

Review: mothers with HIV infection worked hard to protect their children and preserve a positive maternal identity

Sandelowski M, Barroso J. Motherhood in the context of maternal HIV infection. *Res Nurs Health* 2003;**26**:470–82.

Q How do women with HIV infection experience motherhood?

METHODS



Data sources: {16 electronic databases; reference lists; and hand searches of *Qual Health Res* and *J Assoc Nurses AIDS Care*.}*



Study selection and assessment: published and unpublished qualitative studies on women who had HIV infection and lived in the US. Metasummary and metasynthesis techniques were used to synthesise findings across reports.

*Barroso J, Gollop CJ, Sandelowski M, et al. *West J Nurs Res* 2003;**25**:153–78.

MAIN RESULTS

56 studies (36 published, 20 unpublished) met the selection criteria. *Mother work.* Mothers with HIV worked to deal with their illness and its social consequences. They sought to protect their children from HIV infection and HIV related stigma. Tasks included finding information for making decisions; weighing the benefits and costs of disclosing their HIV status; establishing and maintaining the mother-child relationship; coping with the physical aspects of their illness and child care; and grieving the death of HIV positive children. Different factors influenced maternal work: age and HIV status of the child, maternal health status, ethnic/racial and socioeconomic position, maternal temporal orientation, and mothers' relationships with healthcare providers. *Paradoxes.* Although motherhood added to the burden of decision making about disclosure of HIV status, child care and custody, reproduction, use of healthcare services, and use of antiretroviral drugs, it also provided women with social support, self esteem, and a reason to live and fight HIV infection. Another paradoxical relation was the effect of mothers' actions. The same maternal action (eg, disclosing HIV status) could lead to either increased or decreased social support; furthermore, 2 opposite actions could result in the same outcome. Another paradox was that mothers with HIV fulfilled a cultural norm by having children, but because having HIV was deemed deviant, they were caught in a cultural double bind. *Virtual motherhood.* Mothers with HIV needed to preserve their children's lives and themselves as good mothers. They practised virtual motherhood, which involved embodied and transcendent maternal practices for self care and child care. When they could not physically mother because of their illness, they recast the role as that

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of overseeing their children and found ways to be present in their children's minds and hearts. *Shared and distinctive features of motherhood with HIV.* Similar to mothers in other adverse circumstances, women with HIV found motherhood to be a source of strength, self esteem, and refuge. However, motherhood placed women with HIV precariously between life as a normal woman and life as a deviant one because HIV infection was viewed more with condemnation than sympathy. As marginalised women, mothers with HIV found it difficult to escape the idea that they were bad mothers and bad women for even wanting motherhood. They had to negotiate their identities to present themselves as good mothers.

CONCLUSIONS

Mothers with HIV infection negotiated the demands of their illness and the role of mother. Although motherhood provided strength and self esteem, they had to work to prove themselves to be good mothers because of the stigma of HIV.

Commentary

Sandelowski and Barroso collected a large number of reports since the first appeared in 1991 and combined the reports using metasummary and metasynthesis techniques that provide a useful synopsis of mothers with HIV. This research integration also adds a new perspective by providing information on the frequency of the occurrence of themes in reports, something that is not possible in single studies. The use of a 14 item guide to assist with data extraction, abstraction, and analysis (metasummary) may reconstruct the original authors' interpretations of their data. The authors who created the meta-summary tool also analysed the data, which may increase or decrease the credibility of the findings. This paradox mirrors the experience of mothers with HIV who found that a single action could produce contradictory outcomes.

However, thoughtful and comprehensive analysis is provided on the impact of reporting data that are "...at least three times removed from the lived experiences they are meant to faithfully represent" (p 478). The authors present alternate ways for readers to interpret the summary data. The authors highlight the mainstream researchers' desire across reports to offset negative images and give voice to marginalised women through their stories of motherhood and the participants' desire to reduce negative images and present themselves in a positive light. This larger picture of motherhood in the context of maternal HIV infection is in itself an important finding. The authors note that this research can function as a foundation for evidenced-based practice as long as the definitions and paradoxes of motherhood are considered and that programmes of care acknowledge the centrality of motherhood to the physical and social survival of these women.

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