2017

Road to recovery: an online guide to prepare parents of children who have sustained a major burn injury for successful home and community transition

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Road to Recovery: An online guide to prepare parents of children who have sustained a major burn injury for successful home and community transition

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A Scholarly Project
Submitted to the Occupational Therapy Department of the University of North Dakota
In Partial fulfillment of the requirements

For the degree of Master’s of Occupational Therapy

Grand Forks, North Dakota
May 2017
This Scholarly Project Paper, submitted by Michelle Jones & Chad Oppegaard in partial fulfillment of the requirement for the degree of Master's of Occupational Therapy from the University of North Dakota, has been read by the faculty advisor under whom the work has been done and is hereby approved.

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4/7/2017
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Title Road to Recovery: An online guide to prepare parents of children who have sustained a major burn injury for successful home and community transition

Department Occupational Therapy

Degree Master’s of Occupational therapy

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ACKNOWLEDGEMENTS

The authors wish to express appreciation to their scholarly advisor:

Cherie Graves, MOT, OTR/L

A special thanks to our family and friends, specifically Jaime Oppegaard and Ryan Jones,

for their support throughout the last three years.
ABSTRACT

Children are the most vulnerable population and represent the highest rate of nonfatal burns resulting in prolonged hospitalization, disfigurement, and disability. These injuries can be a severely stressful experience for children and their families. As a result, it is important for the patient and family members to not focus only on immediate treatment, but recognize the importance of long-term care following discharge in order to effectively reintegrate the child back into the home and community.

A literature review was conducted to investigate the key components of burn care throughout the duration of recovery. Research identified that many parents feel helpless, incompetent, or unqualified to provide the adequate care their child needs following discharge from a pediatric burn inpatient rehabilitation facility. While parents are provided with educational material and therapeutic interventions, there is currently a lack of information addressing if parents are compliant with their child’s treatment plan.

To address this need, the goal of this project is to develop an online resource tool that occupational therapists can utilize with caregivers of children who have sustained a burn injury. The goal is to empower parents by educating them on how to manage the needs of their child and to increase compliance prior to their child being discharged from an inpatient rehabilitation facility. This scholarly project will utilize the Model of Human Occupation (MOHO) and the adult learning theory to not only educate the parents, but increase their level of confidence so they are able to successfully meet the physical and psychosocial needs of their child at home and in the community.
CHAPTER I

INTRODUCTION

In 2013, approximately 126,000 US children required emergency room care for fire and burn related injuries (Safe Kids, 2015). Of these children, approximately 10% are admitted to an inpatient rehabilitation facility (IRF) after receiving emergency room care (Marino, Kimble, & Stockton, 2015). After children receive care from these facilities, it is expected each child’s parents continue certain aspects of care once they are discharged home. However, parents may experience a sense of guilt and elevated distress, contributing to feeling overwhelmed with new responsibility of continuing care outside the IRF (De Young, Hendrikz, Kenardy, Cobham, & Kimble, 2014). Many parents may also feel they are unqualified to provide the adequate care their child needs, complicating matters further (Rimmer et al., 2015b). This can result in serious complications of the burn injury if the child receives insufficient follow-up care.

To support the parents and increase the likelihood the children are receiving the care they need, an online program has been developed that aims at educating and preparing parents for their child to return home approximately one month before discharge. A literature search was conducted to find what information is essential to the parents to address both their own needs and their child’s needs. It was found the child’s physical needs include pain management, skin care, wound dressing, contractures and scar management, exercise, and nutrition. The psychosocial demands of the child and parents alike were found to include emotional management, family involvement, school
transition, and leaving the hospital. The online program utilizes the adult learning theory to address different learning styles and to support adult learning in general (Bastable et al., 2011). The cognitive apprenticeship model is also used to convey this information effectively to adult learners by applying modeling, coaching, articulating, and reflecting to learn new material and when practicing new techniques with their child (Lyons et al., 2016).

The aim of this product is to develop a program that assists occupational therapists to promote ongoing parental care in the treatment of school-aged children who have sustained a burn injury after the child is discharged from an IRF. The specific population chosen for this project are parents and their child aged 6-12 who has sustained a burn injury and has undergone treatment in an IRF. The occupational therapy theory utilized for this program is the Model of Human Occupation (MOHO) created by Gary Kielhofner. MOHO consists of four components including volition, habituation, performance capacity, and the environment, all of which were considered when developing the online program to address parent and child needs alike (Kielhofner, 2008). The primary components addressed were parental volition and habituation, which are affected when the parent feels unprepared to provide care, must take on a new health care role, and must adapt their routine to incorporate caregiving into their daily lives.

The following chapters address components of the proposed online program. Chapter II is a literature review focusing on the physical and psychosocial needs of the child, the psychosocial needs of the parents, and the theories and models used throughout the project. Chapter III examines the methodology employed to create the product. Chapter IV is the physical layout of the online program that was designed to address
occupational therapy aspects of care for a child who has sustained a burn injury and considerations for transitioning home while also considering parent and family member needs. Chapter V entails the scholarly project summary including limitations and recommendations for further program development and utilization. References used throughout the process concludes the scholarly project.
CHAPTER II
REVIEW OF LITERATURE

Burns are one of the most common causes of nonfatal injuries sustained by children in the United States (US) that require hospitalization (Marino, Kimble, & Stockton, 2015). In 2013, approximately 126,035 US children required emergency room care for fire and burn related injuries (Safe Kids, 2015). Among this staggering number, many children who have sustained a burn injury required immediate and ongoing treatment and rehabilitation services. According to the Kids’ Inpatient Database (KID), a comprehensive list of hospital records in the US published every three years to address current trends in children’s health, a total of 19,422 children under the age of 20 were admitted to general inpatient pediatric care for burn related injuries in the years ranging from 2001 to 2009 (Soleimani et al., 2016). While the KID provides a large sample size from two to three million pediatric inpatient hospital stays, it is only to be referred to as a guide as there is little known about the rates of admissions to inpatient rehabilitation facilities (IRFs) for burn-related injuries (Kid’s Inpatient Database, n.d.; Greene, Pham, Esselman, & Rivara, 2015).

While a majority of pediatric burn patients in middle-to-high income countries receive outpatient care, approximately 10 percent are admitted to IRFs after receiving emergency room care (Marino et al., 2015). Although IRFs provide successful intervention strategies to improve independent living after sustaining a major burn injury, there is very little knowledge on how parents are adapting to the impending need of care
that a pediatric burn patient requires following discharge (Greene et al., 2015; Rimmer et al., 2015). In addition, there is currently a lack of knowledge pertaining to the trajectory of patients being discharged from an IRF, specifically in the area of parental compliance and accountability in providing ongoing care to reduce the number of subsequent admissions to rehabilitation facilities (DiVita et al., 2014). Therefore, the aim of this scholarly project is to develop a resource tool that occupational therapists can utilize with parents of children who have sustained a burn injury to increase compliance in managing the needs of their child prior to being discharged from an inpatient rehabilitation facility.

Although burn injuries are preventable, children are the most vulnerable population and represent the highest rate of nonfatal burns resulting in prolonged hospitalization, disfigurement, and disability (World Health Organization [WHO], 2014). In a 25-year retrospective study involving 1,586 pediatric burn patients between 1987 and 2012, Trop et al. (2014) determined that a significant number of pediatric burn injuries occur due to a lack of supervision, preexisting impairment, parental illiteracy, living in a congested household, and low socioeconomic status. In addition to improper adult supervision and environmental factors, the WHO (2014) also identified a considerable number of pediatric burn injuries as the direct result of child maltreatment which contributes to approximately 10% of all child abuse cases in the United States. Although the pediatric burn fatality rate in the United States has decreased 47.5% since 1999, more children who have sustained major burn injuries require serious medical attention during their convalescence every year (Safe Kids, 2015; Atiyeh & Janom, 2014).

Burn injuries can result in serious complications if not addressed and provided with adequate follow-up care. The degree classification, total body surface area (TBSA)
percentage, location, and the mechanism of the burn all impact the injury characteristics and treatment options (Grossman & Porth, 2014). However, common general physical complications of burns during the acute care phase include intestinal disturbances, shock, skin sloughing, erysipelas, pneumonia, immune system impairment, scarring, nephritis, gangrene, systemic edema, and pulmonary complications (Venes & Taber, 2009; Smith-Gabai & American Occupational Therapy Association [AOTA], 2011; Boyt Schell, Gillen, & Scaffa, 2014). Long term complications can include contractures, hypertrophic scarring, loss of muscle tone, anxiety, depression, grief, and post-traumatic stress disorder (PTSD) (Grossman & Porth, 2014; Smith-Gabai & AOTA, 2011; Venes & Taber, 2009). These long-term complications inhibit range of motion, decrease energy, and diminish mental health, making completing functional ADLs and other occupations more difficult for the child.

Burn injuries can be a severely stressful experience for children and adolescents; significantly suppressing their ability to reach crucial developmental milestones including age appropriate social, motor, and cognitive functioning (Atiyeh & Janom, 2014). According to Valenciano, Itakussu, Trelha, and Fujisawa (2015), children are often affected by burns physically and psychologically where hypertrophic scar tissue can reduce self-esteem and contribute to functional limitations in growth and development. As normal physiological functioning is rarely achieved in patients with major burns, overall quality of life is also decreased and provides challenges for burn survivors to successfully reintegrate into the community (Porter, Hardee, Herndon, & Suman, 2015). Not only is the recovery process long and painful, but it can be a stressful experience for children that can persist well into adulthood (Atiyeh & Janom, 2014). As a result, it is
important for the patient, family members, and healthcare providers to not focus only on immediate treatment, but also recognize the importance of long term follow-up care after discharge in order to effectively reintegrate the child back into the home, classroom, and community (Atiyeh & Janom, 2014).

Patients who have sustained major burns often transition from emergency rooms to intensive care units, to pediatric IRFs where they receive three hours of intense daily therapy which can last from a couple days to a couple months (DiVita et al., 2014). According to DiVita (2014), the primary goal of an IRF is to address the complex medical needs of the client in effort to achieve a high level of functioning resulting in only minimal assistance needed from caregivers upon discharge from the rehab facility. Although advances in modern burn care units have significantly increased the functional improvements with burn survivors, there is currently a lack of information addressing whether or not parents are compliant with their child’s treatment plan following discharge from an IRF (DiVita et al., 2014; Greene et al., 2015). When dealing with pediatric burn patients, it is important to accurately address progress following discharge from an IRF as it helps to determine how well the parents are transitioning into their new role as healthcare providers (Rimmer et al., 2015b). However, there is very little knowledge regarding the progress following discharge; therefore, it is difficult to assess how parent and child are performing (DiVita et al., 2014).

According to Rimmer et al. (2015b), many parents feel that they are helpless, incompetent, or unqualified to provide the adequate care their child needs upon discharge from a pediatric burn IRF. Due to elevated distress and feelings of guilt following a traumatic burn injury, parents become overwhelmed with the responsibility of meeting
the emotional and physical needs of their child during and following the months of
rehabilitation (De Young, Hendrikz, Kenardy, Cobham, & Kimble, 2014). Although
parents fully intend on providing adequate care, they are often noncompliant in making
sure that the child is receiving the rehabilitation services they require (personal
communication, April 11, 2016). In order to develop an effective resource tool designed
to assist parents during this difficult transition, it is imperative to address the physical and
psychosocial needs of the child while considering the needs of the parents by providing
them with a holistic approach to healthcare management and an opportunity to practice
and participate in the care of their child during the inpatient stay with hopes of building
healthy habits and routines and empower parents to continue care upon discharge.

Child

**Physical.** While the frequency and intensity of pain typically decrease within two
years of the burn, pain is still present in children (Valenciano et al., 2015). This demands
treatment planning to address the issue of ongoing pain. Effective pain management is
still challenging to target in children who have sustained burn injuries (Rimmer et al.,
2015a). At this time, there is both a pharmacologic and non-pharmacologic pain
management approach that is used concurrently at the beginning of treatment. The
pharmacologic approach includes a variety of prescribed medications, whereas non-
pharmacologic strategies include distraction, aromatherapy, guided imagery, therapeutic
touch, music therapy, and relaxation (Jennings et al., 2015). It is also important to
consider how a child copes with the pain. According to Rimmer et al. (2015a), coping
strategies utilized by children often include an active approach, passive approach, or by
simply managing their pain through behavioral distraction. As children learn to
successfully incorporate effective self-management techniques to handle pain, parents report increased confidence and less fear with their child’s participation in intensive rehabilitation programs (Logan, Conroy, Sieberg, & Simmons, 2012). Because coping strategies can have a significant impact on future psychological issues and chronic pain, it is necessary to incorporate effective strategies to help manage pain to improve the quality of life for these children (Rimmer et al., 2015b).

For clients who have been severely burned, it is imperative to incorporate exercise management into post rehabilitation as catabolism, the metabolic breakdown of soft tissue, and muscle wasting are two physiological stress responses that may persist for as long as one year (Pena, 2016). Muscle wasting is exacerbated by physical inactivity where rehabilitative exercise training has proven to be an effective means to build muscle mass and restore normal physiological functioning (Porter et al., 2015). According to Porter et al. (2015), it is imperative that children with severe burns receive individualized, supervised exercise routines during post-acute care as it has been shown to increase lean muscle mass and improve cardiorespiratory fitness. Although a physician should be consulted as each child’s condition is different, a typical exercise plan following discharge from an IRF should consist of 20-40 minutes as tolerated of aerobic exercise five days a week, as well as resistance training three days a week (Pena, 2016).

Additional complications of burns likely include scarring and contractures which have the potential to cause social and physical dysfunction, specifically decreased range of motion (Atiyeh & Janom, 2014). Without the implementation of consistent scar management techniques, the injured area can cause keloids and hypertrophic scars which can lead to long term complications (Valenciano et al., 2015). Children are at an extreme
risk for secondary deformities as burn scar contractures may restrict normal growth (Atiyeh & Janom, 2014). According to Atiyeh and Janom (2014), occupational therapy services are used to address contractures and can be managed through exercise and stretching therapy while scars are managed by pressure garments, gel sheeting, and massage therapy. Although there is a plethora of publications describing medical care for children with burn injuries, there are currently no publications addressing burn care programs which focus on establishing procedures for pediatric burn wound management following discharge from an IRF (Jennings et al., 2015). Therefore, the need to address scarring and contractures is necessary for the physical and social well-being of the child for effective, long term recovery.

Nutrition management is equally as important as exercise management when addressing catabolism and muscle loss; therefore, it is imperative to incorporate this into the resource tool for parents to follow (Porter et al., 2015). Burns cause hypermetabolism, which puts children especially at risk for malnutrition because they expend a tremendous number of calories due to growing and having a high rate of physical activity (Chan & Chan, 2009). The specific number of calories a child needs is determined by the size of the burn area, but is typically more than 5,000 calories per day (Chan & Chan, 2009). It is recommended the child receive a mixture of carbohydrates, fats, and protein. Because too many calories of these nutrients can also delay the healing process, it is important to find the right balance (Chan & Chan, 2009). It is also essential to include vitamins and minerals such as Vitamin A, C, and D to aid in the healing process (Chan & Chan, 2009). Nutrition is used to prevent losing muscle protein, prevent organ dysfunction, support healing, and decrease probability of infections (D’Cruz et al.,
The long-term effects of hypermetabolism could include osteoporosis, difficulty concentrating, fatigue, irritability, and unpredictable and excessive emotional reactions, all of which have the potential to interfere with daily occupations and quality of life (D’Cruz et al., 2013).

**Psychosocial.** When discharging from an IRF, a child who has sustained a burn injury undergoes a significant transition adjusting to daily life while incorporating their ongoing treatment and addressing their needs regarding school, sports/playing, and interactions with their siblings. School reintegration is a concern among the child and parents alike and should be considered while the child is still in the hospital (Arshad et al., 2015). When the child returns to school, there typically is anxiety that occurs during the transition which can ultimately interfere with learning and socializing with peers. Among these concerns, teasing and staring are the most commonly seen, especially if the child has visible scar tissue or if they are wearing pressure garments (Rimmer et al., 2015a). The child also may experience a fear of falling behind the work schedule for classes (McGarry et al., 2014). Therefore, it is imperative that the child continues with their schoolwork during their inpatient stay to instill a sense of normality (Arshad et al., 2015).

Another need of the child that requires attention is helping them adjust to their limited functional movements in sports and playing. Some children report being upset and disappointed that they are unable to participate in their sport, especially if they had been training for an extended period of time (McGarry et al., 2014). For these children, their sport often was motivation to engage in rehabilitative exercises and provided hope during the recovery process (McGarry et al., 2014). However, according to McGarry et
al. (2014), some children are overly protective of their scars and choose to not participate in sports any longer.

Lastly, emotional management is very important for all people who have sustained burn injuries as they can have a negative impact on body image and self-esteem (D’Cruz et al., 2013). The child also has to learn how to deal with stigmas in their social environment (Egberts et al., 2015). Sustaining a burn injury makes a child vulnerable to mental health issues such as posttraumatic stress symptoms (PTSS), depression, and anxiety (Egberts et al., 2015). Therefore, emotional and psychological support is necessary for the child to cope with these issues (D’Cruz et al., 2013). Participating in exercises that reduce physical deformities can help increase the child’s self-confidence and gain independence (Atiyeh & Janom, 2014). Parental support and whether or not they are avoiding trauma-related stimuli can also have an impact on the emotional well-being of the child. As children are reintegrated into the community, it is important to incorporate meaningful therapeutic activities to improve psychological wellbeing (Porter et al., 2015).

**Parent**

**Physical.** Parents may experience physical challenges while providing long-term care to their child. In general, caregiving can create physical strain over time due to the amount of chronic stress a parent experiences (Schulz & Sherwood, 2008). The stress is produced for a variety of reasons including the lack of control or predictability about the injury and how vigilant the parent must be about their child’s care (Schulz & Sherwood, 2008). According to Lynch and Lobo (2012), the specific physical symptoms parents may encounter are sleep disturbances, hypertension, tachycardia, weight changes,
headache, gastrointestinal complaints, fatigue, muscle tightness, and exhaustion. When the parent is highly focused on their child, it may result in the parent ignoring their own health by means of maintaining a poor diet and failing to attend any of their own health care appointments (Schulz & Sherwood, 2008). Therefore, if the parents are experiencing negative physical symptoms of caregiving and not addressing them, the symptoms are likely to get worse and result in poorer physical health.

**Psychosocial.** A childhood burn injury has been identified as one of the most stressful experiences a parent can endure (Rimmer et al., 2015b). Approximately 69% of parents experience symptoms of general anxiety during the acute phase, where feelings of guilt, anger, and self-blame have been reported even ten years after their child’s burn event (Rimmer et al., 2015b; Ravindran, Rempel, & Ogilvie, 2013). Anxiety can also be experienced by parents when they are reminded of the injury as this can invoke a feeling of inability to protect their child (Oster et al., 2014). According to McGarry et al. (2013), factors of being a witness to the event, feeling helpless during the event, and having a daughter sustain an injury compared to a son make the event significantly more stressful and leave the parents with less resilience compared to parents whose experiences did not include those factors.

Depression is another psychological consequence, where 23% of parents reported having extremely severe levels of depression within the first six months following their child’s burn injury (De Young et al., 2014). According to Bakker (2013), rates of depression are typically high during the acute phase but the rates drop lower six months post burn. In addition, symptoms of anxiety and depression can persist beyond six months if the parents’ psychological distress is not addressed (McGarry et al., 2013;
As many parents experience anxiety and depression, they often become less emotionally available which can lead to their child internalizing and externalizing post burn behavioral problems (Egberts et al., 2015). According to Bakker et al. (2014), common behaviors associated with pre-school children at six months post burn include increased temper tantrums and behaviors that meet the diagnostic criteria for separation anxiety disorder and oppositional defiant disorder (ODD).

Parents of a child who sustained a burn injury often find themselves with new roles and responsibilities outside the normal realm of parenting (Rimmer et al., 2015b). Parents have to shift into the role of a healthcare provider for their child and often feel lonely and uncertain making treatment decisions (Oster et al., 2014). According to Rimmer et al. (2015a), one of the most difficult challenges related to a child’s burn care following discharge is addressing the parent’s feelings of uncertainty and hopelessness to ensure the child continues to receive the ongoing care they require following discharge. In addition to their new roles, parents also have to adapt to a new routine for the rest of the family, including the child’s siblings (Oster et al., 2014). According to Oster et al. (2014), during the inpatient phase, parents’ focus is primarily on the child who sustained a burn injury, which may lead siblings to feel that they are not equally as important to their parents. Siblings may experience depressive symptoms or resentment towards the child, which may be indirectly related to the amount of attention they have received (Rimmer et al., 2015a). In other instances, siblings reported warmth and closeness with their injured sibling and also indicated they would have liked to be more involved in caring for their injured brother or sister (Bakker et al., 2013). By encouraging the parents to provide “kid-friendly” updates regarding the patient’s status, siblings better understand
the unequal distribution of care and attention, where open communication can diminish fear and anxiety among other family members (Rimmer et al., 2015b).

**Conceptual Framework**

**Model of Human Occupation.** The Model of Human Occupation (MOHO) by Gary Kielhofner is a client-centered, occupation-based model that addresses the person and how they participate in occupations in the environmental context (Turpin & Iwama, 2011). Within the model, the person is viewed as being comprised of the three interacting components of volition, habituation, and performance capacity (Kielhofner, 2008; Boyt Schell, Gillen, & Scaffa, 2014). These concepts impact what occupations a person chooses to engage in, how often they are engaged in said occupations, and how the occupations are performed (Boyt Schell, Gillen, & Scaffa, 2014). MOHO will also be used in conjunction with the adult learning theory when addressing effective teaching and learning strategies to use with parents when providing education needed to care for their child upon discharge.

**Adult Learning Theory.** One important resource that healthcare practitioners can use to help change the behavior, knowledge, skills and attitudes of caregivers is the adult learning theory (Woods, Wilcox, Friedman, & Murch, 2011). The adult learning theory refers to a variety of methods and theories which identify ways adult learning can be optimized (Trivette, Dunst, Hamby, & O’Herin, 2009). According to Friedman, Woods, and Salisbury (2012), the adult learning theory is increasingly incorporated into early intervention practice as it builds the caregiver’s capacity to effectively care for their child while embedding intervention into everyday routines and activities. It is a theory that is often used by healthcare professionals to educate caregivers on recommended...
treatment plans as this can lead to increased cooperation, decision making, satisfaction, and independence with therapeutic regimens (Bastable, Gramet, Jacobs, and Sopczyk, 2011).

**Cognitive Apprenticeship Model.** An effective method to guide application of the adult learning theory is the cognitive apprenticeship model, as this has been shown to give the adult learner the opportunity to observe, engage in, and practicing applying knowledge while demonstrating skills (Boling, Hough, Krinsky, Saleem, & Stevens, 2012). This theory-based approach is gaining popularity in health sciences education as observable skills and cognitive processes allow the learner to visualize the complexities of clinical thinking (Lyons, McLaughlin, Khanova, & Roth, 2016). When adult learners are challenged with concepts or tasks that are too difficult to understand or accomplish on their own, the cognitive apprenticeship model incorporates guided experience through expert demonstration and coaching to achieve these tasks (Dennen & Burner, n.d.). As adult learners are able to articulate their rationale for decision making, they are asked to reflect on their performance, allowing them to explore different situations where they can apply their new skills (Lyons et al., 2016).

**Summary**

Parents often feel overwhelmed and incompetent in providing the necessary care for their child when they transition from an IRF to home after their child sustained a burn injury (Rimmer et al., 2015a). The parents also have to take on a new role as a healthcare provider as well as maintain their existing roles, which can include a parent, spouse, or worker among many other potential roles. In order to address this new demanding role, the goal of this project is to develop a resource tool that occupational therapists can
utilize with caregivers of children who have sustained a burn injury. The goal is to empower parents by educating them on how to manage the needs of their child and to increase compliance prior to their child being discharged from an inpatient rehabilitation facility. This scholarly project will help to educate the parents on how to take a holistic approach to health care in order to meet the physical and psychosocial needs of the child as they transition back into the home, school, and community.
CHAPTER III

METHODOLOGY

To begin the project, communication with an occupational therapist was initiated to determine the need of the targeted populations. An occupational therapist from a regional hospital was contacted for information related to children who have sustained a burn injury and to learn if there was a tool available to parents to promote ongoing care after a child discharges from an inpatient rehabilitation facility (IRF). The occupational therapist explained there was a need for increased adherence to ongoing care outside the IRF. She also relayed that while many of the parents desire and try to provide adequate care, it still presents an often overwhelming challenge that makes it difficult to follow through on care as suggested.

After contacting the occupational therapist, a literature review was conducted by using a variety of sources. The majority of information was found via online databases, among which included Academic Search Premier, PubMed, and PsycInfo. From these databases, information was gathered about both the child and parent experience of the child sustaining a burn injury, the physical and psychosocial needs of the child, and the psychology of the parents and the family pertaining to the child’s recovery. Information for current statistics for children who have sustained a burn injury was collected from credible online databases. Information was also gathered from an assortment of occupational therapy, medical, adult education, and theory text books. From these text books, material was collected concerning occupational therapy for individuals who have
sustained a burn injury, principles of adult education, and the Model of Human Occupation (MOHO) theory.

From the literature, it was found that a child who has sustained a major burn injury requires intense medical care after first sustaining the injury and that the child continues to require time consuming care once they are discharged from an IRF. It was also found that the parents and child alike often struggle with the transition. The child may experience difficult feelings after the burn and have apprehension about returning to school and the community. The parents often feel overwhelmed and incapable of attending to the numerous tasks to provide adequate care of their child. Therefore, the Model of Human Occupation (MOHO) was chosen to address parental volition, habituation, and performance capacity in their home environment to assist parents in feeling capable, to acquire the adequate skills to take on the new role of healthcare provider, and to make it manageable in their daily routine. The adult learning theory and cognitive apprenticeship model was also chosen to utilize a variety of learning methods to effectively convey the information and to allow the parents a hands-on opportunity with the guidance of an occupational therapist to actively practice providing care for their child.

The application of the information was utilized to create the online product titled, “Road to Recovery: A Parent’s Guide to Burn Care.” The product can be utilized by occupational therapists preparing for a child’s discharge home and into the community. The principles of MOHO were used in each of the eight learning modules to address parental personal causation, roles, habits, and performance capacity to prepare them to provide care for their child in the home environment outside of the hospital. The adult
learning theory and the cognitive apprenticeship model were applied throughout the product to convey the information in an accessible manner to maximize learning.

The goal of this project is to provide a tool for occupational therapists and parents alike to empower and prepare the parents for their child’s discharge home from an IRF. The online product promotes ease of access and multiple formats of learning. It is expected that by offering this product to parents, they will feel better prepared to provide their child holistic care to meet the physical and psychosocial needs of their child as they transition back into their home, school, and community. Chapter four contains the physical product including the developed pre-program survey, the eight learning modules, and outcomes survey.
CHAPTER IV

PRODUCT

Introduction

The purpose of this product is to design and incorporate a resource tool for occupational therapists to help parents facilitate and follow-through with treatment after their child has been discharged from an inpatient rehabilitation facility (IRF). Due to elevated distress and feelings of guilt following a traumatic burn injury, parents often become overwhelmed with the responsibility of meeting the emotional and physical needs of their child during the following months of rehabilitation (De Young, Hendrikz, Kenardy, Cobham, & Kimble, 2014). As a result, many parents feel incompetent in providing the adequate care their child needs upon discharge (Rimmer et al., 2015). To assist parents in becoming successful in this new role, the adult learning theory is used to build the caregiver’s capacity to effectively care for their child while embedding intervention into everyday routines and activities (Friedman, Woods, & Salisbury, 2012).

The learners will be introduced to online educational modules where the use of computer assisted technology allows for parents to self-pace their learning independently (Bastable et al., 2011). According to Bastable et al. (2011), this instructional tool also allows for flexibility, accessibility, and provides the learner with immediate feedback.

Description of Product

The product is an online resource tool for parents to learn about their child’s recovery and the different components involved to prepare them for their child’s
impending discharge home. The product includes eight modules and addresses the following areas of therapy: pain management, skin care and wound dressing, contractures and scar management, exercise and nutrition, emotional management, family involvement, school transition, and leaving the hospital. Every module was written at or below an 8th grade level and includes a five-question quiz at the end to support comprehension. The majority of modules include a combination of pictures, diagrams, and videos when applicable to provide material for different types of learners and to ensure parental understanding. Before the parents are to start the online program, they are expected to be provided an overview, sign a learning contract to encourage active participation throughout the process, and take a pre-program survey to establish a baseline. Parents will complete a similar survey at the end of the program to see if they feel more prepared to provide care to their child at discharge. The product is designed to be self-paced which allows parents to complete it as they are able to; however, learners are encouraged to access two modules per week. This would pace the program to last approximately one month, allowing the parents time to ask their occupational therapist any questions they may have about the material prior to their child’s discharge from the IRF.

**The Model of Human Occupation**

The Model of Human Occupation (MOHO) was one of the models chosen to build this product. The concepts of volition, habituation, performance capacity, and environment were all considered. Volition includes personal causation, or the feelings about one’s abilities and effectiveness while carrying out occupations (Kielhofner, 2008). Parents may feel they may not have the ability to effectively perform the numerous new
tasks their child needs once they are discharged home from the hospital. Habituation includes roles and habits, which are identifying roles and performing in expected ways, and performing in consistent ways, respectively (Kielhofner, 2008). Parents are expected to undertake a new role of healthcare provider in addition to being a parent, and this may leave them feeling unprepared or unable to take on this new role. Parents’ daily habits will also have to be altered to allow for time to meet the new demands of their child at their environment at home. The parents’ performance capacity, or their mental and physical abilities to perform occupations, may also be altered due to the parents’ emotional state or their desire to not cause their child any pain (Kielhofner, 2008). Due to all of these factors, the parents’ needs as well as the child’s needs were assessed under MOHO.

**Adult Learning Theory**

The adult learning theory refers to a collection of methods used to optimize the process of learning (Trivette et al., 2009). As parents of children with burn injuries are the target market for this product, it was imperative to incorporate this theory into the product as recent meta-analytical work has supported the idea that active learner participation can increase the abilities for adults to acquire and retain new information for skill acquisition (Friedman et al., 2012). According to Friedman et al. (2012), adults learn best when they are actively engaged in material that is relevant to their lives, where learning is organized in real-life context. As parents will be directly working hands-on with their child in providing therapeutic interventions while admitted in the IRF, it is believed that the adult learning theory would help to maximize the potential of the learner.
One of the most significant aspects to consider when incorporating the adult learning theory into practice is the assumption that the learner is self-directed, presents with a readiness to learn, and embraces the opportunity for active learning participation (Trivette et al., 2009). Under the adult learning theory, the cognitive apprenticeship model was specifically implemented as this product allows the adult learner the opportunity to observe the therapy session, apply knowledge, and demonstrate skills while receiving coaching from the occupational therapist. According to Dennen and Burner (n.d.), the cognitive apprenticeship model allows the learner to first acquire the knowledge, followed by guided experience through expert demonstration and coaching to complete the desired task. As the parents complete the online learning modules, this will better prepare them for the hands-on training they will receive from the occupational therapist when providing therapeutic interventions with their child.
Road to Recovery:

An online guide to prepare parents of children who have sustained a major burn injury for successful home and community transition

Michelle Jones, MOTS & Chad Oppegaard, MOTS
University of North Dakota
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Welcome to the Road to Recovery:  
A Parent’s Guide to Burn Care

Introduction
The Road to Recovery: A Parent’s Guide to Burn Care is designed to help you prepare for the care your child will need once discharged from the hospital. We encourage you to take part in your child’s recovery process through hands-on training with an occupational therapist. The training aims to improve your confidence and ability to care for your child at home while helping them get back to their favorite activities. The program will help prepare you to care for your child’s burn injury and explain how to provide the treatment your child needs at home.

Program Outline
Your occupational therapist will recommend your start date as your child gets closer to going home. The program includes 8 modules consisting of lesson plans, videos, quizzes, and additional online resources. Each class session will provide information on specific areas of treatment that your child will need when they go home. The online modules will take around 15 minutes to complete and can be accessed on your home computer or mobile device. A brief description of each module is listed below.

- **Module 1: Pain Management** – Managing your child’s pain can be an ongoing process. The new forming skin can be very itchy, sensitive, and painful when lightly touched. This pain can interfere with your child’s ability to do many things such as: play, getting dressed, and exercising. This class session will give you different ideas on how to handle your child’s pain.

- **Module 2: Skin Care and Wound Dressing** – As your child’s skin begins to heal, it may break down and require protective dressing until it heals. It is important to monitor the color of the skin and keep the area moist. This class session will help you to aid in the healing process by understanding how to properly care for your child’s skin and change dressings. The module also includes details of how to protect your child’s skin during play activities such as going outside to play in the sun.

- **Module 3: Contractures and Scar Management** – It is important to manage your child’s scars and contractures as they can negatively impact their physical and emotional needs. Without consistent scar management, the injured area can tighten up and cause deformities that can restrict your child’s ability to complete showering, dressing, and playing among other activities. This class session will help you aid skin healing to minimize scar formation.
- **Module 4: Exercise and Nutrition** – Loss of muscle mass occurs immediately after a burn injury. This is because the body requires a lot of energy during the healing process which can lead to extreme weight loss. This class session will help you become familiar with the exercise and nutrition needs of your child to maintain a healthy weight and how to incorporate these activities into your child’s every day routine.

- **Module 5: Emotional Management** – Burn injuries can be a stressful time for your child. Their physical appearance and limited ability to move the injured body part can affect their self-esteem. In addition, watching your child go through this experience can also be very stressful. This class session will help you and your child learn how to manage difficult feelings as a result of the burn injury. The session will also provide some ideas of activities your child can engage in to learn how to deal with difficult emotions.

- **Module 6: Family Involvement** – Active involvement from the entire family is important when your child returns home. Some family members might be nervous to help, while others might be upset that they are getting less attention. This class session will help you learn how to involve the family in therapy and day to day routines while not neglecting other members.

- **Module 7: School Transition** – Leaving the hospital and returning home can be difficult for your child. The fear of going back to school and seeing old friends can make your child feel nervous, sad, or scared. Participating in school, interacting with peers, and playing can be intimidating at first. This class session will help your child prepare for transition out of the hospital and back into school and the community.

- **Module 8: Leaving the Hospital** – Leaving the hospital can be a very exciting time for you and your child. This class session will address any questions or concerns that you or your child might have for your occupational therapist. We want to make sure that you are comfortable in caring for your child at home so they can continue their road to recovery.

**Program Expectations**
Although you can work at your own pace, we recommend that you read each module before the therapy session in which you will collaborate with the occupational therapist. The information in the lesson plans will be covered by your occupational therapist, so it is important that you have a basic understanding coming in to the therapy session. The lessons will help prepare you to better understand the therapy your child will receive that day. The modules will take around 15 minutes and will include a written lesson plan, pictures, videos, and a brief quiz. It is completely normal to have questions when going through the modules. You are encouraged to write down any questions you have which can later be answered by your occupational therapist during the therapy session.
We are excited to have you in the program and look forward to helping you better understand the ongoing needs of your child!
Learning Contract

The purpose of the learning contract is to specify the goals, expectations, and time frame of the program you are about to participate in. This gives you an idea of what the program is going to be like and what the program requires. Remember, we are here to help you, and we are on a team together to help you feel as prepared as possible when your child goes home.

Please initial each statement for agreement.

- I understand the program includes 8 modules. 

- I will attend the ongoing therapy sessions with my child. 

- I understand I will be practicing hands-on therapy techniques with my child during therapy sessions. 

- I will complete my online lessons prior to the session. 

- I will complete all of the items in the modules, including short readings, videos, quizzes, and practices. 

- I understand the occupational therapist will have access to see my progress on the online program. 

- I will talk to my occupational therapist if I have any questions or concerns about a topic.

I have read the learning contract and understand the expectations. I understand the intent and benefit of this program is to help prepare me and my child for the transition out of the hospital and to help my child succeed at home, at school, and in the community.

______________________________  __________________
Signature                      Date
Pre-Program Survey

The purpose of this Pre-Program survey is to learn about your current knowledge and comfort level in caring for your child who has sustained a burn injury. We will also be able to see progress made when comparing to the same survey completed at the end of the program. Parents often report a lack of understanding in their child’s ongoing needs once they leave the hospital. Some parents feel nervous and unsure of their ability to care for their child after a burn injury. This survey will help identify your strengths and areas for improvement when caring for your child at home. The information will be used to track changes in your confidence and ability to address the new needs of your child before discharging home.

1. Number of parents providing the child with care at home:  
   - 1 Strongly Disagree  
   - 2 Disagree  
   - 3 Agree  
   - 4 Strongly Agree

2. Number of parents completing the Road to Recovery program guide:  
   - 1 Strongly Disagree  
   - 2 Disagree  
   - 3 Agree  
   - 4 Strongly Agree

3. I am confident that I can continue my child’s treatment needs once discharged from the hospital.

   - 1 Strongly Disagree  
   - 2 Disagree  
   - 3 Agree  
   - 4 Strongly Agree

| Physical |  
| --- | --- |
| **Question** | **Answer (Please circle one)** |
| 1. I have been given information on how to decrease my child’s pain when they leave the hospital. | Yes  
No |
| 2. I feel certain that I can decrease my child’s pain. | 1 Strongly Disagree  
2 Disagree  
3 Agree  
4 Strongly Agree |
| 3. I have been given information about why exercise is important for my child when they leave the hospital. | Yes  
No |
<table>
<thead>
<tr>
<th>Question</th>
<th>Response Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>4. I feel certain that I can help my child with their exercises at home.</td>
<td>1 Strongly Disagree, 2 Disagree, 3 Agree, 4 Strongly Agree</td>
</tr>
<tr>
<td>5. I have been given information on skin care and dressing changes for my child when they leave the hospital.</td>
<td>Yes, No</td>
</tr>
<tr>
<td>6. I feel certain that I can manage my child’s skin care needs when they leave the hospital.</td>
<td>1 Strongly Disagree, 2 Disagree, 3 Agree, 4 Strongly Agree</td>
</tr>
<tr>
<td>7. I have been given information on specific treatments to reduce the chances of my child forming contractures when they leave the hospital.</td>
<td>Yes, No</td>
</tr>
<tr>
<td>8. I feel certain that I can reduce the chances of my child getting contractures.</td>
<td>1 Strongly Disagree, 2 Disagree, 3 Agree, 4 Strongly Agree</td>
</tr>
<tr>
<td>9. I have been given information on how to reduce my child’s scar tissue formation when they leave the hospital.</td>
<td>Yes, No</td>
</tr>
<tr>
<td>10. I feel certain that I can treat my child to reduce the formation of scar tissue.</td>
<td>1 Strongly Disagree, 2 Disagree, 3 Agree, 4 Strongly Agree</td>
</tr>
<tr>
<td>Question</td>
<td>Answer (Please circle one)</td>
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<tr>
<td>11. I have been given information on how to handle my emotional needs.</td>
<td>Yes  No</td>
</tr>
<tr>
<td>12. I feel confident that I can manage my emotional needs.</td>
<td>1 Strongly Disagree 2 Disagree 3 Agree 4 Strongly Agree</td>
</tr>
<tr>
<td>13. I have been given information on how to handle the emotional needs of my child when they leave the hospital.</td>
<td>Yes  No</td>
</tr>
<tr>
<td>14. I feel certain that I can meet my child’s emotional needs.</td>
<td>1 Strongly Disagree 2 Disagree 3 Agree 4 Strongly Agree</td>
</tr>
<tr>
<td>15. I have been given information on how to transition my child back to school when they leave the hospital.</td>
<td>Yes  No</td>
</tr>
<tr>
<td>16. I feel certain that I will be able to transition my child back into school.</td>
<td>1 Strongly Disagree 2 Disagree 3 Agree 4 Strongly Agree</td>
</tr>
<tr>
<td>17. After completing this survey, I am confident that I can continue my child’s treatment needs once discharged from the hospital.</td>
<td>1 Strongly Disagree 2 Disagree 3 Agree 4 Strongly Agree</td>
</tr>
</tbody>
</table>
Module 1: Pain Management
Lesson 1: Pain Management

Introduction
Recovering from a burn injury can be very painful for your child. While the frequency and intensity of pain typically decreases within the first two years, your child may continue to feel pain throughout the recovery process. As a parent, it is difficult to see your child in pain. Parents often say that managing their child’s pain is the most important, yet challenging aspect of the recovery process. As a result, your occupational therapist will show you several ways to help manage your child’s pain level.

Is it pain or itching?
It is hard for a child to tell the difference between pain and itching. Itching is very common as new skin is tender and is sensitive to even the lightest touch. This can be uncomfortable where constant irritation can cause the child to break down new skin and develop open wounds. These open wounds can cause your child more pain and slow down the healing process. It is important to let your child know that itching is normal and is a good sign because it means the skin is healing. Whether it is pain or itching, two helpful strategies that can help manage your child’s pain are medications and diversion techniques.

Medication
To help your child deal with itching, medications like Benadryl or Atarax can be given. You should always consult with your doctor beforehand to make sure your child will not have a bad reaction. Your doctor can also recommend lotion or medicated ointment that can be applied to the injured area. This can be applied several times a day and can help to protect the skin from air flow, which often causes irritation and itching. Lastly, if your child is really uncomfortable and continues to itch, notify your doctor for prescription medication.

If your child is in pain, medication may be prescribed from your doctor. The prescription will come with a recommended dosage that should be given at specific times of the day. It is important that you create a schedule with daily reminders. It is best that your child has a dose of pain medication 30-60 minutes before wound dressing or before completing an exercise program. This will reduce pain that may occur as the result of therapy. Below is a list of strategies that may help you to manage your child’s pain medication:

- **Calendar:** Write on a calendar the hours of the day that your child’s medication should be given.
- **Checklist:** Use colors to represent different medications and what time they should be given.
- **Alarms:** Alarms can be set on your phone or watch to remind you when your child needs medication. Hearing an alarm helps you remember to complete the task.
- **Daily routine:** Routines can help you stay consistent when giving your child their medication. An example could be scheduling your child’s pain medication to be given with certain meals of the day.
• **Pillbox:** A pillbox will help you keep track of the medications that you have given your child throughout the day. It can also help you realize if you forgot to give your child their medication.

• **Promote buy-in:** Educate your child on the importance of taking medication and reward them each time they remind you. This could be in the form of verbal praise or allowing them to have their favorite food or drink once they have taken their medication.

**Diversion Techniques**

In addition to medication, you can also use diversion techniques to help manage your child’s pain. Diversion techniques allow your child to use other senses to focus on different activities. This approach helps distract your child from the pain they might be experiencing. You should try different diversion techniques to see which one works best for your child. These techniques can be combined with one another and may include, but are not limited to, the following:

• **Distraction with play:** Using the child’s interests such as their favorite game or toy can help them to focus on play rather than pain.

• **Guided imagery:** This is a form of meditation where you have your child lie down, close their eyes, and listen to you read or tell them a story about their interests and hobbies. Your child is then asked to picture the story in their head while you are guiding them through the activity.

• **Therapeutic touch:** A calm, light touch on healthy skin can help to relax your child and relieve pain.

• **Music therapy:** Playing soothing music can help create a relaxing environment. This is often used with other diversion techniques where your child can associate the music with feeling calm and relaxed. Additional benefits can be experienced by working with a board certified and licensed music therapist. More information can be found at [www.musictherapy.org](http://www.musictherapy.org).

• **Relaxation:**
  - **Progressive Muscle Relaxation (PMR)** – Have your child lie down while listening to soothing music. Next, ask your child to tighten and relax each muscle starting with their hands and working down to their toes. Below is an example of PMR that can be used with your child: [https://www.youtube.com/watch?v=DalxIqYuKYk](https://www.youtube.com/watch?v=DalxIqYuKYk)
  - **Deep breathing** – Deep breaths and slow breathing can help your child relax and reduce their pain.

• **Aromatherapy:** Adding essential oils and certain plants extracts can help your child to relax.

• **Animal-assisted therapy:** Animal-assisted therapy allows your child to interact with an animal such as a dog, cat, horse, or even a rabbit. Playing with an animal can be relaxing. Another option is having a therapy animal present during occupational therapy sessions. For example, your child may be motivated to stretch out their arms to pet a dog or cat while completing stretching exercises. If your child likes animals, either option can serve as another diversion technique. Talk to your occupational therapist about getting in contact with a local animal-
assisted facility. Below is an example of how animals can assist your child in the recovery process: https://www.youtube.com/watch?v=mb2tv8jT6r8

**Take Home Point**
Although there are many options to manage your child’s pain, it is important that you determine which one works best for your child. Once you find out which strategy works best, you can establish a routine to successfully manage your child’s pain.
Lesson 1 Summary Quiz: Pain Management

1) When should your child receive pain medication when changing their wound dressing?
   a. After you have changed the bandage
   b. 10 minutes before you change their bandage
   c. 30-60 minutes before you change their bandage
   d. Do not give your child pain medication

2) If your child complains that their skin itches, you should_________
   a. tell them this is normal.
   b. give them Benadryl if approved by your doctor.
   c. apply lotion or medicated ointment.
   d. All of the above

3) Which strategy would you not use when managing your child’s pain medication?
   a. Set alarms
   b. Establish a routine
   c. Create a calendar
   d. It is not important to manage their pain medication

4) All diversion techniques will reduce your child’s pain.
   a. True
   b. False

5) You should only use one diversion strategy to manage your child’s pain.
   a. True
   b. False
Module 2: Skin Care and Wound Dressing
Lesson 2: Skin Care and Wound Dressing

Introduction
As your child is recovering from their burn injury, the appearance of their skin goes through many changes. Changes in appearance may include skin color, dryness, and scarring. Your child may also have wounds at the time of discharge. Wound dressing care is important to help your child’s skin heal after the injury, and depending on the severity of the wounds, you may be responsible for completing wound care at home. Skin care and changing wound dressings are discussed below so you are prepared to care for these aspects of your child at home.

Skin Care
- **Appearance:** At the time of discharge, your child’s skin may appear bright red. If your child becomes ill or flushed, their skin may turn from bright red to purple. This is a normal reaction. Over the next several weeks, this bright red color will fade to a light, pale pink. Eventually the skin will return to its normal color (see Figure 2.1 and 2.2). It is important to know that in some cases the skin might be lighter or darker, depending on the severity of the burn injury.

![Figure 2.1](image1)

![Figure 2.2](image2)
● **Sensation:** As the wound generates new skin, the site of the burn injury may become extremely sensitive. Your child may report uncomfortable feelings of itching and experience a tingling sensation. As you learned in Lesson 1, this is normal as it means the wound is healing. To reduce skin irritation, make sure that the wound is kept moist with recommended lotion or ointment. To avoid damaging the new skin, have your child “pat” the area of skin rather than itch it.

● **Re-injury:** As the skin is healing, it is very fragile and vulnerable to breakdown. It is important that you check your child’s skin every day to search for blisters, bleeding, or areas that might look raw. These injuries can occur from rough play, scratching, or gentle rubbing from clothing. If you see any infected areas, use medicated ointment and cover the wound. If the infected area does not seem to improve, contact your healthcare provider.

● **Protective clothing:** Your child’s injured skin will be sensitive to the sun for at least 1 year. Ensure your child is wearing light cotton shirts and pants that cover their injured skin completely while they are outside. This includes wearing a wide-brimmed hat and gloves if your child has an injury in those areas.

● **Sunscreen:** As your child forms new skin, it becomes very sensitive to the sun. It is important that you always protect your child’s burn injury from the sun’s harmful UV rays. This involves applying and reapplying sunscreen when your child is outside. These steps will help protect your child from the sun:
  ○ Sunscreen with SPF 30 or higher should be applied at least 30 minutes before going outside, even if it is cloudy. Sunscreen should also be reapplied as often as the label suggests, which is usually every 90 minutes.
    - Sports sunscreens work well for hands and faces (see Figure 2.3 for an example of a brand)
    - Oil-based sunscreens work well for dry skin (see Figure 2.4 for example of a brand)
    - Water-based sunscreens work well on skin that tends to breakout (see Figure 2.5 for example of a brand)
○ Be aware that the sun’s rays are strongest between 10:00 am and 4:00 pm. Your child can still play outside, but make sure you are taking extra precautions during this time such as re-applying sunscreen as directed.
○ You should not use sunscreen over grafted or donor sites for at least 12-18 months after the surgery.

Wound Dressing Care
Wound dressing care is extremely important. It helps your child’s injury heal, but it can also be an area that can easily become infected and lead to problems. This is why it is important to keep the injured area and the wound supplies as clean as possible.

- **Wound Dressing Care: Hospital** – At the hospital, it is recommended for you to be involved in wound dressing changes. Your ongoing participation with wound dressing changes helps ensure that you are able to complete them by yourself at home. The following three steps will assist you:

  1. **Observe** - You will watch your occupational therapist complete a dressing change on your child. They will explain how to do it and will encourage you to ask questions about the process.
  2. **Assist** - You will be asked to help with the dressing change. The occupational therapist will teach you how to change your child’s wound dressings while you perform the dressing change yourself.
  3. **Demonstrate** - You will complete the dressing change on your own with the occupational therapist supervising you. The occupational therapist is there to support you by answering questions and assist your when needed.

- **Wound Dressing Care: Home**: Once your child is discharged, you will likely complete the wound dressing changes at home. Keep in mind, your child can bathe or shower on the day of the dressing change if cleared by the burn team. If dressings stick to the burn, you can get them wet in the bath or shower to make them come off easier. Baths tend to be more comfortable as the new-forming skin
might be sensitive to pressure from the showerhead. Be sure to use non-scented soaps. Once your child is done bathing or showering, gently dry the skin by patting it with a clean towel. If you choose not to bathe or shower your child, you can also apply burn ointment on the dressings or purchase saline at a pharmacy to loosen the dressings. Below are the steps for completing a wound dressing change at home:

1. **Give pain medicine** – Give your child pain medicine (as prescribed by their physician) 30-60 minutes beforehand. This allows the medication to kick in before you start removing the dressing which can oftentimes cause pain. Ask your doctor which medication is best for your child.
2. **Clean the area** – Clean the surface where you are going to put the dressing supplies, such as the kitchen counter or bedside table.
3. **Prepare the supplies** – Prepare the dressing supplies by opening and organizing the supplies you will need.
4. **Wash your hands** – Wash your hands with soap and warm water. Wash them long enough to sing the ABC’s. You don’t have to use gloves if you do proper hand washing (you can wear gloves if you prefer).
5. **Apply antibiotic ointment** – Squirt the antibiotic ointment onto the non-stick shear gauze (adaptic) or telfa pad. Squirt enough ointment to cover the gauze, as if you were frosting a cake. Smear it into the gauze.
6. **Cover the area** – Cover the burned area with a gauze pad where the greasy side is face down. Roll on the white gauze (kling or kerlix) dressing.
7. **Secure with therapy tape** – Apply the Coflex® or Coban® tape over the white gauze. The tape is wrinkly so make sure you don’t pull it so tight that you can’t see the wrinkles. If the tape is too tight to fit one of your fingers between the dressing and your child’s skin, or if there are no wrinkles, unwrap the dressing and re-wrap it more loosely. If the dressing covers a joint, have your child straighten that joint (versus bending it) while wrapping it with gauze and tape.

**Considerations**
- If your child bleeds a little with the dressing change, don’t be alarmed. Hold gentle but firm pressure over the bleeding site with a clean gauze or a towel until the bleeding stops.
- Do not allow the dressings to become wet on the days in between dressing changes. If they do become wet, they will need to be changed. It is okay for the dressings to become slightly dirty as long as there are enough layers to protect the wound.
- Upon discharge the hospital will provide you with enough dressing supplies to get you started. If you run out, the supplies are available at your local pharmacy. If you run out of ointment, you can use over-the-counter products. These include Bacitracin, Neosporin®, Polysporin®, or a generic clear antibiotic ointment.
Coflex® or Coban® is also available at your local pharmacy, or you can find it in pet stores under the name “vet tape.” This tends to be a cheaper option.

- Call your doctor if your child has any of the following:
  - Fever over 100.4 degrees F
  - Uncontrollable pain, crying, or fussiness
  - Decrease in urine

**Take Home Point**

As your child’s skin heals, there are going to be many changes that you will continuously need to monitor. These changes include the color, moisture, and condition of your child’s skin. To better prepare you for this responsibility, we fully intend to work with you throughout your child’s stay at the hospital. The purpose of this lesson is to prepare you for the next therapy session where you will work hands-on with an occupational therapist to address skin care and wound dressing changes. This will help you to feel more confident in your abilities when caring for your child at home.
Lesson 2 Summary Quiz: Skin Care

1) When your child requests to go outside, what should you do to protect their skin from the sun?
   a. Apply sunscreen at least 30 minutes before they go outside
   b. Dress in lightweight cotton clothing
   c. Reapply sunscreen throughout the day
   d. All of the above

2) What is the first step you should take when changing your child’s wound dressings?
   a. Squirt antibiotic ointment on the wound
   b. Give them pain medication
   c. Remove the bandage in water
   d. Wash your hands

3) It is normal for the appearance of my child’s skin to _______
   a. appear bright red, then turn pale pink.
   b. turn purple when my child becomes flustered or ill.
   c. become lighter or darker depending on the severity of the burn.
   d. All of the above

4) What is the correct order when participating with wound dressing changes with your occupational therapist in the hospital?
   a. Observe, assist, demonstrate
   b. Assist, demonstrate, observe
   c. Observe, demonstrate, assist
   d. Demonstrate, observe, assist

5) When should you call your doctor during a dressing change?
   a. If your child bleeds a little
   b. If your child’s temperature is over 100.4 degrees F
   c. If you child cries a little
   d. If there is slight increase in urine
Module 3: Contractures and Scar Management
Lesson 3: Contractures and Scar Management

Introduction
The healing phase of your child’s burn injury may last up to two years. During this time, contractures and scars may form. Contractures can decrease functional movements depending on the location of the injury. For example, if your child has contractures on the stomach or back, this can cause poor posture. If your child has contractures near joints, such as a burn injury to the hand, it can make those joints harder to bend or fully straighten. Contractures and scarring may impact normal growth as your child continues to grow. That is why it is important that we discuss contractures and scar massage to help you care for your child when you are at home.

Contractures
Contractures are when muscles and tendons start to “harden” and cause the injured area to become stiff. This joint stiffness can restrict normal movement and lead to deformity. To prevent contractures, your child may require a splint in addition to their range of motion exercises, both of which will be addressed by your occupational therapist.

- **Splinting:** Splinting and positioning usually occurs immediately following the injury. Often the splint is worn for as long as 2 to 3 months following the injury (see Figure 3.1 and Figure 3.2 for examples of splints). The occupational therapist will help your child create a splint wearing schedule. They will also encourage your child to wear the splint so this can be part of their everyday routine. This may include allowing your child to personalize the splint by choosing the color or decorating it with markers and stickers (see Figure 3.3). Splinting should be combined with exercise, which we will talk about in lesson four.

![Figure 3.1](image1.png)  
*Figure 3.1*

![Figure 3.2](image2.png)  
*Figure 3.2*
• **Range of Motion:** Any joints that have been affected by a burn injury should be moved and stretched several times per day. The occupational therapist will decide the amount of movement and range of motion that your child receives. Range of motion is determined on a case-by-case basis and will be created specifically for your child. This will be addressed by your occupational therapist in the following therapy session.

**Scar Management**

• **Pressure garments:** These are tight fitting elastic garments designed to apply constant, even pressure over your child’s scar tissue (see Figure 3.4). The use of pressure garments can help to improve the flexibility, texture, and color of your child’s skin. They have also been shown to reduce the thickness and height of scars. They are generally worn up to 23 hours per day. They are removed only for cleaning and scar massage. Pressure garments are typically worn one to two years after the burn injury or as recommended by your healthcare provider.
If your child needs a pressure garment, your occupational therapist will order and custom fit your pressure garment before your child leaves the hospital (see Figure 3.5). Your occupational therapist will help you create a wearing schedule and find ways to encourage your child to wear the garment so this can be part of their everyday routine. This may include allowing your child to personalize their garment by choosing the color or design.

**Figure 3.5**

- **Gel sheeting**: This is a silicone gel material used to promote elasticity of the skin and reduce thickness of scars (see Figure 3.6). Gel sheeting increases the temperature of the area, keeping the skin moist. It also can reduce redness and promotes flattening of the scar. Although the wearing schedule will be determined by your child’s doctor, they are normally worn between 12 and 24 hours per day. Gel garments may also be worn with a pressure garment. Table 3.1 highlights the pros and cons of using gel sheeting.

**Figure 3.6**
Gel sheeting can be beneficial; however, be sure to check with your doctor and occupational therapist before using it on your child. It should be applied only when healing of the wound is complete and no open wounds remain. When applying silicone gel sheeting to your child’s scar, it is important to follow these steps:

1) **Clean the area** with soapy water, rinse thoroughly, and dry the area.
2) **Cut the gel sheet** with scissors to match the size and shape of the scar.
3) **Apply the gel sheet** directly to the scar.
4) **Secure the gel sheet** in place with Coflex® or Coban® tape.

Your child may wear the gel sheeting for 12-24 hours. Stop using gel sheets if your child has a rash or skin breakdown.

<table>
<thead>
<tr>
<th>The Pros and Cons with using Gel Sheetig</th>
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<tbody>
<tr>
<td><strong>Pros</strong></td>
<td><strong>Cons</strong></td>
</tr>
<tr>
<td>- May reach areas that pressure</td>
<td>- Can cause severe itchiness</td>
</tr>
<tr>
<td>garments cannot provide enough</td>
<td>- Can increase risk of rash and</td>
</tr>
<tr>
<td>pressure</td>
<td>skin breakdown</td>
</tr>
<tr>
<td>- Forms an effective bacterial barrier,</td>
<td>- Can be smelly</td>
</tr>
<tr>
<td>which can decrease infection</td>
<td>- Lotion can break down the gel</td>
</tr>
<tr>
<td>- Can be washed and reused up to 6</td>
<td>and cause a rash</td>
</tr>
<tr>
<td>weeks</td>
<td>- Cannot be used if the wound is open</td>
</tr>
</tbody>
</table>

*Table 3.1*

- **Scar Massage:** Massage therapy provides firm pressure over the scar that helps break up collagen to make the scar lay flat. Massage should only be completed when healing of the wound is complete and no open wounds remain. If available, you should use Vitamin A and D ointment or lotions that contain cocoa butter (see Figure 3.7 for technique).

- A. Rub along the scar in circles
- B. Rub along the width of the scar
- C. Rub along the length of the scar

*Figure 3.7*
Your occupational therapist will show you how to perform massage therapy during your next therapy session. In the meantime, please refer to the following video: https://www.youtube.com/watch?v=N2cSNORk37E

**Take Home Point**
As your child continues to grow, their skin is required to stretch. This puts them at risk for developing contractures. To prevent this from happening, it is important that your child develops a structured routine immediately after the injury. This routine involves range of motion, stretching, and wearing splint and pressure garments while engaging in play activities. This includes getting your child in the habit of wearing their splint and pressure garments and following a daily routine which includes scar massage and range of motion exercises. This will help to minimize scarring and prevent deformity.
Lesson 3 Summary Quiz: Contractures and Scar Management

1) Which statement about contractures and scar management is not true?
   a. Splinting usually occurs immediately following an injury
   b. Splints may be worn up to three months
   c. Splinting does not help contractures
   d. Place ointment over the gel sheeting

2) Any joints that have been affected by a burn injury should be moved and stretched several times per day.
   a. True
   b. False

3) What should I do if my child develops a rash or open wound from the gel sheeting?
   a. Wash the gel sheeting and reapply it to the skin.
   b. Stop using the gel sheeting and talk to your doctor.
   c. Apply new gel sheeting to the skin.
   d. Apply moisturizing lotion to the scar and then reapply gel sheeting.

4) Which statement about pressure garments is true?
   a. They apply constant, even pressure to reduce your child’s scar
   b. They are generally worn up to 23 hours a day
   c. They are typically worn for one to two years after a burn injury
   d. All of the above

5) When massaging my child’s scar, I should _________
   a. apply lotion with cocoa butter or with vitamin A and D.
   b. use firm pressure over the scar area.
   c. rub the length of the scar, across the scar, and in circles.
   d. All of the above
Module 4: Exercise and Nutrition
Lesson 4: Exercise and Nutrition

Introduction
A common stress response after a burn injury is muscle wasting, which means your child’s muscles become weaker and smaller. As your child continues to heal, their body needs constant energy which can result in weight loss and fatigue. A growing child with a burn injury can use upwards of 5,000 calories per day depending on the severity of their burn. As a result, your child’s body will actually start breaking down muscle and using it for energy. Muscle wasting can last from a couple months to several years following a burn injury. To prevent muscle wasting it is important to provide a combination of exercise and nutrition to help your child recover.

Exercise
Exercise is physical activity that will help your child recover from their burn injury. Two forms of exercise that will be part of your child’s weekly therapy program include aerobic and strength training.

- **Aerobic:** Aerobic exercise helps bring oxygen in the blood to working muscles. This can increase your child’s energy level and reduce fatigue. Your occupational therapist will look at your child’s heart rate, oxygen levels, and functional abilities. The goal is to create an aerobic exercise plan that your child can safely do at home. This usually involves an aerobic exercise plan that is 60 to 80 percent of your child’s peak ability. Although it will be specific to your child, aerobic exercise programs are usually 20 to 40 minutes per day, five days per week. The stages of aerobic exercise are listed below:
  - **Warm-up phase** – This is done before your child starts to exercise and usually lasts for five minutes. This light activity is used to warm up the muscles and get the blood flowing before a workout.
  - **Exercise phase** – This is used to increase your child’s heart rate. This is usually done by having your child use a treadmill, exercise bike, elliptical, or rowing machine. Your occupational therapist will work with you and your child to determine exercise training that involves play such as riding bikes or playing games with friends. This can make the exercise more meaningful for your child and increase their motivation to participate.
  - **Cool-down phase** – This involves returning your child’s body to how it was before the workout. As your child works out, their muscles get strained and must repairs themselves. The cool-down is used to promote recovery from the workout and prevent injury.
- **Strength Training:** Strength training helps to build muscle and increase body mass. Your occupational therapist will look at your child’s functional abilities and range of motion. This will help them create a strength training program that your child can safely do at home. This involves finding out what your current resources are and how you and your occupational therapist can tailor a workout program that will meet your child’s needs. Although the strength training program will be specific to your child, they are usually 30 minutes per day, three days per week. Strength training includes the following:
  - **Warm-up phase** – This is done before your child starts to exercise and lasts for five minutes. This light activity is used to warm up the muscles and get the blood flowing before a workout. This might include having your child stretch their muscles and warm up their muscles with light resistance.
  - **Exercise phase** – This is the act of using resistance to build muscle mass. This is done by having your child use free weights, resistance machines, or therabands. Your occupational therapist will determine the exercise, resistance, and number of repetitions that your child should complete. The occupational therapist will also look at your child’s interests and hobbies to create an exercise routine that is enjoyable. This can make exercise more meaningful for your child and increase their motivation to participate.
  - **Cool-down phase** – This involves returning your child’s body to how it was before the workout. As your child participates in strength training, their muscles become strained and repair themselves. The cool-down is used to promote recovery from the workout and prevent injury.

**Nutrition**
As your child’s body begins to heal, it is always using energy. Even at rest, your child is burning a large number of calories. This is a common stress response and can occur for up to two years. On average, a child who has received a major burn injury needs at least 50% more calories than their normal diet. For example, if a child is on a 2,000 calorie diet, they would now need around 3,000 calories each day. Depending on how severe the burn injury is, some children need more than 5,000 calories per day. It is important for you to talk with your dietician to figure out the number of calories your child will need each day to prevent weight loss. They will also help you determine which high protein foods will increase your child’s body weight.

Your occupational therapist will be able to help you create a feeding schedule to make sure that your child is getting the daily calories they require. Your occupational therapist
will also show you ways to help your child become more engaged in meeting their dietary needs. This includes giving them food options and having them assist you in preparing their weekly menu. Involving your child throughout the process of meal preparation can help them to establish a daily eating routine.

**Take Home Point**
Your child’s body weight cannot be increased by nutrition or exercise alone. You must consider both methods to reduce fatigue and increase body mass. Aerobic exercise and muscle strengthening programs are equally important and should be done at home. Your occupational therapist will help create a program that will be effective and provide motivation for your child to participate at home.
Lesson 4 Summary Quiz: Exercise and Nutrition

1) Muscle wasting after a burn injury can last up to two years.
   a. True
   b. False

2) What is the correct order when using the phases of exercise?
   a. Warm-up, Cool-down, and Exercise
   b. Exercise, Warm-up, and Cool-down
   c. Warm-up, Exercise, and Cool-down
   d. Cool-down, Exercise, and Warm-up

3) Which exercise below is an example of strength training?
   a. Riding an exercise bike
   b. Lifting free weights
   c. Running on a treadmill
   d. Using a row machine

4) It is best to use exercise and nutrition together to prevent muscle wasting.
   a. True
   b. False

5) Which statement is true about nutrition?
   a. Foods high in protein can help increase my child’s body weight
   b. Children with major burn injuries need 50% more calories every day
   c. A feeding schedule can help monitor your child’s calorie intake each day
   d. All of the above
Module 5: Emotional Management

How are you feeling today, kiddo?
Lesson 5: Emotional Management

Introduction
Parents and children alike often experience difficult emotions following a child’s burn injury. Some of the emotions will be similar but the experience of the child and parent in this situation may be different. This lesson begins by discussing the often overlooked emotional management of the parents, followed by emotional management of the child.

Parents
Posttraumatic Stress Disorder (PTSD) and Depression: After a child has had a burn injury, parents can experience or develop PTSD and/or depression. Parents often report high levels of depression, specifically after their child has been discharged from the hospital. Some reasons why parents may have depression symptoms include:

- There is a disruption in their child’s routine
- There is a lack of understanding regarding their child’s healthcare needs
- Not knowing what their child’s future holds

Stress: Parents often find themselves having to take on the role of a healthcare provider in addition to being a mom or dad, and this can be stressful. Mothers often acknowledge their increase level of stress following their child’s burn injury and attribute it to changes in role. Stress is often caused by the high level of responsibility placed on the parents. As your child’s primary caregiver, some new responsibilities that can create stress include:

- Bringing your child to and from medical appointments.
- Assisting your child with showering and dressing.
- Ensuring your child is receiving adequate stretching and range of motion.
- Managing your child’s skin care.
- Making sure your child’s nutritional needs have been met.
- Budgeting for the financial costs associated with your child’s healthcare.

How do I deal with these difficult feelings?
In addition, parents typically are given a lot of information at the hospital when they are stressed out. Since they are in a high stress situation, it can make it difficult to remember all of the information and to carry out what they need. It is important for you as a parent to have your own physical and emotional needs met in order to deal with difficult emotions. It will be easier to take care of your child emotionally if you yourself are taking care of yourself physically and emotionally. Below are some strategies on how to handle these difficult situations:
Rehearse your response: Many parents find it difficult to respond when people ask about their child’s injury. Some parents become angry and feel as though it is none of their business. As a result, they might respond in anger or simply ignore the person. Other parents might over-explain and provide too many intimate details. The best way to handle questions from strangers about your child is to rehearse your response. This involves responding with three simple sentences. Steps to create the three sentences are as follows:

1) **State how your child was burned** – For example: “My child was accidentally burned by spilling a pot of hot soup.”
2) **State how your child is doing** – For example: “They are making progress every day, but they still have a ways to go.”
3) **End the conversation** – For example: “Thanks for your concern.”

It is important to put some thought into how you would like to respond. Once you have figured out your response, write the three sentences down on a sheet of paper. When you have your three sentences memorized, it is important to rehearse. Remember to speak in a friendly tone, make eye contact, and give people a confident smile. This conveys a message that you have addressed their question, but respectfully choose not to discuss this any further.

Be encouraged to talk about it: You suddenly are dealing with a lot of difficult emotions after your child has sustained a burn injury. Some parents find it hard to know what to do or who to talk with after experiencing an event like this. Below are a few strategies that can help you identify and work through difficult feelings.

- **Journaling** – Anger, guilt, and depression are feelings that parents often have after their child has received a burn injury. Journaling allows you to identify difficult feelings without fear of judgement or punishment. In addition, journaling can help you become aware of unconscious feelings. This can help you to gain control of your emotions and effectively cope with your child’s traumatic injury.

- **Hospital resources** – Many hospitals will have resources available to you such as a mental health counselor, licensed social worker, chaplains, etc.

- **Identify support groups** – There are support groups and online support groups that allow you to talk with others who have been through similar experiences. The people in these groups may be able to offer helpful advice because they themselves have gone through this process and know what was helpful. One example of a support group is called Phoenix
SOAR. Click on the link to read more about this support group: https://www.phoenix-society.org/our-programs/soar

- **Talking to therapist** – Talking to a therapist can be incredibly useful if you are having a hard time moving on from the experience. A therapist can help you identify what is bothering you, provides an outlet for you to talk about how you truly feel, and offers you ways to deal directly with the problem. Sometimes it is best to talk to a therapist early to prevent negative feelings from becoming a big problem.

- **Take time for yourself:** Caring for your child after a traumatic event can be physically and emotionally draining. Taking a break is not only normal, but essential. This allows you to re-energize so that you can be a more effective caregiver. Time away from your role as the primary caregiver helps to provide balance in your life. Balance can be achieved by establishing healthy habits and routines. This involves slowly getting back to the occupations that you find meaningful. This could be anything from taking your dog for a walk to spending leisure time with friends.

- **Respite Care** – Respite care is an available option that provides you with the ability to take time for yourself. Respite care allows for trained caregivers to temporarily relieve you from your duties and watch over your child while you take time for yourself. Respite care is available through community agencies and home health care. For more information, ask your occupational therapist during your next therapy session.

**Children**

Your child may experience difficult emotions as the result of their burn injury. Children who have sustained a major burn injury may experience posttraumatic stress symptoms (PTSS), depression, and anxiety. These are common stress responses that can follow them well into adulthood. It is important for you to recognize and address difficult feelings that your child may be experiencing during and after their hospital stay. Below is a list of the symptoms associated with each emotional disorder and ways your child may exhibit difficulty with his/her emotions.
<table>
<thead>
<tr>
<th>PTSS</th>
<th>Depression</th>
<th>Anxiety</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Avoids talking about the injury</td>
<td>• Feeling sad and hopeless</td>
<td>• Excessive worrying</td>
</tr>
<tr>
<td>• Going out of their way to avoid the place where the injury happened</td>
<td>• Decreased interest in activities</td>
<td>• Difficult to stop worrying</td>
</tr>
<tr>
<td>• Recurring thoughts about the event</td>
<td>• Change in weight</td>
<td>• Restlessness</td>
</tr>
<tr>
<td></td>
<td>• Sleeping too much or too little</td>
<td>• Being easily fatigued</td>
</tr>
<tr>
<td></td>
<td>• Low energy</td>
<td>• Irritability</td>
</tr>
<tr>
<td></td>
<td>• Decreased ability to think or concentrate</td>
<td>• Tight muscles</td>
</tr>
<tr>
<td></td>
<td>• Sometimes can have irritable mood</td>
<td>• Sleep disturbance</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(difficulty falling or staying asleep, or restless, unsatisfying sleep)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Difficulty concentrating</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• May have panic attacks</td>
</tr>
</tbody>
</table>

If you are worried your child may have any of these, it is best to contact your doctor in order for your child to see a therapist. However, it is expected for your child to be sad and anxious to a certain extent. There are ways you can support your child emotionally, including:

- **Rehearse your response:** Your child might find it difficult to respond to questions about the way they look after the burn injury. They might find it difficult to talk about their scar or why they have to wear splints or pressure garments. To help prepare your child for these uncomfortable questions, you can help them rehearse their response. This involves responding with three simple sentences. The steps are as follows:

  1) **State how you were burned** – For example: “I was burned in a house fire.”
  2) **State how you are doing** – For example: “I am doing better now” or “I have to wear these garments to help me heal.”
  3) **End the conversation** – For example: “Thanks for your concern.”

Once you and your child have determined a response, the next step is to write the three sentences down on a sheet of paper. It is helpful to rehearse with your child to help them memorize their response. Remind them to speak in a friendly tone, make eye contact, and give people a confident smile at the end. This conveys a message that your child has addressed their question and respectfully chooses not to discuss it any further. This will be further reviewed in Lesson 7 as your child prepares to go back to school.
- **Encourage your child to talk:** As a parent, you can help your child with expressing and dealing with their emotions. It is not healthy to “bottle up” tough emotions and it is best to encourage your child to work through these difficult feelings. It has been reported that parents who avoid talking about the accident can negatively impact how the child feels. If the parent is scared to talk about the burn injury, the child may be scared to talk about it too. You can encourage your child to express themselves in a number of ways to help them face these difficult emotions. Below are a few ways that you can encourage your child to identify and work through these difficult emotions.

  - **Role playing** – This is a way that you can help teach your child how to handle potentially difficult situations in a controlled environment. For example, when using role playing, you might tell your child the following:

    ■  *Okay, I want you to pretend that I am one of your classmates in school. As one of your classmates, I might stare at you because you look different from the last time I saw you. I might even say something like ‘You look really bad’ or ‘Take off your Halloween mask.’ How do these statements make you feel? How would you handle this situation?*

    Although this is difficult for your child to hear, it is important that you address this in a safe environment. For other possible scenarios, please consult with your occupational therapist on your next therapy session.

  - **Journaling** – Journaling is a healthy way to manage stress and anxiety. This allows your child to identify difficult feelings without fear or punishment. As your child writes their emotions on paper, it can help them become aware of unconscious feelings. This can help them to gain control of their emotions and effectively cope with their traumatic injury.

  - **Drawing or painting** – This activity is similar to journaling in that it allows your child to express their emotions but in a different way than writing words. If your child enjoys art, they may find it easier to use this method to express how they are feeling.

- **Do the exercises:** Having your child do their exercises for contractures and scar management will help reduce the chance of deformities. This can help your child gain self-confidence and also gain independence. When your child is able to complete the activities they care about, they feel better about themselves and feel like they can do more things on their own. This may also help your child feel like they have more control over their life and the things they can do.
**Prepare and practice:** The Phoenix Society has created techniques that can help you and your child feel confident in social situations. You’ve already read about “rehearse your response” above, but there are some other techniques that can help you navigate social situations:

- **S.T.E.P.S.** – Sometimes when people go out in the community for the first time, they feel a little uncomfortable at first because of the attention they receive from other people. S.T.E.P.S. is a tool for you or your child to use when meeting new people or going into public places. The tool helps show others you are confident and allows you to have control over the image you want to project to others.
  - S: Self-Talk. This is what you say and believe.
  - T: Tone of Voice. Your tone of voice should be friendly and enthusiastic.
  - E: Eye contact. Look people in the eye
  - P: Posture. You should stand or sit up straight and have your shoulders back.
  - S: Smile. This shows you are kind, warm person.

- **Staring:** Life changes after a burn injury in that your child may receive unwanted attention. You and your child should go back to your usual activities, but some people may stare at your child if they have never seen a burn injury. These people don’t mean to be rude, but you will need a tool to help you deal with this new attention. When someone stares, the fastest and easiest way to stop the staring is to:
  - Stand up straight, look the person in the eye, and confidently say, “Hi, how are you doing?” or “Hi, nice day, isn’t it?” or any friendly small talk that you usually say and feels comfortable to you.
  - After saying this, the person staring usually says hello back and responds to you in a friendly way. The staring usually ends if you start a conversation because it changes the “energy” of the interaction.

- **Conversation distractors:** This tool is similar to the “staring” tool previously mentioned. It changes the subject from your child’s burn to another subject. You and your child can make up some conversation starters to memorize and use. Some examples might include:
  - “Did you watch (insert TV show or cartoon) last night?”
  - “How did you do on that math test last week?”
  - “Do you want to go play on the swing set?”
“Who is your favorite superhero?”

“Do you shop here a lot?” (if it is a supermarket, hardware store, etc.)

“I really like McDonald's. How about you?”

**Take Home Point**

A burn injury can be very traumatic for your child. Changes in the way they look can bring unwanted attention and negatively affect their self-esteem. As a parent, you may also have difficult feelings related to your child’s injury. This might be feelings of guilt, anger, or depression. It is important for both you and your child to find coping strategies that can help you address these difficult feelings. In addition, your child may be disappointment that they are unable to play games or participate in their favorite sport. They might also fear returning to school after their injury. These emotions are important to address and will be covered in more detail in Lesson 7.
Lesson 5 Summary Quiz: Emotional Management

1) Parents do not have to worry about their own emotions after their child is discharged and should only focus on taking care of their child.
   a. True
   b. False

2) What is not part of your child’s “rehearse your response?”
   a. State how you were burned
   b. State how long you were in the hospital
   c. State how you are doing
   d. End the conversation

3) What common disorder might your child be at risk for?
   a. Posttraumatic stress symptoms
   b. Anxiety
   c. Depression
   d. All of the above

4) Parents should avoid talking with their child about their burns because it will only bring up painful memories.
   a. True
   b. False

5) What strategy can help you identify difficult emotions?
   a. Journaling
   b. Joining a support group
   c. Talking to a therapist
   d. All of the above
Module 6: Family Involvement
Lesson 6: Family Involvement

Introduction
Burn injuries can be a traumatic experience for all members of the family. It is important to update family members on the condition of your child and the progress that they are making at the hospital. A strong support team can also help your child recover. When your child is about to leave the hospital, it is important that you talk with your family members about how their roles might change when your child returns home. Each family member should know exactly what is expected of them and how they can help in the recovery process. The following lesson will provide strategies to help you talk to your family about your child’s condition and how their roles will change to meet their needs.

Siblings
Your child’s burn injury can be a serious, sometimes life-changing event. Caring for your child may require a large amount of your time and attention. As a result, your other children may feel less important and resent their brother or sister because of their burn injury. Making time for each child, even if it is just 5 minutes each day of alone time, can help them feel special.

In addition to scheduling alone time, encourage open communication with “kid-friendly” updates. This helps them to better understand why you are spending more time at the hospital and less time with them. Open communication can also reduce the fear and anxiety that siblings might have once the child has returned home from the hospital. As children are updated on their brother or sister’s condition, they are more likely to assume their new roles and find motivation to provide care.

Books are available for parents to explain how burns happen and help connect what has happened to their sibling who was in the hospital. One helpful book is Brayden Bear Visits the Burn Center. This book is offered in English and Spanish. Lizzie’s Accident is a free online interactive book that is also offered in English and Spanish. It can be used as a preventative book for siblings and even students at school. To access an online version of this book, click on the website under Figure 6.1.
Parent

When your child comes home, we encourage you to resume your regular duties as much as possible. Of course, your routines will change to manage your child’s care. If more than one parent is providing care, it is important for both parents to communicate with one another and create a schedule to meet your child’s needs. Using a planner or monthly schedule to decide how to break up tasks can keep your organized and help you settle into a normal routine. Not every child will need the same exact care, but some responsibilities include:

- Doctor appointments
- Budgeting
- Healthcare documents (bills, insurance statements, etc.)
- Pain medication
- Therapy schedule (exercise, scar massage, etc.)
- Calorie intake
- Activities of daily living (showering, dressing, etc.)
- Dressing changes

Other topics you should consider discussing with your partner include:

- Financial costs
- Scheduling time for other family members
- Asking for help from extended family or friends (financial support, assistance, meals, etc.)
**Take Home Point**
While your child is in the hospital, there are ways to keep your family connected in effort to maintain relationships. It is very important that you have open communication among all family members within the household. This allows for each person to understand what their new roles are and why the changes have been made. As family members understand the needs of the child recovering from a burn injury, their motivation to help provide ongoing care is likely to increase when the child is discharged. Once each family member becomes aware of their expectations, a new family routine will develop that incorporates caring for the child into daily activities.
Lesson 6 Summary Quiz: Family Involvement

1) Why is it important to update your child’s siblings on your child’s condition at the hospital?
   a. It will help reduce sibling fear
   b. It will help reduce sibling anxiety
   c. It will help siblings understand why you are spending time away from home
   d. All of the above

2) Open communication is key to helping the family understand your child’s injury.
   a. True
   b. False

3) All family member’s roles will be the same after your child returns home.
   a. True
   b. False

4) Which statement below is false?
   a. It is not expected that family members will change their routine when the child returns home from the hospital.
   b. It is important to schedule time with other family members.
   c. Friends and family can be an important resource in providing additional support.
   d. A possible increase in costs related to your child’s care should be addressed with your significant other.

5) Using a planner or monthly schedule can help you to __________
   a. monitor your child’s pain medication.
   b. follow through with doctor’s appointments.
   c. monitor your child’s calorie intake.
   d. All of the above
Module 7: School Transition
Lesson 7: School Transition

Introduction
The thought of going back to school can be stressful for your child. This is a normal response as your child may be concerned about their appearance or physical limitations. It is important to let them know that a regular school schedule can actually benefit the healing process. As a result, you should encourage your child to return to school early in the healing process. To address the concerns that many parents have, the following lesson will convey the information in a question-answer format.

When should I start preparing my child to return to school?
On average, a child with a major burn injury is absent from school around 8 weeks. Although this might seem like a long time, the process to reintegrate your child back to school should start immediately. Within the first 2-3 days, you should contact your school to notify them about the accident. Staff members at the school that should be aware of your child’s injury include the principal, teacher, and social worker/guidance counselor. Once all parties have been notified, you should have one point of contact moving forward, preferably the teacher.

How often should I stay in contact with the school?
It is important to stay connected with your child’s teacher and provide updates on a weekly basis. Most hospitals will have a contact person who can help you stay in contact with the school. This might be a teacher employed by the hospital or a child life specialist.

Maintaining steady communication allows the teacher time to emotionally and physically prepare for a successful transition when your child is ready to return to school. Updates on your child’s progress can help the teacher answer difficult questions and address difficult feelings from students. There is also a chance that your child’s injury can emotionally impact the teacher. Providing consistent updates can help your child’s teacher deal with their own difficult feelings about the accident.

In addition, open communication allows for the teacher to prepare class materials and assignments for your child to complete while in the hospital. This may seem early, but it is important to have your child to continue with schoolwork as soon as they are medically stable. Not only does schoolwork prevent your child from falling behind, but it helps them to realize that they will get their life back. Consistent schoolwork also helps your child maintain a structured routine and lets them know that they have not been forgotten.
How can my child stay in touch with their classmates and friends?
This has been a common worry for many parents because some children feel lonely in the hospital while they are away from their friends and family. One program created by Shriners Hospital for Children is designed to encourage teachers and students to remember your child while they are away. It also provides social support to your child from their friends while they are recovering. Participating in a program such as this allows your child to stay in touch with friends and may help make transitioning back to school easier. The program is called Remember Me and is described below.

- **Remember Me**: The Remember Me program can help your child stay in touch with their classmates while they are in the hospital. The program includes a toolkit of instructions, a teddy bear, and a large postage-paid envelope. The instructions for the program are:
  - Place the teddy bear (or stuffed animal of your child’s choice) in their desk at school.
    - The presence of the teddy bear (or stuffed animal) encourages the teacher and students to talk about your child while they are away from school.
  - Place the envelope on your child’s desk.
    - Instruct the class that the envelope is meant to be filled by your child’s classmates, teachers, and school staff with letters, cards, and pictures.
  - The envelope is then mailed to your child at the hospital once it is full.
  - The teacher replaces the sent envelope with another empty one to be filled. This process continues until your child has returned to school.

What are common concerns for children returning to school?
While many children report they are happy to return to school and see their friends, some children with burns have some concerns about making this transition. Common concerns may include:

- Needing to “catch up” in school after missing classes
- Worries about their routine or needs being met while at school
- Wearing pressure garments and having classmates ask about them
- Having to answer people’s questions
  - Some questions may make the child embarrassed or uncomfortable
- Dealing with mean kids
  - Teasing
- Dealing with classmate’s shocked expressions when they first see the child
● Having unwanted attention
  ○ Staring
● Not being able to participate in gym class or sports

Your occupational therapist will provide you with strategies on how to address these concerns with your child. You can also refer to Lesson 5: Emotional Management for additional support.

**How can I talk to my child about their concerns?**
An excellent tool recommended to start the conversation of your child’s concerns is the Phoenix Society for Burn Survivors Journal Workbook. Your child’s occupational therapist will introduce the workbook to your child and the activities about school transition can be completed during the therapy sessions. At that point, your child can complete the workbook by themselves or you may assist them with completing the activities. The workbook activities encourage your child to reflect upon such topics as their hospital stay and their friendships outside the hospital. To preview the document, click on the following link:


**Should I be worried about bullying?**
Unfortunately, bullying is a concern for your child returning to school. It has been reported that 61% of children are bullied because of visible scars. Some kids may not report bullying to an adult, so it is important to speak with your child about this and watch for signs. If you suspect that your child is being bullied in school, you are encouraged to notify their teacher, principal, and social worker as soon as possible. Common signs of bullying include:

● Headaches
● Stomachaches
● Faking illnesses
● Avoiding school
● Avoiding people
● Difficulty sleeping or frequent nightmares

**When should my child’s first day of school start?**
Once your child has been discharged from the hospital, it is important for them to adapt to their new routines at home. This process can take anywhere from 7-10 days depending on the severity of injury. This helps your child to become familiar with the home environment and changes to their routine before facing new challenges at school. In
effort not to overwhelm your child, it is important to establish a home routine before introducing them to a new one. Therefore, your child’s first day back will likely be within 7 to 10 days of discharge, but talk to your child’s occupational therapist to determine when your child is ready for this transition.

**My child has been discharged from the hospital, what do I do now?**

Now that your child has been discharged from the hospital and is settling into their new routines at home, the next step is to prepare them for physically attending school. At this point, you should notify your child’s teacher and schedule a face-to-face appointment with them and your child’s occupational therapist. Let the teacher know that your child will be attending school shortly and that you would like to address the class.

You and the occupational therapist will discuss your child’s injury to the class. This includes how the injury may have changed their appearance and physical abilities, how the skin heals, and social stigma. It is also important to create a safe environment where the children are encouraged to ask questions about your child's injury. Your occupational therapist will help you present this information to the class by using age-appropriate materials. These materials include:

- Books (see Lesson 6: Family Involvement)
- Puppets
- DVD’s
- Role playing (see Lesson 5: Emotional Management)

* In the event that your child’s occupational therapist is unable to attend the school meeting, you can contact the school occupational therapist. If your child’s school does not have an occupational therapist, a social worker or guidance counselor can help you facilitate the meeting.

**Take Home Point**

School transition can be a stressful event for your child following a burn injury. It is important to contact your child’s school early in the recovery process to notify them of the injury and update them on progress. It is helpful for the child to stay connected with their peers and continue with their schoolwork during the recovery process. It is normal for your child to be concerned about this transition. Encouraging your child to speak openly about their feelings can help ease their fears. Before your child goes back to school, it is important to discuss your child’s injury with their class using age-appropriate material.
Lesson 7 Summary Quiz: School Transition

1) What is the first step when planning for your child to return to school?
   a. Contact the school within 2-3 days of injury.
   b. Contact the school once your child has been discharged from the hospital.
   c. It is not important to contact the school.
   d. Contact the school the day your child returns.

2) Who do you need to contact at the school to notify them of your child’s burn injury?
   a. The principal
   b. Your child’s teacher
   c. The social worker/guidance counselor
   d. All of the above

3) I should encourage my child to participate in school work as soon as they are medically stable at the hospital.
   a. True
   b. False

4) What may be a concern for your child for returning to school?
   a. Having unwanted attention such as staring or people asking questions
   b. Feeling behind in their classes and needing to catch up
   c. Not being able to participate in physical activities during recess or gym class
   d. All of the above

5) When should my child return to school?
   a. While they are still in the hospital
   b. Immediately after they are discharged home
   c. Once familiar with their home routine (about 7-10 days)
   d. Three months after they have been discharged home
Module 8: Leaving the Hospital
Lesson 8: Leaving the Hospital

Follow-up Visits
If your child’s burn injury crosses a joint, they may require periodic follow-up visits until they have stopped growing. This helps to make sure your child does not have any problems with movement as a result of the scar. Before your child is discharged, your occupational therapist will determine how often your child should receive therapy.

Getting Back to Occupations
Once your child returns home, it is important to get them back to their daily routine. This includes making sure they are able to do the things they use to do prior to the burn injury. Occupations that are part of your child’s daily routine may include the following:

- **Activities of Daily Living (ADLs)** – Taking a bath, using the toilet, getting dressed, eating, and being able to brush their teeth and comb their hair
- **Instrumental Activities of Daily Living (IADLs)** – Caring for a pet, cleaning their room, and making a snack
- **Sleep** – Getting ready for bed (putting pajamas on, brushing teeth, etc.)
- **Education** – Going to school, playing in sports, and playing an instrument
- **Play** – Planned or unplanned activity that provides enjoyment
- **Social Participation** – Interacting with friends, family, and people in the community

*Note: Your child may not physically be able to participate in occupations right when they get home. This is because the new forming skin is very sensitive and can damage easy. Rough and tumble play with friends, sport activities, and the sun’s UV rays can damage the skin. It is important that you talk with your occupational therapist to help determine which occupations are safe for your child.

Make it Fun!
When you are working with your child at home, it is important to make sure the therapy session is fun. When you bring fun into the therapy session, your child is more likely to participate. Fun should not only be used in therapy, but also when your child is completing daily occupations. This can be something as simple as making a game out of having your child put on their pajamas. This helps distract the child from any pain they might have when doing the activity. Fun can also help with your child’s current emotional state. It can cheer them up and make them feel better when they are struggling with an occupation. Your occupational therapist will give your ideas on how you can introduce fun into daily occupations.
The Last Therapy Session Before Discharge
Before your child leaves the hospital, we want to make sure that you are confident in caring for your child. Your occupational therapist will ask you to lead the therapy session and work hands on with your child from start to finish. Don’t worry; your occupational therapist will be standing right next to you providing support when needed. We will also ask you questions throughout the session to help prepare you for your child’s discharge. At this time, we also encourage you to ask any questions that you might still have before you leave the hospital.
Post-Program Survey

The purpose of this post-program survey is to learn about your current knowledge and comfort level in caring for your child who has sustained a burn injury after completing the Road to Recovery program guide. This post-program survey will help us determine if the program was overall helpful and to encourage you to give us feedback to improve the program in the future.

1. Number of parents providing the child with care at home: 1 2

2. Number of parents completing the Road to Recovery program guide: 1 2

<p>| Physical |
|------------------------|------------------------|
| <strong>Question</strong> | <strong>Answer (Please circle one)</strong> |
| 1. I have been given information on how to decrease my child’s pain when they leave the hospital. | Yes No |
| 2. I feel certain that I can decrease my child’s pain. | 1 Strongly Disagree 2 Disagree 3 Agree 4 Strongly Agree |
| 3. I have been given information about why exercise is important for my child when they leave the hospital. | Yes No |
| 4. I feel certain that I can help my child with their exercises at home. | 1 Strongly Disagree 2 Disagree 3 Agree 4 Strongly Agree |
| 5. I have been given information on skin care and dressing changes for my child when they leave the hospital. | Yes No |</p>
<table>
<thead>
<tr>
<th>Question</th>
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<tr>
<td>6. I feel certain that I can manage my child’s skin care needs when they leave the hospital.</td>
<td>1 Strongly Disagree 2 Disagree 3 Agree 4 Strongly Agree</td>
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<td>7. I have been given information on specific treatments to reduce the chances of my child forming contractures when they leave the hospital.</td>
<td>Yes No</td>
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<td>8. I feel certain that I can reduce the chances of my child getting contractures.</td>
<td>1 Strongly Disagree 2 Disagree 3 Agree 4 Strongly Agree</td>
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<td>9. I have been given information on how to reduce my child’s scar tissue formation when they leave the hospital.</td>
<td>Yes No</td>
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<td>10. I feel certain that I can treat my child to reduce the formation of scar tissue.</td>
<td>1 Strongly Disagree 2 Disagree 3 Agree 4 Strongly Agree</td>
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<td><strong>Question</strong></td>
<td><strong>Answer (Please circle one)</strong></td>
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<td>11. I have been given information on how to handle my emotional needs.</td>
<td>Yes No</td>
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<td>Question</td>
<td>Response Options</td>
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<td>12. I feel confident that I can manage my emotional needs.</td>
<td>1 Strongly Disagree</td>
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<td>2 Disagree</td>
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<td>3 Agree</td>
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<td></td>
<td>4 Strongly Agree</td>
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<td>13. I have been given information on how to handle the emotional needs of my child when they leave the hospital.</td>
<td>Yes</td>
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<td>14. I feel certain that I can meet my child’s emotional needs.</td>
<td>1 Strongly Disagree</td>
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<td>3 Agree</td>
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<td>4 Strongly Agree</td>
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<td>15. I have been given information on how to transition my child back to school when they leave the hospital.</td>
<td>Yes</td>
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<td>16. I feel certain that I will be able to transition my child back into school.</td>
<td>1 Strongly Disagree</td>
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<td>4 Strongly Agree</td>
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<td>17. I found this program to be helpful.</td>
<td>1 Strongly Disagree</td>
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<td>4 Strongly Agree</td>
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18. I am confident that I can continue my child’s treatment needs once discharged from the hospital.

1. Strongly Disagree
2. Disagree
3. Agree
4. Strongly Agree

19. What did you like about the program?

20. What would you change about the program?

21. Do you have any suggestions on how we can improve?
References


Appendix
Quiz Answers

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<th>Quiz 1: Pain Management</th>
<th>Quiz 5: Emotional Management</th>
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CHAPTER V

SUMMARY

This scholarly project provides an occupational therapy-based program designed to help educate and prepare parents of children who have sustained a major burn injury for discharge from an IRF. After conducting a thorough review of literature, it was identified that parents often feel unprepared in providing the care their child requires following discharge. In addition, there is currently a lack of knowledge in determining whether or not parents are accessing and comprehending the educational material provided by clinicians. The proposed program has the potential to benefit the ongoing care these children will require during the lengthy recovery process by increasing the caregiver’s competence and feelings of self-efficacy. Through online learning modules and working hands-on with an occupational therapist, it is believed that the parents will be prepared to care for their child following discharge.

The program developed utilizes the Model of Human Occupation (MOHO) to address the role of the parents, change in habits pertaining to the child’s newly acquired needs, and feelings about their own abilities throughout the recovery process. In addition to MOHO, the adult learning theory and cognitive apprenticeship model will be the vehicle to deliver the information to parents through a variety of learning methods which include text, videos, pictures, and hand-on interaction as directed through an occupational therapist.
After completing the online educational program, it was determined that there are several limitations regarding the appropriateness of this program. In attempt to stay consistent with health care literature, the entire online program was written at an eighth-grade level. While this increases the accessibility, it does not guarantee that all parents are able read and/or comprehend all the information within each learning module. In addition, the information is currently only available in English and has not been translated into other languages. Lastly, the product has not been tested in research; therefore, the validity and reliability of the online program has not been determined.

In regard to future recommendations, it has been identified that the program should become more interactive among parents of children who have sustained major burn injuries. This could be accomplished by incorporating a blog on the website where parents can share their experiences and post questions to other members. In attempt to make the program more accessible, the online learning modules should be available through an app accessible via mobile device. Lastly, expansion of evidence-based research should be incorporated to support the effectiveness of online learning modules to contribute to the occupational therapy literature base.
REFERENCES


