Post-Traumatic Stress Symptoms among Siblings of Terminally Ill Children

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Abstract Background: The sibling relationship is usually the first, most intense, and longest peer relation that an individual will ever have. Therefore, having a brother/sister with terminal illness poses a risk to the siblings' mental health because of the stress they are under and insufficient support from others. Aim: This study aimed to assess post-traumatic stress symptomatology among siblings of terminally ill children in Ismailia city. Design: descriptive design was adopted for this study. Sample: purposeful sample of eighty one siblings of children with terminal illness. Tool of data collection: the data was gathered through structured interview where the tool was divided into two parts: the first part includes: demographic characteristics of the studied subjects and the second part includes: The Child PTSD Symptom Scale (CPSS). Results: All siblings of children with terminal illness in this study have met criteria of post-traumatic stress symptomatology (PTSS) with nearly half of them had severe symptoms. Conclusion: siblings of children with terminal illness are at substantial risk for PTSS. Recommendation: Create supporting groups for siblings as an ongoing service where siblings of children with terminal illness have an opportunity to meet with others in a similar situation and share their experiences and feelings.

Keywords: siblings, terminal illness, post-traumatic stress symptoms


1. Introduction

Illness not only affects a person’s life in many ways but affects the whole family system as well. At times, it consumes a person’s life and can turn the family life upside down, especially when it is a child who is sick. Even the simplest childhood illness can have an impact on the relationships among family members, family’s stress level, and income [1,2]. When the illness becomes chronic or life-threatening or terminal, it becomes one of life’s most difficult experiences and an extremely stressful event for a family because it is out of the natural order of things as children represent health and hope [3].

Children’s illness poses several challenges to family units as a whole, and to the corresponding members within them. Siblings in particular face challenges associated with the illness of a child within their household [4]. These challenges include the complication of the sibling relationship and jealousy, the shift in parental attention toward the sick child, and potentially even a period of separation from not only one or both parents but also the sick sibling [5].

As a result of these household changes, the siblings may experience a relationship based more on caregiving than mutual companionship [6,7]. Often, the parents are focused on the sick child so that well siblings may feel abandoned. The well siblings may feel guilty that they are annoyed with all the attention that their sick sibling is receiving. Hence, conflicting emotions can overwhelm the well siblings [8]. Therefore, clinicians worry that the siblings’ well-being may suffer because of the pressure they are under and insufficient support from others especially the parents [9].

According to the fourth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV), medical events such as severe injuries and life-threatening illnesses have been recognized as potentially traumatic events. Potentially traumatic events are defined as events in which individuals were exposed to real or perceived threats to life or physical integrity or sexual violence to themselves or their loved ones. A child may be traumatized through directly experiencing the event, or witnessing it as it happened to others, or hearing about another person’s experience of the event, especially if this event happened to the parents, siblings, close relative or close friend [10].

Therefore, having a child diagnosed with life-threatening or terminal illness may put the siblings at increased risk for posttraumatic stress disorder (PTSD) and clinically elevated levels of posttraumatic stress symptoms (PTSS).
Previous studies showed that one-half to two-thirds of the siblings reported moderate to severe post-traumatic stress symptoms [12]. Elevated PTSS can include: difficulty regulating negative affect and cognitions related to the trauma; feeling of reliving the trauma through distressing dreams, flashbacks or memories; attempts to avoid thoughts and emotions related to the trauma; restricted range of affect; feelings of detachment from others; increased irritability and anger; and difficulty regulating physiological and emotional arousal in response to trauma-related cues. These symptoms can interfere with cognitive processes, executive functioning, memory, and attention [10]. Furthermore, childhood traumatic stress varies from adult trauma in that the symptoms are more often event-specific. Physical arousal, strong emotions, and an altered expectation of their security and safety in the world will decrease over time in their daily lives, but reminders and events can promptly bring them back to life. The traumatic experience in this way can continue to have an impact long after the immediate experience; hence, surviving siblings may experience psychiatric problems as children and into adulthood [13,14,15].

2. Aim of the Study

The aim of the present study was to assess post-traumatic stress symptoms among siblings of terminally ill children in Ismailia city.

3. Subject and Methods

3.1. Research Design

A descriptive design was utilized for the current study.

3.2. Research Setting

This study was conducted in four hospitals in Ismailia city, Egypt, namely: Suez Canal University Hospitals, Suez Canal University Specialized Hospital, Ismailia General Hospital, and Ismailia Oncology Teaching Hospital; at different units and departments including: Pediatric Intensive Care Units, General Intensive Care Unit, Neurology Intensive Care Unit, Neurology Department, Neuropsychiatry Department, and Oncology Department.

3.3. Sample

A purposive sample of 81 siblings from the previously mentioned settings were comprised the sample of the present study. It included children aged from 7 to 18 years old who have previous awareness that their sibling has a terminal illness, and excluded the siblings with any psychiatric, mental health problems, physical disability or chronic disease.

3.4. Tool of Data Collection

Data was gathered through structured interview. The tool was divided into two parts:

Part I: Demographic data includes:
- Demographic characteristics of the siblings, it includes (Age, gender, birth order, etc).
- Demographic & medical background of the terminally ill children, it includes (Age, gender, diagnosis …….etc).

Part II: includes:

Tool I: The Child PTSD Symptom Scale (CPSS): was developed by Foa et al., [16] and adopted and translated into Arabic by the researcher to assess post-traumatic stress symptoms. It is designed to assess children and youth between the ages of 7 to 18 years. It has strong reliability as Chronbach’s alpha = 0.70 - 0.89 for the total and subscales symptom scores. It is a total of 24 items and includes two parts:

Part A: has 17 items corresponding to the DSM-IV criteria and measures the type and frequency of PTSD symptoms. It is categorized by symptoms type, with items 1-5 refer to re-experiencing symptoms, items 6-12 refer to avoidance symptoms, and items 13-17 refer to arousal symptoms.

Part B: has 7 items and measures the degree of functional impairment these symptoms cause.

Scoring System:

Part A: The 17 items are rated on a scale from 0 to 3, (where "0" indicates (Not at all /only at one time), "1" indicates (Once a week or less/ once in a while), "2" indicates (2 to 4 times a week/ half the time) and "3" indicates (5 or more times a week/almost always)). A total score for the 17 items range from 0 to 51. A clinical cutoff of 15 or greater is appropriate for diagnosing PTSD (0 - 10 = below threshold; 11 - 15 = subclinical; 16-20 = mild; 21- 25 = moderate; 26-30 = moderately severe; 31-40 = severe; 41-51 = extremely severe).

Part B: Scores for the functional impairment items are scored dichotomously as absent (0) or present (1). A total score range from 0 to 7 with higher scores indicating greater functional impairment.

3.6. Ethical consideration

Primary approval was obtained from the research ethics committee in the Faculty of Nursing, Suez Canal University, Egypt. Also, official permission was obtained from the directors of the above-mentioned settings. Oral affirmative consent was obtained from children while written consent was obtained from their mothers to participate in the study after full explanation of the nature and the main aim of the study, its expected outcomes, and their rights to voluntarility participate and their right to withdraw from the study at any time without any rationale.

3.7. Field of Work

Data were collected within nine months period. Data was collected three days/ week from the previously mentioned settings by rotation from 3 to 6 P.m. (according to the patients’ visit hours of the hospital). Each interview with the mother of the terminally ill children and their siblings the researcher started by introducing self and gives a brief explanation about the aim of the study. Written consent was obtained from each subject before data collection. The researcher interviewed each subject individually using the previously mentioned tools for
15-20 minutes according to the physical and mental readiness of them and the mitigating circumstances in each study setting.

4. Results

The present study showed that the mean age of the siblings was 11.8±3.0 SD, where more than half of them (51.9%) were females. Concerning the birth order, more than half of them (53.1%) were firstborn child, while 50.6% of them were living in families in which the number of children was ranged between 2 to 3. Regarding the parents' work, 49.4% of the fathers were manual worker, while 63.0% of their mothers were housewives. Moreover, the mean age of the terminally ill children was 6.9 ± 5.4 SD, where 63.0% of them were males. Regarding their terminal illness diagnosis, more than half of them (58.0%) were having non-congenital disease; with 76.5% of them was having their illness for three years or less, and 87.7% of them were diagnosed as being terminally ill for three months or less.

![Figure 1](image1.png)

**Figure 1.** Level of post-traumatic stress symptoms among the siblings according to the Child PTSD Symptom Scale (CPSS) (n = 81)

![Figure 2](image2.png)

**Figure 2.** Percentages distribution of the studied sample according to each symptom within PTSD Criterion B (Re-experiencing) (n = 81)
Figure 1 shows the level of post-traumatic stress symptoms among the siblings according to the Child PTSD Symptom Scale (CPSS). It shows that most of the siblings ranged between (severe, very severe, moderate, and moderately severe post-traumatic stress symptoms) with the percentage of (40.7%, 29.6%, 18.5%, and 7.4% respectively), while only 3.7% of them had mild post-traumatic stress symptoms.

Moreover, it was found that the highest percentage of the siblings had "almost always" symptoms of post-traumatic stress including (Re-Experiencing Symptoms, Avoidance Symptoms, and Arousal Symptoms) with a percentage of (59.7%, 33.9%, and 54.6% respectively). Regarding re-experience symptoms, 84.0% of the siblings reported almost always "Feeling upset when thinking about the event or hearing about it". While for the intrusion symptoms, 69.1% of them reported almost always "Not feeling close to the people around ". Also for the arousal symptoms, 61.7% of them reported almost always "Having trouble concentrating". Furthermore, 84.8% of the siblings reported that post-traumatic stress symptoms (PTSS) had interfered with their functioning, with all of the siblings had reported that PTSS had interfered with "general happiness within their life" (Figure 2, Figure 3, Figure 4).

Furthermore, there was a statistically significant relation between the total post-traumatic stress symptoms and the number of children (r = -0.419/ p < 0.001). Moreover, there was a statistically significant relation
between the gender of the terminally ill children and their siblings' post-traumatic stress symptoms (t = 2.073/p = 0.041) (Table 1, Table 2).

Table 1. Relation between the siblings' demographic characteristics and the total post-traumatic stress symptoms (PTSS)

<table>
<thead>
<tr>
<th>Demographic data</th>
<th>PTSS Total PTSS (Mean ±SD)</th>
<th>Test</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>- r 0.068</td>
<td>0.547</td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Males</td>
<td>35.1 ±8.1</td>
<td>t</td>
<td>0.653</td>
</tr>
<tr>
<td>Females</td>
<td>33.9 ±8.4</td>
<td></td>
<td>0.516</td>
</tr>
<tr>
<td>Birth order</td>
<td>- r 0.172</td>
<td>0.124</td>
<td></td>
</tr>
<tr>
<td>Number of children</td>
<td>- r -0.419</td>
<td>&lt;0.001*</td>
<td></td>
</tr>
<tr>
<td>Mother work</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Working</td>
<td>35.3 ±7.2</td>
<td>t</td>
<td>1.191</td>
</tr>
<tr>
<td>Not working</td>
<td>33.1 ±9.7</td>
<td></td>
<td>0.237</td>
</tr>
</tbody>
</table>

Table 2. Relation between the terminally ill children demographic & medical background and their siblings' total post-traumatic stress symptoms

<table>
<thead>
<tr>
<th>Demographic data</th>
<th>PTSS Total PTSS (Mean ±SD)</th>
<th>Test</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>- r 0.075</td>
<td>0.505</td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Males</td>
<td>33.1 ±8.5</td>
<td>t</td>
<td>2.073</td>
</tr>
<tr>
<td>Females</td>
<td>36.9 ±7.2</td>
<td></td>
<td>0.041*</td>
</tr>
<tr>
<td>Diagnosis</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Congenital</td>
<td>34.4 ±7.6</td>
<td>t</td>
<td>0.099</td>
</tr>
<tr>
<td>Non- Congenital</td>
<td>34.6 ±9.1</td>
<td></td>
<td>0.922</td>
</tr>
<tr>
<td>Illness duration</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(Years)</td>
<td>- r -0.068</td>
<td>0.544</td>
<td></td>
</tr>
<tr>
<td>Duration since</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>diagnosis of terminal illness (Months)</td>
<td>- r 0.137</td>
<td>0.222</td>
<td></td>
</tr>
</tbody>
</table>

5. Discussion

Regarding the post-traumatic stress symptoms (PTSS), this study found that all the siblings had met the criteria for PTSS, with more than two fifth of them, had severe symptoms. Also, most of the siblings reported that PTSS had interfered with most of the domains of their functioning. This may be due to many reasons including: the siblings' knowledge that their brother/sister would die; knowing or even hearing about other children with the same condition who died; witnessing the emergency department and intensive care admissions; witnessing the potentially traumatizing invasive medical procedures; observing their ill sibling's altered appearance; and exposure to the physical and emotional suffering of their brother or sister such as pain, being comatose, unable to breathe or talk or respond to them, being mechanically ventilated, and having feeding difficulties.

Furthermore, the siblings may be surrounded by the parental intensified emotions when they come home as the inevitability of death dominates family life. The parents themselves may have post-traumatic stress symptoms which may increase the children PTSS as it is widely recognized that a child's response to a traumatic event is greatly influenced by their family context [17,18,19].

The prior results aren't in the same line with Long et al., [2], which titled "The role of contextual threat in predicting self-reported distress among siblings of children with cancer" who revealed that more than half of the siblings had mild posttraumatic stress reactions as a result of their brother or sister’s experience with the illness. On another hand, the current results are in accordance with the study of Long et al., [12] which titled "Psychosocial functioning and risk factors among siblings of children with cancer: An updated systematic review" who revealed that one-half to two-thirds of the siblings reported moderate to severe post-traumatic stress symptoms.

Moreover, concerning the avoidance symptoms, the current study revealed that the highest percentage of the siblings reported that they didn't feel close to the people around and they had much less interest in doing things they used to do. This may be due to that they used to do everything with their terminally ill sibling especially if they are of the same age. Also, their peer relationship and activities are affected due to the upheavals that are affecting their family and because of the emotional impact that the terminal illness diagnosis imposes on them. Moreover, parents are frequently focused on the sick child so that well siblings may feel abandoned and not close to their own family and the people around them [5,8].

The prior result isn't in the same line with the study of Kaplan et al., [11] which titled "Cancer-related Traumatic Stress Reactions in Siblings of Children with Cancer" who reported that, regarding the avoidance symptoms, the highest percentage of the siblings reported that they were trying not to think about, talk about, or have feelings about the illness of their sibling. They further explained that this avoidance may allow for a break from reminders of the event and allow resumption of other necessary tasks.

Furthermore, regarding the re-experience symptoms of the PTSS, the current study revealed that, the highest percentage of the siblings reported that they felt upset when thinking about terminal illness of their sibling or hearing about it (e.g. feeling scared, angry, sad, guilty, etc.) and that they had bad dreams or nightmares. This guilt feelings may be due to their imaginary thinking, as they may believe that their angry words, secrete wishes to be the one who get the attention, and jealousy from the sick child is what cause the illness for their sibling [3]. Their angry and scary feelings may also be due to that they can't do anything to change or ease what is happening within their family.

Furthermore, during the interview with one of the children, he said "I frequently have nightmares that I hated to go to sleep. I always see my deceased grandparent take my brother away with him and tell me that I will never be able to see him again because i didn't let him play with me and because I hated him as he get all the gifts and toys and nobody give me anything. Sometimes, I wish I was sick too so that everybody deals with like him. I regret all this now; he is very sick and going to die. I don't want any gifts, I just want my brother back and I will play with him and do everything to make him happy". This prior result goes along with the result of Kaplan et al., [11] who reported that concerning the re-experience symptoms, the highest percentage of the siblings reported that they were feeling upset when they think about or hear about the illness of their sibling (e.g. feeling scared, angry, sad, guilty, etc.).

Moreover, concerning the arousal symptoms, the current study revealed that the highest percentage of the siblings reported that they were having trouble...
concentrating, having trouble falling or staying asleep, and being overly careful. This may be due to the siblings trying to watch for themselves as they don't want to increase the anxiety and problems for their parents. During my interview with one of the children, he said "After seeing what happened to my life and my family when my brother had the accident, I become overly careful with everything around me especially my health. I don't want to increase the worry and the problems for my parents. I don't want to see them suffer like they are now with my brother".

Additionally, another child said "When I'm in the class I can't pay attention to what the teacher is saying or anything around me. I'm physically with them but my mind is in another place. I think of my family and what would happen when my sister dies and what would happen to me and her. I can't imagine my life without her. I can't sleep at night as my mind can't stop thinking which make me exhausted the next day and unable to concentrate in the class". The previous result goes along with the study of Kaplan et al., [11] who revealed that, regarding the arousal symptoms, the highest percentage of the siblings were having problems with sleeping and concentrating, and being overly careful, jumpy or easily startled.

Focusing on the statistical relation between the current study variables, the present study revealed that, there was a statistically significant relation between the number of children and the healthy siblings' total post-traumatic stress symptoms. This may be because larger families mean more members who would be able to provide more social and emotional support to each other. Also, they may have more opportunities to talk with each other about what is going on within their family, and express their feelings about that, which would assure them that they are not alone and they are all share the same struggles, and feelings.

Moreover, the current study revealed that there was a statistically significant relation between the terminally ill children’s gender and their healthy siblings’ total post-traumatic stress symptoms in which the healthy siblings had more PTSS when they have a female terminal ill sibling. This may be due to the female are more expressive about what they are feeling and going through. The females are also kind, involved and nurturing [20]. Therefore, seeing them going through the terminal illness suffering might increase the post-traumatic stress symptoms.

6. Conclusion

Based on the findings of the present study, it can be concluded that, all the siblings of the terminally ill children in this study had met the criteria for post-traumatic stress symptoms, with nearly half of them had severe symptoms. In addition, most of the siblings had these symptoms interfered with most of the domains of their functioning.

7. Recommendations

Based upon the result of this study, the following recommendations can be suggested:

1. Encourage presence of a liaison psychiatric nursing unit in each hospital as possible in order to provide support and council to the whole family especially the siblings, during the child terminal illness, till his/her death, continue to offer long-term therapeutic care after the death of the terminally ill child if needed.

2. Create supporting groups for siblings as an ongoing service, where siblings of children with terminal illness have an opportunity to meet with others in a similar situation and share their experiences and feelings, and whereby cognitive behavioral and psycho-educational interventions can be used.

3. Development of an educational program about the impact of having a child with terminal illness on the overall well-being of his/her siblings and the needs of those siblings.

References


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