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Health care workers' perspectives about disclosure to HIV-infected children; Cross-sectional survey of health facilities in Gauteng and Mpumalanga provinces, South Africa

Sphiwe Madiba, Mathildah Mokgatle

The perspectives and practices of health care workers (HCWs) regarding disclosure to HIV-infected children have not been adequately investigated ten years after the roll-out of pediatrics antiretroviral therapy (ART). The aim of the study was to examine the opinions of HCWs about disclosure to HIV-infected children and determine their role in disclosure to children accessing ART in centers in South Africa. This was a cross-sectional survey using a semi-structured questionnaire among HCWs in ART centers at three hospitals and 48 primary health facilities in two provinces in South Africa. Of the 206 HCWs, 140 (68.2%) were nurses, 44 (21.5%) were lay counsellors, and 4 (2%) were doctors. The majority (n=183, 89.3%) felt that disclosure benefits children and they should be told about their HIV status. Over half (n=93, 51.4%) recommended 11-18 years as the appropriate age to disclose. Half (n= 99, 48.5%) said that caregivers should take the lead to disclose, 87 (42.7%) said that disclosure is a shared responsibility of caregivers and HCWs, and 18 (8.8%) said HCWs should lead disclosure. HCWs perceived their role as that of preparing the caregiver for disclosure and the child to understand the disease. However, the lack of guidelines and training on disclosure counselling for children affects their ability to fully participate in disclosure to children. There is a need to adopt the World Health Organizations' disclosure guidelines for children and adapt them to the local cultural and community contexts and train HCWs to guide, support, and assist caregivers in their disclosure to HIV-infected children.

1 **Health care workers' perspectives about disclosure to HIV-infected children; Cross-**
2 **sectional survey of public health facilities in Gauteng and Mpumalanga provinces, South**
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21 Introduction

22 The advancements made in the provision of antiretroviral treatment (ART) and the increased
23 survival of HIV-infected children have made disclosure a major challenge for caregivers ([Wiener
24 et al. 2007](#)) and health care providers of HIV-infected children ([WHO 2011](#)). As a result, there are
25 significant numbers of children and adolescents who are receiving treatment without being
26 informed about their HIV status ([Madiba 2012b](#); [Spiegel 2011](#)). In many developing countries,
27 health care workers (HCWs) lack the support of policies and guidelines on when and how
28 children should be informed about their HIV status or their caregivers' HIV status ([WHO 2011](#)).
29 While guidelines on disclosure of HIV status among adults have received considerable attention
30 ([Wiener et al. 2007](#)), until the recent guidelines developed by the World Health Organization
31 ([WHO 2011](#)), there were no such guidelines for assisting caregivers and HCWs to make
32 decisions about disclosure to infected children in resource-limited settings ([Moodley et al. 2006](#);
33 [Myer et al. 2006](#); [Oberdorfer et al. 2006](#); [Rujumba et al. 2010](#)).

34 On the other hand, many caregivers are reluctant to inform their HIV-infected children about their
35 status ([Biadgilign et al. 2009](#); [Butler et al. 2009](#); [Funck-Brentano et al. 1997](#); [Heeren et al. 2012](#);
36 [Mahloko & Madiba 2012](#)). One of the major barriers to disclosure is that caregivers, particularly
37 from resource-limited settings, lack knowledge, skills, and guidance on how to approach
38 disclosure to HIV-infected children ([Madiba & Mokwena 2012](#); [Mahloko & Madiba 2012](#);
39 [Oberdorfer et al. 2006](#)). It is argued that for disclosure to occur, caregivers have to first trust in
40 their own readiness and ability to disclose ([Dematteo et al. 2002](#); [Madiba & Mokwena 2012](#)).
41 Thus, HCWs need considerable support during the process of disclosure to children, often
42 expressed by some of the caregivers from sub-Saharan Africa ([Brown et al. 2011](#); [Heeren et al.
43 2012](#); [Madiba & Mokwena 2012](#); [Moodley et al. 2006](#); [Oberdorfer et al. 2006](#); [Vaz et al. 2010](#)).
44 In order to support caregivers to disclose, the World Health Organization recommends that health
45 services need to provide strategies to facilitate full disclosure by the age of 12 years ([WHO
46 2011](#)). This has been reiterated by HCWs that where caregivers lacked knowledge and skills to
47 disclose, health services should adopt a disclosure program that would allow them to support
48 caregivers to disclose to HIV infected children ([Kallem et al. 2010](#)). Furthermore, it has been
49 shown that caregivers who discuss disclosure with HCWs are more likely to disclose HIV status
50 to their children ([Merzel et al. 2008](#); [Mumburi et al. 2014](#)).

51 However, studies conducted on disclosure to HIV-infected children have focused on the
52 experiences of caregivers, but the perspectives and practices of HCWs regarding disclosure have
53 not been adequately investigated ([Fair & Walker 2011](#); [Rujumba et al. 2010](#)). Recent data from a
54 situational analysis for pediatric HIV/AIDS care in Ethiopia ([Rujumba et al. 2010](#)) show that
55 HCWs are still constrained by inadequate knowledge about pediatric HIV care as well as lack of
56 knowledge of pediatric counselling. Fair and Walker argue that to fully understand disclosure to
57 HIV-infected children, it is essential to understand the perspectives of all HCWs involved in the
58 disclosure process ([Fair & Walker 2010](#)). The purpose of the study was to assess how disclosure
59 to HIV-infected children is being implemented in public health facilities. We examined the
60 opinions of health care workers about disclosure to HIV-infected children and determined their
61 role in disclosure to children accessing ART in primary health facilities in South Africa. There are
62 limited studies on the perspectives and practices of HCWs on disclosure to HIV-infected children
63 almost ten years after the roll-out of pediatric ART in South Africa and other sub-Saharan
64 countries. Interventions to facilitate disclosure to HIV-infected children should incorporate the
65 experiences and practices of caregivers, HCWs, and infected children.

66 **Methods and materials**

67 **Study design**

68 We used a mixed-method approach to conduct the study among HCWs who provide HIV
69 treatment and care services for adults and children in the ART centers of selected hospitals and
70 primary health facilities. Since 2011, ART has been accessible in primary health care facilities in
71 South Africa through the Nurse Initiation and Maintenance of Antiretroviral Therapy (NIMART)
72 initiative of the Ministry of Health ([Cameron et al. 2012](#)). The HIV services provided through
73 NIMART included adult and pediatric counselling and testing and initiation of ART. The study
74 covered two districts in two provinces in South Africa: Tshwane district in Gauteng province and
75 Nkangala District in Mpumalanga province. Data were collected in ART centers based in an
76 academic hospital and two community hospitals, as well as 47 primary health care facilities. Of
77 these, 17 were primary health centers (PHC) and 20 were eight-hour clinics. The health facilities
78 in Tshwane district were located in urban and peri-urban communities, while those in Nkangala
79 district were located in three sub-districts, one urban and two rural. The study participants
80 included medical doctors, nurses (professional, enrolled and assistant nurses), social workers, lay
81 counsellors, pharmacists, and pharmacy assistants. The sample consisted of all HCWs in each
82 primary health facility and ART center at the time of data collection because we wanted to gather

83 the opinions of all HCWs who come in contact with HIV-infected children and their caregivers.
84 Primary health facilities are generally understaffed in South Africa, and most of the eight-hour
85 clinics, particularly in the rural districts of Mpumalanga province, have on average two
86 professional nurses per shift. There were also no resident doctors, social workers, or
87 psychologists in the Mpumalanga health facilities. There are, however, doctors and a psychologist
88 available for consultation on cases that may be HIV-related or any other condition that needs the
89 attention of other members of the multidisciplinary team. To limit selection bias, we collected
90 data from HCWs across all shifts, but excluded all HCWs who were on leave. Data collection at
91 the hospitals included all HCWs working in ART clinics and excluded all other HCWs.

92 **Data collection**

93 We collected data between January and September, 2013, using semi-structured individual
94 interviews and focus group discussions. This paper reports on the quantitative data collected from
95 individual HCWs. Fieldwork was led by the second author (MM), who oversaw the training of
96 seven field workers and the implementation of study activities (data collection, cleaning, and
97 coding). The tool consisted of structured close-ended questions and a set of open-ended
98 questions. Close-ended questions captured information about the participant's demographic
99 characteristics, whether the child should be told about their HIV status, the appropriate age of
100 disclosure, whether they received training in disclosure counselling, and about the availability of
101 disclosure guidelines in their facilities. The open-ended questions captured information relating
102 to their opinions about disclosure and their involvement in disclosure counselling for HIV-
103 infected children. We first asked HCWs why it was important to disclose to infected children,
104 followed by a series of questions including the following: who should disclose? They were also
105 asked to describe their role in disclosure and how they would like to be supported to disclose.
106 The questionnaires were in English and were distributed to the health facilities at the beginning of
107 a shift and collected at the end of a shift.

108 **Ethics**

109 Ethical clearance was obtained from the Medunsa Research Ethics Committee
110 (MREC/H/168/2012: IR) of the University of Limpopo. In addition, permission to conduct the
111 study was obtained from relevant authorities from the two provinces as well as the management

112 of the hospitals and primary health facilities. Informed consent was obtained from health care
113 workers.

114 **Results**

115 **Description of study participants**

116 Of the 206 HCWs who participated in the survey, the majority (n=185, 90.2%) were female and
117 the mean age was 41.3 years (range 20-64 years). Professional nurses constituted half (n=103,
118 50.2%) of the HCWs, 44 (21.5%) were lay counsellors, 37 (18%) were enrolled and assistant
119 nurses, 16 (7.8%) were pharmacists and pharmacist assistants, and 4 (2%) were doctors. The
120 mean time of employment was 6.5 years, and three quarters (n=117, 71.3%) reported that they
121 treat adults and children infected with HIV daily (Table 1).

122 **The reasons for telling children that they have HIV**

123 The majority (n=183, 89.3%) of HCWs said HIV-infected children should be told about their HIV
124 status. HCWs were also asked an open-ended question about why it was important to tell children
125 about their HIV status; their responses are presented in Table 2. The most common reasons cited
126 were that caregivers disclose so that children adhere to ART (n=51, 21.7%), know their status
127 (n=55, 23.5%), take responsibility for their treatment and care (n=36, 15.3%), understand the
128 disease (n=33, 14%), understand the reasons for taking medication (n=30, 12.8%), protect others
129 from HIV infection (n=18, 7.7%), and live a positive and healthy life (n=12, 5.1%).

130 **The right age and time for telling children that they have HIV**

131 Over a third (n=64, 35.4%) of HCWs said the child should be told between 11-14 years, 62
132 (34.2%) said between 8-10 years, 29 (16%) said between 15-18 years, and 26 (14.4%) said
133 between 5-7years. The results show that over half (n=93, 51.4%) of the HCWs recommended an
134 older age of above 10 years as the right age to tell children about their HIV status. HCWs were
135 also asked about the right time to tell the child about their disease, and 79 (40.9%) said the child
136 should be told when he/she could understand the disease and its implications, 51 (26.4%) said
137 puberty was the right time to tell the child, 32 (16.6%) said the child should be mature enough at
138 disclosure, and 29 (15%) said the child should be told at school age (Table 1).

139 **The right persons to tell children that they have HIV**

140 Almost half (n=99, 48.5%) of the HCWs said that the caregivers are the relevant and appropriate
141 people to disclose to children; 87 (42.7%) said that disclosure to HIV-infected children is a shared
142 responsibility of the caregivers and the HCWs. However, the role of the HCWs in this regard was
143 to support the caregiver's disclosure, but not to lead or initiate disclosure. A few (n=18, 8.8%)
144 said that HCWs should lead and initiate disclosure; and nurses, doctors, psychologists, social
145 workers, and lay counsellors were the categories of HCWs mentioned (Table 1). In some of the
146 primary health facilities in Gauteng province, there were resident social workers, while none
147 were available in the health facilities in Mpumalanga province. With regards to why caregivers
148 should take the lead in disclosure, 96 (47%) said the caregiver had a close relationship with the
149 child to monitor the reaction to disclosure, 26 (12.7%) said that the child trusts the caregiver, 8
150 (3.9%) said that the caregiver knows the right age to disclose, 7 (3.4%) said that the caregiver
151 will support the child to adhere to the prescribed treatment plan, 6 (2.9%) said that the caregiver
152 will support the child to cope with disclosure, and 8 (3.9%) said the child will be comforted if the
153 caregiver discloses (Table 3).

154 **The reasons why caregivers delay telling children that they have HIV**

155 The most cited reasons why caregivers delayed disclosure were fear of hurting the child (n=33,
156 18.6%), fear that the child would be angry, hate, blame, judge, and reject them (n=31, 17.5%),
157 that the child is too young and cannot understand the HIV diagnosis (n=28, 15.8%), fear of the
158 stigma related to HIV/AIDS (n=25, 14.1%), that parents blame themselves and feel guilty about
159 infecting the child (n=20, 11.3%), caregivers are not ready to disclose and therefore it is not the
160 right time to disclose (n=20, 11.6%), and (n=19, 10.7%) caregivers' lack of experience in
161 disclosure (Table 4).

162 **The role of health workers in disclosing to HIV-infected children**

163 The healthcare workers were asked to identify their roles in disclosing to HIV-infected children
164 who access ART in their health facilities. The most common roles mentioned included supporting
165 caregivers to disclose and children's acceptance of their status (n=65, 38.2%), providing
166 continuous health education to children (n=31, 18.2%), providing ongoing counselling to
167 caregivers and children (n=31, 18.2%), educating the child about the disease (n=30, 17.6%),
168 ensuring that the child adheres to treatment (n=18, 10.6%), and providing information to
169 caregivers and children (n=17, 10%). Only 4 (2.4%) of the HCWs said that their role was to assist
170 caregivers in disclosing to HIV-infected children (Table 5).

171 **The support needed by HCWs to facilitate disclosure to HIV-infected children**

172 Over three quarters (n=123, 76.9%) of the HCWs reported that there were no guidelines on
173 disclosure counselling for children in their health facilities, and 133 (82.1%) did not receive any
174 formal training on disclosure counselling for children. HCWs also responded to a question that
175 asked them how they would like to be supported to participate in the disclosure process for HIV-
176 infected children. The majority (n=84, 40.8%) reported that they need to be trained on disclosure
177 counselling for children, 49 (23.8%) need to attend workshops on pediatric HIV management, 35
178 (17%) need formal guidelines on disclosure counselling for children, and 13 (6.3%) need ongoing
179 counselling and debriefing to deal with HIV-infected children (Table 6).

180 **Discussion**

181 This study examined the perspectives of HCWs about disclosure to HIV-infected children ten
182 years after the initiation of ART in South Africa. The majority (89.3%) felt that HIV-infected
183 children should be told about their HIV status because they have a right to know what they are
184 being treated for. However, they believed that disclosure to children depends on the age and
185 maturity of the child. Research shows that caregivers have similar views about disclosure to HIV-
186 infected children ([Kiwanuka et al. 2014](#); [Motshome & Madiba 2014](#); [Vaz et al. 2010](#)). HCWs also
187 stated that children benefit from disclosure because it gives them an understanding of their
188 condition so that they can participate in their treatment plan and program. Furthermore, they
189 believed that when children know their status they become aware of the importance of taking
190 medication and are able to adhere to treatment and seek medical attention when necessary. Telling
191 children that they are HIV-positive is also crucial for the acceptance of their HIV status in order
192 to live a healthy life. HCWs believed that the process of disclosure should provide children with
193 ongoing support and counselling and adequate information to answer questions to allay fears of
194 dying. Children can learn to protect others when they know their status, while adolescents will
195 know how to protect themselves from secondary infections and to protect others from HIV
196 infections. HCWs in Kenya cited similar benefits of disclosure ([Beima-Sofie et al. 2014](#)). In
197 addition, the benefits of disclosure stated by HCWs are consistent with those cited by caregivers
198 of HIV-infected children in developing countries ([Bhattacharya et al. 2011](#); [Bikaako-Kajura et al.](#)
199 [2006](#); [Kiwanuka et al. 2014](#); [Madiba 2012a](#); [Motshome & Madiba 2014](#); [Vaz et al. 2010](#);
200 [Vreeman et al. 2014](#)).

201

202 HCWs gave different ages when the child should be told about the disease, but over half
203 suggested an older age of above 10 years as the right age to tell children about their status. HCWs
204 who suggested an older age of disclosure (above 10 years) believed that children are mature
205 enough around this age and will understand the disease and the importance of taking ART. This
206 was also the age when children are likely to be engaging in sexual activities. HCWs who
207 suggested a younger age for disclosure (below 10 years), believed that this is the time when
208 children start asking questions about their disease as well as being curious about taking
209 medication continuously. This is also the age when children start attending school and have a
210 general understanding about HIV infection and transmission order to protect others from HIV
211 infection. HCWs in a previous study conducted in South Africa also mentioned that children
212 should be informed about their HIV status when they start formal schooling ([Myer et al. 2006](#)).
213 Studies conducted among caregivers documented similar ways of thinking when caregivers
214 selected the appropriate age of disclosure or age for future disclosure ([Abebe & Teferra 2012](#);
215 [Bhattacharya et al. 2011](#); [Kallem et al. 2010](#); [Madiba 2012b](#); [Mahloko & Madiba 2012](#)).

216 The data suggest that the recommended age of disclosure to children is subjective and is likely to
217 be influenced by community and social contexts of disclosure. The current findings showed a
218 relatively older age (above 10 years, range 11-18 years) of disclosure as compared to an age of 6
219 years that was suggested by HCWs in a much earlier study conducted in South Africa (Myers,
220 2006). However, a recent study in South Africa recommended 12 years as the age when children
221 should be informed ([Heeren et al. 2012](#)), while caregivers in studies conducted in developing
222 countries recommended the age of 10-13 years ([Kallem et al. 2010](#); [Sahay 2013](#)). The current
223 data support the viewpoint held by HCWs that disclosure to children is difficult for both
224 caregivers and HCWs. Disclosure to children is also evidently more complex than disclosing to
225 adults ([Myer et al. 2006](#); [Rujumba et al. 2010](#); [Salter-Goldie et al. 2007](#)). The fact that caregivers
226 continue to delay disclosure to HIV-infected children despite children being on ART influences
227 the perceptions of HCWs about disclosure to infected children. On the other hand, HCWs are
228 members of communities where HIV-related stigma is still a barrier to disclosure of HIV status to
229 infected adults and children, hence their recommendations of a much older age of disclosure.

230 Almost half, or 99 (48.5%), of the HCWs thought that caregivers are the relevant and appropriate
231 individuals to disclose to; 87 (42.7%) thought that disclosure to children is a joint responsibility
232 of the caregivers and the HCWs. A previous study conducted in South Africa reported similar

233 findings ([Myer et al. 2006](#)). The view that disclosure was the responsibility of the caregivers was
234 reported by HCWs ([Kallem et al. 2010](#); [Kidia et al. 2014](#); [Mumburi et al. 2014](#)), and caregivers
235 of HIV-infected children in other studies ([Heeren et al. 2012](#); [Kiwanuka et al. 2014](#); [Madiba &
236 Mokwena 2012](#); [Motshome & Madiba 2014](#); [Mumburi et al. 2014](#)). A disclosure intervention
237 developed by Salter-Goldie and colleagues also recommends that caregivers take the lead in
238 disclosure, and should plan where, when, with whom and what will be said during disclosure
239 ([Salter-Goldie et al. 2007](#)). In the current study, HCWs argue that because disclosure depends on
240 the age and maturity of the child, the caregiver knows when the child is ready for disclosure.
241 They also stated that hearing about the disease from the caregiver will reassure the child and allay
242 fears because children trust their parents more than HCWs. Furthermore, the caregiver is always
243 with the child and understands the child better and will be able to provide emotional support. Our
244 data supports current findings from a study conducted in Kenya ([Beima-Sofie et al. 2014](#)).

245 Although the HCWs acknowledged that caregivers might have limited information about HIV,
246 they have the ability to explain the source of HIV infection in a way that is made understandable
247 for children and can answer the questions that the child might ask. Furthermore, caregivers can
248 make the children understand their treatment. HCWs believed that when caregivers disclose, they
249 take the responsibility to support the child to adhere to the prescribed medication. With regards to
250 the HCWs taking the initiative to disclose, they believed that only when the caregiver has
251 difficulty to disclose should the HCW assist. They argue that the disclosure process should
252 facilitate a child's understanding of the disease and an acceptance of living with the disease.
253 Thus, HCWs perceived their role in the disclosure process as that of providing additional
254 information and explanations about HIV as well as ongoing support and counselling to the
255 caregiver and the child. Similar findings on the role of HCWs were reported in a recent study
256 conducted among HCWs in Kenya ([Beima-Sofie et al. 2014](#)).

257 HCWs who were of the opinion that disclosure is a shared responsibility believed that caregivers
258 need the assistance of HCWs to tell children about their HIV status because it is a very difficult
259 task for the caregiver. This is in line with the expressed needs of the caregivers to be supported in
260 the disclosure of the HIV status to infected children ([Heeren et al. 2012](#); [Kiwanuka et al. 2014](#);
261 [Madiba & Mokwena 2012](#)). Furthermore, HCWs maintain that children need re-assurance to
262 accept their status and that HCWs can explain HIV better than the caregivers. They also believed
263 that HCWs will be able to prepare the children psychologically before telling them about their

264 HIV status. Moreover, HCWs were in a better position to deal with negative reactions to
265 disclosure because they are qualified and have adequate knowledge and counselling skills. The
266 majority of HCWs, particularly nurses, see their role in this regard as that of preparing the
267 caregiver for disclosure and to make the disease understandable for the child and ensure they
268 adhere to ART. These roles are similar to what has been reported in a disclosure intervention that
269 involved a health care team's approach to disclose to infected children ([Salter-Goldie et al. 2007](#)).
270 Consistent with previous studies, only a few (8.8%) HCWs said that disclosure should be led and
271 initiated by them ([Heeren et al. 2012](#); [Myer et al. 2006](#)), and nurses, doctors, psychologists, social
272 workers, and lay counsellors were the categories of HCWs that were mentioned. This view that
273 doctors and nurses should initiate disclosure is also held by a small proportion of caregivers of
274 HIV-infected children ([Biadgilign et al. 2009](#); [Kallem et al. 2010](#); [Madiba 2012b](#)).

275 The involvement of HCWs in disclosure to HIV-infected children has been steadily increasing
276 according to data from sub-Saharan countries ([Heeren et al. 2012](#); [Madiba 2012b](#); [Mahloko &
277 Madiba 2012](#); [Rujumba et al. 2010](#); [Vaz et al. 2010](#)), despite the lack of training on disclosure
278 counselling of children ([Beima-Sofie et al. 2014](#)). One of the major concerns of HCWs in the
279 current study was the lack of formal guidelines on child counselling to guide them on when and
280 how to disclose to children. Lack of guidelines on child disclosure counselling was also
281 mentioned by HCWs in previous studies ([Myer et al. 2006](#); [Rujumba et al. 2010](#)). However, the
282 recently published World Health Organization disclosure guidelines for children have not yet
283 been adopted and utilized by HCWs in most health facilities in South Africa. Moreover, HCWs
284 caring for HIV-infected children in many sub-Saharan countries are hardly ever trained in
285 pediatric HIV and in disclosure counselling of children, further constraining this critical
286 information delivery ([Rujumba et al. 2010](#)). In the current study, the majority of HCWs had not
287 received any formal training on disclosure counselling of children and lacked skills to assist
288 caregivers to disclose. HCWs reported that attending workshops and receiving training will give
289 them skills and increase their confidence in assisting caregivers to disclose but also support HIV-
290 infected children to understand the disease. Training in pediatric HIV for HCWs was identified as
291 crucial in providing them with skills to assist caregivers to facilitate disclosure to HIV-infected
292 children ([Beima-Sofie et al. 2014](#); [Kallem et al. 2010](#); [Rujumba et al. 2010](#); [Wiener et al. 2007](#)).

293 While the lack of training and formal guidelines on child counselling are major constraints in
294 disclosing to children, caregivers' fears and concerns also play a crucial role in delaying

295 disclosure. Consistent with findings from a previous study ([Rujumba et al. 2010](#)), HCWs reported
296 that caregivers delay disclosure to HIV-infected children because they believe that when children
297 learn about their HIV status they will be hurt. Fears of unforeseen consequences of disclosure to
298 the child are similar to what has been reported in studies conducted among caregivers of HIV-
299 infected children ([Abebe & Teferra 2012](#); [Heeren et al. 2012](#); [Kallem et al. 2010](#); [Kiwanuka et al.](#)
300 [2014](#); [Madiba & Mokwena 2012](#)). While the most cited reason for delayed disclosure was that
301 disclosure will hurt the child, in this study and others caregivers delayed disclosure because they
302 believed that the child was too young to understand HIV/AIDS ([Kidia et al. 2014](#)). Madiba and
303 Mokwena found that when caregivers said the child was too young, they also meant that the child
304 was unable to understand the ramifications of so serious a diagnosis. Age was often not used in
305 determining the child's ability to understand because the age when caregivers say the child is too
306 young is subjective ([Madiba & Mokwena 2012](#)). This point of view was apparent in the current
307 study where HCWs recommended an older age of above 10 years as the right age to tell children
308 about their HIV status. They argued that children are mature enough around this age and, thus,
309 will understand the disease and the importance of taking ART, but the recommended age ranged
310 from 10-18 years. The data suggest that age is not necessarily the determining factor for
311 disclosure and should not be used to guide parents and caregivers in the decision to disclose HIV
312 status to children.

313 Other reasons cited for why caregivers delay disclosure to children were similar to findings from
314 studies conducted with caregivers. These included fear of stigmatization and discrimination, lack
315 of disclosure skills, self-blame and guilt for infecting the child with HIV, and fear of being
316 rejected by the child ([Beima-Sofie et al. 2014](#); [Biadgilign et al. 2009](#); [Kallem et al. 2010](#); [Madiba](#)
317 [& Mokwena 2012](#); [Mahloko & Madiba 2012](#); [Motshome & Madiba 2014](#); [Vaz et al. 2011](#);
318 [Vreeman et al. 2014](#)). HCWs also stated that often disclosure is delayed because the caregiver is
319 not ready to disclose. Madiba and Mokwena argue that caregiver readiness is the determining
320 factor in disclosure. Thus, when a caregiver is not ready to disclose, they will simply avoid
321 informing the child of their HIV status ([Madiba & Mokwena 2012](#)). The current study found that
322 HCWs believed that their role in disclosure was to prepare the caregiver for disclosure by
323 providing continuous health education and ongoing counselling. However, the majority of
324 professionals lacked guidelines and skills on how to approach disclosure. It is expected that when
325 HCWs are well-trained and participate fully in disclosure, children can be informed of their HIV
326 status in an appropriate, sensitive manner.

327 **Limitations**

328 Because of the limited involvement of HCWs in disclosure, the data presented here represent
329 their opinions rather than their practice of disclosure. The majority made recommendations on
330 what HCWs who are involved in disclosure should do. Nevertheless, these study findings have
331 revealed the current disclosure practices among HCWs in primary health facilities. In addition,
332 these findings form a baseline on disclosure from the perspectives of HCWs, which will inform
333 the development of interventions to facilitate disclosure.

334 **Conclusion**

335 HCWs believed that children should be told about their status and argue that the disclosure
336 process should facilitate a child's understanding and acceptance of living with the disease.
337 However, the recommended age of disclosure was set much higher than previously documented in
338 South Africa. To ensure that the outcome of the disclosure process is positive, HCWs believed
339 that the caregiver should take the lead in disclosure while being supported by the HCWs. HCWs
340 perceived their role as that of preparing the caregiver for disclosure and to make understandable
341 the disease for the child by providing ongoing support and counselling. But, they pointed out that
342 lack of guidelines and training on disclosure counselling of children affects their ability to
343 facilitate disclosure. As a result, HCWs delayed disclosure unintentionally by recommending that
344 children should be told about their status between 10-18 years old. Their attitudes towards the
345 right time to disclose are also influenced by the cultural and social contexts of disclosure within
346 their communities.

347 To facilitate disclosure, adoption of the World Health Organization disclosure guidelines for
348 children and their adaptation to the local cultural and community contexts is crucial. These
349 guidelines should form the basis for training of HCWs to equip them with appropriate skills to
350 support caregivers in disclosing HIV status to children and to ensure that they are counselled
351 suitably to accept their condition.

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Table 1 (on next page)

Characteristics of health workers and

Table 1: Characteristics of healthcare workers and opinions about disclosure to HIV-infected children in primary health facilities and ART

	Frequency	Percentage
Gender		
Female	185	90.2
Male	20	9.8
Age category		
20-30 years	22	10.8
31-40 years	64	31.4
41-50 years	83	40.7
51-60 years	33	16.2
61-70 years	2	1.0
Mean age 41.3 years		
Professional qualifications		
Professional Nurse	103	50.2
Lay Counsellor	44	21.5
Assistant Nurse	23	11.2
Enrolled Nurse	14	6.8
Pharmacist	11	5.4
Pharmacist Assistant	5	2.4
Medical Doctor	4	2.0
Social worker	1	0.5
Disclosure guidelines available		
No	123	76.9
Yes	37	23.1
Received training on disclosure		
No	133	82.1
Yes	29	17.9
Children should be told about their HIV status		
No	22	10.7
Yes	183	89.3
Age of disclosure		
5-7 years	26	14.4
8-10 years	62	34.2
11-14 years	64	35.4
15-18 years	29	16.0
Mean age 10.9 years		
Right time for disclosure		
When the child enters teenage	2	1.0
At puberty	51	26.4
When the child can understand	79	40.9
When the child is mature enough	32	16.6
At school age	29	15.0
Appropriate person to disclose		
Parent/caregiver	99	48.5

Parent/caregiver and health provider	87	42.7
Health care provider	18	8.8

Table 2 (on next page)

Health workers' perceptions on disclosure

Table 2: Healthcare workers' perceptions about telling children that they have HIV

	Frequency	Percent age
So that children should adhere to medication	51	21.7
To allow children to know their HIV status	49	20.9
For children to take responsibility for their own treatment and care	36	15.3
For children to understand the disease (HIV)	33	14.0
To know the reasons why they are taking medication	30	12.8
To protect others from being infected with HIV	18	7.7
To live a healthy life	12	5.1
Children have a right to know their disease	6	2.6

Table 3 (on next page)

Perceptions on who leads disclosure

Table 3: The perceptions of healthcare workers on why the caregiver or healthcare workers should take the lead in disclosure

Caregivers should lead disclosure	Frequency	Percentage
The caregiver/parent is close to the child and is always there to monitor the child's reaction to disclosure	96	47.1
The child trusts the caregiver/parent and will accept the reality of their condition if the caregiver discloses	26	12.7
The caregiver/parent knows the right age to tell and knows what and how to tell the child about the disease	8	3.9
The caregiver/parent is always there to help the child to understand the importance of taking medication and support the child's adherence to prescribed treatment plan	7	3.4
The caregiver/parent is always there to give the child emotional support to cope with disclosure	6	2.9
The caregiver/parent is always there and the child will be comfortable if the caregiver/parent is the one who discloses	8	3.9
Healthcare workers should lead disclosure		
HCWs are qualified and skilled and should take the lead in disclosing	35	17.2
HCW gives on-going support to the child and parents/caregiver	13	6.4
HCW gives on-going counselling to the child and parents/caregiver	5	2.5

Table 4(on next page)

Reasons caregivers delay disclosure

Table 4: Healthcare workers' perceptions about the reasons caregivers delay disclosure to infected children

	Freq.	Percent
Fear of hurting the child	33	18.6
Afraid that the child will be angry and/or hate, blame, judge, and reject the parents	31	17.5
Child is too young and can't understand HIV	28	15.8
Afraid of the stigma related to HIV	25	14.1
Caregivers are not ready to disclose and it is not the right time to disclose	20	11.3
Parents blame themselves and feel guilty about infecting the child	20	11.3
Caregivers don't know how to disclose	19	10.7
Caregivers are afraid to disclose	15	8.5
Caregivers lack in-depth HIV related information	10	5.6
Afraid that the child will react negatively to disclosure and will be confused	8	4.5
Afraid to answer questions about HIV	7	4.0
Caregivers lack support to disclose	5	2.8
Afraid the child will tell others about their HIV diagnosis	3	1.7

Table 5 (on next page)

Roles of health workers in disclosure

Table 5: The roles of healthcare workers in the process of disclosing to HIV-infected children

	Freq.	Percent
Support the caregiver through the disclosure process and the child after disclosure to live a healthy life	65	38.2
Provide health education to children to take care of themselves	31	18.2
Provide ongoing counselling to caregivers to manage disclosure and to children so that they accept their status	31	18.2
To ensure that after disclosure the child understands HIV and treatment	30	17.6
Provide ART and ensure that the child adheres to treatment	18	10.6
Provide information about the importance of disclosure to assist caregivers to disclose	17	10.0
Provide HIV-related information after disclosure so that the child understands the disease and the importance of adherence to medication	17	10.0
Facilitate and initiate disclosure to the child when the time is right to disclose	10	5.9
Monitor the reaction of the child after disclosure	5	2.9
Answer questions that the child and caregiver ask about HIV during disclosure	5	2.9
Prepare the child for the process of disclosure	4	2.4
Encourage caregivers to disclose	4	2.4
Assist caregivers to disclose	4	2.4

Table 6 (on next page)

Supporto to facilitate disclosure

Table 6: Support needed by healthcare workers to facilitate disclosure to children in primary health facilities

	Freq.	Percent
In-service education and training on disclosure counselling	84	40.8
Workshops and training on HIV management	49	23.8
Guidelines on disclosure counselling for children	35	17.0
Counselling to be able to deal with HIV-infected children	13	6.3