"I am a Mother and Care Giver of My Child" Psycho-social needs Looking after Children with Traumatic Brain Injury

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Abstract:

Background:

Mothers nurture children early in life, in case of illness, she continues to provide caregiving role especially in the neurosurgical conditions like TBI. Psychosocial needs of mothers looking after children with TBI is over looked. Thus, the present study focused to understand the psychosocial needs of mothers providing care for children with TBI.

Methodology:

The study adopted the qualitative approach, 30 care givers were recruited for the study after obtaining informed consent. The data was collected in face to face interviews. All the interviews were audio recorded. Thematic analysis was used to for qualitative data and descriptive statistics were used for quantitative variables. The R software was used for data analysis.

Results:

The study findings reported that average age was found to be 32.13 ± 5.99 years. The majority belong to Below Poverty Line (BPL). All mothers have experienced mild level distress, anxiety and stress. From the qualitative analysis, the major themes were: information about the illness and treatment choices, financial difficulties, mothers personal feelings and concerns, social support and coping, and long term professional supportive care.

Conclusion:

There is an urgent need to provide psychosocial care for mothers' of children with TBI during hospitalization as well as at home and need to form advocacy group in the community.

I. BACKGROUND

Young children are more vulnerable to injuries. In many countries including India, injuries are leading cause of death among children and adolescents.(Singh & Aggarwal, 2010) Nearly 20% of all unintentional deaths worldwide occur in children below 15 years of age in particular Infants aged 0 to 4 years and adolescents aged 15 to 19 years are more likely to sustain Traumatic Brain Injury (TBI). (Langlois, Rutland-Brown, & Wald, 2006) Road accidents and falls in childhood constitute a significant public health problem. World Health Organization reported that 98% of childhood injuries occur in the poorest countries in the world than industrialized nations. However, there is a paucity of data regarding the incidence of TBI with respect to children in developing countries. (Bartlett, 2002). TBI is defined as an acquired brain injury caused by "a bump, blow or jolt to the head or penetrating head injury that disturbs the normal function of the brain. (CDC, 2014) TBI can impact the children's intellectual, behavioral, and social function. (Crowe, Catroppa, Babl, & Anderson, 2012). Further, younger age is associated with poor recovery after TBI among younger children compared to older children. (Andruszkow et al., 2014). Physical, emotional, psychological, behavioral and social issues among children will create significant impact on parents in terms of immeasurable distress and guilt to the parents. On an other hand, parents experience significant emotional distress, relationship issues, caregiving burden, and difficulties in parenting role, support, and poor coping abilities. (Brown, Whittingham, Sofronoff, & Boyd, 2013a), (Singh & Aggarwal, 2010). Many research studies have done on children from Epidemiological perspective and its impact on children and young adolescents. TBI research is lacking in India especially on psychosocial issues (Agrawal et al., 2016), (Wade, Taylor, Drotar, Stancin, & Yeates, 1998). Therefore, the current study focused to identity the psychosocial needs of mothers who involved in care giving of children after TBI.

II. METHODOLOGY

Research Design:

The study adopted the qualitative approach. Women care givers in particular mothers who were providing care for children with Traumatic Brain Injury had been considered as universe of the study. The study had conducted in National

Institute of Mental Health and Neuro Sciences, Bengaluru. The sample was recruited with the help of convenience sampling technique. The following pre-designed inclusion and exclusion criteria were followed to recruit the sample in the study. Mothers who were providing care for children with TBI, who can communicate in Kannada and English were recruited in the study. 50 mothers who were providing care for children with TBI were contacted. Out of 50, 15 subjects did not give consent for the study and 05 subjects were withdrawn due to personal reasons during interview, hence 30 subjects were recruited in study.

Data tools and Data Collection:

Socio-Demographic Data Sheet:

Socio-demographic details such mother's age, marital status, domicile, education, occupation etc., were collected with help of semi-structured interview schedule prepared by the researcher and face validated prior to its application. The children illness details were collected from the hospital records.

Semi-Structured Interview Schedule:

To explore the qualitative data the semi-structured Interview schedule was used with open ended questions. The following questions were asked For example: How did you feel and managed when your child had TBI? What made you feel more worried? What are your current concerns with respect to your child? All the qualitative interviews were audio recorded after obtaining permission from the subjects.

Data Collection Procedure:

Data had been collected from the In-Patient as well as Out-patient, in NIMHANS who were seeking treatment. The participants were informed verbally by the researcher of basic interests and aims of the research, and were also given an information sheet explaining the nature of the study. Interviews were held in a separate room over a period of 1year from 2014 to 2015. Interviews were lasted between 30 – 45 minutes. Initially the socio demographic sheet was filled up. As the interview started, participants were briefly asked to share child's condition, subsequently questions related to study were collected. The interview was concluded when all the questions were asked.

Data Analysis:

The R software 3.2.4 version was used for qualitative and quantitative data analysis. For quantitative data mean and standard deviation, for categorical variables proportions were calculated. For qualitative data analysis, the simple descriptive thematic analysis was used. The interviews were audio-recorded and translated to English. All the transcriptions were read a number of times to achieve an understanding of the data as a whole and then coded followed by themes were generated. The coding was done by 2 trained researchers, the data was triangulated with field observations, daily field notes, and memos. The data saturation was ensured. The ethical clearance was obtained from National Institute of Mental Health and Neurosciences, Bengaluru.

III. RESULTS

The results showed that the participant's average age was found to be 32.13 ±5.99 years. The majority of mothers were illiterate 76%, and engaged in various occupations such as homemakers 43.3%, self-employed 40%, and working in private sectors16.7%. Participates were currently living under below poverty line 83.3%, above poverty line 16.7%, living in nuclear family 70%, and joint family 30%. In addition, participants belong to urban background 56.7% and rural background 43.3%. Most of the care givers follow Hindu religion 83.3% and least 16.5 follow the non-Hindu religion. Table 1 depicts the personal and family details of the care givers.

The average age of children with TBI was found to be 8.43 ± SD = 3.35 years. The 50% children were male and 50% children were female. The Glasgow Coma Scale, an average score was 13.30± 1.96, which indicated children were suffering with mild injury. The mode of injury was 80% fall and motor vehicle accidents 20%.

The following themes were derived from the qualitative data.

Information and Education about the illness and treatment choices:

The majority of the participants reported that they need information with respect to various treatments available for TBI, information of about causes, consequences, prognosis, information about long term care, information about emergency management at home. The mothers expressed high need to know about head injury and its impact on children on long term care. This theme was supported by the following verbatim illustration from participant;

"When I heard that my child had to undergo surgery for head injury, I was really broken down. Doctors explained to me about the need for surgery, and its associated complications. But I felt, the information provided was not adequate" (P1).

Financial difficulties:

The other theme that resulted was financial struggles faced by mothers during hospitalization and at home in day to day child care. Mother's had struggled in bearing treatment investigations such as Computerized Tomography (CT) scan, Magnetic Resonance Imaging (MRI), blood investigations, surgical cost, and medication. They also lost their job due to long stay in the hospital and even after discharge. Below Poverty line families got treatment concession. Some subjects borrowed money from known relatives for interest, yet this was not sufficient to meet treatment expenses on long term. One of the participant said;

"My family belong to below poverty line. I work as daily wager in tailoring shop. Now I lost that job since my child completely dependent on me. I borrowed money from my known relatives for interest." There was nobody to support me financially…..(expressed her helpless) still I am struggling to purchase medicine" (P-17, P-09, P-07).

Personal feelings and concerns related to child's future:

The other theme derived from the qualitative interview was different personal feelings. Subjects expressed feeling of guilt, distress, anxiety, self-blame, stress, denial and uncertainty about children's future.

One of the participant reported in her own words "My child met with an accident while she was playing in the balcony that time I was preparing food for my husband. This happened one year back, even now, every day I use to feel guilty as a mother. I should have been more careful with my child….then this would have not happened. Now I do not know what is going to happen for her (child) future. Her future is spoiled because of my negligence (Cried……) (P-20, P-13, P-15).

Social support and coping:

Another theme derived from the verbatim results was difficulty in accessing social support and coping with illness and day to day caregiving responsibilities. Mothers expressed that there was nobody to share their feelings, and daily concerns. They felt that there was less social support from spouse, family members, friends, and siblings. In addition to that, there was no support in household chores, taking care of other children, and respite care from daily caregiving responsibilities. The only source to adjust with illness was praying to God. This was evident from the following verbatim.

"I do not have support from my spouse, family members, and friends. I have to look after my other children too, and house hold chores. I am praying god to give me strength to lead my life (cried….P-3, P-6)

Long term professionals' supportive care:

Other theme was supportive care needs. All most, all mothers expressed their need to get support from various professionals such as doctors, social workers, nurses, peer support during hospitalization, at home and supportive groups in the community. This was evident from the following case illustration;

"When my child was at hospital, I had lot of concerns regarding my child, I had lots of queries on his condition, surgical outcome, and about studies. Does he come to his normal life? I was totally distressed during hospitalization thinking about my child. Neither my family members, nor my husband supported me. Only doctors helped us but they were always busy to interact. Only support that I got was fellow care givers during hospitalization. Now also I use to talk to them over phone whenever I feel sad thinking about my child's future (P- 15, P-16, P- 28)". Figure 1 depicts the qualitative themes and categories that derived from the qualitative data.

Discussion:

The psychosocial needs and psychosocial issues of care givers of persons with Traumatic brain Injury is less studied especially mothers of children with Traumatic Brain Injury in the Indian context. The traumatic brain injury is defined that "TBI is not just one disease, but includes a wide spectrum of different pathologies and is characterized by a broad heterogeneity in terms of etiology, mechanism, pathology, and severity. The term 'head injury' is often used synonymously with TBI, but may refer to injury of the skull only with no pathological abnormalities in the brain. In our study the TBI definition was considered.

Our study found that the socio-demographic details of mothers of children with TBI was heterogeneous. The mothers of children with TBI average age was 32 years. The majority were illiterate and coming from low and middle income group. They engaged in a variety of occupations such as home makers, self-employed, and working in private sector with less daily wages. The socio-demographic details were similar to in our previous study.(Raju, Lukose, Raj, Reddy, & others, 2016), (A Krishna Reddy, A Durai Pandi, & Atiq Ahemed, 2007), (A Durai Pandi & Atiq Ahemed, 2007)

This study highlighted that economic burden on the family, less knowledge about illness among mothers, less social support in the family and increased care giver burden at home was found. This result is similar to previous studies reported that financial loss among families of TBI and to the nation is estimated at about Rs.350 crores annually, even changes in occupation and occupational loss also reported (Gururaj, 2013), (Wade et al., 1998), .

The children with TBI had reported a variety reasons for TBI. Our study found that the major mode of injury among children was fall from heights. This is supported by another study that fall was the common mode of injury among children. (Shekhar, Gupta, Premsagar, Sinha, & Kishore, 2015), (Wade et al., 1998) The Glasgow Coma Scale (GCS) measures the severity of the TBI among persons after injuries including children. The GCS score of <8 was severe, 9-12 moderate, and 13 to 15 mild. The average score of head injury of children was 13.30 with standard deviation of 1.96. Which clearly showed that the in the current study children were suffering from mild level of head injury. This is similar to previous studies reported that children have greater risk of suffering with mild injury, smaller proportion of children suffer from moderate, and severe injury.(Shekhar et al., 2015),(Parslow, Morris, Tasker, Forsyth, & Hawley, 2005)

The qualitative results depicted that mothers experienced a variety of psychosocial needs during care giving process. One among the need was informational and educational during and after TBI. Participants expressed desire to know detailed information about illness, treatments available for TBI, after care, outcome and emergency management at home. Further, care givers expressed high desire to know about head injury and its impact on children's education and future. This finding is in line with previous studies reported that providing knowledge on illness to caregivers, addressing caregiver's belief along with social support is important in service delivery. (Blake, 2013)

Another finding of the study was mild level of stress, anxiety, depression, self-blame, denial and uncertainty about children's future among mothers. This finding goes in line with previous studies reported that parents undergo significant psychological distress. However, it is associated with child adaptive functioning after TBI. (Micklewright, King, O'Toole, Henrich, & Floyd, 2012) Further, complex and enduring problems and hardships that family caregivers face social isolation, anger, blame, lack of knowledge about brain injury, and persistent guilt (Perlesz, Kinsella, & Crowe, 2000). What we observed was care giving was not an easy task for mothers. They had to look after home, family members, other children, and dedicate time for themselves. Over a period of time there is unlikely that family support available due to nuclear family that exists in the present sample. This could be one of the reasons for reduced social support. Though, care giving was a difficult task, still mothers cope with day to day care giving and nurturing well. This area can be explored further by researchers in detail.

The other finding of the study was support from various professionals such as doctors, social workers, and nurses. Further, need for advocacy group was observed. These needs were highly ranked among mothers of children with TBI in our study. Earlier studies also reported that health care professionals working in the trauma care setting must support families in meeting psychosocial needs. (Brown, Whittingham, Sofronoff, & Boyd, 2013b).

Clinical Implications:

TBI impacts the families in many ways. Care givers of children with TBI experience an immense amount of stress at the time of injury and even after injury for years. In addition, care giving burden, emotional strain, need to manage ongoing behavioral and functional difficulties of children. Recovery process does not follow a linear course in general, but rather includes short term improvements, no improvement and late emerging difficulties. This shows the importance of ongoing services and support for parents as care givers during hospitalization, after discharge and in the community.

Social work profession is to improve the quality of life for all individuals by meeting the basic needs of people through empowerment. Care givers of children with TBI face variety of challenges in terms of emotional, psychological and physical wellbeing including financial constraints. Medical and psychiatric social workers must take the lead role by meeting educational, informational, and financial needs by taping existing various resources.

IV. STUDY LIMITATIONS AND CONCLUSION

The study had small sample and collected conveniently. Thus, there is a possibility of recall bias among sample since data was collected after one year. Therefore, generalization of study results are cautioned to other settings.

Thus, we conclude that based on the study results, there is an urgent need to address the psychosocial needs of mothers of children with TBI without delay. The psychosocial interventions for care givers needs to be designed keeping the long term consequences of TBI particularly children, parents and family members.

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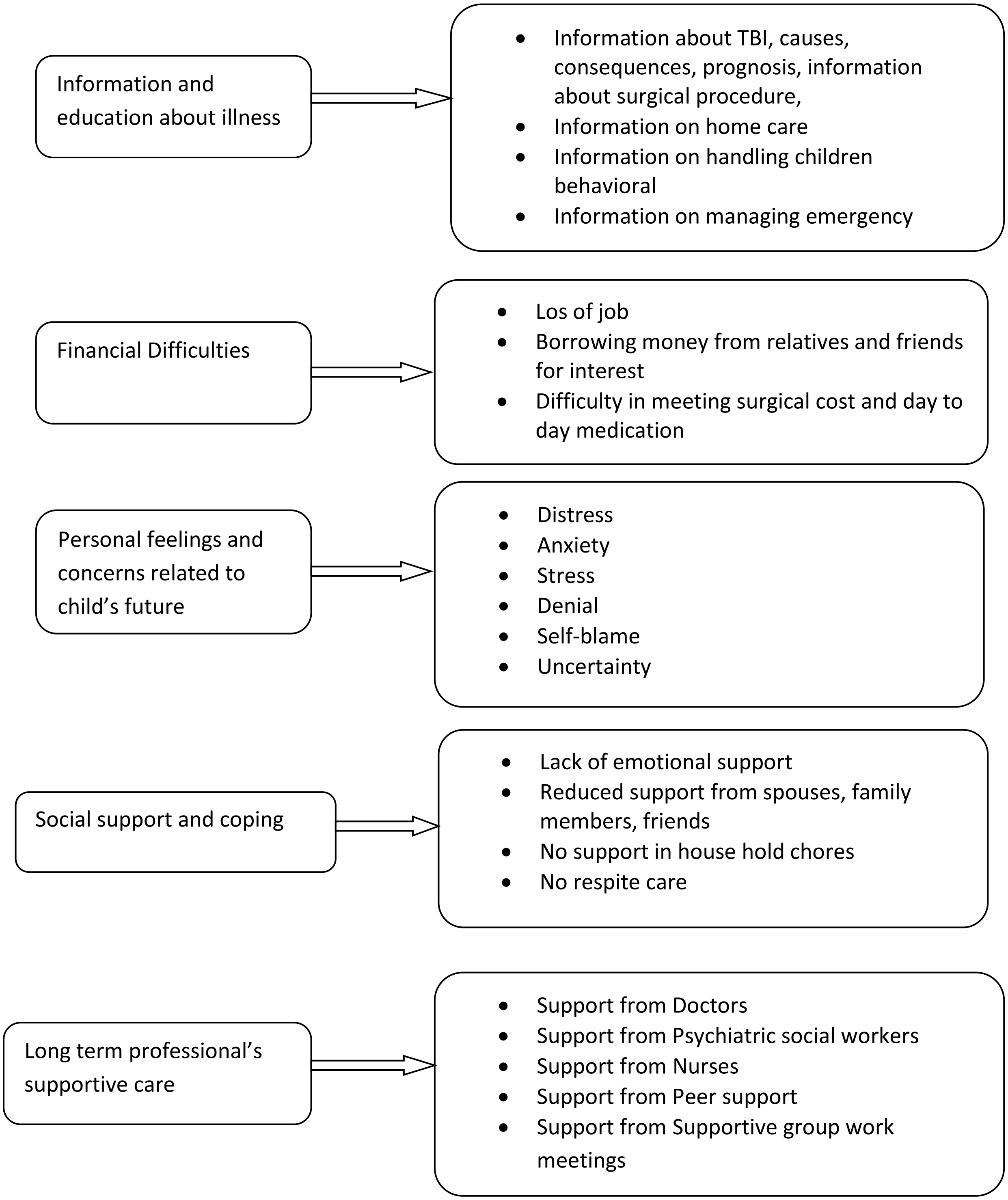
Figure 1: Depicts the themes and categories that were derived from the qualitative data



Information and education about illness

- Information about TBI, causes, consequences, prognosis, information about surgical procedure,
- Information on home care
- Information on handling children behavioral
- Information on managing emergency

Financial Difficulties

- Los of job
- Borrowing money from relatives and friends for interest
- Difficulty in meeting surgical cost and day to day medication

Personal feelings and concerns related to child's future

- Distress
- Anxiety
- Stress
- Denial
- Self-blame
- Uncertainty

Social support and coping

- Lack of emotional support
- Reduced support from spouses, family members, friends
- No support in house hold chores
- No respite care

Long term professional's supportive care

- Support from Doctors
- Support from Psychiatric social workers
- Support from Nurses
- Support from Peer support
- Support from Supportive group work meetings

Table 1: Depicts the personal and family details of subjects (mothers)

Variable	**Category**	**Frequency**	**Percentage (%)**
Education	Illiterate	8	26.7
	Primary education	8	26.7
	High school	8	26.7
	Graduation and above	6	20.0
Occupation	Home maker	13	43.3
	Self employed	12	40.0
	Working private sector	05	16.7
Marital status	married	29	96.7
	Separated or widows	1	3.3
Family category	Below poverty line	25	83.3
	Above poverty line	05	16.7
Type of family	Nuclear family	21	70
	Joint family	09	30
Domicile	Urban	17	56.7
	Rural	13	43.3
Religion	Hindu	25	83.3
	Non-Hindu	05	16.7