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Through children's eyes : understanding visible and invisible injury in military parents : a project based upon an independent investigation

Meredith Grace Morray
Smith College

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Through Children's Eyes:
Understanding Visible and
Invisible Injury in Military
Parents

ABSTRACT

This qualitative study explores how young children (age 5-11) experience and

develop empathy about parents who are suffering from physical and psychological

injuries. This study was based on a Sesame Workshop film which depicts five families

with a parent returning from war with either a visible (arm or leg amputation) or an

invisible (Post Traumatic Stress Disorder or Traumatic Brain Injury) wound. Children of

military families (n= 28 children) and children of civilian families (n= 42 children)

comprised the study sample. Focus groups based on a semi-structured interview guide

were conducted after the viewing of the film. Findings indicated children's difficulty in

understanding the abstract nature of emotions associated with invisible injuries as well as

their thirst for knowledge, even when this is accompanied by fear or anxiety about the

subject matter. Suggestions for family educational materials are provided.

THROUGH CHILDREN'S EYES: UNDERSTANDING VISIBLE AND INVISIBLE

INJURY IN MILITARY PARENTS

A project based upon an independent investigation,
Submitted in partial fulfillment of the requirements
For the degree of Master of Social Work.

Meredith Morray

Smith College School for Social Work
Northampton, Massachusetts 01063

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CHAPTER 1

INTRODUCTION

When a parent is suddenly injured, either mentally or physically, the family enters

into the world of disability with scarce information to guide them into this life-altering

transition. Clinical attention to parenting and illness/injury has primarily focused on

situations of an ill or disabled child, while parental injury has remained a largely

unexplored territory. Researchers have shown that the consequences of traumatic events

are not limited to the persons immediately exposed to the event, as they often affect

significant others in their environment such as caregivers and children (e.g., Dekel &

Goldblatt, 2008; Cozza, Chun & Polo, 2005; Galovski & Lyons, 2004). This potential

"secondary traumatization" can be overwhelming to all those involved. More specifically,

the challenge of adapting to an "invisible" injury – one that affects a parent's behavior

and mood but not his appearance, may engender particular difficulties for young

children's understanding and coping. These parents may be physically present, but may

be emotionally absent, or the injured parents may seem different in their behavior yet

unchanged in their appearance. Appropriate clinical intervention and family education to

support these families is severely lacking (Rolland, 1999).

The current study focuses on how children understand visible and invisible

injuries and how they develop empathy about parents who are suffering from such

injuries. Given the recent wars in Iraq and Afghanistan, and the current national climate

of unrest, I will be emphasizing invisible injuries such as post traumatic stress disorder

(PTSD) and traumatic brain injury (TBI), common in military populations, as a backdrop for the broader purposes of this study. I use the example of injuries in the context of military families to talk with both military and civilian children and to hear from their voices how visible and invisible injuries are understood.

While this paper is a study using the military as a framework for how we can better understand the challenge of explaining visible and invisible injuries to children, it does not delineate understanding into two separate worlds, military and civilian. This need for understanding is not only applicable to the military, but to the general population, as well. Victims of violence and those who experience any traumatic event are at risk for invisible injuries. I seek to gain understanding of how children can identify and empathize with adult/parental symptoms and emotions even when their own families are not directly affected. With this in mind, the study presented in this thesis poses the following question: How do children between the ages of 5 and 11 understand and talk about visible physical injuries and "invisible" injuries (e.g. Traumatic Brain Injury) in parental figures?

Military Families as a Backdrop

In the midst of the wars in Iraq and Afghanistan, there has been increased interest in the health and well being of the children and families of military service members. Currently, more than 700,000 American children under age five have a parent deployed in military service, the highest number since World War II (American Psychological Association, 2007). As a result, there is a vast population of young children of service members who face unique challenges. Some of these issues include stress or anxiety regarding homecomings - especially for those children whose parents have been wounded

in service, who struggle with the added emotional stress associated with a parent's combat related stress or injury. Nearly 90% of service members who are wounded survive combat related injuries, but many are left with serious, life changing side effects, including both those that can be seen visibly and increasingly, wounds that are relatively invisible (APA, 2007). Although there are various kinds of invisible injuries, the focus of this paper will be on two kinds of invisible injuries relevant to this study: post traumatic stress disorder [PTSD] and traumatic brain injury [TBI].

Wounded military service members must cope with changes to their bodies and minds. Numerous studies have highlighted the efforts of spouses and parents to help their loved ones navigate medical treatment, regain abilities, or adjust to permanent disabilities (Galovski & Lyons, 2004; Matsakis, 2007; Wright et al, 2006). Little is known about the needs and fears of the children in these families. However, it is clear a child's developmental maturity will influence how he or she is able to comprehend and respond to having an injured parent (Diarme, Tsiantis, Romer, Tsalamanios, Anasontzi, Paliokosta & Kolaitis, 2007). Once we understand how children make sense of injury and the ways in which they cope with these challenges, we will be more capable of talking to them about these issues in effective and sensitive ways. This is especially pertinent at the current time as increasing numbers of military personnel are coming home to a society where people are going to need to understand their struggles and the challenges their families face.

Sesame Workshop's Role in Linking Military and Civilian Families

Careful adaptation of educational materials to meet the developmental levels of young children is imperative. The materials under girding this study were developed by Sesame Workshop, a company well known for its educational material that has reached young people across the world in developmentally appropriate and culturally sensitive ways. Sesame professes, "Research is our anchor and our compass. Sesame Workshop pioneered a model for *Sesame Street* that has proven successful for decades. We attribute much of that success to our collaborative, research-intensive approach to the development of programs and activities. The Workshop's offerings reflect both a deep understanding of children's developmental needs and the best ways to address those needs. As a result, Sesame Workshop's programs and products are richer, more thoroughly researched and tested to ensure they engage children in a way that maximizes learning." (Sesame Workshop, 2010). Researchers for the current study chose to use the Sesame Workshop program, *Coming Home: Military Families Cope with Change,* as the stimulus for children to react and respond to various images of families affected by the physical and/or psychological injury of a parent.

CHAPTER 2

LITERATURE REVIEW

To date, more than 3,240 Americans deployed in support of the Global War on Terrorism (2001-present) have been killed and over 33,000 have returned from a combat zone with physical wounds and a range of permanent disabilities. According to the VA Office of Research and Development (December 2008), blasts are the most common cause of injury in the Global War on Terror. Blast injuries are often polytraumatic, meaning they affect multiple body systems or organs. Because of improvements in body armor, as well as battle-site and acute trauma care, service members from OIF and OEF are surviving beyond the acute phase of blast injuries. However, they are surviving with new and complex patterns of injuries including traumatic limb amputation, nerve damage, burns, wounds, fractures, vestibular damage, vision and hearing loss (VA Office of Research and Development, 2008). The current study uses the example of traumatic limb amputation (amputation of legs and arms) to represent "visible" injuries.

In addition to physical wounds, as many as one-fourth of all returning service members are struggling with less visible psychological injuries (APA, 2007). Two of the most common invisible injuries affecting service men and women and their families are post traumatic stress disorder and traumatic brain injury. These injuries are not uncommon in civilian populations as well. We continue with a brief review of traumatic limb amputations, and then will focus on the two types of invisible injuries that are being presented in this study.

Traumatic Limb Amputation

When an individual loses a limb there are a number of symptoms, both physical and emotional, that may accompany this traumatic wound. Some amputees experience extreme pain including phantom limb pain: the perception of sensations, including pain, in a limb that has been amputated (Nelson-Hogan, 2007). In addition to this physical pain, it is not uncommon for individuals to experience depression, anxiety, flashbacks, resentment, anger, rage, fear, helplessness, and the loss of body integrity (Wain, 2008). Amputees must re-learn basic skills and tasks of every day life-some having to learn to walk again, to tie their shoes, and to get dressed. Wounded individuals must mourn the loss of their former appearance, as well as their former way of functioning, athletic ability, and hobbies. While this can be devastating for the injured parent, it may be more confusing and equally devastating for children in the family. The child may think that because the parent looks physically different he or she is not the same parent from before the injury. The child may fear that the injury will happen to him, that it is his fault, that it is contagious, or be afraid that his parent will no longer be able to play with him. Understanding these fears and the common misconceptions of children is central to the development of educational materials aimed at supporting families adapting to the life-altering change.

Post Traumatic Stress Disorder

Post traumatic stress disorder (PTSD), as defined by the Diagnostic and Statistical Manual of Mental Disorders (4th ed., text rev.; American Psychiatric Association, 2000), develops in some people after they have been exposed to a traumatic event such as sexual

abuse, a serious road traffic collision, a natural disaster, criminal victimization, or military combat. PTSD is characterized by a range of symptoms: vivid re-experiencing of the trauma (e.g., intrusive memories, recurrent nightmares), avoidance of trauma-related stimuli (e.g., effortful attempts to avoid places, people, or recollections of the trauma), emotional numbing (e.g., difficulty experiencing close emotional connections to other people), and hyperarousal (e.g., hypervigilance, irritability, or insomnia). To be diagnosed with PTSD, at least one re-experiencing symptom, at least three avoidance or numbing symptoms, and at least two hyperarousal symptoms must be present for at least a month. Recent research (Kessler, 2000; APA, 2000; Breslau, 2002) estimates that 12% of the American population develops PTSD at some point in their life.

There are few objective data that help us in our understanding of the impact of psychological injury on the family and –specifically-- the children. The vast majority of literature focuses on the impact of living with an individual suffering from PTSD (e.g., Dekel & Goldblatt, 2008; Cozza et al., 2005; Galovski & Lyons, 2004). Rosenheck and Nathan (1985) described the negative impact of PTSD in Vietnam veterans on their children. Others have described the significant impact of PTSD (reduced family cohesion, decreased interpersonal expressiveness, greater interpersonal conflict, and reduced problem solving ability) on the families of Vietnam veterans with PTSD. Researchers have recently begun to explicate the nature of the associations between PTSD symptoms and family adjustment difficulties. With regard to children and family adjustment, both avoidance/numbing and hyperarousal symptoms were found to be associated with poorer adjustment (Evans, McHugh, Hopwood, & Watt, 2003; Hendrix, Erdmann, & Briggs, 1998). It is important to note that these studies use the accounts of

other family members to assess children's responses to parental injury. Research focused directly on children's perceptions is scarce (e.g. Davidson & Mellor, 2001; Harkness, 1993).

<div align="center">*Traumatic Brain Injury*</div>

Traumatic brain injury (TBI) is an injury to the brain resulting from an externally applied mechanical force that affects the brain and leads to loss of consciousness or coma (Defense and Veterans Brain Injury Center, 2008). Most cases of TBI result in changes that affect cognitive, emotional, communicative and social functions (Stratton & Gregory, 1994). Depending on the severity of the injury, the presence of these changes may be either subtle or obvious. When a family member suffers a TBI, this adversely affects each individual and the system (family) as a whole.

Studies that address the impact of traumatic brain injury on the family suggest that psychological, cognitive and behavioral changes in the injured individual may produce significant and enduring stress for the rest of the family (Brooks, Campsie, Symington, Beattie & McKinaly, 1987; Lezak, 1988; Pessar, Coad, Linn, & Willer, 1993; Thomsen, 1974). Although considerable data have been reported about the stresses imposed by head-injured patients on primary caretakers within a family, we know relatively little about how children are affected when parents sustain such injuries (Urbach, 1989). Of great concern to injured individuals and spouses are the psychological and social disruptions within the family that may influence children's psychological and social well being (Willer, Allen, Liss, & Zicht, 1991). Children living with a parent with a brain injury have been reported to be at higher risk for emotional and behavioral difficulties that include running away, delinquency and truancy, dropping out

<div align="center">8</div>

of school, diminished social competence and insecurities in peer relationships (Lezak, 1978; Urbach and Culbert, 1991; Pessar, Coad, Linn, & Willer, 1993).

The frequency of TBI, especially as a result of the wars in Iraq and Afghanistan, implies that many children will grow up facing such injuries either in a primary caregiver or in their social world. Among surviving soldiers wounded in combat in Iraq and Afghanistan, TBI appears to account for a larger proportion of casualties than it has in other recent U.S. wars. According to the Joint Theater Trauma Registry, compiled by the U.S. Army Institute of Surgical Research, 22 percent of the wounded soldiers from these conflicts who have passed through the military's Landstuhl Regional Medical Center in Germany had injuries to the head, face, or neck (Okie, 2005). It has been noted that the true proportion is probably higher, since some cases of TBI are not diagnosed promptly. In the Vietnam War, by contrast, 12 to 14 percent of all combat casualties had a brain injury, and an additional 2 to 4 percent had a brain injury plus a lethal wound to the chest or abdomen. Because mortality from brain injuries among U.S. combatants in Vietnam was 75 percent or greater, soldiers with brain injuries comprised only a small fraction of the casualties treated in hospitals (Okie, 2005). Present advancements in military medicine and protective body armor have resulted in increased numbers of American military service members surviving devastating injuries in Iraq and Afghanistan (Collins & Kennedy, 2008). TBI is being called the "signature wound" of these wars.

With a peak incidence of TBI occurring in individuals under the age of 35, this injury befalls many parents (or parents to be) of young children (Uysal et al. 1998). The frequency of TBI in people of child rearing age implies that many children will grow up in families affected by TBI and there is a need to understand how young children are able

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to cope with this often "invisible" injury in their parental figures.   There are few

objective data that aid us in our understanding of the impact of injury in general to

military parents during wartime on children, let alone the more specific needs of children

grappling with TBI and the symptoms and issues associated with it.

Children's Response to Parental Injury: A Developmental Perspective

Diarme et al. (2007) highlighted that children's psychological needs, issues, and

behavioral manifestations in response to parental illness and injury vary depending on the

child's developmental stage. Using a developmental approach, Armsden and Lewis

(1993) elaborated four major issues pertaining to children's reactions to parental physical

illness; (a) *security and separation anxiety* (younger children may react with fear, anger,

and aggression toward others or toward themselves, whereas adolescents are more likely

to experience conflict between autonomy and responsibility); (b) *interpersonal*

understanding (younger children may not clearly differentiate a parent's feeling state

from their own and thus may tend to link an ill parent's condition with their own

behavior, whereas adolescents can consciously reflect on how to reduce an ill parent's

burden); (c) *concepts of illness and death* (whereas younger children tend to define

illness through observable behavior, such as lying in bed, adolescents may be

preoccupied with the fear of potential of genetic transmission of their parent's illness to

themselves); and (d) *fantasies* (in children's coping strategies, fantasies can be both

helpful and stressful).

This developmental framework provides a foundation for understanding how

children perceive and respond to information about their parents' medical illness. It is not

known whether the same framework applies to children's understanding and response to invisible injuries such as PTSD and TBI. Nevertheless, the framework may be quite helpful for guiding our thinking about children's reactions to parental injury, as many developmental and familial challenges are similar between life-changing or threatening illness and injury.

For starters, the information that parents share with children about a parent's injury or illness may or may not be developmentally appropriate. The information shared may be based more on the anxieties of parents than the needs of the children. Parents may choose to share either too much or too little information with children, making it difficult for them to understand the nature or seriousness of the injury and its realistic implications for the injured parent (Cozza et al., 2005). A framework, guiding parents and professionals in the realistic expectations for how children might be able to formulate an understanding of the complex and abstract aspects of invisible injury, is necessary and lacks previous study.

Researchers (Rolland, 1999; Stallard et al., 2004) suggest a need to explore how effective communication between parents and children can be facilitated, so that children do not feel responsible for their parent's illness. Children's knowledge about their parent's mental and/or physical health needs to be assessed, and communication must be structured at a developmentally appropriate level. Younger children, for example, will need more practical and concrete information, whereas adolescents may be interested in more abstract and complex issues.

Understanding Emotion and the Development of Empathy

When an individual is injured, the after effects include physical symptoms as well as emotional consequences. Some residual problems related to amputations include phantom pain (a feeling of pain in the missing limb), grief, and medical complications (War Related Illness and Injury Study Center, 2010). These symptoms are troubling to the individual experiencing them, and also may be anxiety provoking for family members unable to understand the exact experience of their injured loved-one. Common symptoms of brain injury include, but are not limited to, feeling sad, anxious, or listless, becoming easily irritated or angered, and feeling tired all the time (Defense and Veterans Brain Injury Center, 2008). Similarly, the symptoms of PTSD include loss of interest in activities, feeling detached from others and emotionally numb, and irritability or outburst of anger (APA, 2000). These "emotional" symptoms, when seen in parental figures, would be difficult for young children to understand, especially due to the somewhat abstract nature of the cause of the emotion which they are not yet developmentally capable of comprehending.

There is general agreement in the literature that children's emotional reactions to other people's emotions and their understanding of other people's emotional states are both relevant to their social behavior and interpersonal relations (Hughes, 1981). Over the last two decades, several cognitive developmental studies have demonstrated important changes in children's understanding of emotion from the ages of 18 months through 12 years. These changes include children's developing understanding of the nature of emotions, their causes and the ability of a child to regulate and control emotions and their expression (Harris, 2000; Manstead, 1994; Pons, Harris, & deRosnay, 2000).

With this developmental maturation occurring over 12 years, younger children will struggle to a great extent with physical injuries and disabilities, and even more so with the abstract nature of emotion accompanying both PTSD and TBI.

Empathy is a response to another's emotional state or condition. The core of the empathic experience is an affective state congruent with the other's situation. Hoffman (1987) provides a detailed theoretical account of the potential role of cognition in empathy. Young children tend to focus on readily observable, external characteristics of people. With increasing age, this focus is shifted to internal dimensions of the person (Barneboim, 1977; Peevers & Secord, 1973; Shantz, 1983). This developmental change in perspective taking is apparent when children explain their empathic feelings. Thus compared to younger children, older and adolescent children are more likely to explain their empathic feelings by referring to the internal psychological perspective of the target person (Hughes, Tingle, & Sawin, 1981; Strayer, 1989).

While numerous researchers (e.g., Bateson et al., 2003; Eisenberg, Shea, et al., 1991; Feshbach, 1978; Hoffman, 1982) have examined how empathy and perspective taking are developed in young children in general, there is scant literature on how this development affects a child's ability to cope with and understand more abstract and ambiguous states of mind and emotion in others, for example, in response to PTSD and TBI. Within this small body of literature, researchers have focused on PTSD and how the symptoms of anger, aggression, depression, and withdrawal have influenced an individual's ability to parent and disrupts the development of a positive parent-child relationship (e.g. Rosenheck, 1986; Davidson & Mellor, 2001; Ruscio, Weathers, King, & King, 2002). New research is needed in this area in order to better understand how to

discuss these issues with young children in order to enhance their understanding of the emotional states that accompany more "invisible" injuries, as well as promote empathy toward this population of injured individuals and their families, as they become an increasingly visible part of our population.

Summary

The return of an injured parent from war is not something for which a young child is ever prepared. Injuries sustained by service members often include physical wounds as well as invisible wounds such as TBI, and mental health disorders, including PTSD. The service member's own level of adjustment or grief, as well as the spouse's reaction to the injury, undoubtedly impacts their abilities to relate as parents to their children and care for their emotional needs. Service providers have limited literature to guide them in their work with individuals and families coping with combat injuries. Similarly, we know little of how these injuries get discussed and coped with in civilian families, whether these issues arise in their own families and lives or in their social environments. In the current research I therefore seek to explore how young children (ages 5-11) describe and understand visible and invisible injuries in their parental figures, with the goal of facilitating the development of educational materials to promote healthy coping behaviors, with an emphasis on the less studied and newer area of invisible injuries.

The specific areas of inquiry in this study are:

(1) How young children describe an injury, generally, and an "invisible injury" more specifically;

(2) How young children explain emotions such as anger and sadness that are expressed

by the injured parent; and

(3) How young children are able to empathize with the injured parent, as well as other

children who are adjusting to the experience of having an injured parent;

CHAPTER 3

METHODOLOGY

As little research exists in the area of children's understanding of parental injury, an exploratory study was designed. A qualitative method whereby focus group interviews were used as the primary data source was utilized in order to gather rich descriptive data directly from the child's perspective. The current research was done in conjunction with the evaluation project of Sesame Workshop's video *Coming Home: Military Families Cope with Change*, conducted by Dr. Marsha Kline Pruett. This study utilizes a small part of that evaluation as well as some additional questions developed for this thesis.

Researchers for the larger study's evaluation utilized both quantitative and qualitative methods to gauge 1) parents' reactions to the program for themselves and their children; 2) whether parents report an increase in their own awareness of issues facing military families and empathy for the challenges presented upon homecoming, and 3) what the children felt toward the children in the Sesame produced video. In the current study, the selected sample was drawn from the larger sample of Sesame project participants, and additional qualitative data were collected in conjunction with the information being gathered as a part of the larger project. The research questions were assessed based on children's reactions to the injured parental figures depicted in the Sesame Workshop film.

Recruitment of Participants

Military Families

The initial recruitment of military families for the larger study started by researchers distributing flyers to bases with strong military involvement and an historical relationship with Sesame Workshop. Key contacts from those sites that expressed interest in taking part in the screening of *Coming Home: Military Families Cope with Change* were then sent an email describing the study and inviting communities to participate. From among the sites who responded favorably to participation in the study, Sesame and researchers selected five sites based on 1) a strong prior relationship with the primary contact at the site; 2) easy access from a major transportation hub (plane or train); and 3) anticipated size of the audience at the site. Sites with high familiarity, easy access, and an anticipated audience size of more than 40 families were given preference for selection. In addition, several military sites were contacted through personal contacts of Smith College School for Social Work faculty and students.

Civilian Families

Screenings for civilian families were organized by identifying agencies or organizations (schools, churches, social service agencies) through personal contacts among Smith faculty and alumni and contacting those organizations directly. Efforts were made to obtain diversity in the civilian groups, to identify communities not unlike the military communities that participated, and to reach out to a mixture of civilian groups that served both normative and vulnerable populations. The purpose of the latter

was to reach civilian parents who had or might have to cope with family changes and injuries that bore some similarity to those the military families faced. The civilian agencies that chose to participate agreed to prescreen the show and be part of the research.

Sample

In total, nine sites participated in the study, with four sites receiving the expanded focus group interviews designed for the current study. Participants were 70 children between the ages of 5-11 years. The sample represents Hispanic, African American and Caucasian participants. Two sampling groups were included in the study: children of military families (n= 28 children) and children of civilian families (n= 42 children). Children were recruited through sites previously arranged for the larger Sesame Workshop research project as well as through personal contacts of this researcher. At each of the sites, a focus group was conducted with children ages 5 or older, targeting 5-8 years old (see Table 1 for demographic breakdown).

Data were collected in different areas of the country to have a greater chance of obtaining ethnic, socioeconomic, and residential diversity in the sample. The civilian children were included as a comparison group to learn if the show evoked similar reactions in civilian as military children, and if the civilian children expressed empathy for the children in the film.   For the purpose of the study, military children were defined as children in which at least one parent is or has been a member of one of the military branches (including the National Guard and the National Reserve), and is or has been deployed in the current war in Iraq and Afghanistan. Civilian children were defined as having families in which neither parent is or has been a member of any of the military

branches. Due to the design of the study, using the children's reactions to experiences of families and children in the film instead of reflecting on personal experience, having an injured parent was not a part of inclusion criteria. Nevertheless, this descriptive data was assessed so that it could be taken into account during analysis.

Data Collection

The stimulus for this research was Sesame Street Workshop's film, *Coming Home: Military Families Cope with Change*. The film uses Sesame Street's beloved characters of Elmo and Rosita, along with celebrities Queen Latifah and John Mayer, to explore issues of parental injuries with children. The film also aims to help parents more effectively communicate with their children. The film includes stories of families coping with physical injuries, such as limb amputations, as well as families coping with "invisible" injuries, such as PTSD and TBI. While the larger program evaluation used both quantitative and qualitative data collection, only the data from the focus groups are used in this study. Focus groups based on a semi-structured interview guide included four questions designed for the larger evaluation, which addressed injuries in general, and four questions added for the current study that focus more specifically on invisible injuries (see Appendix A for a full list of questions used in the research). The latter four questions were added after the initial focus groups when it became clear that if children were not directed to talk about invisible injuries, they were more likely to answer only about the visible injuries, such as arm and leg amputations. Therefore, the first four focus groups were conducted with the original questions that aimed at a child's understanding of parental injury in general (both visible and invisible) and subsequent groups used the

Table 1

Civilian Focus Group Demographic Information

Location	Race	Age	Unique Characteristic
Tulare Lindsay, CA	9 Hispanic	All ages (5-11)	All Spanish speaking
Depelchin-1 Houston, TX	3 Hispanic 6 African American 4 Caucasian	All ages (5-11)	All involved in child welfare system
Depelchin-2 Houston, TX	3 Hispanic 6 African American	All ages (5-11)	All involved in child welfare system
Northampton-1 Northampton, MA	1 African American 1 Caucasian 1 Asian	Young (5-8)	
Northampton-2 Northampton, MA	1 African American 7 Caucasian	Older (9-11)	

Table 2

Military Focus Group Demographic Information

Location	Race	Age	Unique Characteristic
Contra Costa Concord, CA	2 Hispanic 8 Caucasian	All Ages (5-11)	Parents – Coast Guard
Houston VA Houston, TX	2 African American 4 Caucasian	All Ages (5-11)	
W. Orange Armory West Orange, NJ	5 African American	All Ages (5-11)	Parents - National Guard
Veterans Resource Center New Brighton, MN	2 African American 5 Caucasian	All Ages (5-11)	Parents - Active Duty, National Guard, and Reserves

expanded focus group protocol which included four questions designed to assess more directly the area of invisible injuries. The data collection was flexible in that follow up questions and clarifying questions were utilized to get a more in depth understanding of the children's thoughts. Children were allowed to reflect on questions with one another, with the researcher re-directing to the specific interview question if necessary.

At each participating site, a contact person organized the screening, recruited families to attend the screening with their children, identified spouses and children willing to participate in the focus groups ahead of time, and obtained the space for the screening. Smith evaluators brought evaluation materials, Sesame trinkets, and provided food for a snack. Data were collected by this researcher, or by a trained Smith masters/graduate level student.

At each site a focus group of 5-8 children was conducted with children ages 5-11. Whenever possible, children were divided into two focus groups based on age (5-7 and 8-11) to facilitate analysis based on age groupings of younger or older children. Although we aimed to get 5-8 children in each group, due to logistical considerations (i.e., parents were in their own groups and they wanted their children to participate), some groups were necessarily larger and some were smaller. Also, in one group, younger children were included in the group (3-4 year olds) because parents at the site encouraged it and the researchers made every effort to accommodate the parents. This group provided very little data, and the researchers became less accommodating after the first groups included a larger number of and/or younger children. Each group took approximately 45 minutes to conduct. The parents of the children in the focus groups were invited to be in the room during the session and to observe the proceedings, but they declined for all groups.

Parents were informed of the questions being asked of their children to prepare them for possible questions and emotions that might arise after the research session. Participation would have been declined for any child who was reluctant to participate, despite his/her parent's enthusiasm, although this did not occur at any site. Children were given verbal permission at the start of the focus group to end their participation if they felt uncomfortable in any way.

Informed Consent Procedures

Approval for this research was obtained on March 2, 2009 from the Smith College School for Social Work Human Subjects Review Committee (see Appendix B). In keeping with procedures set out by the Committee, and as noted above, consent for child participants was obtained from a parent or guardian of the child before they took part in the study (see Appendix C). In addition, verbal consent was obtained from each child in the form of willingness to be part of a focus group. The informed consent form explains the purpose of the study, the risks and benefits of participation, and the right to refuse to answer any question or to withdraw from the study at any time. The consent form also explains how the study will maintain the confidentiality of participants. A second copy of the consent was provided in each parent's packet and they were instructed to keep the extra copy for their records as well as for contact information should any questions or concerns arise from their participation in the study.

Data Analysis

The focus group sessions were audio taped and transcribed verbatim. The focus group that was conducted in Spanish was transcribed, translated, and then retranslated by

a second party. Data were analyzed using the constant comparative approach whereby comments are coded and codes are compared with each other to derive a set of themes. The four qualitative interview questions that were a part of the larger evaluation study were analyzed thematically by five researchers, then reviewed and compared. The four subsequent questions designed for this independent research were analyzed, coded and broken into themes by this researcher and Dr. Marsha Pruett. For each focus group question, a spreadsheet was designed to capture the relevant data according to topic and across participants and groups; thus providing a visual representation of the data that allowed for easier identification of themes and patterns. Representative quotes were used to substantiate these themes or ideas. Only two of the more "general" questions designed for the larger study were analyzed and used in the current study.

CHAPTER IV

RESULTS

Question: What do you think the children on the show were feeling?

Military Focus Group

When military children were asked the question about how they thought the children in the film were feeling, most participants in this group felt that the children would be feeling sad (nine comments). Some of the comments were "Sad, because his Daddy's hand was messed up;" "Sad, because it's sad when people hurt things; " and "Sad and worried because their dads got hurt and they had to come back a little....worried."

Being worried was mentioned three times. There were also two participants who felt that the child might feel "mad because of what happened to his family." One of those children explained the whole grieving process and how being angry fit in: "At first they were really, really worried, and then they got sad, and then they might have gotten really angry because of what happened to their dad, and then they might have gotten a little bit confused, but then they would be happy again… like when they realize that their dad is the same except that they're hurt."

Other children identified with happy emotions as well. There was a comment that the child whose father lost a leg might be "happy because [his father] only had one leg, but now [that he has a fake leg] he's happy 'cause he can do stuff!" One of the military

children's main themes was curiosity about the injuries presented on the film and a fascination with the "fake" limbs (five comments). The participants expressed inquisitiveness about how the fathers on the film had gotten injured and how the prosthetic devices worked. Some of their questions include:

"What happened to his leg?"

"Why did the dad not have a leg?"

"Can [his leg] grow out?"

"Why did he have a robotic leg...How did he get injured?"

The younger military children, perhaps having been exposed to the possibility of a parent getting hurt, were more likely to be curious about the specific details of the injury, than to focus on the emotion and fear of such a thing occurring. These children wanted information. In a group with somewhat older participants, the children also dwelled on sadness and worry as the most likely emotions felt by the children on the show.

Civilian Focus Group

In comparison to the majority of the military children, when civilian children were asked to describe how they thought the children in the film were feeling, the majority of participants expressed that the children may be feeling worried and scared (11 comments). Compared to the lack of fear expressed by most of the military children, scared and worried themes loomed large among the civilian children. Participants believed that the children in the show might be worried about the changes that have taken place physically and psychologically with their parent, and the children in the show might be concerned about whether the person returning was going to be the same and "still their

dad." Examples of specific comments include that they may be "worried that their dad was different…maybe it wasn't their real dad." One child felt that the child might be "scared because they hadn't seen their parent in so long. Nervous that they wouldn't remember them and they weren't like they used to be." Another child stated that he thought the child in the film might be "scared and confused because their dad went away and they didn't know if he would come home or somebody else." Many expressed that the fear may be about whether the parent was going to die. The children commented that the show's children were "scared and not sure what was going to happen. Was his dad going to die? Was he going to come home?" Another said the children were "scared and worried that their dad might get more injuries and die;" and another offered they were "scared because they didn't know if they were going to come home or die."

Many participants expressed that they thought the children in the film might be feeling sad (nine comments). A few of these comments were focused on the sadness about the parent getting injured, as well as feelings of sadness about their Dad's absence and fear of his death. Some of the civilian children stated "they would be sad because he's hurt;" they were "sad because their Dad was in the military and might die;" or "sad because their Dads weren't there."

A group of participants (five comments) believed that the children might be feeling angry or annoyed. The children specified that this anger and annoyance was probably directed at the *situation* rather than directly at the parent. Comments included: "mad because the dad got hurt and they were in the war for a long time and they thought that maybe he was dead;" and "I think some of them were sort of annoyed...not at their dad, but at the situation…that it happened to their dad and not somebody else's dad."

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A smaller group of participants (three comments) felt that the children might be feeling happy and proud. The happiness was generally about the situation not being worse. One child commented, "They could just be happy that the parent didn't die." One child spoke emphatically about how proud a child might feel of his military parent. He said, "I think it also showed them really like their Dad. Like once they get over the shock, fear and anger – that kind of stuff – they start thinking 'Wow! My Dad is really cool!' They are proud of him and think he's really brave." These civilian children focused on the themes of anxiety and sadness in their assessment of what the children in the film who had an injured parent were feeling. It may be that these children have had few opportunities or reasons to think about the death or injury of a parent, hence giving way to a strong sense of anxiety and sadness. Nevertheless, a few civilian children were able to take away the positive emotions being expressed by the young children in the show – the feelings of relief and pride that their parent returned home safely and with the sense of their father as a hero.

Question Summary

Both civilian and military children suggested that the children in the film would likely be feeling sadness about their parent's injury and the situation of their father being absent for extended periods of time. Within this theme, civilian children had a greater focus on sadness that they associated with the possibility of their parent dying, while military children expressed more feelings of sadness about a parent's injury. Civilian children were generally more likely to perceive feelings of fear and anxiety in the children on the film, although one group of military children also discussed worry. This

fear focused on the many aspects of change and the unknown. In contrast, military children were more likely to express curiosity about what these changes would look like and mean for the family.

Question: If the kids in the video were your friends what would you want to say to them about their family?

Military Focus Group

For the most part, the military children focused on normalizing the injured parent and offered optimism and a positive perspective. One commented, "It's alright. Your dad's going to be normal, he's going to be different, but he still loves you and cares for you, right?" Another also expressed confidence in the doctor's ability to rehabilitate the injured parent, reassuring, "It's going to be okay – your parents are going to be alright. If your mom had no leg, the doctor will give her a leg and she'll still play." Still others offered, "I would say that their family was still the same, but their dad looks a bit different;" "I hope that their dad gets better on their arm or their legs and to remember that he is the same person so they don't need to be scared;" and "They're the same people, but they look a little different, but they'll always be the same person."

Some military children also expressed encouragement and appreciation through succinct comments. When asked what they would say to a child in a military family, some mentioned brief words of appreciation and encouragement including, "Thank you," "Good luck" and "Good job" or "I worry about your Dad." One longer comment was "I would say I'm sorry and I'll try to be a good friend so you have someone to play with while your Dad is in the hospital."

In one focus group of military children, most responses to the question of what they would want to say to the children in the video centered on curiosity and pragmatic questions about the parent's injury (similar to their responses in the previous question). In this group of children, all the participants offered questions including, "How did your father injure his arm? What happened to his leg? How did the doctor put the leg on his foot?" (refering to the prosthetic limb) and "How did it stay on?"

The normalizing responses and positive encouragement to others shown by the military children suggest a useful coping skill that may have been encouraged by the show. The children's questions also demonstrate their thirst for information and acquisition of understanding.

Civilian Focus Group

When focus group participants were asked what they would like to say to the children on the show, the greatest number of children responded with expressions of compassion and reassurance. One civilian child imagined responding with sympathy and empathy to a girl in the video whose father had PTSD and expressed explosive anger. This child stated, "I would probably say, 'I'm really sorry. That's probably really scary." Another child stated, "I would say I was sorry that their father had been hurt and I hope everything is o.k." Others commented, "I want them to be happy and have their dad" and "I would want to tell them I wish their dad gets well, and that he has a good rest of his life." The children offered reassurance, caring, and generosity, saying, "Everything is going to be o.k. and they have my support" and "If you ever want to come over just give us a call." It is important to note that the majority of participants who answered in this

empathetic way were older children, older than the age of nine. These children were at a developmental level that was more conducive to taking the perspective of others.

Some civilian children commented that they would advise the kids to appreciate and take care of their parents. For example, some children stated that they would tell the kids to take care of the mom or dad "while they are still living." Another said that he or she would "tell them to help their dad." One child also encouraged, "Remind them that they still have their mom, even though their dad is away."

Within the theme of offering empathy and encouragement, four civilian children said that they would ask the children questions about their families. One would ask, "What was it like to have a dad or mom in the military and have them go away?" Another child identified with the theme of a father's separation and projected what might happen to the father if he was not able to reintegrate with the family. "I would want to ask what it would be like if their dad didn't live with them. He might have to live on the street and get hit by a car because nobody is there to help him. Other similarly personalized responses were given by a small group of participants who had suffered their own separations and trauma in their lives. They seemed curious about what other children and families experience and were able to connect their concerns about the show's children with their own experiences and concerns.

Four other comments among civilian children focused on asking the children how they were feeling and inviting them to talk about their feelings. These children were all in the 9-11 age range, suggesting that older children may have a greater capacity to give emotional help and understanding. Two children were cautious about being intrusive. They assumed that the kids were probably feeling sad and angry and might not want to

talk about their feelings. One commented, "They would probably be really sad. So I would just ask how their dad was and then I'd be done with it because they probably wouldn't want to talk about it . . . because it would make them sad." Another child expressed, "…if they are feeling sad, you'd probably ask them if they want to talk about it. But I think if they were mad, you might not want to talk to them because they might snap at you or something." Another child agreed, "You don't want to be intrusive and ask too many questions because your friend might feel put out or avoid you."

Although the children were asked what they would say to the children in the video, two children focused on the Sesame Street characters. They wanted to know more about the families of Elmo and Queen Latifah. One child wanted to thank the children. One child focused on the concept of mistreating people because they are different: "I would ask why you would be mean to somebody because they look different." Another child asked why only fathers and not mothers were depicted as parents returning injured.

Question Summary

The most common theme of both civilian and military children was empathy and encouragement. Children from both groups normalized the injury and tried to reassure the children that the parent "will be okay" and "he is the same person." Recognizing that military children may be experiencing stress, some civilian children emphasized treating them with greater caution and deference. In particular, they recommended caution to avoid upsetting the child. In contrast, many military children focused on questions about the injury rather than on the children themselves. Asking questions about the injury may be a way to avoid discussing difficult feelings, or show the need for more information

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before they can focus on feelings. It also may be that the military children, experiencing or facing deployments of their parents, learn to respond more pragmatically and rationally than emotionally, dwelling on sadness or fear.

Question: When somebody has a hurt body we can tell because
they are in a wheelchair or wear a cast on their arm.
How can you tell if somebody has a hurt brain or a hurt mind?

Military Focus Group

When military children were asked how they might know if someone has a psychological or brain injury, the majority thought that the only way to tell would be to ask, alluding to the "invisible" nature of the injury. Two children stated simply, "By asking!" and "I would have to ask them". Two children, following along with the notion of asking, said they believed the person might not be able to talk or hear. They stated, "You could ask them [if anything is wrong] in sign language if they don't talk" and "You could write it on paper".

Others believed that there would be a physical attribute that might indicate an injury. One child stated, "He might wear strange glasses". When the interviewer followed up asking the child if he knew why the man in the show was wearing sunglasses, the child responded with "because he got hurt…something hit him…he fell down and something hurt his brain. It like bumped his brain and then he couldn't remember anything that well". Another child stated, "Like if they have a helmet on to help their head". It seems that these children dealt with the "invisible" nature of the injury by identifying physical symbols of the injury, and notably these symbols were all associated with the head.

Finally, two children listed cognitive/behavioral attributes to people with brain/mind injuries. One participant stated that you might be able to tell because he/she might be "crabby", and another said that the individual might not be able to remember things that they used to know before the injury saying, "like their kids' friends and they don't remember you from before when they went into the army".

Civilian Focus Group

In contrast to the military children, when civilian children were asked how they might be able to identify somebody with a hurt mind or brain, the majority of civilian children believed they might be able to see behavioral differences in the injured individuals (six comments). Two children simply stated that the person might "act weird". Another child stated that "they might be spacey or out of it". Another child believed there would be noticeable *inactivity* saying, "They might not do anything – they might just stay in bed". And two children commented on the importance of watching their actions and reactions. "I think it's kind of like 'don't judge a book by its cover because you don't know by how they look sometimes. If they have a mental or emotional injury you kind of can't tell, so you have to tell by different ways of looking at them…like seeing how they act or react to things". This particular quote was taken from a slightly older child (in the 9-11 age group) who was in a focus group containing children of parents who were either graduate students or professionals in the "helping" professions.

Two children focused on the possibility of cognitive impairments. One believed an individual with a hurt brain/mind would talk and process slower – "They might be a

bit slower and if you are talking to them they might be slower in processing it because they have something wrong with their brain." Another commented on cognitive impairment stating, "I think if they had a brain injury and you show them a bunch of pictures, and you know that there are three big pictures and three little pictures, and there are six all together…if you ask them how many big pictures they would probably say two…they might get the wrong answers to questions."

Question Summary

Both military and civilian children were able to identify ways that they might know that someone was suffering from an injury of the brain or the mind. With this being said, there was still a great deal of confusion and ambiguity in both groups about what this would actually "look" like. Many attributed behaviors or characteristics that had no correlation with a brain or mind injury such as being deaf and/or mute and a number of children were not able to answer the question at all.

Question: What do you think the Daddy with the hurt brain is feeling?

Military Focus Group

When the military children were asked what they thought the man with the brain injury was feeling in the show, the most common response was that the dad was feeling mad or angry (six comments). The descriptions of this emotion ranged from anger at others, to anger at himself, and finally, to anger at his injury. Some notable quotes were:

"Mad at the people who did that to him"

"Mad because it happened to him and he was doing the right things but somebody hurt him"

"First he would be mad and then he would be sad because he hurt his kid's feelings, then he would feel really upset."

"He was feeling really angry because when he hurt his brain, when it hit him, it made him lose some of his memory, so it makes something else happen…and…he yells a lot, and that made him mad and yell, because some of the memories went away and something else went into his brain…something went in that never happened before."

Another common response from military children was that the father might be feeling sad (four comments). One child noted, "sad because he gets angry a lot and because he's angry with [his kids]" and another stated "sad because his kids might feel mad that he got hit." Similarly, one child responded to the question saying the dad was feeling "sorry because he yelled at [his children]." These quotes may lead one to believe that at this pre-adolescent age, the emotions of sadness and anger are hard for a child to distinguish. Sadness for these children seems to be associated with anger, and one might wonder if the two are somewhat interchangeable in young children's minds. In addition, many of the participants mentioned feeling upset about the way the father was feeling about his children or his behavior towards his children, possibly suggesting that this is a very salient, meaningful aspect of the show for the young participants.

Civilian Focus Group

The civilian participants identified a wide array of emotions when answering the question about what the man with the brain injury might be feeling. Responses included sad, mad, good, bad, angry with himself, scared, and out of control, with approximately two comments for each emotion. Notable in comparison to the military group were the two responses that indicated positive feelings. One child stated, "They might feel good because everyone was concerned for them and opens their hearts to them." Another responded "when [the dad] had his other kid and he started feeling better I think I would start feeling really happy and grateful." The civilian children were also more likely to attribute the father's anger to *himself* rather then to external sources such as the injury or his children. The majority of these comments came from the focus group with older children between the ages of 9 and 11. These comments showed a striking ability to show empathy and for these children to take their father's perspective. There was a clear understanding of the lack of emotional control that is so often associated with brain injuries and PTSD. One stated, "I know if I was in that situation I would feel really hard because you can't control yourself…I would probably feel so awful that I was like scaring my kids or being a bad parent." Another child said, "I think he feels really angry at himself and he can't control his anger when he just can't control it. He doesn't' mean to take it out on the kids but he can't control himself obviously". One child was able to describe the loss of control in great detail, stating, "I think that he might be feeling as though…like when he was doing it he wouldn't be thinking about in his head wanting to do it...it would just be something that he did…He wouldn't feel the emotions of other

people around him as other people would, he would just do it. He wouldn't think about it and stop himself, he would just keep going and then feel bad about it".

Question Summary

Although all the children demonstrated an ability to take another's perspective in their assessment of how the injured parents were feeling, civilian children identified a much wider range of emotions, while military children focused on the emotions of sadness and anger. Civilian children showed a greater capacity to be positive and empathetic in their perceptions.   In addition, while there were no opportunities to divide focus groups into more distinct age groups for a comparison based on age, it seems from the limited data that the older children were more able to attribute the injured parent's emotion to internal experience rather than external stimuli. This is likely to have implications for the child's understanding of emotion as a symptom as well as the child's likelihood to blame him or herself for a parent's behavior and injury.

Question: When the Daddy with the brain injury got mad at his two girls,
what do you think made him angry or mad?

Military Focus Group

When military children were asked to identify the cause of the father in the show's anger, the majority of the participants attributed his anger to the actions and behaviors of his children. It is important to note that one focus of the film was to convey to children that anger was a symptom of the injury, and yet there still seemed to be a tendency for the children to find external causes. The children commented, "[his kids]

might have done something bad," "he got mad at his daughters because they would ask him questions and he was mad because he didn't want to talk about it with them;" and "[his kids] might have done something wrong." It may be that these children are at a developmental level that they are looking for a clear "cause and effect" in situations and that the abstract notion of anger as a symptom is a difficult one.

A few participants attributed the father's anger to frustration about his injury (two comments) and one was able to identify the anger as a symptom of the injury. It should be noted that these comments came from two different sites and from children in the older (7-11) age range. Children responded with comments such as, "He might be mad because he hurt his head" and "sometimes he was angry because if you've read a lot of books when you were young, like if you had a lot of information in your brain and then it got lost, it would be kind of frustrating because you wasted a lot of time." One child seemed to understand anger as a symptom, saying: "If you had PTSD then you have bad memories and you feel frustrated." The increased ability to understand emotion as a symptom of an invisible injury seems to be forming in the older children and will be discussed further in the discussion.

Civilian Focus Group

This question was only asked in one of the two civilian focus groups, as one of the groups did not have the attention span for the entire set of questions. Therefore, it is difficult to do an accurate comparison between the military and civilian responses. Of the children who had the opportunity to answer this question, only three responded. Had there not been a plethora of responses from the military children, this researcher would

have attributed the lack of response to the format or content of the question. The three

responses were:

"Nothing. Because his brain was real messed up because he had brain surgery"

"[His kids] didn't do what they were supposed to"

"I don't know"

The child that responded with "nothing" seemed to understand the concept of

anger as a symptom of his injury. It is interesting to note that this child was in the

younger age group (5-7) but was able to describe this complex, difficult concept.

Question Summary

Both military and civilian groups tended to attribute the film father's anger to the

behaviors of his children. This makes sense developmentally, as younger children tend to

need more concrete "external" reasons for emotions as well as have a more egocentric

view of the world. Children also articulated the worry that a parent might be mad at

his/her child for asking questions about the injury.

*Question: What kinds of things can a kid do to feel better when they are
upset about something like this?*

Military Focus Group

There was a wide array of responses to this question, indicating that the military

children were aware of or picked up on a number of coping skills. There was no

particular trend in the themes, with one or two children identifying a particular set of

individual coping skills. The most frequent response was that children could do an

individual activity such as reading or drawing (three responses). While two of these responses seemed to think of this coping skill as a way to "separate" from the emotion or the situation, one child thought of it as a way of learning more about injured people. The child stated, "They could read a book that…they could go to the library and get a book that tells them what they could do to make them feel better…to see what, a book for people who get hurt brains, if they get hit in the brain they could go to the library and search for a book that can cure the brain." Other coping skills that more than one child identified were: talking to their Dad (two responses), writing in a diary (two responses), talking to somebody else (two responses), and looking on the "bright side" of the situation (two responses). It is worth noting that many of the children felt that talking to an adult would be helpful to them. It may be assumed then, that these children expected that they would be listened to and possibly understood. Both children who suggested talking with their Dad felt that this would be beneficial in order to "make things right" or "say they were sorry," alluding to the notion that the children felt they had done something wrong that had upset their Dad.   The two children that suggested "looking on the bright side" stated the following: "Instead of looking at the dark things like their dad is gone, they could look at the good things like their dad's probably going to come back soon, or if their dad is there, that their dad is the same person" and "Instead of looking at the dark side that makes them feel sad, they could look on the bright side and forget all about it." These responses show the interesting contrast between using a coping skill to work through emotions and process an event versus to avoid looking at a painful event, a contrast that will be addressed further in the question summary. Other children answered

the question of what to do to feel better with "play sports", "Watch the Elmo thing", and "Make a flat dad", each receiving one comment.

Civilian Focus Group

Civilian children suggested a number of responses to this question, as well. The most frequently cited coping skill was to talk to someone about what was happening. One child stated, "They might want to talk to someone, to a family member who isn't injured". Another child said "get it out to a person". This was a main theme of the Sesame Street program – the characters reiterate time and again that family members need to talk and be open with one another. The theme song for the film was "Say What You Need To Say" by John Mayer, emphasizing this point throughout the program.

Some children emphasized the need to get distance from the problem as a way to cope. One child stated, "You could go outside and run and run and run until you couldn't run any more and then go climb a tree". Another child responded with "Maybe they will run away and run and run until they are tired out and then they will go to another house". These responses may suggest feelings of fear in the children about the situation and their instinct to run from danger. These responses all emanated from the younger children (ages 5-7), suggesting that they might benefit from educational materials for this age group that identify coping skills that could lessen their anxiety.

Similar to the military children, two civilian children felt that writing in a diary might help them to feel better. This is a teaching point of the Sesame Street program. Also similar to the military groups, two children mentioned reading and drawing as useful coping tools. One child stated, "It depends on what they like to do, but I think if it

were me I would probably read a book that maybe had something to do with what was going on or I would draw". Another stated "I think I would do something that would let you get out your feelings – like draw your feelings, but I don't think I would read or something because you are kind of holding your feelings in".

Question Summary

While both military and civilian children were able to identify a wide range of coping skills and responses, there appeared to be a difference in the purpose of many of these coping skills. While some skills seem to "separate" or distance an individual from a problem or emotion, other coping skills address it more directly by providing further understanding of the emotion or problem at hand. There was an emphasis in both the military and civilian populations on wanting to understand more about what is going on with their injured parent. Military children suggested reading books about the injury, watching Sesame Street programs on the subject, and making a "flat dad" (a cardboard cut-out of Dad in order to have a physical representation of him around). Civilian children suggested reading books and talking to others about the situation. Civilian children were more likely than military children to suggest methods of coping that emphasized separation and distance from the injured parent, as evident in the responses of running away and removing themselves from the situation.

CHAPTER V

DISCUSSION

The specific areas of inquiry in this study include: (1) How young children describe an injury, generally, and an "invisible injury" more specifically; (2) How young children explain emotions such as anger and sadness that are expressed by the injured parent; and (3) How young children are able to empathize with the injured parent, as well as other children who are adjusting to the experience of having an injured parent.

Although only a relatively small sample was included in the present study, the findings present a complex picture of the ways children understand and talk about visible and invisible injuries in parental figures. For the purpose of this discussion, the developmental approach of Armsden and Lewis (1993) will be used as a framework for exploring children's understanding of parental injury based on their developmental level. The following themes highlighted by this framework will be explored: *security and separation anxiety, interpersonal understanding,* and *concepts of injury.*

The themes of *security and separation anxiety* in relation to a parent's illness (or injury in this case) are reflected in younger children's reactions involving fear, anger, and/or aggression toward others or toward themselves. In contrast, adolescents manifest these reactions through their expression of conflict between autonomy and responsibility. Children's responses to the question "What do you think the children on the show were feeling?" gave insight into their developmentally-determined thought processes. The pre-adolescent population that was the focus of this study expressed predictable

responses that focused on fear, anger, and aggression when confronted by the instability and unpredictability of the relationship with an injured parent.

Children also reacted strongly to the inaccessibility of parents in the military, as well as the fear of losing the parent. They wondered if the parent would be the same as he/she was pre-injury. Examples of their comments included: "worried that their dad was different…maybe it wasn't their real dad"; "scared and confused because their dad went away and they didn't know if he would come home or somebody else"; and "scared because they didn't know if they were going to come home or die." While it seems that some of this anxiety is related to more general issues surrounding deployment, there was a clear need for children to know that even though their mom or dad may look differently, and possibly act differently, than he or she did pre-injury, that he or she is still the same parent and the family is still intact.

As researchers (e.g. Rolland, 1999; Stallard et al., 2004) suggest, open communication regarding details of a parent's injury or absence is critical and may be overlooked by a spouse who is distracted and/or overwhelmed by the situation him/herself. Rolland (1999) highlights the uncanny ability of children to sense danger and threat of loss even when this is not communicated directly with them. The present study supports this notion, and reinforces the need for children to learn about, understand, and come to terms with nature of the parent's injury.   When age-appropriate communication is established, parents can address children's fears, both realistic and exaggerated, about the parent's condition.

The theme of *interpersonal understanding* reflects the tendency of younger children to lack the capacity to clearly differentiate a parent's feeling state from their

own. Thus, young children may link an ill parent's condition with their own behavior. This tendency was demonstrated by the children in our study in their responses to the question, "When the Daddy with the brain injury got mad at his two girls, what do you think made him angry or mad?" In keeping with the proposed developmental framework, most of the younger children in the study (5-8 years) attributed the injured parent's angry or aggressive behavior to the children's behaviors rather than to the injury itself (ex. " [his kids] might have done something bad" and "[His kids] didn't do what they were supposed to"). This is striking given that most of the children participating in the study did not have direct experience with parental injury, and were reacting only to the experiences of characters in the film.

This finding supports prior research on the transmission of trauma, such as Srour & Srour's (2005) study on the transmission of trauma in father/son relationships. These researchers found that fathers with PTSD often project their intense emotions (e.g. aggression, shame and guilt) onto their children. As a result, the children may identify with the projected parts of their fathers' emotions and perceive his experiences and feelings as their own. In extreme situations, these unconscious processes can make it difficult for the child to form a separate sense of self, and may result in the development of symptoms that replicate the disturbances of the father, including social isolation, guilt and detachment (Ancharoff, Munroe, & Fisher, 1998; Op den Velde, 1998). Results from the current study allude to the origin of these feelings in less extreme and more indirect situations.

In contrast to the framework's supposition, some children in this younger age group *were* able to attribute the parent's anger to the injury rather than to the child's own

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behavior. A military child commented, "If you had PTSD then you have bad memories and you feel frustrated" and a civilian child commented that "…his brain was real messed up because he had brain surgery". Such comments were expressed by children across age groups , about parents with both visible and invisible injuries, and in both military and civilian focus groups. It is possible that developmentally appropriate material, such as that which was the focus of this study, may facilitate the comprehension of these difficult concepts in younger children.

Some pre-adolescent children, especially those from the group comprised of more educated, suburban families, expressed a desire to help the injured parent and alleviate their physical and/or psychological pain – a reaction seen as more developmentally mature within the context of this framework. This was reflected in the children's responses to the question, "If the kids were your friends what would you want to say to them?" Civilian children in the older (9-11) age group commented that they would advise the kids to appreciate and take care of their parents. For example, one child would tell the kids to take care of the mom or dad "while they are still living."   Another said that he or she would "tell them to help their dad." Therefore, while the model posits that by adolescence this helping behavior would be more pervasive, we see from this select sample of children that in certain environments, this understanding and cognitive shift may be fostered at an even earlier age.

The third theme, *illness and death* reflects the developmental perspective that younger children tend to define illness through observable behaviors, such as someone lying in bed. Adolescents, in contrast, may be preoccupied with what caused the illness and whether they too could be affected. Researchers have agreed that the older the child,

the greater his or her capacity to understand the causes and consequences of illness and to appreciate the experiences of the parent (Bibace and Walsh, 1979; Burbach and Peterson, 1986; and Carson, 1992).

Even though this model focuses on *illness* rather than *injury*, it seems that the developmental concepts apply to parental injury in a similar way. Due to the more abstract nature of invisible injury, children's understanding of what these injuries "look like" was the primary focus of this study. Children were asked the question, "When somebody has a hurt body we can tell because they are in a wheelchair or wear a cast on their arm. How can you tell if somebody has a hurt brain or a hurt mind?" This question was one of the most difficult for children to answer. Many did not answer at all, and others simply stated that they "didn't know". In keeping with the model, the younger children in our groups tended to identify a physical attribute that might represent the injury or an observable behavior. These included not being able to speak or not getting out of bed, or wearing items such as a helmet or sunglasses (one of the characters in the film who had a TBI wore sunglasses).

A small group of children, mostly from civilian families, were able to identify cognitive impairments, presumably linking a "brain injury" to behaviors associated with thinking and memory. Similar to the previous themes identified in this framework, the most developmentally advanced understanding of invisible injury was offered by children in the civilian group from highly-educated families, with a large percentage of the parents studying or working in the mental health field. These children may have been exposed to the idea of "emotional" injuries and were therefore more comfortable with the abstract nature of the topic. It is interesting to note that while it would seem that the military

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groups would have had more exposure to these types of injuries, the military children had

a more limited understanding of how these injuries might be identified and their

responses were more consistent with their developmental level. One might wonder if

military parents have a reluctance to share this information with the children for fear that

it might upset them or lead to anxiety about their enlisted parents.

Clinical Implications

These results highlight the complexity of feelings associated with questions

related to invisible injuries (more than visible ones), and the associated behaviors and

symptoms. The children's responses to questions also demonstrate their thirst for

information and developmentally- influenced acquisition of knowledge about invisible

injuries. Notably, the majority of participants, both military and civilian, described that

their emotions of fear, anger, and sadness were a result of having unanswered questions

about the parent's injury or the situation. The element of "not knowing" and "not

understanding" seemed to present significant anxiety in the children. As the Sesame

Workshop's "Coming Home: Military Families Cope with Change" conveyed, children

have a desire to be involved and informed from the onset of a parent's injury, and this

information may alleviate rather than exacerbate their fears. Heath care professionals and

parents need to balance the wish to protect children from the difficult subject matter with

awareness of children's tendencies to form catastrophic fears and or fantasies to help

them explain the unknown.

While this study drew from a military population with high potential to be

exposed to visible and invisible injuries, there are numerous other populations that may

benefit from this area of study.   One such population is that of children involved in the child welfare and foster care systems, who have often been exposed to violence and trauma in their family systems. As two of our civilian groups included many children involved in the child welfare system through foster care, it became clear to us that it is not the specificity of the trauma that is important. Rather, it is having experienced a life-changing event that allows these children to provide social support and empathy stemming from shared understandings of these events.

One of the ways this study differed from previous studies on injury and illness in parental figures is that it also addresses how children with little to no exposure to issues such as parental injury are able to relate to other children or families struggling with these difficult issues. Notably, the results highlight that while the civilian children may be able to respond to other children in a more expressively positive, empathetic way -- possibly due to their distance from the situation -- this distance may not fully protect them from feelings of fear and worry. Therefore, this study points to the importance of developing age-appropriate information and psychosocial material for all children, not only those directly affected by visible and invisible injuries such as TBI and PTSD.

Children reported that talking with a trusted adult was one of the most important ways they and other children might cope with the difficult scenarios that face them. The level of illness or injury-related information provided to a child is considered to be an important moderator influencing the ways in which the child is affected by the presence of an ill or injured parent (Lewandowski, 1992). It is likely that a parent's level of comfort or discomfort with such information will influence their ability to communicate in an effective way with their children. This suggests a need for psychoeducational

materials that not only help to explain parental injury to children, but that also help parents gain skills and confidence in communicating about these matters in a developmentally appropriate way to their children. Educational materials that target parents are beneficial not only in terms of alleviating anxiety triggered in parents as they contemplate discussing these difficult topics with children, but also in terms of helping parents to resolve their own struggles in a less-threatening manner. Materials that focus on facilitating factual as well as emotional communication within the family and helping children share their worries and thoughts are indicated.

It should be noted that important cultural differences may exist concerning the ways in which children are informed of a parent's injury, and the degree of openness within the family in discussions of the injury and its associated emotions and concerns. In our small study, children who speak Spanish as a primary language did not seem to differ in important respects from children whose parents were migrant farm workers from Mexico. Further study in this area is indicated in order to provide a basis for culturally relevant and sensitive material development.

Strengths and Limitations

The central limitation of this study was also one of its greatest strengths. By drawing data primarily from a policy-focused study, we were able to access a vulnerable and under-studied population. Studies that offer insight from the voices of children themselves, let alone military children, are scarce due to the ethical and clinical concerns related to work with this population. With this in mind, our ability to fully explore the clinical intricacies of this subject area was limited. Future studies should focus upon

more in-depth psychological inquiry into these topics. Examples of this might be further inquiry into the effects of children personalizing and/or internalizing their injured parent's emotional symptoms of anger and aggression, or further inquiry into how having an injured parent affects a child's sense of self.

There are a number of issues with the design of the study that should be highlighted. First, the current study did not use comparable control groups, but rather, comparison groups of convenience with efforts made to achieve limited comparability. Therefore, while preliminary comparison could be made between military and civilian groups, it must not be considered generalizable to these populations as a whole. While a strength of the study was the ethnic diversity of participants, the variability of demographic data within and between groups should be noted.

Second, focus group questions designed to assess a child's understanding of invisible injuries often led with the notion that the parent had such an injury. For example, the question "When the Daddy with the brain injury got mad at his two girls, what do you think made him angry or mad" leads with the fact that the father has a brain injury, removing the important "invisible" nature of the injury. The results may be influenced by this disclosure, increasing the likelihood of children attributing their parent's behaviors to the injury as opposed to the child's behavior or some other external stimuli.

The use of Sesame Street as a communication tool for mental health and psychosocial information was a great benefit to this study. Sesame Street and the character of Elmo have the ability to attract and captivate audiences of all races, cultures, and socioeconomic classes. Our sample ranged from an all-Spanish speaking group in a

rural town in California to a group of children involved in the child welfare system in Texas, to an urban military community in NJ. People (adults and children) came to the focus groups because of their fascination with and love of Sesame Street, and then subsequently became exposed to the educational material on the physical and mental wounds of war. Had there not been this element of popular culture, it would seem that participation would have been limited to only those open to the concepts and to mental health issues in general. Elmo crosses cultural and geographic lines and brings with him information that may otherwise be seen as inaccessible and unapproachable.

Conclusion

With the war overseas reaching its tenth year, a striking number of children and families have been and will be impacted by the physical or mental injury of a loved-one. Helping children as well as adults understand how to integrate these changes into their lives will undoubtedly be a much needed and valuable area of research and clinical focus. The knowledge acquired has implications for work with children within the military population, as well as for those who experience traumas of other kinds. It is our hope that this work will serve to highlight children's capacities for understanding and empathy, and that this will benefit both the mental health field and society at large.

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APPENDIX A

Semi-Structured Interview Guide

CHILD FOCUS GROUP
(Questions in **bold** were analyzed for the current study)

Warm up question: Which Sesame Street character is your favorite and why?

1. Which child on the show do you remember best and why?

2. What do you think that child was feeling?

3. If that child was your friend, what would you want to say to him/her about his/her family?

4. If you were having a play time with that child, what would you want to do with him/her?

5. When somebody has a hurt body, we can usually tell because they are in a wheel chair, or wear a big bandage, use crutches, or have an arm missing like the Dad on the show. How can you tell if someone has a hurt brain or a hurt mind?

6. What do you think the Daddy with the hurt brain is feeling?

7. In the video we just saw, the Daddy with the two girls sometimes got mad or angry. What do you think made him angry or mad?

8. What kinds of things can a kid do to feel better when they are upset about things like this?

APPENDIX B

Human Subjects Review Approval Letter

SMITH COLLEGE
School for
Social Work

Smith College
Northampton, Massachusetts 01063
T (413) 585-7950
F (413) 585-7994

March 2, 2009

Marsha Pruett, Ph.D.
Smith College School for Social Work
Lilly Hall 310
Northampton, MA 01063

Dear Marsha,

Your revised materials have been reviewed and we are delighted to give the evaluation of Sesame Street's "Coming Home, Military Families Cope with Change" our approval. It is a fascinating and timely project and it is fine that the School for Social Work can make some useful contribution to their very important efforts on behalf of these families. As a forty year fan of Elmo, I am particularly interested in his amazing ability to reach children (and adults.)

Please note the following requirements:

Consent Forms: All subjects should be given a copy of the consent form.

Maintaining Data: You must retain all data and other documents for at least three (3) years past completion of the research activity.

In addition, these requirements may also be applicable:

Amendments: If you wish to change any aspect of the study (such as design, procedures, consent forms or subject population), please submit these changes to the Committee.

Renewal: You are required to apply for renewal of approval every year for as long as the study is active.

Completion: You are required to notify the Chair of the Human Subjects Review Committee when your study is completed (data collection finished).

We would appreciate it if when your Spanish translations of the materials are complete, you would send us copies for the permanent file. Good luck with the study.

Warm regards,

Ann Hartman, D.S.W.
Chair, Human Subjects Review Committee

Informed Consent Form

Dear Participant:

Thank you for your interest in participating in this study. I am a faculty member in the School for Social Work at Smith College who along with David Cohen, Research Director at Sesame Workshop, Inc, for its military projects, are conducting an evaluation of *Coming Home*, a new public television show and DVD developed for Sesame's ongoing program to assist military families. This part of the project focuses on helping families deal with the return of a family member from a recent deployment or series of deployments. We are interested in learning whether the show is engaging and helpful to you and your family. In essence, we are seeking your reactions to and opinions of the show.

Necessary criteria for participating in the study are:
1) You have at least one child between the ages of 2 and 8 (though families with an 8-10 year old will be included if space allows).
                              And either
 2) You are a) a spouse of a deployed or recently returned member of any branch of the armed service (including National Guard or Reserves) or b) you are a military person yourself and you wish to participate with your spouse.
                              Or
3) If you are from a *civilian* family, neither you nor your spouse have ever served in the military.

There are two ways you can participate in this aspect of the study.
Parent Focus Group: If you choose to be part of a parent group we will hold after viewing the show, you will be asked to join 8-10 other parents in a one hour group and respond to a series of questions on you and your children's reactions to the program. These questions will allow us to learn about your reactions to the show and what you learned from it in detail. The focus group will be audiotaped and transcribed; we will maintain your confidentiality as discussed below.

Child Focus Group: If you choose to have your child aged 5-8 years participate in a group, they will meet for up to 45 minutes with 6-8 other children who will participate in a group that meets after the show. You are invited to be in the room and observe the proceedings. Some of you will be asked to take notes about what the children are saying. The focus group also will be audiotaped.
  The children in the focus group will be asked to respond to one warm up question (Which is your favorite Sesame Street character and why?) and four substantive questions:

- Which child on the show do you remember best and why?
- What do you think that child was feeling?
- If that child was your friend, what would you want to say to him/her about his/her family?
- If you were having a play time with that child, what would you want to do with him/her?

There are no physical, economic, or legal risks associated with participating in any part of this study. However there may be some psychological discomfort. Although we will not ask for specific details about your injuries or life events, you may re-experience or re-live the painful memories of past or present stressful life events and how they have changed your life. In case you wish to talk further about the feelings that emerge, each person participating in the study, or having a child participating, will be given a program kit from Sesame Street that will include a list of referral sources. Referral resources also can be obtained through the Sesame Street website.

The primary benefit of participating in this study is that you will be contributing to the body of knowledge about the issues confronting military families, particularly children. The knowledge gained in this project will aid in the development of future Sesame projects aimed toward the benefit of military families as well as for civilian families living in the societal context of war. A tangible benefit of participation is that all participants will be given a Sesame kit that includes discussion guides, resource materials for follow-up, stickers and simple Sesame Street books for children, and information about where and how to get more involved with supporting military families. All focus group child participants will receive an extra book or music CD starring the characters from Sesame Street.

The data collected from this group will be used by Sesame Street to think about future shows that could benefit families, and by Smith faculty in conjunction with Sesame Street for potential presentations and publications. Your identity as a participant will be kept confidential. You will be assigned a code number we will use in data transcription and analysis. Any publication or presentation that results from this study will report primarily group data, which will not allow identification of any individual who participated in the study. In addition, any stories, quotes, or vignettes we use will be carefully disguised to protect your confidentiality and privacy. All data and consent forms will be kept in a secure location for a period of three years as required by federal guidelines and all data stored electronically will be protected. Should the data be needed beyond the three year period, they will be kept in a secure location and destroyed as soon as they are no longer needed.

Your participation in this study is voluntary. If you wish to have your child participate but he/she is uncomfortable doing so, we will decline his/her participation. You and they may refuse to answer any question and you or they stop participating at any time prior to or during the groups. However, once the groups have met, we cannot remove your individual data because we will not know to whom any individual statements belong.

Should you have additional questions or concerns you may contact me by email at mpruett@email.smith.edu or by telephone at 413-585-7997. In addition, should you have concerns about your rights or any aspect of the study you are encouraged to contact me or the Chair of the Smith College School for Social Work Human Subjects Review Committee at 413-585-7974.

YOUR SIGNATURE INDICATES THAT YOU HAVE READ AND UNDERSTAND THE ABOVE INFORMATION AND THAT YOU HAVE HAD THE OPPORTUNITY TO ASK QUESTIONS ABOUT THE STUDY, YOUR PARTICIPATION, YOUR RIGHTS, AND THAT YOU AGREE TO PARTICIPATE IN THE STUDY.

I agree to participate in the study: _____ Date:_____

I agree to have my child participate in the study:_____ Date _____

Researcher _____ Date_____