



Published in final edited form as:

Res Nurs Health. 2008 October ; 31(5): 454–465. doi:10.1002/nur.20278.

“Distorted Into Clarity”: A Methodological Case Study Illustrating the Paradox of Systematic Review

Margarete Sandelowski, PhD, RN, FAAN[Cary C. Boshamer Professor],
University of North Carolina at Chapel Hill School of Nursing

Corrine I. Voils, PhD[Assistant Professor of Medicine],
Durham Veterans Affairs Medical Center & Duke University Medical Center

Julie Barroso, PhD, ANP, APRN, BC[Associate Professor], and
Duke University School of Nursing

Eun-Jeong Lee, MPH, RN[Doctoral Student]
University of North Carolina at Chapel Hill School of Nursing

Abstract

Systematic review is typically viewed in the health sciences as the most objective—that is, rigorous, transparent, and reproducible—method for summarizing the results of research. Yet, recent scholarship has shown systematic review to involve feats of interpretation producing less certain, albeit valuable, results. We found this to be the case when we tried to overcome the resistance to synthesis of a set of qualitative and quantitative findings on stigma in HIV-positive women. These findings were difficult to combine largely because of fuzzy conceptualizations of stigma and the volume of unique quantitative findings. Our encounter with findings resistant to synthesis heightened our awareness of the extent to which all systematic reviews are accomplished by practices that paradoxically “distort [research findings] into clarity.”

Keywords

HIV-positive women; qualitative research synthesis; quantitative research synthesis; research methods; research synthesis; stigma; systematic review

Systematic review is typically viewed in the health sciences as the most objective—that is, rigorous, transparent, and reproducible—method for summarizing the results of research. The increasing incorporation of qualitative research findings into systematic reviews (e.g., Dixon-Woods, Agarwal, Jones, Young, & Sutton, 2005; Harden & Thomas, 2005; Sandelowski, Voils, & Barroso, 2006), and intensive study of the systematic review process (Hammersley, 2001; MacLure, 2005; Moreira, 2007; Mykhalovskiy, 2003; Sandelowski, Voils, & Barroso, 2007), however, have shown systematic review to entail feats of interpretation producing less certain, albeit valuable, results. The assumptions and work practices of systematic reviews have been increasingly challenged. Moved to center stage are the backstage judgments and compromises required to make research reports “docile” to the review process (Moreira, p. 181), the “comparability work” required to make incomparable findings combinable (Sandelowski et al., 2007); and, the reading and writing practices that undermine claims of the greater objectivity of systematic review over other

Correspondence to: Margarete Sandelowski.

Contact information: #7460 Carrington Hall, Chapel Hill, NC 27599; Tel: 919.966.4298; FAX: 919.843.9969; Email: msandelo@email.unc.edu.

kinds of reviews of research (Sandelowski, in press). As we illustrate in this methodological case study, reviewers are compelled paradoxically to “distort [research findings] into clarity” (Law, 2004, p. 2) to render them malleable to synthesis. The viability of the systematic review process depends on these distortions.

Method

This article is an account of our efforts to synthesize findings on stigma contained in 38 reports of studies conducted with HIV-positive women. These reports were retrieved in an ongoing study, the purpose of which is to develop methods to synthesize qualitative and quantitative research findings in health sciences research. These 38 reports are part of a larger and still growing collection that includes also reports of studies of antiretroviral adherence and of studies explicitly examining the link between HIV-related stigma and antiretroviral adherence. We selected the topics of HIV-related stigma and of antiretroviral adherence because of their significance to the advancement of healthcare for HIV-positive women, their primacy in HIV/AIDS research, and their fit with our respective backgrounds in HIV/AIDS care (JB), social psychology (CV), and women’s health (MS). Because of the primacy of these topics in HIV/AIDS research, we assumed also that we would have studies with enough methodological diversity (i.e., varieties of qualitative, quantitative observational, and intervention studies) to achieve the central aim of our project, namely, to develop methods to synthesize qualitative and quantitative research findings.

The 38 reports featured in this paper are of empirical qualitative and quantitative studies focused on HIV-related stigma conducted with HIV-positive women living in the United States of any race/ethnicity, class, or nationality. We accepted reports of studies conducted with HIV-positive women that included HIV-positive men if an explicit research purpose—as indicated in the report title and abstract—was to examine sex/gender differences as they related to HIV-related stigma and if the findings featured those differences. We accepted also reports of studies conducted with HIV-positive women that included HIV-negative women, if comparisons of these two groups of women were explicitly featured in the findings on stigma. To accommodate the way research purposes are conceived and questions are asked in both qualitative and quantitative studies, we defined studies of HIV-related stigma broadly to include research reports featuring findings addressing how HIV-positive women understood, experienced, or managed the social consequences of being HIV-positive, and predictors and covariates of, or interventions to manage, stigma in women. Among these reports are those addressing disclosure of HIV status. We searched for reports published in or after 1997 to account for the advent of antiretroviral therapy, as it was instrumental in changing HIV infection from a mortal to a chronic disease and, thereby, likely altered social attitudes toward HIV infection and HIV-positive persons. All of the delimitations we set were primarily to obtain a sample size and composition with enough methodological diversity yet topical uniformity to accommodate the detailed analysis and experimentation required by a methods study, not to produce a comprehensive synthesis of findings per se.

The 38 HIV-related stigma reports accepted for inclusion were published between 1997 and 2006. They were retrieved in July of 2005 and in June and August of 2006 using electronic databases housing citations to literature across the health, behavioral, and social sciences. (Further information about databases and search terms used is available from the authors on request.) We augmented electronic searching with the use of ancestry and descendency approaches (Cooper, 1998), in addition to hand-searching the print collections of our university libraries for books, anthologies, and other documents on HIV/AIDS likely to include relevant reports. These 38 reports of 15 qualitative and 23 quantitative studies are profiled in Table 1 and cited (*) in the reference list.

We extracted from each of these reports information on research purpose, theoretical framework, design, and methodology. We used metasummary techniques and taxonomic analysis (Sandelowski & Barroso, 2007) to extract, group, and conceptually order findings from the qualitative reports. We extracted from the quantitative reports all relationships in which an empirical indicator of stigma or disclosure appeared as an independent or dependent variable, and computed their effect sizes (Cohen's *d*, or the standardized difference in means; Cohen, 1988). Each report was reviewed by the first three authors and all subsequent analytic work was conducted by at least two members of the research team. Rules for extraction and computation of findings were developed in meetings of the entire research team. Extractions generating uncertainty or disagreement were addressed also in team meetings. We excluded no report that met our selection criteria, as we considered every report potentially valuable to delineate some methodological point. As Pawson (2006) observed, the value of a report for any systematic review can be determined only in the course of conducting the review. We are here drawing a distinction between quality and utility, as even the methodologically weakest studies may have value for knowledge development. Moreover, our lean was toward inclusion of reports as the long-term aim of our study is to expand the methodological options available to accommodate the diversity in health sciences research.

Challenges to Synthesis of the Stigma Findings

The 38 reports of stigma presented sizeable challenges to our synthesis efforts involving the conceptualizations of stigma and disclosure, respectively, and the prevalence of unique over shared findings.

Conceptualization of Stigma

The most important of these challenges involved the use of the term *stigma*. Stigma functions in these reports as a “sensitizing concept”... the character or existence of which is not itself subject to scrutiny” (Manzo, 2004, p. 404). Reports contain passing, or “ceremonial” (Wickes & Emmison, 2007, p. 312), references to Goffman's (1963) master work on stigma. Readers are presumed to know what stigma means and stigma is presumed to mean just about anything negative associated with HIV infection in the experiential or psychosocial realm.

In addition to the challenge of “conceptual inflation” (Deacon, 2005, p. ix), whereby a term comes to mean almost anything, was the problem of conceptual conflation. Here findings addressing what are usually referred to as women's “perceptions of stigma” blur three different domains: (a) general knowledge that HIV-positive persons are often treated poorly; (b) fear of being treated poorly; and, (c) actual personal experiences with poor treatment. This blurring reflects the largely atheoretical nature of the studies reviewed, as neither data collection nor analysis were typically directed toward differentiating between *felt* and *enacted* stigma, or between what the affected persons fear or feel and what others actually do to the affected person, respectively (Jacoby, 1994). Such events as social rejection, discrimination, and violence, are similarly blurred as they are variously treated as both empirical manifestations and outcomes of stigmatization.

The way *stigma* appears in the reports reviewed reflects the generally “fuzzy” (Grönvik, 2007) conceptual status of research on stigma. Since Goffman (1963) introduced it as a subject for study, stigma has become one of the most used and, arguably, overused concepts in the health and social sciences (Link & Phelan, 2001; Manzo, 2004). Widely deployed as an “interpretive...explanatory...(and) discursive resource” (Manzo, p. 402), *stigma* has become a “social scientific gloss” (p. 402) revealing less about the experiences of the persons interpreted or explained by it and more about the work practices of the researchers

who rely on it for interpretation or explanation. Reidpath, Chan, Gifford, and Allotey (2005, p. 470) referred to the conceptual development of stigma as “patchy” and proposed that stigma research may have “fallen into a stagnant and unpromising form of... Kuhnian... normal science.”

Nowhere is this more apparent than in the research on living with HIV infection. Stigma has become virtually synonymous with the infection itself (Parker & Aggleton, 2003). Manzo (2004, p. 408) proposed that HIV/AIDS was the condition most studied because it meets virtually all of the “stigma-identifying qualities” researchers have deemed appropriate for the study of stigma, including visibility, severity, contagiousness, culpability, difference, and deviance. Indeed, HIV/AIDS is considered to have such “unique fittingness as a stigma-relevant topic” that it has “earned (its) own form of stigma, (namely) HIV-related stigma.”

So conflated is *HIV infection* with stigma that a search for literature on stigma in the context of HIV infection will exclude few reports of studies of HIV infection in the experiential, psychological, or sociocultural domains. The virtual fungibility of HIV and stigma challenged us even to decide what studies would constitute the body of research on stigma. The delimitations we set for the selection of stigma studies were, in part, to address this problem. For example, we debated whether to include reports of studies conducted with HIV-positive women with findings on social support and interaction, emotions and mood, and psychological functioning, as these findings were often presented as implying the operation of stigma. Yet, to include these studies would have meant excluding virtually no study in the experiential and psychosocial realm. In a previous systematic review we had conducted of all published and unpublished qualitative studies addressing the experience of living with HIV infection in HIV-positive women, 93 of the 114 reports retrieved contain findings pertaining to stigma, yet only 16 of the studies featured in these reports had been targeted toward the study of stigma (Sandelowski, Lambe, & Barroso, 2004).

Conceptualization of Disclosure

A second challenge was that although stigma is central to the 38 reports reviewed, it is actually disclosure of HIV status that is empirically center stage. *Disclosure* is seen to occur against the background of stigma, which is assumed to drive or inform all thoughts, feelings, and actions related to whether, whom, when, and what to tell. Disclosure is treated as a proxy for or index of stigma even when it may not be related to stigma. This is best illustrated in reports of studies addressing mothers’ disclosure of their own HIV infection to their children. In these reports, mothers’ disclosure is tied primarily to the developmental capacity of the child to handle any serious illness in or mortal threat to their mothers. Disclosure here may, therefore, be better understood within a child development, as opposed to stigma, framework. Even the finding that children’s perceived inability to keep a secret is a typical reason mothers did not disclose their HIV infection to them may have been related more to the women’s views of privacy and habits of self-disclosure than they were to stigma per se.

Like stigma, disclosure in these reports is difficult to pin down conceptually. Classifications of disclosure are not in the same semantic plane. For example, terms like *selective* and *full* simultaneously refer, in the same report and across reports, both to the (a) type or number of persons to whom HIV infection was disclosed and to (b) what or how much of something about HIV was disclosed. Although disclosure is recognized as a process occurring over time, in most of the reports, it is treated as if it were a discrete yes/no event in time. Most of the findings were from cross-sectional analyses, including those from longitudinal parent studies.

Prevalence of Unique Over Shared Findings

A third challenge, due largely to the way stigma and disclosure were treated conceptually in the 38 reports, was extracting findings that actually address the same thing. After extracting 488 relationships in the quantitative reports (393 bivariate and 95 multivariable), we searched for instances in which the same relationship was measured in at least two studies with the intention of synthesizing them using meta-analysis. Yet, we found only six instances in which the same relationship was measured more than once and, in all of these, the relationship was measured only twice. Moreover, because of the different ways in which the independent variables were measured and treated, we were able to pool the effect sizes for only 2 of the 6 instances. In short, although the quantitative reports all ostensibly address the same topic (i.e., stigma and disclosure in HIV-positive women), their findings were not synthesizable either by meta-analysis or by a modified vote counting procedure we had used in another study (Voils, Sandelowski, Barroso, & Hasselblad, 2008).

Meta-analysis and vote counting are based on an assimilation logic requiring that at least two relationships obtained from at least two different samples be deemed the same for them to be combined statistically. Yet merely having any one finding repeated in only two studies does not produce an informative quantitative synthesis of quantitative findings. This is in contrast to the treatment of qualitative findings, where a finding that appears in only one report and in one case in that report, will be accounted for in a research synthesis. The mandate in qualitative research synthesis is that findings not be differentially weighted or treated on account of sample size. Qualitative research findings do not derive their significance from repetition, but rather from their capacity to illuminate or explain.

Because we could not produce a meaningful assimilation of quantitative findings, we attempted to create a configuration of findings. As we have described elsewhere (Voils et al., 2008), in contrast to assimilations of findings entailing the actual incorporation of recurring findings into each other, configurations of findings are coherent arrangements of findings that do not require repetition to be included in the arrangement. Whereas assimilated findings are merged, configured findings are meshed into taxonomies, theories, conceptual maps, meta-narratives, lines of argument, or other coherent arrangements. The taxonomy we created from the qualitative findings is an example of such an arrangement.

We, therefore, tried to apply a configuration logic to the quantitative findings, whereby findings with at least a small effect size ($d \geq .20$; Cohen, 1988) could be assembled into a coherent arrangement without regard to whether they appeared in only one report. But this effort was difficult too because the quantitative reports were characterized by large numbers of unique findings even within reports. The quantitative reports contain more unique findings (i.e., appearing in only one report) than the qualitative reports, which, in turn, contain more sets of repetitive findings (i.e., appearing in two or more reports) than the quantitative reports. Even taking into account the difference in numbers of qualitative (15) and quantitative reports (23), this is contrary to expectations. Qualitative studies in a shared domain of research are expected to have more unique findings and, therefore, to produce a less comparable dataset than quantitative studies because of the open-ended nature of data collection in qualitative research. In our dataset, all 45 bivariate relationships addressing various forms of abuse, by intimate partner or other perpetrator, before and after HIV diagnosis, appear in only one report (Gielen, McDonnell, Burke, & O'Campo, 2000). All 87 relationships addressing reasons for (non)disclosure to persons other than children appear in only one report (Derlega, Winstead, Greene, Serovich, & Elwood, 2002), which contributed almost 18% of the relationships across reports (87 of the total 488). These relationships consist of various combinations of 5 reasons for disclosing, 6 reasons for not disclosing, and 3 types of persons disclosed to (parent, intimate partner, and friend), in both women and men together and in women in comparison to men.

Overcoming the Challenges to Synthesis

To overcome these challenges, we worked to find ways to make the findings more comparable to make them cohere. An excerpt of the end-product of our labors is shown in Table 2.

We translated similar ideas into a common language. For example, we used the words *selective* and *full* consistently to refer to just one idea, namely, the content of disclosure, and *restricted* and *unrestricted* to refer to the persons to whom HIV infection was disclosed. We distinguished among instances of felt stigma, enacted stigma (Jacoby, 1994), and general knowledge of HIV-related stigma whenever simply stigma or *perceived stigma* were used to refer to instances of two or more of these manifestations of stigma. We inferred from the way variables were operationalized and positioned in relation to each other the actual concepts addressed. This is another instance of translation, but one that addresses the problem of using one term to tap different aspects of a phenomenon (as opposed to more than one term to tap the same aspect). For example, in reports in which perceived stigma was stated as the concept but the measurement tools used to operationalize it indicated that *knowledge of stigma* was actually being tapped (as opposed to felt or enacted stigma), we renamed the concept as knowledge of stigma and then grouped it with other findings addressing knowledge of stigma. Had we not engaged in this form of “distortion” of the original text, we would have been summing highly divergent findings about stigma, albeit all named perceived stigma. In the studies of abuse mentioned previously, we conceived abuse, losing a job, losing a home, and family rejection as empirical instances of enacted stigma in an effort to impose some reasonable conceptual order on the findings and, thereby, to make them more amenable to combination with other findings.

Such translations exemplify distortions, or re-writings, of reports. As more fully described elsewhere (Sandelowski, in press), no matter whether a review includes reports solely of qualitative, quantitative, or of both qualitative and quantitative studies, data are never simply “extracted” as given in these reports, but rather they are “transformed, transposed, converted, tabulated...funnel- and forest-plotted... or otherwise manipulated, modified, and reconfigured” to permit the comparison of the previously incomparable and the combination of the previously uncombinable. Other examples of such transformations include the reciprocal translation of metaphors and concepts into each other in meta-ethnography (Noblit & Hare, 1988), and the calculation of effect sizes from different statistical expressions of findings in meta-analyses (Cohen, 1988), both of which also require reviewers to make individual judgments.

Conclusion

Any one body of literature selected for and subjected to systematic review presents reviewers with a distinctive set of challenges that will require a distinctive set of solutions, or may even resist solution. Overcoming the resistance to synthesis of the qualitative and quantitative findings in this particular dataset was challenging because of the different ways stigma and disclosure were conceptualized and treated. Synthesis was difficult also because of the volume of unique findings within and across individual quantitative studies that precluded our linking them in a meaningful way to the qualitative findings (e.g., to create a conceptual model). That said, there is some evidence that the developmental capacity of children influenced mothers' disclosure of their own HIV status to their children, and that the more HIV symptomatology, the more likely mothers were to disclose. The synthesized qualitative finding—that disclosure decision-making was a dynamic, taxing, and continuous evaluative process—encompass all of the quantitative findings explicitly linking persons disclosed to, content and timing of disclosure, and reasons for (non)disclosure with a host of

demographic, clinical, psychological, and other variables. Whether these conclusions constitute a meaningful or even worthwhile synthesis of qualitative and quantitative findings on stigma in HIV-positive women is for users of reviews to decide.

Given the familiar lament in reviews of the literature and discussion sections of research reports about the need for conceptual clarity and consistency in measurement in research, reviewers of research findings will likely encounter more or less the same challenges we encountered, no matter what the domain of research. This raises the questions yet to be fully answered of other challenges that reviewing qualitative and quantitative research may present and of whose responsibility it is to make research findings more docile to the systematic review process: reviewers of research findings or the researchers who create them.

Any coherence the results of our work have is because of the considerable effort we put into rewriting, modifying, and re-assembling the results in the reports reviewed, that is, paradoxically distorting them: not to misrepresent, but rather more faithfully to represent, them. Although typically hidden in claims for the rigor and transparency of systematic review, the process is inescapably a highly subjective, albeit disciplined, encounter whereby reviewers “deconstruct,” in order to “reconstruct,” the information in reports into a form useable for review (Harden et al. 2004, p. 796). This is the case even in meta-analyses of the results of clinical trials in which what ends up being compared and combined, and the manner in which this is accomplished, are outcomes of reviewer and user judgments about what constitute meaningful comparisons and combinations (Cooper, 1998; Deeks, Higgins, & Altman, 2006; Sandelowski et al., 2007). Highlighting the subjectivity of systematic review is in no way an argument against it, but rather an exercise in the transparency toward which it is directed.

Acknowledgments

The study referred to in this paper, entitled “Integrating qualitative & quantitative research findings,” is funded by the National Institute of Nursing Research, National Institutes of Health (5R01NR04907, June 3, 2005-March 31, 2010).

References (*included in systematic review)

- *. Abel E, Rew L, Gortner E-M, Delville CL. Cognitive reorganization and stigmatization among persons with HIV. *Journal of Advanced Nursing*. 2004; 47:510–525. [PubMed: 15312114]
- *. 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 and Behavior*. 1999; 3:195–204.
- *. Armistead L, Tannenbaum L, Forehand R, Morse E, Morse P. Disclosing HIV status: Are mothers telling their children? *Journal of Pediatric Psychology*. 2001; 26:11–20. [PubMed: 11145728]
- *. Black BP, Miles MS. Calculating the risks and benefits of disclosure in African American women who have HIV. *JOGNN: Journal of Obstetric, Gynecologic, & Neonatal Nursing*. 2002; 31:688–697.
- *. Carr RL, Gramling LF. Stigma: A health barrier for women with HIV/AIDS. *Journal of the Association of Nurses in AIDS Care*. 2004; 15(5):30–39. [PubMed: 15358923]
- *. Chin D, Kroesen KW. Disclosure of HIV infection among Asian/Pacific Islander American women: Cultural stigma and support. *Cultural Diversity and Ethnic Minority Psychology*. 1999; 5:222–235.
- *. Clark HJ, Lindner G, Armistead L, Austin B-J. Stigma, disclosure, and psychological functioning among HIV-infected and non-infected African-American women. *Women & Health*. 2003; 38(4):57–71.

Cohen, J. *Statistical power analysis for the behavioral sciences*. 2. Hillsdale, NJ: Erlbaum; 1988.

- *. Comer LK, Henker B, Kemeny M, Wyatt G. Illness disclosure and mental health among women with HIV/AIDS. *Journal of Community & Applied Social Psychology*. 2000; 10:449–464.
- Cooper, H. *Synthesizing research: A guide for literature reviews*. 3. Thousand Oaks, CA: Sage; 1998.
- Deacon, H. *Understanding HIV/AIDS stigma: A theoretical and methodological analysis*. Cape Town, South Africa: Human Sciences Research Council Press; 2005.
- Deeks, JJ.; Higgins, JP.; Altman, DG. Analyzing and presenting results. In: Higgins, JP.; Green, S., editors. *Cochrane handbook for systematic reviews of interventions 4.2.6 (Section 8)*. Chichester, UK: John Wiley & Sons; 2006 September. Retrieved October 29, 2007, from <http://www.cochrane.org/resources/handbook/Handbook4.2.6Sep2006.pdf>
- *. Derlega VJ, Winstead BA, Greene K, Serovich J, Elwood WN. Perceived HIV-related stigma and HIV disclosure to relationship partners after finding out about the seropositive diagnosis. *Journal of Health Psychology*. 2002; 7:415–432.
- Dixon-Woods M, Agarwal S, Jones D, Young B, Sutton A. Synthesizing qualitative and quantitative evidence: A review of possible methods. *Journal of Health Services Research & Policy*. 2005; 10:45–53. [PubMed: 15667704]
- *. Gielen AC, Fogarty L, O'Campo P, Anderson J, Keller J, Faden R. Women living with HIV: Disclosure, violence, and social support. *Journal of Urban Health: Bulletin of the New York Academy of Medicine*. 2000; 77:480–491. [PubMed: 10976619]
- *. Gielen AC, McDonnell KA, Burke JG, O'Campo P. Women's lives after an HIV-positive diagnosis: Disclosure and violence. *Maternal and Child Health Journal*. 2000; 4:111–120. [PubMed: 10994579]
- *. Gielen AC, O'Campo P, Faden RR, Eke A. Women's disclosure of HIV status: Experiences of mistreatment and violence in an urban setting. *Women & Health*. 1997; 25(3):19–31.
- Goffman, E. *Stigma: Notes on the management of spoiled identity*. Englewood Cliffs, NJ: Prentice Hall; 1963.
- Grönvik L. The fuzzy buzz word: Conceptualizations of disability in disability research classics. *Sociology of Health & Illness*. 2007; 29:1–17. [PubMed: 17286703]
- *. Grove KA, Kelly DP, Liu J. "But nice girls don't get it": Women, symbolic capital, and the social construction of AIDS. *Journal of Contemporary Ethnography*. 1997; 26:317–337.
- Hammersley M. On "systematic" reviews of research literatures: A "narrative" response to Evans & Benefield. *British Educational Research Journal*. 2001; 27:543–554.
- Harden A, Thomas J. Methodological issues in combining diverse study types in systematic reviews. *International Journal of Social Research Methodology*. 2005; 8:257–271.
- *. Ingram D, Hutchinson SA. HIV-positive mothers and stigma. *Health Care for Women International*. 1999; 20:93–103. [PubMed: 10335159]
- Jacoby A. Felt versus enacted stigma: A concept revisited. *Social Science & Medicine*. 1994; 38:269–274. [PubMed: 8140453]
- *. Jeffe DB, Khan SR, Meredith KL, Schlesinger M, Fraser VJ, Mundy LM. Disclosure of HIV status to medical providers: Differences by gender, "race," and immune function. *Public Health Reports*. 2000; 115:38–45. [PubMed: 10968584]
- *. Kalichman SC, DiMarco M, Austin J, Luke W, DiFonzo K. Stress, social support, and HIV-status disclosure to family and friends among HIV-positive men and women. *Journal of Behavioral Medicine*. 2003; 26:315–332. [PubMed: 12921006]
- *. Kirshenbaum SB, Nevid JS. The specificity of maternal disclosure of HIV/AIDS in relation to children's adjustment. *AIDS Education and Prevention*. 2002; 14(1):1–16. [PubMed: 11900106]
- Law, J. *After method: Mess in social science research*. London: Routledge; 2004.
- *. Lekas H-M, Siegel K, Schrimshaw EW. Continuities and discontinuities in the experiences of felt and enacted stigma among women with HIV/AIDS. *Qualitative Health Research*. 2006; 16:1165–1190. [PubMed: 17038751]
- *. Letteney S, LaPorte HH. Deconstructing stigma: Perceptions of HIV-seropositive mothers and their disclosure to children. *Social Work in Health Care*. 2004; 38(3):105–123. [PubMed: 15149914]
- Link BG, Phelan JC. Conceptualizing stigma. *Annual Review of Sociology*. 2001; 27:363–385.

- MacLure M. Clarity bordering on stupidity”: Where’s the quality in systematic review? *Journal of Education Policy*. 2005; 20:393–416.
- Manzo JF. On the sociology and social organization of stigma: Some ethnomethodological insights. *Human Studies*. 2004; 27:401–416.
- * Mizuno Y, Moneyham LL, Sowell RL, Demi AS, Seals BF. Effects of sociodemographic factors, stage of illness, and perceived stigma on the identification of a support person among women with HIV infection. *Sociological Spectrum*. 1998; 18:5–23.
- Moreira T. Entangled evidence: Knowledge making in systematic reviews in healthcare. *Sociology of Health & Illness*. 2007; 29:180–197. [PubMed: 17381812]
- * Murphy DA, Roberts KJ, Hoffman D. Stigma and ostracism associated with HIV/AIDS: Children carrying the secret of their mothers’ HIV+ serostatus. *Journal of Child and Family Studies*. 2002; 11:191–202.
- * Murphy DA, Roberts KJ, Hoffman D. Regrets and advice from mothers who have disclosed their HIV+ serostatus to their young children. *Journal of Child and Family Studies*. 2003; 12:307–318.
- * Murphy DA, Steers WN, Dello Stritto ME. Maternal disclosure of mothers’ HIV serostatus to their young children. *Journal of Family Psychology*. 2001; 15:441–450. [PubMed: 11584794]
- * Murphy LM, Koranyi K, Crim L, Whited S. Disclosure, stress, and psychological adjustment among mothers affected by HIV. *AIDS Patient Care and STDs*. 1999; 13:111–118. [PubMed: 11362099]
- Mykhalovskiy E. Evidence-based medicine: Ambivalent reading and the clinical recontextualization of science. *Health*. 2003; 7:331–352.
- Noblit, GW.; Hare, RD. *Meta-ethnography: Synthesizing qualitative studies*. Newbury Park, CA: Sage; 1988.
- Ortiz CE. Disclosing concerns of Latinas living with HIV/AIDS. *Journal of Transcultural Nursing*. 2005; 16:210–217. [PubMed: 15980048]
- * Ostrom RA, Serovich JM, Lim JY, Mason TL. The role of stigma in reasons for HIV disclosure and non-disclosure to children. *AIDS Care*. 2006; 18:60–65. [PubMed: 16282078]
- Parker R, Aggleton P. HIV and AIDS-related stigma and discrimination: A conceptual framework and implications for action. *Social Science & Medicine*. 2003; 57:13–24. [PubMed: 12753813]
- Pawson R. Digging for nuggets: How “bad” research can yield “good” evidence. *International Journal of Social Research Methodology*. 2006; 9:127–142.
- * Pilowski DJ, Sohler N, Susser E. Reasons given for disclosure of maternal HIV status to children. *Journal of Urban Health: Bulletin of the New York Academy of Medicine*. 2000; 77:723–734. [PubMed: 11194312]
- Reidpath DD, Chan KY, Gifford SM, Allotey P. He hath the French pox”: Stigma, social value and social exclusion. *Sociology of Health & Illness*. 2005; 27:468–489. [PubMed: 15998347]
- Sandelowski M. Reading, writing, and systematic review. *Journal of Advanced Nursing*. In press.
- Sandelowski, M.; Barroso, J. *Handbook for synthesizing qualitative research*. New York: Springer; 2007.
- Sandelowski M, Lambe C, Barroso J. Stigma in HIV-positive women. *Journal of Nursing Scholarship*. 2004; 36:122–128. [PubMed: 15227758]
- Sandelowski M, Voils CI, Barroso J. Defining and designing mixed research synthesis studies. *Research in the Schools*. 2006; 13:29–40. [PubMed: 20098638]
- Sandelowski M, Voils CI, Barroso J. Comparability work and the management of difference in research synthesis studies. *Social Science & Medicine*. 2007; 64:236–247. [PubMed: 17029691]
- * Sayles JN, Wong MD, Cunningham WE. The inability to take medications openly at home: Does it help explain gender disparities in HAART use? *Journal of Women’s Health*. 2006; 15:173–181.
- * 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.
- * Serovich JM, Kimberly JA, Greene K. Perceived family member reaction to women’s disclosure of HIV-positive information. *Family Relations*. 1998; 47:15–22.
- * Shaffer A, Jones DJ, 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. *Journal of Child and Family Studies*. 2001; 10:301–313.

- *. Siegel K, Lekas H-M, Schrimshaw EW. Serostatus disclosure to sexual Partners by HIV-infected women before and after the advent of HAART. *Women & Health*. 2005; 41(4):63–85.
 - *. Simoni JM, Demas P, Mason HR, Drossman JA, Davis ML. HIV disclosure among women of African descent: Associations with coping, social support, and psychological adaptation. *AIDS and Behavior*. 2000; 4:147–158.
 - *. Sowell RL, Lowenstein A, Moneyham L, Demi A, Mizuno Y, Seals BF. Resources, stigma, and patterns of disclosure in rural women with HIV Infection. *Public Health Nursing*. 1997; 14:302–312. [PubMed: 9342922]
 - *. Sowell RL, Seals BF, Phillips KD, Julious CH. Disclosure of HIV infection: How do women decide to tell? *Health Education Research*. 2003; 18:32–44. [PubMed: 12608682]
 - *. Stanley LD. Transforming AIDS: The moral management of stigmatized identity. *Anthropology & Medicine*. 1999; 6:103–120.
 - *. Vallerand AH, Hough E, Pittiglio L, Marvicsin D. The process of disclosing HIV serostatus between HIV-positive mothers and their HIV-negative children. *AIDS Patient Care and STDs*. 2005; 19:100–10. [PubMed: 15716641]
 - *. Vanable PA, Carey MP, Blair DC, Littlewood RA. Impact of HIV-related stigma on health behaviors and psychological adjustment among HIV-positive men and women. *AIDS and Behavior*. 2006; 10:473–482. [PubMed: 16604295]
- Voils CI, Sandelowski M, Barroso J, Hasselblad V. Making sense of qualitative and quantitative findings in mixed research synthesis studies. *Field Methods*. 2008; 20:3–25. [PubMed: 18677415]
- Wickes R, Emmison M. They are all “doing gender” but are they all passing? A case study of the appropriation of a sociological concept. *The Sociological Review*. 2007; 55:311–330.

Table 1

Profile of Reports (N=38)

Ref. #	Report, publication year ¹	Method ²	Sample size & racial/ethnic composition ³
Qualitative Reports (n=15)			
1	Black & Miles, 2002	Qualitative description	48 (all AA)
2	Carr & Gramling, 2004	Ethnographic	9 (all W)
3	Chin & Kroesen, 1999	Qualitative	9 (all A/PI)
4	Gielen, O'Campo, Faden, & Eke, 1997	Qualitative	50 (43 AA; 5 W; 1 H; 1 O)
5	Grove, Kelly, & Liu, 1997	Ethnographic	22 (18 W; 4 O)
6	Ingram & Hutchinson, 1999	Grounded theory	18 (9 W; 8 AA; 1 H)
7	Lekas, Siegel, & Schrimshaw, 2006	Thematic analysis	158 (68 AA; 46 W; 44 PR)
8	Murphy, D. A., Roberts, & Hoffman, 2002	Ethnographic	47 (23 AA; 10 M/O; 6 H; 4 W; 2 NA/AL; 2 A/PI)
9	Murphy, D. A., Roberts, & Hoffman, 2003	Qualitative description	47 (23 AA; 10 M/O; 6 H; 4 W; 2 NA/AL; 2 A/PI)
10	Ortiz, 2005	Qualitative description	19 (all H)
11	Schrimshaw & Siegel, 2002	Thematic analysis	45 (15 AA; 15 PR; 15 W)
12	Serovich, Kimberly, & Greene, 1998	Grounded theory	13 (7 W; 3 AA; 3 H)
13	Siegel, Lekas, & Schrimshaw, 2005	Thematic analysis	158 (68 AA; 46 W; 44 PR)
14	Stanley, 1999	Fieldwork	15 (all W)
15	Vallerand, Hough, Pittiglio, & Marvicsin, 2005	Qualitative description	35 (31AA; 4 NS)
Quantitative Reports (n=23)			
16	Abel, Rew, Gortner, & Delville, 2004	Pilot intervention	11 (4 AA; 6 W; 1H)
17	Armistead, Morse, Forehand, Morse, & Clark, 1999	Descriptive/correlation	100 (all AA)
18	Armistead, Tannenbaum, Forehand, Morse, & Morse, 2001	Descriptive/correlation	87 (all AA)
19	Clark, Lindner, Armistead, & Austin, 2003	Descriptive/correlation	98 HIV+ & 146 HIV-negative women (all AA)
20	Comer, Henker, Kemeny, & Wyatt, 2000	Descriptive/correlation	176 (72 AA; 57 H; 47 W)
21	Derlega, Winstead, Greene, Serovich, & Elwood, 2002	Descriptive/correlation	145 total: 105 HIV+ men (59 W; 38 AA; 3 O; 2 H; 3 MD) & 39 HIV+ women (27 AA; 9 W; 2 H; 1 O) & 1 sex-unknown HIV+ person
22	Gielen, Fogarty, et al., 2000	Descriptive/correlation	257 (236 AA; 21 O?)
23	Gielen, McDonnell, Burke, & O'Campo, 2000	Descriptive/correlation	310 (293 AA; 17 O)
24	Jeffe et al., 2000	Descriptive/correlation	202 total: 106 HIV+ men (55 AA; 51 W) & 96 HIV+ women (75 AA; 21 W)
25	Kalichman, DiMarco, Austin, Luke, & DiFonzo, 2003	Descriptive/correlation	331 total: 233 HIV+ men & 98 HIV+ women (238 AA; 76 W; 17 O)
26	Kirschenbaum & Nevid, 2002	Descriptive/correlation	56 (28 AA; 23 H; 5 W?)
27	Letteney & LaPorte, 2004	Descriptive/correlation	88 (37 AA; 37 H; 11 W; 1 M?)
28	Mizuno, Moneyham, Sowell, Demi, & Seals, 1998	Descriptive/correlation	256 (209 AA; 46 O; 1 MD)
29	Murphy, D.A., Steers, & Dello Stritto, 2001	Descriptive/correlation	135 (53 AA; 35 H; 28 W; 11 NA/AL; 8 M/O)
30	Murphy, L. M., Koranyi, Crim, & Whited, 1999	Descriptive/correlation	40 (22 W; 16 AA; 2 M)

Ref. #	Report, publication year ¹	Method ²	Sample size & racial/ethnic composition ³
31	Ostrom, Serovich, Lim, & Mason, 2006	Descriptive/correlation	45 HIV+ women (36 AA; 8 W; 1 H) & 45 children
32	Pilowski, Sohler, & Susser, 2000	Descriptive	29 (21 AA; 7 H; 1 W)
33	Sayles, Wong, & Cunningham, 2006	Descriptive/correlation	1910 total: 1378 HIV+ men & 532 HIV+ women (?race distribution)
34	Shaffer, Jones, Kotchick, Forehand, & The Family Health Project Research Group, 2001	Longitudinal/descriptive/Correlation	99 HIV+ women (all AA) & 99 HIV- children
35	Simoni, Demas, Mason, Drossman, & Davis 2000	Descriptive/correlation	143 (106 AA; 37 B/H)
36	Sowell, Lowenstein, et al., 1997	Descriptive/correlation	82 (56 AA; 26 W)
37	Sowell, Seals, Phillips, & Julious, 2003	Descriptive/correlation	322 (266 AA; 35 O?)
38	Vanable, Carey, Blair, & Littlewood, 2006	Descriptive/correlation	221 total: 124 HIV+ men & 97 HIV+ women (93 AA; 101 W; 27O)

Notes.

¹ Unpublished reports were not included as they offered no methodological variation not found in published reports.

² We found only one pilot intervention study conducted with HIV-positive women to address stigma.

³ All women were HIV-positive unless otherwise noted.

AA=African American; B/H-Black/Hispanic; A/PI=Asian/Pacific Islander; H/PR=Hispanic/Puerto Rican; M=Mixed race; NA/AL=Native American/Alaskan Native; MD=Missing data reported; NS=Not stated; O=Other or race/ethnicity not stated; W=White; ?=error or unclear in report

Table 2**Alignment of Related Qualitative and Quantitative Findings (Excerpts)**

HIV-Related Stigma
<p><i>Qualitative findings</i></p> <p>Strategies to manage stigmatization included normalization,⁵ education of others about HIV,^{7,14} helping others prevent infection,¹ public advocacy and support of other HIV-positive persons,^{1,14} attributing HIV-stigma to sexism and/or racism,^{5,7} identity management,^{2,5,6,14} and information management.^{all}</p> <p><i>Quantitative findings</i></p> <p>Among Black women, knowledge of HIV as stigmatizing, felt stigma, and enacted stigma were positively associated with psychological functioning (.847mv) and number of persons disclosed to (-1.036mv).¹⁹</p>
<p>Felt Stigma</p> <p><i>Qualitative findings</i></p> <p>Felt stigma consisted of HIV-positive women's own feelings of shame, devaluation,^{1,2,3,7,13,14} fear of rejection and social ostracism,^{1,4,5,6,9} fear for personal safety,⁴ fear of discrimination,⁵ and negative Redefinition of self as HIV-positive.^{2,3}</p> <p><i>Quantitative findings</i></p> <p>Women with (versus without) felt stigma had greater odds of identifying a support person (.614mv).²⁸</p> <p>A greater percentage of Black women than White women feared rejection by their family (.453).³⁶</p>
<p>Enacted Stigma</p> <p><i>Qualitative findings</i></p> <p>Enacted stigma consisted of others' rejecting behaviors^{3,4,6,11} discrimination,^{7,11} and violence.⁴</p> <p><i>Quantitative findings</i></p> <p>The number of persons disclosed to increased the odds of enacted stigma (.279mv), but having instrumental social support decreased the odds of enacted stigma (-.300mv).²²</p> <p>Being abused by a perpetrator prior to HIV diagnosis increased the odds of being abused after diagnosis (.476mv).²³</p>
<p>Timing of Disclosure</p> <p><i>Qualitative findings</i></p> <p>Timing of disclosure was immediately after diagnosis,¹⁰ delayed until women accept/adjust to diagnosis⁴ or child is developmentally ready^{1,10,11,15} or until assess impact on others,⁴ before imminent disclosure by others (preemptive disclosure),¹⁰ or at any opportune moment, when it felt right.¹</p> <p><i>Quantitative findings</i></p> <p>Among Black women, the number of months between diagnosis and disclosure to father (-.222), to extended family (-.239), to children (-.263), to partner (-.433), and to mother (-.449) was shorter than the number of months between diagnosis and disclosure to friends.¹⁷</p>
<p>Target of Disclosure</p> <p><i>Qualitative findings</i></p> <p>Women variously chose to restrict or not to restrict disclosure to children, partners, family, friends, acquaintances, employers, co-workers, religious leaders, and other HIV-positive persons.^{all}</p> <p><i>Quantitative findings</i></p> <p>A greater percentage of women with AIDS (.524) or who were symptomatic (1.490) disclosed to their sexual partners compared to asymptomatic women, and a smaller percentage of women with AIDS disclosed to their sexual partners compared to symptomatic women (1.490).³⁶</p> <p>A greater percentage of women than men disclosed to extended family (.215) and to mother (.326).²⁵</p>
<p>Benefits of, Reasons for Disclosure (excluding children)</p> <p><i>Qualitative Findings</i></p> <p>Conditions, or rules, for disclosure included the need to know,¹ right to know/duty to inform,¹³ capacity or readiness to know,^{1,10} likelihood of burden to others from knowing,¹ degree of acceptance of HIV, trustworthiness, ability to keep a secret,¹ physical proximity, intimacy, and quality of relationship with other,^{3,10} and perceived benefit versus risk of harm to self or others.^{1,10}</p>

Perceived benefits of disclosure, or reasons to disclose included positive social support,^{1,3,4,5,6,10,11,13} reconciliation with family,¹⁰ avoidance of stress/burden of secrecy, catharsis, relationship authenticity,^{2,11,13} control of disclosure process,¹⁰ minimization of felt stigma,^{2,14} and healing, wellbeing, improved quality of life, growth, renewed interest in life.^{3,4}

Quantitative Findings

Testing other's reactions was endorsed to a greater extent by women than men as a reason for disclosing to an intimate partner (.389) and to a friend (.562).²¹

Catharsis was endorsed to a greater extent by women than men as a reason for disclosing to a parent (.401), friend (.563), and to an intimate partner (.637).²¹

Similarity (having something in common) was endorsed to a greater extent by women than men as a reason for disclosing to a parent (.487).²¹

Risks of, Reasons for Nondisclosure (excluding children)

Qualitative Findings

Perceived risks of disclosure, or reasons not to disclose included loss of positive or negative social support,^{3,13} stigmatization,^{2,11} disappointment, burden, suffering, stigmatization of loved ones,^{1,3,6} culturally incongruent roles (adult child cared for by parent instead of reverse),³ loss of privacy,⁴ and uncontrolled (unplanned) disclosure.^{1,7,10,13}

Quantitative Findings

Protecting the other as a reason for not disclosing to a friend was positively associated with knowledge of HIV as stigmatizing among women (.402) and among men (.246); as a reason for not disclosing to a parent was positively associated with knowledge of HIV as stigmatizing among women (.928) and among men (.723); and as a reason for not disclosing to an intimate partner was positively associated with knowledge of HIV as stigmatizing among women (.254).²¹

Self-blame as a reason for not disclosing to an intimate partner was positively associated with knowledge of HIV as stigmatizing among women (.270) and among men (.272); as a reason for not disclosing to a friend was positively associated with knowledge of HIV as stigmatizing among women (.523) and among men (.415); and as a reason for not disclosing to a parent was positively associated with knowledge of HIV as stigmatizing among women (1.317) and among men (.711).²¹

Content of Disclosure

Qualitative Findings

Disclosure was full (everything), partial, or totally concealed.^{2,5,6}

Partial disclosure or total concealment was enabled by virtue of not being seen as at risk for HIV,⁵ having no visible signs of illness, covering, passing, and by circumventing the need to disclose.⁶

Quantitative Findings

(All quantitative findings on content of disclosure are in relation to children.)

Disclosing Maternal HIV to Children

Qualitative Findings

Reasons for disclosing to children included perceived ability of older children to understand or cope with the effects of maternal HIV,^{1,8,9,10,11,15} perceived ability of older children to keep HIV a secret,^{8,11} desire to protect children from transmission and from courtesy stigma,^{8,11,15} felt obligations to children (right to know, to tell the truth, should hear it from mother),^{9,11,15} desire to preserve good relations with children and identity as good mother,^{8,11} and mothers' own health and need for help.^{9,11,15}

Quantitative Findings

The odds of needing more physical assistance or social support were greater among mothers who disclosed to children than mothers who did not (.366mv); mothers who disclosed to children had greater personal feelings of social support than mothers who did not (.544mv).²⁹

A greater percentage of mothers with AIDS than symptomatic mothers (.293)²⁷ and asymptomatic mothers (.386)²⁷ & (.330)¹⁸ disclosed to children; a greater percentage of symptomatic mothers than asymptomatic mothers disclosed to children (.444).¹⁸

Not Disclosing Maternal HIV to Children

Qualitative Findings

Reasons for not disclosing to children included perceived inability of young children to understand or cope with the effects of maternal HIV,^{1,9,10,11,15} perceived inability of young children to keep HIV a secret,^{1,8,11} desire to protect children from transmission and from courtesy stigma,^{8,11,15} desire to preserve good relations with children and identity as good mother,^{8,11} and disclosure seen as too threatening.¹¹

Quantitative Findings

Not disclosing to children because of not wanting to burden them (1.036), fear that child will tell others (1.124), and to keep information from them (1.036) were positively associated with felt stigma.³¹

Not disclosing to children because HIV was deemed personal (1.008) was positively associated with knowledge of HIV as stigmatizing (1.008).³¹

Note. Superscript numbers refer to reports listed in Table 1. All relationships are bivariate, except where indicated as multivariable (mv).