

Effect of Health Education intervention on Aroused Shame and Stress Level among Parents of Cerebral Palsied Adolescents

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Abstract

Health education is an effective approach for health-care management and developing healthy behaviors. It is principally important with family, caregivers, and mainly, with parents who have teenagers with profound disabilities such as cerebral palsy (CP). Parents' health teaching about their cerebral palsied adolescents may alleviate their psychological suffering. Nurses in adult care, psychiatric and mental health and nursing education fields have a significant role in developing the health educational process with those parents. **Aim of the study:** to determine the effect of health education intervention about cerebral palsied adolescents care management on parents' shame and stress level. **Design:** a quasi-experimental study. **Setting:** The study was conducted at the Vocational and Rehabilitation Association of Children with Special Needs and Disabilities in Elrasafa, Moharam Bek, Alexandria, Egypt, which is affiliated to the Ministry of Insurance and Social affair. **Subjects:** a purposive sample of one hundred parents with cerebral-palsied adolescents. Parents were randomly distributed into study and control groups, fifty in each. **Tools:** Through interview schedule procedure, triple section questionnaire was used in data collection, which included: **Parental Aroused Shame Scale (PAS), Parenting Stress Index Short Form (PSI-SF) – distress subscale, A Socio-Demographic assessment sheet.** **Results:** Results revealed that there was a significant decrease in parents' aroused shame and stress level post health education implementation, in the 2nd and 3rd assessments among the study group considerably. In addition, the study proved that there is a parallel positive relation between aroused shame and stress level among parents with CP adolescents. **Conclusion:** Health education intervention is a successful approach for nurturing aroused shame and stress level among parents with CP adolescents. **Recommendations:** Continuous health education programs for parents with CP adolescents are needed as well as investigation of its effects on other physical, psychological, intellectual, social, and spiritual parameters.

Key words: Health education, Parental aroused shame, Parenting Stress level, Cerebral palsied adolescents.

Introduction:

Health education is focused on the change in human behavior and nurturing attitudes with patients or healthy people. It is defined as "a process with intellectual, psychological and social dimensions related to educational activities that increase the abilities of individuals to make informed healthy decisions". It is also, considered as "the sum of all experiences that favorably influence knowledge, attitude and practice related to individuals' health". Families and patients with chronic diseases, post-traumatic stress disorders, depression, or cancer and disabilities are the ones who require continuous health teaching as a dynamic need to those conditions.

(Abd El Mohsen., 2009; Draper, 2009; Emam et al., 2020)

Hence, patient', family' and caregiver's health education is the most effective mean of restoring control of the chronic diseases. In the course of chronic illness such as cerebral palsy (CP) in which the affected patients have several complains, caregiver' health education is the key of preventive and curative methodology. It can nurture the negative physical and psychological impacts with both patients and their caregivers. Adult parents, primarily, with cerebral-palsied adolescents have many health educational needs, because, those adolescents are in a critical developmental stage, who need concentrated care (Abd El Mohsen., 2009;

Draper., 2009; Emam et al., 2020; Kiani et al., 2020; Rankin & Stallings., 2001).

Cerebral palsy (CP) is “a chronic neuro-developmental disorder, due to a non-progressive brain lesion, which is acquired early in life before, during or after birth causing motor disability” (Odding et al., 2006). It is characterized by dysfunctions in muscle tone, movement, or posture which cause activity limitations. This disability state is a long-lasting disorder. Due to differences in the size, type, and location of the brain lesion, there is a variety in the severity and type of dysfunctions that adolescent experience (Rosenbaum et al., 2007).

There are numerous categories of cerebral palsy, including diplegia, quadriplegia, hemiplegia, athetoid cerebral palsy, ataxic cerebral palsy, and mixed type. Therefore, the affected child, or adolescent suffers from sensory, motor and communication problems. In addition, intellectual, learning, behavioral, hearing and vision disturbances, poor balance and convulsions are the observed features with this persistent illness. They may have diminished muscle tone and atypical postural mechanism that is a basic element of CP sufferings. These various abnormalities lead to many problems with the performance of daily living activities tasks. (Dieleman et al., 2019; Goodman & Katz., 2008; Louw., 1998; Newey., 2008; Sue-Mae Gan et al., 2008).

In addition, the degree of neuromuscular and musculoskeletal damage accompanied with CP is greatly variable and, accordingly, motor function varies in ability to walk, play, and dependence on caregiver or using of assistive devices in mobility. These children often experience comorbid physical, cognitive, and social-emotional impairments, such as epilepsy, intellectual disability, and peer problems (Rosenbaum et al., 2007). In Egypt, CP incidences increase day by day Studies revealed that there is a correlation between good CP disorder's care-management and a the level of health education literacy of the caregivers (Elsayed et al., 2013; Mahmoud et al., 2016).

With cerebral-palsied adolescents, families, parents, or caregivers have a lot of responsibilities and problems which increased

with the degree of their adolescents' disabilities. The routine activities of feeding, toileting, grooming, hygiene, traveling, and communicating are considerable factors that affect parents' physical and emotional aspects. As well, the greater cost of care, treatment, and follow-up. (Chau., 2009; Dieleman et al., 2019;Imran et al., 2020; Masasa.,2005).

Therefore, parents are faced with insecurity about the child's development: they must consult medical experts on a regular basis, organize specific healthcare, and make practical adaptations to their daily life. Parents might also need to adapt their expectations regarding their parent-role, re-organize their family life, and learn specialized caregiving behaviors. (Pousada et al., 2013). Parents with cerebral-palsied adolescents often, are at risk for decreased levels psychosocial difficulties such as; depressive feelings, shame, and stress than those who have not (Brehaut et al., 2004; Guyard et al., 2017; Parkes et al., 2011; Pousada et al., 2013).

Shame and stress are the apparent psychological complaints among parents with cerebral-palsied adolescents. These negative emotions can affect adversely on parents' feelings and adolescent's educational success, interpersonal functioning, and life satisfaction in general. Aroused shame has been described by Harper in 2011 as "feelings of embarrassment, humiliation, guilt, inadequacy, worthlessness, incompetence, or contempt for oneself". It is a negative emotion that harmfully affects all aspects of parents' life. (Harper, 2011; Masasa, 2005)

Furthermore, stress is another parents' complaint with cerebral palsied adolescents. It is defined as “a state of mental and psychological tension and uneasiness triggered by life problems”. All parents' activities with disabled adolescents are full of stress and fear. (Akpinar et al., 2021; Bertule & Vetra., 2020; Chau., 2009; Harper., 2011) The most observed factors that provoke stress with those parents are unawareness about care-management, complications, child danger signs, and his/her safety, adolescent period' mood strikes, heterosexual relationships, and worry about the adolescent's prospect. Moreover, parents frequently have poor coping behaviors which

are approved leading factors to many stressful situations. (Chau., 2009; Gan et al., 2008; Imran et al., 2020; Louw., 1998; Mahmoud et al., 2016; Masasa., 2005)

On the other hand, parents with high health literacy and awareness about their adolescent's care management, have the greatest motives and aptitudes to appraise the threatening stressors and effectively deal with any negative emotions such as shame or stress. (Dieleman et al., 2019; Mahmoud, 2016; Syed et al., 2020) Accordingly, health education interventions may be the most effective and nurturing tool in aiding those parents. It tends to provide parents with understanding, and efficacy to deal with all their challenges with their CP adolescents. (Chau., 2009; Draper., 2009; Gan et al., 2008; Fathi., 2006; Fathi et al., 2015; Mahmoud et al., 2016)

Health teaching is a science that is derived from several fields to be inherited and equipped by the nurses as health educators who are obligated to apply standardized, and organized teaching approaches a unified element of nursing management process with such CP patients and their caregivers. Nurses in adult care, psychiatric & mental health and nursing education fields are the professionals who are able to apply different management and educational interventions related to many physical and/or psychological illnesses. (Abd El Mohsen., 2009; Chau., 2009; Emam et al., 2020; Fathi et al., 2015; Mahmoud et al., 2016)

Significance of the study

Studies have shown that parents with CP adolescents are mostly at risk to increase shame and stress levels. Accordingly, a more comprehensive and in-depth insight into their experiences is needed to better understand their sufferings and handle a fit support to them. Therefore, it is possible to use health education as a mediator to nurture the parenting experience of shame and stress. Consequently, it can improve parents' feelings, tolerance, and knowledge and care-management skills with their affected adolescents, and CP adolescent's care at all. Thus, the **aim of the current study** is to determine the effect of health education intervention about cerebral palsied adolescent's care-management on parents' shame and stress

level. To accomplish this aim, the hypotheses below were settled:

***H1:** Parents with cerebral palsied adolescents who receive health education intervention about their adolescents' care management exhibit lower aroused shame than those who do not.

***H2:** Parents with cerebral palsied adolescents, who receive health education intervention about their adolescents' care management exhibit lower stress than those who do not.

Material and method

Study design: A quasi-experimental design was utilized to accomplish this study.

Setting: The study was conducted at the Vocational and Rehabilitation Association of Children with Special Needs and Disabilities in Elrasafa, Moharam Bek, Alexandria, Egypt, which affiliated to the Ministry of Insurance and Social affair.

Subjects: The sample size was determined by an epidemiological statistical program (minimum sample size was 82 according to the **Fishers' formula $z^2pq/d2$**). The researchers decided to work on a purposive sample of 100 parents to overcome any data collection missing errors. The subjects are the parents who have cerebral palsied adolescents in the above-mentioned setting, with the following inclusion criteria: male and female, alert, able to read, write and communicate, considered a primary caregiver for the cerebral palsied adolescent and willing to participate in the study. Moreover, the CP adolescent should have such disorders since at least for three years, with motor, sensory, emotional, and social problems (as parent discussion), with moderate severity (that can be managed by caregiver, not hospitalization), have CP' type of Specific, Unilateral, OR Bilateral type and with one of the three levels of GMFCS (Gross Motor Function Classification System). CP should have no associated diseases, except, the CP multiple complains (such as joint stiffness or vision alteration). The subjects were randomly

assigned to either study group A or control group B with 50 parents in each group.

Tools: a triple section questionnaire was used through parents' structured interview. It includes the following tools:

Section I: Parental Aroused Shame Scale

(PAS): Parental Aroused Shame Scale (PAS) was developed by Anna Lau in 2013 to evaluate parental shame regarding their own children externalizing behaviors and academic performance. For the purpose of the present study, only the items relating to the children externalizing problems were used and the sum of scores was divided by 17 to calculate the mean. High scores indicated high aroused shame and vice versa. Based on interviewing approach, parents were asked to specify, to which level they accepted the phrase or the scale item and pointed on a 5-point likert scale, in terms of: 1= strongly disagree and 5 = strongly agree. The negative statements were scored reversely. This instrument approved satisfactory internal consistency; $\alpha = 0.85$ and was correlated with parents' appraisal of adolescent's problem; $r = 0.7$. (Lau, 2004; Lau et al., 2013). Validity and reliability were repeated by the researchers. Reliability revealed statistical result $r = 0.8$

Section II: Parenting Stress Index Short Form

(PSI-SF) - distress subscale: It was originally developed by Abidin in 2012. It is the most commonly used in measuring stress level suffered by parents with cerebral palsied adolescents. It is comprised of 36 items that are distributed in three subscales: Parental distress with 12 statements, parent-child dysfunctional interaction with 12 items and difficult child with other 12 items. The researchers used only the first subscale that measures parental distress which refers to parents' perceptions of their own behavior. It includes perceived competence, marital conflict, views of social support, and life restrictions because of the parenting demands, (e.g. 'I feel trapped by my responsibilities as a parent'). The parents provided their responses within a range of Likert scale; 1= strongly disagree and 5= strongly agree. The negative statements were scored reversely. High score specified high stress and vice-versa. The PSI-SF itself has been shown to be a valid and

reliable tool to measure parenting stress (Abidin., 1982; Abidin., 2012; Chau., 2009; McKelvey et al., 2009; Pritzlaff., 2001).

Section III: A Socio-Demographic Structured Interview Schedule for parents with CP adolescents. It comprised of two parts to elicit data about:

Part 1: parents' socio-demographic data such as age, gender, marital status, occupation, educational level, monthly income, health problems and leisure time.

Part 2: adolescents' characteristics such as age, gender, type and distribution of the cerebral palsy, and gross motor function level.

Method

1. An official approval for conducting the study was obtained from the Ethical Research Committee at the Faculty of Nursing, Alexandria University
2. An official approval was obtained from the director of Vocational and Rehabilitation Association of Children with Special Needs and Disabilities in Elrasafa, Moharam Bek, Alexandria, Egypt, to conduct the study. The authorities in the study setting approved the study plan with a written permission.
3. Section I (**Parental Aroused Shame Scale (PAS)**) and section II (**Parenting Stress Index Short Form (PSI-SF)**) - distress subscale) were translated into Arabic language. Arabic translation was double checked and corrected.
4. Section III (**A Socio-Demographic Structured Interview Schedule for parents with CP adolescents**) was developed by the researchers.
5. The translated sections (I and II) were re-tested for content validity by five experts in the fields of Medical- Surgical Nursing, Psychiatric and Mental Health Nursing & Nursing Education, and accordingly essential modifications were done. Both sections proved to be valid.
6. Reliability testing: the study tool was statistically tested for reliability by Cronbach Alpha Coefficient Statistical Test that approved its reliability was 0.8
7. Pilot study: Before embarking on the actual study, a pilot study was carried out on 10% of total sample of the study, 10 parents who

were out of the study subjects and were attending the mentioned setting and using the study tool, after obtaining their consent. Accordingly, few modifications were done.

8. **Ethical considerations:** Written approvals were taken from the stated setting, after description of study aim. Written informed consents were obtained from the study subjects, after full study' clarification (aim, data collection method, their roles in the study). The participants were certain that they should join in the study with their complete voluntary decision. The parents' privacy was respected and protected. Additionally, they were determined that all their data were treated in a wholly confidential method. Each parent was assigned to a code without his/her name, so, anonymity was ensured. Study subjects were informed that they have freedom and autonomy to withdraw at any time of the study. Extra, permissions to use sections I, and II of the study tools from the original authors were obtained by e-mails.

9. The following field work was established

- At the study setting, all parents attending were screened to identify those who meet the predetermined inclusion criteria. They invited to sit in a separate room that is assigned only for visitors where the researchers took permission from the setting' authority to conduct the subject's interview in. It is well ventilated, organized and with 2 tables and 5 chairs. Most of time the researcher met the parent alone or with his/her CP adolescent.
- Before starting data collection, each recruited parent was interviewed individually to establish rapport and assigned to the study & the control groups, 50 parents for each.
- The researcher explained the purpose of the study and then, the parent was asked to participate in the study and sign consent.
- Parents of both groups were fully informed about that all information was kept confidential with anonymity basis. Then, the researcher started to fill study tool (sections I, II and III) by discussion.
- Matching as much as possible between study and control subjects was considered by the researchers.
- The duration of each parent's interview ranged from 30-60 minutes according to parent's cooperation and ability.
- The interviewing process continued until the required number of study subjects (study & control) was recruited.
- Data were collected from 9 AM to 1 PM daily, six days weekly over a period of 4 months from November (2019) to end of February (2020).
- Parents of the control group were left to receive the routine health education and guidance in the study setting (they receive only some data about CP adolescents' medications and exercises if needed, from doctors, but nurses considered the documentations for cases only)
- The health education sessions for parents of the study group were developed and implemented in the following phases:

Preparatory phase: Grounded on a comprehensive review of related literature and the data that collected from both groups previously using the study tool, health education unit about cerebral palsy care-management with adolescents was prepared and organized. It included objectives, and content outline about: Cerebral palsy definition, signs, symptoms, diagnosis, dangerous signs and treatment. Adolescent's care-management with age requirements clarifications, physical and psychological care (how to deal with shame feeling, stress, psychological burden, and stigma), nutrition, exercises and rehabilitation care were covered. A booklet with pictures and real photos was designed, used as a tutorial aid; investigated for content validity by 3 jury members of Medical-Surgical, Education and Psychiatric & Mental Health Nursing departments, Faculty of Nursing, Alexandria University, Egypt.

The researchers prepared themselves for teaching role and trained themselves on the common care for cerebral palsied adolescent to help parent's learning and improving their care-management skills with their CP adolescents. Teaching sessions were planned for the study group only, on individualized base. The sessions included proper teaching approaches, discussion and demonstration,

illustrations, and pictures. The sessions' time and the place of conduction in the mentioned setting were arranged before parent meetings (visitor room, as mentioned before, lab top, audiovisuals and role play were used). Booklet was given to the study group only for free, as well, and gifts such as clothes, wipe tissues, watches and lunch breaks were offered.

Implementation phase: (for study group only).

Each parent received 2 teaching sessions about knowledge and skills for care-management of their cerebral palsied adolescent within one week and each session lasted 2 hours. During each session, they were asked to repeat and re-demonstrate the knowledge and skills that were given under the researchers' supervision. Illustrations, clarifications, answers, and descriptions during the teaching sessions were given. Parents were asked to repeat all taught knowledge and skills with their CP adolescent at home. After that, follow up was firmly prescribed every two days by telephone calls or interviewing in the study setting. They were asked again about all taught knowledge and skills and how apply them with their CP adolescent at home. The researchers encourage those who apply all taught knowledge and skills and stressed or give clarifications to those who have any mistakes in application.

Parents in both groups (study & control) were re-assessed again by using the interview schedule approach, using the study tool. Hence, the study tool was used three times: 1- before the implementation of the health education sessions, as a starting point for first assessment. 2- after the health teaching sessions by one week, as a second assessment, and 3- after the health teaching sessions by four weeks, as a third assessment. The scores of the study tool before and after the health education sessions for both groups (study & control) were compared, in the three assessments times, and then, the similarities and dissimilarities between the three assessments' scores to assess the accomplishment of the study aim.

Data Analysis:

Data was collected, computerized, coded, analyzed, and tabulated. The researchers used

Statistical Packages for the Social Sciences (SPSS) version 15.0 for Windows and Microsoft Excel Spread Sheet Package (Office 2007) for managing the results of the study. Mean and standard deviation, as well as percentage, frequency, chi-square, and P values were used for significance.

Results

Table I shows the distribution of the studied groups in relation to their socio-demographic data and their adolescents' characteristics. Approximately half of study and control groups (56% and 52% respectively) were in thirties and forties age-wise. Moreover, around two thirds (68% and 60% respectively) of both groups were females. Nearly half of study subjects (40% and 42% respectively) were widowed and about the same proportions (46% and 50% respectively) were unemployed. As well, nearly two thirds of both (64% and 66% respectively) had lower than moderate and low literacy educational level. Additionally, 64% and 62% respectively of both groups had an income in between 250 to 1500 pounds. While an equal percentage of parents in both groups (54%) had gastrointestinal and heart diseases as associated health problems and the majority of parents in both groups (88% and 82% respectively) reported that they haven't any leisure time.

Table II illustrates CP adolescent's characteristics, about half of study and control groups (46% and 48% respectively) aged between 12 and 14 years and about two thirds of them (66% and 60% respectively) were males. For CP type and distribution, 40% of the control group has adolescents with specific CP, and an equal percentage in study group have adolescents with unilateral CP. The majority of adolescents in study and control groups (68% and 72% respectively) have level I CP. Generally, no statistically significant differences were found between the study and control groups in relation to their socio-demographic data and their adolescents' characteristics; this means that both groups were matching.

Table III shows aroused shaming mean score as perceived by study and control groups in relation to adolescents' external behaviors before and after the intervention. It was found that, apparent positive changes in the study and control groups' responses in relation to aroused shame in the 2nd and 3rd assessments in all scale items, in

favor of the study group with a statistically significant difference between both groups. In the first assessment, it is clear that both groups had high aroused shame mean scores, which was lowered in the second and third assessments after the health educational intervention, in the side of study group. Concerning the study group, for example in items 6, 7, 8, 10, 14 and 16; the mean scores were above 4 (indicate high aroused shaming) in the first assessment and before the health education sessions, that declined to be below 2.5 in the third assessment, after the educational intervention. Therefore, the health education intervention had an effective effect on parents' aroused shame. It is obvious when comparing the total mean scores in the 1st, 2nd, and 3rd assessments for both groups that, there was a STRONG statistically significant difference between the 1st, 2nd and 3rd assessments for all scale items; $P = 0.000$ in favor of the study group.

Table IV shows the distress mean score among the study and control groups before and after the intervention. When comparing the total mean scores in the 1st, 2nd, and 3rd assessments for both groups, statistically significant differences in the second assessment of most scale items among the study group were found. It is also clear that, high statistically significant differences in the third assessment of all scale items were obvious among the study group's distress mean scores after the intervention; $P = 0.000$. It is worth mentioning here that, the health education intervention had an effective effect on parents' distress. For the control group, there was no statistically significant difference between all items of their distress mean scores.

Table V illustrates the Correlation coefficient between aroused shaming and distress level among the study group before and after the intervention. It can be noted that, there was a significant positive relation between aroused shame and distress level among the study group before and after the intervention. The table reflects an obvious parallel correlation between both variables.

Table VI shows relationship between the study groups' socio-demographic data and their aroused shame and distress level after intervention 3RD STAGE. It is obvious that parents of the study group who were in fourteens had lower perceived aroused shame and distress mean scores than other age groups. Furthermore,

male parents perceived lesser aroused shame than females; while female parents exhibited lesser distress mean scores than males. As well as married and widowed parents gained lesser aroused shame and distress mean scores than other marital status groups. As regards occupation; workers, employee, retired and unemployed parents reported high aroused shame mean scores; while workers, employee, farmers, and retired parents had less distress mean scores.

Correspondingly, parents with high educational level and those who had income 1500 to 2000 pounds/month obtained low aroused shame and distress mean scores. Parents in the study group who had monthly income ranged between 250 to less than 1500 pounds/month suffer from high aroused shame and stress levels. On the other hand, parents with heart diseases perceived less aroused shame mean scores; while parents with respiratory diseases had less distress mean scores. Parents who had leisure time had lower aroused shame and distress mean scores than those who did not have any leisure time.

As regards adolescents' characteristics among the study group in the third assessment after the implementation of the educational intervention, parents' who had CP adolescents in sixteenth till eighteenth years old and males obtained higher aroused shame and distress mean scores than those who had their adolescents in both other age groups and female ones. But parents with CP adolescents who had specific type and level I GMFCS reflected lesser aroused shame and distress mean scores than those who had CP adolescents with advanced types and other advanced CP levels.

The table displays no statistically significant differences between the study groups' age in years, gender, marital status, occupation, education, income & health problems; as well as adolescents' characteristics including age, gender & Gross Motor Function Classification and parents' aroused shame and distress mean scores after educational intervention. While there was statistically significant difference between the study groups' leisure time & distress mean scores and adolescents' cerebral palsy type and distribution & their aroused shame after educational intervention ($T2 = 4.819$ & $P = 0.033$, $F1 = 3.848$ & $P = 0.028$ respectively)

Figure 1& 2 represents the mean percent of the improvement of the study group in decreasing aroused sham and stress levels from 1st, to 2nd, and to 3rd assessments, before and after implementing the health education intervention, comparing with control group.

Table I: Distribution of the study and control groups in relation to their socio-demographic data. (N= 100)

Variables	Study Group (N=50)		Control Group (N=50)		Test of Significance
	No.	%	No.	%	
Parents' socio-demographic data					
Age					
20 –	6	12	8	16	X ² = 1.114 p-value = 0.892
30 –	10	20	11	22	
40 –	18	36	15	30	
50–	6	12	8	16	
60-70	10	20	8	16	
Gender:					
Male	16	32	20	40	X ² = 0.694 p-value= 0.405
Female	34	68	30	60	
Marital status					
Married	10	20	9	18	X ² = 4.408 p-value= 0.221
Divorced	12	24	11	22	
Separated	8	16	9	18	
Widowed	20	40	21	42	
Occupation					
Worker	2	4	1	2	X ² = 0.6026 p-value= 0.963
Employee	10	20	9	16	
Farmer	8	16	7	18	
Retired	7	14	8	16	
Unemployed	23	46	25	50	
Education					
High level ●	9	18	11	22	X ² = 0.979 p-value= 0.806
Moderate level ●●	9	18	6	12	
Lower than moderate level ●●●	20	40	19	38	
Low literacy (reading & writing)	12	24	14	28	
Income/month					
250 ≤ 500 pounds	10	20	9	18	X ² = 0.398 p-value= 0.995
500 ≤ 1000 pounds	11	22	10	20	
1000 ≤ 1500 pounds	11	22	12	24	
1500 ≤ 2000 pounds	7	14	8	16	
2000 ≤ 3000 pounds	7	1	6	12	
3000 ≤ 4000 pounds	4	8	5	10	
Parents' Health Problems:					
Gastrointestinal disease	10	20	8	16	X ² = 1.439 p-value= 0.919
Heart disease	17	34	19	38	
Renal disease	7	14	6	12	
Respiratory disease	8	16	6	12	
Cancer	6	12	7	14	
None	2	4	4	8	
Parents' leisure time:					
Yes	44	88	41	82	X ² = 0.7059 p-value= 0.401
No	6	12	9	18	

● = bachelor or associate education

●●● = preparatory or primary education.

●● = technical or secondary education

X² = *Chi square* test, P: level of significance ≤ 0.05

Table II: Distribution of the study and control groups in relation to their adolescents' characteristics. (N= 100)

Variables	Study Group (N=50)		Control Group (N=50)		Test of Significance
	No.	%	No.	%	
Adolescent's characteristics					
Age					
12≤ 14	23	46	24	48	X ² = 0.212 p-value= 0.899
14≤ 16	13	26	14	28	
16≤ 18	14	28	12	24	
Gender					
Male	33	66	30	60	X ² = 0.386 p-value= 0.534
Female	17	34	20	40	
Cerebral palsy (type and distribution)					
Specific	18	36	20	40	X ² = 0.704 p-value= 0.703
Unilateral	20	40	16	32	
Bilateral	12	24	14	28	
GMEFS (Gross Motor Function Classification System)					
Level I	34	68	36	72	X ² = 0.307 p-value= 0.858
Level II	9	18	7	14	
Level III	7	14	7	14	

● = bachelor or associate education

●● = technical or secondary education

●●● = preparatory or primary education.

X² = Chi square test, P: level of significance ≤ 0.05**Table III:** Parental Aroused Shame mean scores as perceived by the study and control groups in relation to adolescents' external behaviors before and after the intervention. (N= 100)

Parental Aroused Shame Scale items	Study group (N=50)			Control group (N=50)			Test of Significance P value		
	Before	After		Before	After		1 st	2 nd	3 rd
	1 st Mean ± SD	2 nd Mean ± SD	3 rd Mean ± SD	1 st Mean ± SD	2 nd Mean ± SD	3 rd Mean ± SD			
1. I want to keep these behaviors a secret	3.7 ± 1.8	2.1 ± 1.2	1.7 ± 0.5	3.3 ± 1.9	3.2 ± 0.8	3.4 ± 0.7	t= 1.081 P= 0.283	t= 5.393 P= 0.000*	t= 13.974 P= 0.000*
2. I try to have a sense of humor about these behaviors	4.3 ± 0.7	2.5 ± 1.4	2.2 ± 1.9	4.6 ± 1.2	4.2 ± 1.6	4.0 ± 0.9	t= 1.527 P= 0.130	t= 5.654 P= 0.000*	t= 6.054 P= 0.000*
3. I think these behaviors are common in children	3.7 ± 1.8	2.2 ± 0.6	2.0 ± 1.1	4.0 ± 1.3	3.6 ± 1.4	3.7 ± 0.8	t= 0.955 P= 0.342	t= 6.499 P= 0.000*	t= 8.837 P= 0.000*
4. I think that others will look down on my family	3.4 ± 1.2	2.4 ± 1.1	2.1 ± 1.3	4.0 ± 0.8	3.5 ± 0.7	3.8 ± 1.2	t= 2.942 P= 0.004*	t= 5.965 P= 0.000*	t= 6.795 P= 0.000*
5. I feel that I haven't lived up to my parental duties Mean ±SD	3.8 ± 1.7	2.0 ± 1.1	1.7 ± 0.7	3.8 ± 1.8	3.6 ± 0.9	3.3 ± 1.2	t= 0.0 P= 1	t= 7.960 P= 0.000*	t= 8.144 P= 0.000*
6. I feel sad	4.6 ± 1.3	2.4 ± 1.2	2.1 ± 1.1	4.4 ± 1.8	3.72 ± 0.8	3.4 ± 0.7	t= 0.637 P= 0.526	t= 6.374 P= 0.000*	t= 7.050 P= 0.000*
7. I feel guilty	4.4 ± 1.3	3.1 ± 1.5	2.4 ± 1.3	4.5 ± 0.6	3.6 ± 1.4	3.6 ± 1.2	t= 0.494 P= 0.623	t= 1.723 P= 0.088	t= 4.796 P= 0.000*
8. I feel embarrassed	4.7 ± 1.8	2.8 ± 0.6	2.1 ± 1.3	4.3 ± 1.6	3.89 ± 1.4	3.5 ± 0.6	t= 1.174 P= 0.243	t= 5.060 P= 0.000*	t= 6.914 P= 0.000*
9. I feel angry Mean ±SD	3.7 ± 1.1	2.4 ± 1.6	2.0 ± 1.8	4.1 ± 0.8	3.7 ± 1.1	3.6 ± 1.8	t= 2.079 P= 0.040*	t= 4.734 P= 0.000*	t= 4.444 P= 0.000*
10. I fear that I will be criticized as a parent	4.7 ± 1.3	3.2 ± 1.6	2.2 ± 0.8	4.4 ± 0.9	3.8 ± 0.8	3.5 ± 1.3	t= 1.342 P= 0.183	t= 2.372 P= 0.019*	t= 6.022 P= 0.000*
11. I expect these behaviors in children of this age	4.1 ± 0.7	3.2 ± 1.5	2.6 ± 1.4	4.3 ± 1.7	3.8 ± 1.4	3.6 ± 0.8	t= 0.769 P= 0.444	t= 2.068 P= 0.041*	t= 4.385 P= 0.000*
12. I am worried	4.4 ± 1.6	3.1 ± 1.5	2.0 ± 0.9	4.5 ± 0.6	3.8 ± 1.2	3.8 ± 1.9	t= 0.413 P= 0.679	t= 2.577 P= 0.012*	t= 6.054 P= 0.000*
13. I am hopeful my child will outgrow this behavior	4.4 ± 1.3	3.2 ± 1.5	2.7 ± 1.3	4.7 ± 1.4	4.3 ± 1.4	4.6 ± 0.7	t= 1.110 P= 0.269	t= 3.791 P= 0.000*	t= 9.099 P= 0.000*
14. I am disappointed	4.6 ± 1.4	2.5 ± 0.7	2.2 ± 0.8	4.4 ± 0.9	3.5 ± 1.4	3.6 ± 1.4	t= 0.849 P= 0.398	t= 4.517 P= 0.000*	t= 6.139 P= 0.000*
15. I am concerned the behaviors are serious	4.2 ± 1.1	2.8 ± 1.3	2.2 ± 1.6	4.8 ± 1.1	4.4 ± 0.8	4.2 ± 0.7	t= 2.727 P= 0.008*	t= 7.412 P= 0.000*	t= 8.097 P= 0.000*
16. I am ashamed	4.5 ± 1.3	3.0 ± 1.4	2.1 ± 0.8	4.2 ± 1.2	3.9 ± 1.4	3.8 ± 1.1	t= 1.199 P= 0.233	t= 3.214 P= 0.002*	t= 8.838 P= 0.000*
17. I am afraid that the behaviors will get worse	4.2 ± 0.7	3.1 ± 1.2	2.7 ± 1.6	4.6 ± 1.6	3.4 ± 0.8	3.2 ± 1.5	t= 1.619 P= 0.108	t= 1.471 P= 0.144	t= 1.612 P= 0.110
Total	3.95 ± 1.07	2.5 ± 1.16	2.02 ± .09	4.02 ± 1.15	3.56 ± 1.09	3.49 ± 0.00	t= 0.315 P= 0.753	t= 4.708 P= 0.000*	t= 7.027 P= 0.000*

* = p ≤ 0.05

** = p ≤ 0.01

*** = p ≤ 0.001

DF = Degree of freedom=1

Table IV: Distribution of distress mean scores among the study and control groups before and after the intervention. (N= 100)

Parenting distress subscale items	Study group (N=50)			Control group (N=50)			Test of Significance P value		
	before	After		Before	After		1 st	2 nd	3 rd
	1 st	2 nd	3 rd	1 st	2 nd	3 rd			
1. I often have the feeling that I cannot handle things very well	3.5 ± 1.1	2.3 ± 0.75	1.7 ± 0.95	3.9 ± 1.4	3.2 ± 1.8	3.2 ± 1.6	t= 1.589 P= 0.115	t= 3.264 P= 0.002*	t= 5.700 P= 0.000*
2. I find myself giving up more of my life to meet my child's needs than I ever expected	4.0 ± 1.7	3.1 ± 0.87	2.2 ± 1.2	3.6 ± 1.5	3.5 ± 1.6	3.5 ± 0.85	t= 1.248 P= 0.215	t= 1.553 P= 0.124	t= 6.251 P= 0.000*
3. I feel trapped by my responsibilities as a parent	3.7 ± 1.4	2.2 ± 0.88	1.9 ± 0.78	4.2 ± 1.5	3.8 ± 1.1	3.6 ± 1.8	t= 1.723 P= 0.088	t= 8.031 P= 0.000*	t= 6.128 P= 0.000*
4. Since having my child I have been unable to try new and different things	3.7 ± 1.0	3.6 ± 1.1	2.1 ± 0.83	4.0 ± 1.8	3.9 ± 1.4	3.6 ± 1.7	t= 1.030 P= 0.306	t= 1.192 P= 0.236	t= 5.607 P= 0.000*
5. Since having my child I feel that I am almost never able to do things that I like to do	3.8 ± 1.2	3.6 ± 1.3	2.3 ± 0.7	3.8 ± 1.8	3.5 ± 1.3	3.4 ± 1.0	t= 0.0 P= 1	t= 0.385 P= 0.701	t= 6.372 P= 0.000*
6. I am unhappy with the last purchase of clothing I made for myself	4.2 ± 1.6	2.8 ± 1.0	2.1 ± 0.9	4.6 ± 1.3	3.7 ± 1.8	3.4 ± 1.1	t= 1.372 P= 0.173	t= 3.091 P= 0.003*	t= 6.468 P= 0.000*
7. There are quite a few things that bother me about my life	4.5 ± 1.0	3.1 ± 1.7	2.2 ± 1.0	4.3 ± 1.4	3.6 ± 1.0	3.6 ± 1.4	t= 1.527 P= 0.130	t= 0.822 P= 0.413	t= 5.754 P= 0.000*
8. Having a child has caused more problems than I expected in my relationship with my spouse	3.3 ± 1.2	2.5 ± 1.0	1.5 ± 0.73	3.8 ± 0.6	2.8 ± 1.1	2.6 ± 1.3	t= 2.635 P= 0.009*	t= 1.427 P= 0.157	t= 4.743 P= 0.000*
9. feel alone and without friends	3.8 ± 1.0	2.4 ± 1.2	1.7 ± 0.8	4.0 ± 1.2	3.8 ± 0.81	3.3 ± 0.88	t= 0.905 P= 0.368	t= 6.838 P= 0.000*	t= 9.513 P= 0.000*
10. When I go to a party I usually expect not to enjoy myself	4.7 ± 1.5	2.7 ± 1.2	2.3 ± 1.7	4.5 ± 0.9	3.9 ± 0.8	3.3 ± 0.73	t= 0.808 P= 0.421	t= 5.884 P= 0.000*	t= 3.822 P= 0.000*
11. I am not as interested in people as I used to be	3.8 ± 1.2	2.2 ± 1.5	2.0 ± 1.1	4.4 ± 1.2	3.8 ± 1.0	3.6 ± 1.4	t= 2.500 P= 0.014*	t= 6.276 P= 0.000*	t= 6.354 P= 0.000*
12. I don't enjoy things as I used to	4.2 ± 1.2	3.1 ± 1.0	2.0 ± 0.79	4.5 ± 1.6	4.2 ± 1.3	3.8 ± 1.2	t= 1.061 P= 0.292	t= 4.742 P= 0.000*	t= 8.859 P= 0.000*
Total	3.93 ± 1.3	2.8 ± 1.1	2.0 ± 0.96	4.1 ± 1.35	3.6 ± 1.3	3.4 ± 1.2	t= 0.654 P= 0.515	t= 2.076 P= 0.041*	t= 6.442 P= 0.000*

* = p ≤ 0.05

** = p ≤ 0.01

*** = p ≤ 0.001

DF = Degree of freedom=1

Table V: Correlation coefficient between aroused shame and distress level among the study group before and after the intervention. (N= 50)

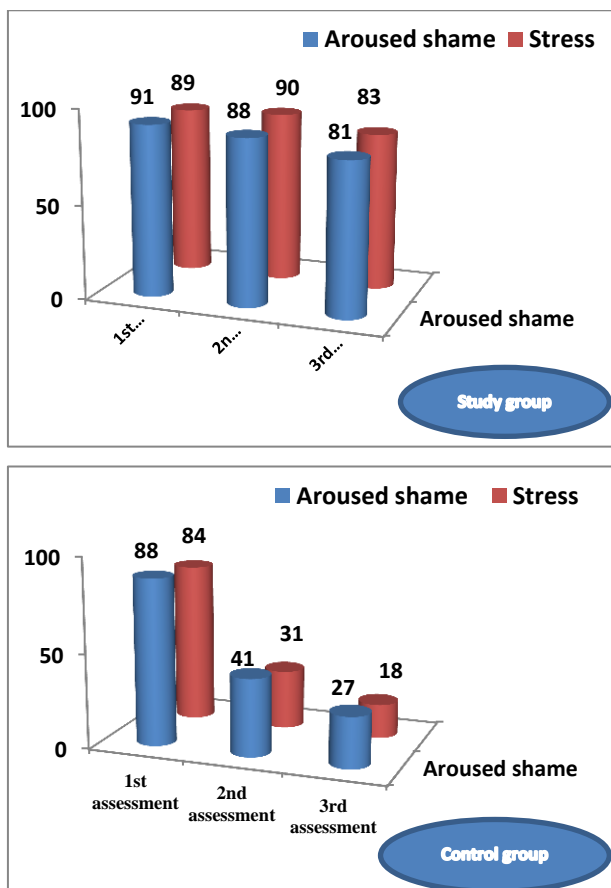
Correlation		Aroused shame		
		1 st	2 nd	3 rd
Distress level	R value	0.142	0.500	0.500
	P value	0.204	0.000*	0.000*

* Significant at P ≤ 0.05

Table V: Relationship between the study groups' socio-demographic data and their aroused shame and distress level after intervention 3RD STAGE. (N= 50)

Variables	n=50	Aroused shame		Distress level		Test of Significance P value	
		3 rd		3 rd			
		\bar{X}	SD	\bar{X}	SD		
<u>Socio-demographic data</u>							
<u>Age</u>							
20 –	6	2.1	0.95	1.9	0.78	F1 = 0.383	P= 0.820
30 –	10	2.2	1.2	2.1	0.83		
40 –	18	1.9	0.78	1.7	0.7		
50-	6	2.1	0.83	2.1	0.9		
60-70	10	2.3	0.7	2.2	1.0		
<u>Gender:</u>							
Male	16	1.7	1.8	2.2	0.95	T1 = 1.306	P= 0.259
Female	34	2.3	1.7	1.9	1.2		
<u>Marital status</u>							
Married	10	1.8	0.83	2.0	0.9	F1 = 0.611	P= 0.681
Divorced	12	2.3	0.7	2.7	1.3		
Separated	8	2.1	0.9	2.2	0.8		
Widowed	20	2.0	1.0	1.9	1.6		
<u>Occupation</u>							
Worker	2	2.0	0.9	2.2	1.2	F1 = 1.254	P= 0.302
Employee	10	2.7	1.3	2.0	0.78		
Farmer	8	1.6	0.8	2.1	0.83		
Retired	7	2.2	1.6	2.3	0.7		
Unemployed	23	2.1	0.8	1.8	0.9		
<u>Education</u>							
High level ●	9	2.0	0.76	1.7	1.0	F1 = 0.192	P= 0.901
Moderate level ●●	9	2.2	1.7	2.5	1.2		
Lower than Moderate level ●●●	20	2.2	1.1	2.6	1.5		
Low literacy (reading & writing) ●●●●	12	2.4	1.2	2.2	1.0		
<u>Income/month</u>							
250 ≤ 500 pounds	10	2.0	1.4	2.5	1.3	F1 = 1.138	P= 0.357
500 ≤ 1000 pounds	11	2.7	1.0	2.1	0.88		
1000 ≤ 1500 pounds	11	2.8	1.4	2.0	1.3		
1500 ≤ 2000 pounds	7	1.6	1.1	1.8	1.4		
2000 ≤ 3000 pounds	1	2.1	0.78	2.4	1.3		
3000 ≤ 4000 pounds	4	2.4	1.2	2.2	0.7		
<u>Parents' Health Problems:</u>							
Gastrointestinal	10	2.0	1.2	2.1	0.93	F1 = 0.115	P= 0.988
Heart	17	1.8	1.1	2.4	0.68		
Renal	7	2.2	1.4	1.9	0.97		
Respiratory	8	2.0	0.8	1.7	1.1		
Cancer	6	2.0	1.8	2.1	1.2		
None	2	2.0	1.6	2.0	1.2		
<u>Parents' leisure time:</u>							
Yes	44	1.8	1.5	1.6	0.85	T1 = 0.390	P= 0.535
No	6	2.2	1.2	2.4	0.72		
<u>Adolescents' characteristics</u>							
<u>Age</u>							
12 ≤ 14	23	2.0	1.2	2.2	0.93	F1 = 0.656	P= 0.524
14 ≤ 16	13	1.9	1.1	1.7	1.6		
16 ≤ 18	14	2.4	1.4	2.5	0.97		
<u>Gender</u>							
Male	33	2.5	0.8	2.6	1.1	T1 = 1.862	P= 0.179
Female	17	2.0	1.8	2.2	1.2		
<u>Cerebral palsy: type & distribution</u>							
<u>Specific</u>							
Unilateral	18	1.7	1.1	1.6	1.2	F1 = 3.848	P= 0.028*
Bilateral	20	2.5	1.2	2.0	1.1		
	12	2.7	0.84	2.2	1.4		
<u>GMFCS (Gross Motor Function Classification)</u>							
Level I	34	1.8	1.6	1.7	1.3	F1 = 1.943	P= 0.155
Level II	9	2.7	1.8	2.1	0.88		
Level III	7	2.8	1.1	2.7	1.1		

* Significant at $P \leq 0.05$



Discussion

Health educational interventions are designed for parents with CP adolescents should be according to their needs physically, intellectually, and psychologically. Awareness and literacy about care management with CP adolescents is congruent with alleviating stress, decreasing shame behaviors and thoughts, among parents with CP adolescents, (the critical age of developmental stages). (Fathi et al., 2016; Kiani et al., 2021; Lau, 2004; Pritzlaff et al., 2001)

Therefore, the current study figured out that, health education intervention had an effective role on decreasing parents' aroused shame among study groups that were observed after 2nd and 3rd assessments respectively. This is supported by Corrigan 2000, Lau 2004 and Akpinar 2020 who stressed that parental shame with their children/adolescents with CP is rooted from their stigma about mental illness that can be managed through health education

services. In the same line, Martin et al in 2005 reported that the conceptualized stigma of CP children is an illustration of false knowledge structures of attributes. Public have stigmatized and shame perceptions regarding mental disabilities, as dangerous, uncontrollable and have vulnerability complaints. They do not view the disability needs. Therefore, by health education, these attributions will be converted to positive mediators that nurture parents and child relationship and, thus, aroused shame will disappear (Akpinar et al., 2020; Corrigan, 2000; lau., 2004).

Contradicting with these points of views, Tsang et al in 2003 reported that stigma and shame feelings with CP child may lead to relationship disturbance and may be conceptualized within a cultural cognitive framework which cannot be changed and stands as a barrier against serving the child or parents' coping. But there are illustrations in several teaching and learning theories about significant improvement in cognitive processing and

cultural modifications by education process. (Tsang et al., 2003; Akpınar et al., 2020, Lau & Taekuchi., 2001)

Regarding parents' stress level, the present study documented a significant decrease in parents stress level post health education implementation, in the 2nd and 3rd assessments among study group, significantly. Parallel to this view, Sipal et al in 2010, Pritzlaff in 2001 and Wells in 2018 mentioned that the changes in behavior and mental imbalance of the children put parents under high levels of stress that require persistent and focused awareness and education about proper CP care management. Moreover, parents with CP child/adolescent experience different degrees of stress according to the percent of mental and motor impairments of their children. (lau., 2004; Ribeiro et al., 2014; Pokhrel., 2020). Most parents with CP adolescents have a serious lack of scientific based knowledge and skills to provide care management for their adolescents which provokes restlessness and stress.

The present study proved that there is a parallel relation between aroused shame and distress levels among parents with CP adolescents among study group. This result is noticed in the 2nd and 3rd assessments after implementation of the educational intervention. Both shame and stress are psychological complaints that have the same reasons. Matching this point, McEwen in 2007 clarified that stress is a universally psychological and physiological complaint that results as a response to internal or external stimuli, like shaming and anxiety. Parenting stress and shame feelings are originated from their evaluation of parenting roles and child's needs or problems (McEwen., 2007; Wells., 2018). In contrary, other studies revealed that, not all parents of children with CP experience mental health problems, with high levels of stress or aroused shame (Pousada et al., 2013). This variation in the well or ill-being of parents of children with CP has been linked with child (e.g., the presence of comorbid problems) and parent characteristics (e.g., parents' self-efficacy) and contextual factors (e.g., social support) (Guyard et al., 2017; Pousada et al., 2013; Raina et al., 2005).

As regards, association between socio-demographic data and aroused shame and distress levels among parents with CP adolescents (study group) after the educational intervention, as regards 1st, 2nd and 3rd assessments, results of the current study revealed that parents of the study group who were in fourteens had lower perceived aroused shame and distress mean scores than other age groups. Moreover, male parents perceived lesser aroused shame mean scores than females, while female parents exhibited lesser stress mean scores than males. Much current evidence reported that socio-demographic criteria are a strong factor that is directed to increase or decrease stress or shame feelings. (McKelvey et al., 2009; Ribeiro et al., 2014; Tsang, et al., 2003; Wells, 2018). In Egyptian culture, shame is experienced with females than males. But stress is very common to be increased in males than females, which may justify and support the current results. (Emam et al., 2021; Mahmoud et al., 2016)

In addition, the current study exhibits that married parents gain lesser aroused shame and distress mean scores than other marital status groups. Matching with this finding, Walton, 2013; and Ross & Buliung, 2019 discussed that children with married couple homes experience more safety and care achievements with limited stigma feeling among parents. Moreover, single parents are frequently under extra stress and shame. Likewise, Vandewater & Bickham, 2004 and Wells, 2018 studied that the possible causes of stress in parents with CP children and concluded that, there are many factors lead to high levels of stress including marital status, employment status, income, and depression.

The present study revealed important findings about specific occupation that contributed with shame or stress experiences among parents with CP adolescents. Workers, employees, retired and unemployed parents reported high aroused shame mean scores; while workers, employees, farmers, and retired parents had less distress mean scores. This finding is in the same line with Walton, 2013 and Pokhrel, 2020 who mentioned that occupational nature and prestige affect greatly on aggravating or decreasing stress and experiencing shame behaviors. Other studies discussed that occupation nature help to

provoke stress and stigma feeling of parents toward their disabled children (Imran et al., 2020; Kiani et al., 2020).

Another result in the current study is that parents with high educational level obtained lesser aroused shame and distress mean scores. This result is approved by McKelvey et al in 2009 who reported that low educated parents suffer from high stress levels. As well as Ribeiro et al in 2014 clarified that mothers with low education levels have high levels of stress and several negative experiences for themselves and their disabled children. Levels of parents' education obviously affect stress levels and disturbing feelings such as shame and jealousy (Kiani et al., 2021). Moreover, the present study finding exhibited that about two thirds of parents in the study group had monthly income ranged between 250 to less than 1500 pounds. Those parents suffer from high aroused shame and stress levels. Many researchers reported that parents with little revenue exhibit many psychosocial stressors in their social relations and public surroundings (Gundersen et al., 2008; Ross & Buliung., 2019).

The current study revealed that parents who had leisure time had lower aroused shame and distress mean scores than those who did not have any leisure time. This is a logical result that was reported in numerous studies which discussed that mothers, who have no leisure events, are exposed to stress more than other mothers with leisure times (Ribeiro et al., 2014 and Wells, 2018). In the same line, other studies mentioned that leisure activities contributed to better: family functioning, family image, coping with stress, raised feelings of competence and better psychological health (Kiani et al., 2021; Wanamaker & Glenwick., 1998 and).

As regards to adolescents' characteristics among the study group in the third assessment after the implementation of the educational intervention, parents' who had CP adolescents from sixteen till eighteen and males have higher aroused shame and distress mean scores than those who had their adolescents in both other age groups and female ones. Although, parents with CP adolescents who had specific type and level I GMFCS reflected lesser aroused shame and distress mean scores than those who had CP adolescents with advanced types and other advanced CP levels. Supporting these findings,

many studies found that parents with older children (16-18 years) have multiple burdens and psychological complaints. (McKelvey et al., 2009; Wanamaker & Glenwick., 1998). Harmoniously with these responses, other researchers explained that more care-management and safety activities are needed by parents to meet their adolescents' needs, in such critical age, particularly with more physical or mental disability. This can be determined by the GMFCS and interactive difficulties of the children/adolescents, who secondarily increase stress levels and shame among those parents. (Kiani et al., 2020; Raina et al., 2005; Ribeiro et al., 2014)

Conclusion

Based on the results of the current study, it can be concluded that health education intervention as a significant nursing role about adolescent's care management is a successful approach for nurturing aroused shame and stress levels among parents with CP adolescents. Such teaching methodologies tended to improve and support parents' psychological complaints, which, in turn, are reflected on CP adolescents' care. Moreover, the current study revealed that there is a parallel relation between aroused shame and stress levels among parents with CP adolescents.

Recommendations:

- Continuous health education programs for parents with CP adolescents are needed as well as investigation of its effects on other physical, psychological, intellectual, social, and spiritual parameters.
- Collaborative and continuous in-service training programs for adult care, psychiatric and mental health nurses, and nursing educators for updating their knowledge and skills regarding health education paradigms for CP adolescents' parents to promote their mental health are needed.
- More collaborative and relevant researches in nursing education, medical-surgical, psychiatric & mental health, and pediatrics nursing to CP child/adolescent safety and parent's self-efficacy for managing their needs should be a key focus of future research.
- Further researches are needed to allow a more comprehensive and in-depth understanding of parents' experiences to identify the most

important targets for their support and to develop more tailored interventions for them.

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