Itching and Parental guilt: Parent Responses to Children's Symptoms Following Unintentional Burn Injuries

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Abstract

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Background: Unintentional burn injury can be a traumatic and stressful event for the affected children and their parents. Young children experience persistent itching and emotional distress associated with the injury. Parents assume the responsibility to manage their child's itching since young children have limited strategies to cope with the overwhelming effects of itching. Yet very little research has been focused on the experience of parents when managing their child's itching. There is a lack of understanding about ways parents assess and respond to the child's itching. In addition, parents experience guilt due to their perceived failure to protect the child. There is a paucity of literature examining the process of parental guilt after the incidence of burn injury. Little is known about the representation of guilt in parental responses to a child's burn and the consequences of that guilt for the parents.

Purpose: The purpose of this dissertation is to explore parents' lived experience of managing itching in young children and the phenomenon of parental guilt following unintentional burn injuries. There are three papers in this dissertation. *Paper 1* examines parents' lived experience of managing itching in young children following moderate to severe unintentional burn injury. *Paper 2* discusses the conceptual and empirical literature on parental guilt and its measures. Paper 2 also proposes a framework to understand the process of guilt in the familial and social context. *Paper 3* examines guilt and its representation in parental responses to a child's burn. Paper 3 also identifies the immediate consequences of that guilt for the parents.

Methods: *Paper 1* and *paper 3* are based on the semi-structured interview data conducted with 20 parents of children with unintentional burn injury. Parents of children with burns were recruited from a regional burn center in eastern China. Study participants were eligible if (a) they were a parent or primary caregiver of a child who was 16 months to 5 years old at the time of the burn injury; (b) their child had deep second-degree or third-degree burns at the time of the injury; (c) their child was 1–10 month(s) post-burn injury during his/her clinic visit; and (d) they were able to read, speak, and understand Mandarin. After enrollment, confidential semi-structured interviews were conducted with the participants. The interview consisted of 14 open-ended questions. Interviews lasted 40 to 70 minutes, and the audio was digitally recorded. *For paper 1*, data from three of the 14 interview questions were analyzed using inductive content analysis. *For paper 3*, data from five of the 14 interview questions were analyzed using a combination of deductive and inductive content analysis. *Paper 2* reviews the empirical literature on parental guilt to build a conceptual model of this concept. Searches were restricted to the context of parental guilt related to children's unintentional burn injury and restricted to English and Chinese language journals published within the past 30 years.

Results: *Paper 1* Twenty parents of children 34 (±11.5) months with moderate to severe burns of 11.2% (±8.7) total burn surface area participated in interviews. The mean length of time since burn injury was 6.4 (±3.1) months. Scratching the Itch with My Child was the core construct that captured the lived experience of parents' itching management. Parents assessed their child's itch by observing their child's behavior, by the child explicitly telling the parent about the itch, and the parent's guessing at what the child was experiencing post-burn. Parental management of their child's itch involved five domains: shifting attention, physical touching, cooling the child, taking care of the scar, and yelling at the child. *Paper 2* We discussed the nature and process of guilt. The empirical evidence on the relationships between guilt and various types of psychological symptoms in parents and children are summarized. Following this, several variables that are thought to regulate the guilt process are also discussed. A conceptual model is presented to depict guilt appraisal, which molds or structures human action, expression, and perception toward self in the context of guilt. Finally, recommendations for research and clinical practice are made regarding assessment and interventions targeting the cause and sequelae of guilt. *Paper 3* Parents expressed feelings of guilt using the word "guilt" or sentences that conveyed the manifest meaning, which reflected the definition of guilt. Analysis of the data produced three conceptual domains of the consequence of guilt: (1) reappraisal of guilt toward the self, (2) motivational reactions toward the child, and (3) other accompanying emotions.

Conclusion: This dissertation adds new information to the body of knowledge on parents' experiences managing their child's itching after the incidence of traumatic burn injury and their guilt experience. Parents were distressed managing their child's itch, and they struggled with what more they could do to relieve the child's incessant itching. Interventions are needed that directly assist parents or caregivers in promoting developmentally appropriate parent-child

interaction in the context of itching management. As for parental guilt, results from the literature review provide insight into ways to measure guilt experiences. The proposed conceptual framework allows scholars to understand the implication of guilt on the individual behavioral tendency; that is, the resultant outcomes between maladaptive and adaptive guilt. Finally, the data-based examination of guilt suggests that guilt and its consequences are, by definition, correlated but have distinct semantic representation. Understanding the consequences of that guilt offers a new opportunity to improve the provision of care and long-term support as we position the parents of the child in the social context of their family.

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Chapter 1. Parental Responses to Children's Itching after Unintentional Burns

Abstract

Objectives: This study examined parents' lived experience of managing itching in young children following moderate to severe unintentional burn injury.

Methods: Semi-structured interviews were conducted with parents or primary caregivers during their child's outpatient follow-up visit in the hospital in eastern China. We used inductive content analysis to analyze the interview data.

Results: Twenty parents of children 34 (±11.5) months with moderate to severe burns with 11.2% (±8.7) total burn surface area participated in interviews. The mean length of time since burn injury was 6.4 (±3.1) months. Scratching the Itch with My Child was the core construct that captured the lived experience of parents' itching management. Parents assessed their child's itch by observing their child's behavior, by the child explicitly telling the parent about the itch, and the parent's guessing at what the child was experiencing post-burn. Parental management of their child's itch involved five domains: shifting attention, physical touching, cooling the child, taking care of the scar, and yelling at the child.

Conclusion: Parents struggled essentially on their own to read their children's behaviors and to relieve the child's incessant itching. Interventions are needed that directly assist parents or caregivers to promote developmentally appropriate parent-child interaction in the context of itching management.

Keywords: parental responses; itching; symptom assessment; pediatric burn; pruritus

Introduction

The incidence of unintentional pediatric burns ranges from 2.9% to 20.6% in China (Shi et al., 2014). Children under the age of five are particularly vulnerable, accounting for more than two-thirds of all the pediatric burn cases in China (Fan et al., 2017; Li et al., 2017; Wang et al., 2006). Burn trauma profoundly affects all parts of the injured individual's and family's life (Bakker, Maertens, Van Son, & Van Loey, 2013; Duke, Boyd, Randall, Rea, & Wood, 2015). Young children experience physical trauma, developmental delays in both injured children and their siblings, and symptoms of unresolved trauma and traumatic loss (Graf, Schiestl, & Landolt, 2011; Maskell, Newcombe, Martin, & Kimble, 2013). In addition, grief and trauma responses have been reported in parents and caregivers (De Young, Hendrikz, Kenardy, Cobham, & Kimble, 2014). The family also bears a long-term financial burden from medical costs.

Post-burn itch is the most common and persistent symptom in burn survivors (Carrougher et al., 2013; Schneider et al., 2015). Schneider and colleagues found that the incidence rate in pediatric burn survivors was up to 93% of children at hospital discharge and 87% at six months post-injury (Schneider et al., 2015). Itch usually starts during the proliferative phase of wound healing (Ikoma, Steinhoff, Ständer, Yosipovitch, & Schmelz, 2006). The frequency and intensity of itch subside over time, but for some patients, it persists for years (Van Loey, Bremer, Faber, Middelkoop, & Nieuwenhuis, 2008). Significant predictors of post-burn itching include time since burn, the depth and total burn surface area (TBSA), age, grafting and level of posttraumatic stress symptoms (Kwa et al., 2018; Nieuwendijk, de Korte, Pursad, van Dijk, & Rode, 2018; Van Loey et al., 2008). Post-burn itch poses challenges for both the child's caregiver and the child. The sensation of itching as well as the urge to scratch often result in psychological symptoms and behavioral problems (Graf et al., 2011; Sveen, Sjöberg, & Öster, 2014), impaired

concentration with daily activities (Everett et al., 2014; Morris et al., 2012), and nocturnal itch and disrupted sleep (Lavery, Stull, Kinney, & Yosipovitch, 2016; Meyer, Robert, Murphy, & Blakeney, 2000; Patel, Ishiuji, & Yosipovitch, 2007; Rose, Sanford, Thomas, & Opp, 2001). In addition, scratching and rubbing can create blisters in areas that heal and the newly grafted tissue, which put the graft at risk of failing and perhaps necessitating another skin graft (Parnell, Nedelec, Rachelska, & LaSalle, 2012). Prior studies on post-burn itch have highlighted the significant impact of itch on the quality of life in burn survivors (Carrougher et al., 2013; Sveen et al., 2014; van Baar et al., 2011).

Few studies have examined the itching behavior of children as perceived and reported by parents and caregivers, especially with toddlers and preschoolers who are preverbal (Everett et al., 2014). One study suggested that experienced parents and caregivers usually know the child's typical behavioral responses to a specific symptom based on a careful observation (Herr, Coyne, McCaffery, Manworren, & Merkel, 2011). For toddlers, speech does not become the predominant means of communication until 2.5 years of age, and preschoolers have many ways to communicate the need for comfort but still are not able to explicitly describe their symptom experience and needs (Linder, 2008). As children transition from toddlerhood to preschool years, their means of communicating the need for comfort change dramatically as they mature. Such a transition requires parents to adapt their ways of symptom assessment and responses based on their child's developmental capacity in this parent-child interaction.

Children turn to their parents for comfort and protection when they are anxious or distressed, and parents and family caregivers are the first to respond. They not only console the child when observing his or her distressing behavior (Kazis et al., 2002; van Baar et al., 2011) but also discern the causes of the distress (Rimmer et al., 2015). Parental responses to the child's

request shape the parent-child interaction and consequently shape the child's attachment relationship with their parent (Crittenden, Dallos, Landini, & Kozlowska, 2014).

Literature examining parental responses to symptoms has been limited to parents with children with chronic and recurrent pain. Five types of parental responses to a child's pain have been identified, including protective behavior (positive or negative reinforcement for pain complaints), solicitous behavior (giving special privileges or gifts), distractive behavior (distraction from the child's pain), minimizing behavior (displaying anger or a lack of concern in response to pain complains) and monitoring behavior (asking child about symptoms) (Noel et al., 2016, 2015; Walker, Levy, & Whitehead, 2006). Several parental responses to a child's pain (i.e., solicitousness, minimizing) have been associated with a variety of negative child outcomes, including functional disability (Claar, Simons, & Logan, 2008; Guite, McCue, Sherker, Sherry, & Rose, 2011; Peterson & Palermo, 2004; Simons, Claar, & Logan, 2008; Walker et al., 2006) and somatic and depressive symptoms (Claar, Guite, Kaczynski, & Logan, 2010; DuPen et al., 2016).

The purpose of the current study was to describe how parents assess and respond to burn-related itch in their toddlers and preschoolers. The underlying framework that guided this study was the University of California San Francisco (UCSF) Theory of Symptom Management (Bender, Janson, Franck, & Lee, 2018). According to the Theory of Symptom Management, symptom experience is a simultaneous perception, assessment, and response to a change in sensation. In young children, however, parents often assume the responsibility to assess and respond to their child's symptom.

Methods

Sample & setting

This analysis was part of a larger descriptive study that examined parental behavioral and psychological responses to children's symptom of itch following unintentional burn injury. Parents of young children with burns were recruited from a regional burn center in eastern China. This center sees about 450 burn injuries in children every month; approximately one-third of these patients are children under the age of 3.

Study participants were eligible if (a) they were a parent or primary caregiver of a child who was 16 months to 5 years old at the time of burn injury; (b) their child had deep second-degree or third-degree burns at the time of injury; (c) their child was 1–10 month(s) post-burn injury during his/her clinic visit; and (d) they were able to read, speak, and understand Mandarin. The 1-to-10-month post-burn period was purposefully chosen to capture parental responses to their child's itching, since itching is the most prevalent symptom during the first 3-6 months following the injury (Mason & Hillier, 1993; Schneider et al., 2015). Caregivers of a child with suspected abusive burns were excluded from the study due to the different nature of burn injury and the parent-child relationship.

Procedures

The study was approved by the Institutional Review Board (IRB) at the University of Washington and Ruijin Hospital affiliated with Shanghai Jiaotong University School of Medicine, Shanghai, China. The on-site burn surgeon provided access to a child's daily appointment list and medical records (age, gender, burn degree). A study intermediary first identified potential eligible parents of children with burn injuries during a clinical appointment

between October and December 2017. Parents were approached while they were waiting to meet with the physician about their child's post-burn care.

The study intermediary briefly introduced the study using a script that the principal investigator (PI) provided. If the parent agreed to learn more about the study, the intermediary screened for eligibility based on the inclusion and exclusion criteria. If eligible and interested, the parent was introduced to the PI. The PI then explained the study in detail and allowed the parent to ask questions. Once signed informed consent was obtained, the parent was considered enrolled and was assigned a study ID.

Data Collection

After enrollment, confidential face-to-face interviews were conducted in a private exam room by the PI in China. The participant was asked to complete the demographic and burn history form, and the parental itch-assessment form. The interview consisted of 14 open-ended questions asked of all participants. This paper focuses on parents' responses to three of the 14 questions:

1. How do you know your child is/was itching?
2. What did you do to help your child to relieve the itching?
3. What challenges, if any, do you have when caring for the child? How do you deal with this? Does it work?

Interviews lasted 20 to 35 minutes and the audio was digitally-recorded. Digital recorded interviews were first transcribed verbatim in Mandarin by Xunfei Transcription (www.iflyrec.com), and then the transcriptions were verified by the principal investigator (PI) and a trained assistant for 100% accuracy against the digital recordings. All of the Mandarin interview data were then translated into English by the PI and a professional translator. Any

discrepancies between the two versions of translation were discussed until the two translators reached 100% agreement.

Data Analysis

SPSS 19.0 (IBM, Armonk, New York) was used to analyze the quantitative data. Demographic and burn injury data were summarized with descriptive statistics, including frequencies and percentages for categorical variables and mean and SD for continuous variables.

Following transcription and verification for accuracy, and translation and verification for accuracy, qualitative interview data were analyzed by a multi-phase process based on inductive content analysis adapted from grounded theory (Corbin, Strauss, & Strauss, 2008; Lewis & Deal, 1995; Shelley & Krippendorff, 1984). Data analysis occurred in five phases (see Table 1). ATLAS.ti 7.5.18 (ATLAS.ti Scientific Software Development GmbH, Berlin), a qualitative data analysis program, was used to manage and analyze the data and to provide an audit trail.

The trustworthiness of study results was protected by field notes, memo writing, and formal peer debriefing with an expert researcher, and maintaining an audit trail. Field notes were recorded for immediate observations and interpretations by the interviewer and served as a reference during data analysis. Memos and written records of analysis began with the first analytic session and continued throughout the analytic process. Memos were also used for peer debriefing.

Peer debriefing occurred at these junctures: 1) unitizing the data (the process of identifying the unit of analysis for coding, see Table 1); 2) initial categorizing of the data, 3) refining the categories and definitions of categories, 4) the formation of domains, and 5) identification of core construct. Constant comparative analyses were carried out by a peer debriefer for comparisons identified in Steps 3, 4 and 5. Disagreement about any aspect of the

analysis was discussed and resulted in a refinement of the definition of a category/domain, a reassignment of a unit/category, or the generation of a new category/domain (Lewis & Deal, 1995).

Results

Study sample description

Study participants were 20 parents or primary caregivers of children with unintentional burn injury. The average length of time since the child's burn accident was 6.4 months (*SD = 3.12*), which ranged from 1 month to 10 months. At the time of the burn accident, nine children (45%) were taken care of by grandparents; the remainder of the children were taken care of by either one of the parents with or without assistance from grandparents. After the burn injury, ten children (50%) were exclusively taken care of by the mother; eight children (50%) were taken care of by the mother with assistance from father or grandparents. Half of the children (50%) had siblings. The average total burn surface area (TBSA) was 11.2% (±*8.7*), and six children (30%) received grafts, with an average grafted TBSA of 13.7% (±*10.3*). Child demographic and burn injury information is shown in Table 1.2.

Parents and caregivers of the burned children ranged in age from 27 to 55 years, with a mean of 34 years (*SD = 8.6*). Thirteen parents (65%) had completed high school or less education. The majority of the family had an income of between ¥4000-20,000 in Chinese Yuan per month (approximately U.S. $600-3000 per month). The educational level of this sample was similar to the education level of the Chinese population in census data [51]. Parent demographic information is presented in Table 1.3.

Domains and Related Categories

The core construct that depicted the parents' reported experience with their child's burn itch was called **Scratching the Itch with My Child**. Children experienced burn itch directly during the long-term wound healing process, and parents witnessed and managed their child's itching and distress in everyday life. Scratching the itch was the child's instinctive desire to

mitigate the symptom. However, when parents were advised by professionals to stop scratching as well as to prevent the child's scratching, they listened. They became the co-experiencer of their child's itching as they tried to find ways to relieve the itching and to provide comfort for the child. Parents managed the itching as they assessed and responded to their child's itch symptom experience. Parents talked about ways to know their child's itch, including listening and observing their child's verbal and non-verbal cues. Parents also described their responses when they witnessed their child's struggle with itching. Scratching the Itch with My Child involved two categories of processes: parental itch assessment and parental itch responses. Itch assessment involved three domains: telling me, observing, and guessing. Parental responses to itch involved five domains: shifting attention, physical touching, cooling the child, taking care of the scar, and yelling at the child. A description of the domains and related categories follows, including illustrative quotes from the parents. See Tables 1.4 & 1.5.

Domains and categories related to itching assessment

Domain 1: Telling me

Telling me included three categories: *Telling me itching or hurt, Making requests* and *Crying.* Parents or caregivers knew about their child's itching through the child's signal of help to relieve the itching, including saying itching words, the cries related to itching, as well as the explicit requests of help.

Telling me itching or hurt. Parents knew their child's itching when their child communicated the symptom with simple words that explicitly included "itching." As one parent stated, "*He would tell me, and itching was the word he spoke most often*." Besides itching, children also used the word "hurt" to describe their itching sensation. One parent said, "*She says 'mommy, my butt hurts.' She is not able to say itching, she says hurt, but actually, it is itching*."

Older children were able to specify the location and intensity of itching. This parent offered, "*She would tell me where she is uncomfortable, or she is very itchy or itchy a little, she would tell me*."

Making requests. Parents also learned about their child's itching when the child requested that their parents scratch for them, requested medication, or requested that the parent remove the pressure garment. One parent said, "*He would say "mommy, itching, mommy, scratch my neck, my thigh,' and he also used my hand to scratch*." Children also asked their parents to scratch during their sleep and would not let the parents stop. Another parent offered, "*Always in the midnight, she wakes up due to itching, and asks you to scratch her, at least 15 min*."

Although scratching was the most frequently requested action from the children, some also requested that their parents apply the cream, give an oral medication [prescribed by the physician], or remove the child's pressure garment to relieve the child's itching. One parent said, "*After bathing and applying medication on the scar, he is still itching, and then he would request me to apply (medication) again, and I will do it*." Another stated, "*If he doesn't feel comfortable, either itching or sweating, he would pull the pressure garment and ask you to unzip it, he doesn't want to wear it*."

Crying. Parents noticed that their child also expressed itching related distress through crying, especially when the child was overwhelmed by the non-stop intense itching. "*He keeps crying and crying because of unrelieved itching*." For toddlers and preschoolers, crying was a way to express the frustration; another parent, said, "*He even cries if he is super itchy*."

Domain 2: Observing with My Heart

Observing included four categories: *Scratching him/herself*, *Observing the child every day*, *Hearing the scratching sounds*, and *Asking about the behavior*. Parents observed their

child's overt behaviors to know about their child's itching and itching related distress. They paid careful attention to itching behaviors, and such behaviors consequently triggered parents to ask about their child's feelings to elicit verbal confirmation of the itching experience.

Scratching him/herself. Parents reported a variety of child's scratching behaviors. Children either scratched the itching spot with their hands or they rubbed the itching spot against the mattress, the edge of a surface, or against their leg or foot. "*When he is scratching, you know he is itching, and I will hold his hand from his scratching, and then he will rub his leg with his other feet*." Some children even removed parents' hand and scratched the itching spot more intensely themselves. "*If I removed his hands and stroked his scar, he would reject my hands and scratch himself*."

Observing the child every day. Parents knew their child's symptoms because they took care of the child every day, and they observed their child with their heart. "W*e take care of him every day and take care of him with all our hearts. We know his every move, such as rubbing with his foot or scratching with his hand, we put on his glove to protect the scar, and the itching spot feels burning hot*." While observing, parents also evaluated the effectiveness of treatment, and their observations consequently informed what they did to manage the itch. "*When we massage the scar, we will observe. For example, his scar feels like a hard lump, so we are trying a different massage maneuver and are searching for better (treatment) options*."

Hearing scratching sounds. Parents sometimes were awakened by hearing the child's scratching sounds during the night. This parent offered, "*Sometimes the sound of the scratch was loud, and he was scratching intensely during sleep*."

Asking the child. Parents actively sought their child's confirmation of the parent's interpretation of the child's itching behaviors; they directly asked how the child felt. Questions

from the parent were often triggered by the parent's observing the child's facial expression or itching behaviors. "*Sometimes she scratches, and I would ask her if she itches.*"

Domain 3 Guessing the Symptoms

Guessing the symptoms included two categories: *Guessing a child's behaviors* and *Being difficult to know*. Parents tried to guess the meanings, and the intentions of their child's itching behaviors in an effort to understand their child's behaviors and the itching symptoms. Some parents expressed difficulty in understanding the child because of their child's limited verbal capacity.

Guessing the itching behaviors. Parents guessed the meanings, reasons, intentions associated with their child's unique itching behaviors, together with other itching cues such as facial expression, simple itching words or unique behaviors. For example, one parent stated that "*pulling off the pressure garment*" and "*removing the silicone scar sheet during sleep*" was also related to itching. Another parent pointed out, "*she has a growing temper, especially when she itches intensely, if you didn't give her what she wanted, she would say something like 'mommy and daddy don't love me,' it seems that she knows how to get your attention*." In addition, some parents speculated reasons of intense itching, as one stated, "*I guess because she didn't have pores on the skin, so unable to dissipate heat, and the heat was trapped inside.*" Another parent reflected, "*He itches more intensely during the night, maybe because he is resting*."

Being difficult to know. Parents expressed frustration when they were not able to fully understand their child's itching experience, especially in parents of toddlers since toddlers use predominantly non-verbal ways to express their distress or feelings. "*I didn't wear it (the pressure garment) myself, so I would not know, and he is too young to tell me. Since he cannot talk, so sometimes it is very difficult to know how he feels*," another parent offered, "*He cannot,*

he cannot say anything else besides 'mommy, medicine' or 'mommy, scratch for me,' *and there are no other requests*." Such statements indicated that even though parents sought verbal or behavioral cues from their child to better understand the child's itching experience, they simultaneously questioned the accuracy of their interpretation.

Domains and categories related to parental responses to itching

Domain 1: Shifting attention

Parents or caregivers shifted or distracted their child's attention away from itching and instead attempted to engage their child in a sensory experience that involved sight, hearing, taste, smell, or touch. The Mandarin character of distracting [分散] or shifting [转移，打岔] was used interchangeably during interview conversations. Shifting attention included three categories: *Distracting*, *Soothing*, and *Bargaining*.

Distracting. Parents frequently talked about using distraction strategies to relieve the child from itching. They knew what their child loved to do, and common distracting activities mentioned by the parents included watching videos, playing with cell phone games, reading books, playing toys, and giving their child some special treats. For example, "*I will shift his attention toward having sweets, playing toys or seeing the scenery outside.*" Another parent added, "*If she wants to play games and I ask her not to scratch, she will stop scratching*." Some statements also indicated that parents indulged their children in certain types of activities because they didn't have other options to provide comfort for their child. "*She likes watching cartoon at home, the children's channel on TV, so she always wants to watch TV, every day. You don't have other options*," another parent shared, "*He is less likely to scratch if his hands are busy, so I just let him do what he likes, emptying the things from the drawer and then showing everything at the same place. As long as he is not scratching and not being cranky, I am fine*."

Soothing. In the Mandarin language, the word 'hong [哄]' denotes two layers of meaning: soothing and bargaining. Thus, we separated into two categories based on the type of behaviors that parents did to relieve their child's itching and itching related distress. Parents used words or hugs to soothe the child when their child was distressed by itching. "*Usually I praise him, 'good job, you are terrific,' it (itching) doesn't matter, doesn't matter,' words like this.*" Others expressed their understanding of their child's discomfort and at the same time asked their child not to cry, "*I rock him in my arm and tell him 'not to cry, I know you are not comfortable.*"

Bargaining. Parents tried to relieve their child's distress related to itching by offering the child some toys or activities to engage, as an exchange to stop crying caused by an itching sensation. For example, one mother stated, "*I tell him not to cry, and if he stops crying, I will take him to the park.*"

Domain 2: Physical touching

Parents used a variety of hand maneuvers that varied in the degree of pressure the parent applied to or near the scar area, either initiated by the parent or explicitly requested by the child to relieve moderate to severe itching. This domain included four categories: *Stroking or rubbing*, *Patting*, *Massaging,* and *Bathing/wiping the body parts*. See Table 6 for the English translation and their corresponding Mandarin characters that illustrate the distinctions between rubbing, patting, and massaging.

Stroking or rubbing. Parents often touched the itching spot to relieve itching using the palm or the fingers with back and forth movement. Compared to stroking, rubbing involved touching with more focused pressure on the itching spot. "*I would stroke her and rub the scar area for her*," "*Even if he strongly demands me to scratch harder, I am afraid to scratch him, I gently rub him*." Parents seldom used the word "scratch" to describe how they relieved the

child's itching using hand maneuvers because they knew they need to protect the wound from scratching.

Patting. Parents patted the child to help relieve itching, and patting was recognized as an especially effective way at night. Parents often patted their children to help them fall asleep, as one parent put, "*We must keep patting him until he is comfortable, sometimes, patting him for hours before he went to sleep.*" Other parents patted the child to go back to sleep when the child was awakened by itching, "*When she woke up, she asked you to scratch, and she could only go back to sleep with your patting and rubbing*." Patting also helped the child keep sleeping, "*Even after he fell asleep, we would not stop gently patting in case he woke up*."

Massaging. More than half of the parents said that they massaged the scar after applying the prescribed scar medicine to relieve their child's itching. This was the standard treatment that the doctor instructed parents to follow. "*Finally, we use the medication prescribed here, and seems to have some effect*." "*Sometimes she requested medicine, feels like that she was much more comfortable after the medicine. She likes me to massage her scar*." Parents also talked about massaging without the medicine, "*if she were itching, I would massage the scar for her*." One parent reported using massage oil to massage the itching spot.

Bathing/wiping the body parts. Parents claimed that bathing their child or wiping their child's itching spots would help relieve the itching. Bathing, always accompanied by rubbing and followed by applying medicine and massaging, was an effective multidimensional strategy (including physical touch, medicine, massage, and cooling) to relieve intense itching and nocturnal itching. Several parents commented on this strategy, "*If she is super itching, I would bathe her. She is comfortable when bathing. I bathe her twice a day, in the morning and the evening. During the summer, she bathed several times a day, whenever she itched a lot.*" Parents

even used this strategy in the middle of the night when their child was not able to go back to sleep due to nocturnal itching. One parent commented, "*Sometimes he woke up in the middle of the night sleep, and we would wipe him with water to comfort him*."

Domain 3: Cooling the child

Parents used diverse and creative ways to alleviate the child's itching, such as regulating the temperature. This domain involved *Cooling the scar* and *Lowering the room temperature*.

Cooling the scar. Parents reported three ways to cool the scar: using a cooling pad, applying aloe gel, and letting the child sleep on the bamboo mat. One parent shared, "w*e freeze the silicone scar sheets in the refrigerator before applying on his scar*." Another parent said, "*we also came up with aloe gel, which also gave cool feelings after using because you could not always apply meds to relieve itching*."

Lowering the room temperature. Parents perceived that room temperature played a major role in regulating itching sensation. One parent reported, "*Lowering room temperature with air-conditioning relieves itching most*." And it was not surprising that parents came up with itching relieving strategies based on children's behaviors, "*We turned on the air-conditioner, and he wanted to be right under the air conditioner, and receive direct blows. If you moved him away, and then he would not sleep. He kept scratching with his hands. And then when you brought him right in front of the air-conditioner, he immediately went to sleep*."

Domain 4: Taking care of the scar

During the long period of post-burn recovery, parents talked about taking care of the wound/scar rather than taking care of the child. The wound/scar became the focus of daily life. The domain involved: Protecting the wound from scratching, Looking for itching therapy, and Asking the child to bear the itch.

Protecting the wound from scratching. In order to prevent small wounds caused by the child scratching the scar, parents asked their child to stop scratching. Instead, parents rubbed or patted the scar as they concurrently acknowledged their child's discomfort. "*Sometimes it's too itchy, she wanted to scratch herself, but I would tell her not to scratch and help to rub the itching spot. Otherwise, she was super uncomfortable if you don't allow her to scratch*." Other parents said they trimmed children's nails or put on gloves to prevent skin breakdown.

Looking for itching therapy. Parents sought alternative, more effective itching therapy for their child by consulting with physicians from several hospitals or even trying folk remedies. One parent reported using folk therapy to relieve their child's intolerable itch: "*And also tried the folk recipe, boiling the herb and applying decoction on the scar, effective immediately, but didn't last*."

Asking the child to bear the itch. Parents sometimes asked their child to bear the itch as they didn't have other options to relieve the itch besides everything they tried. One parent shared, "*Sometimes it's too itchy, she wanted to scratch herself, but I would tell her not to scratch and rub the itching spot. I also told her to bear it, to bear it. Sometimes she listened!*" Another parent explained that "*Sometimes he is not itching a lot, and he still complained loudly*," and the parent believed the child exaggerated the itching for his attention. Another parent thought her child wanted a stroke, and instead of saying what she needed, she complained about itching: "*sometimes she wanted you to give her stroke, even if she is not that itch*."

Domain 5: Yelling at the Child

A few parents yelled at the child to express their anger or frustration, especially when their child was throwing a tantrum or crying intensely. Only two participants reported such responses. One grandparent said, "*He is very clingy to his mom, every day. When his mom was*

tired, she (the mother) just yelled at him, saying 'don't call me, I am so tired,' and she (the mother) also lost her voice these days." Another parent shared, "*So devastated, I was irritated, and if she cries intensely, I yelled at her*." Although parents talked about their attitude toward the child, they also recognized their reaction was not appropriate, but could not control their emotion at that moment. This same mom noted, "*I know this doesn't help, but I could not control myself*."

Discussion

Parents actively tried to understand their child's itch experience. They assessed and responded to the itching when they observed their child's itching expressions. When the itching sensation dominated their child's symptom experience, parents assumed the responsibility to comfort their child to the best of their ability. They assessed the itch through their child's verbal and non-verbal cues, their keen observations, and their interpretation of these cues. Substantial evidence revealed that parents knew about their child's itch, even with preverbal children. Parents also actively looked for and chose various itch relieving strategies based on treatment outcomes. Most parents, however, expressed despair when it came to helping their child relieve the itch. As much as they did to relieve the itching, parents were dejected because there were no better options except to keep doing what they were doing even if it did not entirely relieve the itch.

Parents used words to communicate with the child about itching symptoms along with observing children's itching behaviors. In this study, the average age of the child was 34 months, ranging from 18 to 55 months. Preschoolers frequently used the word "itchy" to tell their parents they were itchy and distressed. They also engaged in scratching behaviors. From a developmental perspective, we know that children as young as two years of age may be able to express the presence of pain (Gaffney, McGrath, & Dick, 2003). At the age of three, they may be able to quantify pain using simplified self-report scale (von Baeyer, Chambers, Forsyth, Eisen, & Parker, 2013). This study provided supporting evidence on the ways children communicate itch with their primary caregiver. In addition, children as young as 18 months are known to develop an understanding of causal relationships, such as between itching and relieving actions (Dise-

Lewis, 2001). By making requests, children also gain a sense of control over their physical abilities (Dise-Lewis, 2001).

Study results also captured parental itch relieving strategies and parent-child interaction in the context of itch management. Parents used strategies that they perceived to be effective and available to them. Some parents responded to their child's distress and requests for comfort with inappropriate parent-child interaction, such as asking the child to bear the itch or yelling at the child. Such parental responses may further intensify the child's anxiety (Crittenden et al., 2014). Although parents' yelling may due to their own anxiety, their inability to cope with their child's negative affect, or their lack of knowledge regarding child development; we can speculate that such parental responses may also reflect posttraumatic stress symptoms (Bakker et al., 2013; El Hamaoui, Yaalaoui, Chihabeddine, Boukind, & Moussaoui, 2006; Kassam-Adams, Bakker, Marsac, Fein, & Winston, 2015; Kornhaber, Childs, & Cleary, 2018).

Parental responses to a their child's distress and request for comfort greatly shape the attachment relationship with the parent in the long run, especially during early childhood (Crittenden et al., 2014). With the emerging evidence on posttraumatic growth in children after burn injury, further research is needed to examine the impact of parental responses on children's symptom experience and long-term behavioral and functional recovery. In addition, we interpret the parents' behavior as reflecting more concern about the recovery of the wound rather than the recovery of the child. Taking care of the scar/wound on the child occupied the center of the family's daily life. Additional research is needed to explore this phenomenon. Symptom Management Theory (SMT) was the framework that guided the questions and design of the current study (Bender et al., 2018; Dodd et al., 2001). Although the theory acknowledges the role of family members in the child's care, such as family members' proxy report of a child's

symptoms and their involvement in symptom management strategies, it does not specify the location of the family members within the theory (Linder, 2010). Our study results suggest that parents described their child's itching based on an evaluation of a child's responses to symptoms, which is one of the three components in the symptom experience dimension of SMT. Parental responses to the child's itch showed that parents not only tried to understand their child's itch experience but also tried to relieve their child's itch. The intention of parental evaluative responses was aligned with the definition of the aspects of symptom management strategies, a key aspect within the theory. Gedaly-Duff and colleagues (2006) proposed to place parents of children with cancer in the environment dimension. This dimension includes physical, cultural, and social variables representing the "aggregate of conditions" in which a symptom is occurring (Dodd et al., 2001). We argue, however, that parents were co-experiencing their child's itch. Evidence from the current study suggests parents should not be put in the environment dimension of that theory; such placement minimizes the impact of the role parents, and family members have in symptom management. We recommend a parent or caregiver component in the center of the figure that overlaps with the three components: symptom experience, symptom management strategies, and outcomes (Figure 1).

Limitation

The study results are limited to parents or family caregivers of toddlers and preschoolers with moderate to severe unintentional burn injury. It may not apply to other cultures outside of China. While the sample size was appropriate for qualitative research, it may not generalize to larger populations. Results are also limited to parents or caregivers who were willing to participate in the study.

Clinical Implications

Two tentative clinical implications are suggested by study results. First, there is a need to better support parents with managing a child's itching and itching related distress. Parents, especially at the early stage of itch management, face a steep learning curve to understand their child's itch experience, in addition to several struggles related to their child (wound care, child's appearance, behavioral issues) and related to themselves (sleep deprivation, jobs, finance). Current practice at this study site does not include steps to prepare the parents as well as the child practically and psychologically to respond to the challenge of post-burn itching. There are no printed educational materials or pamphlets on itching management available for parents in China, and there is a lack of supportive services offered by burn professionals to provide timely education for those caregivers performing wound care at home. Parents struggled to try to read their children's behaviors and struggled with what more they could do to relieve the child's incessant itching. Results from our study may also help parents better understand their child's emotional and behavioral cues related to itching. This may help them be more perceptive to their child's symptom cues and consequently may add to the accuracy of the parental proxy report on child's itch symptoms.

Second, there is the potential long-term effect of parental responses to itching on the parent-child relationship during this early childhood period. The maturation stage of burn wound healing for these young children lasts for at least one and a half years or longer after the injury, which could span from toddlerhood to school years. The parent-child relationship undergoes dramatic changes as the child matures physically, cognitively, and affectively. Thus, parental responses contribute to the quality of the parent-child relationship and further shape the quality

of the child's attachment relationships. Further research could explore how parents' responses effects child development and parent-child relationship after burns.

References

Bakker, A., Maertens, K. J. P., Van Son, M. J. M., & Van Loey, N. E. E. (2013). Psychological consequences of pediatric burns from a child and family perspective: a review of the empirical literature. *Clinical Psychology Review*, *33*(3), 361–371. https://doi.org/10.1016/j.cpr.2012.12.006

Bender, M. S., Janson, S. L., Franck, L. S., & Lee, K. A. (2018). Theory of Symptom Management. In M. J. Smith & P. R. Liehr (Eds.), *Middle Range Theory for Nursing* (4th ed., pp. 147–178). New York: Springer International Publishing.

Carrougher, G. J., Martinez, E. M., McMullen, K. S., Fauerbach, J. A., Holavanahalli, R. K., Herndon, D. N., … Gibran, N. S. (2013). Pruritus in adult burn survivors: postburn prevalence and risk factors associated with increased intensity. *Journal of Burn Care & Research : Official Publication of the American Burn Association*, *34*(1), 94–101. https://doi.org/10.1097/BCR.0b013e3182644c25

Claar, R. L., Guite, J. W., Kaczynski, K. J., & Logan, D. E. (2010). Factor structure of the Adult Responses to Children's Symptoms: validation in children and adolescents with diverse chronic pain conditions. *The Clinical Journal of Pain*, *26*(5), 410–417. https://doi.org/10.1097/AJP.0b013e3181cf5706

Claar, R. L., Simons, L. E., & Logan, D. E. (2008). Parental response to children's pain: the moderating impact of children's emotional distress on symptoms and disability. *Pain*, *138*(1), 172–179. https://doi.org/10.1016/j.pain.2007.12.005

Corbin, J. M., Strauss, A. L., & Strauss, A. L. (2008). *Basics of qualitative research : techniques and procedures for developing grounded theory*. Sage Publications. Retrieved from https://books.google.com/books/about/Basics_of_Qualitative_Research.html?id=0TI8Ugvy

2Z4C

Crittenden, P. (2017). Gifts from Mary Ainsworth and John Bowlby. *Clinical Child Psychology and Psychiatry*, *22*(3), 436–442. https://doi.org/10.1177/1359104517716214

Crittenden, P., Dallos, R., Landini, A., & Kozlowska, K. (2014). Toddlerhood and the beginnings of awareness and intention. In *Attachment and Family Therapy* (pp. 31–51). Milton Keynes, United Kingdom: Open University Press. Retrieved from https://www.mheducation.ca/professional/products/9780335235902/attachment+and+family+therapy/

De Young, A. C., Hendrikz, J., Kenardy, J. A., Cobham, V. E., & Kimble, R. M. (2014). Prospective evaluation of parent distress following pediatric burns and identification of risk factors for young child and parent posttraumatic stress disorder. *Journal of Child and Adolescent Psychopharmacology*, *24*(1), 9–17. https://doi.org/10.1089/cap.2013.0066

Dise-Lewis, J. E. (2001). A developmental perspective on psychological principles of burn care. *The Journal of Burn Care & Rehabilitation*, *22*(3), 255–260. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/11403251

Dodd, M., Janson, S., Facione, N., Faucett, J., Froelicher, E. S., Humphreys, J., … Taylor, D. (2001). Advancing the science of symptom management. *Journal of Advanced Nursing*, *33*(5), 668–676. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/11298204

Duke, J. M., Boyd, J. H., Randall, S. M., Rea, S., & Wood, F. M. (2015). Childhood burn injury-impacts beyond discharge. *Translational Pediatrics*, *4*(3), 249–251. https://doi.org/10.3978/j.issn.2224-4336.2015.07.05

DuPen, M., van Tilburg, M., Langer, S., Murphy, T., Romano, J., & Levy, R. (2016). Parental Protectiveness Mediates the Association between Parent-Perceived Child Self-Efficacy and

Health Outcomes in Pediatric Functional Abdominal Pain Disorder. *Children*, *3*(3), 15. https://doi.org/10.3390/children3030015

El Hamaoui, Y., Yaalaoui, S., Chihabeddine, K., Boukind, E., & Moussaoui, D. (2006). Depression in mothers of burned children. *Archives of Women's Mental Health*, *9*(3), 117–119. https://doi.org/10.1007/s00737-006-0124-1

Everett, T., Parker, K., Fish, J., Pehora, C., Budd, D., Kelly, C., … Hayes, J. (2014). The construction and implementation of a novel postburn pruritus scale for infants and children aged five years or less: introducing the Toronto Pediatric Itch Scale. *Journal of Burn Care & Research : Official Publication of the American Burn Association*, *36*(1), 44–49. https://doi.org/10.1097/BCR.0000000000000129

Fan, X., Ma, B., Zeng, D., Fang, X., Li, H., Xiao, S., … Xia, Z. (2017). Burns in a major burns center in East China from 2005 to 2014: Incidence and outcome. *Burns : Journal of the International Society for Burn Injuries*, *43*(7), 1586–1595. https://doi.org/10.1016/j.burns.2017.01.033

Gaffney, A., McGrath, P. J., & Dick, B. (2003). Measuring Pain in Children: Developmental and Instrument Issues. In N. L. Schechter, C. B. Berde, & M. Yaster (Eds.), *Pain in Infants, Children, and Adolescents* (2nd ed., p. 128). Lippincott Williams & Wilkins.

Gedaly-Duff, V., Lee, K. A., Nail, L. M., Nicholson, H. S., & Johnson, K. P. (2006). Pain, Sleep Disturbance, and Fatigue in Children With Leukemia and Their Parents: A Pilot Study. *Oncology Nursing Forum*, *33*(3), 641–646. https://doi.org/10.1188/06.ONF.641-646

Graf, A., Schiestl, C., & Landolt, M. A. (2011). Posttraumatic stress and behavior problems in infants and toddlers with burns. *Journal of Pediatric Psychology*, *36*(8), 923–931. https://doi.org/10.1093/jpepsy/jsr021

Guite, J. W., McCue, R. L., Sherker, J. L., Sherry, D. D., & Rose, J. B. (2011). Relationships among pain, protective parental responses, and disability for adolescents with chronic musculoskeletal pain: the mediating role of pain catastrophizing. *The Clinical Journal of Pain*, *27*(9), 775–781. https://doi.org/10.1097/AJP.0b013e31821d8fb4

Herr, K., Coyne, P. J., McCaffery, M., Manworren, R., & Merkel, S. (2011). Pain Assessment in the Patient Unable to Self-Report: Position Statement with Clinical Practice Recommendations. *Pain Management Nursing*, *12*(4), 230–250. https://doi.org/10.1016/j.pmn.2011.10.002

Ikoma, A., Steinhoff, M., Ständer, S., Yosipovitch, G., & Schmelz, M. (2006). The neurobiology of itch. *Nature Reviews. Neuroscience*, *7*(7), 535–547. https://doi.org/10.1038/nrn1950

Kassam-Adams, N., Bakker, A., Marsac, M. L., Fein, J. A., & Winston, F. K. (2015). Traumatic Stress, Depression, and Recovery: Child and Parent Responses After Emergency Medical Care for Unintentional Injury. *Pediatric Emergency Care*, *31*(11), 737–742. https://doi.org/10.1097/PEC.0000000000000595

Kazis, L. E., Liang, M. H., Lee, A., Ren, X. S., Phillips, C. B., Hinson, M., … Tompkins, R. (2002). The development, validation, and testing of a health outcomes burn questionnaire for infants and children 5 years of age and younger: American Burn Association/Shriners Hospitals for Children. *The Journal of Burn Care & Rehabilitation*, *23*(3), 196–207. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/12032370

Kornhaber, R., Childs, C., & Cleary, M. (2018). Experiences of guilt, shame and blame in those affected by burns: A qualitative systematic review. *Burns*, *44*(5), 1026–1039. https://doi.org/10.1016/j.burns.2017.11.012

Kwa, K., Pijpe, A., Rashaan, Z., Tuinebreijer, W., Breederveld, R., & Loey, N. (2018). Course

and Predictors of Pruritus Following Burns: A Multilevel Analysis. *Acta Dermato Venereologica*, *98*(7), 636–640. https://doi.org/10.2340/00015555-2935

Lavery, M., Stull, C., Kinney, M., & Yosipovitch, G. (2016). Nocturnal Pruritus: The Battle for a Peaceful Night's Sleep. *International Journal of Molecular Sciences*, *17*(3), 425. https://doi.org/10.3390/ijms17030425

Lewis, F. M., & Deal, L. W. (1995). Balancing our lives: a study of the married couple's experience with breast cancer recurrence. *Oncology Nursing Forum*, *22*(6), 943–953. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/7567612

Li, H., Wang, S., Tan, J., Zhou, J., Wu, J., & Luo, G. (2017). Epidemiology of pediatric burns in southwest China from 2011 to 2015. *Burns*, *43*(6), 1306–1317. https://doi.org/10.1016/j.burns.2017.03.004

Linder, L. (2008, August 1). Developmental Diversity in Symptom Research Involving Children and Adolescents with Cancer. *Journal of Pediatric Nursing*. W.B. Saunders. https://doi.org/10.1016/j.pedn.2007.10.003

Linder, L. (2010). Analysis of the UCSF Symptom Management Theory: implications for pediatric oncology nursing. *Journal of Pediatric Oncology Nursing : Official Journal of the Association of Pediatric Oncology Nurses*, *27*(6), 316–324. https://doi.org/10.1177/1043454210368532

Maskell, J., Newcombe, P., Martin, G., & Kimble, R. (2013). Psychosocial functioning differences in pediatric burn survivors compared with healthy norms. *Journal of Burn Care & Research : Official Publication of the American Burn Association*, *34*(4), 465–476. https://doi.org/10.1097/BCR.0b013e31827217a9

Mason, S. A., & Hillier, V. F. (1993). Young, scarred children and their mothers--a short-term

investigation into the practical, psychological and social implications of thermal injury to the preschool child. Part II: implications for the child. *Burns : Journal of the International Society for Burn Injuries*, *19*(6), 501–506. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/8292234

Meyer, W. J., Robert, R., Murphy, L., & Blakeney, P. E. (2000). Evaluating the psychosocial adjustment of 2- and 3-year-old pediatric burn survivors. *The Journal of Burn Care & Rehabilitation*, *21*(2), 178; discussion 179-84. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/10752752

Morris, V., Murphy, L. M., Rosenberg, M., Rosenberg, L., Holzer, C. E., & Meyer, W. J. (2012). Itch assessment scale for the pediatric burn survivor. *Journal of Burn Care & Research : Official Publication of the American Burn Association*, *33*(3), 419–424. https://doi.org/10.1097/BCR.0b013e3182372bfa

Nieuwendijk, S. M. P., de Korte, I. J., Pursad, M. M., van Dijk, M., & Rode, H. (2018). Post burn pruritus in pediatric burn patients. *Burns*, *44*(5), 1151–1158. https://doi.org/10.1016/j.burns.2018.02.022

Noel, M., Alberts, N., Langer, S. L., Levy, R. L., Walker, L. S., & Palermo, T. M. (2016). The Sensitivity to Change and Responsiveness of the Adult Responses to Children's Symptoms in Children and Adolescents With Chronic Pain. *Journal of Pediatric Psychology*, *41*(3), 350–362. https://doi.org/10.1093/jpepsy/jsv095

Noel, M., Palermo, T. M., Essner, B., Zhou, C., Levy, R. L., Langer, S. L., … Walker, L. S. (2015). A Developmental Analysis of the Factorial Validity of the Parent-Report Version of the Adult Responses to Children's Symptoms in Children Versus Adolescents With Chronic Pain or Pain-Related Chronic Illness. *The Journal of Pain*, *16*(1), 31–41.

https://doi.org/10.1016/j.jpain.2014.10.005

Parnell, L. K. S., Nedelec, B., Rachelska, G., & LaSalle, L. (2012). Assessment of Pruritus Characteristics and Impact on Burn Survivors. *Journal of Burn Care & Research*, *33*(3), 407–418. https://doi.org/10.1097/BCR.0b013e318239d206

Patel, T., Ishiuji, Y., & Yosipovitch, G. (2007). Nocturnal itch: why do we itch at night? *Acta Dermato-Venereologica*, *87*(4), 295–298. https://doi.org/10.2340/00015555-0280

Peterson, C. C., & Palermo, T. M. (2004). Parental reinforcement of recurrent pain: the moderating impact of child depression and anxiety on functional disability. *Journal of Pediatric Psychology*, *29*(5), 331–341. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/15187172

Rimmer, R. B., Alam, N. B., Bay, R. C., Sadler, I. J., Foster, K. N., & Caruso, D. M. (2015). The reported pain coping strategies of pediatric burn survivors-does a correlation exist between coping style and development of anxiety disorder? *Journal of Burn Care & Research : Official Publication of the American Burn Association*, *36*(2), 336–343. https://doi.org/10.1097/BCR.0000000000000109

Rose, M., Sanford, A., Thomas, C., & Opp, M. R. (2001). Factors altering the sleep of burned children. *Sleep*, *24*(1), 45–51. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/11204053

Schneider, J. C., Nadler, D. L., Herndon, D. N., Kowalske, K., Matthews, K., Wiechman, S. A., … Ryan, C. M. (2015). Pruritus in pediatric burn survivors: defining the clinical course. *Journal of Burn Care & Research : Official Publication of the American Burn Association*, *36*(1), 151–158. https://doi.org/10.1097/BCR.0000000000000145

Shelley, M., & Krippendorff, K. (1984). Content Analysis: An Introduction to its Methodology.

Journal of the American Statistical Association, *79*(385), 240. https://doi.org/10.2307/2288384

Shi, X.-Q., Qi, Y.-H., Shi, D., Yan, C., Shi, J., Cao, B.-L., … Wang, H.-Y. (2014). Features and Risk Factors of Nonfatal Injury among the Rural Children: A Survey of Seven Schools in a Mountain Area in Southwest China. *PLoS ONE*, *9*(7), e102099. https://doi.org/10.1371/journal.pone.0102099

Simons, L. E., Claar, R. L., & Logan, D. L. (2008). Chronic pain in adolescence: parental responses, adolescent coping, and their impact on adolescent's pain behaviors. *Journal of Pediatric Psychology*, *33*(8), 894–904. https://doi.org/10.1093/jpepsy/jsn029

Sveen, J., Sjöberg, F., & Öster, C. (2014). Health-related quality of life in Swedish pediatric burn patients and associations with burn and family characteristics. *Burns : Journal of the International Society for Burn Injuries*, *40*(5), 987–994. https://doi.org/10.1016/j.burns.2013.10.005

van Baar, M. E., Polinder, S., Essink-Bot, M. L., van Loey, N. E. E., Oen, I. M. M. H., Dokter, J., … van Beeck, E. F. (2011). Quality of life after burns in childhood (5-15 years): children experience substantial problems. *Burns : Journal of the International Society for Burn Injuries*, *37*(6), 930–938. https://doi.org/10.1016/j.burns.2011.05.004

Van Loey, N. E. E., Bremer, M., Faber, A. W., Middelkoop, E., & Nieuwenhuis, M. K. (2008). Itching following burns: epidemiology and predictors. *The British Journal of Dermatology*, *158*(1), 95–100. https://doi.org/10.1111/j.1365-2133.2007.08278.x

von Baeyer, C. L., Chambers, C. T., Forsyth, S. J., Eisen, S., & Parker, J. A. (2013). Developmental data supporting simplification of self-report pain scales for preschool-age children. *The Journal of Pain : Official Journal of the American Pain Society*, *14*(10),

1116–1121. https://doi.org/10.1016/j.jpain.2013.04.008

Walker, L. S., Levy, R. L., & Whitehead, W. E. (2006). Validation of a measure of protective parent responses to children's pain. *The Clinical Journal of Pain*, *22*(8), 712–716. https://doi.org/10.1097/01.ajp.0000210916.18536.44

Wang, X., Zhang, Y., Zhang, Q., Liu, J., Tanuseputro, P., Gomez, M., … Liao, Z. (2006). Characteristics of 1494 pediatric burn patients in Shanghai. *Burns : Journal of the International Society for Burn Injuries*, *32*(5), 613–618. https://doi.org/10.1016/j.burns.2005.12.012

Appendix

Table 1.1 *A Multi-Phase Process of Inductive Content Analysis*

Steps	Descriptions
Step 1	Reading and unitizing the data. Each unit was a direct quotation of a complete idea. A complete idea is defined as a verbal expression that included both a verb and noun, which could be explicit or implicit.
Step 2	Open coding. Each unit was open coded using a code that included a gerund verb.
Step 3	Refinement of initial codes and identification of initial categories. The codes were organized into an initial set of categories.
Step 4	Naming and defining the categories. Category names were chosen from the parent's own words (the emics) to preserve the study participants' perspectives as much as possible. Each category was defined, and each category was distinct from each other. Constant comparative analysis was used to verify the unique fit of each unit within each category.
Step 5	Identification of higher order domains, naming and defining domains. Domain names were chosen to best capture the manifest meaning of the categories, using emics. Constant comparative analyses were carried out to examine each category's fit within each domain.
Step 6	Formation of the core construct. The core construct achieves the highest level of parsimony of the analysis and capture the essence of the data. It is identified after the final set of domains and definitions were generated.

Table 1.2 *Child Demographic and Burn Injury Information*

	Categories	N / Mean (*SD*)	% / Median (IQR[§])
Caregiver	Parent	18	90
	Grandparent	2	10
Child Age (month)	-	34 (*11.5*)	34.5 (17.8)
Gender	Female	8	40
	Male	12	60
Number of Siblings	None	10	50
	one	10	50
Birth Order	First child	13	65
	Second child	7	35
Degree of burns	First and third degree	2	10
	Deep second degree	7	35
	Deep second and third degree	7	35
	Third degree	4	20
TBSA burn size (%)	-	11.2 (*8.7*)	8.5 (10.6)
Grafting	Yes	6	30
	No	14	70
Grafting TBSA (%)	-	13.7 (*10.3*)	10 (10.5)
Month post-injury	-	6.4 (*3.1*)	7.2 (4.5)
First Aid	No	7	35
	Remove cover	9	45
	Rinse in water < 5 minutes	2	10
	Ambulance	2	10
Insurance	Child insurance	10	50
	No insurance	5	25
	NCMS[*]	4	20
	Commercial	1	5
Primary Caregiver before the injury	Grandparents	10	50
	Mom	5	25
	Mom and others[**]	4	20
	Dad and others[**]	2	10
Primary caregiver after the injury	Mom	10	50
	Mom and others[**]	8	40
	Grandparents	2	10

[§]IQR: Interquartile ranges
[*]NCMS: new rural cooperative medical system
[**]Others: Other family members include parents and grandparents

Table 1.3 *Parent or Caregiver Demographic Information*

	Categories	**N / Mean (*SD*)**	**% / Median (IQR[§])**
Caregiver Age (year)	-	34 (*8.6*)	29.5 (9.5)
Gender	Female	15	75
	Male	5	25
Marriage	Married	19	95
	Divorced	1	5
Education	Elementary school	3	15
	Middle school	5	25
	High school or equivalent	5	25
	Associate degree	2	10
	Bachelor's degree	4	20
	Master's degree and above	1	5
Ethnicity	Han	20	100
Residency Place	Shanghai	13	55
	Others	7	35
Work Status	Working	9	45
	Stay home	6	30
	On leave	4	20
	Retired	1	5
household Income (per month in Yuan & U.S. Dollar)	￥40,000 ($6,000) or over	1	5
	￥20,000-39,999 ($3,000-6,000)	3	15
	￥10,000-1,9999 ($1,500-3,000)	8	40
	￥4,000-9,999 ($600-1,500)	7	35
	Less than ￥3,999 ($600)	1	5

[§]IQR: Interquartile ranges

Table 1.4 *Domains and Categories of Parental Assessment & Numbers and Percentage of Parents Reporting*

Domains	Categories	Reporting parents	%
Telling me	Telling me itching or hurt	12	60
	Making requests	8	40
	Crying	8	40
Observing	Scratching her/himself	15	75
	Observing the child every day	6	30
	Hearing sounds of scratch	2	10
	Asking about the behaviors	2	10
Guessing	Guessing child's behaviors	10	50
	Being difficult to know	2	10

Table 1.5 *Domains and Categories of Parental Responses to Itch & Numbers and Percentage of Parents Reporting*

Domains	Categories	Reporting parents	%
Shifting attention	Distracting	13	65
	Soothing	3	15
	Bargaining	1	5
Physical touching	Stroking and rubbing	8	40
	Patting	7	35
	Massaging	14	70
	Bathing/wiping the body parts	4	20
Cooling the child	Cooling the scar	4	20
	Lowering the room temperature	2	10
Taking care of the scar	Protecting the wound from scratching	5	25
	Looking for itching therapy	4	20
	Asking the child to bear the itch	1	5
Yelling at the child		2	10

Table 1.6 Translation scheme of different types of physical touch

Physical touch translations	Corresponding Mandarin Characters
Stroke	摸，撸
Rub	揉，搓
Pat	拍
Massage	按摩，捏
Scratch	抓, 挠

Figure 1.1: Proposed modification of the UCSF Theory of Symptom Management Model

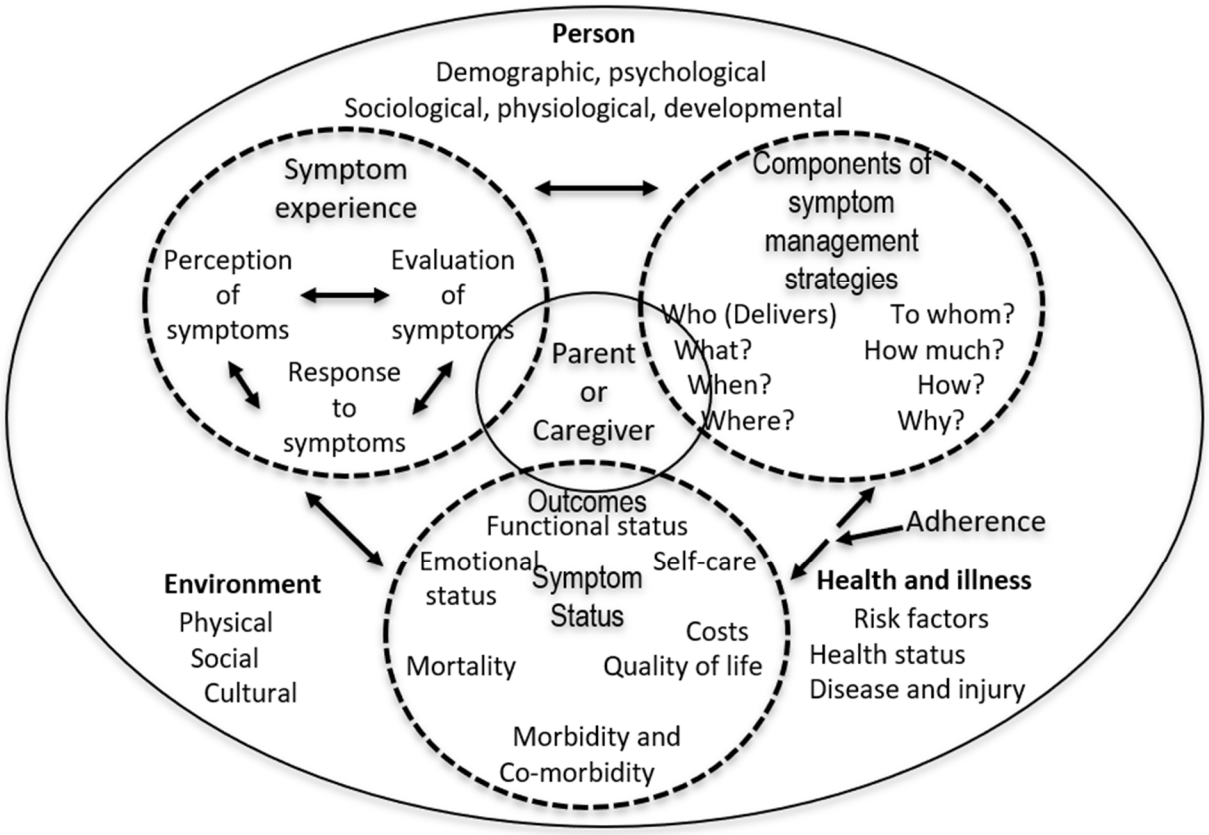


Figure Adapted from University of California San Francisco Theory of Symptom Management Model

Chapter 2. Guilt in Parents of Children with Unintentional Burns: A Conceptual Model

Abstract

Aims: We aim to discuss the conceptual and empirical literature on parental guilt following their children's burn and its measures, and proposes a framework as one of the means to understand the process guilt in the familial and social context.

Background: Parental guilt is a pervasive and complex social emotion that plagues the parents or family members after children's unintentional burn injury. Empirical evidence suggests it appears to be an important predictor of prolonged symptoms of psychological sequelae in parents. Guilt, however, is considered a fundamental adaptive emotion that motivates one to rectify undesired actions or behaviors in literature. Such conflicting views on guilt call for scrutiny of the empirical literature.

Methods: Relevant empirical literature was identified from searches of databases including PubMed, CINAHL, PsycINFO, EMBASE, CNKI (China National Knowledge Infrastructure), and WANFANG DATA using the terms "guilt," "blame," "scalding" and "burn injury." Searches were restricted within the context of parental guilt related to children's unintentional burn injury and also restricted to English and Chinese language journals published within 30 years.

Results: We discussed the nature and outcomes of guilt process. The empirical evidence on the relationships between guilt and various types of psychological symptoms in parents and children are summarized. Following this, several variables that are thought to regulate the guilt process are also discussed. A conceptual model is presented to depict guilt appraisal, which molds or structures human action, expression, and perception toward self in the context of guilt. Finally, recommendations for research and clinical practice are made regarding assessment and interventions targeting the cause and consequences of guilt.

Implications for Nursing: Guilt is a patterned, unconscious social process that influences individual experiences and interpersonal relationships. This conceptual framework allows scholars to understand the implication of guilt on individual adjustment as a resultant outcome between maladaptive and adaptive guilt. This provides insight into ways to measure guilt experience and the provision of care and long-term support to parents in the social context of their family.

Keywords: Parent Guilt, Burns, Pediatric Nursing

Introduction

Guilt is a pervasive and self-conscious emotion that strikes parents and family members after their child is afflicted by an unintentional burn injury. Empirical evidence reveals that feelings of guilt are reported in 27-81% of mothers at multiple longitudinal time points postburn (Bakker, Van Loey, Van Son, & Van der Heijden, 2010; El Hamaoui, Yaalaoui, Chihabeddine, Boukind, & Moussaoui, 2006; Mason, 1993; Rivlin & Faragher, 2007). Mothers were more likely to report feelings of guilt compared to fathers (Bakker et al., 2012), and parents of younger children appeared to experience more guilt feelings than those of older children (Bakker, Van der Heijden, Van Son, & Van Loey, 2013). In addition, mothers of children with burns reported higher rates of guilt and were more symptomatic (worry, depression, tension, anxiety, lack of energy, and lower self-confidence with other people) compared to mothers of children with fracture (Rivlin & Faragher, 2007).

Although the trajectory of the incidence of clinically significant posttraumatic stress symptoms (PTSS) decreased over time, roughly 18 -- 25% mothers and 6% -- 27% fathers reported PTSS at 18 months postburn (Bakker, Van der Heijden, Van Son, & Van Loey, 2013; Fukunishi, 1998; Mason & Hillier, 1993). Feelings of guilt are identified as a risk factor for prolonged symptoms of posttraumatic stress and depression in a growing body of literature. Within the first month after the burn injury, Fukunishi (1998) found that maternal level of guilt feelings was positively correlated with three symptoms of posttraumatic stress disorder (intense distress at a similar event, restricted range of affect, and hypervigilance). Bakker and colleagues (2012) examined acute stress responses (symptoms of intrusion and avoidance) in couples of children with burn injury and found that more feelings of guilt and anger were significantly associated with higher intrusion scores. Cella et al. (1988) found that feelings of guilt,

characterized by blaming oneself strongly, predicted persistent parental distress at six to eight months postburn. The relationship between parental self-blaming and their PTSS is consistent with a more recent study (De Young et al., 2014). Parents who criticized and blamed themselves may be more vulnerable to feeling distressed. Bakker and colleagues (2010) conducted a multiple regression analysis suggesting that feelings of guilt and the interaction between the feeling of guilt and burn severity (as indicated by total body scarred area) were significant predictors of PTSS in parents at two years post-burn.

With this burgeoning clinical relevance of guilt, however, less attention has been directed to elucidate the causal relationship between guilt and the psychological symptoms. We argue that the links between guilt and PTSS are not as straightforward as they might seem at first glance. The complexity of the problem lies in two aspects. First, whether one should expect a link between guilt and the negative psychological sequelae. Recent clinical literature has generally cited feelings of guilt in connection with prolonged symptoms of posttraumatic distress, the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-V) includes "Feelings of worthlessness or excessive or inappropriate guilt nearly every day (e.g., ruminating over minor past failings)" as one of the likely symptoms of a major depressive disorder. In this regard, both the frequency and intensity of feelings of guilt should be taken into consideration. Second, we believe that guilt is multidimensional with both positive and negative consequences. Thus, it is critical to find a method to acknowledge the adaptive part of the guilt while capturing the nature of maladaptive guilt.

A functional model of emotion processing suggests that emotions are grounded in human expressions and action, cognitive appraisals, and social interactions (Fischer & Tangney, 1995a; Tracy & Robins, 2007). Three main components are described in the emotion process: identity-

goal concerns, coping potential, and action tendency. First, identity-goal concerns described two groups of concerns that have been reported. One group of concerns relates to the change involved whether the event interferes with personal goal attainment. Another group of concerns involves reflection on self or evaluation of self-behavior against the social and cultural standards for moral behaviors. Secondly, coping potential is conceived as the causal appraisal of the event shapes the way people respond to the emotional event. Fischer & Tangney (1995) illustrated that if the event led to undesired outcomes, people judge whether something can be done to overcome or reverse the concerns or escape from it in some way. Most recently, Tracy & Robins (2007) suggested that causal appraisal of the event about the controllability and stability of the "global self" helps to distinguish the emotional states between guilt and shame. For example, people tend to guilt about their behavior and shame about themselves. Lastly, the action tendency is a function of prior learning, which reflected in three aspects: physical or physiological changes, feelings and thoughts, and overt behaviors. Physical changes include changes in expression, posture, heart rate, or other observable measures when an individual experiences emotion. In overt behavior, the action tendencies lead to emotional and verbal expression and thoughts about the appraised event. For example, the counterfactual statements about changing a stable global aspect of the self (e.g., "if only I were a better mother") lead to greater shame and less guilt than do counterfactuals changing a specific behavior (e.g., "if only I had not poured the hot water") (Niedenthal, Tangney, & Gavanski, 1994). Also, the process of reappraisal of action tendency produces an "emotion about the emotion." For example, when people react with guilt in the initial appraisal, the re-appraisal of that reaction sometimes leads to shame or anger.

Within this framework, various empirical studies suggest that guilt fosters an adaptive, constructive orientation toward others (Kim, Thibodeau, & Jorgensen, 2011). People tend to feel

guilt about their behaviors and are motivated to offer an apology or to make the repair, and to show understandings of moral/behavior standards (Barrett, 1995, *p*.42). On the other hand, Tangney and colleagues argued that a tendency to experience guilt complicated by shame is related to psychological maladjustment (Tangney, Burggraf, & Wagner, 1995).

Therefore, perceiving the feelings of guilt as a predictor of posttraumatic sequelae in parents and caregivers of children with burns warrants further scrutiny. The purpose of this study was to conduct a systematic review of the literature to build a conceptual framework for understanding factors influencing the guilt.

Methods

We began with the literature review on studies related to parental guilt following children's unintentional burn injury. We were interested in how parental guilt was studied in both quantitative and qualitative research. Based on the literature review, we developed a new model of parental guilt after childhood burn injury. The model was developed based on the broad assumption that emotions are fundamentally adaptive, promoting human functioning more than interfering with it. The literature was reviewed in relation to the experiential, and consequential influences of guilt appraisal on individual functioning. Physical changes induced by guilt emotion was not included here as these were not reported in the included studies. While the underlying process of the individual process is not clearly understood, a related general functional model of emotion processes proposed by Fischer & Tangney (1995) and Tracy & Robins (2007) provides a basic structure to understand emotion appraisal processes.

The search strategy

Relevant empirical literature was identified from searches of the PubMed, CINAHL, PsycINFO, EMBASE, CNKI (China National Knowledge Infrastructure), and WANFANG databases using the keywords "guilt," "blame," "burn injury," "scalding" and "thermal injury." Searches were restricted to English and Chinese language journals published within 30 years (1989-2018). The search strategies for each database are shown in the Appendix: Search strategy by the database. Controlled vocabularies of the journal databases such as MeSH, Emtree terms are used where possible to index articles.

Inclusion criteria

Qualitative studies were included in the review if they were original research articles that contained personal experiences or feelings after their child's unintentional burn injury. Research

participants could be parents, primary caregiver, or extended family members. Quantitative studies were included in the review if they utilized a quantitative measure of guilt and provided sufficient detail concerning the measurement method to permit categorization. Studies were also required to be available in English and Chinese language with full text.

Exclusion criteria

Studies were excluded if the study participants were children or adults who contracted burn injuries. Review articles, clinical protocols, expert reviews, and articles without full text were also excluded.

Appraisal of the search results

For quantitative studies included in the review, we focused on the guilt assessment in parents or caregivers of children with burns in terms of the scale used to assess feelings of guilt, and the methods to deliver the scale. Qualitative articles were critically appraised using the Critical Appraisal Skills Programme (CASP) for Qualitative Studies Checklist. It has been cited extensively to assess the quality and rigor of research while catering to the various qualitative approaches proposed.

Data abstraction

Data extracted from the quantitative studies included: author/year, study aims, key findings, participants, time of the guilt assessment, and how guilt was measured. Data extracted from the qualitative studies included: author/year, study aims, methodology/methods, participants/setting, key findings, how guilt was studied. Figure 2.1 shows the PRISMA flow diagram of included studies.

Results

Study characteristics

Demographics

The studies included in this review employed two main methodological approaches to study guilt: (a) quantitative measurement of parental guilt; and (b) qualitative interviews with the parents and family members of children on post-burn and guilt experiences. Seven studies with a detailed description of guilt measurement are included in the review. Thirteen qualitative articles were critically appraised using the CASP for Qualitative Studies Checklist. Six studies met the quality criteria for inclusion.

Among quantitative studies, the seven studies were conducted across four countries: The Netherlands (Bakker, Van der Heijden, et al., 2013; Bakker et al., 2012, 2010; Egberts, van de Schoot, Geenen, & Van Loey, 2017), Australia (De Young et al., 2014), Japan (Fukunishi, 1998), and Sweden (Josefin Sveen & Willebrand, 2018). Among qualitative studies, the six studies were conducted across five countries: United Kingdom (Andrews et al., 2018; Heath, Williamson, Williams, & Harcourt, 2018; Horridge, Cohen, & Gaskell, 2010; Mason, 1993), Australia (McGarry et al., 2015), Brazil (Rossi, Vila, Zago, & Ferreira, 2005), India (Ravindran, Rempel, & Ogilvie, 2013b), and United States/Malawi (Barnett, Mulenga, Kiser, & Charles, 2017).

Self-report guilt feelings

In quantitative research, guilt was studied as feelings as opposed to experiences. In some studies, the parents were asked whether or how often he/she felt guilty for causing children's health problems, and the response format was a frequency-based scale (Bakker, Van der Heijden, et al., 2013; Bakker et al., 2012, 2010; Egberts et al., 2017; Fukunishi, 1998; Josefin Sveen &

Willebrand, 2018). In the study by De Young and colleagues (2014), the feeling of self-blame was studied as a substitute for the feeling of guilt. The self-blame subscale consisted of two questions asked to assess parental guilt feelings: "I've been criticizing myself" and "I've been blaming myself for things that happened." Parents were asked to use a four-point scale ranging from 1 ("I haven't been doing this at all") to 4 ("I've been doing this a lot") to indicate the intensity of the feelings. Dichotomous responses to the question asking parents if they had feelings of guilt regarding the burn event were also used to assess the parental guilt (Bakker et al., 2010). Sveen and colleagues (2018), however, studied trait guilt in addition to the feelings of burn-related guilt. Table 2.1 summarizes the included quantitative studies.

In-depth interview exploring parental guilt experiences

The expression of guilt emotion was revealed in the narratives shared by parents and caregivers of children with burn injury. Four studies aimed to explore parents' overall experience and patterns of response after their child's burn injury (Heath et al., 2018; McGarry et al., 2015; Ravindran et al., 2013b; Mason, 1993). In one study, parents described mixed feelings of guilt, blame, and anger when they perform wound care, and such feelings contributed to the non-adherence of pressure garment treatment (Andrews et al., 2018). In another study, caregivers shared their inter-related feelings of guilt, self-blame, and anger after child's injury and their burdened rumination about the impact of burn associated stigma on child's future (Barnett et al., 2017). Table 2.2 summarizes the included qualitative studies.

Overview of the Conceptual Model of Parental Guilt

The proposed model of parental guilt emotion comprised an adaptation and elaboration of the relevant concepts of a general model of emotion processes. Empirical evidence depicting the guilt emotions in parents or caregivers of children with burn injuries is exceedingly limited; thus,

much of what proposed here is speculative. Despite this limited development in the literature, evidence bearing upon the model is presented whenever possible.

Relationships within the Model

The parental guilt process after an unintentional burn injury is portrayed schematically in Figure 2.2. Although the boxes indicate an approximate sequence, the processes typically occur in parallel, so that the diagram is not intended to indicate a rigid ordering. Also, the analysis into component processes can make them seem cognitive and deliberate, but most of the processes occur unconsciously and virtually automatically after initial learning and development (Lewis, 2006, *p*.134). The resultant outcomes between maladaptive guilt and adaptive guilt aim to illustrate the possibility of the co-occurrence of two types of guilt with distinct characteristics that influence the grand guilt appraisal.

The unintentional burn injury

In the incident of a child's unintentional burn injury, parents may believe that their failure to protect their child resulted in the burn injury. The injury happens as an evident change in the family's daily living, and parents continue processing the consequence of the injury to its affective meaning, "appraising" it. The impact of the burn injury on the family in general (Barnett et al., 2017; Horridge et al., 2010; McGarry et al., 2015), the interaction between child and family members within the social context (Andrews et al., 2018; Ravindran et al., 2013b; Rossi et al., 2005) and burns visibility (wounds or scars) (Mason, 1993) may act as signifiers of the accident that perpetuates the response.

Appraisal of the injury

The appraisal occurs quickly and unconsciously as a function of prior learning. The outcome is a generally positive or negative evaluation, based on an appraisal of the situation and

a wide array of concerns. Also negative evaluation leads to negative emotions and vice versa. In an instance of burn injury, parents or family members of children with burns are often directly involved in the traumatic event. Emotions that were reported by parents or extended families included guilt, shame, anger, shock, panic, horror, hysteria, and disbelief in response to a child's burn injury (Horridge, Cohen, & Gaskell, 2010; Mason, 1993; McGarry et al., 2015) and positive emotions reported included reacting calmly and thoughtfully (Horridge et al., 2010). The following discussion depicts the guilt appraisal process based on this theoretical understanding and empirical study of injury appraisal.

Reacting to burn injury

The guilt emotion starts with parents or caregivers relating to the burn injury with which they participated or in which they are embedded. According to Fischer and Tangney (1995), individual appraisal of the event focuses on how a person can promote or modify the affect-producing event. In the context of burn injury, a judgment that the injury could have been prevented or the physical damage to the child can be mitigated (with appropriate first-aid actions) may lead to emotions such as guilt. Feelings of guilt in parents and family members were reported in a number of studies when their child was hurt during an unintentional burn injury or when another person was seen as ultimately responsible for the harm that was inflicted on the child — such as carelessly leaving something like a bottle of boiling water within the child's reach.

Concerns about the child's recovery

Parental concerns about children's treatment and recovery also trigger guilt emotion (Mason, 1993). Parents reported intensified guilt feelings when they listened to their child during painful dressing changes (McGarry et al., 2015). Parents and family members expressed

rumination of guilt as they repeatedly felt concerned about a child's scar and recovery shaped by cultural and social values (Barnett et al., 2017).

Concerns about self or self-behaviors

Another group of concerns that trigger guilt emotion result from the evaluation of self: whether it is the "self-behaviors" or the "self" who is responsible for the injury. Currently, the most dominant basis for distinguishing the consequential emotions between guilt and shame centers on the negative evaluation of the global self and the negative evaluation of specific behaviors (H. B. Lewis, 1971; Tangney, 1995; Tracy & Robins, 2006). The distinction with an emphasis on self (global "I") versus self-behavior (my specific behavior) gives rise to distinct emotional experiences associated with distinct action tendency and subsequent appraisal. Guilt involves evaluations that one has done something wrong or caused harm to other people. An exemplary counterfactual expression from parents would be "what if I had or hadn't done something, it wouldn't have happened" (Horridge et al., 2010). The coexistence of shame and guilt involves additional evaluations that one is bad or that someone thinks one is bad (Barrett, 1995). The consequence of shame-guilt emotion may contribute to parents' self-blaming behavior (Andrews et al., 2018). The experiences of self-blaming for a child's injury have been shared by mothers from several cultures (Bakker et al., 2010; McGarry et al., 2015; Ravindran et al., 2013b), which may be related to maternal role self-expectations shaped by cultural and social values (Rossi et al., 2005). Outsiders, including relationship partners, negatively evaluate and react toward the person who expressed guilt alone or guilt in conjunction with shame. The perception from an outsider indirectly conveys outsiders' evaluations of the moral view about who is responsible for the injury. They can initiate a serious of further exchanges affecting the member's moral orientation. Several studies reported that parents endured blame from family

members or health care providers questioning their competence as parents (Mason & Hillier, 1993b; McGarry et al., 2015) and one study conducted by Ravindran and colleagues (2013b) portrayed parents'process of internalizing blame, submitting to blame, rising above blame, and avoiding blame. Guilt is a self-conscious emotion-laden with familial and social meanings; consequently, the perceived contextual factors such as mother's role in the family or the expected parenting rules that prevail in society shape the content of individual guilt appraisal (Grill, 2013; Ortony, 1987; Stocc, 1972). For example, mothers reported more feelings of guilt than fathers (Bakker, Van der Heijden, et al., 2013; Josefin Sveen & Willebrand, 2018). In Chinese American families, however, the father is expected as the head of the family to be responsible for the family's health (Chin, 2005), and these fathers' feelings of self-blame could be similar to mothers (Lee & Weiss, 2009).

Action tendency

Emotion appraisal produces a particular patterned reaction, called an "action tendency" (Fischer & Tangney, 1995a), which constrains or structures human activity and thought. In general, guilt that arises from a negative evaluation of a self-behavior generates feelings of regret, remorse, and concern for an injured party; such feelings were recognized to have an adaptive function on individual consequent behaviors. Shame, on the other hand, that arises from a negative evaluation of the 'self,' produces a desire to hide (Tangney, 1995).

To understand the adaptive guilt from an interpersonal perspective, Baumeister and colleagues (1994) suggested that guilt strengthens social bonds and relationships. Guilt brings one closer to other people rather than distancing one from others, motivates one to confess, apologize, or make amends for the harm for which he or she was responsible. In examining the qualitative literature parents responded to their child's injury with child protection actions. For

example, parents spoiled the child, in hopes of repairing the relationship with the child; or they were hyper-vigilant to potential environmental risks to a child's safety (Horridge et al., 2010; Mason, 1993). Parents also engaged in actions to decrease skin disfiguration such as practicing skills for wound care, learning knowledge about the injury and adapting the increased workload to the daily routine. Such behaviors correspond to the roles of guilt as a relationship enhancer described by Baumeister and colleagues (1994). Doing what they can to protect the child from further harm and to promote recovery is viewed as a way of coping for parents facing a child's medical condition and relieves parents from guilt feelings (Zhang et al., 2014).

Maladaptive guilt is characterized by chronic self-blame and an obsessive rumination over objectionable behaviors. Tangney, Burggraf, and Wagner (1995) proposed that a shame-colored guilt experience is likely to lead to rumination. Blaming was a significant theme revealed in several qualitative studies of burn injury. When reflecting on the causes of the burn injury, parents expressed that they either blame themselves or blame others who were responsible for the injury (Ravindran et al., 2013b; Rossi et al., 2005). Parents or family members received blaming or judgment from family members, health care providers, or even neighbors (Ravindran et al., 2013b). Blaming may produce further emotions, such as anger or resentment. Some parents reported feelings of shame and embarrassment induced by neighbors' curiosity about their child's appearance and not wanting to talk to others such as other family member or neighbors (Rossi et al., 2005). Others have also reported these avoidance symptoms and behaviors among mothers and couples of children with burn injury (Bakker et al., 2013; Mason & Hillier, 1993b). The combined influence of guilt, anxiety, and ruminating feelings was found to contribute to parents' self-doubt about their confidence in parenting (Horridge et al., 2010).

Self-monitoring action tendency

Self-monitoring depicts a continuous appraisal process after the initial appraisal, as shown in the arrow on the left of Figure 2.2. Through a reappraisal of action tendency of the emotion, an "emotion about the emotion" is produced. Such an emotional loop likely explains why parents respond to the burn event with a variety of emotions mentioned earlier (Fischer and Tangney, 1995).

Discussion

This proposed conceptual framework of guilt offers a perspective useful to understanding the dynamic process of guilt appraisal in parents following their child's physical trauma of a burn injury. The complexities of the experienced guilt emotion are produced by various combinations of parental concerns that are suggested in the literature in conjunction with individually unique perceptions and appraisal. Consequently, we view the individual action tendencies as the resultant outcomes between adaptive guilt and maladaptive guilt. Albeit there are still many gaps in the evidence base, we provide a possible framework to view guilt holistically and within the interpersonal context.

It is worth noting that the quantitative research reviewed focuses on guilt as a feeling with levels of intensity, and the experiences that are part of the emotion. It neglects or omits the other dimension of guilt in the proposed model, especially the nature and implication of guilt on individual adjustment, to put simply, the "meaning" of guilt, which can be viewed as the outcomes of an appraisal between adaptive and maladaptive guilt. Qualitative studies revealed that it is not uncommon that parents ruminated about the cause and consequence of the injury with excessive guilt (Horridge et al., 2010; Mason & Hillier, 1993a). Expressions such as "*what if I hadn't done…*," "*I really regretted doing…*" illustrated those internal thoughts that parents struggled with.

Another major drawback identified from the quantitative literature is the misconception that guilt studied in isolation precludes the occurrence of other emotions. The crux of the issue lies in the researcher's tendency to blur the distinction between blame, shame, and guilt. The assessment of blame, either self-blaming or being blamed by others, has been used as a substitute to assess the feelings of guilt (Cella et al., 1988; De Young et al., 2014). Parental guilt relates to

a sense of responsibility and the cause of harm to the child; whereas blame indicates a shift in responsibility and accountability. Moreover, blame was a prime issue identified across the post-burn journey (McGarry et al., 2015; Ravindran, Rempel, & Ogilvie, 2013a; Ravindran et al., 2013b). When parents are responsible for the injury, blame from family members or healthcare providers' toward the parents may consequently result in parental self-blame, triggering guilt emotions (Kornhaber et al., 2018). When it comes to shame, the experience of shame received less attention compared to guilt and blame. Parents of a child with visible scar reported feelings of shame and embarrassment to other people's remarks and judgment (Öster, Hensing, Löjdström, Sjöberg, & Willebrand, 2014; Rossi et al., 2005). This gives rise to typical behavioral patterns of being reluctant to socialize with other people and trying to minimize the visibility of the scar, to avoid inquiry and conversation with other people.

Based on the review of studies, it seems that each emotion leads to unique patterned behaviors, and thoughts and overt behaviors can be viewed as the product of a combination of emotions. A recent systematic review suggested that guilt was not a significant correlate/predictor of PTSD when controlling for shame (Pugh, Taylor, & Berry, 2015). It is worth considering that guilt becomes maladaptive most typically when it occurs with a negative appraisal of a mixture of emotions such as shame and blame, among others. The consequential maladaptive guilt overshadows the adaptive function of guilt in the current literature. Further studies are needed to examine the role of guilt, blame, and shame on individual psychological symptoms and define the nature of maladaptive guilt.

Implications for Nursing

The new conceptual model of guilt proposes the process of guilt appraisal as a resultant outcome between adaptive guilt and maladaptive guilt. It provides a framework for

understanding the role of guilt on individual emotional expression and overt behaviors in parents and members of the family of a child with burn injury. We highlighted some related emotions, such as shame and blame, that received less attention in contemporary literature. A distinction ought to be made among these emotions presented by these parents as it may lead to different psychological sequelae.

The proposed model and review of the literature also has implications for research. The ongoing issue regarding the conceptual overlap between these related emotions poses challenges in emotion assessment. The best change to the assessment of guilt may well be through a mixed methods approach in order to capture the experience of guilt, especially the meanings embedded in the social and familial context perceived by the individual. This proposed perspective to understanding parent emotional responses after a child's traumatic event provides insights for clinicians and researchers to care for the child while positioning the parents of the child in the social context of the family.

Conclusion

This paper proposed a conceptual model of guilt appraisal based on the theoretical and empirical literature on guilt emotion within the context of families of a child with unintentional burns. The approach incorporated consideration of the two sides of guilt: adaptive guilt that motivates one in a positive way and maladaptive guilt that poses risks to an individual's psychological sequelae. We attempt to portray the complex and dynamic process of individual guilt appraisal that could facilitate the understanding of guilt emotion. The empirical literature on guilt in parents of burn survivors is quite limited with unclear conceptual distinction among guilt and related emotions; this model could be used to guide future guilt research, to further explore the role of guilt emotions on individual well-being and increase our understanding of guilt appraisal, particularly in cases of childhood burn injury.

References

Andrews, N., Jones, L. L., Moiemen, N., Calvert, M., Kinghorn, P., Litchfield, I., … PEGASUS Study Group. (2018). Below the surface: Parents' views on the factors that influence treatment adherence in paediatric burn scar management — A qualitative study. *Burns*, *44*(3), 626–635. https://doi.org/10.1016/j.burns.2017.09.003

Bakker, A., Maertens, K. J. P., Van Son, M. J. M., & Van Loey, N. E. E. (2013). Psychological consequences of pediatric burns from a child and family perspective: a review of the empirical literature. *Clinical Psychology Review*, *33*(3), 361–371. https://doi.org/10.1016/j.cpr.2012.12.006

Bakker, A., Van der Heijden, P. G. M., Van Son, M. J. M., & Van Loey, N. E. E. (2013). Course of traumatic stress reactions in couples after a burn event to their young child. *Health Psychology : Official Journal of the Division of Health Psychology, American Psychological Association*, *32*(10), 1076–1083. https://doi.org/10.1037/a0033983

Bakker, A., Van Loey, N. E. E., Van der Heijden, P. G. M., & Van Son, M. J. M. (2012). Acute stress reactions in couples after a burn event to their young child. *Journal of Pediatric Psychology*, *37*(10), 1127–1135. https://doi.org/10.1093/jpepsy/jss083

Bakker, A., Van Loey, N. E. E., Van Son, M. J. M., & Van der Heijden, P. G. M. (2010). Brief report: mothers' long-term posttraumatic stress symptoms following a burn event of their child. *Journal of Pediatric Psychology*, *35*(6), 656–661. https://doi.org/10.1093/jpepsy/jsp090

Barnett, B. S., Mulenga, M., Kiser, M. M., & Charles, A. G. (2017). Qualitative analysis of a psychological supportive counseling group for burn survivors and families in Malawi.

https://doi.org/10.1016/j.burns.2016.09.027

Barrett, K. C. (1995). A functionalist approach to shame and guilt. In J. P. Tangney & K. W. Fischer (Eds.), *Self-Conscious Emotions: The Psychology of Shame, Guilt, Embarrassment, and Pride* (pp. 25–63). Guilford Press. https://doi.org/10.3348/kjr.2012.13.2.189

Baumeister, R. F., Stillwell, A. M., & Heatherton, T. F. (1994). Guilt: an interpersonal approach. *Psychological Bulletin*, *115*(2), 243–267. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/8165271

Behrendt, H., & Ben-Ari, R. (2012). The Positive Side of Negative Emotion. *Journal of Conflict Resolution*, *56*(6), 1116–1138. https://doi.org/10.1177/0022002712445746

Bender, M. S., Janson, S. L., Franck, L. S., & Lee, K. A. (2018). Theory of Symptom Management. In M. J. Smith & P. R. Liehr (Eds.), *Middle Range Theory for Nursing* (4th ed., pp. 147–178). New York: Springer International Publishing.

Benjamin, K., Waterston, K., Russell, M., Schofield, O., Diffey, B., & Rees, J. L. (2004). The development of an objective method for measuring scratch in children with atopic dermatitis suitable for clinical use. *Journal of the American Academy of Dermatology*, *50*(1), 33–40. https://doi.org/10.1016/S0190-9622(03)02480-0

Bringhurst, C., Waterston, K., Schofield, O., Benjamin, K., & Rees, J. L. (2004). Measurement of itch using actigraphy in pediatric and adult populations. *Journal of the American Academy of Dermatology*, *51*(6), 893–898. https://doi.org/10.1016/j.jaad.2004.05.039

Carrougher, G. J., Martinez, E. M., McMullen, K. S., Fauerbach, J. A., Holavanahalli, R. K., Herndon, D. N., … Gibran, N. S. (2013). Pruritus in adult burn survivors: postburn

prevalence and risk factors associated with increased intensity. *Journal of Burn Care & Research : Official Publication of the American Burn Association*, *34*(1), 94–101. https://doi.org/10.1097/BCR.0b013e3182644c25

Cella, D. F., Perry, S. W., Kulchycky, S., & Goodwin, C. (1988). Stress and coping in relatives of burn patients: a longitudinal study. *Hospital & Community Psychiatry*, *39*(2), 159–166. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/3345979

Claar, R. L., Guite, J. W., Kaczynski, K. J., & Logan, D. E. (2010). Factor structure of the Adult Responses to Children's Symptoms: validation in children and adolescents with diverse chronic pain conditions. *The Clinical Journal of Pain*, *26*(5), 410–417. https://doi.org/10.1097/AJP.0b013e3181cf5706

Claar, R. L., Simons, L. E., & Logan, D. E. (2008). Parental response to children's pain: the moderating impact of children's emotional distress on symptoms and disability. *Pain*, *138*(1), 172–179. https://doi.org/10.1016/j.pain.2007.12.005

Corbin, J. M., Strauss, A. L., & Strauss, A. L. (2008). *Basics of qualitative research : techniques and procedures for developing grounded theory*. Sage Publications. Retrieved from https://books.google.com/books/about/Basics_of_Qualitative_Research.html?id=0TI8Ugvy2Z4C

Crittenden, P. (2017). Gifts from Mary Ainsworth and John Bowlby. *Clinical Child Psychology and Psychiatry*, *22*(3), 436–442. https://doi.org/10.1177/1359104517716214

Crittenden, P., Dallos, R., Landini, A., & Kozlowska, K. (2014). Toddlerhood and the beginnings of awareness and intention. In *Attachment and Family Therapy* (pp. 31–51). Milton Keynes, United Kingdom: Open University Press. Retrieved from

https://www.mheducation.ca/professional/products/9780335235902/attachment+and+family+therapy/

De Young, A. C., Hendrikz, J., Kenardy, J. A., Cobham, V. E., & Kimble, R. M. (2014). Prospective evaluation of parent distress following pediatric burns and identification of risk factors for young child and parent posttraumatic stress disorder. *Journal of Child and Adolescent Psychopharmacology*, *24*(1), 9–17. https://doi.org/10.1089/cap.2013.0066

Dise-Lewis, J. E. (2001). A developmental perspective on psychological principles of burn care. *The Journal of Burn Care & Rehabilitation*, *22*(3), 255–260. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/11403251

Dodd, M., Janson, S., Facione, N., Faucett, J., Froelicher, E. S., Humphreys, J., … Taylor, D. (2001). Advancing the science of symptom management. *Journal of Advanced Nursing*, *33*(5), 668–676. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/11298204

Duke, J. M., Boyd, J. H., Randall, S. M., Rea, S., & Wood, F. M. (2015). Childhood burn injury-impacts beyond discharge. *Translational Pediatrics*, *4*(3), 249–251. https://doi.org/10.3978/j.issn.2224-4336.2015.07.05

DuPen, M., van Tilburg, M., Langer, S., Murphy, T., Romano, J., & Levy, R. (2016). Parental Protectiveness Mediates the Association between Parent-Perceived Child Self-Efficacy and Health Outcomes in Pediatric Functional Abdominal Pain Disorder. *Children*, *3*(3), 15. https://doi.org/10.3390/children3030015

Ebata, T, Iwasaki, S., Kamide, R., & Niimura, M. (2001). Use of a wrist activity monitor for the measurement of nocturnal scratching in patients with atopic dermatitis. *The British Journal of Dermatology*, *144*(2), 305–309. Retrieved from

http://www.ncbi.nlm.nih.gov/pubmed/11251563

Ebata, Toshiya. (2016). Measurement of Itch: Actigraphy. In L. Misery & S. Ständer (Eds.), *Pruritus: Second Edition* (2nd ed., pp. XV, 453). Springer International Publishing. https://doi.org/10.1007/978-3-319-33142-3

Egberts, M. R., van de Schoot, R., Geenen, R., & Van Loey, N. E. E. (2017). Parents' posttraumatic stress after burns in their school-aged child: A prospective study. *Health Psychology*, *36*(5), 419–428. https://doi.org/10.1037/hea0000448

El Hamaoui, Y., Yaalaoui, S., Chihabeddine, K., Boukind, E., & Moussaoui, D. (2006a). Depression in mothers of burned children. *Archives of Women's Mental Health*, *9*(3), 117–119. https://doi.org/10.1007/s00737-006-0124-1

El Hamaoui, Y., Yaalaoui, S., Chihabeddine, K., Boukind, E., & Moussaoui, D. (2006b). Depression in mothers of burned children. *Archives of Women's Mental Health*, *9*(3), 117–119. https://doi.org/10.1007/s00737-006-0124-1

Elman, S., Hynan, L., Gabriel, V., Mayoà, M., & Mayo, M. J. (2009). The 5-D itch scale: a new measure of pruritus. *British Journal of Dermatology*. https://doi.org/10.1111/j.1365-2133.2009.09586.x

Everett, T., Parker, K., Fish, J., Pehora, C., Budd, D., Kelly, C., … Hayes, J. (2014). The construction and implementation of a novel postburn pruritus scale for infants and children aged five years or less: introducing the Toronto Pediatric Itch Scale. *Journal of Burn Care & Research : Official Publication of the American Burn Association*, *36*(1), 44–49. https://doi.org/10.1097/BCR.0000000000000129

Fischer, K. W., & Tangney, J. P. (1995a). Self-conscious emotions and the affect revolution: Framework and overview. In J. P. Tangney & K. W. Fischer (Eds.), *Self-Conscious Emotions: The Psychology of Shame, Guilt, Embarrassment, and Pride.* (pp. 3–22). Guilford Press. https://doi.org/10.3348/kjr.2012.13.2.189

Fischer, K. W., & Tangney, J. P. (1995b). Self-conscious emotions and the affect revolution: framework and overview. In J. P. Tangney & K. W. Fischer (Eds.), *Self-conscious emotions: the psychology of shame, guilt, embarrassment, and pride* (1st editio, pp. 3–24). Guilford Press.

Fukunishi, I. (1998). Posttraumatic stress symptoms and depression in mothers of children with severe burn injuries. *Psychological Reports*, *83*(1), 331–335. https://doi.org/10.2466/pr0.1998.83.1.331

Gaffney, A., McGrath, P. J., & Dick, B. (2003). Measuring Pain in Children: Developmental and Instrument Issues. In N. L. Schechter, C. B. Berde, & M. Yaster (Eds.), *Pain in Infants, Children, and Adolescents* (2nd ed., p. 128). Lippincott Williams & Wilkins.

Gedaly-Duff, V., Lee, K. A., Nail, L. M., Nicholson, H. S., & Johnson, K. P. (2006). Pain, Sleep Disturbance, and Fatigue in Children With Leukemia and Their Parents: A Pilot Study. *Oncology Nursing Forum*, *33*(3), 641–646. https://doi.org/10.1188/06.ONF.641-646

Graf, A., Schiestl, C., & Landolt, M. A. (2011). Posttraumatic stress and behavior problems in infants and toddlers with burns. *Journal of Pediatric Psychology*, *36*(8), 923–931. https://doi.org/10.1093/jpepsy/jsr021

Guite, J. W., McCue, R. L., Sherker, J. L., Sherry, D. D., & Rose, J. B. (2011). Relationships among pain, protective parental responses, and disability for adolescents with chronic

musculoskeletal pain: the mediating role of pain catastrophizing. *The Clinical Journal of Pain*, *27*(9), 775–781. https://doi.org/10.1097/AJP.0b013e31821d8fb4

Hall, E., Saxe, G., Stoddard, F., Kaplow, J., Koenen, K., Chawla, N., … King, D. (2006). Posttraumatic stress symptoms in parents of children with acute burns. *Journal of Pediatric Psychology*, *31*(4), 403–412. https://doi.org/10.1093/jpepsy/jsj016

Heath, J., Williamson, H., Williams, L., & Harcourt, D. (2018). Parent-perceived isolation and barriers to psychosocial support: a qualitative study to investigate how peer support might help parents of burn-injured children. *Scars, Burns & Healing*, *4*, 2059513118763801. https://doi.org/10.1177/2059513118763801

Henniger, N. E., & Harris, C. R. (2016). Can negative social emotions have positive consequences: An examination of embarrassment, shame, guilt, jealousy, and envy. In W. G. Parrott (Ed.), *The positive side of negative emotions* (pp. 76–97). New York, NY: Guilford Press. Retrieved from http://eds.a.ebscohost.com.offcampus.lib.washington.edu/ehost/detail/detail?vid=5&sid=56671694-d0e4-4001-9aea-6c0b0a2ad15b%40sessionmgr4007&bdata=JnNpdGU9ZWhvc3QtbGl2ZQ%3D%3D#AN=2014-05881-004&db=psyh

Herr, K., Coyne, P. J., McCaffery, M., Manworren, R., & Merkel, S. (2011). Pain Assessment in the Patient Unable to Self-Report: Position Statement with Clinical Practice Recommendations. *Pain Management Nursing*, *12*(4), 230–250. https://doi.org/10.1016/j.pmn.2011.10.002

Horridge, G., Cohen, K., & Gaskell, S. (2010). BurnEd: Parental, psychological and social

factors influencing a burn-injured child's return to education. *Burns*, *36*(5), 630–638. https://doi.org/10.1016/j.burns.2009.08.013

Ikoma, A., Steinhoff, M., Ständer, S., Yosipovitch, G., & Schmelz, M. (2006). The neurobiology of itch. *Nature Reviews. Neuroscience*, *7*(7), 535–547. https://doi.org/10.1038/nrn1950

Kassam-Adams, N., Bakker, A., Marsac, M. L., Fein, J. A., & Winston, F. K. (2015). Traumatic Stress, Depression, and Recovery: Child and Parent Responses After Emergency Medical Care for Unintentional Injury. *Pediatric Emergency Care*, *31*(11), 737–742. https://doi.org/10.1097/PEC.0000000000000595

Kazis, L. E., Liang, M. H., Lee, A., Ren, X. S., Phillips, C. B., Hinson, M., … Tompkins, R. (2002). The development, validation, and testing of a health outcomes burn questionnaire for infants and children 5 years of age and younger: American Burn Association/Shriners Hospitals for Children. *The Journal of Burn Care & Rehabilitation*, *23*(3), 196–207. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/12032370

Kim, S., Thibodeau, R., & Jorgensen, R. S. (2011). Shame, guilt, and depressive symptoms: A meta-analytic review. *Psychological Bulletin*, *137*(1), 68–96. https://doi.org/10.1037/a0021466

Kornhaber, R., Childs, C., & Cleary, M. (2018). Experiences of guilt, shame and blame in those affected by burns: A qualitative systematic review. *Burns*, *44*(5), 1026–1039. https://doi.org/10.1016/j.burns.2017.11.012

Krippendorff, K. (2013). Unitizing. In *Content analysis: an introduction to its methodology* (3rd ed., pp. 98–111). Sage PublicationsSage CA: Thousand Oaks, CA.

Kwa, K., Pijpe, A., Rashaan, Z., Tuinebreijer, W., Breederveld, R., & Loey, N. (2018). Course and Predictors of Pruritus Following Burns: A Multilevel Analysis. *Acta Dermato Venereologica*, *98*(7), 636–640. https://doi.org/10.2340/00015555-2935

Lavery, M., Stull, C., Kinney, M., & Yosipovitch, G. (2016). Nocturnal Pruritus: The Battle for a Peaceful Night's Sleep. *International Journal of Molecular Sciences*, *17*(3), 425. https://doi.org/10.3390/ijms17030425

Lee, S.-Y., & Weiss, S. J. (2009). When East meets West: intensive care unit experiences among first-generation Chinese American parents. *Journal of Nursing Scholarship : An Official Publication of Sigma Theta Tau International Honor Society of Nursing / Sigma Theta Tau*, *41*(3), 268–275. https://doi.org/10.1111/j.1547-5069.2009.01290.x

Lewis, F. M., & Deal, L. W. (1995). Balancing our lives: a study of the married couple's experience with breast cancer recurrence. *Oncology Nursing Forum*, *22*(6), 943–953. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/7567612

Lewis, H. B. (1971). Shame and guilt in neurosis. *Psychoanalytic Review*, *58*(3), 419–438. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/5150685

Li, H., Wang, S., Tan, J., Zhou, J., Wu, J., & Luo, G. (2017). Epidemiology of pediatric burns in southwest China from 2011 to 2015. *Burns*, *43*(6), 1306–1317. https://doi.org/10.1016/j.burns.2017.03.004

Linder, L. (2008, August 1). Developmental Diversity in Symptom Research Involving Children and Adolescents with Cancer. *Journal of Pediatric Nursing*. W.B. Saunders. https://doi.org/10.1016/j.pedn.2007.10.003

Linder, L. (2010). Analysis of the UCSF Symptom Management Theory: implications for pediatric oncology nursing. *Journal of Pediatric Oncology Nursing : Official Journal of the Association of Pediatric Oncology Nurses*, *27*(6), 316–324. https://doi.org/10.1177/1043454210368532

Maskell, J., Newcombe, P., Martin, G., & Kimble, R. (2013). Psychosocial functioning differences in pediatric burn survivors compared with healthy norms. *Journal of Burn Care & Research : Official Publication of the American Burn Association*, *34*(4), 465–476. https://doi.org/10.1097/BCR.0b013e31827217a9

Mason, S. A. (1993). Young, scarred children and their mothers--a short-term investigation into the practical, psychological and social implications of thermal injury to the preschool child. Part I: Implications for the mother. *Burns : Journal of the International Society for Burn Injuries*, *19*(6), 495–500. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/8292233

Mason, S. A., & Hillier, V. F. (1993a). Young, scarred children and their mothers--a short-term investigation into the practical, psychological and social implications of thermal injury to the preschool child. Part II: implications for the child. *Burns : Journal of the International Society for Burn Injuries*, *19*(6), 501–506. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/8292234

Mason, S. A., & Hillier, V. F. (1993b). Young, scarred children and their mothers--a short-term investigation into the practical, psychological and social implications of thermal injury to the preschool child. Part III: Factors influencing outcome responses. *Burns : Journal of the International Society for Burn Injuries*, *19*(6), 507–510. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/8292235

McGarry, S., Elliott, C., McDonald, A., Valentine, J., Wood, F., & Girdler, S. (2015). "This is not just a little accident": a qualitative understanding of paediatric burns from the perspective of parents. *Disability and Rehabilitation*, *37*(1), 41–50. https://doi.org/10.3109/09638288.2014.892640

Meyer, W. J. 3rd, Robert, R., Murphy, L., Blakeney, P. E., III, M. W. J., Robert, R., … PE, B. (2000). Evaluating the psychosocial adjustment of 2- and 3-year-old pediatric burn survivors. *Journal of Burn Care & Rehabilitation*, *21*(2), 178–184. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/10752752

Meyer, W. J., Robert, R., Murphy, L., & Blakeney, P. E. (2000). Evaluating the psychosocial adjustment of 2- and 3-year-old pediatric burn survivors. *The Journal of Burn Care & Rehabilitation*, *21*(2), 178; discussion 179-84. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/10752752

Morris, V., Murphy, L. M., Rosenberg, M., Rosenberg, L., Holzer, C. E., & Meyer, W. J. (2012). Itch assessment scale for the pediatric burn survivor. *Journal of Burn Care & Research : Official Publication of the American Burn Association*, *33*(3), 419–424. https://doi.org/10.1097/BCR.0b013e3182372bfa

Niedenthal, P. M., Tangney, J. P., & Gavanski, I. (1994). "If Only I Weren't" Versus "If Only I Hadn't": Distinguishing Shame and Guilt in Counterfactual Thinking. *Journal of Personality and Social Psychology*, *67*(4), 585–595. https://doi.org/10.1037/0022-3514.67.4.585

Nieuwendijk, S. M. P., de Korte, I. J., Pursad, M. M., van Dijk, M., & Rode, H. (2018). Post burn pruritus in pediatric burn patients. *Burns*, *44*(5), 1151–1158.

https://doi.org/10.1016/j.burns.2018.02.022

Noel, M., Alberts, N., Langer, S. L., Levy, R. L., Walker, L. S., & Palermo, T. M. (2016). The Sensitivity to Change and Responsiveness of the Adult Responses to Children's Symptoms in Children and Adolescents With Chronic Pain. *Journal of Pediatric Psychology*, *41*(3), 350–362. https://doi.org/10.1093/jpepsy/jsv095

Noel, M., Palermo, T. M., Essner, B., Zhou, C., Levy, R. L., Langer, S. L., … Walker, L. S. (2015). A Developmental Analysis of the Factorial Validity of the Parent-Report Version of the Adult Responses to Children's Symptoms in Children Versus Adolescents With Chronic Pain or Pain-Related Chronic Illness. *The Journal of Pain*, *16*(1), 31–41. https://doi.org/10.1016/j.jpain.2014.10.005

Öster, C., Hensing, I., Löjdström, T., Sjöberg, F., & Willebrand, M. (2014). Parents' Perceptions of Adaptation and Family Life After Burn Injuries in Children. *Journal of Pediatric Nursing*, *29*(6), 606–613. https://doi.org/10.1016/j.pedn.2014.06.010

Parnell, L. K. S., Nedelec, B., Rachelska, G., & LaSalle, L. (2012). Assessment of Pruritus Characteristics and Impact on Burn Survivors. *Journal of Burn Care & Research*, *33*(3), 407–418. https://doi.org/10.1097/BCR.0b013e318239d206

Patel, T., Ishiuji, Y., & Yosipovitch, G. (2007). Nocturnal itch: why do we itch at night? *Acta Dermato-Venereologica*, *87*(4), 295–298. https://doi.org/10.2340/00015555-0280

Peterson, C. C., & Palermo, T. M. (2004). Parental reinforcement of recurrent pain: the moderating impact of child depression and anxiety on functional disability. *Journal of Pediatric Psychology*, *29*(5), 331–341. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/15187172

Pugh, L. R., Taylor, P. J., & Berry, K. (2015). The role of guilt in the development of post-traumatic stress disorder: A systematic review. *Journal of Affective Disorders*, *182*, 138–150. https://doi.org/10.1016/J.JAD.2015.04.026

Ravindran, V., Rempel, G. R., & Ogilvie, L. (2013a). Embracing survival: a grounded theory study of parenting children who have sustained burns. *Burns : Journal of the International Society for Burn Injuries*, *39*(4), 589–598. https://doi.org/10.1016/j.burns.2012.12.016

Ravindran, V., Rempel, G. R., & Ogilvie, L. (2013b). Parenting burn-injured children in India: A grounded theory study. *International Journal of Nursing Studies*, *50*(6), 786–796. https://doi.org/10.1016/J.IJNURSTU.2012.06.011

Rimmer, R. B., Alam, N. B., Bay, R. C., Sadler, I. J., Foster, K. N., & Caruso, D. M. (2015). The reported pain coping strategies of pediatric burn survivors-does a correlation exist between coping style and development of anxiety disorder? *Journal of Burn Care & Research : Official Publication of the American Burn Association*, *36*(2), 336–343. https://doi.org/10.1097/BCR.0000000000000109

Rivlin, E., & Faragher, E. B. (2007). The psychological sequelae on mothers of thermally injured children and adolescents: future directions: Part 3. *Dev Neurorehabil*, *10*(2), 183–190. https://doi.org/10.1080/17518420701309758

Rose, M., Sanford, A., Thomas, C., & Opp, M. R. (2001). Factors altering the sleep of burned children. *Sleep*, *24*(1), 45–51. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/11204053

Rossi, L. A., Vila, V. da S. C., Zago, M. M. F., & Ferreira, E. (2005). The stigma of burns. *Burns*, *31*(1), 37–44. https://doi.org/10.1016/j.burns.2004.07.006

Schneider, J. C., Nadler, D. L., Herndon, D. N., Kowalske, K., Matthews, K., Wiechman, S. A., … Ryan, C. M. (2015). Pruritus in pediatric burn survivors: defining the clinical course. *Journal of Burn Care & Research : Official Publication of the American Burn Association*, *36*(1), 151–158. https://doi.org/10.1097/BCR.0000000000000145

Shelley, M., & Krippendorff, K. (1984). Content Analysis: An Introduction to its Methodology. *Journal of the American Statistical Association*, *79*(385), 240. https://doi.org/10.2307/2288384

Sheridan, R. L., Hinson, M. I., Liang, M. H., Nackel, A. F., Schoenfeld, D. A., Ryan, C. M., … Tompkins, R. G. (2000). Long-term outcome of children surviving massive burns. *JAMA*, *283*(1), 69–73. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/10632282

Shi, X.-Q., Qi, Y.-H., Shi, D., Yan, C., Shi, J., Cao, B.-L., … Wang, H.-Y. (2014). Features and Risk Factors of Nonfatal Injury among the Rural Children: A Survey of Seven Schools in a Mountain Area in Southwest China. *PLoS ONE*, *9*(7), e102099. https://doi.org/10.1371/journal.pone.0102099

Simons, L. E., Claar, R. L., & Logan, D. L. (2008). Chronic pain in adolescence: parental responses, adolescent coping, and their impact on adolescent's pain behaviors. *Journal of Pediatric Psychology*, *33*(8), 894–904. https://doi.org/10.1093/jpepsy/jsn029

Sveen, J, Sjöberg, F., & Öster, C. (2014). Health-related quality of life in Swedish pediatric burn patients and associations with burn and family characteristics. *Burns : Journal of the International Society for Burn Injuries*, *40*(5), 987–994. https://doi.org/10.1016/j.burns.2013.10.005

Sveen, Josefin, & Willebrand, M. (2018). Feelings of guilt and embitterment in parents of

children with burns and its associations with depression. *Burns*, *44*(5), 1135–1140. https://doi.org/10.1016/j.burns.2018.02.005

Tangney, J. P. (1995). shame and guilt in interpersonal relationship. In J. P. Tangney & K. W. Fischer (Eds.), *Self-Conscious Emotions: The Psychology of Shame, Guilt, Embarrassment, and Pride* (1st eds, pp. 114–139). New York: Guilford Press.

Tangney, J. P., Burggraf, S. A., & Wagner, P. E. (1995). Shame-proneness, guilt-proneness, and psychological symptoms. In J. P. Tangney & K. W. Fischer (Eds.), *Self-Conscious Emotions: The Psychology of Shame, Guilt, Embarrassment, and Pride.* (1st ed., pp. 343–367). Guilford Press. https://doi.org/10.3348/kjr.2012.13.2.189

Tracy, J. L., & Robin, R. W. (2007). The self in self-conscious emotions: a cognitive appaisal approach. In J. L. Tracy, R. W. Robins, & J. P. Tangney (Eds.), *The self-conscious emotions: theory and research* (pp. 3–20). Guilford Press.

Tracy, J. L., & Robins, R. W. (2006). Appraisal Antecedents of Shame and Guilt: Support for a Theoretical Model. *Personality and Social Psychology Bulletin*, *32*(10), 1339–1351. https://doi.org/10.1177/0146167206290212

Tracy, J. L., & Robins, R. W. (2007). The self in self-conscious emotions: A cognitive appraisal approach. In J. L. Tracy, R. W. Robins, & J. P. Tangney (Eds.), *The self-conscious emotions: Theory and research* (pp. 3–20). Guilford Press. https://doi.org/10.3892/ijo.2013.2179

van Baar, M. E., Polinder, S., Essink-Bot, M. L., van Loey, N. E. E., Oen, I. M. M. H., Dokter, J., … van Beeck, E. F. (2011). Quality of life after burns in childhood (5-15 years): children experience substantial problems. *Burns : Journal of the International Society for Burn*

Injuries, *37*(6), 930–938. https://doi.org/10.1016/j.burns.2011.05.004

Van Loey, N. E. E., Bremer, M., Faber, A. W., Middelkoop, E., & Nieuwenhuis, M. K. (2008). Itching following burns: epidemiology and predictors. *The British Journal of Dermatology*, *158*(1), 95–100. https://doi.org/10.1111/j.1365-2133.2007.08278.x

von Baeyer, C. L., Chambers, C. T., Forsyth, S. J., Eisen, S., & Parker, J. A. (2013). Developmental data supporting simplification of self-report pain scales for preschool-age children. *The Journal of Pain : Official Journal of the American Pain Society*, *14*(10), 1116–1121. https://doi.org/10.1016/j.jpain.2013.04.008

Walker, L. S., Levy, R. L., & Whitehead, W. E. (2006). Validation of a measure of protective parent responses to children's pain. *The Clinical Journal of Pain*, *22*(8), 712–716. https://doi.org/10.1097/01.ajp.0000210916.18536.44

Wang, X., Zhang, Y., Zhang, Q., Liu, J., Tanuseputro, P., Gomez, M., … Liao, Z. (2006). Characteristics of 1494 pediatric burn patients in Shanghai. *Burns : Journal of the International Society for Burn Injuries*, *32*(5), 613–618. https://doi.org/10.1016/j.burns.2005.12.012

Zhang, W.-X., Wei, H., Shen, Z.-Y., Peng, X., Chen, X.-G., Li, W., … Niu, Y.-J. (2014). Concerns of and coping strategies by parents of pediatric liver transplant recipients: a qualitative study from China. *International Journal of Clinical and Experimental Medicine*, *7*(12), 5723–5729. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/25664098

Appendix

Table 2.1 *Summary of included studies with a quantitative approach (n=7)*

Author/ Year	Purpose of the study	Key findings	Participants	Time of the assessment	How guilt was measured
Sveen & Willebrand, 2018	To examine guilt and embitterment in mothers and fathers of children with burns and its associations with depression and burn severity	Burn-specific and general guilt were higher in mothers than fathers, but there were no differences in embitterment or symptoms of depression. General guilt was associated with depression	Parents of children (<18 years age) with burns	0.8–5.6 years after their child's burn	One item of burn-related guilt: (1) I usually feel guilty or see myself as being responsible to some extent for my child's injuries, two items of generalized guilt: (2) I often feel guilt for things that I have done or failed to do. (3) I have felt guilt for no reason, and one item of embitterment: (4) I often feel bitterness toward some things or someone whom I feel, to some extent, feel is responsible for my child's injuries. The items are rated on a 5-point scale ranging from 0–4 (0 = never applicable, 4 = always applicable) with higher scores indicating a higher degree of guilt or embitterment.
Egbert et al., 2017	To examine the course and potential predictors of parents' posttraumatic stress symptoms (PTSS) after burn injury in their child	The perceived life threat and feelings of guilt and anger linked to the burn event were significantly related to parental PTSS, especially in mothers.	Couples with children (8-18) with acute burns	Prospective longitudinal 18 months	"To what extent do the following emotions (guilt and anger) apply when you think about the accident that caused the burn?" Answers were rated on a 5-point Likert scale ranging from 0–4 (0 = not at all, 4 = a lot)
De Young et al., 2014	To identify risk factors for posttraumatic stress symptoms (PTSS) in young children and their parents.	Risk factors identified for parent PTSS included prior trauma history, acute distress, a greater number of child invasive procedures,	120 parents of 1–6-year-old children with unintent	Prospective longitudinal survey at 2 weeks, 1 and 6 months.	The self-blame subscale was used to assess parent guilt. This subscale consists of the following two yes/no questions: "I've been criticizing myself" and "I've

		guilt, and child PTSS.	ional burn injuries		been blaming myself for things that happened."
Bakker, Van der Heijden, et al., 2013	To examine traumatic stress reactions in couples that were followed prospectively for 18 months.	Parental feelings of guilt affected the level of symptoms throughout the entire 18 months	Couples with children (0-4) with acute burns	Prospectiv e longitudin al 18 months	To what extent do the following emotions apply when you think about the accident that caused the burn, on a 5-point Likert scale, ranging from 0–4 (0 = not at all, 4 = a lot)
Bakker, Van Loey, Van der Heijden, & Van Son, 2012	To examine acute stress reactions in couples following a burn event to their preschool child.	Parents with feelings of guilt reported high intrusion symptoms (Impact of Event Scale)	Couples with children (0-4) with acute burns	Within first-month post burn	Same above.
Bakker et al., 2010	To examine the role of burn severity and feelings of guilt on the course of posttraumatic stress symptoms (PTSS) in mothers	27% of mothers reported feelings of guilt and the interaction between feelings of guilt and scars were significant predictors of the course of PTSS.	Mothers of children with burns	In-depth interview 1-11 years post burn	Yes/no question on whether they had feelings of guilt regarding the burn event.
Fukunishi, 1998	To examine posttraumatic stress symptoms and depressive symptoms in mothers of children with thermal injuries	Ratings of the three symptoms of posttraumatic 'stress disorders for the mothers were significantly and positively correlated with scores for guilt feelings. (intense distress at a similar event, restricted range of affect, and hypervigilance)	Mothers and child	Post-burn 2-18 months	Feelings of guilt that they did not pay close enough attention to children's behaviors.

Table 2.2 Summary of included studies with a qualitative approach (n=6)

Author	Purpose of the study	Methodology /Methods	Participants /setting	Key findings	How was guilt studied?

Andrews et al., 2018	To outline parents' view on the factors that influence adherence on scar treatment.	Interpretive description /semi-structured in-person interviews	22 parents of pediatric burn patients aged 0-9 years /6-month post pressure garment treatment	Feelings of guilt, blame, and anger related to the accident was signified when parents see the scar as they manage the scar and may contribute to pressure garment treatment non-adherence.	Interview questions were not disclosed in the paper
Heath et al., 2018	To explore parents' experiences of support after their child's injury and their thoughts on peer support specifically	Qualitative /Thematic analysis on semi-structured interviews (a choice of interview methods: in-person, Skype, telephone, or email responses)	12 parents or grandfather of a child with accidental burns (mean age 3.6) / average 3 years post-burn	Results suggested that recurrent parental feelings of guilt could be a barrier for them to seek psychosocial support as parents don't want to be questioned.	Interview questions were not disclosed in the paper
Barnett et al., 2017	To report patients and caregivers' experience in a burn support group that allow them to discuss emotions and struggles while finding mutual support from other group members.	Qualitative /Thematic analysis on group discussion on pre-determined topics	18 caregivers of burn patients aged 13-45 years / During hospitalization	Caregivers revealed their guilt and self-blame for their child's injuries, their perception of the anger, and struggles with a rumination about their child's injury and future, especially about burn associated stigma.	Group discussion on topics: 1) the relationship between psychological stress and patients' physical recovery; 2) coping with physical and emotional pain following burns; 3) stress management, depression following burns and benefits from participating in group therapy sessions.
McGarry et al., 2015	To describe the experiences	Phenomenology	19 parents of pediatric burn patients aged	Parents blamed themselves or others based on the causes	Unstructured, open-ended questions were

	of parents of children with burns	/in-depth analysis of an unstructured in-person interview.	8-month to 15 years /6-month post-burn	of the accident. Blame was a strong emotion felt throughout and resulted in feelings of either anger or guilt. Parents were unable to process such negative feelings as they wanted to talk but never did.	asked about the accident, admission to hospital, surgery, and recovery to explore the experiences, perceptions, thoughts, and feelings of the parents.
Ravindran et al., 2013b	To discover the process of parenting burn-injured children in India	Constructivist grounded theory / inductive analysis and focused coding on a semi-structured in-person interview	22 parents and family caregivers of pediatric burn patients aged 2-15 years /post-burn 8 months to 9 years	Parents suffered the double trauma of their child's burn and blame from family members, health providers, others. Parenting their child involved a process of enduring the blame, including internalizing blame, submitting to blame, rising above blame, and avoiding blame.	Interview questions: 1) Can you tell me your experiences related to your child's burn injury? 2) What was the most challenging thing about looking after your burn-injured child? 3) How did you manage the wound?
Mason 1993	To describe the mother's response pattern after the child's thermal injury.	Constructivist grounded theory /inductive analysis on a semi-structured interview	57 mothers of pediatric burn patients aged < 5 years / prospective at 1 week, 2-month and 6-mo following discharge	The phasic pattern of mothers' responses after child's thermal injury. Guilt process was described.	Interview questions focus on: 1) any worries or fears the mother may have when the child returns home 2) to immediate and continuing problems, reaction to changes over time

Figure 2. 1 *PRISMA Flow diagram of included studies*

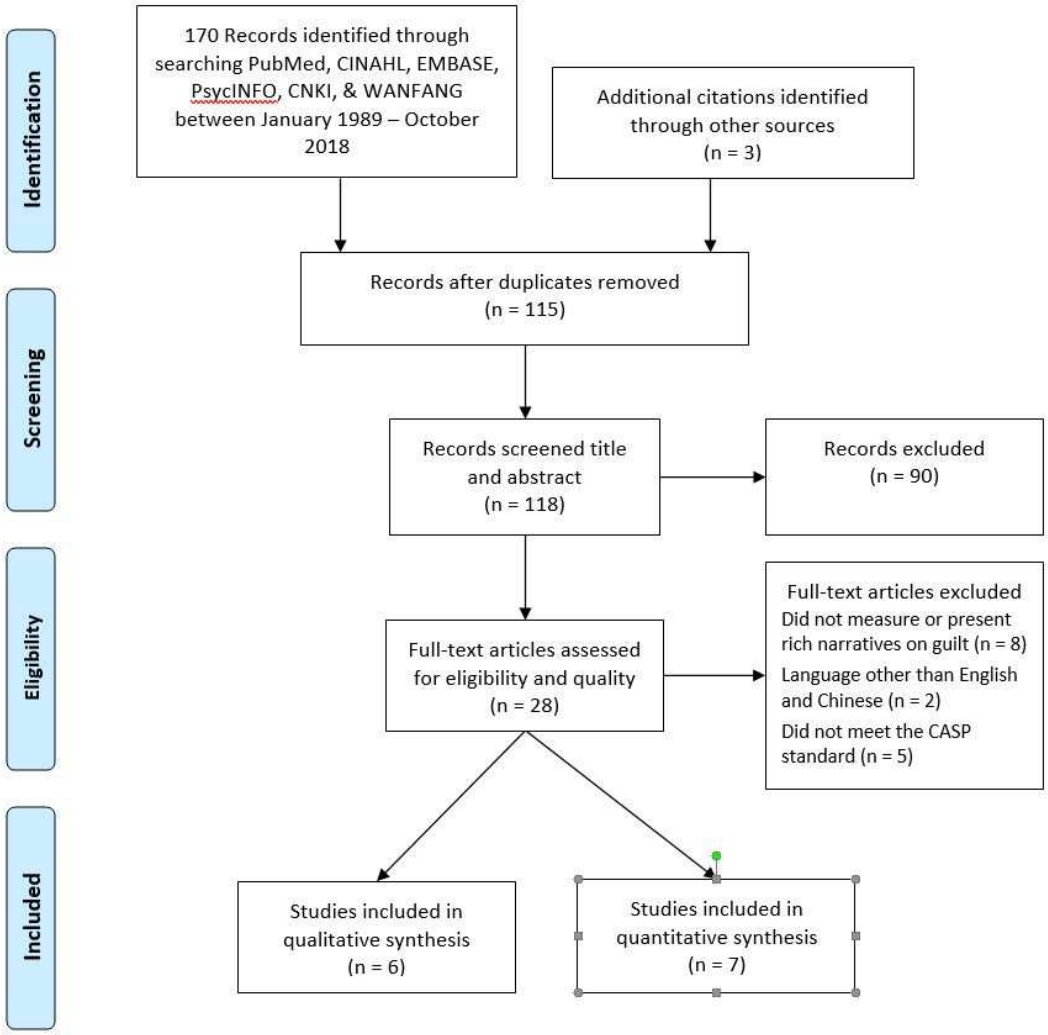
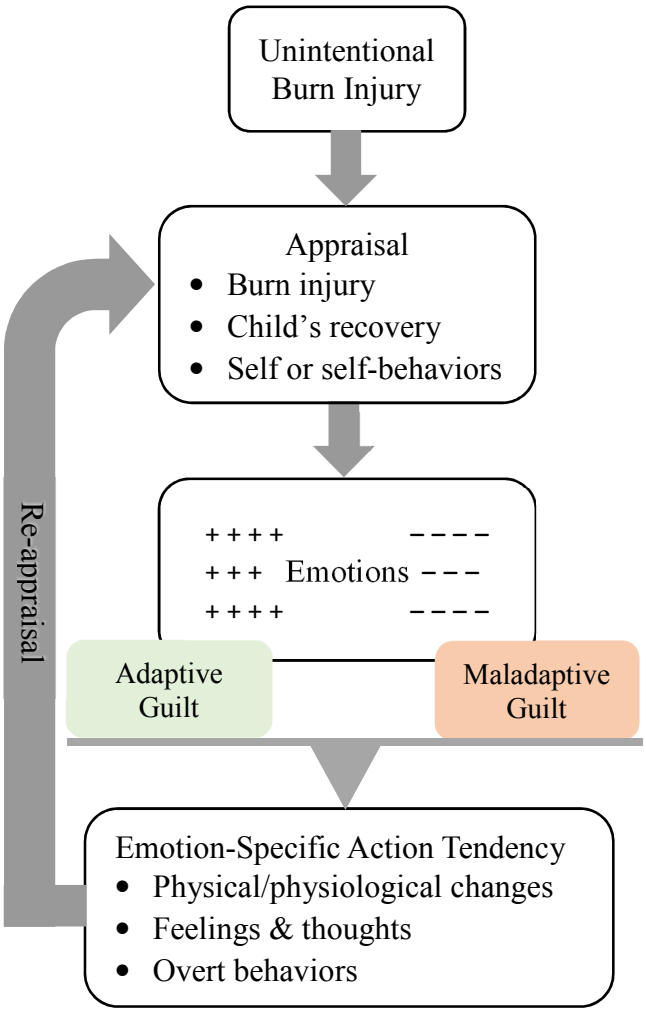


Figure 2.2 *Conceptual model of parental guilt appraisal*



Chapter 3. Representation and Consequences of Guilt in Parents of Young Children with Unintentional Burns

Abstract

Objectives: The purposes of this study were to examine guilt and its representation in parental responses to a child's burn, and to look for the immediate consequences that guilt for parents.

Methods: Semi-structured interviews were conducted with 20 parents or caregivers in the hospital during their child's clinical visit. We used a combination of deductive and inductive content analysis to analyze the interview data.

Results: Parents expressed feelings of guilt using both the word "guilt" or sentences that conveyed the manifest meaning, which reflected the definition of guilt. Analysis of the data produced three conceptual domains of the consequence of guilt: (1) reappraisal of guilt toward the self, (2) motivational reactions toward the child, and (3) other accompanying emotions.

Conclusion: Guilt and its consequences are correlated but have distinct semantic representation. However, guilt and its related emotions were often expressed within one parent's account of his or her emotional experience. The results of this study suggest that guilt appears to promote both prosocial and antisocial emotions and behaviors in parents. Interventions are needed that directly assist parents who are in greater need of professional mental health support. Further research is needed to elucidate the role of guilt in the development and persistence of emotional distress in parents facing their child's unintentional burn injury.

Introduction

The incidence of unintentional burn injuries provides a natural condition that induces guilt and other emotions, such as blame in the parents of the inflicted child. Parents feel guilty when they deem themselves directly or indirectly responsible for their child's unintentional burns (Mason, 1993; McGarry et al., 2015). In the Oxford English Dictionary, guilt is defined as "*a feeling of having committed wrong or failed in an obligation*." To blame, on the other hand, is defined as to "*feel or declare that (someone or something) is responsible for a fault or wrong*." To some extent, blame could be viewed as the consequence of guilt. Guilt is a warranted emotional reaction that entails a learned cognitive appraisal process based on prior experience (Fischer & Tangney, 1995a). The effects of guilt may shed light on the essential nature and its consequences. Empirical evidence generated in the field of psychology has suggested that the consequences of guilt include the desire for punishment, prosocial behaviors (e.g., expression of remorse, making reparations, confession, changing behaviors) (Baumeister et al., 1994; Behrendt & Ben-Ari, 2012; Tracy & Robin, 2007), and antisocial behaviors (tendency to avoid the victim) (Baumeister et al., 1994). Such interpersonal actions presumably reduce the feeling of guilt (Baumeister et al., 1994).

Our search of the literature for studies that explored the guilt experience expressed by parents of children with unintentional burn injury yielded five qualitative studies. Although these studies aimed to explore the general experience among parents and family caregivers post-burn, feeling of guilt was revealed as one of the major themes.

The first known longitudinal study of maternal responses after child's scalding, conducted by Mason and Hillier (Mason, 1993; Mason & Hillier, 1993a, 1993b), portrayed a phasic pattern of mothers' responses after a child's thermal injury. The feeling of guilt was

related to the mother's perception of self, feelings of isolation and stigma, stress and anxiety, wound care, and actions taken to protect the child.

When McGarry and colleagues (2015) interviewed 19 parents to describe their reactions to their child's burn injury, they found that after about six months post-burn, many parents described guilt that resulted from feeling responsible for the accident, and they constantly ruminated on thoughts of guilt. Blame was a strong emotion felt throughout and resulted in feelings of either anger or guilt. Parents blamed themselves or others depending on the causes of the accident, and they were unable to process such negative feelings, as they wanted to talk but never did.

Barnett and colleagues (2017) reported findings from the supportive group counseling sessions with 18 caregivers of patient with burn injury aged 13 to 45 years during hospitalization. Thematic analysis of the transcripts revealed that caregivers felt guilt and self-blame for their child's injuries. Guilt created distance in the relationship between the child and their caregivers. Caregivers struggled with rumination about the injury and its impact on the child's future, and concerns about burn-associated stigma.

Heath, Williamson, Williams, and Harcourt (2018) conducted semi-structured interviews with 12 parents of a young child with accidental burns to explore parents' experiences of support following their child's injury and their thoughts on peer support. After an average of 3 years post-burn, many parents still felt guilty about their child's injury. The results suggested that parents recognized the need to talk but felt difficulty addressing their thoughts. The results also suggested that such recurrent feelings of guilt can be a barrier for parents to seek psychosocial support because they don't want to be questioned if others perceive that they didn't do the right thing at the time. In addition, access to peer support was more acceptable when the peer support

included parents who were not judgmental in responses to the shared experiences and feelings of guilt and shame.

Andrews et al. (2018) outline parents' views on the factors that influence parental adherence on scar treatment for pediatric burn patients aged 0–9 years after 6 months of pressure garment treatment. Parents felt a combination of guilt, blame, and anger related to the accident when they saw the scarring as they managed the scar treatment, and this may have contributed to pressure garment treatment nonadherence.

Therefore, the effects of guilt on parental behavioral and emotional outcomes have long-term implications. The dynamics of guilt may consequently shape parent-child interaction during the post-burn care. Nevertheless, to our knowledge, the cognitive appraisal processes involved in developing and maintaining the guilt responses linked to the incidence of burn injuries have not been sufficiently studied. The purposes of this study were (1) to examine guilt and its representation in parental responses to a child's burn; and (2) to look for the immediate consequences that guilt has had for parents. We constructed an open-ended interview to collect data in an effort to understand the parents' experiences in their own words.

Methods

Sample & setting.

This analysis is part of a study that examined the parental behavioral and emotional responses to their young children following an unintentional burn injury. Parents of young children with burns were recruited from a regional burn center in eastern China. This center sees about 450 burn injuries in children every month; approximately one-third of these patients are children under the age of 3.

Study participants were eligible if (a) they were a parent or primary caregiver of a child who was 16 months to 5 years old at the time of burn injury; (b) their child had deep second-degree or third-degree burns at the time of injury; (c) their child was 1–10 month(s) post-burn injury during his/her clinic visit; and (d) they were able to read, speak, and understand Mandarin. The 1-to-10-month post-burn period was purposely chosen to capture parental responses to their child's itching since itching is the most prevalent symptom during the 6 months following the injury and peaks at 2 months (Mason & Hillier, 1993a; Schneider et al., 2015). Caregivers of a child with suspected abusive burns were excluded from the study due to the different nature of burn injury.

Procedures

The study was approved by the Institutional Review Board at the University of Washington and the burn center in Shanghai, China. The script used to introduce potential participants to the study and the interview guide were reviewed and approved by IRB. The on-site burn surgeon provided access to a child's daily appointment list and medical records (age, gender, burn degree). A study intermediary first identified potential eligible parents of children with burn injuries during a clinical appointment between October and December 2017. Parents

were approached while they were waiting to meet with the physician about their child's post-burn care.

The study intermediary briefly introduced the study using a script that the principal investigator (PI) provided. If the parent agreed to learn more about the study, the intermediary screened for eligibility based on the inclusion and exclusion criteria. If eligible and interested, the parent was introduced to the PI. The PI then explained the study in detail and allowed the parent to ask questions. Once signed informed consent was obtained, the parent was considered enrolled and was assigned a study ID.

Data Collection.

After enrollment, confidential face-to-face interviews were conducted in a private exam room by the PI in China. The participant was asked to complete the demographic and burn history form and the parental itch-assessment form. The interview consisted of 14 open-ended questions. This paper focuses on five of the 14 questions listed below:

1. How do you feel about your child’s burn injury?
2. What, if any, situations cause the [feelings mentioned by the interviewee]?
3. Is there a time when you experience [feelings mentioned by the interviewee] more than others?
4. How, if at all, do you think [feelings mentioned by the interviewee] affect your interaction with the child?
5. How have other members of your family responded to the burn injury?

Interviews lasted 20 to 35 minutes, and the audio was digitally recorded. All participants were asked the same questions.

Digital recorded interviews were first transcribed verbatim in Mandarin by Xunfei Transcription (www.iflyrec.com), and then the transcriptions were verified by the senior researcher and a trained assistant for 100% accuracy against the digital recordings. All the interview data were translated into English by the PI and a professional translator. Any discrepancies between the two versions of translation were discussed until the two translators reached 100% agreement.

Data Analysis

SPSS 19.0 (IBM, Armonk, New York) was used to analyze the quantitative data. Demographic and burn injury data were summarized descriptively with frequencies and percentages for categorical variables and mean and SD for continuous variables.

Following transcription and verification for accuracy, and translation and verification for accuracy, the data were analyzed by using a combination of deductive and inductive content analysis. Data analysis occurred in three steps (see Table 3.1 for a brief description). We aimed (1) to examine guilt and its representation in parental responses to a child's burn, and (2) to look for the immediate consequences that guilt has had on the parents. We began the analysis by identifying the unit of analysis according to two kinds of distinctions: categorical distinctions and propositional distinctions (Krippendorff, 2013). The categorical distinction of guilt is based on the definition of guilt from the *Oxford English Dictionary*: "*A feeling of having committed wrong or failed in an obligation*." See Table 3.2 for the definition of guilt and its related concepts. The unit of analysis was the feeling expressed by the parents on their judgment about their behaviors, and each unit was evaluated by comparing the manifest meaning of the unit with analytic criteria based on the definition of guilt. The manifestations of the guilt included parents' direct expression of guilt (i.e., using the word "guilt") or their indirect expression of a feeling of

having committed wrong or failed in an obligation. To identify the consequences of guilt, we delineated the units after decomposing long sequences of thoughts and feelings using propositional distinction, that is, those units that exhibited consequential semantic relations with guilt. Each unit was captured at the manifest meaning of the data. An example of the unitizing process has been presented in Table 3.3. There are areas of data in which it was not clear if the consequence was from the guilt or something else. So, we took the liberty of including those data when there was a potential but not definitive link. After unitizing the data, the consequences of guilt were grouped into an initial set of categories. Finally, we inductively grouped the categories of the consequence of guilt into higher domains.

The ATLAS.ti 7.5.18 (ATLAS.ti Scientific Software Development GmbH, Berlin) qualitative data analysis program was used to manage and analyze the data and to provide an audit trail.

Peer debriefing occurred to verify the fit of verbatim quotes under each inductive category, and each category was distinct from other categories using constant comparisons. Disagreement about any aspect of the analysis was discussed and resulted in a refinement of a category/domain, a reassignment of a unit/category, or an identification of a new category/domain (Lewis & Deal, 1995).

The trustworthiness of the study results was protected by field notes, analysis memos, and formal peer debriefing with an expert researcher. Field notes were recorded for the immediate observations and interpretations of the interviewer and served as a reference during the data analysis. Memos and written records of analysis began with the first analytic session and continued throughout the analytic process (Corbin et al., 2008). Memos were also used for peer debriefing.

Results

Analysis of the data produced three conceptual domains of the consequence of guilt: (1) reappraisal of guilt toward the self, (2) motivational reactions toward the child, and (3) other accompanying emotions. Each domain describes the experiential and behavioral consequences of the guilt expressed by the parents and family caregivers. The number and percentage of parents or caregivers who reported in each category are summarized in Table 3.4.

Domains of the consequences of guilt

Domain 1: Reappraisal of Guilt toward the Self

Reappraisal of the guilt toward the self included eight categories: *Regret*, *Blaming myself*, *Thinking about* why, *Not wanting to talk*, *Wanting to be punished*, *Blaming others*, *Having trouble sleeping*, and *Feeling irresponsible*.

Regret. About 65% of the participants shared feelings of regret, either personal regret or the reported regret in other family caregivers. This category included parental verbatim statements describing a repentant or disappointed feeling over something that they have done or failed to do. Parents regretted not knowing first-aid procedures after the incidence of burn injury in their child. For instance, one mother said, "*I did not know, we were quite ignorant; if I had cut his pants and rinsed the burn with cool water, he would not have such a deep scar. We felt regret for a long time*." Parents cited multiple sources of regret, including pouring hot water for drinking and accidentally knocking it over and spilling it on the child; having the child live with grandparents in a parent's hometown while both parents were working in the city; or having transient thoughts wondering if it would have been better if they hadn't had this child.

Blaming myself. More than half of the parents described blaming themselves in response to the guilt. They made no secret of declaring that they felt guilty for their failure to protect the child or

felt they were not doing enough to promote wound healing: "*I blame myself if his wound didn't look well, and my mother (note: this refers to the child's paternal grandma) was really blaming herself after the injury*," "*I blame myself, it is my fault, this happened because of my carelessness, I also felt upset*." Parents experienced intensified self-blaming when they were by themselves or watching their child experience pain or itching.

Thinking about why. Some parents wondered why their child got burned, given that the incident happened when the child was under the supervision of an adult. "*There was a period when I had some emotions toward the grandparents, always wondering why they didn't carefully look after him*." Some parents had recurrent memories of the burn injury happening: "*I couldn't help but recall that day, that night, what each person in the family was doing, every step and every minute, wanting to know what exactly went wrong*." Parents also struggled to accept why something like this would happen to their child: "*Why did the accident happen to my child under my watch? I cannot accept it*."

Not wanting to talk. For some parents, the incidence of burn injury was felt to negatively affect their openness to communicate with others. They described reasons for keeping what happened inside. These included a fear of being asked about the injury by neighbors or friends, concern about the impact of expressing negative emotions on another family member, and reluctance to talk to someone who appeared to blame the parent for the child's injury.

Blaming others. Some parents felt guilty for not taking good care of the child and blamed the person who appeared to be responsible for the injury. One father shared, "*I felt a lot of guilt, regret, self-blame, I have blamed her (the child's mother) earlier, felt like… (sigh), as parents, (we did) not expect the child to end up like this*." When blame was expressed, some parents were able to control the blaming thoughts, while other parents filled the blame with anger and cannot

forgive the person. One mother reflected, "*The first thought was that my mother-in-law didn't keep a close eye on him. Later, when my mind came back, [I thought] really, how could you blame the elders, this [the injury] was accidental*." Another mother said, "*I will never forgive his grandmother*."

Wanting to be punished. Parents described an expectation of inflictions of pain or suffering on themselves. They wanted to be the one who got burned rather than their child: "*It would be better if I were the one who got scalded*." They wished to be punished by other people: "*My parents tried to comfort me, but I thought I would feel better if only my father could slap me in the face, which he did not*." Some parents wanted to offer their skin for a child's skin grafting: "*I wonder, if he needed grafting, whether he could use my skin. He was so skinny, and getting a piece of skin for grafting, how can he survive?*"

Having trouble sleeping. Parents experienced disruptions in their sleeping and eating when they had recurrent memories about the injury: "*I could not sleep at night, and every time I think of her, I have cold sweats*."

Feeling irresponsible. Parents described feeling "irresponsible as a parent" when it came to reflect on the cause of the injury: "*I felt guilty, how could you be so irresponsible as a parent*?"

Domain 2: Motivational reactions toward the child

Motivational reactions toward the child were sorted into four categories: *Paying more attention to prevent injuries*, *Feeling sorry for the child*, *Providing the best care*, and *Placating the child*.

Providing the best care. Parents wondered about the best treatment for their child. They considered the child care as the priority, rising above their emotional distress. For example, one mother shared, "*We tried to be rational, channel those emotional reactions (self-blame, sadness,*

or anger) into actions of performing better wound care."

Paying more attention to prevent injuries. Parents made a greater effort to protect the child from inflicting potential injuries (e.g., falling, getting scalded), including checking for safety risks in the house; constantly reminding oneself to be more and more careful; being anxious about any further potential danger to the child, especially when the child was out of sight; or warning the child of the dangers of thermal injury.

Feeling sorry for the child. Parents felt deeply apologetic for what has happened to their child' since the burn injury. One parent said, "*..., I would rather an adult was burned than she was. Honestly, I feel sorry for my child for the rest of my life*." Parents also experienced grief over the pain and loss that their child has gone through, "*..., I didn't exercise enough prevention caution, I didn't know first-aid procedures, it (the consequence) was serious. You see, (I) spent so much time and energy (on his treatment), that's what I deserve; but for my child, I felt sorry for him.*"

Placating the child. Some parents attempted to placate their child when they tried to sooth the child with the internal feelings of guilt, "*I placated her, and she was spoiled. Before the injury, I would not do that, but now I felt guilty, felt sorry for her, so I just let her have her way, she could do whatever she wants*." Another mother added, "*We tried to placate him when he cried or irritable, I felt that… if his foot were not scalded, he would not behave like this. So right now, just let him have his way*."

Domain 3: Accompanying emotions

Parents mentioned three emotions when they described their feeling of guilt, including *Anger*, *Heartache,* and *Upset*. We do not assume any relationship between guilt and the accompanying emotions; rather, we want to acknowledge the presence of these emotions that reflected the emotional dynamics within the members of the household.

Upset. Parents felt upset when they perceived themselves, adding the pain and distress to their child, who already suffered unnecessarily because of the failure to prevent the injury. "*When he feels pain and itching, I blame myself more, I felt very upset, very upset*." Such feelings fed back to the mothers' feelings of guilt and her stress and anxiety and were reinforced if the child protests.

Anger. Some parents expressed a strong feeling of anger toward the other family member. For example, one mother commented, "*When the grandparents took care of the child, and they overlooked something; I blamed myself, sometimes, I got angry*." Parents were found to express anger toward the child, especially when the child cried or threw a tantrum. Parents either controlled or lost temper in response to anger.

Heartache. Parents often talked about the feeling of heartache related to their child's injury, "*To me, guilt is… I felt my heartache when I saw him wounded like this. Most children are growing well in their family, why it (the accident) happened when I looked after my child?*" The feeling of heartache sometimes followed with self-blame, even if the parent was not responsible for the burn, "*Heartache, definitely heartache, then I blame myself because he got scalded when I went back to my hometown, just wondered what if I had not been away, what if I had been with him…*"

Discussion

Accidental burn injury is a natural situation in which to study the source and subjective experience of guilt within the context of the parent-child relationship. This study has set out to understand the representation of guilt and its related consequences for the parents experiencing such guilt and the child with a burn injury.

The results of our study show that guilt and its consequences, have distinct semantic representation. In our study, roughly half of the parents (55%) expressed guilt directly by using the word "guilt" (Mandarin: 内疚，愧疚). Six parents expressed guilt indirectly, but in a way that reflected the definition of guilt. Two parents expressed guilt when the interviewer probed further with the question, "Did you feel guilty after your child's injury?" And one parent who could not find a word to describe his emotion stated that "*no words could describe my feelings*." Some parents may experience a temporary denial of guilt, but the time taken to accept some responsibility varies from minutes to months (Mason, 1993). Although we distinguished between guilt and its consequences, we also acknowledged the possibility of a reversed relationship. For example, guilt was sometimes interpreted as a consequence of self-blame and anger (McGarry et al., 2015). The challenge lies in the phenomenon of "an emotion about the emotion," that is, the re-appraisal of the consequence of one emotion is found to trigger another emotion (Fischer & Tangney, 1995b). Further research is needed to test the causal relationship between guilt and its related affective reactions.

Guilt, regret, rumination, or blame, along with other distressing emotions such as heartache, anger, upset, or sadness, were often expressed within one parent's account of their feelings (Table 2). These findings are consistent with those reported in other qualitative studies, where a combination of resultant behaviors and feelings was found to negatively contribute to

parental adherence to the child's post-burn treatment (Andrews et al., 2018), parental willingness to access psychological support (Heath et al., 2018), parental confidence in parenting (Horridge et al., 2010), parental perception of the burn event (Barnett et al., 2017), and parental mental health (McGarry et al., 2015).

Blaming has been a significant reaction among parents and family caregivers, including self-blaming and blaming others. It has been understood as a mechanism for redistributing emotional distress within the relational dyad (Baumeister et al., 1994). On some occasions, blaming had an affective component of anger or control of anger (Andrews et al., 2018; Barnett et al., 2017; McGarry et al., 2015). Both themes of blaming and being blamed have been discussed in the literature. Blaming may reinforce the feelings of isolation and fear of the stigma associated with burn scar a parent of a child with a burn injury (Mason, 1993). Our findings suggest that parents tended to shut down their feelings and emotions or keep their feelings to themselves, which speaks to the fact that parents may anticipate blame and judgmental comments from neighbors and strangers and consequently they tried to avoid such encounters (Mason, 1993; Ravindran et al., 2013a). Being blamed, on top of the distress parents felt in the event of their child's burn injury, dragged parents into a situation of double trauma (Ravindran et al., 2013a). Ravindran and colleagues (2013) described a process of enduring the blame as parents faced blame from family members, strangers, and providers. Some parents chose to put up with the blames as a strategy to focus their attention on their child's burn care (Ravindran et al., 2013a). Further research is needed to explore the phenomenon of blame within the familial and social context, to understand the cognitive process that causes parents to hold their thoughts and emotions inside. Emerging evidence suggests that peer support is more acceptable when parents' concerns and distress are discussed with empathy (Heath et al., 2018).

Guilt appears to promote a variety of prosocial effects. In particular, our findings suggest that parents were motivated to pay more attention in the future to prevent the incidence of injury, to express their apologies to the child, to provide the child with the best care they could offer, and to placate the child. There is ample research suggested that feeling of guilt makes a person want to do something for someone to relieve the feeling of guilt, especially within the parent-child relationship (Henniger & Harris, 2016). These findings may have significant implications for parental mental health issues. Previous research reported that roughly 25% of the parents reported posttraumatic stress symptoms (PTSS) at 18 months post-burn (Bakker, Van der Heijden, et al., 2013; Fukunishi, 1998; Mason, 1993), and guilt has been identified as a risk factor for prolonged PTSS and depression in parents of children with burn injury (Bakker et al., 2012; De Young et al., 2014; Fukunishi, 1998). Considering the methodological flaws in measuring guilt in previous studies (Lin et al., 2019 in progress), it is worthwhile to reconsider the role of guilt in regulating parental PTSS. In addition, the prosocial effects discussed in our findings also need research and clinical attention. The motivational actions toward the child can be viewed as a relationship enhancer within the parent-child dyad (Baumeister et al., 1994). Further research is needed to generate and test a hypothesis to elucidate the process of guilt.

This paper's findings help to extend our theoretical understanding of the guilt and its effects on the development and persistence of emotional distress in parents facing their child's unintentional burn injury. What's more, these results have practical implications for professionals caring for parents or family caregivers who are in greater need of professional mental health support, given the long-term recovery period in children with moderate to severe burn injury and the meaning and visibility associated with the burn scars.

Limitations

The results of this study are limited to parents and family caregivers caring for children with unintentional burn injury. Although guilt is a universal emotion, the results of our study may be specific to the Chinese population, and the culture and social context in which the study was conducted should be taken into account when interpreting the results. In addition, there are areas of data in which it was not clear if a consequence was from guilt or other factors. For example, anger is related to blaming or when parents responded to the child's distress. Sadness and upset, according to the definition of regret, can be part of the feeling of regret. And other factors besides guilt can cause sadness and upset feelings. In future studies, more time needs to be allowed for the parents to tell the full story of their feelings. However, it is also challenging for parents to name the emotions that they have felt and to give a balanced account of their experience.

References

Andrews, N., Jones, L. L., Moiemen, N., Calvert, M., Kinghorn, P., Litchfield, I., … PEGASUS Study Group. (2018). Below the surface: Parents' views on the factors that influence treatment adherence in paediatric burn scar management — A qualitative study. *Burns*, *44*(3), 626–635. https://doi.org/10.1016/j.burns.2017.09.003

Bakker, A., Maertens, K. J. P., Van Son, M. J. M., & Van Loey, N. E. E. (2013). Psychological consequences of pediatric burns from a child and family perspective: a review of the empirical literature. *Clinical Psychology Review*, *33*(3), 361–371. https://doi.org/10.1016/j.cpr.2012.12.006

Bakker, A., Van der Heijden, P. G. M., Van Son, M. J. M., & Van Loey, N. E. E. (2013). Course of traumatic stress reactions in couples after a burn event to their young child. *Health Psychology : Official Journal of the Division of Health Psychology, American Psychological Association*, *32*(10), 1076–1083. https://doi.org/10.1037/a0033983

Bakker, A., Van Loey, N. E. E., Van der Heijden, P. G. M., & Van Son, M. J. M. (2012). Acute stress reactions in couples after a burn event to their young child. *Journal of Pediatric Psychology*, *37*(10), 1127–1135. https://doi.org/10.1093/jpepsy/jss083

Bakker, A., Van Loey, N. E. E., Van Son, M. J. M., & Van der Heijden, P. G. M. (2010). Brief report: mothers' long-term posttraumatic stress symptoms following a burn event of their child. *Journal of Pediatric Psychology*, *35*(6), 656–661. https://doi.org/10.1093/jpepsy/jsp090

Barnett, B. S., Mulenga, M., Kiser, M. M., & Charles, A. G. (2017). Qualitative analysis of a psychological supportive counseling group for burn survivors and families in Malawi. https://doi.org/10.1016/j.burns.2016.09.027

Barrett, K. C. (1995). A functionalist approach to shame and guilt. In J. P. Tangney & K. W. Fischer (Eds.), *Self-Conscious Emotions: The Psychology of Shame, Guilt, Embarrassment, and Pride* (pp. 25–63). Guilford Press. https://doi.org/10.3348/kjr.2012.13.2.189

Baumeister, R. F., Stillwell, A. M., & Heatherton, T. F. (1994). Guilt: an interpersonal approach. *Psychological Bulletin*, *115*(2), 243–267. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/8165271

Behrendt, H., & Ben-Ari, R. (2012). The Positive Side of Negative Emotion. *Journal of Conflict Resolution*, *56*(6), 1116–1138. https://doi.org/10.1177/0022002712445746

Bender, M. S., Janson, S. L., Franck, L. S., & Lee, K. A. (2018). Theory of Symptom Management. In M. J. Smith & P. R. Liehr (Eds.), *Middle Range Theory for Nursing* (4th ed., pp. 147–178). New York: Springer International Publishing.

Benjamin, K., Waterston, K., Russell, M., Schofield, O., Diffey, B., & Rees, J. L. (2004). The development of an objective method for measuring scratch in children with atopic dermatitis suitable for clinical use. *Journal of the American Academy of Dermatology*, *50*(1), 33–40. https://doi.org/10.1016/S0190-9622(03)02480-0

Bringhurst, C., Waterston, K., Schofield, O., Benjamin, K., & Rees, J. L. (2004). Measurement of itch using actigraphy in pediatric and adult populations. *Journal of the American Academy of Dermatology*, *51*(6), 893–898. https://doi.org/10.1016/j.jaad.2004.05.039

Carrougher, G. J., Martinez, E. M., McMullen, K. S., Fauerbach, J. A., Holavanahalli, R. K., Herndon, D. N., … Gibran, N. S. (2013). Pruritus in adult burn survivors: postburn prevalence and risk factors associated with increased intensity. *Journal of Burn Care & Research : Official Publication of the American Burn Association*, *34*(1), 94–101. https://doi.org/10.1097/BCR.0b013e3182644c25

Cella, D. F., Perry, S. W., Kulchycky, S., & Goodwin, C. (1988). Stress and coping in relatives of burn patients: a longitudinal study. *Hospital & Community Psychiatry*, *39*(2), 159–166. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/3345979

Claar, R. L., Guite, J. W., Kaczynski, K. J., & Logan, D. E. (2010). Factor structure of the Adult Responses to Children's Symptoms: validation in children and adolescents with diverse chronic pain conditions. *The Clinical Journal of Pain*, *26*(5), 410–417. https://doi.org/10.1097/AJP.0b013e3181cf5706

Claar, R. L., Simons, L. E., & Logan, D. E. (2008). Parental response to children's pain: the moderating impact of children's emotional distress on symptoms and disability. *Pain*, *138*(1), 172–179. https://doi.org/10.1016/j.pain.2007.12.005

Corbin, J. M., Strauss, A. L., & Strauss, A. L. (2008). *Basics of qualitative research : techniques and procedures for developing grounded theory*. Sage Publications. Retrieved from https://books.google.com/books/about/Basics_of_Qualitative_Research.html?id=0TI8Ugvy2Z4C

Crittenden, P. (2017). Gifts from Mary Ainsworth and John Bowlby. *Clinical Child Psychology and Psychiatry*, *22*(3), 436–442. https://doi.org/10.1177/1359104517716214

Crittenden, P., Dallos, R., Landini, A., & Kozlowska, K. (2014). Toddlerhood and the beginnings of awareness and intention. In *Attachment and Family Therapy* (pp. 31–51). Milton Keynes, United Kingdom: Open University Press. Retrieved from https://www.mheducation.ca/professional/products/9780335235902/attachment+and+family+therapy/

De Young, A. C., Hendrikz, J., Kenardy, J. A., Cobham, V. E., & Kimble, R. M. (2014). Prospective evaluation of parent distress following pediatric burns and identification of risk

factors for young child and parent posttraumatic stress disorder. *Journal of Child and Adolescent Psychopharmacology*, *24*(1), 9–17. https://doi.org/10.1089/cap.2013.0066

Dise-Lewis, J. E. (2001). A developmental perspective on psychological principles of burn care. *The Journal of Burn Care & Rehabilitation*, *22*(3), 255–260. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/11403251

Dodd, M., Janson, S., Facione, N., Faucett, J., Froelicher, E. S., Humphreys, J., … Taylor, D. (2001). Advancing the science of symptom management. *Journal of Advanced Nursing*, *33*(5), 668–676. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/11298204

Duke, J. M., Boyd, J. H., Randall, S. M., Rea, S., & Wood, F. M. (2015). Childhood burn injury-impacts beyond discharge. *Translational Pediatrics*, *4*(3), 249–251. https://doi.org/10.3978/j.issn.2224-4336.2015.07.05

DuPen, M., van Tilburg, M., Langer, S., Murphy, T., Romano, J., & Levy, R. (2016). Parental Protectiveness Mediates the Association between Parent-Perceived Child Self-Efficacy and Health Outcomes in Pediatric Functional Abdominal Pain Disorder. *Children*, *3*(3), 15. https://doi.org/10.3390/children3030015

Ebata, T, Iwasaki, S., Kamide, R., & Niimura, M. (2001). Use of a wrist activity monitor for the measurement of nocturnal scratching in patients with atopic dermatitis. *The British Journal of Dermatology*, *144*(2), 305–309. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/11251563

Ebata, Toshiya. (2016). Measurement of Itch: Actigraphy. In L. Misery & S. Ständer (Eds.), *Pruritus: Second Edition* (2nd ed., pp. XV, 453). Springer International Publishing. https://doi.org/10.1007/978-3-319-33142-3

Egberts, M. R., van de Schoot, R., Geenen, R., & Van Loey, N. E. E. (2017). Parents'

posttraumatic stress after burns in their school-aged child: A prospective study. *Health Psychology*, *36*(5), 419–428. https://doi.org/10.1037/hea0000448

El Hamaoui, Y., Yaalaoui, S., Chihabeddine, K., Boukind, E., & Moussaoui, D. (2006a). Depression in mothers of burned children. *Archives of Women's Mental Health*, *9*(3), 117–119. https://doi.org/10.1007/s00737-006-0124-1

El Hamaoui, Y., Yaalaoui, S., Chihabeddine, K., Boukind, E., & Moussaoui, D. (2006b). Depression in mothers of burned children. *Archives of Women's Mental Health*, *9*(3), 117–119. https://doi.org/10.1007/s00737-006-0124-1

Elman, S., Hynan, L., Gabriel, V., Mayoà, M., & Mayo, M. J. (2009). The 5-D itch scale: a new measure of pruritus. *British Journal of Dermatology*. https://doi.org/10.1111/j.1365-2133.2009.09586.x

Everett, T., Parker, K., Fish, J., Pehora, C., Budd, D., Kelly, C., … Hayes, J. (2014). The construction and implementation of a novel postburn pruritus scale for infants and children aged five years or less: introducing the Toronto Pediatric Itch Scale. *Journal of Burn Care & Research : Official Publication of the American Burn Association*, *36*(1), 44–49. https://doi.org/10.1097/BCR.0000000000000129

Fischer, K. W., & Tangney, J. P. (1995a). Self-conscious emotions and the affect revolution: Framework and overview. In J. P. Tangney & K. W. Fischer (Eds.), *Self-Conscious Emotions: The Psychology of Shame, Guilt, Embarrassment, and Pride.* (pp. 3–22). Guilford Press. https://doi.org/10.3348/kjr.2012.13.2.189

Fischer, K. W., & Tangney, J. P. (1995b). Self-conscious emotions and the affect revolution: framework and overview. In J. P. Tangney & K. W. Fischer (Eds.), *Self-conscious emotions: the psychology of shame, guilt, embarrassment, and pride* (1st editio, pp. 3–24).

Guilford Press.

Fukunishi, I. (1998). Posttraumatic stress symptoms and depression in mothers of children with severe burn injuries. *Psychological Reports*, *83*(1), 331–335. https://doi.org/10.2466/pr0.1998.83.1.331

Gaffney, A., McGrath, P. J., & Dick, B. (2003). Measuring Pain in Children: Developmental and Instrument Issues. In N. L. Schechter, C. B. Berde, & M. Yaster (Eds.), *Pain in Infants, Children, and Adolescents* (2nd ed., p. 128). Lippincott Williams & Wilkins.

Gedaly-Duff, V., Lee, K. A., Nail, L. M., Nicholson, H. S., & Johnson, K. P. (2006). Pain, Sleep Disturbance, and Fatigue in Children With Leukemia and Their Parents: A Pilot Study. *Oncology Nursing Forum*, *33*(3), 641–646. https://doi.org/10.1188/06.ONF.641-646

Graf, A., Schiestl, C., & Landolt, M. A. (2011). Posttraumatic stress and behavior problems in infants and toddlers with burns. *Journal of Pediatric Psychology*, *36*(8), 923–931. https://doi.org/10.1093/jpepsy/jsr021

Guite, J. W., McCue, R. L., Sherker, J. L., Sherry, D. D., & Rose, J. B. (2011). Relationships among pain, protective parental responses, and disability for adolescents with chronic musculoskeletal pain: the mediating role of pain catastrophizing. *The Clinical Journal of Pain*, *27*(9), 775–781. https://doi.org/10.1097/AJP.0b013e31821d8fb4

Hall, E., Saxe, G., Stoddard, F., Kaplow, J., Koenen, K., Chawla, N., … King, D. (2006). Posttraumatic stress symptoms in parents of children with acute burns. *Journal of Pediatric Psychology*, *31*(4), 403–412. https://doi.org/10.1093/jpepsy/jsj016

Heath, J., Williamson, H., Williams, L., & Harcourt, D. (2018). Parent-perceived isolation and barriers to psychosocial support: a qualitative study to investigate how peer support might help parents of burn-injured children. *Scars, Burns & Healing*, *4*, 2059513118763801.

https://doi.org/10.1177/2059513118763801

Henniger, N. E., & Harris, C. R. (2016). Can negative social emotions have positive consequences: An examination of embarrassment, shame, guilt, jealousy, and envy. In W. G. Parrott (Ed.), *The positive side of negative emotions* (pp. 76–97). New York, NY: Guilford Press. Retrieved from http://eds.a.ebscohost.com.offcampus.lib.washington.edu/ehost/detail/detail?vid=5&sid=56671694-d0e4-4001-9aea-6c0b0a2ad15b%40sessionmgr4007&bdata=JnNpdGU9ZWhvc3QtbGl2ZQ%3D%3D#AN=2014-05881-004&db=psyh

Herr, K., Coyne, P. J., McCaffery, M., Manworren, R., & Merkel, S. (2011). Pain Assessment in the Patient Unable to Self-Report: Position Statement with Clinical Practice Recommendations. *Pain Management Nursing*, *12*(4), 230–250. https://doi.org/10.1016/j.pmn.2011.10.002

Horridge, G., Cohen, K., & Gaskell, S. (2010). BurnEd: Parental, psychological and social factors influencing a burn-injured child's return to education. *Burns*, *36*(5), 630–638. https://doi.org/10.1016/j.burns.2009.08.013

Ikoma, A., Steinhoff, M., Ständer, S., Yosipovitch, G., & Schmelz, M. (2006). The neurobiology of itch. *Nature Reviews. Neuroscience*, *7*(7), 535–547. https://doi.org/10.1038/nrn1950

Kassam-Adams, N., Bakker, A., Marsac, M. L., Fein, J. A., & Winston, F. K. (2015). Traumatic Stress, Depression, and Recovery: Child and Parent Responses After Emergency Medical Care for Unintentional Injury. *Pediatric Emergency Care*, *31*(11), 737–742. https://doi.org/10.1097/PEC.0000000000000595

Kazis, L. E., Liang, M. H., Lee, A., Ren, X. S., Phillips, C. B., Hinson, M., … Tompkins, R.

(2002). The development, validation, and testing of a health outcomes burn questionnaire for infants and children 5 years of age and younger: American Burn Association/Shriners Hospitals for Children. *The Journal of Burn Care & Rehabilitation*, *23*(3), 196–207. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/12032370

Kim, S., Thibodeau, R., & Jorgensen, R. S. (2011). Shame, guilt, and depressive symptoms: A meta-analytic review. *Psychological Bulletin*, *137*(1), 68–96. https://doi.org/10.1037/a0021466

Kornhaber, R., Childs, C., & Cleary, M. (2018). Experiences of guilt, shame and blame in those affected by burns: A qualitative systematic review. *Burns*, *44*(5), 1026–1039. https://doi.org/10.1016/j.burns.2017.11.012

Krippendorff, K. (2013). Unitizing. In *Content analysis: an introduction to its methodology* (3rd ed., pp. 98–111). Sage PublicationsSage CA: Thousand Oaks, CA.

Kwa, K., Pijpe, A., Rashaan, Z., Tuinebreijer, W., Breederveld, R., & Loey, N. (2018). Course and Predictors of Pruritus Following Burns: A Multilevel Analysis. *Acta Dermato Venereologica*, *98*(7), 636–640. https://doi.org/10.2340/00015555-2935

Lavery, M., Stull, C., Kinney, M., & Yosipovitch, G. (2016). Nocturnal Pruritus: The Battle for a Peaceful Night's Sleep. *International Journal of Molecular Sciences*, *17*(3), 425. https://doi.org/10.3390/ijms17030425

Lee, S.-Y., & Weiss, S. J. (2009). When East meets West: intensive care unit experiences among first-generation Chinese American parents. *Journal of Nursing Scholarship : An Official Publication of Sigma Theta Tau International Honor Society of Nursing / Sigma Theta Tau*, *41*(3), 268–275. https://doi.org/10.1111/j.1547-5069.2009.01290.x

Lewis, F. M., & Deal, L. W. (1995). Balancing our lives: a study of the married couple's

experience with breast cancer recurrence. *Oncology Nursing Forum*, *22*(6), 943–953. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/7567612

Lewis, H. B. (1971). Shame and guilt in neurosis. *Psychoanalytic Review*, *58*(3), 419–438. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/5150685

Li, H., Wang, S., Tan, J., Zhou, J., Wu, J., & Luo, G. (2017). Epidemiology of pediatric burns in southwest China from 2011 to 2015. *Burns*, *43*(6), 1306–1317. https://doi.org/10.1016/j.burns.2017.03.004

Linder, L. (2008, August 1). Developmental Diversity in Symptom Research Involving Children and Adolescents with Cancer. *Journal of Pediatric Nursing*. W.B. Saunders. https://doi.org/10.1016/j.pedn.2007.10.003

Linder, L. (2010). Analysis of the UCSF Symptom Management Theory: implications for pediatric oncology nursing. *Journal of Pediatric Oncology Nursing : Official Journal of the Association of Pediatric Oncology Nurses*, *27*(6), 316–324. https://doi.org/10.1177/1043454210368532

Maskell, J., Newcombe, P., Martin, G., & Kimble, R. (2013). Psychosocial functioning differences in pediatric burn survivors compared with healthy norms. *Journal of Burn Care & Research : Official Publication of the American Burn Association*, *34*(4), 465–476. https://doi.org/10.1097/BCR.0b013e31827217a9

Mason, S. A. (1993). Young, scarred children and their mothers--a short-term investigation into the practical, psychological and social implications of thermal injury to the preschool child. Part I: Implications for the mother. *Burns : Journal of the International Society for Burn Injuries*, *19*(6), 495–500. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/8292233

Mason, S. A., & Hillier, V. F. (1993a). Young, scarred children and their mothers--a short-term

investigation into the practical, psychological and social implications of thermal injury to the preschool child. Part II: implications for the child. *Burns : Journal of the International Society for Burn Injuries*, *19*(6), 501–506. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/8292234

Mason, S. A., & Hillier, V. F. (1993b). Young, scarred children and their mothers--a short-term investigation into the practical, psychological and social implications of thermal injury to the preschool child. Part III: Factors influencing outcome responses. *Burns : Journal of the International Society for Burn Injuries*, *19*(6), 507–510. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/8292235

McGarry, S., Elliott, C., McDonald, A., Valentine, J., Wood, F., & Girdler, S. (2015). "This is not just a little accident": a qualitative understanding of paediatric burns from the perspective of parents. *Disability and Rehabilitation*, *37*(1), 41–50. https://doi.org/10.3109/09638288.2014.892640

Meyer, W. J. 3rd, Robert, R., Murphy, L., Blakeney, P. E., III, M. W. J., Robert, R., … PE, B. (2000). Evaluating the psychosocial adjustment of 2- and 3-year-old pediatric burn survivors. *Journal of Burn Care & Rehabilitation*, *21*(2), 178–184. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/10752752

Meyer, W. J., Robert, R., Murphy, L., & Blakeney, P. E. (2000). Evaluating the psychosocial adjustment of 2- and 3-year-old pediatric burn survivors. *The Journal of Burn Care & Rehabilitation*, *21*(2), 178; discussion 179-84. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/10752752

Morris, V., Murphy, L. M., Rosenberg, M., Rosenberg, L., Holzer, C. E., & Meyer, W. J. (2012). Itch assessment scale for the pediatric burn survivor. *Journal of Burn Care & Research :*

Official Publication of the American Burn Association, *33*(3), 419–424. https://doi.org/10.1097/BCR.0b013e3182372bfa

Niedenthal, P. M., Tangney, J. P., & Gavanski, I. (1994). "If Only I Weren't" Versus "If Only I Hadn't": Distinguishing Shame and Guilt in Counterfactual Thinking. *Journal of Personality and Social Psychology*, *67*(4), 585–595. https://doi.org/10.1037/0022-3514.67.4.585

Nieuwendijk, S. M. P., de Korte, I. J., Pursad, M. M., van Dijk, M., & Rode, H. (2018). Post burn pruritus in pediatric burn patients. *Burns*, *44*(5), 1151–1158. https://doi.org/10.1016/j.burns.2018.02.022

Noel, M., Alberts, N., Langer, S. L., Levy, R. L., Walker, L. S., & Palermo, T. M. (2016). The Sensitivity to Change and Responsiveness of the Adult Responses to Children's Symptoms in Children and Adolescents With Chronic Pain. *Journal of Pediatric Psychology*, *41*(3), 350–362. https://doi.org/10.1093/jpepsy/jsv095

Noel, M., Palermo, T. M., Essner, B., Zhou, C., Levy, R. L., Langer, S. L., … Walker, L. S. (2015). A Developmental Analysis of the Factorial Validity of the Parent-Report Version of the Adult Responses to Children's Symptoms in Children Versus Adolescents With Chronic Pain or Pain-Related Chronic Illness. *The Journal of Pain*, *16*(1), 31–41. https://doi.org/10.1016/j.jpain.2014.10.005

Öster, C., Hensing, I., Löjdström, T., Sjöberg, F., & Willebrand, M. (2014). Parents' Perceptions of Adaptation and Family Life After Burn Injuries in Children. *Journal of Pediatric Nursing*, *29*(6), 606–613. https://doi.org/10.1016/j.pedn.2014.06.010

Parnell, L. K. S., Nedelec, B., Rachelska, G., & LaSalle, L. (2012). Assessment of Pruritus Characteristics and Impact on Burn Survivors. *Journal of Burn Care & Research*, *33*(3),

407–418. https://doi.org/10.1097/BCR.0b013e318239d206

Patel, T., Ishiuji, Y., & Yosipovitch, G. (2007). Nocturnal itch: why do we itch at night? *Acta Dermato-Venereologica*, *87*(4), 295–298. https://doi.org/10.2340/00015555-0280

Peterson, C. C., & Palermo, T. M. (2004). Parental reinforcement of recurrent pain: the moderating impact of child depression and anxiety on functional disability. *Journal of Pediatric Psychology*, *29*(5), 331–341. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/15187172

Pugh, L. R., Taylor, P. J., & Berry, K. (2015). The role of guilt in the development of post-traumatic stress disorder: A systematic review. *Journal of Affective Disorders*, *182*, 138–150. https://doi.org/10.1016/J.JAD.2015.04.026

Ravindran, V., Rempel, G. R., & Ogilvie, L. (2013a). Embracing survival: a grounded theory study of parenting children who have sustained burns. *Burns : Journal of the International Society for Burn Injuries*, *39*(4), 589–598. https://doi.org/10.1016/j.burns.2012.12.016

Ravindran, V., Rempel, G. R., & Ogilvie, L. (2013b). Parenting burn-injured children in India: A grounded theory study. *International Journal of Nursing Studies*, *50*(6), 786–796. https://doi.org/10.1016/J.IJNURSTU.2012.06.011

Rimmer, R. B., Alam, N. B., Bay, R. C., Sadler, I. J., Foster, K. N., & Caruso, D. M. (2015). The reported pain coping strategies of pediatric burn survivors-does a correlation exist between coping style and development of anxiety disorder? *Journal of Burn Care & Research : Official Publication of the American Burn Association*, *36*(2), 336–343. https://doi.org/10.1097/BCR.0000000000000109

Rivlin, E., & Faragher, E. B. (2007). The psychological sequelae on mothers of thermally injured children and adolescents: future directions: Part 3. *Dev Neurorehabil*, *10*(2), 183–190.

https://doi.org/10.1080/17518420701309758

Rose, M., Sanford, A., Thomas, C., & Opp, M. R. (2001). Factors altering the sleep of burned children. *Sleep*, *24*(1), 45–51. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/11204053

Rossi, L. A., Vila, V. da S. C., Zago, M. M. F., & Ferreira, E. (2005). The stigma of burns. *Burns*, *31*(1), 37–44. https://doi.org/10.1016/j.burns.2004.07.006

Schneider, J. C., Nadler, D. L., Herndon, D. N., Kowalske, K., Matthews, K., Wiechman, S. A., … Ryan, C. M. (2015). Pruritus in pediatric burn survivors: defining the clinical course. *Journal of Burn Care & Research : Official Publication of the American Burn Association*, *36*(1), 151–158. https://doi.org/10.1097/BCR.0000000000000145

Shelley, M., & Krippendorff, K. (1984). Content Analysis: An Introduction to its Methodology. *Journal of the American Statistical Association*, *79*(385), 240. https://doi.org/10.2307/2288384

Sheridan, R. L., Hinson, M. I., Liang, M. H., Nackel, A. F., Schoenfeld, D. A., Ryan, C. M., … Tompkins, R. G. (2000). Long-term outcome of children surviving massive burns. *JAMA*, *283*(1), 69–73. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/10632282

Shi, X.-Q., Qi, Y.-H., Shi, D., Yan, C., Shi, J., Cao, B.-L., … Wang, H.-Y. (2014). Features and Risk Factors of Nonfatal Injury among the Rural Children: A Survey of Seven Schools in a Mountain Area in Southwest China. *PLoS ONE*, *9*(7), e102099. https://doi.org/10.1371/journal.pone.0102099

Simons, L. E., Claar, R. L., & Logan, D. L. (2008). Chronic pain in adolescence: parental responses, adolescent coping, and their impact on adolescent's pain behaviors. *Journal of Pediatric Psychology*, *33*(8), 894–904. https://doi.org/10.1093/jpepsy/jsn029

Sveen, J, Sjöberg, F., & Öster, C. (2014). Health-related quality of life in Swedish pediatric burn patients and associations with burn and family characteristics. *Burns : Journal of the International Society for Burn Injuries*, *40*(5), 987–994. https://doi.org/10.1016/j.burns.2013.10.005

Sveen, Josefin, & Willebrand, M. (2018). Feelings of guilt and embitterment in parents of children with burns and its associations with depression. *Burns*, *44*(5), 1135–1140. https://doi.org/10.1016/j.burns.2018.02.005

Tangney, J. P. (1995). shame and guilt in interpersonal relationship. In J. P. Tangney & K. W. Fischer (Eds.), *Self-Conscious Emotions: The Psychology of Shame, Guilt, Embarrassment, and Pride* (1st eds, pp. 114–139). New York: Guilford Press.

Tangney, J. P., Burggraf, S. A., & Wagner, P. E. (1995). Shame-proneness, guilt-proneness, and psychological symptoms. In J. P. Tangney & K. W. Fischer (Eds.), *Self-Conscious Emotions: The Psychology of Shame, Guilt, Embarrassment, and Pride.* (1st ed., pp. 343–367). Guilford Press. https://doi.org/10.3348/kjr.2012.13.2.189

Tracy, J. L., & Robin, R. W. (2007). The self in self-conscious emotions: a cognitive appaisal approach. In J. L. Tracy, R. W. Robins, & J. P. Tangney (Eds.), *The self-conscious emotions: theory and research* (pp. 3–20). Guilford Press.

Tracy, J. L., & Robins, R. W. (2006). Appraisal Antecedents of Shame and Guilt: Support for a Theoretical Model. *Personality and Social Psychology Bulletin*, *32*(10), 1339–1351. https://doi.org/10.1177/0146167206290212

Tracy, J. L., & Robins, R. W. (2007). The self in self-conscious emotions: A cognitive appraisal approach. In J. L. Tracy, R. W. Robins, & J. P. Tangney (Eds.), *The self-conscious emotions: Theory and research* (pp. 3–20). Guilford Press.

https://doi.org/10.3892/ijo.2013.2179

van Baar, M. E., Polinder, S., Essink-Bot, M. L., van Loey, N. E. E., Oen, I. M. M. H., Dokter, J., … van Beeck, E. F. (2011). Quality of life after burns in childhood (5-15 years): children experience substantial problems. *Burns : Journal of the International Society for Burn Injuries*, *37*(6), 930–938. https://doi.org/10.1016/j.burns.2011.05.004

Van Loey, N. E. E., Bremer, M., Faber, A. W., Middelkoop, E., & Nieuwenhuis, M. K. (2008). Itching following burns: epidemiology and predictors. *The British Journal of Dermatology*, *158*(1), 95–100. https://doi.org/10.1111/j.1365-2133.2007.08278.x

von Baeyer, C. L., Chambers, C. T., Forsyth, S. J., Eisen, S., & Parker, J. A. (2013). Developmental data supporting simplification of self-report pain scales for preschool-age children. *The Journal of Pain : Official Journal of the American Pain Society*, *14*(10), 1116–1121. https://doi.org/10.1016/j.jpain.2013.04.008

Walker, L. S., Levy, R. L., & Whitehead, W. E. (2006). Validation of a measure of protective parent responses to children's pain. *The Clinical Journal of Pain*, *22*(8), 712–716. https://doi.org/10.1097/01.ajp.0000210916.18536.44

Wang, X., Zhang, Y., Zhang, Q., Liu, J., Tanuseputro, P., Gomez, M., … Liao, Z. (2006). Characteristics of 1494 pediatric burn patients in Shanghai. *Burns : Journal of the International Society for Burn Injuries*, *32*(5), 613–618. https://doi.org/10.1016/j.burns.2005.12.012

Zhang, W.-X., Wei, H., Shen, Z.-Y., Peng, X., Chen, X.-G., Li, W., … Niu, Y.-J. (2014). Concerns of and coping strategies by parents of pediatric liver transplant recipients: a qualitative study from China. *International Journal of Clinical and Experimental Medicine*, *7*(12), 5723–5729. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/25664098

Appendix

Table 3.1 *A Combination of Deductive and Inductive Content Analysis*

Steps	Descriptions
Step 1 Deductive coding	Reading and deductively unitizing guilt and its related consequences. Feelings expressed by parents on their judgment about their behaviors were compared to the definition of guilt. And the consequences of guilt were identified using propositional distinctions.
Step 2 Deductive coding	Refinement of the initial set of consequences. Each consequence of guilt was organized into an initial set of categories of consequences.
Step 3 Inductive coding	Identification of higher order domains, naming and defining domains. Constant comparisons were utilized to examine the category fit within each domain.

Table 3.2 *Examples of Verbatim Units*

	Examples of verbatim units
Direct expression of guilt	Two or three months after he was burned, [my feeling of guilt] was most strong because he was crying almost all the time, having pain, and after the pain, the itching followed, he is restless…
Indirect expression of guilt	Every time he threw a tantrum, I would want to spank him, after the spanking, felt that… he was already injured, how can I do that…(sigh)
Consequences of guilt	• and when he feels pain or itching, I blame myself more. • I would feel very upset, very upset at that time, • I would think about being the one who got burned, so I would be the one bearing the pain

Table 3.3 *Domains and Categories of the Consequences of Guilt & Numbers and Percentage of Parents Reporting*

Domains	Categories	Reporting parents	%
Reappraisal of guilt toward self	Regret	13	65
	Blaming myself	10	50
	Thinking about why	7	35
	Not wanting to talk	7	35
	Blaming others	5	25
	Wanting to be punished	5	25
	Having trouble sleeping	4	20
	Feeling irresponsible	3	15
Motivational Actions toward the child	Providing the best care	6	30
	Paying more attention to prevent injuries	5	25
	Feeling sorry for the child	4	20
	Placating the child	3	15
Accompanying emotions	Upset	11	55
	Anger	8	40
	Heartache	3	15

Figure 3.1 *Sample coding scheme: The domain of "Cognitive reappraisal toward self."*