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The role of minor and adult children in the adjustment of women living with HIV

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Abstract

The present study examined how having children can relate to the psychological functioning of HIV-positive women, and the place and function children have in their mother's social support and social burden networks. As part of initial face-to-face interviews with 46 HIV-positive women enrolled in a longitudinal study, participants indicated their maternal status, the nature of their social support and burden (with a modified Multidimensional Social Support Inventory) and their levels of depressive symptoms (Brief Symptom Inventory). Using Analysis of Variance (ANOVA) and non-parametric analyses when statistical assumptions were not met, findings indicate that women with minor children reported fewer depressive symptoms and more confidence in regulating social support than women without children. Maternal status was not significantly related to other measures of social support. Women with minor children reported greater comfort and confidence in regulating social burden and reported experiencing less social burden than women with adult children only. Women with adult children only reported intermediate levels of depression, but high levels of received burden and low levels of comfort and confidence in regulating (lessening) this burden. Analyses of women's social networks (Fisher's Exact Test) indicated that minor children were less likely to be named regarding support than adult or other family members and were infrequently turned to for practical, emotional, or HIV-related support. Adult children were more often listed as providing various types of support than minor children, yet these relationships were also often associated with relatively higher levels of social burden.

Keywords

HIV/AIDS; women; social support; social burden; children

With the advent of highly active antiretroviral therapy, HIV-positive women are less likely to develop AIDS (Gauge et al., 2002) and are more likely to contemplate having and raising children. While much is being learned about factors that influence the physical and mental health of women living with HIV, less is known about factors that influence HIV-positive

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women who are also mothers. In particular, very little is known about how having children affects the way women adjust to their HIV status.

For women in general, parenting can increase psychological distress (Goldsteen & Ross, 1989; McLanahan & Adams, 1989). Furthermore, HIV-positive mothers describe having children as particularly stressful and worrisome (Faithfull, 1997; Keigher, Zabler, Robinson, Fernandez, & Stevens, 2005; Metcalfe, Langstaff, Evans, Paterson, & Reid, 1998; Semple et al., 1993; Simoni, Davis, Drossman, & Weinberg, 2000). In addition, children of HIV-positive mothers can express more psychological and behavioral challenges than children of comparable non-infected mothers (Brackis-Cott, Mellins, Dolezal, & Spiegel, 2007; Dorsey et al., 1999; Forehand et al., 2002). Having children who feel they must provide for their HIV-positive parent may contribute to higher levels of maternal distress (Klein et al., 2000).

There is also evidence supporting the adjustment enhancing effects of having children for HIV-positive mothers (Barroso, 1997; Keigher et al., 2005; Pivnick, 1994) although no work that examines minor and adult children separately. If direct support is the primary mechanism through which children serve as protective factors, then women with adult children might report greater support and higher levels of functioning. If meaning associated with being a mother (e.g., role as caregiver, purpose for living) is the main mechanism, then women with minor children might report better functioning. Unfortunately, most research examining HIV-positive mothers and their children is restricted to minor children and with one exception related to stigma no studies have explicitly examined the potential role of adult children and mothers' well-being (Bogart et al., 2008).

In addition to providing meaning and potential support, children can also be burdensome. While the role of social support and social burden in the lives of HIV-positive women has been shown to be important (Fleishman et al., 2000; Ingram, Jones, Fass, Neidig, & Song, 1999; Murdaugh et al., 2006; Swindle, Heller, & Frank, 2000), little is known about support and burden derived from children.

The present study examines the potential role of children in the psychological wellbeing of women living with HIV by examining data primarily from the first wave of a longitudinal study on psychological growth in women living with HIV. Levels of depressive symptoms, perceived social support, perceived social burden and the extent minor children, adult children, and other family members appear in the social support and social burden networks of HIV-positive women with and without children (minor or adult only) are compared.

Method

Participants

In order to complete a multi-year longitudinal sample of 30 participants, between 1 January 1998 and 1 April 2000, 46 HIV-positive English-speaking women (one participant was deaf and an interpreter was used), ranging in age from 24 to 56 were recruited through public announcements and via contacts with HIV health-care providers and service organizations. Data for this study come from these initial interviews. Self-reported primary ethnic identities (39% Caucasian, 24% Hawaiian/Part Hawaiian, 13% Hispanic, 13%, Asian/Pacific Islander

other than Hawaiian/Part Hawaiian) and reported routes of transmission (29% via intravenous drug use, 61% sexual contact, 4% blood transfusion, and 5% unknown) closely reflect the epidemiology of HIV among women where the study was conducted. Most participants were poor (59% with household incomes <\$12,000/year) and most (59%) reported no education beyond high school. At time of interview, participants had known of their HIV status for an average of 4.5 years. Twenty (43%) had received an AIDS diagnosis, and an additional 10 (22%) were HIV symptomatic. During the four months preceding the interview, about 39% reported using alcohol (once or more), 28% used marijuana, 13% amphetamines, and 11% sedatives.

We divided the sample into three groups: those without children ($n = 12$, 26%), those with adult children only ($n = 9$, 20%) and those with one or more minor child (< 18 years old) at the time of the interview ($n = 25$, 54%). Eight of the women with minor children also had one or more adult child. About one-half of all minor children resided with their mothers at the time of the interview, compared to only 10% of adult children.

Procedures and measures

Interviews were conducted in the participants' homes and included informed consent, collection of socio-demographic information and self-reported physical and psychological functioning. At the completion of the interview, participants received \$50.00 compensation.

Two measures provide data for the present study. Depressive symptom level scores were taken from the Brief Symptom Inventory (BSI) and reflect the mean endorsement on six items (suicidal thoughts, feeling lonely, feeling blue, feeling no interest in things, feeling hopeless, and feeling worthless) scored from zero to four (not at all to extremely distressful; Derogatis, 1993). Cronbach's alpha was 0.91 in the present study.

A modification and extension of the Multidimensional Social Support Inventory (MSSI; Bauman & Weiss, 1995) was used to assess various dimensions of social support and social burden. For the present study, we modified the MSSI by focusing only on functional and structural characteristics of social support and by adding a parallel set of probes derived from a prior qualitative study designed to elicit information about burdensome relationships (Dunbar, Mueller, Medina, & Wolf, 1998). First, participants listed important and/or frequently encountered people in their lives. Then participants indicated which listed individuals provided 28 different types of support (see Table 3) and burden (see Table 4) over the prior four months. Specific probes were organized into the four types of support developed by Bauman and Weiss (1995) (i.e., practical, emotional, affirmational, and HIV related) and five rationally derived types of burden (i.e., demand, emotional, devaluation, harm, and HIV related). After responding to all support probes, participants rated their confidence in getting any support they wanted (1–10-point scale), their comfort with asking for support (1–10-point scale), and the extent to which they have received support over the last four months (1–4-point scale, from “almost none of the time” to “all of the time”). Once participants responded to all burden probes, they were asked to rate their confidence and comfort in regulating (lessening) the amount of burden that people put on them (both 1–10-point scales), and the extent to which they have experienced burden (1–4-point scale).

Comparisons across the three participant groups were made using ANOVA for continuous variables and Fisher's Exact Test for dichotomous data. When examining distributions, two continuous variables did not meet the assumption of homoscedasticity and were then subjected to non-parametric tests (Kruskal–Wallis and Mann–Whitney Test).

Results

Depressive symptoms

The mean level of depressive symptoms in this sample ($M = 1.07$) placed participants between scores from the BSI normative sample for adult women non-patients ($M = 0.36$, $SD = 0.56$) and women receiving out-patient psychiatric services ($M = 1.90$, $SD = 1.05$; Derogatis, 1993). Maternal status had a significant effect on symptom level, $F(2, 43) = 6.40$, $p < 0.01$ (normality and homogeneity assumptions were met). As shown in Table 1, women with minor children reported significantly less depressive symptom distress compared to women without children. Women with only adult children scored between these two groups but did not differ significantly from either.

Maternal status was unrelated to measures of physical illness, months since HIV notification, education level, household income, or ethnic identity. Women with adult children only were older ($M = 47.67$) than women with minor children or women with no children ($M = 34.76$ and 32.33 years, respectively), $F(2, 43) = 20.88$, $p < 0.01$. A non-significant trend indicated that women with minor children lived in the largest households ($M = 2.64$) followed by women with only adult children ($M = 2.13$) and women without children ($M = 1.45$), $F(2, 41) = 2.81$, $p < 0.10$ (two missing data on household size). Depression scores correlated with number of HIV-related physical symptoms and total physical symptom discomfort scores, $r(46) = 0.50$, $p < 0.01$ and $r(46) = 0.52$, $p < 0.01$, but were not significantly correlated with any other measures. Given potentially confounding variables, a hierarchical regression was conducted with age, household size, number of symptoms, and level of symptom discomfort entered before examining the relationship between maternal status and depression symptoms. The results indicate a significant relationship between parenting status and depression scores above and beyond that due to the combined effects of these four other variables, R^2 change = 0.183, F change (1, 41) = 13.84, $p < 0.001$.

Perceptions about and receipt of support and burden

A multivariate analysis of variance (MANOVA) conducted on the eight interrelated measures of perceptions of participant's social network indicated a significant overall effect related to maternal status, $F(8, 37) = 2.49$, $p < 0.05$. As shown in Table 2, women with minor children reported significantly more confidence in their ability to regulate the support in their network compared to women without children, $F(2, 43) = 4.19$, $p < 0.05$. Women with minor children reported more comfort and confidence in regulating social burden and received (experienced) more burden compared to women with adult children only (Kruskal–Wallis Test $\chi^2(2; N = 46) = 13.27$, $p < 0.001$, $F(2, 42) = 3.23$, $p < 0.05$, $F(2, 42) = 3.56$, $p < 0.05$, respectively). No other effects were significant.

Family members in women's support and burden networks

Based on the MSSSI, we calculated the number of people listed as network members and those who were named once or more to support or burden probes. Size of participants' overall, support, and burden network did not significantly differ as a function of maternal status. ($M = 14.22$, $M = 10.85$, $M = 6.54$, respectively). Of the 654 people named in participants' initial networks, 324 (49.5%) were nuclear or extended family members. Of these, 43 (13.3%) were minor children and 30 (9.3%) were adult children of participants. As expected, family members accounted for a higher percentage of all network members for women with children (57%) compared to those without children (39%), $\chi^2(2; N=46) = 24.89$, $p < 0.001$.

Both minor children (81%) and adult children (93%) were more likely to be named to one or more *support* probes compared to other family members in the network (69%); $\chi^2(2; N=46) = 9.58$, $p < 0.01$. However, the percentage of minor children (60%) or adult children (60%) named to one or more *burden* probes did not significantly differ from that for other family members (62%), $\chi^2(2; N=46) = 0.01$, $p > 0.95$.

Given that the number of times specific family members were named in response to support or burden probes was skewed (possible range 0–13 for support and 0–15 for burden), a median test was conducted to compare the three types of family relationships. Minor children were named to fewer support probes ($M = 2.06$, Median = 2.00) than other family members ($M = 4.05$, Median = 3.00) or adult children ($M = 4.00$, Median = 3.50), $\chi^2(2, N=46) = 12.94$, $p < 0.01$. There was no significant difference in frequency of being named to burden probes as a function of family relationship, $\chi^2(2, N=46) = 2.01$, $p > 0.30$.

Tables 3 and 4 depict the percent of minor children, adult children, and other family members named to each support and burden probe. Minor children were most likely to be named in response to the three affirmational probes, one support probe ("care for you when you are sick"), and one HIV-related probe ("understands your HIV"; all probes > 25% of minor children). Less than 10% of minor children were named to any other support probe. Comparing across type of family relationship, a larger percent of minor children were named to the affirmational probe "accept you as you are" (65%) compared to other family members (48%). Minor children were less likely than adult children to be named to seven probes and less likely to be named than other family members in response to eight of the 13 probes.

The percent of adult children named to any given probe did not significantly differ from the corresponding percent of other family members across any of the support probes. The three affirmational probes produced the highest percent of adult children nominees. Affirmational and two of three practical support probes ("loan you \$50" and "help in an emergency") produced the highest percent of other family nominees.

Table 4 shows results from the burden probes. Minor children were most likely to be named in response to two demand burden probes, "ask or expect too much" and "expect you to be strong and care for them," and were more likely to be so named compared to other non-child family members.

Compared to minor children, adult children were more likely to be named in response to four burden probes (“makes you feel guilty or ashamed,” “bring you down,” “lecture rather than listen,” and “inappropriately discloses your HIV-status”). Compared to other family members, adult children were more likely to “expect you to be strong or to take care of them” and “to make you feel guilty or ashamed.”

Discussion

In this study, HIV-positive women with minor children reported fewer depressive symptoms and more confidence in their ability to call upon their network of support compared to women without children. In addition, women with minor children reported more comfort and confidence in regulating social burden and experienced less such burden from their network than women with adult children only.

Minor children were named to fewer support probes than adult children or other family members suggesting a limited reliance on minor children for multiple support roles. Minor children were most often reported to provide affirmational support along with some practical and HIV-related support (“understanding your HIV”). With the possible exception of caring for their mother when she is ill, there was little evidence of minor children assuming developmentally inappropriate roles (e.g., emergency back up, serving as a confidant regarding her HIV status). Although, some minor children were identified when asked about who “asks or expects too much,” “expects strength and care” or “frustrates or angers you,” very few minor children were named to any other burden probes (e.g., being a bad influence, gossip, threats, and judgmental attitudes).

The findings point to differences related to having adult or minor children. Women with only adult children reported intermediate levels of depression, but also reported higher levels of received burden and lower ratings of comfort and confidence in regulating these burdens than did women with minor children. While adult children were often named in support roles, they were also more likely to be named in response to various burden probes (compared to minor children). In the absence of other studies that examine the differential roles of minor and adult children in the lives of people living with HIV, these findings provide the first examination of how adult children might support but also burden their mothers.

Overall, our findings point to the benefit of having young children who seem to affirm the HIV-positive mother, but provide little adult-like support or burden. Adult children (and other family members) can provide support, but an (un)healthy dose of burden as well.

Although beyond the scope of this paper, unanalyzed narrative accounts in these interviews reflected themes of children as motivation for living and being a good parent. Themes of family shame and rejection also emerged, often tied to adult children and other family members. Related cultural themes also emerged, where participants saw themselves as part of multi-generational families and where children were part of the present and future intergenerational family constellation.

Given our small sample size, caution should be exercised when generalizing findings. While participants were representative of women living with HIV in the study community, results might not hold in other settings. Second, the measure of social burden was created for this study and is of unknown psychometric properties. While it was carefully constructed to reflect findings from an exploratory qualitative study of women living with HIV and to parallel a well-established measure of support, findings from this measure need to be replicated in other studies.

Even with its limitations, the present study contributes to our nascent knowledge about the potential role of children in the lives of HIV-positive women. While women living with HIV report struggles raising their children and some of these children are likely to have additional behavioral and emotional challenges, there might be positive mechanisms within these relationships that are beneficial to parents and children as well. Furthermore, the details of how support and burden operate for minor and adult children seem to differ. If we can better understand how minor and adult children affect the mental health of adults living with HIV (e.g., exactly what parent–child interactions are helpful and harmful), we can then design and test psychosocial interventions that might benefit such women and their families.

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References

- Barroso J. Social support and long-term survivors of AIDS. *Western Journal of Nursing Research*. 1997; 19(5):554–582. [PubMed: 9330563]
- Bauman, L.; Weiss, E. *Multidimensional social support inventory-revised*. New York: Albert Einstein College of Medicine; 1995.
- Bogart L, Cowgill B, Kennedy D, Ryan G, Murphy D, Elijah J, et al. HIV-related stigma among people with HIV and their families: A qualitative analysis. *AIDS Behavior*. 2008; 12:244–254. [PubMed: 17458691]
- Brackis-Cott E, Mellins C, Dolezal C, Spiegel D. The mental health risk of mothers and children: The role of maternal HIV infection. *Journal of Early Adolescence*. 2007; 27:67–89.
- Derogatis, LR. *BSI: Administration, scoring & procedures manual for the Brief Symptom Inventory*. 4th. Minneapolis, MN: National Computer Systems; 1993.
- Dorsey S, Forehand R, Armistead LP, Morse E, Morse P, Stock M. Mother knows best? Mother and child report of behavioral difficulties of HIV-infected mothers. *Journal of Psychopathology and Behavioral Assessment*. 1999; 21(3):191–206.
- Dunbar HT, Mueller CW, Medina C, Wolf T. Psychological and spiritual growth in women living with HIV. *Social Work*. 1998; 43(2):144–154. [PubMed: 9528390]
- Faithfull J. HIV-positive and AIDS-infected women; challenges and difficulties of mothering. *American Journal of Orthopsychiatry*. 1997; 67(1):144–151. [PubMed: 9034030]
- Fleishman JA, Sherbourne CD, Crystal S, Collins RL, Marshall GN, Kelly M, et al. Coping, conflictual social interactions, social support, and mood among HIV-infected persons. *American Journal of Community Psychology*. 2000; 28(4):421–453. [PubMed: 10965385]
- Forehand R, Jones D, Kotchick D, Armistead L, Morse E, Simon P, et al. Noninfected children of HIV-infected mothers: A 4-year longitudinal study of child psychosocial adjustment and parenting. *Behavior Therapy*. 2002; 33:579–600.

- Gauge SJ, Barron Y, Greenblatt RM, Anastos K, Minkoff H, Young M, et al. Effectiveness of highly active antiretroviral therapy among HIV-1 infected women. *Journal of Epidemiology and Community Health*. 2002; 56(2):153–159. [PubMed: 11812817]
- Goldsteen K, Ross C. The perceived burden of children. *Journal of Family Issues*. 1989; 10(4):504–526. [PubMed: 12282415]
- Ingram KM, Jones DA, Fass RJ, Neidig JL, Song YS. Social support and unsupportive social interactions: Their association with depression among people living with HIV. *AIDS Care*. 1999; 11(3):313–329. [PubMed: 10474630]
- Keigher S, Zabler B, Robinson N, Fernandez A, Stevens PE. Young caregivers of mothers with HIV: Need for supports. *Children and Youth Services Review*. 2005; 27:881–904.
- Klein K, Armisted L, Devine D, Kotchick B, Forehand R, Morse E, et al. Socioemotional support in African American families coping with maternal HIV: An examination of mother's and children's psychosocial adjustment. *Behavior Therapy*. 2000; 31:1–26.
- McLanahan S, Adams J. The effects of children on adults' psychological well-being: 1957–1976. *Social Forces*. 1989; 68(1):124–146.
- Metcalfe KA, Langstaff JE, Evans SJ, Paterson HM, Reid JL. Meeting the needs of women living with HIV. *Public Health Nursing*. 1998; 15(1):30–34. [PubMed: 9503951]
- Murdaugh C, Moneyham L, Jackson K, Phillips K, Tavakoli A. Predictors of quality of life in HIV-infected rural women: Psychometric test of the chronic illness quality of life ladder. *Quality of Life Research*. 2006; 15:777–789. [PubMed: 16721638]
- Pivnick A. Loss and regeneration: Influences on the reproductive decisions of HIV positive, drug-using women. *Medical Anthropology*. 1994; 16:39–62. [PubMed: 7877463]
- Semple SJ, Patterson TL, Temoshok LR, McCutchan JA, Straits-Treoster KA, Chandler JL, et al. Identification of psychobiological stressors among HIV-positive women. HIV Neurobehavioral Research Center HNRC Group. *Women & Health*. 1993; 20(4):15–36. [PubMed: 8171874]
- Simoni JM, Davis ML, Drossman JA, Weinberg BA. Mothers with HIV/AIDS and their children: Disclosure and guardianship issues. *Women & Health*. 2000; 31:39–54. [PubMed: 11005219]
- Swindle R, Heller K, Frank M. Differentiating the effects of positive and negative social transactions in HIV illness. *Journal of Community Psychology*. 2000; 28(1):35–50.

Table 1

Mean (standard deviation) depression symptom score as a function of maternal status.

Maternal status	Minor children	Adult children only	No children
Depression	0.64 (0.77) _a	1.39 (1.16) _{ab}	1.74 (1.01) _b

Note: Symptoms scores could range from 0 to 4. Means that do not share subscripts differ at $p < 0.05$ in the Tukey's honestly significant difference comparison.

Table 2

Mean (standard deviation) ratings of social support and burden as a function of maternal status.

Network measure	Maternal status		
	Minor children	Adult children only	No children
Social support			
Comfort	7.32 (2.66)	8.44 (1.81)	5.67 (3.67)
Confidence *	8.84 (1.65) _a	8.11 (2.20) _{ab}	6.83 (2.40) _b
Receipt	3.20 (0.82)	2.89 (0.78)	2.75 (0.75)
Proportion of network	0.81 (0.17)	0.77 (0.15)	0.64 (0.26)
Burden			
Comfort **	7.96 (2.19) _a	4.00 (1.80) _b	5.67 (3.25) _{ab}
Confidence *	7.72 (2.26) _a	5.11 (3.25) _b	7.00 (2.89) _{ab}
Receipt *	1.68 (0.48) _a	2.33 (0.87) _b	1.83 (0.72) _{ab}
Proportion of network	0.44 (0.23)	0.52 (0.22)	0.43 (0.28)

* $p < 0.05$;

** $p < 0.001$.

Note: Based on univariate F -test, except for support and burden comfort where Kruskal–Wallis Test was used due to heteroscedasticity. Means in the same row that do not share subscripts differ at $p < 0.05$ in the Tukey's honestly significant difference comparison or Mann–Whitney Test ($p < 0.016$). All comfort and confidence scales ranged from one to 10. The receipt scales ranged from one to four.

Table 3

Percent of minor children, adult children, and other family members mentioned in network who were also named to specific support probes.

Support probe category	Abbreviated item	Minor children (n = 43)	Adult children (n = 30)	Other family members (n = 251)
Practical	Care for you	26	27	25
	Loan \$50 **	07 _a	20 _{ab}	37 _b
	Help in emergency **	09 _a	33 _b	41 _b
Emotional	Could talk to **	07 _a	27 _b	29 _b
	Understands **	00 _a	27 _b	27 _b
	Gives good advice **	00 _a	20 _b	22 _b
Affirmational	Values you	26	47	40
	Accepts as you are **	65 _a	63 _{ab}	48 _b
	Shows respect	40	50	37
HIV related	If hospitalized will care for **	02 _a	27 _b	28 _b
	Talk to re-HIV **	00 _a	17 _b	24 _b
	Understands your HIV **	26	30	29
	Talk to re-HIV worries/fears	00 _a	13 _b	19 _b

*
 $p < 0.05$;

**
 $p < 0.01$.

Note: Scores within rows with different subscripts significantly differ, Fischer's Exact Test (1), $p < 0.05$. Using X2 (2; $N=46$) for each item, probability value.

Table 4

Percent of minor children, adult children, and other family members mentioned in network who were also named to specific burden probes.

Burden probe category	Abbreviated item	Minor children (n = 43)	Adult children (n = 30)	Other family members (n = 251)
Demand	Ask or expect too much *	28 _a	27 _{ab}	14 _b
	Expect strength and care **	30 _a	43 _a	15 _b
	Give – expect more in return	09	23	11
Emotional	Make guilty or ashamed **	00 _a	30 _b	11 _c
	Bring you down **	00 _a	23 _b	21 _b
	Frustrate or anger you	19	37	21
Devaluation	Don't understand you	05	10	16
	Judge you – feel worthless	00	07	08
	Lecture rather than listen **	00 _a	17 _b	19 _b
Harm	Threat/actual physical harm	00	00	06
	Talk behind your back *	00 _a	00 _{ab}	09 _b
	Bad influence on you	00	00	03
HIV related	Need to keep HIV secret from	12	00	08
	Not accept/deal with status	05	20	08
	Inappropriate disclosure *	00 _a	17 _b	10 _b

* $p < 0.05$;

** $p < 0.01$ for overall χ^2 (2; $N=46$).

Note: Scores within rows with different subscripts significantly differ, Fischer's Exact Test (1), $p < 0.05$.