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ADOLESCENT EXPERIENCE WITH TRAUMA AND ORTHOPEDIC EXTERNAL  
FIXATION

APRIL 2007

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**“Adolescent Experience with Trauma and Orthopedic External Fixation”**

A Dissertation Presented

By

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I dedicate this work to all the adolescent participants and orthopedic trauma patients for whom I have cared. Thanks to all of you and countless others, my Old Self is No More and I am Forever Changed!

## ABSTRACT

### ADOLESCENT EXPERIENCE WITH TRAUMA AND ORTHOPEDIC EXTERNAL FIXATION

APRIL 2007

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Over 13 million adolescents sustain traumatic injuries yearly, resulting in functional disability, disfigurement, psychosocial problems and fractures. These fractures are increasingly being treated with orthopedic external fixation devices (EFDs). The purpose of this study was to describe the experience of traumatically injured adolescents treated with EFDs. The 4 aims of the study focused on the circumstances leading to the traumatic event, experiences following the traumatic event, the impact of EFD treatment, and adolescents' role in pin-care self-management, which is crucial to preventing infection.

This longitudinal, qualitative descriptive study used purposive sampling to recruit 5 male and 4 female adolescents, 13-20 years old, from a New England level-1 trauma center. Participants were injured in motor vehicle crashes (including an all-terrain vehicle), falls, by gunshot, trampoline and football trauma. Interview questions were framed by two themes from a study of adult recovery from physical injury, i.e., the event and fallout. Participants were interviewed within days of the injury, 2 weeks after returning home, and within one month of

EFD removal. Data were coded from verbatim transcripts using NVIVO and organized into themes guided by the principles of qualitative analysis.

An overarching theme of “old self no more; forever changed” emerged from 26 interviews. The participants’ experience affected all tasks of adolescence: independence from parents, accepting body image, peer relations, and forming an identity. Major themes included “*what risk?*”, regarding circumstances leading to the traumatic event, *mastering the environment*, was 2 part first, *processing the event*, where determining fault and realizing everything has changed, they were ambivalently lucky, and not invincible. Secondly “*suck it up and deal with it*”, where strategies to deal with traumatic injury emerged (i.e. medication, channeling outlets, and slow caution). EFD experience revealed “*Space age robot*” and “*they’ll do it themselves*” as emergent themes. EFDs were described as painless, robotic, no big deal and necessary. One draining pin-site was noted. Findings related to use of self-administered analgesics, information technology, recall of detail, and gender differences in coping may lead to future interventions. These findings lay the groundwork for future studies that may improve care of adolescents during acute recovery from traumatic injury.



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## CHAPTER 1

### INTRODUCTION

#### Introduction to the Problem

##### *External Fixation Devices and Pin-Site Infection*

Over 13 million adolescents were injured in 2005 from falls, motor vehicle, sports, bike and pedestrian accidents, many resulting in fractures requiring treatment with orthopedic external fixation devices (EFD) (National Center for Injury Prevention and Control, 2006). These devices are external metal frames with skeletal pins that penetrate soft tissue (pin-site) to anchor in bone, thus stabilizing fractured bone. Superior outcomes with EFD treatment of fractures have led to an increased use in acutely injured adolescents (Bernardo, 2001; Buckley, 1997; El Hayek et al., 2004; Hedin, Hjorth, Rehnberg, & Larsson, 2003; Pape, 2002; Rixen et al., 2005; Smith et al., 2005). The rate of pin-site infection, the most common complication with EFDs, has been reported between 3-100% (depending on the study definition for pin infection) (Althausen & Hak, 2002; Brereton, 1998; Davis et al., 2001; Green, 1983; Green & Ripley, 1984; Patterson, 2005; Sims & Saleh, 2000).

This study evolved from the results of a pin-care methods study (Patterson, 2005). That study found a significant inverse relationship between age and rate of pin-site infections ( $r = -0.285, p < .01$ ), with higher rates noted in children/adolescents, mostly in the 9-20 year-old age range. Pin-site infections, which are painful and can result in severe complications, may lead to deep infections, pin loosening, loss of fixation or stability of the fracture, and

osteomyelitis. These complications require surgical intervention and long-term intravenous antibiotics for people of all ages (Rockwood, 1996; Wood, 2001). Self-management of EFDs is crucial to successful treatment and prevention of infection (Bernardo, 2001; Brereton, 1998; Lee-Smith, Santy, Davis, Jester, & Kneale, 2001; McKenzie, 1999; Nemeth & Mattingly, 2001; Santy, 2000).

### *Traumatic Injury, External Fixation, and Adolescents*

Adolescence is a time of great physical and cognitive growth. As adolescents adjust to the changes in their bodies, they experience a strong preoccupation with body image (Radzik, 2002). They may spend hours in front of a mirror critically evaluating their appearance or think that a blemish on their face is the “end of the world.” During this time, adolescents struggle with their identity and try to be like their peers. It’s not hard to imagine that wearing a bulky metal frame with pins running through one’s leg or arm could have a strong impact on an adolescent’s life.

As adolescents strive for independence, they may have conflicts with their parents. They feel omnipotent and indestructible, and may take risks (Radzik, 2002). These normal adolescent behaviors are expressions of developmental tasks or milestones that can be influenced by traumatic injury and EFD treatment. In response to elective correction of long-bone deformities, adolescents have demonstrated negative emotional and behavioral reactions (e.g., depression, suicidal ideation, and concerns about body image and changes in socialization) (Morton, 1998; Olson, Ustanko, & Warner, 1991b;

Patterson, 2006; Ramaker, Lagro, van Roermund, & Sinnema, 2000). Such psychosocial issues may hinder pin-care self-management ability.

Pin-care self-management entails inspecting, cleansing and wrapping pin sites, obtaining supplies, meticulously washing hands, and identifying and reporting any pin-site problems to clinicians. This responsibility may be shared by parent/adolescent dyads and can be affected by the location and severity of the injury, parent and adolescent knowledge, ability and attitude, and available resources. Understanding the reasons for failure or success in pin-care self-management will enhance successful EFD treatment for this vulnerable population.

Adolescents treated with an EFD for acute traumatic injury face a unique set of challenges, i.e., the unexpected trauma, painful injury, hospitalization and surgery for which they were not prepared (Blakeney, 1998; Santy, 2000). Most have never seen an EFD. Adolescents involved in traumatic injury frequently have different social/environmental issues than other adolescents, e.g., lower socioeconomic status, unemployment, past arrest, living with one parent, lower levels of spirituality, higher levels of anger/aggression, thrill-seeking and risk-taking behaviors (Paris et al., 2002; Redeker, Smeltzer, Kirkpatrick, & Parchment, 1995), and may have drug, alcohol or depression issues in addition to normal adolescent developmental concerns (Marcin, Pretzlaff, Whittaker, & Kon, 2003; Redeker et al., 1995; Spain et al., 1997). Previous studies with adolescents (treated with EFDs) focused on *elective* treatment for limb deformities and excluded cases of acute, traumatic injury. To date, adolescents

who sustain acute traumatic injury have not been studied. Therefore the purpose of this study was to explore the experiences of acutely injured adolescents (13-20 years) under treatment with EFDs.

## Background to the Study

### *Rationale*

Four related issues provided a rationale for this study. First, the number of adolescents that sustain non-fatal injuries and are treated with EFDs is growing yearly. Second, little is known about the psychosocial impact of treating acutely injured adolescents with EFDs. Third, the incidence of pin-site infections has been reported to be higher in children/adolescents (most studies do not separate these age groups), whether or not their EFD treatment was acute or elective (Dormans, Criscitiello, Drummond, & Davidson, 1995; Gregory, Pevny, & Teague, 1996; Patterson, 2005). Finally, little is known about pin-care self-management by adolescents treated with EFDs. Understanding pin-care self-management issues in this population may lead to understanding the basis for their increased pin-site infection rate. These four important issues provided the rationale for exploring the injured adolescent's experience with EFD treatment and role in pin-care self-management.

### *Increasing Incidence of Adolescent Traumatic Injury*

Disparities have been noted by the US Department of Health and Human Services (2002) between the health care of adolescents and other age groups. As a result, the health and well-being of adolescents has been made a priority. As noted above, over 13 million American adolescents sustained non-fatal

injuries in 2005, an increase of over 1 million in 3 years (National Center for Injury Prevention and Control, 2006). In 2003, over 20,000 Massachusetts adolescents (10-19 years old) were treated for fractures, with 1,546 requiring hospital admission (Massachusetts Department of Public Health, 2006). Despite almost twice as many younger adolescents (11-15 years) sustaining fractures, those over 16 have more serious injuries and are hospitalized 3 times as often (USDHHS, 2002). Little has been reported on the experience of adolescents who sustain trauma. Male adolescents who recovered from injury in a rehabilitation center expressed feeling “like garbage” and needing social support of family friends and healthcare professionals (DeWitt, 1993). They wanted to be treated like normal people and desired to return to their pre-injury state. It is not known if these experiences will be similar for injured adolescents who return home with EFDs or for injured females.

#### *Psychosocial Impact of EFD Treatment after Acute Traumatic Injury*

No studies have concentrated on the impact of treating acutely injured adolescents with EFDs. However, adolescents treated with EFDs for elective long-bone correction have been shown to suffer physiological, psychological, social, and functional consequences (Ghoneem, Wright, Cole, & Rang, 1996; Martin, Farrell, Lambrenos, & Nayagam, 2003; Morton, 1998; Patterson, 2006). Physiological issues center on pain, pin-site infection, and outcomes of the treatment (Patterson, 2006). Reported psychological issues include depression, emotional difficulties, anxiety, anorexia, fear, body image disturbance, regression, guilt and suicidal ideation (Patterson, 2006). Social issues for

adolescents treated with EFDs for elective correction include fewer social contacts with peers (Hrutkay & Eilert, 1990), changes in their roles (Olson et al., 1991), and interruption of school (Ramaker et al., 2000). Functionally, these adolescents saw either an improvement (Hrutkay & Eilert, 1990; Lavini, Renzi-Brivio, & de Bastiani, 1990) or decline in walking and mobility (Olson et al., 1991b; Paley, 1990; Ramaker et al., 2000). They also reported significant problems with concentration (Olson et al., 1991b; Ramaker et al., 2000) and sleep disturbances (Morton, 1998; Paley, 1990; Ramaker et al., 2000).

The psychosocial impact of treatment with EFDs may be different for adolescents who sustain traumatic injury. As previously mentioned, this group may have lower socioeconomic status, come from single-parent households, demonstrate poor judgment and risk-taking behavior, and use alcohol and/or drugs (Paris et al., 2002; Redeker et al., 1995). Given the crisis and pain levels of traumatic injury, adolescents experiencing this type of injury do not have the benefit of pre-admission teaching or visits with their surgeon and nurses to develop relationships, which are available to adolescents treated electively with EFDs. Thus, the issues for traumatically injured adolescents treated with EFDs may be quite different from those previously reported for adolescents undergoing elective EFD treatment.

#### *Incidence of Pin-Site Infections*

Pin-site infection is the most common complication of EFD treatment, with rates between 3-100%, depending on the study definition of infection (Patterson, 2005). One would expect a higher incidence of infection in those with risk

factors such as poor nutrition, multiple medical problems, or severe injuries such as open fractures, but this is not the case. In a recent study on pin-care methods (Patterson, 2005), younger patients (9-20 years) who had an EFD placed acutely or electively had a significantly ( $r = -0.285, p < .01$ ), higher rate of pin-site infection than older patients (21-80 years). Two studies on children and adolescents treated with EFDs reported pin-site infection rates as high as 100% (Gordon, Kelly-Hahn, Carpenter, & Schoenecker, 2000; Hutson & Zych, 1998). This finding is a concern because individuals in this age range are in their physiologically healthiest years (Loveland-Cherry, 1999).

#### *Pin-Care Self-Management by Adolescents*

Pin care is thought to decrease infection by cleansing crusts away from pin sites, thus allowing drainage of the fluid that is produced by friction at the pin/skin interface (Jones-Walton, 1991). If this fluid is allowed to accumulate and become colonized by bacteria that commonly live on the skin surface, infection may ensue. Pin care involves many components such as obtaining supplies, washing hands, cleansing pin sites, and wrapping pins. Some adolescents cannot tolerate looking at the pin going into their skin or participate in self-care due to the location of the EFD. Reporting tenderness, drainage, erythema or problems to clinicians or even parents may be another obstacle to pin care for adolescents. Parents and adolescents are thought to share this responsibility, but no reports have documented how this responsibility is divided or carried out. It is unknown how adolescents handle the many aspects of pin-care self-management or if the psychosocial impact of trauma and injury affect pin-site care. Information

regarding the adolescent's role in pin-care self-management may illuminate areas to intervene and support this vulnerable group. These issues indicate a need for further investigation.

#### Significance of the Problem

The incidence of adolescent trauma has increased by well over a million in from 2001 to 2003 (National Center for Injury Prevention and Control, 2006), thus increasing functional disability, disfigurement and psychosocial problems (such as fear of death and/or re-injury, depression, anger, hostility, posttraumatic stress disorder, and social anxiety) (Blakeney, 1998; Rusch, Grunert, Sanger, Dzwierzynski, & Matloub, 2000; Scheidt et al., 1995; Stoddard & Saxe, 2001). Studies on adolescent trauma have generally been epidemiologic, illuminating environmental and social characteristics, risk-taking behaviors, and poor decision-making (Marcin et al., 2003; Redeker et al., 1995; Schwarz, 1993; Spain et al., 1997). A study on adult recovery from physical trauma (Richmond, Thompson, Deatrck, & Kauder, 2000) explored the complex nature of the recovery trajectory and identified 3 themes: the event (the traumatic injury), fallout (effects of the traumatic event and injuries) and moving on (returning to normal). These 3 themes may help frame the trauma experience for adolescents who sustain fractures.

Fractures, the most common injury in adolescent trauma, increasingly require treatment with EFDs. Treatment of traumatic fractures with EFDs may reduce both disability and disfigurement with superior outcomes (Pape, 2002), but may be accompanied by pin-site infection. Indeed, the overall pin-site



infection rate with EFDs was 34%, with the highest rates among adolescents (Martin et al., 2003; Patterson, 2005). Pin-site infections generally result in pain and the need for antibiotic treatment and more frequent pin care (i.e., cleansing the site and changing dressings). Healthcare costs escalate with pin-site infections. Depending on the severity of the infection, antibiotic treatment can range from oral to intravenous for 4-6 weeks for deep infections. Costs may also accrue for supplies, visiting nurse fees, lost school days, and lost work days for parents (Whitehouse, Friedman, Kirkland, Richardson, & Sexton, 2002). Osteomyelitis, a complication of severe pin-site infections, may require re-hospitalization and costly surgical intervention such as bony debridement. Early removal of EFDs may result in delay, non-union or shortening of fractures, leading to permanent disability and disfigurement.

Little is known about the acute experience of adolescents involved in traumatic injury, especially those treated with EFDs. Previous studies were conducted with adolescents who had elected treatment with EFDs for limb deformities and excluded cases of acute, traumatic injury. Insight may be gained for this population on issues surrounding the injury itself, adjustment to injuries and to the EFD, possibly revealing areas for intervention. Psychosocial reactions have been demonstrated in adolescents treated electively with EFDs (Eckhouse-Ekeberg, 1994; Ghoneem et al., 1996; Hrutkay & Eilert, 1990; Lavini et al., 1990; Martin et al., 2003; Morton, 1998; Olson et al., 1991b; Paley, 1990; Ramaker et al., 2000). Although these studies did not mention pin care, it is conceivable that adolescent developmental tasks could conflict with the pin-care self-management

process. Little is known about the adolescent's role in pin-care self-management, another area where identified issues could lead to the design of interventions to support the self-management process, thereby reducing pin-site infection and sequelae.

### Purpose Statement

The purpose of this longitudinal, qualitative descriptive study was to explore the experience of acutely injured adolescents (11-20 years) being treated with EFDs. A comprehensive understanding of this experience was gained using an organizing framework and 3 in-depth interviews throughout the acute and healing course of treatment with EFDs.

The specific aims of this study were to:

1. Describe the circumstances leading to the traumatic injury
2. Describe the day-to-day experiences following the injury
3. Describe the day-to-day experiences with EFDs
4. Describe the adolescents' role in pin-care self-management as they recover from trauma.

### Summary

In summary, a growing number of adolescents are sustaining traumatic injuries each year and many are being treated with EFDs, resulting in improved fracture outcomes. Problems have been noted with elective EFD use in this age group and are possibly related to the normal adolescent developmental tasks of defining identity, being preoccupied with body image issues, and working toward

independence from parents, as well as issues related to the treatment itself. A higher pin-site infection rate has also been found in adolescents.

Most of the information about caring for adolescents treated with EFDs has been gained from studies on the elective use of these devices. However, those studies did not report the practice of pin-care self-management by adolescents, making it a poorly understood phenomenon. Adolescents involved in traumatic injury are a vulnerable population, and their issues may indeed be radically different from those who elect EFD correction of long-bone deformities.

To fill the gaps in knowledge about adolescents' experience with EFD treatment for traumatic injury, especially in the acute phase, or their role in pin-care self-management, an exploratory study is needed. The purpose of this qualitative descriptive study was to explore the experience of acutely injured adolescents (11-20 years) under treatment with EFDs.

## CHAPTER 2

### REVIEW OF THE LITERATURE

#### Overview

This chapter will review the conceptual framework for this study and the literature on adolescent development, traumatic injury, and external fixation devices (EFDs). The empirical literature will also be reviewed on pin-site infection, pin-care self-management, and adolescents treated with EFDs.

#### Conceptual Framework

The conceptual framework for this study was based on the findings of a qualitative study of 63 adults recovering from traumatic injury not including injuries to the head or spinal cord (Richmond et al., 2000). In that study, recovery from physical injury was characterized by 3 themes: the event, fallout and moving on. The traumatic event was a perceptual and contextual experience and the starting point of an unexpected journey. This event was noted as the “line of demarcation” separating participants’ lives into two phases: before and after the event. The phase following the event, the “fallout,” was when participants became aware of the effects of the injury on their lives. This period encompassed physical, psychosocial, economic, and legal entanglements. Moving on was the phase in which they resumed their lives, overcoming dependence on others, and realizing that their lives would never be the same. Adult participants in this study sustained life-threatening injuries, and the event caused them to reevaluate the meaning of their lives and their mortality, resulting in a loss of trust in a safe world.

The fallout phase was seen as the most difficult for adults since it impacted every aspect of their lives, especially their ability to return to work. Due to their limited experience and belief in being indestructible, adolescents might be expected to have similar or stronger reactions than adults (Richmond et al., 2000). Adolescents involved in trauma are described as a high-risk, vulnerable population (Stoddard & Saxe, 2001). They frequently have social/environmental issues such as lower socioeconomic status, unemployment, past arrest, living with less than two parents, lower levels of spirituality, higher levels of anger/aggression, thrill-seeking and risk-taking behaviors (Marcin et al., 2003; Paris et al., 2002; Redeker et al., 1995; Schwarz, 1993; Spain et al., 1997) and may have drug, alcohol, or depression issues added to the normal adolescent developmental concerns (Marcin et al., 2003; Redeker et al., 1995; Spain et al., 1997). The phase, "moving on," in the Richmond study lasted several months to years and was highly individual, as it depended on the participant's inner resilience and external resources. To date, few studies have examined the adolescent's acute experience with physical trauma.

The experience of recovery from trauma in a rehabilitation center was examined in a phenomenological study of male adolescents (14-18 years old) (DeWitt, 1993). Although the specific types of trauma were unknown, two participants were reported to be recovering from head injury. The study identified 10 themes: the love my family gave me, I didn't know if I would ever be well, getting well is a scary experience and it takes a long time, treat me like a normal person, time to think about how I have changed, I want to do things for myself, a

special person was there for me, and feeling like garbage. Factors important to getting well were family, the healthcare team and peers. Adolescents who were successfully recovering were reported as a great source of support to newer residents with similar injuries. The limitations of this study were the omission of questions pertaining to the injury and treatment experience; and the exclusion of females. There were no interviews conducted in the acute stage or after these gentlemen returned home.

Little is known about gender differences in the experiences of traumatically injured adolescents. However, important gender differences have been found among more than 1000 adult (18 years and older) trauma patients in outcomes of quality of life and psychological morbidity (Holbrook & Hoyt, 2004). Women were found to have worse quality of life and well-being than men, regardless of mechanism or severity of injury. Thus, studies are needed to provide information on gender differences among traumatically injured adolescents. The findings of Richmond et al.'s study (2000) provide an organizing structure for exploring the injured adolescent's acute experience with EFD treatment.

#### Adolescent Development

To understand the effects of treating traumatically injured adolescents with EFDs and to explore the subsequent self-management issues, it is helpful to first understand that normal adolescent development occurs in 3 stages: early (between 11-14 years), middle (15-17 years) and late adolescence (18-20+ years) (Table 1). These stages are marked by achieving certain developmental

tasks rather than by reaching a certain age (Dashiff, 2001; Montgomery, 2002; Steinberg & Morris, 2000). These tasks involve both physical and psychosocial changes. Psychosocial development is related to 4 tasks: developing independence from parents, accepting body image, developing peer relations, and forming an identity (Radzik, 2002).

### *Physical Development*

Early adolescence is associated with the development of secondary sexual characteristics (Steinberg & Morris, 2000). During early and middle adolescence, there is rapid skeletal growth through the physes or growth plates at each end of long bones. This rapid growth leads to problems with coordination as adolescents adjust to their longer limbs. Middle and late adolescence is a time of adjusting to and accepting body changes, as well as being most physically fit (Loveland-Cherry, 1999; Radzik, 2002; Schmidt & White, 2002).

From an orthopedic perspective, physical development is based on skeletal maturity, determined by closure of physes. Open physes may limit orthopedic treatment options. If a physis is crossed with a surgical implant, bone growth may be arrested in that location (Rockwood, 1996). EFDs may be used to stabilize bone while avoiding contact with physes.

### *Psychosocial Development*

#### *Independence*

The task of developing independence from parents begins in early adolescence, with parent-child conflict peaking in middle adolescence (Radzik, 2002; Steinberg & Morris, 2000) Table 1). These conflicts often result in limit testing and rebellious or withdrawn behavior (Busen, 2001; Steinberg & Morris, 2000)

Table 1

*Process of Adolescence*

Associated Tasks	Early 10-13 years Middle School	Middle 14-17 years High School (HS)	Late 17-21 years College/Work after HS
	Characteristic/Behavior		
Achieve independence from parents	Devalues parental advice, rude, emotionally labile, mood swings, & more expressive in speech. Search for love to fill void of separating from parents	Less conflict with parents, spends more time with peers	Firm identity, can delay gratification, ability to think through ideas, stable interests, greater ability to make decisions/compromise Drives, earns money
Adopt peer codes, lifestyles	Same-sex idealized friendships, intense feelings may lead to homosexual exploration, fears & relationships, deep crushes, opposite sex contact in groups	Intense peer subculture, clubs sports, gangs, conformity in dress, values, dating sexual experimentation, intercourse	Peers less important, single-person relationships develop, less exploration
Body image - importance and acceptance	Pubertal changes, preoccupied w/self, uncertainty about appearance, attractiveness, compares body w/others, sexual Anatomy & Physiology anxiety & ?s.	Pubertal changes complete, more acceptance of body, works to make self attractive w/clothes, make-up, eating disorders may begin	Unconcerned with body image unless an abnormality
Establish identity: Ego, sexual, vocational and moral	Begins abstract thinking, turns inward, self-interest, fantasy, as if always "on-stage," daydreams, idealistic, unrealistic job aspirations, sexual feelings emerge, tests authority, more privacy needs, keeps diary, lacks impulse control, magnifies problems	Larger scope, can see others' feelings, openness, more intellect & creativity, less idealistic vocational aims, feels omnipotent, invincible, greater risk-taking	Rational, realistic conscience, perspective, practical vocational goals, financial independence begins, refines moral, religious and sexual values.



Adapted from Radzik et al. (2002)

2000). Adolescent rebellion may contribute to non-adherence to pin care, which may in turn result in increased infection. In the later stages of adolescence, individuals develop an increased ability to compromise and once again accept parental values and advice (Radzik, 2002). Middle or late adolescence may mark the beginning of work and driving, offering new freedoms and responsibilities. These aspects of adolescent life could be dramatically if a traumatic injury occurred at this stage and caused a fracture requiring an EFD.

### *Body Image*

Early adolescent thinking can have a narcissistic quality (Radzik, 2002). Adolescents at this stage are preoccupied with pubertal changes and body image, with a disproportionate concern for how they appear to peers or to an imaginary audience. Perceived inadequacy in this respect can result in low self-esteem (Busen, 2001; Steinberg & Morris, 2000).

Middle adolescents begin to accept body changes and to focus their efforts on becoming more attractive (Busen, 2001; Radzik, 2002). EFDs are typically unattractive, obvious and unusual, aspects that may affect adolescent body image as well as socialization. Middle adolescents are beginning to accept their body image and may begin dating and sexual experimentation. The importance of their peer subculture is expressed by conformity in dressing, values and sensitivity to body image, all of which can occasionally result in eating disorders (Radzik, 2002). Older adolescents begin to accept their body image if there are no abnormalities. Adolescents who sustain disfiguring trauma face extraordinary challenges at middle and late stages of adolescence. They may

face pain and treatment for the injury as well as the reaction of their peers to any disfigurement (Blakeney, 1998) .

### *Peers*

Socially, early adolescents develop strong same-sex relationships and become intensely involved with peers (Radzik, 2002; Steinberg & Morris, 2000). Their need for privacy is great (Dashiff, 2001). The importance of interacting with peers peaks during middle adolescence, as demonstrated by striving for conformity of clothing, language and values and by frequently gathering in clubs, sports or gangs (Radzik, 2002; Steinberg & Morris, 2000). Adolescents at this stage value group over family identity (Busen, 2001; Radzik, 2002). Older adolescents become less concerned with peers as they form intimate dyadic relationships (Steinberg & Morris, 2000). After acute injury, support from peers may be preferred to that of family. This support may be compromised by decreased mobility stemming from injuries and EFD treatment

### *Identity*

In their struggle to define their identity, early and middle adolescents experience phases of fantasy, idealism, omnipotence, and risk taking, some with little impulse control (Radzik, 2002). Early adolescents are developing the ability to think abstractly. They can follow instructions and understand abstract concepts and the consequences of their actions. However, researchers believe that rapid growth of the pre-frontal cortex (responsible for judgment and impulse control) and problems with synaptic connections during adolescence create a tendency for adolescents to respond with the primitive limbic system (Strauch, 2003).

Older adolescents work toward forming an identity or role in society and may begin educational or experiential preparation for this goal (Radzik, 2002). In other words, these adolescents are deciding and becoming what they want to be when they grow up.

Parents may believe that their child is capable of independently caring for the EFD at this stage of development. However, risk taking and omnipotent thinking patterns may be the basis for early and middle adolescents to disregard warnings and instructions for care and safety. Adolescents involved in traumatic injuries are noted to have multiple risk-taking behaviors, including the use/misuse of alcohol, which may impact their ability for pin-care self-management (Spain et al., 1997; Strauch, 2003).

#### Traumatic Injury

It is not known how adolescents deal with traumatic injury resulting in treatment with an EDF. Coping is a process that involves thinking or behaving to master, reduce, minimize or tolerate environmental and inner demands or stress (Mandleco & Peery, (2000). This coping is thought to result from the cognitive appraisal of stress, or making sense of what an event means personally to oneself (Thies & Walsh, 1999). Knowledge of the day-to-day experience of acutely injured adolescents treated with an EDF may fill gaps in understanding how they evaluate and deal with the traumatic event and subsequent treatment with EDF.

The impact of traumatic injury on adolescent is not well understood, but physical and psychological studies are emerging. In a 10-year review of

adolescent trauma, Stoddard et al. (2001) warn that the psychological sequelae of millions of adolescents injured each year are unknown and need further study. Most studies of adolescents involved in traumatic injury focus on posttraumatic stress disorder (PTSD), for which risk factors include limb fracture, over age 12, being female, and elevated pulse rate in the emergency room (Winston, Kassam-Adams, Garcia-Espana, Ittenbach, & Cnaan, 2003). These risk factors are frequently seen in adolescents treated with EFD for traumatic injury.

Adults involved in a traumatic event often viewed the event as a dividing line in their lives, leading many of them to confront their mortality and lose trust in a safe world (Richmond et al., 2000). For some adults, the event had positive effects, e.g., a renewed appreciation for life and determination to make the most of it (Richmond et al., 2000). For adolescents, traumatic events are common (24 per every 100 children, 14-17 years old) with over 13 million adolescents in the US sustaining non-fatal injuries yearly, a number that is growing (National Center for Injury Prevention and Control, 2006). In 2002, over 20 thousand Massachusetts adolescents (11-20 years) were treated for fractures, with 1,640 requiring hospital admission (Massachusetts Department of Public Health, 2002). Despite almost twice as many younger adolescent (11-15 years) sustaining fractures, those over 16 have more serious injuries and are hospitalized 3 times as often (Massachusetts Department of Public Health, 2002). In their struggle to define their identity, adolescents experience phases of fantasy, idealism, omnipotence, and risk taking, some with little impulse control (Radzik, 2002; Steinberg & Morris, 2000). Little is known about adolescents' confrontation with

injury and mortality issues. Understanding the circumstances leading to traumatic injury may illuminate areas for intervention and prevention of trauma. The fallout, or the effect of traumatic injury on the lives of adults, can be best understood in terms of the event's 4 identified repercussions: physical, psychosocial, economic and legal (Richmond et al., 2000). Male adolescents recovering from trauma in a rehabilitation hospital are known to desire to be normal and return to their pre-injured state (DeWitt, 1993). They faced uncertainty and depended on family, peers and healthcare professionals for support (DeWitt, 1993). It is unknown if these issues are also important to female adolescents or those treated with EFDs.

## External Fixation

### *External Fixation Devices*

External fixation is a general term for a metallic orthopedic device with two essential components: skeletal pins and a frame worn on the outside of the body. Pins (threaded or smooth) or wires are placed through small incisions in the skin and soft tissue and are secured into bone via grooves carved in the cortical bone by drill bits (Figure 1). Another method for fixation uses transfixion pins, which pass directly through soft tissue into bone and out the opposite side of the bone and soft tissue. These EFDs are used for both elective and traumatic conditions.



Figure 1. External fixator with half-pins

### *Elective Use of EFDs*

EFDs were first used for elective procedures by Dr. Ilizarov, a Russian orthopedist who designed a method to lengthen limbs of children with achondroplasia (dwarfism)(Martin et al., 2003) . This method uses a cluster of layered metal rings, rods, wires and pins. These devices are placed on intact



bone and a corticotomy (complete circumferential cut of the bone cortex) is performed. Bone transport is a slow, tedious process lasting weeks to months, depending on the final length or angle correction desired, and taking about one month for every centimeter of length (American Academy of Orthopedic Surgeons (AAOS), 2001). The body heals the bone by sending out osteoblasts (bone building cells) from the cut bone ends. Seven days after the corticotomy, the frame(s) is slowly manipulated by turning nuts (on threaded rods projecting from the external frame) one-quarter turn every 6 hours daily to transport bone to a new location or angle over several weeks or months. The object is to keep the bone ends pulling apart microscopically, so healing does not occur and more osteoblasts are laid down between the bone ends. When the desired length or angular correction is reached, turning is stopped. The frame remains on until the bone solidifies and can bear weight without the support of the frame (Figure 2).

Figure 2. New bone growth

EFDs are frequently applied during early adolescence to correct long bone deformities, such as Blount's deformity (Figure 3). The Ilizarov fixator has been successfully used to treat complicated skeletal and soft tissue deformities and inequalities in limb length, leading to expanded uses internationally for traumatic fractures (American Academy of Orthopedic Surgeons (AAOS), 2001; Martin et al., 2003).



Figure 3 Blount's Deformity with Ilizarov Correction

#### *EFDs Used to Treat Traumatic Injury*

Superior properties of EFDs make them an indication rather than a choice for fracture fixation in children and adolescents. (El Hayek et al., 2004; Rinker, Valerio, Stewart, Pu, & Vasconez, 2005; Smith et al., 2005). Open physes (growth plates) may limit orthopedic treatment options. If a physis is crossed with a surgical implant, bone growth may be arrested in that location (Rockwood, 1996). EFDs may be used to stabilize bone while avoiding physes; to allow access to wounds, skin grafts and muscle flaps (Figure 4); to allow joint motion above or below a fracture; and to act as portable traction to allow patient mobility and/ or early discharge. Some adolescents in EFDs return to activities, including school, within days of the device being applied (Figure 5). Frame design and pin

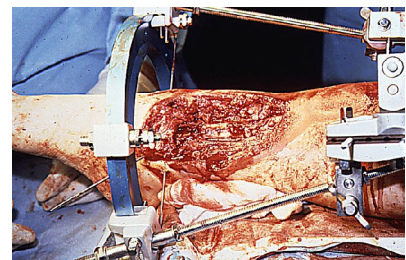


Figure 4. Ankle hybrid fixator for soft tissue loss

placement are versatile and depend on the fracture configuration or correction requirements.

### *Benefits of EFDs*

Benefits of external fixation include (1) rapid anatomic stabilization of bone, (2) early patient mobility, (3) improved joint function, and (4) reduction of general systemic complications in multi-trauma

patients. EFDs also (1) facilitate undisturbed physes (growth plates), (2) ease access to wounds, skin grafts and muscle flaps, (3) need little anesthetic for removal, (4) leave small scars, (5) allow early discharge from

hospitals, (6) hasten the return to weight-bearing activities and school, and (7) enhance the ability to

dynamize a fracture (Patterson, 2006). Dynamization refers to the mechanical compression of bone ends to promote callous formation and healing. Cost effectiveness of EFDs has been demonstrated in treating femur fractures in children (Hedin, Borquist, & Larsson, 2004). The number of days in the hospital significantly influence the cost of treatment, which was lowest in children treated with EFDs (despite surgical costs) (Hedin et al., 2004).



Figure 5. Ready for discharge post-op day 3

### *Disadvantages of EFDs*

Disadvantages of EFD treatment include physical and psychosocial problems. The most commonly reported physical problems with EFDs are pin-site infection and pain (Gordon et al., 2000; Hedin et al., 2003; Martin et al., 2003; Patterson, 2005, 2006; Ramaker et al., 2000). Other less common



problems include muscle contractures, joint stiffness and luxation (joint slippage), neurological and vascular injuries, reflex sympathetic dystrophy and refracture (Ghoneem et al., 1996; Lavini et al., 1990; Paley, 1990).

### *Pin-Site Infections*

Pin-site infection is a reported complication in most studies of EFDs (Althausen & Hak, 2002; Bernardo, 2001; Davis et al., 2001; Green & Ripley, 1984; Hedin et al., 2003; Hutson & Zych, 1998; Lee-Smith et al., 2001; McKenzie, 1999; Nemeth & Mattingly, 2001; Patterson, 2006; Sims & Saleh, 2000). Infections are related to tissue reactions to a foreign body (Green, (1983). In the case of EFDs, bodily tissue reacts to the placement of a metallic skeletal pin (foreign body) by developing a bursal membrane that isolates the foreign body from adjacent tissues. This bursal membrane produces fluid to lubricate the tissue/pin interface. Because the pin penetrates the skin, the fluid can become contaminated by microorganisms. Cleansing crusts from pin sites allows the fluid to drain, decreasing the concentration and virulence of microorganisms. Antibiotic solutions/ointments and dressings are applied to pins to provide further protection from infection. Because contamination is always present at the site where the pin exits the skin, pin-site care is crucial to preventing infection (Jones-Walton, 1988).

The first sign of infection at the pin site is pain (Gordon et al., 2000) . Progression of pain, erythema, swelling, drainage and pin loosening indicate worsening infection (Green, 1983; Patterson, 2005; Rockwood, 1996). These pin-site infections may progress to deep infections causing bone destruction, pin

loosening, loss of fixation or stability of the fracture, osteomyelitis requiring surgical intervention, and costly, long-term intravenous antibiotics (Green & Ripley, 1984; Patterson, 2005; Rockwood, 1996; Wood, 2001).

To determine the best pin-care method for preventing pin-site infection, Patterson (2005) studied 92 patients (3-80 years old) with 527 EFD pins and found an overall pin-site infection rate of 34%. The number of pins infected was inversely related to age ( $r = -0.285, p < .01$ ), with pre-adolescent and adolescent EFD recipients (9-19 years) having more pin-site infections. Given the overall good physical health of this age group, this finding suggests other etiology for the increased pin-site infection rate. The results of this study and the researcher's clinical experience provided impetus for this study.

#### *Pin-Care Self-Management*

The process of pin-care self-management (e.g., cleansing, wrapping, and frequency) varies somewhat across settings. However, the University of Massachusetts Memorial Health Center (UMMHC) currently uses the steps outlined in Table 2 (Patterson, 2005).

Steps 1-5 are performed twice daily and take 20-40 minutes to complete, depending on the number of pin sites. Pin site care may be done after showering if allowed by the surgeon. Caution should be exercised to not expose EFDs to extremes of temperature as the pins will conduct cold or heat to the bone and pin sites will burn easily. For example, exposure to hot sun at the beach should be avoided. Swimming in ponds, lakes or oceans and baths are not permitted because bacteria in the water can easily enter at the skin opening (pin site) and

travel down along the pin, contaminating the soft tissues and breeding infection. Padding the pin ends prevents inadvertent injury. This pin-care self-management regimen demonstrates several areas that could affect families of adolescents treated with EFDs.

Table 2

*Major Areas of Concern for Pin-Care Self-Management*

Step	Rationale/Method	Area for Concern
1. Wash hands/gather supplies		Requires running water and previous purchase of supplies
2. Examine pin sites	For erythema, drainage, odor, crusting, tenting loosening or fever	Requires ability to look at pin site to determine a problem and ability (phone and phone number) to notify clinician if problems are present
3. Cleanse each pin	cleansing solution 1:1 hydrogen peroxide /saline mixture 1 cotton swab/pin site	Requires ability to tolerate looking at and reaching the pin site and to understand sources of contamination (e.g., use of a swab for more than one pin site)
4. Dry each pin site	1 cotton swab/pin site pushing skin down to prevent tenting	Requires understanding the need to apply pressure so skin stays flat at the pin and ability to tolerate discomfort, if present
5. Wrap each pin	Gauze or Xeroform or Ilizarov sponges close to the pin/skin interface	Requires ability to afford supplies and manual dexterity to wrap pins

Adolescent Experiences with EFDs

Much of what is known about adolescents and EFDs comes from research on long-bone correction after elective osteotomy (surgically cutting or fracturing bone) (Ghoneem et al., 1996; Hrutkay, & Eilert, 1990; Lavini et al., 1990; Martin et al., 2003; Morton, 1998; Olson et al., 1991; Paley, 1990; Ramaker et al., 2000). An integrative research review of these 9 studies (Patterson, 2006)

compared adolescents' reactions to EFD treatment for elective limb corrective/lengthening procedures. The reported reactions (behavioral changes) were categorized according to their psychological, social, functional and physiological dimensions (Table 3).

### *Psychological Dimension*

Depression was by far the most pronounced psychological reaction found in every study. Some adolescents treated with EFDs experienced depression to the point of suicidal ideation or attempts (Ghoneem et al., 1996; Hrutkay & Eilert, 1990; Patterson, 2006), whereas for some depression was temporary (Ghoneem et al., 1996; Lavini et al., 1990) or seen even after removal of the EFD (Ramaker et al., 2000). Many adolescents exhibited anorexia or appetite changes (Hrutkay & Eilert, 1990; Martin et al., 2003; Paley, 1990; Ramaker et al., 2000). Difficulties with guilt, anxiety and anger were reported in several studies (Ghoneem et al., 1996; Hrutkay & Eilert, 1990; Lavini et al., 1990; Olson et al., 1991b; Ramaker et al., 2000).

One adolescent exhibited self-destructive behavior by contaminating pin sites of the EFD (Hrutkay & Eilert, 1990; Olson et al., 1991b). Many adolescents reported fear, especially at night, during the lengthening phase. Although the frequency of night fears gradually decreased over the course of treatment, adolescents were occasionally frightened during the night (Hrutkay & Eilert, 1990; Olson et al., 1991b).

Table 3

*Adolescents' Reactions to EFD Treatment for Elective Orthopedic Procedures*

Dimension	Reaction
Psychological	Depression, Suicidal ideation, Self-destructive behavior, Emotional difficulties Anorexia Fear, Anxiety Body image issues Guilt, Regression
Social	Fewer contacts School/peer problems Role change Opposite sex issues
Functional	Walking – mobility Loss of sleep Difficulty concentrating in school
Physiological *	Pain Pin-site infection Joint stiffness/luxation

Altered body image was a significant problem for over half of the subjects in two studies, with many having problems even after the EFD was removed. One boy felt “a bit sick” when he woke up to see all the pins in his leg (Martin et al., 2003). Many of the 25 patients treated with a halo EFD reported feelings of mutilation due to forehead scars, lumps and indentation, with two seeking plastic surgery (Olson et al., 1991b). Only 17% of adolescents in one study (Eckhouse-Ekeberg, (1994), demonstrated a “good” adjustment to the EFD treatment prior to instituting an interdisciplinary team approach that included psychological support. When asked about satisfaction with EFD treatment, 45% of 13-18 year-olds and 83% of 6-12 year-olds reported that scars and duration of treatment were significant ( $p=0.01$ ) deterrents to repeating EFD treatment (Ghoneem et al.,

1996). These results contrast to the 68% of 7-16 year-olds that reportedly would “do it again” (Hrutkay & Eilert, 1990) and the 88% of 6-17 year-olds that would “have the procedure again” in the Netherlands study (Ramaker et al., 2000). This latter finding may have been magnified by the intensive team approach and report that 20% of the patients screened for the procedure were delayed for behavioral or family treatment and to learn coping skills.

### *Social Dimension*

Of the 5 studies that discussed social effects of treatment with EFDs (Hrutkay & Eilert, 1990; Lavini et al., 1990; Martin et al., 2003; Olson et al., 1991b; Ramaker et al., 2000), only one spoke to the adolescents’ preoperative social concerns for the “need to be like others” and importance of relationships with the opposite sex (Lavini et al., 1990). Adolescents reported disliking the stares and negative reactions of the public and their peers to these devices (Olson et al., 1991b; Ramaker et al., 2000). Four studies noted that social contacts or plans decreased for up to one-third of the adolescents during as well as after using the EFD (Lavini et al., 1990; Martin et al., 2003; Olson et al., 1991b; Ramaker et al., 2000). However, Lavini et al. (1990) noted increased social contacts and improved relations with the opposite sex after the EFD was removed. The qualitative findings of a mixed-method study (Martin et al., 2003) underscored the importance of peer social support for adolescents treated with EFDs. This valuable information was not captured by the psychometric tests included in the same study. Others have described behavioral disturbance in

non-compliance with hospital ward rules and in confrontations with nurses (Hrutkay & Eilert, 1990; Martin et al., 2003).

Parents of adolescents treated with EFDs reported facing interruptions or changes in their parental role. They were distressed about having to learn complex medical procedures and EFD care for a child undergoing limb lengthening (Hrutkay & Eilert, 1990). Parental difficulties with and distress over role changes and pin care may be carried over to interactions with the adolescent unless he/she assumed pin-care self-management responsibility. Adolescents treated with halo EFDs reported being distressed because the apparatus interfered with their school or work (Olson et al., 1991b).

#### *Functional Dimension*

The effect of EFDs on physical function was expressed in multiple ways in each of the 9 studies reviewed. Preexisting limited physical function was the reason that subjects had elected the limb correction/lengthening procedure. For example, they wanted to improve walking, ability to drive (especially difficult for patients with achondroplasia; (Lavini et al., 1990), or ability to participate in gym class (Paley, 1990; Ramaker et al., 2000). Postoperatively, the most prominent functional effect was sleep disturbance related to pain and fear (Paley, 1990; Ramaker et al., 2000). Decreased attention span and poor school work were the only cognitive function problems reported (Olson et al., 1991b; Ramaker et al., 2000).

Dependence on others for care was a substantial issue for adolescents with EFDs (Hrutkay & Eilert, 1990; Martin et al., 2003; Olson et al., 1991b).

Those who needed care because of the EFD's location tended to have conflicts with nurses and parents (Hrutkay & Eilert, 1990). Regressive behaviors emerged even when teens were able to perform self-care (Hrutkay & Eilert, 1990; Ramaker et al., 2000). At first physical adaptation to the bulky EFD frame itself frustrated some adolescents (Martin et al., 2003; Olson et al., 1991b; Ramaker et al., 2000), but most adjusted within the first month (Martin et al., 2003; Olson et al., 1991b).

### *Physiological Dimension*

Physiological complications as a result of the EFD procedure included muscle contractures, joint stiffness and luxation (slipping of a joint), neurological and vascular injuries, reflex sympathetic dystrophy, and refracture (Ghoneem et al., 1996; Lavini et al., 1990; Olson et al., 1991b; Paley, 1990). After the EFD was removed, adolescents were found to have conflicting outcomes. Two children reported improved function, mobility and cosmesis (Hrutkay & Eilert, 1990), whereas some adolescents reported feeling less attractive after removal of the EFD or unable to perform regular physical activity (Lavini et al., (1990) Ramaker et al., (2000).

The two predominant physiological problems noted in every study reviewed were pain and pin-site infection. Most studies described some pain "at all times," with the worst pain immediately after surgery and during the lengthening phase. Pain was reported to be worse at night, frequently interfering with sleep (Paley, 1990; Ramaker et al., 2000). Use of medications such as codeine or morphine was stressed as a priority and thought to "decrease



psychological vulnerability” in adolescents (Ghoneem et al., 1996; Gregory et al., 1996; Hrutkay & Eilert, 1990). Hrutkay and Eilert (1990) reported that no patients developed addiction.

Although pin-site infection was listed as a complication or problem in 8 of 9 studies, it was not the focus of these studies (Eckhouse-Ekeberg, 1994; Ghoneem et al., 1996; Hrutkay & Eilert, 1990; Lavini et al., 1990; Martin et al., 2003; Olson et al., 1991b; Paley, 1990; Ramaker et al., 2000). Current treatment for these infections now includes oral or intravenous antibiotics, but Paley (1990) described the painful treatment of peppering the area around the infected pin site with daily injections of antibiotic for a week. Only one study reported a direct link between pin-site infection and behavior, i.e., an adolescent had deliberately contaminated pin sites to cause an infection (Hrutkay & Eilert, 1990).

### *Summary*

To date, few empirical studies have explored adolescents’ experiences with EFDs. The seminal mixed-method, longitudinal study by Martin et al. (2003) described adolescents’ experience with an elective Ilizarov frame (one type of EFD). These adolescents (N=15, 11-18 years old) had long-bone deformities for which Ilizarov frame treatment had been planned and applied. Subjects were interviewed 7 days before surgery, 6 months after applying the EFD, and one month after removing the EFD. Psychometric measures for depressive symptoms, body and self-image were administered at these times as well as at 1 week and 1 month following surgery. Although approximately 30% of the adolescents in the study reported depression before surgery, mood gradually

improved over the course of treatment, with only one participant self-reporting depressive symptoms after the EFD was removed (Martin et al., 2003). Although the sample was too small (N=15) for meaningful analysis of the psychometric tests, their results were used for descriptive purposes. Low body image (below 1 SD of norm) was seen preoperatively (n=6), at 7 days (n=7), at 30 days (n=6), at 4-6 months (n=6), and after EFD removal (n=8).

This mixed-method study (Martin et al., 2003) provided important information for health professionals to better understand the experience of adolescents treated with EFDs, but it did not include adolescents treated for traumatic fracture, nor did it interview them in the acute phase of their experience. The issues faced by an adolescent with a congenital deformity are potentially quite different from those of a healthy adolescent with an unexpected fracture requiring EFD treatment (Martin et al., 2003). Adolescents with congenital deformities can prepare for surgery to improve their appearance and/or function, whereas those treated for traumatic injury may have unique psychosocial issues. For example, adolescents must not only cope with the trauma of the event itself, but also deal with painful and frightening medical treatment and “the reaction of others (real or imagined) to their disfigured body” (Blakeney, 1998 p.197). No studies to date have explored these issues with the acutely injured adolescent dealing with EFD treatment.

#### Adolescent Role in Pin-Care Self-Management

To date, no studies have been found that explore pin-care self-management in adolescents. However, a concept analysis of self-management

for adolescents with diabetes suggests that self-management is influenced by relationships between families, friends and healthcare providers (Schilling, Grey, & Knafl, 2002). The adolescent with diabetes shares with parents the responsibility for self-management of daily care, which changes with increasing age (Schilling et al., 2002). In the case of the adolescent with an EFD, daily care revolves around pin care rather than insulin dosage. Several studies have reported that even when adolescents are capable of caring for EFDs, they may exhibit regressive behaviors (Hrutkay & Eilert, 1990; Olson et al., 1991b), such as capitalizing on the “sick role” and relinquishing pin-care responsibility to parents or nurses (Hrutkay & Eilert, 1990; Olson et al., 1991b). Hospitalized adolescents with an EFD have been reported to have problems adhering to ward rules or pin-care regimens (Hrutkay & Eilert, 1990). Poor adherence may lead to confrontations, withdrawal, and/or threats of violence toward nurses (Ramaker et al., 2000). Ramaker et al. (2000) recommended that such adolescents be managed by nurses accustomed to dealing with adolescents with EFDs. Because these studies were conducted when hospital stays were dramatically longer than now, one wonders if parents may become the recipients of this behavior during the post-hospitalization period or whether other acting-out behaviors would emerge. In addition, adolescents’ perception of their parents’ role in daily pin care is poorly understood and has not been documented.

In summary, responsibility for pin-care self-management is thought to be shared by parent-adolescent dyads, and multiple potential problems have been identified. No study to date was found on the adolescent’s role in pin-care self-

management. Despite the researcher's belief that parents play a role in pin-care self-management, it is beyond the scope of this study to conduct in-depth interviews with parents as well as adolescents. Instead, this study will focus on the adolescent's experiences and will explore the adolescent's perception of his/her parent's role in pin-site management.

#### Gaps in the Literature

This review of the literature found only 10 research studies on adolescent experiences with EFDs, indicating the paucity of information available on this topic. These studies were limited by the exclusion of trauma patients and lack of information on experiences during the acute phase of EFD treatment. The second gap is notable, as Martin et al. (2003) believe that the first few weeks with an EFD is the most problematic time for adolescents.

It is clear, however, that the advantages of EFD treatment indicate its use for fractures in children and adolescents. Little is known about the psychosocial impact of EFDs on injured adolescents or why pin-site infection rates are higher for this age group. No studies have reported on pin-care self-management and the role of adolescents in this care. To address these gaps in knowledge, this study was designed to explore the experience of adolescents treated with EFDs for traumatic injury and to identify pin-care self-management practices of adolescents.

## CHAPTER 3

### DESIGN AND METHODOLOGY

#### Overview

To explore the traumatically injured adolescent's experience with EFDs, a qualitative research design was employed. This chapter describes the qualitative method and framework of the study. Details of the procedure for data collection, management and analysis are explained, as well as consideration of human subjects, trustworthiness, and study limitations.

#### Description of Qualitative Approach

This study used a longitudinal, qualitative descriptive design to describe the circumstances leading to the trauma, the day-to-day experiences of acutely injured adolescents treated with EFDs, and their role in pin-care self-management. Fundamental qualitative descriptive design, drawing on the principles of naturalistic inquiry, provides a pragmatic approach to “staying close to the data” while exploring and describing adolescents' day-to-day experiences with an EFD. To reduce possible bias, theoretical frameworks are purposely not used at this basic research level. However, the study was undergirded by themes derived from research on adults recovering from physical injury (Richmond et al., 2000), aspects of adolescent development (Radzik, 2002; Steinberg & Morris, 2000), and self-management (Schilling et al., 2002).

The term “fundamental” is used by Sandelowski (2000 p. 335) to distinguish this qualitative descriptive design from more widely used and interpretive qualitative descriptive approaches (e.g., grounded theory,

phenomenology and ethnography). While fundamental qualitative description is not free from interpretation, data obtained with this approach are interpreted with a lower degree of inference than other forms of descriptive qualitative analysis, likely resulting in “easier consensus among researchers” (Sandelowski, 2000p. 335). The findings are typically presented in the participants’ words and are readily understood by participants and non-researchers. This method of study has the potential to translate directly to healthcare situations and to enable the development of interventions for vulnerable populations whose complex and contextual characteristics and concerns may not be readily accessible by other means (Sullivan-Bolyai, Bova, & Harper, 2005) .

Purposeful sampling is typically used to provide maximum variation in the sample. Data are collected by interviewing individuals to discover the “who, what, when, where, and why” of an experience. This pragmatic method also uses documents, observation and other pertinent material to provide rich comprehensive synopses of participants’ experiences with the phenomenon under study. Fundamental qualitative description allows for analysis of qualitative and quantitative data. Interview transcripts and documents undergo qualitative content analysis using a modifiable coding system developed from the data collected. Quantitative data are analyzed in a quasi-statistical method whereby numbers summarize data with descriptive statistics.

The central purpose of this methodology is understanding the latent variable, which is not easily discernible but is present (Sullivan-Bolyai et al., 2005). A latent variable may be key to understanding a complex experience and

potentially useful in assessing and developing interventions with vulnerable populations. For example, Bova (2001) used qualitative descriptive methodology in a mixed-method study to identify factors that influenced the adjustment of HIV-positive women to their chronic illness. After identifying that a lack in “life skills” seemed to affect adjustment to chronic illness, Bova (2001) created an intervention called “the positive life skills workshop.”

The findings of this methodology provide a rich description of the experience of interest and can be reported in keeping with the data, such as chronologically, by topic, or frequency of occurrence (Sandelowski, 2000). Using qualitative description in the study filled the gaps in the literature about the acute experience of adolescents treated with EFDs for traumatic injury, as well as their role and experience with pin-care self-management.

#### Organizing Framework

The study was guided by two portions of Richmond’s et al.’s (2000) 3-part framework: the Event and Fallout. Based on this framework, 3 interviews were designed to understand the injured adolescent’s experience with EFD treatment (Figure 6). As the interview data were analyzed, new themes or patterns emerged to guide the study in a new direction, thus altering the original framework, which is typical of qualitative research (Miles & Huberman, 1994; Munhall, 2001).

This study built on the studies of Richmond et al. (2000) and Martin et al. (2003). Martin et al. (2003) used a prospective, longitudinal, mixed-method design to explore adolescents’ perceptions of living with an Ilizarov frame after

elective surgery. That study used 3 interviews one week before surgery, 6 months after surgery, and one month after frame removal. Adolescents were not interviewed in the early postoperative period, and acutely injured adolescents were excluded. The current study explored the acute experiences of adolescents who had been traumatically injured and treated with EFDs. Participants were interviewed within 4 days of surgery or awareness of EFD, 2-4 weeks after discharge to home, and following removal of the EFD. Interviewing participants close to the EFD experience ensured a more accurate description by the adolescent and allowed the researcher to interview participants in the hospital environment. Interviewing face-to-face allowed the researcher to hear the participant as well as the sounds in the environment, see the EFD and any disfigurement, and to see and interpret body language. Obtaining this contextual information would have been severely limited by quantitative research methods such as questionnaires or chart reviews.

The interview scheduled at 2-4 weeks following EFD application occurred shortly after hospital discharge. A study of 38 patients treated with halo EFDs Olson et al., (1991b) found that their focus changed from physiological needs during hospitalization to psychological issues after discharge. In the present study, the perspective of adolescents on the pin-care experience at home and how pin-care roles are decided was probed by interview questions that focused on participants' transition to home and on pin-care self-management.

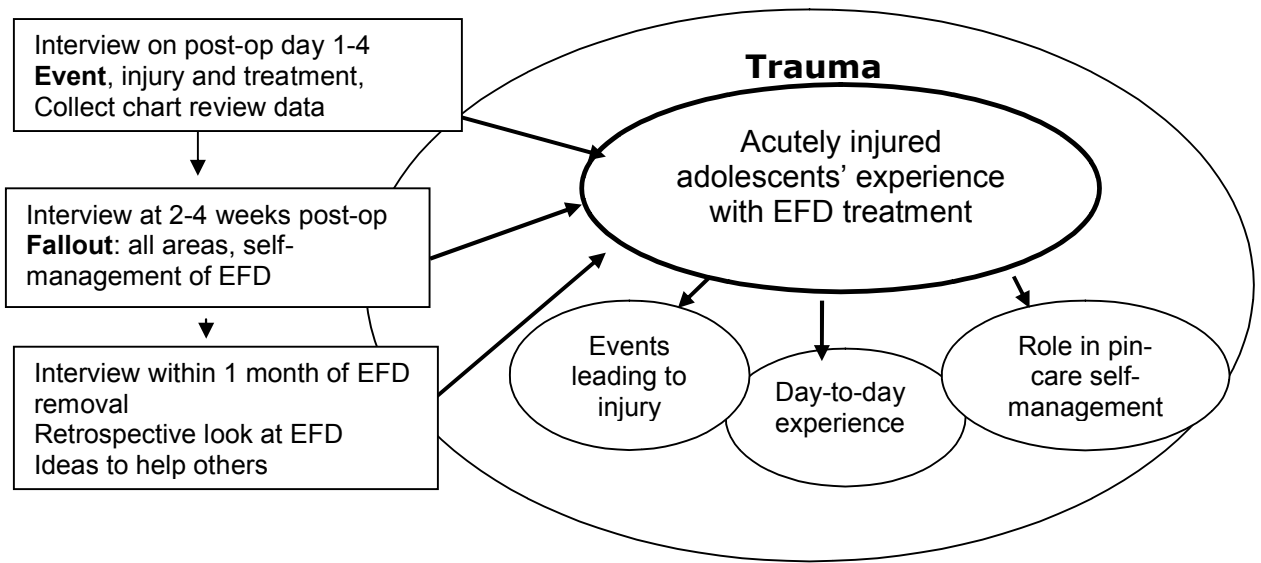


The final interview (within one month of EFD removal) provided a longitudinal perspective of the experience, offering an opportunity for participant reflection, and providing advice for others who may need EFD treatment.

Figure 6

*Framework for Studying Acutely Injured Adolescents' Experience with EFD*

*Treatment*



*Sample*

Purposive sampling was used to recruit adolescents (11-20 years). This age range was chosen to include adolescents with a broad range of developmental stages, ethnic backgrounds, and injuries of varying severity. The age of participants ranged from 13 to 20 years. Although 11-16 year-olds sustain more fractures, 16-20 year-olds have more severe injuries and are hospitalized more often (Massachusetts Department of Public Health, 2002; Olson et al., 1991b). A wide range of ages is preferred for cross comparisons of the acute EFD experience, allowing a fuller understanding at a variety of developmental

levels (Miles & Huberman, 1994). Initially, 10 subjects (5 male and 5 female) were recruited for 26 interviews. One female participant was excluded because she did not meet inclusion criteria as her EFD was for elective correction. Saturation of themes was reached by the seventh participant (Sandelowski, 1995), but an even number of females was desired. Although no new themes were identified in interviews with these additional female participants, their descriptions of their experiences strengthened the results for coping and body image findings.

#### *Inclusion/Exclusion Criteria*

To be included in this study, participants could be either female or male, but had to be 11-20 years old, treated with an EFD for acute injury, have the EFD placed within 10 days of injury, not have severe cognitive impairment as determined by their orthopedic clinician, and they and their parents all had to speak English. Participants were willing with parental consent to be interviewed alone on 3 separate occasions. The inclusion age range covered younger adolescents (known to have a higher rate of fractures) and older adolescents (who may have more severe injuries). Developmental levels did vary within this age range, providing a variety of experiences at different stages of development. The criteria of speaking English and being free of severe cognitive impairments ensured that participants could respond meaningfully to interview questions. Participants previously treated with an EFD were excluded because of their experience and knowledge. Those who planned to leave the area were excluded, as follow-up interviewing would have become logistically difficult.

### *Attrition*

Based on the researcher's experience with this population, attrition was limited. In a previous longitudinal study of pin-care methods among 3-80 year-olds at UMMHC, the attrition rate was 3.1% (Patterson, 2005). Three of 96 adult participants dropped out of that study, one due to incarceration and two others lived outside the geographic region. One participant left the area before the last interview. Recruiting participants who lived locally and planned to follow-up in the orthopedic clinic at UMMHC reduced possible attrition by making participation more convenient. Participants lived locally and were within driving distance when in-home interviews were chosen for the follow-up interviews. Strategies for retention included 1) giving participants \$20 cash, 2) giving parking vouchers for interviews at UMMHC, 3) offering flexible interview schedules to coincide with follow-up visits, and 4) making reminder phone calls.

### *Setting*

The sample was recruited from the pediatric and adult inpatient units of the UMMHC, Worcester, MA. UMMHC provides the tertiary care for seven surrounding hospitals and is the only pediatric level-1 trauma center in central Massachusetts. The UMMHC orthopedic database revealed that from July 2000 to July 2002, 102 adolescents (11-20 years old) were treated with EFDs for fracture, or approximately 50 per year (Leclair, 2003). More males (66%) than females (33%) were treated with EFDs and more adolescents were treated in the fall and early winter months (Leclair, 2003). Racial/ethnic statistics were not collected. However, the racial distribution of 1,640 adolescents (11-20 years)

hospitalized in Massachusetts for fracture treatment in 2002 was 76% White, 7% Black, 7.6% Hispanic, 1.5% Asian, 0.06% American Indian, 2% other and 4.8% unknown (Massachusetts Department of Public Health, 2002). To maximize enrollment, the researcher recruited participants through summer, fall and winter.

#### *Accessible Population*

The Chair of the Orthopedic Department at UMMHC wrote a letter of support ensuring the researcher access to the adolescents (see Appendix A). Both the pediatric and trauma orthopedic surgeons had expressed interest in this study and its results to improve their practice with this complex age group. These supportive relationships assured the study's successful completion.

#### Data Collection Procedure

##### *Pilot Study*

After obtaining Institutional Review Board (IRB) approval, the researcher pilot tested the interview guide (see Table 4) with two adolescents who had completed treatment with an EFD for traumatic injury. The purpose of this pilot study was to check the content and language of the interview questions, as well as the time to administer them. The results of the pilot study were used to revise the interview questions or adapt the method of questioning.

##### *Recruitment*

The researcher presented the study to the orthopedic department and pediatric and adult orthopedic/trauma nursing units when enrollment began. The orthopedic surgeons and nurse practitioners helped the researcher identify potential study participants. The researcher met with the orthopedic staff on a

monthly basis and the nurse practitioners and orthopedic residents on a weekly basis to apprise them of the study criteria and to answer questions. Orthopedic nurse practitioners or surgeons informed their patients about the study and gained permission for the researcher to tell them about the study.

The researcher approached interested adolescents (>18 years old) or parents of interested adolescents (if under 18 years) to explain the study. Nine willing adolescents (11-20 years) treated with an external fixation device for traumatic injuries were recruited and enrolled because they met the inclusion criteria. No participants declined enrollment.

#### *HIPAA Authorization*

A hospital insurance portability assurance act (HIPAA) form, which authorizes use and disclosure of health information for research purposes, was signed by the parent/participant to learn more about the study. The data that required disclosure included medical records and lab database information. The authorization remained in effect until completion of the study.

#### *Informed Consent*

The researcher obtained informed consent from participants over 18 years old (Appendix B). The informed consent contained the names and contact information for the researcher, faculty advisor and participant. For participants under 18 years old, a parent or guardian signed the consent form and the minor signed an assent form (Appendix C). Copies of these forms were given to the participants. Both the consent and assent forms included the study purpose, procedure, risks, potential benefits, inconveniences, certificate of confidentiality

of information, measures to protect confidentiality of information, and the participant's right to withdraw from the study at any time. This right was explained by first stating that participation was voluntary (and by repeating this statement before each interview). Participants were next assured that they could decide to not take part or to quit at any time without any penalty or consequence. Their choice to participate or not would in no way affect the care they receive from their orthopedic surgeon or staff. During recruitment, the researcher informed participants that a certificate of confidentiality would be maintained during interviews, and that a certificate of confidentiality was obtained from the National Institutes of Health.

#### *Protection of Human Subjects*

The study was started after obtaining IRB approval. Human subjects' rights were protected at all times and participants were informed that the purpose of the study was to better understand what it is like for adolescents to be treated with EFDs for acute traumatic injury. Even though informed consent and assent were obtained upon enrollment in the study, participants were reminded frequently that participation was completely voluntary and that they could withdraw from the study at any time without penalty or consequence. Participants were informed of any new information or changes in the study that might have affected their participation. They were assured that their choice to participate or not would in no way impact the care they received from their orthopedic surgeon or staff.

No physical risks were anticipated for participants in this study. The only possible risk of participating was that participants may have experienced stress when recalling the traumatic experience leading to EFD treatment. This risk was minimized by having the interviews conducted by a researcher experienced with interviewing adolescents, limiting interviews to a maximum of 3, and conducting interviews in a private setting, at a time chosen by the adolescent. The researcher is experienced in adolescent trauma care and was aware of cues indicating discomfort or distress. Three one-hour interviews were proposed, but if any participant required a shorter interview, that wish was accommodated. A plan was in place to deal with psychologic issues with immediate referral options (such as escort to the emergency mental health center or call to primary care physician) if problems arose during clinic interviews. This extra protection was warranted due to the known risk for depression and suicidal ideation of adolescents treated with EFD. During the study, the researcher believed that a participant who revealed depressive thoughts needed intervention. He was referred to his mental health counselor.

Participants may have benefited from the therapeutic relationship with the researcher by being allowed to express feelings and tell their stories. Study findings will be used in the future to help other traumatically injured adolescents treated with EFDs. The risk of emotional stress directly related to this study was minimal compared to the risks of depression and pin-site infection associated with EFD treatment. Understanding the experience of acutely injured adolescents with EFD treatment is the first step toward developing interventions to support

this population. Confidentiality concerns were allayed by the researcher obtaining the certificate of confidentiality, which protected participants' information being used by any legal or insurance party. This certificate allowed the participants to speak freely without concern that their information could be used against them.

### *Demographic and Clinical Measures*

Baseline demographic information and clinical data were collected for descriptive purposes from the medical record/chart review and/or participants, or participants' parents. Demographic information included age, ethnicity, grade in school, insurance, family constellation, parent occupation, housing situation, school attendance throughout treatment, and hospital length of stay. Clinical data included day and time of injury, mechanism of injury, vital signs, presence of alcohol or drugs, details about the EFD, fracture type, and safety measures taken such as seat belts and helmets. These demographic and clinical measures were chosen because the review of the literature suggested that they are pertinent to adolescents involved in trauma (Marcin et al., 2003; Paris et al., 2002; Redeker et al., 1995; Spain et al., 1997).

### *Interviews*

The researcher used the interview guide (Table 4) to separately interview each adolescent in a private setting with which he/she was comfortable. Privacy and freedom from interruptions aided concentration and protected modesty and confidentiality, which are important to developing trust in this age group (Dashiff, 2001). Most all participants were interviewed in their hospital room and no roommates were present during the interviews, but there were frequent



interruptions by the nurse call box on the wall and hospital personnel coming into the rooms for various reasons. While the personnel were in the room, the interviews were stopped and only resumed after the personnel had completed their intended interaction with the participant.

Table 4

*Preliminary Guide for Interviewing Adolescents*

Components of Interview #1	Examples of Probe Topics
<p><i>The Event</i></p> <p>Can you tell me all about what happened?</p>	<p>Circumstances    Physical    Independence</p> <p>Risk-taking        Parents        Other</p>
<p><i>Fallout</i></p> <p>What has changed since the injury?</p>	<p>Physical    Independence    Family function</p> <p>Psychosocial    Legal        Depression</p> <p>Future thoughts    Return to work    Social</p>
<p><i>EFD</i></p> <p>Can you please tell me what it has been like to have an EFD?</p>	<p>Peers                    Parents            Identity</p> <p>Emotional            Nutrition            Depression</p> <p>Sleep                    Pain                Function</p>
<p><i>Pin care</i></p> <p>Can you please tell me about taking care of your EFD?</p>	<p>Pin-care                Roles                Infection</p> <p>Other</p>

Adolescents were interviewed without their parents because it was believed that adolescents may talk more freely if they were not concerned about their parents' reactions (Dashiff, 2001). One participant's parent did come back into the room, unseen behind the curtain but the adolescent was aware of his parent's presence. All major issues in the interview guide were addressed and probes were used as needed. At the end of interviews, the researcher asked if

participants had any questions, thanked them for participating and set up the next meeting. Field notes were made throughout and after the interview to record observations, e.g., participant's apparent comfort level, environmental surroundings, body language. Confidentiality was assured by using only a code letter to identify participants and by keeping the journal, tapes and roster in a locked file cabinet. Debriefing occurred with the researcher's dissertation chairperson and the transcriptionist on several occasions after intense interviews.

The first interview was conducted on the pediatric or adult inpatient unit within the first 4 days after application of the EFD or when the participant had become aware of the EFD. Many were intubated or had closed head injuries or were medicated and unaware of their condition for several days after admission. The second and third interviews were conducted 2-4 weeks after applying the EFD and within one month after removing the EFD, respectively. These interviews were held in the orthopedic outpatient clinic in a designated room, or in the participants' homes, depending on the level of privacy preferred (Dashiff, 2001).

#### *Interview Guide*

The interview guide contained topics used as a basis for open-ended questions to elicit participants' in-depth descriptions of their traumatic event and experiences with EFDs. The pilot-tested and adapted interview guide was used after the researcher introduced herself and assessed how well the participant understood the purpose of the research and level of participation expected (Kanner, 2002). Open-ended questions were asked about the circumstances

leading to the traumatic injury, the adolescent's experience with EFD treatment, with a focus on risk factors, as well as psychosocial and physical dimensions identified in the literature review (see Table 1).

After the open-ended questions, probing questions were used as needed (see Table 4). Questions and topics were added or changed as topics were identified in the interviewing process. Each interview took approximately 60 minutes. The initial postoperative interview was curtailed in two cases because it seemed to be a burden on the participant. The researcher's experience in orthopedic trauma enabled her to assess the situation and she periodically asked participants if they would like to stop or keep going.

Similar questions were asked at the second and third interviews. Questions were altered or reworded to fit the sequence of interviews and cognitive level of participants (Thies & Walsh, 1999) . For example, the question "What have you heard about caring for your EFD?" in the first interview changed to "What are you doing to care for your EFD?" in the second interview, to "What was the hardest part of caring for your EFD?" in the last interview. The final interview was scheduled within 4 weeks of removing the external fixator (typical postoperative visit) to get the most reliable data about participants' post-procedure reaction (Docherty & Sandelowski, 1999). In addition to the questions asked in the first two interviews, the final interview asked participants to recommend ways to help other adolescents with the EFD experience.

All major issues in the interview guide were addressed and probes were used as needed. When the interview was finished, the researcher asked if

participants had any questions, thanked them for participating, and set up the next meeting.

### Data Management

The experience of traumatically injured adolescents treated with EFDs was described by qualitative data from a series of 3 audiotaped interviews. These interviews were transcribed verbatim by a professional transcriptionist. Confidentiality was maintained during the taping and transcribing of interviews by identifying participants only by a coded identification letter. All documents, tapes and transcripts were kept in a locked file in the researcher's office at UMass. Participants' were assured their names will not appear in any reports or publications of this study.

A structured form was used to collect demographic and clinical data (Appendix D). Participants were identified on this form only by a coded identification letter. Participants' medical records and the study site database were used to retrieve information on their injuries, reported risks (e.g., drug and alcohol use), or safety information (e.g., seatbelt or helmet use), day and time of admission, length of hospitalization, pertinent clinical data about their EFDs, and pin-site care documentation. These data were collected on the form and entered into an SPSS database. Confidentiality was maintained by 1) assigning a coded identification letter to the data collection form, 2) having the database stored in a password-protected computer designated for this project, and 3) keeping forms in a locked file.

## Data Analysis

Qualitative inquiry is an iterative process of gathering and analyzing data, which overlap throughout a study (Sandelowski, 1995). Maintaining a chain of evidence is key to enhancing trustworthiness of data (Lincoln & Guba, 1985; Munhall, 2001). NVivo, a qualitative data management software package, was used to assist with management, organization and retrieval of interview data (Richards, 1999). This software provided date and time stamps for each entry, thus helping to produce an audit trail (Richards, 1999). NVivo was chosen for its ease of use, its ability to color code data and memos, and its familiarity to two of the researcher's dissertation committee members and 3 other faculty nurse researchers (Richards, 1999). The researcher kept a journal to record all protocols, ideas, procedures, interview and coding decisions, and thoughts regarding the study, and developed an audit trail to support trustworthiness.

### *Demographic and Clinical Data*

It was anticipated that the demographic and clinical data collected from the proposed sample of 9 participants would be insufficient to generate a meaningful statistical analysis. The purpose of collecting these data was for descriptive purposes only. These data, which were analyzed by descriptive statistics such as frequencies and means, were linked to interview data through the NVivo program (Richards, 1999).

### *Interview Data*

Interview transcripts were checked against tapes for accuracy and summarized for general tone and context by the researcher. Case summaries

gave the researcher an overview of the data on adolescents' perceptions of their experiences, thus facilitating the analysis process. Next, each transcript was coded, reflecting the major elements of the adolescents' interviews, which was the basis for identifying themes that characterized all the adolescents' experiences. Constant comparison was used throughout data analysis to establish linkages across themes (Lincoln & Guba, 1985) . Having only one interviewer increased the dependability of the study. The use of journaling and case summaries also ensured completeness.

The researcher and dissertation chairperson worked together to review transcripts and to systematically describe and code themes. A codebook for NVivo (Lincoln & Guba, 1985) was developed from the data and linked to the research questions and specific interview questions (see Interview Guide, Table 4). This process led to identifying major themes common to the experiences of all adolescents interviewed.

The process for these analyses followed steps adapted for this study (see Table 5) from methodologies for within-case and across-case approaches (Ayres, Kavanaugh, & Knafl, 2003; Miles & Huberman, 1994). This process produced descriptions of the common and individual experiences of adolescent participants regarding the circumstances leading to the traumatic event/injury (Aim 1), day-to-day experiences of injured adolescents treated with an EFD (Aims 2 and 3), and their role in pin-care self-management (Aim 4).

Table 5

*Within- and Across-Case Analytic Strategies*

Comparison	Purpose	Strategy	Product
Within individual adolescent cases	Identify important aspects of the experience from the individual's perspective	Analytic immersion in all interviews, close reading of interviews and summaries	Coded categories & themes, e.g., description of the event
Across all adolescent cases	Identify variations around themes	Data coding and display	Subthemes
Within adolescent cases (gender)	Identify configurations of themes within gender	Close reading of interviews and summaries	Additional themes based on gender

This analysis also described how decisions about responsibility were reached, as well as obstacles faced. Credibility and transferability were achieved by using adolescent participants' own words to accurately describe their day-to-day experience of being treated with an EFD for acute traumatic injury.

*Trustworthiness/Rigor*

In qualitative research, trustworthiness or rigor is akin to validity and reliability in quantitative research. Several measures were employed to establish rigor, which is determined by evidence of credibility, transferability, dependability and confirmability (Burns & Grove, 2001; Lincoln & Guba, 1985; Munhall, 2001). Credibility is supported by prolonged engagement with participants and was established in this study by employing multiple (3), in-depth interviews over the

course of EFD treatment (Lincoln & Guba, 1985) . Credibility is also maintained through referential adequacy (use of recording devices), triangulation (using multiple data sources or methods to verify or negate information), peer debriefing (2 committee members read all participant transcripts and reviewed coding and interpretation of the data), and member checking (transcript or interpretation approved by participants), all of which were present in this study (Lincoln & Guba, 1985; Miles & Huberman, 1994; Munhall, 2001).

Transferability occurs when the description of an experience enables a reader to understand how that particular experience might fit other contexts or be applicable to other situations (Munhall, 2001). This aspect is thought to be a key aspect of the trustworthiness of qualitative research and is provided by vivid descriptions (Lincoln & Guba, 1985). The goal of the in-depth interviews was to provide a comprehensive understanding and description of the experience of injured adolescents treated with EFDs.

Dependability is supported when the research process includes easily tracked documentation of the decisions made at each step (Lincoln & Guba, 1985). Throughout this study, decisions, procedures and coding choices were documented and tracked through journaling in the NVivo system. This documentation process provided an audit trail that could be followed.

Confirmability is evidenced by explicit, congruent links between interpretations of the data and the study's conclusions, and by the study's meaningful contribution to nursing science (Munhall, 2001). The qualitative descriptive method that was used yielded descriptions of the participants'



experiences with EFDs in their own words and with very little interpretation, allowing confirmability or understanding by the participants, other researchers and the general public (Sandelowski, 2000; Sullivan-Bolyai et al., 2005).

### Summary

The paucity of literature on adolescent trauma, especially those treated with EFDs, clearly warranted the need for this exploratory level research. Qualitative descriptive method seemed the most fitting way to understand the injured adolescent's experience with EFD treatment and pin-care self-management.

## CHAPTER 4

### FINDINGS

#### Overview

In this chapter, the study findings on the experience of adolescents who sustained traumatic injuries and were treated with an external fixation device (EFD) are divided into two sections. First, the demographic characteristics of the participants will be presented. Second, a rich description of the themes and subthemes will be presented with direct quotes to illustrate the findings. Analysis of 26 interviews was framed within Richmond et al.'s (2000) trauma structure of the event, fallout, and moving on (see Figure 7).

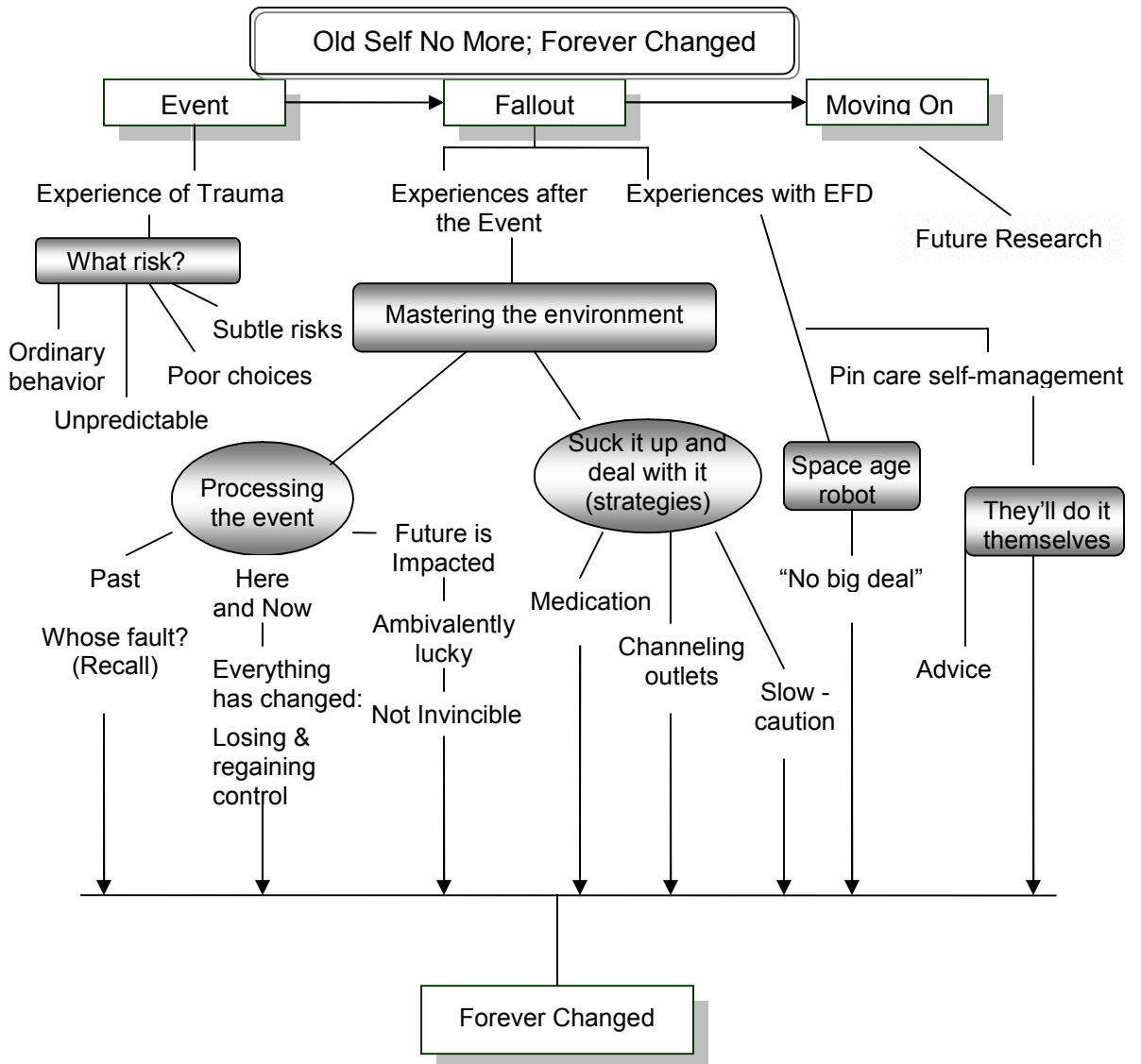
An overarching theme of “old self no more, forever changed” emerged and captured the adolescents’ experience with the event itself, as well as the fallout that occurred after the event. “Moving on” was outside the realm of this study. The experience described by adolescents was one of struggling to get back to their old self. Every time they felt they were close to this goal, they were confronted with evidence that this old self no longer existed and had been forever changed. This central theme incorporated a cluster of 6 major experience themes (shaded in Figure 7): “what risk?” mastering the environment, processing the event, “suck it up and deal with it” (strategies), “space age robot,” and “they will do it themselves,” as well as 12 associated subthemes.

Aim 1 led to descriptions of the circumstances leading to the traumatic injury (the event). A major theme, “what risk?” emerged, in which the adolescents described their behaviors as ordinary, with either unpredictable or

unpreventable outcomes. In a few instances, they described making poor choices (alcohol consumption), but didn't appreciate the risk associated with the behavior at the time of the injury. Social and family-related issues also emerged as subtle risks.

Figure 7

*Adolescent Experience with Traumatic Injury and EFD Treatment*



Aim 2 led to descriptions of the second major theme, mastering the environment, which described how adolescents attempted to master their environment to regain control after the injury and resulting placement of the EFD (the fallout). Two themes emerged: processing the event, and “suck it up and deal with it” as strategies to cope with the fallout. Participants gave rich descriptions of processing the event in 3 dimensions: the past, the here and now, and the future. At first, they tried to make sense of what had happened to them and wanted to know “whose fault is it?” (e.g., assigning blame, determining responsibility), but these experiences were clouded by changes in their ability to recall details. In the here and now, they described feeling that “everything has changed” (physical, emotional, mortality, social, financial, and educational issues) as they were losing and regaining control. Finally, they described their concern about how the event impacted their future (e.g., feelings of invincibility, luck, career changes and view of the disabled).

Whereas the first theme dealt with cognitive processing of the event, the second major theme under mastering the environment was related to actions described by participants to deal with the fallout. “Suck it up and deal with it” represented strategies used over the course of the experience and encompassed physical, social and emotional challenges. In their attempts to “suck it up and deal with it,” participants described strategies such as using medication and channeling outlets (emotional, verbal, physical, social, and spiritual), especially reaching out to peers and using information technology. They planned to use

prevention strategies by slowing down and proceeding with caution. In addition, they described being forever changed in a variety of ways.

Aim 3 focused on descriptions of specific EFD experiences. The adolescents described in great detail looking like a "space age robot" and how they dealt with the EFD over time. They also described peer reactions to the device, strategies used to hide it, how living with it was "no big deal," and other feelings about the EFD.

Aim 4 led to descriptions of the adolescents' learning and participating in the pin-care experience, which was captured in the sixth major theme, "They'll do it themselves." This theme also included their role in and methods used in pin-care self-management. Finally, a brief description of adolescents' advice to others with an EFD is provided. These pearls of wisdom include practical and emotional support not only for the injured but also for healthcare providers.

### Participants

Nine adolescents (5 males, 4 females; 13-20 years old) who met the study criteria agreed to participate and were interviewed between June 2005 and August 2006. Their mean age was 16.4 years, with a distribution shown in Table 6. Two participants, who were 19 and 20 years old, depended on their families for housing and/or financial support. Five others were in high school, and one was in junior high. The majority were Caucasian ( $n=7$ ), 1 black male, and 1 Latino female who identified herself as Puerto Rican. The majority of participants ( $n=6$ ) came from traditional two-parent, middle-class households in suburban and rural neighborhoods. However, at the time of the acute injury a few participants

were experiencing difficult family situations. For example, one had moved with her mother from another state after her parents divorced, another was in foster care, and a third was living with his grandparents after being kicked out of his mother’s home for “flunking out of school.” The average hospital stay was 12 days, with a range from 2 to 20 days, with half of the participants staying over 2 weeks.

Table 6

*Participant Age and Hospital Length of Stay (N=9)*

	N	Minimum	Maximum	Mean	SD
Age (years)	9	13	20	16.4	2.5
LOS	9	2	20	12.4	6.4

LOS: Length of stay

Several participants ( $n=3$ ) were injured in late spring (May and June) and in the fall ( $n=4$ ; October to December). One participant was injured in March and one in August. No traumatic injuries were directly related to weather conditions.

Day and time of injury varied (Table 7). The two injuries related to alcohol consumption occurred late Saturday night, and participants were admitted to the emergency room early Sunday morning. More injuries occurred on Wednesday ( $n=3$ ), and most were evening injuries ( $n=6$ ).

Alcohol consumption, the only drug use reported, was involved in the injuries of 2 participants. Two participants were appropriately wearing helmets either to ride in an all-terrain vehicle (ATV) or to play football when they were injured. One driver wore a seatbelt at the time of the crash, whereas two others did not. Of these, one explained that his seatbelt did not work.

Table 7

*Injury Distribution by Day and Time (N=9)*

Day of Injury	Sun	Mon	Tues	Wed	Thurs	Fri	Sat
AM	1:30 <sup>a</sup> 5:00 <sup>b</sup>			9:00 <sup>c</sup>			
PM		7:30 <sup>d</sup>	6:30 <sup>e</sup>	6:30 <sup>c</sup> 9:00 <sup>f</sup>	9:00 <sup>g</sup> 11:00 <sup>c</sup>		

<sup>a</sup> Gun-shot wound, <sup>b</sup> Jump from 8 feet, <sup>c</sup> Motor vehicle crash, <sup>d</sup> Fall from second story, <sup>e</sup> All-terrain vehicle crash, <sup>f</sup> Football, <sup>g</sup> Trampoline

The only other safety issue that surfaced was that all trampolines post a warning that only one person at a time should jump. This safety recommendation was not followed by one participant who was bouncing on a trampoline at the same time as 3 others.

All adolescent participants were approached while in the hospital and none refused to participate in the study. All were informed of the certificate of confidentiality and the protection it offered. All parents approached for consent agreed to let their adolescent participate in the study.

The family of one participant had signed the consent with the understanding that their adolescent would be interviewed alone, but the father remained in the room on the other side of the curtain during the entire interview. He stated that it was his right as a parent to be present. On subsequent interviews with this same participant, his mother was seated within listening distance in the next room. This parental behavior was acknowledged and respected throughout the interviews.

## Interview Process

The first interview for all participants took place in their hospital room. For most participants ( $n=7$ ), this interview was within the first 4 days of admission. However, 2 patients were medicated and intubated for several days after admission and were not interviewed until they were awake and extubated, on days 6 and 10 of their admission, respectively (see Table 8). All participants spoke freely and seemed have a need to tell their story despite being in obvious pain. In fact, 3 of them were crying from pain while telling their story, but when asked if they wanted to stop the interview, preferred to continue. An interesting finding was that all of the males ( $n=5$ ) kept their rooms quite dark. Overhead lights were not turned on and outside curtains were drawn. When healthcare personal came into the room and turned lights on, the two participants were quick to turn the lights off when the personnel left the room.

Table 8

### *Time of Initial Interview*

Hospital Day	1	2	3	4	6*	10*
Participants ( $n$ )	1	3	0	3	1	1

\*Within 4 days of awareness of EFD

Subsequent interviews were either at the participant's home ( $n=9$ ) or in the orthopedic clinic ( $n=8$ ) per their choice (Table 9). On several occasions, one participant was not at home at the time she had selected, requiring several visits before she could be interviewed. One participant was lost to follow-up for her last interview. Timing of the third interview (one month after EFD removal) was



delayed in the 3 cases because these participants had their EFD removed prior to discharge for the hospital. The timing made it very close to the second interview when they had only been home for 2 weeks.

Table 9

*Participation in Interviews (N=9)*

Interview	n	In hospital	In clinic	At home
1	9	9	0	0
2	9	0	2	7
3	8*	0	6	2
Total	26	9	8	9

\*2 of these interviews lasted less than 20 minutes.

Interviewing the adolescents at times was difficult especially when they used one- or two-word answers. Many probes were used to get them to expand on their ideas. Participants were more verbal in the hospital and for the home interviews and least verbal during clinic or third interviews.

*Factors Impacting Participant Information*

Some important information was gathered that was not part of the aims (i.e., adolescents' experience) but underscored the importance of a family focus in research. While participants were being interviewed, 3 parents offered details about the traumatic injury and issues the family was facing due to the trauma. One parent completed the interview about her daughter's injury because the daughter had sustained a head injury and was not remembering parts of it. A second mother (who listened to the interview) offered that her son had some problems with pain and spasms that he did not talk about during the interview. She also talked about her strong belief in protecting her family (explaining her need to remain near her teen while being interviewed). A father stopped the PI in

the hall shared how he was overwhelmed with his son’s injuries, his wife’s cancer and his own back problem and pain as well as problems at work. This parent information enriched the understanding of the adolescent’s experiences.

### Injuries

Participants sustained traumatic injuries from a variety of circumstances, including being tackled in a football game, a missed bounce on a trampoline, a head-on collision between an ATV and sports utility vehicle (SUV), a gunshot, 3-car crashes, a jump from a second story window, and a fall from 10 feet. Most participants experienced a major trauma involving injury to more than one system (see Table 10). The severity of participants’ injuries is underscored by the high acuity of treatment needed. One participant was intubated at the scene and 3 others were intubated and admitted to the intensive care unit (ICU). The severity of injuries was significant; 8 participants had limb-threatening or life-threatening injuries. Only 1 participant had a single-limb injury (football trauma).

Table 10

*Participant Injuries (N= 9)*

Site/type of Injury	n	Fracture site	Fracture distribution (N=9)		
			Total	Right	Left
Head	2	Femur	4		4
Lung	1	Tibia	2		2
Spleen	3	Ankle	3	3	1
Abdomen	3	Wrist	1	1	1
Intubated/ ICU	4				
Vascular	2	Spine	3	2 (lumbar)	1 (cervical)
Facial lacerations	4	Pelvis	1		
Fractures	9	Nasal facial	2		

For most participants ( $n=8$ ), more than one system was affected. All had fractures ( $N=9$ ) and some sustained injuries to the abdomen ( $n=3$ ), spleen ( $n=3$ ), lungs ( $n=1$ ), head ( $n=2$ ), or facial bones ( $n=2$ ). All participants had scars from lacerations and surgical incisions, some on the trunk ( $n=3$ ) or extremities ( $n=9$ ), and 4 (2 males and 2 females) had scars on their faces.

Most EFDs were located on a lower extremity ( $n=7$ ); of these, 4 were on left femurs and 3 were on ankles. One EFD was placed on a pelvis and another EFD was a halo body jacket fixed to the skull. EFDs were used for fractures of the femur, tibia, pelvis, cervical spine, foot and ankle. Many fractures involved soft tissue injury/loss due to crushing or tearing of the skin, muscle, nerves and vessels surrounding the bone. All participants were initially placed on intravenous (IV) medication for pain. All received typical prophylactic IV antibiotics as part of their surgical course when the EFD was applied. Data were not collected on antibiotic use during hospitalization. When asked, none revealed that they had taken oral antibiotics after discharge.

#### Aim 1 - Circumstances Leading to Traumatic Injury: What Risk?

##### *Overview*

The first aim of this study was to describe the circumstances leading to the traumatic event. Analysis of the interviews about the activity that preceded the traumatic injury revealed the theme, "What risk?" Most participants ( $n=6$ ) saw nothing risky about what they were doing at the time. Some viewed this activity as their ordinary behavior and did not see it as risky. Some participants described being in an unpredictable or unpreventable situation, whereas others

saw that they made poor choices when they participated in behaviors (identified as risky by literature), never thinking that such a traumatic event would ever happen to them.

### *Ordinary Behavior*

Many of the adolescent participants talked about the circumstances leading to the traumatic event as their usual activity or they did not see any particular risk. Those who felt that they were doing nothing risky were involved in activities such as playing football, riding an ATV on a public road, or jumping on a trampoline in the dark.

The young man involved in an ATV crash described the circumstances leading to the event as an ordinary day for him and his buddy. He described living in a boarding town to his friend and that he always drove his ATV on the road to meet his friend.

Basically, me and my friend we go riding almost every day after school. When his mom or my dads aren't with us, we'll go riding. We both have 4 wheelers. So we go riding off on the 4 wheelers and we ride up to the pits.

In recounting the event, this participant also talked about going very fast on the road and "being in fourth gear" as if these activities were very common for him. Another participant not only thought he was not doing anything risky when the event occurred, he explained about the times he did risky or "crazy" things.

Usually all the neighborhood kids [go] jumpin' around on the trampoline. It was me and two of my buddies, and we weren't even doing anything crazy. We were just jumping around, and one time when I went down, I just landed wrong and bent it [his leg] up. ...

To emphasize how little risk he felt, he volunteered other behaviors that were more risky.

It's such a freak accident. I mean, I have a dirt bike at my house, I have a four wheeler, I bike, I skateboard. Me and my friends, we actually take old bike parts and tape them up and jump on the trampoline with the bikes, with the skateboard, with the scooters. We actually tape them all up so they won't rip it [the trampoline], and we... you know what I mean. We're crazy like that, we're crazy like that, but that one night we were just jumping around and it was just a weird bounce I had and I fell and my body was above myself.

*Event was Unpredictable or Unpreventable*

Of the 3 participants involved in a motor vehicle crash, most did not feel they had any control over the circumstances. For example, a 19 year-old had done heavy labor for 8 hours, went shopping for several hours, had dinner with his mother, dropped her off, and was driving several miles back to his grandparents' house (where he was presently living). He was involved in a car crash and denied any risk taking. He said, "I am gonna say I was tired."

One participant involved in a motor vehicle crash could recall minute details of the circumstances leading to the crash, which she felt was unpredictable and unavoidable.

We were drivin' down [the highway] ... there was a green Explorer in front of me. We were all doin' the speed limit, 60-65. All of a sudden the green Explorer swerved into the median um and took a left around whatever object was in the road. He turned, all of a sudden there was a big tractor trailer tire in the middle of the road. There was nothing I could do to avoid it [a tire in the road]. It was blocking the lane, so I took a left to try and avoid the tire, hit my brakes. My car was a sports car with low profile tires, so it kinda just took off on the grass, like a skating rink. We hit the rocks, flew up in the air, um 20 ft, rolled over.

The third participant was skipping school with her girlfriends. They were pulling out of a convenience store parking lot one morning, when she described being hit by a speeding car carrier/ tractor trailer with faulty brakes. Details were

sketchy as she lost consciousness, and most reports of the incident were her father's version. The accident was in front of his office.

### *Poor Choices/ Influence of Alcohol*

The circumstances leading to some other injuries were related to making poor choices with two related to alcohol consumption (a known injury risk factor). Even so, these participants did not think they were at risk for injury at the time. For example, a 17 year-old described his choice to return to a place where the night before he had experienced discomfort because people were drinking and shooting guns inside a house. He related how he incurred a gunshot wound to his foot:

I had an accident with my friend. We were out drinking, you know, and he accidentally shot me with a shotgun, a 12 gauge. Yeah, it was at night. Well, I have this thing with guns. I don't like guns unless there is a responsible person around. Last Friday we were out drinking and this guy pulled a gun out where we were hanging out at, and I don't like guns 'cause everybody there was drunk. So like I did my best to avoid [the situation], staying out of the room and everything like that ... they were like blasting holes in the wall and everything like that ... I didn't like it at all and I wanted to leave the whole night. Luckily nothing happened that night. ... And then the next night, right, we got a call from the guys' house that we were at, his fiancée called us asking us to go down there again and like I didn't want to go down at all, and she said, she was like just tell him (me) there's no shotgun shells, my fiancé has already passed out, he's already passed out drunk, stuff like that. And like all that was true. But I'm like, whatever, I'll go down there and hang out. So I went down there and hung out, I mean the fiancé was passed out. There were no shotgun shells. The shotgun wasn't around. ... We started, we were drinking and a couple hours [later], the fiancé wakes up and they get into a discussion about how they were shooting the shotgun off the night before and then the fiancé was like oh I have shotgun shells hidden. So I'm like, oh well, whatever, so I just went out and ended up falling asleep in the back of my buddy's car, in the back seat of my buddy's car and next thing you know I wake up to a burning pain in my ankle, being shot by a shotgun.

Others freely admitted they had made poor choices after the fact, but still did not think anything would happen to them. One participant described drinking too much and having a habit of thrill-seeking behaviors.

I actually climbed up on top of that tractor-trailer storage box and I don't know how tall that is, a little over, maybe around 10 feet or somethin'. And there was a bus..., parked right where that van is right there, but a little bit closer. And I had a few too many to drink and I went to, I climbed up there and went to jump to the top of the bus and I made it to the top of the bus. And then I tried to jump back from the top of the bus and because it was raining outside and I was barefoot, I slipped out, my feet flew out from underneath me, and I obviously didn't make it to the storage container and I fell on my back and um, I didn't know I broke my neck or anything.

Some did not see the risks for injury because they were focused on something else. An example of a poor choice not related to alcohol consumption was a 14 year-old who jumped from a second story window to run away from the foster home where she had been placed. She did not appreciate the height from which she was jumping because she just wanted to return to her mom's house. She did not expect to get hurt.

### *Subtle Risks*

In only two cases, participants clearly were participating in known high-risk activities such as dealing with alcohol and guns. Participants described stressors from family-related and social issues. The interviews revealed that many participants had recent stressors in their family unit. In addition to the obvious stress of being placed in foster care, other situations were less obviously stressful. One young man was facing his step-mother's cancer diagnosis, his father's back injury, and having no contact with his biological mother. One young woman had to face her parents relocating to a new home outside her school district. She had been very involved in a competitive sport with her friends at

school. A 20-year-old had recently moved from another state after her parents divorced due to her father's alcoholism. A participant who was living with his grandparents had been thrown out of his parents' home for poor grades and for dropping out of school.

### *Summary*

Risk taking was central to the majority of traumatic events, even though most participants did not see their behavior as risky. Most at first thought of themselves as participating in ordinary activity that they had done many times before and had not been injured. Others found themselves in what they believed to be unpredictable or unpreventable circumstances. Those who had consumed alcohol and admitted making poor choices after the fact did not think they were at risk at the time they were hurt.

### Aim 2 - Day-to-Day Experience Following Traumatic Injury: Mastering the Environment

#### *Overview*

The second aim of this study, to describe the day-to-day experiences of adolescents following acute traumatic injury, led to identification of the second major theme, mastering the environment. The findings of this theme will be divided according to experiences dealing with the trauma and with the injuries. Mastering the environment captured the participants' reactions to their perceived loss of control because everything had changed; they struggled to regain control in any way possible. As mentioned in the overview, mastering the environment



revealed two distinct but interactive themes, processing the event and “suck it up and deal with it,” strategies to deal with the fallout.

Processing the event was described in 3 aspects: the past, the here and now, and the future. First, participants tried to recall the event and make sense of what had happened to them by exploring “*whose fault is it?*” (subtheme 1). Second, participants dealt in the here and now with immediate concerns and tried to regain control because “*everything has changed*” (subtheme 2). Third, they processed how the event and its fallout would more permanently impact their future. The theme “*ambivalently lucky*” (subtheme 3) reflects the participants’ juxtaposition of the dreadful aspects of the trauma with how lucky they were to be alive and not paralyzed; things could have been worse. The powerful realization that developed while they were waiting to heal was that they were “*not invincible*” (subtheme 4). The impact of this realization seemed to outweigh all the other subthemes.

The fourth major theme revealed was “suck it up and deal with it” as strategies to deal with the fallout. This section will present adolescents’ descriptions of methods used to deal with physical, social, and emotional changes resulting from the traumatic injuries. These descriptions are captured in strategies to regain control with *medication* (subtheme 5), *channeling outlets* for frustration (subtheme 6), and *slow - caution* (subtheme 7) for prevention. These descriptions changed over time in 3 ways: amount of detail offered, use of pain medication, and perception of their own accountability.

Participants used various methods to cope. From their descriptions of coping and waiting to heal, the major theme “suck it up and deal with it” best captured the strategies used during the fallout phase of recovery. This theme also reflected participants’ strategies for mastering the environment (major theme) and their gradual realization they were forever changed (overarching theme). The following pages provide a rich description of the 7 subthemes revealing adolescents’ experiences following a traumatic injury.

### *Mastering the Environment: Processing the Event*

Over time, the participants seemed to process the circumstances of the traumatic event in 3 dimensions: past (“*whose fault is it?*”), here and now (“*everything has changed*”), and future (“*ambivalently lucky*” and “*not invincible*”). At the beginning of the process, participants were able to tell the details of everything that happened during the event. When it came to finding fault, a majority of them initially either transferred the blame to something external or minimized their involvement and their responsibility for the injury. These two characteristics, details and responsibility, changed over the course of the 3 interviews spanning several months. Participants talked about having time to think things over and wishing they had more distractions. They did not like having the time to think about “it” (the traumatic event). Two weeks after they had been home, most could recall few, if any, details of the event. The younger participants gradually seemed to take on more accountability for their actions or their role in their injury. Through this process, they struggled to get back to their “old self,” only to realize it was gone and had been forever changed. They had to change

their mind-set of who they now were, with a newly injured body that was now vulnerable to re-injury. For most of them, this process involved facing the loss of their perceived invincibility.

### *Recall of Details*

During the first interview in the hospital, a majority of participants could relate every detail of the event. A few participants gave graphic descriptions of their fear and physical pain. While recounting the event, most of them did not move at all in their beds. Of the 9 participants, 6 used their patient-controlled analgesia (PCA) machines while describing their experiences. The 3 without PCA pressed their nurse call light to ask for more medication during the interview. Most pressed their PCA for more medication when they were describing the point at which they realized they had a significant injury; for example, when “I told my mother I think I broke my leg,” or “I woke up to searing pain in my foot and realized I was shot,” or “I felt the helmet hit my leg.” One participant pressed the PCA as she recounted the injury:

Well, I was scared. I was real scared at first when I had fallen. I was scared for my life. Like all right, when I got here I thought I couldn't walk, ya know what I mean. So like at first I couldn't feel my other leg [presses PCA]. So then I started moving it and got the hang of it. I was just scared. I'm scared now that I can't even walk, ya know. But they told me I can go back to walking hopefully soon and I gotta wait until I recover. Wow. The pain made me think like I was just like gonna die. Like I couldn't handle it. The way I was breathing wasn't good [gasping], like if I was an asthmatic and everything. Like it was crazy; the feeling was real crazy.

When the researcher noticed so many participants using the morphine PCA while telling the painful parts of their story, she asked one participant why he thought this happened. He said,

Um, depending, depending on the dose that it gives you, oh yeah. You know what I mean, like the first morphine shot I got, it was like a punch in the face, it was like whoa, it really calms you down. It makes you less worried and less, I mean, paranoid about what is going on. So I think it does help, especially when it's [the event is] fresh, 'cause you're so, like, oh my god.

An example of a detailed account, with colors, sounds and sensations, is shown by a participant's description immediately after the car crash.

We hit the rocks, flew up in the air, um 20 ft, rolled over and crashed onto the rocks in the median. Um, after we crashed I heard my sister screaming, she kicked the door open and she proceeded to get out of the car and walk around. I heard a lady run up to me on the other side of the road and she said she was dialing 911. She had blonde hair; um I heard my friend T in the back screaming about her lungs and her legs and how she couldn't move and how she just wanted to get out. I was in the front; um I saw a whole bunch of people running towards me. I couldn't breathe. I thought my lungs had collapsed. Um, there was severe pain in my left abdominal area and I felt burning in my feet. My feet went through the back panel near the floor, behind the pedals, the gas pedal and the brake pedal. [presses PCA] They were burning, so I pulled them out, and I looked at them and there was no skin on the bottom of my feet. It was all open. Um, a volunteer EMT ran up my car; he held my head in place for a while until the ambulance and the EMTs got there. The state police were already on their way, because somebody had previously called them about the tire in the road so they weren't that far down the road. Um, it took them about a half an hour to get us out of the car. Um, they needed the Jaws of Life to get us out. And there was just a whole bunch of screaming and excruciating pain. I was thinking about what it's like at the hospital, my friend T was taken by ambulance, six minutes they were there 'cause she couldn't wait for Life Flight to get there. She had severe internal injuries. And then they took me into the ER. That's all I remember.

At the second interview (either in their home or the clinic), several participants denied knowledge of the event details that they had previously related. For example, the participant whose response is described above gave a different account in the second interview:

And then I kinda blanked out for a while. Then, when I came to they were getting me out of the car. [Someone] mentioned something about Life

Flight, wheeled me in um then I just... then I was just screamin' for them to put me out. 'Cause I couldn't deal with the pain. And the next thing I knew, when I woke up I guess it was in the ER room, I don't really remember. Saw the lights and there was a nurse over me and she told me to hold on for a second and I just felt the doctor pull my ankles down and heard a pop and then I was out. I woke up two days later and I had a tube in my throat and a drain. I thought my feet were gone. But then I woke up and saw the external fixators on 'em. Kinda scary. After that it was a lot of surgery, a lot of pain, from what I remember

One participant who had previously given rich details about the events preceding his gunshot wound (see page 70) said, "I don't really remember anything that night because I was in shock. It's just a blank." When asked the first thing he remembered, he replied, "Pain and waking up at the hospital Sunday at 6 o'clock at night." Similarly, another participant who had described in great detail an ATV ride with twists and turns in the road, hitting an SUV, going over the handle bars, and the rescue said, "I don't actually remember much about it. All I remember is the aftermath." Even after being prompted with previously disclosed details, the participants could not remember.

*"Whose Fault is It?"*

When asked about risk taking, most participants denied such behavior during the initial interview. Younger adolescents placed blame for their injuries on external factors. For example, the participant who was riding his ATV down the middle of the road when he collided head-on with a SUV blamed the town for making the roads too narrow. External blame for injuries was described as "a freak accident," "big guy on the other [football] team," "slipped on the thin window edge trying to get back in the house," and a "truck with bad brakes." One participant returned to party and drink at a house where "drunks had been

playing with guns” the day before. He went outside to sleep in the back of his friend’s car, where he was shot. At first, he did not blame his drunken friend who shot him.

Um, yeah most of my friends are all good people. The kid who shot me was my best friend, my best friend in the world. I mean it was a total accident; he had no idea I was sleeping in the back of his car.

When the researcher expressed disbelief, he continued,

Yeah. So like I don’t blame it on him or anything; I blame it more on the guy that owned that gun because he was being irresponsible and letting like... ‘cause he was like 35 years old and he was letting teenagers use the gun while he was drunk and passed out.

The blame or responsibility of the younger adolescents changed over the course of recovering from injuries. This shift was most apparent in interviews with the 14 year-old participant who first blamed the town for not making the roads wide enough. In the second interview, he started questioning his behavior.

I look at myself and I’m like, why did I do that? Why? And then I’m mad at myself because now I can’t walk and then like, I’m also like sad ‘cause I can’t walk. But then like... Can’t move my wrists, I can’t grab anything very small. I can’t write, I get bored all the time. So, ... I’m kinda mad at myself a lot though.

By the third interview, he and the younger participants took responsibility for their actions. During his final interview, this participant said, “I feel angry at myself for getting into this accident. ...I learned a lot of lessons. ... Yeah, like life never goes your way. And it doesn’t revolve around you.” When asked if he had many frustrations and problems, he continued, “No, it’s just that I probably could’ve prevented it.” Others took responsibility indirectly by saying, “I won’t be throwing myself” out the window again.

The older (19 to 20 year-old) adolescents described their behavior or actions as either causing the injury or contributing to it. Although all participants involved in motor vehicle crashes (MVC) denied speeding or reckless driving, one indirectly described taking responsibility when he said jokingly that he would now “keep his eyes open” and not fall asleep. Older participants described taking partial or full responsibility early on.

For instance, the 19 year-old woman who tried to jump across some storage bins took some responsibility for her actions and blamed “being intoxicated” and “doing something stupid” when she fell 10 feet and broke her neck. Two participants involved in multi-victim MVCs shared their feelings of guilt for being responsible for the injuries of others. A 20 year-old woman involved in a car crash said,

Every day it plays in my mind what I coulda done different. Um, why it happened to us. It's like, why did I even decide to go on [a highway] that day? It always plays in mind, my mind - what hurts the most. Why I couldn't like take away the pain for everybody and it's hard 'cause I was the driver of the car. Everything that could have gone different, wouldn't have hurt us or but everybody explains to me that it was just something that happened and I did my best to keep everybody safe. Ya know I wasn't speeding or anything and ... If was speeding, then [the car] coulda flipped over to the other side of the highway and gone into the other lane of traffic and we would not even be here. It's been hard.

By the final interview, the 19-year-old who believed that his motor vehicle collision was due to his falling asleep at the wheel said,

Uh, it is my fault. 'Cause I coulda just ... like it would have all been avoided if I'd stayed at my mom's house and just slept over her house and I had work the next day anyway.

## *Summary*

Over the course of the interviews, some form of cognitive processing occurred and affected participants' recollection of the event and their assessment of responsibility. The ability of most participants to relate specific details of the event changed drastically from the first interview in the hospital to the second interview. After being home for 2 weeks, most participants could not recall details they had previously related, saying they had been in shock or that their first memory of the event was waking in the hospital. Many used patient-controlled analgesia while telling the painful aspects of their injury. Blame for the traumatic event changed over time from external to internal, with most participants eventually assuming personal responsibility.

### *Processing the Event: Here and Now*

#### *Everything has Changed: Losing and Regaining Control*

The participants faced many temporary daily changes while in the hospital and when they transitioned to home. This experience was captured by the subtheme "*everything has changed; losing and regaining control.*" The changes brought about by the traumatic event affected participants both physically and emotionally. Physically, participants described an immediate loss of control and changes in activities of daily living such as mobility, sleep, comfort, and nutrition. They also described the changes and importance of relationships with peers and family. Emotionally, the participants needed to deal with pain, fear, physical changes and limitations, boredom, legal issues and loss of their old self. Through



the process of dealing with all the changes related to the traumatic event, adolescents found they were changed.

The first 5 participants interviewed were young men. In describing their injuries, they tended to use hospital jargon. At first, they seemed to be trying to be “cool” or “tough,” but this behavior later appeared as their response to a loss of control and trying to master a new environment. The environment was frightening and many felt an enormous loss of control. Some woke up “all alone,” “in pain,” “scared,” “tied down,” and “full of tubes.” One participant described the fear related to a loss of control. This participant had vascular repair surgery, recovered in an adult ICU, and made some astute observations about his experience:

... I woke up; it was the first time I woke up after surgery. I forget what time it was, it was dark. I remember waking up, at that point I did have 6 IVs in me, 4 in one arm and 2 in the other, and it was the first time I saw the bars [of the EFD]. No nurses were in my room. I was alone. It was all dark, except for the hallway light. ... I wanna say it was more frightening because I really didn't know what happened, so maybe because I didn't know what was going on and I had no control over it; maybe that was it. ... I was just wanted to get out of that situation. I just wanted to get out of it. I was away from everybody. The nurse was probably at the front desk. The clock was going so slow. That night was probably the longest night. It was because I was drowsy, too, from the anesthesia. It was dark and gloomy and just a crappy situation. That was really the bad part.

One participant described being a little confused when he first woke up in the hospital, but felt an instinct to act to get control of his body back.

Ah, when I woke up, I had, like I was full of tubes all over the place and there was a tube down my mouth, which I guess was helpin' me breathe when I was in the coma. But it was choking me when I woke up. And the only thing I could think about was getting it out, but none of the doctors would help me 'cause I was strapped down to the bed so I kind of scooted all the way to my hand and pulled it out myself. Which they didn't seem to

like. "You're not supposed to do that!" It was choking me; if you're not pulling it out, I'm gonna.

He also described other strategies he used to regain control over issues related to his restraints.

And afterward they didn't want to let my arm restraints go because they said I was gonna pull everything out, but I made a little bargain with one of the Asian doctors here, I'm not sure what his name was, like I told him, "I promise I won't pull nothin', I promise." So he was the guy that let my arms go, and I had a scratchin' frenzy. It felt pretty good.

Many participants indirectly indicated a loss of control over their environment by describing their rooming situation as places with "crying babies," "loud fathers," "annoying visitors," or having a "complete stranger" for a roommate and knowing the roommate had a "bad" illness. One participant felt a sense of control when she learned from her roommate about her medical device, a wound vacuum assistive closure (VAC) device. The participant was also comforted by knowing that others had been through a similar situation.

Many participants also felt a sense of control when they understood the hospital routine and care plan and could use the same language as their healthcare personnel. These participants explained how the hospital system, nurses or machines worked and were proud to share their new knowledge. They used terminology such as IVs, "TPN, that's protein," "crit is your blood count," "NG tubes," and "PCA with a 6-minute lock out." They also talked about timing and nursing shifts.

The participants also took control when given the opportunity by keeping their room dark and having some of their own belongings around. Many wore their own clothing, had their cell phone with them, had parents bring in food from

home, and asked for an internet connection. They wanted to get back to their normal selves. One participant was upset that she couldn't put her belly ring back in. Most felt more control or more comfortable with the environment when their family was present. This point was illustrated best by an observation made by a 15 year-old who spent time in an adult ICU.

When I got to my final room [on the pediatric floor] there was, I had a window seat, ya know what I mean, it was much bigger and ah um, ya know, there were less machines around and there was more, there was more like family present, too. It was made for people to come and see you. My room downstairs [ICU] ya know, it didn't have any chairs in it or anything so, it's not like anybody could stay the night.

Most participants were visited by family or friends, some of whom stayed in their rooms for long periods. All participants on the pediatric floor had someone sleep in their rooms with them at night. In many cases participants had gained a sense of mastering the immediate environment, and then were able to reflect on other aspects of their lives that had changed for them.

### *Mobility/Independence*

The biggest struggle discussed by participants both in the hospital and at home was not being able to do things for themselves. Every participant talked about being frustrated by having to depend on other people for very basic needs such as pain medication, eating, drinking, toileting, showering and dressing. Two participants commented that their friends thought it must be good to have everybody wait on you hand and foot. Most did not like being waited on, particularly having to wait for help. They were not as concerned about people getting them food, but they hated to "bother" them. One adolescent said that his

mother “works so hard and I know she needs her time without me interrupting her.”

Participants talked about why they had to submit to being dependent on someone because they were “too weak,” “could not use my arms,” or “stuck in a wheelchair.” They also struggled with having their mothers and occasionally fathers help them shower or dress. Some thought that being dependent on others was the worst part of the injury, especially since they perceived themselves as being totally independent before the injury. For example, one participant had both arms broken and in heavy splints, one leg was elevated on pillows, and an EFD protruded from the side of his left femur. When asked about the hardest part of being in the hospital, he said,

... Not being able to do much. ‘Cause I can’t eat or drink. And that’s really what I really want to do. ‘Cause, you know, you want to have something to drink or eat, or that kind of stuff. It’s just really hard. ‘Cause I can’t eat. I haven’t eaten for seven days. ... I don’t know...Not being able to use your arms, not being able to use your legs. Having to have other people do stuff for you. Not that it’s bad or anything. Well, I kinda expect them to help me out because you look at me; I’m incapable of doing it myself. For me ... I would do it for them.

Similarly, another adolescent described his frustration at depending on others for basic needs and his desire to be independent again. He described an incident in which he used all his ingenuity and patience to take care of himself:

I like the people that are taking care of me, but at the same time, I don’t really like being waited on. ...Although this thing [nurse call button] is away 90% of the time but instead of like calling them down [to ask], “Oh, can you get this out of there? Can you get that out of there?” I must’ve spent 40 minutes moving that chair off of there [bedside unit], I ... like gripped it ... by the little corner. That chair is pretty heavy, too, for not being able to get up and move it. I finally got that chair off, and I opened up the top drawer and stuck my finger in there and was able to pull it ‘cause it’s on wheels. So I could get it next to me so I could get the stuff myself. ‘Cause I don’t... it’s like, I dunno, it does take them like a couple

minutes to get over here. When you press the button and stuff and it's just like, you gotta wait. So I can't walk or nothin' and it's like if this thing got to the point where I can't reach it, it sucks. Like if I wanted like my Playstation and it was over where that chair is, I can't get it myself but I can see it. And it's just, oh man. 'Cause ya know, I can't get up and go over there. I'd rather be able to do that rather than sit here and call on them for the littlest things.

Another participant described gaining a sense of independence from using the PCA rather than waiting for a nurse to bring pain medication:

But um, it [the PCA] did help a lot. 'Cause at least it was there when you needed it. And you didn't have to have a nurse come in and give you a shot every five seconds. So that gave me a little sense of independence.

Executing some of the basic care was difficult and embarrassing for the adolescents, especially with toileting. They had difficulty dealing with being exposed in a public place. Bedpan use was extremely embarrassing for these adolescents, as well as having to ask people to leave the room instead of going into a bathroom. For example one participant said,

Well because, the first time was in a bed pan, which I don't ever, ever want to do again. In the hospital, it was right next to window. Even though the curtains were shut it was weird, ya know. Somebody being 12 feet away from me, nurses coming in, telling them not yet, then I have to bug them when I'm done.

Many participants commented with pride when they had been able to get to the commode or bathroom by themselves.

Another aspect of independence discussed by several participants was not being able to go out or get up whenever they wanted. This issue was expressed by all but the youngest participant whose 3 brothers kept him company at home and who was allowed to return to school early with his EFD. For some participants, it was especially difficult knowing that their friends were out and they could not "hang out" with them. Having visitors helped, but the most

difficult and “boring” days were when people were at school or work. For example, one participant said,

It obviously is different. Usually like, usually every weekend, somebody’s having a party, somebody’s having people over. So I can’t go there. So I really don’t see them on the weekends because they’re out with the crowd. So I’m really stuck home, but that really doesn’t bother me. But, we just, all we can really do is play video games. I was out here [in the living room] last night playing cards by some of my buddies. Ya know, just talking, hanging out, listening to music.

### *Disturbed Sleep*

All the participants expressed that their day-to-day sleep experiences were radically changed due to the event, injuries or treatment. Most commented about roommates, noise, hospital routines and pain interrupting their sleep in the hospital. Most participants talked about sleep problems due to wearing the EFD, the injuries themselves, or changing their usual sleeping position. Some talked about having pain when they turned in bed or needing to ask for help to get into a comfortable position. Pain medication was helpful. Several adolescents said they were used to sleeping in a prone position and they had difficulty adjusting to sleeping on their back. These participants described their sleep problems as resolving when they got used to their EFD, healed a little from their injuries, or had the EFD removed. Sleeping was especially problematic for one participant with a halo EFD for a cervical spine fracture. When asked if she was getting sleep, she replied,

Oh my God no. It’s like so painful. It’s like they’re two pegs in the front, and one in my left side in the back, and one in right, and the only one that really hurts is the right one. And like to try, I’m not really supposed to sleep on my side, but I’ve been trying to sleep on my side, and it’s really hard with this bar on the side of my face. But I really don’t get any sleep at all. I think the most sleep that I’ve gotten in one period of time, is an hour today, and that was while my mother was here. From 12 to 1 and

that's ... the doctor actually put the sign up on the outside of my thing [room door] saying just to let me sleep. Like last night all I was able to do was to sleep for 12 or 20 minutes at a time.

Two participants, in particular, talked about sleep disturbances related to emotional issues such as depression and nightmares. One participant experienced a positive change in sleep patterns:

My sleepin', yeah. I can sleep when I want to now. Like before I wasn't able to, like I would stay awake because of my depression and just many thoughts going through my mind. And like I said, now I let things slip so I don't let that bother me at all

The other participant had a more negative experience, as shown by his response to a question about his sleep experience:

Nightmares – yeah. I have nightmares every night of my best friend standing over me with a shotgun. The reason I'm having so many nightmares, I think, is that it [the shooting] happened while I was sleeping in the back of my friend's car. When I'm sleeping and I wake up with pains in my ankle, I'm thinking it happened again, like I don't even know. I wake up screaming and it hurts so bad.

### *Pain*

The participants shared their experiences with pain at the site of the traumatic event, in the hospital and at home. In the hospital, patients tended to discuss pain from injuries suffered in the trauma, procedures needed to treat the injuries, or occasionally emotional pain from the trauma. Several described the most intense pain when they were being transferred to the hospital or in the emergency room. For example, one young lady described her pain on the way to the hospital as “scary.”

I felt like dying in a way. I couldn't handle the pain; it was too much, too much. I was like, “Just cut my leg off; I don't even wanna suffer this pain.” Um, like when I first got here, I was like crying so the doctor's not even touching my leg. 'Cause I was in pain. Um, and they were like giving me

the medication, like the morphine and like I was in so much pain, like it wasn't working for me. After I was all swearin' 'cause I was like in real pain. And now it's like numb. I have a little pain, but it's still numb. I can move it though.

Some participants described experiencing pain as they were moved to an x-ray table or stretcher before their broken bones were immobilized. For example, one participant said, "It didn't hurt 'til they picked me up and moved me to the table." Another said, "They left my leg on the first bed as they whipped me over to the other one, and that hurt my leg so bad. 'Cause my kneecap couldn't really bend at the time." Some participants talked about the pain of treatments for their injuries, such as the application of a halo. Most described not liking the "shots for blood thinners," "flushing IVs," or "needles for blood draws."

Two participants did not separate emotional and physical pain. One hinted that the emotional pain was being treated with analgesic medication. "I don't remember much of my hospital stay because, like getting shot is not a joke; it hurt so bad. All's you want to do is be drugged up so much you can't remember any of it." Similarly, another participant described her pain experience the day after a halo was applied for her cervical spine fracture:

... they were twisting them, the pegs, in and I have 4 of them in my head right now. And they told me it would feel like a really, really bad headache, and it feels probably like about... you ever had a really, really bad migraine, just double that by probably about a hundred. It [the pain] just keeps going up. It's like the worse thing I've ever felt in my life, and today they said they were just going to tighten the pieces on the front of it [the halo], and they actually ended up tightening them [the pins]. ...and it's like bad, I had no pain..., like no pain killers in my system or anything like that, and I could feel my skull cracking some more. They were puttin' the bolts in or something. ...so I felt everything. I was terrified when they did it. Um, ...knowing that I would have scarring afterwards and everything.



The pain was still very memorable to many participants at the second interview, 2 weeks after they had returned home. One adolescent most vividly remembered the pain from her nearly 3-week stay in the hospital, as described below.

All I can remember is the pain and that's it. Um, there was a lot of agony, I know that. Um I think the worst thing was the back. Because from what I understood, like there were VAC dressings... it [the VAC dressing] was there to help hold up my stomach, but as it was closing up, my stomach like it grew with it, so like whenever they ripped it out [changed the dressing] or whatever, oh God that was so painful. They had to give me so many meds just to change it.

The experience of intense pain from injuries was a new experience for the participants. Traumatic injury pain at the scene was the most frightening, especially when participants moved or were moved. Throughout their hospitalization, participants encountered painful treatments, and medication was seen as very helpful. Description of pain frequently had emotional and physical components.

### *Nutrition*

Besides experiencing pain and changes in sleep patterns, many participants had to face changes in their eating habits in the hospital, mostly due to their injuries and surgical procedures. Four participants were not allowed to eat because of abdominal injuries that required nasogastric tubes (NG), which were attached to a wall-mounted suction device that continually removed liquid contents from the stomach. While their abdomens were healing, these participants received total parenteral nutrition (TPN) and IV hydration. Others were prevented from eating for other reasons, for example, being on bed rest with a cervical collar, having a wired jaw, vomiting from pain medication and

anesthesia, and not being allowed to eat prior to surgery. Some participants stated that they did not get as hungry or eat as much as usual. All seemed to return to their normal appetite and weight when food restrictions were lifted.

### *Relationships*

*Family relationships.* Some participants described changes in family relationships. Most commented that their parents did not care what they looked like, as long as they were alive and OK. Family roles changed, too. While participants were in the hospital their parents did not go to work, but stayed with their children. Some parents alternated visits with the other parent. Several participants mentioned that because of their lack of mobility they would “hang out with their parents more” and that they were “more open with their parents now.” Some did not like to see their parents upset and felt responsible. One participant said, “I really didn’t like seeing them [family members] crying. Kinda hurt me, like damn, it’s my fault they’re crying.” Many participants felt that family relationships had been strengthened by the event, as shown by the following comments:

I think this injury kinda brought the whole family together. It was such a freak accident, everybody has to stop and focus on this. So it’s almost as if during the injury, it brought the family closer for that moment. Um I think having them here makes me feel better, you know what I mean. I can’t go to them, so they’re gonna come to me when I’m in a time of need. It kinda put me in a better mood. Making you feel better. My brother will come by and we’ll play video games and that makes it so much more better. And we’ll talk, ya know, about what’s been going on, what’s up. So it’s just good to hear what other people are doing.

On the other hand, some participants thought the improvement in family relationships was short lived. For example, another participant said,

Um, well things are almost back to normal now, but like for a really long time our family was so much more close and we’d... they’d like do

anything for me. It was so nice like, like hey [sister], wanna get me a glass of water, and she'd just run and do it. Before she was like, get up and get it yourself – shut up. Like, I don't care. It kinda brought the family together. Kind of a hard way to do it, but... I couldn't do it for myself. They were like, oh God, they started caring and being helpful. My Dad is kinda mean now that I am home, but my mom is still the same.

The event also put stress on families, as shown by one participant's recognition that her mother was not only emotionally stressed but also financially stressed.

She's stressed. She's stressed, but she deals with it. She has to take time off work to come take me to the doctor's and she is a single working mother and doesn't get any child support, and she has to pay bills, and she is kinda like on the low end on the income [scale], and everything so she gets really stressed out and stuff and that bothers me.

One participant described having a better ability to deal with her mother and being more open with her. She said, "We socialize about everything, and I mean everything."

*Peer relationships.* Many participants talked about the changes in relationships with their friends. Friends' visits and socialization at and after school were limited for the injured participants. Many tried to keep communication lines open with their friends with cell phones and e-mail. Many had friends visit after school at their homes. Some friends were described as supportive, e.g., "there for me," or "better than I thought possible." However, others who had been part of the participant's support system or "best friends" were unable to provide the usual support because of their part in the traumatic event. One friend had been put under arrest and the other had been sent to another medical facility for severe injuries sustained in the same event.

In a few instances, participants lost old friends due to the circumstances of the injury. For example, one participant related that the other girls involved in the accident stopped communicating with her.

My friends really spoiled me the whole time. They were always coming to the hospital to visit me and even when I got home, there were always people around. Actually, the girls I got in the accident with, we're not really that close anymore. And I don't really know what that's all about because we used to be best friends, but things change. 'Cause I was like not around for a while so, I kinda figured they have a life.

Friendships were also changed on purpose, as in the case of the young man who decided that drinking was not a healthy behavior. He said that he "doesn't hang with them [friends who drink] anymore." He was discouraged that his brush with mortality had no effect on his old friends and had drifted away from hanging out with them.

I was drinking a lot, and it takes something like this to happen to realize that it was wrong, you shouldn't be doing that. And like I'm laying here and all my friends are still out there partying. All I want to do is get out of here and let them know that it's not all right to do that [crying]. I have not had alcohol since that day.

### *Life after Hospitalization*

The traumatic injury interrupted school or work for all participants. All of the school-age adolescents ( $n=7$ ) were supposed to have tutors arranged when they were discharged from the hospital, but even after they had been home at least 2 weeks, no tutor had appeared. At least another 2 weeks passed before tutoring began. One injured adolescent had work brought home from school by his brothers, an arrangement made by the participant's mother. This participant was the first to return to school with his EFD still in place. When he returned to school, he did well. Although some classmates stared at him, most gave him

positive attention by helping to carry his books and pushing his wheelchair from class to class.

Six participants described their daily life at home as boring and had difficulty getting around or out of the house. (Table 11). Most did not feel they had the capacity to study and described a typical day as getting up, having something to eat, and spending most of the day on the couch or chair, watching TV, playing video games, or surfing the internet. In the first few days of being home, many participants were in pain and had to take pain medications. For the first couple of weeks at home, most slept more than usual. All eventually had home tutors for several weeks. Most talked about the boredom and frustration of waiting for their friends and family to return from school or work.

Table 11

*Reported Changes Due to Traumatic Injury*

Change	Participants (n)
Everything	9
Stuck in the house	9
Unable to attend school/work	
Worry about limitations due to injury or re-injury	9
No car to get around	4
Changes in career choices due to injuries	5
Healthcare career aspiration	5
Body image	9
Appreciation for disabled	7

One participant who had sustained a significant head injury with cranial nerve damage spent much of her time going to various medical and surgical specialists. Because of this trauma, her ability to compute numbers and facts

was impaired for a long time. She was tutored enough to pass the requirements to graduate, but her grades were too low for her to apply to the Ivy League colleges that were her pre-injury choices.

### *Legal and Financial Repercussions*

A few participants ( $n=4$ ) had to deal with the legal implications of the events leading to their injuries, and several ( $n=5$ ) with financial stressors. The participant who had been injured by gunshot expressed concern and stress about his best friend going to jail for shooting him. Of the 3 participants involved in motor vehicle crashes, only one had received a traffic violation citation. However, all 3 participants had to deal with significant expenses for a replacement car, insurance, and lost income from being out of work. One adolescent struggled with the issue of determining who was at fault for her accident and with her father suing the truck company to pay for her injuries.

Um, well, they're trying to figure out who was at fault because obviously I was at fault for pulling out, but he was at fault for speeding and having faulty brakes and also, I guess, for having kept track of a log [of rest stops] or something and so it's not one person totally at fault, 'cause there is like so many other factors. But, um, I guess my Dad is suing the truck company and I guess... I'm not sure what's going on. They're [the insurance company] trying to find some stuff. I guess they are just trying to pay for the injuries [pause]. Basically, I think he's suing the trucking company, I think.

### *Processing the Event: Future is Impacted*

All of the traumatically injured participants described many permanent changes (in contrast to the more transient changes outlined under the subtheme, *everything has changed*) in their day-to-day lives resulting from their injuries (Table 11). By the second interview, when they had been home for 2 weeks, they seemed to worry more about their long term physical limitations, ability to recover

fully, and what had been “forever changed” (i.e., permanent changes). Several worried that they would not get full function of their “wrists” or “knees” or be able to “walk right,” “jump,” “run,” “do flips,” or “play” a sport. Two realized that their facial scars eliminated a modeling career. All worried about re-injuring themselves, e.g., damaging a “2-vessel leg,” getting a “broken back,” or having another “accident.” All began to worry about protecting their injured body part in the future. Some ( $n=4$ ) were frustrated by not having any way to escape dealing with their situation because they were used to jumping in a car and driving off.

### *Changed Body Image*

All participants ( $N=9$ ) talked about changes in body image, not only in terms of appearance but also physical abilities. They described a need to tolerate the devices or treatment and commented on their scars. Some talked about hiding the new deformities with ace wraps, clothing, and large sunglasses or by staying inside. Those who went out in public were met with stares that were especially difficult to tolerate. Many said they wished that people would ask questions, not just stare. These participants had a desire to tell their story so others would have insight into what they have been through; that despite their appearance they were nice people. Most talked about getting back to “my old self” or normal, but in the same breath they would give an example of why they couldn’t. For example, having scars was not part of the pre-injured self. One participant said, “I am the same person. Just [with] extra markings on myself.”

A few participants wanted to explain how their injury, scarring, and deformity were even worse for them because of previous interests that depended on physical appearance. For example, one adolescent said,

Well, I look kinda like a goon with this thing on my head. And my friends are like, oh you look so cute and... but from the looks I get from people obviously like, I look a lot different because I have something so big on my head. And I can't use my body like other people can, like their head. But I think once all this is done and over with, I'm just gonna respect my body more. And like, I was actually into modeling. I've been doing modeling for a few years and I don't look like it [a model] right now.

### *Physical Abilities*

Concern about body image was also tied to physical abilities. Several participants had been very involved in activities that required physical skills, e.g., elite sports, and their physical abilities were a source of pride. In their interviews, these adolescents continually struggled with accepting that their physical abilities were no longer the same as before the traumatic event. This event had been a life-changing event for most. One participant remarked that the EFD was “no big deal” but worried that his injuries would not allow him to return to break dancing and doing flips. Another participant struggled with a radical change in her abilities to do elite level sport tumbles. This realization was forced on her when she had to tell people who did not know about her injuries that she could barely even do a cartwheel: She described her struggle with her self-image in these words:

Well ... before the accident I was like a three-time national champion in [a sport]. After the accident, I'm laying in bed most of the time trying to get so I can walk. So, it was like total different extremes.

Kind of funny, because a couple of people had no idea I was even in the accident, 'cause they're not from around here. They are like [athletes] I met somewhere else, people's mothers. I used to coach their daughters in [a sport], and they'd be like a week before the accident, they go like, “Oh,



what do you have for tumbling and stuff?” and I’d be like, “Oh ya, rotating double, handstand double fault,” like whatever, and now they’re like, “Oh, what do you have? Tumbling?” and I’m like, “Cartwheel?” [laughter]. Maybe. If I’m lucky. On a good day. So that’s totally different because it’s like so much different in the [elite sport] world [pause] ... our team was the first team to get its ... to get a bid to the World Championship. Nominees can get to go the World Championship, and we were the first team in [her state]. Ever! I was on that team.

These self-image and body image changes made it more difficult for the participants to get back their “old self.” For example, one participant’s struggle to accept that her old self no longer existed is evident in the following response to a question about her current level of activity.

Not as much as I want to be because, like I said, I’m very active. [pause] I used to be very active. Now it’s different because, well obviously when my leg was like in pieces, there was not much I could do.

#### *Ambivalently Lucky*

Most of the participants had a hard time believing that such a traumatic event could have happened to them. Many asked why it had happened to them, but expected no answer. However, when asked their global feeling about the entire event, most ( $n=6$ ) described feeling a balance of lucky and unlucky. They talked about the severity of their injuries and that they couldn’t “walk” or “jump” or wouldn’t “ever look the same.” Such comments were balanced by noting how “it could have been worse,” how they “definitely feel lucky,” and “you hear about people who don’t even get into that kind of accident and die.” For example, one participant talked about the bad luck of the car she bought and her injuries and said,

A lot of people don’t even come out of car wrecks the way that my car looked. My car was totally demolished. Like I know, I was upset that my feet went through the firewall and my heel got burned and I was just mad at the way the car was made and that it was so hard for them to get us

out, it took so long. But in all reality, thank God we're OK. It's gonna be OK then... So I am pretty lucky.

### *Not Invincible*

The traumatic injury had a huge impact on the participants' day-to-day lives in terms of believing in their own invincibility. This subtheme contained two branches: dealing with mortality, and becoming more cautious. Dealing with mortality was the processing portion of the *not invincible* theme, whereas living a future with caution was the action or strategy that was designed to deal with their awareness of not being invincible. Separating these subthemes is difficult and more details about specific strategies regarding caution elements will appear in the next portion of this chapter as the theme *slow - caution*.

*Dealing with Mortality.* Five participants spoke of how they could have died, and 6 worried that they could have been paralyzed. Four participants used the phrase "not invincible" to describe a newfound vulnerability. One spoke of how "precious life is" and described being alive as a "miracle." For example, one adolescent's experience reflected both subthemes, as shown in the following excerpt:

Um, it scared me; I didn't know what to do. I was just like... there is really no way to put anything into words as to the feeling. It's just being terrified... everything. Never had anything like that. Never had a broken bone. I've fractured a couple bones, but never broken anything that severe, especially in my neck. Just thinkin' that if I like didn't go in when I did. I could've been paralyzed or dead if I had moved my neck the wrong way.

I definitely don't have the goal to do anything stupid like that anymore. Obviously with this thing on [halo] and everything, but I really have no desire to be risky and take risks anymore. Before I had... I loved adrenaline rushes, I loved doin' stupid things, thinkin' that I was invincible, knowing that I wasn't, but never figured that anything like that would ever happen to me. So I just won't take any chances doing anything stupid like that anymore.

### *Healthcare Career*

Time alone, which most participants disliked, allowed them time to think how the trauma would affect their future, especially their career options. Several ( $n=5$ ) made new career choices due to their injuries. Due to their injuries, these participants believed they could no longer do “carpentry,” “lift 100-pound cement forms,” “participate in cheerleading,” or join “the military.”

A surprising number ( $n=5$ ) considered careers in the healthcare professions. Two female participants had already been planning to be nurses and they believed their experience would make them better nurses because they would better understand their patients’ experiences. On the other hand, one participant commented that she could not be a nurse because she could not bear to see anyone hurt as she had been.

### *Appreciation for the Disabled*

Along with physical changes, adolescents became aware of aspects of their surroundings that they had never noticed before. Several participants ( $n=7$ ) described a new awareness and appreciation for the challenges faced by physically disabled people. One participant said that he “notices them now,” and others felt empathy for the disabled or commented, “I can’t believe they are never getting out of their chairs.” One participant described his increased awareness in this way: “I probably wouldn’t have even noticed it before. It woulda been like, oh that guy’s in a wheelchair. That’s crappy. But now that I’ve been a wheelchair, I know it’s real crappy.” Another participant described how this awareness impacted his behavior:

Cause a couple weeks ago I saw a guy, and he was in a wheelchair and he was grocery shoppin' and stuff and I asked him if he needed help. And he was kinda grouchy about it. He was like, "Yeah, I don't need your help buddy." I just kept buggin' him anyway. He was in a wheelchair and he had like 16 bags or something, tied onto his arms and coming through the bag holes, he was movin' slow. I finally bugged him into letting me help him, get the bags off the ground, throw 'em in the back of his car.

*Strategies to Deal with Fallout: "Suck it up and Deal with It"*

The day-to-day experiences of adolescents after traumatic injury were filled with meeting and dealing with physical, social and emotional challenges. Analysis of the interview data revealed many efforts for dealing with the fallout. Most initially used strategies to regain control such as medication and seeking information. Most also described the need to just "suck it up and deal with it." They needed to wait out the process of healing, having their EFD, cast, or brace removed, and returning to their old self. One participant said, "Well, there is nothing you can do about it [having an injury treated with an EFD]. You just have to suck it up and deal with it. It's really no big deal, you just have to wait 'til you're healed up and they free you." Only later did they realize that their bodies and their thinking had been forever changed. Because of this changed thinking, they also developed plans for being more cautious to prevent re-injury or reoccurrence.

*Medication*

All the participants depended on friends and family to help them deal with their experience. Pain medication (morphine, in particular) was mentioned as a method for dealing with physical pain, and in one case its use was discussed in relation to emotional pain. As previously discussed, analgesic medication was

also used during interviews and after discharge to home. However, many described a variety of other strategies they felt helped them throughout their experience, as shown in Table 12. This list of strategies is neither exclusive nor exhaustive.

Table 12

*Adolescent Mechanisms for Coping with Day-to-day Experiences after Traumatic Injury*

Coping Mechanism	Participants (n)
Taking pain medication	9
Talking with friends	9
Being with parents/ family	9
Suck it up /Wait it out	8
Crying	7
Video games /board games/TV	5 (all male)
Writing /Journaling /Poetry	4 (all female)
Talking with nurses/ doctors	4
Having a plan	5
Telling the story	4
Laughing	4
Seeing x-rays	4
Rationalizing, e.g., the EFD is better than not walking again	3
Having a positive attitude	2
Spirituality	2
Yelling - acting out	2
Going outside for fresh air	1

*Channeling Outlets for Coping*

Participants commonly described coping by channeling their feelings into emotional, verbal, physical, social and spiritual outlets. Emotional coping, for example, was expressed by laughing ( $n=4$ ) and crying ( $n=7$ ). One participant, whose sustained eye damaged, said, “I only cried out of one eye. I can’t even do

that right.” Verbal coping was described in participants who enjoyed or needed to tell their story. Four participants who had drawn stares in public described the need to tell people their story so others could understand what had happened to them and that they were “nice” or “normal” people under the EFD.

Male participants described being helped by physically “channeling their frustrations” into video and board games, whereas all 4 females reported writing about their feelings as a method for coping with their aggravations. For example, one male participant said,

Like right now I’m not that mad, but like I said and then I channel it into my game. I just play Risk and that’s what I cope and do. They [my parents] get mad at me ‘cause I get mad while playing Risk and ‘cause they say it’s just a game. It’s not, it’s conquering the world – come on.

On the other hand, one female participant described dealing with her feelings this way: “And basically like, having a little journal, just writin’ all my thoughts and feelings; that’s actually how I let things slip, just writing.”

Some participants ( $n=4$ ) said that a very helpful coping mechanism was physically seeing the x-rays showing the alignment and healing of their bones. Seeing their x-rays gave them a clearer picture of what their fractured bones looked like and helped them understand the doctor’s explanation of how much longer the healing would take. A few participants ( $n=3$ ) coped by rationalizing. For example, one participant said, “I would rather have this thing on my pelvis than not be able to walk again.” Only two participants spoke of coping by maintaining a positive attitude through the trying times of their experience, and half ( $n=5$ ) explained that having a plan or reason to get better was helpful in coping with the experience.

Two participants admitted to physically and emotionally acting out as a coping strategy. One said, "I just yell at them [people who stare]." The other described yelling at people in frustration when he faced the challenge of opening a heavy door at a movie theatre. Confined to a wheelchair, he couldn't push the door open to go out and get some popcorn. He yelled at the kids behind the candy counter about their lack of caring for people in wheelchairs and about how dangerous the doors were. He later thought that his acting out was not directed at the right people to make a difference, but he felt better.

Two participants involved in MVCs briefly expressed both jealousy and thankfulness that the others in the car had not been as badly hurt as they and could continue their lives. Another 2 participants had similar beliefs about healing. Both thought that having a positive attitude and doing everything in one's power to get better would speed up the healing process, as shown by the words of one participant.

Because I don't, ya know what I mean, most people will sit there and will be there and like my legs broken, blah blah blah, take pain meds all day, don't even talk, just sit there. I want to try to be as active and as talkative and interactive with people, telling them about it, get in the wheelchair a lot and walk around, so maybe my body will adjust and maybe try to heal faster, instead of just sitting in bed all day.

Only 2 of the 9 participants shared their spiritual beliefs. They were sure that the prayers of their friends and family had made them feel better and helped them to cope. One adolescent believed that getting fresh air was extremely important for her to deal with her frustrations while waiting for her spine and ankle fractures to heal.

## *Peer Support*

Peer relationships were used to “help get through it” and were discussed from 3 perspectives: companionship, distraction, and support. First, peers were the most important sources of support for participants, after their parents. Some participants even said that without their friends, they would not have been able to deal with “it.” Friends were seen as important for sharing their experience, as a distraction to keep participants from feeling alone and bored, and as sources of emotional and physical support.

*Companionship.* Several participants talked about liking their friends’ visits in the hospital, their bringing cards and balloons, and “hanging out.” Many were hospitalized a distance from their homes, so visits were not easy for friends. Participants also talked about getting daily support from by talking to friends on cell phones or through instant messaging (IM) via the internet. All of the participants smiled when they talked about their friends visiting. Two cried when they spoke about not being able to see or be with their best friend.

The advice from friends appeared to be frank, honest, and accepted by the participants because “they want the best for me.” Friends were described as commenting that “it was stupid of me to jump out the window,” “you should get your diploma,” and “it was kinda retarded of me to drop out of school in the first place.” The importance of peer companionship is shown in the following words:

Well, I know that like I used to call my best friend on the phone. It always has been [that way], but more than ever now. If I got down and I’d call people and I wouldn’t even have to say anything - they would just know that I was upset and they just do everything, like reassure me, like [say], “I love you, I know it’s OK, you’ll be fine. You’re strong.” And I was like, yeah, you’re right, I am strong.



Some older participants demonstrated that support from friends was more important than parental support. For example, one 19 year-old described a call to her best friend. "And I told her about like right before I was gettin' the halo on. I called her and I was hysterically crying, looking for support and everything even though my mother was in the room with me and stuff."

The adolescents who could not get support from their best friend seemed to have a harder time coping. In the 2 cases where best friends were not available for support, one had been injured and transferred to another hospital, and the other was under house arrest for inflicting the participant's gunshot wound. This participant's distress was obvious in his commentary.

The kid who shot me was my best friend, my best friend in the world. I mean, it was a total accident; he had no idea I was sleeping in the back of his car. I mean, I wish my buddy that shot me, my best friend that shot me could come out here and see me, but he can't because he's all tied down with this court stuff now because of it ... Yeah, he got arrested. They didn't think, they didn't know it was an accident until a couple of days after because I wasn't able to talk to the police until 2 or 3 days after it happened, because I was in such pain. [Crying] Yeah. Like, he's in lock down. He's locked down 24 hours a day at his house now and he's staying at his house thinking about how he shot his best friend, his best friend coulda been dead [crying]. All because he wanted to be stupid and shoot off the shotgun while he was drinkin' [crying].

The other participant's best friend (T) had been in the same accident and suffered injuries that prevented them from communicating for several weeks.

This situation motivated the 20 year-old participant to get better faster. She said that her friends, family, and T helped her to cope.

I knew I had to get better for T. ...Um me and my sister and T, we're all like sisters and I'm the older one and I'm kinda like the protector of them. I'm always lookin' out for them and my sister. She's younger than me and she's gonna have to take care of me and it's just hard, 'cause I can't be

there for them. 'Cause T is still in the ICU in Boston. I know when I was in the hospital, I couldn't move, I couldn't get out to see her and that was hard. But it didn't matter to her because she was out [unconscious], but it just hurt me 'cause I couldn't do anything for her [crying].

*Distraction.* Many participants talked about having friends over and not wanting to be alone. Some mentioned being bored, and others talked about the need to be distracted from "sitting there crying all the time 'cause I had no idea what happened to me" or "thinking about it way too much" or "going over and over it in my head." A few were even able to bring awareness of their feelings to the next level by saying that friends distracted them from thinking about all that had happened to them. They did not want to think about their accountability or responsibility for the event. For example, one participant said,

Well, talking to people helps um, bein' alone like makes you think about everything way too much. Like if you're around people, it definitely helps me, I know that much. Um, keeping yourself occupied. I think about stuff, but it's like I'm active so I'm not like sitting around being depressed and moping and I try and like be out and about as much as I can. Um, just thinkin' about like how you're not gonna do it again in the future, obviously, 'cause like that'd be stupid.

*Support.* Some participants were supported by friends who brought them things, carried books at school, brought their homework, or defended them in public. For example, one participant and her friends were walking on the boardwalk of a prominent beach and people were staring at her.

There's huge groups of people that walk around and people just stare and stare and stare, and my friends get like so angry and aggravated and like yell things at them like, "Yeah – she broke her neck," and yeah... like picture some obscenities and swears and stuff 'cause they're protecting me but.... , I'm like it's all right.

Another interesting finding was that some ( $n=3$ ) participants expressed that they could only take so much, that there was a limit, and they had reached it.

They talked about needing a break or “day off” from the pain or treatment and they would be able to handle it again. As one participant said, “I couldn’t deal with it at all. And then I think the body just deals with it after you can’t take it anymore.” Another participant commented,

It [the EFD] makes me think about it [the event]. Like I know, this [points to the halo] isn’t forever, but being in it and being in the position and having to wear it and having to deal with it every single day and not being able to just be OK. I’m like gonna take it off, I’m done with it, I’ll put it back on tomorrow or something like that. You just have to deal with it, no matter what, like no one is ever gonna make me feel 100%.

### *Slow - Caution*

Many participants said they would be more careful, would not repeat whatever behavior had caused their injury, e.g., throwing themselves out a second story window or falling asleep at the wheel or at least not behave as crazy or reckless as they had before. All involved in any motor vehicle injury talked about a new healthy respect for how dangerous driving a car or ATV or 18-wheeler could be, and that they would drive “slow,” “like [at] the speed limit,” not “like a maniac” again, and use “caution.” Both participants involved in alcohol-related incidents stopped drinking and even stopped seeing the friends who were drinking with them before the traumatic event. Although all participants involved in motor vehicle crashes denied speeding or reckless driving, many mentioned these risky behaviors as ones they would no longer engage in.

These comments were made when the participants were trying to make sense of what had happened to them and what behaviors they would change. The 2 participants with single-limb injuries at first thought they would not play football or jump on a trampoline, but on the last interview they both conceded

they might do it again. It is interesting to note neither of these participants ever thought their life was at risk while engaged in the behavior that led to the traumatic event.

Some participants were concerned that their injury had changed their self-image, for example, as an extreme BMX bike rider, carefree ATV rider, or one who enjoyed the “adrenaline rush of speeding” or crazy risk-taking activities. Especially bothersome was that this traumatic event had changed their feelings about being as reckless with their bodies as before. The idea that this perceived invincibility, which had been part of their self-image, was now gone is illustrated by one participant’s words: “I am not invincible. Life hurts and you never get a second chance.” This dilemma was articulately expressed by another adolescent:

Ahh, I’ve been thinking of that lately because I’m into BMX riding, like I said. I like to ride dirt bikes, too. Yet everybody has three veins in each foot, and you can live with two, and that’s pretty much what I’m doing now. I’m thinking, I’m 15, I’ve already had my get-out-of-jail-free card, so maybe I should be a little more, you know what I mean... it’s going to take me a real while to get back into that, if I do again, because, I really cannot... because if this happens again they’re gonna have to amputate my leg, no questions about it, and I wouldn’t want to live that. So I’m gonna have to be real careful and that’s what I’ve been thinking about. When I get back onto my feet, what am I and what am I not gonna want to do.

All the participants who sustained life-threatening injuries ( $n=7$ ) realized their own mortality, which forever changed their feelings of invincibility and left them with a new, unwanted cautiousness. This caution was another obstacle to regaining their old self. This struggle, to get the old self back but facing changes that hindered their goal, is illustrated by one 14 year-old participant who said,

I will be careful for a while and get back to my old self. I’ll probably do that [ride ATV] again. I will just be careful for a while. ...I want to get back to what I was. It’s just that like when you first like do something, like getting in an accident, you’re scared of doing it again. So I’m going to take it easy

for a while and then I'll probably go back to my old self. Probably be way more cautious on the streets. When I get my license I'll probably be a very slow driver. I'll be like at the speed limit or something.

### *Summary*

The participants felt that everything had changed in their day-to-day experiences following the traumatic injury. They first needed to master their new hospital environment to feel some sense of control. Cognitive processing of the event led them to lose details of that event and to gain accountability. They expressed a feeling that “everything has changed” in their lives. A struggle ensued of losing and regaining control, starting with physical limitations. Hospitalization and injuries forced them to relinquish their independence for basic needs and activities of daily living. However, they continued struggling to regain their independence. Most coped by saying they had to “suck it up” to deal with all the changes and wait for the healing to happen before they could get back to their “old self.” They channeled their emotions and energies in various ways to cope. They felt ambivalently lucky that they were still alive, but their experience had been horrible. Because of the traumatic event, some struggled with the realization that they now had to deal with their mortality. This struggle was strongly influenced by a newfound awareness that they were not invincible, that they were now vulnerable to re-injury and would be more cautious. Half reconsidered their career choices and a future in healthcare, and a new appreciation for disabled people surfaced. Although the participants passionately struggled to get back their old self, this process of struggling and the fact of their

injuries and scars led to the realization that they were mortal, forever changed. The old self was gone.

### Aim 3 - Life with an EFD: "Space Age Robot"

#### *Initial Reaction*

The third aim was to describe the participants' experience in the EFD following traumatic injury. The interview data led to the major theme "space age robot," which was echoed throughout many participants' descriptions of the EFD. When asked what life in an EFD was like, many participants said, "I feel like a space age robot!" In addition to the impact of the EFD on the adolescents' daily activities, this section includes the adolescents' initial reactions to the EFD and the reactions of their parents and friends to the hardware.

None of the adolescents with EFDs for traumatic injuries had previously seen one. When describing their reactions to the device, they used terms from science fiction: "terminator," "bionic," "robot," "something out of Star Wars or a TV show alien kind of thing," or "space age robot." Their reactions ran the spectrum from curiosity ("What is it? It looks weird," "It is very odd to me") to distress ("freaked out") or repulsion ("disgusted," "grossed out"). Most participants very quickly got used to their EFD and said they did not feel pain from the fixator itself, but from the fractures. Parents' reactions were summed up by one adolescent who said, "They could care less what it [the EFD] looks like. They just care that I'm all right." One commented that the EFD was "no big deal."

### *Peer Reactions*

Peer reactions were similar to those of the participants, i.e., ranging from curiosity to repulsion. Most peers asked what the EFD was or called the participants names like “mechanical man” or “Robocop.” When asked how his first day back at school had gone, one adolescent said, “Good. They [his classmates] were like, what is that sticking out of your leg? It’s gross.” He told them, “At least my bones are healed, that’s all.” Everyone at his school seemed supportive and helped him carry books and get to class. Some participants’ classmates had different reactions. For example, one participant said,

Oh, they freaked out. They don’t like to see it [the EFD]. They don’t like to think of it, ya know, if I banged into anything or hit these [pins] on anything, they would all like, their eyes would get huge and they would get scared and I’m like.... Someone backed into me once, and like barely touched me and they like flipped out; they felt really bad. I’m like, it doesn’t, it didn’t hurt me, ya know, at all. But they... it does, it kinda spooks ‘em.

One adolescent said that some of his friends were “cool with it” and some did not want to see the EFD, but he felt an advantage because he had sent his friends photos of his leg in the EFD by e-mail so they would not be surprised.

Um, it [seeing friends for the first time] was a lot easier because I had pictures. Ah and I’ve been e-mailing pictures to all my buddies who wanted to see it and haven’t seen it. I must have told the stories 50 times by now, ya know what I mean, what they did to my right and left leg.

### *Hide it [the EFD]*

Reactions to the EFD were not unlike reactions to scars and braces. Just as one participant used big sunglasses to hide a problem with her eye, most participants ( $n=6$ ) used clothing to hide their EFD. One wore a sweatshirt over a pelvic EFD, and others wore “baggy pants” or “Ace wraps” so people could not

see it when they went out in public. Although one participant's EFD was removed before she left the hospital, she wore another medical device, a plastic body jacket called a thoracolumbarsacral orthotic. She was embarrassed by her orthotic, and her friends called her Robocop and turtle to make her laugh. People were curious and asked about it, too. She tried to wear a big sweatshirt over it, but found that difficult in the summer heat.

### *No Big Deal*

The traumatic injuries themselves were responsible for some participants' limited mobility, but in some cases, it was directly related to the EFD. For example, pins got caught on upholstery and objects or the skin around pelvic pins would stretch if one adolescent turned quickly or leaned too far in a certain direction. These experiences were described as "annoying." Most could not feel the pins, although they saw them going in their legs and were curious. Because they did not feel pain from the pins, they sometimes tapped them to see if it would hurt. One participant talked about the EFD making him walk too slowly; another about the great shelf it made for his Playstation controller. One participant said, "It is no big deal." Three others said the EFD prevented them from sleeping on their stomachs. Wearing clothing and dressing were challenges no matter where the EFD was placed. Participants needed help dressing and all altered their clothing to accommodate the EFD. All longed to shower, and some couldn't wait to swim again.

All the participants mentioned trying hard to make sure the EFD did not bump into objects. Some padded the pins to "keep [them] from catching on stuff"



or hurting their other limb. One participant, whose halo was placed on the hottest week of the summer, was annoyed because she could not go out in the hot sun because her halo pins would heat up. Another, who was injured in winter, talked about his pins getting cold when he went outside.

### *Being Sick of it [the EFD]*

Some participants initially had difficulty with bulk of the EFD frame and its continued restriction of their mobility. Many thought it was not hard to get used to and adapted to it quickly. Two participants said they got “sick of it” and felt like removing the EFD by themselves, but knew they would not heal right if they did. One participant wished for a short vacation from her EFD so she could deal with it better. Continually wearing an EFD also had a negative psychological impact. One participant dreaded looking at it everyday because doing so made him feel “like a loser.” He called it “a burden on his life.” He appeared to associate or blame the EFD for reminding him about the event and the circumstances that surrounded his injury.

### *Summary*

The theme, “space age robot,” reflects the phrase used by participants and peers to describe the person in the EFD. Most participants and their friends had never seen an EFD and were curious about it, though some described being “grossed out.” Participants seemed to get used to having an EFD and said it was “no big deal” and that the pins did not hurt, although they were sensitive to temperature extremes. They grew “sick” of dealing with the EFD and were

tempted to remove it. One participant perceived the EFD as an emotional reminder and called it a “burden on his life.”

#### Aim 4 - Adolescents’ Role in Pin Care: Pin-Care Self-Management

To discern the adolescent’s role in pin care self-management following traumatic injury, participants were asked, “Can you tell me about caring for your EFD pins?” This question sought to determine who did the pin care and how it was decided who did this care. Methods of pin care and pin problems were also described by the participants.

#### *Pin Care Self-Management: They’ll Do it Themselves*

While all participants were in the hospital, pin care was initiated by a nurse (Table 13). Three participants spent considerable time in the hospital or a rehabilitation hospital recovering from other injuries, and their EFDs were removed or converted to other types of internal fixation prior to discharge home. Before adolescents were discharged, their parents were taught pin care.

Table 13

#### *Pin-Care Responsibility*

Pin Care	Nurse in hospital	Mother at home	Father at home	Visiting nurse	School nurse	Self
Participants ( <i>n</i> )	9*	3	2	5	2	6**

\* 9 participants had EFDs in hospital but only 6 went home with EFDs

\*\* One 13 year-old participant only removed old dressings because his mother didn’t allow more responsibility.

For all adolescents discharged with an EFD (*n*=6), visiting nurses were engaged to ensure that parents demonstrated adequate pin care. Many parents needed to manage pin care at least once daily or on weekends when visiting

nurses were unavailable. Three mothers (2 were RNs) and 2 fathers were the main parent responsible for pin care at home. Two participants (whose fathers assumed pin care responsibility) described their mothers as too squeamish or “creeped out” and unable to do pin care.

Injuries kept many participants on bed rest or prevented them from reaching their EFD pins for a long time. These participants were kept in bed by positioning restrictions for vascular and plastic surgery repairs, chest tubes, abdominal wound VAC, and spine fractures. One participant had abdominal injuries and two broken wrists.

Although most participants were at first unable to do their pin care, all 6 participants sent home in EFDs did take part in pin care. One participant was solely responsible for his own pin care after he was discharged to an aunt’s house. One young adolescent was only allowed (by his mother) to remove the old dressings. Two participants could not reach some pins due to a knee locked out straight and not being able to see halo pins in the back of her head. Another participant said, “they [other adolescents with EFDs] will all want to do their own pins when they can.”

#### *Pin-Care Self-Management: Method*

To determine how pin care was actually done at home, participants were asked to describe how their pins were cared for. All participants had been treated at the same hospital and had been instructed in pin care while in the hospital. As described earlier, most participants ( $n=6$ ) described having a visiting nurse go over the pin-care procedure again and watch them or their parent to verify that

they knew the procedure. All described their pin care similarly. None talked about washing their hands, and all 6 began by explaining how to remove the dressings. Some called the dressing by its brand name, "Xeroform," and one participant described the dressing as needed to "keep the skin moist so the hole did not close up." All participants sent home with EFDs ( $n=6$ ) described using cotton-tipped swabs (Q-tips) to clean around the pins. The Q-tips were dipped into a cleansing solution, which most participants knew contained hydrogen peroxide. Some ( $n=5$ ) knew this solution was "peroxide" mixed with equal amounts of saline. Five of the 6 expressed an understanding that the pins had to be cleaned to prevent infection. Some ( $n=3$ ) explained the need to push the skin down around the pin so it would not "cause a tent" that allowed bacteria to collect. Several talked about scabs being a problem, because they could be another source of trapped bacteria. The next step explained in pin care was rewrapping the pins with a dressing (Xeroform). One participant described different ways nurses did pin care:

I mean different ways, I mean they were all doin' the same thing, but just, ya know what I mean, some of them would just take 10 minutes to unwrap it, so slow, and I would just be "take it off!," ya know what I mean, just get it over with. And then some would wrap it different, and some would use more swabs than the other, but they were all good.

When asked to describe his own method of pin care, one adolescent said, "I whipped right through because it, I... ya know, I wanted to get it over with. Ya know, I did what I was supposed to do. Most, most kids with a fixator will probably wanna do it themselves."

Participants did pin care twice daily at first and later switched to once daily, at the orthopedic surgeon's prompting. Three participants had burning or "stinging" at one pin site.

### *Infections*

Several weeks after the EFD application, 3 participants experienced pin-site problems at home. When they were seen in orthopedic clinic, 2 participants were told that they did not have infections, just irritations at the pin sites. Both problems were successfully treated by increased cleansing. For example, one participant who thought she had a pin-site infection described a scab around one pin. She talked about her experience with the nurse practitioner in clinic who told her it was "not infected because there was no redness, and all she needed to do was clean off the scab and apply Bacitracin to the pin site."

One participant's pin site began to drain purulent fluid, just prior to his fixator removal. He received IV antibiotics during the operating room procedure for EFD removal and did not require any further antibiotics. However, he did need to perform wound care for the site where the pin had been and described the process of cleaning that site daily for 2 weeks until it healed. The PI's examination of the wound revealed an apparent debridement (a known treatment for pin-site infection), but it was unclear if the surgeon had diagnosed this event as a pin-site infection.

### *Summary*

Pin-care roles were mostly determined by the extent of the participant's injuries and location of the EFD. If the participants could not physically reach

their pin sites due to other injuries or pin location, pin care was done by others. Nurses in the hospital and visiting nurses at the participants' homes assumed the responsibility for pin care until they were confident that parents and/or adolescents could manage the care themselves. One parent, usually the mother, took responsibility for pin care. Two of these mothers were RNs. In two cases, fathers who were either less squeamish or more available cared for the pins. All participants discharged in EFDs were eventually able to participate in their own pin care.

#### Participants' Advice for Care of Adolescents with EFDs

The final question posed to the participants was, "Do you have any advice to tell nurses or other teens that are treated with a fixator?" The advice for nurses ranged from satisfying physical needs (e.g., 3 participants said they needed more pillows in the hospital) to emotional ones (e.g., one adolescent asked for understanding if patients were a little "snappy"). Four participants recommended that nurses move patients more slowly and carefully, especially when transferring from the bed, to minimize pain. One participant suggested nurses could minimize a patient's pain by lifting and supporting the limb where it is broken. They shared that nurses should listen to and heed their patients' descriptions of what feels best. For example, one participant said, "I liked when they [nurses] asked what they could do for me. I felt cared for." One participant reported that she appreciated the problem-solving abilities of the healthcare professionals "when the medicines weren't working, the doctors and nurses were quick to find something else that would work."

The advice for other adolescents treated with an EFD ran from light-hearted (“don’t get one”) to practical (“tape up the ends so they don’t poke you”). Much of their advice focused on emotional aspects, for example, “roll with the punches,” “people will be staring at you; that’s how people are,” and “you gotta think of yourself.” Several participants recommended looking on the bright side. For example, one participant said,

Um, the only thing I can say is that it’s really hard to have to cope with having them [EFDs], but I look at the bright side and realize that you’re going to be OK. And that you are still here. Um, and not to give up, to keep pushin’ yourself and saying it’s gonna be OK. Don’t just sit there and wallow in your pain and everything that happened. You’re not going to get anywhere [that way]. You gotta push yourself to get better.

### Summary

The adolescents in this study who sustained an acute traumatic injury that was treated with an EFD faced a life-changing event with multiple physical and emotional challenges. They struggled to get back to their “old self,” first by mastering their environment, then by “sucking it up” and waiting for their injuries to heal. Those who faced life- or limb-threatening injuries initially used their PCA or narcotics while talking about the details of the traumatic event. Attitudes about the risks they took and about their responsibility in the event changed over the course of the interviews. Participants felt that the event had changed everything in their lives, from their activities of daily living to their ideas about themselves and their invincibility. A struggle emerged between believing they could get back their old self and the fact that they now had physical, emotional and belief changes that did not belong to that old self. Their own ideas about their vulnerability had changed, but they were not yet able to process this new self.

They had developed a healthy respect for the dangers of motor vehicles, heights, or guns. Most participants and their friends perceived that with their EFDs they had entered a “space age.” Some participants felt they had become somewhat “robotic” with the EFD, but did not see it as painful or a major problem. The injuries and pin site locations determined the decisions for pin care.



## CHAPTER 5

### DISCUSSION

#### Overview

To date, little research has focused on adolescents' experiences with EFDs for treatment of traumatic injury; therefore, this qualitative study was conducted to explore these experiences. Although one aim of the overall study was to learn why adolescents had more pin-site infections than adults treated with EFDs, participants considered pin-care self-management as "no big deal" and it seemed to be the least of their problems. Most of the participants' descriptions of their experience centered on the acute trauma. The struggle of dealing with the effects of the traumatic event and its fallout were all encompassing and powerful for these adolescents. In-depth interviews with participants revealed the overarching theme *old self no more; forever changed*. Adolescents were continuously struggling to get back to their old self. However, this goal was frustrated by evidence that the "invincible," carefree, unblemished, old self had been forever changed by the traumatic injury.

The overarching theme, themes, and subthemes were also linked to the study's theoretical framework via two of its components: the Event and Fallout (Richmond et al., 2000). Another component of the framework, Moving On, was not intended as part of this study's scope, but is planned for a future study.

This chapter will discuss the participants' characteristics, factors that may have influenced the findings, and the findings as they relate to the study's 4 specific aims: 1) circumstances leading to the traumatic injury, 2) adolescents'

experience following the traumatic injury (or fallout), 3) their experience in an EFD following traumatic injury, and 4) their role in pin-care self-management. Implications for policy and practice will be discussed as they appear under these aims. The chapter will conclude with study limitations and research recommendations.

### Participant Characteristics

The characteristics of participants' traumas, such as timing of injuries (evening, late spring and fall, Saturday night), alcohol and gun use, and more severe injuries with older adolescents who drive, are supported by empirical evidence (Galano, Vitale, Kessler, Hyman, & Vitale, 2005; Spain et al., 1997), suggesting that the study sample was a representative sample. However, the majority of participants came from traditional two-parent, middle-class families in rural and suburban neighborhoods, unlike traumatically injured adolescents in the literature (Ameratunga, Alexander, Smith, Lennon, & Norton, 1999; Marcin et al., 2003; Redeker et al., 1995; Scheidt et al., 1995; Schwarz, 1993; Spain et al., 1997). The adolescents' average hospital length of stay (12 days) was much longer than the reported national average for similar injuries (4.1-6.1 days) (National Center for Injury Prevention and Control, 2006), suggesting the severity of the participants' injuries. The rich description of this sample's experiences greatly adds to the body of knowledge about adolescent trauma.

The study sample was designed to have equal numbers of males and females to explore the role of gender in traumatic injury. Analysis of interviews demonstrated redundancy of the overarching theme, *old self, no more; forever*

*changed*, with no new themes following the seventh participant (5 males, 2 females). However, recruitment/sampling continued to discern if more participants (including more females) would reveal any new themes. Sample size in qualitative research has been explained by Sandelowski (1995) as the volume necessary to provide a deep case-oriented analysis and rich description. The quality of information collected from the first 7 participants gave a rich understanding of the meaning for mostly male (5) adolescents of the complex experience of being treated with an EFD for traumatic injury. Additional participants strengthened some gender-related findings however conducting research with a larger, gender specific sample would further inform this aspect of the study.

### Factors Impacting Participant Information

#### *Interview Methodology*

In the course of analyzing the data, the findings appeared to be influenced by the interview method, schedule and location in some aspects. First, the adolescent participants often responded with one-word answers and were reluctant to expand on their feelings. To encourage them to explain their ideas and feelings, many prompts were used, as described in a report on adolescent data collection (Dashiff, 2001).

Second, the amount of information revealed by adolescents varied with the timing and environment of the interview. Hospital and home interviews were more productive in terms of volume of information, whereas some clinic interviews were less productive (especially for the third interview). Three

participants seemed eager to leave. These interviews were scheduled before or after their appointment with their surgeon. It is not clear if the appointment time or the sequence (third interview) influenced the curt answers.

Because some participants' EFDs were removed prior to hospital discharge, the time between their second and third interviews was shorter (2 to 4 weeks) than for the other participants (4 to 12 weeks), even when the third interview was delayed. The short time between these interviews may have contributed to these participants offering less information about the traumatic event since they had less time to process the event. However, this phenomenon warrants exploration because it is not known why participants were reluctant to discuss details of the traumatic event at the final interview. Their reluctance may have been related to processing the event or feeling they had already told the story to the researcher.

### *Parental Input*

While participants were being interviewed, 3 parents offered the researcher details about the traumatic injury and family issues due to the trauma. One mother "filled in the blanks" about her daughter's injury because the daughter had sustained a head injury and could not remember parts of the event. Another parent (a father) confided to the researcher that he felt overwhelmed by his son's injuries, his wife's cancer treatment, and work-related injuries.

A second mother (who had listened to the interview) offered that her son had some problems with pain and spasms, which he did not talk about during the interview. She also talked about her strong belief in protecting her family

(referring to the need to remain near her teen while he was interviewed). Having this parent close by for her son's interview was distracting, but this situation also allowed family norms to be introduced into the research on injured adolescents. These situations allowed a glimpse of important family issues that could potentially inform research on injured adolescents.

#### Aim 1 - Circumstances Leading to Traumatic Injury: The Event

##### *"What Risk?"*

The most important finding in this portion of the study was that adolescents did not believe they were at risk for injury at the time they were injured. This finding is significant because traumatic injuries are commonly believed to be preventable; in fact, many trauma healthcare professionals would like to ban the word "accident" (Neira & Bosque, 2004). Prevention of traumatic injury focuses on identifying and decreasing risks and risk-taking behaviors. However, not all traumas can be prevented since even playing football is expected to produce occasional injuries. It is well documented that driving a car with other teenagers or while tired can be dangerous (Ameratunga et al., 1999; Schwarz, 1993; Spain et al., 1997; Wan & Neff-Smith, 1996). Legislation and guidelines have been implemented to minimize risks for adolescents. Trampolines have warnings against improper use, Pop Warner football leagues have weight restrictions for participants, and vehicles are inspected to prevent unsafe vehicles from being driven on public roads. Despite these precautions, trucks lose their treads, people drive when they are tired, and all-terrain vehicles (ATVs) are driven on public roads.

The absence of negative consequences for repeated behaviors (driving daily on roads, jumping on a trampoline with friends, partying with alcohol) likely resulted in the adolescent participants' decreased perception of risk for injury and thus increased their sense of invulnerability, (along with normal adolescent omnipotence) (Reyna & Farley, 2006). Although many participants reported enjoying thrill-seeking behaviors, the group as a whole did not fit the classic description of adolescents involved in traumatic injuries. These characteristics include being male, unemployed, having past arrests, coming from less than a two-parent household, weekday drinking, low levels of spirituality, high education level, increased anger, not wearing helmets or seatbelts, impulsivity and thrill-seeking behaviors (Redeker et al., 1995; Scheidt et al., 1995; Spain et al., 1997; Spirito et al., 2001).

Participants expressed surprise that their behavior led to such a traumatic injury and felt that their injuries had been unpreventable (e.g., they were not drinking or speeding). This finding is consistent with reports that adolescent perceive their risk as low or "no risk at all" for events such as automobile crashes (Quadrel, Fischhoff, & Davis, 1993; Reyna & Farley, 2006). This perception has been explained by Reyna and Farley (2006) as due to an optimistic bias on the part of egocentric adolescents. They only think of their own role when appraising the risk of an accident and do not consider outside antecedents, such as other bad drivers, dangerous driving conditions, or other possible circumstances. The participants' perceived role or accountability in the event changed over the course of the interviews, as will be discussed later in this chapter. The

participants apparently lacked good reasoning, or good judgment in several instances (jumping from one high place to another in the rain, pulling out in front of an 18-wheeled car carrier, imbibing alcohol where guns were brandished). These decisions could partially be explained by immature brain development, which can limit logical reasoning, resulting in impulsivity and sensation and thrill seeking (Reyna & Farley, 2006; Strauch, 2003). Decreased reaction time for adolescent decision making is another explanation for these injuries.

This phenomenon is illustrated by responses of adolescents and adults to questions such as “Is it a good idea to drink a bottle of Drano?” or “Is it a good idea to set your hair on fire?” (Baird & Fugelsang, 2004) The adolescents responded more slowly than adults to these questions. All these characteristics can lead to poor judgment and risk taking. For similar reasons, ATV riding is extremely dangerous for those under 16 years of age. Young adolescents do not recognize or understand the dangers and risks of a high-powered machine. Most also lack the strength to control these large machines, resulting in severe injuries or death. Compared to adults, ATV riders under age 16 have been shown to have a 4.5 to 12 times greater risk of death (Humphries, Stone, Stapczynski, & Florea, 2006). Taken together, these findings suggest that a policy restricting the use of ATVs to those at least 16 years old can potentially save lives. These issues can also be addressed by working with legislators for relevant legislation and regulation. For example, the National Association of Orthopaedic Nurses has issued a position paper against allowing children under 16 years old to drive or ride on ATVs (Voss, 2005).

Another concern was alcohol consumption by 2 underage injured adolescents. Alcohol consumption is known to significantly increase the risk of injury by 2 to 4 times (Spain et al., 1997; Watt, Purdie, Roche, & McClure, 2006; Watt, Purdie, Roche, & McClure, 2004), but this outcome can be confounded by the relationships between drinking patterns, personality type and engaging in more risky behavior (Watt et al., 2004). Volume of alcohol consumed and combined drinking of hard liquor or “spirits” have also been associated with severity of injury (Watt et al., 2006). Positive experiences with alcohol have also been suggested to influence perception and behavior for adolescents (Goldberg, Halpern-Felsher, & Millstein, 2002). This influence was seen in the case of this study’s participant who was shot at a house where he had previously drunk alcohol and seen guns brandished.

#### *Implications for Practice*

The practice implications related to the first aim focus on parental education and regulations in prevention strategies. Adolescent participants saw themselves as participating in ordinary behavior or believed that the activity in which they were involved at the time of the event would not result in injury. However, their injuries and hospitalization produced a very strong teaching moment. Nurses treating adolescent patients during recovery from traumatic injury could discuss alcohol use and treatment, gun safety, trampoline and ATV rules and safety. Health care professionals can alert legislators to the dangers of trampolines and ATV use for adolescents.



## *Summary*

Despite legal and social mechanisms for preventing injury (legal drinking age, road rules for ATVs, highway safety laws), these adolescents were involved in traumatic injury. Denying or underestimating risk may be related to adolescent development or experiences that did not have negative outcomes. These participants did not see risk in the moment of their injury, thus making it difficult to suggest interventions to decrease risk taking or prevent injury in this population. The use of alcohol by underage adolescents contributes to injury. However, healthcare professionals can take advantage of the hospitalization period after a traumatic injury to teach injured adolescents about risk categories such as safety on trampolines, driving safety for ATVs, driving fatigue, and alcohol use. Although adolescents may not respond to preventive teaching on these issues, nurses can bring these issues to parental, public and legislator awareness, particularly the dangers of ATVs and improper use of trampolines.

Aim 2 - Day-to-Day Experience Following Traumatic Injury: The Fallout

### *Mastering the Environment*

The most unusual finding of this study was alterations over time in participants' ability to recall details of the traumatic event. The vivid detail given by participants in their initial recall of the traumatic injury has not been previously described in the empirical literature. In fact, few studies have interviewed adolescents so close to the traumatic event, and most studies have relied on participants' long-term memory (one month or longer after the injury; (Griffiths & Jordan, 1998; Richmond et al., 2000).

The ability of participants in this study to recall the details of a traumatic event is also contrary to the literature on acute stress disorder. Children and adults involved in a life-threatening event have been reported to have immediate dissociative symptoms and be unable to immediately recall details, a state described as being “dazed” or “in a fog” (Daviss et al., 2000; Holbrook & Hoyt, 2004; Kassam-Adams & Winston, 2004; Saxe et al., 2005).

The recall ability of this study’s participants may have been due to the availability and use of narcotics during the first interviews. No reports of a similar phenomenon could be found in the literature. It is not known whether early retelling or reminiscing about the traumatic injury experience with access to the safety/comfort of medication has better psychological outcomes for these adolescents. Although a large body of research on reminiscing has been associated with reframing negative events (Fivush & Reese, 2002; Webster & Haight, 2002) and traumatic brain injury (Fish & Richeson, 2005), further studies are needed to explore this recall/reminiscence method in facilitating the emotional healing for adolescents who have experienced traumatic physical injury. It will also be interesting to explore narcotic-protected retelling in the early acute stage after trauma, as it may be beneficial to adolescents in allowing complete disclosure of the event. In addition, the certificate of confidentiality in the assent/consent form and the nonjudgmental nature of the researcher may have given participants more confidence to speak freely, especially in light of the legal implications described.

Reminiscing and describing in detail the traumatic injury also may have provided the participants with an emotional outlet that helped them better process the event to master their environment (Ryan-Wenger, 1996). The inability to recall details during the second and third interviews in several cases may have been a defense mechanism or protection from painful memory (Craighead & Nemeroff, 2001) since participants were no longer using narcotics. Another explanation for this phenomenon may have been a delay in the emergence of acute stress disorder symptoms, which are typically seen 2-28 days after a traumatic event (Kassam-Adams & Winston, 2004). This is an area where exploratory research is needed with a larger sample of adolescents.

The phenomenon of participants' initially blaming external factors (especially the younger adolescents) and later acknowledging or taking responsibility for their risky behaviors is supported by developmental studies showing that phases of narcissism and omnipotence are gradually relinquished for realistic assessment of one's behaviors (Radzik, 2002). Taking responsibility for one's actions is influenced by adolescent development, which involves the tasks of establishing ego, sexual, vocational, and moral identities (Radzik, 2002; Steinberg & Morris, 2000). Individuals in middle adolescence tend to think of themselves as omnipotent and invincible, which leads to risk-taking behaviors, whereas those in late adolescence begin to develop a more rational, realistic perspective, a conscience and practical vocational goals (Radzik, 2002).

Most participants in middle adolescence suffered a traumatic injury that threatened their life or limbs, consistent with the reported link between the

involvement of this age group in motor vehicle crashes and gunshot wounds with high morbidity and mortality (Schwarz, 1993). Over the course of the interviews in this study, the participants' experiences with traumatic injury seemed to have contributed to a new perception of their vulnerability, forcing them to reflect with a more mature perspective on the meaning of life. Similarly, children and adolescents involved in caring for their disabled parents have a perspective of life that is "wise beyond their years" (Aldridge & Becker, 1999; Dearden, Becker, & Aldridge, 1995; Pakenham & Burnsnall, 2006),

Mastering the environment went beyond processing who was at fault. Participants needed to deal with changes in their immediate environment. The control and independence they had previously possessed was gone. They were now in a situation they had never experienced, in a strange environment with people, bedding, rooms, machines, sounds, smells, lights and noises that were foreign to them. They wanted to escape the unfamiliar situation of being hospitalized and return to the comfort of a situation they knew about. All participants seemed to struggle to regain control and to learn as much as possible about the new environment in which they needed to function. Learning and using medical terminology and familiarizing themselves with the hospital routines seemed to give them a sense of accomplishment and to enhance their confidence. They seemed reassured by the presence of familiar people (family), sights (windows), and conditions (fewer machines, their clothing and belongings, cell phone). The aversion to fluorescent light by participants may have been a reaction to unfamiliar surroundings. One participant said that he felt more

comfortable knowing the names of nurses who took care of him several days in a row. These reactions seem like a natural tendency for people who enter a new environment, but were not described in other studies on adolescent traumatic injury. However, similar findings in a study of hospitalized children (Ryan-Wegner, 1996) were explained as information seeking as a method of coping. The present study's findings may have been due to the early timing of interviews in the acute period.

The many changes described by the participants after the injury (e.g., , loss of independence, disturbed sleep, pain, changes in body image and in socialization, being bored, tired, and sore) have been described in the literature on injured children and adults (Gofin, Adler, & Hass, 1999; Griffiths & Jordan, 1998; Holbrook & Hoyt, 2004; Rusch, Gould, Dzwierzynski, & Larson, 2002). This study's findings concur with those of Rusch et al. (2002) on the psychological impact of traumatic injuries in children and adolescents. These effects included symptoms such as flashbacks, fear of re-injury, mood disorders, changes in body image secondary to disfigurement, sleep disturbances and anxiety (Rusch et al., 2002).

Although many participants worried about re-injury and the effect of the injuries on their appearance, only a few hinted about mood changes with words like "moping" or "wallowing." Similarly, traumatically injured adults and adolescents have been reported to experience mood changes and to worry about ability to do regular activities (eating, dressing, walking), to participate in sports, and to carry out future career-related physical demands (DeWitt, 1993; Griffiths &

Jordan, 1998; Richmond et al., 2000). Only one participant reported nightmares. This participant, whose depressed mood was obvious during interviews, had been referred for counseling.

Despite several possible indicators for posttraumatic stress disorder (PTSD) such as thinking one might die, age ( $\geq 12$  but  $< 20$  years), being female, having an extremity fracture, and having a high pulse rate when taken to the hospital (Winston et al., 2003), no participant was diagnosed with acute stress disorder or PTSD.

The memory of pain during the event and medical treatments were discussed by many of the participants. In particular, one individual talked about remembering the excruciating pain of having vacuum-assisted closure (VAC) dressings removed from her wound. This description represents pain and stress associated with a necessary medical treatment. Recognizing and treating such medically induced stress and pain is needed to prevent recurring and long-term effects (Kazak et al., 2006). The use of a hypnotic /amnesic medication such as midazolam (Versed®) may be appropriate in preventing post medical treatment stress such as those induced by changing VAC dressing. Although sedating a patient to change VAC dressing would be staff intensive and time consuming, it may alter the patient's recall and decrease the stress and negative experience.

#### *Family and Peer Relations*

The findings of this study suggest a new feature of mastering the environment and coping among adolescents under stress, i.e., using information technology. A crucial aspect of participants' experience with the EFD for

traumatic injury was the support of family and peer relations. Consistent with the developmental task of achieving independence from parents (Radzik, 2002; Steinberg & Morris, 2000), older adolescents preferred peer support over parental support whereas the desire for parental support and presence was higher for the younger participants. This need for family and peer support is echoed in other studies of traumatically injured adults and adolescents (DeWitt, 1993; Richmond et al., 2000).

To get this support, adolescents in this study were very creative and used (requested) access to information technology. Using electronic media such as cell phones, e-mail and instant messaging via the internet helped them to maintain almost constant contact with friends and provided another means of adding familiarity and normalcy to their lives. The participants also talked at length about their families, not wanting their parents to be upset by their injuries, and the support they derived from parental prayer. Both of these findings were echoed in phenomenological findings on injured adolescents (DeWitt, 1993). These findings, along with the parents' desire to help with the participant interviews support the need for more family-centered research with acutely injured adolescents.

Lengthy school absenteeism had social, emotional and academic consequences for the study participants, similar to the effects on children with chronic illness (Thies, 1999). Many participants of the present study were absent from school for more than a month. Many did not receive tutoring and fell behind in school, causing some to change their college plans. Interestingly, the

participants attempted to contact peers and some teachers via internet. The increasing availability of hospital and home internet connections, as well as the emergence of distant learning and video classrooms, may be used to alleviate tutor delays, to help homebound injured adolescents participate in class work, and to maintain social connections. Some of these options have been suggested for pediatric oncology patients who have a high rate of absenteeism from school (Suzuki & Kato, 2003). These findings suggest a need for nurses to address schooling issues with parents prior to discharge.

*“Suck it up and Deal with It” Strategies for Coping*

The theme “suck it up and deal with it” was echoed by participants who described resigning themselves to not being able to change their situation until they healed and needing to find ways to cope. This resignation of participants to their situation as a way of coping with EFD treatment for traumatic injury was similar to that seen in Martin et al.’s (2003) research on adolescents with elective EFDs. This resignation was also seen in another study of adolescents recovering from trauma (DeWitt, 1993). Those participants felt that they “just had to get through” until they were healed, that “getting well takes a long time,” and “you have to have will power” to get better (DeWitt, 1993).

Male participants in the present study described channeling their frustrations into video and board games, whereas all 4 females coped by writing in their journals or writing poems. This was an exclusive gender difference; no males reported writing and no females reported using games. This finding is consistent with the results of a survey study on the self-initiated coping behavior



of diary keeping among 477 university students where females described diary use as an outlet for dealing with feelings, clarifying thoughts and emotions (Burt, 1994). The present study findings suggest that diary keeping may help injured adolescents (especially females) deal with their emotions following traumatic injury.

Many participants needed reassurance and repeated information about the process of healing from nurses and surgeons. One mechanism for coping with this lack of understanding about the healing process was seeing x-rays that demonstrated healing of their injuries. Lack of knowledge about healing and recovery was also a common theme in other studies of injured adults and adolescents (DeWitt, 1993; Griffiths & Jordan, 1998; Richmond et al., 2000).

Some participants believed that healing would be hastened by a positive attitude or by prayer. These mind-body interventions are described as integral to healing and commonly used by over 50% of the US population (NCCAM, 2004).

Many of these coping measures (social support, stress modification, endurance, cognitive restructuring, emotional expression, behavioral distraction, spiritual support and problem solving), have been described by Ryan-Wegner (1996) in a synthesis of the literature on 15 significant coping strategies used by children with chronic and acute illness. Children in that review used the same coping mechanisms for stressors not related to health, but tended to alter the type and frequency of coping mechanism for illness or injury (Ryan-Wenger, 1996). All strategies found in the present study of adolescents were reflected in Ryan-Wegner's synthesis of coping mechanisms used by children. The coping

strategies most frequently seen in this study were social support, use of pain medications, and “sucking it up and dealing with it.” These findings mirror those of Ryan-Wegner’s synthesis, in which the most commonly reported coping strategies were social support, stressor modification (medication), and endurance.

### *Ambivalently Lucky*

A new facet of processing the traumatic event was the emergence of the theme *ambivalently lucky*. Most participants recognized they could have been killed or paralyzed by the event and felt lucky that they were alive and not paralyzed. However, each time they talked about their luck, they gave examples of how they were not lucky, e.g., their injuries prevented them from running, flipping, tumbling, or seeing normally. The event and its fallout were the worst things that had ever happened to them. A strong undercurrent in their descriptions was that if they were really lucky they would not have been hurt at all. This theme of feeling ambivalently lucky could not be found in the literature. This ambivalence might have been due to the influence of adults reframing the outcome, often remarking on the adolescents’ luck in escaping more serious injuries.

Another perception that changed for many participants following the event was recognizing and appreciating the struggle of disabled people. This change may have developed from their brief experience of being confined to a wheelchair or from maturing enough to realize that others were worse off than they were. This process is seen in development as moving from egocentricity

during early adolescence, to more openness in middle adolescence when one can see others and understand their feelings, and later moving toward development of conscience, which occurs in late adolescence (Radzik, 2002)

The career choices of participants also changed after the event. During their time alone, many re-evaluated their ability to perform the work they had previously considered or were doing. Similarly, injured adults were found to deal with psychological concerns in the months following injury as well as concerns about work (Kralik, 2001; Olson, Ustanko, & Warner, 1991a). Returning to work was seen as a goal for recovery of injured adults (Richmond et al., 2003). However, the recovery goals of adolescents in this study were not considered due to the brevity of the study.

One noticeable difference between the responses of this study's participants and adults to a traumatic event and its fallout was the adults' ability to process the significance of the event ((Richmond et al., 2000). Adolescents focused on explaining their role in the event. No participant talked about the event as the dividing line in their life or even used the word "before" in describing their experiences. Adolescents were more concerned with returning to the only state or condition they had ever known. A high ratio (5 of 9) of participants planned to pursue careers in health care, feeling they would be better prepared to care for injured people. This change in career choice occurred in the early recovery period; it is unclear if the plans would change in the future. To address this question, long-term research would be needed on career outcomes of adolescents who sustain trauma.

Similar to adults (Richmond et al., 2000) and adolescents (DeWitt, 1993) in previous studies, this study's participants went through phases or a process of trying to make sense of what happened to them before facing their mortality and permanent changes in their lives. This journey is analogous to the process described in a concept analysis of searching for meaning in negative events (Skaggs & Barron, 2006). According to this analysis, when a negative event shatters one's global meaning (view of life as understandable) or upsets the values and beliefs that shape one's life goals, a person feels a loss of control and begins to search for meaning in the event (Skaggs & Barron, 2006). This search reflects a process used to cope with the event.

The coping process begins with re-attribution, i.e., reassigning meaning or responsibility to a negative event (*Whose fault?*). The person then creates an illusion to gain personal control as he/she tries to build self-efficacy (*mastering the environment*). This step of the process was seen as the participants tried to master their hospital environment by learning its language and adapting their hospital rooms to reflect their own tastes. In the next step, creating the illusion of a favorable aspect of the negative event, most participants used a downward comparison, e.g., they noticed when they were better off than someone else or compared their current situation to a worse outcome ("it could have been worse; I could have died or been paralyzed"). Participants then used positive reappraisal, looking at the event in a positive light; for example, many thought that the event brought their families together.

In the fourth step, participants used problem-focused coping, making realistic goals that they could achieve, thus increasing their self-esteem. For example, one participant worked for 40 minutes to get an item from his bedside unit by himself. Similarly, all participants spoke proudly of regaining their ability to transfer, toilet or walk by themselves. The final step of Skaggs and Barron's process is revaluing ordinary events. Many participants of the present study talked about taking one day at a time as they were waiting out the time to heal and have their EFD removed. During later interviews, many participants expressed a new appreciation for life with words like "miracle" and "lucky." As mentioned above, one participant helped a disabled man, and many seriously considered careers in health care, reflecting involvement with their community. The concepts of sharing self with others and involvement in the community are described by Skaggs and Barron (2006) as temporal, individual and recursive. Some participants may have been at different stages of making meaning of their experience, a process that might be illuminated in a longer study.

#### *Forever Changed*

The theme "forever changed" was the result of physical and emotional components that were so interlaced, it was hard to see where one ended and the next began. Similar to adults (Richmond et al., 2000) and adolescents (DeWitt, 1993) in other studies, participants in this study commented that they did not like being alone, but that it forced them to think about everything that happened to them and how things were changed forever. In a previous study on adolescents (Dewitt, 1993), the theme "time to think about how I changed" described both

positive and negative changes. The participants of the present study could see evidence of physical changes (scars, mobility changes, injuries, treatments). These physical changes kept colliding with their self-image. Unlike the traumatically injured participants in the other studies, the ultimate struggle for the present study's teens was getting back to their old self.

Emotionally, most participants thought of themselves as invincible, which is normal at their developmental level (Goldberg et al., 2002; Radzik, 2002; Steinberg & Morris, 2000). Because they had been through a life- or limb-threatening experience, they faced the realization that they were not invincible. They did not necessarily lose faith in a safe world, as found by Richmond et al. (2000), but they had lost their perceived invincibility and wanted it back. Instead, they had become afraid of re-injury and adopted caution. This realization was very difficult for them to embrace since it meant letting go of a cherished aspect of their old self. This theme is similar to findings of other studies on elective EFD treatment (Hubley, 2004; Martin et al., 2003) and cancer survival (Little & Sayers, 2004), in which participants wanted to get back to normal and adolescents specifically wanted to get to their "pre-injury state" (Griffiths & Jordan, 1998). For the participants in the present study, this pre-injured state meant having unmarred skin, carefree ("invincible") playing/ riding/ driving/drinking/ participating in a sport/ living, and not experiencing the extremely painful event that had changed them so much. Their recent experience and its effects made it impossible for them to get back to their old self. This realization had a deep,

almost philosophic impact on them, as shown by one participant's words: "You never get a second chance." The old self was gone, forever changed.

### *Implications for Practice*

With respect to aim 2, (day-to-day experiences following traumatic injury) the findings have several implications for practice. The first implication is to encourage adolescents to tell the story of the traumatic event in a confidential manner, early in hospitalization, and to allow access to narcotics (by PCA or injection) while talking. To encourage the process, nurses could use a nonjudgmental manner and assure confidentiality.

One of the best ways for healthcare professionals to optimize the experience of newly injured adolescents is to medicate quickly for pain and to use nonpharmacologic measures (splinting, guided imagery or deep breathing) when painful procedures can't be avoided, such as transfers from stretcher to x-ray table or bed. The problem of remembered pain, as described by one participant who recalled the painful removal of VAC dressing, may be alleviated by treating patients with a combination medication such as midazolam (Versed®) plus morphine. Professionals could move slowly and carefully, prevent jarring of fractured extremities and allowing adolescents as much control as possible. Similarly, acutely injured adolescents can be given more control of their new hospital environment, which this study found they need to master. Allowing the use of clothing, music and even incandescent lighting may provide a less harsh, more home-like environment. Professional caregivers could explain to adolescents each new situation, introduce new machines and procedures,

explain medical jargon/ terms, and introduce new caregivers and their roles. To provide support for adolescents during hospitalization, health professionals could encourage visitors, especially family and peers. At the hospital level, the findings suggest a relatively simple and inexpensive change: allowing chairs and parent visitors to stay with adolescents who need to board in an adult ICU. If a hospital does not have such a policy in place, it can be developed to the benefit of adolescents who sustain traumatic injury. If family and friends live too far away to visit often, caregivers could encourage their virtual presence by electronic media (cell phones, internet).

While in the hospital, caregivers could work with parents to plan for tutoring and school work after discharge. Parents could also be encouraged to inquire about information technology for school work, as many secondary schools can video- or audio-tape classes, thus allowing adolescents to continue their studies while hospitalized or restricted to home. Some schools may also have the technological equipment for distance-learning and may be able to video stream classes to the adolescent's home.

### Aim 3 - Day-to-Day Experience with EFD

#### *Life with an EFD after Traumatic Injury*

The participants' first reactions to the EFD were similar to those of their peers. All wanted to label this new device based on their experiences, similar to the prisoners' interpretations of shadows they saw on the walls of a cave, as described in Plato's *Allegory of the Cave* (Zucker & Borg, 2005). This allegory demonstrates that when exposed to a new image or object, one tends to think



about this new object based on past knowledge and experience. Because the EFD looked like something from science fiction or fantasy movies, the participants used space-age terms such as robot, bionic, terminator or alien. Most participants and their peers initially reacted with curiosity. Some were repulsed by seeing the skeletal pins enter the skin, similar to the reactions of adolescents who were treated electively with an EFD (Martin et al., 2003). Other similarities and differences were noted in the experiences of adolescents with EFDs placed electively and for traumatic injury. Similar to adolescents who had EFDs for elective limb correction/lengthening (Patterson, 2006), participants' physical function was restricted, their mobility was limited, sleep was interrupted, they attended fewer social events, missed school or work, and spoke of transient depression. In both groups, most disliked being dependent on others and were embarrassed by needing help with toileting and hygiene. For both groups of adolescents, parents and family were important and their roles in the adolescents' lives changed. Some parents missed work to be with their adolescent at the hospital. At least one parent of traumatically injured adolescents remained at the hospital for 24 hours while they were critically ill. This issue was not mentioned by adolescents treated electively with an EFD. Family members helped both groups of adolescents with small tasks they could no longer easily do (get food, drinks and other objects).

#### *Similar Adolescent Experiences with EFD for Trauma vs. Elective Treatment*

Participants in this study were impacted by EFD treatment for trauma in several ways: changes to activities of daily living, limits on mobility, loss of

independence, embarrassment at needing help with toileting and dressing, work school, sleep, appetite and body image disruptions, fears about healing, and decreased social contacts. These findings are similar to those in the literature on elective application of EFDs (Martin et al., 2003; Patterson, 2006). However, the EFD experiences of this study's participants were often overshadowed by limitations imposed by the traumatic injuries and treatment (e.g., chest tubes, NG tubes, spinal fractures, head injuries).

The participants also faced emotional difficulties and described friends as their key support, both helpful and protective, similar to reports on adolescents treated electively with EFDs (Martin et al., 2003). Younger participants (13-15 years old) treated with EFDs for traumatic injury valued parental support over peer support, whereas many older adolescents viewed peers as the most supportive resource. For instance, one participant called her friend for support while she was having a halo placed, even though her mother was in the room. This finding is consistent with the course of adolescent development, during which individuals strive to achieve independence from parents and peer relations become more important (Radzik, 2002).

Unlike adolescents treated with EFD for elective correction the participants in the current study had issues with body image related to the EFD as well as traumatic injuries and tried to hide them. A few participants in the current study talked about scars from the EFD, but most talked about scars from surgeries and injuries. For example, 2 participants described being more impacted than other teens because they had previously been involved in activities such as modeling

and cheerleading, in which physical appearance was an important factor. One of these participants was concerned because her feet had been deformed by the accident.

A strong finding of this study was that participants hated being stared at when they went out in public and the EFD was visible. This experience resulted in attempts to hide the EFD with clothing. However, the same feelings were described by other study participants whose injuries (eye damage and spine fracture treated with a plastic brace) were visible but didn't involve an EFD. This was similar and contrary to adolescents treated electively with EFDs who hated stares (Olson et al., 1991a) yet anticipated improved body image as a result of the EFD treatment (Lavini et al., 1990; Martin et al., 2003). These concerns about appearance reflect the developmental tasks of middle adolescence, in which body image is developed, peer codes and lifestyles are adopted, and conformity in dress becomes important (Radzik, 2002).

#### *Unique Adolescent Experiences with EFD for Traumatic Injury*

Adolescents treated with EFD for traumatic injury had several experiences that differed from those of adolescents with electively applied EFDs. The most poignant finding of the EFD experience of traumatically injured adolescents was the initial reaction to the EFD. They didn't have the opportunity for pre-operative sessions that introduced them to the EFD. They were very curious about it and reacted the same way as their peers, i.e., seeing it as something from the future. Some saw their EFD pins go into their skin, but could not feel them, so they tapped them to see how it felt. They didn't feel any sensation unless they turned,

causing the skin to pull at the edges of pin sites. This lack of preparation ran counter to the experience of electively treated adolescents, who had seen the EFD before it was applied (Martin et al., 2003).

The surprise of seeing the EFD prompted several participants in the current study to e-mail digital photos of their EFDs to friends so they could “get used to it” before their visits. This type of technology use to prepare friends and gain support from peers has not been mentioned in any previous studies on EFDs. With the internet generation (those born after 1994) predicted to spend 20 years of their lives interacting via internet (Biocca, 2000), this communication method seems like a natural progression for adolescents comfortable with this medium. The idea of using the internet (e-mail and chat rooms) for hospitalized pediatric oncology patients has been mentioned as a method of psychosocial support to link them to teachers, peers and others with cancer around the world (Suzuki & Kato, 2003).

Pain was also different for this study’s traumatically injured participants, especially when they were being transported with multiple injuries from the event site to the hospital. Those treated electively with an EFD had anesthesia and pain medication available from the application of the frame onward. They were also prepared by pre-operative teaching for the pain of the treatment, which most believed was not as bad as anticipated (Martin et al., 2003). Adolescents with an elective EFD were found to worry and become depressed that function might not improve after EFD removal (Patterson, 2006), whereas the injured adolescents in this study worried more about the injuries and issues related to the traumatic

injury that persisted well after their EFD was removed. For these adolescents, the EFD was not that “big of a deal.” This finding, which may have been related to the severity and extent of their injuries as well as the lack of pain from the EFD, was the biggest difference between the experience of these adolescents and those treated electively. Another factor that may have contributed to this difference was that EFDs for trauma were typically on for a shorter time (7 days to 12 weeks) than for deformity correction (typically 3-12 months) (Patterson, 2006). The shorter EFD treatment and the use of intra-operative IV antibiotics may also explain the finding of fewer infections in this study. This study clarifies the differences between adolescents’ experiences with EFDs applied electively versus for traumatic injury.

#### *Implications for practice*

The implications for practice arising out of findings from the third study aim centered on the adolescents’ getting used to the EFD. Adolescents could be encouraged to look at the EFD while a nurse or surgeon is present. Encouraging them to touch it and find out how stable it is will give them confidence. Before friends come to visit, adolescent patients can send digital photos by internet or cell phone, to show their friends what the EFD looks like. The most important intervention for adolescents before they go out in public with an EFD would be to prepare them for reactions to the device. Since people will naturally stare, nurses can role play with adolescents to practice their reactions to stares or questions. Another recommendation for practice is to teach adolescents about the many options for altering clothing to fit over EFDs and to allow easy access for

dressing and pin care. In this respect, Velcro can be used to alter the seams of shirts and pants.

#### Aim 4 – Adolescents Experience with Pin-Care Self-Management

Injuries and inability to reach the EFD prevented most adolescents in this study from caring for their own pin sites. Roles for pin care were decided by visiting nurses and parents until adolescents were able to participate in this care. Two participants stated that other adolescents would want to take care of their own pins. This preference may reflect the developmental norms of becoming independent and participating in self-care. Participants noted different methods of pin care used by nurses (e.g., unwrapping slowly or quickly) and chose their preferred method as another way to be independent. The adolescents' appreciation for the importance of good pin care to prevent infection was apparent in the way they meticulously followed pin-care instructions. One participant even continued to swab the site twice daily after the surgeon told him that once-a-day care was sufficient. One possible pin-site infection was noted among the 9 participants who had an EFD for acute traumatic injury, and 3 had sensitive pin sites. One participant was treated with antibiotics when his EFD was removed but did not remain on them for longer than the usual operative prophylaxis (3 perioperative doses). His pin-site area was debrided, a common treatment for infected pin sites, but he was not placed on oral antibiotics following discharge. These facts make it hard to determine if an infection was diagnosed. More information on antibiotic use and chart review could aid future studies to determine this information. The limited infections in this group differs greatly from

the experience of adolescents treated electively with an EFD; these teens experienced up to 4 pin-site infections each (Patterson, 2005). This difference is likely due to the shorter time of EFD application for traumatic injury than for elective limb lengthening, in agreement with a reported correlation between time with an EFD and rate of pin-site infection (Patterson, 2005).

#### *Implications for Practice*

The findings related to the fourth aim revealed that, despite healthcare professionals' concern about pin-site problems, pin-care self-management was not an issue for the participants. However, teaching about pin-site care was understood, retained and executed. Traumatically injured adolescents who can not initially care for their pins will most likely eventually do so; thus, both parents and adolescents should be taught pin care. Alerting adolescents to the problems associated with extreme temperatures will also help alleviate the discomfort of pin sites conducting extreme temperatures to sensitive inner tissues.

#### *Limitations*

The generalizability of the study findings are limited by the small sample of only 9 adolescents, 5 males and 4 females. The sample included only one black and one Hispanic participant, which limited the ability to give examples of racial or cultural differences in experiences with an EFD. Studies with a greater number of exclusively minority or female participants may enhance understanding of the EFD experience in adolescents from a cultural or gender perspective. One participant was interviewed with a parent present. This participant talked less than other participants and may have limited his information because of this

parental presence. His limited sharing may also have been influenced by his age as he was the youngest in the study. The use of one- or two-word answers by 3 young participants and the need for frequent prompts may have biased responses.

Interviewing in the clinic after appointments with the surgeon may not have been the best choice of timing for the final interview. Two participants whose interviews were scheduled after their appointment with the surgeon offered a limited amount of information and they both seemed rushed. This limitation might have been avoided by scheduling the final (third interview) prior to the appointment or interviewing in the participant's home.

The study findings are complicated by the multi-system injuries suffered by participants in this study. The experience of these adolescents is likely to be more complex than that of adolescents treated with EFDs for single-limb injuries. Recruiting a sample with single-limb injuries was compromised because of a change in EFD treatment of femur fractures. In the past many adolescents with femoral fractures were treated with an EFD to avoid injuring their physes. The number of femoral fractures treated with EFDs has decreased dramatically due to new surgical techniques and the use of flexible intramedullary nails. Therefore, most participants in this study had significant multi-system injuries. Since the future trend of EFD treatment will be for patients with multiple injuries, however, this study's findings provide baseline information for future studies with this population. Saturation of interview data was not reached for participants with single-limb or normal/common injuries. This characteristic of the study sample



likely skewed the focus of the entire study to the experience of acute traumatic injury rather than the experience of an injury treated with an EFD.

Interpretation of the findings may also be limited by the timing of the final interview. Final interviews were scheduled after EFD removal (approximately 3-4 months); however, participants had not completely healed and had not returned to regular activities. Longer follow-up may have provided more complete information about the experience.

Another limitation of the study was that information was not collected regarding use of pain medication before and after the interview. Thus, no conclusions can be drawn about changes in the pattern of medication use related to discussing the traumatic injury. Such information would be helpful in future studies to determine the effectiveness of medication use for telling about a painful experience. Furthermore, no information was collected on antibiotic use while participants were hospitalized, which may have affected pin-site infection outcomes. This area warrants future exploration.

#### Research Recommendations

The findings of this exploratory qualitative study inspire further nursing research on the adolescent experience of traumatic injury in at least 7 areas. First, the theme of *old self no more; forever changed* should be studied over a longer timeline, e.g., several months or years, with a larger sample and more females to ascertain if this experience remains constant or if it shifts to a “new normal” or “moving on” as found with adults (Richmond et. al., 2000). Second, related studies should focus on the family, to see how traumatic injury and the

all-encompassing process of recovering from the event affect the family unit. Third, a more in-depth exploration is needed of the alterations in adolescents' ability to recall details of the event over time. More study is needed on the connection between using PCA/narcotics for "telling the story" in the acute period and patient outcomes. Fourth, interventions could be designed to help adolescents cope with traumatic injury and learn about related risks by using information technology. Fifth, methods to increase adolescents' response to open-ended questions could be explored. Sixth, future studies could explore differences in the experiences of adolescents treated with or without an EFD for traumatic injury. Finally, studies could examine how the experience of injury, hospitalization and care by nurses, surgeons and therapists after trauma influence adolescent perceptions of healthcare professionals and career choice. It is unknown if these experiences lead adolescents to prepare for such careers or to become better caregiver for traumatically injured patients, as suggested by emerging patient-mentor programs (Geiger, Mullen, Sloman, Edgerton, & Petitti, 2000; Perry, Swartz, Kelly, Brown, & Swartz, 2003; Sullivan-Bolyai et al., 2004).

### Conclusion

Adolescents' experience of EFD treatment for acute traumatic injury is more complex than the experience with the EFD itself. The overarching theme of adolescents' experience with EFD treatment after traumatic injury was struggling to get back to their old self. The adolescents in this study discovered that they could not recover their old self because the traumatic event had affected every

aspect of their lives from their appearance, friendships, physical limitations and scars, to the realization that they were not invincible.

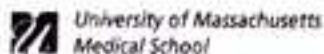
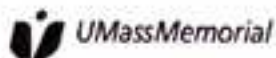
The study participants did not share many of the characteristics typical of adolescents involved in trauma. Because the adolescent participants did not see their behaviors as risky at the time of the event, prevention strategies are difficult to design for other teens. Educating parents and legislating or regulating use of ATVs, guns, motor vehicles, and trampolines are better pathways to prevent traumatic injuries. Adapting to an EFD may be easier for traumatically injured adolescents than adapting to their injuries. Pin-care self-management was seen by participants as no big deal and was determined by physical ability to reach and care for the pins. All adolescents participated in pin care when they were able.

The use of patient-controlled analgesia by acutely injured adolescents in the early days of hospitalization may have important implications for practice. Such use would not only allow timely control over pain, but may also provide a mechanism to help adolescents more comfortably explain the traumatic event. The coping mechanisms found in this study, particularly gender differences in outlets (girls used diary keeping whereas boys used electronic games) and the use of communication technology may influence practice by allowing nurses to offer more coping and educational options to traumatically injured adolescents.

This study's findings describe the adolescent experience of traumatic injury treated with orthopedic external fixation. These findings provide a

foundation for future studies on adolescents who suffer traumatic injuries, and offer areas for intervention by healthcare professionals.

APPENDIX A



Department of Orthopedics  
and Physical Rehabilitation

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July 9, 2004

David C. Ayers, MD  
Professor and Chair

To: Reviewer Ruth L. Kirschstein National Research Service Award

Re: *NRSA Proposal Adolescent Experience with External Fixation* by Miki M. Patterson

Dear Sir/Madam:

This is a letter in support of the research "*Adolescent Experience with External Fixation*" proposed by Miki Patterson, doctoral student in the Graduate School of Nursing here at the University of Massachusetts Medical School. As Chair of the Department of Orthopedic and Physical Rehabilitation at UMass Memorial Health Care, I support research between the department of Orthopedics and the Graduate School of Nursing.

I believe Ms. Patterson to be bright, focused and capable of conducting the proposed research in the time frame allotted. After reading the proposal, I understand my role and will assure access to the population and support of the Orthopedic Department. There will be a clinic room available for interviewing participants if needed. I will also be available for consultation for orthopedic or research issues and concerns.

If you need any additional information please do not hesitate to contact me.

Sincerely,

David C. Ayers, M.D.  
The Arthur M. Pappas Professor & Chair  
Department of Orthopedics & Physical Rehabilitation

## APPENDIX B

HSC Docket # H- 11505

UNIVERSITY OF MASSACHUSETTS MEDICAL SCHOOL  
COMMITTEE FOR THE PROTECTION OF HUMAN SUBJECTS IN RESEARCH  
UMass/Memorial Medical Center

### CONSENT TO PARTICIPATE IN A RESEARCH PROJECT

Title: **Adolescent Experience with Orthopedic External Fixation**

Principal Investigator: Dr. Susan Sullivan-Bolyai

Co-Investigators: Miki Patterson MS NP, and David Ayers MD

Research Subject's Name: \_\_\_\_\_ Date: \_\_\_\_\_

#### Invitation To Take Part and Introduction

You/Your child are invited to volunteer for a research study. You/Your child are asked to take part because you/your child is being treated with and External Fixation Device (EFD) for a traumatic injury.

#### Purpose of Research

The goal of this research is to see what it is like for young people 11-20 years old, to have an EFD. If we understand the whole experience we can try to design ways to help other teens deal with the treatment and care for their pin sites.

#### You/Your child Rights

It is important for you/your child to know that:

- Your/Your child's participation is entirely voluntary.
- You/Your child may decide not to take part or decide to quit the study at any time, without any changes in the quality of the health care you receive.
- You/Your child will be told about any new information or changes in the study that might affect your participation.

#### PROCEDURES

To be included in this study you/your child must be

- a. 11-20 years of age.
- b. treated with and EFD for acute injury.
- c. speak English
- d. be willing and able to be interviewed 3 different times with out a parent in the room.

#### Visit 1

This first visit will take place within the first 4 days of having an EFD placed and will involve a one hour interview. A brief (15 minute) interview that will be tape recorded, may occur with the parent / guardian around this time in person or by phone.

Version 7/15/04

APPROVED  
STUDY APPROVAL EXPIRES 12-21-07  
REVISION # 1  
REVISION APPROVAL DATE 4-29-05  
DOCKET # 11505

HSC Docket # H- 11505

**Visit 2**

You/your child will be interviewed 2-4 weeks after the placement of the EFD that will be tape recorded. This visit will take about an hour and can be done before or after your regular follow up appointment in orthopedic clinic if you would like or in your home. A brief (15 minute) interview that will be tape recorded may occur with the parent / guardian around this time in person or by phone

**Visit 3**

You/your child will be interviewed 2-4 weeks after the removal of the EFD that will be tape recorded. This visit will take about 1 hour and can be done before or after your regular follow up appointment in orthopedic clinic if you would like or in your home. A brief (15 minute) interview that will be tape recorded may occur with the parent / guardian around this time in person or by phone

You/Your child's participation in the research will last up to the time your EFD is taken off; require a total of 2 visits after discharge which can be at the same time as You/Your child's post operative follow- up visits if you choose.

This is the same follow up schedule you/your child would have if you were not in the research study.

**CONFLICT OF INTEREST DISCLOSURE - NONE**

**RISKS**

There is no physical risk expected of participants in this study. The only possible risk of participating is that you may experience stress when recalling traumatic experiences that led to the EFD treatment. If you/your child share information during the interview that may in the opinion of the interviewer, negatively affect your /your child's mental or physical well being, the interviewer will notify your health care providers or proper authorities immediately and will make emergency mental health services available to you / your child.

**RISKS OF STANDARD PROCEDURES BEING DONE FOR PURPOSES OF THE RESEARCH WHICH YOU MIGHT NOT NEED TO HAVE IF YOU WERE NOT IN THE STUDY**

NONE

**BENEFITS**

You / your child may not benefit directly from being in this research study. However, you/your child's participation may help others with this condition in the future because of knowledge gained from the research.

**REASONS YOU MIGHT BE WITHDRAWN FROM THE STUDY WITHOUT YOUR CONSENT**

You/Your child may be taken out of the research study if:

1. The investigator decides that continuing in the study would be harmful to you/your child.
2. You/Your child fail to keep your appointments for interview.



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4. The study is canceled by the University of Massachusetts Medical School Institutional Review Board.

#### **ALTERNATIVES**

If you/your child decide not to take part in this research study, your treatment will not be changed.

#### **COSTS**

There will be no additional cost to you/your child from being in this research study. The interviews visits that are done for research purposes will be free. Any costs for the standard treatment of you/your child's condition will be billed to you or your health insurance.

#### **COMPENSATION**

You/Your child will be paid the following amount to reimburse you for your time, travel and other expenses associated with this research study. A stipend of \$20 for your and /or your child's one hour interview and \$5 dollars for parking for each 1 hour interview completed at UMMHC. The parking compensation is eliminated if the interviews occur in your home.

#### **CONFIDENTIALITY**

You/Your child's privacy is important to us. To help keep information about you confidential, we have obtained a Confidentiality Certificate (CC) from the Department of Health and Human Services (DHHS). The Confidentiality Certificate adds special protection for research information about you. The Confidentiality Certificate will protect the investigators from being forced, even under a court order or subpoena, to release information that could identify you. We may release identifying information in some circumstances. You should be aware, however, that the investigators may release identifying information in some circumstances. If we see something that would immediately endanger you or others, such as child abuse, we may discuss it with you, if possible, or seek help. For example, we may disclose medical information in cases of medical necessity, or take steps (including notifying authorities). Also, because this research is sponsored by NIAAA, staff from that and other DHHS agencies may review records that identify you for audit or program evaluation. They, too, will protect your privacy. The federal auditors can use their audit information only for audit or evaluation of the program. They can't report anything that would harm the research subjects. This Certificate does not imply that the Secretary, DHHS, approves or disapproves of the project.

You should understand that a Confidentiality Certificate (CC) does not prevent you or a member of your family from voluntarily releasing information about yourself or your involvement in this research. Note however, that if an insurer or employer, learns about your participation, and obtains your consent to receive research information, then the investigator may not use the CC to withhold this information. This means that you and your family must also actively protect your own privacy.

**YOUR PARTICIPATION IN THIS PROJECT IS ENTIRELY VOLUNTARY. YOU MAY WITHDRAW FROM THE STUDY AT ANY TIME.**

**THE QUALITY OF CARE YOU RECEIVE AT THIS HOSPITAL WILL NOT BE AFFECTED IN ANY WAY IF YOU DECIDE NOT TO PARTICIPATE OR IF YOU WITHDRAW FROM THE STUDY.**



### **RESEARCH INJURY/COMPENSATION**

If you are injured or have any harmful effects as a direct result of your being in this research, treatment will be made available to you/your child at UMass/Memorial Medical Center (UMMMC). If you have health care insurance, the costs associated with this treatment may be billed to your insurer. You will not have to pay any charges resulting from the harmful effect or injury that are not covered by your insurance. If you/your child do not have insurance, you will not have to pay any charges resulting from the harmful effect or injury. This arrangement applies only when you receive medical care at UMMC. Only necessary medical treatment will be offered to you/your child; you/your child will not receive any additional compensation from UMMC. The fact that UMMC provides this treatment is not an admission by UMMC that it is responsible for the injury.

### **QUESTIONS**

Please feel free to ask any questions you may have about the study or about you/your child's rights as a research subject. If other questions occur to you later, you may ask Dr. Sullivan-Bolyai at 508-856-4185, the Principal Investigator. If at any time during or after the study, you would like to discuss the study or your research rights with someone who is not associated with the research study, you may contact the Administrative Coordinator for the Committee for the Protection of Human Subjects in Research at UMMS. The telephone number is (508) 856-4261.

**CONSENT TO PARTICIPATE IN THE RESEARCH PROJECT**

Title: **Adolescent Experience with Orthopedic External Fixation**

P.I. Name: Dr. Susan Sullivan-Bolyai

Subject's Name:

I understand the purpose and procedures of this research project and the predictable discomfort, risks, and benefits that might result. I have been told that unforeseen events may occur. I have had an opportunity to discuss the risks and benefits of this research with the investigator and all of my questions have been answered. I agree to participate as a volunteer in this research project. I understand that I may end the research study at any time. I have been given a copy of this consent form.

\_\_\_\_\_ Date: \_\_\_\_\_  
Subject's signature

**STATEMENT OF PERSON OBTAINING CONSENT**

I, the undersigned, have fully explained the details of this clinical study as described in the consent form to the subject named above.

Signature of person obtaining consent: \_\_\_\_\_ Date: \_\_\_\_\_

Subject's Representative if appropriate:

Name: \_\_\_\_\_ Relationship to Subject:  
(Print)

\_\_\_\_\_ Date:  
Representative's Signature

**INVESTIGATOR'S DECLARATION**

As the principal investigator or co-investigator on this study, I attest to the following:

- the nature and purpose of the study and study procedures, as well as the foreseeable risks, discomforts and benefits have been explained to the above-named subject
- this subject has been given the opportunity to ask questions and to **have those questions** answered by knowledgeable research staff

HSC Docket # H- 11505

- this subject meets the inclusion/exclusion criteria for this study

**I have considered and rejected alternative procedures for answering this research question.**

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

I have communicated with Dr. \_\_\_\_\_ on \_\_\_\_\_ and in his/her opinion it is acceptable for this patient to participate in this study.

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

## APPENDIX C

University Massachusetts Medical School  
Committee for the Protection of Human Subjects in Research  
UMass/Memorial Health Care

ASSENT TO PARTICIPATE IN RESEARCH  
Adolescent Experience with Orthopedic External Fixation  
Miki Patterson MS NP, Susan Sullivan-Bolyai DNSc, David Ayers MD

12-21-01  
4-29-01  
11505

1. My name is Miki Patterson, I am a student in the graduate school of nursing.
2. We are asking you to take part in a research study because we are trying to learn more about what it is like for injured young people 11-20 years old to be treated with and external fixation device.
3. If you agree to be in this study I will interview you three different times for about an hour each time. The first interview will happen in the next few days while you are in the hospital, if and when you are ready, the next interview will be in a couple weeks and once after you get the fixator off.
4. I will ask you to tell me about what happened and how things are going. I will record what we say with a tape recorder so I do not forget anything or get anything wrong. I would like you to choose the time and we will find a private spot so no one else will hear you. We will talk without your parents in the room so you may say anything you want without worrying about what they think. We are doing this study to find out what it is like for young people to have an external fixator so we can try to find ways to help them deal with it. At the end of each interview you will get \$20 dollars for your time and a coupon or \$5 for parking for your parent, if done at UMMHC.
5. There are no tests or blood work, just talking, but sometimes talking about a bad experience can make you sad or emotional.
6. You may get something from this study by being able to tell your story and sometimes that makes people feel better. You might feel good about helping us understand what this is like for you so we can help other teenagers with the same problem in the future.
7. Please talk this over with your parents before you decide whether or not to join the study. We will also ask your parents to give their permission for you to take part in this study. But even if your parents say "yes" you can still decide not to do this.
8. Your joining the study is totally your choice. If you don't want to be in this study, you don't have to. Remember, being in this study is up to you and no one will be upset if you don't want to join or even if you change your mind later and want to stop. Your medical care will not be changed if you do not want to participate.
9. You can ask any questions that you have about the study. If you have a question later that you didn't think of now, you can call me Miki Patterson 978-302-0095 or ask me next time. You may call me at any time to ask questions about your treatment.
10. We have also obtained a Confidentiality Certificate (CC) from the US Department of Health and Human Services (DHHS) to protect the researchers from being forced, even by court order or subpoena, to identify you. (The Certificate does not imply approval or disapproval of the project by the Secretary of DHHS. It adds special protection for the research information about you.) You should know, however, that researchers may provide information to appropriate individuals or agencies if harm to you, harm to others, or child abuse becomes a concern. Also, because this research is sponsored by NIAAA, staff from that and other health agencies may review records that identify



you. The federal auditors can use their audit information only for audit or evaluation of the program. They can't report anything that would harm the research subjects.

11. You should understand that a Confidentiality Certificate (CC) does not prevent you or a member of your family from voluntarily releasing information about yourself or your involvement in this research. Note however, that if an insurer or employer, learns about your participation, and obtains your consent to receive research information, then the investigator may not use the CC to withhold this information. This means that you and your family must also actively protect your own privacy.
12. Signing your name at the bottom means that you agree to be in this study. If in any way you decide not to join or change your mind later on; your doctors will still to take care of you just as they had before you were in this study. You and your parents will be given a copy of this form after you have signed it.

\_\_\_\_\_  
Name of Subject

\_\_\_\_\_  
Date

UNIVERSITY OF MICHIGAN  
APPROVED  
EFFECTIVE PERIOD EXPIRES 12-21-07  
REVISION # 1  
REVISION APPROVAL DATE 4-29-05  
OFFICE # 11505

APPENDIX D  
Demographic and Clinical Data Questionnaire Form

Participant Code
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Demographic Measure	Time #1 1-4 days	Time #2 2-4 weeks	Time #3 EFD removal
Age (years/mos)	/	-----	-----
Grade in school		-----	-----
Race		-----	-----
Ethnicity		-----	-----
Insurance Y/N	Y/N	Y/N	Y/N
Family constellation in present home M=mother F= father # brothers # sisters S==step O= other explain	M    F _ B _ S SM SF SB  SS O _____	M    F _ B _ S SM SF SB SS O _____	M    F _ B _ S SM SF SB SS O _____
Parent occupation	M _____ F _____	-----	-----
School attendance Y/# days missed	Y/ days	Y/ days	Y/ days
Hospital Length of stay	-----		-----

Clinical Measures	Time #1 1-4 days	Time #2 2-4 weeks	Time #3 EFD removal
Day/Time injury	x	-----	-----
Mechanism of injury	x	-----	-----
Vitals signs ISS	P ___ R ___ BP /_____ T    ISS	-----	-----
Alcohol/drugs Seatbelt / helmets	+ / -	-----	-----
Location EFD	x	-----	-----
Fracture type	x	-----	-----
No & size of pins	x	-----	-----
Type EFD	x	-----	-----

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