

LIVED EXPERIENCE OF CAREGIVERS HAVING CEREBRAL PALSY SCHOOL AGE CHILDREN: A QUALITATIVE STUDY - EGYPT

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Abstract

Background: School age children with cerebral palsy (CP) rely on caregivers for their daily needs, leading to stress as they seek interventions and support to improve their abilities. Caregivers must provide complete primary caregiving, including feeding, locomotion, bathing, managing seizures, and carrying the child to medical reviews
Aim: To explore the lived experience of caregivers having Cerebral Palsy School Age Children
Design: A qualitative research design was used.
Setting: The study was conducted at the national institute of neuromotor system in 1 El-tayarFekrystreet. Kornish El-nail-lmbaba-Giza.
Sample: a purposive sample of 12 caregivers having children with CP was selected.
Tools for Data Collection: Two tools were used
First tool: Demographic characteristics of Caregivers with their cerebral palsy school age children structured questionnaire:-It was developed by the researcher. It included 2 parts:-Part one: - Demographic data of caregivers. Part two: - Demographic data of cerebral palsy child & Second tool: - Caregivers of school age children semi-structured interview guide.
Results: The current study identifies eight major themes in exploring experience of caregivers quality of life who had Cerebral Palsy children:- (I) Support people & Culture norms, (II) Fulfillment of needs, (III) Realization of life potential, (IV) Biological order, (V) well-being, (VI) Life satisfaction,(VII) Happiness, & (VIII)Meaning in life . The major themes classified into Sixty sub-themes .The major and sub themes are based on quality of life (QOL) scale.
Recommendations: Based on data analysis of major and sub themes recommendation of the current study is the caregivers needed to support from family members to help and assist them while caring of children with CP.

Keywords: Lived Experience, Caregivers, Cerebral Palsy, School Age Children.

1. INTRODUCTION

School-age children are more graceful than they were as preschoolers, and they are steadier on their feet. Their bodies take on a slimmer look, with longer legs, varying body proportions, and a lower center of gravity. Posture improves over that of the preschool period to facilitate locomotion and efficiency in using the arms and trunk. These proportions make climbing, bicycle riding, and other activities much easier. Fat gradually diminishes, and its distribution patterns change, contributing to the thinner appearance of children during the middle years. When children enter the school years, they begin to acquire the ability to relate a series of events and actions to mental representations that they can express both verbally and symbolically [1].

Cerebral palsy (CP) is a cluster of heterogeneous neurologic childhood developmental, non-progressing, lifelong disabilities, characterized by constellation of bodily signs such

as abnormal posture, inability to maintain balance and atypical movement. Other definition Cerebral palsy is one such developmental disorder that begins in early childhood as a set of functional limitations that stem from disorders of the developing central nervous system [2].

Cerebral palsy is a major cause of disability and most survivors are left with residual disability and are dependent on parents/caregivers for essential care .Caregivers of children with cerebral palsy has to undergo various struggles and difficulties while parenting their children with CP, which is a long-term process. This prolonged caregiving can affect their quality of life and wellbeing [2], [3]. [4] Who studied " Quality of life of Caregivers of Children with Cerebral Palsy: A Systematic Literature Review".He showed that, lower quality of life in caregivers of children with cerebral palsy in various dimensions.

Caring for a child with CP includes many challenges. [4] Say that psychosocial challenges for caregivers of children with CP are inadequate facilities and service, unsupportive interaction, limitation of parent's social relation, social seclusion, intrapersonal conflict and sense of loneliness. Also, the higher level of disability in children contributes to a higher burden among caregivers. This can be because of the physical strain involved when taking care of them such as moving the child, feeding, cleaning or the physical therapy that need to be done regularly. Many of these families or caregivers face financial instability due to their children's health requirements or their long-term care giving leads to unemployment.

Child with CP can affect the parents in various aspects of their lives such as: (a) Leisure time (because they neglect their own needs and self-care to become constant caregivers); (b) employment, (because often one of the parents quit their job to devote more time to the needs of their child); (c) social relationships, (resulting from a perceived lack of support and rejection by their social environments); (d) family dynamics, (e) physical and psychological health, (because most parents experience a high degree of stress and anxiety as well as multiple physical ailments resulting from care provision); and (f) relationships with their partners, (which often become neglected due to the high level of attention that their child requires)[5] .

Caregivers for children with cerebral palsy need information about practical skills to deal with every day problem .Therefore, empowerment education program and effective management can improve the quality of life for CP child and their caregiver. Moreover, improve functionality and capabilities toward independence and enhancing child and care provider interaction, also, providing family support. So the Family Health Nurse (FHN) plays a key role in teaching the caregivers how to care for their Cerebral Palsy children and providing them with an emotional support. She must teach them about all special needs of the CP child, the proper handling, the homecare and training about the manual skills and activities of daily living which proceeds a long developmental lines and according to the child's functional level, So the aim of the study is to explore the lived experience of caregivers having Cerebral Palsy School Age Children .

2. METHODS

2.1 Aim

The aim of the study is to explore the lived experience of caregivers having Cerebral Palsy School Age Children.

Research question

To fulfill the aim of this study, the following research question was formulated:

Q: - What is the lived experience of caregivers having Cerebral Palsy School Age Children?

2.2 Design

A qualitative research design using the phenomenological approach was utilized in the current study. Phenomenological research requires a researcher to focus on people's lived experiences of a phenomenon to obtain comprehensive details that provide a basis for reflective structural analysis that ultimately reveals the essence of the experience [6]. Qualitative research is inductive in nature, and allows researcher to generally explore meanings and insights in a given situation. It is described as an effective model that occurs in a natural setting and enables the researcher to develop a level of details from high involvement in the actual experiences [7].

2.3 Setting

The current study was conducted at the national institute of neuromotor system in 1 El-tayar Fekry street, Kornish El-nail-Imbaba-Giza., this institute was established in - June 1967, which is affiliated to Ministry of health, governmental and The General Organization for Teaching Hospitals and institutes.

2.4 Participants

The present qualitative research used 12 participants included both children and their caregivers having Cerebral Palsy School Age Children who attained to the national institute of neuromotor system for physiotherapy. Sampling process was ended when the researcher got saturated with collected data, when no more information or themes were added to the study.

Inclusion criteria:-

The inclusion criteria for children with CP will be as follows:

- 1- School age from 6-12 years old.
- 2- Child had a medical diagnosis of cerebral palsy from birth.
- 3- Free from any complications from congenital heart disease, epilepsy, and other serious diseases.
- 4- Free from mental retardation or other musculoskeletal disorders.

The caregivers' inclusion criteria are as follows:

- 1- Age \geq 18 years.
- 2- Child's parent who are the main caregiver of a son/daughter of school age children.
- 3- Normal communication and expression skills.
- 4- Caregivers free from mental illness or handicapping conditions.

2.5 Data Collection Tools

First tool: Demographic characteristics of Caregivers with their cerebral palsy school age children structured questionnaire:-

It was developed by the researcher. It included 2 parts:-

Part one: - Demographic data of caregivers:- It consist of eleven questions started from (1-11) questions included age, caregivers, place of residence, level of education, work of caregivers, relation between father& mother, caregivers suffer from chronic illness, family member& income.

Part two:- Demographic data of cerebral palsy child :- It consist of eleven questions started from (1-11) questions included child age, gender, child rank, child go to school, causes to left school, health status of child and problems, child problems during labour , full term baby & causes .

Second tool: - Caregivers of school age children semi-structured interview guide:-

It was developed by the researcher's based on quality of life scale, national and international review of literature special to qualitative research used to guide the conversation and included 8 open ended questions classified into two parts (4 questions relate to objective quality of life & 4 questions relate to subjective quality of life) in order to help caregivers having school age children with cerebral palsy in expressing the lived experience. Each interview was began with the open-ended question included:-

Objective interview questions:

1. How would you describe your support people? How can this affect your cultural norms?
2. Do you mind expressing about your lived experiences with cerebral palsy school age child? How did you school your child? Alone-time, doctor appointments and therapies, educational activities, transportations, daily needs of the child, etc.
3. Express changes occurred in your family dynamics in the moment of diagnosis on a social, economic /work, and leisure level and as a couple or with the child's other siblings or relatives? Have these changes been maintained in the cerebral palsy school age children?
4. Explain in detail what you did daily for your child with CP, as well as your belief on its effect on your own physical, social and mental health? What do you believe about life and reality?

Subjective interview questions:

5. Explain the most difficult problems you experience in the process of taking care of your child?
6. Describe meaning of satisfaction are you with your life nowadays? Can you tell me how you meet your expectations, needs, and desires in life by the surrounding world?
7. Clarify your greatest joy/ happiness in mothering/ care given to this child?
8. Clear up your future when caring for your child?

2.6 Procedure

The data were collected over a period of one year started May 2023 and ended April 2024 through two phases: preparation and interview phases which included two interviews.

Preparation: - In this phase, tools were developed by researcher and revised by 5 experts in community health nursing department. The researcher constructed and developed tools, based on extensive literature review. The study was primary approved by the Research Ethical Review Committee at Faculty of Nursing , Cairo University at 15 /5/2023 (Appendix, D). Then an official permission was obtained from ethical committee of The General Organization for Teaching Hospitals and institutes and an official permission was obtained from the institute to start collecting data from participants after reviewing protocol and reviewing tools for data collection.

Interview: - researcher introduced herself to caregivers and explanation for each caregivers individually the aim and nature of current study. The interview was done inside the institute after arrangement with the manager of the institute to allow free expression of feelings and experiences of caregivers.

1st interview: - Written informed consent and data related to demographic data of caregivers and their children with cerebral palsy and medical history was obtained. Every caregiver was interviewed individually two times or more (as repeated interview) and each interview session will take 25-35 minutes. It was done for seven participants, at this time interview was done at Saturday and Thursday from each week and the researcher interviewed with one to two participants in each interview, individual interview with each participants. During the interview session the researcher tried not to interrupt or judge the participants and explain questions by different ways to simplifying it and allows participants enough time to express their feelings.

- **The second interview** was done for the seven participants after three days and the six participants were interviewed for the first time then after six days as a break period 2nd interview: according to [8] who urges that, segments of the interview for each participant be separated between three days to a week. It start with remembering participants about research question and checking responses collected previously in the first interview to ensure that those data were exactly what did the participants intend. The second interview was intended also to go ahead with member check. **Saturation:** - Data collection continued until repetition of data and no new themes were being generated. After

saturation was achieved; the study was finally approved by Research Ethical Review Committee at Faculty of Nursing, Cairo University at April 2024.

- i. **Audio recording instrument** (phone recording): It was used to document verbatim of the participant and increase the accuracy of data collection as it was recorded the exact words of the interviewees because it plays an important role in data collection in qualitative studies.
- ii. **Field notes:** The researcher started with introducing her and explanation for each participant individually the aim and nature of current study.

Data analysis phase:

The data analysis for the current study was done by using Colaizzi's (1978), phenomenological method consisting of 7 steps. These steps include reading all the description given by the informants, extracting significant statements, formulating meanings, organizing formulated meanings into clusters of themes, integrating the themes into exhaustive description of the phenomenon, identifying the essential structure of the phenomenon, and validating the identified structure and nature of the phenomenon from the informants' description by member checking to check trustworthiness and congruency of the written themes with what they exactly meant to assure validation [9] .

Firstly, in this study, data analysis began after the first interview; transcription of the audiotape was done by researcher for only three participants then stopped. The researcher completed by transcription of all field notes and observations taken by researcher, which included all participants' verbatim, reactions and or responses. Then the researcher went through the transcripts done from the written interviews and reviewed word by word and line by line very closely and re-read several times to extract the whole picture.

The second step of analysis done by composing significant statements and pertaining to the participants' view of point regarding phenomenon and were written in a separate sheet as reducing the huge data. Then the transcript was read by expertise (professor supervising the research study) to extract the significant statements to ensure its validity of the content analysis. After extracting the significant statements, researcher formulated meanings to these statements. Each meaning was coded in one category as it reflects an in depth description of data. Then after these categories were completed, themes were initiated and each cluster of themes was coded to include all formulated meaning related to that group of meaning. Next, group of clusters of themes that reflect a particular meaning issue were combined together to form a definite construct of theme.

The integration of the major themes into exhaustive description of the phenomenon, and validating the identified structure and nature of the phenomenon from the participants' description was then done as a final step. Validating the identified structure and nature of the phenomenon from the participants' description by member check was done. All written materials were transcribed and translated into English. The identified themes were put together in a diagram.

2.7 Statistical Analysis for quantitative data:-

Statistical package for the social science (SPSS) software, version 20 was used for data entering and analysis. Data management was carried out by coding and entering responses into the computer. The researcher was checked all data to avoid any discrepancies. Descriptive statistics was used to analyze the sample population. Mean and frequency distributions was used.

2.8 Qualitative analysis of the themes and subthemes.

3. RESULTS

Part one (A): Demographic characteristics & medical history of Caregivers with their cerebral palsy school age children:-

Table 1: Percentage distribution of studied caregivers according to their demographic characteristics and medical history (n. =12).

Table (1):
 Percentage distribution of studied caregivers according to their demographic characteristics & medical history (n. =12).

| Variables | No. | % |
|--|--------------|-------|
| *Age of caregivers | | |
| 28 ≤ 38 | 5 | 41.7 |
| 38 ≤ 48 | 5 | 41.7 |
| 48 or more | 2 | 16.6 |
| Mean ±SD | 40.66 ± 7.13 | |
| Caregivers | | |
| Mothers | 12 | 100.0 |
| Place of residence | | |
| Rural | 1 | 8.3 |
| Urban | 11 | 91.7 |
| Work of caregivers | | |
| Employee | 1 | 8.3 |
| House wife | 11 | 91.7 |
| Relation between the father and mother | | |
| No relation | 7 | 58.3 |
| 1 st degree | 1 | 8.3 |
| 3 rd degree | 4 | 33.4 |
| Family members | | |
| 3-5 | 7 | 58.3 |
| 6 or more | 5 | 41.7 |
| Income | | |
| Enough | 4 | 33.3 |
| Not enough | 8 | 66.7 |
| Caregiver suffer from a chronic illness | | |
| Yes | 2 | 16.7 |
| No | 10 | 83.3 |
| Types of chronic illness | | |
| Diabetic | 1 | 8.3 |
| CNS disease | 1 | 8.3 |
| No | 10 | 83.4 |
| If complain from problems :- | | |
| During pregnancy | | |
| No | 12 | 100.0 |
| During labour | | |
| Yes | 6 | 50.0 |
| No | 6 | 50.0 |

*N.B:- Age (18 ≤ 28) equal zero.

Table (1) indicates that age of caregivers 41.7 % of mothers aged between 28 to less than 38 years old and between 38 to less than 48 years old respectively while 16.6% were between 48 or more years. Also the table shows that, 100% of caregivers were mothers. Concerning their place of residence, 91, 7% of families were living in urban. Regarding the work of caregivers 91.7 % of them were housewives while 8.3 % of them were employed. Regarding relation between the father and mother only 8.3 % of them cousins while 58.3 % of them were no relation. Considering family members 58.3% of families were 3-5 members while 41.7 % were 6 or more members within family. Regarding income of family, 66.7% of families didn't have enough income. Also the table shows that, 83.4% of caregivers couldn't suffer from a chronic illness. As regarding problems of caregivers during pregnancy Table (1) indicates that 100% of caregivers didn't have any problems while 50% of them have problems during labour.

Part one (B): Demographic characteristics of school age children with cerebral palsy:-

Table 2: Percentage distribution of studied children with Cerebral palsy according to their demographic characteristics (n. =12).

Table (2):
 Percentage distribution of studied children with Cerebral palsy according to their demographic characteristics (n. =12).

| Variables | No. | % |
|--|--------------------|------|
| Age | | |
| 6- 8 Year | 3 | 25 |
| 8- 10 Year | 4 | 33.3 |
| 10-12 Year | 5 | 41.7 |
| Mean ±SD | 9.08 ± 1.84 | |
| Sex | | |
| Male | 9 | 75 |
| Female | 3 | 25 |
| Child go to school | | |
| Yes | 2 | 16.7 |
| No | 10 | 83.3 |
| *Causes of out of school | | |
| No speaking | 8 | 66.7 |
| Fall during walking | 1 | 8.3 |
| Fear for schooling | 1 | 8.3 |
| No specialized school | 3 | 25 |
| Poor relationship with child & teacher | 1 | 8.3 |
| Crippled children | 5 | 41.7 |
| Blindness children | 1 | 8.3 |

*More than one Mutual response.

As regarding age of children Table (2) indicates that 41.7 % of children aged were between 10-12 years, while 25% were between 6-8years. Also the table shows that, 75%

of children were male. Also the table shows that, 66.7% of children no speaking while 8.3% of children complain from fall during walking, fear from schooling and poor relationship with child and teacher.

Table 3: Percentage distribution of studied children with Cerebral palsy according to their problems (n. =12).

Table (3):
 Percentage distribution of studied children with Cerebral palsy according to their problems (n. =12).

| Variables | No. | % |
|--|-----|-------|
| Child suffers from health or social problems? | | |
| Yes | 12 | 100.0 |
| * Child Problems | | |
| Back pain | 5 | 41.7 |
| Always fall | 2 | 16.7 |
| Epilepsy | 1 | 8.3 |
| Violence | 1 | 8.3 |
| Operation in leg | 4 | 33.3 |
| Difficult in swallowing | 5 | 41.7 |
| Urinary incontinence | 3 | 25.0 |
| Tuberculosis | 1 | 8.3 |
| Fear from people | 1 | 8.3 |
| Child have problems during labour | 12 | 100.0 |
| *Child Problems | | |
| Hypoxia | 5 | 50.5 |
| Jaundice immediate after birth | 2 | 16.7 |
| Convulsion | 2 | 16.7 |
| Don't able to interact | 1 | 8.3 |
| Brain hemorrhage | 3 | 25.0 |
| Meningitis | 1 | 8.3 |
| Prolonged of labour | 4 | 33.3 |
| Brain atrophy | 4 | 33.3 |
| Full term baby | | |
| Yes | 11 | 91.7 |
| No | 1 | 8.3 |

*More than one Mutual response.

Table (3) indicates that 100% of children suffered from health and social problems while 8.3% of children suffered from Fear from people, Tuberculosis, epilepsy and violence and 41.7% of them suffered from back pain and always fall during walking. As regarding problems of children during childbirth Table (3) indicates that 100% of children suffered from problems during childbirth while 50.5% of children suffered from hypoxia and 8.3% of them suffered from don't able to interact and meningitis. Also the table shows that, 91.7% of children were full term baby.

Part two: Qualitative Findings

This part includes experiences of caregivers having Cerebral Palsy School Age Children. The current study identifies eight main themes in exploring experience of caregivers

quality of life who had Cerebral Palsy children:- (I) Support people & Culture norms, (II) Fulfillment of needs, (III) Realization of life potential, (IV) Biological order, (V) well-being, (VI) Life satisfaction,(VII) Happiness, & (VIII)Meaning in life. These Themes and the existential subthemes are described in table (4).

Table 4: Illustrate the major themes and existential subthemes of qualitative analysis based on integrative theory of the Global Quality of Life Concept of (IQOL) as mentioned by participants :-

Table (4):- Illustrate the major themes and existential subthemes of qualitative analysis based on integrative theory of the Global Quality of Life Concept of (IQOL) as mentioned by participants :-

| 1- Objective quality of life | | |
|-------------------------------------|--|-------------------------------|
| Major themes | Existential Sub-themes | Participants numbers |
| I.1-Support people | 1- Lack of support from spouse <ul style="list-style-type: none"> • physical burden • depending on mother | (1,2,11&12) |
| | 2- Sometimes support from family members. | (3,4,5,6,7,8,9&10) |
| I.2- Culture norms | 1- Sadness <ul style="list-style-type: none"> • Stigma, • blame from surrounding people, • Social withdrawal. | (1,5,6,7,8,11&12) |
| | 2-Knowing our God, <ul style="list-style-type: none"> • acceptance of child, • satisfaction, • hope for future because of religious belief, • encouragement, • Support from family members. | (2,3,4,9&10) |
| II-Fulfillment of needs | 1- Feeding, <ul style="list-style-type: none"> • Drinking, • bathing, • changing clothes | (1,4,5,7,8,9&10) |
| | 2- Poverty | (2,3,6,11&12) |

| | | |
|---|--|---------------------------------------|
| | <ul style="list-style-type: none"> • coast of caring, • lack of awareness, • stubborn, • suffering, • Lack of interest. | |
| III- Realization of life potential | 1- Satisfaction <ul style="list-style-type: none"> • hope for future because of religious belief, • blessing from God 2-Sadness, <ul style="list-style-type: none"> • blame, • caring • Scourge. | (1,4,6,7,9&10) (2,3,5,8,11&12) |
| IV- Biological order | 1-Social withdrawal, <ul style="list-style-type: none"> • pain, • lack of assistive devices for transfers, • psychological effect, • hope • difficult of breathing, 2 -prelude, <ul style="list-style-type: none"> • pity, • hope • Empathy. | (1,2,3,5,6,9,10,11&12) (4,7&8) |
| 2- Subjective quality of life | | |
| Major themes | Existential Sub-themes | Participants numbers |
| I-Wellbeing | 1- Hopelessness <ul style="list-style-type: none"> • profound sadness, | All participants (1-12) |

| | | |
|----------------------------------|--|--|
| | <ul style="list-style-type: none"> • carelessness • financial burden • lack of assistive devices for transfers • suffering | |
| II-Satisfaction with life | 1- Satisfaction, <ul style="list-style-type: none"> • Love • a blessing from God • hope 2- Hopelessness <ul style="list-style-type: none"> • sadness | (1,3,4,5,7,8,9,10 &12) (2,6&11) |
| III- Happiness | 1- Happiness <ul style="list-style-type: none"> • Compensate • Hope. 2- Committed to caring and sadness. | All participants except (8) (8) |
| IV-Meaning in life | 1- Sometimes frustration <ul style="list-style-type: none"> • Caring 2 - Hope <ul style="list-style-type: none"> • pray for children | All participants (1-12) |

Part two: Data analysis related to Objective quality of life among caregivers having Cerebral Palsy School Age Children.

The second part of this study presents themes' analysis of data related to objective quality of life among caregivers having cerebral palsy school-age children. Four major themes: support people & culture norms, fulfillment of needs, the realization of life potential & biological order.

Major theme: 1.1 Support people (Participants: from (1 - 12) :

In the process of analyzing the transcripts, the participants numbers (1,2,11&12) revealed a lack of support from family and their spouse, physical burden, and dependence on their mothers, In addition to the participants numbers (3,4,5,6,7,8,9&10) clarified that they sometimes had support from family members.

Major theme: 1.2- Culture norms (participants: from (1- 12) :-

In the process of analyzing the transcripts, the participants numbers (1, 5, 6, 7, 8, 11&12) revealed sadness, stigma, and blame from surrounding people, In addition to the participants numbers (2, 3, 4,9 & 10) stated that knowing our God, acceptance of child, satisfaction, support from family members, encouragement, and hope for future because of religious belief.

Major theme: 2- Fulfillment of needs (participants: from (1 - 12) :-

In the process of analyzing the transcripts: the participants numbers(1,4,5,7, 8,9&10) reported Feeding, Drinking, bathing, changing clothes, In addition to the participants numbers (2,3,6,11&12) revealed poverty, coast of caring, lack of awareness, stubbornness, Suffering, and lack of interest.

Major theme: 3- Realization of life potential (participants: from (1 - 12) :-

In the process of analyzing the transcripts: the participants numbers (1,4,6,7,9&10) reported the Satisfaction, hope for future because of religious belief, and blessing from God, In addition to the participants numbers (2,3,5,8,11&12) reported sadness, blame, caring and scourge.

Major theme: 4- Biological order (participants: from (1 - 12) :-

In the process of analyzing the transcripts: the participants numbers (1,2,3,5,6,9,10,11&12) revealed social withdrawal, pain, lack of assistive devices for transfers, psychological effect, and difficulty of breathing, while the participants numbers (4,7,&8) reported that hope, prelude, pity and empathy.

- Data analysis related to subjective quality of life among caregivers having Cerebral Palsy School Age Children.

The third part of this study presents an analysis of data related to the subjective quality of life among caregivers of school-age children with cerebral palsy. Four major themes emerged: well-being, life satisfaction, happiness, and meaning in life.

Major theme: 1- Wellbeing (participants: from (1 - 12) :-

In the process of analyzing the transcripts: all participants numbers from (1-12) stated that hopelessness and profound sadness, carelessness, financial burden, and lack of assistive devices for transfers.

Major theme: 2- Satisfaction with life (participants: from (1 - 12) :-

In the process of analyzing the transcripts: the participants numbers (1,3,4,5,7,8,9,10&12) reported satisfaction, love, blessing from God and hope, In addition to the participants numbers (2,6&11) revealed hopelessness and sadness.

Major theme: 3- Happiness (participants: from (1 - 12) :-

In the process of analyzing the transcripts: all participants revealed that happiness, compensate, and hope, only participant number eight reported that committed to caring, and sadness.

Major theme: 4- Meaning in life (participants: from (1 - 12) :-

In the process of analyzing the transcripts: all participants stated: frustration sometimes, caring, hope and pray for children.

4. DISCUSSION

As the table (1) shows that, all the study participants of caregivers were mothers. This result is in agreement with the results of a study done by [10] .Who studied "Caregivers' experiences of having a child with cerebral palsy. A meta-synthesis in Africa "on 171 caregivers of children with CP, They reported that, 88.8% of participants were mothers and were unemployed. Also, finding was also similar to the findings by [11] who studied "Mothers' experience of having a child with cerebral palsy. A systematic review "on 292 mothers of children with CP in Australia, They reported that, Mothers assumed the role of key caregiver. This agreement between studies from the researcher point of view because of the most responsibility and burden of caring for the children with cerebral palsy depend on mothers.

Regarding the work of caregivers table (1), the results of the current study showed that the majority of caregivers were housewives while 8.3 % of them were employed. This result was compatible with the study conducted by [12]. who performed" Effect of Supportive Educational Intervention for Mothers of Female Adolescents with Cerebral Palsy on Their Caring Practices" in Egypt on 50 mothers of children with CP recruited from pediatric hospital at Ain Shams University and revealed that slightly more than half of them were housewives . From the researcher point of view, these similarities in both studies may be due to the study's nature.

Regarding income of family Table (1) shows that, around two third of families didn't have enough income, this result in congruence with results of a study done by [13]. who studied " Experience of Caregivers Caring for Children with Cerebral Palsy in Accessing Oral Health Care Services: A Qualitative Study " on Ten caregivers of children with CP in Kota

Bharu, Kelantan, who found that majority of the caregivers were complain from the lower socio-economic status. From point of view, most of the caregivers have three or more children which directly incurred the total expenditure of the family thus increasing the caregiver financial burden and may be the caregiver's lack of available time and opportunity to work because of the high caregiving demands needed to care for their child.

As regarding age of children Table (2), the results of the current study showed that the more than one third children aged were between 10-12 years, this result was agreement with results of a study done by [14]. who studied " Effects of Caregivers-Centered Package on Functional Balance and Activities of Daily Living in Children with Cerebral Palsy: Randomized Control Tria " on 80 caregivers and their children with CP in Mansoura University, Egypt, who found that the mean age of CP children was nine years. From the researcher point of view, these similarities between both studies may be due to characteristics of the studied sample and inclusion criteria in this study.

As regarding child go to school Table (2), the results of the current study showed that the majority of children didn't go to school. This result was agreement with results of a study done by [15]. Who studied "Challenges Faced by Cerebral Palsy Children at Kitwe Teaching Hospital, Zambia "in Zambia, on 21 children with CP, who found that unable to go to school. From point of view this return to most of them required wheel chairs, and having someone to take them to school every day. In addition, they also explained that these children fail to play like other children in the community due to their inability to walk and some due to inability to talk. This agreement between studies from the researcher point of view because of the poor design of facilities that limited their child's participation in society and in the typical activities of being a child as going to school.

The results of the current study Table (3) showed that, all the children suffered from health and social problems. This result was agreement with results of a study done by [14]. who studied " Effects of Caregivers-Centered Package on Functional Balance and Activities of Daily Living in Children with Cerebral Palsy: Randomized Control Tria " on 80 caregivers and their children with CP in Mansoura University, Egypt, who found that the Children with cerebral palsy (CP) are suffered from several associated health problems, such as sensory, intellectual, communicative, and motor function impairments. From the researcher point of view, these similarities between both studies may be due to characteristics of the studied sample and inclusion criteria in this study.

As regarding problems of children during Labour Table (3), all the children suffered from problems during Labour such as half of children suffered from hypoxia and only 8.3% of them suffered from don't able to react and meningitis. This result was agreement with results of a study done by [16].Who studied " Comorbidities in children with cerebral palsy: a single-centre cross-sectional hospital-based study." In India on 436 children with CP, who found that the birth and perinatal complications such as hypoglycaemia (102/384; 26.6%), hypoxia (90/384; 23.4%) and bilirubin encephalopathy (24/384; 6.3%), which were the leading causes of CP in our cohort. From the investigator's point of view, these similarities in both studies may be due to the study's nature.

Also the table (3) shows that, the majority of children were full term baby. This result was agreement with results of a study done by [16]. Who studied "Comorbidities in children with cerebral palsy: a single-centre cross-sectional hospital-based study." In India on 436 children with CP, who found that Sixty per cent of children in our study were born term, 25% were born moderate to late preterm and 15% were very or extremely premature. The profile of gestational age at birth is similar to some of the reports from LMICs and HICs. From the researcher point of view, these similarities between both studies may be due to characteristics of the studied sample.

As the table (4) shows that, the sub- theme that was extracted from the data collected were stigma, blame from surrounding people, acceptance of child, acceptance of child, support from family members, financial burden & lack of assistive devices for transfers. This result is in agreement with the results of a study done by [11]. Who studied "Mothers' experience of having a child with cerebral palsy. A systematic review". The included studies were conducted in Australia (n = 3), n = 2 from Brazil, Taiwan, India, Iran, Canada and n = 1 from Zambia, Saudi Arabia, Spain, and Ghana., They reported that, Five overarching themes reflecting the experiences and perceptions of mothers raising and caring for a child with cerebral palsy are developed: 1) adapting and making sacrifices; 2) guilt and cultural blame; 3) social stigma and marginalization; 4) physical, environmental, and financial challenges and 5) healthcare experiences. This agreement between studies from the researcher point of view, Family caregivers were worried about the future because they did not know when their children with CP would recover or how long they needed to take care of their children.

Also the table (4) reported that, the sub- theme that was extracted from the data collected was as mention, cost of caring, suffering, lack of assistive devices for transfers, love & financial burden. The finding was also similar to the themes extracted by [17]. Who studied " Caring for children with severe cerebral palsy: the lived experience of parents " In Iowa, Michigan, and Florida, on 11 participants who are caregiving parents of their child with CP, They reported that, Four themes emerged from the analysis: (1) Life is hard, heavy with burden, worry, and love; (2) Remarkable; (3) Identity transformation and empowerment towards authenticity; and (4) Living a life that is planned, forced with structure and without spontaneity.

As well as the study was done by [10]. Who studied "Caregivers' experiences of having a child with cerebral palsy. A meta-synthesis "in Africa on 171 caregivers of children with CP, They reported that, Sixty-seven findings were extracted from the 12 included studies. The findings were grouped into eleven sub-themes and then into five synthesized themes. The synthesized themes are 1. Need for convenient healthcare facilities, therapeutic services, and accessible public places, 2. Need for healthcare information and financial aid, 3. Psychological, and physical constraints, 4. Societal rejection and stigma, and 5. Overwhelming caring burden. Conclusion: Caregivers face many challenges in adjusting their lifestyles to meet the needs of the child with cerebral palsy. Some adjustments reported included giving up full-time jobs and businesses to be full-time caregivers, giving up leisure activities, and confinement to one place. This agreement between studies from

the researcher point of view children with CP need for Holistic care management of children with CP requires convenient access to adequate, funded healthcare facilities and accessible public places.

5. CONCLUSION AND RECOMMENDATIONS

Based on the findings of the current study, it can be concluded that, the main concept extracted from the collected qualitative data was the lived experience of caregivers of school age children with cerebral palsy. It reflects how the CP affect all aspects of QOL including overall QOL, physical health, psychological health, social health, environmental health, personal independence and religious aspects of caregivers and children with CP . It can also be concluded that life with children with CP is greatly affected by all personnel engaged in providing care to children with CP including administrative personnel and policy makers.

Based on the results of the current study, the following recommendations are suggested:

- 1- The caregivers needed to support from families to help and assist them while caring of children with CP.
- 2- Basic physical, psychological and social needs must be available by adequate or free governmental health services.
- 3- Increasing awareness of community about their economic needs of children with CP.
- 4- Integrate caregivers having children with CP in different aspects of the community activities such as clubs & schools.

6. LIMITATIONS

Although every effort was made to conduct this trial as described in the protocol, inevitably certain limitations existed. Some were beyond control of the researcher and some simply were over sighted. The limitations of the trial were as follows:

- The findings are limited in generalizability due to the fact that the sample was selected from a single geographical area in Egypt.

7. ABBREVIATIONS

| | |
|-------|----------------------------------|
| CP | Cerebral palsy |
| QOL | Quality of Life |
| FHN | Family Health Nursing |
| LMICs | Low- and middle-income countries |
| HICs. | high-income countries |

8. DECLARATIONS

8.1 Ethical Considerations

A primary written approval to conduct the study was obtained from the Research Ethics Committee of Faculty of Nursing, Cairo University. After acceptance of ethical committee of The General Organization for Teaching Hospitals and institutes, data collection started and written consent for acceptance to conduct the interview and participation in the study was obtained from participants (caregivers) after description of the study or from their legal guardian. Caregivers of children were informed that participation in this study is voluntary; each participant has the right to withdraw from the study at any time. After each interview, the researcher wrote verbatim transcription for each interview and replaced the names of participants by coded numbers to ensure privacy. Also, participants will be assured that these data will not be reused in another research without their permission. Final approval was obtained from Faculty of Nursing, Cairo University Research Ethics Committee After completion of data collection. Finally the recorded data via mobile were kept in a safely folder accessible only by the researcher of the study to keep confidentiality.

8.2 Availability of data and materials

The data that support the findings of this trial are available from the corresponding author upon reasonable request.

8.3 Competing Interests

The authors declare that they have no competing interests.

8.4 Funding

This trial received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

Acknowledgment

The authors would like to thank all the team in the national institute of neuromotor system and the caregivers who participated in this trial.

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