Research article

The effects of perceived therapist guidance and advice on adherence to home-based exercise programs in mothers of children with cerebral palsy in Rwanda

Japhet Niyonsenga [a,b,*], Liliane Uwingeneye [g], Inès Musabyemariya [d], Jean Pierre Nteziryayo [f], Thèodat Siboyintore [a], Jean Baptiste Sagahutu [e], Francesca Cavallini [b], Rutembesa Eugene [a], Stefan Jansen [h], Nadia Monacelli [c], Luca Caricati [b], Jean Mutabaruka [a]

[a] Department of Clinical Psychology, College of Medicine and Health Sciences, University of Rwanda, Kigali, Rwanda
[b] Department of Social Sciences and Humanities, University of Parma, Parma, Italy
[c] Department of Economy, University of Parma, Parma, Italy
[d] Department of Physiotherapy, International Committee of the Red Cross – ICRC, Geneva, Switzerland
[e] Department of Physiotherapy, College of Medicine and Health Sciences, University of Rwanda, Kigali, Rwanda
[f] Department of Public Health, College of Medicine and Health Sciences, University of Rwanda, Kigali, Rwanda
[g] Department of Business Administration, College of Business and Economics, University of Rwanda, Kigali, Rwanda
[h] Center for Research and Innovation, College of Medicine and Health Sciences, University of Rwanda, Kigali, Rwanda

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ABSTRACT

Background: The alarming prevalence of non- or poor adherence to Home-based Exercise Programs (34–79.2 %, HEP) in parents of Children with Cerebral Palsy (C-CP) is a global health concern due to its detrimental effect on treatment outcomes.
Objective: To examine whether Perceived Therapist Guidance and Advice (TGA) or social support moderate the effects of PTSD, depression, parenting stress, low self-efficacy, the burden of care, or the effects of perceived family stigma on adherence to HEP.
Method: A stratified random sample of 301 mothers of C-CP attending the largest seven physical rehabilitation hospitals or centres in Rwanda participated in this study. Data were collected using validated measures of all investigated constructs. We conducted hierarchical multiple linear regressions, and the nature of moderation was scrutinized using the process macro 4.1 model number 1 within SPSS version 28.
Results: The prevalence of adherence to HEP in the present sample was 32.9 %. Mothers' TGA and social support were positively associated with adherence to HEP; whereas mothers' stressors, including PTSD, parenting stress, depression symptoms, low self-efficacy, burden of care, and family stigma were negatively associated with adherence to HEP. In addition, TGA significantly moderated the associations of the different mothers' stressors with adherence to HEP, leading to increased HEP adherence for mothers with high stressor levels. Social support did not moderate any of these associations. Our respondents often reported poor family and friends' social support due to family stigma-related to caring C-CP.
Conclusions: Therapists play a vital role by providing education, support, and counselling to parents, emphasizing the importance of adherence, and addressing any stigma-related concerns,

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* Corresponding author. Department of Clinical Psychology, College of Medicine and Health Sciences, University of Rwanda, Kigali, Rwanda.
E-mail address: niyonsengajaphet74@gmail.com (J. Niyonsenga).

especially for mothers who experience high levels of stress. Therapists should be aware that mothers of C-CP frequently relied solely on their support to improve adherence to HEP.

1. Introduction

Cerebral palsy (CP) encompasses a range of lifelong neurological conditions impacting muscle tone, posture, mobility, and hand function [1]. Its prevalence is approximately 1.8–2.3 per 1000 children globally [1–3] and 2–10 per 1000 in Africa [4,5]. CP commonly presents with comorbidities, such as epilepsy (35–66.36 %) [6,7], speech impairment (43.5 %), visual impairment (25–58 %) [7,8], and cognitive impairment (24 %) [7]. The severity of motor problems varies, from mild to very severe, often leading to complete dependency on caregivers [1,9].

A home-based exercise program (HEP) in paediatric patients is a treatment extension in which a medical professional trains parents or caregivers on how to carry out the recommended program at home and between physical therapy visits [10,11]. HEP is one of the most robust rehabilitation strategies worldwide for a range of clinical conditions. Compelling evidence shows that the HEP accounts for 50–80 % of total therapy received by children with cerebral palsy (C-CP) and delivers positive clinical outcomes [9,11–13]. Worryingly however, a recent review of parents with C-CP has shown that the rate of non or poor adherence to HEP in different countries ranges from 34 % to 79.2 % [14], exceeding the global prevalence in adult patients (50%–66 %), [15,16]. Non or poor adherence to HEP in parents was reported to be the primary reason for treatment failure in cerebral palsy [15] and is related to unnecessary and harmful changes in the treatments proposed by health professionals [15].

Based on the latest review [14], much research has been devoted to investigating the factors underlying the poor adherence to HEP among parents of C-CP in the last two decades. These factors may be categorized as parental-related factors, child-related factors, and physiotherapist guidance and advice-related factors [14]. Parent-related factors include parental self-efficacy [17–20], parental depression and anxiety [20–22], parenting stress and emotional burden [20,23], social support [17,18,20,24,25] and education [16, 18,22,26]. Child-related factors focus on gross motor functions and child's age [17,18,23]. Regarding therapist guidance and advice, the factors include the number of exercises prescribed, their outcomes, the absence of adverse outcomes, and the level of physiotherapist support [17–22,24].

The factors contributing to non- or poor adherence to HEP by parents of C-CP may vary in different contexts, but a recent review [14], has indicated that only one qualitative study was conducted in African contexts to address this question [25]. We hypothesised that parents of C-CP in these contexts may experience a heightened burden of care, PTSD symptoms, parenting stress, and family stigma due to cultural stereotypes and community perceptions of the disability, low education, and financial constraints. Other factors could also contribute to non- or poor adherence to HEP related to parental stress. Scholars have found that parents may be at a greater risk of developing mental disorders [27–29], because of a variety of related stresses, such as increased caregiver duties and financial pressures [30]. Similarly, scholars have found that mothers of CP may report more physical and mental problems than mothers of typically developing children [28] which in turn may hamper the health care and well-being of a child with CP [31,32]. It has been also shown that caring for a child with a disability, cerebral palsy puts an emotional burden on parents, which might contribute to future mental health problems [27–29].

We aim at contributing to the scientific literature by assessing the interrelationship between the burden of care, mental disorders, self-efficacy, family stigma, social support, perceived Therapist Guidance and Advice (TGA), and adherence to HEP among parents of C-CP. Notably, this study explores the moderating role of parental perceptions of TAG on the factors influencing adherence to home exercise programs (HEP) in the context of paediatric cerebral palsy rehabilitation. Despite the recognized importance of TAG in promoting adherence to HEP [17–22,24], there exists a gap in understanding how parents' perceptions of this TGA influence their adherence behaviours. This study seeks to bridge this gap by investigating the extent to which parental perceptions of TAG can impact adherence to HEP, acknowledging that these perceptions may not always align with the actual TAG provided. Understanding this distinction is crucial, as parental perceptions can significantly influence rehabilitation outcomes, potentially more so than the actual TAG received.

Evaluating the effects of TAG on adherence to HEP among parents of C-CP because it is a dimension that can easily be 'managed' by health professionals, though overlooked by researchers. Faced with parents who arrive with their own problems that are difficult to modify, it may be important to be able to model the kind of support that can still help them to adhere to HEP. When therapists provide education, support, and counselling to parents, emphasize the importance of adherence, and address any stigma-related concerns that may enhance coping strategies with mental disorders' symptoms, caring burden as well as increasing parental self-efficacy may upturn adherence to HEP. As such, we hypothesised that therapist guidance and advice would moderate the associations of parenting stress, depression, PTSD symptoms, the burden of care, self-efficacy, and family stigma on adherence to HEP. Despite the recent inclusion of the child's illness among traumatic events [33,34], the relationship between PTSD symptoms and adherence to HEP among parents of C-CP has never been explored [14]. Given Rwanda's recent history, we examined how parental PTSD symptoms related to the 1994 Genocide against the Tutsi can affect caring for C-CP, family stigma stemming from community misconceptions of the disability, and ultimately hamper adherence to HEP in parents of C-CP.

We further hypothesised that social support would moderate the associations of these mental disorders, the burden of care, self-efficacy, and family stigma with adherence to HEP. Consistently, evidence shows that social support generally has a positive impact on the psychological well-being of people [35] and that higher levels of social support can lessen the negative effects of stressful events on a person's mind and body, weaken the link between stress and mental disorders and thus lessen the severity and generation

of mental disorders [36,37]. Family and friend support lower psychological stress, caring burden, and stigma, and improves well-being, promoting psychological health and preventing depression in later life [37]. Social support also makes people feel loved and cared for, which is good for combating family stigma, and the maintenance and growth of physical and mental health [38]. This may undoubtedly increase parental involvement in HEP. Similarly, scholars have evidenced the moderating effect of social support in the relationship between mental depression and physical activity in older adults [38].

2. Methods

2.1. Study design, participants, and procedure

This study employed a multicenter, cross-sectional design with self-reported questionnaires, aimed at efficiently capturing a snapshot of the experiences and challenges of mothers of C-CP. This method was selected for its effectiveness in collecting broad data across various geographical areas within a constrained timeframe. Three hundred and one mothers were selected from the largest seven physical rehabilitation hospitals and centres, representing all Rwandan provinces (HVP Gatagara Nyanza, HVP Gatagara Gikondo, Heroes Day-care Centre, Rilima Paediatric Orthopaedic and Rehabilitation Centre, Inkurunziza Orthopaedic Specialized Hospital, and Murunda district hospital). Moreover, the principal investigator did the data collection in collaboration with the head of the departments of physiotherapy and occupational therapy for reaching the respondents. Acknowledging the potential literacy challenges among participants, the study implemented oral administration of questionnaires for those with literacy issues. Trained researchers and local healthcare professionals provided support, ensuring understanding and accurate responses, thereby safeguarding participant welfare and data reliability. Ethical clearance was sought from the Institutional Review Board of the College of Medicine and Health Sciences and written informed consent was obtained from all participants. Participation was anonymous, and participants could withdraw from the study at any time.

2.2. Sample size

The mapping activities were initially conducted to estimate the population of parents of C-CP in the largest rehabilitation hospitals and centres, identifying 700 paediatric cases of CP on a trimestral basis. Thereafter, the Yamane's formula [39] was applied to estimate the sample size for this study ($n = N/(1+N*e^2)$). Where n is the sample size, N is the population size (N = 700), and e = marginal error (e = 0.05). The formula led to the sample size of n = 254 which was required according to Yamane, to get the best statistical power. Assuming a non-response rate of 20 %, the final sample size was therefore adjusted upward to n = 254 +(254*20 %) = 305. This non-response rate aligned with the literature recommendation that medical research should incorporate a 20 %–30 % increase over the minimum necessary sample size to accommodate potential non-response subjects [40]. A stratified random sampling method was applied to estimate the number of respondents required in each hospital or centres. A random sample was taken from each stratum (i. e., hospital) in proportion to its size relative to the total population. Randomization was conducted using the Excel sheet based on the list of parents with C-CP attending paediatric rehabilitation services in each hospital (stratum). The actual non-response rate in the current study was 1.3 % (n = 4).

2.3. Inclusion and exclusion criteria

The inclusion criteria included being Rwandan and being a mother of C-CP aged below 14 years. The mothers were excluded if they demonstrated unstable medical or psychiatric conditions that would impair communication.

2.4. Data collection tools and cultural translation

To ensure cultural relevance and accessibility of the measurement scales, a comprehensive 3-week workshop supported by Humanity & Inclusion was held. This workshop, involving multidisciplinary professionals focused on selection, content validity, cultural adaptation, translation, and piloting of the scales, including the therapist involvement and support scale. The workshop involved 15 physiotherapists, 4 occupational therapists and 6 prosthetists and orthotists, 5 nurses, 4 mental health professionals, 4 social workers, 1 physician and 4 individuals in charge of quality improvement. Any disagreement was resolved by a discussion.

Evidence of scale accessibility and relevance was ensured through piloting with the target population, with adjustments made based on feedback to enhance comprehension and cultural appropriateness. The choice of scales, including the therapist involvement and support scale, was based on their established validity and adaptability to the Rwandan context, as confirmed through the comprehensive workshop process. This method was preferred over others due to its ability to facilitate large-scale data collection on sensitive topics such as mental health and caregiver burden, while also allowing for the cultural adaptation of measurement tools.

2.4.1. Adherence to the home exercise program questionnaire

Adherence to home-based rehabilitation strategies was assessed using the Adherence to home exercise program questionnaire [17, 24]. The questionnaire has 9 items concerning the extent parents adhere to HEP and each item is scored on a five-point Likert scale ranging from never (0) to every day (4). The total score ranges from 0 to 36, with at least 18 as a cut-off score. The Cronbach's alpha was $\alpha = 0.82$ in the current study.

2.4.2. Therapist involvement and support scale

The therapist involvement and support scale were used to measure the extent to which parents perceived they are receiving support, guidance, and advice regarding the implementation of the home exercise program for children [17]. It's important to note that this scale does not measure the actual level of support, guidance and advice provided by therapists but rather captures the parents' subjective perception of this support, guidance, and advice. The scale had 7 items scored on a six-point Likert scale ranging from never (0) to every day (5). The Cronbach's alpha was 0.76 in this study.

2.4.3. The patient health Questionnaire-9 (PHQ-9) and generalized anxierty-7

The PHQ-9 and GAD-7 are self-reported questionnaires that assess depression (9 items) and anxiety (7 items) respectively. The scales were scored on a 4-point Likert scale graded from 0 (never) to 3 (almost every day), [41]. The total score can range from 0 to 27 for depression and from 0 to 21 for anxiety. The cut-off score for probable diagnosis is 8 for depression and 6 for anxiety diagnosis [42]. The Cronbach's alpha was $\alpha = 0.91$ for depression and $\alpha = 0.92$ for anxiety in the current sample.

2.4.4. The Parenting Stress Index/Short Form (PSI)

The Parenting Stress Index/Short Form (PSI) is a 36-item instrument designed to measure the source and magnitude of stress in the parent-child relationship [43]. PSI has three subscales: parental Distress (12 items, $\alpha = 0.914$), Parent-Child Dysfunctional Interaction (12 items, $\alpha = 0.70$) and Difficult Child (12 items, $\alpha = 0.814$). Each item is scored on a 5-point Likert ranging from 1 (strongly disagree) to 5 (strongly agree). A total score ranged from 36 to 180 and the scores at least 90 indicate a clinical level of stress. The Cronbach's alpha for a total scale was 0.89 in the current sample.

2.4.5. The brief PTSD screener (PCL-6)

The six-item post-traumatic stress disorder (PTSD) Checklist (PCL-6) [44], is an abbreviated version of the 17-item PCL Civilian Version [45]. PCL-6 includes two items that assess the main two symptoms of each of the three clusters from original version (re-experiencing, avoidance, and hyperarousal). PCL-6 ratings vary from 6 to 30, with each item scored on a 5-point Likert scale (1–5). A cut-off score of 10 is used for a probable diagnosis of PTSD. The Cronbach's alpha was 0.86 in the current sample.

2.4.6. The Zarit Burden of care interview

The Zarit Burden of Care Interview is a self-administered measure consisting of 22 items designed to assess the experience of the burden in caregiving [46]. It evaluates the caregiver's health, psychological well-being, social life, finances, and the relationship between the mother and C-CP. Each item is rated on a 5-point Likert-type scale ranging from never (0) to nearly always (4). In congruence with the original validation of the scale [46], we found five factors: health, psychological well-being, social life, finances, and relationship with the care recipient [46] in this study. Scale reliability was good in the current sample ($\alpha = 0.87$). The burden was categorized as little or no burden (20), mild (21–40), moderate (41–60), or severe (>60) based on the total score.

2.4.7. The multidimensional scale of perceived social support

The Multidimensional Scale of Perceived Social Support [47] was a 12-item scale that uses a 5-point Likert scale (1 = strongly agree to 5 = strongly disagree) to assess the perceived adequacy of social support from three sources: family, friends, and significant other. The Cronbach's alpha was 0.95 in the current study.

2.4.8. The Family Stigma Instrument (FAMSI)

The Family Stigma Instrument (FAMSI) was a 26-item self-report measure of family stigma as experienced by family caregivers of individuals with intellectual and developmental disabilities [48]. FAMSI assessed perceived family stigma (8 items, $\alpha = 0.96$), its application to self and internalization (affiliate stigma: 12 items, $\alpha = 0.84$), and positive aspects of caregiving across five factors (6 items). This study used the first two subscales of the tool. The participants rated each item on a 5-point Likert-type scale, from strongly disagree (1) to strongly agree (5). The Cronbach's alpha was 0.92 in the current sample.

2.4.9. The General Self-Efficacy Scale (GSES)

The General Self-Efficacy Scale (GSES) was utilized to measure parental self-efficacy [49]. This 10-item scale, scored on a 4-point Likert scale ranging from 1 ("Not at all true") to 4 ("Exactly true"), assesses an individual's belief in their ability to cope with a wide range of stressors. The GSES is designed to gauge optimistic self-beliefs in problem-solving and managing unexpected events, with total scores ranging from 10 to 40, where higher scores indicate greater self-efficacy. The scale is renowned for its high reliability, validity, and applicability across diverse cultural contexts, making it an ideal tool for exploring how parental self-efficacy affects adherence to home exercise programs for children with cerebral palsy. The Cronbach's alpha was 0.93 in the current sample.

2.5. Statistical analysis

We computed means and standard deviations for all continuous variables using SPSS software (Version 28). Prevalence rates of mental disorders, and family stigma were generated through frequency counts and percentages. Pearson's r coefficient was used to assess the zero-order correlation between adherence to HEP and continuous variables including mother's age. Furthermore, we conducted independent *t*-test to examine the associations between binary sociodemographic variables (child's age, child's gender and having a sponsored project) and adherence to HEP, whereas one-way ANOVA explore the relationships involving sociodemographic

variables with more than two categories (marital status, education level, province, social category among others). The PROCESS macro model number 1 within SPSS version 28 [50] was used for moderation analyses. Two separate hierarchical regression analyses were computed based on R-square change where additional variables are added to the model predicting adherence to HEP. The first model explored the culturally and contextually relevant factors (i.e., PTSD, depression, and family stigma) of adherence to HEP; and how their interaction with therapist guidance and Advice (TGA) were associated with adherence to HEP. The second model explored common factors of adherence to HEP known from the literature (burden of care, parenting stress, and self-esteem); and how their interaction with TGA were associated with adherence to HEP. To better understand the significant interactions, simple slopes were examined to assess the relationship between perceived burden of care, mental disorders, and HEP across two levels of the moderating variables (TGA and social support levels at $-1SD$, $+1SD$), while controlling for demographic covariates that we significantly associated with HEP (i.e., child's age and mother's education), with 5000 bootstrapped samples. As all variables were continuous, they were mean-centred before inclusion in regression for multicollinearity concerns.

3. Results

3.1. Sociodemographic characteristics

A total of 301 mothers of C-CP were selected to participate in the current study. The age range of the respondents was 18–55 years old (mean = 35.5 years, SD = 10). The most represented social category was the 2nd social category (43.5 %) while none of the participants was in the 4th social category. Most participants identified as married or cohabitating (n = 240, 79.8 %), were jobless (n = 143, 47.5 %) or farmers (n = 88, 29.2 %), and had completed a primary school level (n = 72, 23.9 %). Full information on the demographics of this sample may be found in **Appendix 1**.

The rate of adherence to HEP was 32.9 % in the current sample, whereas 67.1 % of the respondents were not adherent. Further, the prevalence of probable depression stood at 61.3 %, PTSD symptoms at 57.5 %, anxiety disorder at 73.4 % and parenting stress stood at 81.4 %. The respondents who reported moderate to severe burden of care was 81.4 %.

3.2. The correlates of adherence to HEP in mothers of children with cerebral palsy

As shown in Table 1, the strongest correlates of adherence to HEP were PTSD Symptoms (r = −0.48, p < 0.001), therapist guidance and advice (r = 0.41, p < 0.001), parenting stress (r = −0.40, p < 0.001), generalized anxiety (r = −0.39, p < 0.001), burden of care (r = −0.33, p < 0.001), self-efficacy (r = 0.30, p < 0.001), perceived family stigma (r = −0.30, p < 0.001), and depression symptoms (r = −0.29, p < 0.001). Moreover, parental mental disorders were strongly related to perceived family stigma, and social support (see Table 2). Also, adherence to HEP was significantly related to mother's education level (r = 0.13, p = 0.020) and child age (r = −0.19, p = 0.001), while no significant associations appeared with caregiver age (r = 0.07, p = 0.260), Social category (p = 0.15), occupation (p = 0.120), sex of child (p = 0.85) and marital status (p = 0.320).

3.3. Moderation analyses

3.3.1. Moderating effect of perceived therapist guidance and advice in the relationship between depression, PTSD symptoms, perceived family stigma and adherence to HEP

Table 2 depicts each of the hierarchical models predicting adherence to HEP. Elevated child age (b = −0.48, SE = 0.2, β = −0.14, p = 0.01) and high education attainment (b = 0.84, SE = 0.26, β = 0.18, p = 0.002) were respectively associated with low and high adherence to HEP (Adj.R^2 = 0.063). Once perceived family stigma (PFS) was added to the model in step 2, only education level, and PFS were significantly associated with adherence to HEP (ΔR^2 = 0.035). However, when therapist guidance and advice (TGA) was added to the model in Step 3, only TGA, child's age and education level were significantly associated with adherence to HEP (ΔR^2 = 0.161). Once depression symptom severity was added to the model in Step 4, only TGA, the child's age and education level remained significant predictors of adherence to HEP (ΔR^2 = 0.01). In step 5, PTSD symptoms, TGA, child's age, and education level were the only

Table 1
Descriptive statistics and intercorrelation between investigated variables.

	M(SD)	AHEP	Dep	TG &A	PTSD	PSS	BC	SE	PSI	DC
HEP Adherence (AHEP)	14 (7)									
Depression (Dep)	10.3 (7)	−0.28[a]	−							
Therapist guidance and advice (TI)	14 (5)	0.41[a]	−0.32[a]	−						
PTSD symptoms	9.6 (6)	−0.48[a]	0.54[a]	−0.28[a]	−					
Social support (PSS)	28 (22)	0.34[a]	−0.28[a]	0.17[a]	−0.36[a]	−				
The burden of care (BC)	47.4 (41)	−0.33[a]	0.22[a]	−0.14[b]	0.43[a]	−0.30[a]	−			
Self-efficacy (SE)	15 (8)	0.30[a]	−0.45[a]	0.23[a]	−0.41[a]	0.36[a]	−0.21[a]	−		
Parenting stress (PS)	110.3 (24)	−0.4[a]	0.53[a]	−0.37[a]	0.62[a]	−0.44[a]	0.53[a]	−0.4[a]	−	
Perceived family stigma (PFS)	**21(11.6)**	**−0.3[a]**	**0.44[a]**	**−0.14***	**0.47[a]**	**−0.44[a]**	**0.46[a]**	**−0.3[a]**	**0.57[a]**	**0.40[a]**

[a] Correlation is significant at the 0.01 level (2-tailed).
[b] Correlation is significant at the 0.05 level (2-tailed).

Table 2

Hierarchical regression model for culturally and contextually relevant factors predicting adherence to HEP.

	Steps 1 & 2		Step 3		Step 4		Step 5		Step 6	
	b (SE)	β	b (SE)	β	b (SE)	β	b (SE)	β	b (SE)	β
Child's age	−0.31 (0.2)	−0.09	−0.48** (0.18)	−0.14	−0.54** (0.18)	−0.16	−0.6** (0.17)	−0.176	−0.19 (0.11)	−0.056
Mother's education	0.55* (0.27)	0.12	0.71** (0.24)	0.16	0.68** (0.24)	0.15	0.52* (0.23)	0.115	0.39* (0.14)	0.087
Perceived family stigma (PFS)	−0.14*** (0.04)	−0.23	−0.09** (0.033)	−0.15	−0.064 (0.037)	−0.10	0.000 (0.03)	0.001	0.012 (0.023)	0.020
TGA			0.59*** (0.07)	0.41	0.56*** (0.07)	0.337	0.49*** (0.07)	0.337	0.098* (0.05)	0.08
Depression					−0.096 (0.057)	−0.098	−0.034 (0.57)	0.035	0.08* (0.04)	0.081
PTSD							−0.4*** (0.07)	−0.37	−0.26*** (0.04)	−0.223
Depression x TGA									0.06*** (0.003)	0.75
PTSD x TGA									−0.02*** (0.005)	−0.122
PFS x TGA									−0.006* (0.003)	−0.074
Adjusted R²	0.105[a]		0.265		0.270		0.355		0.742	
ΔR²	0.035		0.161***		0.01		0.085**		0.375***	

[a] Estimate is for Step 2 (Step 1 Adjusted R² = 0.07).**Abbreviations**. b, unstandardized coefficient; β, standardized coefficient; SE = standard error; PTSD, posttraumatic stress disorder; TGA, therapist guidance and advise; PFS, perceived family stigma; ***P < 0.001; **p < 0.01; *P < 0.05.

predictors of adherence to HEP (ΔR² = 0.085). For PTSD, as symptom severity increased, adherence to HEP decreased. In the final model, TGA, mother's education, depression and PTSD symptom severity remained significant independent predictors of adherence to HEP, and the three interaction terms (depression x TGA, PTSD x TGA, PFS x TGA) were also significant (Adj.R² = 0.742, ΔR² = 0.375), Table 2.

To probe the interaction effects on adherence to HEP, the simple slopes of Depression, PTSD symptom severity and perceived family stigma on adherence to HEP were analysed under conditions of low therapist guidance and advice (−1 SD), and high therapist guidance and advice (+1 SD), (see Figs. 1–3). Fig. 1 demonstrates that at −1SD, elevated PTSD symptom severity was significantly associated with reduced adherence to HEP (b = −0.55, t = −7.05, p < 0.001); whereas at +1 SD, greater PTSD symptom severity is associated with a small decline in the adherence to HEP (b = −0.36, t = −4.05, p < 0.001). This indicates a consistently negative impact of PTSD symptom severity on adherence to HEP regardless of the level of therapist guidance, but the negative effect is attenuated with higher therapist guidance.

Furthermore, Fig. 2 shows that at -1SD, elevated depression severity was associated with a significant decrease in adherence to HEP (b = −0.32, t = −4.97, p < 0.001). However, at +1SD, greater depression symptom severity was no longer associated with declines in adherence to HEP (b = 0.027, t = 0.40, p = 0.686), suggesting that high therapist guidance mitigates the negative impact of depression severity on adherence to HEP. The same pattern was found for perceived family stigma at -1SD (b = −0.303, t = −6.73, p < 0.001) and at +1SD (b = −0.0294, t = −0.73, p = 0.462), Fig. 3.

In summary, the interaction effect analysis reveals that the impact of perceived family stigma, PTSD, and depression symptom
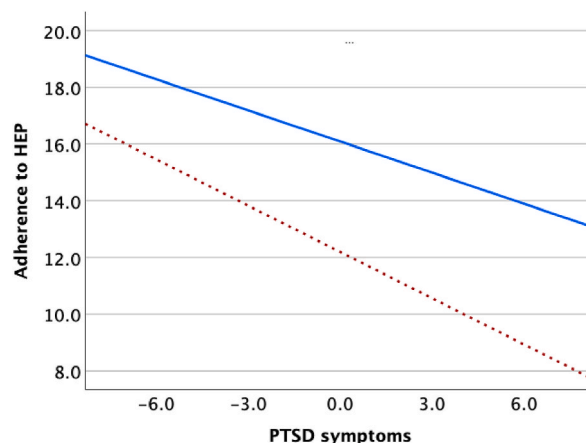

Fig. 1. Level of adherence to HEP, according to PTSD symptom severity, across two levels of perceived therapist guidance and advice.
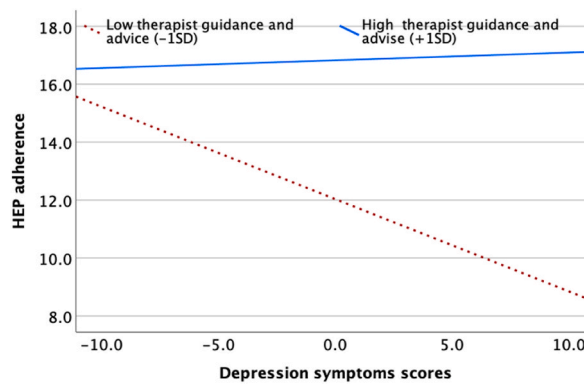
Fig. 2. Level of adherence to HEP, according to depression symptom severity, across two levels of perceived therapist guidance and advice.
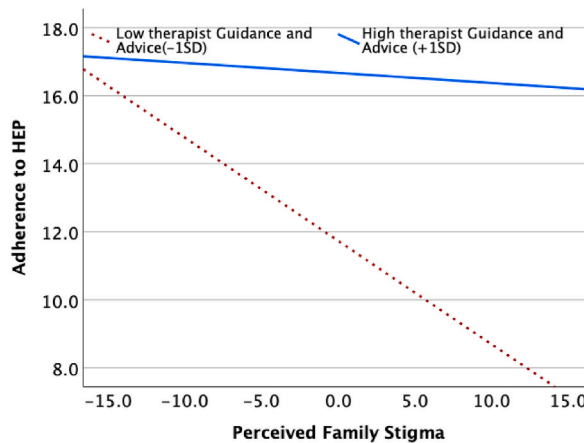

Fig. 3. Level of adherence to HEP, according to perceived family stigma severity, across two levels of perceived therapist guidance and advice (low versus high).

severity on adherence to HEP is negative at low levels of therapist advice guidance and advice, these negative effects are significantly reduced or rendered non-significant at high levels of therapist guidance and advice. Therefore, the direction of the interaction effects is consistently negative for low therapist guidance and advice and becomes negligible or positive with high guidance and advice.

3.3.2. Perceived therapist guidance and advice moderate the effects of the burden of care, parenting stress, and self-efficacy on adherence to a home exercise program

Table 3 depicts each of the hierarchical models predicting adherence to HEP. Elevated child age (b = −0.48, SE = 0.2, β = −0.14, p = 0.01) and high education attainment (b = 0.84, SE = 0.26, β = 0.18, p = 0.002) were respectively associated with low and high adherence to HEP (Adj.R^2 = 0.063). Once the burden of care (BC) was added to the model in step 2, only education level, and BC were significantly associated with adherence to HEP (ΔR^2 = 0.086). Parenting stress was added to the model in step 3, only parenting stress, caregiver burden of care, and education level were significantly associated with adherence to HEP (ΔR^2 = 0.06). Once self-efficacy was added to the model in step 4, only self-esteem, parenting stress, caregiver burden of care, education level and self-esteem were only predictors of adherence to HEP (ΔR^2 = 0.021). In step 5, therapist guidance and advice (TGA), child's age, education level, caregiver burden of care and self-efficacy remained significant predictors of adherence to HEP were the only predictors of adherence to HEP (ΔR^2 = 0.099). In the final model, TGA, mother's education, child's age, education level, caregiver burden of care and self-efficacy severity remained significant independent predictors of adherence to HEP, and the three interaction terms (burden of care x TGA, parenting stress x TGA, self-efficacy x TGA) were also significant (Adj.R^2 = 0.372, ΔR^2 = 0.056), Table 3.

To probe the interaction on adherence to HEP, the simple slopes of caregiver burden of care (CBC), parenting stress symptoms severity, and self-efficacy on adherence to HEP were analysed at low (−1 SD) and high (+1 SD) therapist guidance and advice scores (see Figs. 4–6).

Fig. 4 shows that at −1SD, higher caregiver burden of care scores was significantly associated with greater declines in adherence to HEP (b = −0.16, t = −4.73, p < 0.001), whereas at +1 SD the strength of the association was reduced by almost half (b = −0.09, t = −2.82, p = 0.005). Furthermore, Fig. 5 illustrates that elevated parenting stress symptoms at -1SD were associated with a significant decrease in adherence to HEP (b = -0.11, t = -5.17, p < 0.001) while at +1SD greater parenting stress symptom severity was associated

Table 3

Hierarchical regression model for theoretically known factors predicting adherence to HEP.

	Steps 1 and 2		Step 3		Step 4		Step 4		Step 5	
	b (SE)	β	b (SE)	β	b (SE)	β	b (SE)	β	b (SE)	β
Child's age	−0.32 (0.19)	−0.09	−0.31 (0.18)	−0.09	0.66* (0.24)	0.15	−0.47** (0.17)	0.17	−0.44** (0.17)	−0.13
Mother's education	0.76** (0.25)	0.17	0.72** (0.24)	0.16	−0.34* (0.18)	−0.1	0.75*** (0.22)	−0.14	0.69** (0.22)	0.15
Caregiver burden of care	−0.14*** (0.025)	−0.3	−0.07** (0.029)	−0.15	−0.07 (0.03)	−0.15	−0.08** (0.03)	−0.17	−0.10***	−0.21
Parenting stress			−0.09*** (0.018)	−0.29	−0.07 (0.02)	−0.22	−0.03 (0.02)	−0.10	−0.02 (0.02)	−0.07
Self-efficacy					0.14 (0.05)	0.16	0.12** (0.05)	0.13	0.14** (0.04)	0.16
PGA							0.5*** (0.07)	0.34	0.5*** (0.07)	0.35
BCxPGA									0.014*** (0.004)	0.23
PSIxPGA									−0.01** (0.003)	−0.19
SELxPGA									0.02** (0.007)	0.14
Adjusted R²	0.148		0.205		0.224		0.321		0.372	
ΔR²	0.086***		0.06*		0.021		0.099***		0.056**	

Abbreviations. b, unstandardized coefficient; β, standardized coefficient; SE = standard error; SEL, self-efficacy; BC, burden of care; TGA, therapist guidance and advise; PSI, parenting stress; ***P < 0.001; **p < 0.01; *P < 0.05.
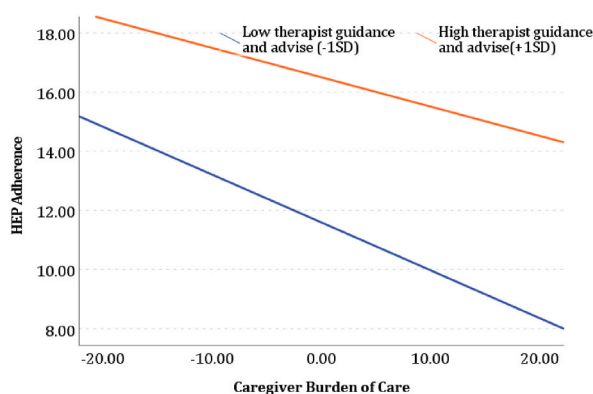

Fig. 4. Levels of adherence to HEP, according to caregiver burden symptom severity, across two levels of perceived therapist guidance and advice.
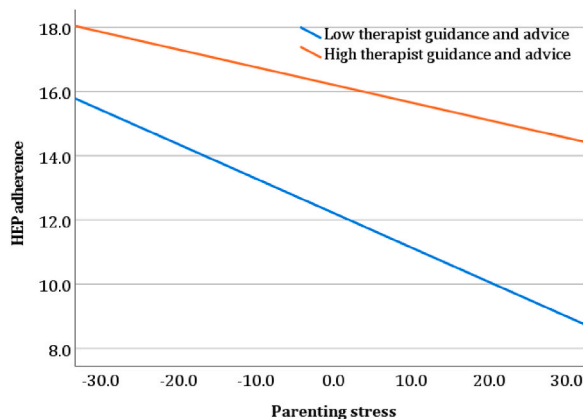

Fig. 5. Levels of adherence to HEP, according to parenting stress symptom severity, across two levels of perceived therapist guidance and advice.
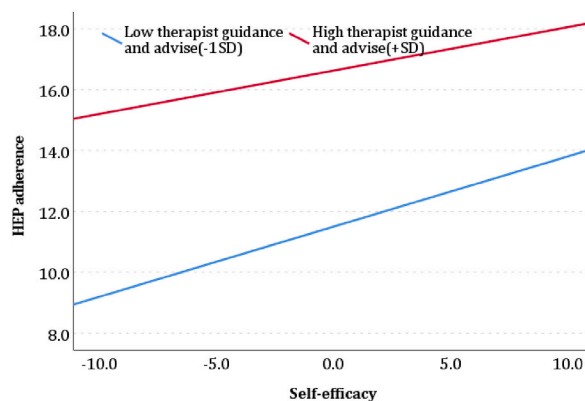
Fig. 6. Levels of adherence to HEP, according to self-efficacy scores, across two levels of perceived therapist guidance and advice.

with smaller declines in adherence to HEP (b = -0.06, t = 2.51, p = 0.013). Fig. 6 indicates that at -1SD, high self-efficacy scores (b = 0.23, t = 3.82, p < 0.001) were associated with high adherence to HEP, but at +1SD high self-efficacy was related to low adherence to HEP (b = 0.14, t = 2.07, p = 0.04), suggesting that parents with high self-efficacy only need low therapist guidance and advice.

These results demonstrate that the negative impacts of caregiver burden and parenting stress on adherence to HEP are mitigated by higher therapist guidance, whereas the positive impact of self-efficacy on adherence decreases with increased guidance.

3.4. Moderating effects of social support

Our findings highlight that social support was low in the current sample; and that social support was positively related to adherence to HEP. To examine the moderating effects of social support, we replicated the above hierarchical regression models by replacing therapist guidance and advice with social support. The results showed that social support did not moderate the effects of maternal mental disorders (PTSD symptoms, depression, parenting stress), the burden of care, self-efficacy, or the effects of perceived family stigma on adherence to HEP.

4. Discussion

To the best of our knowledge, this is the first quantitative study to explore in detail the factors affecting mothers that predict adherence to HEP conducted in Africa or post-genocide countries. To bridge the literature gap revealed in the recent systematic review of the factors of adherence to HEP in mothers of C-CP [14], this study was guided by four main objectives. First, we sought to explore whether contextual factors such as PTSD, depression symptoms and family stigma were related to adherence to HEP. Secondly, we explored whether perceived therapist guidance and advice (TGA), and social support moderated these relationships in mothers of C-CP in Rwanda. Notably, the prevalence of probable PTSD (57.5 % versus 20 %) [51], depression (61.3 % versus 17.5–46 %) [52], and perceived family stigma were substantially higher in this study, compared to the previous similar studies. Worryingly, our findings showed that PTSD, depression, and perceived family stigma were strongly negatively associated with adherence to HEP in mothers of C-CP. But, encouragingly, we found that the impact of perceived family stigma, PTSD, and depression symptom severity on adherence to HEP decreased as therapist advice guidance and advice increased; to the extent that no significant impact of depression and perceived family stigma remained for those reporting high TGA. In other words, TGA moderated and reduced the associations between perceived family stigma, PTSD, depression symptom severity and adherence to HEP. On the contrary, even though social support is positively associated with adherence to HEP, there is no evidence that social support moderates the relationship between mothers' stressors and adherence to HEP.

Caring for C-CP can be demanding and stressful [53], which may contribute to the development or worsening (in the context of post-genocide situations) of PTSD symptoms. Consequently, PTSD symptoms such as intrusive thoughts, avoidance behaviours, and hyperarousal [34] may interfere with parents' ability to engage in and adhere to a prescribed HEP, and their willingness to confront the challenges it presents. They may experience difficulties in concentration, motivation, and emotional regulation, which can hinder their ability to consistently perform exercises with their children. The same can be thought for depression symptoms, a strong comorbid of PTSD. Our findings are congruent with other three studies that have found that symptoms of depression humper adherence to HEP among parents of children with CP [20–22].

This study also sheds light on the relationship between family stigma and adherence to home exercise programs and how therapist guidance and advice moderate this relationship. While several studies have explored stigma within families of C-CP and how it could affect caregivers' experiences differently [54–59], no study has associated it with adherence to HEP. It can be said that stigma can lead to feelings of self-doubt, guilt, and shame, and undermined the sense of competence and autonomy [48], which may undermine parental confidence in implementing the exercises effectively. It can also contribute to social isolation, limiting the availability of support networks and resources that could facilitate adherence.

Traditional beliefs related to disability especially in African contexts are powerful and pervasive. As in previous studies, Rwandan mothers reported carrying an excessive amount of caregiving responsibility, feeling embarrassed and undervalued by their husbands and in-laws due to cultural misconceptions of the disability [54–61]. They reported abandonment, marital discord, inability to remarry, domestic violence because of the blame placed on them, being insulted or negative language, getting dirty looks, and being 'blacklisted' by relatives and neighbours for having children with a disability in the context of Africa [54–61]. For instance, in Ghana, the children are perceived to cause misfortune to the family unless killed, and the mother is blamed for bringing misfortune into the family as an outsider [54,62,63]. Therefore, parents may pretend to hide the child from the community and other family members for the child's safety or fear the social stigma, thus exacerbating social isolation [54,59].

The third objective of this study was to shed light on how parenting stress, caregiver burden of care, and self-efficacy are related to adherence to HEP, and the fourth was to examine how therapist guidance and advice, and social support moderate these relationships. Supporting existing literature, our results confirmed that parenting stress and burden of care [20–22], and self-efficacy [17–20] are significantly associated with adherence to HEP among Rwandan mothers of C-CP. Interestingly, this study adds to the existing literature that therapist guidance and advice significantly moderated these relationships.

About social support, our findings highlight that social support was low in the current sample and that social support was positively related to adherence to HEP. However, social support did not moderate the association of the maternal mental disorders, the burden of care, self-efficacy, or the association of perceived family stigma on adherence to HEP. This contrasts with previous studies suggesting that social support can act as a buffer against stress and improve health outcomes [64,65]. For example, social support has been found to moderate the relationship between physical activity and depression in older adults [38], and reduce the negative impact of caregiving stress on mental health [65]. However, in our study, the lack of moderating effects of social support could be attributed to the cultural context and the nature of social support available to the mothers in Rwanda. The social support networks in this context may not be robust or reliable enough to buffer the stressors associated with caring for children with cerebral palsy. This finding underscores the importance of culturally tailored interventions that not only provide direct support but also strengthen community and social networks to enhance the efficacy of home exercise programs.

5. Conclusions

Our results highlight an alarming rate of PTSD, depression, stress, and family stigma among parents of C-CP. We found that PTSD, depression, parenting stress, family stigma, and self-efficacy as independent factors or in interaction with therapist guidance and advice (but not in interaction with social support) significantly predict adherence to HEP. Due to cultural misconceptions of disability, therapists should be aware that mothers of C-CP frequently relied solely on their support to improve adherence to HEP regardless of mothers' own coping strategies and resources. Therapists play a vital role by providing education, support, and counselling to parents, emphasizing the importance of adherence, and addressing any stigma-related concerns. Creating a supportive and inclusive environment, promoting positive attitudes, and fostering social connections can also help parents overcome stigma-related barriers and improve adherence. However, collaborative efforts between therapists and mental health professionals to address complex PTSD symptoms and parenting stress that may not easily improved by TGA can potentially improve adherence to HEP and enhance the overall well-being of both the parents and their C-CP. It's important to note that while social support did not moderate the association of mental disorders, caring burden, and self-efficacy with adherence to HEP, it can still have a positive impact on overall well-being and mental health. Social support can provide emotional comfort, companionship, and a sense of belonging, which are essential for individuals with mental disorders.

5.1. Study limitations and strengths

This study had some limitations. First, the study design, being cross-sectional warrants caution in generalizing findings to other populations. Second, the study noted the lack of participation of fathers, a point that gains significance when acknowledging that, during the study period, only mothers were naturally involved in receiving treatment. This situation aligns with the practical reality, especially in the Rwandan context, where maternal caregivers frequently serve as the primary figures in treatment interventions for children with cerebral palsy. About strengths, this study is pioneering in its quantitative exploration of adherence to HEP for mothers of children with cerebral palsy (C-CP) in post-genocide African settings, addressing a significant literature gap. It robustly investigates the psychological and social determinants of adherence, highlighting not only the detrimental effects of mothers' stressors but also the beneficial moderating influence of parental perceived TGA. By digging into the cultural context of disability and caregiving in Africa, the study offers vital insights into the impact of societal attitudes and family stigma on HEP adherence, underlining the importance of culturally sensitive therapeutic interventions. Overall, this study provides valuable directions for clinical practice and future research.

Data availability statement

The dataset of this study is publicly accessible in the Zenodo via the following link: https://doi.org/10.5281/zenodo.10613841.

CRediT authorship contribution statement

Japhet Niyonsenga: Writing – review & editing, Writing – original draft, Software, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Liliane Uwingeneye:** Writing – review & editing, Software, Project administration, Formal

analysis. **Inès Musabyemariya:** Writing – review & editing, Validation, Resources, Investigation. **Jean Pierre Nteziryayo:** Writing – review & editing, Resources, Investigation, Data curation. **Thèodat Siboyintore:** Writing – review & editing, Project administration, Investigation. **Jean Baptiste Sagahutu:** Writing – review & editing, Methodology, Formal analysis. **Francesca Cavallini:** Writing – review & editing, Supervision, Methodology, Conceptualization. **Rutembesa Eugene:** Writing – review & editing, Supervision, Methodology, Investigation, Formal analysis, Conceptualization. **Stefan Jansen:** Writing – review & editing, Writing – original draft, Supervision, Methodology, Investigation, Data curation, Conceptualization. **Nadia Monacelli:** Writing – review & editing, Writing – original draft, Supervision, Software, Methodology, Formal analysis, Data curation, Conceptualization. **Luca Caricati:** Writing – review & editing, Validation, Supervision, Software, Methodology, Formal analysis, Data curation. **Jean Mutabaruka:** Writing – review & editing, Validation, Supervision, Software, Methodology, Investigation, Formal analysis, Data curation, Conceptualization.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Appendix 1. Sociodemographic characteristics of the sample

Variables	Category	Frequency	Percentage	P value
Province				0.34
	Kigali	100	33.20	
	Eastern	24	8.1	
	Southern	75	21.01	
	Western	38	12.8 %	
	Northern	48	16.1 %	
Mother's Education Level				<0.001
	Illiterate	33	11.0 %	
	Not completed primary	67	22.3 %	
	Completed Primary	72	23.9 %	
	0 level	55	18.3 %	
	A level	38	12.6 %	
	University (A1, A0)	29	9.6 %	
	Post-graduate	7	2.3 %	
Occupation				0.10
	Farmer	88	29.2 %	
	Government employee	10	3.3 %	
	Student	2	0.7 %	
	TVET (carpentry, manicure and pedicure, hair salon etc)	8	2.7 %	
	No job	143	47.5 %	
	Business	26	8.6 %	
	Others	24	8.0 %	
Marital status				0.59
	Single	49	16.3 %	
	Married	195	64.8 %	
	Cohabitated	45	15.0 %	
	Divorced	12	4.0 %	
Social category				0.15
	1st	71	23.6 %	
	2nd	131	43.5 %	
	3rd	99	32.9 %	
	4th	0	0.0 %	
Having a sponsored project				0.41
	No	179	59.5 %	
	Yes	122	40.5 %	
Child age				<0.001
	<1 year	27	9.0 %	
	1–2 years	41	13.6 %	
	2–3 years	44	14.6 %	
	2–3 years	31	10.3 %	
	4–5 years	43	14.3 %	
	5–6 years	40	13.3 %	
	7–8 years	75	24.9 %	
Number of children with disability				0.167
	1	293	97.3 %	
	2	6	2.0 %	
	4	2	0.7 %	
Child's Gender				0.85
	Male	165	54.8 %	
	Female	136	45.2 **%**	

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