

Care Burden and Coping Strategies Among Caregivers of Paediatric HIV/AIDS in Northern Uganda: A Cross-sectional Mixed-method Study

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Research

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1. **Care burden and coping strategies among caregivers of paediatric HIV/AIDS in**
2. **northern Uganda: A cross-sectional mixed-method study**

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13. Abstract

14. **Background:** Family caregivers provide the bulk of care to children living with HIV. This
15. places an enormous demand and care burden on the caregivers, who often struggle to cope in
16. various ways, some of which may be maladaptive. This may adversely affect their quality of
17. care. Very few literatures exist in resource-limited contexts on the burden of care experienced
18. by caregivers on who children living with HIV/AIDS depend for their long term care. We
19. assessed care burden and coping strategies among the caregivers of paediatric HIV/AIDS
20. patients in Lira district, northern Uganda.

21. **Methods:** A mixed-methods cross-sectional study was conducted among 113 caregivers of
22. paediatric HIV patients attending ART clinic at a tertiary healthcare facility in Lira district,
23. northern Uganda. Consecutive sampling method was used to select participants for the
24. quantitative study, while 15 respondents were purposively sampled for the qualitative data.
25. Quantitative data were collected using standard interviewer-administered questionnaires
26. while in-depth interview guides were used to collect qualitative data. Data were entered,
27. cleaned, and analysed using SPSS version 23. Qualitative data were analysed thematically.

28. **Results:** Majority of the caregivers 65.5% (74) experienced mild to moderate burden.
29. The mean burden scores significantly differed by caregivers' age ($P=0.017$), marital status
30. ($P=0.017$), average monthly income ($P=0.035$) and the child's school attendance ($P=0.039$).
31. Accepting social support, seeking spiritual support and reframing were the three most
32. commonly used strategies for coping. Marital status and occupation were respectively
33. positively and negatively correlated with information seeking as a coping strategy, while
34. monthly income was positively correlated with psychosocial support as a strategy. Seeking
35. community support was negatively correlated with the duration of the child's care.

36. **Conclusions:** Our findings show that care burden is a common problem among the
37. caregivers of children living with HIV in the study context.

38. **Keywords:** Care burden, coping strategies, caregivers, paediatric HIV

39. **Background**

40. It is estimated that about 1.7 million of the over 37.9 million people living with HIV globally
41. in 2018 were children aged below 15 years, the majority of whom are in sub-Saharan Africa
42. [1]. In Uganda, the country with the fifth-highest prevalence in the region, up to 100,000
43. (7.1%) of the estimated 1.4 million people living with HIV in 2018 were children under the
44. age of 15 years, of which an estimated 7,500 were new HIV infections [2]. The high burden
45. of HIV has resulted in both direct and indirect effects on the population in low- and middle-
46. income countries, leading to various social and economic challenges for an already
47. vulnerable group of people [3].
48. Although anti-retroviral drugs and treatment have burgeoned, the burden of caregiving has
49. not changed [4]. Antiretroviral therapy (ART) has reduced morbidity and mortality among
50. people living with HIV, including children, thus making HIV become a chronic disease [5].
51. Chronic diseases, and therefore HIV, not only affect the lives of those suffering from the
52. illness but also affect the lives of family members who take care for them [6], with both
53. positive and negative consequences. Providing chronic care to children living with
54. HIV/AIDS presents unique demands and burden to families and the entire health care system
55. [7], often associated with negative effects on caregivers [4, 8]. The negative effect of
56. caregiving has been described as caregiver burden [9] and encompasses the physical, social,
57. emotional and financial toll of providing care [4, 8]. According to Chandran et al., (2016),
58. caregiver burden refers to “the physical, emotional and financial hardships associated with
59. providing care to a diseased individual” [5]. In low resource settings, Uganda inclusive, care
60. burden is often contributed to by high levels of poverty, illiteracy and disruption of the family
61. social support systems. Evidence suggest an increasing level of stress in caregiving and this

62. requires adequate attention to understand and help reduce this stress [4, 10].

63. Caregivers, and by extension, families have often struggled to cope with this burden through

64. various ways, including concealment of the child's health status, drawing strength from their

65. faith and belief in God, and reaching out for support, among others. These reactions to cope

66. with stressful situations and the demands of caregiving can be adaptive or maladaptive where

67. some caregivers adapt well while others do not [11, 12]. Failure by caregivers of children

68. living with HIV to appropriately cope can adversely affect care-related outcomes, including

69. poor retention in chronic HIV care and poor adherence to ART, consequently contributing to

70. low viral load suppression among children.

71. While several studies have been done to assess care burden and identify coping strategies

72. among caregivers, these have majorly centred on adults and other debilitating diseases such

73. as psychiatric disorders, dementia, autism and general HIV patients [13-18]. Little attention

74. has been paid to the care burden experienced by the persons on whom children living with

75. HIV depend for onward lifelong support, and there is a paucity of data on the same in

76. resource-limited contexts like the current study setting. The few studies that focused on

77. caregivers of children were largely qualitative and in contexts which differ from that of the

78. current study setting [4]. This study, therefore, assessed care burden and coping strategies

79. among caregivers of paediatric HIV/AIDS patients in a resource-poor setting in northern

80. Uganda.

81. **Methods**

82. **Study design and setting**

83. We used a cross-sectional mixed methods design to collect quantitative and qualitative data

84. during the month of August 2020. The study was conducted in the antiretroviral therapy

85. (ART) clinic of Lira regional referral hospital (LRRH) – a tertiary care health facility in Lira

86. district, northern Uganda. The facility receives patients from over 9 districts in the sub-region
87. and beyond, with a catchment population of about 2.3 million, offering a wide range of
88. general and specialized curative, promotive and preventive health services. To date, the
89. facility has over 34,000 clients enrolled on ART, about 500 of who are children under 15
90. years. This site was selected because of its high client load; in addition to serving clients
91. referred from all ART clinics in the sub-region and therefore provides a relatively good
92. representative population.

93. Study population

94. Our study comprised caregivers of paediatric HIV/AIDS patients aged 2-12 years who
95. received ART services from a tertiary level facility, and who have spent at least 6 months
96. caring for the child.

97. Sample size estimation

98. Quantitative data

99. The method for estimating sample size for cross-sectional studies (Leslie Kish, 1965) [19]
100. was used for this study, based on the formula: $N = Z^2 p(1-p)/e^2$, at 95% level of confidence,
101. $p=8\%$ [20] and allowable error (e) of 5%. The estimated sample size of 113 was obtained.

102. Qualitative data

103. We interviewed 15 respondents for the qualitative data.

104. Sampling criteria

105. We used a consecutive sampling technique to recruit study participants for the quantitative
106. data, while a purposive sampling technique was used to select respondents for the individual
107. in-depth interviews.

108. Data collection instruments

109. For the quantitative data, we used a standard 22-item Zarit Burden Interview (ZBI) tool [21]
110. to assess caregivers' perceived burden of providing care. The questions focus on caregiver's

111. health, psychological well-being, finances, social life and interpersonal relationship that
112. cause stress and strain. Reliability of the ZBI tool measured by Cronbach's coefficient has
113. been reported to range from 0.77–0.94 [11, 21-23]. The 22 items are assessed on a 5-point
114. Likert scale, ranging from 0 = 'never' to 4 = 'nearly always'. Individual item scores are
115. added up to give a total score ranging from 0 to 88, with higher scores indicating higher
116. perceived burden. The cut-off points for the ZBI were as follows: 0–20 (little or no burden),
117. 21–40 (mild to moderate burden), 41–60 (moderate to severe burden), and 61–88 (severe
118. burden). Besides, a standard 29-item Family Crisis Oriented Personal Evaluation Scale (F-
119. COPES) was used to assess caregivers' coping. The F-COPES has an internal consistency of
120. 0.89 [15, 24], and is based on a 5-point scale with scores ranging from 1 to 5; where
121. 1=strongly disagree, 2=moderately disagree, 3=neither agree nor disagree, 4=moderately
122. agree, and 5=strongly agree. The five subscales designed in the F-COPES include acquiring
123. social support, reframing, seeking spiritual support, mobilizing family to acquire and accept
124. help, and passive appraisal [24]. The tools were used to collect socio-demographic
125. information, care burden and coping strategies.
126. For the qualitative data, we developed an in-depth interview guide in line with our study
127. objectives to explore caregivers' perspectives and experiences of caring for HIV infected
128. children.

129. Data collection

130. Quantitative data

131. Caregivers of paediatric HIV clients who accessed ART services from LRRH were identified
132. at the time of their appointment visits. Data were collected from consenting participants using
133. an interviewer-administered questionnaire after explaining the purpose, research procedure
134. and their rights as participants in the study. The interview took approximately 20-25 minutes.

135. Qualitative data

136. Individuals identified for the qualitative study were approached and those who agreed to
137. participate were interviewed after giving informed consent. The interview was moderated by
138. the researchers using a semi-structured in-depth interview guide and was audio recorded, in
139. addition to taking notes. Each session took about 30 minutes.

140. Data management and analysis

141. Quantitative data

142. Completeness of data was ensured during data collection through daily reviews and taking
143. corrective actions. Data were entered; cleaned and analysed using Statistical Package for
144. Social Sciences (SPSS) software (IBM SPSS Statistics for Windows, Version 23.0. Armonk,
145. NY: IBM Corp.). Descriptive statistics were used to summarize the data obtained from the
146. participants. Continuous variables with approximately normal distribution were described
147. using means (standard deviations) while non-normally distributed variables were described
148. using medians (interquartile ranges). The analysis of variance (ANOVA) and independent t-
149. tests were used to examine the differences in the mean burden scores with regard to the socio-
150. demographic characteristics. An exploratory factor analysis using principal component
151. analysis with varimax rotation was used on the coping data to assess the empirical support of
152. the original scales applied to this sample of the population. Factor analysis provides a
153. preliminary analysis of how a scale measures the concepts it is designed to measure [13]. The
154. scree test and the eigenvalues >1 rule and a factor loading of at least 0.35 [25] were used to
155. determine the number of factors. Factors with at least three items loading on them were
156. viewed as more psychometrically stable [26]. Internal consistency was estimated using
157. Cronbach's α coefficient. Pearson correlation coefficient and multiple linear regression
158. analyses were used to assess the relationship between the coping scales and socio-
159. demographic characteristics. Statistical significance was set at $P < 0.05$.

160. Qualitative data

161. The qualitative data generated from the in-depth interviews were transcribed and analysed
162. manually using content thematic analysis. The researchers read, coded and agreed on the
163. subthemes.

164. **Results**

165. **Socio-demographic characteristics of study participants**

166. The majority, 75.2% (85) of the 113 respondents were females, with a median age of 38 years
167. (IQR 12) and age range of 18-74 years. More than one half of the caregivers, 69.0% (78)
168. were the biological parents to the child while 31.0% (35) were other relations that typically
169. comprised other extended family members (Table 1). At least 16.8% (19) of the respondents
170. were caring for two or more children living with HIV. The median age of the children was 9
171. years (IQR 4), over half of whom were females (55.8%) and at least 15.0% (17) had been
172. in care for over 10 years (median 5 years [IQR 4]). Up to 21.2% (24) of the children had
173. been generally sickly despite ART. The rest of the socio-demographic characteristics are as
174. shown in [Table 1](#).

175. **Descriptive statistics (Mean/SD) of individual care burden scores**

176. Table 2 summarizes the individual mean care burden scores related to each of the 22-item
177. ZBI care burden questions. The mean scores for the individual questions ranged from a low
178. of 0.53 for the question, "Do you feel uncomfortable about having friends because of your
179. child?" to a high of 3.58 for the question, "Do you feel you should be doing more for your
180. child?" Also notable was the low mean score relating to the question "Do you feel that you
181. don't have enough money to take care of your child in addition to the rest of your expenses?"
182. (Mean=1.23). Views from the in-depth interviews though suggested that financial constraint
183. could be an important factor of care burden. For example, some caregivers reported that they
184. were not able to afford proper food, clothing and shelter for their children and spending a lot

185. of money on transport costs to and from the health facility for the child's related medications.

186. This was exemplified by a statement from one respondent who asserted thus:

187. *"...at times, she refuses to take her medication because I have not been able to afford*

188. *buying for her good food such as "mukene"(silver fish) and others..."* a 29 year old

189. *mother.*

190. Similarly, the mean score to the question "Do you feel that your child negatively affects your

191. relationships with other family members or friends?" was low (Mean=0.89). This was not at

192. par with expressions from the qualitative study where some respondents felt stigmatized and

193. discriminated against because of their children's HIV status; *"...the neighbours also fear me*

194. *because they think I also have HIV/AIDS,"* said one respondent.

195. The low ranking of the question, "Do you feel you have lost control of your life since your

196. child's illness? (Mean=0.64) demonstrates some sort of resilient and shows that the "burn-out

197. syndrome" has not yet cropped up among the caregivers in the study context ([Table 2](#))

198. Level of care burden

199. The overall mean burden score was 36.9 ± 9.7 , where all the respondents experienced one

200. form of care burden or the other to varying extents. The majority of the caregivers, 65.6%

201. (74) had mild to moderate care burden, 30.1% (34) had moderate to severe burden, 2.7% (3)

202. had little or no burden, and only 1.8% (2) had severe burden ([Figure 1](#)). The widespread

203. experience of care burden as noted in the quantitative findings was also echoed by

204. respondents in the in-depth interviews where all reported at least some form of burden.

205. These emerged under the following themes: psychosocial, stigma and discrimination,

206. financial and healthcare-related burdens, as exemplified by the following voices:

207. *"...I have been suffering from nursing him in the hospital considering that he is always*

208. *ill especially when he had TB..."* stated a 37-year-old mother

209. *"...I also have to work hard weeding people's gardens in order to take care of the*

210. *children and sometimes they don't pay me on time*" said a 54-year old grandmother.

211. The relation between care burden and caregivers' socio-demographic characteristics

212. The mean care burden score was significantly higher among caregivers in the 30-39 years age
213. range (39.07 ± 10.70 , $p=0.017$), caregivers who were divorced (44.00 ± 14.46 , $p=0.017$) and
214. those with an average monthly household income less than \$67 or approximately \$2 a day
215. (39.24 ± 10.14 , $p=0.035$) (Table 3). Likewise, respondents caring for HIV positive children
216. who were attending school had lower burden scores (36.30 ± 9.30) compared to those caring
217. for children who were not in school (42.64 ± 11.99), and this difference was statistically
218. significant, $p=0.039$. The burden scores in relation to the rest of the caregiver and child socio-
219. demographic characteristics are as shown in [Table 3](#).

220. The effect of household income on care burden was supported by the views expressed by
221. participants in the qualitative study as exemplified by an assertion from one respondent who
222. said:

223. *"...I do odd jobs to take care of the child and as I am old, it is hard for me..."* a 60 year
224. old grandfather.

225. Likewise, the effect of parenting on care burden was highlighted by respondents in the
226. qualitative study where one respondent, a 36 years old female caregiver reported:

227. *"...the most painful of my experiences was the loss of this child's mother. From then, I*
228. *found it very difficult to give the medication to the child, defaulting medication time..."*

229. Descriptive statistics of the coping strategies assessment

230. Table 4 summarizes the mean scores for each of the 29-item F-COPES used to assess coping
231. strategy among the respondents. This ranged from a low of 1.77 for the strategy relating to
232. item C26 "seeking advice from a minister", to a high of 4.99 relating to item C29 "having
233. faith in God" as the coping strategies. A mean score per-item of greater than 3.0 indicated
234. that the item was a support component strongly used by the respondents ([Table 4](#)).

235. Furthermore, as shown in figure 2, the respondents used all the original five subscales as
236. coping strategies to varying extents. Acquiring social support was the strongest support
237. system and ranked highest (Median=4.2) in the extent of use, followed by seeking spiritual
238. support (Median=4.0) as the next highly ranked support system while acquiring and
239. accepting help (Median=2.8) was the weakest coping strategy (Figure 2). The internal
240. consistency of the scale for this study, as indicated by the Cronbach's alpha estimate was
241. 0.68, while the inter-item coefficients (Cronbach's α) for each of the original five subscales
242. were Acquiring Social Support (0.69), Reframing (0.74), Seeking Spiritual Support (0.09),
243. Acquire & Accept Help (0.40), and Passive Appraisal (0.48).
244. Findings from the qualitative study regarding how respondents coped did not differ much, as
245. sharing the problems faced with other friends caring for HIV infected children (social
246. support) was a theme that emerged as one of the commonly used coping strategies by the
247. caregivers. This was exemplified by the following expressions:
248. *"...a friend of mine was almost giving up on caring for her child, I said to her, now that*
249. *you know your child is suffering from HIV/AIDs, don't let her die, take care of her and*
250. *you get blessings, and now the child is 8 years old and healthy..."*, said a 22 year old
251. mother.
252. *"...It was only one day that me and some other people caring for children living with*
253. *HIV/AIDs underwent a training conducted by LUCITA in caring for these children, so*
254. *this gave me courage to continue caring for this child"* said a 46 year old male.
255. Similarly, spiritual support also emerged as one of the themes that relate to how the
256. respondents coped. A number of the respondents expressed attending prayer sessions, reading
257. the bible, and surrendering themselves to God as a way of getting relief from the burden of
258. caregiving (spiritual support). One of them asserted:
259. *"I have completely surrendered these children and myself to God. Without God, I*

260. *wouldn't have persevered all this long together with these children. So, I put God first*
261. *and ART medication second...*” said a female respondent.

262. Relation of coping strategies with caregivers' socio-demographic characteristics

263. A principal component factor analysis with varimax rotation was performed on the coping
264. data to assess the experiential support for the original five scales applied to the current
265. sample population. Using an eigenvalue of >1.0 as the criterion resulted in 10 factors being
266. extracted from the entire pool of items. However, based on the original five-factor scale and
267. given the marked drop in the percentage of variance explained from the sixth factor on the
268. scree plot, a five-factor solution was accepted as the best one and was used for the
269. exploratory factor analysis. These explained 47.3% of the total variance in the 29-item F-
270. COPES as applied to the current study population. The new explanatory factors could be
271. categorized as follows: Factor 1: Internal Strength (6 items: 3, 7, 11, 12, 13, 21) and
272. accounted for 13.9% of the variance. Factor 2: Seeking Community Support (4 items: 8, 10,
273. 27, 28) and accounted for 11.6% of the variance. Factor 3: Information Seeking (7 items: 1,
274. 2, 4, 5, 16, 19, 24) and accounted for 8.9% of the variance. Factor 4: Acceptance (4 items: 15,
275. 22, 23, 25) and accounted for 6.9% of the variance. Factor 5: Psychosocial Support (4 items:
276. 6, 9, 20, 26) and accounted for 6.0% of the variance. Each item's loading on the five extracted
277. factors is shown in [Table 5](#). The Cronbach's alpha estimates for the five extracted factors
278. were higher than for the original subscales and ranged from 0.51 for the Psychosocial
279. Support subscale to 0.80 for the Internal Strength subscale. The overall Cronbach's α
280. coefficient for the factors that loaded (25 items) was 0.71. Four items of the original 29-item
281. F-COPES “dropped out” by not loading on any factor greater than .35. These were
282. “Attending church services” (item 14), “Knowing luck plays a big part in how well we can
283. solve family problems” (item 17), “Accepting that difficulties occur unexpectedly” (item 18),
284. and “Having faith in God” (item 29).

285. The relationship between coping strategies and socio-demographic characteristics

286. Table 6 shows the correlation and multivariate linear regression beta coefficients of the
287. relationship between the extracted coping subscales and respondents' socio-demographic
288. characteristics. Marital status was positively correlated with Information Seeking, implying
289. that use of information seeking becomes more frequent as the marital status changes from
290. "single" to "widowed". Likewise, the level of monthly income showed a positive relationship
291. to the Psychosocial Support subscale, indicating that caregivers with higher income used
292. more of psychosocial support for coping. There was a negative correlation between
293. occupation and Information Seeking, implying that caregivers less frequently used
294. information-seeking strategy as their occupation status tends towards being unemployed.
295. Caregivers used less of the strategy of Seeking Community Support the longer the child
296. remains in care.

297. Discussion

298. There is a paucity of literature on caregiving and its associated burden among family
299. caregivers of children living with HIV in low-resource settings. Consequently, there is a poor
300. understanding of the care burden and how individuals and families respond to such a demand
301. for chronic care. This study investigated the care burden among caregivers of HIV-infected
302. children in a low-resource context and how the respondent population coped with the
303. demands and burden of caregiving. The study thus offers new insight and understanding of
304. caregiver burden and coping strategies for Paediatric HIV in resource-limited contexts.

305. Level of care burden

306. We found that the majority (65.6%) of the caregivers experienced mild to moderate burden,
307. while 1.8% experienced severe burden. This finding contrasts with that reported by Ochigbo
308. et al., (2018) in Nigeria where the majority (76.4%) of the caregivers had no or minimal

309. burden and only 16.4% had mild to moderate burden [27]. The level of care burden as found
310. in the current study also differs from that reported among adults caring for people living with
311. HIV/AIDS in Southern India where 27.8% and 10.0% had mild-moderate and severe levels
312. of burden respectively [5]. The above variation could be attributed to differences in the
313. patient types and the study contexts. We believe that the widespread experience of care
314. burden in the context of our study could be attributed to the high level of poverty, illiteracy
315. and disruption of family support systems, and could have important implications on the care
316. for the HIV infected children, including poor retention, poor adherence, and low viral load
317. suppression.

318. There were strong bearings of some specific items within the ZBI tool on the level of care
319. burden experienced by the study participants. The highest scores were observed for the
320. questions “Do you feel your health has suffered because of your involvement with your
321. child?” (Item 20), “Do you feel your child is dependent on you?” (Item 8), and “Do you feel
322. that your child seems to expect you to take care of him/her as if you were the only one he/she
323. could depend on?” (Item 14). This finding is similar to that previously reported by other
324. authors [21, 28]. However, in contrast to previous reports, the response to the question “Are
325. you afraid of what the future holds for your child?” (Item 7) generated a low score. This
326. finding is uniquely important and suggests a high level of conviction of hope among the
327. respondents, a factor shown to be important in handling the challenging situations of
328. caregiving [29].

329. Factors associated with care burden

330. The burden of caregiving was significantly influenced by certain caregivers’ socio-
331. demographic factors. Our results showed that caregivers aged 30-39 years experienced more
332. burden than those in other age categories, which closely mirrors that reported in a study by
333. Rahmani et al., (2019) among caregivers of schizophrenic patients in Iran [11], suggesting a

334. tendency to higher burden at an older age. Rutakumwa et al., (2015) in a previous study in
335. Uganda contends that older persons encounter significant challenges in their care-giving role
336. attributed to the high occurrence of poor health associated with advancing age, thus
337. undermining their ability to optimally provide for children in their care [30]. The large
338. number of the caregivers aged ≥ 40 years (44.2%) in the current study should therefore be
339. concerning. Our finding, however, contrasts with that reported by Robson (2000) in
340. Zimbabwe [31] and Lindsey et al., (2003) in Botswana [32] where young girls bore a high
341. burden of caregiving with untoward consequences. Furthermore, our results suggest a
342. significant association between divorce and an increase in the level of care burden
343. experienced. This could be attributed to the role dynamics that these caregivers have to play
344. in addition to caring for the HIV-infected child, compounded by the fact that divorce is a
345. stressor in itself.

346. Caregivers with an average monthly income of less than 250,000 Uganda shillings
347. (approximately \$67) significantly experienced higher burden compared to those with an
348. average monthly income $\geq 250,000$ Shs, a finding that was also echoed by respondents in the
349. qualitative study. This finding corroborates with that reported by Boon et al., (2010) which
350. showed a lower care burden among caregivers who had fewer financial problems [21]. While
351. Rahmani et al., (2019) reports a contrary finding of higher care burden among caregivers with
352. perceived income adequacy [11], we believe the current finding may not be surprising since
353. caring for an HIV positive child requires financial resources to meet many of the child's
354. needs. This is a situation reported by Kipp et al., (2007) in the pre-scale up of ART in
355. Uganda where all the caregivers reported deterioration of their economic status since
356. becoming caregivers, with over half (59%) requesting for direct financial assistance [33].
357. Furthermore, respondents caring for children who were attending school significantly
358. experienced lower levels of care burden than those caring for children who were not in

359. school. While the reason for this is not immediately obvious, we postulate that this could
360. relate to the fact that in this study, children who were not attending school were younger
361. (median age = 7 years [IQR 4-7]) than those in school (median age = 9 years [IQR 7-9]) and
362. therefore more dependent on the caregiver. Furthermore, a higher proportion (36.4%) of
363. children who were not attending school were reported to have been sickly compared to only
364. 19.6% of children who were already at school, which, coupled with the younger age, is likely
365. to have increased the level of care burden.

366. Coping strategies and related caregivers' socio-demographic factors

367. Based on the original subscale, the three coping strategies with the highest median scores
368. were accepting social support, seeking spiritual support and reframing, a finding similar to
369. that reported by Guada (2012) in a study among African American families with a
370. schizophrenic loved one [13]. By contrast, in a study among parents of children with cancer
371. in Shiraz, Southern Iran, spiritual support ranked highest followed by seeking help,
372. reframing, passive appraisal and social support [14]. While these studies all used the same
373. tool (the F-COPES), they diverge on the disease spectrums studied. The high extent of use of
374. social support among respondents in the current study, as has also been reported by other
375. authors [34, 35] is not unexpected given the socio-cultural contexts where extended family
376. and community systems form the basis of children's upbringing. Furthermore, the religious
377. conviction as found in this study is in keeping with that reported by Osafo et al., (2017) in a
378. qualitative study in Uganda where spirituality with high rates of religiousness was noted as a
379. way of coping among caregivers [4]. This finding also bodes well with that found among
380. caregivers of children with cancer in Iran [14] and is indeed in accord with the results of our
381. qualitative findings where caregivers expressed turning to God for strength and hope,
382. characterised by attending prayer sessions, reading the bible, as well as believing that the
383. disease will go away when they pray to God.

384. In this study, we also sought to investigate for some more unique ways of coping among the
385. sampled study population that was not suggested by the original subscales. We derived five
386. coping factors from a principal component factor analysis of the F-COPES that best
387. explained how the population in the context of this study respond to the demands and burden
388. of caregiving for children living with HIV/AIDS. These factors could best be described as
389. Internal Strength, Seeking Community Support, Information Seeking or gathering,
390. Acceptance, and Psychosocial Support. This finding has similarities with those reported
391. among various population groups and disease contexts [13, 36, 37], with ingredients that can
392. be considered as emotion-and problem-focused. These factors more reliably explained coping
393. among the study population as shown by the improvement in the overall Cronbach's alpha
394. coefficient from 0.68 to 0.71 and the marked improvement in the subscale coefficients
395. compared to the original subscales.

396. The first factor, Internal strength, demonstrates that the caregivers relied on the inherent
397. strengths and resilient within the family systems to overcome the demands and burden of
398. caregiving, and presents a unique coping strategy which is not demonstrated in the original
399. factor subscale. A similar finding has previously been reported by Guada (2012), who also
400. contends that family interventions should emphasize a family's sense of its inherent
401. capabilities for managing stress [13]. This is an important finding on which programs can
402. leverage to support caregivers and families to explore and make use of their inherent
403. strengths, where possible, as a first line of coping.

404. The sampled population also coped by seeking community support (the second factor),
405. particularly from neighbours while also taking a passive approach by believing that if they
406. wait long, the problem will go away. Conceptually, this approach is similar to the original F-
407. COPES subscale of Acquire & Accept Help [24]. The adoption of this strategy was

408. significantly negatively correlated with the duration of the child's care, implying the longer
409. the child takes in care, the lesser the caregivers sought community support. Results from the
410. qualitative data reaffirmed the role of this strategy in coping, where respondents shared their
411. problems with persons similarly caring for children with HIV as a way of receiving support.
412. This finding is of significance and demonstrates the importance of involving family members
413. and the community in care [38], which re-emphasizes the need to address the barriers of
414. stigma, discrimination and non-disclosure. These are barriers likely to hamper the beneficial
415. roles of other family members and the community in coping.

416. The third factor centred on seeking information from others as a means of dealing with
417. stressors, particularly from friends and extended family members, in addition to seeking
418. information and advice from persons in other families who have faced the same or similar
419. problems. The use of this coping strategy was significantly positively correlated with being
420. divorced or widowed but was less adopted as the caregiver drifts in the direction of being
421. unemployed. Programs should therefore support a proactive strategy of providing useful
422. information that aids coping; including information that address stigma and discrimination.

423. The fourth factor was labelled as Acceptance, an emotion-focused coping strategy that family
424. members utilize to cope [15, 37]. This is an important coping strategy and therefore a
425. uniquely important finding not previously demonstrated in the original subscale. It has been
426. argued that by employing this strategy and accepting their difficult situations, families are
427. better placed to redefine stressful events to make them more manageable [15]. Similarly,
428. according to McCubbin et al., (1996), family members who use acceptance do not necessarily
429. view their situation as negative, but as a part of their everyday life, a fact which helps to
430. reduce stress and improve the relationship with other family members [24].

431. The last factor, labelled as Psychosocial Support, is conceptually similar to the original
432. subscale of Acquiring Social Support and has previously been reported [36, 39]. We found a

433. positive correlation between the average household income and the use of psychosocial
434. support as a major coping strategy. This finding contrasts with that reported by Phyllis et al.,
435. (2011) in a study among family members of hospitalized psychiatric patients, who found no
436. significant relationship between coping and the family's socioeconomic status [15]. This
437. difference could be methodological and/or due to disease factors since difference diseases
438. present unique challenges in caregiving.

439. This study has some limitations. One of the limitations of this study is the relatively small
440. sample size which is likely to limit its external validity. However, this weakness was
441. overcome by employing a mix-method design where findings from the qualitative study
442. reinforced the quantitative data. Furthermore, being a cross-sectional study, it was not
443. possible to establish any precise causal relationship between coping strategies, burden and
444. caregivers' socio-demographic factors.

445. Conclusions and recommendations

446. This study shows that care burden is common among the caregivers of children living with
447. HIV in the study context. Caregivers depend on both internal and external strengths for
448. coping with the burden of caregiving. We recommend that appropriate health and social
449. policies should be directed by programs supporting HIV care and treatment services to
450. alleviate the caregiver burden in this and similar population.

451. List of abbreviations

452. AIDS: Acquired Immune Deficiency Syndrome; ART: Anti-retroviral therapy; HIV: Human
453. Immunodeficiency Virus; LRRH: Lira Regional Referral Hospital

454. Declarations:

455. Ethics approval and consent to participate

456. The study protocol was reviewed and cleared by the Institutional Research and Ethics
457. Committee of Gulu University (GUREC-042-20). The protocol was further cleared for

458. collection of data in Uganda by the national research regulator, the Uganda National Council
459. for Science and Technology (RESCLEAR/01). Administrative clearance was obtained from
460. the district and hospital administrations. Written informed consents were obtained from all
461. respondents before participating in the study.

462. Consent for publication

463. Not applicable

464. Availability of data and materials

465. The datasets used and/or analysed during the current study are available from the
466. corresponding author on reasonable request.

467. Competing interests

468. The authors declare that they have no competing interests

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476. Authors' contributions

477. MI, MP, NS, WA, NF, and AP conceptualized this work, participated in proposal writing and
478. data collection. ASB and NR participated in proposal writing, data analysis and drafted the
479. manuscript together with MI and MP. All authors read and approved the final manuscript.

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493. List of figures:

494. Figure 1 Level of care burden
495. Figure 2 Usage of the F-COPES subscale support system

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Table 1 Socio-demographic characteristics of study participants

Characteristics	Frequency; N (%)
<i>Caregivers characteristics</i>	
Gender	
Male	28 (24.8)
Female	85 (75.2)
Age (years)	
18-29	21 (18.6)
30-39	42 (37.2)
≥40	50 (44.2)
Relation to child	
Mother	58 (51.3)
Father	20 (17.7)
Others	35 (31.0)
Highest level of education	
Primary	65 (57.5)
Secondary	28 (23.0)
Tertiary	11 (9.7)
No formal education	11 (9.7)
Occupation	
Formal employment	12 (10.6)
Self-employed	44 (38.9)
Peasant farmer	38 (33.6)
Unemployed	19 (16.8)
Marital status	
Single	54 (47.8)
Married	30 (26.5)
Divorced	10 (8.8)
Widowed	19 (16.8)
Children living with HIV/AIDS in household	
1 child	94 (83.2)
2 and more	19 (16.8)
Average monthly household income	
<250,000	46 (40.7)
≥250,000	67 (59.3)
<i>Child characteristics</i>	
Gender	
Male	50 (44.2)
Female	63 (55.8)
Age (years)	
5 and below	17 (15.0)
Above 5	96 (85.0)
School attendance	
Yes	102 (90.3)
No	11 (9.7)
Duration in HIV care	
<10 years	96 (85.0)
≥10 years	17 (15.0)
Health condition since ART	
Healthy	89 (78.8)
Sickly	24 (21.2)

Table 2 Mean scores of caregivers' responses to care burden assessment questions, n=113

Item No.	ZBI Care burden questions	Mean	SD	Variance
B1	Do you feel that your child needs more help than he/she needs?	3.07	1.03	1.07
B2	Do you feel that you don't have enough time for yourself because of the child?	1.48	1.30	1.70
B3	Do you feel stressed caring for the child and trying to meet other responsibilities for your family or work?	2.43	1.32	1.75
B4	Do you feel embarrassed about your child's condition?	0.75	1.17	1.37
B5	Do you feel angry when you are with your child?	0.76	1.10	1.20
B6	Do you feel that your child negatively affects your relationships with other family members or friends?	0.89	1.29	1.67
B7	Are you afraid of what the future holds for your child?	1.88	1.52	2.31
B8	Do you feel your child is dependent on you?	3.46	0.79	0.63
B9	Do you feel strained when you are around your child?	0.55	1.04	1.10
B10	Do you feel your health has suffered because of your involvement with your child?	1.33	1.31	1.72
B11	Do you feel that you don't have as much privacy as you would like because of your child?	0.86	1.22	1.50
B12	Do you feel that your social life has suffered because you are caring for your child?	0.59	1.13	1.28
B13	Do you feel uncomfortable about having friends because of your child?	0.53	1.17	1.36
B14	Do you feel that your child seems to expect you to take care of him/her as if you were the only one he/she could depend on?	3.38	0.96	0.92
B15	Do you feel that you don't have enough money to take care of your child in addition to the rest of your expenses?	1.23	1.45	2.09
B16	Do you feel that you will be unable to take care of your child much longer?	1.52	1.43	2.06
B17	Do you feel you have lost control of your life since your child's illness?	0.64	1.09	1.18
B18	Do you wish you could leave the care of your child to someone else?	1.12	1.36	1.84
B19	Do you feel uncertain about what to do about your child?	1.34	1.41	1.98
B20	Do you feel you should be doing more for your child?	3.58	0.69	0.48
B21	Do you feel you could do a better job of caring for your child?	3.02	1.16	1.34
B22	Overall, how burdened do you feel?	2.50	1.23	1.52

SD: Standard deviation

Table 3 Care burden scores and socio-demographic characteristics of caregivers of HIV infected children in northern Uganda

Variables	n	Mean ± SD	Statistics	P-value
<u>Caregivers characteristics</u>				
Gender				
Male	28	34.54±8.51	1.51 ^a	0.135
Female	85	37.71±10.00		
Age (years)				
18-29	21	31.76±8.73	4.26 ^b	0.017*
30-39	42	39.07±10.70		
≥40	50	37.28±8.56		
Relation to child				
Mother	58	37.76±10.14	0.62 ^b	0.541
Father	20	35.00±9.29		
Others	35	36.63±9.31		
Highest level of education				
Primary	65	37.45±9.48	1.23 ^b	0.304
Secondary	26	37.35±9.04		
Tertiary	11	31.64±12.81		
No formal education	11	38.09±8.89		
Occupation				
Formal employment	12	38.83±13.81	0.46 ^b	0.710
Self-employed	44	37.73±10.72		
Peasant farmer	38	35.92±7.55		
Unemployed	19	35.84±8.44		
Marital status				
Single	54	34.48±8.32	3.53 ^b	0.017*
Married	30	38.87±8.62		
Divorced	10	44.00±14.46		
Widowed	19	37.05±10.34		
Children living with HIV/AIDS in HH				
1 child	94	36.23±9.90	-1.68 ^a	0.095
2 and more	19	40.32±8.13		
Average monthly household income				
<250,000	46	39.24±10.14	2.14 ^a	0.035*
≥250,000	67	35.33±9.15		
<u>Child characterises</u>				
Age (years)				
5 and below	17	35.88±10.00	-0.48 ^a	0.635
Above 5	96	37.10±9.70		
School attendance				
Yes	102	36.30±9.30	-2.09 ^a	0.039*
No	11	42.64±11.99		
Duration in HIV care				
<10 years	96	37.03±9.96	0.29 ^a	0.774
≥10 years	17	36.29±8.40		
Health condition since ART				
Healthy	89	36.13±9.74	-1.67 ^a	0.098
Sickly	24	39.83±9.22		

^aIndependent t-test (df=1); ^bANOVA (F); *P-value is significant; HH=Household

Table 4 Descriptive Statistics of caregivers' responses to the coping strategy questions, n=113

Item No.	Item	Mean	SD	Variance
C1	Sharing our difficulties with relatives	4.13	1.36	1.85
C2	Seeking encouragement and support from friends	4.12	1.29	1.67
C3	Knowing we have the power to solve major problems	2.80	1.55	2.41
C4	Seeking information and advice from persons in other families who have faced the same or similar problems.	4.13	1.27	1.62
C5	Seeking advice from relatives (grandparents etc.)	4.14	1.24	1.53
C6	Seeking assistance from community agencies and programs designed to help families in our situation	2.01	1.47	2.17
C7	Knowing we have the strength within our family to solve our problems	2.74	1.51	2.28
C8	Receiving gifts and favours from neighbours	3.15	1.64	2.70
C9	Seeking information and advice from the family doctor	2.47	1.68	2.81
C10	Asking neighbours for favours and assistance	3.23	1.62	2.61
C11	Facing the problem 'head-on' and trying to get the solution right away	3.71	1.55	2.41
C12	Watching T.V.	2.40	1.46	2.12
C13	Showing that we are strong	3.00	1.67	2.80
C14	Attending church services	4.91	0.34	0.12
C15	Accepting stressful events as a fact of life	4.46	1.04	1.07
C16	Sharing concerns with close friends	4.47	0.99	0.98
C17	Knowing luck plays a big part in how well we can solve family problems	1.81	1.17	1.37
C18	Accepting that difficulties occur unexpectedly	4.58	0.74	0.55
C19	Doing things with relatives (get-togethers, dinners, etc.).	4.34	1.09	1.19
C20	Seeking professional counselling and help for family difficulties	3.47	1.64	2.70
C21	Believing we can handle our problems.	3.12	1.57	2.47
C22	Participating in church activities	4.80	0.70	0.49
C23	Defining the family problem more positively so that we do not become too discouraged	4.01	0.94	0.88
C24	Asking relatives how they feel about the problems we face	3.93	1.15	1.32
C25	Feeling that no matter what we do to prepare, we will have difficulty handling problems.	3.95	1.03	1.05
C26	Seeking advice from a minister,	1.77	1.24	1.54
C27	Believing if we wait long enough, the problem will go away.	3.91	1.31	1.71
C28	Sharing problems with neighbours	3.90	1.45	2.11
C29	Having faith in God	4.99	0.09	0.01

SD: Standard deviation

Table 5 Five-factor loading of items in the coping strategy (F-COPES) assessment scale, n=113

F-COPES items		Factor loadings				
		1	2	3	4	5
C1	Sharing our difficulties with relatives	.102	-.130	.730*	.071	-.016
C2	Seeking encouragement and support from friends	.145	.235	.484*	-.342	-.299
C3	Knowing we have the power to solve major problems	.742*	-.009	-.046	.099	.088
C4	Seeking information and advice from persons in other families who have faced the same or similar problems.	.129	.272	.426*	-.148	.063
C5	Seeking advice from relatives (grandparents etc.)	.020	-.129	.671*	.177	.185
C6	Seeking assistance from community agencies and programs designed to help families in our situation	.084	-.091	.196	-.142	.442*
C7	Knowing we have the strength within our family to solve our problems	.812*	.033	-.126	.052	.077
C8	Receiving gifts and favours from neighbours	.175	.831*	.026	.016	.092
C9	Seeking information and advice from the family doctor	.265	.100	.094	-.109	.548*
C10	Asking neighbours for favours and assistance	.017	.859*	.082	.083	.048
C11	Facing the problem 'head-on' and trying to get the solution right away	.497*	.409	.089	.230	.034
C12	Watching T.V.	.643*	-.017	.322	-.037	-.066
C13	Showing that we are strong	.737*	-.059	.137	.334	-.226
C14	Attending church services	.078	-.022	-.127	-.266	.069
C15	Accepting stressful events as a fact of life	-.083	.305	-.063	.418*	-.580
C16	Sharing concerns with close friends	-.215	.305	.541*	-.197	-.277
C17	Knowing luck plays a big part in how well we can solve family problems	-.120	-.085	-.107	-.713	.145
C18	Accepting that difficulties occur unexpectedly	-.007	.245	.065	.120	-.717
C19	Doing things with relatives (get-togethers, dinners, etc.).	.216	.143	.535*	.142	.111
C20	Seeking professional counselling and help for family difficulties	-.104	.074	.017	-.125	.551*
C21	Believing we can handle our problems.	.672*	-.075	.049	-.120	.072
C22	Participating in church activities	-.003	-.168	.199	.454*	.029
C23	Defining the family problem more positively so that we do not become too discouraged	.378	.120	-.051	.632*	-.103
C24	Asking relatives how they feel about the problems we face	-.135	.141	.526*	.244	.010
C25	Feeling that no matter what we do to prepare, we will have difficulty handling problems.	.105	.170	-.115	.592*	-.025
C26	Seeking advice from a minister,	-.062	.110	-.103	.271	.526*
C27	Believing if we wait long enough, the problem will go away.	-.220	.480*	-.046	.311	-.107
C28	Sharing problems with neighbours	-.251	.614*	.272	-.025	-.216
C29	Having faith in God	.183	-.089	.036	-.089	-.214

Table 6 Correlation coefficients and standardized beta weights between the five coping subscales, caregiver and child socio-demographic characteristics, n=113

	Factor 1		Factor 2		Factor 3		Factor 4		Factor 5	
	<i>r</i>	<i>b</i>								
Gender	.052	-.101	-.115	-.034	-.128	-.236*	.017	-.033	-.149	-.103
Age	-.118	-.129	.055	.085	.105	-.021	.041	.049	-.036	.029
Relation	-.103	-.024	-.103	-.095	.061	.063	-.025	-.050	-.009	-.040
Education	.044	-.039	-.180	-.031	.098	.125	.025	.025	.158	.063
Marital status	.155	.160	-.152	-.117	.258**	.285*	-.029	-.103	-.020	.000
Occupation	-.311**	-.256	.176*	.069	-.223*	-.196*	.035	-.003	-.129	-.114
Income	.047	.054	-.149	-.153	-.175	-.202	.003	.015	.360**	.314*
No. HIV+ children	-.055	.003	.152	.209	.029	.028	.125	.124	-.046	.098
Child's age	-.145	-.262	-.054*	.128	.073	.037	-.172	-.264*	.083	.024
Schooling	.084	.058	-.014	-.049	.092	.084	-.079	-.105	-.232*	-.143
Duration in care	.098	.220	-.254**	-.295*	.079	.003	.003	.145	.034	.015
Child's health	.091	.036	-.113	-.058	-.009	-.070	-.037	-.029	.061	.080
Adj <i>R</i> ²		.075		.075		.113		-.042		.082

*Factor 1: Internal strength; Factor 2: Seeking community support; Factor 3: Information seeking; Factor 4: Acceptance; Factor 5: Psychosocial support. *P < 0.05; **P < 0.01; r=Pearson's coefficients; b=Standardized beta coefficients*

Figures

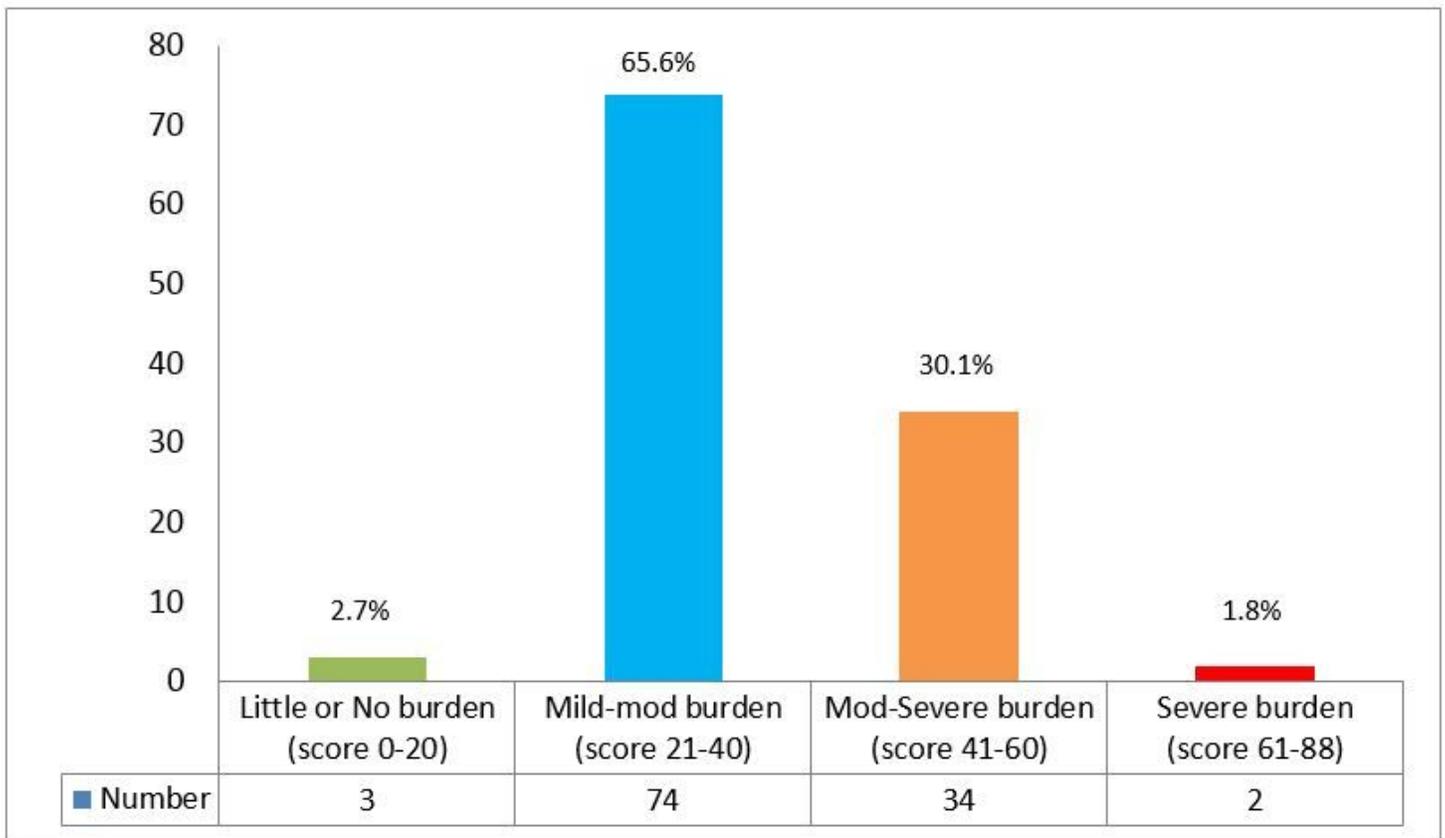


Figure 1

Level of care burden

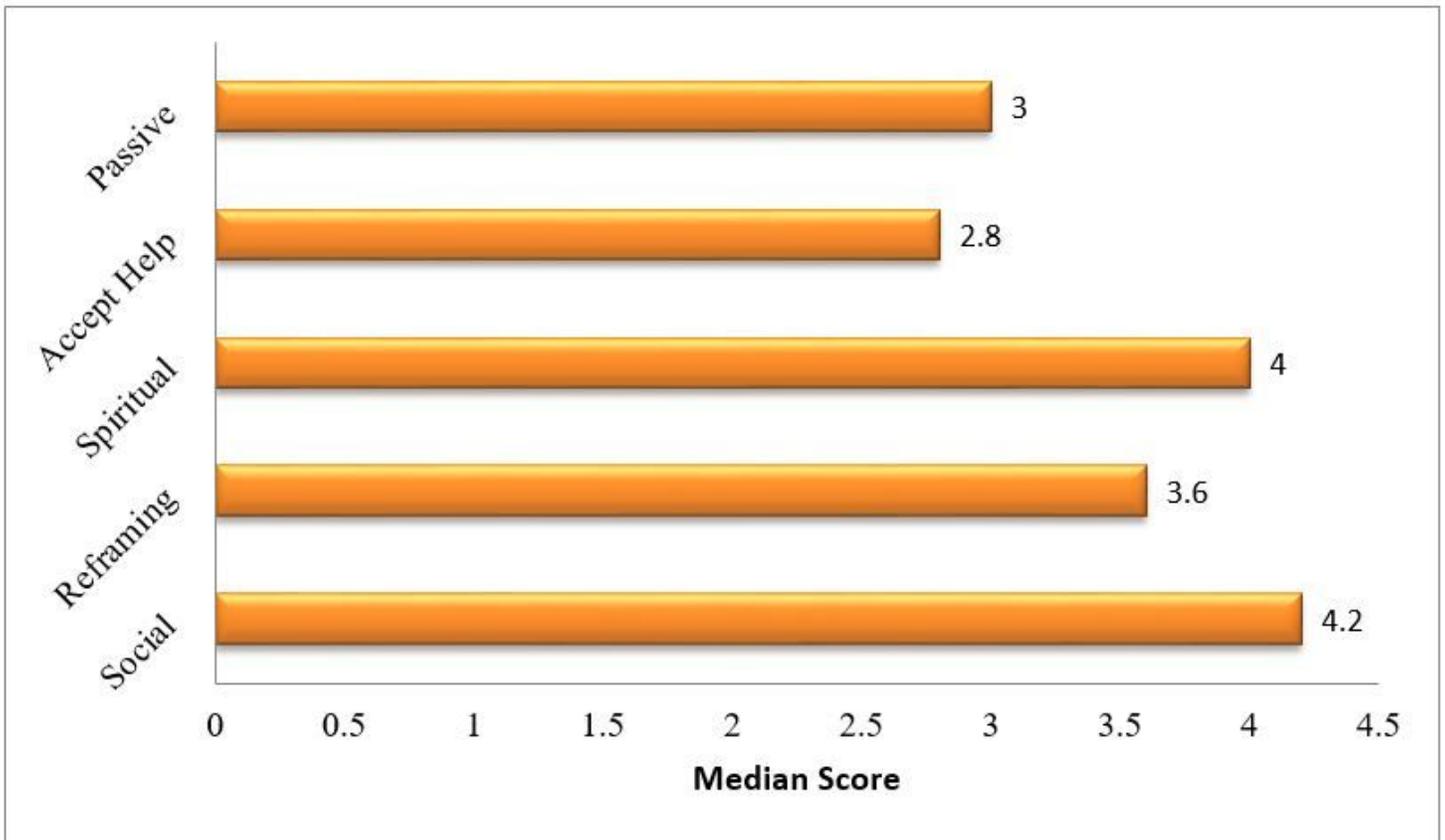


Figure 2

Usage of the F-COPES subscale support system