential. Before we start duplicating and scaling up any identified promising strategies, we need to document and evaluate extant programmes providing assistance to the families of drug users and sex workers, while tailoring new programmes to the needs and conditions of specific contexts.

Research from the United States and Europe is a useful place to start, but we must take up the challenge to find and (when they cannot be found) develop strategies that help to strengthen fragile families [38]. The net results of the findings from this review, the United Nations Children's Fund (UNICEF) Framework for the Protection, Care and Support of Orphans and Vulnerable Children Living in a World with HIV and AIDS [39], and the Joint Learning Initiative on Children and AIDS [40] highlight some core approaches backed by evidence, including among low- and middle-income countries.

These include integrated interventions for families and communities similar to those already being implemented by MAMA+ for IDU and TASINTA:

- Strengthening family caring capacity through home visitation and peer support for vulnerable parents to provide mental health support, parenting skills coaching, and monitoring of child welfare
- Early childhood development programmes for children, educational assistance, crèches and drop-in centres
- Economic strengthening and job skills training projects.

Understanding the specific context in which drug use or transactional sex interacts with a parent's ability to take care of a child is of critical importance. However, we must carefully weigh competing risks and benefits when generalizing about vulnerability, need and optimal family-centred practices. The environment in which these children live can increase vulnerability, but removing children may also mean separating them from parents who they love, and who love them and are doing their best.

In a number of ways, this literature review has generated as many questions as it has answered. We have synthesized research on the vulnerabilities faced by children of drug users and sex workers and documented two family-centred interventions being implemented in Ukraine and Zambia. But much remains to be done as we work toward implementing the UN Convention on the Rights of the Child for the children of highly vulnerable, socially marginalized parents around the world.

Competing interests

The authors declare they have no competing interests.

Authors' contributions

The paper was written by JB, and GB designed the literature search protocol, carried out research, and drafted and revised the manuscript. JC and JLS participated in drafting and revising the manuscript. MIB, MO, MB and DF designed the literature search protocol, carried out research, and contributed to the written content. All authors read and approved the final manuscript.

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Author details

[1]Center for Global Health and Development, Boston University, 801 Massachusetts Avenue, Boston, Massachusetts, USA. [2]Alumni Medical Library, Boston University Medical Center, 72 East Concord Street, Boston, Massachusetts, USA.

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RESEARCH **Open Access**

The impact of HIV and high-risk behaviours on the wives of married men who have sex with men and injection drug users: implications for HIV prevention

Sunil S Solomon[1], Shruti H Mehta[2], Amanda Latimore[2], Aylur K Srikrishnan[1] and David D Celentano*[2]

Abstract

Background: HIV/AIDS in India disproportionately affects women, not by their own risks, but by those of their partners, generally their spouses. We address two marginalized populations at elevated risk of acquiring HIV: women who are married to men who also have sex with men (MSM) and wives of injection drug users (IDUs).

Methods: We used a combination of focus groups (qualitative) and structured surveys (quantitative) to identify the risks that high-risk men pose to their low-risk wives and/or sexual partners. Married MSM were identified using respondent-driven recruitment in Tamil Nadu, India, and were interviewed by trainer assessors. A sample of wives of injection drug users in Chennai were recruited from men enrolled in a cohort study of the epidemiology of drug use among IDUs in Chennai, and completed a face-to-face survey. Focus groups were held with all groups of study participants, and the outcomes transcribed and analyzed for major themes on family, HIV and issues related to stigma, discrimination and disclosure.

Results: Using mixed-methods research, married MSM are shown to not disclose their sexual practices to their wives, whether due to internalized homophobia, fear of stigma and discrimination, personal embarrassment or changing sexual mores. Married MSM in India largely follow the prevailing norm of marriage to the opposite sex and having a child to satisfy social pressures. Male IDUs cannot hide their drug use as easily as married MSM, but they also avoid disclosure. The majority of their wives learn of their drug-using behaviour only after they are married, making them generally helpless to protect themselves. Fear of poverty and negative influences on children were the major impacts associated with continuing drug use.

Conclusions: We propose a research and prevention agenda to address the HIV risks encountered by families of high-risk men in the Indian and other low- and middle-income country contexts.

Background

Since the first cases of AIDS were described in 1981, significant progress has been made in the prevention and management of HIV disease. New challenges have continued to emerge and solutions are not always straightforward. Injection drug use and men having sex with men remain two drivers of the HIV epidemic in the developing world, a fact that is commonly overlooked in the planning and implementation of treatment and prevention programmes [1, 2].

Many of these men who have sex with men (MSM) and injecting drug users (IDUs) are married; they face unique risks and social pressures in many resource-constrained settings, which place their female sex partners and, by consequence, their children at high risk for HIV and associated co-infections. Solutions for these men and their families are far less straightforward in such settings, especially when targeted behaviours are not socially accepted and may be illegal.

India is home to ~2.3 million HIV-infected persons, the third largest group of HIV-infected individuals in the world; this reflects a population prevalence of approximately 0.3% [3]. Nearly 65% of HIV infections in India are concentrated in the western state of Maharashtra and the

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*Correspondence: dcelenta@jhsph.edu
[2]Johns Hopkins Bloomberg School of Public Health, Baltimore, MD, USA
Full list of author information is available at the end of the article

southern states of Andhra Pradesh, Karnataka and Tamil Nadu [4], where the epidemic has been driven by sexual transmission (85%), most of which is believed to be heterosexual [5]. However, the ability to discriminate between homosexual and heterosexual transmission in India is challenging because many MSM are married and/or bisexual, and are hesitant to self-identify as homosexual or bisexual. Injection drug use drives the HIV epidemic in the north-east, but has also been increasingly recognized in other parts.

Recent evidence suggests that the heterosexual HIV epidemic has stabilized and may even be on the decline in the southern states (based on prevalence rates among sexually transmitted infection clinic attendees, female sex workers and women attending antenatal clinics), presumably as a result of prevention and treatment efforts and better epidemiologic assessment [6-8]. However, this declining prevalence is not reflective of all risk groups and recent sentinel surveillance data from the National AIDS Control Organization (NACO) suggest that HIV epidemics among other high-risk groups in India, such as IDUs and MSM, are not showing any signs of decline and may even be on the rise (Figure 1*)*.

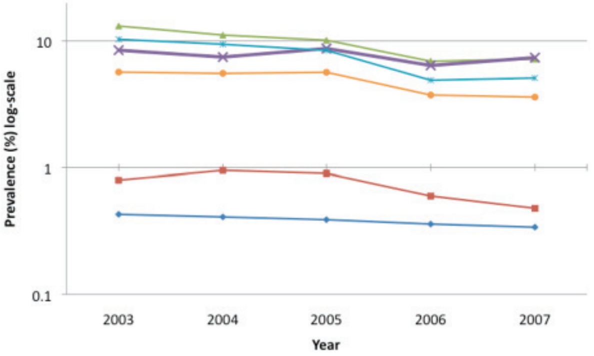

Figure 1. HIV prevalence according to sentinel surveillance by risk group over time (2003-2007).

Same-sex behaviour is common in India, although overt homosexuality is rare. In a survey of male patients attending a hospital in Mangalore, Karnataka, 12% reported a sexual preference with a partner of the same sex [9]. Another sample of 2910 men from rural settings in India identified the prevalence of same-sex practices to be 10% among married men and 3% among single men [5].

Cultural norms in India ensure that there are predetermined roles for women and men that impact on sexuality [10]. Women are raised from an early age to repress sexual desires and adopt the role of the obedient wife, whose primary responsibility is to reproduce. No such restrictions are placed on male children; masculinity is not defined by sexuality, but rather by fatherhood. Further, in Indian culture, close physical contact between individuals of the same gender is not considered inappropriate. Close contact between men of the same sex often begins in adolescence and, in some cases, evolves to sexual contact between men. Most men would not consider this behaviour to be inappropriate, nor would they identify themselves as "homosexual", especially when this behaviour occurs within the expectation or reality of marriage and fatherhood. Indian societal norms allow large numbers of men, who may or may not self-identify as homosexual, to have sex with men, while at the same time being married to women [10].

Although a transformation of sexual practices and awareness is certainly occurring in modern India, the open practice of a homosexual lifestyle remains uncommon. The primary reasons for this are: (1) Section 377 of the Indian Penal code, which has historically criminalized anal sex and forces many MSM to remain hidden (this law was repealed by the Delhi High Court only recently, in July 2009) [11]; and (2) the norm of marriage to the opposite sex, which results in a large proportion of MSM marrying to satisfy social pressures and/or to prove their masculinity to themselves and their families. However, a large proportion of MSM marry for the same reasons as heterosexual men – to have children, to conform with cultural norms of marriage and to avert suspicion of their sexual practices.

Epidemiologic studies have identified that between 30% and 60% of Indian men reporting same-sex behaviours are married [12, 13]. Further, compared with unmarried MSM, married men tend to have higher HIV and sexually transmitted infection (STI) prevalence [14], lower rates of condom use [15, 16], higher rates of anal sex, and greater numbers of sexual partners, both male and female [5].

It is likely that married MSM tend to partake in more high-risk behaviour than other MSM because of the need for anonymity. It has been reported that married MSM often indulge in hurried anonymous sex for fear of being identified as "homosexual" in social settings [17]. Despite the fact that married MSM engage in high rates of sexual risk, use of condoms with their wives is very limited. Among a sample of 821 MSM in Mumbai, India, 53% reported never using a condom with their female partners. The primary reasons for not using condoms were related to: (1) availability (33%); (2) perception that their partners were safe (32%); and (3) reduced sexual pleasure (18%) [14].

The combination of marriage to satisfy societal pressures with the observation that married MSM in particular have higher HIV prevalence and associated risk behaviour makes them an important bridge population. Their wives and children are at high risk for HIV and likely have very low risk perception. It has previously been shown in India that married women have low risk perception for HIV despite the high-risk behaviours of their husbands [18-20]. This perception is probably applicable to wives of MSM as well. Further, they remain difficult to target and reach through interventions.

India has approximately three million opiate users, the largest population in Asia [21]. Because of India's proximity to the Golden Triangle, injection drug use has been most prevalent in the north-eastern states [3]. However, injection drug use has been increasingly recognized in the southern states of India [9]. Over time, the epidemic has disseminated to other states and today, all cities with recognized injection drug use have reported HIV among IDUs, although the estimates of prevalence vary between 1% and 64% [4, 8, 22-26].

The majority of IDUs in India are male. Although there are limited reports of female injecting drug use in the north-east [27], most women married to IDUs are exposed to HIV through sexual contact. Given that a high proportion of IDUs (50-70%) are married, this risk is substantial. Further, IDUs put their wives and children at risk, not only because of their drug use behaviour leading to income loss, but also because they tend to have a higher than normal risk of transmitting HIV to their spouses and offspring [27-29].

Several studies have examined prevalence of HIV and STIs among sexual partners of IDUs, and have found both to be high. In a study of 332 HIV-positive IDUs from Manipur, the prevalence of HIV among spouses was 45% [30]. Another cross-sectional study among 226 IDUs and their regular sex partners in Chennai observed that the prevalence of HIV among IDUs was 30%; the prevalence among all regular sexual partners was 5%, but the prevalence was 16% among sexual partners of HIV-positive IDUs [31].

In another study examining HIV, syphilis and HSV-2 infection in IDUs and their non-injecting female partners, researchers found a 1% and 2% prevalence of syphilis in IDUs and their female regular sexual partners, respectively [32]. In addition, females with HIV-positive IDU male partners had 2.38 times the odds of having a non-HIV infection. In a convenience sample of 72 concordant and 89 discordant HIV-infected couples in Manipur, factors associated with HIV infection in wives of IDUs included current STI in either partner, as reported by the husband [33].

Despite the high prevalence of HIV and STIs among female partners of IDUs, low risk perception and low levels of HIV knowledge prevail. In a study of 3328 female regular sex partners of drug users and/or IDUs from 21 sites across India, 26.3% of women had never heard of HIV/AIDS [34]. Due to low risk perceptions, rates of condom use among these women were extremely low. In one study, female partners of IDUs with a single regular sexual partner had 40% reduced odds of condom use. A study among IDUs and their spouses in Chennai suggested that many regular sex partners viewed sex as a means of bonding, and had unprotected sex with their substance-using husbands to prove intimacy and trust in the relationship. Condoms were used only at times of menstruation or as a family-planning method, and not as a tool to protect against HIV infection [27].

This paper highlights some unique aspects of HIV epidemics among men who have sex with men (many of whom reported having sex with both men and women) and IDUs in one developing country setting, India. We illustrate some key issues regarding these marginalized populations using mixed-methods data. In particular, we highlight the impact of high-risk behaviour in these populations on female sexual partners, offer recommendations for future prevention initiatives, and identify gaps in our current knowledge of the influence of male sexual and drug use behaviours on families' risks.

Methods

Quantitative survey among MSM

Mixed research methods were used for both populations presented in this report. For married men with male partners, we conducted a rapid assessment to measure HIV/STI prevalence among MSM in the southern state of Tamil Nadu between October and November 2008 [35]. We recruited 721 MSM through respondent-driven recruitment, starting with 19 seeds who were identified by local non-governmental organizations as MSM, three of whom were married. We restricted our chain of referrals to three levels. Participants were eligible for participation if they: (1) were at least 18 years of age; (2) self-identified as male; (3) had a history of oral and/or anal intercourse with a man in the prior year; and (4) provided informed consent.

A structured questionnaire was administered by trained male interviewers to the identified men. The questions covered: demographics; marital history; lifetime sexual history, including age at sexual debut and gender of partner, lifetime numbers of female and male partners, lifetime use of sex workers (both female and male), and other transactional sex; history of sexually transmitted diseases; recent sexual history (previous six months); and sexual concurrency. Standard laboratory assays were used to test for the presence of HIV, hepatitis C, herpes simplex virus type 2 and syphilis. We restrict the current analysis to the 247 married men who reported sex with another male.

Quantitative survey among wives of IDUs

A similar structured questionnaire was created for the female partners of male IDUs in Chennai. A cohort study (the Madras Injection Drug User and AIDS Cohort Study) was initiated in Chennai of active IDUs (with a history of injecting in the previous six months) in 2005-06 to characterize the incidence and associated risk factors for HIV among a sample of 1158 IDUs; all but three were male [36]. From April to September 2009, we recruited a convenience sample of 400 wives and/or regular sexual partners of these men for a cross-sectional survey of their risks. Women underwent a standardized questionnaire that collected demographic information, as well as HIV risk information of both sexual and drug use practices. Women were also asked about their husbands' injection drug use patterns and the impact on their families. All women underwent testing for HIV, hepatitis C virus (HCV) and hepatitis B virus (HBV).

Qualitative data

For married MSM, we conducted five semi-structured focus groups (each with 12 participants) in the Tamil language, led by experienced, trained facilitators. The principal targets of the groups were concerns about same-sex behaviour for the family, experiences with disclosure, how common it was to have male partners, worries and concerns about being caught having sex with a man, stigma and discrimination, consequences of coming out, and the use of alcohol and drugs prior to sex. We also inquired into reasons for and barriers to HIV testing.

We conducted similar focus group discussions with both male IDUs and their female partners in gender-specific groups in Chennai. The targets of these discussions were disclosure of injection drug use and HIV to wives, and impact of injection drug use on families of IDUs.

Research protocols were reviewed and approved by the Institutional Review Boards of the YR Gaitonde Centre for AIDS Research and Education and the Johns Hopkins Bloomberg School of Public Health.

Statistical analysis

Quantitative data is presented primarily as descriptive with median and interquartile range (IQR) for continuous variables and number (percentage) for categorical variables. All analyses were conducted in Intercooled STATA Version 10.0 (College Station, Texas). All focus group discussions were audio-taped, transcribed into Tamil, and then coded by two individuals experienced in the analysis of qualitative data. The data were analyzed using Atlas-TI. The themes that emerged from this analysis are presented in relation to the quantitative data on infection rates and the risks that these men's behaviours pose in terms of transmitting HIV to their wives.

Results

Characteristics and risk behaviours of married MSM

The median age of the married MSM was 35 years (IQR, 30-42), and 75.7% had at least secondary level education. The prevalence of HIV and associated STIs among married MSM was high (HIV=13.4%; HSV2=32.4%; syphilis=11.3%). HIV prevalence among married MSM was largely explained by higher risk behaviours among married MSM, including having a greater number of male partners and not reporting a primary male partner [37].

Most (95%) married MSM self-identified as bisexual. While nearly all (97%) had disclosed their same-sex behaviour to other MSM, virtually none had disclosed their behaviour to their wives (2%), other family members (6%), and health care professionals (15%). Nearly half (51%) had been previously tested for HIV, but only 63 had received an HIV test in the prior six months, suggesting a low frequency of regular testing. Further, only four of the 33 HIV-positive married MSM were aware of their status at the time of our survey.

Half reported that they had previously received some information on HIV prevention from a counsellor. Despite this, high-risk behaviours with both men and women were common among MSM who were married. Sixty-one percent reported having a main male partner, but the majority reported having multiple male partners in the prior year (93%); 192 men (78%) reported sexual intercourse with a male commercial sex worker in the prior year; 96 (39%) reported some unprotected anal intercourse; and 26% reported always having unprotected anal intercourse with their male partners.

These married MSM also reported high-risk practices with women. Overall, 62% of married MSM had only one female partner in the prior year (wives), and 23% had multiple female partners [median: 4 (IQR: 3–8)]. One-fifth of the married MSM reported exchanging money for sex. Among those men who had sex with multiple female partners in the prior year, 88% had unprotected vaginal sex with at least one non-spousal female partner, and 128 (37%) reported vaginal sex with multiple female partners other than their wives. Three-quarters (72%) had unprotected vaginal sex with their wives in the prior year. Reported anal intercourse with spousal or non-spousal partners was rare.

Risk context among married MSM

The qualitative data provide insight into some of the reasons for the high rates of reported risk behaviours reported by married MSM. Stigma and discrimination were identified as their biggest concerns; most participants reported fear that their families would not accept their sexuality as one of their biggest barriers to disclosure of their sexual preferences. Further, the majority concurred that the primary reasons for getting married were due to parental pressures and the fear that if they did not get married, their younger siblings would also not be able to get married, a situation that is customary in India.

Married MSM reported living in fear that their spouses would learn of their practices and divorce them. Married MSM also reported that their inability to discuss their sexuality with their children was a constant worry. In terms of substance use, smoking marijuana and alcohol use were nearly universal; the primary reason for alcohol use was personal frustration. The primary barrier to regular HIV testing was fear related to exposure of their HIV status and/or sexual practices. We also asked men in the focus groups about the high prevalence of HIV among married MSM. Men suggested that those who were married had to be more secretive about their behaviours and tended towards high-risk and multiple partnerships.

Characteristics and risk behaviours of wives of IDUs

The median age of the women was 31 years. Thirteen percent were widowed and 7% were not currently living with their spouse; 89% reported having less than a secondary level education; and 99% reported that children were currently living in their household. Overall, risk for HIV based on their self-reported behaviours was low. Only four (1%) reported injecting drugs in the prior six months, although 22% reported non-injection drug use and 25% reported alcohol use. The majority reported only a single lifetime sexual partner (85%), and 37 (9%) reported exchanging sex for money [38].

However, risk due to their husbands' behaviours was high. Condom use was rare: 75% of the married women reported never using condoms with their husbands. As previously reported, the prevalences of HIV, HBV and HCV were 2.5%, 3.76% and 0.5%, respectively; among spouses of HIV-positive IDUs (n=78), the prevalences of HIV, HBV and HCV were 10.3%, 1.3% and 1.3%, respectively [38].

The strongest predictor of HIV infection was spousal HIV status (OR: 17.9; $p < 0.001$). While all of the wives were aware of the fact that their husbands were IDUs, the majority (97%) learned of their husbands' injection practices only after marriage when they observed them injecting. The majority of the wives (84%) had seen a report of their husbands' HIV status: 68% reported that their husbands did not have HIV; 14% reported that they did have HIV; and the remainder were unsure. Risk perception in this population was actually high: nearly 60% of the women felt they were at risk of acquiring HIV, HBV and HCV from their husbands. Despite high risk perceptions, less than one-third (31%) reported that they had been tested for HIV.

We asked these women about the potential impact of their husbands' injection drug use on their family. Of 400 respondents, almost all (96.5%) were concerned that the drug use would result in the loss of income for their families and 291 (74.1%) were concerned that the drug use was a negative influence on their children. A further 218 reported that they were concerned that their husbands' injection practice placed them at high risk for domestic violence. Indeed, when we asked specifically about experiences with violence, 222 (55.5%) of the cohort reported that they were subject to some form of domestic violence, including high levels of physical and sexual violence..

Risk context for families of IDUs

Focus groups with both the IDUs and their wives reinforced the important role of the family. The majority confirmed that women were not aware that their husbands were IDUs prior to marriage; perhaps not surprisingly, parents were often aware of their sons' behaviours. HIV-positive IDUs revealed that few spouses were aware of their HIV status; most were interested in disclosure, but needed help to do so.

We have previously reported that IDUs vacillate between living at home and on the street [39], and our focus groups confirmed that during periods when husbands are actively using drugs, wives often throw them out of the home. Further, they also confirmed the role that women might play in transitioning IDUs out of drug use. In a separate analysis from the IDU cohort, where we observed that more than 90% stopped injecting after the baseline interview, 56% and 35% reported that family encouragement and family pressure, respectively, were important in injection cessation.

Discussion

Our data support other studies in India that have observed that a large proportion of MSM and IDUs are married. Social pressures in India lead many MSM to marry and have children despite their sexual preference for men. This forced duplicity drives many of these men underground and leads them to high-risk behaviours, putting them and their families at high risk for HIV and associated infections. Similar pressures likely drive IDUs to marry without disclosing their status to their future wives, leaving them vulnerable to HIV and associated consequences.

Not surprisingly, there are no published reports on the children of MSM or drug users, nor on the wives of MSM. Children will be challenging to study directly, as will the wives of MSM given the hidden nature of their husbands' behaviours, which drives their low risk perception. Given the differences observed in our analysis, we consider consequences and potential interventions for these groups separately.

Before interventions can be designed to reach the wives and children of high-risk men, there is a need for additional primary data from this population. However, the overwhelming challenge in obtaining such data is that women married to high-risk men are likely to be mostly unaware of their husbands' same-sex behaviour, as was demonstrated in our study. Reaching such women thus would require disclosure by their spouses of not only HIV risk and serostatus, but more importantly, of their same-sex behaviour.

Our qualitative study identified that disclosure to spouses and/or children is one of the largest burdens that MSM and IDUs face. Participants in our focus groups felt that they would face extensive levels of stigma and discrimination, not only from their immediate family, but also from the community in which they lived if they disclosed their status. Further, it is important to consider the options once disclosure takes place. Divorce, though becoming more common in India, is not the norm, especially in lower income groups.

Large-scale, community-level interventions to target stigma and discrimination towards men who are married but report same-sex behaviour may help more men disclose their status to their wives, and potentially help those who have not yet married follow a different path. The time for such interventions is ripe given the recent change in the law that no longer criminalizes anal intercourse.

However, such interventions are not without challenges. Changing community norms in a conservative culture, where religion plays a major role, will not be easy and will likely require many years of work. Open discussion of same-sex behaviour may actually backfire and result in even more stigma and discrimination targeted at MSM and their families. For these reasons, such interventions will require buy in from stakeholders (e.g., religious leaders, police force) and monitoring of ongoing community perceptions.

Another approach is to target the families of high-risk men themselves; given that the focus cannot be only on sexual behaviour, drug use or HIV, one option would be to centre these issues around access to primary health care. The idea would be that engaging families in primary health care, which carries little stigma, would open up avenues for discussions and interventions with respect to sexual health and HIV. Centres that are homosexual-friendly and offer comprehensive services (e.g., HIV testing, drug and alcohol abuse counselling) are likely to be most effective. Challenges to such interventions include sensitizing health care providers to the needs of marginalized populations to minimize stigma and discrimination, one of the primary barriers to accessing health care in our study. Care should be provided in centres that are friendly, but are not identified with any particular risk group to further minimize stigma. Finally, men should be reassured that disclosure of same-sex preference is a not a requirement of their wives receiving health care in such centres.

A major assumption made in most HIV research in India and the potential interventions described in this paper is that these women are unaware of their husbands' high-risk behaviours. However, no primary data from wives of MSM is available, and it is possible that a large number of these women may suspect or be aware of their husbands' behaviours. In such cases, interventions to provide support to these women, who are or become aware of their husbands' behaviours, are another option. Examples of such interventions include peer support groups or "hotlines" that women can call to receive anonymous support and advice.

Compared with the wives of MSM, there are more primary data available on wives of IDUs, although limited data exist on children. In some ways, interventions will be easier to implement in this population because the issues of disclosure are not as great a barrier. Our data demonstrate that health care access remains limited for the wives of IDUs and likely, by translation, for their children, too. As with MSM, interventions to provide primary health care to the wives and children of IDUs will be a first step at integrating other services, such as HIV and STI testing and counselling for domestic violence. The major barrier here is to make services affordable and accessible given the low socio-economic status of most of these families. Government centres do provide some services free of charge, but access is limited due to long waiting times. An alternate strategy would be to target increased use of the already available services. However, it would be ideal to supplement these basic services with other counselling services, such as those for domestic violence.

Interventions among high-risk populations tend to focus on the individuals themselves, including those interventions that are aimed at providing economic opportunities. India is a patriarchal society, and particularly in lower education communities, it is the husband's responsibility to earn and provide for the family while the woman tends to household activities. However, it is clear from our data that the male presence in the household is inconsistent given that these men vacillate between living at home and on the street, which negatively impacts on economic resources for most families.

While promoting stable incomes among IDUs is important, creating economic opportunities for women would both empower them and ensure a constant source of income that will enable provisions for the family when husbands cannot provide adequate income. We observed that a small proportion of these women turned to sex work to earn money for their families; alternate sources of income will prevent these women from putting themselves at even higher risk of HIV infection and will improve the quality of life for their families.

The value of family-based approaches to HIV prevention should also be recognized in other respects, both in terms of primary and secondary prevention, in addition to the provision of economic opportunity. In terms of primary prevention, optimal HIV prevention for the family is cessation of injection drug use, which will also facilitate other improved outcomes (e.g., improve economic opportunities and reduce domestic violence). Interventions to promote cessation of injection drug use do not typically involve the wives or families of IDUs. However, the nature of Indian society and the evidence from our data that family does play a key role in encouraging cessation of drug use argues for a shift from individual-focused interventions to family-focused interventions.

For HIV-positive men, secondary prevention models incorporating family-based adherence interventions for antiretroviral therapy (e.g., modified directly observed therapy) should also be extended to include wives and families to reduce further HIV transmission. Considering the current state of female-controlled prevention methods and the barriers to condom use, especially among married couples, this represents a more feasible method for women to protect themselves. Barriers to including women in such interventions include disclosure of both drug use and HIV status to the wives. However, our ability to recruit wives of IDUs into a research study and our findings from qualitative studies suggest that there is a willingness by IDUs to disclose their HIV and drug use status to their wives if given appropriate support.

Conclusions

The Indian social and cultural context of HIV/AIDS is not dissimilar from many parts of Asia and Africa. Homosexuality and drug use are widely considered non-normative and are heavily stigmatized. Denial is rampant, and treatment for drug addiction, if available, is generally very limited or not sought. Same-sex practices and drug use are associated with social marginalization and discrimination, which is widespread. Nevertheless, available data clearly indicates that these behaviours are not rare.

The high level of bisexual concurrency among men in this study demonstrates why the Indian HIV epidemic cannot be eradicated until interventions targeted at these men and their spouses are implemented. The wives of both MSM and IDUs have little control over their spouses' risk practices, and in the case of MSM, women are probably unaware of the risks their spouses expose them to. In reality, disclosure remains the province of men, and given the stigma and discrimination perceived, it is not likely that we will see rapid increases in voluntary disclosure. The case remains much the same for wives of IDUs: while they may be far more aware of their partners' risks, there is little they can do to protect themselves from HIV.

What remains undocumented at present is the greater impact of HIV/AIDS on families: to marital stability, to household income, to food security and to the wellbeing of children. How HIV influences normal childhood development, educational attainment and prospects for future employment is unknown. In most cases, HIV leads to economic drift, which cannot have any positive features for the family.

However, these impacts on families remain speculative, with little empirical data in existence from which to draw any firm conclusions. While a rich ethnographic literature is growing [40-42], quantitative population-based evidence is not yet available. The first step in designing effective, culturally sensitive interventions will require more systematic data collection on the risks, perceptions and impacts of the husbands' high-risk behaviours in this context.

Competing interests

The authors declare that they have no competing interests.

Authors' contributions

SSS, SHM and DDC conceived these studies, designed the data collection methods and interpreted the data. SSS and AKS oversaw the collection of the data. SSS and SHM conducted the data analysis. All authors assisted in drafting the manuscript, and read and approved the final manuscript.

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Author details

[1]YR Gaitonde Centre for AIDS Research and Education, Chennai, India. [2]Johns Hopkins Bloomberg School of Public Health, Baltimore, MD, USA.

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REVIEW **Open Access**

Family-based HIV prevention and intervention services for youth living in poverty-affected contexts: the CHAMP model of collaborative, evidence-informed programme development

Arvin Bhana*[1,2], Mary M McKay[3], Claude Mellins[4], Inge Petersen[2] and Carl Bell[5]

Abstract

Family-based interventions with children who are affected by HIV and AIDS are not well established. The Collaborative HIV Prevention and Adolescent Mental Health Program (CHAMP) represents one of the few evidence-based interventions tested in low-income contexts in the US, Caribbean and South Africa. This paper provides a description of the theoretical and empirical bases of the development and implementation of CHAMP in two of these countries, the US and South Africa. In addition, with the advent of increasing numbers of children infected with HIV surviving into adolescence and young adulthood, a CHAMP+ family-based intervention, using the founding principles of CHAMP, has been developed to mitigate the risk influences associated with being HIV positive.

Introduction

Three decades into the HIV epidemic, it is clear that HIV/AIDS is a family-based disease and that youth across the globe are particularly vulnerable. While the need for family-based HIV prevention and treatment programming is widely recognized [1], there are only a few such programmes to date that have been tested, particularly in low-resourced contexts [2]. The majority of family-based programmes internationally have focused on prevention of mother to child transmission or general child health care, educational needs or child mental health [3].

The Collaborative HIV Prevention and Adolescent Mental Health Program(CHAMP) [4] is an example of a family-focused, developmentally timed programme targeting pre- and early adolescents (9-13 years), providing a model of primary and secondary HIV prevention programme development and one that has been tested in numerous studies in the United States, sub-Saharan Africa, the Caribbean and South America.

The purpose of this paper is to provide an overview of the development and implementation of family-based programmes in poverty-affected contexts, with a particular focus on CHAMP. The aim is to draw out lessons for family-based HIV prevention and intervention programming for young adolescents, including those already infected or affected by HIV and their adult caregivers.

Global threat of HIV

HIV infection is one of the most serious threats to the health and wellbeing of young people, and requires a continued, intensive focus on youth as they account for an estimated 45% of all new infections worldwide [5,6]. While the HIV epidemic has stabilized somewhat, the level of new HIV infections and AIDS deaths remain unacceptably high, particularly in sub-Saharan Africa [7].

The consequences of the AIDS epidemic for families can be devastating. Nearly 12 million children under the age of 18 have lost one or both parents to HIV in sub-Saharan Africa [6]. In South Africa, approximately 2.8 million children have lost at least one parent, with an estimated 1.4 million (49%) presumed to be due to AIDS [6,8]. It is estimated that 80% of children who lose a parent to AIDS are likely to have a surviving parent for whom support and care becomes critical [9]. Children orphaned by AIDS may be a particularly vulnerable group in terms of emotional problems, behavioural risk taking and school drop out [10,11].

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*Correspondence: abhana@hsrc.ac.za
[1] Child, Youth, Family & Social Development Research Programme, Human Sciences Research Council, South Africa
Full list of author information is available at the end of the article

Even in contexts where access to antiretroviral treatment (ART) and preventative interventions are more plentiful, such as the US or Europe, the HIV epidemic continues to take a toll on the health and wellbeing of children and adults. Those affected by this still life-threatening and stigmatizing disease disproportionately reside in urban communities of colour, affected by high rates of poverty, substance abuse, and exposure to community and familial violence [12,13].

In the US, for example, the majority of HIV/AIDS cases are in large inner-city communities; African Americans comprise 51% of all newly reported HIV infections, with an additional 18% accounted for by Latinos [14]. Almost one-half of the more than 40,000 new HIV infections in the US each year are among people aged 25 years and under.

Conversely, the introduction of widespread HIV counselling, testing, and ART use during pregnancy and the birth process in countries with access has led to a dramatic drop in the rate of vertical transmission [15,16]. Access to ART has also meant that many HIV-infected children who were not expected to outlive their childhood are entering adolescence [17] and are presenting with: (1) serious mental health difficulties [18,19]; (2) high-risk sexual behaviours and substance use [20-22]; and (c) non-adherence to ART [23-25]. Even brief episodes of ART non-adherence can permanently undermine treatment and lead to increased resistance to medications. Thus, perinatally infected adolescents may be living with a multidrug resistant virus and have poor health outcomes.

This grim reality becomes a serious public health issue as youth transition though adolescence, a time of increased experimentation with sexual risk behaviour and drug use. Unfortunately, few family-based programmes focused on the prevention of risk behaviour have been developed or tested with this population in high- or low-resource countries [26].

HIV prevention and intervention efforts across the globe

Over the past three decades, there have been targeted efforts to decrease the risk for HIV infection among uninfected youth [27,28]. Despite some of the early HIV prevention efforts leading to improvements in youth knowledge regarding the significance of HIV and modes of transmission, and short-term changes in sexual risk behaviour [28,29-31], long-term behavioural change has been difficult to maintain [32]. Further, in a recent review of preventative interventions delivered in sub-Saharan Africa, no programme was associated with a significant decrease in actual rates of HIV infection [28,33].

As the epidemic entered its second decade, there were increasing calls for more complex models of HIV prevention and intervention programming, particularly those capable of targeting both risky and protective relational and contextual influences on youth behaviour, such as multi-level HIV prevention and care models for youth that incorporated strong partnerships with families and communities [34]. Marshalling family, social network and community-level resources around vulnerable urban youth was thought to be a critical HIV prevention and health promotion strategy [28,31,34,35].

Case description

Although a number of family-based HIV prevention programmes have been developed and evaluated, few have actually been implemented and tested in low-resource settings where the burden of HIV exists and where the focus has been on school-based and community-based programmes targeting youth [36,3,2]. CHAMP [4,36,37,38] is one of the few HIV preventative efforts that was initially focused on vulnerable youth and their families in the US, and then adapted for multiple international settings.

The first family-based programme was developed in the mid-1990s based on critical streams of influence: (1) adolescent developmental models; (2) ecologically focused models that include multi-level factors (e.g., knowledge, skills and mental health characteristics of youth and their adult caregivers; interactional qualities with key protective resources, such as parents; social support systems; health-oriented institutions; and health-promoting influences of families and communities); and (3) existing empirical findings and intensive collaboration with youth, families and target community members.

Adolescent developmental models

Initially, CHAMP embraced the developmental model with two basic views: (1) for HIV prevention to be successful, programmes need to intervene with youth prior to the initiation of sexual and drug risk-taking behaviour, specifically in pre- and early adolescence; and (2) adolescent sexual decision making occurs within social relationships and reflects a combination of social and psychological factors that need to be addressed [39].

More specifically, family and peer relationships significantly predict high-risk sexual and drug use behaviours in adolescents [40,41]. For example, family availability and monitoring are critical protective factors for reducing high-risk behaviours, while family conflict and low levels of communication are associated with increased sexual and drug use behaviour [42,43,44,]. Also, research with youth has indicated that peers are a strong influence on sexual activity and the use of condoms, and friendships with peers who are not involved in problem behaviours are also protective factors for reduced sexual risk behaviour [12].

Ecological theories of youth risk

As prevention efforts shifted from first generation models, a number of more complex ecological theories were employed.

The Triadic Theory of Influence (TTI) [45,46] is organized along two dimensions: levels of causation; and streams of influence. It thus represents both: (1) a theory of the problem in which the focus is on explanation and prediction of health behaviour change; and (2) a theory of action that emphasizes guiding the development of health-promoting interventions. Three relatively distinct streams of influence are proposed: intra-personal influences that contribute to: *one's self-efficacy* regarding specific behaviours; interpersonal social influences, the social situations and/or contexts that contribute to *social normative beliefs* about specific behaviours; and cultural-environmental influences, which constitute multiple socio-cultural macro-environmental factors that contribute towards *attitudes* about specific behaviours.

The theory proposes that some variables (such as intentions) have a direct effect on behaviour and are causally proximal, while others, like motivation to comply, have effects mediated through numerous other variables, such as social normative beliefs, and are considered to have a more distal influence.

The TTI has been translated into seven community field principles to provide a conceptual framework for the adaptation of CHAMP for South African uninfected youth [47-50]. The seven field principles included: (1) re-establishing the village (social networks); (2) providing access to health care (referral service); (3) improving bonding, attachment and connectedness dynamics (parenting styles and communication skills); (4) improving self-esteem (developing self-understanding and knowledge); (5) increasing social skills; (6) re-establishing the adult protective shield through monitoring (parental monitoring); and (7) minimizing residual effects of trauma (promoting supportive community networks).

Social Action Theory (SAT) [51] is an alternative model of behaviour change that also emphasizes the context in which behaviour occurs, but also refers to the developmentally driven self-regulatory and social interaction processes, and the mechanisms by which these variables result in adaptive and risky health behaviours. It was developed for uninfected populations, but has been used in studies with populations infected and affected by HIV and multiple life stressors [52,53].

Most recently, an adapted SAT model has been used to posit that HIV prevention and care outcomes for perinatally infected youth are influenced by: (1) context (e.g., family and living situation, life events, service systems); (2) self-regulation processes that promote adaptive behaviours (e.g., child capabilities and motivation factors and self-efficacy for treatment or prevention); and (3) social regulation factors (e.g., family and community support resources, caregiver supervision and involvement, social stigma of illness) [54]. This model was used to inform the development of the CHAMP+ programme within both the US and South Africa.

Existing empirical evidence guiding youth-oriented HIV prevention

In addition to theoretical models, the CHAMP model of programme development also prioritizes basic research studies to inform interventions. More specifically, two studies – CHAMP I, a longitudinal study of 400 inner-city pre- and early adolescents living in a high sero-prevalence community, and Child and Adolescent Self-Awareness and Health (CASAH), a longitudinal study of 200 perinatally HIV-infected and 150 uninfected by perinatally HIV-exposed youth – were highly influential in informing CHAMP and CHAMP+, respectively.

CHAMP I data found that the following variables were associated with risk behaviour in uninfected youth: (1) family processes (e.g., communication, decision making, conflict, supervision/monitoring, support); (2) outside family parental support network resources; (3) youth and family HIV/AIDS knowledge and comfort discussing sensitive issue; and (4) youth communication, social problem solving, and refusal skills. Thus, the findings suggest that HIV prevention programmes targeting inner-city young adolescents need to focus on these variables in order to reduce opportunities for initiation of sexual experience and reduce risk for HIV [55].

Few HIV prevention programmes or determinant studies of behaviour exist for perinatally HIV-infected youth. CASAH was developed to identify the mental health and risk behaviour prevention needs of this population. In CASAH, high rates of psychiatric disorder were found among the predominantly African American and Latino youth living in inner-city communities, with higher rates (60%) in HIV-positive youth as compared to HIV-negative youth (47%, $p=0.05$). Among the HIV-positive youth, 10% had initiated sexual behaviour, with one-third of those youth reporting unprotected sex, and among those on ART, 50% reported recent non-adherence to ART. Family variables (e.g., communication, supervision, and caregiver mental health) predicted behavioural outcomes, suggesting a need to focus family-based interventions on this population of youth to improve mental health and reduce sexual risk behaviour [19,21,22,56].

Community collaborations

A critical component of CHAMP is the high level of intensive involvement of stakeholders in the design of the intervention for each community. Thus, within the CHAMP model of programme development, data from previous studies is placed in the hands of key stakeholders to inform the design of interventions that are culturally and contextually relevant and that can be sufficiently flexible to navigate the barriers within targeted communities. This process was used to develop the first CHAMP intervention and for subsequent iterations, including CHAMP+ [34,57,41].

Collaborative design, delivery and testing of HIV prevention programmes has been emphasized as a means of overcoming the significant obstacles to reaching vulnerable youth and their families [58]. In particular, HIV continues to be highly stigmatizing, and specific cultural concerns arise when health-related programmes are lead by “outsiders” that can significantly impede HIV prevention efforts [59]. As a result, community-based participatory research methodology has emerged as a critical research tool for developing and sustaining efficacy-based interventions.

Thus, in each context, CHAMP has consistently sought out: (1) community representatives as advice and consent givers; (2) influential community representatives as endorsers of the research programme; (3) community members as advisors (e.g., hired as front-line staff); and (4) community members as participants in the direction and focus of the research [4].

Discussion and evaluation

CHAMP and CHAMP+ results in the US

The CHAMP+ family-based intervention is currently delivered through multi-level group modalities, which include both multiple family sessions and parent/child group sessions. Sessions focus on: (1) parent-youth communication and decision making, particularly around sensitive topics and sexual possibility situations; (2) parental supervision and involvement; (3) family support; and (4) youth problem solving and negotiation skills. This is in addition to more traditional HIV prevention activities, including HIV knowledge.

Outcome findings available to date are summarized in multiple articles, including 17 recently published [4]. In brief, significant changes in parental reports of key family-level variables have consistently been associated with CHAMP participation relative to comparison families in the following domains: family decision making, with parents more likely to make decisions within the family for CHAMP participants; parental monitoring; family communication; and comfort related to family communication. Further, pre-adolescent youth have reported significantly less exposure to situations of sexual possibility at post-test relative to comparison youth, and parents have reported significant decreases in youth externalizing behavioural difficulties in the programme condition relative to comparison youth.

The CHAMP+ intervention represents an adaptation of the CHAMP primary prevention programme to meet the needs of HIV-positive youth and their adult caregivers. The intervention protocol focuses on: (1) the impact of HIV on the family; (2) loss and stigma associated with HIV disease; (3) HIV, health, and antiretroviral medication protocols; (4) family communication about puberty, sexuality and HIV; (5) parental supervision and monitoring related to sexual possibility situations and sexual risk-taking behaviour; (6) helping youth manage their health and medication; and (7) social support and decision making related to disclosure.

In CHAMP+, there was a clear need communicated by the target community to address issues that are specific to HIV before discussion related to family processes, such as family communication and supervision and monitoring, can proceed. Thus, HIV-specific topics, such as coping, stigma, loss, disclosure, medication taking, health and risk behaviours, were created for use with infected populations.

The adaptation process resulted in: (1) significant consumer involvement with regards to programme content; (2) strong sense of programme ownership from health care sites; and (3) high participation rates in CHAMP+. Post-intervention findings for CHAMP+ participants relative to comparison youth and adult caregivers included: increases in child reports of caregiver supervision and monitoring of peer-based activities; decreases in selected youth depression symptoms; decreases in caregiver reports of difficulties with youth; and improvements in HIV knowledge and communication about HIV with others. Manuscripts summarizing results are currently in preparation or under review and findings have been presented at multiple national and international conferences (e.g., [60]).

CHAMP and CHAMP+ results in South Africa

South Africa adopted similar strategies to the original CHAMP and CHAMP+ in the US, namely to establish strong community and institutional partnerships so that prevention efforts are supported by communities and institutions, and to use empirical evidence reflecting relevant experiences of youth and families in the local setting to form the basis of the intervention. Key issues emerging from focused ethnographic studies for uninfected and infected South African youth [62,65] were used to inform the adaptation of the US-based programme for the South African context.

In particular, caregivers of uninfected youth in South Africa complained of disempowerment, which was a product of the erosion of traditional norms and social practices associated with protective parenting, as well as poor levels of HIV knowledge and information. A lack of trust and investment in community networks was also found to limit protective parenting in the target community [62]. For infected youth, similar psychosocial

Table 1. Summary of CHAMP Results

Items	Std error	Adjusted p value	Treatment group	Control group	Pooled SD mean	Effect size mean
CHAMPSA (Caregivers)						
HIV transmission knowledge	0.25	0.0084	0.190	1.336	1.817	0.631
Less stigma toward HIV-infected people	0.47	0.0187	0.207	1.991	4.427	0.403
Caregiver communication comfort	0.58	0.0021	1.025	3.423	5.897	0.407
Caregiver communication frequency	0.55	0.0412	1.966	2.969	5.095	0.197
CHAMPSA (Youth)						
AIDS transmission knowledge	0.27	0.0647	0.88	0.12	1.54	0.50
Less stigma toward HIV-infected people	0.92	0.0045	3.96	-0.25	6.03	0.70
CHAMP+US (Youth) Experimental control comparisons				F (sig)§		
Medication support by parents				2.0*		
HIV treatment knowledge				1.9*		
CHAMP+US (Caregivers)						
Youth emotional difficulties				3.1*		
Youth conduct problems				2.2*		
Youth impairment				2.9*		
CHAMP US (Caregivers)						
Family decision making				2.1*		
Parental monitoring				5.3*		
Family communication				6.8**		
Comfort related to family communication				10.4**		
Parental perceptions of lower child behavioural difficulties				3.3*		
CHAMP US (Youth)						
Exposure to situations of sexual possibility				3.0*		

§Varying designs and analyses and samples in USA and South Africa preclude direct comparison of results. * p <0.05; ** p <0.01.

difficulties to those found in US samples emerged, with loss of biological parents to AIDS being a key issue given the late roll out of ART in South Africa [65].

In keeping with other CHAMP interventions, CHAMPSA and CHAMP+SA are developed, manualized, family group interventions focusing on intrapersonal, family/interpersonal influences and community influences to strengthen family processes at each of these levels [36]. An innovation to the programmes in the South African context is the use of open-ended participatory cartoon narratives, given low literacy levels and to facilitate small group participatory experiential learning [64,66].

The CHAMPSA intervention results showed that, compared to controls, intervention families had significantly better knowledge of AIDS transmission, had less stigmatizing attitudes towards people with HIV, and talked more and had greater comfort in talking about sensitive issues to their children, as well as increased monitoring of their children. In addition, they utilised their social networks more effectively in soliciting social support [38]. Community protective influences were also strengthened through facilitating greater informal social controls and promoting social actions to create a more health-enabling community for youth [63].

Preliminary findings of the impact of CHAMP+SA suggest that families engaged with the programme reported positive experiences in helping families cope better with the diagnosis of HIV. They also reported being able to better identify problems and possible solutions [66]. Analysis of follow-up data is currently underway (Table 1).

In each context, CHAMP is implemented by three to four facilitators who co-lead the groups, allowing for separate adult and youth sub-groups for part of the sessions. The manualized intervention allows the use of lay facilitators, such as trained parents or lay counsellors, in most settings, with or without psychologists. In South Africa, given the shortage of mental health specialists, psychologists are utilized mainly in training and supervisory capacity in keeping with the concept of task shifting suggested for low-resourced settings [67].

Lessons learned

The development and implementation of CHAMP and CHAMP+ has suggested a number of important lessons for the field of family-based HIV prevention and mental health treatment. These include:

1. Intervention efforts are likely to be more successful and sustainable if they are collaborative in nature and involve a community advisory board that participates in the design and delivery of the intervention.
2. Universal principles of intervention based on science can be applied across continents and different contexts; yet these must be informed by local knowledge and empirical evidence to ensure cultural congruence.
3. An ecological framework within a developmental context is important in understanding complex family processes and cultural contexts, regardless of the micro-level theories used to inform specific behaviour change strategies within the ecological levels.
4. Family-based interventions should be group based to enhance social networking to enable the collective renegotiation of social norms regarding protective parenting practices.
5. Harnessing these social networks is important in fostering social support, which can enhance protective parenting, particularly in poor communities, as well as protective peer support networks for youth.
6. Social networks developed through group and community collaborative processes are important to build protective community environments, including re-building social controls to strengthen parental or adult supervision and care.
7. Lay facilitators can be successfully utilized to deliver the intervention with the support and supervision of mental health specialists in keeping with the move towards task shifting to increase access to mental health services in low-resourced settings.

Conclusions

There is a substantive need for family-based HIV prevention and intervention programmes across the globe; yet few family-based programmes have been tested. CHAMP and CHAMP+ represent a model of family-based HIV prevention and mental health treatment that has been used across contexts (Chicago, New York, South Africa, Trinidad and Argentina) and with a range of target populations (youth in need of preventative services, HIV-positive youth, homeless youth).

Further, the resulting programmes are informed by existing empirical findings and data drawn directly from the target youth and/or families, as well as collaboration with key stakeholders. The model is based on the understanding that in order to impact youth HIV risk outcomes (attitudes, beliefs, knowledge, behaviour), interventions need to target both risk and protective factors at the level of the child, family and context.

Using this model of intervention development, the content of the intervention can be modified to address the specific needs of youth and their families situated in unique contexts. The collaborative model of development enhances the chances that by co-designing, co-delivering and co-testing interventions with collaborative partners, including members of the target community, agency or medical setting, programmes and services can reach highly vulnerable youth and families that would otherwise be missed.

Further, the resulting efficacy-based programmes can reflect the cultural values and priorities that can be both universal and specific and ensure that programmes can be integrated into the settings they were developed for after the research phase.

Competing interests

The authors declare that they have no competing interests.

Authors' contributions

All authors are responsible for the gathering and interpretation of the material, the compilation of the paper, and the decision to submit the paper for publication. All authors have read the final manuscript and approved it for publication.

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Author details

[1]Child, Youth, Family & Social Development Research Programme, Human Sciences Research Council, South Africa. [2]School of Psychology, University of KwaZulu-Natal, South Africa. [3]Mount Sinai School of Medicine, New York, USA. [4]HIV Center for Clinical and Behavioral Studies, New York State Psychiatric Institute and Columbia University, New York, USA. [5]Community Mental Health Council, Inc., Chicago, IL, USA, and Institute for Juvenile Research, Department of Psychiatry, School of Medicine, University of Illinois at Chicago, IL, USA

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COMMENTARY Open Access

Family-centred HIV interventions: lessons from the field of parental depression

Mark Tomlinson*

Abstract

Traditionally, HIV prevention focuses on individual behaviours that place one at risk for HIV infection. Less widely regarded as a fundamental public health issue is parental depression and the detrimental effects it exerts on infant and child development, as well as its key contribution to non-fatal burden. Much like many HIV prevention and treatment interventions, programmes for depression focus almost exclusively on individuals and individual behaviour. This paper will use the extensive evidence base from research into parental depression as a model to argue for a family-based approach to HIV prevention and treatment. The aim of this will be to make a case for targeting a broader set of behaviours that occur within families when developing and implementing interventions.

Introduction

As a crucial public health problem, HIV/AIDS offers a stark challenge to dominant models of health promotion and prevention. Traditionally, HIV prevention focuses on individual behaviours that place one at risk for HIV infection. Less widely regarded as a fundamental public health issue is parental depression and the detrimental effects it exerts on infant and child development, as well as its key contribution to non-fatal burden. Much like many HIV prevention and treatment interventions, programmes for depression focus almost exclusively on individuals and individual behaviour.

Claeson and Waldman have argued for a move from disease-specific to people-specific interventions through promoting a limited set of household behaviours directly linked to the prevention and cure of common childhood illnesses [1]. This paper will use the extensive evidence base from research into parental depression as a model to argue for a family-based approach to HIV prevention and treatment. This will take the important person-centred approach of Claeson and Waldman one step further to include other family members and the interactions between them. In so doing, it argues for a paradigm shift in the treatment and prevention of HIV to one of a family-based approach in order to promote better child outcomes.

Depression

In the most recent analysis by the “Countdown to 2015” collaboration, only 16 of the 68 priority countries that accounted for 97% of maternal and child deaths in 2005 were on track to meet targets for Millennium Development Goals 4 and 5 to reduce maternal and child mortality [2].

A key contributor to child wellbeing, which has been largely neglected in the broader discussion of maternal and child health, is the issue of mental health. Depression is the largest cause of non-fatal burden and the fourth leading cause of disease burden [3]; in many countries, it is the leading cause [4]. Mental disorders are not only linked to many other health conditions, but are also among the most costly medical disorders in terms of projected health care expenditure needed to treat them [5]. There are, however, significant barriers to care, with up to 70% of people with mental disorders never receiving any kind of care [6].

In the World Health Organization (WHO) World Mental Health survey, prevalence rates for any mood disorder ranged from 3.3% in Nigeria to 21.4% in the USA, while projected lifetime risk for any mood disorder ranged from 7.3% in China to 31.4% in the USA [7]. Depression is often co-morbid with other health conditions, such as diabetes, which in the case of South Africa, affects 2.6 million people and was the sixth leading cause of natural death in 2005 [8].

Impact of depression on infants and children

Depression is a multi-generational disorder in that its psychological, social, biological and social consequences are felt by all members of the family and not solely by the

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*Correspondence: markt@sun.ac.za
Department of Psychology, Stellenbosch University, Stellenbosch, South Africa

person who is depressed [9]. This is particularly the case for children, but the impact of depression on other adult family members is also a concern [9]. Depression has been shown to affect social and leisure activities [10], to increase marital discord and conflict within families of depressed women [11], to be associated with heightened financial problems within families [10], and to increase demoralization in the non-depressed parent [12]; it also has a detrimental impact on the partners' own mental health [10]. In this way, depression is similar to HIV with regard to its effects on the broader family network.

Physical development

The bulk of research on the impact of maternal mood on child development has focused on psychological, rather than physical, development, probably because most research has taken place in developed countries, where physical growth is not an area of particular concern. Cooper and colleagues [13] have, for example, shown in a British sample how postpartum depression can interfere with the mother's feeding of her infant.

The chief focus of this work, however, is on interactional issues, rather than on the implications of feeding problems for physical growth. Physical growth is, however, a major concern in developing countries, and the question arises as to whether this may be affected by maternal mood. In a study of low-income women in Goa, India, the presence of maternal depression in the postpartum period was found to be significantly associated with low infant weight and with shorter infant length at six months [14].

Rahman and colleagues [15] found that in rural Pakistan, infants of mothers depressed in the prenatal and the postnatal period showed growth retardation at several time points in the first year of life. In addition, chronic depression carried a greater risk for poor outcome than did episodic depression, while maternal mental state was associated with a higher risk of diarrhoea in infants. Based on these data, it has been estimated that the incidence of infant stunting in rural Pakistan would be reduced by 30% if maternal depression was eliminated from this population [6].

Rahman outlines a number of mechanisms that link depression to physical morbidity [6]. These include poor self-care skills, poor illness detection and poor care-seeking behaviour. In addition, as a result of the social withdrawal that is characteristic of depressed women, they are more likely to receive inadequate antenatal care [16]. There is also an increased risk of poor fetal growth, premature birth and low birth weight among antenatally depressed women [17,18]; depression is also associated with riskier lifestyles, such as poor diet and smoking [19]. Rahman makes the important point that in low- and middle-income countries, environments are hostile and caregivers need to be vigilant of potential dangers to their infants and children [6]. So, for instance, high maternal responsiveness to a malnourished child's need for food and comfort has a direct positive impact on child growth [6].

Socio-emotional development

An important question in seeking to understand the development of children growing up in conditions prevailing in low- and middle-income countries concerns the nature of the parenting that is possible under conditions of pervasive adversity. Preoccupation with external problems (e.g., poverty, lack of partner support), as well as more immediate difficulties (e.g., trauma and loss), may directly affect the parent's capacity to be responsive to his or her child. This difficulty may be further compounded by maternal mental health problems and, in particular, by the occurrence of depression.

Depression in the postpartum period has been found to affect between 10% and 15% of women in high-income countries [20], while rates in low- and middle-income countries have ranged from 23% in India [14] to 28% in Pakistan [15] and 34.7% in South Africa [21]. A large body of research evidence has implicated such depression in disturbances in the early mother-infant relationship and in compromised child development [22].

Depression in the postpartum period is particularly important in that the emerging processes of self and mutual regulation and social capacities make infants particularly vulnerable to early disruptions to interactions with their caregivers. Infants are born as social creatures primed for interaction with others [23]; infants are able to imitate facial expressions in the first hour after birth [24] and prefer their mothers' faces to those of strangers [25]. By three months of age, the capacities of the infant are even more sophisticated, having developed the ability to engage in complex turn-taking in interaction with an interactive partner [26].

In a South African study, depressed mothers were significantly less sensitive (more remote and more intrusive) in interaction with their infants in early face-to-face interactions than were non-depressed mothers, and infants of depressed mothers were also less positively engaged with their mothers [21]. These findings are consistent with those of several studies from low- and middle-income countries that have demonstrated how maternal depression results in less optimal maternal behaviours, such as unresponsiveness, insensitivity, intrusiveness and a lowered ability to assist infant affect regulation [26,27].

One of the consequences of such disturbances in the mother-infant relationship is an irritable and withdrawn infant, who may be more likely to develop an insecure attachment to his or her remote or intrusive mother

[27,28]. Longitudinal research has found a raised rate of insecure infant attachment, impaired cognitive development, specifically in boys, and an elevated rate of behavioural and emotional problems in children of mothers with postpartum depression [22].

Stein reported increased anger and less affective sharing [29], while Murray found an increased level of behaviour problems in infants of depressed mothers [30]. In the South African study, children of depressed mothers were more likely to be insecurely attached at 18 months [31]. In the same study, maternal intrusive-coercive behaviour and remote-disengagement at two months, and sensitivity at 18 months, predicted infant attachment security [31].

Depression and HIV as ports of entry for intervention

Given the high prevalence rates and disease burden of depression, key interventions have attempted to use depression as the port of entry into a family. Using depression as the port of entry is not without its complexities in that most people do not have access to the mental health system in order to be diagnosed with mental health problems. For example, in China, as few as 8% of people with mental health disorders seek professional help [32].

A key problem then is how to target interventions for depression as populations at high risk for depression remain difficult to identify [33]. One approach has been to use screening instruments, but their specificity is poor [34]. When depression has been successfully identified, there are a number of successful interventions that have been developed to treat it. Many of these interventions (although focused on the depression, either pharmacologically or behaviourally) have included, as one of their aims, the mitigation of the impact of the depression on the infant and the child.

An important finding in this regard has been that in some cases, even when the depression has been successfully treated, parenting quality does not necessarily improve [9]. If the aim of these interventions is the depression itself without a focus on the child (or when no children are present), this is not a problem. If the focus, however, is on the mitigation of the impact on children and the family, these data have important implications for where interventions should be targeted.

HIV is also commonly used as the port of entry into a family. One of the difficulties with this (and this is true of depression as well) is that it is a highly stigmatized disease. Rotheram-Borus and colleagues [35] have argued that using family wellness as the port of entry into the family will not only effectively combat HIV, but will also simultaneously avoid a narrow focus on sexual behaviour (that leads to stigma).

Another limitation of a narrow focus on depression or HIV as the port of entry is that the intervention fails to account for the fact that depression and HIV are exacerbated by problems in interpersonal relationships [36] and embedded in social and familial contexts characterized by substance abuse [14] and domestic violence [37]. Both HIV and depression form part of a constellation of other risk factors [9] frequently overlooked when the narrow focus is on HIV or depression.

Treatment and prevention of depression

There is a considerable evidence base from high-income countries for the treatment of depression, both for antidepressant pharmacotherapy and for a variety of interpersonal- and cognitive behaviour-based psychotherapeutic interventions. The evidence base from low- and middle-income countries is less extensive. A randomized trial conducted in India showed a benefit of antidepressants over placebo [38], while a trial in Pakistan by Rahman and colleagues showed the effectiveness of a cognitive behavioural therapy (CBT)-based programme delivered by women health workers [39]. There is also evidence of the benefits of structured group CBT programme in Chile [40], and the effectiveness of group interpersonal psychotherapy in rural Ugandan villages [41].

Another approach has been to develop interventions that prevent depression. A number of psychosocial preventive interventions have been implemented (mostly in high-income countries), but evidence of effectiveness is limited. Dennis and Creedy [42] conducted a meta-analysis of psychological/psychosocial interventions that specifically targeted depression during the postpartum period, and found no preventive effect.

In the light of this lack of success of preventive interventions, an alternative approach has been to design interventions that improve the mother-infant relationship or parenting skills without directly targeting the depression. The rationale for this is to try and mitigate the impact of the postpartum depression during infancy, a highly vulnerable period for the infant. These approaches have been more promising, with benefits to parenting and the mother-infant relationship without an accompanying effect on maternal mood [9,43]. Targeting the effects of a particular disease (rather than the disease itself) is an intriguing idea, with implications for the prevention and treatment of a host of health conditions in low- and middle-income countries.

Individual- and disease-focused interventions

Focus on the individual

HIV/AIDS offers a stark challenge to dominant models of the role of psychology in health promotion and prevention. Traditionally, HIV prevention focuses on individual behaviours that place one at risk for HIV infection.

Models of health-promoting behaviours, such as the Theory of Reasoned Action [44] or the Health Belief Model [45], to name just two, have been used to try to understand individual behaviours and decision making that leads to HIV risk. HIV prevention programmes that draw on these models may have a primary aim of changing the factors that cause individuals to make the risk-taking decisions that they do. This is often achieved, for example, through education about health risk and protective behaviours, providing choices that aid decision making, and perhaps addressing some of the social factors, for example, the effects of stigma, that may influence individuals' behaviours and decisions.

The traditional health psychology approach has been vulnerable to criticism for its consistent focus on the individual as the unit of analysis and intervention. For example, Campbell [46] has argued that the utility of traditional models of health psychology in explaining complex behaviour and informing interventions is limited as they: (1) focus mainly on proximal determinants of behaviour, such as behavioural intentions and perceived norms; (2) often fail to show how these proximal determinants are determined by contextual realities; and (3) offer insight into which individual cognitive factors are related to health behaviours, but do not adequately provide guidance on how to change these cognitive factors.

Depression interventions often involve the targeting of a particular family member (the "depressed person") with little understanding of, sensitivity to, or interventions directed at how the depression may be determined by contextual realities.

A family-based approach requires us to question the notion that it is the rational intentions of individuals that are the key to health behaviour outcomes. We need to understand the degree to which these intentions are not only constrained by, but also shaped by, broader social factors, such as socio-economic factors and issues of power relations, including gender relations. Safe sex, to give a key example, is only marginally an issue of individual choice or reasoned action in a context within which risky sexual encounters that are detrimental in the long term may constitute the only available means of gaining access in the short term to food and money, and to avoiding violence and physical abuse. Finally, focusing on the individual, rather than the family, is not only less preferable, but in fact creates problems, such as when women are identified as HIV+ before their partners and families often resulting in them being blamed with subsequent stigma, exclusion and, in many cases, violence [47].

Focus on the disease

Claeson and Waldman [1] have convincingly argued that significant gains in child survival and improvements in child health will depend to an increasing degree on what happens in the household, in combination with a responsive and supportive health system. They go on to argue that there should be a focus on the promotion of a limited number of household behaviours that have a direct link to childhood illness.

Traditionally, a narrow disease-focused model has dominated health interventions. For example, the primary aim of most interventions that target pregnant, HIV-positive women is to prevent transmission. Once transmission has been prevented, the programme considers itself to be successful and usually ends. Programme failure to cast a gaze beyond its immediate disease-specific aim has a number of consequences. One recent example of this is the emerging evidence of increased mortality and morbidity among HIV-exposed, uninfected infants and children [48]. A broader focus on wellness within a family-based approach would reduce the potential for the broader implications of HIV infection (not simply transmission) to be overlooked.

Another example of the limitations of a disease-focused intervention from the parental depression literature is the finding of Seifer and colleagues [49] that poor parenting practices associated with depression may persist following a depressive episode and when the parent is relatively symptom free. This provides further evidence for a broader programme focus, rather than simply focusing on the depression [43].

A focus on early parenting that has characterized a number of interventions in the parental depression field has important lessons for HIV treatment and prevention. Punitive and coercive parenting has been associated with externalizing behaviour in children: children who exhibit these behaviours are more likely to get into trouble at school [50], have an earlier sexual debut [51], and engage in risky sexual behaviour [52], factors that are likely to increase the risk for HIV infection. Benefits of parent responsiveness-focused interventions have also been shown to extend to other areas of child health, including physical growth [53].

It has also been shown how a family-based approach impacts health, quality of life, and compliance with treatment regimens among HIV-positive parents [54]. Parental support and close family relationships are associated with later sexual initiation and increased condom use [55,56], while family cohesion and support are related to less risky sexual behaviour and fewer health-risk behaviours [57,58].

A generational and developmental approach

In the light of the compelling evidence of the effects of depression on parenting skills and consequent child health and development, it is crucial that interventions are developed taking into account developmental stages of children, as well as using a generational approach. A two-generational approach (parent and child) or three-generational approach (grandparent-parent-child), together with a focus on siblings, immediately embeds any intervention in a broader familial-ecological context [59]. A family-based approach is, at its core, a generational approach. In the conventional understanding of the term, it is generational by virtue of the fact that it includes parents, children, siblings and grandparents.

In the context of maternal depression, the presence of other involved caregivers (father, grandparent, aunt or other) mitigates the impact of the maternal depression on the infant and child [9]. In the case of HIV, an individualized focus often ignores the significant familial barriers to, for example, exclusive breastfeeding driven by cultural and generational (mother-in-law, grandmother) prescriptions about appropriate infant feeding [60]. Unless significant family members, such as elders or mothers-in-law, "buy into" the notion of exclusive breastfeeding, it is highly unlikely that the decision to exclusively breastfeed (no matter how well intentioned) will find sufficient support within the family context to be successful.

In another understanding of a generational approach, family-based approaches (to depression or to HIV) are generational in that they have the potential to improve the context of children born into households at risk, and in so doing, improve long-term infant and child outcome. This form of intervention will reduce the likelihood of children engaging in risky behaviour across their life spans. A parenting intervention with parents and grandparents aimed at improving monitoring of young children and facilitating less permissive parenting has been shown to be associated with adolescents having fewer sexual partners and fewer pregnancies [61]. The evidence presented here on the moderating effect of other (non-depressed) family members in the context of maternal depression further strengthens the argument for a generational approach.

Parental depression that occurs during infancy, upon the transition to school, or during adolescence has particular developmental implications that may be different from parental depression occurring at other developmental points. This is also the case with HIV, most pertinently, of course, in the context of mother to child transmission,, but it is also true at other stages of development. Financial constraints resulting in children not enrolling in school, or the implications of food insecurity for childhood stunting and malnutrition are two common examples. A family-based approach is "developmental" to the extent that it acknowledges how particular developmental milestones may throw up particular challenges to families, which may then require an intervention specifically tailored to fit the particular developmental stage of the child. Such sensitivity is difficult to incorporate when the focus is on the individual, and a narrow conception of disease.

Family-based interventions

Weissbourd [62] has outlined four principles of family interventions that are pertinent to this discussion. The first principle is that there is no such thing as a child without a family, and that families only exist in the larger context of community life. The second principle is based on the evidence that families are better able to support themselves when they receive appropriate support; this is known as the family self-sufficiency model. The third principle is that it is cost effective and appropriate to foster positive and favourable development, rather than to merely avoid problems. The final principle is the recognition of the importance of the early years for infant and child development, and that in terms of brain development, it is through relationships with other people that synaptic connections are formed. Broad family-based interventions to mitigate the impact of parental depression usually comprise all or most of these four elements.

A focus on the family in no way excludes a focus on the health system or disease-specific strategies. What it does do, however, is include in programme design an understanding of how any health issue is firmly embedded within a familial context. In the case of infant feeding, for example, it acknowledges that simply providing information about exclusive and appropriate feeding, and even convincing HIV-positive women about it, is simply the first step in a complex chain of familial negotiations that will have to take place for the knowledge to become translated into practice. Interventions must address the environmental barriers to implementation.

Siblings constitute an important aspect of the family environment that is seldom considered. Positive sibling relationships can be protective for children exposed to stressors, especially in homes characterized by parental conflict [63,64]. When designing interventions, it is important that consideration be given to strengthening relationships between siblings with a view to reducing the effects of adverse experiences [63]. With the increasing occurrence of child-headed households, implementing preventive family-based interventions that target siblings from the outset is vital.

Given the cost of treating depression, and the lack of access to mental health care and psychotropic medication because of weak health systems in many low- and middle-income countries, an important consideration is the role of alternative caregivers [33]. There is evidence that infants of depressed mothers respond positively during interactions with their non-depressed fathers [65], as well as other caregivers, such as child minders or day-care nurses [66].

Interestingly, Cohn and colleagues [67] found a positive benefit for the mother-infant relationship when the depressed mother was not based at home full time. Alternative care has also been shown to reduce behaviour problems in children, aged two and three years, of depressed mothers [68]. These data are highly pertinent for HIV in that they illustrate how the functioning of other family members is central for beneficial child outcomes (even in the context of maternal depression).

Discussion

Rotheram-Borus and her colleagues [35] have argued that a paradigm shift is needed in HIV prevention, treatment and care. The lack of skilled staff, poorly developed health systems and financial constraints all make the continuing focus on categorical funding (disease specific) ineffective [35]. Categorically funded, vertically integrated HIV interventions are highly stigmatized and will not have the capacity to address the health needs of Africa [35]. This is also true for depression, and unless packages of care for depression or other mental disorders [69] are integrated into community- and family-based intervention models, they are unlikely to be successfully implemented at scale.

While family-level interventions offer the potential for significant gains in the prevention and treatment of HIV, their implementation will face many of the same barriers that individual-focused interventions do. Scaling up family-based interventions will need to be linked to existing service delivery systems and integrated with the existing health care system. In addition, they will require a trained, well-managed and adequately supported workforce in order to deliver the interventions.

In the context of the significant human resource crisis that characterizes many low- and middle-income countries [70], community health workers are increasingly being used to deliver interventions. There are, however, significant barriers to the effective deployment of community health workers (such as training, monitoring and supervision). Another option to scaling up services that has met with some success has been to make use of the least costly health workers who are able to complete the task, otherwise known as task shifting [71]. A successful example of task shifting has been the use of surgically trained assistant medical officers to perform caesarian sections [72]. Recently, however, it has been argued that task shifting should not be seen as a panacea for the human resources challenges faced by low- and middle-income countries [73].

Depression and HIV are both highly stigmatized conditions. Furthermore, they are both chronic illnesses with repercussions for family members that go beyond the individuals and their illness. As a result, a family-focused wellness perspective is likely to be a more acceptable vehicle of intervention than a focus on any single condition or disease entity. Models of intervention focusing on early parenting, familial cohesion, illness detection and appropriate health-seeking behaviour, cognitive-behavioural strategies of behaviour change, linking people to poverty alleviation programmes, and comprehensive strategies that begin early in life and continue over time (characteristic of many successful intervention programmes in the domain of youth violence [74]) are urgently needed.

The broad diffusion of these successful programmes has not happened in any significant way [35]. There are many reasons for this, not least of which is the continuing search for the "magic bullet" for HIV prevention. One of the reasons for poor diffusion is that delivering efficacious treatments under ideal conditions is quite different from implementation at scale in community settings. Interventions are embedded within the "messiness" of family life, the chaos of families without meaningful routines, and with multiple familial actors that all contribute to both the problem and its solution. Behavioural change can only be sustained when it is supported by the routines and personal relationships that characterize daily family life [35]. This is simply not possible in individual-focused, disease-targeted interventions.

All disease-specific (or individual-focused) interventions are, to a greater or lesser degree, targeted responses. Stand-alone, single disease focused interventions for depression or HIV remain narrow in focus and are unlikely to impact meaningfully on child outcomes. So while the response to HIV is not like the mass eradication programmes characteristic of polio eradication or child health days (vitamin A supplementation, de-worming), the underlying focus is still on a specific disease.

The evidence from parental depression offers insights into how a shift from viewing HIV or depression as the primary focus, together with a family-based approach, allows us to "see" with greater clarity the extent to which these are embedded in contexts characterized by interpersonal violence, poor child attendance at school, absent fathers, chaotic family routines, intergenerational transmission of trauma, mental illness, youth violence and risk taking, and disempowerment of women.

Any move to a family-centred approach in poor countries will need a parallel development of a research agenda. The advantage of an individualized, disease-targeted approach is that measures of efficacy/effectiveness are often single outcomes linked to a single, (relatively) easily measured intervention (de-worming, vitamin A supplementation). Family-centred approaches, on the other hand, involve complex interactions between many levels of intervention and with multiple outcomes. Measurement is complex and this needs to be factored in when implementing and measuring family-based interventions.

Conclusions

The aim of this paper has not been to set up individual, disease-targeted programmes in opposition to family-centred interventions. There is a place for both. It would be a mistake to now assume that family-based interventions are the next "magic bullet". I would argue, however, that the focus on individual, disease-focused interventions has tended to neglect the reality of how people are always embedded within families and broader communities, which has resulted (certainly in the case of depression and HIV) in an overemphasis on finding the magic bullet.

In the case of HIV, each and every magic bullet has failed [35] and shown to be hopelessly optimistic. Wagner and Blower [75] have shown, for example, how the latest magic bullet, the test-and-treat strategy that the WHO has argued would eliminate HIV within 10 years [76], is likely to be ineffective, and that even under optimistic conditions, HIV elimination using the test-and-treat strategy is (theoretically) possible only in 70 years' time.

The treatment and prevention of HIV requires, just as parental mental illness does, a multigenerational, developmentally appropriate and integrated family-centred approach. Unless this is done, the fruitless search for the next magic bullet will continue unchecked.

Competing interests

The author declares that they have no competing interests

Author's contributions

MT drafted the manuscript. The author has approved the final manuscript.

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