

Maternal HIV status disclosure to young uninfected children: Psychological variables of the mother

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Abstract

Mothers living with HIV are faced with the dilemma of when and how to disclose their HIV-positive status to their young uninfected children. In this study, a South African sample of mothers living with HIV, with young uninfected children (6-10 years) in the city of Tshwane was studied. In the sample of 406 mothers, 11.6% reported that they disclosed their HIV status to their young uninfected children. The research compared 47 mothers who disclosed (29 full disclosure and 18 partial disclosure) and a random sample of 50 mothers who did not disclose to their children, in terms of depression symptoms, parenting stress and coping strategies. The results showed that single and widowed mothers disclosed significantly more to their uninfected young children than mothers who had partners or were married. Mothers in the three disclosure groups did not differ in their experience of depression symptoms, parental distress and coping styles. Mothers who disclosed partially reported less parent-child dysfunctional interaction. Time since disclosure did not influence level of disclosure and was not significantly related to psychological outcome of mothers. Mothers who disclosed reported significantly more emotional and instrumental support as coping strategies than mothers who did not disclose. Mothers thus mostly disclose their status to their children to get support and family closeness. Mothers who disclosed and had not disclosed did not differ in terms of psychological variables. Some mothers perceived partial disclosure as age-appropriate for young children. It is recommended that HIV-positive mothers receive psychosocial support services to equip them to disclose their health status in an age appropriate way to their children, as it is documented that maternal disclosure benefits both mother and child.

Key words: Maternal HIV status, maternal HIV disclosure, depression symptoms, coping style, coping strategy, parenting stress, socio-demographic characteristics.

Introduction

Maternal disclosure of HIV status to children is a complex issue as it involves maternal and child characteristics, the family environment, culture as well as the stigma communities attach to HIV (Dass-Brailsford, Eckman, & Kwasnik, 2014). Although maternal HIV status disclosure is regarded as beneficial in families (World Health Organization, 2011; Mkwanzazi, Rochat, Imrie, & Bland, 2012; Crankshaw et al., 2014; Rochat, Arteche, Stein, Mkwanzazi, & Bland, 2014), there is a low rate of maternal disclosure to children worldwide (Qiao, Li, & Stanton, 2013). Maternal disclosure to young children varies from as low as 11% to as high as 84% across a number of studies in different countries (Mkwanzazi et al., 2012).

In South Africa, where 20.6% of the population 15 to 49 years are HIV-infected (HSRC, 2018), many children are raised in HIV affected families (UNAIDS, 2016). Improved access to Antiretroviral Therapy (ART) makes it possible for parents living with HIV to lead a healthier and longer life (Oguntibeju, 2012) and to take care of their children for a longer period of time (Bor, Herbst, Newell, & Bärnighausen, 2013). Disclosure of parental or maternal HIV status has, therefore, become a significant issue in relationships and health of many families (Madiba & Matlala, 2012; Mkwanzazi et al., 2012). A systematic review of literature showed that current research focuses on understanding maternal HIV status disclosure in relation to maternal mental health, children's health, family relationships, parenting and custody planning (Qiao et al., 2013). Mothers living with HIV often need support to disclose their HIV status to their uninfected children. Parents with pre-school and primary school-aged children experience greater difficulty in disclosing their status to their children. They are concerned whether the child is old enough to understand the HIV diagnosis, whether the disclosure will be an emotional burden to the child or expose the child to stigma (Mkwanzazi et al., 2012). Their own discomfort to talk to children about sex, illness and death and their uncertainty whether they will be able to answer children's questions, play a role in decisions to disclose or not (Mkwanzazi et al., 2012). Mothers also feared secondary disclosure by the child (Murphy, 2008; Palin et al., 2009; Murphy, Armistead, Marelich, Payne, & Herbeck, 2011; Qiao et al., 2013).

Previous research shows that maternal disclosure of HIV status appears to be associated with benefits in mental health for both mother and child (Mkwanzazi et al.,

2012; Rochat, Mkwazazi, & Bland, 2013). Children benefit from disclosure as a result of improved custody planning and increased knowledge about HIV and AIDS following disclosure (Mkwazazi et al., 2012). Children's initial reactions to maternal HIV disclosure include sadness, shock, worry and anxiety caused by concerns about the mothers' health and life expectancy (Palin et al., 2009; Rochat et al., 2014), however the children's concerns abated over time. Children's long-term reactions and adjustment to disclosure over time are regarded as mostly positive (Hawk, 2007; Murphy, 2008; Qiao et al., 2013; Sipsma et al., 2013; Rochat et al., 2014). There is evidence that mothers experience psychological benefits from disclosure to their children (Wiener, Mellins, Marhefka, & Battles, 2007; Murphy et al., 2011; Obermeyer, Bajjal, & Pegurri, 2011; Mkwazazi et al., 2012; Rochat, Arteché, Stein, Mitchell, & Bland, 2015), because they experience a sense of relief from no longer having to keep their HIV status a secret (Schrimshaw & Siegel, 2002). Disclosure to children creates increased social support (Armistead et al., 2001), it strengthens parent-child relationships and improves family cohesion (Tenzek, Herrman, May, Feinerd, & Allenb, 2013). In contrast, some studies found no difference in depression symptoms or level of support of mothers who disclosed or did not disclose to their children (Simoni, Davis, Drossman, & Weinberg, 2000; Delaney, Serovich, & Lim, 2009). A small number of mothers regretted disclosing their HIV status to their children (Murphy, 2008). The main reasons for regret were not having planned for the disclosure event and burdening their young children. They often disclosed to their children during an emotional time which led them to just blurting out their HIV status (Murphy, Roberts, & Hoffman, 2003; Murphy, 2008).

Most research on maternal HIV disclosure in South Africa has focused on child characteristics and the effect of disclosure on child outcomes (Rochat et al., 2013; 2014; Sipsma et al., 2013). Research on maternal disclosure to date contributed to a sound understanding of factors that influence maternal HIV disclosure and how children react to their mother's HIV status. However, there is a gap in research to understand maternal characteristics and mental health in the context of maternal disclosure. The question is whether mothers experience different levels of psychological wellbeing after disclosure to their young children. This research specifically focused on whether mothers experience significant differences in depression symptoms, parenting stress and coping strategies because of different

levels of disclosure to their young uninfected children. Maternal disclosure may vary from non-disclosure, partial disclosure to full disclosure. Non-disclosure is when an individual does not reveal to others that he/she is living with HIV or may become ill. Partial disclosure refers to the process of revealing one's health status – the fact that one is or may become ill, but not specifically disclosing that one has an HIV positive diagnosis. Full disclosure is the process whereby an individual reveals to others that he/she is living with HIV (Wiener et al., 2007). In this research maternal characteristics and psychological well-being are compared in terms of different levels of maternal disclosure to enable contributions to future interventions.

Methods

Background of the research

This study entails a secondary analysis of the baseline data of the Kgolo Mmogo project (Eloff et al., 2014) where mothers living with HIV were interviewed at clinics in Tshwane where they received treatment. The eligibility criteria included 1) being in the possession of a positive HIV test result; 2) being a primary caregiver of a young uninfected child (6-10 years) and 3) speaking one of the four local languages (Sepedi, Sesotho, Setswana and isiZulu). Participants were excluded from the study if the child was living with HIV or if there was a family member in the household other than the mother with a serious illness that could influence the relationships in the household (Sipsma et al., 2013). Data was collected by research assistants through one-on-one interviews with the mothers in the mothers' vernacular. As part of the data collection process mothers were asked what they have told their children about their health. They were asked specifically whether they have told the child that they have HIV; whether they have told the child that they have an illness or use medication (but did not say it was HIV) and whether they have not told the child anything about their health. Additionally, data was collected on the psychological well-being of mothers, their coping strategies and the mother-child relationship. This baseline data was analysed in this study.

Study design

In this study a comparative descriptive design is used to compare psychological variables of mothers who have disclosed their status fully or partially or not at all, to

their young children. A comparative descriptive approach involves describing the specific differences between two or more groups as they occur in the environment without introducing manipulation (Taylor, Kermode, & Roberts, 2006; Sousa, Driessnack, & Mendes, 2007; Mitchell & Jolley, 2012; Creswell, 2013).

Sample

As part of the original study, 406 mothers living with HIV responded to the disclosure question. Of these mothers 88.4% indicated that they did not disclose their health status to their young children, while 7.1% indicated full disclosure (*I have told my child I have HIV/AIDS*) and 4.5% indicated partial disclosure (*I have told my child I have a serious health/ medical condition*).

For the current analysis, data of mothers who fully and partially disclosed were used as the disclosure groups. Because of the large number of mothers who did not disclose (n=356), a random sample of these mothers was selected using SPSS's random selection of cases, to obtain a more equal size comparison group. In the analysis the data of 29 mothers who fully disclosed and 18 mothers who partially disclosed to their young children was compared to the data of a random sample of 50 mothers who did not disclose.

Data collection instruments

From the original Kgolo Mmogo dataset the following socio-demographic data, illness history and psychological scales were used to compare mothers who disclosed and not.

Socio-demographic variables and illness data

Questions were asked related to the mothers' and the children's ages, employment status, marital status and level of education. Time since diagnosis, time since disclosure and level of disclosure were asked.

Centre for Epidemiological Studies-Depression scale (CES-D).

The CES-D is a widely used self-report instrument with 20 items for assessing depression symptoms (Radloff, 1977). Participants are asked to rate the frequency of experience of depression symptoms the preceding 7 days, using a 4-point Likert scale

ranging from “rarely or none of the time” to “most or all of the time”. Scores range from 0 to 60, with a score of 16 or above indicating significant depression symptomatology (Radloff, 1977).

Because of the potential overlap between somatic symptoms of depression and HIV symptoms, which might inflate depression scores (Kalichman, Rompa, & Cage, 2000; Cook et al., 2002), the five items that assess somatic symptoms of depression in the CES-D scale (items that assess fatigue, insomnia, apathy, difficulty in concentrating, and weight or appetite loss) were removed. This has also been done in previous research in South Africa (Makin et al., 2008; Eloff et al., 2014). The scores thus ranged from 0-45, with an estimated score around 12 and above indicating significant depression symptoms. In the current research the CES-D scale showed high internal consistency, with a Cronbach Alpha coefficient of 0.887.

Parenting Stress Index (PSI)

The mother-child relationship was assessed using two subscales of the PSI, a self-report measure assessing stress in the parent-child relationship (Abidin, 1990). The first subscale Parenting Distress (11 items) measures the mother’s perception of own behaviour such as perceived competence, marital conflict, views of social support and life restrictions due to parenting demands (e.g. *I find myself giving up more of my life to meet my child’s needs than I ever expected*). The second subscale Parent-Child Dysfunctional interaction (12 items) measures the mother’s views and expectations of the child (e.g. *my child rarely does things that make me feel good*). Participants respond on a five point Likert scale which ranges from 1 = strongly agree to 5 = strongly disagree with high scores indicate parenting stress (Boeving-Allen et al., 2014). The PSI subscales showed good reliability. The Parenting Distress had a Cronbach alpha coefficient of 0.832, while the Parent-Child Dysfunction had a Cronbach alpha coefficient of 0.812.

Brief COPE

The coping strategies of mothers living with HIV were assessed using the Brief COPE scale, which is an abbreviated version of the COPE inventory (Carver, 1997). The scale has 14 subscales consisting of 2 items each which measure different coping strategies. These coping strategies can be grouped in two sub-scales namely active

and avoidant coping (Smith et al., 2001). The following coping strategies can be categorised as *active coping*: active coping, planning, humour, positive framing, acceptance, religion, use of emotional support, and use of instrumental (practical) support. Other strategies can be grouped into *avoidant coping*: self-distraction, denial, substance use, behavioural disengagement, self-blame, and venting. The participants were asked to indicate how often they use a coping strategy to deal with stressors. Responses were provided on a four point Likert response scale ranging from “not at all” to “a lot of the time”. The reliability for the active coping style was acceptable with a Cronbach alpha coefficient of 0.777 (n=97) and the avoidant coping style had lower reliability with Cronbach alpha coefficient of 0.637.

The measuring instruments were existing scales. In order to adapt these instruments for the South African context, cultural modifications were made through a process of consultation with local personnel. Thereafter professional translators translated the instruments into four South African languages. The scales were then back translated by project staff fluent in the different languages to ensure quality translations. In addition, a pilot study was conducted with 22 mothers living with HIV to test their level of understanding and cultural appropriateness of the questions. The subsequent modification of the instruments were of a minor nature and included changes like substituting words that were not clearly understood with more colloquial terms that provided more clarity (Eloff et al., 2014).

Ethics procedures

The original study was ethically cleared and the project leaders gave permission for the use of the data in this study. The current study was ethically cleared by the Ethics Committee of the Faculty of Humanities, University of Pretoria. All mothers signed informed consent forms before they were interviewed and entered into the study (Eloff et al., 2014).

Data Analysis

Data analysis was conducted using the Statistical Package for the Social Sciences (SPSS) version 23®. Preliminary descriptive analysis was conducted for the three groups of mothers and time since diagnosis and disclosure. Cross tabulations and the Chi-square test for independence were conducted to explore the relationship between

maternal disclosure and socio-demographic variables. Non-parametric statistics, specifically the Kruskal Wallis H test, was used to compare the three groups of mothers for differences in depression scores, parenting stress and coping strategies. The Kruskal Wallis H test is regarded as a non-parametric alternative to a one way ANOVA for independent samples, when the assumptions of equal variances between groups are not met (Pallant, 2010). The Mann-Whitney test was used to explore time since disclosure and level of disclosure. Spearman rho correlations were used to analyse the relationship between time since disclosure and psychological variables.

Results

Socio-demographic information

The socio-demographic characteristics of the mothers are given in Table 1 (total column). The age of the mothers varied from 22 to 52 years, the largest group being 30 years and younger (42%). The average age of the children was 8.1 years and 51.9% were male. The majority of mothers (52%) had some high school education, while 27% had Grade 12 or some tertiary education as their highest qualification. Two thirds of the sample of mothers were unemployed (69%). The majority of mothers (58.8%) had partners but were not married, whereas 22.7% of mothers indicated that they were single and 4.1% were widowed. In this sample 14.4% of the mothers were married – this low percentage is often found in Southern Africa.

The mothers reported being diagnosed between one and 156 months (13 years) ago – average 25.92 months and median 14 months ago. They disclosed much later to their children. Time since disclosure to their young children was average 9.02 months ago (median 7 months; range 1 to 31 months ago).

Using the Pearson Chi-square test, differences between the three groups of mothers' socio-demographic variables were explored. There were no significant differences in the mothers' age, employment status and level of education. The Chi-square test for independence (with Fisher's exact test) indicated a significant association between maternal HIV disclosure and marital status, $\chi^2(2, n = 97) = 12.356, p = 0.034$ with a medium effect size (Cramer's $V = 0.248$). Mothers who were single and widowed were more likely to disclose their HIV status to their young uninfected children, whereas mother who had partners and who were married disclosed less to their young children.

Table 1 Socio-demographic characteristic of mothers

Age	No disclosure	Partial disclosure	Full disclosure	Total	Chi square
30 and younger	23 (46%)	4 (22.2%)	14 (48.3%)	41 (42.2%)	
31 – 35 years	13 (26%)	7 (38.9%)	5 (17.2%)	25 (25.8%)	
36 and older	14 (28%)	7 (38.9%)	10 (34.5%)	31 (32.0%)	X ² =4.72
Total	50	18	29		P=0.32
Highest education					
Primary school	10 (20.4%)	5 (27.8%)	5 (17.2%)	20 (20.8%)	
High school	27 (55.1%)	8 (44.4%)	15 (51.7%)	50 (52.1%)	
Gr 12 and tertiary	12 (24.5%)	5 (27.8%)	9 (31.0%)	26 (27.1%)	X ² =6.205
	49	18	29		P=0.67
Employment					
Full time	4 (8.0%)	1 (5.6%)	2 (6.9%)	7 (7.2%)	
Part time	11 (22.0%)	2 (11.1%)	4 (13.8%)	17 (17.5%)	
Self-employed	3 (6.0%)	2 (11.1%)	1 (3.5%)	6 (6.2%)	
Unemployed	32 (64%)	13 (72.2%)	22 (75.8%)	67 (69.1%)	X ² =8.875
	50	18	29		P=0.56
Marital status					
Single	8 (16%)	7 (38.9%)	7 (24.1%)	22 (22.7%)	
Have a partner	33 (66%)	6 (33.3%)	18 (62.1%)	57 (58.8%)	
Married	9 (18%)	3 (16.7%)	2 (6.9%)	14 (14.4%)	
Widowed	0 (0%)	2 (11.1%)	2 (6.9%)	4 (4.1%)	X ² =12.36
	50	18	29		P=0.03

Note: 50% to 66.7% cells had low counts

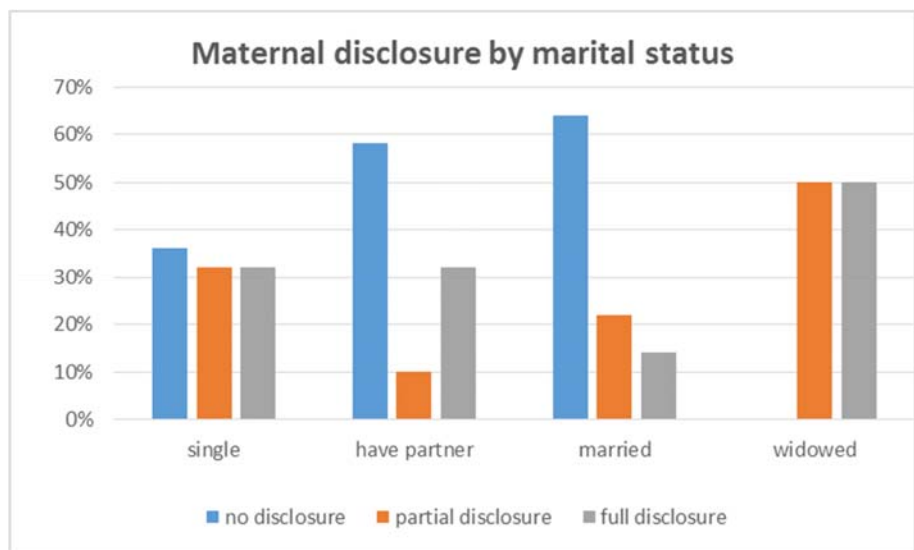


Figure 1: Graph of maternal disclosure and marital status

Almost equal numbers of mothers who were single and widowed disclosed partially and fully. (See figure 1). Time since diagnosis did not show a significant relationship with level of disclosure to children. Similarly, a Mann-Whitney U test revealed no significant difference in time since disclosure and level of disclosure (partial or full disclosure).

Comparison of psychological variables between the groups

The Kruskal Wallis H test was conducted to investigate differences between the three groups of mothers in terms of their depression symptoms, parenting stress and coping strategies (Table 2). Table 3 gives a summary of correlations between time since disclosure and psychological variables.

Depression symptoms

The results indicated that there were no significant differences in the depression symptoms of the three groups of mothers. The researchers noted the high levels of depression in the group as a whole (with median scores higher than 12, indicating significant depression symptoms) (See table 2). Time since disclosure was not significantly related to depression scores (Table 3).

Parenting stress

The Kruskal Wallis revealed no significant difference in the experience of parental distress of mothers in the three disclosure groups, but there was a statistically significant difference in the Parent-Child Dysfunctional Interaction subscale of the PSI across the three groups ($\chi^2(2, n = 97) = 11.57; p=0.003$). Mothers who partially disclosed reported a lower median score and thus experienced less difficulty in interacting with their children than mothers in the other two groups (See table 2). Time since disclosure was not significantly related to parental stress (Table 3).

Coping style and coping strategies

The results revealed no significant difference in the active and avoidant coping styles of the three groups of mothers (See Table 2). Time since disclosure was also not significantly related to coping styles (Table 3). In an analysis of the various coping strategies, significant differences were found in the use of the following three coping strategies: emotional support, instrumental support and self-distraction (Table 4).

Table 2: Comparisons of psychological variables between the groups

Scales	Full disclosure Mean rank (n=29)	Partial disclosure Mean rank (n=18)	No disclosure Mean rank (n=50)	Kruskal Wallis H test results
Depression symptoms: CES-D scale	49.53 (median 17)	49.75 (median 13.5)	48.42 (median 18.5)	KW= 0.045; p=0.98
Parenting stress: Parental Distress	47.88 (median 27)	43.78 (median 26.5)	50.55 (median 29)	KW=0.804; p=0.67
Parenting stress: Parent-Child Dysfunctional Interaction	57.05 (median 26)	29.25 (median 20)	50.64 (median 26)	KW=11.57; p=0.003
Active coping style: Brief COPE	52.43 (median 53)	55.08 (median 54.5)	44.82 (median 52)	KW=2.38; p=0.30
Avoidant coping style: Brief COPE	51.66 (median 29)	49.94 (median 28)	47.12 (median 28)	KW=0.503; p=0.78

Table 2: Comparisons of psychological variables between the groups

Scales	Full disclosure Mean rank (n=29)	Partial disclosure Mean rank (n=18)	No disclosure Mean rank (n=50)	Kruskal Wallis H test results
Depression symptoms: CES-D scale	49.53 (median 17)	49.75 (median 13.5)	48.42 (median 18.5)	KW= 0.045; p=0.98
Parenting stress: Parental Distress	47.88 (median 27)	43.78 (median 26.5)	50.55 (median 29)	KW=0.804; p=0.67
Parenting stress: Parent-Child Dysfunctional Interaction	57.05 (median 26)	29.25 (median 20)	50.64 (median 26)	KW=11.57; p=0.003
Active coping style: Brief COPE	52.43 (median 53)	55.08 (median 54.5)	44.82 (median 52)	KW=2.38; p=0.30
Avoidant coping style: Brief COPE	51.66 (median 29)	49.94 (median 28)	47.12 (median 28)	KW=0.503; p=0.78

Table 3 Correlation between time since disclosure and psychological variables of mothers

Scales	Spearman rho
Depression symptoms: CES-D scale	0.017 (p=0.91)
Parenting stress: Parental Distress	-0.182 (p=0.24)
Parenting stress: Parent-Child Dysfunctional Interaction	-0.066 (p=0.669)
Active coping style: Brief COPE	0.151 (p=0.32)
Avoidant coping style: Brief COPE	0.135 (p=0.37)

Table 4: Significant differences in use of coping strategies

Coping strategy	Full disclosure Mean rank (n=29)	Partial disclosure Mean rank (n=18)	No disclosure Mean rank (n=50)	Kruskal Wallis H test results
<i>Use of emotional support</i>	52.78 (median 8)	58.92 (median 8)	43.24 (median 7)	KW=6.20; p = 0.045
<i>Use of instrumental support</i>	52.07 (median 8)	62.31 (median 8)	42.43 (median 6)	KW=8.52; p=0.014
<i>Self-distraction</i>	44.81 (median 6)	63.25 (median 7.5)	46.3 (median 6)	KW=6.08; p=0.048

Mothers who disclosed (partially and fully) tend to use emotional and instrumental support significantly more than mothers who did not disclose. Mothers who partially disclosed used self-distraction as a coping strategy more often than the other two groups of mothers.

Discussion

The goal of this study was to investigate whether there were differences in psychological variables between mothers who have fully or partially or have not disclosed their HIV status to their young uninfected children. This research showed that marital status was significantly associated with maternal HIV status disclosure to children. Mothers who were single and widowed were more likely to disclose (partially and fully) to their young children, than mothers who had partners or who were married. Mothers with no partners may live closer to their children and rely on them for support, especially for household chores (Geiselhart, Gwebu, & Krüger, 2008). This research shows that mothers disclose to their young children to gain support and closeness in the family. It is interesting that Rochat et al. (2014) found the opposite. In their study mothers with current partners were almost three times more likely to fully disclose to their young children after an intervention. Disclosure to children may thus be a complex issue in families or the intervention could have decreased mothers' fears to disclose. Age, employment and level of education were not associated with maternal disclosure. This research shows that factors associated with HIV disclosure to children are not the same as those associated with partner disclosure. Disclosure to partners were mostly done by younger women (Ahn et al., 2016), not dependent on partners for survival (Antelman et al., 2001; Simbayi et al., 2007) and with higher levels of education (Medley, Garcia-Moreno, McGill, & Maman, 2004; Batte et al., 2015). This was not found in this research.

It was expected that mothers who disclosed their status to their children may experience lower levels of depression symptoms as they would feel relieved from no longer having to keep their status a secret from their children and they may receive support from their children (Murphy et al., 2011; Mkwanazi et al., 2012). Similar to findings of Delaney et al. (2009) this research found that mothers did not experience less depression based on their disclosure to their children, neither did time since disclosure influence depression symptoms. Among various distresses mothers with

HIV may experience (Chida & Vedhara, 2009; Medley, Kennedy, Lunyolo, & Sweat, 2009; Kotze, Visser, Makin, Sikkema, & Forsyth, 2013), disclosure to children may not have such a significant effect on their long term experience of depression symptoms. The results of this study indicated that mothers in all disclosure groups presented with high levels of depression (scoring above 12 on the CES-D scale). Depression is common among people living with HIV (Sherr, Clucas, Harding, Sibley, & Catalan, 2011) but often goes undetected (Cook et al., 2014; Andersen, Kagee, O'Cleirigh, Safren, & Joska, 2015).

Previous research indicated that parental stress is common in families affected by HIV/AIDS (Murphy et al., 2011; Lachman, Cluver, Boyes, Kuo, & Casale, 2014; Murphy, Armistead, Marelich, & Herbeck, 2015). The current study investigated whether significant differences exist in the mother-child relationship related to the level of disclosure. There were no significant differences in parental distress between the three groups of mothers, but mothers who *partially* disclosed scored significantly less in the Parent-Child Dysfunctional Interaction subscale of the PSI. The small group of mothers who partially disclosed thus experienced less difficulty in interacting and bonding with their children, than mothers in the other groups. They thus experience the relationship with their child as more positive than the other mothers. Previous research identified the strengthening of mother-child relationship and creation of family cohesion as benefits of disclosure (Tenzek et al., 2013). But why do mothers that *partially* disclose experience such benefits? The research of Sipsma et al. (2013) that studied the effect of maternal disclosure on children's reactions, found that partial disclosure was associated with positive behaviour and psychological functioning of the young child. The same was not found for children when mothers fully disclosed or said nothing about their health. These mothers may regard partial disclosure as age-appropriate for young children (6-10 years). They may have considered the potential effects of disclosure on young children (Mkwanazi et al., 2012; Qiao et al., 2013) and decided to give enough information not to burden but to promote the relationship. Rochart et al. (2014) on the other hand, found mental health improvement in children regardless of the type of disclosure – although full disclosure appeared to be associated with more benefits for the child. Partial disclosure can therefore not be considered more effective for all young children. The World Health Organization (2011) guidelines on age appropriate maternal disclosure need to be taken into

account. Decisions about disclosure should take into account the child and family circumstances and should be made on a child-by-child basis (Armistead et al., 2001; Rochart et al., 2014). Because of the nature of the results, it is also possible that mothers who partially disclosed their status to their young children may have had a better quality relationship with their children.

Mothers who fully disclosed their status to their young children in this study rated their parent-child relationship more negative than those who partially disclosed. They experience similar difficulty in bonding and interacting with their child than mothers who did not disclose at all. It is possible that mothers plan the timing of disclosure to their children according to their health status. A meta-analysis of research found that disclosure was linked to the stage of disease of the mother (Mkwanazi et al., 2012). Rochart et al. (2014) confirmed that mothers in good health were less likely to fully disclose their status to their children, even after participating in an intervention. The mothers' health status could thus have influenced her level of disclosure or perceived relationship with her child.

In this study, the groups of mothers did not differ in their use of active and avoidant coping styles to deal with their life stressors. They, however, differed in the use of some coping strategies. Mothers who disclosed their status to their young children (fully and partially) reported that they received significantly more emotional and instrumental support than mothers who did not disclose. Disclosure to children could have been a way to obtain support (Crankshaw et al., 2014). In previous research mothers cited assistance with household responsibilities as one of the reasons for disclosing their health or HIV status to children (Geiselhart et al., 2008; Rwemisisi, Wolff, Coutinho, Grosskurth, & Whitworth, 2008).

Mothers who partially disclosed their status used self-distraction significantly more to cope, than other mothers. Self-distraction is a form of avoidant coping where the individual distracts him/herself through other activities to take one's mind off the stressor (Carver, Scheier, & Weintraub, 1989). For HIV infected mothers this may be a very positive way of coping to carry on with other activities and not to focus too much on their HIV status. Partial disclosure may fit into this coping strategy, as they disclose aspects of their health status, but do not focus on their HIV status.

Time since diagnosis did not influence level of disclosure to children. This was also found some time ago by Armistead et al. (2001). Similarly, time since disclosure to young children did not influence whether mothers fully or partially disclosed and was not related to depression, parental stress and coping in this research. The results did therefore not show the nuances of psychological experiences expected before and shortly after disclosure. It may be that anxieties after disclosure reduce quickly and do not reflect in a survey that studies longer term reactions.

Limitations of the study

The current study used existing data to study maternal HIV disclosure. In the original research only 11.6% of a large sample of mothers disclosed their HIV status to their young uninfected children at baseline. The small sample size thus limited the analysis and results of the study, especially the analysis of the mothers who fully (n=29) and partially (n=18) disclosed to their children. The reliability of the chi square results may be in question because of low frequencies in various categories. Disclosure to young children is generally low (Mkwanazi et al., 2012; Qiao, Li, & Stanton, 2013), except in research where disclosure is encouraged through an intervention.

Some variables that could have been valuable, such as the health status of the mother, social support and experience of stigma were not included in the original data. These variables could have played a vital role in mothers' disclosure and relationship with her child.

The study used cross-sectional data to determine differences between groups. It is thus not possible to determine causality from the data. Longitudinal data could contribute to understanding whether the findings determined disclosure (e.g. whether high depression symptoms resulted in maternal disclosure) or if the findings are a consequence of disclosure (e.g. mothers' experience high depression symptoms because of disclosure). In this study the results are interpreted using the latter perspective, as mothers have already disclosed their HIV status before the data collection.

Conclusion

Despite the limitations, the results of the current study provide meaningful insight into the challenges of disclosure faced by mothers living with HIV with young uninfected

children in a natural context and not as a result of an intervention. In this research a small number of mothers disclosed their HIV status to their young children. It seemed that maternal disclosure seeks to enhance support and closeness in the family and instrumental support in the form of household assistance. Mothers thus have different motivation to disclose to their children than to other family members and partners.

The findings indicated that timing and level of maternal disclosure did not influence their experience of depression, parenting stress and coping style on the long term. Maternal disclosure of HIV status to young children thus does not necessarily improve maternal mental health. The small group of mothers who partially disclosed, reported less dysfunction in their relationship with their young children. This raised questions about the age-appropriateness of different levels of disclosure to young children. The research shows that maternal HIV status disclosure is a complex phenomenon which should take into account individual differences and the context of the larger social system.

Previous research has shown that when maternal HIV status disclosure is coupled with social support there is an improvement in maternal mental health (Simoni et al., 2000; Delaney et al., 2009; Mkwanazi et al., 2012). Mothers facing with the dilemma of disclosing their status can thus benefit from mental health support services as integral part of HIV and AIDS care to improve their mental health and parenting skills. Interventions to assist mothers to disclose their HIV status to their children, similar to the Amagugu intervention (Rochat et al., 2013; 2015) and the Teaching, Raising, And Communicating with Kids (TRACK) program (Murphy et al., 2011), can help mothers to reduce their psychological distress, gain confidence to disclose to their children and improve communication between mothers and children.

References

- Abidin, R. R. (1990). *Parenting Stress Index (PSI)*. Charlottesville, VA: Paediatric Psychology Press.
- Ahn, J. V., Bailey, H., Malyuta, R., Volokha, A., & Thorne, C. (2016). Factors associated with non-disclosure of HIV status in a cohort of childbearing HIV-positive

women in Ukraine. *AIDS and Behavior*, 20(1), 174-183. doi: 10.1007/s10461-015-1089-8.

Andersen, L., Kagee, A., O'Cleirigh, C., Safren, S., & Joska, J. (2015). Understanding the experience and manifestation of depression in people living with HIV/AIDS in South Africa. *AIDS Care*, 27(1), 59-62. doi: 10.1080/09540121.2014.951306

Antelman, G., Fawzi, M. C. S., Kaaya, S., Mbwambo, J., Msamanga, G. I., Hunter, D. J., & Fawzi, W. W. (2001). Predictors of HIV-1 serostatus disclosure: A prospective study among HIV-infected pregnant women in Dar es Salaam, Tanzania. *Aids*, 15(14), 1865-1874. Retrieved from: http://journals.lww.com/aidsonline/Abstract/2001/09280/Predictors_of_HIV_1_serostatus_disclosure__a.17.aspx.

Armistead, L., Tannebaum, L., Forehand, R., Morse, E., & Morse, P. (2001). Disclosing HIV status: Are mothers telling their children? *Journal of Paediatric Psychology*, 26(1), 11-20. Retrieved from: <http://www.ncbi.nlm.nih.gov/pubmed/11145728>.

Batte, A., Katahoire, A. R., Chimoyi, A., Ajambo, S., Tibingana, B., & Banura, C. (2015). Disclosure of HIV test results by women to their partners following antenatal HIV testing: A population-based cross-sectional survey among slum dwellers in Kampala Uganda. *BMC Public Health*, 15, 1-8. doi: 10.1186/s12889-015-1420-3.

Boeving-Allen, A., Finestone, M., Eloff, I., Sipsma, H., Makin, J. D., Triplett, K., Ebersohn, L., Sikkema, K., Briggs-Gowan, M., Visser, M., Ferreira, R., & Forsyth, B. W. C. (2014). The role of parenting in affecting the behavior and adaptive functioning of young children of HIV-infected mothers in South Africa. *AIDS and Behavior*, 18, 605–616. doi: 10.1007/s10461-013-0544-7.

Bor, J., Herbst, A. J., Newell, M., & Bärnighausen, T. (2013). Increases in adult life expectancy in rural South Africa: Valuing the scale-up of HIV treatment. *Science*, 339 (6122), 961-965. doi:10.1126/science.1230413.

Carver, C. S. (1997). You want to measure coping but your protocol's too long: Consider the Brief COPE. *International Journal of Behavioral Medicine*, 4, 92-100. Retrieved from: <http://www.ncbi.nlm.nih.gov/pubmed/16250744>.

Carver, C. S., Scheier, M. F., & Weintraub, J. K. (1989). Assessing coping strategies: A theoretically based approach. *Journal of Personality and Social Psychology*, *56*(2), 267-283. Retrieved from: https://www.psy.miami.edu/media/college-of-arts-and-sciences/psychology/documents/faculty/p89_COPE.pdf.

Chida, Y., & Vedhara, K. (2009). Adverse psychosocial factors predict poorer prognosis in HIV disease: A meta-analytic review of prospective investigations. *Brain, Behavior, and Immunity*, *23*(4), 434-445. doi:10.1016/j.bbi.2009.01.013.

Cook, J. A., Burke-Miller, J. K., Grey, D. D., Cocohoba, J., Liu, C., Schwartz, R. M., & Cohen, M. H. (2014). Do HIV-positive women receive depression treatment that meets best practice guidelines? *AIDS and Behavior*, *18*(6), 1094-1102. doi: 10.1007/s10461-013-0679-6.

Cook, J. A., Cohen, M. H., Burke, J., Grey, D., Anastos, K., Kirstein, L., & Young, M. (2002). Effects of depressive symptoms and mental health quality of life on use of highly active antiretroviral therapy among HIV-seropositive women. *JAIDS Journal of Acquired Immune Deficiency Syndromes*, *30*(4), 401-409. doi: 10.1097/01.QAI.0000018280.16783.FE.

Crankshaw, T. L., Voce, A., King, R. L., Giddy, J., Sheon, N. M., & Butler, L. M. (2014). Double disclosure bind: Complexities of communicating an HIV diagnosis in the context of unintended pregnancy in Durban, South Africa. *AIDS and Behavior*, *18*(1), 53-59. doi: 10.1007/s10461-013-0521-1.

Creswell, J. W. (2013). *Research design: Qualitative, quantitative, and mixed methods approach* (4th ed.). Thousand Oaks, California: Sage publications.

Dass-Brailsford, P., Eckman, A. K., & Kwasnik, D. L. (2014). The complexity of women's lives: decision-making about maternal HIV disclosure. *Current Psychology*, *33*(4), 557-577. doi: 10.1007/s12144-014-9229-2.

Delaney, R. O., Serovich, J. M., & Lim, J. Y. (2009). Psychological differences between HIV-positive mothers who disclose to all, some, or none of their biological children. *Journal of Marital and Family Therapy*, *35*(2), 175-180.

Eloff, I., Finestone, M., Makin, J. D., Boeving-Allen, A., Visser, M., Ebersohn, L., Ferreira, R., Sikkema, K.J., Briggs-Gowan, M., & Forsyth, B. W. C. (2014). A

randomized clinical trial on an intervention to promote resilience in young children of HIV positive mothers in South Africa. *AIDS*, 28 (3), 347-357. doi:10.1097/QAD.0000000000000335.

Geiselhart, K., Gwebu, T. D., & Krüger, F. (2008). Children, adolescents and the HIV and AIDS pandemic: Changing inter-generational relationships and intra-family communication patterns in Botswana. *Children Youth and Environments*, 18(1), 99-125. Retrieved from: <http://www.jstor.org/stable/10.7721/chilyoutenvi.18.1.0099>.

Hawk, S. T. (2007). Disclosure of maternal HIV infection to seronegative children: A literature review. *Journal of Social and Personal Relationships*, 24(5), 657-673. doi: 10.1177/0265407507081453.

Human Sciences Research Council [HSRC] (2018). The fifth South African national HIV prevalence, incidence, behaviour and communication survey, 2017. Cape Town: HSRC press. Kalichman, S. C., Rompa, D., & Cage, M. (2000). Distinguishing between overlapping somatic symptoms of depression and HIV disease in people living with HIV-AIDS. *Journal of Nervous and Mental Disease*, 188 (10), 662-70. doi: 10.1097/00005053-200010000-00004.

Kotze, M., Visser, M. J., Makin, J. D., Sikkema, K. J., & Forsyth, B. (2013). Psychosocial factors associated with coping among women recently diagnosed HIV-positive during pregnancy. *AIDS Behaviour*, 17(2), 498–507. doi: 10.1007/s10461-012-0379-7.

Lachman, J. M., Cluver, L. D., Boyes, M. E., Kuo, C., & Casale, M. (2014). Positive parenting for positive parents: HIV/AIDS, poverty, caregiver depression, child behavior, and parenting in South Africa. *AIDS Care*, 26(3), 304-313. doi:10.1080/09540121.2013.825368.

Madiba, S., & Matlala, C. (2012). Disclosure of parental HIV positive status: What, why, when, and how parents tell their children in the era of HAART in South Africa. *World Journal of AIDS*, 2(3), 194-202. doi: 10.4236/wja.2012.23025.

Makin, J. D., Forsyth, B., Visser, M. J., Sikkema, K. J., Neufeld, S., & Jeffery, B. (2008). Factors affecting disclosure in South African HIV infected pregnant women. *AIDS Care*, 20(9), 1138-1145. doi:10.1089/apc.2007.0194.

Medley, A., Garcia-Moreno, C., McGill, S., & Maman, S. (2004). Rates, barriers and outcomes of HIV serostatus disclosure among women in developing countries:

Implications for prevention of mother-to-child transmission programmes. *Bulletin of the World Health Organization*, 82(4), 299-307. Retrieved from: <http://www.scielosp.org/pdf/bwho/v82n4/v82n4a13.pdf>.

Medley, A. M., Kennedy, C. E., Lunyolo, S., & Sweat, M. D. (2009). Disclosure outcomes, coping strategies, and life changes among women living with HIV in Uganda. *Qualitative Health Research*, 19(12), 1744-1754. doi: 10.1177/1049732309353417.

Mitchell, M., & Jolley, J. (2012). *Research design explained* (8th ed.). Unites States of America: Wadsworth Cengage Learning.

Mkwanazi, N. B., Rochat, T. J., Imrie, J., & Bland, R. M. (2012). Disclosure of maternal HIV status to children: Considerations for research and practice in sub-Saharan Africa. *Future Virology*, 7(12), 1159-1182. doi:10.2217/fvl.12.109.

Murphy, D. A. (2008). HIV-positive mothers' disclosure of their serostatus to their young children: a review. *Clinical Child Psychology and Psychiatry*, 13 (1), 105-122. Retrieved from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2384146/pdf/nihms-44685.pdf>.

Murphy, D. A., Armistead, L., Marelich, W. D., & Herbeck, D. M. (2015). Parenting deficits of mothers living with HIV/AIDS who have young children. *Vulnerable Children and Youth Studies*, 10(1), 41-54. doi: 10.1080/17450128.2014.931614.

Murphy, D. A., Armistead, L., Marelich, W. D., Payne, D. L., & Herbeck, D. M. (2011). Pilot trail of a disclosure intervention for HIV+ mothers: The TRACK program. *Journal of Consulting and Clinical Psychology*, 79(2), 203-214. doi: 10.1037/a0022896.

Murphy, D. A., Roberts, K.J., & Hoffman, D. (2003). Regrets and advice from mothers who have disclosed their HIV-serostatus to their young children. *Journal of Child and Family studies*, 12(3), 307-318.

Obermeyer, C. M., Baijal, P., & Pegurri, E. (2011). Facilitating HIV disclosure across diverse setting: A review. *American Journal of Public Health*, 101(6), 1011-1023. doi: 10.2105/AJPH.2010.300102.

Oguntibeju, O. O. (2012). Quality of life of people living with HIV and AIDS and antiretroviral therapy. *HIV/AIDS*, 4, 117-124. doi: 10.2147/hiv.s32321.

Palin, F.L., Armistead, L., Clayton, A., Ketchen, B, Ludner, G., Kokot-Louw, P., Pauw, A. (2009). Disclosure of maternal HIV-infection in South Africa: Description and relationship to child functioning. *AIDS and Behavior*, 13(6), 1241-1252.

Pallant, J. (2010). *SPSS survival manual*. Berkshire, England: McGrawHill.

Qiao, S., Li, X., & Stanton, B. (2013). Disclosure of parental HIV infection to children: A systematic review of global literature. *AIDS and Behavior*, 17(1), 369-389. doi: 10.1007/s10461-011-0069-x.

Radloff, L.S. (1977). The CES-D Scale: A self-report depression scale for research in the general population. *Applied Psychological Measurement*, 1, 385-401. doi: 10.1177/014662167700100306.

Rochat, T. J., Arteche, A. X., Stein, A., Mitchell, J., & Bland, R. M. (2015). Maternal and child psychological outcomes of HIV disclosure to young children in rural South Africa: the Amagugu intervention. *AIDS*, 29(1), 67-79. doi: 10.1097/QAD.0000000000000668.

Rochat, T. J., Arteche, A. X., Stein, A., Mkwazazi, N., & Bland, R. M. (2014). Maternal HIV disclosure to young HIV-uninfected children: an evaluation of a family-centered intervention in South Africa. *AIDS*, 28 (3), 331-341. doi: 10.1097/QAD.0000000000000333.

Rochat, T. J., Mkwazazi, N., & Bland, R. (2013). Maternal HIV disclosure to HIV-uninfected children in rural South Africa: A pilot study of a family-based intervention. *BMC Public Health*, 13(1), 147- 163. doi: 10.1186/1471-2458-13-147.

Rwemisisi, J., Wolff, B., Coutinho, A., Grosskurth, H., Whitworth, J. (2008). '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*, 23(1), 36–42. doi: 10.1093/heapol/czm040.

Schrimshaw, E. W., & Siegel, K. (2002). HIV-infected mothers' disclosure to their uninfected children: Rates, reasons, and reactions. *Journal of Social and Personal Relationships*, 19 (1), 19-43. doi: 10.1177/0265407502191002.

Sherr, L., Clucas, C., Harding, R., Sibley, E., & Catalan, J. (2011). HIV and depression: A systematic review of interventions. *Psychology, Health & Medicine*, 16 (5), 493-527. Retrieved from: <http://dx.doi.org/10.1080/13548506.2011.579990>.

Shisana, O., Rehle, T., Simbayi, L. C., Zuma, K., & Jooste, S. (2009). *South African national HIV prevalence incidence behaviour and communication survey 2008: A turning tide among teenagers?* Cape Town, South Africa: HSRC Press.

Simbayi, L. C., Kalichman, S. C., Strebel, A., Cloete, A., Henda, N., & Mqeketo, A. (2007). Disclosure of HIV status to sex partners and sexual risk behaviours among HIV-positive men and women, Cape Town, South Africa. *Sexually Transmitted Infections*, 83(1), 29-34. doi:10.1136/sti.2006.019893.

Simoni, J. M., Davis, M. L., Drossman, J. A., & Weinberg, B. A. (2000). Mothers with HIV/AIDS and their children: Disclosure and guardianship issues. *Women & Health*, 31(1), 39-54. doi: 10.1300/J013v31n01_03.

Sipsma, H., Eloff, I., Makin, J., Finestone, M., Ebersohn, L., Visser, M. J., Sikkema, K.J., Boeving Allen, C.A., Ferreira, R., & Forsyth, B. (2013). Behavior and psychological functioning of young children of HIV positive mothers in South Africa. *AIDS Care*, 25(6), 721-725. doi:10.1080/09540121.2013.779627.

Smith, L., Feaster, D. J., Prado, G., Kamin, M., Blaney, N., & Szapocznik, J. (2001). The psychosocial functioning of HIV+ and HIV- African American recent mothers. *AIDS and Behavior*, 5(3), 219-231. doi: 10.1023/A:1011336525599.

Sousa, V. D., Driessnack, M., & Mendes, I. A. C. (2007). An overview of research designs relevant to nursing: Part 1: Quantitative research designs. *Revista latino-Americana de Enfermagem*, 15(3), 502-507. Retrieved from <http://dx.doi.org.innopac.up.ac.za/10.1590/S0104-11692007000300022>.

Taylor, B. J., Kermode, S., & Roberts, K. L. (2006). *Research in nursing and health care: Evidence for practice* (3rd ed.). Melbourne: Thomson Learning Nelson (Cengage).

Tenzek, K. E., Herrman, A. R., May, A. R., Feinerd, B., & Allenb, M. (2013). Examining the impact of parental disclosure of HIV on children: A meta-analysis. *Western Journal of Communication*, 77, 323–339 doi:10.1080/10570314.2012.719092.

UNAIDS (2016). Children and HIV fact sheet.

https://www.unaids.org/sites/default/files/media_asset/FactSheet_Children_en.pdf

Wiener, L., Mellins, C. A., Marhefka, S., & Battles, H. B. (2007). Disclosure of HIV diagnosis to children: History, current research and future directions. *Journal of Developmental and Behavioural Paediatrics*, 28(2), 155-166. doi: 10.1097/01.DBP.0000267570.87564.cd.

World Health Organization. (2011). Guideline on HIV disclosure counselling for children up to 12 years of age. Retrieved from: http://whqlibdoc.who.int/publications/2011/9789241502863_eng.pdf.