

What are the Benefits and Barriers of Communicating Parental HIV Status to Seronegative Children and the Implications for Jamaica?

A Narrative Review of the Literature in Low/Middle Income Countries

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ABSTRACT

Objective: To examine the benefits/barriers for HIV positive parents of communicating their status to seronegative children in low/middle income countries in order to inform policy and practice in Jamaica.

Methods: The authors carried out a systematic search of published literature on parental disclosure in low/middle income countries written in the English language between January 1991 and September 2012, identified from databases: Academic Search Complete, CINAHL, EBSCOhostEJS, Gender Studies Database, Health Policy Reference Centre, MEDLINE (includes the West Indian Medical Journal), PsycARTICLES, PsycINFO, SocINDEX, AMED, Global Health, Embase, Social Policy and Practice, Maternity and Infant Care. The authors also refer to articles on parental disclosure in high-income countries which appeared in peer-reviewed journals and conducted a local search in Jamaica for articles on HIV disclosure in the Caribbean region.

Results: Global estimates of parental disclosure rates were 20–97% in high income countries and 11–44% in resource constrained countries. Mean age of children at disclosure was age 10–18 years. Mothers were more likely to disclose to older children, female children, and when they had strong support networks. Barriers included fear of stigma/discrimination, not knowing how to tell the child, fear of the child disclosing to others and believing a child was too young to cope. Of the 16 articles identified which met the search criteria, 10 studies and three reviews noted positive benefits of disclosure on parental health and the parent-child relationship.

Conclusion: Significant differences in attitudes and rates of maternal disclosure in low/middle income countries compared to high income countries reflect the impact of cultural, structural, economic and social factors and highlight the need for culturally-specific research. Implications for policy and practice in Jamaica are discussed.

Keywords: HIV/AIDS, Jamaica, parental disclosure

¿Cuáles son los Beneficios que se Producen y las Barreras que se Erigen Cuando los Padres Comunican Su Condición de VIH a Sus Hijos Seronegativos, y Cuáles son las Implicaciones para Jamaica? Una Revisión Narrativa de la Literatura en los Países de Ingresos Bajos/Medios

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RESUMEN

Objetivo: Examinar los beneficios y las barreras que se producen cuando los padres comunican su condición de VIH a sus hijos seronegativos en los países de ingresos bajos/medios, y disponer de información para conformar las políticas y la práctica en Jamaica.

Métodos: Los autores realizaron una búsqueda sistemática de la literatura publicada sobre revelaciones de los padres en los países de ingresos bajos/medios, escritas en idioma inglés entre enero de 1991 y septiembre de 2012, e identificadas en las bases de datos siguientes: Academic Search

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Complete, CINAHL, EBSCOhostEJS, Base de datos de estudios de género, Centro de referencia de políticas de salud, MEDLINE (incluyendo West Indian Medical Journal), PsycARTICLES, PsycINFO, SocINDEX, AMED, Glo-bal Health, Embase, Política y práctica social, Maternidad y atención infantil. Los autores también consultaron artículos sobre las revelaciones hechas por padres en países de altos ingresos, las que aparecieron en revistas arbitradas, y realizaron una investigación local en Jamaica, en busca de artículos sobre revelación del VIH en la región del Caribe.

Resultados: Los estimados mundiales de las tasas de revelación de los padres fueron 20–97% en los países de ingresos altos, y 11–44% en los países de recursos limitados. La edad promedio de los niños a la hora de escuchar la revelación fue 10–18 años de edad. Las madres eran más propensas a revelar a los niños mayores, y a las niñas, así como a hacer revelaciones cuando tenían fuerte apoyo de las redes. Las barreras incluyeron temor al estigma/discriminación, no saber cómo decirle al menor, el miedo de que el menor revelara la condición a otros, y el creer al niño o la niña demasiado joven hacer frente a la información. De los 16 artículos identificados que cumplieron los criterios de búsqueda, 10 estudios y tres reseñas señalaron beneficios positivos con respecto al revelar la salud de los padres, y a la relación padre-hijo.

Conclusión: Las diferencias significativas en actitudes así como en tasas de revelación por parte de las madres en los países de ingresos bajos/medios en comparación con los países de altos ingresos, reflejan el impacto de los factores culturales, estructurales, económicos y sociales, y destacan la necesidad de realizar investigaciones orientadas a culturas específicas. Se discuten las implicaciones para las políticas y la práctica en Jamaica.

Palabras claves: VIH/SIDA, revelación de los padres, Jamaica

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INTRODUCTION

Since 1994, strong clinical evidence has prompted the use of highly active antiretroviral therapy (HAART) for the prevention of mother-to-child transmission [MTCT] (1), resulting in the majority of children being born seronegative to mothers with HIV. In Jamaica, MTCT rates are currently 4.6%, down from 10% in 2005 (2). Although there is considerable research on parental disclosure to seronegative children in high income countries (3–13), little is known about the benefits and challenges for families and communities in resource constrained settings, including Jamaica.

Global estimates of disclosure rates show a contrast between parental disclosure in high income countries (20–97%) and resource constrained countries [11–44%] (14); the higher disclosure rates are generally found by studies which include some children known to be HIV positive. Research in high income countries has shown significant mental health benefits for parents, especially mothers, in disclosing to their children [eg lower anxiety and depression, higher perceived social support and family cohesion] (7). Several studies identify additional benefits of disclosure including social benefits (eg networking), physical benefits (eg assistance with housework/caring responsibilities), or emotional benefits [eg reduced anxiety] (12, 15, 16). In resource constrained countries, specific socio-economic factors, including high levels of ‘felt’ and ‘enacted’ stigma (17) in relation to HIV and the comparatively low levels of professional psychosocial support may help to explain the relatively low levels of parental disclosure to children (14, 18–32).

This narrative review seeks to examine the benefits/barriers for HIV positive parents of communicating their status to seronegative children in low/middle income countries in order to inform policy and practice in Jamaica.

SUBJECTS AND METHODS

The authors carried out a systematic search (Fig. 1) of published literature on parental disclosure in low/middle income countries written in the English language between January 1991 and September 2012, identified from databases: Academic Search Complete, CINAHL, EbscohostEJS, Gender Studies Database, Health Policy Reference Centre, Medline (includes the West Indian Medical Journal), PsycARTICLES, PsycINFO, SocINDEX, AMED, Global Health, Embase, Social Policy and Practice, Maternity and Infant Care.

A local search of The University of the West Indies library database yielded no published articles on parental disclosure in the Caribbean. However, 11 Caribbean studies referring to HIV disclosure to partner, family or healthcare professionals were found.

Sixteen of the 167 studies found met the inclusion criteria: eight from middle income countries, one from a low income country, three looked at African immigrants in Europe, three were global reviews and one was World Health Organization (WHO) guidance. Methodologies comprised one systematic review, two literature reviews, ten qualitative studies and three cross-sectional surveys. Four papers focussed on mothers, ten on parents and two on caregivers.

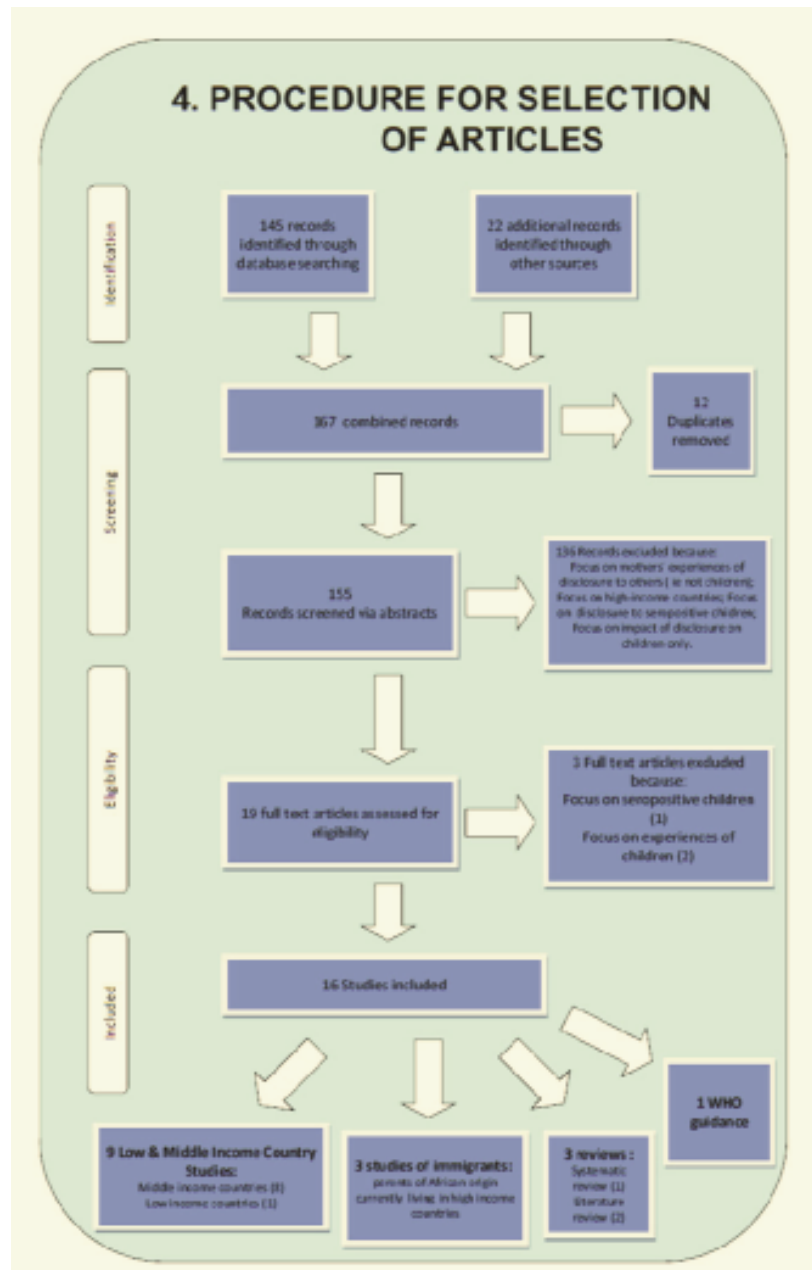


Fig. 1: Procedure for selection of articles.

Source: Moher *et al*, The PRISMA Group; 2009 (38).

To provide a global comparison, the authors also refer to articles on parental disclosure in high income studies (mainly the United States of America (USA)) which appeared in peer-reviewed journals.

In order to examine the experiences and views of parents concerning disclosure of their status to their seronegative children, the authors highlighted and grouped themes identified by the literature. Three overarching themes emerged: benefits of disclosure (as perceived by parents), barriers to disclosure (as perceived by parents) and the

broader implications of particular studies which could be applied to other populations. The benefits and challenges of disclosure for children will not be addressed in this article.

RESULTS

Perceived benefits in low/middle income countries

Studies identified a number of benefits parents attributed to the disclosure of their status to their seronegative children (Fig. 2). In terms of physical health, parents stated that they received practical help from children [eg taking on household

"I wanted them to get it from me directly....it makes me feel good that I told them instead of knowing it from someone else".

38-year old mother of five children aged eight to 24, Uganda (27).

"I love it when my kids remind me of the medication....she will just run to the bedroom and give me a glass of water".

38-year old single mother two children aged 14 and 16, Botswana (22).

"I've told my kids. Because they had to take care of me- they have to be aware, when I was very sick and I didn't want to put them at risk".

38-year old single mother of two children aged 12 and 16, Botswana (22).

"We are closer and more concerned about each other".

Thai mother comments on her relationship with her daughter after disclosure (19).

Fig. 2: Comments from parents on the benefits of disclosing their status to their children.

responsibilities, collecting medication, caring for parents when ill] (20, 27–29); that they found it easier to take their medication and attend medical appointments (22) and that they had increased energy as they were no longer guarding the secret (19).

Parents also recognized mental health benefits of disclosure. These included direct benefits to the parents, such as: being able to grieve and work through feelings of anger/guilt (20), receiving emotional support from children (19), freedom from worry that the child will guess or find out from someone else (19, 20, 23, 27), reduced stress as parents are able to be open about their status/health issues within the family [and thereby potentially access other support] (29, 30, 32). Parents also identified indirect mental health benefits as a result of the peace of mind that they obtained from preparing children for adverse events [such as discrimination or parental illness/death] (19, 27); and providing children with information to protect themselves from infection through caring for an ill parent, drug use or unprotected sex (20).

Additionally, some parents talked of disclosure prompting a strengthening of the parent-child relationship, particularly when the parent (rather than someone else) tells the child (19, 22, 31).

Perceived barriers in low/middle income countries

Fear featured prominently as a barrier to disclosure (Fig. 3). Parents were fearful of the potential negative effect of disclosure on the child; especially that the child might feel depressed, anxious, fearful, angry or ashamed, that the child might have social problems at school, their grades might suffer and that their behaviour might change, leading to conflict and disruption at home (19, 23, 25, 28–30). Parents feared that disclosure would damage the parent-child relationship and lead to rejection by the child or a loss of respect for the parent (19, 27, 28).

Parents, especially those in resource constrained settings, may feel unprepared and unsupported in disclosing in an age appropriate way to their child and managing children's reactions over time (14, 26). This may contrast with high income countries which tend to be better resourced in terms of providing emotional and psychological support through counsellors, social workers, and schools. For example, a 1997 study in Scotland found that 72% of HIV-affected families received support from voluntary or statutory agencies (33). Studies of immigrants from low income countries currently residing in high income countries have found that positive relationships with healthcare profession-

"How can I? Where do I begin? The old one or the young one? What if they ask how I got it?"

43-year old father of thirteen children aged four to 23, Uganda (27).

"There are children of different natures, some withdrawn and quiet. It is better not to tell them". "Some children are aggressive. It is better a counsellor deals with disclosure issues". Mothers, Southern India (28).

"I feel so sad about it and I know they would be sadder, cry and do all those heart-breaking things that I am not ready for".

39-year old mother of six children aged nine to 22, Uganda (27).

"If we tell him [the child], he may tell other kids in our village. He knows nothing about the seriousness of it. Sometimes gossip is very unpleasant and offensive".

Mother, China (31).

Fig. 3: Comments from parents on the barriers to disclosing their status to their children.

als can support persons living with HIV (PLHIV) with disclosure issues (18), suggesting that this model of care could also be effective in resource constrained settings.

Parents feared the reaction of others, specifically that the child or family would experience stigma, discrimination, ostracism, or isolation, and that the child would be excluded from school or by other children (22, 23, 27–32). Implicit in this fear was the assumption that the child would tell others (20, 25, 27, 28, 31). This fear may be of particular importance in resource constrained settings where families are more likely to rely on family and community networks for practical, material and financial support (24) which may be jeopardized by a negative reaction to HIV disclosure and cause individuals to be less likely to be open about their status.

Other barriers included: a desire to protect the child from distress (23, 29), avoid the loss of a carefree childhood (22), a lack of perceived benefits of disclosure to the child (27), a perception that the child was unaware of the illness (31), waiting for the child to ask questions (19), uncertainty about what exactly and how much to tell children of different ages, and a feeling that the child was too young/immature

(20, 28, 30, 32). However, children can be perceptive, noticing details, overhearing conversations, and constructing their own understanding of events (20). Many children will have been aware of periods of illness experienced by their parents and, if not given implicit or explicit permission by their parents to talk about their illness, may feel unable to raise the topic (19). Despite this, many children will have some knowledge of their parents' illness. In a 2001 American study, 92% of mothers stated that their children knew they were taking medications and of these, 39% believed their children to be anxious about this (7). However, few studies in resource constrained settings acknowledge the potential anxiety and confusion that silence and uncertainty could place on the child, although this is evidenced in the literature from high income countries (34, 35).

Parents also reported uncertainty about the best way of communicating their status, including: uncertainty about how or when to disclose (19, 23), a feeling that they lacked skills or guidance (20, 27), the need for help from healthcare providers (28), a belief that there was a lack of counselling and support services (28), finding it difficult to talk about sex or death with children (20, 22, 25, 29) and not having enough

knowledge about HIV to be able to explain and answer children's questions (31). Some parents felt they had already told their child indirectly [eg by sending the child to collect medication or taking the child to HIV-related appointments] (20).

Additionally, a number of studies have identified the emotional needs of parents themselves as they come to terms with their diagnosis as a barrier to disclosure to their children. Some parents are unable to see beyond the emotional pain of disclosure (27), fear regret or repercussions (19, 25), have difficulty confronting their own mortality (19, 29) or are still coming to terms with their own feelings (19).

CONCLUSION: IMPLICATIONS FOR JAMAICA

Several studies (20–22, 24, 25) identified that, in resource constrained countries, both the benefits and the risks of disclosure may be heightened. In high-income settings, where families' material needs are more likely to be met, the benefits of disclosure tend to be access to psychological support and relief from keeping a secret; in resource constrained settings, emotional and psychological benefits are often secondary to the potential for increased practical, material and financial support. Obermeyer's (24) review article examined 231 disclosure articles, including 76 from low/middle income countries and reported that both the potential benefits and risks of disclosure were higher in low resource settings where there were limited support services and where PLHIV look to families and communities for practical, material and financial help, as well as emotional support. The high levels of stigma and discrimination and the additional financial and social challenges, such as the possibility of isolation and ostracism, may discourage families from providing support to PLHIV (24). Disclosure has been found to be higher when people expect to receive help and lower when they expect blame and discrimination, and in many resource constrained countries there is an arguably higher level of stigma and discrimination (or of fear of stigma and discrimination) which may act as a disincentive to disclose (24, 36).

The stigma attached to HIV in Jamaica has an impact on the health-seeking behaviours of HIV patients, delaying entry into treatment, care and support (37). In addition, up to 20% of women and 5% of HIV exposed infants do not receive treatment through the current MTCT prevention programme, due to late presentation to antenatal care, failure to disclose HIV status when presenting to care (36) or by avoiding the healthcare system entirely. It is not uncommon for HIV infected mothers to refuse replacement formula feeds, fearing that failing to breastfeed may be seen as evidence of their HIV status (36).

The issues identified by existing studies of disclosure in low/middle income countries with potential implications for Jamaica fall into two broad categories: the need for professional support and the need for social support. Studies have identified a need for enhanced intervention programmes which are culturally sensitive and adaptable to local contexts

(19, 28), addressing parenting, family support and social networking (21). Programmes would include practical guidance on age-appropriate disclosure to children (15, 26), managing parental fears and children's responses (22), planning for the future (22), using tools such as story books and memory books (27), and balancing advantages and disadvantages in specific family contexts (23).

Parental disclosure is an important issue because of the far-reaching impact it can have on the health and well-being of families as well as the broader implications for public health and community cohesion. There is a lack of research into maternal disclosure in the Caribbean, where specific cultural and economic factors affect the choices that parents make. The importance of particular psychosocial factors (including family involvement and communication, planning for the future, providing peer support, and reducing stigma and discrimination) in supporting families affected by HIV across the world, are well documented (20, 22–25, 29–31). Jamaica has a strong track record of reducing MTCT (2) and providing effective medical treatment to PLHIV (37). The gaps in providing psychosocial support to families (including supporting parental disclosure to seronegative children) could be addressed by adapting successful global programmes to the Jamaican context.

REFERENCES

1. Connor EM, Sperling RS, Gelber R, Kiselev P, Scott G, O'Sullivan MJ et al. Reduction of maternal-infant transmission of human immunodeficiency virus type 1 with zidovudine treatment. *Pediatric AIDS Clinical Trials Group Protocol 076 Study Group. N Engl J Med* 1994; **331**: 1173–80.
2. Ministry of Health, Jamaica. *Jamaica Country Progress Report 2012*. Kingston: Ministry of Health.
3. Armistead L, Tannenbaum L, Forehand R, Morse E, Morse P. Disclosing HIV status: are mothers telling their children? *J Pediatr Psychol* 1994; **26**: 11–20.
4. Armistead L, Morse E, Forehand R, Morse P, Clark L. African-American women and self-disclosure of HIV infection: rates, predictors, and relationship to depressive symptomatology. *AIDS Behav* 1999; **3**: 195–204.
5. Letteney S, LaPorte HH. Deconstructing stigma: perceptions of HIV-seropositive mothers and their disclosure to children. *Social Work in Healthcare* 2004; **38**: 105–23.
6. Letteney S. Mothers' disclosure of maternal HIV status to children: key psychosocial correlates. *J HIV/AIDS Social Services* 2006; **5**: 67–84.
7. Murphy DA, Steers WN, Dello Stritto ME. Maternal disclosure of mothers' HIV status to their young children. *J Family Psychol* 2001; **15**: 441–50.
8. Murphy D. HIV-positive mothers' disclosure of their serostatus to their young children: a review. *Clin Child Psychol Psychiatry* 2008; **13**: 105–122.
9. Murphy DA, Roberts KJ, Hoffman D. Regrets and advice from mothers who have disclosed their HIV+ serostatus to their young children. *J Child Fam Stud* 2003; **12**: 307–18.
10. Murphy DA, Armistead L, Marelich WD, Payne DL, Herbeck DM. Pilot trial of a disclosure intervention for HIV+ mothers: The TRACK program. *J Consult Clin Psychol* 2011; **79**: 203–14.
11. Nelms TP, Zeigler VL. A study to develop a disclosure to children intervention for HIV infected women. *J Assoc Nurses AIDS Care* 2008; **19**: 461–9.
12. Schrimshaw EW, Siegel K. HIV-infected mothers' disclosure to their uninfected children: rates, reasons, and reactions. *Journal of Social and Personal Relationships* 2002; **19**: 19–43.

13. Shaffer A, Jones DD, Kotchick BA, Forehand R. The Family Health Project Research Group. Telling the children: disclosure of maternal HIV infection and its effects on child psychosocial adjustment. *J Child Fam Stud* 2001; **10**: 301–13.
14. Qiao S, Li X, Stanton B. Disclosure of parental HIV infection to children: a systematic review of global literature. *AIDS Behav* 2013; **17**: 369–89.
15. Lee MB, Rotheram-Borus M. Parents' disclosure of HIV to their children. *AIDS* 2002; **16**: 2201–07.
16. Wiener L, Mellins CA, Marhefka S, Battles HB. Disclosure of an HIV diagnosis to children: history, current research, and future directions. *J Dev Behav Pediatr* 2007; **28**: 155–66.
17. Scrambler G, Hopkins A. Being epileptic, coming to terms with stigma. *Sociology of Health and Illness* 1986; **8**: 26–43.
18. Åsander A, Björkman A, Belfrage E, Faxelid E. HIV infected African parents living in Stockholm, Sweden: disclosure and planning for their children's future. *Health and Social Work* 2009; **34**: 107–15.
19. Dane B. Disclosure: the voices of Thai women living with HIV/AIDS. *International Social Work* 2002; **45**: 185–204.
20. Geiselhart K, Gwebu TD, Krüger, F. Children, adolescents and the HIV and AIDS pandemic: changing inter-generational relationships and intra-family communication patterns in Botswana. *Children, Youth and Environments* 2008; **18**: 99–125.
21. Mkwanazi NB, Rochat TJ, Bland RM. The importance of counselling around disclosure in preparation for parental disclosure to children. Canadian International Development Agency; 2011.
22. Nam SL, Fielding K, Avalos A, Gaolathe T, Dickinson D, Geissler PW. Discussing matters of sexual health with children: what issues relating to disclosure of parental HIV status reveal. *AIDS Care* 2009; **21**: 389–95.
23. Nöstlinger C, Jonckheer T, de Belder E, van Wijngaerden E, Wylock C, Pelgrom J et al. Families affected by HIV: parents' and children's characteristics and disclosure to the children. *AIDS Care* 2004; **16**: 641–8.
24. Obermeyer CM, Baijal P, Pegurri E. Facilitating HIV disclosure across diverse settings: a review. *Am J Public Health* 2011; **101**: 1011–23.
25. Palin FL, Armistead L, Clayton A, Ketchen B, Lindner G, Kokot-Louw P et al. Disclosure of maternal HIV-infection in South Africa: description and relationship to child functioning. *AIDS Behav* 2009; **13**: 1241–52.
26. Rochat TJ, Bland R, Coovadia-Hoosen H, Stein A, Newell M. Towards a family-centered approach to HIV treatment and care for HIV-exposed children, their mothers and their families in poorly resourced settings. *Future Virology* 2011; **6**: 687–96.
27. Rwemisisi J, Wolff B, Coutinho A, Grosskurth H, Whitworth J. 'What if they ask how I got it?' Dilemmas of disclosing parental HIV status and testing children for HIV in Uganda. *Health Policy and Planning* 2008; **23**: 36–42.
28. Thomas B, Nyamathi A, Swaminathan S. Impact of HIV/AIDS on mothers in Southern India: a qualitative study. *AIDS Behav* 2009; **13**: 989–96.
29. Thorne C, Newell M, Peckham CS. Disclosure of diagnosis and planning for the future in HIV-affected families in Europe. *Child Care Health Dev* 2000; **26**: 29–40.
30. World Health Organization. Guideline on HIV disclosure counselling for children up to 12 years of age. Geneva: WHO; 2012.
31. Xu T, Yan Z, Rou K, Wang C, Ye R, Duan S et al. Disclosure of parental HIV/AIDS to children in rural China. *Vulnerable Children Youth Stud* 2007; **2**: 100–05.
32. Zhou Y, Zhang L, Li X, Kaljee L. Do Chinese parents with HIV tell their children the truth? A qualitative preliminary study of parental HIV disclosure in China. *Child Care Health Dev* 2013; **39**: 816–24. doi: 10.1111/j.1365-2214.2012.01394.x. Epub 2012 Jun 8.
33. Mok J, Cooper S. The needs of children whose mothers have HIV infection. *Arch Dis Child* 1997; **77**: 483–7.
34. Delaney RO, Serovich JL, Lim J-Y. Reasons for and against maternal HIV disclosure to children and perceived child reaction. *AIDS Care* 2008; **20**: 876–80.
35. Tompkins T. Disclosure of maternal HIV status to children: to tell or not to tell ... that is the question. *J Child Family Stud* 2007; **16**: 773–88.
36. UNAIDS. UNGASS Country Progress Report 2010: Jamaica National HIV/STI Programme. [cited 2011 Aug 17]. Available From http://www.unaids.org/en/dataanalysis/monitoringcountryprogress/2010progressreportsubmittedbycountries/jamaica_2010_country_progress_report_en.pdf
37. Duncan J, Grant Y, Clarke TR, Harvey KM, Gibson RC, Barrow G et al. Sociodemographics and clinical presentation of HIV in Jamaica over 20 years: a comparative analysis of surveillance data. *West Indian Med J* 2010; **59**: 409–17.
38. Moher D, Liberati A, Tetzlaff J, Altman DG. The PRISMA Group. Preferred reporting items for systematic reviews and meta-analyses: The PRISMA Statement. *PLoS Med* 2009; **6**: e1000097. doi:10.1371/journal.pmed1000097.