University of Alberta

Parenting Processes in Families of Children Who Have Sustained Burns: A Grounded Theory Study

by

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Dedication

This dissertation is dedicated to all children who suffer burn injury in whom I have a special interest, proportionately small and insignificant when compared to the devotion of their parents.

Abstract

The impetus for this study came from my clinical practice with burn-injured children in India. Burn injury is one of the most traumatic accidents a child can suffer. Parents are profoundly affected when their child is burn-injured. The number of pediatric burn admissions in low-income countries such as India is higher than in high-income countries with worse burn-related sequelae, including poorer psychosocial outcomes. Family support and a cohesive family environment positively affect long term child outcomes after burn injury. How parents provide this support and related challenges are not well articulated. The aim of this study was to discover the post-hospitalization parenting and/or caregiving processes for families of children in India who have sustained burns. Based on constructivist grounded theory methodology individual and group interviews were conducted with nine mothers, nine fathers, one aunt and three grandmothers of 12 burn-injured children (less than 16 years) who had sustained 20 to 60 % total surface area burns. Open, focused and theoretical coding were used to delineate code categories and concepts. Memos were written to elaborate categories. Further conceptualization and abstraction occurred with constant comparisons of data between and within participants' accounts.

This paper-based dissertation includes an introductory chapter, four publishable papers, and a final general discussion chapter. In the first paper, a comprehensive review of pediatric burn literature on long-term pediatric burn outcomes is presented. The second paper describes one of the substantive processes of parenting burn-injured children: "Embracing the Survival." The process of embracing involved three stages: suffering the trauma, sustaining the survival, and shielding from stigma. In the third paper another substantive process that occurred in parallel to embracing the survival, “Enduring the Blame” is elaborated. Parents endured the blame they encountered by internalizing, accommodating, adjusting and, anticipating and avoiding blame. The final paper is a critical reflection of the tensions and challenges of generating methodologically rigorous and ethically sound qualitative data in India. Possibilities for dual processes and a theory of parenting are contemplated in the concluding general discussion. The dissertation concludes with implications for practice, research and suggestions for knowledge transfer.

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Introductory Chapter

Prologue

I enter Room 25 bracing myself. I am about to meet three-year old Anand. He was severely scalded yesterday when he accidently fell over a pot of hot sambar [lentil curry]. His mother had left it on a stool in the kitchen. Anand has sustained 30 percent second degree burns to his neck, right hand, part of his chest and back. His upper body is covered in white bandages. His face is puffy and his small body is swollen. He is crying and it is obvious he is in much pain.

I take in the scene of this young child and am close to crying with him as he suffers the pain and agony of his traumatic burn injury. Resentment towards the adults in this child's life wells up in me as I assume they were not being careful enough to prevent such an accident. I cast a glance at Anand's mother, who is standing near his bed. The moment passes and I shift my entire focus on what I need to do for Anand to address his pain and do all I can to get him home as soon as possible. I elaborate my care plan for Anand to Sheela and explain what needs to be done to achieve this (my) goal. In my customary way I quickly explain about daily dressings, best position for the child, need for a naso-gastric supplemental feeding, importance of high protein diet and most important of all, restriction of visitors to prevent infection. I emphasize the hospital's "one-person-near-the-bed" policy. Sheela shakes her head vigorously affirming her understanding. In a way I pity her as I know she is the one who is going to shoulder the heavy responsibility of caregiving in the hospital and later at home.

I assume extended family members will help at home but while the child is in the hospital the staff expects the mother to stay with the child.

As another nurse and I give the burn bath and dress the large wound, we encourage Sheela to be with the child whose pain and distress worsens. We know it is hard for Sheela. We try to support her and affirm her help in the care. I ask Sheela not to worry and tell her that Anand will be ok soon. Murali, Anand’s father, is prompt in getting the medication from the pharmacy that is needed for Anand’s hospital treatment. After Anand undergoes a skin graft, his recovery is quick. Soon Anand is smiling and playing and is ready to go home. Although there is an unhealed area that needs monitoring and dressing changes, I see relief in Sheela’s eyes. We are all happy for Anand. I give Sheela and Murali some important information related to Anand’s care at home and instruct them to regularly return for follow-up. Anand is discharged and goes home after staying in the hospital for 13 days. I am pleased to see Anand leave the hospital. I enjoy my sense of accomplishment as I know I have been a part of Anand’s recovery.

Anand is constantly in my thoughts for the next one week. I call Jasmine, the staff nurse in the outpatient clinic to enquire about Anand. “Oh, yes Anand came for dressing once” she says. After that it becomes unclear whether Anand is brought back for follow up and I wonder what happens at home. Finally, after two months, I see Anand. He is waiting to see the doctor in the out-patient clinic. As he and his parents rise from their seats to enter the consultation room, I am shocked to see the scars and contractures that have developed. The wound has healed but the journey for this child’s family is far from over.

Introduction

My experience with Anand and his parents has been repeated innumerable times during my twelve years of nursing burn-injured children in India. Each time I have diligently assessed the needs of the child, planned care, and suffered the burn bath and other painful procedures with the child intending to save the child. Although some children did not survive their burn injury, the majority of the time I felt “successful” and “jubilant” when the burn-injured child survived and eventually went home. After every child was discharged home, I wondered about how the parents were managing their child’s care at home and whether they were following the instructions we had given them regarding exercises, diet and wound care. When I would discover that yet another child was developing disfiguring scars and contractures I could not help but question the parents’ role in this. Had the parents not done the exercises enough or brought their child for follow-up soon enough or often enough? Although I had some negative feelings about the parents, I also could not help but wonder what it was like for the parents to see the scars and contractures develop, a constant reminder of the burn injury that they perhaps thought was in the past.

The impetus for my study came from a simple clinical question “For parents of children who have been burn-injured, what are burn caregiving responsibilities at home and how do they manage these responsibilities?” The objectives of this introductory chapter are to provide an overview of the: 1) assumptions and beliefs I held as I entered the study; 2) burn injury and burn outcomes literature that was instrumental in refining and justifying my research question; and, 3) dissertation project that will be presented through the four papers that follow.

My Assumptions and Beliefs

The assumptions and beliefs that informed this study regarding parenting burn-injured children were based on my 12 years of professional nursing experience in a tertiary referral pediatric burn centre in South India. My personal experiences as a mother, friend, neighbour and relative in India also shaped my assumptions and beliefs that were as follows:

1. Children depend on parents to protect them from harm. In the event of a burn injury they depend on parents to access life-saving care for them as well as follow through with needed therapies as the child recovers at home. Therefore I believe that the child’s ability to return to pre-burn life depends on the parents and other family members who care for the child who has sustained burns.
2. Although neglect can be suspected as a cause of burns in children, the majority of burns in children in India occur due to family circumstances beyond parents’ control such as poor cooking facilities, lack of space at home to safely move around, and use of open fire and lamps for cooking and lighting.
3. Mothers who are the primary caregivers for their children experience extreme guilt as they feel responsible for child’s burn injury. In addition, family members often hold the mother responsible for what happens to a

child. Therefore it is possible that mothers are more stressed than other family members in the child's post-burn period.

4. Interactions between parents and their extended family members concerning decisions related to continuing rehabilitative care for the child may influence the treatment trajectory of children with burns. The father's parents may have considerable influence on decisions.
5. Extended family members take an active role in the care of the burn-injured child as children are given priority within the extended family system.
6. What happens in one family is usually known to others in the community in most areas in India. Neighbors, related or not related, share their opinions about what happens in events like injury, hospitalization or care at home. What community members say may influence the beliefs, attitudes, feelings and actions of family members related to care of a child with burns.
7. Belief in fate and punishment from God may contribute to passive acceptance of a child's disfigurement and influence parents' decisions to pursue follow-up care.
8. The focus of health professionals is more on saving life in the acute stage than on preparing the family for home care, which is vitally important for a child who has survived severe burns.

Overview of Literature

Tremendous insight has been gained about childhood illness, injuries and health in the past few decades. Specifically, much is being discussed about triggers, contextual factors, courses, outcomes, and caregiving issues of various pediatric chronic illnesses and disabilities in the current medical, nursing, psychology, and sociology literature. Although burn injury has been one of the most common phenomena in childhood, is considered the most serious of all injuries in children, and has many common characteristics of long term illnesses such as physical and psychological morbidity, other chronic illnesses of childhood have gained more attention than burn injuries (Tarnowski, 1994). Such relative inattention may be attributed to the unique aspects of burn injury. Burn injury is characterized by features of acute as well as chronic illness. The accidental and potentially traumatic nature of burn injury means that it affects several members of the family simultaneously. Additionally, burn injury can result in permanent disfigurement, entails protracted periods of painful rehabilitation, and presents challenges that often exceed the coping abilities of the child, family or even the health care professionals (Tarnowski). Burn injury as a complex issue renders practice and research processes in nursing difficult and probably is the reason why sparse empirical nursing evidence addressing child and family issues in the acute or the rehabilitative stage after burn injury is available. The lack of such research is particularly evident in low and middle-income countries (LMICs) such as India.

Overview of Burn Injuries

Burn injury represents a wide spectrum of presentation when compared to other forms of trauma in children (Burd & Yuen, 2005). Burns are a form of trauma to the skin and the underlying organs. Burn injury is caused by thermal, chemical, radiation or electrical energies that disrupt the function of the skin as a protective organ. Although burns directly affect the skin, extensive burns alter the physiological function of all body organs and create increased risk of infection and death directly related in magnitude to burn size (Purdue, Hunt, & Burris, 2002). Burn severity is assessed by the burn size and depth. Burn size is expressed as *percent* of total body surface area (TBSA) or body surface area (BSA) burned. The depth of injury is expressed in *degrees* in relation to how far the injury has extended beyond the epidermal layer of skin and is expressed as first degree (superficial), second degree (partial thickness) or third degree (full thickness) burns. In children, burns are considered major if the burn (irrespective of depth) involves more than 20% TBSA or a full thickness burn equal to or greater than 10% TBSA (Tarnowski, 1994). Although burn injury is obvious on simple examination, the severity is often underestimated initially by family and health professionals (Purdue et al., 2002). As young children have a high surface area to body mass ratio and thinner skin than older children and adults, burn injury causes devastating effects in children (CT Safe Kids, 2008).

Epidemiology

Children under the age of 15 years constitute about one third of burn unit admissions as well as burn-related deaths (Purdue et al., 2002). Epidemiology of pediatric burn admissions worldwide is 0.79/ 1000 population (Burd & Yuen, 2005). Africa has the highest number of pediatric burn admissions at 1.08 /1000 population. Although Asia, Europe and the Middle East have comparable incidences (0.80, 0.84 and 0.80/ 1000 population), India and China have more burn patients than the burn beds available because of overall population density.

Asia eclipses the rest of the world by number of people involved. In LMICs, burns are a major cause of morbidity, disability and death. According to a population-based study on the epidemiology of burns, burn morbidity ranks third after acute respiratory infections and diarrhoeal diseases in children between 1 to 4 years in Bangladesh (Mashreky, et al., 2008).

Burns occur widely in children less than four years of age and predominantly in males. Scalds, the most common type of burn injury in this age group, occur at home most often (Han et al., 2005; Mukerji, Chamania, Patidar, & Gupta, 2001; Ryan, Shankowsky, & Tredget, 1992; Sakallıoğlu et al., 2007). The type of burn, the age and the gender distribution in relation to pediatric burn injury are similar worldwide. Irrespective of these similarities, there are definite differences in social, cultural and economic factors associated with risk of burn injury between as well as within countries.

A systematic review of socio economic factors and burns (Edelman, 2007) revealed that burn incidents were higher in non-white, low income, large families or single parent families and in the unemployed population in most of the high-income countries. Illiteracy, low maternal education, substandard living conditions, and overcrowding were common factors reported from LMICs such as Ghana, Peru, Egypt and India. Family structure was identified as a significant factor in the incidence of pediatric burns. Single parent or large families, and mothers being away from home were major family-related risk factors in countries like the United States, France and South Africa. In addition, practices such as low-level cooking, cooking and living in the same room, and storing flammable substances at home (Forjuoh, Guyer, & Ireys, 1996), and indirect factors such as demanding work load for care givers, limited household spaces, and religious and supernatural belief systems (Van Niekerk, Seedat, Menckel, & Laflamme, 2007) were identified as risk factors in some LMICs. Although large families as a factor is applicable to Asia, literature on the influences of other family factors such as single parent home is not available. An understanding of these factors is vital to comprehend the home, family, and community contexts in which the burn occurred and to which the child returns when discharged after hospitalization for burn injury.

Changing Paradigm in Burn Care

Nearly all patients who sustain burns are now regarded as candidates for survival. This has led to a recent paradigm shift in the predictors of outcome in burn care (Pereira, Murphy, & Herndon, 2004). As acute care in burns has advanced, burn mortality in children has significantly reduced over the recent years in high-income countries when compared to LMICs (Keswani, 2000; Latenser et al., 2007; Senel et al., 2009). In high-income countries like the United States the burn mortality has decreased from 9% in the 1960s to 1% in the 1980s (Tompkins et al., 1988) and to 0.5% in 2009 (Light et al., 2009). Similar reports of precise reduction in mortality are not available from LMICs. The mortality related to pediatric burns is for example 5.6% in Turkey (Senel et al.), 6.4% in Iran (Maghsoudi & Samnia, 2005), 8.2% in Korea (Han et al., 2005) and 10 to 20% in India (Gupta, Gupta, & Goil, 1992; Light et al.; Verma, Srinivasan, & Vartak, 2008). The decrease in mortality is attributed to advances in the technological support of burned children and also increased knowledge of treatment regarding inhalation injury, fluid replacement, and wound management and infection control during the acute period of hospitalization (Herndon & Blakeney, 2007). As more children are now surviving burn injuries, quality of life is gaining importance over mortality as an outcome measure. This shift is also evident in LMICs like India (Keswani, 2000).

The Need for the Study

The psychosocial recovery during rehabilitation is long and may take one to two years for children and adults who have sustained burns (Blakeney & Creson, 2002). Increased societal expectations regarding post-burn quality of life related to functional and cosmetic results, necessitate the involvement of highly qualified therapists from the time of injury assessment until optimum post- burn function and quality of life are established (Sheridan, 2002). This has been achieved through the establishment of special burn units/hospitals and rigorous follow-up care in high-income countries (e.g., Shriners Hospitals for Children, 2009). In LMICs like India, there are few burn centers and a dedicated burn team and follow-up program are rarely available (Munster, 1994; Ramakrishnan, Jayaraman, Andal, Shanker, & Ramachandran, 2004).

There are several factors that contribute to the disparity in burn care and burn outcomes between high-income and low/middle-income countries. Firstly, in many hospitals in LMICs, children and adults with burns are not treated on dedicated burn units. Rather, they are treated alongside other surgical patients. Additionally, there is more emphasis on the sequelae of neurological and orthopedic injuries than burn injury (Ramakrishnan et al., 2004), contributing to less reduction in mortality and morbidity in comparison to high- income countries. Further, the high cost involved in burn care and rehabilitation as well as other constraints such as inadequate transport facilities and a lack of expert burn care professionals and resources, hinder provision of comprehensive care. It can be assumed that the burden of acute care and rehabilitation of a person with burns therefore is born by family members and health workers in the community who are not experts in burn care.

Family members are also affected when their child is burn-injured. It may take about six months for parents of children with burns to recover from the impact of the burn event (Blakeney & Creson, 2002). Research evidence from high income countries has shown that parents of burn-injured children are anxious, depressed, suffer guilt feelings and post traumatic stress symptoms (PTSS) (Bakker, Van Loey, Van Son & Van der Heijden, 2010; Kent, King & Cochrane, 2000; Phillips & Rumsey, 2008). Parents' ability to care for themselves decreases and their overall well-being is severely compromised as they witness their child's painful experiences related to treatment and rehabilitation (Cahners, 1988; Zengerle-Levy, 2006). One study has shown that parents manifest PTSS even after ten years of the burn event (Bakker et al., 2010). It is also well established that parents' physical and emotional support during hospitalization and the period of protracted rehabilitation is crucial for recovery for burn-injured children (Landolt, Grubenmann & Meuli, 2002; Zengerle-Levy). In addition to support, families who were described as cohesive, organized and independent had a positive effect on their child’s burn outcomes (Blakeney, Herndon, Desai, Beard & Wales-Seale, 1988; Landolt, et al., 2002; LeDoux, Meyer, Blakeney & Herndon, 1998; Rosenberg et al., 2007). In a study which explored nurses’ experiences of giving care to burn-injured children, nurses affirmed the importance of assessment of family functioning, which assisted them to provide family-centered care when a burn-injured child was hospitalized (Zengerle-Levy). Nurses also recognized and met families’ expectations of informational and emotional support from health care professionals within a respectful, non-judgmental, and caring context.

In contrast, in another study parents perceived less support from nurses compared to the nurses’ reports of provision of adequate support in relation to dressing changes (Smith, Murray, McBride, McBride-Henry, 2011). Although parental support and family environment are well recognized as factors contributing to positive quality of life in burn-injured children and the psychosocial effects of a child’s burn on parents are well documented, parents’ experiences of caring for their burn-injured children and the process of parenting either in the hospital or at home in the rehabilitative period, amid their own emotional trauma is rarely addressed, especially in low and middle income countries like India. The primary aim of my qualitative study was to address this gap in evidence by studying the processes that parents in India used to parent their burn-injured children. A secondary aim was to differentiate the term parenting from the term caregiving as pertaining to parents and their interactions with their burn-injured children in the post-hospitalization period.

The Dissertation Project

This study was conducted between March 2010 and May 2011 as part of the requirements for my PhD in Nursing at the University of Alberta. The study was carried out in a city in South India with a population of 900,000. The purpose of the study was to explore and discover the processes at play for Indian families related to the parenting and/or caregiving of post-hospitalized children who sustained burns.

Understanding subjective perspectives involves exploring meanings that individuals attach to events and their actions and interactions related to the events. Symbolic interactionism theory, the philosophical foundation for grounded theory methodology, has been widely used to understand the meanings that mediate the actions, interactions and interpretations of various phenomena by individuals/groups (Blumer, 1969). Symbolic interactionism within a family perspective (LaRossa & Reitzes, 1993) addresses the interpretation of roles that each family member assumes and the meanings a family attaches to their behaviour. Families of children who have been burned may attach meanings to what they do and do not do in relation to the care of a child with burns. They are thrust into the role of rehabilitative care providers having to provide complex post-burn care. Exploring and theorizing these actions, interpretations, and meanings was a complex yet essential process to answer clinical questions regarding home care of children who had sustained burns.

A constructivist grounded theory approach was appropriate to address the study's research question because it (a) focuses on a process and trajectory that identifies phases and stages; (b) uses gerunds (Charmaz, 2006; Glaser, 1978) to capture the actions of the parents rather than focusing on the person/parent; (c) has a core variable or category and basic social process/es that portrays the evolving theory (Glaser, 1978); and, (d) aims to develop theory that is abstract (Morse, 2001). Through grounded theory I intended to identify the basic social processes involved in parenting/caregiving burn-injured children.

Grounded theorists aim for inductive logic, rigorous data analysis, and development of a grounded theory (Charmaz, 2009). Constructivist grounded theory methodology hinges on multiple realities, the researcher's entry into the participants' worlds and theory that is constructed based on both the researchers and participants' views (Charmaz, 2004; 2006). These methodological features fit with my nursing background with burn-injured children and my belief that parents and parenting are central to a child's full recovery from the burn. A constructivist approach to grounded theory gave me the opportunity to account for the inevitable influence of my personal and professional knowledge, views, and experiences as an experienced burn nurse would influence on the construction of knowledge in my study with families of burn-injured children. A constructivist grounded theory, built on principles of the classic grounded theory method (Glaser & Strauss 1967; Glaser 1978) was a good fit for my research both in relation to my research question but also in relation to my clinical nursing background.

Data were generated using interviews which started with an overview question about how it was for the parents when the child was burn-injured.

Participants readily shared their experiences related to caring for their burn-injured family member. As participants shared their stories, probing questions were asked to clarify meanings or elicit rich description of the experiences. Field notes were written which served as additional data. Including multiple family members in the study helped me to understand family perspectives about burn care and also helped in data triangulation. Interviewing family members separately and sometimes as a group assisted me in capturing data that were unique to each person as well as to a family. The interviews were conducted in Tamil, digitally recorded, transcribed in Tamil and then translated to English. The grounded theory approaches of concurrent data collection and analysis, and constant comparative analysis (Charmaz, 2006; Glaser, 1978) enabled me to identify similarities and contrasts within as well as between participants' accounts. As data generation and analysis progressed, interview questions became more focused to elicit data relevant to a concept or category that was emerging through data analysis. Second interviews were conducted with three participants from three families to saturate categories that emerged from the data. Ongoing comparisons of data and further conceptualization assisted in identifying substantive processes of parenting children with burn injury.

I ensured rigour by addressing validity, reliability, and generalizability which are considered as trustworthiness in qualitative research (Golafshani, 2003). Validity in my study involved getting the right story from the right participants in relation to parenting/caregiving burn-injured children. I also ensured that the emerging categories and theory represented the data. Frequent debriefing sessions with my dissertation supervisors and peers, and maintaining an audit trail assisted in enhancing reliability. I further addressed reliability by preserving linguistic and cultural connotations in participants' accounts during the translation process. Abstracting and theory development, which are essential processes in grounded theory will help me to generalize the study findings. Ensuring methodological coherence through selecting appropriate participants, collecting rich data, relating sampling, data collection and data analysis, and theorizing (Morse, Barret, Mayan, Olson, & Spiers, 2002) further enabled me to address rigour.

My dissertation project is presented as four publishable papers and a concluding chapter. The first paper is a review of the pediatric burn literature on pediatric burn outcomes. The next two papers highlight the major findings from the study. The fourth paper focuses on the methodological challenges faced by the researcher in India. In the concluding chapter, a general discussion of the study findings, I share my inability to differentiate between the terms parenting and caregiving which was one of my research aims. I argue for a dual process of parenting instead of basic social process. I then situate my study findings within the existing theoretical literature. Subsequently I present the findings that surprised me and refuted my assumptions about parenting/caregiving. The implications for practice and research are considered and suggestions for future research are summarized in the conclusion.

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Paper 1: Long-term Outcomes of Pediatric Burn Injury

Background

Burn injury is one of the most traumatic injuries children experience and often results in long-term hospitalization, painful procedures and protracted rehabilitation. As acute care has advanced, burn mortality in children has declined, more dramatically in high-income countries (HICs) than in low and middle-income countries (LMICs) (Keswani, 2000; Latenser et al., 2007; Senel et al., 2009). Most patients with burns are now regarded as candidates for survival. This has led to a paradigm shift in the predictors of outcome in burn care (Pereira, Murphy, & Herndon, 2004), with quality of life gaining importance over mortality as an outcome measure. This shift is also evident in LMICs like India (Keswani, 2000). Quality of life in burned individuals refers to their ability to resume normal physical, emotional and family functions, reintegrate into the community, and participate in social activities (Herndon, 2007). Contractures, scarring, disfigurement, and psychological problems are burn outcomes that could affect quality of life. As disability associated with scars and contractures occurs over time (Herndon, 2007), rehabilitation is a significant phase of burn care.

Post burn rehabilitation unfolds at home within the socio-cultural context. The effects of trauma related to the injury event and painful experiences during hospitalization, the long recovery associated with intense therapies to prevent complications, and the challenge of individual and social reintegration can have profound effects on the burn-injured child, the parents, and other family members. It is imperative that health care professionals know the burn outcomes and contextual factors that influence outcomes in the pediatric population to plan and implement interventions that optimize positive outcomes and quality of life. The need is greater in LMICs where there is dearth of follow-up services.

Aim

The aim of this literature review was to examine and synthesize data on pediatric burn outcomes in terms of functional status, comparing data from HICs and LMICs where possible, so as to identify gaps in the literature that could be addressed through further research.

Method

We conducted a systematized review (Grant & Booth, 2009). In this method, some but not all elements of a systematic review process are included. The search may or may not be comprehensive and may or may not include quality assessment. The aim of the review is to synthesize what is known about a topic and identify uncertainties and gaps in the findings and methodologies.

Pediatric burn literature was comprehensively searched through MEDLINE, CINAHL, EMBASE, and PsycINFO using the search terms “child”, “burns”, “rehabilitation”, and “outcomes.” The terms “developing countries”, “low and middle-income countries” and selected names of some LMICs that frequently appeared in the burn literature were additional search terms. The World Bank’s list was used to determine HICs and LIMCs (The World Bank, 2011). Relevant data from the theoretical and research articles published after 1980 were analyzed and synthesized. Epidemiological studies and surveys representing high and low and middle income countries were included to describe the pediatric burn injury patterns. Excluding the epidemiological studies, 476 articles were scanned to include 86 studies that yielded data on burn outcomes and factors associated with the outcomes. Thirty-eight studies were included for review after excluding interventional and instrument validating studies and non-English articles. Using The World Health Organization's (WHO) International Classification of Functioning, Disability and Health (ICF) Model (WHO 2002), the results are discussed under three main topics: 1) pediatric burn injury; 2) burn outcomes in terms of physical, physiological, psychological outcomes, activity and participation; and, 3) the contextual factors that influence the outcomes. Data from HICs and LIMCs are compared where possible. Implications for research, practice, and policy are discussed.

Results

Pediatric Burn Injury

Approximately one third of burn unit admissions are children under 15 years and about one third of all burn deaths involve children (Purdue, Hunt & Burris, 2002). Over half a million children are admitted with burn injuries per year globally, with the majority occurring in LMICs in Asia and Africa (Burd & Yuen, 2005).

Type of burn, age, and gender distribution in relation to pediatric burn injury are similar worldwide. Burns occur widely in children less than four years of age and predominantly in males. Scalds, the most common type of burn injury in this age group, most often occur at home (e.g**.,** Han et al., 2005; Sakallıoğlu et al., 2007). Irrespective of these similarities, socioeconomic factors related to burns differ worldwide (Edelman, 2007). In HICs burn incidents are higher in non- white, low income, large families or single parent families, and those in which parents are unemployed. In LMICs such as Ghana, Peru, Egypt and India, illiteracy, low maternal education, substandard living conditions, and overcrowding are common factors. Single parent or large families and mothers being away from home were major risk factors in countries like the US, France, and South Africa. Practices such as low-level cooking, cooking and living in the same room, and storing flammable substances at home (Forjuoh, Guyer, & Ireys, 1996), as well as indirect factors such as demanding work load for care givers, limited household spaces, and religious and supernatural belief systems (Van Niekerk, Seedat, Menckel & Laflamme, 2007) are identified in some low-income settings.

Advances in acute care have reduced mortality in children with burns. In HICs the burn mortality in the pediatric population decreased from 9% in the 1960s and 1% in the 1980s (Tompkins et al., 1988) to 0.5% in 2009 (Light et al., 2009). Similar reports of reduction in mortality are not available from LMICs. Although the mortality related to pediatric burns is declining (Keswani, 2000), it remains comparatively higher in LMICs; for example, 0.49% to 9.08% in China (Kai-Yang et al., 2008), 5.6% in Turkey (Senel et al., 2009), 6.4% in Iran (Maghsoudi & Samnia, 2005), 8.2 % in Korea (Han et al., 2005), and 10 to 20% in India (Light et al.; Verma, Srinivasan, & Vartak, 2008). Burn mortality and morbidity differ from center to center in LMICs depending on the acuity level of patients and the availability of specialized professionals and facilities. In some LMICs, burns are a major cause of childhood morbidity, disability, and death. Burn morbidity ranks third after acute respiratory infections and diarrhoeal diseases in children between 1 to 4 years in Bangladesh (Mashreky et al., 2008a).

Burn Outcomes

Physical and physiological outcomes. The regeneration of nerve endings in deep burns causes discomfort due to varying sensations. Itching can persist for weeks to months in the post-burn period (Tyack, Ziviani & Pegg, 1999). Impaired tanning, diminished tactile sensibility, and increased reddening of the grafted and regenerated areas of skin were identified as long-term functional sequelae in another pediatric burn population (Zeitlin, Jarnberg, Somppi & Sundell, 1998). A thickened scar may form two to six months after major burns and may contribute to the development of contractures (Herndon, 2007). Such contractures limit range of motion of joints in children with major burns (Moore et al., 1996) compared to children with less than 20% burns (Gorga et al., 1999).

In the literature on burn outcomes in children from HICs, presence or absence of hypertrophic scarring and contractures in burned children are reported in only a few studies (Herndon et al., 1986; Robert et al., 1999). In contrast, observational reports from LMICs such as Ghana and India have reported high incidence of scars, keloids (overgrowth of scar), contractures, and loss of body parts even when comparatively less body surface area (BSA) is involved (Forjuoh, Guyer, & Ireys, 1996; Ramakrishnan, Jayaraman, Andal, Shanker & Ramachandran, 2004).

Psychological outcomes. Research reveals mixed results concerning psychological reactions of children after burn injury. Some studies of North American adolescents and young adults (13-28 years) who sustained an average of 30% burns as children suggest that the burn survivors' emotional adjustment, anxiety, and self worth are equal to their reference norm on standardized measures (e.g., Quality of Life Short Form-36, Child Behaviour Check List (CBCL)) (Baker, Russell, Meyer & Blakeney, 2007; Knudson-Cooper, 1981; LeDoux, Meyer, Blakeney & Herndon, 1996; Robert et al., 1999). However, one study from the same North American setting that measured psychological adjustment in persons above 12 years who were severely burned (> 40%) as children showed that while 50% were well adjusted, the others harboured thoughts of hopelessness, and had suicide ideation, negative self-evaluation and hostility (Blakeney, Portman & Rutan, 1990).

In studies and clinical observations from both HICs and LMICs that included younger children with burn injury (1 to 17 years, 15-80% burned), a wide range of psychological sequelae such as nightmares, bedwetting, sleep walking (Kravitz et al.,1993), excessive fear, neurosis, regression (Herndon et al. 1986), anxiety, depression, post traumatic stress disorder (Ramakrishnan et al., 2004; Stoddard et al., 2006), withdrawal from activities, social isolation, aggressiveness, and drug addiction (Ramakrishnan et al.) were reported. The majority of these results were based on case studies, clinical observations, and/

or parent and child interviews. Comparison groups were not involved. Denver Developmental Screening tests over one year post-burn revealed developmental delay, specifically delay in language development in children aged six months to six years (Gorga et al., 1999). In three reports, however, young children and adolescents did not have significant psychological sequelae when their mean scores of post burn adjustment measured by the CBCL were compared to scores of control groups of acutely ill children, children with fractures, non-ill non-injured children (Kent, King & Cochrane, 2000), a norm group (Landolt, Grubenmann & Meuli, 2002), or a matched control of non-burned children (Tarnowski, Rasnake, Gavaghan-Jones & Smith, 1991).

Psychological outcomes in children appear to differ depending on the age when the burn injury occurred, time since injury, and the measurement tools. Also, psychological sequelae may lessen over time (Tarnowski et al., 1991). Studies that had comparison groups and/or used standardized scales generally reported none or less difference in the mean scores of psychological outcome measures both in the young adults (13-28 years) and the children (1-17 years) groups. Similar conclusions were made by Tarnowski et al. in their review of psychosocial outcomes in burn-injured children. In some instances, although standardized instruments identified psychological functioning as within normal limits, subjective assessments revealed anxiety, struggles with body image, and self-esteem issues in adolescents and young adults burned as children (Baker et al., 2007; Knudson-Cooper, 1981). Such variation in results calls for researchers' attention to assessment and evaluation methods.

Psychological effects of burn injury on family members. Pediatric burn injury has effects on the family. Parents may feel guilty, angry, and depressed and these feelings can project as negative self image in children (Knudson-Cooper, 1981). The Parenting Stress Index and the Hospital Depression and Anxiety Scale were used to objectively measure parents' psychological reactions to their children's burn injury and recovery in studies done in the UK and North America. High levels of anxiety and depression were observed at six to 24 months post-burn (Phillips & Rumsey, 2008). Mothers were found to have comparatively higher anxiety than their children in the immediate post-burn period and six months post injury (Kent et al., 2000). Parents were observed to have higher levels of anxiety than depression in the initial post-burn stage and higher levels of depression after six months or even as late as two years after their child's burn injury (Blakeney et al., 1993b; Phillips & Rumsey).

In an ethnographic study conducted in Brazil, interviews and informal meetings with family members (mothers, fathers, wife, sisters, aunts, and grandmothers) of 25 patients with burns, (4 to 21 years =17, > 21= 8) revealed that family members had shame about scars, fear of how others would look at the patient, fear of stigma, sadness, anger, and denial (Rossi, Vila, Zago & Ferreira, 2005). Similar results were reported in a UK-based study in which siblings of adults or children with burns expressed difficulty in coping with their sibling's scars or people teasing their brother or sister (Phillips, Fussell & Rumsey, 2007). Family relationships were strained because of the burn event, associated guilt feelings, and the adjustment processes in the post-burn life. Irrespective of these feelings and reactions, family members are expected to function as expert caregivers for children who may or may not have functional impairments related to burn injury.

Activities of daily living. The primary goal of post burn care and rehabilitation is to ensure that affected children can participate in age-appropriate activities in their family and community. Dependence on assistance in activities of daily living and inability to walk or run were reported in 15 to 50% of children who survived burns greater than 70% (Herndon et al., 1986; Sheridan et al., 2000). In contrast, the majority of children with less than 30 to 40% burns were able to function normally (Baker et al., 2007; Gorga et al., 1999; Tyack & Ziviani, 2003). Participation in physical education classes was affected by tight skin or joint impairments (Tyack et al., 1999) and probably contributed to adolescents between 13 and 20 years who were burn-injured rating themselves as low in athletic competence (Robert et al., 1999). In one study, young adults who were burned as children (mean BSA 28%) manifested impaired peripheral strength (wrist and grasp), which affected some self care skills (Baker et al.).

Participation. Evidence related to social functioning is available from research in HICs. Social functioning of children who sustain burns is frequently similar to that of their non-burn counterparts during childhood or later (Knudson–Cooper, 1981; Sheridan et al., 2000), and sometimes is even higher (LeDoux et al., 1996; Robert et al., 1999), if mean scores of standard scales are compared for domains of self worth/ self esteem, social acceptance, marital life, job competence, and popularity. The results were based on self reports from the adolescents or adults who were burn-injured at various ages in their childhood. Landolt et al. (2002) reported similar results from parents of children aged five to 17 years. However, negative social consequences for preschool and school age children, such as problems in social interaction and integration, sexual identity (Blakeney et al., 1993a), establishing relationships or social initiative (Andersson, Sandberg, Rydell & Gerdin, 2003; Zeitlin, 1997), involvement in intellectual and cultural events (Rosenberg et al., 2007), and in playing with other children (Tyack et al., 1999) were identified by parents or teachers when they completed inventories such as CBCL or by adolescents themselves in their self reports.

Returning to school is a vital reintegration activity for a child's post-burn rehabilitation. Issues with coping with school work were reported by children aged nine to 13 years and their parents in an Australian study (Tyack et al., 1999). Concentration problems and externalizing behaviours were reported by the teachers in a study in Sweden (Andersson et al., 2003). Children's accounts of lack of confidence because of their appearance (Gaskell, 2007) emphasize the problems burned children may have related to successful school re-entry. Although adolescents or adults who were burned as children overall rate themselves as well adjusted, they are concerned about their physical appearance, body image, self-esteem, stigma, and social isolation even in countries where burn follow up has been rigorous (Cox et al., 2004; Kundson-Cooper, 1981;

Robert et al., 1999). These concerns can be covert and hinder successful social functioning.

Although research results suggest satisfactory adaptation in children in their post-burn life, the disfigurement and associated distress can hinder the burn-injured children from developing to their fullest potential. Therefore, factors that maximize functional outcomes and quality of life of burn-injured children need attention.

Contextual Factors Influencing Burn Outcomes

Survival, rehabilitation, and post-burn quality of life depend on many factors. Injury- related, personal, environmental, and family factors that influence burn outcomes have been explored in many studies.

Injury related factors. Burn rehabilitation starts from the time of admission as conditions related to the burn injury itself can have a profound effect on long term outcomes. Injury-related factors such as burn depth, percentage of body surface area (BSA) burned, number of body parts involved, or scars were not associated with functional outcomes and quality of life of children in some studies (Andersson et al., 2003; Blakeney et al., 1993a; Robert, Blakeney & Meyer, 1998; Landolt et al., 2002; Tyack & Ziviani, 2003). In contrast, greater percentage of BSA was associated with problems in activities of daily living and mobility or general quality of life in other studies (Baker et al. 2007; Forjuoh et al., 1996; Herndon et al., 1986; Pope, Solomons, Done, Cohn & Possamai, 2007). An earlier review of studies related to psychological outcomes in burn-injured children did not identify a definite relationship between burn severity or length of hospitalization and psychological outcomes (Tarnowski et al. 1991). However, greater disfigurement in burn survivors aged 7- 19 years was significantly related to presence of psychiatric illnesses in one earlier study (Stoddard, Norman & Murphy 1989). Maternal anxiety in the post burn rehabilitative stage was not associated with burn severity in one study (Phillips & Rumsey, 2008). The process of healing and compliance to rehabilitation regimens can depend on personal factors.

Personal factors. Age at which the child was burned has been identified as a significant factor (Tarnowski et al., 1991). While individuals who were burned at a young age, generally three years or less, showed stress symptoms in the immediate post-burn period (Stoddard et al., 2006), they were better adjusted and reported better quality of life than those burned when older (Landolt et al., 2002; Pope et al., 2007; Tyack & Ziviani, 2003; Zeitlin, 1997). Poor functional outcome was related to presence of pre-morbid behaviour suggestive of prior psychological or psychiatric problems (Tyack & Ziviani). Extroverted, socially amiable, adventurous, and bold individuals were observed to have better adjustment to their post- burn status (Moore et al., 1993). Children rated by professionals as non-resilient had lower scores on egocentricity and higher scores on coping deficit index (Holaday & Terrell, 1994). Personal factors, although they influence outcomes, are difficult to manipulate.

Environmental factors. Demographic factors such as suspect home environments (Gorga et al., 1999) predicted adverse long term burn outcomes in children in HICs. Being a large family of higher socio-economic status and high social involvement predicted positive child adjustment in the post-burn period (Tarnowski et al., 1991). In LMICs, lack of finances, inability to buy necessary burn garments (Mashreky, et al., 2008b; Ramakrishnan et al., 2004), and limited transport facilities to the burn center are problems that families encounter with rehabilitative burn care.

Skilled care received from multi-professional burn teams in well-established burn care facilities and regular follow-up has consistently been associated with better outcomes in HICs (Baker et al., 2007; Gorga et al., 1999; Landolt et al., 2002; Sheridan et al., 2000). Further, additional support from burn camps has improved the children/adolescents' process of adaptation (Cox, Call, Williams & Reeves, 2004; Gaskel, 2007). Similar support and rehabilitative care are lacking in LMICs (Peck, Molnar & Swart, 2009). Delay in funding for establishing a burn rehabilitation unit hinders provision of optimal follow-up care in LMICs (Sujatha, 2010).

Family environment. The most consistently documented factor influencing the post- acute post- burn outcome is the family environment. Better family functioning with stable housing and support of extended family predicts better physical functioning in individuals who were burned as children (Sheridan et al., 2000). Families' expressiveness and cohesion, and absence of conflict within a family, strongly predict positive psychological outcomes in children who sustain burns (Landolt, et al., 2002). Lower level of anxiety in the primary caregiver, with more social support and problem solving skill, has a positive effect on functional outcomes in children (Tyack & Ziviani, 2003). Well-adjusted adolescents and young adults who were burned described their families as more cohesive and more independent than their less well adjusted cohorts (Blakeney, Herndon, Desai, Beard & Wales-Scale, 1988) and increased family conflict was associated with increased problems in young adults who were burn-injured (Rosenberg et al., 2007). Family environments in which commitment to each other was strong and where cohesion allowed expression of individual differences and encouraged autonomy in children predicted better psychological adjustment (Rosenberg et al.). Poor maternal and family adjustment were associated with poor child adjustment (Tarnowski et al., 1991). Children of parents with high trait anxiety and poor coping strategies were likely to have more non-adaptive outcomes after a burn injury (Simons, Ziviani & Copley, 2010). Children in families that encouraged passive dependence adjusted poorly (Blakeney et al., 1990). Studies related to family support are all from HICs. How families of LMICs support their burn-injured children is unknown to date.

The family environment is not only important for the burn-injured children but also for the mothers. One study reported poor family functioning as an important vulnerability marker for mothers' distress in the post burn period (Phillips & Rumsey, 2008). How family members are affected during this process of support and their adaptation process are rarely discussed.

Discussion

Research evidence may be available in languages other than English in other country specific databases. Exclusion of studies in languages other than English is a limitation of this review. Most of the research evidence on burn outcomes in children is from HICs, specifically from well-established burn centers. Little is known about severity of structural and functional outcomes in children from LMICs after they are discharged from the hospital. Research predominantly focuses on adolescents or adults who have been burned as children. In studies including children, parental and/or teachers' perceptions have been given major consideration. We need to elicit children's perceptions of burn outcomes. Further, issues related to school and community reintegration during the rehabilitation stage and the role of each family member in this process need to be explored.

When the burn-injured child is discharged from the hospital, the family becomes an extension of the burn team. As family members deal with their reactions to the child's injury, they are also expected to take up the role of rehabilitative professional and comply with the follow- up care (Blakeney et al., 1993b). In LMICs, where the cost of burn care is enormous compared to the family income and in the absence of burn specialists or adequate follow- up, home care of children is particularly challenging. Evidence related to impact of family environment on burn outcome is well established. Reactions of parents, predominantly those of mothers, are also explicated. Yet, how family members provide the care and support amidst their own and their burn-injured children's positive or negative reactions and the needs of these caregivers have rarely been studied. Similarly, the majority of literature on burns explicates the factors that contribute to burn outcomes in terms of quality of life, but does not explore experiences of recovery or caregiving. A “best model” for adjustment to burn injury is needed (Blakeney, Partridge & Rumsey, 2007, p. 599).

To date the pediatric burn literature has been dominated by quantitative research designs (Simons, Ziviani & Tyack, 2004). Although standardized scales have been used to measure outcomes, the diversity of scales and measures is a disadvantage (van Baar et al., 2006). Patients’ responses to open-ended questions or interviews elicit what is not identified by standardized scales. Therefore, qualitative methods, which encourage participants to tell their story within the researcher-participant interactive-relationship, are needed to explicate experiences of burn-injured children and their families.

As families are central for positive outcomes and quality of life in children who have sustained burns, interventions to support parents and family members in the care of their children at home are needed (Blakeney, Partridge, & Rumsey, 2007). Identifying supportive factors and mobilizing support networks to assist families in their caregiving experiences would benefit family members and children. Psychological trauma extends into the post-hospitalization stage not only for children but for parents and family members as well and demonstrates the need for continued psychological support. Further, developmentally supportive interventions are needed to address issues that evolve as the children grow with their scars and disfigurements. An inter-disciplinary team approach is needed for both clinical and research endeavours. In LMICs where such teams may not be available, nurses can take up the challenge of preparing the family for caregiving at home and providing on-going support.

The limited evidence of child and family outcomes from LMICs implies the need for devising flexible interventions to improve access to care, rehabilitation support, and subsidized or free follow-up for burn-injured children. Funding for burn rehabilitation has to be increased especially in LMICs, which will help burn centers set up rehabilitation units, hire professionals, and assist families to access rehabilitation aids. Although burn-injured children may not fit immediately into disability categories suggested by funding agencies, early access to rehabilitative gadgets and funds for follow-up will considerably reduce long term disability. Models of assessment that examine existing disability as well as recognize potential disability should be established. Investment in follow-up services will assist families in giving care, optimize positive outcomes, and will enable burn-injured children to live happy and productive lives. As burn injury can take a heavy toll on family resources, prevention of burns should be emphasized as a part of child safety measures in parental education sessions in the mass media, especially in LMICs. Burn prevention should be a part of national health-care strategies (WHO, 2008).

Conclusion

This literature review has provided a synthesis of evidence on pediatric burn outcomes highlighting the lack of empirical evidence from LIMCs. The review results also draw attention to the diverse instruments that are used to study outcomes and the lack of involvement of children as participants in studies. Further, it directs our focus to the family members who are vital for influencing better outcomes but receive little attention themselves in relation to how they provide the support for their burn-injured children. Health professionals involved in burn care need to keep these factors in mind as they plan for future practice and research innovations.

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Paper 2: Embracing the Survival: Experiences of Parenting Children in India Who Have Sustained Burns

Introduction

Pediatric burn injury is one of the worst traumas a child can suffer. As acute care in burns has advanced, burn mortality in children has declined, more dramatically in high-income countries. In low- and middle-income countries, burns remain a major cause of morbidity, disability, and death (Keswani, 2000; Latenser et al., 2007; Senel et al., 2009). According to a population-based study on the epidemiology of burns in Bangladesh, burn morbidity ranks third after acute respiratory infections and diarrheal diseases in children between 1 to 4 years (Mashreky, et al., 2008a). Asia has the highest number of pediatric burn admissions, and India and China have more pediatric burn patients than the burn beds available because of overall population density (Burd & Yuen, 2005).

When burn-injured children are hospitalized, they suffer enormous pain, fear, and anxiety in response to the burn event and the treatment procedures (Smith, Murray, McBride, & McBride-Henry, 2011). Wound dressings and range-of-motion exercises that need to be continued at home are painful. Research evidence from high-income countries suggests that the majority of children have good physical and psychosocial outcomes when compared to referenced norms for other ill children (Baker, Russell, Meyer, & Blakeney, 2007; Kent, King, & Cochrane, 2000; Knudson-Cooper, 1981; Landolt, Grubenmann, & Meuli, 2002; LeDoux, Meyer, Blakeney, & Herndon, 1996; Robert et al., 1999; Tyack & Ziviani, 2003). Some children have psychosocial issues and problems with daily activities (Blakeney, Portman, & Rutan, 1990; Kravitz et al., 1993; Stoddard, Norman, & Murphy, 1989; Stoddard, Ronfeldt, et al., 2006). Furthermore, burn-related disfigurement and disability and psychosocial distress such as aggressiveness, social isolation, and depression are reported from low- and middle-income countries (Forjuoh, Guyer & Ireys, 1996; Mashreky et al., 2008b; Ramakrishnan, Jayaraman, Andal, Shanker, & Ramachandran, 2004).

With increasing numbers surviving life-threatening burns, the predictor of outcome in burn care has shifted from mortality to quality of life (Pereira, Murphy, & Herndon, 2004). This shift is evident in low- and middle-income countries like India (Keswani, 2000). Contractures, scarring, disfigurement, and psychological problems are some of the burn outcomes that affect quality of life. In burns, disability associated with scars and contractures occurs over time, often after discharge from hospital (Sheridan, 2002). Hence, rehabilitation at home is also a protracted and significant phase of burn care, with the onus of care being on the burn-injured child's parents and family.

Parents also suffer when their children are burn-injured (Cahners, 1988).The family as a unit becomes the patient in the post-burn period (Blakeney & Creson, 2002; Young, 2004). Parents, especially mothers of children with burns, report negative outcomes such as depression, anxiety, guilt feelings, and posttraumatic stress symptoms from the time of admission until up to even 10 years postburn (Bakker, Van Loey, Van Son, Van der Heijden, 2010, Kent et al., 2000; Knudson-Cooper, 1981; Phillips & Rumsey, 2008; Rossi, Vila, Zago, &

Ferreira, 2005). Despite the negative reactions that parents experience, family environment and support from family members have been consistently identified as factors influencing burn outcomes and quality of life in children who have sustained burns (Blakeney, Herndon, Desai, Beard, & Wales-Seale, 1988; Blakeney, Portman, et al., 1990; Landolt et al, 2002; Rosenberg et al., 2007; Tyack & Zivani, 2003). However, how family members provide care and support amid their own and their burn-injured children's positive or negative reactions and what helps or hinders these family caregivers have rarely been studied. This study aimed to explore the experiences of parenting burn-injured children.

With the need to reduce hospitalization costs, burn-injured children are discharged as soon as they are stable and family members are expected to be involved in burn care and rehabilitation with or, in many situations, without the assistance of rehabilitation experts or the burn team (Sheridan, 2002). Despite this enormous expectation placed on families, their specific issues and challenges related to burn caregiving remain unaddressed from a clinical or research perspective, especially in low- and middle-income countries. Marginal parent compliance in bringing children for follow-up has been posited as the reason for poor outcomes in low- and middle-income countries (Ramakrishnan et al., 2004). If burn care and burn outcomes are to be improved, it is imperative to determine how families in low- and middle-income countries like India manage burn caregiving responsibilities that include adherence to an exercise routine, wound care, scar prevention, frequent follow-up visits to hospital, and reintegration of the child into the family and community.

Although family issues related to burn caregiving have been inadequately addressed by researchers, the responsibilities, experiences, processes, and patterns of caregiving for families of children diagnosed with other chronic illnesses and disability have been reported in the literature. For instance, in families of children with diabetes, parents had to manage their child's illness, identify and access community resources, maintain the family unit, and maintain themselves as parents (Sullivan-Bolyai, Sadler, Knafl, & Gilliss, 2003). Stress was perceived by all parents irrespective of their child's type of illness, disability, impairment, or behavioural outcomes (Atkin & Ahmad, 2000; Dellve, Samuelsson, Tallborn, Fasth, & Hallberg, 2006; Judge, 1998; Mandel, Curtis, Gold, & Hardie, 2005; McDonald, Poertner, & Pierpont, 1999). According to a metasynthesis of literature on the experiences of parents caring for children with chronic illnesses, parents continued to carry on the burden of caregiving as they also struggled to remain stable as a family (Coffey, 2006).

In contrast to caring for children with chronic illness or other disabilities, the burn injury is a sudden, traumatic event, and the acute and rehabilitative care for burn-injured children involve activities and exercises that cause considerable pain to the burn-injured child. Such activities cause stress and distress for parents who care for their children (Blakeney et al., 1993). Further, the disfigurement associated with severe burn injury poses problems for the child and family in terms of reintegration into the community (Lawrence, Rosenberg, Mason &

Fauerbach, 2011). Within overarching societal beliefs and values about impairment and disfigurement, and financial and support constraints or liberties as well as the possible negative or positive reactions to injury (Resch et al., 2010) how families parent and provide care and support to burn-injured children to promote optimal quality of life needs to be explored.

Quantitative research design using standardized scales has been the norm in most studies related to pediatric burns (Simons, Ziviani, & Tyack, 2004). Data generated through patients' and family members' subjective accounts uncover what cannot be identified by standard scales (Rossi et al., 2005; Tyack et al., 1999). Therefore, a qualitative research design that incorporates a researcher-participant interactive-relationship and facilitates participants' recounting of their experiences was necessary to understand processes of parenting for families of children who have been burn-injured. The aim in this qualitative study was to explore and discover processes of parenting children in India who have sustained burns and to develop a conceptual model to inform interventions.

Method

Research Design

Constructivist grounded theory methodology was used to identify the process of parenting burn-injured children. Grounded theory is based on the premises that individuals have multiple subjective views and that knowledge is socially constructed (Charmaz, 2006). Grounded theory methodology guides the researcher not only to explore life events but also to focus on how individuals perceive and respond to the events, and to identify the social process that they use to address issues related to an event (Schreiber & MacDonald, 2010). This is made possible by exploring, analyzing, and interpreting peoples' actions and meanings that are tacit or taken for granted (Charmaz, 2006).

Setting and Participants

The study was conducted in a city in Tamil Nadu, South India. Potential participants were contacted by the health care professionals working in outpatient and community settings. The nurses in the pediatric surgery outpatient department of the study hospital approached family members who accompanied their child to their follow-up appointment, usually the parents, about the study. Community health nurses approached family members in the community whose children were not attending the follow-up clinic or were treated or followed up in other hospitals. The initial recruitment involved briefly explaining the study and ascertaining the family's willingness to be contacted by the researcher regarding study participation.

Through a purposive sampling method, 9 fathers, 9 mothers, 3 grandmothers, and 1 aunt of 12 burn-injured children (less than 16 years) with total surface of burn area (TSBA) greater than 20% and at any post-hospitalization stage who were willing to share their experiences were included in the study. The children, 4 girls and 8 boys, had suffered 20% to 60% TBSA burns to various body parts, such as face, neck, trunk, and upper and lower extremities, including hands and feet, at ages 8 months to 9 years. Six children sustained scalds, 5 suffered flame burns and 1 child was electrocuted. Length of time since injury ranged from 6 weeks to 6 years. The initial hospitalization period for these children ranged from 2 days to 2 months. All those who were contacted were willing to participate in the study. The study was approved by the appropriate institutional medical research board in India and health ethics review board in Canada.

Simultaneous Data Collection and Analysis

Interviews were conducted in Tamil (the regional language) with the family members using a semi- structured interview guide to elicit data related to parenting burn-injured children. The interview started with the open ended question, “Can you tell me how it was for you when your child was burn-injured?” As participants narrated their stories, the researcher asked probing questions to assist the participants to explain the what, why, and how of their actions. Some trigger questions, such as what the most challenging thing was for the parents when they cared for their child, were added to elicit comprehensive data. Interview lengths ranged from 30 minutes to 2 hours. The digitally recorded interviews were transcribed verbatim and then translated into English. Detailed field notes were written after the interview and were used as additional data. QSR NVivo software version 8 was used for data management (QSR International Pty Ltd., 2008).

Data collection and analysis were concurrent to make early and ongoing effective comparisons between and within participants’ accounts and between families. Simultaneous data collection and analysis, and constant comparative analysis characterize grounded theory methodology. Open and focused coding, memos, and theoretical sampling were used to sufficiently interpret participants’ accounts to identify a process of parenting. Open coding through line-by-line analysis of three interviews yielded 94 code concepts (e.g., life threat, travel, support versus nonsupport, emotions). These concepts were then used for focused coding of subsequent interview data. Some additional concepts were added, and some were combined. Constant comparison of accounts and writing of memos related to the codes helped in answering questions about what was happening and in identifying relationships between concepts. Nineteen categories (e.g., managing the wound, focusing on the child, shielding from stigma) evolved from interrelated concepts. Three parents from three families were interviewed a second time to answer questions related to the evolving categories. This step, known as theoretical sampling, helped in saturation of code categories, meaning that no additional code categories were identified even when new data were added (Charmaz, 2006). Ongoing analysis, interpretation, and conceptualization of categories and meanings from the participants' accounts, multiple discussions with supervisors who were experts in grounded theory and parenting theory, and peer debriefing assisted in moving the interpretations from a descriptive to a conceptual level. This resulted in identifying a process of Embracing the Survival.

Findings: Embracing the Survival

Parenting children with burn injury involved a process of embracing the survival. The process of embracing the survival included three stages: suffering the trauma, sustaining life, and shielding from stigma. The action of embracing means *accepting, taking up something, and/or encircling or holding close*

("Embracing," 2011). For parents of burn-injured children, embracing involved *accepting* what had happened to their child in the midst of feeling shocked and traumatized both physically and emotionally as they suffered alongside their burn-injured child as well as accepting help from others. Parenting also involved *taking up* the numerous challenges related to their child's evolving injury trajectory, which included managing a large wound, making the burn-injured child a priority, and mobilizing resources to sustain the life of their burn-injured child. Embracing survival further involved *encircling* or *holding* on to their child as a means of shielding him or her from stigma as disfiguring scars and contractures developed and parents considered their child's future as a survivor of a serious burn.

Suffering the Trauma

Irrespective of where and how it happened, for the parents the burn was a *shocking* event and was "an incident that should not even be thought of in life" (Mother Family (F) 9) that they had to come to terms with. Immediately after the burn incident all families took their burn-injured children to a hospital or clinic, which demonstrated their realization that their child's injury required urgent professional attention. At first, however, parents did not expect that the burn "would be so serious." The burns were serious, however, and all of the children in the study were eventually referred to hospitals where specialized pediatric burn care was available. It was then that parents understood the precariousness of their child's survival. Their "child was in live-or-die state; here [in the local hospital] they said that it was not possible [to treat]" (Mother F1). Parents recalled the health professionals at the tertiary hospital saying things like “this case will not survive” (Aunt F2) and “there is no guarantee [that the child will survive]” (Father F5). Parents feared for their child’s survival and wondered, “Will our child leave us?” (Mothers F4, F12) and “Will we see our son [alive]?” (Father F1). One grandmother (F7) “did not think he [grandson] will live.”

The hospitalization period was traumatic for all parents. As they witnessed their child’s suffering, they suffered both emotionally and physically. Emotionally, many mothers were overwhelmed by fear, dread, and anxiety as they stayed at the hospital with their critically ill child, who suffered repeated painful treatments. They described the hospital time as “frightening” and the hospital as “hell” (Mother F7). Many mothers and fathers vividly recalled the state of their traumatized child and the emotional pain they endured as the child was treated in the hospital:

> I looked at Gowtham [pseudonym] and cried. This God has given me so much trouble. Why do I have to see this child, like this? Like that [I had] many different thoughts. My heart was not at peace. I had some bad thoughts. That was why it was difficult. Gowtham’s problem [burn] one side and this fear [fear that child will die] was another side. (Mother F7)

A father’s anguish was evident when he said that he “wanted to commit suicide” (F3) when he witnessed his son’s suffering after his burn-related below-the-elbow amputation. Parents struggled to deal with the pain that the child endured during the phase of active wound management:

> Even if it is a small injury when the skin peels it will be so painful for us, but this child [daughter] bore all the pain. I looked at how much pain she was tolerating and would feel like crying... I cried. (Father F8)

Physically, the parents were also affected as they stayed with the child in the hospital and could not eat or sleep as they kept constant vigil to meet their child's needs. Fear that their child might die kept them awake at night. Some parents lost weight. A pregnant mother who was attending her burn-injured child explained:

> Initially, pada pada like that the shock will come. I won't be able to stand, so I will sit. [My] legs will become weak. I could not eat food. If I go near the food I will think of the child only. I will remember only how he cries (with wobbling voice, tears). I won't even be able to eat… Because of that I even stopped eating for some time. The doctor [obstetrician] scolded me, "Your weight has reduced a lot. You were 50 kilograms last month...this month your weight is 41; you have reduced nine kilograms." (Mother F1)

Similarly, a father reported his experience*:* "I reduced from 65 to 52 kilograms in 2 months...I felt so bad he did not take food so I used to take food once in 2 days" (Father F3).

Amid the emotional and physical struggles, parents also faced blame from family members and health care professionals. They constantly faced questions such as, "How did you allow this?" The implicit as well explicit statements of blame brought into question the parents' ability to look after their children and shook their sense of competence. They recalled wondering, “Will I harm my own child?” (Mothers F7, F8). Parents internalized the blame, felt guilty, and thus endured emotional trauma related to blame as they suffered emotional and physical trauma because of what their child was going through. It was not only a “live-or-die” state for their child; the parents also questioned their own survival.

Despite the shock and physical and emotional trauma that the parents endured, they readily accepted and embraced their role as the one their child needed the most and said “we both only looked after the child” [Mother, Father F1]. Hospital policies encouraged the mothers to be near the child, but many described feeling “alone” and “scared.” Some mothers received psychological and instrumental support from maternal grandmothers who were not part of the extended family with whom the parents and their child lived.

> My mother only supported me. “Don’t be frightened. Our child will return to us… We did not sin against anyone.” Like that the person who stood in support was only my mother. No one [in-laws] understood me at that time. I had done something like every one scolded me only. (Mother F12)

As most of the mothers endured the hospitalization period, they depended on their spouses for psychological as well as instrumental support. Fathers’ support helped the mothers to get through this period.

> I will wait for my husband...My husband will bring food. When I saw my husband I used to feel a little brave. I had a language problem. My

> mother was outside the ward and would be allowed inside only during the visiting hours. So it was difficult for me to look after Gowtham. I myself was there for 22 days. I had to stay nearby. Gowtham won't go to anyone. (Mother F7)

The hospitals' visiting policies were not, however, supportive of or sensitive to the need for parental mutual support, limiting, for example, the time of day that fathers could visit. Regarding support from health care personnel, most of the parents said that they did not express their physical or psychological needs to health professionals, nor were they asked about them. Although parents from three families expressed that the health professionals had said, "Don't cry. The child is going to be OK" and prayed for the child, their attention to parents' physical and emotional needs was minimal. Irrespective of some accounts of lack of satisfaction with their child's care, most parents said the health professionals looked after the child well.

Most of the parents held on to their faith and "were going on praying to God" (Mother F2). Their faith and prayer helped them to endure this painful period of trauma so that they could look after the child:

> God is there. His grace is mighty. He will save my child's life. He won't take away the gift he has given me. Saying this I asserted myself and went to the hospital to look after the child. (Mother F8)

The initial hospitalization period for the children whose family members participated in this study ranged from 2 days to 2 months. Children were discharged from the hospital as soon their condition was stabilized and the wound showed signs of healing or the child recovered after skin grafting. Parents described their happiness and immense relief; their child had survived the burn, and the threat of death was lifted. Parents had also survived their trauma and were happy when “they [health care professionals] said ‘discharge’” (Mother F7). Parents and family members referred to the child’s survival as “died and survived” or “another life.” One father (Father F2) said it this way: “Coming back [home], we had some peace. Because our child’s life. … He escaped with life... [survived].” Parents, however, soon realized the challenges of caring for a severely burn-injured child in the immediate post hospitalization period at home as the burn injury was extensive.

Sustaining Survival

At home, parents took up the role of health professionals and faced the challenges of caring for their burn-injured child. They worked hard to sustain their child’s survival by managing the large wound, making the child a priority and mobilizing resources. Although the children were at home and not in the hospital, they still had a wound. It was “Bandage, all bandage... hand, leg, head, all bandage” (Mother F2). The data reflected parents’ experiences of the wound at different stages of healing that needed daily to weekly dressing changes. Although wound dressings were done initially in the outpatient settings, health care professionals instructed the parents to continue wound care at home. In some families it was difficult for parents to provide wound care between the dressing changes because of the pain that the child endured:

> For the dressings they asked us to wash the wound and come... we tried. We washed with water but he suffered. So we did not do it. When we went to the hospital the nurse scolded us. (Father F7)

Despite the difficulties and the blame they encountered, parents took up the role of health professionals unquestioningly and concentrated on what was best for their children: wound healing. Amid their regular work and home life parents continued the care that was provided in the hospital. “We will gently clean the skin and will give bath. After giving bath I will go to work” (Father F8) Many parents had “money problem” (Father F2) or “no one’s help” (Father F6) and “debts” (Mother F4), yet diligently followed all the instructions that were given by the health care professionals regarding caring for their burn-injured children as much as they could by making the child the priority for their time and attention.

Parents’ accounts emphasized the central place their burn-injured children claimed as they cared for their child at home. For parents, their child’s “life was important” and “their life [as parents] was not important” (Mother F6). Issues related to the travel, finance, work, care of siblings or even their own well-being blurred in comparison to ensuring wound healing and preventing complications, such as a wound infection, that could put their child’s life in jeopardy again. Parents explicitly expressed that their struggles were directed at the child’s well-being. “If my son becomes well it is OK. For the boy [son] only we are struggling so much. If the boy becomes well it is enough” (Father F1).

This father did not hesitate to bring the child to the hospital for follow-up even though there was limited affordable transport.

> We don’t have bus from my village... First [we] went by auto. Up and down it was costing 100 rupees, for going 50 rupees, coming 50 rupees. Now boy has less pain. [He] is better. He is sitting a little well. So [I] carry him on my shoulder [and walk]... It takes one hour. (Father F1)

For parents, “all other things were not important.” The fathers especially wondered, “How can I leave [not care for] my child? Money and cash will come and go, but the child is important” (Father F6), and acknowledged that they “can earn money somehow but what [is important is]... child should become alright for us” (Father F2).

The concern for wound healing and prevention of infection was uppermost for many parents. They wanted to sustain the life of their child who had survived the burn. The priority they placed on their child meant that they did not hesitate to keep relatives away who wanted to visit, even though that caused unhappiness for some extended family members.

> The doctor said she might get infection. Here [in the house] all the relatives are coming and sitting [visiting]. If you ask them to leave, they feel bad. If you consider them, it is not going to be good for the child. So I said no one should come to the house. If they fought also it was not a problem for me. (Father F5)

Parents’ continued focus on the burn-injured child at home required mobilizing their inner as well as the human and community resources. Similarly to what parents did to survive the trauma, some parents continued to rely on their faith in God as they sustained their child's survival. They constantly talked about how "thankful" they were to God for "saving their child" and it was all "God's will." The maternal grandmothers' help lessened after the hospitalization period for most mothers. In some instances, family members assisted the parents in indirect ways by accommodating the burn-injured child and family in their house or pledging jewels to provide financial support. Most mothers indicated that their in-laws were not helpful in giving the burn care but that they helped with the cooking for the first few days or looking after the siblings when the child was back at home. In one family neighbours looked after the sibling when parents brought the burn child for follow ups. Parents were the ones focused on sustaining their child's survival:

> Looking after and all was me only. Looking after means... they [in-laws] will be there, but I am the person who looked after her. I will only do... My father will come to see and will give me money. (Mother F8)

Parents who were unable to mobilize financial resources to return to the tertiary centres for follow-up approached the local clinics for assistance with wound care. As health care professionals in the local clinics were not confident in taking care of a large wound, parents mobilized their own resources to do wound dressings.

> It costs about 500 to 600 rupees to go to the hospital... So I am doing the dressing quietly. She [doctor in a local clinic] wrote and gave some

> medicines for my father [who was also burn-injured]. Same medicines I bought and did the dressing for him [son] myself. (Father F2)

In all families except two, the parents formed an effective dyad and mobilized their own strengths to focus on taking care of the child. They did the bath and wound dressings, took turns to look after the child at home, and supported each other psychologically when they faced blame from the family or health care professionals. Although many fathers resumed work, they continued to provide their child's post-burn care when they were at home.

> He [husband] will lay him [son] on his chest and will make him sleep. When he is awake I will sleep and when I sleep he will be awake. Like this, me and him took turns [to look after him]. (Mother F6)

Psychological and instrumental help was minimal for a single mother in one family. She described her continued grief for the lack of support and her inability to mobilize resources even 5 years after her child's burn incident.

Parents were happy when the wound started healing and the child started to resume pre-burn activities. They did their best for their child, whose care they considered a priority, by managing the wound and mobilizing resources. With minimal assistance for burn care, parents succeeded in sustaining the life of their burn-injured child. Parents referred to the caregiving activities as "no difficulty" (Father F1) or "sweet burdens" (Father F12). As the wound gradually healed, the demands on the parents regarding wound care at home and follow-up visits lessened and contacts with health care providers decreased. When the scars and contractures began to form, however, parents began to worry about the scars and the future of the child.

Shielding from Stigma

All children had some level of scarring, from some discoloured spots to major keloids in different body parts. Three children had contractures, and three had lost body parts: one arm, five fingers, or both ears. Parents were devastated by the scars and disfigurement, and shielding their child from stigma characterized their parenting at this stage in their child's burn injury trajectory. They did their best to minimize the scars and contractures and protect their child from the insensitive responses of others to the scars and disfigurement. Parents also could not help but consider their child's future in relation to their scars.

To minimize the scars and contractures, parents initiated follow-up visits or sought guidance for further treatment for their children. However, the specialists who treated the wound could not manage the scars or contractures. Therefore, children were referred to plastic surgery specialists or facilities that sold special devices such as pressure garments and splints for management of contractures and scars. Parents had to navigate this transfer of care:

> The first time, [they] kept in bones [burns] ward. Yes, all treatment was in bones [burns] ward. Afterwards, what doctor said, "wound has healed, now the nerves in the hand are being pulled." So what they said, "Go to plastic surgery ward" like that... I am doing treatment there now. (Father F2)

Parents followed the instructions given by the health care professionals and incorporated their own healing rituals as well:

> These fingers and all were a little bent. So every day morning I myself will like this moved, moved and moved and it became straight now. Before that all these [fingers] had dropped [bent] and the nerves were tightly pulled like this. We put this oil with prayer, massaged the hands and all like this, as we said victory to the blood of Jesus... now it has become a little steady. (Mother F1)

As parents worked on minimizing scars and contractures, they recognized or witnessed the stigma that their child suffered or might suffer because of the scars:

> That day he [son] came and said, looking at his hands, “This is bad (looks horrible/awful) for me. Cut this with a knife and keep another thing.” He did not know to express it well... When I asked what to be kept he said, “You go to the hospital and bring the knife,” like that. We said, “We will do that when you become a little older.” Children at school are teasing him it seems asking, “What is this da? What is this da? It looks awful. What is this?” (Mother F6)

Parents were distraught and saddened when their child suffered stigmatizing behaviours, or they anticipated comments and thus focused on protecting their child from others. One father was scared that “his friends may ask, ‘Why is your hand like this?’ and I feel terrible. I do not know whether he [son] has such feelings.” (Father F3). One mother instructed the child’s siblings not to comment about the scar. They were vigilant about threats related to stigmatizing behaviours and constantly engaged in activities that would protect their children from them. These activities included checking whether anyone talked to their child about the scars and covering the scars by specially selected clothing:

> This hand appears a little different to look at it seems. So his parents do not want to show it to anyone. They think that the child may feel at heart if others see... If relatives come and ask also they don't show. They always dress him in full sleeve shirt. (Grandmother F7)

One mother explained her efforts to prevent stigma:

> To select an outfit that would hide my [daughter's] scar, I will visit many stores... I will undo the stitches in the neck, alter it, make the neck small. Without doing that I will not dress her up at all. (Mother F9)

Some hoped that the "scar will disappear" over time (Mother F11). Parents as well as other family members contemplated the future of the burn-injured child. Many parents wondered whether their children would be able to function independently at future stages of their development, get a job, or get married. Parents whose daughters had burn scars were worried that "when she gets married it is going to be difficult... even my uncle asked, how are you going to get her married?" (Mother F9, Child aged 5 years).

Loss of limbs implied chronic dependency on parents. Parents wondered, "Tomorrow if I die suddenly, who will look after my child?" (Mother F4) and thought of ways their child could become independent in spite of the scars and the stigma. “In the future after she completes her studies, we have to search somewhere some job, a job that she can do... For that she has to be educated” (Single Mother F4).

Family members’ accounts illustrated their untiring efforts in shielding the child from stigma by managing or preventing the scars and contractures as well as planning in view of the child’s future survival. They had a long-term vision for their child who had survived the burn. Lack of accounts of health professionals’ concerns related to prevention of scars or stigma suggest their focus on child’s short-term physical survival.

Discussion

The process of Embracing the Survival encapsulates the challenges parents encounter and the strategies that they adopt to parent their burn-injured child. The challenges changed as the stages of the process evolved. The shock and trauma of the child’s injury and precarious survival were predominant in the first stage, and parents suffered physically and emotionally along with their child during the period of hospitalization. The anxiety, fear, and stress symptoms that the parents, especially the mothers, articulated are consistent with other findings in the burn literature (Kent et al., 2000; Knudson-Cooper, 1981; Phillips & Rumsey, 2008; Rossi et al., 2005). Many parents described experiences that mirrored posttraumatic stress symptoms, such as inability to sleep or eat and recurring thoughts of the child’s struggles, similar to previous research findings (Bakker et al., 2010; Rizzone et al., 1994). Contrary to the trusting environment created by nurses, which facilitated expressions of emotions for parents of burn-injured children, that was reported by Zengerle-Levy (2006), parents' accounts in this study indicated that health care professionals did not acknowledge or address their psychological and physical concerns during the child's hospitalization or after discharge. Blame was perceived more than support, and parents had moments of doubt about their parenting abilities. This finding is not reported in the literature and warrants further consideration. Questions related to subtle or overt blame from health professionals from the parents' *and* the health professionals' perspectives need to be explored.

All families in the study had to deal with partially healed wounds that were at risk for infection. Managing a burn wound at home was an enormous task for which the parents were not prepared adequately. Although parents were willing to take responsibility, wound care was a painful procedure for the child as well as for the parents. Moreover, the father, who was an important partner in caregiving at home, was not allowed to be part of the care in the hospital because of restrictive policies related to visitors. This prevented the valuable opportunity of both parents being prepared for home care. In the previous studies on burn care, it is unclear how parents managed wound care or rehabilitative care at home. Some reports imply that there was regular follow-up for a few years post-burn and that the health care professionals or parents provided care within a secure, well established, supervised environment (Baker et al., 2007; Landolt et al., 2002).

Contrary to the assumption that parents in India are noncompliant with follow-up or rehabilitation-related activities (Ramakrishnan et al., 2004), parents in this study demonstrated their perseverance in meeting their burn-injured child’s needs at home, many times by initiating follow-up care themselves. The environmental and economic constraints such as inability to access wound care facility, transport issues and financial burden that the parents faced are consistent with what is already reported in South Asian literature on pediatric burn care (Mashreky et al., 2008a; Ramakrishnan et al.) and care of children with disability or seizures (Edwardraj, Mumtaj, Prasad, Kuruvilla, & Jacob, 2010; Pal, & Chaudhury 1998). Amid such constraints and limited support from family members and health care professionals, parents in this study became proficient in giving care and mobilized resources that assisted them in the care of their child. Parents’ consistent focus on the burn-injured child to support the child to recover, to manage others’ responses to the child’s scars, and to resume normal activities refutes the findings from previous studies that parents in India found their children with disability or chronic illness a burden (Edwardraj et al., 2010; Pal & Chaudhury, 1998). Although some parents expressed substantial financial burden, unlike the finding in Edwardraj’s study in which some parents gave up on follow-up because of financial issues, all parents in this study were determined to do everything they could for their child despite many obstacles.

Extended family members’ lack of involvement in the wound and rehabilitative care of children was an unexpected finding. In a culture that is child oriented and in which a child’s needs are considered as priority and where in-laws’ over involvement is assumed as well as reported (Atkin & Ahmad, 2000), accounts of limited support from extended family members who were living under the same roof were unexpected. Pre-existing family tensions or blame related to the circumstances of the burn injury could be reasons for noninvolvement. The difficult and painful procedures related to burn care at home might also have been a deterrent to family members' involvement. Mothers appreciated the temporary support they received from their mothers. Maternal grandparents as the only source of support has been reported in Edwardraj et al.'s (2010) study on Indian mothers' and health workers' perceptions of intellectual disability in children.

Fathers' proactive involvement in the care of children was an important finding in this study, given the cultural setting where mothers are considered the primary caregivers. Contrary to previous findings from Asian studies on caring for children with physical or intellectual disabilities (Edwardraj et al., 2010; Holroyd, 2003), fathers in this study were intentionally involved in sharing the caregiving tasks and responsibilities with mothers; for example, giving baths, doing wound dressings, providing exercises, and planning and taking children for follow-up visits to the hospitals. In most of the families, mothers and fathers formed an effective team and focused on the care of their burn-injured child. This finding replicates the finding of an earlier study in Canada on parenting children with a lethal congenital heart defect (Rempel & Harrison, 2007). Even amid strained relationships in a few families, parents were in agreement as far as the child was concerned and formed a cohesive duo when caring for their burn-injured child. In the extensive literature on influences of family environment and support on burn-injured children’s recovery, such vital and tacit details of the type of support are not presented.

Our findings on stigma-related issues in children with burns are similar to those from other studies (Knudson-Cooper, 1981; Lawrence et al., 2011; Tyack et al., 1999). Parents’ worry about their children’s future is also consistent with the previous research on parents of children with chronic illness or disabilities (Johnson, 2000; Monsen, 1999). What this study adds is an explicit process by which parents shield their child from stigma irrespective of whether the child perceived stigma.

To summarize, two main areas have implications for practice that would enhance care of burn-injured children. First, health care professionals need to be sensitive to the parents’ needs as they are involved in the care of the burn-injured child. Assessing for parental physical and emotional reactions and providing ongoing psychological support as their children are treated need to be vital components of burn care. These measures will enhance the family-centered approach which will enable and empower parents to look after themselves and their burn-injured children in the hospital and later at home.

Second, support from extended family members should not be taken for granted when caregiving is needed in India. Simple tools like genograms and ecomaps can be used at the time of admission to identify the support system/group/individuals who may help parents effectively with home care and also may assist in understanding the reason for non-involvement (Rempel, Neufeld, & Kushner, 2007). Such individuals/group can be involved in discharge planning and teaching on home care. As fathers have demonstrated their intense involvement in the care of their burned children, promoting family-centred care where the father is also empowered and supported in giving care should be an integral part of the care plan of burn-injured children.

Although parents mentioned sibling care, it did not emerge as a main category from the data. Parents’ intense focus on their burn-injured children could have overshadowed the needs of their other children during the time of hospitalization and the rehabilitation at home. The influence of pediatric burn injuries on siblings needs to be explored and articulated.

Limitations

A limitation of this study was eliciting data only from family members. Accounts from health care professionals and the burn-injured children would have been valuable. Interviews or focus group discussions will be conducted with these groups in subsequent studies as the research program evolves. It is hoped that findings from further studies will assist in strengthening the model and developing a grounded theory. However, obtaining the perspectives of multiple family members in this study enabled data triangulation. The participation of equal numbers of fathers and mothers was a unique feature compared to many previous parenting studies, in which the majority of participants were mothers. Although the sample was small, children in the study were in various stages of the post-burn period, with a wide range of injury-related factors. Therefore, the sample had adequate representation of the population of interest to identify the process of parenting.

Conclusion

To our knowledge this is the first study which has articulated as its focus the experiences of parenting burn-injured children. The study has added essential evidence related to pediatric burn care in India and has made a contribution to address the gap in research from low and middle income countries. Research related to interventions that promote cohesiveness of the parental dyad through ongoing instrumental and psychological support of parents of burn-injured children would be a useful next step.

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Paper 3: Parenting Burn-Injured Children in India:

A Grounded Theory Study

Background

Burn injury is a serious trauma that can cause death. While technological advances and increased knowledge of treatment of the burn wound and its complications have improved survival of burn-injured children (Herndon, 2007) even in low and middle income countries (LMICs) (Keswani, 2000; Latenser et al., 2007; Senel et al., 2009), debilitating sequelae may occur (Landolt et al., 2009). Rehabilitation to prevent complications such as scars and contractures extends into the post hospitalization phase. Caring for burn-injured children, therefore, is a long process. Family members, especially parents, become responsible for providing this rehabilitative care at home (Sheridan, 2002).

Burn caregiving is a challenging process for families. The family as a unit becomes the patient in the post-burn period (Blakeney & Creson, 2002; Young, 2004). Parents often suffer as much, if not more, than their children in response to their children’s pain, disability or disfigurement (Cahners, 1988). Parents of burn-injured children reported feelings of guilt, anger and self blame (Bakker, Van Louey & Van der Heijeden, 2010; Horridge, Cohen & Gaskel, 2010; Knudson-Cooper, 1981; Rizzone, Stoddard, Murphy & Kruger, 1994), and experienced sadness, denial, and fear of stigma (Rossi, Vila, Zago & Ferreira, 2005). Mothers in particular developed anxiety and depression at various stages of burn injury (Blakeney et al., 1993b; Phillips & Rumsey, 2008) and were more anxious than their burn-injured children (Kent, King & Cochrane, 2000).

Parents, especially mothers, may manifest stress symptoms over many years (Bakker et al., 2010; Rizzone et al., 1994) with mothers who reported guilt feelings exhibiting high stress scores even 11 years after their child's burn event (Bakker et al.). Despite these effects, parents care for their burn-injured children and their support improves burn outcomes in children (Sheridan, 2002). Such empirical evidence about the effects of burn injuries on parents and other family members is not available from low and middle income countries like India. Challenges of parenting burn-injured children remain unaddressed from a clinical or research perspective.

The aim of the study was to discover the process of parenting children in India who have sustained burns. Two substantive processes, Enduring the Blame and Embracing the Survival, emerged from this study. The objective of this paper is to delineate the process of "Enduring the Blame" that mothers and fathers adopted to parent their burn-injured children.

Study Design

A constructivist grounded theory (GT) methodology was adopted to explore the experiences of parents of children who have sustained burns (Charmaz, 2004; 2006). Constructivist GT assumes a relativist stance, views knowledge as socially constructed, and views both the participants and the researcher as having multiple viewpoints. It places emphasis on the researcher's reflexivity towards his/her own actions, situations, participants in the field settings, and analytic constructions that emerge from the data (Charmaz 2009).

Theoretical Background

Symbolic interactionism and human ecology theory as underlying and guiding frameworks, respectively, assisted in discovering the process of parenting burn-injured children. Symbolic interactionism focuses on meanings that mediate the interpretation of interactions which occur within dynamic social activities (Blumer, 1969). Based on symbolic interactionism, GT focuses on the meanings given to events and actions and the interactions that are attached to these events within the individual/groups' social, cultural, historical or religious contexts (Corbin, 2009). Human ecology theory purports the interdependency of an individual or family with their socio cultural environment as well as the environment within the family (Bubolz & Sontag, 1993). Human ecology theory is based on the assumption that individuals and families through the process of needs evaluation, decision making and management constantly adapt to and act upon the environment. I therefore assumed that parents of children who have been burned attach meanings to their actions in relation to the care of child with burns. Their actions depend on their interpretations and perceptions of interactions within the family and community, and/or with the health professionals (HPs). I also assumed that the family members and others had input into the care of the child and influenced decisions and actions related to follow up. Further environmental constraints like transport can affect burn follow-up. Exploring and theorizing these actions, interpretations, and meanings is a complex yet essential process to answer clinical questions regarding care of children who had sustained burns.

Research Setting

The study was conducted in a town in south India with a population of 900,000. A tertiary hospital that provided specialized pediatric burn care was the center through which the participants were recruited. Ethical clearance was granted from institutional review boards in Canada and India.

Participants

Families of burn-injured children who were 15 years of age or younger with more than 20 percent burns were approached by either the nurse in the outpatient clinic or the community health nurses working in the tertiary hospital. Using purposive sampling, nine fathers, nine mothers, three grandmothers and one aunt who were directly or indirectly involved in the care of the burn-injured child either in the hospital or at home and were willing to share the parenting experiences were included in the study.

All families who were approached agreed to participate. Mothers were between 25 to 33 years of age and fathers' ages ranged from 28 to 41 years. Except for two mothers, all of the parents had some formal education. One father was a university lecturer and one father was an office attendant. Four families had small scale businesses. None of the remaining parents had regular paid jobs and their income was based on employment on a day by day basis. Eight families lived with paternal grandparents and other family members. Burn-injured children, four girls and eight boys, ranged in age from 2 to 15 years at the time of the first interview. The age at which the burn occurred ranged from eight months to nine years and the total body area burned was between 20 and 60 percent.

Data Collection

Data were collected through in-person interviews and detailed field notes. Once the participants gave consent to participate in the study, interviews were set up in the place and at the time that was most convenient for them. Three interviews were conducted in the out-patient clinic, two in the family-owned shop, one in a field, and the rest in the participants' homes. Individual interviews were planned, but in four families it became a group interview as other family members participated with the consent of the parents.

Interviews were conducted in Tamil and started with an overview question "Can you tell me your experiences related to your child's burn injury?" Trigger questions, such as "What was the most challenging thing about looking after your burn-injured child?" or "How did you manage the wound?" were asked to help parents and other participants to reflect on their experiences in depth. In GT, data collection and analysis occur simultaneously (Charmaz, 2006; Glaser, 1978). As categories such as suffering the blame and protecting from stigma emerged from the data, three parents from three families whose children had different types of burns that happened at different locations (i.e., inside the home or outside the home) and who were at a different post-burn stages from the time of initial interview were selected for second interviews to enhance theoretical saturation of the categories.

Interviews lasted from 30 minutes to two hours and were digitally recorded, then transcribed and translated into English. Back translation of two interviews verified translation accuracy. Data were managed using NVivo 8 software (QSR International Pty Ltd., 2008).

Data Analysis

The inductive process of data analysis in GT focuses on emergence of code categories rather than a deductive process of applying pre-existing codes. It involves an iterative process of constant comparison of data from one participant to another and comparing incidents within and between accounts (Glaser 1978). Initial line-by-line coding of the first three interviews yielded 94 code categories that were then used to code subsequent interviews (focused coding). Focused coding helped in grouping related codes and identifying 19 categories. As data between participants and families were compared, memos were written on the categories and concepts to help in interpretation, construction and abstraction. Further conceptualization occurred when data were collected through the second interviews with participants from three families to answer questions like, Is the trajectory similar in all the families? Did blame vary according to type of burn or location where it happened? The data were compared with initial data. A core category and a process of parenting emerged as theoretical analysis progressed. The core category was the core issue that parents were grappling with and the core process was the way by which parents tackled the core issue (Schreiber & MacDonald, 2010). The core category “Blame” and the core process of “Enduring the Blame” emerged from the data.

Findings

Although my aim was to discover the post-hospitalization parenting process of children who have sustained burns, parents' accounts invariably included their experiences of the burn event and their child's hospitalization. As these experiences were related to their experiences of parenting in the post hospitalization period it was imperative to include all phases of burn trajectory in the analysis and conceptualization.

Family members' accounts brought forth a three-phased burn trajectory; namely, the Injury Phase, Wound Phase, and the Scar Phase. The injury phase included the burn event and the period of hospitalization. The wound phase extended from the time of hospital discharge until the wound healed. The scar phase began when the scar appeared. In most of the families it was primarily the parents who cared for the child. Blame evolved as a core category from the participants' accounts as parents cared for their burn-injured children through all phases of the burn trajectory.

Blame: The Core Issue

Blame was one of the core issues that the parents experienced as they cared for their burn-injured children. Blame is defined as *finding fault or holding someone responsible* ("Blame," 2011). It is the *act of censuring, holding responsible, and/or making negative statements* about an individual or group that their action or actions are socially or morally irresponsible. Parents' and family members' accounts consistently brought forth the blame that parents suffered as they cared for their children. Parents were criticized and censured for not protecting their child from the burn event. Blame occurred at all phases of the injury trajectory and from family members, health care professionals (HPs) and strangers in the social environment and called into question the parents' competence.

Blame from family members. Parents were stricken by the blame that came from their relatives. Their parents and parents-in-law and other close family members blamed parents for causing the burn. Mothers were blamed more when the burn event happened at home. Mothers described their heartache when their parents blamed them for not considering the child as a priority:

> Then aunt [mother-in-law] phoned to everyone... Everyone came. My mom, my dad, my younger brother. Mm. (with a teary voice) yes all of them came and all of them were yelling at me, "Don't you know how to look after the child? Why do you have a child? Is the child important or cooking is important?" (Mother Family (F) 7)

Family members held the parents, especially the mothers, responsible and accused them of being irresponsible and the cause of the burn:

> My sister-in-law and all had come to the hospital. "You have destroyed the child... You have allowed the child to go near the pump stove. That's why like this." Like that every one scolded me. (Mother F12)

Although the burn event was an accident in all families, the blame forced mothers to defend themselves:

> I was crying, like a mad woman I was crying, "I did not do anything, I thought there was cold water only in that [bucket]" like that, but

> everyone was scolding as they liked, you have done like this.... after doing what she did see how she is crying like that and all they [parents-in-law and sister-in-law] talked. (Mother F8)

Accounts from other family members also brought forth the blame they directed toward the mother.

> Just like that she held that pot without a cloth you see, she dropped the pot. Child was holding her sari and standing there you see, the water spilled on him... but she [mother] was near him but nothing on her hand, not even a bit splashed on her. The whole thing spilled on the child. (Paternal Grandmother F7)

Blame between spouses also was common. Husbands blamed their wives for the injury and wives blamed their husbands for the injury or for not being there to prevent it. A mother of a daughter who was burned with boiling water from a pot in the cooking area on the floor passionately described the mutual blame:

> Even now [after four years of injury event] I fight with him [husband]. Because of you only it happened like this, you left the toy there. Trying to grab that only she was burned. I say like this and he will blame me for not looking after her carefully. (Mother F9)

Although most of the accounts of fault finding from family members were in the injury phase of the burn, in some families it persisted. During the time the child was hospitalized and in the subsequent post hospitalization wound phase parents also faced blame from HPs.

Blame from health care professionals. Although blame from family members was exceedingly difficult for parents, blame from HPs was more devastating as parents had expectations that the professionals would be caring. Rather, they encountered HPs who were insensitive to their feelings and emotions. Parents were blamed for the burn event itself, for not seeking treatment on time and at the right place, or for not adhering to treatment protocols at home and not coming for regular follow-up. The blame from HPs was more likely to be directed at both parents than one parent. Questions such as, “How did you pour water on your child?” openly accused the parents who brought their child with a scald. The repeated accusation of “You have done this to the child” (Mother F4) was heard by most of the parents when they took their children to the hospital. Other questions such as “Don’t you know to look after well? Don’t you have the knowledge (skill) to look after?” (Mother F7) raised doubt about the mothers’ and fathers’ parenting abilities. Some parents recounted feeling that the HPs were suggesting that the child might have been burned intentionally. “The nurses will blame as if we have done this on purpose... you have done like this for a child who was well… like that.” (Father F7)

Although all parents in this study sought professional help as soon as the burn injury happened, they were sometimes blamed for not taking their child to the appropriate specialized facility soon enough. When parents in Family Six took their burn-injured son, who was treated initially by a local practitioner, to the specialized city hospital they experienced ridicule from the physician.

> Finally we went to the local Government hospital. There what the doctor said, “What? Are you mad? You are educated. What have you studied? You [father] have completed a technical course and she [mother] has studied 10th. Don’t you know this? Medicine has just been applied and inside it is all infected. If you go first [immediately] to [tertiary hospital in town] only you will be able to see this child alive. Otherwise you will not be able to see [he may not survive]” like that he said. (Mother F6)

In spite of the blame that at times raised suspicion regarding parenting ability, parents did their best to safeguard their child’s life. In some families financial and travel related issues prevented them from keeping every follow-up appointment. As parents struggled with their child’s wound infection and associated issues such as a stinking wound there was further blame about parental caregiving ability. One father, who had worked as a health professional and whose daughter was burned by bath water, shared his insight about the response of the HPs:

> Health professionals did not understand. Mistakes and accidents can happen in anyone’s life irrespective of whom and what they are. Such mistakes should not be used against them [as a weapon of mockery]. Instead of accepting it as an accident and saying comforting words, “Why did you do like this? After having a child you should also know to look after” like that saying and also showing in their behaviour were things I did not like. (Father F8)

Parents did not receive the comfort and support they expected from HPs. This blame from an unexpected source was added to the blame that parents experienced from family members.

Blame from others. Further accumulation of blame was experienced when neighbours and strangers placed the responsibility for the burn on the parents. Although many were curious to know what and how the burn happened, they added words that implicitly held the parents and sometimes the family responsible. The aunt of the child who was burned in a house fire exclaimed:

> No one walked by simply. Even those who were walking on the road, looked at the child and asked, “How did this happen to this child? How did you leave him? Where were you gone? Why did you not come away running?” Like these and all they asked. Only the crows and birds did not ask. (Aunt F2)

Blame from the burn-injured child. Apart from the blame from adults in the family, the HPs, and others, another source of blame that eight families experienced or anticipated was blame from the burned child. The mother in Family Two expressed how her seven year old son often referred to the burn incident in which his sister was not injured as “You saved your girl but you left me no? Why did you not save me?” (Mother F2)

In three families where school age boys were burned while playing outside, blame was attributed to fate. “No one said [blamed] anything. They [sons] cannot be watched all the time. The time was like that for him and it happened.” (Mother F10)

In spite of the blame that parents experienced they continued to look after their child. Within the context of devalued parenting, parenting of children who have sustained burns was characterized by a process of Enduring the Blame.

Enduring the Blame: The Psychological Process

The pervasiveness of the blame directed at parents was matched by the parents’ concerted and persistent efforts to parent and provide care despite the difficult circumstances of their child’s injury and the responses of others. Fundamental to their ability to continue parenting was a process of Enduring the Blame. For parents enduring meant bearing the blame yet persisting in their roles as parents. The process of enduring the blame involved four stages; internalizing blame, accommodating blame, adjusting to blame, and anticipating and avoiding future blame.

Internalizing blame. Internalizing blame involved parents adopting others’ beliefs and attitudes about them either consciously or unconsciously. Internalizing blame also involved being silent about the blame they were experiencing. They continually thought about the blame they encountered but did not provide accounts of talking openly with others about it. Rather parents recounted repeatedly and in much detail the specific experiences of being blamed.

Family members, health professionals and others “scolded” and “yelled” at parents for not being responsible. Parents’ own family members said, “they are not to fit to parent.” Parents responded by feeling humiliated and guilty for not being good /competent parents. Despite parents’ clear descriptions of the burn injury as being accidental, not intentional, parents internalized the blame. As their parenting ability was questioned and devalued they began to question themselves and assume some responsibility for the burn injury. They wondered aloud how they could have “let this happen to my child” and said “it was my mistake” and “I did not take care of the child well.” Parents described feeling alone and depressed as their self blame was added to the myriad of blame from others. Parents expressed how they were “hurt” and how “difficult” it was for them and said, “there were no days that we did not cry” especially during the injury and wound phases. Parents suffered mental trauma as they witnessed their child suffering the physical trauma of the burn and burn treatment. One mother aptly expressed her emotional status, “Child’s suffering was one side ... getting scolding from everyone was another suffering.” Parents felt unwanted, stigmatized and fearful that they had become outcasts as they did not meet societal standards of parenting. Parents wondered “what sin I did” for a “punishment” like this. Their hearts were “not at peace” and many parents said they did not express their feelings of anguish to anyone.

When the child was in the acute injury phase many parents had thoughts of their own death in addition to their child’s potential death. One mother experienced “uncontrolled emotions” and most of them asked themselves, “Will I do anything intentionally to my own child? Why does no one understand me?” In another family the mother was upset about her husband’s blame and said she wondered “whether to live or die.” Parents also wondered whether they could survive if something further happened to their child; if their child died. Most of the mothers said something similar to this mother's statement, "I would have died if something had happened to the child." One mother bargained with God, "If you want, take my life but give my child's life back." Another mother became hysterical after her daughter's burn incident with the bath water and the blame that followed. She had to be admitted to a mental health facility for two days.

Despite the intense emotions that parents experienced and in some cases exhibited, few parents said that HPs consoled them or offered encouraging words when they cried. Even when asked directly about their interactions with HPs some parents could not recall being consoled by them. Similarly, parents did not describe emotional support from extended family except for some maternal grandmothers. The main strategy that parents used to get through this stage was to pray. Even if they could not overtly express their agony to others, they "prayed a lot" to their own gods.

Accommodating blame. Parents moved from their anguished state of internalizing blame to a less intense emotional state as they accommodated the blame. Accommodating blame involved fitting the blame into their everyday life for the benefit of the child. During the injury phase they accommodated to blame because they wanted to avoid conflicts with their family members and the HPs during this crucial period. The unequal power relationships within the family or within the health care system disadvantaged parents and prevented them from expressing their suffering and re-establishing their position as competent parents.

They felt unable to express their emotional anguish as the family members, HPs and others had witnessed the tremendous pain that the child had suffered.

Parents recognized that any expression of their perspectives or their suffering at this time may not be viewed favourably by others and might target them for further blame. One mother expressed, “They yelled and I will cry. The nurse will scold. Why are you crying? After doing this why are you crying? Like that.” So they “did not talk” and kept “silent.” One mother asked, “What can I achieve by talking?” They did not want to jeopardize the care that was being delivered to their children. They wanted their child to survive, “become well.” If their child “became well” it was “OK” for them. They “let whoever wanted to say whatever they wanted” but they wanted their “child to live;” they endured the blame by accommodating to the blame from HPs. This painful, humbling and at times humiliating process was worth it for the parents when they realized that “they [HPs] looked after the child well.” The care given to their child overcame or trumped the blame that they suffered. Their child’s clinical care became the priority during the stage of accommodating. In the hospital, considerations in paying hospital charges or free treatment in certain facilities such as a government/public hospital also may have influenced the accommodation of blame as families were happy when dressings were done free of cost or they did not have to pay for hospitalization or when blood for transfusion was arranged by hospital staff.

At home, pre-existing family issues further ignited the blame issue. Parents, especially mothers, accommodated blame by attributing the burn incident to their incompetency with the household work or their immaturity. One mother whose son was burned when she was cooking expressed;

> I had not cooked in my mother's house, I did not know cooking. So cooking was difficult and cooking had to be done fast for my aunt [mother-in-law]... "Do it fast, do it fast" like that she will say but I will cook slowly and that only became bad for me. If I had been able to cook faster this would not have happened to [my son]."

The differential power dynamics within in-law relationships prevented parents from ventilating their feelings but rather to accommodate blame. When people other than family members or HPs blamed the parents and advised them to be careful in taking care of the child, they did not know "what to say" and just answered "yes."

Internalizing and accommodating blame happened when the blame was in the forefront and caregiving activities were performed mostly by the HPs. When children were ready to leave the hospital, parents realized that they had to take up the responsibilities of the HPs at home. They could not let blame be at the fore as it could hinder activities that were vital to the care of their children at home. They had to adjust to blame in order to move forward.

Adjusting to blame. Adjusting to blame involved achieving a mental and behavioural balance between the blame that they had experienced and continued to experience and their need to demonstrate that they were competent parents. The fear that blame would have overwhelmed them if the child had died was resolved and parents' relief set a context for adjusting to blame. As their child survived and left the hospital, parents took charge of the caregiving activities at home and continued to encounter blame. Paternal grandparents especially made the burn event a part of everyday conversation and “said things with hidden meanings” which indirectly raised doubt about the mothers’ and fathers’ parenting abilities. There also was blame from HPs related to the parents’ caregiving abilities.

In the wound phase parents adjusted to blame by considering the burn-injured child as “our priority” and trying to do everything for their child. They did not give importance to “whatever someone said” as their child was “important” and as parents they knew what needed to be done. One mother said “I will do everything for the child. I will not allow anyone else to do anything.” It was as if they were conveying the message that they were competent and could do whatever was expected of them as far as their child was concerned.

Adjusting to blame was facilitated by parents learning to regulate the blame by devising their own ways of performing what in the hospital had been HPs’ roles. Within economic, work and transportation related constraints, parents modified their caregiving activities. Although some families were “disappointed” or “much upset” about the lack of support from family members, in most of the families the burn related care was shared by the parents. As spouses they formed a strong team and took care of the child. As this father expressed, “truly my wife and I looked after the child day and night.” Even amid strained spousal relationships in a few families, parents were cohesive as far as the child’s burn care was concerned. In other families, mothers and fathers found instrumental as well as psychological support from each other, which assisted them in adjusting to the blame. They shared their experiences of blame with each other and facing the blame together helped diffuse the blame. One mother said, “My husband only helped me, in all ways... mentally... everything. My husband only was my support.” Mothers were blamed more than fathers and mothers articulated more about their emotional trauma related to the burn compared to fathers. Many fathers, however, willingly faced the blame with the mothers, which helped both parents adjust. One father explained how he supported his wife when his parents blamed her. “Don’t say anything. Don’t press her. First it was my mistake also. I should not have kept hot water there. It was not only her mistake. It was mine too.”

For families in which there was mutual blaming within the spousal relationship, the process of adjusting to blame was difficult as there was unresolved tension between the husband and wife. This caused parents, particularly mothers, to harbour resentment. As the wound started healing and the need for follow-up and treatments lessened for all parents, they were relieved. As the child’s pre-burn activities resumed, the blame parents endured started to dissipate. This relief, however, was short lived.

Anticipating and avoiding future blame. The scar phase of the burn trajectory brought forth new challenges for the parents. As scars started appearing, parents realized that the scars would remain as life-long reminders of the burn incident. There was anticipation and worry that the burn event would be revisited by all those who saw the scar. The blame that had dissipated would be rekindled. The worry was that “if someone saw [the scar] they will ask, ‘What happened?’” Such questions would initiate a cycle of blame.

The parents’ accounts of this stage of blame highlighted the societal stigma related to altered appearance of the child because of burn injury scarring, contractures and disfigurement. Parents were doubly motivated to protect or shield their child’s scars from the eyes of others. They were concerned for the child but they also tried to hide the scars and contractures to protect themselves from the blame and the stigma or social disapproval of their parenting abilities. One mother whose child was scalded while she was cooking said, “If I go to my mother’s place, I won’t remove his outfit. First I will change only the lower part of his outfit. In my mother’s house I have not shown his scars to anyone.” When she was asked why she did not want to show the scars she replied, “Everyone will ask. What answer will I give?”

While the parents recognized their child’s inability to understand the enormity of stigma-related issues at this time, they anticipated and constantly worried about whether their child would eventually blame them for what happened or the treatment given/not given for the scars and contractures. They feared that the child might ask, “How this happened and why this happened” and, “Why did you do this?” and that they would not have answers. In one family where the child had lost her fingers because of a flame burn from an oil lamp, the grandmother worried that the child might wonder, “Why this happened and why her hands are not like others.” In another family, the mother felt sad that her seven year old child already blamed her and said, “You only left me in the fire" when their house was burned. This family's account indicated the possibility of this parental worry becoming a reality thus placing them again in a vulnerable position as parents. They wanted to avoid blame from their child and had a strong desire to fulfill their societal responsibilities to be competent parents. As one father said, "In the future when he grows up, he [son] should not think that his father and mother have not done what they should have done [for the scar]. I should not give place for that."

Anticipation of blame also occurred during the injury phase. At the time of admission to hospital in one family in which the mother accidently placed the child in hot bath water, the parents were scared to give the true account of the burn incident fearing blame from the HPs. To avoid blame they provided an alternative explanation for the burn event by stating, "Child pulled the bucket over herself." During the wound phase parents did what the HPs instructed; for example, in one family, parents agreed to a second admission of their child in the hospital, as "it may be wrong to do otherwise when doctor is telling" and they may be blamed later.

Ironically, in spite of all the blame and stigma directed to parents in this study, no one took over the parenting responsibilities. Parents continued to parent in response to their child's profound need for them through the trajectory of their burn injury.

Discussion

Family members, HPs, strangers and their own children blamed parents for the burn injury. In response, parents in this study used a process of Enduring the

Blame that involved internalizing, accommodating, adjusting, anticipating and avoiding blame. Enduring the Blame was a non-linear cyclical process with parents anticipating and encountering blame at all stages of the burn-injury trajectory. As parents endured blame they engaged in activities to protect themselves from further blame. Many findings of this research in India are congruent with research in other countries.

Parents', especially mothers', actions and behaviours are monitored by others as they are considered to be responsible for the well being of their children (Jackson & Mannix, 2004). Parental activities of feeding, clothing, communicating, disciplining, educating, and protecting a child are based on the moral responsibility of rearing a socially acceptable/accepted human being. When a child is burn-injured there is an alteration in the physical status of the child, the potential of both physical and emotional scars, and the possibility of stigma or disability later in life. People in the social environment believe that the disruption of the child's normalcy in life is a result of a breach in the parents' moral responsibility. Attributing blame to the parents is a logical consequence.

The intense pain and suffering that the child experienced were visible to everyone. The comments "See how this child is suffering." and "This child is struggling so much with pain. It is so difficult to see" were common from HPs and family members. In everyone's eyes, even in their own child's eyes, parents were incompetent and had failed in their responsibility of protecting their children. Parents felt like outcasts with everyone viewing them like an "unwanted thing." Mother blame is a global phenomenon and is widely reported in the literature. In an Australian study on mother blaming (2004), mothers encountered blame from family members, HPs and others when their children misbehaved or did things that were considered outside the norm and when they sought professional help to care for their children.

Experiences of blame are reported also by parents of children and adolescents with mental health issues (Moses, 2010), attention deficit hyperactive disorder (ADHD) (Peters & Jackson, 2008; Wilcox, Washburn & Patel, 2007), intellectual disabilities (Edwardraj, Mumtaj, Prasad, Kuruvilla & Jacob, 2010), and physical disabilities (Holroyd, 2003). Mother blame predominated. In the few studies where fathers participated, fathers either experienced self blame (Moses, 2010; Wilcox, Washburn & Patel, 2007) or blamed their spouses for ADHD (Wilcox et al., 2007) in their child. In contrast in the present study, although mothers faced more blame than fathers, in most families both parents faced blame from HPs. When mothers were subjected to blame, some fathers willingly shared the blame. Sharing the blame or supporting mothers when they faced blame enabled parents to adjust to blame and focus on caring for their child. Spousal blame, as reported in Wilcox et al.'s study, emerged in a few families in this study and was predominant in one family. Such blame hindered these parents' adjustment to blame and made the activities of burn caregiving a burden mainly for the mother.

Feelings of guilt, self blame and doubt about parenting skills are consistent with existing evidence on parenting children with burns (Bakker et al., 2010; Horridge, Cohen & Gaskel, 2010; Rizzone et al, 1994). Guilt or self blame is widely reported also in studies on parenting children with disabilities (Holroyd, 2003; Pal, 1998), mental health and intellectual ability issues (Edwardraj et al., 2010; Moses, 2000), autism spectrum disorder (Mak & Kwok, 2010) and ADHD (Peters & Jackson, 2008). Unlike the findings from this study, guilt and self blame in these studies are not reported as dependent on blame from others. The accident associated with burn injury may explain the difference. Similar to this study's finding, Jackson and Mannix (2004), in their study on mother-blaming about child rearing practices, associate blame from others with internalization. The loss of confidence in their parenting ability that was manifested in the stage of internalization in this study was similar to findings in previous studies (Horridge et al, 2010; Kent et al., 2000; Rizzone et al., 1994).

Despite the emotional trauma parents experienced related to imposed blame and stigma, parents in this study did not give up on their parenting. They did not succumb to their guilt or the emotional suffering, although at times they had thoughts of death that were parallel to findings reported by Edwardraj et al. (2010). A recent study of 48 mothers' post-traumatic stress symptoms (PTSS) measured using the impact of event scale has shown that mothers who felt guilty had significantly higher PTSS even 10 years after their child's burn (Bakker et al., 2010). While parents in my study were not assessed for PTSS, some mothers had sleep disturbances and emotional upsets related to the burn event as much as three to five years later. One mother in this study needed psychiatric intervention. Most parents, however, were able to accommodate and adjust to blame by making their child the priority.

The lack of support from HPs was devastating for parents. HPs were not only insensitive to parents' emotional needs but were instrumental in perpetuating blame. A parent being traumatized because of their child's burn is well established. The emotional trauma related to blame from others, especially HPs, is not reported in the burn literature. A possible explanation of the blame directed to parents is that other family members, HPs and strangers also suffered when they observed the extent of the child's burn injury. Their instinctive response was to blame those closest to the child - the parents. Although everyone expressed concern for the child's suffering, no one acknowledged the effects of the child's burn and people's blame on the parents.

Parents in this study were able to accommodate and adjust to blame because of two factors. First, all parents clearly stated that they would do anything for the survival of the child. Parents who encountered blame made a conscious choice to keep blame at bay by moving it to the background so that they could remain focused on the needs of the child and not on their own needs as parents. Second, in most families, parents worked together to care for their child and field blame when it occurred. Although Horridge et al. (2010) in her study on parents' perception of their burn-injured child's school reintegration suggested that parents made personal sacrifices for the benefit of their burned child's wellbeing, the present study explicitly indicated the utmost importance the parents gave to their burn-injured child and this priorizing was not articulated as a sacrifice by the parents. This is contrary to findings in an Indian study in which, according to HPs’ perceptions, mothers wished that their children with intellectual disabilities were dead (Edwardraj et al., 2010).

Another unique finding in this study was that fathers were subjected to blame. Sometimes they took onus for the burn event, faced blame and/or supported the mothers during the process of enduring the blame. The assumptions that fathers play a passive role in caring for their children and so are less subjected to blame (Jackson & Mannix, 2004) and that fathers remain unconcerned about their children, especially in an Indian cultural setting (Edwardraj et al., 2010), are refuted and should be questioned.

Anticipating and avoiding blame was a defense mechanism that parents used to survive the blame and protect themselves from further emotional harm. Parents hesitated to disclose the true nature of the burn incident because of the fear of blame and stigma, which is similar to parents of children with ADHD who hesitated to disclose the diagnosis to other people (Peter & Jackson, 2008). All parents anticipated blame from their burn-injured children in the future. While worry about what their children would ask them was a source of ongoing stress for parents, this concern is not reported in previous burn literature.

Implications for Practice and Research

Parent blame, especially mother blame, does not appear to be culture bound. Therefore some of the findings of this study may be generalizable to other parent populations of children with chronic illness or disability. Parent blame increases self blame and guilt, and guilt increases as well as prolongs post traumatic stress (Bakker et al, 2010), which could decrease the parents’ confidence to parent and expose the child to further risk. HPs need to be sensitive to the emotional trauma that parents experience and refrain from blaming attitudes that cause further suffering for parents. Parents need support as their child receives treatment and HPs are professionally and ethically committed to provide this support.

Fathers' support was critical for mothers and it was easier for the parents to adjust to blame when they were a cohesive couple. Encouraging fathers to participate actively in care and fostering a family-centered approach to the nursing of burn children will likely help parents move beyond blame. Parents need ongoing psychological support as they can experience and anticipate guilt and self blame for many years. Consequently, long-term assessment and support for parents of burn-injured children are needed.

Further research is needed to explore HPs' and burn-injured children's perspectives of burn and blame in order to gain a more holistic understanding of parenting children with burn injury. The extent of post traumatic stress is unclear in the population in this study and deserves further investigation. The concept of parental blame warrants further study in different contexts. Following these families for a longer period of time may further elucidate the longer term sequelae and adjustments of Enduring the Blame.

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Paper 4: Qualitative Data Generation: A Narrative from India

Introduction

Qualitative data generation through interviewing is a challenging process. Intense efforts are required to establish and maintain research relationships within which the participants feel safe and comfortable to share their stories (Duncan, Drew, Hodgson, & Sawyer, 2009). This is essential for rigorously and ethically generating rich data related to the phenomenon of interest from participants' perspectives. Although there is an established body of literature addressing the ethical and practical challenges of data generation through qualitative interviewing, most of this literature is based in the western context (Adams, 2010; Clancy, 2011; Duncan et al., 2009; Hegney & Chan, 2010; Houghton, Casey, Shaw & Murphy, 2010; Mitchell & Irvine, 2008).

Qualitative research methods are emerging within the health care sector in India. As a senior nurse clinician and faculty member from India pursuing doctoral education in a western university context, I specialized in qualitative research methodology with an intention to share the knowledge and expertise that I gained when I returned to my Indian research community. Additionally, my clinical phenomenon of interest, parenting children with extensive burns fit with a qualitative design and individual qualitative interviews. As I embarked on my dissertation research in India, I anticipated applying the procedures of recruitment and qualitative data generation following sound ethical principles that I had studied extensively in the western university. I assumed that my deeply situated "insider" position as an individual of the same culture and ethnicity as that of my research participants as well as the “inside” knowledge and experience that I had as a burn nurse would moderate the complexities of qualitative data generation through interviews. It was in conducting interviews with study participants that I realized the naivety of such thoughts.

Much has been discussed in the literature about a researcher’s positionality as insider/outsider (Banks, 1998; Clingerman, 2007; Kanuha, 2000; Kusow, 2003; Ochieng, 2010) and about challenges faced in cross cultural research (e.g., Mill & Ogilvie, 2002; Riessman, 2005). Most of these discussions, however, were based on research conducted either by western researchers in non western contexts (Mill & Ogilvie, 2002; Riessman, 2005) or by researchers who, as immigrants themselves, conducted research with immigrants in a western context (Kanuha, 2000; Kusow, 2003; Ochieng, 2010). How the insider-outsider perspectives are viewed and acted out within a native context with a native population by a native researcher engaged in qualitative data generation and the challenges faced by native qualitative researchers in non western countries is rarely discussed.

In this paper I present a brief introduction of my qualitative research project and my reflections on the tensions and challenges that had to be recognized, articulated and resolved as a novice qualitative researcher who took the insider position for granted during the data generation process. My reflections take a narrative form under two main headings: 1) Establishing a trusting and respectful relationship, and, 2) Generating rich data. The ethical aspects of qualitative data generation are woven into both of these sections.

Insights into data generation in settings like India related to reflexivity are also discussed. First though, I review some essential background to qualitative data generation.

Qualitative Data Generation

The drive in qualitative data generation is collecting rich data. Quality, suitability and sufficiency are criteria that are applied to rich data that are generated through the accounts shared by research participants about a phenomenon (Charmaz, 2006). Another criterion that can be applied to richness in qualitative data is the understanding of a phenomenon within its natural context (Speziale & Carpenter, 2007), which helps us to interpret participants' actions and meanings in relation to their context. Such interpretive research requires entering the participants' worlds and observing what happens or hearing their stories in their natural settings (Charmaz). Ensuring rich data therefore demands rigorous data generation methods within the participants' settings. When interviewing is used as a data collection method, the procedure involves crossing the insider-outsider boundary in a respectful manner (Duncan et al., 2009). The researcher builds a trusting relationship with the participant by setting up interview appointments at a time and place that are convenient for the participants and initiating interview conversations with adequate explanations about the research as well as the researcher (Adams, 2010). Keeping the interview conversations to the topic while ensuring clarity and depth and recording the conversation to preserve the data also characterize rigorous data generation methods (Rubin & Rubin, 2005).

Qualitative researchers not only need to generate rich data, but also need to ensure that the data are obtained in an ethically sound manner (Rubin & Rubin, 2005). Standards for qualitative research reflect the ethical principles of autonomy, beneficence and justice (Beauchamp & Childress, 1994). Measures are taken to protect participants from harm during the study as well as after the study when publications are released. Participants are respected for who they are and what they bring to the researcher–participant relationship (Orb, Eisenhauer & Wynaden, 2001; Houghton et al., 2010).The principle of autonomy is ensured by inviting participants to enter and continue in the study voluntarily after an informed consent. The ability to withdraw from the study without penalty and to choose whether information already shared can be used is always available (Houghton et al.). Further, the participants' ability to share the information privately is given priority to ensure confidentiality of the information that they provide (Duncan et al., 2009). In summary, qualitative research involves ethical engagement with participants and rigorous collection of data.

The Research Project

The purpose of the constructivist grounded theory study from which the reflections for this article were drawn was to discover the parenting processes within families in India with burn-injured children. Burn injury is a serious trauma that leads to devastating sequelae. In India and China, the incidence and hospital admissions for pediatric burns are high compared to other countries (Burd & Yuen, 2005). The prolonged burn rehabilitation in the post-hospitalization period and limited resources in the low and middle income countries force parents and family members to take up health professionals' roles. Some evidence is available on the effects of the child's burns on the parents, especially mothers from high income countries (Kent, King, & Cochrane, 2000; Phillips, Fussell, & Rumsey, 2007). Little is known about the experiences of families in India with burn-injured children. The impetus for my study came from the clinical question, how do families of burn-injured children in India manage post hospitalization burn care at home?

Twenty-five interviews with nine mothers, nine fathers, three grandmothers and one aunt from 12 families with burn-injured children were conducted over a period of one year from March 2010 to May 2011. I conducted the study in Vellore, a densely populated city in the state of Tamil Nadu, South India. Of 12 families, eight families lived with extended family members. In all eight families, paternal grandparents formed the extended family. There were three nuclear families. In one family, parents and children were staying at the maternal aunt's house as their house was destroyed in the fire that injured their child and other family members. Twenty-two interviews were conducted in and around the homes of the participants and three interviews were conducted in the clinic when parents brought the child for follow-up.

Establishing a Trusting and Respectful Relationship

The generation of rich qualitative interview data in the context of a trusting and respectful relationship begins with a well-devised and ethical plan for recruitment. As a nurse manager and senior clinical teacher on the pediatric burn ward of a private multi-specialty hospital I was welcomed as an "insider" to the pediatric surgery out-patient clinic despite my student role as a researcher. The first surprise for me at this early stage of my study was the lack of understanding among my colleagues about the ethically important practice of someone other than myself making the first contact with the families. The common understanding in this setting was that I could approach families, tell them about my study, and endeavour to enroll them. That the researcher should remain detached and unknown until the participant has given consent to meet the researcher to avoid any coercion (Hegney & Chan, 2010) was a guiding principle for me that contributed to ethical recruitment. I convinced the team of the necessity of having an intermediary make contact with families who were eligible for the study to obtain their consent for me, the researcher, to contact them. The out-patient clinic nurse, community health nurses, and the community health workers (who assist the community health nurses) working in the urban and the rural areas of Vellore facilitated this first stage of recruitment.

The community health workers found the procedure of getting the consent-to-contact form signed and returned to me before I could contact the families a waste of time and energy. “We will get the permission and let you know sister; these forms are not necessary” they said when I met them to explain my study and talk about recruitment. I endeavoured to explain to them what I had learned and believed about research ethics. I was not sure whether they understood but they obliged, “if it is so important for you and the study.” When a family member provided consent to be approached, I contacted the family by telephone, confirmed their interest in study participation, and set up interviews with family members. In most families at least one family member had a cellular phone. In a few families for whom there was no contact phone number, the community health worker helped arrange the interview time.

At my first interview I tried to remember all the steps in interviewing and the procedures that needed to be followed to generate “good” data. I assumed that I was well prepared for all possibilities and therefore was surprised by the numerous challenges I encountered.

Participant Knowledge about Research

An understanding of what research entails is crucial for participants to enter into the study fully informed (Houghton et al., 2009). In my earlier experiences with conducting research in India, measures were not taken to ensure that the research participants understood what research was, what the study was about, and what benefits and harms were associated with their research participation. My doctoral research training in a western university shifted my thinking in this regard and I learned the steps involved in ensuring informed consent. Family members’ participation in my study without knowing what the research entailed would have been unethical.

In contrast to the notion that Indians do not know about research (DeCosta et al., 2009), the participants I encountered understood the nature of health research. Many had heard about or had experience of a family member being part of a research study. I soon learned however, that their understanding of research included the participants being compensated for their participation. In one rural area there had been some clinical trials and free treatment and check-ups in the clinics were offered for the duration of the study. With this prior working knowledge of research, participants wondered whether similar concessions would be available for their burn-injured children if they participated in the study. I was unable to offer such reward.

To ensure informed consent, I explained the scope of my study as being one or two interviews with several family members, each on their own. I emphasized my student role and was clear that compensation such as further care for their child was not available through this study. All families seemed to understand my intentions as a student researcher and consented to participate. I wondered however, whether they had an unspoken agenda for participating in the interview related to their hope that I would influence their child's future care in some way. My concerns were somewhat allayed when many participants expressed that even if the study results might not be helpful for their own children, they were happy that the results would benefit other children in the future.

Entering the Field

The underlying philosophy of qualitative research is interpretation and construction of multiple realities of human experiences based on a researcher-participant bond and the ongoing interaction and dialogue within this relationship (Guba & Lincoln, 1994). Such a relationship was necessary to understand the processes by which families managed burn caregiving. Using mediators to introduce the researcher to participants helps in moving smoothly into the researcher-participant relationship, thus helping the researcher to become an insider (Suh, Kagan & Strumpf, 2009). Although Suh et al.'s suggestion for mediators related to research in a culture other than one's own, broader application of this advice was evident in my study.

Although I belonged to the same culture as the research participants and spoke the same language, the presence of a community health nurse or a community health worker was vital to developing relationships with some of the study families. The fact that I was from the same organization as that of the community health worker did not matter. The community health workers were known to the participants and already had a trusting relationship with the family. One community health worker gently explained their influence on the community: "They check with us before they say yes to anyone else for anything [such as research]." This trusting relationship facilitated my relationships with the participants.

In some families the participants encouraged the community health worker to be present during their interview with me and the community health workers did not object to this proposal. As much as I had learned to follow the lead of the research participant, I was reluctant to introduce the dynamic of having a community member present during the interview as there was the possibility that the community health workers may be compelled to add their own accounts to what the participants were sharing. Although the participants themselves did not worry about confidentiality, it was also difficult to let go of my ideals "related to individual in-depth interviews conducted privately" that I had elaborated in my research proposal. When I suggested that the community health worker be available nearby but not part of the interview, all involved were in agreement.

Accommodating Participants’ Schedules or Lack of Schedules

Another key principle about conducting interview research is that the researcher is to make every effort to accommodate the participant’s schedule and to confirm the pre-arranged time before travelling to the interview site (Adams, 2010). The Indian notion of time, however, is different from a western notion of time. Indians have a flexible and relaxed attitude towards time (Laungani, 2007). Setting up interview times was challenging as family members did not commit to a specific time. They were vague about the time that they would be available to talk. For example, when I asked which time would be most convenient, they said “in the morning” or “in the evening” or “any time.” Setting a specific meeting time and strictly adhering to that time is not a usual practice in India. When I arrived at the home for the interview, some parents had already left for work. After agreeing to an afternoon interview the parents in another family said that they needed to visit someone upon my arrival. In one family, even after agreeing to a particular time, the aunt and mother expressed their inability to participate in the interview that day because of other responsibilities. As I was returning to the bus stop, they called me back to do the interview. Plans changed instantaneously for some families and had to be accommodated.

Obtaining Informed Consent

Informed consent is a basic ethical principle that guides research with human subjects (Beauchamp & Childress, 1994). Individuals should enter the study with a complete understanding of what research means and the benefits and risks involved in the study (The Tri-Council Policy Statement, 2010). This means that research participants must be fully informed about procedures and risks involved in research and must give their consent to participate (Houghton et al., 2010). The consent to participate should be affirmed throughout the study period and the option to opt out of the study at any time should be reinforced with participants.

After defending the importance of attending to participants' rights during all stages of the research process to the institutional review boards and intending to abide with all the procedures related to ethics, it was frustrating to find that the research participants in my study attached little importance to the informed consent process. "What is all this fuss about paper, explanation, and signatures when we have already agreed to share our story?" their behaviour implied. When I explained their option not to talk or to stop participating at any time, one grandmother exclaimed, "Ha, when you have come all the way to our house to talk to us, how can we send you away?" In our research related dialogues, many researchers have expressed similar inattention to essentials of the entire consent procedure by participants in their studies in a western context. I have experienced the same with the few participants I have interviewed in a western country for another study. My indigenous mind, however, wondered whether all the participants in India understood every point in the consent, a question that did not arise for me with the western participants.

Many family members were ready to tell their stories even before the consent process was completed. They wanted to talk about their experiences and I wanted to do the consent. At the first two interviews I found myself entering into the research conversation before the consent procedure was completed. In subsequent interviews I stopped our conversation, explained the importance of consent, and proceeded with the interview only after we signed the consent form. I was insisting on something that was important to me but was not important to them. In many instances I felt like I was defying the purpose of consent, doing what I had to do and not what the participants wanted to do.

The universal requirement of a written consent prior to research participation evoked further issues in my research setting where literacy was not a given. Literacy plays a vital role in understanding the research procedure and giving a written consent. In a study on informed consent procedure in rural North India (DeCosta et al., 2004), researchers found that to facilitate participants' comprehension of the research process, the information had to be detailed in simple and understandable terms that were translated appropriately into the local language. In my research with 22 family members from 12 families, two mothers and two grandmothers were illiterate and the rest of the participants had at least some formal education. Although all literate participants could speak Tamil, only some were fluent in reading and writing in Tamil, the language of consent procedure documents. I could not translate the consent procedures into different languages or dialects as I did not know participants' particular language fluency until I met them for the interviews. Therefore I read and explained each point in the consent procedure before inviting confirmation of their consent through signing the form. Irrespective of their literacy levels, all participants were able to sign the consent.

Ensuring Voluntary Participation

Although informed consent is vital, the researcher needs to assure the consent is given voluntarily and can be withdrawn at any time during the research (Beauchamp & Childress, 1994). Participants can be unduly influenced to give consent because they are coerced by others such as researchers or family members or those in power in the community. Sometimes they give consent because they fear deprivation of some privilege or benefit. Implicit faith in medical personnel and belief that medical personnel will only do what is good for them coupled with an ignorance of what information to seek before participation may unduly influence subjects’ participation in research, especially in non-Western settings (DeCosta et al., 2009). Participants may feel morally obliged to participate if the researcher was involved in their life earlier or will be involved later, especially as a health care provider (Mill & Ogilvie, 2002). The purpose of the research and the role of the researcher need to be explained to avoid any false expectations by participants (Orb et al., 2001).

A key consideration was whether family members in my study had an unexpressed or hidden motivation for their research participation. As I reflected on the first few interviews, I wondered whether my self-identification as a ‘burn nurse’ and a ‘doctoral student’ had influenced their decisions to participate and the information they shared in the interview. Participants may perceive the research encounter as an opportunity for receiving expert advice or help especially when they know the researcher is a professional (Duncan et al., 2009). As a burn nurse, participants expected me to answer their questions related to caring for their child who had been burned. My identity as a doctoral student was consistently misunderstood and participants addressed me as if I was a medical doctor. They wondered whether I would be able to arrange any further treatment for their children in the tertiary hospital. When I stressed my researcher role, "yes of course," they understood, "but can you do anything after you are done with your research?" These types of questions persisted throughout the study. I noted all of their expressed needs in my field notes. I did not make definite promises to them but promised myself I would do something. This incongruence between my expectations as a researcher and their expectations as participants disturbed me. I wondered whether it was coercion and like Riessman (2005) I wondered whether the consent procedure in India was meaningful. In subsequent interviews, I started to downplay my identities as burn nurse and doctoral student referring to myself as a nurse who worked with children, was doing higher studies in nursing, and was conducting this research as a student. I was less concerned about issues of voluntary participation after that as I perceived a change in expectations in the participants' responses.

Maintaining Researcher/Participant Relationships

Researchers must be mindful of the ethical implications when managing the relationships that develop through research (Houghton et al., 2010). Once I introduced myself it was not difficult to establish a trusting relationship that was generative of rich data. At the same time I was aware of the power dynamics at play and took steps to establish less of a nurse-parent relationship than a researcher-participant relationship. Participants addressed me as sister or madam, terms of respect used for a nurse (sister) or those in authority (madam). I was given the best chair or the best place to sit whereas the participants sat on the floor most of the time. This is not unusual in India and most often as an Indian health care professional I take it for granted. However, my doctoral preparation in a western university had sensitized me to such power issues. I wondered whether my attitude or these privileges influenced the interview process. I was surprised, even appalled, at my authoritative nurse tone that I noted as I listened to the first interview. I made a conscious effort to tone my voice down. I also requested that I sit down on the floor with the participants during the interview. While some participants agreed to this, many other participants would not allow such a disrespectful act in their house.

Participants also felt a constant need to nourish and hydrate me. They asked, “Shall I make coffee or tea?”, “I will buy you a cool drink”, “Please have breakfast”. Such hospitality is common in India, but I was frustrated as these suggestions interrupted the interviews and the telling of their stories. However, I had to answer them or even accept their offers as it was important for the participants and their family members to show this respect. Sometimes it was also the time for tea for them and they could not drink the tea without me drinking along with them. When one mother offered to buy a drink after the interview, I explained to her that I avoided carbonated drinks. I knew it would be an extra expense for her family. “At least have some water” she said and I showed her my water bottle. “You must taste the water from our village. It is sweeter than your bottled water” she persisted. “Is it clean water?” my health professional’s mind wondered. I accepted the glass of water she gave and drank it, the least I could do for someone who shared her stories to a near stranger.

Generating Rich Data

Everything that participants share is vital data (Glaser, 1978) and meanings in participants’ accounts matter in qualitative research (Charmaz, 2004). Therefore uninterrupted conversations and clear audio recordings of interviews are crucial to capture all that the participants share (Easton, McComish & Greenberg, 2000). Private and individual interviews also enhance participants’ capacity to share their stories freely (Duncan et al., 2009). The environmental constraints as well as cultural beliefs and practices were challenges that I constantly faced during my qualitative interviews.

Selecting a Place for the Interview Conversations

A quiet location that is free from distraction is ideal for interviews as it allows the participants to freely share their stories and is instrumental in obtaining a high quality audio recording (Adams, 2010; Creswell, 1998). Finding a quiet location was nearly impossible for most of the interviews in my study. In the clinic setting where I conducted some interviews, there were no noise proof rooms available. I gained permission to conduct interviews in the office of the nurse in-charge for privacy but the background noise in the busy clinics made recording a difficult process. The strong background noise from the fan in the room also distorted an early interview recording. In subsequent interviews I requested that fans be switched off where they were available. However the heat became unbearable as the temperature rose to 40 to 42 degrees Celsius.

In home settings as well, finding a quiet area for interviewing was challenging. When I suggested that the participant take me to another room for the interview it seemed that many participants were reluctant to take me further into their house. The front room was the best room in the house and the desired location for the research interview, although not quiet. Other interview locations were equally challenging. One interview was conducted near a cattle shed and another one in the field [sugar cane] as this was where the participant could talk. One was conducted in a small shop that the family owned as the father and mother spent the whole day in the shop and that was the most convenient place for them. The noise of traffic or people's conversations was a constant background element of interviews. I took measures to optimize the digital recording by using an external microphone with the recorder and by reminding the participants to speak loudly so that their recorded words would be audible above the background noise.

Many of the distractions present in the interviews related to common living and working conditions in lower and middle income countries. The noise generated by children, who were present during most of the interviews, was considerable despite my efforts to encourage them to be quiet. Children were drawn to the digital recorder as it was thought to be a toy and so I was constantly attending to the recorder. Noisy intrusions from animals and birds, including cows and roosters, were common and on several occasions the place of interview was changed for our comfort and protection, which also contributed to clearer recording. Many families did not have chairs or tables in their homes. The digital recorder had to be held in my hand in these homes and also in settings like the floor of the cattle shed or the sugar cane field. This prevented me from taking notes while the participants talked. In some instances we improvised and buckets and cardboard boxes acted as tables. Transcribing data from such recordings was challenging as I did not anticipate these difficulties. I oscillated between the need to do interviews in a conducive environment, especially for the participant, and the need to have a clear recording.

Providing Privacy

Privacy, a requisite for confidentiality in relation to interviewing (Adams, 2010), was a foreign concept in India. This was not surprising for me and I was confident that I would be able to persuade family members to talk to me individually in a private setting and thus fulfill another ethical principle that also became more of an ideal than a reality. Intrusion, a threat to privacy between the participants from within the same family, poses an ethical dilemma when multiple family members are interviewed (Forbat & Henderson, 2003) and was the case in my study. Although I stressed my intent to conduct the interviews privately and separately and explained the ethical rationale, there were constant breeches of privacy by family members and others. I could not keep the children from entering the room where the interview was taking place. In many homes, the room where the interview was conducted was the area where everyone in the family spent most of their time and so it was difficult to send family members away. In spite of explaining to the participants the need for individual interviews, family members joined in as they liked, contributed to the interview, and in many families the planned individual interview became a family interview. All were eager to share stories related to the traumatic burn event. “Why do you need a private interview when it is all about the child?” their enthusiastic intrusions implied. Some mothers felt more comfortable talking along with other family members than on their own. Many grandparents expressed that they did not have much to share as the parents were the primary care-givers and said that they did not have a separate story to tell. They were willing, however, to add to what the parents had to say.

As most participants did not object to the presence and participation of others in “their” interview, I had to relinquish my intention to talk to them privately. Some of these additional interview participants provided individual consent but some said it was enough if the parents had given consent. The consent procedure had to be constantly renegotiated with the participants. In two families where there were ongoing family issues, the paternal grandparents did not join in the interview but were hovering nearby either at the beginning of the interview or for a few minutes during the interview. The parents did not invite them to be part of the interview. I sensed that the grandparents were suspicious of what was happening. I introduced myself and explained the intent of my visit to them, which helped to neutralize a charged environment. I also sensed a change in the way the participants were sharing their story at the time when these other family members were present. One mother lowered her voice and another father's answers were clipped when the paternal grandmother came near. I detected these nuances, asked general questions about parents' work or business, and waited for the grandparents to leave before asking more personal questions.

Quality of Interviews

Indians tend to initiate social conversations spontaneously. Indians, unlike westerners, ask for or share personal information such as age, marital status, number of children one has, one's occupation, and income without any inhibition (Laungani, 2007). This made it easier for me to establish rapport and discuss sensitive issues. In the initial interviews participants were sharing important information before I was ready to record the interview. Sometimes they shared something new after we completed the interviews. I also received stories of the burn and of the families from people other than family members like the community health workers. I was not sure when and what I should audio tape. I audio taped as much as I could, or judged that I should, and recorded additional data in my field notes.

Interruptions in the interviews were common. Although I had expected such interruptions, I did not anticipate the extent of their effects on the qualitative interviewing process and the data. My hopes of ensuring ideal set-ups crumbled. Neighbours and relatives dropped by in need of something. They were curious to know what was happening. A friend of a young father yelled for him to come out and wondered openly what the father was saying to someone for such a long time. A mother wanted a break to worship the deity that was being brought around the village in a chariot and a family disappeared for about ten minutes as they had to solve some issues related to an electricity bill. This caused disruptions in the stories and also gaps in the interviews. It was also difficult for the transcriber to understand who was saying what. I had to spend as much time in editing the Tamil transcripts as it took to transcribe them to ensure accuracy in accounts.

Being an insider culturally also brought forth issues related to understanding the meanings from participants' views. One important purpose of qualitative research is clarifying the taken for granted social, cultural, and health related assumptions (Charmaz, 2006). During the first two interviews I was unaware of how my experience as a burn nurse, as well my cultural inheritance that was similar to that of the participants, was influencing the importance I gave to probing for meanings. I did not pursue generalities or participant- initiated leads with follow-up probes. One participant said, "If my boy becomes steady, that is enough." The general assumption is that the parents are referring to becoming well. I did not probe on what "steady" meant for him because I thought I knew implicitly what he was referring to. Another participant talked about avoiding fish in the child's diet. I did not question this any further as I assumed that her concern was related to the belief about the association of fish to healing. These assumptions proved to be cultural blinders (Davies et al., 2009) that prevented me from probing for meanings. Having my non-Indian supervisors read the transcripts and answering to their questions for clarification raised my awareness of what I was taking for granted. Good interviewing entails reflective practice (Adams, 2010). As I read and re-read the initial transcripts, I recognized the need for going to the interview with an attitude of unknowing. I realized the importance of being aware of my professional biases, cultural assumptions, and my own beliefs during the interviews. I consciously and actively began to attend to the potential for cultural blindness and delve deeply into the responses from participants in order to obtain rich data.

Discussion

Qualitative data generation in India posed numerous challenges. There were constant tensions that had to be subjected to thoughtful reflections. Although most of what happened in the field was not uncommon in India, my perspective as a qualitative researcher made things more challenging. I was persistent in applying the principles and procedures I learned and thought as ideals but the research participants were unaware of what was expected of them. I could not modify the environment to suit my purpose in many situations. When I started data collection I was confident that I could change things as I had an advantage of being an insider because of the culture I shared with the participants. I realized the inappropriateness of this early in my data generation process. As far as my qualitative research was concerned, for the research participants and sometimes to my colleagues, I remained an outsider.

As an Indian from South India, I took my insider position for granted. I assumed it would be easy for me to apply the principles and procedures that I had learned about qualitative data generation in South India (my place and my people). It was when I initiated the procedures related to ethics and my field work that I recognized my naivety. For most of my participants I was an outsider in more than one way. I was a stranger; they did not know me and my educational and social class was different. I was also a professional and an academic. In addition to these differences, I was coming into the study with recently acquired western perspectives about ethical standards and rigour related to research process. This situated me as an outsider to my research colleagues and the academic research environment in India. I became an outsider to the Indian environment as well, as my preparation for generating rich qualitative data within a western academic setting had sensitized me to the need for ‘ideals’ related to the data generation environment. It was therefore a question of how my insider assumptions and outsider perspectives had to be constantly negotiated within the professional as well as researcher-participant relationship to generate data that was neither ethically nor qualitatively compromised.

Is qualitative research possible in India? I questioned repeatedly. The qualitative researcher part of me that had been inflated with all that I learned as a part of research preparation started to deflate. The dependability and trustworthiness of qualitative data depends on the richness of the data that are collected and must be aligned with the ethical imperatives of minimal harm to the participants (Easton, McComish, Greenberg, 2000). Then “Is the quality of my data compromised?” and “Am I inadvertently breaking ethical principles?” were questions I constantly asked myself.

Similar questions have been asked by western researchers engaged in research with non- western participants in a non-western context (Mill & Ogilvie, 2002; Riessman, 2005) and debated by indigenous researchers involved in field research (Banks 1998; Kanuha, 2000; Kusow, 2003; Ochieng, 2010). My experiences in the field may also not be distinct from what other qualitative researchers encounter during data generation. From my experiences I have learned that one should not assume that the perceived insider status to a cultural group (be it professionals or participants) facilitates generating ethically sound rich data. For the native researcher, the expectation of knowledge generation as a scholar implicitly compromises his or her insider status (Kanuha). Further I have understood that ethical dilemmas are part of any qualitative research done in any context.

I realized amid all the interruptions and related struggles that participants were able to share what they wanted to share. The environment in which they shared their stories provided a context for how they parented their children and assisted me in conceptualizing the process of parenting. I continued to reflect on the methods as my qualitative research unfolded and I adapted to their views of research participation. My interviewing methods improved as I continued to converse with my supervisors. I responded to the participants’ cues as to whom they wanted present and whom they did not want to be present during the interviews. Further, I came to appreciate their ability to decide and negotiate the interview setting and the interview process according to what was important and what was not important for them. Reflexivity enhances rigour and can supplement theoretical sensitivity in grounded theory studies (Hall & Callery, 2001). I believe that the reflexivity that I exercised during the data generation process helped me to address the rigour of my grounded theory study and improved my theoretical conceptualization.

Conclusions

Qualitative data generation is a process that moves beyond the researcher’s perception of his/her insider/outsider stance. Ethical standards for qualitative research should evolve from a view that a dialogical process that is common in qualitative data generation can bring about unanticipated ethical concerns. Researchers need to be open to confronting issues that may not have been encountered or reported in the literature (Speziale & Carpenter, 2007). To remain ethical in all situations, however, the researcher should renegotiate the informed consent as and when necessary. This involves a process-oriented consent in which consent is an ongoing event (Munhall, 1993). In my study, as participants allowed other family members to be part of the interview conversation, consent was redone. Others’ participation in the interview was clarified.

As much as researchers are worried about intrusion of others, we must realize that we are ourselves the primary intruders. When participants have consented and agreed to share their stories with the primary intruders, I believe that they have the capacity to decide who can be part of their interviews. Looking back on all of the interviews, I now understand how a few participants who wanted to avoid family members chose the time and place of their interviews. One participant needed to be reassured that what she said would not be shared with her husband. Participants can understand and control their research encounters (Mitchell & Irwine, 2008). As researchers we need to respect their decisions.

Participants' experiences involve how they live in their context. Environment and family as context bring life to the participants' stories and add to the understanding of their experiences. Behaviours and their meanings will not make sense and may even influence conceptualization if context is not part of data (Hinds, Chaves, & Cypess, 1992). Researchers need to accept and adapt to the cultural aspects of the interview environment instead of trying to change it. Advances in technology have brought about digital recorders that include powerful microphones and that can be set to control or minimize background noises. Keeping technology at one's side helps the researcher to get a clearer recording.

Finally, researchers need to be reflexive. Reflexivity or "self–reflection" is the "responsibility of the researchers to examine their influence in all aspects of qualitative inquiry" (Speziale & Carpenter, 2007, p. 36). A critical analysis and understanding of our influence on our data generation procedure will improve the research process. Reflexivity enhances researcher-participant interactions (Hall & Callery, 2001) and is a critical element of ethical research (Hewitt, 2007). Reflecting on all aspects of my interviews and noting my weaknesses and strengths helped me to enhance my relationships with the participants and improve my interviewing techniques. It assisted me in the understanding and negotiation of my outsider status throughout the data generation process. When these reflections were shared with my supervisors, their questions and suggestions further enriched and strengthened my qualitative data generation in the Indian context as enacted through my bicultural eastern/western lens.

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General Discussion and Conclusions

This dissertation document was organized as an introductory chapter, four publishable papers, and a concluding discussion chapter. The first paper was a review of the pediatric burn literature on pediatric burn outcomes. The second paper highlighted the process of embracing the survival that parents adopted in response to the burn trauma that their child sustained and suffered. The third paper explicated the process of enduring the blame as parents dealt with blame from family members, health care professionals, others, and their burn-injured child. The fourth paper focused on the methodological challenges faced by the researcher in India.

The purpose of this final chapter is to 1) describe how the research question evolved based on methodological and conceptual influences, 2) argue for a dual process of parenting instead of a single basic social process, 3) situate my study findings within the existing theoretical literature, 4) present findings that refute my initial assumptions, and, 5) identify implications for practice, policy and research including my progress and plans regarding dissemination of my findings.

Evolution of the Research Question

The purpose of my study was to explore and discover the processes of parenting and/or caregiving for families in India with children who had sustained burns, survived, and were in the post-hospitalization phase. My original research question in this grounded theory study was: What is the post-hospitalization parenting and/or caregiving processes for families in India with children who have sustained burns? As is the nature of grounded theory methodology my research question changed and evolved as data generation progressed. In a grounded theory study, the researcher may start with a question that focuses on the research problem but the researcher may have to refine the question as part of generation and analysis of data (Speziale & Carpenter, 2007). As my study progressed the research question evolved in two ways; the first development was methodological in nature and related to the phase of burn injury that was addressed in the research question. Rather than focusing only on the post-hospitalization phase, the research question evolved to include burn injury phase as well. Regarding the concepts of parenting and caregiving I came to decide that conceptually parenting was the appropriate term to use in my findings. Reflection on the methodological and conceptual factors influenced the evolution of my research question.

Methodological Reflection

In my interviews with parents and family members of children who had been burn-injured, I initiated the interview dialogue by asking the participants how they managed the care of their child at home after the child had been discharged from the hospital. Early in my data generation process, I realized the need to modify this first interview question that I asked the participants.

As my aim was to understand the parenting process during the post-hospitalization stage, I started with the question how it had been for them since the child had come home after hospitalization. I noticed however, that it was difficult for the parents to tell their story without referring to the burn event itself or what happened in the hospital. They had to reflect on the beginning to make sense of their story. The burn event set the sequence of actions and reactions that influenced the process of parenting/caregiving for their burn-injured children. Participants compared what happened at the time of the burn event to the period of hospitalization and to what happened and how they felt when they returned home with their child. They revisited decisions that they made at the time of the burn incident that influenced what happened later in their child's life. They ended the story with their concerns related to their burn-injured child's future. They needed to tell their story from beginning to end. When storied experiences such as a child's burn injury and recovery are shared, participants reflect on their experiences, select details of experiences that are in their consciousness, and recount the stories with a beginning, plot and end (Polkinghorne, 1995). When a researcher attempts to break this thread by only wanting to know about one part of the story, it becomes difficult for the participants to share a complete story. The researcher can end up with a broken story with a lot of gaps.

Grounded theory questions address experiences in which change is expected, and focus on understanding the change and the processes associated with it (Richards & Morse, 2007). Grounded theorists engage in identifying patterns of behaviour and consider how these behaviours and actions change over time. This is a crucial step in developing a grounded theory. I understood the importance of getting the story as a whole after I read the initial two interview transcripts. Therefore, beginning with the third interview my overview question changed from "Can you tell me how it was for you when your child came home after being in the hospital for burn?" to “Can you tell me how it was for you when your child was burn-injured?” I invited participants to start from the beginning and then probed more into the post hospitalization experiences. Such a change in approach and flexibility in questioning as the research evolves was possible in my study and is encouraged in grounded theory methodology (Charmaz, 2006). The data that consisted of comprehensive stories helped in identifying the burn injury trajectory in terms of parenting processes from the time of the burn injury until the present and therefore the research question was changed to reflect a shift away from an exclusive focus on the post-hospitalization period.

Conceptual Reflection

Conceptually delineating the distinctiveness between parenting and caregiving children with burn injury was one objective of the study. In the extensive body of literature regarding childhood chronic illness, parenting (e.g., Hassink et al., 1998; Johnson, 2000, Monsen, 1999; Ray, 2002; Rempel & Harrison, 2007; Scorgie & Sobsey, 2000; Seideman & Kleine, 1995; Young, Dixon-Woods, Findlay & Heney, 2002) and caregiving processes (e.g., Atkin & Ahmad, 2000; Gayer & Ganong, 2006; Mandell, Curtis, Gold & Hardie, 2005; Turner-Henson, Holaday, & Swan, 1992; Wennick & Hallstrom, 2006), skills (Maltby, Kristjanson, & Coleman, 2003; Schumacher, Beidler, Beeber, & Gambino, 2006), and associated stress (Dellve, Samuelsson, Tallborn, Fasth & Hallberg, 2006; Krulik et al., 1999; McDonald, Poertner, & Pierpont, 1999) have been studied, yet the terms parenting and caregiving are not defined.

The research evidence from these studies has made a valuable contribution to pediatric and family nursing practice in relation to aspects such as stress, coping and family management. It was however not clear to me whether these researchers' particular conceptualizations would have been different if the distinctions between parenting and caregiving had been considered in the research design and/or interpretation of findings. As the existing literature did not clearly delineate parenting and caregiving processes, I included both terms in my research question and aimed to determine the most appropriate term through my research. To provide a point of reference, I defined the terms parenting and caregiving at the outset of my study.

Parenting is broadly defined as an act of raising a child ("Parenting," 2009). Parenting involves providing warmth and love, managing a child's behaviour through the use of rules and regulations and expectations, providing supervision, communicating with them, and protecting them from harm by adequate monitoring (Huynh-Nhu et al., 2008). It also involves nurturing children and caring for them physically and psychologically. The term caregiving is broadly defined as an act of providing direct care ("Caregiving," 2009). It denotes providing unpaid care for children or people with illness or disability. Caregiving includes monitoring the illness process, interpreting observations, making decisions, taking action, making adjustments, accessing resources, providing hands-on care, working together with the ill person, and navigating the health care system (Schumacher et al., 2006). I decided to use Huynh-Nhu et al.'s description for defining parenting and Schumacher et al.'s explanation for defining caregiving as points of reference for delineating what the participants expressed in my study.

In my study, participants referred to caring for their burn-injured children as “taking care” or “looking after.” For the parents in my study, taking care or looking after involved activities such as providing food and a safe environment, being there for their children, considering their child as priority, ensuring burn care in spite of all the challenges, protecting them from physical and emotional harm such as infection and stigma, and forming a united front as parents. Some parents also described the behaviour and discipline issues they encountered when taking care of their burn-injured children. Looking after their burn-injured children further involved making decisions, mobilizing resources and providing hands-on care. All of these activities reflected parenting as well as caregiving.

The term caregiving, whether in the literature or in my definition, however, denoted disease or illness specific actions and meanings. In contrast, the term parenting reflected child specific activities and meanings. In my study the parents’ accounts brought forth the centrality of their child in their lives. For them “looking after” their burn-injured child involved a child centered approach to caring. Therefore I decided that parenting, not caregiving, was the more appropriate term and included parenting in the research question in the findings papers. As a result of this conceptualization, as well as the need to include the burn trajectory as a whole, not just the post-hospitalization phase, my research question evolved to “What is the process of parenting children in India who have sustained burns?”

Double Issue and a Dual Process of Parenting

The “Burn” and the “Blame” evolved as two core issues from the participants’ accounts with two corresponding substantive processes, “Embracing the Survival” and “Enduring Blame.” Explicating these two co-existing processes became vital to understanding the process of parenting children with burn injury. The methodological question that I repeatedly considered was: Can a single grounded theory study yield two core issues and two processes? Research literature to address this question was not easy to locate.

According to Glaser (1978), identifying the core category/variable from the coding activity, memos, and constant comparisons is the first step in moving towards theory development. The core category is the main theme that the researcher is looking for as he/she is analyzing the data. The core category is the theme that best fits the data, is central, and relates to as many other categories as possible, recurs frequently and relates meaningfully to other categories. While a core category is always present in grounded theory research, a basic social process (BSP) may not emerge (Glaser, 1978). While Glaser argues for a theory that resolves a main concern/issue related to the phenomenon (Glaser, 2001), Charmaz’s (2006) constructivist approach expands the idea to include the possibility of identifying diverse issues that are related to the substantive phenomenon or area under study. The core category is the core issue that parents are grappling with and the core process is the way by which parents tackle the core issue (Schreiber & MacDonald, 2010). The theory development process moves from identifying core issues and substantive processes to explaining what is happening and then moving towards identifying a generic process (Charmaz). A generic process is one that can be applied to various problems within various substantive areas.

The findings I have presented in Papers #2 and 3 highlight two core issues (Burn and Blame) that the parents grappled with and two substantive processes that they used to address these issues. Based on my constructivist stance, I have identified the core issues as double trauma and the two processes as a dual process as they occurred simultaneously. Parents experienced double trauma related to the burn and the blame. The process of embracing survival occurred in a social realm in response to the near fatal burn wound that the child sustained while the process of enduring blame occurred within a psychological domain in response to the blame that parents suffered. Embracing the survival encompassed suffering the trauma, sustaining the survival, and shielding from stigma. Enduring the blame encapsulated internalizing blame, accommodating blame, adjusting to blame, and anticipating and avoiding blame. The strategies that parents used during the processes were multiple and were discussed in the individual findings papers. Two strategies that were identified as important categories early on in the study, making the child the priority and parents as a cohesive duo, overlap and form the core of the dual process of parenting burn-injured children. A model depicting the dual process is given in Figure 1.

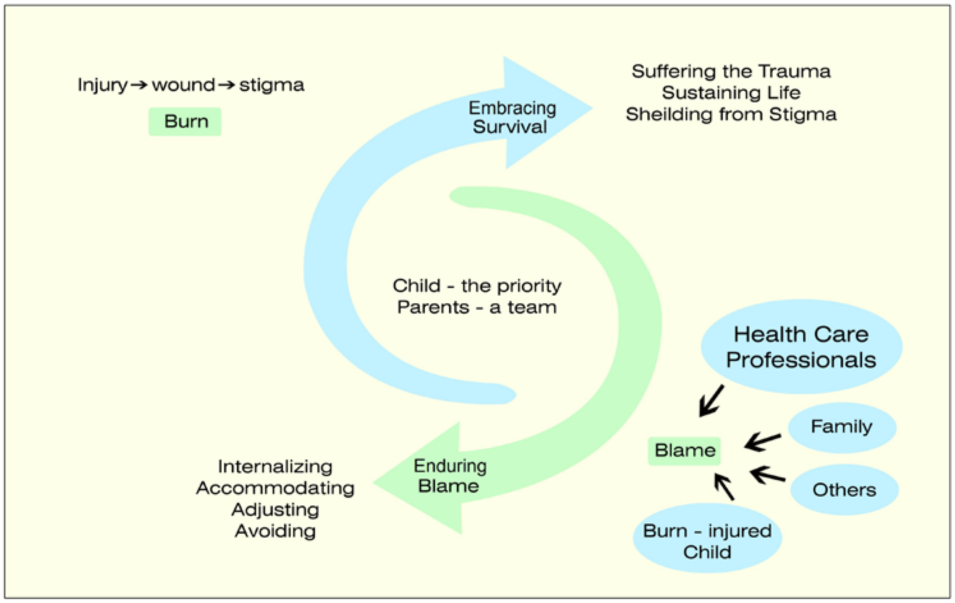

Figure 1. Dual Process of Parenting Burn-injured Children

These findings provide a foundation for a theory of parenting children with burns. Further research that explores health professionals' perceptions of caring for burn-injured children in the hospital or in the home and the perceptions of burn-injured children themselves about the challenges they encounter and their expectations regarding care will enhance further development of theory of parenting burn-injured children. The points of overlap in the current conceptual model may become concepts from which a theory may develop.

Situating Study Findings in Existing Literature

Situating my findings within the existing literature on parenting will move findings that have evolved from my study towards developing a theory of parenting. Theory development hinges on the vital concept of theoretical sensitivity that is stressed in grounded theory (Glaser, 1978). Theoretical sensitivity is “the ability of the researcher to recognize what is important in the data and give it meaning” (Morse & Field, 1995, p. 161). Theoretical sensitivity is developed by being immersed in the data through data collection and analysis and also being well grounded in the substantive literature. Below I demonstrate how the category “making the child the priority” fits the previously identified parenting process of “safeguarding precarious survival” that emerged in a study on parenting children with life-threatening congenital heart defects (CHD) (Rempel & Harrison, 2007). I contend that safeguarding can evolve as a generic process of parenting children with life-threatening or chronic illnesses or disability.

I enter into this discussion after much thought and reflection as Rempel is one of my supervisors and as her doctoral student I have worked on her projects on children with CHD. While I am aware of the influence that these two factors have on the following discussion, after thoughtful consideration of the literature on parenting/caregiving, I am also positive about the fit of the categories that evolved from my study to the categories that are depicted in the findings of Rempel and Harrison’s study on parenting children with CHD, specifically around the process of safeguarding (2007). The discussion, however, does not exclude or disregard vital findings from other parenting/caregiving studies. The aim of this discussion is to elaborate the findings from Rempel and Harrison’s study using the findings from my study, as I further strengthen the constructs of the potential theory of parenting from other parenting/caregiving studies.

Central to enduring the blame and embracing the survival was the fathers’ and mothers’ clear focus on giving their burn-injured child top priority in their lives. They endeavored to safeguard their child at all costs. This finding resonates with the finding from previous research on parenting a child with a lethal congenital heart malformation where, within a context of uncertainty, parents adopted a process of safeguarding the precarious survival of their child (Rempel & Harrison, 2007). Parents safeguarded the survival of the child, self, and couple relationships. The processes of embracing the survival and enduring the blame in my study were similar to the processes of safeguarding the child and safe guarding self in Rempel and Harrison’s study. Parents of children with CHD safeguarded the child from infection and complications by taking charge of the care of their children, involving others as necessary, and struggling for a balance between overdoing things or not doing enough for their children. Similarly, parents of burn-injured children safeguarded their children by suffering the trauma, sustaining the survival, and shielding the child from stigma.

Parents of children with life-threatening CHD and life-threatening burns both suffered in relation to the uncertainty of the child’s immediate survival. Although this struggle was not evident for parents of burn children once the child survived the acute injury stage, it continued for parents of children with CHD because of the nature of the heart condition. Dealing with uncertainty due to the unpredictable nature of illness/defect was also evident in other grounded theory studies on parenting children with mild to moderate physical disability associated with various congenital abnormalities (Johnson, 2000) or juvenile rheumatoid arthritis (Sallfors & Hallberg, 2003).

Taking charge that was depicted in safeguarding children with CHD resonates with the efforts that burn parents took to manage the burn wound to sustain the survival of the child. Similar strategies, such as mastering the caregiving tasks and becoming an expert, were used by other parents to stay in control of the caregiving tasks for their children with chronic illness or disability (Atkin & Ahmad, 2000; Judge, 1998; Sallfors & Hallberg, 2003). Heart parents' need to accept help from others to provide care parallels burn parents' strategy of mobilizing inner and external resources. Mobilizing physical and social resources is already established as a vital factor influencing family adaptation and resiliency in earlier studies on parenting children with chronic illness or disability (McCubbin, Balling, Possin, Frierdich, & Bryne, 2002; M. McCubbin, McCubbin et al., 1983; Ray, 2002). While heart parents were engaged in preventing infections and complications, burn parents were occupied with protecting their child from stigma and maximizing function. These findings are consistent with the findings from other parenting studies. Protecting their child from illness and treatment related complications was a great concern for parents of children with arthritis (Sallfors & Hallberg) and shielding their child from stigmatization was a worry for another group of parents with obese or overweight children (Haugstvedt, Graff-Iversen, Bechensteen & Hallberg, 2011).

The parents in my study struggled to balance the blame they experienced which devalued their parenting ability at the instance staying competent to take care of their burn-injured children. Struggling for balance was explicated in Rempel and Harrison’s (2007) study in the way parents struggled to balance between doing what was necessary and doing too much for their children. Similar issues of balancing related to considering the child’s need for activity/independence and their need for protecting their child was a constant dilemma for parents of children with arthritis and obesity (Haugstvedt et al., 2011; Sallfors & Hallberg, 2003).

Parents of heart children safeguarded themselves against worry and strain by buffering the severity of injury and by staying on the same page in taking care of their children. These strategies were replicated in the burn study in which parents formed a team as spouses and remained on the same page as far as the care of the child was concerned, which helped them to buffer burn severity, endure blame, and provide the necessary care for the child. Parents of burn-injured children mitigated the severity of injury by being happy with the child’s survival, which was different from the normalizing perceptions that parents of heart children adopted to avoid worries. Normalizing involved viewing their child as normal irrespective of the abnormalities and delays in their child’s development. Normalization has been explicated in other parenting studies as well (Johnson, 2000; Sallfors & Hallberg, 2003). Some studies also reveal that parents engaged in positive framing of their child’s illness and optimistically appraised their condition (Atkin & Ahmad, 2000; Judge, 1998; McCubbin, Balling et al., 2002; McCubbin, McCubbin et al., 1983; Woodgate, Ateah & Secco, 2008). Both burn and heart groups of parents buffered their worry by trusting God and trusting the health professionals who looked after their children. Burn parents’ accommodation to blame from health professionals was because of their belief that their children were being looked after well by health care professionals. Believing in God and seeking religious support were also identified in other studies as strategies that parents used for getting relief from worry and gaining emotional strength (Atkin & Ahmad; Judge; Sallfors & Hallberg).

The category “enduring blame” that was a major finding in this study did not emerge from the data in the study of parents of heart children (Rempel & Harrison, 2007). Blame, however, is reported by parents of children with mental health issues (Moses, 2010), attention deficit hyperactive disorder (ADHD) (Peters & Jackson, 2008; Wilcox, Washburn & Patel, 2007), intellectual disabilities (Edwardraj, Mumtaj, Prasad, Kuruvilla & Jacob, 2010) physical disabilities (Holroyd, 2003), and obesity (Haugstvedt et al., 2011). Enduring blame (either subtle or overt) could be a crucial aspect of parenting children with any illness or injury even for parents of heart children. It may not be articulated by all parents.

Contrary to the findings of extensive family involvement in the care of the child with CHD (Rempel & Harrison, 2007), in this study, parents of children who had been burned received minimal support from family members and managed the burn care amid their everyday responsibilities. For the parents of burn-injured children, the presence or absence of family support in burn-related care did not alter their decisions or abilities to parent their burn-injured children. Fathers and mothers acting as a cohesive team were found to have positive effects in both Rempel's (2007) as well as my study and influenced the care they gave their children with CHD or burn injury. Further, the team effort had a positive effect on parents' psychological well being. Parent mutuality has been identified as a strong predictor of family resilience (Walsh, 2003). In both the heart and burn studies, parents perceived minimal support from health care professionals, especially with care at home. Similar results on lack of support from health care professionals have been reported in other parenting studies (Hatton, Canam, Thorne, & Hughes, 1995; Jerrett, 1994; Wennick & Hallstrom, 2006). An added dimension for the parents of burn-injured children in my study was the blame they perceived from health care professionals during and after hospitalization.

The categories identified in the present study are similar to most of the concepts in the process of safeguarding identified in Rempel and Harrison's study (2007). As many concepts depicting the process of safeguarding have also been identified in various parenting studies, the process of safeguarding can be applicable for parenting children with any illness or disability. The concept of safeguarding therefore has the potential to evolve as a theory of parenting children with life-threatening and chronic illness and/or potential or actual disability. The processes and stages of embracing the survival and enduring the blame can be vital theoretical components of safeguarding. If Rempel and Harrison's (2007) concept of safeguarding can be theoretically elaborated, safeguarding children will involve 'suffering' as the parents experience uncertainty and struggle for balance, 'sustaining' as the parents take charge and mobilize resources and 'shielding' as they become involved in preventing infections and other complications and protecting their children from stigma. Parallel to safeguarding children, safeguarding self as parents will involve 'buffering worry' by normalizing/positive framing/ mitigating and trusting and 'enduring blame' that involves internalizing, accommodating, adjusting to and avoiding blame. Mutual support between parents which has evolved as an overlapping category between safeguarding child and self will mediate these two aspects of safeguarding (Figure 2).

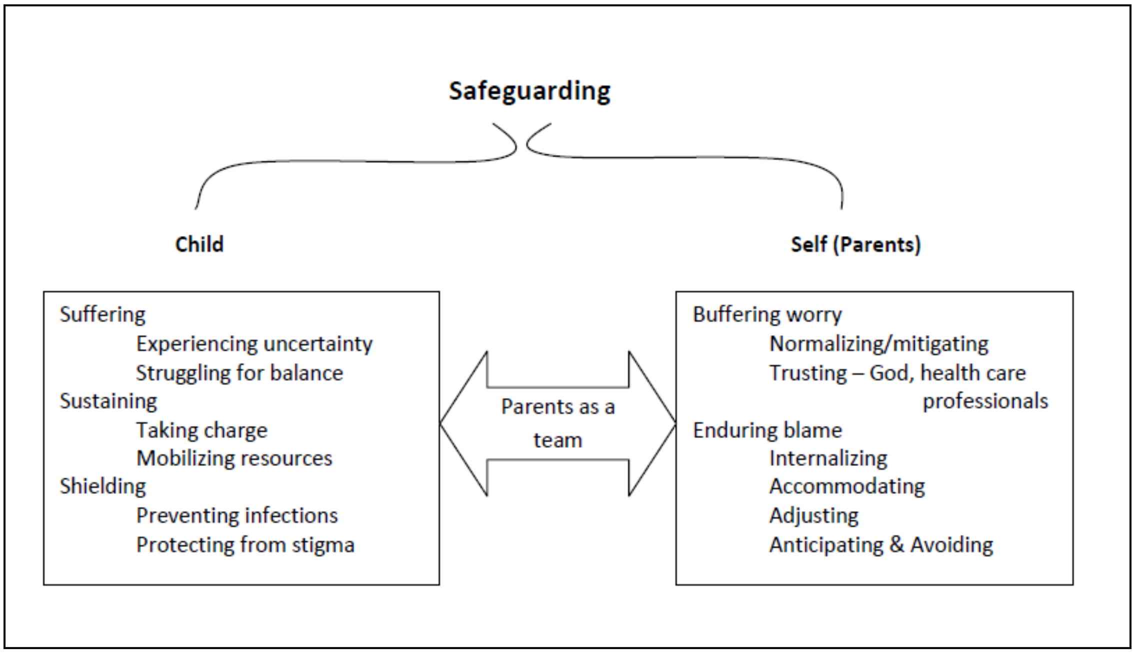

Figure 2. Theory of Safeguarding

A limitation of both studies (i.e., Rempel and Harrison's and this study) as well as other parenting studies is the lack of understanding about the perceptions of health care professionals and the affected children themselves. The experiences of parenting or caring for children with chronic illness or disability and the perceptions of children regarding the care received need to be elicited for further theory development on parenting children with chronic illness/disability.

Initial Beliefs/Assumptions Challenged

The findings from this study have provided essential evidence related to care of burn-injured children in the hospital as well as at home after discharge in India. The study findings challenged several of my assumptions regarding burn care. Habitual questions such as “What happened?” and “What did you do?” are asked by the health care professionals when a child with burn injury is brought to the hospital. I have heard these questions being asked and I too have asked these questions. Professionals ask these questions based on their belief that children should be protected from pain and trauma, and burn injury is an example of pain and suffering for the child that could have been prevented. Health care professionals’ comments such as, “look how this child is suffering” depicted this belief in my study. For the health care professionals, these questions and comments that were so difficult for the parents to handle, may also have been a way that professional caregivers expressed their shock at the extent of the injury and coped with the child’s burn care. Professionals may also be advocating for the child by almost reprimanding the parents on behalf of the child, which then contributes to unintentional or intentional blame. The emotional trauma that these questions invoked in parents, however, was rarely acknowledged or addressed by health care professionals, according to the parents’ accounts.

Beliefs, defined as “truths of subjective reality,” can both be facilitative and constraining (Wright, Watson, & Bell, 1996, p. 41). Facilitative beliefs increase options for solutions to a problem whereas constraining beliefs reduce options for solving the problem. For health care professionals, blame based on their belief that they were advocating for the child, may have helped them to positively/emotionally engage with gravely injured children. For parents, however, it proved to be constraining as blame closed the option of healing from the emotional trauma they suffered due to their child’s burn; rather it induced the double trauma that parents suffered related to the burn and the blame.

The second surprising finding was the fathers’ intense involvement in the care of a burn-injured child. This finding, however, did not fit with how seldom fathers’ participation was sought in giving care in the hospital. It points to the health care professionals’ traditional assumption related to involvement of fathers. In India it is assumed that mothers are the primary caregivers and fathers are providers for the family. Fathers in this study have shown that they can and do share the responsibility of parenting when a child is seriously injured and traumatized. This study finding provides explicit evidence for change in perspectives and practices related to father involvement in the care of children in India.

A third unexpected study finding was the lack of support from extended family members in many families. The minimal support that was available was from the maternal grandparents who did not live with the family in the same dwelling place. My assumption about the active and sometimes over involvement of extended family members in child care, especially the mothers' parents-in-law, was challenged by this finding. I now realize that family support cannot be taken for granted in Indian families. The reasons for the lack of extended family support may be existing family tensions and/or general non-involvement in child rearing and the extended family members' fear that they may be blamed if the child developed complications. The seriousness of injury and the extensive burn wound could also have deterred the family members' involvement. The non-involvement and minimal support did not disrupt the care of burn-injured children as parents formed a team to meet the needs of their burn-injured child. Parents showed their ability to move forward from the stage of suffering to taking charge of the care to sustain their burn-injured child's life amid their day to day activities. In some families, the extended family members took care of the siblings and in others, parents managed the care of the burn-injured children and their siblings.

Family support that is depicted as an important resource in the family resilience models (Patterson 2000a, 2000b; Walsh, 2003) was not available for the majority of the families in this study, yet the lack of it did not affect the steps that parents took to care for their burn-injured child and move forward. Parents' mutual support for each other, however, was an important facilitating factor for parenting the child as well as for parents' personal emotional healing.

Fourthly, in contrast to the assumption and observational reports from India that indicate parental noncompliance with the follow-up care for their burn-injured children (Ramakrishnan, Jayaraman, Andal, Shanker, &

Ramachandran, 2004), parents in my study did not default on their parenting responsibilities despite the trauma they experienced related to the burn-injury event and suffering of their child. They did everything possible for their child. They drew on both their internal and external resources to maximize positive outcomes for their child. Unfortunately, the findings of this study do not indicate a response from the health care system and the health care professionals that matched the parents' need for sensitive, knowledgeable, and timely support.

Implications for Practice and Research

The study findings indicate a need for early and effective changes in practice related to care of burn-injured children and their families. It is vital to address these practice implications and plan for appropriate knowledge transfer strategies which will optimize the quality of care provided for burn inured children. The findings have also raised more questions regarding practices and policies. In the following paragraphs I suggest implications for practice and future research and provide an account of the practice and knowledge transfer strategies that are already underway in our unit in India. My plans for knowledge dissemination are also recounted.

Practice Implications

There are important multi-faceted implications for practice from these findings. Health care professionals need to first acknowledge and affirm the efforts that parents take to safeguard their children's survival and ongoing health in the case of serious injury. Parents suffer physically and emotionally with their burn-injured children. In addition to this, blame induces another emotional trauma and devalues their parenting capabilities. As already established in another study (Zengerle, 2006), health care professionals should provide a caring, non-judgmental, and respectful context to promote healing rather than cause more harm. The family as a unit should be considered as “the patient” in the post burn period (Blakeney & Creson, 2002). In addition to the care that is provided for the burn-injured children, the needs of parents and siblings should also be met. Specifically, parents’ emotional needs should be assessed and appropriate interventions such as counseling need to be initiated as the child is being treated in the hospital.

The mothers’ need for fathers’ support especially during the period of the child’s hospitalization must to be understood by the health care professionals and addressed. Every effort should be taken to promote and encourage fathers’ involvement in the care during hospitalization. This approach will empower the parents to function as a family unit and will further strengthen the mutual support they provide after the child returns home from the hospital. A cohesive family environment positively influences long term burn outcomes in children (Blakeney, Herndon, Desai, Beard, & Wales-Seale, 1988; Landolt, Grubenmann & Meuli, 2002; LeDoux, Meyer, Blakeney & Herndon 1998; Rosenberg et al., 2007). Parental mutual support can also enhance reduction of anxiety and post traumatic stress that family members exhibited in the post burn period in previous studies (Bakker, Van Loey, Van Son & Van der Heijden, 2010, Kent, King & Cochrane, 2000; Phillips & Rumsey, 2008; Rossi, Vila, Zago & Ferreira, 2005).

Parents become the extension of the burn team when they take up the role of burn professionals at home. Findings from this study suggest that professionals expect the parents to manage the care with minimal support. Providing wound care at home was a devastating experience for parents and the blame and lack of support that parents encountered after discharge caused further trauma instead of supporting and affirming them in their new parental role. Many smaller clinics were ill equipped for burn care and the professionals in these clinics were not burn care experts. Parents need to be adequately prepared to provide rehabilitative care at home. They need professional support and care even after hospitalization to deal with the extensive wound. A separate burn clinic needs to be established at least in tertiary level hospitals. An advanced practice nurse who can provide expert and specific advice and guidance for the parents on burn care needs to be available in the clinics to cater to the unique needs of the burn-injured children and their parents. What parents do at home should be supported and validated by the nurse specialist in the clinic. These interventions will assist parents to provide optimal long-term care that is necessary for their burn-injured children.

Managing wound dressings is a painful and difficult process for parents and parents need support and supervision with dressing changes. It could be argued that wound dressings should be done only in a hospital setting where facilities for the dressing with medications to control pain and discomfort are available. Health care professionals need to assess the travel and financial related issues related to follow up care and plan follow up accordingly. In the event of difficulties where a parent is unable to bring the child to the tertiary level hospital, referrals to appropriate facilities that are capable of providing follow up care should be made. Further, families should be referred to community health nurses who will follow the families and will be able to provide advice and support that the families may require in the long term. Parents require assistance in deciding and choosing rehabilitative treatment for scars and contractures. Facilities that provide surgical treatment, material assistance for scar care, and vocational counseling as well as organizations that provide financial support should be identified so that parents can be referred to these services early. Establishing a network that will support burn children and their families in the community is an immediate need in India to improve burn related outcomes both for the parents and the child.

Burn outreach clinics from tertiary hospitals that provide follow-up care can be planned to improve access to care and rehabilitation once the child returns home. As burn trauma can take a heavy toll on family financial resources, free or subsidized follow up care should be made possible. Funding for burn rehabilitation has to be increased as part of health policy that will help burn centers set up rehabilitation units, hire professionals, and assist families to access rehabilitation aids.

The model of dual process of parenting will assist in developing comprehensive assessment checklists/scales and care protocols for burn-injured children and their families. Based on the stages of enduring blame, scales for assessing parents' stress and emotional reactions to the burn injury and outcome during hospitalization and the period of rehabilitation can be developed or introduced if standard scales are available. Psychological interventions can be planned based on the assessment. The model also encourages a family centered approach for planning and providing care in the hospital and at home. The model emphasizes the importance of supporting and caring for the child as well as the family. It enforces the need to acknowledge that parents are also working to safeguard their children as much as the health care professionals and their input and participation in care have to be recognized and accepted with respect. Rather than devaluing their parenting ability, their role as “the” care providers has to be acknowledged and interventions that enable and empower them as competent parents have to be devised and executed.

Knowledge Transfer Strategies

Knowledge transfer strategies and practice changes are already in the early stages of implementation and adoption in the burn unit where I work. The findings about the double trauma are periodically shared with the health care professionals, especially the inpatient unit nurses during staff meetings and educational sessions. Our awareness about the emotional needs has improved and nurses make conscious efforts to refrain from asking blaming questions and rather work to provide a non-judgmental and caring environment.

Instead of restricting fathers’ entry in to the ward to only during visiting hours, fathers are now encouraged to participate in providing care in the hospital. Nurses in the unit have initiated a request for a change in visitors’ policy to invite fathers on to the unit when mothers need them. Plans are underway to start a weekly one-day burn clinic with an assigned burn nurse who will provide follow-up care and will work with parents in providing the rehabilitative care for their burn-injured children. A proposal for the same is being drafted. These changes have become possible as the surgeons and nurses have recognized the need to improve the care of burn-injured children and the support that the family needs. The findings from this study have helped in identifying the weaknesses and gaps in the provision of care and need for changes in our ingrained assumptions. The model challenges health care professionals to consider the family as a unit and emphasizes the need for family-centered care. I anticipate that such changes in practice will be possible in other hospitals in India and other countries which have similar gaps in the provision of care. To motivate this change, the findings of this study will be shared at conferences in India and abroad.

I will also disseminate the findings from this study through publications in international scholarly journals. My research findings will be shared in educational sessions/seminars conducted for nurses and other health professionals in the hospitals and community who may not be able to access journals. Although not presented in this dissertation report, accounts from parents suggested that they lacked knowledge about immediate care of burns and later rehabilitation resources for their children. As many parents cannot access journals, vital information related to assessment of extent of burn injury, first aid, complications, rehabilitation, and resources will be published in newspapers or magazines. Another dissemination strategy is to create and print a story book with the extracts of stories of parents. The story book will be made available as resource material for parents on the pediatric unit.

Research Implications

The study findings have opened up numerous possibilities for further research. The next step would be to elicit the perspectives of health care professionals involved in the care of burn-injured children. Their perceptions about burn care, care of families of burn-injured children, blame, and social support will add theoretical perspectives that will refine the model and enhance development of parenting theory. Perceptions of burn-injured children are vital to elaborate core issues such as blame and stigma. Including children as research participants will be challenging yet will bring a rich dimension to the model of dual process that is evident in parenting burn-injured children. As limited evidence is available on the perceptions of health care professionals or chronically ill or disabled child regarding parenting or caregiving, further categories that link the findings from the present study may evolve from the perspectives of health professionals and burn-injured children, which may strengthen or expand the existing theoretical perspectives of parenting in the literature.

Further research questions include: Does the burn trajectory end with the scar phase where parents are constantly worrying about the child’s scar or is there an ultimate resolution/acceptance phase? And when do parents stop anticipating blame? Is the blame perceived life-long in terms of the burn-injured child blaming the parents later in life? What are the siblings’ reactions to burn?

How do they cope? These are essential questions that need to be answered. Perceptions of adults who were burned as children may extend the trajectory and may provide answers to these questions. Interventions that provide emotional support or enhance father involvement can be devised and tested to improve family-centered care. The effect of burn clinics and specialized follow ups can be evaluated using intervention research strategies. A pre and post intervention or comparative studies can be carried out to test the effectiveness of new policies and procedures that are implemented in the burn unit.

The long term burn outcomes need to be studied and correlated with the availability of family support in India. Standardized instruments can be used to measure post traumatic stress and anxiety in this population in India to quantify stress and anxiety. Multiple and mixed methods/methodology research can be utilized in various settings. Interdisciplinary collaborative research with all health care professionals who are currently involved in or have the opportunity to get involved will be a useful strategy to improve care for the burn child as well as the family.

Two further aspects of my dissertation research will also be addressed as I develop my research program, one being methodological and the other being substantive. A methodological issue yet to be addressed is the process of data generation and analysis when the interviews were conducted in Tamil, transcribed in Tamil and then translated into English for analysis. A further substantive aspect of my research pertains to the data parents provided about their perceptions of the effects of burn injury on their child.

Concluding Comments

As I reflect on the most striking change that has occurred in me as a result of conducting this research, it is my increased awareness of and admiration for all that parents do for their burn-injured children. Through this study I have gained innumerable insights into the challenges that the parents of burn-injured children in India face and the processes and strategies that they use to confront these challenges. In addition, my research with family members of burn-injured children enhanced my learning about and engagement in knowledge development using qualitative methodology. Finally, this study served as a platform to link the knowledge I gained in a western university with the premises and practices of my eastern setting.

Epilogue

I enter Room 25 and meet two-year old Manjula and her family. The toddler sustained 40 % burns from being tripping over a bucket of extremely hot bath water. Manjula is crying incessantly. She is on an intravenous infusion and has a urinary catheter. A feeding tube has been placed to give supplementary feeds to increase her calorie and protein intake. I hold Manjula's hand and try to talk to her in a consoling manner to provide some sort of comfort. Manjula's crying reduces but does not stop. I turn towards Kamala, Manjula's mother who is standing near the bed quietly. I place a comforting hand on her shoulder and ask her how she is doing. Kamala looks at me with surprise and immediately lowers her head. I feel her shoulders gently shake as tears run down her face. I wait quietly. After a few minutes Kamala turns to me and asks, "Will she be

Ok?” I discuss with her the possible interventions that will assist Manjula to recover. I invite Raman, Manjula’s father, to be part of this conversation. Raman listens attentively. Every day I make it a point to ask the parents this simple question, “How are you?”

On the third hospital day Kamala expresses her desire to talk to me. She explains, “Manjula cries a lot in the night and does not sleep well. I am always scared that something will happen to her. Can one more person stay here with me?” she asks. I understand her emotional trauma and write a night pass for Raman giving him permission (hospital policy) to stay in the waiting hall and explain that Raman can come in when Manjula needs him.

Over the next two weeks as we meet the needs of Manjula, I notice the influence that Raman’s presence has on Manjula. Manjula wants to be held by her father. Raman holds her when Kamala takes a break to have a wash or have her meals. I invite his presence and assistance in burn dressing. Although it is hard for him to see his child struggle, he decides to stay and assist with the burn bath and dressing change. As Manjula recovers after the skin graft surgery, Raman follows all the instructions that are given by the health care professionals.

Manjula is discharged after 22 days in the hospital. On the day of discharge I go to the out-patient clinic with Raman and introduce him to Jasmine and others who will do the dressing changes during the follow up visits. Raman and Kamala look relieved and happy as they say good bye in the ward.

There is much I need to do for families like this and I am confident that positive changes in burn care and rehabilitation can be initiated based on my study findings, which will assist the parents also to recover along with their burn-injured children.

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APPENDICES

APPENDIX A

Consent to Contact

Project Title: Post-hospitalization Parenting/Caregiving processes for Families of Children Who Have Sustained Burns

Investigator: Ms. Vinitha Ravindran, Doctoral Candidate, 416-2262368

Supervisors: Dr. Gwen Rempel, Assistant Professor & Dr. Linda Ogilvie, Professor, Faculty of Nursing, University of Alberta, Edmonton, AB, Canada

Vinitha Ravindran is a pediatric nurse who is at present a doctoral student at a University abroad. She works with children who have burn wounds. She wants to know what it is like for family members to care for children with burn wounds. She wants to talk to parents, grandparents, adult brother or sister or any other family member who is involved in giving care for a child with burn wound after they are discharged from the hospital. If you join this study/research, Vinitha will personally meet you, and talk to you about your every day experiences of caring for your child with burns. You can choose the place of interview that will be comfortable for you. She will contact you and give more information, only if you are interested and give permission to contact you. You do not have to take part in this study if you do not wish. If you wish to leave the study, you can do so at any time from this contact until the study ends. You do not have to give a reason.

If you are interested please fill in the details, sign and return the form to the person who is contacting you. Vinitha will speak to you as soon as possible.

Phone: Vinitha Ravindran 416-2262368

Email: paulravi@ualberta.ca

I give Vinitha Ravindran permission to contact me to give me information about her study. I am not saying that I will take part. I just want more information.

Signature ______________________________

Printed name: ___________________________

Phone number: Home______________, Cell__________

Home address: ____

____

Email ____

(Grade level 5.6)

APPENDIX B

Information Letter

Project Title: Post-hospitalization Parenting/Caregiving processes for Families of Children Who Have Sustained Burns

Investigator: Ms. Vinitha Ravindran, Doctoral candidate, 416-2262368

Supervisors: Dr. Gwen Rempel, Assistant Professor, & Dr. Linda Ogilvie, Professor, Faculty of Nursing, University of Alberta, Edmonton, AB, Canada

Purpose: The purpose of this study is to help nurses and other health care workers understand the family members' experiences of giving care to their child with burn wound after discharge from the hospital. Saving a child's life after burn injury is one part of care. Understanding how family members parent or care for their child with a burn wound is also important to improve the care of the child and family at home after discharge. To learn more about your experiences, I want to talk to as many family members of children with burn wounds as possible.

What will happen: I will meet with you either in the outpatient unit or at your home depending on your convenience. I will ask you to share your experiences. I want to hear what it is like to parent/give care for a child with burn wound in the long recovery stage. You can talk about your experiences freely. I will tape record our conversation, which may be one to two hours long.

Privacy: What you say will be kept private. If your child's life is unsafe then it has to be reported to the community health nurse. I will remove your name and identifying information from the typed out interviews. Doctors and nurses who are involved in the child's care have no access to the interviews or the information you share. I will discuss the interviews with the research team only. I will keep the papers related to the interviews in a locked cabinet and the information in the computer will be protected by a password. I will keep all the information that I collect from you for seven years. The final report may have your actual words but nothing will identify you. What you tell me may be used in future studies if you give your permission to do so. I will get the necessary permission from the right committees for this.

It's your choice: This study will give you an opportunity to tell your story. The findings from this study may help in improving the future care of your child. I hope other families of children with burn wound will benefit from what we learn from you. The only risk to you is being uncomfortable about what you share with me. You can stop the interview, however, at any time. If there is anything you would like to be erased from the recording, I will be glad to do that. You are also free to leave the study at any time. I will be happy to give you the report of the findings when I have completed the study.

If you have any worries about any aspect of the study, please contact the Public Relations Office, Christian Medical College, Vellore at 416-2282030. This office has no connection to the study investigators.

Researcher's Initial__________, Participant's Initial___________

(Grade level 7.9)

APPENDIX C

Consent Form

Project Title: Post-hospitalization Parenting/Caregiving processes for Families of Children Who Have Sustained Burns

Investigator: Ms. Vinitha Ravindran, Doctoral Candidate, 416-2262368

Supervisors: Dr. Gwen Rempel, Assistant Professor, & Dr. Linda Ogilvie, Professor, Faculty of Nursing, University of Alberta, Edmonton, AB, Canada

Do you understand that you have been asked to be in a research study?
Yes No

Have you read and received a copy of the information letter?
Yes No

Do you understand the benefits and risks involved in taking part if you share your experiences with the researcher in this research study?

Yes No

Do you understand that you are free not to take part or stop taking part in this study at any time? You do not have to give a reason and it will not affect your child's care. Yes No

Has the issue of privacy about your part in the study been explained to you?
Yes No

Do you understand who all will know about the information that you share?
Yes No

Do you understand that the information you share in this study may be analyzed in future studies?
Yes No

Would you like a report of the study findings when the study is done?
Yes No

This study was explained to me by:___________________ Date:____________

I agree to take part in this study.

	Printed Name	Signature
Research Participant		
Witness (if available)		

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

Signature of Researcher____________________Name______________________

(Grade level 5.8)

APPENDIX D

Demographic Data

Interview Date:

Information about child with burns:

Date of Birth: ______________________
Gender of child: Female______ Male_____
Burn: Percentage of body surface area______ Number of days in the hospital__________
Any other significant illness/disability_______

Information about family members living together in the home:

Siblings		Age Health status
________	Female/ Male	_____________________
_________	Female/ Male	______________________
_________	Female/ Male	______________________
_________	Female/Male	______________________

Others Relationship to the child	
_________ Female/ Male	_____________________
_________ Female/ Male	_____________________
_________ Female/ Male	_____________________
_________ Female/ Male	_____________________
_________ Female/ Male	_____________________

Parents	Mother	Father
Age	______	______
Health status	_______________	_______________
Education		
University or college graduate	______	______
High school graduate	______	______
Some high school education	______	______
Primary school education	______	______
Illiterate	______	______
Employment_		
Professional	______	______
Technical- regular pay	______	______
Technical – Irregular work hours and pay	______	______

Daily wages – Seasonal, unguaranteed work hours ______ ______
Business ______ ______
Unemployed ______ ______

Occupation ___________ ____________

Monthly Family Income
Less than Rs.2000 ________
Rs. 2000- 5999 ________
Rs. 6000- 10,999 ________
Rs. 11,000- 20,000 ________
More than Rs. 20,000 ________

Child's primary care giver: _____________________

APPENDIX E

Trigger Questions

Can you think back to the time when your child was discharged and brought home? Tell me what that time was like for you. (Later this question was changed to- What was it like when your child was burn-injured?)

Can you tell me what it is like to care for a child at home who is burn-injured?

Can you tell me about your family? Who does what in relation to caring for the burn-injured child?

[Can you describe all that you do from the time you wake up till you go to bed at night? What is a typical day like for you?

[How a day's work is different now for you from the time before your child was burned?]

What do you think is important for your child? Why? What do you think that your child sees as important to him/her?

How has your child's burn injury influenced your role and responsibilities as a mother/father/grandparent/sibling? After the burn injury has the way you bring up your child changed? Can you explain how and why?

Are there any factors that you think as important that helped or did not help you with the care of your child? Can you please tell me more about these factors?

What has been the most difficult thing about looking after your child who has burn injury?

What has been the most satisfying thing about looking after your burn-injured child?

Is there anything else that you would like to share about your experiences in caring for your child at home after discharge?