1 **Need and acceptability of storybooks intended to help with the process of informing**
2 **children about their HIV status in Malawi: a mixed methods study**

3 Fatch W Kalembo[1,2], Garth E Kendall[1], Mohammed Ali[1] & Angela F Chimwaza[3]

4 1 School of Nursing, Midwifery and Paramedicine, Curtin University, Perth, Australia

5 2 Faculty of Health Sciences, Mzuzu University, Mzuzu, Malawi

6 3 Kamuzu College of Nursing, University of Malawi, Blantyre, Malawi

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ABSTRACT

The rate of disclosure of HIV status to children living with HIV in sub-Saharan Africa remains low despite the World Health Organisation's recommendation that children should be told about their HIV status by the age of 12 years. The authors of previous studies have identified a lack of disclosure materials as the main barrier to disclosure of HIV status. This study aimed to assess the need and acceptability of a series of age-appropriate children's storybooks intended to help with the disclosure process. Questionnaires, interviews, and focus group discussions were used to collect information from caregivers, healthcare workers, school teachers, adolescents living with HIV, and community leaders across the three administrative regions of Malawi. Information about the need and acceptability of the storybooks was collected using pretested instruments. Quantitative data were tabulated while thematic analysis was used to analyse qualitative data. Almost 600 participants responded to the survey, and 19 interviews and 12 focus groups were conducted with 106 participants. Ninety-eight percent of participants supported the idea of developing the proposed series of storybooks and reported that they would use the books once they are developed. Most of the participants expressed the view that the books will help to improve their knowledge and understanding of the HIV disclosure, increase their confidence on how to disclose, and help to provide consistent information about HIV to children. The process of HIV disclosure to children is a very complex issue that will require the development of materials that are rigorously evaluated prior to dissemination.

KEYWORDS: HIV disclosure, storybooks, children, acceptability

Introduction

The lack of materials to use in informing children about their HIV status has been reported to affect the rate of HIV status disclosure in sub-Saharan countries (World Health Organisation, 2011). To date, rates of HIV disclosure remain below 40% (Dachew, Tesfahunegn, & Birhanu, 2014; Kajubi, Whyte, Muhumuza, Kyaddondo, & Katahoire, 2014). The World Health Organisation (WHO) (2011) has identified the need for health experts to develop materials to help healthcare workers and caregivers with the disclosure process (World Health Organisation, 2011). Despite the great need for disclosure materials, little has been done to address this issue (Beima-Sofie et al., 2014; Sariah et al., 2016). The authors of studies conducted in sub-Saharan Africa have recently reported that parents find the disclosure process difficult and that they need assistance from healthcare workers (McCleary-Sills et al., 2013; O'Malley et al., 2014; Sariah et al., 2016). Healthcare workers have also reported that they lack the skills and materials required to effectively disclose and assist caregivers with the disclosure process (Kidia et al., 2014; Madiba & Mokgatle, 2015a). Healthcare workers and caregivers are asking for standardised materials to guide them through the disclosure process (Kidia et al., 2014; Madiba & Mokgatle, 2015a; Sariah et al., 2016).

In 2015, there were 84,000 children under the age of 14 years living with HIV in Malawi and of these, 60% were on HIV medications (United Nations programme for HIV/AIDS Malawi, 2016). The prevalence and current practices of HIV disclosure to children in Malawi have not previously been reported. Nonetheless, there are reports that the stigma surrounding HIV is substantial and discrimination against people living with HIV is common (Kim et al., 2015; Nyando, 2014). Moreover, there are accounts that parents feel uncomfortable about discussing HIV because it is considered inappropriate to talk to children about sexual issues (Mandalazi, Bandawe, & Umar, 2014). The aim of this study was to assess the need for, and acceptability of, a series of storybooks intended to give children important information about the self-management of HIV and guide primary caregivers, healthcare workers, teachers, and community leaders in the disclosure process.

Methods

Study design, site and study participants

We used a concurrent triangulation design in which quantitative and qualitative data were collected concurrently and analysed separately before the results were compared and contrasted (Creswell, 2003, 2007). The study was conducted from March to July 2015 in the three administrative regions in Malawi. Three districts from the south, three from the centre, and two from the north were selected randomly as study sites. The study participants were the primary caregivers of children living with HIV, healthcare workers, teachers, community

66 leaders, and adolescents living with HIV. Recruitment criteria for primary caregivers were:
67 parent of a child living with HIV or someone providing care to a child living with HIV between
68 the ages of 6 to 12 years for more than six months; 18 years or older; and ability to provide
69 informed consent. Adolescents were recruited into the study if they were: aged between 13
70 and 18 years of age; living with HIV; aware of their positive HIV status; and leaders of
71 childhood HIV support groups (see Table 1 for more detailed information).

72 **Table 1**

73 ***Procedure***

74 Ethical approval was obtained from Curtin University Human Ethics Committee and the
75 Malawi Government Health Science Committee.

76 *Survey*

77 Trained research assistants with a health background recruited primary caregivers in the
78 waiting rooms of antiretroviral (ARV) clinics and collected questionnaire data by interview in
79 rooms assigned for this purpose. Caregivers were recruited using a systematic approach
80 (Martínez-Mesa, González-Chica, Duquia, Bonamigo, & Bastos, 2016). Children were
81 separated from their caregiver during data collection to prevent inadvertent HIV disclosure.
82 The purpose of the study was discussed with senior nurses who recruited healthcare
83 workers in their respective health facilities. Following informed consent, questionnaires were
84 completed anonymously and returned to the researchers.

85 *Focus groups and interviews*

86 Primary caregivers and teachers participated in focus groups while healthcare workers and
87 community leaders participated in one-on-one interviews. The lead researcher facilitated all
88 focus groups and interviews, and a research assistant audio recorded the proceedings.
89 Following informed consent, an interview or focus group guide was used to ensure the topic
90 of HIV disclosure was discussed uniformly. To ensure participants' anonymity and
91 confidentiality, numbers instead of names were used to identify participants when recording
92 the interviews and focus group discussions. Interviews took approximately 30 to 50 minutes,
93 and focus groups took approximately 45 to 60 minutes to be completed. The number of
94 interviews and focus group discussions was determined by saturation of data which was
95 considered to have been reached when there was no new information arising from the
96 interviews and focus group discussions (Tuckett, 2004; Walker, 2012).

97 ***Instruments***

98 Questionnaires, interview, and focus group guides were developed by the research team
99 through review of literature guided by the study aims and objectives. They were translated to

100 Chichewa (the local language) by professional translators using the WHO instrument
101 translation process (WHO, 2014). Once all language issues were corrected the instruments
102 were piloted with participants who were not included in the sample prior to the
103 commencement of data collection.

104 *Survey*

105 One questionnaire was used for primary caregivers and one for healthcare workers. Both
106 questionnaires had two sections. The first section contained questions about
107 sociodemographic characteristics, while the second section contained statements related to
108 the need, acceptability, and importance of developing an HIV disclosure intervention. The
109 second section of both questionnaires contained the statement: "We are planning to develop
110 an HIV status disclosure resource that will be in form of books, developed according to
111 children's emotional and physical maturity. The resource will use pictures, stories, and songs
112 in Chichewa to convey HIV disclosure messages to children". A series of statements
113 followed: It is a good idea to develop such type of a resource; I will be able to use the
114 resource with my child; The resource will help to improve my knowledge of HIV status
115 disclosure to children; The resource will help to improve my confidence in HIV status
116 disclosure to children; and The resource will help to reduce my worries on HIV status
117 disclosure to children. In addition, the healthcare worker questionnaire contained addition
118 statements as follows: I will be able to use the resource in helping primary caregivers to
119 disclose HIV status to children; and The resource will help to increase the rate of HIV
120 disclosure to children living with HIV. Each statement had five possible answers; strongly
121 agree, agree, neither agree nor disagree, disagree and strongly disagree. The five
122 categories were collapsed during data analysis into three categories (strongly agree/agree,
123 neither agree nor disagree, and strongly disagree/disagree).

124 *Focus groups and interviews*

125 The guides for the in-depth interviews and focus group discussions asked about participant's
126 thoughts regarding the need, acceptability, importance, and contents of the proposed
127 intervention. The following statement was read out to participants: "We are intending to
128 make children's books that will be used by caregivers of children living with HIV, healthcare
129 workers and teachers and community leaders to tell children that they have HIV. The books
130 will contain pictures, stories, and songs about what HIV is and how it can affect people's
131 lives. The books will be in Chichewa and will have information for caregivers, healthcare
132 workers, teachers and community leaders on how to use the books". These questions
133 followed the statement: What do you think about this idea?; What are your thoughts
134 regarding the need to develop the books?: What do you think about the use of the books

135 once they are developed?; What issues would you recommend to be included in the
136 children's books? What issues would you not recommend to be included in the children's
137 books? Is there anything you would like to add?

138 ***Data analysis***

139 Descriptive statistics of primary caregiver and healthcare worker's sociodemographic
140 characteristics and the need, acceptability, and importance of the disclosure intervention
141 were tabulated. Prior to data analysis, audio recordings of focus groups and interviews were
142 transcribed. Transcriptions were professionally translated into English, verified, and
143 corrected before the research team commenced data analysis. Six steps of thematic
144 analysis were used to analyse focus group and in-depth interview data: a) familiarisation with
145 the data, b) coding, c) searching for themes, d) reviewing themes, e) defining and naming
146 themes, and f) writing-up (Braun & Clarke, 2006). A list of codes was developed and
147 discussed extensively by the research team before themes and sub-themes were identified
148 (Braun & Clarke, 2006).

149 **RESULTS**

150 ***Response rates and sociodemographic characteristics of participants***

151 Four hundred and twenty-nine primary caregivers completed the survey (99% response),
152 and 168 questionnaires were collected from healthcare workers (99% response). Fifty per
153 cent of the primary caregivers were 40 years of age or younger, and the majority (61%) were
154 the biological mothers of children living with HIV. Slightly more than half (56%) had some
155 primary education, while 22% had no formal education. Forty-two per cent of caregivers
156 were in the wealthiest category of the wealth index (Gwatkin, Rutstein, Johnson, Pande, &
157 Wagstafff, 2000), while 22% were poor or very poor. The age of healthcare workers was
158 evenly distributed (21-30, 31-40, >40 years). Nurse technicians were the largest professional
159 group (33%), followed by counsellors (29%), clinicians (23%), and registered nurses (14%).
160 The majority of healthcare workers (76%) had more than two years' experience working in
161 an ART clinic. Twelve focus group discussions and 19 interviews were conducted with 106
162 participants (see Table 2 for demographic details).

163 **Table 2**

164 ***Survey***

165 Among the primary caregivers, almost all participants (99%) reported that it was a good idea
166 to develop the materials and that they would use the materials once they were developed
167 (see Table 3). They also reported that the materials would: improve their knowledge of
168 disclosure; improve their confidence; and reduce their worries. Almost all healthcare workers

169 reported that the materials would improve their knowledge and confidence. They supported
170 the idea to develop the HIV status disclosure books, they agreed that they will use the
171 materials, and that they will use it to guide caregivers with the disclosure process.

172 **Table 3**

173 ***Focus groups and interviews***

174 Participants' views regarding the proposed HIV disclosure material are presented in the
175 following sub-sections. All names are pseudonyms.

176 *Perceived need and benefit of the storybooks*

177 More than three-quarters of the participants reported that it was a good idea to develop the
178 books because of the benefits they will have for children and carers. Enala, a mother of a 10
179 year old child commented that: *"It is a good idea to have the books because my child will be*
180 *able to read and understand what is happening in her body."* Most participants reported that
181 the books would improve their knowledge on how to take care of, as well as disclose HIV
182 status to the child. One of the nurses, Grace, said that: *"These books will provide important*
183 *information that will help to improve our confidence."* Many teachers were happy with the
184 idea of developing the books because the pictures in the books would facilitate the child's
185 understanding of his or her condition. Mr Gafe, a grade three teacher, reported that: "*A child*
186 *does not forget what he has seen in pictures."* In addition, most of the adolescents living
187 with HIV reported that they lacked reference materials for teaching children living with HIV
188 about their condition. Madalitso, a 15 year old adolescent said that: *"We go around villages*
189 *discussing HIV related issues with children living with HIV, but due to lack of materials like*
190 *the books that you are talking about, we sometimes miss important information."* More than
191 half of the participants felt that the books would act as a standard tool to be used in
192 disclosure of HIV status.

193 *Perspectives about the contents of the books*

194 Many primary caregivers expressed the view that the books should contain general
195 information about the importance of nutrition, while healthcare workers and teachers thought
196 they should contain information about the types of nutritious food to give to the child.
197 Chimwemwe, a nurse said that: *"Some parents do not know what type of food to give to the*
198 *child."* Some participants thought that it would be important to include information about the
199 importance of taking the medication recommended by doctors as well as the consequences
200 of not taking them as directed by healthcare workers. Participants also made suggestions
201 regarding the outlook and layout of the book. Some teachers reported that the books should
202 contain colourful pictures and interesting stories. Mr Sawanga, a teacher, reported that: *"The*

203 *books should have beautiful pictures that can motivate children living with HIV to read."* All
204 adolescents expressed the view that the books should contain a message of hope for
205 children. Yoswa, commented that: "*The books should tell children that having HIV is not the*
206 *end of life but the beginning of another life….. children need to know that they can become*
207 *what they want to be in life."*

208 Participants also made suggestions as to what should not be included in the books.
209 Samawe, a counsellor said that: *"Avoid including pictures of children who are very thin."*
210 Chimwemwe, a 13 year old adolescent said: *"Do not include pictures that will encourage*
211 *people to stigmatise or discriminate against people living with HIV."* Teachers commented
212 that the books should not contain scary pictures. More than half of the participants reported
213 that the books should not contain sexual references. One of the traditional chiefs, Samani
214 commented that: *"You should make sure that nude pictures are not included in the books*
215 *because they can promote risky sexual behaviours and are against our tradition."*

216 *Perceived need for HIV status disclosure training*

217 Participants discussed that it would be important to help children understand the information
218 presented in the books. Minala, a primary caregiver reported that: *"You should train these*
219 *children on how to use them."* Some community leaders reported that they would need
220 training in order to acquire the knowledge and skills related to disclosure. Traditional chief,
221 Masache said that: "*I think the first thing is to train chiefs on this issue. This would give them*
222 *the confidence to teach people in their villages about the importance of disclosure."*
223 Teachers also reported that they would need training about how best to support children
224 undergoing the disclosure process.

225 **DISCUSSION**

226 The findings of this study support the reports of authors of recent studies conducted in sub-
227 Saharan Africa where caregivers and healthcare workers lack confidence and skills to
228 appropriately disclose HIV status to children (Alemu, Berhanu, & Emishaw, 2013; Kidia et
229 al., 2014; Mahloko & Madiba, 2012), as well as disclosure materials (Madiba & Mokgatle,
230 2015b; McCleary-Sills et al., 2013). In the absence of standardised disclosure materials,
231 primary caregivers and healthcare workers in Malawi have to rely on their personal
232 judgement and experience. This is likely to result in confusion among children and their
233 families due to inconsistencies in the information provided to them (Sariah et al., 2016). This
234 study shows that while it is important to develop the proposed storybooks, it is also important
235 to train the stakeholders involved in order to translate the information into meaningful
236 behavioural change.

Despite the perceived benefits of HIV education materials, there are few studies that have reported on their development, availability, and use (Beima-Sofie et al., 2017; Lowenthal et al., 2014; Nelms & Zeigler, 2008). To date, only one study has reported on the development of a brochure to assist primary caregivers with HIV disclosure (Nelms & Zeigler, 2008) and another study has reported the use of a cartoon book to help healthcare workers and primary caregivers disclose to children (Beima-Sofie et al., 2017). In addition, there are a number of resources described in the grey literature that provide age appropriate HIV information for children living with HIV (Wright et al., 2017). The resources are written materials and a video covering different HIV topics that include children and family experience of living with HIV. While these resources may be helpful in guiding the disclosure process, it is important that their development and implementation be evaluated to ensure they are effective (Jensen, Moreno, & Rice, 2014; Rudd, 2011).

It should be noted that the study relied on self-reports from the participants, which might have led to bias related to the provision of socially desirable responses. Nonetheless, the use of mixed methods and collection of data from different groups of people allowed comparison of findings and strengthened the reliability of the findings.

Conclusion

In conclusion, the process of HIV disclosure to children is a complex issue that requires rigorously evaluated interventions that involve all stakeholders in all stages of planning and implementation. It is anticipated that the proposed children books will be written and illustrated by Malawian authors and illustrators. The set of six books will be complimented by instruction manuals for caregivers, healthcare workers, teachers, and community leaders. The financial resources involved in having the materials developed, piloted, modified, and scaled up will be a major challenge in Malawi and other sub-Saharan countries. We envisage that funding from international donors will be required.

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Competing interests

The authors declare that they have no conflict of interest

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Data availability statement

272 The data for this study are available upon request from the corresponding author

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369 **Tables**

370 **Table 1: Recruitment criteria and summary of data collection plan**

Participants	Sample size	Eligibility criteria	Recruitment location
In-depth interviews and focus group discussions			
Primary caregivers,	6 focus groups	• Parent of a child living with HIV or someone providing care to a child living with HIV between the ages of 6 and 12 years for more than six months • 18 years or older • Ability to provide informed consent	Antiretroviral therapy clinics
Healthcare workers	7 in-depth interviews	• Working in children's antiretroviral therapy clinics • Being a nurse, counsellor or clinician • Ability to provide informed consent	Antiretroviral therapy clinics
Primary school teachers	6 focus groups	• Teaching at a primary school • Ability to provide informed consent	Primary schools surrounding participating hospitals
Community leaders	7 in-depth interviews	• Living near the participating hospitals • Being 18 years or older • Having a certain responsibility within the community such as being a community-based organisation leader or a village headman • Ability to provide informed consent	Communities surrounding participating hospitals
Adolescents living with HIV	5 in-depth interviews	• Between 13 to 18 years old • Living with HIV • Aware that they have HIV • Leader of children HIV support groups • Ability to provide informed consent	Antiretroviral therapy clinics Community support groups surrounding participating hospitals
Questionnaire data			
Primary caregivers	429	• Parent of a child living with HIV or someone providing care to a child living with HIV between the ages of 6 and 12 years for more than six months • 18 years or older • Ability to provide informed consent	Antiretroviral therapy clinics
Healthcare workers	168	• Working in children's antiretroviral therapy clinics • Being a nurse, counsellor or clinician	Antiretroviral therapy clinics

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373 **Table 2: Demographic characteristics of study participants who participated in the interviews and focus**
374 **group discussions**

Characteristic	N (%)	Characteristic	N (%)
Primary caregivers	N= 42	**Teachers**	N=45
Primary caregiver's age		Age	
Age range in years (Mean)	18-69 (M=44)	Age range in years (Mean)	31-48 (M=37)
Age of the primary caregiver's child		Sex	
Age range in years (Mean)	6-12 (M=10)	Male	12 (27)
Sex		Female	33 (73)
Male	8 (19)	Level of grade teaching	
Female	34 (81)	Grade 1-3	16 (36)
Relationship to the child		Grade 4-6	19 (42)
Biological mother	24 (57)	Grade 7-8	10 (22)
Biological father	7 (17)	Teaching experience	
Grandparent	8 (19)	Range in years (Mean)	3-16 (M=7)
Others	3 (7)	**Community leaders**	N=7
Education level		Age	
No education	12 (29)	Age range in years (Mean)	41-53 (M=46)
Primary	21 (50)	Sex	
Secondary	5 (12)	Male	5 (71)
College/ university	4 (9)	Female	2 (29)
Occupational status		Type of community leader	
No employment	8 (19)	Community based organisation	5 (71)
Farming	19 (45)	Traditional leaders	2 (29)
Self-employment	9 (22)	**Adolescents living with HIV**	N=5
Employment	6 (14)	Age	
Healthcare workers	N=7	Age range in years (Mean)	13-18 (M=15)
Age		Sex	
Age range in years (Mean)	32-52 (41)	Male	1 (20)
Male	2 (29)	Female	4 (80)
Female	5 (71)	Education level	
Professional group		No education	1 (20)
Registered nurse	2 (29)	Primary	2 (40)
Nurse technician	3 (43)	Secondary	2 (40)
Counsellors	1 (14)	Duration since HIV disclosure	
Clinician	1 (14)	Range in years (Mean)	1-3 (M=2)
Working experience in ART clinic			
Range in years (Mean)	1-7 (M=3)		

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377 **Table 3: Participants' views on the proposed HIV disclosure resource for children**

Characteristic	Strongly agree/ Agree % (n)	Neither Agree nor disagree % (n)	Strongly Disagree/ disagree % (n)
Primary caregivers' views			
It is a good idea to develop the resource	99 (426)	0 (0)	1 (3)
I will use the resource if developed	99 (424)	0 (1)	1 (4)
The resource will improve my knowledge on HIV disclosure	98 (422)	1 (2)	1 (5)
The resource will improve my confidence in disclosure of HIV	99 (425)	0 (1)	1 (3)
The resource will reduce my worries on how to disclose HIV to children	98 (421)	1 (3)	1 (5)
Healthcare workers' views			
It is a good idea to develop the resource	98 (164)	2 (3)	0 (1)
I will use the resource if developed	97 (162)	3 (6)	0 (0)
I will use the resource to guide primary caregivers on disclosure	95 (160)	4 (6)	1 (2)
The resource will improve my knowledge on HIV disclosure	98 (165)	2 (3)	0 (0)
The resource will improve my confidence in disclosure of HIV	97 (162)	3 (6)	0 (0)
The resource will improve the rates of HIV disclosure to children	91 (153)	5 (9)	4 (6)
The resource will reduce my worries on how to disclose HIV to children	86 (144)	5 (9)	9 (15)

378