

UNIVERSITY OF CINCINNATI

Date: May 10, 2004

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hereby submit this work as part of the requirements for the degree of:
Doctorate of Philosophy

in:
Department of Graduate Studies of the College of Nursing

It is entitled:
"The Lived Experience of Adolescents with Burn Injuries"

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THE LIVED EXPERIENCE OF ADOLESCENTS WITH BURN INJURIES

A dissertation submitted to the
Division of Research and Advanced Studies
of the University of Cincinnati

in partial fulfillment of the
requirements for the degree of

DOCTORATE OF PHILOSOPHY (Ph.D.)

in the Department of Graduate Studies
of the College of Nursing

May 10, 2004

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Abstract

THE LIVED EXPERIENCE OF ADOLESCENTS WITH BURN INJURIES

Each year thousands of adolescents suffer burn injuries. Many bear permanent reminders of this trauma such as scars, amputations, and functional limitations. Developmental theories suggest that physical changes can profoundly affect an adolescent as they progress through the complex stage of adolescence. The purpose of this study was to gain an understanding of the experience of adolescents with burn injuries following hospitalization. The hermeneutic phenomenological research design of Max van Manen was chosen to explore this phenomenon. This design explores meanings of everyday experiences from the perspective of the individual. Several data sources were used to illuminate the meanings of this phenomenon: 1) personal experiences with the phenomenon, 2) experiential descriptions of those experiencing the phenomenon, 3) experiential descriptions of the phenomenon in literature, art, and other artistic forms, and 4) idiomatic phrases and etymological sources of words used to describe the phenomenon. Eight adolescents were interviewed however only six were fully analyzed, as two adolescents were unable to reveal the meanings of their experiences. Four common themes were uncovered from the interviews. The lived experience of adolescents with burn injuries is 1) an arduous journey of struggles as each individual freely chooses a unique path to a new way of being, 2) making difficult choices as cherished values are re-examined, 3) creating new images to transform the way of being normal, and 4) becoming empowered while rejoicing in accomplishments and abilities. Two participants contributed creative works which also reflected the themes identified in the interviews. Non-narrative data such as creative and literary works further illuminated the meaning of this phenomenon. A second review of the literature found the experiences of adolescents with chronic illness similar to the adolescents with burn injuries. The findings of this study were congruent with Rosemarie R. Parse's, Human Becoming School of

Thought (1998). The results of this study may be of interest to nurses, teachers, counselors, coaches, physical therapists, occupational therapists, youth counselors and others interacting with adolescents who have sustained a burn injury.

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ACKNOWLEDGEMENTS

I wish to extend my thanks to all members of my dissertation committee: Chairperson, Margaret Miller, RN, Ed.D., and committee members Linda Baas, RN, Ph.D., Elaine Miller, RN, DNS, and Michele Gottschlich, RD, Ph.D. Like the young participants in my study, my journey was arduous. I was not the easiest student. Their patience, tireless hours of reading, support, guidance, and encouragement were invaluable. I could not have completed this project without them.

Special thanks to my colleagues at the College of Mount St. Joseph: To Dean Zane for her support and words of encouragement; to Dr. Vale for her patience, and continued support; to Dr. Nezam Al'Nsair for his computer expertise; to Dr. Susan Johnson my trusted friend, colleague, personal cheerleader, and coach who helped me say "no", I would not be here without your support; and to my other colleagues who offered words of encouragement and "picked up the slack" while I was off doing research.

Most importantly, I thank my family. To my dear children Katie, Charlie, Monica, and Carl: I was truly an absentee mother many times, thanks for your continued love and support. Lastly I wish to thank my husband Charlie, you have been there through it all. You have been my rock and my soul mate. I could not have survived without you and your everlasting love. Thank you, and love always.

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CHAPTER ONE

Introduction

Trauma is a major cause of morbidity and mortality in the pediatric population (American Academy of Pediatrics, 2004). Burns are one of the most common traumatic injuries. Each year in the United States thousands of individuals, including children, suffer burns (Herndon & Spies, 2001). Injuries vary in severity from minor wounds destroying superficial layers of skin to major life-threatening injuries destroying significant amounts of skin and underlying tissues. Psychological aberrations and disfiguring physical changes including scars, contractures, and amputations often result from these burns (Costa, et al., 2003; Kagan & Smith, 2000).

Despite these devastating injuries, victims are expected to return to society to assume pre-burn roles and responsibilities. These individuals must make this re-entrance into society bearing the constant physical reminders of the burn. Children with a burn injury have the additional burden of achieving developmental milestones as well as assuming their pre-burn roles and responsibilities (Gilboa, Bisk, Montag, & Tsur, 1999; Meyers-Paal, et al., 2000; Patterson, Ptacek, Cromes, Fauerbach, & Engrav, 2000).

Burn care within the last several decades has greatly decreased the mortality associated with severe burns. Ever-increasing numbers of severely disfigured individuals are surviving. An increased emphasis has been placed upon the rehabilitation of these victims (Herndon, et al., 1986; Herndon & Spies, 2001). Burn care professionals struggle daily to help these young victims cope with their devastating injuries and regain optimal function. Despite these rehabilitative efforts however, burn care professionals often question how the lives of these individuals are affected when they return to society. Many questioned the quality of life for these children (Munster, 1999; Salvador-Sanz, Snachez-Paya, & Rodriguez-Marin, 1999). Individuals caring for children and adolescents are particularly concerned about the affects of these injuries during formative years of development (Byrne, et al., 1986; Gorga, et al., 1999; Sawyer, Minde, & Zuker, 1983).

Quality of life (QOL) is defined by the World Health Organization (WHO) as an "individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, personal beliefs, and their relationship to salient features of their environment" (WHO, 1997, p. 1). Quality of life research is discussed later in the chapter. Additional conceptual frameworks for QOL are presented in the next chapter.

Purpose

Like other burn care professionals, I witnessed the discharge of pediatric patients with disfigurements and other burn related impairments. I became concerned about the quality of life of these young people outside of the hospital. Of particular concern was the fate of the adolescent client. Perhaps there is no other phase of development that appearance and the opinion of others is greater. This study was conceptualized in response to this concern.

The purpose of this study was to gain an understanding of the experience of adolescents with burn injuries following hospitalization. This qualitative study sought to discover new knowledge through narrative descriptions obtained by interviews with study participants. The hermeneutic phenomenological research design of Max van Manen was chosen to explore this phenomenon.

Hermeneutic phenomenology seeks to understand and describe human experiences as lived from the individual's perspective using the practice of phenomenological reflection and writing (van Manen, 1984). Van Manen's (2001) design also uses the researcher's personal experiences, experiential descriptions in literature, personal diaries or other writings, art, and related phenomenological literature to uncover the meanings of the phenomenon of concern. Some of the sources suggested by van Manen were used to uncover the meaning of the lived experience of the adolescent with a burn injury.

Significance of the Study

Numerous factors made this study significant for the advancement of nursing knowledge and burn care science in general. Investigators have attempted to ascertain the effects of a burn injury on children, adolescents, and adults. Most of these studies assumed an outcome-based focus by examining the incidence of physical discomforts, the ability to perform activities of daily living, the quality of role re-enactment, achievement of developmental milestones, and psychosocial adjustment. Studies involving children often were conducted from the researcher and/or adult perspectives using adult standards. Many studies did not differentiate infants and children from adolescents. Although some studies used qualitative-like data collection techniques, no studies followed the philosophical tenets of qualitative research. This qualitative hermeneutic phenomenological study focused on the personal experiences of adolescent burn victims as they lived their daily lives.

In an early study by Molinaro (1978), 18 children aged 7-19 were interviewed to ascertain what happened to children post-burn as they left the hospital and returned to the community (social re-entry). Using open-ended interviews with specific questions, Molinaro found that children with visible disfigurement had significant problems with social re-entry, particularly in relation to peer relationships. The concept of quality of life (QOL) was not mentioned specifically in the article. As defined by the WHO (1997), social re-entry falls within the social domain of QOL, therefore this study examined QOL to some degree. A qualitative-type data collection method, the open-ended interview, was also used in the investigation but did not follow the assumptions or analysis strategies of a specific qualitative design such as phenomenology. Furthermore, it was unclear how much freedom of response was permitted during the interview. One must question if these researcher-developed questions limited responses from the children. For example, did the interview guide have the flexibility to add additional questions spontaneously to explore a child's unique response? The study did not fully elucidate all the factors influencing a child's societal re-entry and ultimately their QOL.

One of the first comprehensive studies to examine quality of life (QOL) in burned children was the seminal study conducted at the Shriners Hospital for Children in Galveston, Texas (Herndon, et al., 1986). Herndon and colleagues followed 12 survivors of major thermal injuries aged 0.8 -12.4 years (M = 5 yrs.) and involving greater than or equal to 80% of their total body surface area during the first four years post-burn. Children and their parents participated in a two-day outpatient evaluation of the children's physical and psychological function. Physical measures for the children included range of joint motion, medical impairment, exercise tolerance, hearing, performance of activities of daily living, and scar evaluation. Medical impairment was calculated from joint range of motion measurements. Parents were asked to evaluate common burn injury complaints and their child's including participation in recreational activities. Physical complaint items included within parental evaluations were presence of altered perspiration, altered sensations, joint pain, alterations in speaking, difficulty breathing, restricted chest movement, activity limitations, severity of burn scars, degree of burn scar itching, and heat/cold intolerance. Psychological assessments for the children involved a standard child mental status assessment using Simmons' criteria (Simmons, 1981). Parents in contrast, completed a developmental and familial history as well as the Louisville Behavior Checklist (Miller, 1984).

An evaluation of range of joint motion, scars, and medical impairment revealed that children demonstrated a combined extremity impairment of 2 - 82% with a mean of $61 \pm 7\%$. Children tested with a 12-minute walk/run exercise tolerance test were able to tolerate a 12-minute "walk" with good heart rate recovery. Audiometry evaluations revealed significant hearing loss in five children and minor loss in one child; three children were not tested or had incomplete tests. Parents reported significant physical disabilities such as itching and scarring. Conversely, parents reported normal activity levels in their children despite these problems.

Scaled psychological tests using the criteria of Simmons (1981) were administered to the children and revealed moderate to severe degrees of body image disturbance, self-esteem

difficulties, anxiety, depression, aggression, and other disturbances in some of the children. The assessments of activity of daily living performance demonstrated that five children were independent, five others needed assistance, and the remaining two were too young for adequate evaluation. The researchers concluded that many of the children had some physical and psychological difficulties but further evaluation would not be possible until the children reached late adolescence or early adulthood.

The intent of the Herndon et al. (1986) study was to "make preliminary predictions on the quality of life" (p. 609) in severely burned children by assessing the performance of these children on an assortment of physical and psychological tests. Although a fairly comprehensive assessment of many of the domains often associated with quality of life (QOL) was completed, there were several difficulties noted. Researchers made the determination that evaluating physical and psychological function could best assess QOL in these children; they essentially assumed these functional measures were indicators of a child's QOL. Furthermore, they assumed the best way to evaluate these functions would be with standardized instruments and tests. Data were not presented assuring the validity and reliability of these instruments in this population. The sum of all these tests may not have given a clear picture of QOL in burned children. Activities valued by children may not have been captured. Instruments were researcher selected raising concerns about the focus of the questions. Some data given by parents may not be reflective of the child's perspective. Furthermore, the impact of the parent's adjustment to the changed child was not considered when parental data about their child were analyzed.

A later study (Blakeney, et al., 1993) by several of the same researchers from the 1986 Herndon study was concerned with the psychological adjustment following burn injury in the pediatric client. This study explored two domains of QOL, psychological and social. Specifically, they examined the psychosocial sequelae of children who suffered a burn involving greater than or equal to 80% of the total body surface area. These individuals aged 1 -19 years (M = 12 yrs.)

were examined at various times post-injury, from 6 months - 10 years ($M = 5$ yrs.). Children, their teachers, and parent/guardians were interviewed and administered standardized objective tests and questionnaires to ascertain the child's psychological adjustment. Specific instruments included the Child Behavior Checklist, the Teacher Report Form, the Youth Self Report, the Piers-Harris Children's Self Concept Scale, the Parenting Index, and an author produced questionnaire.

The researchers sought to compare adjustment from three different perspectives (child, parent, teacher). Results indicated that the children, parent/guardians, and teachers all rated the children as psychologically and socially competent as a normal reference group. Researchers did, however, find that parents were significantly affected. For instance, parents reported increased stress which they attributed to their child's condition. Parents described their children as being "moody, demanding, and disappointing" in behavior which was again attributed in part to the burn injury (Blakeney, et al., p. 686). Some parents expressed feelings of uncertainty in their parental role. This study attempted to comprehensively examine the psychological and social domains of QOL. By design, the instruments are focused on particular aspects of QOL that reflect the researcher's perspective. One can only question if the child's unique experience was adequately captured.

Findings over the years have been contradictory, inconclusive, and incomplete. For instance, one study found the children to be no less competent and no more troubled than a normal reference group of children (Blakeney, et al., 1993). Another study, however, noted significant physical changes and psychological distress (Molinaro, 1978). Burn care professionals still do not have a clear conception of post-burn effects and quality of life.

A variety of methods were used in burn studies during the last 20 years. Quantitative designs were used most frequently in post-injury studies. Many closed ended psychosocial scales were utilized as well as physical performance tests (Gilboa, et al., 1999; Gorga, et al., 1999; Herndon, et al., 1986; Meyer, Blakeney, LeDoux, & Herndon, 1995; Moore, et al., 1996;

Sawyer, et al., 1983; Zeitlin, 1997). A few studies interviewed children using either structured or semi-structured formats. The interviews did not permit free flowing expression of thought or experience (Molinaro, 1978; Sheridan, et al., 2000). All studies were conducted from the perspective of the researcher versus the participant's perspective. It was not apparent in any study if children or adolescents had been consulted prior to the research to ascertain what elements comprised QOL for them. Qualitative studies using qualitative methods and following qualitative philosophical assumptions were not identified in the literature. Studies which focused on life experiences of children or adolescents following burn injury were absent.

Clients derive needs and perceptions from life experiences. Nurses and other burn care professionals must understand patient perceptions and needs to provide effective care (Cohen, Kahn, & Steeves, 2000). Furthermore, nurses are intimately present in the lives of their clients. They are often with clients during the most difficult times such as death or illness. This intimacy allows nurses exposure to the clients' experiences (Boyd, 2001). Pediatric burn nurses likewise are concerned with the needs of burned children and adolescents.

Despite the number of studies about the effects of a burn injury on adolescents, many questions remain for nursing. After the physical wounds have healed, how can nurses support these adolescents, living with the scars of the burn injury, the forever changed body? What type of interventions will promote a good QOL for these adolescents?

Van Manen's design was used to approach the adolescent burn experience from the adolescent's perspective. This study sought to uncover information affecting an adolescent's post-injury experience unaccounted for in previous studies. For example, did the meaning attributed to a burn injury by an adolescent influence their response? In addition, the study wanted to understand more fully areas identified previously in studies; for example, the criteria adolescents used to determine QOL.

A Phenomenological Design

Numerous inconsistencies and gaps in knowledge were noted in prior studies from the

burn literature. These issues raise concerns as to whether or not the study findings are true reflections of what was occurring in burned children and adolescents. Many methodological and design issues prevented researchers from finding the answers. Clearly a design that allowed a new perspective on the phenomenon was needed. A phenomenological design, that is true to the philosophical underpinnings of phenomenology, would potentially enable researchers to find the elusive answers.

Phenomenological research designs are intimately bound to the philosophy of phenomenology. Phenomenological research focuses upon the meaning of experience. Several major philosophical tenets characterize the various phenomenology designs. These tenets encompass the nature of reality, meaning, experience, reasoning, and holism (Evertz, 2001).

The nature of reality for the phenomenologist is complex. Reality is dynamic and freely chosen by the human. There are multiple realities or truths. For example, the findings in a phenomenological study would have numerous explanations. Humans are viewed as beings who create meanings from their experiences. Meanings are context dependent. To understand a phenomenon, a researcher would uncover the meanings of the experience by interacting with the human experiencing the phenomenon. Phenomenologists use inductive thought processes when engaged in the research process. Lastly, the need to study a phenomenon as a whole to attain full understanding is valued by the researcher in phenomenology (Cohen, et al., 2000; Evertz, 2001; Munhall, 2001).

Phenomenologists strive to gain understanding of the meanings of human behavior from the human's perspective. A glimpse of the world as experienced by that human is thus revealed. Humans have an intimate connection with their world and are inseparable from it (Boyd, 2001). All human behavior is thus within the context of all that is about them such as other people, objects, and situations. Merleau-Ponty (1962) refers to human/world connection as embodiment.

Each human possesses unique ways of acting, existing, and being involved the world.

One individual might be a professor and mother; another might be a cleric and counselor. These unique ways existing are called being in the world (van Manen, 2001).

As humans exist in this world they assume a particular orientation to their actions and consciousness. This orientation defines the way they are connected to their world. For example, at one point an individual may be focused upon a relationship and the feelings associated with it. The individual's overt behaviors will reflect this particular orientation. One is only aware of their orientation retrospectively. Phenomenologists refer to this orientation or way of connecting as intentionality (Boyd, 2001; van Manen, 2001).

This connection to the world is revealed to humans through their perception. Perception provides evidence of the world and humans perceive the world before analyzing it. Since all humans are connected with the world, their worlds may intersect. Humans are unaware of this intersection unless they are informed of it. The intersection is of the subjective world and comprised of essential aspects of human-hood such as feelings, thoughts and principles. This concept is called intersubjectivity (Munhall, 2001; van Manen, 2001).

The experience of humans in the world from their perspective is called the lived experience; understanding the meanings of this experience is central to phenomenology. Reflecting upon lived experience using the structures of the existential lifeworlds can facilitate uncovering meanings. Lifeworlds are multi-dimensional and consist of spatiality (lived space), corporeality (lived body), relationality (lived relations), and temporality (lived time). These worlds are intimately connected (Munhall, 2001; van Manen, 2001)

Eiser and Morse (2001) believed it was essential to obtain the perspective of an individual to fully understand and assess quality of life (QOL) in that individual. This study sought to elucidate the perception of quality of life post-burn from the perspective of the child during the adolescent phase of development. The qualitative hermeneutic phenomenological design of Max van Manen (2001) was used to gain an understanding of an adolescent's life experiences post-burn. This design allowed the researcher to understand the essence of the

nature of the adolescent's experience post-burn within the context of the adolescent's world and from the adolescent's unique perspective. Unlike previous studies, the researcher attempted to obtain the adolescent's unique perspective of QOL by asking the adolescent to tell their life stories. Unstructured interviewing techniques were used to elicit this information. The researcher also asked the adolescent to share with the researcher any literary or creative works, which they composed since the burn injury to enhance the researcher's understanding of the adolescent's experience.

Van Manen's design was used effectively in numerous previous studies to illuminate meanings in life experiences. For instance, Lauterbach (1992) used the design to examine a mother's experience of perinatal death. The aim of the study was to discover the essence of the mother's experience and to promote an understanding of that experience. Lauterbach used in-depth face-to-face interviews, analysis of the mother's journals and writings, sharing of the mothers' memorabilia, historical perspectives of the phenomenon, and artistic representations of the phenomenon as in art, music, and the literature. The study was able to posit a preliminary conceptual model for understanding the mother's experience and identified implications for nursing education, research, and practice.

Contextual Discussion of Phenomenon

When hospitalized during the acute burn injury period, children are supported physically, psychologically, emotionally, and socially by burn care professionals and parents or significant others. Emergent needs are identified and quickly met. With the exception of painful procedures such as dressings and therapy, children and adolescents are essentially in a supportive atmosphere. As they heal and the reality of their scars becomes apparent, they remain in this supportive environment until discharge. The full impact of societal and peer response to the burn is not apparent to the individual or family while within this protective environment, despite some exposure to the non-hospital environment through outings planned by burn care professionals.

Upon discharge, the child is thrust into a society with the ever-present emphasis on beauty and youth. Supportive burn care personnel are not readily present. The child or adolescent must rely upon family, friends, and others at home and school for support. Some studies indicate that family and friends become stressed by the experience of taking the burned child or adolescent home. These individuals may not be as effective in their supportive role and/or abandon the child (Blakeney, et al., 1993; Watkins, et al., 1996). Other studies indicate that despite stressors such as physical limitations or psychological distress, some children and adolescents possess an innate resiliency and cope well (Herndon, et al., 1986; Sheridan, et al., 2000). It is within this uncertain environment that the adolescent with a burn injury must live and find meanings in life. The study was conducted within this context.

Summary

Burns are a devastating injury affecting thousands of children and adolescents each year. Many are disfigured or functionally impaired for life. Numerous studies have been conducted to ascertain the affect of these injuries on a child or adolescent's overall well-being and quality of life. A clear picture of the adolescent with a burn injury 's overall well being remained elusive.

No studies were conducted using a qualitative design that examined the meanings of experiences of adolescent with a burn injury from their perspective. This study examined the life experiences of these adolescents using the research design of Max van Manen. The phenomenological perspective of this design enabled the researcher to gain insight into the essence of the adolescent with a burn injury 's life experience from the adolescent's perspective.

This chapter discussed the introduction, purpose, significance, phenomenological design, and contextual perspective of the study. The next chapter will present the literature review. Relevant topics in the review include societal images of burns, disfigurement, adolescent development and burns, and quality of life.

CHAPTER TWO

Literature Review

Current burn literature has documented the incidence and severity of burn injuries. Studies have explored outcomes in adult and pediatric clients. Many have questioned the quality of life in these individuals when they returned to the community. The pediatric client was a special concern in several studies because of the potential effect of the burn on growth and development. Additional concerns were raised for the pediatric client in the adolescent phase of development because of the developmental tasks related to self-esteem and identity. This chapter will present the literature review. Topics of relevance to this study will include societal images of burns, disfigurement, adolescent development and the potential effect of a burn, and quality of life.

Society, Burns, and Disfigurement

Contemporary stories and images such as those presented in the public media, movies, novels, and comics often contain influential representations of societal values (Carter & Petro, 1998). Often these works infer evaluative and moral meanings to burns and burn injuries; the meanings may be positive or negative. Furthermore, the meanings are often contradictory and unclear. Carter and Petro found five themes evident in media portrayals of burns and burn victims: "(a) a punisher of evil, or a sign of intelligence, (b) a form of purification or a tool of torture, (c) a gift of the gods or God, or an attribute of Satan, (d) a symbol of the end of the world, (e) the burning of the city's trash, be it in the literal or figurative sense, as in burning our street people in their own campfires or electrocuting criminals" (pp. 109-110). Our perceptions of fire and burn victims may be profoundly influenced by these media images. These perceptions may ultimately affect the burn victim's response to the injury as well as the response of others to the victim.

Burns are disfiguring injuries. Disfigurement may result in stigmatization of the individual (Aamot, 1978). Stigmatization is derived from *stigma* meaning, "a social condition marked by

attitudinal devaluing or demeaning of persons who, because of disfigurement or disability, are not viewed as being capable of fulfilling valued social roles”(Taber Cyclopedic Medical Dictionary, 2001, p. 2055). Stigmatization is closely associated with identity. In society, identity is a method used for self-preservation. The group’s identity and membership in that group is based upon certain physical and social criteria. How the society reacts to an individual is based on their conforming to these criteria. A disfigurement may result in a negative reaction from the social group to that individual. Ultimately these individuals may have difficulties with their identity (Aamot, 1978).

A study by Houston and Bull (1994) examined the behavior of passengers on a suburban railway in relation to a facially disfigured individual. Researchers observed whether people on the train would sit in the seats next to an individual with a facial disfigurement. The individual, called *the confederate*, in the study was given one of four appearances by a skilled make-up artist:(a) normal, (b) a port wine stain around the eye, (c) a narrow scar down the forehead and nose ending under the eye, and (d) a bruise around the eye. During the testing period two observers noted whenever one or more individuals chose to sit in one of the seats to either side of the confederate. On average, 2.45 persons sat next to the individual that was *normal*; 1.45 for the *port wine*; 1.65 for the *scar*; 2.05 for the *bruise*. Findings revealed a significant difference between the normal facial appearance and the face with port-wine stain. Although less people sat next to those with a bruise or scar it was not statistically significant. Researchers concluded that the presence of minor facial disfigurements could affect the behavior of others. Furthermore, they noted that the disfigured person could detect this behavior.

In the second phase of a study designed to examine facial deformities, Aamot (1978) studied the effect of deformity upon the reactions of normal individuals. This study built upon the work of Shapiro and Schwarz (1970) and others who stated that behavior and some reactions were under autonomic control and may prevail over cognitive and evaluative processes. The

investigator sought to explore if "(a) normal subjects have other reactions towards facial deformities than towards non-deformities (normal), (b) these reactions are cognitive, or autonomic, or both, (c) normal subjects react differently towards deformities of their own sex compared to those of the other sex, (d) verbally defining i.e. labeling a deformity versus no deformity will be influenced by the unknown information of sex, (e) the degree of deformity will influence the discrimination of sex or the definition of deformity, (f) slight deformities cause ambivalence and wavering i.e. confusion, and (g) the same deformities will rank differently according to sex" (p. 318). Eighty subjects participated in the study. Subjects were shown slides of individuals with disfigurements ranging from slightly altered facial features, such as a swollen nose, to severe deformities such as full thickness burns. Three separate tests were administered. The tests were designed to deliberately place the subjects in situations where their verbal reports would encompass both cognitive and evaluative reactions. The researchers knew these reactions included perception and involved some preliminary sensory reactions. Therefore, there would be a time lapse between the moment the image was seen and the verbal report.

In the first test, 20 male and 20 female subjects were asked to verbally identify the "sex" (Aamot, p. 320) of persons on a series of slides. Response and latency times for each subject were recorded. Subjects did not know the slides would have individuals with disfigurements before the test began. The second test in contrast, asked new subjects, 20 males and 20 females, to verbally report if the individual on the slide was normal or had a defect. Response and latency times for each subject were again recorded. In the final test, all 80 participants were shown 17 pictures of individuals with deformities. Ten of the pictures were from the slides in the first two tests; seven were new. Subjects were asked to answer six statements about the pictures and respond using a scale ranging from none (0) to very large (5). Questions included: (a) physical extent of deformity, (b) impact of deformity on total impression of face, (c) impact of deformity on social contact, (d) impact of deformity on employment, (e) impact of deformity on

marriage, and (f) impact of deformity on self-perception.

Analysis of variance and factorial design were completed for threshold and latency times in test one and two. For test three, factor analysis was completed. Degree of deformity and social handicap were estimated by Cattle's method of composite estimates. The findings of the study overall revealed differences in the subject's reactions toward images of normal persons versus disfigured persons. In test one, both male and female subjects took longer to identify the "sex" (p. 321) of images with deformities; female images took longer than male images. In test two, subjects took longer to report female deformities than male; subjects took longer to report normal males than females. Test three related the deformity effects and the results demonstrated the presence of two factors, degree of deformity and degree of social handicap. The coefficient of reliability was .81. Deformities such as a small scar or swollen nose were rated 0 – 1.5 whereas full thickness burns were consistently rated the most severe 4.17 (male raters) – 4.48 (female raters). Results also indicated that the gender of the subject viewing the image in comparison with the gender of the image affected whether the image was reported as normal or deformed. The researcher concluded that the autonomic response influenced one's reactions when someone was encountered. Furthermore, these reactions interfered with the discrimination of gender of the image. This was illustrated when there was a delay in time between visualization of the image and verbal reporting. Researchers stated this could be explained in part by the theory of identification which states an individual takes longer to identify something when it is complex; an image with a disfigurement would be considered complex. The investigators also stated that negative verbal and nonverbal reactions might occur. Based on these two studies, it can be assumed that the adolescent with a facial burn injury might be exposed to negative reactions by others.

Adolescent Development and Burns

Erik Erikson (1980) revealed in the seminal work, *Identity and the Life Cycle*, that adolescence is the concluding stage of childhood. Erikson posited that an adolescent must

achieve a more mature identity. This is achieved in part as the young people immerse themselves in socialization and competition with peers. Adolescents are frequently thrust into situations requiring difficult choices and decisions. Ultimately they define themselves more clearly and assume stable role patterns. As adolescents engage in these complex processes, they have a desperate need to be recognized by those around them. Recognition must come in the form of function or status.

Other experts in adolescent development stated that self-concept, fear of rejection, and conformity are at their peak during the adolescent period (Long & DeVault, 1990). Furthermore, the rapid physical, cognitive, and emotional changes that are occurring intensify the adolescent's pre-occupation with one's body. Fear of rejection and ridicule are common. If an adolescent were to become disfigured the potential for intense emotional responses is great. Long-term effects may occur. For example, the disfigured young person could choose to isolate themselves thus decreasing the chance of developing socially competent skills. Development of nonfamilial relationships could be affected and result in a poor self image (Long & DeVault, 1990). An adolescent suffering a burn injury resulting in scars, amputations, or other disfigurements could be profoundly affected. Permanent developmental difficulties could result. Such developmental problems could decrease QOL.

Quality of Life

Overview

Numerous perspectives and methods have been taken to ascertain how the life of a burn survivor is affected after the injury. The concept of quality of life (QOL) has been the perspective used by many researchers. Quality of life as defined by the World Health Organization (WHO) is:

...individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns. It is a broad ranging concept affected in a complex way by the person's

physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of their environment. (WHO, 1997, p. 1).

Historical Perspectives on Quality of Life

Although the term QOL is a contemporary one, the concept has been discussed for centuries. The ancient Greeks and Romans for example, valued good health over long life (Bond, 1996). Greek philosopher, Socrates proclaimed, "We should set the highest value, not on living but on living well" (Aiken, 1990, p.17). In an age of a relatively short life expectancy in comparison with modern times, these ancient people in essence, preferred quality versus quantity of life.

Traditionally, the ancient moralist's perspective of QOL was based upon the ontological consideration of human essence or nature. If one could determine the nature of human beings, one could determine what was necessary to obtain happiness and fulfillment. To fulfill one's human essence one had to be rational, self sufficient, just, or pious. Therefore, only these individuals achieved happiness and fulfillment. Quality of life was associated with happiness and fulfillment. In ancient times, if one were striving for QOL it was assumed the goal would be the attainment of the upper level of QOL or the highest level of happiness and fulfillment (Aiken, 1990).

During the 1800s and early 1900s the meaning of the concept of QOL changed in response to societal changes. Social Darwinism, natural rights, and the concept of liberty had become prominent societal worldviews particularly in England, France, and the United States. The rights of all members of society became a concern. Seeking the highest level of QOL for all members of society seemed unattainable. Society thus proposed that a minimal level of QOL should be sought for all members (Aiken, 1990).

The actual term *quality of life* was first used in 1920 by Pigou, in his book entitled, *The Economics of Welfare* (Wood-Dauphinee, 1999). Issues related to the economic welfare of the

country were discussed in this book. Specifically, Pigou examined government support of the lower class and its effect on their lives as well as the effects on the financial status of the nation. QOL of life was used to describe the effects on the lower class. The book met with limited support; the term QOL therefore faded from the common vernacular until after World War II.

Several events occurred which promoted the re-introduction of the term QOL (Wood-Dauphinee, 1999). The WHO adapted a more holistic definition of health by adding physical, emotional, and social well-being dimensions. Also at about this time, the social consciousness of the Western World was stirred in response to social inequalities. Influential citizens began to speak and write of social responsibilities and QOL. Scholars and others attempted to define QOL more clearly and develop instruments for measurement.

As technology was developed that prolonged life, the dilemma of quality versus quantity in life became an issue of concern. The Patient Self Determination Act (S. 1766 or H.R. 5067; 101st Congress) enabled adults to make end of life choices. This legal requirement represented American society's attempt to resolve some of the QOL issues (Bond, 1996).

Conceptual Considerations

In addition to the complex issues surrounding the definition and quantification of QOL, the multidimensional character of this concept made assessment illusive. Cella (1992) identified four common dimensions in QOL: 1) physical well being, 2) functional well being, 3) emotional well being, and 4) social well being. Bond (1996) in contrast, posited that QOL was comprised of five categories of attributes: 1) satisfaction with life, 2) cognitive abilities to evaluate life, 3) presence of social, emotional, physical, and mental health self-evaluation, 4) happiness, and 5) psychological well being. Numerous others have proposed elements when describing QOL (Haas, 1999; McDaniel & Bach, 1994).

The WHO defined QOL in 1997. In addition to the dimensions proposed by scholars, this group emphasized the impact of culture, value systems, and environmental influences on the determination of QOL. Many other groups have also defined QOL (American Burn Association,

2002; American Medical Association, 1994)

Health Related Quality of Life

Recently QOL has been studied in relation to health or specific diseases. Spilker and Revicki (1996) proposed that there are actually two major types of QOL; health-related quality of life (HRQOL) and non-health-related quality of life (NHRQOL). Similar to previous conceptualizations about QOL, both HRQOL and NHRQOL are multidimensional. HRQOL consists of physical, psychological, social, spiritual, role function, and general well being components; internal and external factors influence HRQOL. NHRQOL in contrast, consists of personal-internal, personal-external, external-natural environment, and external-societal environment dimensions (see Table I). Factors associated with NHRQOL may not be directly influenced by healthcare interventions.

Both HRQOL and NHRQOL influence individuals overall QOL, however the degree of influence is dependent on an individual's health status. For example, in an individual experiencing an acute exacerbation of asthma, HRQOL would exert more influence than NHRQOL. Once the asthma symptoms subsided NHRQOL however would be more influential (see Figure 1). Furthermore, health is defined and perceived differently by different individuals. One individual may define healthy as not being hospitalized; another may consider themselves unhealthy if they have a cold.

Table 1

Domains and selected components of non-health-related quality of life

Personal-internal	External-societal environment
Values and beliefs	Cultural institutions/opportunities
Desires and goals	Religious institutions/opportunities
Personality attributes	Schools
Coping strategies	Shopping facilities/opportunities
Spiritual status	Medical facilities/services institutions
Personal-social	Personal safety in environment
Social networks	Transportation & communication
Family structure	Social/recreational institutions/facilities
Social groups	Community spirit and demographics
Financial status	Business institutions
Vocational status	
External-natural environment	
Air	
Water	
Land quality	
Weather	
Geographic characteristics	

From from Rosenbaum, P.L. & Saigal, S. (1996). Measuring health-related quality of life in pediatric populations: Conceptual issues. In B. Spilker (Ed.), *Quality of life and pharmacoeconomics in clinical trials* (2nd ed.) (p. 26). Philadelphia: Lippincott-Raven. Reprinted with permission of publisher.

Spilker and Revicki (1996) also posited that HRQOL and NHRQOL could be applied to individuals or groups such as those with a specific illness like asthma. Furthermore, they noted that QOL conceptualizations could be applied to individual or global concerns. Spilker and Revicki's work however, did not specify whether their beliefs about QOL referred to adults or children. Nevertheless, it might be postulated that their work is applicable to children or adolescents particularly those with a health condition such as a burn injury.

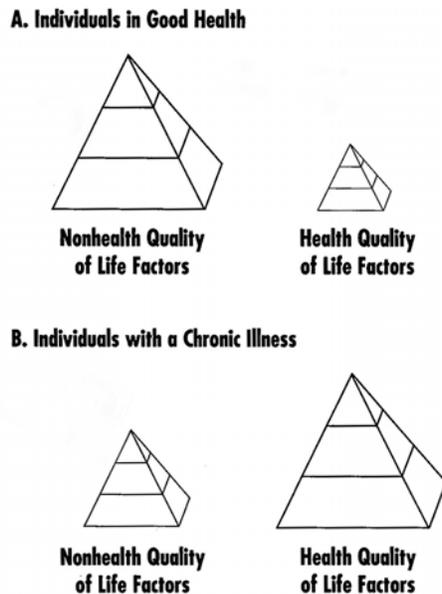


Figure 1. Relative importance of health-related quality of life and non-health-related quality of life

From from Spilker, B. & Revicki, and D.A. (1996). Taxonomy of quality of life. In B. Spilker (Ed.), *Quality of life and pharmacoeconomics in clinical trials* (2nd ed.) (p. 26). Philadelphia: Lippincott Raven. Reprinted with permission of publisher.

Quality of Life in Children and Adolescents

When scholars began to examine QOL in the pediatric population, several perplexing questions were identified. Would traditional domains associated with QOL be applicable to children? Whose perspective should be used when evaluating a child's QOL? Was it even appropriate to evaluate QOL in this population? It was known that children mature cognitively, behaviorally, emotionally, and physically over time. Would QOL assessment and measurement need to reflect the child's development?

Perhaps the most salient issue, which caused difficulties in the assessment of QOL in children, was the child's development. Numerous theorists and researchers indicated that children undergo rapid changes in their physical and psychological abilities as they move through the normal stages of growth and development (Erikson, 1980; Mulhern, et al., 1989; Piaget, 1973).

Erik Erikson (1980) described changes in emotional development as the child confronted

the psychosocial crises associated with the specific stages in development. Adolescents faced the crisis, identity versus identity diffusion. These developmentally-related crisis could ultimately affect the child's or adolescent's perception of QOL.

Piaget (1973) in contrast, observed the development of cognitive abilities as the child progressed through increasingly more complex stages. For example, during the stage of concrete operational thought (7-11 yrs) the child is able to make logical inferences, classify, and deal with quantitative relationships about concrete things. It is not until adolescence, when in formal operational thought, however that adolescents were able to think abstractly. Understanding and applying the concept of QOL to one's personal life requires abstract thought. It would therefore, seem likely, that children would not be able to conceptualize QOL until the adolescent phase of development.

Damon and Hart (1982) studied the changes in self-understanding as children moved from infancy to adolescence. Self-understanding was the basis for self-conception. They argued a developmental model of self-understanding was needed before other aspects of self-concept such as self-esteem could be studied and understood. The researchers also asserted that the concept of self enabled an individual to differentiate themselves from others in society; it was thus the cognitive basis for identity.

Initially Damon and Hart completed a comprehensive review of the psychological literature describing the development of self-understanding. Patterns observed in their review included a) a shift from physical to psychological self-conception as the child matured, b) emergence of a stable social personality characterization of self, c) increased volitional and self-reflective self-understanding, and 5) integration of diverse aspects of self into a unified self-system. The researchers also reviewed the work of William James (1961) on "Me and I" (p.44). The "I" or self-as-subject component of James's theory was composed of the understanding of continuity, distinctness from others, volition, and self-reflection. James stated that the self-assessment object or the "Me" was composed of four self dimensions: physical, active, social,

and psychological self. As a child developed, their knowledge of these dimensions changed in character. In infancy and early childhood for example, the physical self was understood through bodily functions and material possessions. During late adolescence in contrast, physical self was equated with physical attributes and reflected volitional choices or personal and moral standards. Psychological self evolved from momentary moods and feelings in infancy to belief systems, personal philosophy, and self thought processes in late adolescence.

Synthesizing essential elements from William James' work and the literature, including empirical studies, Damon and Hart proposed a theoretical model of self-understanding. They asserted that self-understanding changed as the child developed. Furthermore, the self as object (me) and self-as-subject (I) influenced each other during development; developmental progress in one may positively influence progress in the other.

The work of the developmental theorists Erikson, Piaget, Damon, and Hart indicate the profound influence of development on a child's cognitive functions and overall well being. The stage of the child's development influences self-understanding, self-esteem, and the ability to conceptualize QOL. The relative success of achieving the outcomes for each stage influences the child or adolescents overall well being. It might be postulated that a burn injury could impact development of self-understanding, self -esteem, and ultimately QOL in children and adolescents.

Some studies of QOL in the pediatric population demonstrated methodological concerns. Numerous studies were conducted with instruments developed by adults without the input of children or adolescents (Cobb, Maxwell, & Silverstein, 1990; Herndon, et al., 1986; Wildrick, Parker-Fisher, & Morales, 1996). Researcher developed instruments may have limited the responses of children or adolescents. A limited or inaccurate picture of QOL may have been obtained. Other research indicated that when others rate a child or adolescents, QOL differences may exist between this rating and the child's or adolescent's personal view of their QOL (Blankeney, 1993; Neff & Dale, 1990).

Several studies examined quality of life in the pediatric population with chronic illness or injury other than burns. Stancin, Drotar, Taylor, Yeates, Wade, and Minich (2002) explored health related quality of life (HRQL) in children and young adolescents aged 6-12 years following a traumatic brain injury (TBI). Forty-two children with severe TBI, 42 with moderate TBI, and 50 with orthopedic injury only were included in the study. Parent and child perceptions of HRQL and child adaptive behavior measures such as the Vineland adaptive behavior scale were used. Findings indicated that adolescents and parents sometimes rated HRQL differently. Parents of children with severe TBI rated their HRQL poorer than the parents of children with orthopedic injuries. The adolescents with HRQL did not rate their HRQL differently than the children with orthopedic injuries. The researchers concluded that HRQL tools by themselves were insufficient to adequately assess QOL.

Climont, Reig, Sanchez, and Roda (1995) constructed and validated a quality of life instrument for adolescents with spinal deformities. The instrument was developed with adolescent input. One hundred seventy-four clients aged 10-20 years participated in the study. Subjects were given an 88 item questionnaire with each item to be rated on a 5-point scale.

Subsequently, the questionnaires were analyzed by calculating the intraclass correlation coefficient. Internal consistency was measured with Cronbach's alpha. Factor analysis was used to decrease the original 88-item set. Five factors were identified: psychosocial function, sleep disturbance, back pain, body image, and back flexibility. Overall quality of life was also included. The final quality of life instrument had 21 items with internal consistency of 0.88 and test-retest coefficient of 0.89-0.91. The findings indicated that overall QOL was significantly correlated with the patient's satisfaction of his or her health status. Psychosocial functioning, sleep disturbances, back pain were also significantly correlated. The parents' perception of spinal deformity correlated significantly with the overall QOL score; researchers believed that parental attitudes influenced the adolescents' coping.

The instrument was found to be a simple, feasible tool to provide valid and credible

information to guide practice. Researchers identified psychosocial, functional status and presence of back pain as relevant domains of QOL for this population. Lastly they discovered findings that indicated mothers' attitudes are an important factor that contributes positively to the adolescent's ability to cope with the chronic disability.

The concept of QOL and the study of QOL remained ambiguous particularly in relation to children and adolescents. Some scholars continued to contend that a clear definition of QOL is still lacking for all age groups (Oleson, 1990). Others debated issues such as: 1) Are QOL discussions appropriate in all situations? 2) What factors influence quality? and 3) Who should decide QOL (Goode, 1994; Walter & Shannon, 1990)?

To fully understand and assess QOL in an individual, it is essential to obtain the perspective of that individual (Eiser & Morse, 2001). This study sought to elucidate the perception of quality of life after a burn injury from the perspective of children in the adolescent phase of development. Unlike previous studies, the researcher attempted to obtain the adolescent's unique perspective of QOL by asking the adolescent to tell their life stories. Unstructured interviewing techniques were used to elicit this information. The researcher also asked the adolescent to share with the researcher any literary or creative works which they composed since the burn injury to give the researcher a fuller appreciation of the adolescent's experience.

Summary

This chapter presented the literature review. The impact of societal images of burns and disfigurement was discussed. Adolescent development and potential impact of a burn injury was posited. Quality of life including historical perspectives, conceptual considerations, health-related quality of life, and pediatric quality of life was discussed. Chapter three will present the method of inquiry.

CHAPTER THREE

Method of Inquiry: General Discussion

One cannot fully understand a phenomenological qualitative research design without an understanding its rich historical and philosophical foundations. The Phenomenological Movement began in Europe in response to the inadequacies noted in the positivist tradition of research (Cohen, 1987). Positivists assumed the world was structured and could be understood in an objective fashion. Reality was measurable and based upon empirical data. Prediction and control was paramount for positivists (Munhall, 1988). Specifically, early thinkers in phenomenology found that the philosophical assumptions and research techniques associated with positivist paradigm failed to adequately answer questions of the human condition (Cohen, 1987).

Phenomenological thought evolved through three early phases; the preparatory, German, and French. It was further developed by the Dutch (MacIntyre, R., 2001) and is still considered an evolving philosophy (Spiegelberg, 1975). The research design arose out of this rich philosophy. Assumptions in the philosophy and research are intimately related. Numerous variations in phenomenological research design have evolved over the years. Despite methodological differences, each design seeks to illuminate life experience from the individual's perspective. Furthermore, phenomenologists study "the Lebenswelt, the world of everyday lived experience: individuals are studied in their natural context, not in contrived situations" (Cohen, 1987, p. 31).

This chapter will present a discussion of the method of inquiry from a general and applied perspective. Relevant historical and philosophical elements of the phenomenological movement will be discussed. The design of Max van Manen will be discussed at length including the aim, data sources, and steps of the method.

The Phenomenological Movement

Preparatory Phase

Early phenomenological thought can be attributed to the work of Franz Brentano and Carl Stumpf. Brentano was committed to reforming philosophy, which had been so grounded in the positivist tradition. He valued an awareness of the inner psyche and proposed the concept of intentionality. Intentionality referred to the connection between psychic thought and objects; it represented the human connectedness with the world. All thinking was about something. Carl Stumpf, a student of Brentano also contributed significantly to phenomenology. Stumpf conducted experiments with active mental exploration demonstrating the scientific rigor in phenomenology (Spielgelberg, 1982).

German Phase

Edmund Husserl is considered by most to be the most influential figure during the German phase of phenomenology. Husserl's philosophy matured over a 30 year period. He dedicated his lifework to a search for the Archimedean point or foundation of human knowledge. A commitment to validating the rigor of phenomenology was a prevailing theme throughout this development. Although his contributions were many, the ideas of intersubjectivity, phenomenological intuiting, and phenomenological reduction were of particular importance. Intersubjectivity referred to the sharing of the subjective world between people. The subjective world consisted of feelings, thoughts, and other conceptualizations. One could not know another's subjective world unless that individual told another about it. Phenomenological intuiting was a component of the phenomenological method. When intuiting, a phenomenologist concentrated on the object of interest while remaining open to other influences. Phenomenological reduction was the process in which the phenomenologist opened up to the phenomenon while overcoming personal feelings and theoretical assumptions that might obscure the experiencing of the phenomenon of interest (Spielgelberg, 1982; van Manen, 2001).

Martin Heidegger a former student of Husserl contributed to the development of hermeneutic phenomenology. Being and being-in-the-world were foundational concepts in Heidegger's philosophy. Being in the world referred to the way humans existed (Heidegger, 1962).

French Phase.

Following the Nazi insurgence of Germany, France became the center of the Phenomenological Movement. The pre-eminent French phenomenologists were Gabriel Marcel, Jean-Paul Sartre, and Maurice Merleau-Ponty. These individuals brought greater specificity to existential phenomenology (Parse, Coyne, & Smith, 1985). Marcel focused primarily upon practical applications of phenomenology. He developed a technique for metaphysical reflection using phenomenology. Sartre also favored the practical aspects of phenomenology. He refined Husserl's definition of intentionality by eliminating the problems of mind/body dualism. Sartre proposed that the only way to learn about "human consciousness was to describe the experience" (Cohen, 1987, p. 34; Spiegelberg, 1982).

In contrast to Marcel and Sartre, Merleau-Ponty was more dedicated to the science of phenomenology. In his seminal work, *The Phenomenology of Perception*, Merleau-Ponty exposed the value of the phenomenological approach through an examination of perception. Perception was the original awareness of the phenomenon through human experience (Merleau-Ponty, 1962)

Dutch School

The Dutch also contributed significantly to phenomenological thought. Kierkegaard was one of the most influential Dutch phenomenologists. His work influenced the German and French. He believed that a human's understanding of person is experienced; it was more than a mere reflective appreciation (MacIntyre, R., 2001).

Major Tenets of Phenomenology

Although the philosophy of phenomenology was quite diverse, several essential tenets are shared. These include meaning, perception, and embodiment. Meaning is perhaps the most central tenet. Phenomenology seeks to uncover meanings of human experience. Humans ascribe meanings based on values and beliefs and within the context of the situation.

Perception is a human's original awareness of a phenomenon; it gives humans access to the world. Stimuli are perceived within the context of the experience. All human behavior is within the context of all that is about them such as other people, objects, and situations. Merleau-Ponté (1968) refers to this human/world connection as embodiment (Munhall, 2001).

These phenomenologists revolutionized the way the world was viewed and understood. Scholars began to realize that new phenomenon might be studied using the phenomenological perspective. Unfortunately their current research designs were from the positivist paradigm. They were thus inadequate for the mode of inquiry they desired. Several scholars developed designs that were congruent with the tenets of phenomenology (Parse, 1993; Munhall, 2001).

Essential Concepts and Terms

The language of phenomenology is essential to its meaning and subsequent understanding. Several terms require further explanation and are discussed in detail below.

Being in the World

The term "being in the world" was proposed by one of the founding philosophers of phenomenology, Heidegger. It refers to the ways in which human beings interact in the world via their roles, and responsibilities. An individual might be a mother, wife, teacher, and nurse. Within these roles this individual has different responsibilities and different experiences. Furthermore, this individual influences the world in different ways in these different roles (Munhall, 2001).

Existential Lifeworlds

Lifeworld is a term derived from the German philosopher Husserl's later writings. The term refers to the world in which we live; we experience our world and we derive meanings. There are four existentials within the lifeworld: spatiality, corporeality, temporality, and relationality (Munhall, 2001: van Manen, 2001).

Corporeality

Corporeality refers to our bodily presence in the world. We immediately reveal ourselves to others and in some instances conceal part of ourself. For instance, when an adolescent with a burn injury enters a public space with other non-burned people present, what kind of body language does the adolescent exhibit toward the public? Some adolescents might cling to their significant other; others might hold their head down. Likewise what kind of body language does the public exhibit toward the adolescent? What information about the adolescent with a burn injury and public responses could be obtained through an observation of body language (Munhall, 2001: van Manen, 2001)?

Relationality

Relationality refers to our interpersonal space with others. Whether there is physical contact through touch or some other contact such as a voice, we will have an impression of the individual we are contacting (Munhall, 2001: van Manen, 2001).

Spatiality

Spatiality refers to the space around us that we feel. For instance, the feelings we get from being in our own home are quite different from those in a hotel room. Home often evokes feelings of safety, warmth, and love whereas a hotel might evoke coldness, fear, loneliness etc. (Munhall, 2001: van Manen, 2001).

Temporality

Temporality refers to subjective time versus the time of a clock. A young child in school may feel that time passes very slowly when studying a difficult subject. In contrast, this same

child may feel that time has passed too quickly when at an amusement park (Munhall, 2001: van Manen, 2001).

Lived Experience

Lived experience refers to the way in which humans experience and understand the world in which they live. It involves our immediate, pre-reflective consciousness of life. We can never grasp the lived experience in its immediate manifestation, rather we can only reflect upon it (Munhall, 2001: van Manen, 2001).

Bracketing

When interpreting data in phenomenology the researcher must be open to all possible meanings. Before a study is started the researcher must set aside all beliefs and preconceptions about the phenomenon. Beliefs must be suspended to understand essential structures. Failure to do so may result in misinterpretation of the data. For instance, a burn nurse interested in studying about the experience of a child with a burn injury from the child's perspective would need to bracket personal beliefs. Certainly the experiences of the nurse from a career in burn nursing may have provoked feelings or beliefs within the nurse. If the nurse does not set aside (bracket) those personal feelings or beliefs they could influence the analysis of data in the study. The findings would then be from the perspective of the nurse not the child (van Manen, 2001).

Phenomenological Research Designs

Just as early philosophers in phenomenology were disenfranchised with the positivist tradition because of its inadequacies when used to explain the human condition, so also were researchers dissatisfied with research grounded in positivist methods. Following the phenomenological movement, scholars such as van Kaam, Colaizzi, Paterson and Zderad, and van Manen developed specific phenomenological research designs. Although each had obvious procedural differences, the designs shared common characteristic elements.

Spiegelberg, a noted expert in phenomenology and its evolution, stated that there were seven essential characteristics necessary for a research design to be considered phenomenology (Spiegelberg, 1975). The first essential characteristic was a focus on concrete experiences without conceptual presuppositions. To accomplish this most designs include the technique of bracketing in which the researcher holds preconceptions in abeyance before beginning the study. This process is used so that the researcher does not permit the preconceptions to influence data collection and ultimately analysis. A second characteristic is the inclusion of data of a non-sensual nature such as feelings. The third and fourth characteristics, intuitive foundation and resistance transforming are concerned with the analysis of the experience. The last three characteristics focus upon the actual writing of the experience. A sensitivity to language, cautious objectivity, and faithful description are essential.

One phenomenological researcher, Max van Manen (2001) refined the method even further. He believed elements of human science and semiotics were as essential to the phenomenological research design. Human science approaches focus on the understanding of human experience to explain nature. Semiotic refers to the science of signs. Language is a sign. Through language the meaning of the lived experience is revealed.

Phenomenology of van Manen

Introduction to method

The phenomenological design of Max van Manen (2001) will be used in this study. Van Manen describes his method as a hermeneutic phenomenological human science approach. Phenomenological aspects of van Manen's method are rooted within the philosophical traditions of Merleau-Ponty and Husserl. Van Manen believed scholarly inquiry should be attentive to the lived experience. Any phenomenon which presented itself to consciousness was of interest. Furthermore, van Manen posited that experience would speak for itself. Any study of experience should be done in a pre-reflective manner without conceptualization or classification. A researcher must focus upon the nature of the meaning of experience: What is the essence of

the experience?

Van Manen places increased emphasis on the orientation of the researcher to the phenomenon of concern as well as to the writing of the lived experience in narrative form. Through self-reflection about the meaning of personal experiences with the phenomenon, the researcher is better able to interpret the lived experience. The researcher brings to life the lived experience through linguistic transformation. Linguistic transformation involves creating more phenomenologically sensitive text from the isolated thematic statements in the words of the researcher. Research and writing are thus intimately intertwined in this methodology. Furthermore, the use of literature and art to enhance the understanding of the phenomenon was advocated by van Manen (1990).

Foundational elements.

Hermeneutic elements of van Manen's (2001) design were derived from the work of Dilthey and others. Meanings of the lived experience are expressed through narrative text. Because these meanings are expressed in text, an element of interpretation is present, hence the hermeneutic quality. The interpretation of the experience is rooted in the decisions made as the author selects appropriate verbiage for clear expression of the experience within the narrative text. Interpretation of lived experience occurs through reflection upon the four existentials of the lifeworld; 1) spatiality (lived space), 2) corporeality (lived body), 3) temporality (lived time), and 4) relationality (lived human relation).

The human science aspect of van Manen's (2001) design was also derived from Dilthey. He believed that human phenomena differed significantly from natural phenomena necessitating a different research approach, the human science approach. The subject matter of human science is the human world. This world is characterized by mind, thought, consciousness, roles, feelings, emotions, actions, and purposes. Furthermore, the world is objectified in language, beliefs, arts, and institutions. A human science approach explicates the structures of meaning of the lived world.

Four major steps comprise van Manen's phenomenological design. These include; 1) turning to the nature of the lived experience, 2) existential investigation, 3) phenomenological reflection, and 4) phenomenological writing. When a researcher turns to the nature of the lived experience, the researcher considers the phenomenon on a personal level in relation to past experiences, the personal interest level. Although steps were explicated, van Manen believed methods should not constrain elucidation of the lived experience. Existential investigation is characterized by the examination of rich data sources such as etymological phrases describing the phenomenon and personal experiences with the phenomenon. Phenomenological reflection involves extracting meaning from the data gathered through a reflective process. Phenomenological writing reveals, through words, the essence of the lived experience (van Manen, 1984; van Manen, 2001).

Rationale for Selection of Method

Numerous investigators have attempted to ascertain the effects of a burn injury on adults, children, and adolescents. Most of these studies assumed an outcome-based focus by studying the incidence of physical discomforts, the ability to perform activities of daily living, quality of role re-enactment, the achievement of developmental milestones, and psychosocial adjustment.

Quantitative designs were used most frequently in post-injury studies. Numerous closed ended psychosocial scales were used as well as physical performance tests (Gorga, et al., 1999; Herndon, et al., 1986; Meyer, et al., 1995; Moore, et al., 1996). A few studies interviewed children using either structured or semi-structured formats. These interviews however did not permit free flowing expression of thought or experience (Sheridan, et al., 2000). All studies were conducted from the perspective of the researcher rather than the child or adolescent's perspective. No qualitative studies using qualitative methods and following qualitative philosophical assumptions were identified in the literature that studied life experiences of children or adolescents following burn injury.

A hermeneutic phenomenological design is ideally suited as it examines life experiences and their meanings from the perspective of the individual experiencing it. This method will allow the researcher to give the adolescent an opportunity to freely express their feelings and values. This freedom may result in richer narrative descriptions. Van Manen's (2001) design is particularly suited to adolescents. He uses diverse data sources such as poetry, art and literature. Some adolescents may be able to express themselves easier through these media. The researcher might also gain new and different insights into the adolescent experience with this method.

Method of Inquiry: Applied

Aim

The aim of this qualitative hermeneutic phenomenological study was to gain an understanding of the life experiences of adolescents post-burn injury. By learning the meaning of these experiences, the researcher also hoped to understand the adolescents' perception of the quality of their life. Artistic and literary works allow the expression of intense feelings. The researcher sought artistic works from the participants so that further insights about the adolescent burn experience could be gained.

Outcome of Method

Numerous sources of rich data were sought resulting in a diverse database. Specifically during this study: 1) rich descriptions of the lives of a adolescents with burn injuries through the "life stories" told by the adolescents were obtained, 2) creative/artistic works from adolescents and the public domain about the post- burn experience were collected, 3) these descriptions and works were analyzed using the hermeneutic phenomenological method of Max van Manen (van Manen, 1990), 4) an enhanced understanding of the QOL of adolescents with a burn injury through the description of the adolescent's lived experiences was gained, 5) based on the understanding of the meanings of the adolescent's QOL, the needs of adolescents' post-injury were identified which could be met by nursing and other burn care professionals, and 6)

additional gaps in knowledge about the phenomenon were identified.

Turning to the Nature of the Lived Experience

Personal experience of researcher

As noted by van Manen, a phenomenological researcher is interested in the "meaning of our everyday experiences" (2001, p. 9). The primary investigator of this study has worked with children and adolescents with burn injuries for more than twenty years. A sincere desire to gain insights into the lifeworld of these young people is at the heart of this study. Over the course of these years, children and adolescents were cared for during the acute burn process as well as during rehabilitation. Often children were cared for as they grew from childhood into adolescence or young adulthood. Hundreds of the children and adolescent with burns survived the initial injury only to leave the hospital emotionally scarred and disfigured. Many also returned to less than optimal home situations such as poverty and dysfunctional family systems. Many questions arose: What would be the QOL for these young people? How could burn care professionals improve the QOL?

Many sleepless nights passed while trying to resolve this issue. Attempts were made to conceptualize what a child or adolescent with a burn injury would need to have a good QOL. For instance, 1) Was health status a criterion for QOL in a child or adolescent ? 2) Would the ability to return to childhood activities impact QOL? 3) Would QOL change over time for the same child or adolescent? and 4) Would QOL be different in different age groups?

In trying to resolve this complex dilemma the literature was reviewed. Quality of life was a truly multidimensional concept that could change over time (Cella, 1992). The conceptualization of QOL could differ from one individual to another (Bond, 1996). Quality of life could also theoretically change from developmental age to developmental age. For instance, QOL in infancy might be warmth, adequate nutrition, and nurturing (Mulhern, et al.,1989).

To ascertain if the literature was supported in the clinical area, informal observations were made of the children and adolescents as they returned to the hospital for follow-up care.

Some of the most severely burned and disfigured children and adolescents seemed quite happy and had returned to pre-burn activities. Many were able to overcome significant problems such as amputations and engage in pre-burn activities. Children and adolescents informally stated that support from other peers with burn injuries as well as family members and staff helped them cope. It seemed these children and adolescents had a good QOL.

Unfortunately, other adolescents seemed to have more difficulties. Some seemed unable to overcome physical limitations and other problems resulting in seclusion and behavioral problems. Many of these children seemed to have limited support at home. They seemed to have a poorer QOL.

Observations were random and unscientific. It was impossible to say with any assurance if any of the children had good/poor QOL. Decisions about QOL were from a personal perspective and values. Similarly, identification of specific criteria used by children to make a judgement about their life's quality was not possible.

The perspective of this researcher was one of uncertainty. In some cases it seemed that overall children and adolescents with burn injuries did well if they have adequate support throughout the acute burn and post-burn periods. However, in other cases children and adolescents did not do as well particularly if support from parents or peers was lacking.

The phenomenological question

During this phase of the study the researcher must orient to the phenomenon of interest. The phenomenon is one very important to the researcher. Often an area of practice is the source for the question. The researcher identifies what is inherently interesting about the phenomenon on a personal level. Personal experiences related to the phenomenon are reflected upon. The phenomenological question is then formulated. This question must be formulated in such a way as to enliven the reader's interest in the phenomenon. Subsequently, the researcher would explicate any assumptions or pre-understandings about the phenomenon. This step is essential to prevent premature interpretation of the lived experience (van Manen,

1990).

Existential Investigation

Several techniques are utilized in this step of van Manen's design. Initially the researcher studies etymological and idiomatic phrases related to the phenomenon to look for rich meanings in past linguistic traditions. Participant interviews commonly comprise a major portion of the data. Personal experiences might also be used as data sources if appropriate. These experiences are reflected upon and phenomenologically analyzed for common themes. Van Manen also advocates using literature, art, and other phenomenological writings as data sources.

Phenomenological Reflection

Data collection and analysis occur concurrently in van Manen's method. Once information is gathered, the researcher attempts to grasp the essential meaning of the phenomenon through a process entitled phenomenological reflection. Phenomenological reflection involves uncovering themes and reflecting upon them in relation to the four lifeworld existentials: spatiality, corporeality, temporality, and relationality. Essential and incidental themes are then identified and thematic statements developed. Non-narrative data such as artwork are analyzed in a similar manner (van Manen, 1984; van Manen 1990).

Phenomenological Writing

The final and most difficult step is the transformation of the thematic statements into rich linguistic narratives. A powerful narrative would enable the researcher to "see" the meaning of the phenomenon. The reader would in essence become a part of the experience "reliving the experience".

Summary

This chapter presented the method of inquiry. Historical and philosophical foundations of phenomenology were discussed. The design of Max van Manen was presented. Essential steps in the method were discussed. The next chapter will present existential investigation.

CHAPTER FOUR

Existential Investigation

The intent of this study was to uncover the meanings of the lived experience of adolescents with burn injuries. To gain access to this world as recommended by van Manen (2001), the researcher designed a study with numerous types of data and methods for the data collection. In doing so, the researcher believed the meanings of the experience could be illuminated more clearly.

Design of the Study

A qualitative phenomenological research approach was used to illuminate the meanings of the burn experience for children during the adolescent phase of development. Specifically the hermeneutic, phenomenological approach of Max van Manen was used to examine the life experiences post-burn in these adolescents. This design explores meanings in everyday life experiences from the perspective of the individual living the experience. In this design a variety of data sources are utilized to illuminate these meanings. Data sources include; 1) personal experiences with the phenomenon, 2) experiential descriptions of those experiencing the phenomenon, 3) experiential description of the phenomenon in literature, art, and other artistic forms, and 4) idiomatic phrases and etymological sources of words used to describe the phenomenon. All four data sources were included in this study.

Setting

Following a burn injury, victims are treated for the acute injury. Subsequently, victims are followed in an outpatient setting until burns are fully healed, scars matured, and function returns to optimal levels. Many victims require additional reconstructive or cosmetic surgery following the initial acute burn surgical procedures. For the pediatric burn victim, follow-up and additional surgery may continue into adulthood (Kagan & Smith, 2000; Rieg & Jenkins, 1991).

The primary setting for this study was an internationally known pediatric burn center. This center cares for children during all phases of burn injury including the extensive post-burn

follow-up phase. The institution was selected because of its diverse and extensive population base, that reflects the usual pediatric burn population in relation to age, cause of injury, and extent of injury.

Because the phenomenon of concern was the lived experience of adolescents who have suffered a major burn injury, it was appropriate to obtain participants from a tertiary burn center. The American Burn Association (ABA) recommends the referral of major burns to tertiary burn centers (ABA, 2002).

A secondary setting for the study was the "outreach clinic" sponsored by the burn center. This clinic was offsite of the center, located in the Southeast, and was geographically closer to the homes of some of the patients. Outreach clinics were established to ease the travel burden for patients. This setting was selected because of the number of adolescents who were followed in the clinic.

Within the setting of the burn center or outreach clinic, participants were interviewed in a quiet room such as an empty examining room, office, or patient room. The entry door was kept closed. These locations were selected for participant comfort and convenience as well as privacy.

Participants

Characteristics of participants

Eight participants aged 14 through 18 years and current patients in the burn center system were enrolled in the study. All individuals were at least one year post discharge from the initial injury. All participants had skin grafting and suffered injuries resulting in at least one of the following characteristics; 1) scarring to a body area visible with clothing on (i.e. face, neck, hands, fingers, and forearms), 2) one or more amputations of digits or limbs, or 3) permanent range of motion or gait alterations. Amputations and range of motion were included in the criteria because of the physical change in appearance associated with them. All individuals used English as their primary language, spoke fluently, and understood it.

Adolescents were chosen for several reasons. Piaget (1973) noted in the seminal work on child cognitive development that most children were not capable of mature abstract thought until adolescence. Topics related to QOL have abstract qualities and necessitated the selection of this age group. The adolescent phase of development is also characterized by achievement of sexual identity. Identity is often closely associated with body image in this age group (Erikson, 1982). Because burns may profoundly affect appearance, it was appropriate to select an age group profoundly affected by these changes. Thirteen through eighteen year olds were selected out of convenience to assure a more diverse participant demographically. English speaking participants were selected because the primary investigator was not fluent in another language.

Gaining access

Before the study was initiated, the investigator sought written permission from the burn center Chief of Staff and the national headquarters of the center's sponsoring organization to conduct a study in the institution and at the offsite clinic (See Appendix A). The Director of Health Information at the center was also consulted to confirm access procedures necessary to be in compliance with the Health Insurance Portability Accountability Act (HIPAA). Access to clients was to be obtained by placing a flyer (See Appendix B) describing the study in the outpatient clinic waiting area. Patients or their family members would voluntarily pick up the flyer. Subsequently, if interested they would contact the primary investigator. After several months it was noted that potential participants were not picking up flyers. As a result the researcher was forced to slightly modify the procedure by approaching potential participants with a flyer as they waited for their appointment; if interested they could then contact the researcher.

Protection of Participants

The investigator submitted a proposal for institutional review for protection of human subjects at the university before beginning the study. Once approval was received the study began. Each potential participant (and the participant's parent/guardian if not legal age)

expressing interest after seeing the flyer was approached by the investigator and invited to participate in the study. If the adolescent was willing to participate, written informed consent for those 18 years and for those under 18 years assent and parent permission from parent/legal guardian were obtained (see Appendix C, D, and E). To prevent conflict with the nurse/researcher role, the researcher did not recruit participants who had been cared for by the researcher on the nursing unit.

In addition to the narrative information obtained during the interview, artistic and literary data were requested from the adolescent. This artistic and literary data were to further enrich the investigator's understanding of the experience of the adolescent with a burn injury. Permission to use the artistic or literary data was obtained (See Appendix F); if the adolescent wanted to disclose their name with their work an additional permission was obtained (See Appendix G).

This study was of minimal level of risk to the participants. Participants were only interviewed; no treatments, drugs or other invasive procedures were employed during the study. There was a slight possibility that some adolescents would experience transient emotional upset when describing a disturbing life experience. This upset would be no greater than if they discussed the experience in a home setting. It was believed some adolescents would benefit emotionally from being able to discuss disturbing life experiences in a controlled safe environment. For instance, being able to express sensitive or painful experiences could bring relief to some adolescents. Others could experience increased self-awareness, empowerment, and an overall sense of healing (Hutchinson, Wilson, & Wilson, 1994).

General Steps

The phenomenon of interest was the life experiences of children with burn injuries during the adolescent phase of development and the meaning of these experiences to the adolescents. Max van Manen's hermeneutic, phenomenological design was used in the study. The primary data source was the experiential descriptions of the life experiences of adolescents with burn

injuries obtained during interviews by the investigator. Other data sources included; 1) literary and artistic works from the public domain related to life experiences after a burn injury, 2) literary and artistic works related to life experiences after a burn injury contributed by children and adolescents with burn injuries, and 3) etymological sources of words used to describe burn injuries.

Data collection

Once informed consent or assent and parent/guardian permission were obtained, adolescents were interviewed for a period of time between 30 - 50 minutes. If requested by the parent or participant, the parent could be present during the interview. The adolescent was interviewed in a quiet non-threatening environment. An unstructured, open-ended interview style was used. A global introductory question, "Tell me about your life since the burn" was used to elicit the life story from the adolescent (see Appendix H). The researcher asked the adolescent to include information about how he/she felt during these experiences. Any information which helped the researcher understand the adolescent's lived experience and therefore ascertain the adolescent's perception of the meanings of these experiences and his/her QOL was accepted. Verbal prompts such as, "Could you describe how you felt?" were used as needed. At the end of the interview, the adolescents were asked if they had created any artistic/creative works (drawings, poems, journals, etc) after their burn injury. If a creative work was completed, the investigator asked if these materials could be obtained for inclusion in the study.

The interview was audiotaped and later transcribed by the investigator. Additional handwritten notes depicting nonverbal behaviors occurring during the interview were recorded by the investigator and added to the interview data. All data collected during the interview were kept confidential and stored in a secure location. Only the primary investigator (PI) and PI's advisor had access to the transcript and study materials.

As the primary investigator was completing the interview process with the study

participants, artistic/creative works created by other children and adolescents with burn injuries were requested from burn care professionals. Letters were sent to these individuals (See Appendix I). Those contributing works did so voluntarily without reimbursement. Those individuals were not interviewed. Their works were included in the study without identifying information unless explicitly requested. Individuals submitting literary and artistic works signed a consent permitting the investigator to use the material in the study.

Acquisition of the literary and artistic materials in the public domain occurred simultaneously during the other data collection processes. These materials were obtained following several electronic searches with the help of experienced librarians. Appropriate copyright permission was obtained for materials to be included in the dissertation, publications, or presentations.

Data analysis

Following each interview, the investigator transcribed verbatim the interview tape, checked the transcript for accuracy, and analyzed the content. Listening to the tape also allowed the researcher to focus on the experiences of the adolescents. The principal investigator analyzed each interview before another participant interview was obtained. This process was used to ascertain whether or not the interview guide would need revision to obtain a better understanding.

The text was initially read to obtain an overall sense of the information. Subsequently, the investigator analyzed the data and identified "themes" within the text. After subsequent interviews were analyzed, themes were compared with previous interviews. Essential themes common to all interviews and variations were identified. All other data sources were analyzed similarly and compared with the data from the interviews. The researcher then determined if the data sources supported the essential themes.

After each initial analysis of individual interviews, the original tape, transcript analysis,

and interpretive analyses was forwarded to the investigator's dissertation advisor. The advisor was experienced in qualitative data analysis. The investigator and advisor then discussed the analyzed themes. Themes were revised until there was agreement. When all interviews had been analyzed, the transcripts were reviewed to confirm that the themes were contained in each of the interviews.

The investigator then composed a rich descriptive account of the adolescent's lived experience post-burn. This narrative reflected what the experience was like for the adolescent. A reader of the narrative would have a thorough understanding of the experience.

All study materials including audiotapes, transcriptions, journal notes, analyses, and artistic works were stored in a locked file cabinet in the primary investigator's home accessible only to the investigator. Audiotapes were destroyed at the completion of the study. Other study materials were destroyed following publication and/or presentation of the study findings.

Rigor

Several strategies were used to achieve rigor. Guba and Lincoln (1981) in their seminal work, state that naturalistic inquiries such as a hermeneutic phenomenological study may achieve satisfactory rigor however the terminology used in quantitative studies, such as validity and reliability, were not appropriate. They recommended the use of the criteria: 1) truth value, 2) applicability, 3) consistency, and 4) neutrality. These criteria could be adapted with appropriate terms for either naturalistic or rationalistic inquiries. For naturalistic inquiries the appropriate terms were: 1) credibility, 2) fittingness, 3) auditability, and 4) confirmability. Credibility was concerned with the degree of confidence in the findings for a particular study. Fittingness in contrast, referred to the degree to which the findings of one study with a particular group of participants and a specific context were applicable in other contexts or with other participants. Auditability was concerned with whether another researcher could follow the decision trail of the researcher completing the original study. Confirmability referred to the degree to which study

findings were a result of the participants and conditions of the study. The primary investigator instituted numerous measures to enhance rigor.

Credibility

Initially the primary investigator oriented to the phenomenon of interest by identifying what was of personal interest about the phenomenon. Subsequently, all preconceived assumptions about QOL and adolescents with burn injuries were identified and set aside through the process of bracketing. This enabled the researcher to avoid making preliminary judgments about the nature of the meaning of the phenomenon. The researcher was thus open to learning the meaning of living in the world as an adolescent with a burn injury from the adolescent's perspective rather than the researcher's perspective.

Fittingness

Participants were purposively sampled from the same institution. This institution was a tertiary referral center as well as the local pediatric burn center. The patient population had demographic characteristics similar to those of pediatric burn patients in the United States (Pruitt & Mason, 1996).

Triangulation was also used to enhance fittingness. Triangulation involved the use of multiple methods or perspectives to collect or interpret data about a phenomenon, to converge for an accurate representation of reality (Polit, Beck, & Hungler, 2001). Several forms of data were collected including interviews and artistic/creative works.

Auditability

Specific details about the study were recorded to allow for another researcher to follow the decision trail. Written details of the research protocol were kept with the transcripts. Field notes, personal notes, and written transcriptions of the interviews were also kept. The method of Max van Manen was followed without variation with the exception of the addition of the dissertation committee chair to review the data. The primary investigator provided transcribed narrative, original tapes, and analyses to the dissertation committee chair. This individual who is

an experienced qualitative researcher. Both researchers analyzed the data independently. When the initial analysis was complete, the researchers collaborated to compare findings. Themes were analyzed and revised until both the primary investigator and the chair were in agreement.

Confirmability

Confirmability was evidenced in the findings themselves. When the reader is able to gain some understanding of the meaning of the adolescents with burn injuries life experience, confirmability will be apparent.

Summary

This chapter presented the overall plan for conducting the study. Design, setting, participants, steps, and analysis were discussed. Efforts to enhance the rigor of the study were outlined. Chapter five presents the data analysis.

CHAPTER FIVE

Phenomenological Reflection

Eight adolescent burn survivors were interviewed. Two participants contributed their own original literary or artistic material that reflected their experience. Four participants were male and four were female. Ages ranged from fourteen through eighteen years. All participants were burned more than five years prior to the interview. All were burned before entering school except for two males who were burned during their primary and middle school years. Two participants were sisters. Three participants were Caucasian and five were African-American. Chapter five presents the analyses of the individual interviews and the literary or artistic works using phenomenological reflection. The methodology of Max van Manen (2001) was utilized for this reflection. This methodology is composed of four processes: (a) thematic analysis, (b) isolation of thematic statements, (c) linguistic transformation, and (d) identification of essential themes.

Van Manen (2001) defines thematic analysis as a process of "recovering the theme or themes that are embodied or dramatized" (p. 78) in the experience reflected upon. Themes describe what is unique about the phenomenon of interest. A theme captures the essential meaning of the experience the investigator is trying to uncover. Omitting a theme renders the phenomenon incomplete.

As experiences are reflected upon, van Manen (2001) recommends reflecting upon the four existential lifeworlds: "lived space (spatiality), lived body (corporeality), lived time (temporality), and lived human relation (relationality)" (p. 101). Reflection upon these lifeworlds enables the researcher to explore the structures of the human lifeworld as experienced in an individual's daily experiences.

Isolation of thematic structures involves close examination of the interview text to uncover the meanings. Three procedures were recommended by van Manen (2001) to isolate thematic structures: "1) holistic approach, 2) selective highlighting approach, 3) detailed line by

line approach", (pp. 92-93). This researcher utilized all three approaches to analyze the narrative interview data. First, each individual interview was carefully transcribed into written form and the transcript checked for accuracy. Subsequently, the audiotape was listened to and the transcript read several times to obtain a sense of the whole. Specific sections of text that seemed to express feelings or meanings were then highlighted in a color and coded using the language of the participant. Finally, each transcription was examined line by line to discover what each segment was revealing about the experience. This researcher continued to dwell with the data by repeating steps two and three until the data revealed its meaning. These subsequent analyses were differentiated from previous analyses by using letters (i.e. analysis a, b, etc.).

Linguistic transformation involves creating a phenomenologically sensitive text from the isolated thematic statements in the words of the researcher. The transformation is a creative process and reflects the researcher's reading, research, and experience. This researcher used readings from the participant's own words, poetry, literature, and other phenomenological research to assist in transforming the narrative text themes into true verbal expressions of the meaning of the phenomenon. Literary and artistic materials contributed by participants were also analyzed using the methodology of van Manen as outlined above.

Each individual interview will be discussed separately. A brief profile of each participant will be presented. Essential themes with thematic statements using the participants' own words will be stated. Literary and artistic materials analyses will then be discussed. Pseudonyms were used to protect the identity of the participants.

Participant One

Thematic Analysis of Interview

Andy was a fourteen year old male who suffered an electrical burn when age nine while playing with metal tent poles. The resultant injury required bilateral partial upper extremity amputations. Following healing and rehabilitation of the acute injury, he was fitted with

prostheses. Scarring remained to his lower extremities and feet and the areas surrounding the amputations. Additional intensive rehabilitation was required after the prostheses were fitted. Andy was quite talkative and outgoing. Throughout the interview he maintained excellent eye contact. His voice had a direct and positive quality. He seemed truly engaged in the interview.

This researcher uncovered five themes when Andy's interview was analyzed. Andy did not provide creative and artistic works.

Essential Themes

1. Andy had encountered numerous incidents in which children or adults looked at his burn scars and amputations or asked questions. Some of these encounters were positive however many were negative. He often became aggravated and felt bad about himself. Gradually he came to the realization that he would experience these situations forever. The following interview excerpts reflected the theme of *Accepting the Inevitable*.

It's just aggravating, cause you know there is a kid here, a kid here and I tell em the story. And a kid over here just asks me. Weren't you listening you know?...I am getting sick of repeating and repeating and repeating it.

Some people they do a dead stare and that's really rude. But I know kids look cause they're kids, they need to know. So I tell them what happened, you know, so they know and they just stop looking.

So when, now when I see people look at me it doesn't bother me cause I know people are going to look.... It's, it's not, the world is not just going to sit there and not look at you....They have to look to learn.

2. Andy's burn injury resulted in the amputation of his hands and part of his forearms.

Learning to use prostheses was a formidable task for him. The following excerpts exemplify the experience of participant one *Rising to Challenges*.

...to learn how to use these. That was very very hard therapy. But you know I got on with it and dealt with it.

Like say if I was playing legos...I would have like this thing built you know. I couldn't get this one piece on. I would get so mad I would throw it against my door and then broke the whole thing. That was like back here. But now if I did it, it would be all good because I know how to, adapt. I find, I figure out ways to make it easier. It's just like a puzzle. You have to find the ways to.

Like say you would have an easier challenge but me I'd have a harder challenge because I would have to adapt to the challenge. It's a lot more challenge. I think it's a little fun. Sometimes it can be fun.

Sometimes it can be fun, because I can do stuff people can't do. Like say if I was cooking you know, I can't feel anything that is good. I can take pans out of the ...sometimes it could be useful, very useful to people. Like I was at camp two years. They didn't have a can opener, I opened the can for them. It was very, very fun. Watch people say wow!

It's just a feeling, a good feeling. I like when people say when, that they're amazed in me.

3. Unlike some of the other participants, Andy remembered his life before the burn injury.

As he recalled his story, he spoke of being reminded of the past when he applied his prostheses. Often these remembrances made him upset and "ruined his day." He stated the anniversary date of the accident also evoked similar feelings. Andy revealed how hard therapy was and how frustrated he would become. He stated that he did not want to be upset or frustrated all the time. He seemed to be choosing to take charge of his feelings. The following passages illustrate the theme *Taking Charge of Feelings*.

You know it makes me think back. But I can't make myself, make myself, sad or cause you, then it just ruins the whole day. So I just deal with it and then I go on.

Yea, it's just like a thoughtful emotion. When you think about it and thinking makes you upset and it ruins your whole day.... Cause you're thinking about it all day and day and day.

4. Many months of intense rehabilitation followed Andy's initial hospitalization as he learned to use the prostheses. Often he thought of being able to do the things he could do before. He seemed to equate doing activities as he had done before with being normal. He stated therapy was very hard. With the sometimes tough encouragement of his mother, he learned to use the prostheses. He began to engage in everyday activities and recreation as he had before the accident. The excerpts below eloquently reflect the theme of *Being Normal*.

I would say its normal; it was, it's like the same right now. It's like the same?

Yea, I do everything I did when I was before the burn with these, prosthetics.

I would say its normal; it was, it's like the same right now.

I do everything I did, when, I was before the burn with these, prosthetics. pretty much feel good cause I do everything I used to do with my hands. My real hands you know.

Well when I get up from bed around in the afternoon time because I sleep in. I get changed. I put my arm socks on put my prosthetics on. I eat something. I get dressed and I go out and play, just like a normal kid would.

It makes me feel good inside... It makes me feel me that I am actually doing stuff.

5. As Andy revealed his story he spoke of hard times and easier times. Using the prostheses and reacting to the stares and questions of onlookers was often difficult. Responding to his own feelings and emotions also challenged him. Ultimately Andy began to realize things were getting better. He realized it just took time. The theme *Getting Easier over Time* is expressed in the following passages.

Well, it was hard for me the first couple of years because I had to adapt to these you know, deal with people, but now I'm, it's very comfortable because I adapted to these and I know how to deal with people.

Gradual, it took a couple, you know it took a couple of years you know. It went from hard to middlish to easier. It's like a timeline. You know?

As years went by it got easier, it got, got [sic] more experience with em [sic]. And I do stuff easier.

I don't know, I don't know how to say this. ...It's just, just, like if you watch a movie over and over and over. It gets boring to you right? And you still wanna [sic] watch it again, you know. Well that is how it is. People look and look and look. And you, it just doesn't bother you no more.

Heuristic Analysis of Interview

Corporeality

Each morning as he applied his prosthetic appliances, Andy was reminded of his physical changes. "You know it makes me think back", he stated. They were forever revealing themselves to him as constant reminders of the past. He was saddened by these memories at times, "It just ruins the whole day." Yet he rose to this challenge by becoming fully functional with the prostheses. Furthermore, he sought new challenges such as rock climbing. Andy gradually developed a level of comfort with the prostheses because of the functionality he was

able to achieve. He stated, "I feel like I have arms." Despite this functionality and acceptance Andy realized his body was changed forever. He would always encounter negative and positive comments from others.

Spatiality

Andy spoke at length about the burn camp he attended each summer. He enjoyed the challenging activities he accomplished but also felt special. "I can do stuff people can't do.... They didn't have a can opener, I opened the can for them. Watch people say wow! ...I like when people say ...that they're amazed in me." Furthermore, he valued how comfortable it felt there, "I feel more comfortable there". He spoke of the companionships of fellow campers that further added to this level of comfort. Andy one also spoke of campers with more severe injuries, "There were kids that their whole body was burned. It was really sad." Burn camp was a special, safe, comforting space for him. He was temporarily removed from a world with negative comments.

Temporality

Again and again Andy revealed how hard his experience was and how much time it took to "*adapt*" to his prostheses, "learn to use them" and learn to respond to the negative comments of others. Paradoxically, he also stated that at times it seemed that time went by fast, " It's just like it only happened yesterday. It flowed by like eagles going to a Florida or something, it just flew by so fast."

The past continued to be a part of Andy's daily existence also. He was reminded of the past when applying the prostheses particularly when it was a difficult process. Furthermore, the past haunted him on the anniversary date of the accident each year. Andy learned over time however, to make conscious choices as to how to respond to memories of the past to keep from being swept up in negative thoughts and "ruining the day".

Relationality

As Andy struggled with the challenges caused by his burn injury, he spoke of the

individuals who had assisted him on this arduous journey. His mother, for example, always fostered his independence. He spoke of her pushing him "to my limits". He stated he often would get mad but understood it was for the better. He realized his mother ultimately helped him through hard times. Andy also treasured the relationships with other burned kids. He spoke eloquently of the special relationships at the camp. "When you go to our camp its like a brotherhood there. It's really a spiritual thing.... We call it a brotherhood because we stick up for each other. We would help each other if someone is having problems or you know all that kind of stuff". Supportive individuals who accepted him yet challenged him were important to Andy.

In some ways Andy also developed a relationship with the individuals who presented some of the greatest challenges, the staring public. He developed almost a teacher to student relationship with these individuals. He was convinced that by giving knowledge, the problem would be lessened. Therefore, over time he developed the ability to respond to onlookers by teaching them about his injury.

Participant Two

Thematic Analysis of Interview

Ben was a 14 year old male burned when playing with matches. This accident resulted in burn wounds to most of his body. Following burn wound closure and numerous reconstructive procedures, significant scarring to obvious body sites such as his face remained. He also reported some functional impairment, although this was not obvious during the interview. Ben was quiet and his voice was soft but understandable. He often looked down at the floor as he talked, avoiding direct eye contact. Despite these behaviors, Ben seemed able to express himself openly and tell his story.

Five overall themes were revealed in the interview with Ben. Ben did not contribute any creative or artistic works.

Essential Themes

1. Ben returned home with significant visible scarring and some functional impairment.

He often spoke of the functional differences between himself and others. Such thoughts often saddened him. This sadness was revealed through his vocal intonations and nonverbal behaviors. It was further reinforced between the lines of the text. The theme *Making Comparisons* is revealed in the excerpts below.

Um, uh, wasn't nothin like this, like I am right now....um, things changed a whole lot, uh, dang, like, I couldn't, I can do some stuff that I can do and that I can't do.... I feel bad sometimes that I can't do the stuff.

2. Due to the severity of his burn, Ben had numerous formidable tasks to face. Not only did he have to regain function but also he needed to discover how to respond to negative comments about his burns. He vividly remembered the time before the burn and realized the accidental but preventable nature of the injury, Ben desperately desired to engage in former favorite activities. He often compared himself with others and was saddened by the difference in his performance in comparison with others. He seemed to need to accomplish something. As he struggled with these arduous tasks, thoughts of the past, and what he could never do again haunted his thoughts. Yet he met these challenges and endured. *Overcoming Challenges* is reflected in the following passages. It was further elucidated between the lines of text as well as through his facial expressions, vocal intonations, and other nonverbal behaviors.

Well no, when like I first started going back to school it wasn't like that.... Some people said, 'Oooh look at him' and stuff like that. And it would bother me...It made me feel sad, real bad. It would make me not want to come to school.

[researcher] Ok, did you go to school? [participant] Yea, I, I just really didn't care what other people started saying about me.

It means, it means something big to me. Because I thought I never get to play football or basketball or any other sports like that. And ...so it really does mean something big to me.

3. Having suffered a major burn with severe scarring and some functional impairment, Ben recalled his struggles over time. He urgently wanted to regain function and participate in favorite activities. Desperately he sought an effective way to react to the negative comments of children and others. Ultimately Ben realized the process was going to be slow. The theme

Changing takes Time was illuminated most clearly "between the lines" as he was interviewed. It was also stated in the following quote.

It took me a long time.

It was.. just kind of slow.

4. As has been discussed with other themes, as Ben revealed his story, he talked at length about things he could and couldn't do. He frequently recalled the circumstances of his injury and regretted that he had played with matches. *Regretting the Past* is vividly illustrated in the passage below.

And I can't do a whole lot of stuff like they can.... I mean like, It's just like, I feel, I feel real bad, and then I wish sometimes I say to myself I wish I never was playing with matches.

5. As Ben struggled to find a way to respond to negative comments about his burns, he recalled the advice of his mother, "Don't pay attention". He stated it took time for him to believe what she had told him. Although difficult, Ben made the conscious choice to ignore the comments and not let them bother him. Evidence of *Making Choices* is illustrated in the following excerpt.

It's just, I, I just really didn't care what other people started saying about me....

I really don't pay no attention to um.

Heuristic Analysis of Interview

Corporeality

Ben's burn injury left not only visible scars but also some functional impairments. These impairments were a frequent source of concern for him. Often during our conversation, he would make comparisons between his capabilities and those of family members. A tone of sadness was detected as he noted specific things family members could do that he could not, "My brothers can lift weights. And I can lift weights but I can't lift weights like they can. And I can't do a whole lot of stuff like they can."

Although the functional changes seemed to be more of a concern for Ben, the scars also affected him. School children taunted him about the scars. He revealed he did not want to attend school but ultimately did so.

Over time Ben was able to overcome the restrictions of his body and engaged in school and recreational activities. He even achieved a position on the school football team that was a source of immense pride. " It means, it means something big to me.... Because I thought I never get to play football or basketball or any other sports like that." Ben seemed to become more comfortable and accepting of his body through his accomplishments.

Temporality

Ben was often haunted by memories of the past. As he engaged in activities with his brothers he was reminded of his physical limitations in comparison with theirs. These comparisons brought back memories of the accident caused when he was playing with matches. He wished so much he had not done so, "...and then I wish sometimes I say to myself I wish I never was playing with matches." Ben also, however, struggled with the present. He worked to gain enough function to participate in football and other wished for activities. Furthermore, he wanted to develop the ability to respond to the taunting of others. Eventually, he realized these changes would take time. Ben learned to live in the present as he achieved his functional goals.

Spatiality

Ben did not reveal information related in his experience to spatiality.

Relationality

Although not illuminated well, some effects on Ben's relationality could be detected at times. For example, developmental theory states that going to school is an essential activity for a child. Intense relationships are built with the peer group in this setting (Hockenberry, Wilson, Winkelstein, & Kline, 2003) Ben's scars and the taunting that they precipitated caused sadness and a desire to skip school, "*It made me feel sad, real bad. It would make me not want to come*

to school." Although he ultimately did attend school, until he was able to ignore the negative comments, school relationships were difficult. Ben stated his mother offered much support as he struggled with the negative comments.

It was something that my mom told me.... She told me, she told me that ...like that first day when I started going back to school and somebody said something about me and then I started to cry.... She told me, she said don't just don't pay attention to them. Or like if they ask what happened to you if you want to tell them just tell um. And.. if some people start saying stuff about you stuff like making fun of you don't pay no attention to um. And other stuff like that.

Participant Three

Clarissa was a 15 year old female. She was burned as a toddler in a house fire. Significant visible scarring remained on her face, neck, scalp, forearms and hands as well as other areas. Clarissa's aunt accompanied her into the interview room at the request of both participant three and her aunt.

The entire interview was quite difficult. Clarissa was very quiet. She smiled often but when asked about the meanings of her experiences or her feelings she responded with giggles, yes/no, and few other words. She revealed little unless asked specific direct questions. To these direct questions she responded only with yes/no or an affirmative or negative nonverbal gesture. Occasionally Clarissa's aunt prompted her to say something or the aunt spoke for her. Ultimately the interview did not provide thick rich descriptions of Clarissa's experience as a adolescent with a burn injury. A thorough analysis was impossible due to the lack of information.

Clarissa did verbalize that she chose to ignore negative comments about her burns. Furthermore, she stated she had received and seemed to value the support offered by friends and family. After the interview, this researcher believed that Clarissa's family and friends had created a protective network around her.

Participant Four

Thematic Analysis of Interview

Danny was an eighteen-year-old male. Severe visible scarring remained on his face,

neck, scalp, forearms, and hands as well as other areas. Although somewhat quiet, he appeared at ease during the entire interview. As the interview progressed he became more spontaneous and talkative. Danny revealed feelings freely and discussed the meanings of life events with little difficulty. He offered direct eye contact at intervals and often used nonverbal gestures and changes in voice intonation. These gestures and vocal intonations were imbued with such meaning and expression however, that words were not missed.

This researcher uncovered five overall themes in the interview with Danny. He did not contribute any artistic or literary works that reflected his experience.

Essential Themes

1. Danny had significant scarring to all visible areas. He recalled many circumstances in which others said negative things about him. With the support of family, friends, and God's intercession, he developed a desire to stay positive in the face of adversity. Throughout the interview participant four had a positive tone and manner that clearly illustrated the theme *Staying Positive*. This theme was revealed in the following excerpts.

Well actually I try not to, you know, let it get to me.

Yea, I mean whatever anybody say negative or anything positive you know I listen to positive people I don't listen to negative people.... But if they say things negative, I will, at right now I don't even pay no attention to it. I don't, I um let it try to get to me.

My quality of life is uh...well I could say my quality of life is good so far.

With no disturbance or drama or problems or anything and as of today my qualities are ...good.

Because as long as you can walk, talk, sleep and move around you'll always be alright.

2. When Danny told his story he discussed how his mother had been told of his potential poor functional outcomes. He stated his mother was told he couldn't walk. Proudly he reported he had grown strong and learned to walk despite the grim prediction. A little smile appeared on his face as he recalled this accomplishment. As Danny continued to reveal his experiences, again and again he spoke of the importance of having goals and accomplishing things.

Attending college for example, was a future goal. He equated achieving goals with being a better person. Danny stated that sacred scripture and a close relationship with God had been influential in the attainment of his positive attitude and goal setting. The theme *Accomplishing Goals* was reflected in the following passages.

*And I came to got stronger with it. And I began walking. (little smile).
And doing things.*

Yea, school is going good for me right now. I am just trying to maintain and stay focused and hopefully be in a university or four year college or, by next year.

He was like, don't, don't' let nobody hold you back. Just stay focused and when you stay focused things get better.

In other words when that statement was said to me it was saying that if you want something in life make goals, and you make goals, you will succeed um. And when you succeed your goals you will be a better person in life.

Well actually if I couldn't meet them goals, I would try my best until I meet them. And when I meet them, I wouldn't let anybody hold me back from not getting them.

3. Danny had obvious visible scars. As a younger child he experienced negative remarks about his scars; such comments continued at intervals in later years as well. With the support of family, school counselors, sacred scriptures, and God he stated he was finally able to consciously choose to avoid negative feelings when others commented. *Choosing Attitudes* was illustrated in the following excerpts:

I mean well, they did good, bad, I didn't, you know, pay no attention to um.

Well actually I try not to, you know, let it get to me.

Yea, I.. I don't too much let people say negative things to me. I just "shoo", I don't follow it up I just keep doing what I am doing.

I mean, I used you know I used to get mad or whatever but after that I just realized that, uh, what they said, what they said to me about me is really not goin, it really didn't bother me at that time but when, you know, when I got away from it you know I think I thought about what they was saying and uh, you know it hurts a little bit but it's just like I told you.

My scripture is holding me up.

4. Participant four had made the conscious choice to avoid negative feelings when others spoke unkindly. He also chose to stay focused upon achieving goals. These factors

contributed significantly to participant four's ability to feel normal despite his burn scars. As he discussed his experiences he revealed his sense of normalcy. *Feeling Normal* was revealed in the following passages. It was fully illustrated between the lines and his overall demeanor throughout the interview.

Because you know like I said I, I, you know well, what everybody who I be around and be home attending, playing you know in the yard and stuff with I feel like I am just like everybody else.

Only thing different that I just got a little accident and that was it.

But as far as the day I just feel like I am a normal person just like everybody else.

5. Although not as obviously revealed within the narrative text, the theme, *Accepting It Takes Time*, was evident in Danny's experience. This researcher discovered that Danny realized the changes that occurred in his attitude, the choices he made, and goals he set took time to accomplish. Actually feeling normal took time. This theme was discovered when analyzing the text as a whole and when this researcher clarified information as noted in the quote. [researcher] "But it took a while to get to that point? [participant] Yea."

Heuristic Analysis of Interview

Corporeality

Danny could not hide his burn scars. They were severe and located in the most visible areas such as his face. As many others, he endured the negative commentary regarding his disfigurement and suffered sad feelings at times. Yet Danny seemed to move beyond that pure physical body relationship. He recalled listening to his heart and mind as he struggled to find a way to respond to the negative feelings. He referred to his body being "stripped" as if he could disconnect from his body, rise above this problem, and focus on the positive." it's just my body stripped.... I don't too much let people say negative things to me. I just shoo, I don't follow it up I just keep doing what I am doing." Danny revealed that over time he was able to learn to not pay attention to comments and stay positive most of the time. He seemed to connect normalcy with staying positive and doing things. He developed a feeling of comfort with his body.

Temporality

Danny eloquently described a circumstance of divine intercession when God spoke to him. " When I was about uh, thirteen in the sixth grade, that when they just, both of um just came to me and said uh, do your best.... Don't let nothing hold you back.... God was talking to me." As this researcher listened to him tell his story, it became apparent that there was a distinct difference in Danny's life before and after this event. It was as if time began anew for him after God spoke to him. Following this event, Danny began developing a positive attitude and setting goals. He developed the ability to focus less on the negative events and people in his life and look to the future.

Spatiality

Danny did not reveal information related to the spatial lifeworld.

Relationality

Danny was actively involved in his family life. He spoke of the support they had been for him; friends and school counselors were also supportive. Although Danny spoke of the importance of human relationships, his relationship with God seemed most important to him. He believed God had reached out to him personally. God inspired him each day to stay focused, have goals, and remain positive. This special relationship enabled Danny to respond positively to negative comments. He truly seemed empowered through this divine intercession.

Participant Five

Thematic Analysis of Interview

Eddie was a 17 year old male burned as a young toddler by scalding. Obvious scars were not apparent when he was fully dressed; most were confined to his legs and feet as well as spots such as his forearm. He had endured numerous reconstructive procedures, which required extensive rehabilitation for ambulation. As the interview began, Eddie's voice was clear, distinct, and easy to understand. His tone had a direct, almost overly confident quality to it. Throughout the interview, he seemed to need to reveal how he was exerting his

independence. At times there was a bit of defiance in his tone.

This researcher uncovered four overall themes when the interview with participant five was analyzed. Eddie also contributed an original drawing. He illustrated one of his burn scars.

Essential Themes

1. Eddie had no obvious burn scars when fully clothed with long pants and sleeves. He felt "just like everybody else", because he could do what everybody else did. Paradoxically as he was talking about some experiences at work, school, and during recreation, he acknowledged he was different because of the yearly check-ups at the burn clinic and the accidents he had. Some of these accidents were due to risk taking behavior. He also stated that nobody was normal. The theme, *Defining Normal*, is revealed in the following excerpts.

Pretty much just like everybody else. Except I have to come here once a year to get a check up.

Normal, um, being in school everyday. Going to school. Being boring as the next student.... It's just one of those thing [sic].

[researcher] So are you saying normal is doing what everybody else is doing? Yep, not being yourself. Trying to be like all them.

[researcher] Do you...Do you feel like you're normal?

[participant'] No, not really.... I mean I'm the one, that two months before he was supposed to get his license put a car into a tree. Broke both of his legs, seven ribs, his wrist. Got burned when I was little. Broke my face on the snowmobile.... I'm kind of like the oddball stunt dude. Which is fun.

[researcher] So you're saying you're not normal, your definition of normal is different?

[participant] Nobody is normal.... I'm [added] pretty much just like everybody else except I just had a couple misfortunes.

2. Eddie's biggest challenge seemed to be the discomforts and limitations following reconstructive surgeries. These occurrences forced the reality of his burns back into his life. "Because they don't hurt until you have to come in and get a graft. Then it starts hurting, starts itching, and...". As he spoke about these surgeries, he revealed how important family, friends, familiar caregivers, and support personnel were to his facing these challenges. The theme *Facing Challenges* is reflected in the excerpts below.

Yea those few hundred times I was sitting upstairs in the hospital for seven days because. ...Learning to walk again.... Being stuck in a bed for five days. Um, well like when they'd go to do it in the summer, for a month or 2 or 3 months after they do it you can't ever completely submerge. Which screws everything up in the summer because it gets pretty hot. And then there's the pressure garment, those just suck. And just the little stuff like that.... The treatments are worse than the burns.

3. Eddie was a young toddler when burned. He had no memory of life before the event.

Over and over he stated the scars had been there forever and he couldn't remember when he didn't have them. He seemed to have integrated them into his being. The theme *Believing It's A Part of Me* is reflected in the following passages.

It doesn't make a difference. It's just there.

It didn't matter because I can't remember a time before it wasn't there so. OK I got burned.

Probably because um...I've been here longer than the hospital has.... Well cause I had um for 16 years.

4. As revealed previously in the theme "A Part of Me", Eddie's scars had been present as long as he could remember. He spoke at length about his routine of coming to the hospital. He also discussed how he had the same caregivers throughout this time period. He revealed how comfortable he felt at the burn center. He called it his "second family". Eddie also fondly spoke of burn camp and his ongoing relationship with other burned kids. The theme of, *Belonging*, was one of the strongest themes uncovered in participant five's interview. It is illustrated in the following excerpts.

Probably because um, I've been here longer than the hospital has.... Like I've been coming here longer than this hospital's been constructed.

I, well my doctor's always been the same, my nurse was the same for 14 years, she's still the same.

As long as I can remember they've been there. And I been here once to two to three times a year.

Oh it's like a second family thing going on.... Like I come down for camp pretty much every year and I see most of these same people there and I see all the same people back there in the clinic. So, couple of new people but other than that it's, they've been here since forever.

It's like when you can, like if you went to one school you're whole life. You know everybody there, the whole time except a few people there. And so you feel comfortable around um cause they all know you and stuff like that. Pretty much like that.

Heuristic Analysis of Interview

Corporeality

A long period of time had transpired between the burn injury and Eddie's interview. His scars were not visible when he was fully clothed. These two factors seemed to have influenced participant five's bodily experience. He stated repeatedly that his scars had been present so long they were a part of him. It seemed he ignored them. Even when others commented on them, he chose to give the onlookers the responsibility of deciding whether or not to look.

Reconstructive surgeries however changed his experience. During these times he was re-exposed to the discomforts and limitations imposed by these procedures. He intensely disliked the temporary functional impairments that restricted his activities. Although far removed from the original burn experience, participant five could not escape the physical reminders of burns as long as he continued to require reconstructive surgeries.

Temporality

Although Eddie was moving forward chronologically in time, he was reminded of the past with each reconstructive surgery. The surgery itself was to improve his appearance and function for the future. Outside of the hospital, participant five was struggling to move forward into young adulthood. He discussed at length the trials of school and other activities. He looked forward to being out of school and working.

Eddie was experiencing the past, present, and future sometimes simultaneously. Each was influencing his attitudes and behaviors.

Spatiality

Although hospitalization resulted in discomfort and activity restrictions, this space was one of emotional comfort for Eddie. Here he was reunited with caregivers and friends he had known for years. Burn camp was also a special place for Eddie. He talked at length about the

fun he had participating in activities and hanging out with long time friends. Camp empowered Eddie with new skills that he used outside of camp.

Eddie also spoke at length about his work experiences. He talked fondly of his cooking abilities. As Eddie talked about his work, burn camp, and the hospital experiences, each seemed like a separate world for Eddie.

Unlike the hospital, Eddie spoke at length about disliking school. Authority figures were a problem for him. School was not a place of comfort. It was not clear if this was related to his burn experience or the result of his adolescent developmental phase.

Relationality

Eddie spoke fondly about the longevity of his relationship with the hospital and staff. He referred to them as family. He also spoke fondly of burn camp and treasured the friendships formed there. Family and friends were mentioned as support persons when he was hospitalized. School relationships with authority figures in contrast, were primarily of an adversarial nature.

Thematic and Heuristic Analysis of Literary Works

Eddie contributed a drawing of one of his scars on his forearm. He stated the Phoenix bird partially inspired his work (see Figure 2). The traditional legend of the Phoenix tells of a mythical bird with magnificent crimson, gold, and purple plumage, a sweeping tail and jeweled eyes. It is consumed by fire only to be reborn out of ashes. It is associated with rebirth and renewal (Nigg, 1995).

Eddie's bird in contrast, is blue and yellow with more severe lines and contours to the plumage. This researcher believed the bird seemed to evoke power. As Eddie was interviewed, he demonstrated a sense of self confidence in his tone of voice. Furthermore, the interview text revealed that he had overcome numerous challenges and acquired new skills. He seemed empowered by these skills. The drawing thus reflects some of the same themes as the narrative text: 1) facing challenges, and 2) believing it's a part of me.



Figure 2. Scar drawing.

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Participant Six

Felicia was a 15 year old female burned at age four. A large mature neck scar was visible which had contracted causing distortion of her mouth contour. Other scars were less apparent on her extremities or were hidden beneath her clothes. When assent was obtained from the participant and permission from her mother, this researcher sensed something different about the relationship between the mother and daughter. Neither interacted spontaneously with each other. No eye contact was given and no physical signs of affection such as a smile, caress, or hug was shared. Felicia's voice was soft but understandable.

As we prepared for the interview, Felicia seemed to become quieter and engaged in no spontaneous conversation answering only direct questions. The interview was very difficult. For the first half of the interview session, she would not reveal her feelings and experiences. She answered, "yes/no" or "I don't know". Furthermore she also developed a somewhat negative tone. Later in the interview, Felicia did reveal a little more of her feelings, however, her descriptions were not as thick and rich as other participants.

Thematic Analysis of Interview

In general, the interview with Felicia uncovered little about her life experience as a adolescent with a burn injury. One overall theme emerged. Felicia did not contribute literary or artistic work.

Essential Themes

1. At the time of the interview Felicia was being hospitalized for reconstructive surgery to

her neck. Most of her other scars were not obvious when she was clothed. However, Felicia had been taunted as a young child about her scars. Children accused her of "having a disease." Later others laughed at her. Felicia realized that unless she learned how to respond to unkind remarks she would fall into feelings of self-pity. She stated she consciously chose to ignore the comments because, "it was easier". Supportive friends assisted her as she learned to ignore the comments. Felicia also chose to keep all her feelings private. She shared little with her family.

The theme of *Controlling Feelings* is reflected in the following excerpts.

They used to but they don't know more.

Nothin really I just don't even pay attention to um.

They used to say that, uh, that I had a disease.... I ignored them.... I didn't really take an offensive.

I don't know, it's just one of my things. I don't like talking. I don't think that my business is other people's business. Like my parents and stuff.

Because it's just easier for me.... Like, like if I ignore them I don't have to worry about them.... Like.. if I didn't ignore them I wouldn't look good.... You know ... self-pity stuff.

Heuristic Analysis of Interview

Felicia's interview uncovered little about her experience as an adolescent with a burn injury. A thorough heuristic analysis was not possible. Some illumination of her corporeal and relational lifeworlds could be ascertained; spatiality and temporality however could not be.

Corporeality

Felicia's major visible scars were confined primarily to her neck. Over the years she had been made fun of or accused of having a disease. She had concerns about her appearance. Self pity would arise if she allowed herself to dwell upon her appearance. Felicia desperately wanted to keep self-pity at bay. Ignoring scars seemed an effective means.

Relationality

Before the interview began, this researcher sensed the relationship between Felicia and her mother was problematic. Although no overt hostility was noted, little if any conversation was

noted between the two. Eye contact was minimal. Overt physical signs of affection such as smile, hug, or touch were absent. As the interview progressed Felicia revealed she did not like to tell her mother anything, not even negative comments from others, "No I just don't like.... I don't like to tell my Mom anything". Felicia also stated she did not like expressing her feelings. "I don't know.. it's just one of my things. I don't like talking..I don't think that my business is other people's business. Like my parents and stuff". She seemed to keep her feelings to herself. She was in charge of them as noted previously. Felicia's relationships with others also seemed in question. She revealed some supportive friends when taunting occurred but reported no other socialization with friends or others.

No I just sit around and do nothing....Because, I don't, I don't go out usually to talk to my friends. I just....stay home.

Um hum. They didn't really talk to me. I just made a couple friends here and there.... And the rest of them were just jerks.

Due to the lack of thick, rich data in this interview this researcher left the interview with many unanswered questions about the meanings Felicia had in relation to her corporeal and relational lifeworlds.

Participant Seven

Thematic Analysis of Interview

Participant seven, Gabby, was a fifteen year old female who had been burned in a house fire; her sister, participant eight was also injured. She had significant visible scars to her face and neck as well as other areas. Her voice was soft, but clear and easy to understand. She offered direct eye contact frequently, however, when she revealed difficult memories or revealed deep personal feelings she averted her eyes to her hands or the table. Occasionally she had difficulty finding the appropriate words to express her feelings yet she seemed genuinely interested in telling her story.

This researcher uncovered four overall themes during the interview with participant

seven. Gabby did not contribute artistic or literary work reflective of her experiences.

Essential Themes

1. As Gabby recalled the positive experiences in life she spoke of school. Many supportive individuals were there who helped her through difficult times. As we discussed these times, this researcher asked her if she felt different from others and she replied no. The topic of differences was not explicitly discussed by participant seven except when specifically questioned. Despite this fact, as she revealed events in her life involving other people, it was very clear in her facial expressions and vocal intonations that she felt comfortable and part of the group. The theme *Being like Others* was primarily gleaned from between the lines.

2. Gabby and her sister were placed in foster care after the fire. Although the home was satisfactory initially, she revealed that over time the foster family began leaving she and her sister home alone. Gabby was visibly sad as she recalled these occurrences. As a result of this neglect, the girls were placed in a new foster home. Unfortunately this foster home was less welcoming than the first. Gabby stated she and her sister were not emotionally cared for and were called names. Again she was obviously upset as she recalled these events. Gabby longed for a stable, warm family. Finally, she and her sister were taken in by a new family during their teen years. A smile appeared on Gabby's face and her vocal intonations brightened as she revealed this information. The following excerpts reflect the theme *A Feeling of Family*.

Uh got a lot of friends now, uh, and a good home.

Well we was like in two foster families already.... And they didn't go so well. And now we moved here and everything goes good.

They take care of us, uh, we like do family things together.... Like go bowling or go out to my Dad's restaurant.

3. Gabby had significant scars on most of the areas not covered with clothing. As a young child she was frequently taunted by questions about her scars. Many times she did not want to respond to these questions. The questioning individuals would become upset at her lack of response. Gabby stated this made her even madder. These occurrences continued as she

grew older. Gabby knew if she was already "in a bad mood", questions about her burn would only make her madder. She sought a way to control her feelings and reactions.

Gabby faced even more challenges than learning to respond to negative comments. She yearned for a stable, welcoming home life. She and her sister had endured two unsuccessful foster family relationships already. Desperately she longed for a good home. Gabby also chose to accept the challenge to try out for her school basketball team. Winning a position meant being part of a team and that made her happy.

After many years of adversity. Gabby learned to respond to negative feelings through laughter and the support of friends and family. She also was given the precious gift of a good home. Furthermore she won a position on her school the basketball team. *Facing Challenges* is vividly revealed in the following passages.

Like, when I was, when I was like little or something, well like, people asked me what happened and if I didn't want to tell them they'll get mad at you. Weeeeell sometimes if I'm already in a bad mood it makes me mad.

Well we first got to the first home when we was two we like, it was nice and all that. But when we got a little older they start not coming home, leaving us home alone.... And then we moved to another home.... And she wasn't, well, she wasn't taking care of us that much.... Feelings wise.... Like called us names and stuff.

[researcher] *Do you have any hobbies or anything? Besides going to school?*

[participant] *Basketball. (smiling) Point, center, whatever they put me in... sometimes...play football at home....*

[researcher] *Basketball? So do you play for a school team or a team outside of school?*

[participant] *School team. (smiling)*

4. Gabby endured the hardship of unkind questions and comments as well as the lack of a strong family environment. It seemed adversity was her daily companion. Gabby spoke endearingly about how her sister was the one constant in her life. A unique bond had been forged between them following the tragedies of the fire and foster care. The strength of this bond was revealed not only through the verbiage of Gabby's story but also through her vocal intonations and facial expressions. She deeply cared for her sister. Peers and adults in the school environment also provided support for Gabby as she struggled with her daily challenges.

Being There for Me is eloquently revealed in the following excerpts.

Um...my sister.... Because she's been with me all my life.... And she was kind of like a mother to me when I was little.

We've got this joke book me and my sisters read jokes out of and make me laugh.

Friends.... some teachers....and the people at the office.... counselors, um, people that talks to me.

[researcher] *What makes it (life) good do you think?*

[participant] *Um, people in my life.... my sister.*

Heuristic Analysis of Interview

Corporeality

As a young child Gabby disliked telling onlookers about her scars. If Gabby was in a "bad mood" when the negative comments came she became "mad". If she was in a good mood the comments did not bother her. When she did become mad, Gabby and her sister used humor as a unique way of changing her attitude. Although she knew her scars were ever present, she learned to change her attitude to a more positive one. She developed comfort with her ever changed body and felt just like her peers.

Temporality

The temporal life world was not as clearly elucidated in the interview with Gabby as the other lifeworlds. Gabby did reveal, however, that life had gotten better over time. How she reacted to the negative comments of others had changed and she had moved from foster family to a permanent adoptive family.

Spatiality

As a young child, Gabby had been thrust from the home of her birth parents by a fire. Desperately she sought the comfort and security of a real home again. Home was more than a physical space, she dreamed of a "good home" complete with stable, caring, loving relationships. For most her young life participant seven had been in and out of foster care. Finally in her teen years she received the gift of a "good home." She was at last in a space

surrounded by people who truly cared for her.

Relationality

The tragic house fire forged a unique bond between Gabby and her sister. Both were scarred and endured the negative remarks of others. Each home placement ended in neglect and an uncaring relationship. None of the foster homes met the sisters' needs for comfort and security, or caring. Yet through these adversities they always had each other.

With the exception of her sister, traditional family relationships had eluded participant seven. Desperately she wanted to be truly cared for, only to be disappointed again and again. Ultimately a special caring family found her. She treasured the family relationship which was forming. Participant seven's sister however, remained the most influential figure in her life.

Participant Eight

Thematic Analysis of Interview

Hanna was a seventeen year old female who had been burned in a house fire. Her sister, participant seven, was also injured in the fire. Unlike some of the other participants, she remembered some of her life before the house fire. She had significant visible scars to her face, scalp, and neck as well as other areas. Hanna was quite articulate and spoke freely about her life experiences following the burn injury. She passionately expressed feelings about these events. Hanna had no difficulty revealing her life story.

This researcher uncovered five overall themes in the interview with Hanna. She also contributed a poem reflecting her experience. This poem will be analyzed after the presentation of themes.

Essential Themes

1. Hanna and her sister had been through the horrifying experience of a house fire. Although tragic, Hanna looked upon this event as a positive one. She stated before the fire the environment was "bad." The fire provided an opportunity for positive changes in her life. The theme, *Finding Good in Adversity*, is illustrated in the following passages.

Um, actually it's better.... Because like, before the fire we were living with our birth parents.... And things wasn't so well there.... And after the fire we went to foster homes.... And now we're finally adopted. So...I think a great thing came out of me being burned.

I feel like I ...my belief is everything happens for a reason. So I think me, like me and my sister being burned in a fire.. like that was a real bad thing....But after..in the long run we got like a great reward for it. Like we got burned but we also got taken out of a bad situation, a bad environment.

And we got put in foster home and then we went through some stuff with that and then we finally got adopted....And I'm loving it. I mean if I hadn't got burned I wouldn't been with foster parents.

2. Hanna was faced with numerous difficult challenges. Not only did she have to learn to deal with feelings about her scars but also survive in an unstable home. Furthermore she had to contend with all the normal developmental challenges of adolescence. Hanna developed numerous strategies to help her face adversity. These strategies included writing, music, basketball, humor, and talking to supportive people. She also believed others could successfully face adversity if she did. One of her goals was to help others face difficult problems. *Climbing the Mountain* is eloquently revealed in the following excerpts:

I mean like... its not... it's really good [in reference to adoption] but sometimes it's hard.Cause I have a real strong memory and I remember my birth parents. And I remember the fire but it doesn't bother me.... Like I can stand and talk about the fire and I won't cry....Because it's like ...I don't look at it as a sad thing. It was just a little mountain I had to climb....And now that I'm up there I can help other people get up to where I am.

Growing up in elementary school it was hard.

...but when I got to like the 7th and 8th grade I just developed into my own person, I realized that not everybody is the same and that I'm special in my own way. And my scars are unique, you know.... It makes me.. makes me different and it makes me special.

I mean at first after you're burned and you're like ... growing up... first of all growing up is hard in itself... you know... teenager...I'm a teenager...and sometimes it sucks...you know you just....But and I'm not saying that it's easy to get to where I am....and I'm not saying that nobody is able to get to where I am....Because I'm here....But what I am saying is it's going to take a lot of hard work.

3. Hanna's burn scars were clearly visible on her face, scalp, and other areas. She realized each encounter could potentially result in an unkind comment or stare. She spoke

about how difficult this was for her initially. She wanted so much to be like others. Why did her skin look like this whereas the skin of others did not?

Hanna revealed that gradually over time she was able to look at her scars as special characteristics of herself. She seemed to overcome the negative connotation associated with them. She also redefined normal. She equated normal with "sameness." She believed everyone was unique and that no one was normal. Normality was no longer an issue for her.

The theme, *Valuing the Unique*, is illuminated in the passages below:

I wanted to be like everybody else. I thought I was different back in the days I grew up. Why does my skin look like this and theirs look like that? You know.... And it bothered me growing up like in elementary.

I think, I think no one is normal.... I think there is no definition of normal because if there were everyone would have to be the same to be normal.... Not.. not even twins, they're not the same.... So I, I feel ...I feel regular you know.... I feel like everybody else. I feel important, I feel wanted.

[researcher] So you kind of feel like other kids? [participant] Yea.

[researcher] ok. So you don't feel different in any way? [participant] Nope.

I mean.. yea I had some friends that told me like, " you know (name) even though you burned you are still you, you're unique, ". and the scars well.. they didn't see um.... they don't see um. Like I'm a sophomore in high school and no one sees um. I'm just me.

4. During the interview the researcher observed that Hanna was quite articulate. She spoke easily and richly described her experiences and feelings. As the interview progressed, Hanna revealed that she was a writer. She had composed essays, poems, short stories, and regularly wrote in a personal journal. She stated it was a way for her to express her feelings. She stated it was a "kind of therapy". Hanna also stated she expressed herself through sports.

The theme *Expressing Self* is illustrated in the following excerpts.

Writing helps me and music. Writing, music and basketball. I love basketball.

It's like if I have something on my mind about the fire or about my birth parents or any event that has went on in my life.... And if I'm not able to sit down and express myself to people. I can always go in my room and grab my pen and paper and write. And it comes out so easy. I don't have to worry about what someone is thinking while I'm talking because it's my paper and my pencil and it doesn't matter what anybody think about it because I wrote it. It just helps. It's like a therapy.

Basketball. I've been loving basketball since the fire. It.. like I can.. say I'm having a bad day. I can pick up a basketball, go in a court and play a couple of pick-up games with my brothers and sisters or friends or by myself. And I leave it... I leave that court.... I'm just refreshed. Absolutely? I feel good?. It's also like a form of therapy for me.

Honestly, I don't.. I'm not really sure.. I mean.. when I was little I used to draw pictures.. Pictures of like a house on fire and then I went to writing things and then I just... I took all my anger and negative energy and turned it around.... I turned it into positive energy and I write things.

Me and my sister sit down and we'll joke about each other's burns. And its funny ... that's like a way of us dealing with it

5. As Hanna and her sister endured being placed in one foster family after another, Hanna felt lost and unloved. It seemed that her sister was the only constant source of support and affection. Finally in her high school years she and her sister were placed in a warm loving foster family. This family ultimately adopted Hanna and her sister. *Being Loved* is eloquently revealed in the following passages.

I mean if I wasn't adopted I felt lost, like I didn't belong.... I almost felt like nobody wanted me you know.... But now I know better it's just.. I just had to wait so many years for that perfect family. Now that I have it.

Well in the mean time my little brother (name) which I never met was living with (adoptive mother name). And so we finally figured out that's my brother and we moved in... and now we're all together.

Thematic and Heuristic Analysis of Literary Works

Participant eight revealed again and again that writing helped her deal with life's challenges. She felt writing was a type of therapy for her because she could freely express her feelings. Participant eight contributed an original poem reflecting her experience entitled, "My Skin".

*My skin may look different.
But I still have feelings.
When you laugh it makes me want to cry.
When you point it makes me ask God why.
When I have to go through all the pain. I wonder when will I stop getting hit by the hard rain.
But you and me are the same. I got burned, so whom do I blame?
Take some advice from your grandmother.
And never judge a book by it's cover.*

*Cause whatever you can do. I'm sure I can handle it too.
 You should get to know me before you decide who I am.
 So because I'm scarred up.
 Before you try, you give up.
 You never know I could be your best friend.
 And stick with you till the end.
 All I'm saying is do not push me away because of my skin.*

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The poem, *My Skin*, illustrates several of the same feelings uncovered during Hanna's interview. During her earlier school years, she struggled with the negative reactions from others to her scars. She longed for people to know her for who she was. Why couldn't people see beyond her scars? She was saddened by the rejection because of her scars. The sadness of these episodes is illuminated in the first part of the poem, "*When you laugh it makes me want to cry. When you point it makes me ask God why. When I have to go through all the pain. I wonder when will I stop getting hit by the hard rain.*"

Hanna revealed she had learned to view her scars as unique features of her appearance. She stated this realization was difficult and compared it to climbing a mountain. She now felt she it was her mission to help others get to that point. These sentiments are also illustrated in the poem, "*Cause whatever you can do. I'm sure I can handle it too.*"

Relationships were important to Hanna. She was a source of tremendous support to her sister when other relationships failed. The type of relationship she is capable of is illustrated in these lines, "*You never know I could be your best friend. And stick with you till the end.*" Peers were also important to Hanna. The entire poem seems to reflect Hanna's desire for friendship. This poem eloquently uncovers Hanna's experience in relation to the relational lifeworld.

Heuristic Analysis of Interview

Corporeality

Hanna struggled with the physical appearance of her skin as a child and young pre-adolescent. She questioned over and over why her skin looked different than others. She often felt angry and always felt different. Gradually participant eight began to realize that all people

have unique characteristics about themselves. She began to look upon her scars as a unique quality which only she possessed. Her scars became defining characteristics making her special. They were truly a part of her.

Temporality

Unlike her sister, Hanna had memories of life before the burn. In particular she remembered her birth parents. Over time the sadness of these memories passed but she still found the memories difficult. The past would always be there. As Hanna told her story, time was marked by good and bad times. She seemed to be in a good time period now; she made conscious efforts to maintain this good time. Hanna had also grown up chronologically and developmentally.

Spatiality

The spatial lifeworld for Hanna was quite complex. She had been in and out of several foster homes throughout her childhood and adolescence. These homes were uncaring and unloving. Hanna expressed that she "felt lost" and "unloved". The foster homes did not provide a nurturing environment typically associated with one's home. Ultimately Hanna was adopted and had a stable, nurturing home.

Hanna's room was also a place of importance. Here was a place she could retreat to when she needed to express herself in writing. She was empowered by writing; her room was the space this occurred in.

The basketball court was a nontraditional space of importance for Hanna. She loved the game and used the game to "refresh" herself particularly if she was down. The court was a place of free expression; it also was a place of empowerment for her. Hanna had extended her spatial lifeworld beyond the traditional walls of a house.

Relationality

Hanna had a unique special relationship with her sister. Both had endured the fire as well as poor foster family relationships. Each also supported the other when negative feelings

arose about their scars. They used humor to contend with these feelings.

Hanna loved her new foster family. She admired them for the awesome commitment of caring for a burned person. Despite the wonderful relations with her sister and new family she stated she still had memories of her birth parents. She said these memories were difficult but not sad. Her relational world had improved but past memories of her birth parents still surfaced.

Summary

The interviews of eight adolescents were analyzed using the methodology of Max van

Table 2
Essential Themes of Participant Interviews

Participant	Themes Identified	Participant	Themes Identified
One	Accepting the Inevitable Rising to Challenges Taking Charge of Feelings Being Normal Getting Easier over Time	Five	Defining Normal Facing Challenges Believing It's A Part of Me Belonging
Two	Making Comparisons Overcoming Challenges Understanding Change Takes Time Regretting the Past Making Choices	Six	Controlling Feelings
Three	None identified (participant unable to reveal)	Seven	Being Like Others A Feeling of Family Facing Challenges Being There for Me
Four	Staying Positive Accomplishing Goals Choosing Attitudes Feeling Normal Accepting It Takes Times	Eight	Finding Good in Adversity Climbing the Mountain Valuing the Unique Expressing Self Being Loved

Manen. Essential themes uncovered were identified and supported by quotes from the participant interviews. Original literary and artistic works contributed by two participants were included with the analyses. Following individual analyses, the interviews were analyzed as a whole to uncover common themes and variations essential to the phenomenon, lived experiences of adolescents with burn injuries. Participant themes are listed in Table 2. Themes

of the individual participants will be compared and triangulated with data obtained from personal experience, etymological sources, public media, poetry, literature, art, and music in chapter six. Common themes and variations in the themes as a whole will also be uncovered and discussed.

CHAPTER SIX

Phenomenological Writing

The purpose of this study was to uncover the meaning of the adolescent experience following a burn injury. Following analysis of each individual interview, common essential themes capturing the meaning of this phenomenon were uncovered (see Table 3). Van Manen states, "In determining the universal or essential quality of a theme, our concern is to discover aspects or qualities that make a phenomenon what it is and without which the phenomenon could not be what it is" (2001, p. 107). Incidental themes were also identified. These themes represented variations of the essential theme and added a more holistic picture of the phenomenon.

In addition to the interviews with adolescents, several other sources were used to uncover the meaning of the phenomenon. These sources included personal experience, etymological sources, public media, poetry, literature, art, and music. These sources and the meanings uncovered will be discussed. Following this discussion, the essence of the phenomenon as revealed through all sources including the interviews will be illuminated through phenomenological writing.

Common Essential Themes

Four common essential themes and nineteen variations were uncovered. These themes and their variations will be described. Each adolescent experienced all four themes with the exception of the two adolescents whose interviews had failed to uncover rich, thick descriptions of their experiences. Some adolescents experienced unique variations of the four themes. Interview excerpts illustrating the themes and variations will be included.

1. The lived experience of a burned adolescent is an arduous journey of struggles as each individual freely chooses a unique path to a new way of being.

As each adolescent described their experiences, they alluded to getting from one place to another. They seemed to be struggling to leave a place characterized by unhappy or negative

Table 3.

Relationship of Participant Themes to Common Essential Themes

Common Themes	Participant Themes
1. The lived experience of the adolescent with burn injuries is an arduous journey of struggles as each individual freely chooses a unique path to a new way of being.	Getting Easier over Time (1) * Changing Takes Time (2) Accepting It Takes Time (4) Facing Challenges (5) Being There for Me (7) Being Loved (8) Climbing the Mountain (8)
2. The lived experience of the adolescent with burn injuries is making difficult choices as cherished values are re-examined.	Accepting the Inevitable (1) Taking Charge of Feelings (1) Regretting the Past (2) Making Choices (2) Choosing Attitudes (4) Staying Positive (4) Controlling Feelings (6) Facing Challenges (7) Finding Good in Adversity (8)
3. The lived experience of the adolescent with burn injuries is creating new images of being normal.	Being Normal (1) Making Comparisons (2) Feeling Normal (4) Defining Normal (5) Believing It's A Part of Me (5) Being Like Others (7) Valuing the Unique (8)
4. The lived experience of the adolescent with burn injuries is becoming empowered while rejoicing in accomplishments and abilities.	Rising to Challenges (1) Overcoming Challenges (2) Accomplishing Goals (4) Belonging (5) A Feeling of Family (7) Expressing Self (8)

*Numbers after theme indicate participant number.

feelings and experiences about their burn disfigurements. Desperately they sought a place of comfort and acceptance. Metaphorically they seemed to be embarking on a journey. All acknowledged that this journey took time and was often difficult. At times it was physically exhausting; at other times emotionally exhausting. Setbacks often interrupted progress. Yet each individual struggled on. Throughout the journey, each adolescent chose their unique path.

They relied upon supportive family members, friends and others to guide them up these sometimes difficult paths.

Well, it was hard for me the first couple of years because I had to adapt to these you know, deal with people, but now I'm, it's very comfortable because I adapted to these and I know how to deal with people.

It took me a long time.

And I'm not saying that nobody is able to get to where I am.... Because I'm here. But what I am saying is it's going to take a lot of hard work. You know.

Yea those few hundred times I was sitting upstairs in the hospital for seven days because.... Learning to walk again.... Being stuck in a bed for five days.

Growing up in elementary school it was hard. Like I would, I don't know. I wanted to be like everybody else. I thought I was different back in the days I grew up. Why does my skin look like this and theirs look like that? You know.

Friends at home, family. Like when I'm sitting up there I've got at least one friend calling me like three times a day. And then my mom's usually there. And my dad will call me once a day.

My Mom and Dad are real supportive. My brothers and sisters. And we like, my burns don't bother me at all.

Variations

a) Participant one had the daily reminder of his injury as he applied his prosthetics. At times he would become saddened by this memory. If he continued to dwell upon this he suffered an emotional setback.

Um, it's hard. You know it makes me think back. But I can't make myself, make myself, uh, uh sad or cause you, then it just ruins the whole day.

b) Participant two often made comparisons between his abilities and those of others. He became saddened and remembered the consequences of his injury. He regretted having played with matches. This made the journey more difficult for participant two.

My brothers can lift weights. And I can lift weights but I can't lift weights like they can. And I can't do a whole lot of stuff like they can.... I feel, I feel, real bad, and then I wish sometimes I say to myself I wish I never was playing with matches.

c) In addition to the burn injury, participant seven and eight also had to endure the

burden of unstable, uncaring family relationships in foster care. They felt lost, unloved, and unwanted.

Well we first got to the first home when we was two we like, it was nice and all that, but when we got a little older they start not coming home, leaving us home alone.... And then we moved to another home.... And she wasn't, well, she wasn't taking care of us that much. Feelings wise.... they didn't want us here.

I felt lost.

d) Although family and friends remained important in the life of participant four, he developed a special relationship with God. Through divine intercession he was able to have the strength for his journey and choose a path of promise.

God was talking to me.... He was like... don't, don't let nobody hold you back. Just stay focused and when you stay focused things get better.... And when things get better you achieve things and when you achieve things you accomplish stuff.

e) Participant one attended a special burn camp each summer in the west. He developed a special relationship with fellow campers. They provided a unique support system for him. He was not alone on his journey; he knew he was not the only one.

When you go to our camp its like a brotherhood there. It's really a spiritual thing. Um, it's hard to explain. Because you know a brotherhood but, like, for example, if someone made fun of someone... We call it a brotherhood because we stick up for each other. We would help each other if someone is having problems or you know all that kind of stuff.

f) Participant five felt a special bond with the hospital staff, burn camp participants, and other burned children he had met over the years. They were a source of comfort and support for him. He called them his second family. Participant five was sustained by others.

Oh it's like a second family thing going on, cause I see.... Like I come down for camp pretty much every year and I see most of these same people there and I see all the same people back there in the clinic. So, couple of new people but other than that It's, they've been here since forever. It's like when you can, like if you went to one school you're whole life. You know everybody there, the whole time except a few people there. And so you feel comfortable around um cause they all know you and stuff like that.

g) Participant six, unlike the other study participants, did not identify her mother or other family members as sources of support on her path. It appeared that she was mostly alone on the journey.

No. Everyone in my class was my friends so; I really didn't have nobody to make fun of me.

[researcher] So your friends helped you then get through that you think? [participant] Pretty much.

h) Participants seven and eight were sisters. Their relationship was strengthened by the burn experience. They were the constant in each other's life. Although both were on this journey together, each personally had to prevail.

My sister. Because she's been with me all my life. And she was kind of like a mother to me when I was little.

i) Although supportive, participant one's mother strove to help her son learn to become independent. He recalls his mother's efforts; the mother had confidence in him.

My mom would push me to my limits to, so I can do stuff by myself. She can be hard sometimes cause she's trying to help me out. I understand that. Yeh, I sometimes she just does that and I get mad and I just get upset cause you know that is the way it is.

j) Participant eight found means to express herself on this journey. These included writing, music, and playing basketball. Each activity allowed her to express herself in a special way or allowed her to vent negative feelings as she traveled her personal path.

Writing helps me and music. Writing, music and basketball. I love basketball. Those two things help me.... It's like if I have something on my mind about the fire or about my birth parents or any event that has went on in my life.... And if I'm not able to sit down and express myself to people.... I can always go in my room and grab my pen and paper and write.... And it comes out so easy. I don't have to worry about what someone is thinking while I'm talking because it's my paper and my pencil and it doesn't matter what anybody think about it because I wrote it. It just helps. It's like a therapy.... Basketball. I've been loving basketball since the fire. It, like I can, say I'm having a bad day.... I can pick up a basketball, go in a court and play a couple of pick-up games with my brothers and sisters or friends or by myself. And I leave it, I leave that court, I'm just refreshed. Absolutely? I feel good?). It's also like a form of therapy for me.

2. The lived experience of the burned adolescent is making difficult choices as cherished values are re-examined.

As each adolescent embarked upon their journey, they were faced with difficult choices. No one wanted the burn disfigurement to keep negatively affecting their lives. All wanted to do something that would make things better. Five of the adolescents ultimately chose to either ignore the negative comments or to avoid dwelling upon them because the comments could

threaten their personal being.

Yep, I try to avoid them so I don't ruin my life.

*No, I, I really don't pay no attention to um.
I ignored them.... I didn't really take an offensive.*

I just didn't pay no attention.... See they would like call me names and I'd say no, wouldn't, didn't listen to um.

But if they say things negative, I will, At right now I don't even pay no attention to it. I don't, I um, let it try to get to me.

Variations

a) Although participant one chose to ignore the negative feelings that accompanied the stares of onlookers or their questions, he realized that ultimately the stares and comments would continue forever. He chose to explain to onlookers what happened to him.

It's like a long time ago people, it's been five years you know. You see people look at you, it gets kind of boring.... So when, now when I see people look at me it doesn't bother me cause I know people are going to look.... It's, it's not, the world is not just going to sit there and not look at you.

b) Participant five chose a unique response to individuals who looked at his scars. He decided to place the responsibility upon the onlookers.

If people don't want to look, don't look.

c) Although participants seven and eight chose not to get upset over their scars, they also chose another strategy to raise their spirits. They used humor and laughed to deal with their feelings about their scars and the reactions of others.

We've got this joke book me and my sisters read jokes out of and make me laugh.

Me and my sister sit down and we'll joke about each other's burns. And its funny, that's like a way of us dealing with it. It's like a silly humor.

Numerous other types of choices were made by the adolescents as they struggled on their journey. Some choices pertained to adopting a particular attitude, others involved selecting strategies to deal with difficult tasks or events.

d) Participant one had an arduous period of rehabilitation as he learned to use his

prostheses. Full independence required a conscious decision to exert full effort into his rehabilitation. Although tough, he chose to do so. Furthermore he chose to consider each task a challenge and to have fun in the process.

I find, I figure out ways to make it easier. It's just like a puzzle. You have to find the ways to. ...Like, like short cuts.... To make it easier.

I would have to adapt to the challenge. It's a lot more challenge. I think it s a little fun. Sometimes it can be fun.... Sometimes it can be fun, because I can do stuff people can't do.

e) Participant four chose to maintain a positive attitude about life in general. He set specific goals for himself. He believed one could be a better person if one stayed focused, had goals, and accomplished them.

And when things get better you achieve things and when you achieve things you accomplish stuff.... And when you succeed your goals you will be a better person in life.

f) Although participant eight and her sister had serious hardships in addition to the burn injury, participant eight chose to maintain a positive attitude about life. She truly believed that good had come out of adversity. Furthermore, she believed in channeling negative feelings into positive ones. She hoped in the future to help others overcome adversity as she had.

Because like, before the fire we were living with our birth parents.... And things wasn't so well there.... And after the fire we went to foster homes.... And now we're finally adopted. So.... I think a great thing came out of me being burned. I feel like I, my belief is everything happens for a reason. So I think me, like me and my sister being burned in a fire, like that was a real bad thing.... But after, in the long run we got like a great reward for it. Like we got burned but we also got taken out of a bad situation, a bad environment.

.... I took all my anger and negative energy and turned it around and, how I did that I still don't know? I turned it into positive energy and I write things.

Cause I have a real strong memory and I remember my birth parents. And I remember the fire but it doesn't bother me. Like I can stand and talk about the fire and I won't cry.... Because it's like ...I don't look at it as a sad thing. It was just a little mountain I had to climb.... And now that I'm up there I can help other people get up to where I am.

3. The lived experience of the burned adolescent is creating new images to transform the way of being normal.

As each participant revealed their story the theme of being normal was uncovered in all

interviews. At times it was mentioned verbatim, at other times it was uncovered as a general attitude that the adolescent had assumed. Being normal was being like others, participating in the same activities as others, or resuming pre-burn activities.

I would say its normal; it was, it's like the same right now.

I do everything I did when I was before the burn with these, prosthetics. So it's pretty much the same.

They see me like as a normal person too.

But as far as the day I just feel like I am a normal person just like everybody else.

Variations

a) Participant five had several perspectives about the concept normal. At one point in the interview he stated he was like everyone else because he engaged in the same activities; yet at another point he stated he was not normal because of his recent and past accidents including the burn. Later he stated "no one was normal." Participant five seemed to equate normalcy with sameness, following the expected routine such as going to school and displaying no differences.

Normal? Um, being in school everyday. Going to school. Being boring as the next student.... It's just one of those things. [researcher - So are you saying normal is doing what everybody else is doing?] Yep, not being yourself. Trying to be like all them. [researcher- Do you feel like you're normal?] No, not really.... I mean I'm the one, that two months before he was supposed to get his license put a car into a tree. Broke both of his legs, seven ribs, his wrist. Got burned when I was little. Broke my face on the snowmobile.... I'm kind of like the oddball stunt dude. Which is fun. [researcher- So you're saying you're not normal, your definition of normal is different?] Nobody is normal.

b) Participant eight defined normal as being the same as others. She stated, "no one was normal." However, normalcy for her was a positive concept. She valued the unique qualities each person possessed. In fact she had come to the realization that her burn scars were one of her unique defining characteristics. In contrast to being normal, participant eight considered herself "regular". Regular was being like everyone else, feeling important, and feeling wanted.

I think, I think no one is normal.... I think there is no definition of normal because if there were everyone would have to be the same to be normal.... Not, not even twins, they're not the same..... So I, I feel, I feel regular you know, I feel like everybody else. I feel

important, I feel wanted.

4. The lived experience of burned adolescents is becoming empowered while rejoicing in accomplishments and abilities.

Each participant had chosen a slightly different path as they traveled on their journey. Participants accomplished much during their journey. The burn experience was influenced by these accomplishments. These accomplishments energized them to continue on the journey.

It's just a feeling, a good feeling, I like when people say when, that they're amazed in me.

Um, I pretty much feel good cause I do everything I used to do with my hands. My real hands you know. I do everything I used to with um, everything.

It makes me feel good inside....It makes me feel me that I am actually doing stuff.

Like the people that make prosthetics. They love when I come and get repairs because they know I am using my ha___... [sic] my arms. Because most kids that have these...they don't come in that much for repairs because they don't use them that much. I need repairs around every month because I use them so much. That's how adapted to them I am, I use them sooo [sic] much.

It means, it means something big to me.... Because I thought I never get to play football or basketball or any other sports like that.... And ...so it really does mean something big to me.

When I first found out about it my mom told me that the doctor told her that I wouldn't walk or doing activities.... But, it um, it backfired on um [sic]. And I came to got stronger with it. And I began walking. (little smile).

Last year I got to use the kayak and I do that all the time. All summer long almost every other week, I'm on the river. And I just teach a couple of people how to kayak and its just always fun.

[researcher] So do you play for a school team or a team outside of school or what?

[participant] School team. [researcher] School team? So what position do you play?[participant] Point, center, whatever they put me in.

[researcher to participant] So are you good?[participant] Yea (big smile).

I love to write. I write poems, I write books, I write short stories. Not books but like little long stories and short stories.

I mean at first after you're burned and you're like, growing up, first of all growing up is hard in itself, you know, teenager, I'm a teenager, and sometimes it s_____ [left out] you know you just.... But and I'm not saying that it's easy to get to where I am....and I'm not saying that nobody is able to get to where I am.....Because I'm here....But what I am saying is it's going to take a lot of hard work. You know...

Non-Interview Sources

Personal Experience

Van Manen (2001) states one's personal experience is accessible to no one else. One's personal experience may be "the possible experience of others" (van Manen, 2001; p. 54) and therefore help to uncover the meaning of the phenomenon of interest more fully. Although this researcher had no personal experience as a burned adolescent, this researcher did have 25 years experience as a pediatric burn nurse. A client case is discussed to uncover the personal experience. As the case is described, a pseudonym is used to protect the client's identity.

Case One

Melody, a beautiful, popular teen suffered a major burn when trapped in a burning automobile. In a few tragic minutes, Melody's appearance was forever transformed. After several surgical procedures, Melody was left with no fingers, little hair, and a severely scarred face and body. When Melody first saw her face in a mirror, to the burn center team's surprise, she stated, "Oh it's not as bad as I thought it would be."

Despite a lengthy hospitalization, Melody appeared comfortable in her surroundings. Upon discharge, Melody returned to school and engaged in her favorite recreational activities as before the burn. She graduated from college and married.

Heuristic Interpretation

The anecdote about Melody also seemed to demonstrate the theme of *Making Difficult Choices*. Despite adversity, Melody continued life as an active teen. Melody seemed to display optimism and a desire to carry on despite adversity from her injury. Despite obvious changes in her corporeal existence, Melody seemed able to reflect upon this new image and ascribe meaning to her life. Perhaps her corporeal being was centered inwardly so that when the external changes occurred, Melody was essentially unchanged. Although Melody's lived space was obviously changed during her prolonged hospitalization, Melody again seemed able to transcend the strange environment of a burn center and make it home.

Summary

As this researcher recalled caring for this client, I became open to the variety of possible meanings and responses an individual could have for life experiences. I realized that as I tried to uncover meanings in the interviews, I would need to make sure past experiences were not inappropriately influencing my assumptions.

Following analysis of all the interview data I revisited the personal experiences again. Commonalities between Melody's case and the research evidence could be found. For example, the study participants seemed to be traveling on a journey. Many times they were forced to make difficult choices. The adolescent I cared for clearly chose to not let the burn interfere as she continued on with life.

Etymological Sources

Etymological sources trace the origins and meanings of words from their first appearance in a language. As van Manen (2001) discussed, words often lose some of the richness of their meaning as time passes. When trying to uncover meaning, it can therefore be helpful to examine etymological origins of words used to describe the phenomenon. This researcher was interested in tracing the etymological sources for burn, scar, and normal. Merriam-Webster Collegiate Dictionary (1996) was the reference used to trace these etymological roots.

Burn appeared before the twelfth century, Middle English *birnan* and Old English *byran*. It was similar to the Old High German *brinnan*, to burn. Burn, in the noun form, is defined as (a) an act, process instance or result of burning, (b) a burned area, (c) an abrasion having the appearance of a burn, or (d) a burning sensation (Merriam-Webster, 1996)

In this study, burn was used to specify the injury event and the disfigurement caused by the injury. Only two participants used the word burn in the narrative descriptions of their experience. Burn was used as both noun and verb forms by these participants. In the noun form is was used in the context of an area on their body which had been burned; in most cases this

was a scarred area. When the verbal form was used, the participant referred to being injured or to the sensation of burning. Although other participants did not use the word burn explicitly, they did respond to the use of the word by the researcher in the context of injury event or the disfigured area.

Scar appeared in the fourteenth century, Middle English *eschare*, scar. It was similar to Middle French *escare*, scab; from the Latin *eschara*. Scar is defined as (a) a mark left by the healing of injured tissue, (b) a mark left on a stem or branch by a fallen leaf or harvested fruit, (c) a mark indentation resulting from damage or wear, or (d) a lasting moral or emotional injury.

In this study, scar was used to describe the permanent skin disfiguring changes following a burn injury. This researcher asked each adolescent to reveal their feelings about their scars. The researcher also was interested in the response of the adolescent to the reactions of others to their scars. Ultimately the researcher hoped to determine if the scars affected the meaning of the adolescents' lived experience.

As the meanings in the interviews unfolded, the researcher discovered only one participant used the word scar in the narrative descriptions of their experience. It was used in the traditional meaning indicating a mark left by healing tissue. The obvious absence of the word scar was somewhat interesting as the fourth definition for scar defined scars as a lasting moral or emotional injury. It was not clear if the participants substituted burn for scar or if they consciously avoided the term due its negative connotation.

Normal appeared in approximately 1696 and was derived from the Latin *normalis* and French *norma*. It is defined as (a) perpendicular to a tangent at a point of tangency, (b) according with, constituting or not deviating from a norm, rule, or principle, (c) occurring naturally (Merriam-Webster, 1996).

Normal was used in this study as a descriptive term to refer to a personal quality. Specifically, this researcher used the term synonymously with regular or not deviating from the usual. As each adolescent spoke about their experiences, the researcher asked if they felt

normal.

Six of the eight participants used the word normal in the narrative descriptions of their experiences. Five individuals used the term descriptively to indicate "being the same" or "like everyone else." One individual stated the term normal was a misnomer, "no one is normal". This participant felt normal meant "exactly the same" which would have been too restrictive. The term regular was used by this participant in place of the term, normal. Regular was defined as normal in the dictionary.

Public Media

The public media often presents an unrealistic, negative image of burn victims and their injuries. The horror film series, *Nightmare on Elm Street*, depicts the villain, Freddy Krueger, as a grotesquely disfigured burn victim (Carter and Petro, 1998). He is isolated from society and only appears when committing horrible crimes. Others are both fearful and disgusted by his appearance. He is avoided at all costs.

After the Fire

In 2000, an actual tragic dormitory fire inspired a team from the New Jersey paper, *Star Ledger*, to tell the story of two young victims of this fire. This researcher believed the serial story and photo expose, *After the Fire* (Fisher, 2000; Rainey, 2000) captured the experience of the adolescents in the study. The story and images can be viewed at this URL (<http://www.nj.com/specialprojects/index.ssf?/specialprojects/afterthefire/main.html>)

In the early morning hours of January 19, 2000 an arsonist fire raced through Boland Hall, a freshman dorm at Seton Hall University. Three young students perished and 58 others were injured in this tragedy. Freshman roommates, Alvaro Llanos and Shawn Simons were critically injured in the blaze. Both young men were almost nineteen at the time of the fire. *After the Fire* examined the experiences of Alvaro and Shawn during the eight months following the accident. This period of time encompasses the acute phase of burn injury in which wound healing and coverage occurs. It was characterized by intense pain, itching, and a lengthy

hospitalization.

This study, examined the experiences of adolescents age 13-18, at least one year following their acute injury. Despite the difference in timing, related to the phase of injury and the overall younger age of adolescents in the study, this researcher discovered that many of the experiences and meanings present in *After the Fire* were also uncovered in the study; there were also some variations in the two college students' meanings and experiences. The meanings and experiences in *After the Fire* were captured through both the prose and photographic images.

"...An arduous journey of struggles as each individual freely chooses a unique path to a new way of being."(theme one)

Both young men were critically injured, Alvaro more severely than Shawn. Each traveled a long journey to full recovery. The journey was marked by challenges and set backs. Alvaro developed critical complications and almost died; Shawn fell into depression and almost lost fingers. Both were challenged by the pain, rigor of burn treatments, and therapies. They often became angry, frustrated, or frightened. The experience of the journey and the struggles was gleaned from the text and in the photos. Some of the emotional outbursts reflecting the feelings during their journey are illustrated below.

I hated it when I heard them coming because I knew it meant I was going somewhere where they were going to hurt me.... It really hurt, and I used to get mad, but I couldn't say anything because I couldn't talk.

I can do this myself, let me do it on my own!

You don't know how to do anything! You don't do it like the nurses!

Variations

Shawn who had been injured less severely left the hospital before Alvaro. He still required outpatient therapy but was able to return to previous activities much sooner. Shawn frequently visited Alvaro. He was haunted by feelings of guilt.

'That's why I don't sleep, I think I am blaming myself.' Had he and Alvaro turned the

other way, they might never have been burned at all. 'I wish I went left,' Shawn said with guilt and remorse in his voice.

Alvaro also thought of the past. He was angered because the fire was the result of arson. He felt anger for the boys who died and sadness for their families.

I used to get mad because these kids did something so stupid. I think they probably lit a fire and it got out of control. Something little got real big. I still get mad when I think about the three boys who died. It makes me feel sad to think of how much their families are hurting. But the kids who died are in heaven now, so at least they're safe.

As Shawn and Alvaro traveled their journey of recovery, they were supported by family, friends, and each other. When Shawn left the hospital he continued to visit Alvaro. A special bond was forged between the two former roommates.

Al, you're going to pull through this. It will take a little longer, but you will pull through. He would have known that I was thinking that even though I was going home, I wasn't really leaving him and that I would be there to see him through this no matter how long it took.

It's okay, I'm okay, I'm okay, I'm going to get Mets tickets so we can see a game, Al, you're going to be okay, You've been through a lot. But I'm going to be right here for you. I'm going to be right here.

See, Al. It's my face, too. I look like you. We're going to get through this together.

I have a bond with Alvaro that I can't have with anyone else, ever. We survived a terrible ordeal together, and even though we still talk to each other the way we did before - you know, we still joke and make fun of each other - there's something more. I love Alvaro. Definitely. I love him. Al's going to be all right. I have no doubt in my mind. and I'll be right there with him.

".... is making difficult choices as cherished values are re-examined."(theme two).

As Shawn and Alvaro recovered they made difficult decisions about their care, their attitudes, and their relationships. They often seemed to be on an emotional roller coaster. At times hopeful and motivated; at other times despondent and dependent.

Shawn rarely wore the clear plastic mask prescribed for him, even though the doctors and therapists told him that it could significantly reduce his facial disfigurement by stretching the skin and compressing the scars.The mask was tight, hot and scary. It reminded Shawn of the Michael Myers character in the Halloween horror movies. He would deal with some disfigurement and skin discoloration, he decided, rather than wear it twelve hours a day.

I've thought about it, I don't want more surgery.

The day he came dancing into my hospital room, wearing regular clothes, and I was in bed, made me a little jealous. But it made me stronger. Right then, I decided that I wanted to get better, too.

No, please stay, I want more therapy.

Give me more. Go on. Keep stretching. I want to get out of here and go home.

In the beginning I used to think, 'Why me?' but I don't do that much now. In the beginning I was scared that when I went back to school people would be staring. Now, I'm not scared. Now I'm getting comfortable with who I am. It's like I have been reborn, like I am starting life all over again.

"...is creating new images to transform the way of being normal."(theme three)

Unlike the adolescents interviewed in the study, the theme of feeling normal was not uncovered as clearly in *After the Fire*. Normalcy was not mentioned by either young victim. Instead both boys had concerns about their appearance and the reactions of others. Alvaro seemed to have more serious concerns however. This researcher did have a sense that both boys knew they would not be normal again and grieved for that lost person.

Tears streamed down Alvaro's cheeks. Just the night before he had lain awake fretting about how the kids at Seton Hall would stare at him. A couple of days earlier the stitches were removed from his eyes and he had seen his hands for the first time. He broke down and cried.

Shawn rubbed his left hand. With his right hand trembling violently, Alvaro reached for the mirror and slowly drew it up to his face. He studied his eyes, his cheeks, his chin, saying nothing.

'I am so ugly.' Alvaro said. 'I should have died.'

As he walked around the campus with his parents, students who were friendly with him before the fire now passed without recognizing him. 'I've counted four so far,' Alvaro said as he headed to the university bookstore to buy a Seton Hall decal for his car-though he wasn't well enough to drive. 'They were friends, people I knew pretty well. They didn't know who I was.'

The other day I (Alverno) was standing in line at the movies, and this girl about my sister Shirley's age just stood there staring at me.

I (Shawn) know my mother and a lot of my women friends have always said they look at a man's hands first, and I always kept my hands nice. Catherine says she knows people who continue wearing the gloves after the healing process is done. 'I'm thinking about doing that' or maybe I'll have some nice custom leather gloves made. I guess I hope I don't always feel like I have to hide them.

You know what I love about Tiha? She doesn't care about my burns at all. She wants to work my hands. She puts lotion on them, She asks a lot of questions. 'What hurts? What will change? Tiha's the person I feel most comfortable with besides my mother. I could never, ever see her leaving me because Of my burns. I'm more concerned about stranger's reactions than hers.

Video

While riding in the family car on a family vacation, three year old Joel Sonnenburg was the victim of a motor vehicle accident involving a drunken truck driver. The family's car burst into flames trapping Joel in his carseat. Joel suffered a major burn causing severe disfigurement to his entire body as well as the loss of his fingers and hands. *Scarred Hero: The story of Joel Sonnenburg* is a documentary film about Joel's life since the accident. Joel speaks eloquently about his life experiences. He openly stated that he knew his appearance would not change to any degree and decided to refuse more surgery; Joel did not state at what time he decided this but was in his early twenties at the time of the film. Joel revealed he was happy with his life. He stated he had friends and felt "just like them". He engaged in the same activities as his peers.

Although this video was not created to explore the lived experience of Joel Sonnenburg and Joel was a few years older than the study participants, the movie supported the themes found in this study. In particular the themes concerning being normal (theme 3) and making difficult choices (theme 2) were most evident.

Poetry

Several poems were located within the literature describing experiences of burned individuals. As van Manen (2001) states, "Poetry allows the expression of the most intense feelings in the most intense form," (p. 70). This researcher believed these works captured experiences similar to the experiences of the adolescents in the study.

Charles on Fire

*Another evening we sprawled about discussing
Appearances. And it was the consensus
That while uncommon physical good looks
Continued to launch one, as before in life
(Among its vaporous eddies and false calms),*

*Still, as one of us said into his beard,
 "Without your intellectual and spiritual
 Values, man, you are sunk," No one but squared
 The shoulders of his own unloveliness.
 Long suffering Charles, having cooked and served the meal,
 Now brought out little tumblers finely etched
 He filled with amber liquor and then passed.
 "Say," said the same young man," in Paris, France,
 They do it this way-bounding to his feet
 And touching a lit match to our host's full glass.
 A blue flame, gentle, beautiful, came, went
 Above the surface. In a hush that fell
 We heard the vessel crack. The contents drained
 As who should step down from a crystal couch.
 Steward of spirits, Charles' glistening hand
 All at once gloved itself in eeriness.
 The moment passed. He made two quick sweeps and
 Was flesh again. "It couldn't matter less,"
 He said, but with a shocked, unconscious glance
 Into the mirror. finding nothing changed,
 He filled a fresh glass and sank down among us.*

From: Merrill, J. (1992). Selected poems, 1946-1985 (1st ed)(p. 108) New York, NY: Knopf.

The poem, *Charles on Fire* (Merrill, 1992; p. 108) tells a simple story of friends gathering for a meal. All acknowledged that physical looks is what would open doors, give you an advantage, and first appearances launched you. It was inevitable, although intelligence and values were also essential. A tone of uncertainty about the statement prevailed among the friends, no one wanted to discuss their own appearances. Charles, one of the acquaintances and a burn victim, served liquor and one glass was ignited. The glass broke spilling fluid and flame onto Charles' hand momentarily. For the briefest second, Charles' hand was transformed. The image passed. He quickly snuffed out the flame and it was a hand again. Yet as Charles looked into the mirror with indifference to check his appearance, he realized he had not changed. His burn would always be a part of him.

All adolescents in the study experienced physical changes from the burn. They encountered negative comments about their appearance as they journeyed through life. Several realized the inevitability that their appearance would never change and people would always

make comments. Society judges individuals by their appearance. Some of these adolescents chose to ignore their disfigurements and continue on; others chose to judge themselves by their character or accomplishments. Themes one and two were most clearly supported by the poem.

The Burnt Child

*Matches among other things that were not allowed
Never would be
Lying high in a cool blue box
That opened in other hands and there they all were
Bodies clean and smooth blue heads white crowns
White sandpaper on the sides of the box scoring
Fire after fire gone before*

*I could here the scratch and flare
When they were over
And catch the smell of the striking
I knew what the match would feel like
Lighting
When I was very young*

*A fire engine came and parked
In the shadow of the big poplar tree
Of Fourth Street one night
Keeping its engine running
pumping oxygen to the old women
in the basement
when she died the red lights went on burning*

From: Merwin, W. S. (c 1997). Flower and sand: Poems. 1977-1983. Port Townsend; WA: Copper Canyon Press.

The poem, *The Burnt Child*, also describes an individual remembering the past. The individual played with matches and a fire resulted killing another individual. The memories will not go away, "*when she died the red lights went on burning*".

Three adolescents in the study remembered the burn incident. Two expressed sadness and one remorse for the event. The individual with remorse had been playing with matches. Two were saddened because of lost function resulting from the injury. One was saddened about lost relationships. Each could not escape the memories of the past.

Literature

Fiction

Fictional stories often mimic and eloquently describe life experiences. Two fictional stories were discovered which this researcher believed reflected the experiences of the adolescents in the study.

JRR Tolkien's (1994) *Lord of the Rings* is not a novel about burned adolescents. Yet his epic novel eloquently described what the burned adolescents went through. This researcher believed the story captured the essence of the adolescent's experience.

The story chronicles the journey of Frodo Baggins as he attempts to carry the Ring of Power to Cracks of Doom for destruction. Frodo embarked upon the journey somewhat reluctantly. He had not chosen to be in possession of the ring.

The adolescents also did not want to be burned or have scars. They were reluctantly forced to endure the scars as they traveled through life. Some thought of the past and desired to be not burned again.

I wish I had never found it, and that I had not got it! Why did you let me keep it? Why didn't you make me throw it away, or, or destroy it? (p. 58).

I wish I was back there. (p. 287).

As Frodo traveled his path, it was fraught with physical and emotional peril. The longer the ring was in Frodo's possession the more it would transform him both psychologically and physically into a being he did not wish to become. He desperately struggled against the ring's power. The adolescents were already visually transformed by their scars; they did not want to succumb to the depression, sad feelings, and other sequelae that occurred when others made negative comments about their scars. Furthermore, they did not want the potential permanent physical functional impairment. They struggled to regain the physical functions they had before. They also endured the emotional trauma of negative comments about their scars.

It became difficult to follow the path, and they were very tired. Their

legs seemed leaden (p. 119).

They had to pick their way carefully to keep both dry footed and on their proper course. At first they made fair progress, but as they went on, their passage became slower and more dangerous (p. 178) .

'I can't manage it, Sam' he said. 'It is such a weight to carry, such a weight.'(p. 916)

Although the journey was arduous, Frodo had the support of his faithful servant Sam.

Sam had endured most of the adversities with Frodo. The adolescents in the study also had the support of friends and family.

'Then let me carry it a bit for you, Master,' he said. ' You know I would, and gladly, as long as I have any strength.' (p. 916).

'I'll get there, if I leave everything but my bones behind,' said Sam. 'And I'll carry Mr. Frodo up myself, if it breaks my back and heart. So stop arguing!' (p. 918).

Lauraine Snelling (2000) did not write *Class Act*, a novel for young adults, as a work to illustrate the experience of burned adolescents. The story did capture some of the essence of the adolescents in the study. Similarities between the struggles and feelings of the young heroine of the story and the adolescents in the study are apparent.

D. J. Randall was a 15 year old female burned while rescuing horses from a barn fire. An accomplished equestrian and artist, DJ desperately wanted to return to the activities she loved before the accident. She would embark on a long journey with many challenges. The adolescents in the study also traveled a long journey. They also strived to engage in pre-burn activities and to be like others.

DJ tried to hide her second worst fear- that she would never draw again. How could she live without jumping or drawing?(p. 13)

Will I ever draw again? From the look of her hands right now, both drawing and riding seemed utter impossibilities.(p. 52)

After months of hard therapy, DJ began to rejoice in accomplishments however small.

The adolescents in the study also felt great pride in their accomplishments.

DJ cupped both hands around the handle and, squeezing them as tightly as she could, slowly twisted the knob until the door swung open. Yes! At least I did something! (p.90)
School had really gone better than DJ thought it would.(p. 154)

Nonfiction

Van Manen (2001) states one can turn to autobiographical or biographical texts as rich sources of experiential material. Although, Lucy Grealy's *Autobiography of a Face* is not about the experiences of burned adolescents, this autobiography richly captured the essence of the adolescents' experiences.

Lucy Grealy was diagnosed with Ewing's Sarcoma involving her right jaw at age nine. She embarked on a twenty-year journey of physical and emotional trauma trying to cope with her physical changes. Almost daily she endured cruel taunts and stares from children or adolescents. She tried to ignore the comments but felt isolated and unloved. Desperately she sought ways to overcome her negative feelings. Finally after almost 30 surgeries she began in her words, "the journey back to her face." The adolescents in the study also embarked upon an arduous journey. They too faced cruel stares and taunts. Over time they also developed ways to react to negative experiences. Both Lucy and the adolescents dealt with disfigurement and the reactions of a critical society.

I had been looking forward to going to the lunchroom. As it happened, I sat down next to a table full of boys. They pointed openly and laughed, calling out loudly enough for me to hear, 'What on earth is that? That is the ugliest girl I have ever seen.' (p. 124)

My initial tactic was to pretend I didn't hear them, but this only seemed to spur them on. In the hallways, where I suffered similar attacks of teasing from random attackers, I simply looked down at the floor and walked more quickly, but in the lunchroom I was a sitting duck.(p. 125)

At school the taunts were becoming only harder to take. Somehow I had reasoned that if a bad thing happened often enough it would get easier. It worked with pain, so why wasn't it working with teasing? Every time I was teased, which usually happened several times a day, it seemed incrementally more painful. I was good at not listening, at pretending I hadn't heard, but I could sense myself changing, becoming more fearful. Before I'd been an outgoing person, and in the right circumstances, I still was, but now meeting new people was laced with dread.(p.145)

Maybe life was going to be all right after all. Maybe this wasn't my actual face at all but the face of some interloper, some ugly intruder, and my 'real' face, the one I was meant to have all along, was within reach. I began to imagine my 'original' face, the one free from all deviation, all error. I believed that if none of this had happened to me, I would have been beautiful. I looked in the mirror closely and imagined the lower half of my face filled out, normal. Reaching my hand up, I covered my chin and jaw, and yes, even

I could see that the rest of my face really was beautiful. As soon as I took my hand away, the ugliness of the lower half canceled out the beauty of the upper half, but now this didn't matter so much; it was all going to be 'fixed'.(p. 157).

Over the years my perspective on 'what it was all about' has shifted, but the most important point then was that there was a reason for this happening to me. No longer feeling that I was being punished, as I had during the chemo, I undertook to see my face as an opportunity to find something that had not yet been revealed. Perhaps my face was a gift to be used toward understanding and enlightenment.(p.180)

The journey back to my face was a long one.(p.220)

I felt there was something empty about me. I didn't tell anyone, not my sister, not my closest friends, that I had stopped looking in mirrors. I found that I could stare straight through a mirror, allowing none of the reflection to get back to me.(p. 221)

And now something inside me started to miss me. A part of me, one that had always been there, organically knew I was whole.(p.221)

Art

Linda Rainbow Westlund, Arizona artist created a 13x17 inch giclee entitled, *Under the Skin* in 1993 (see Figure 2). This work is part of a series of paintings entitled, *The Circles*. This painting illustrates experiences of the adolescents in the study. As Linda Westlund wrote:

“Twenty five years ago I started painting The Circles. To me each painting represents a cycle of time, a cycle of universal events, a cycle of natural evolution and a cycle of one's perception.

The focus of each painting is different but collectively they are all one painting. They are all windows from which one may take a step back and see patterns of life in it's entirety” (Westlund, 1993).



Figure 2. Under the Skin.

When describing, *Under the Skin*, Westlund (1993) wrote:

According to anthropologists there are twenty six races of human beings on the planet, although there are no pure races today. Diversity, in human beings, as in all members of life's community, is the divine blueprint of the Creator. The spirit flame of life burns in all men regardless of their race, creed or color. When one opens one's heart and prays, in the silence of his soul, he will find his own path. Under the Skin, no matter who we are, what look like or what we perceive as the meaning of life and the universe, and our place in it, we are all brothers and sisters, of the light and in the hands of God.

Each adolescent chose their own path as they traveled their journey of recovery. They learned to treasure their uniqueness and abilities acquired despite the ever present scars.

Music

As van Manen (2001) states, "Poetry allows the expression of the most intense feelings in the most intense form." (p. 70). Music can be considered a form of poetry also. Two songs were discovered that this researcher believed illustrated the experiences of the adolescents in the study.

Who Knows Whereville (To listen to Joe's Song, please click on the box Below for a video clip)

I woke up this morning
On the wrong side of the bed
I put my feet on the cold floor
Then scratched my head
I started thinking about you
Wondering how you've been
And if you would take a ride with me

Cause I'm going to Who Knows Whereville
Who knows who I'll see
I'm going to Who Knows Whereville
Do you want to ride with me and we'll be
In Who Knows Whereville

I turned on my TV
Channel surfed the day away
Then I took my TV down
To the "Pawn & Pay"
I'm going to take the money
Hey, I'm going to get away
Will you take a ride with me

Cause I'm going to Who Knows Whereville
Who knows who I'll see
I'm going to Who Knows Whereville



Do you want to ride with me and we'll be
In Who Knows Whereville

Who knows me
Who knows you
Who knows who
Who know anybody in Who Knows Whereville

Joe Bates (2000). Copyright 2000, Joe Bates. Used with permission of Joe Bates.

This song is an original composition contributed by a former patient who was burned as an adolescent. Although no longer an adolescent, Joe Bates stated the song was a reflection of his life experiences after the burn. Over the years, Joe Bates had grown to be grateful for the burn injury. He believed his life would have taken a different path had he not been burned. He was happy with his life.

All of the adolescents in the study embarked upon an uncertain journey, who knows where, as they recovered from the burn injury and learned to react to the feelings evoked by negative comments. One of the adolescents in the study believed the burn was a positive event. She stated her life had ultimately improved because of the burn. This researcher believed this song reflected the adolescent's experience.

Climb Ev'ry Mountain

The second song was discovered on the soundtrack for the Sound of Music. Mother Superior sang *Climb Ev'ry Mountain* (Rogers & Hammerstein, 1965) to the young Maria. This song evokes the theme of a difficult journey, "Climb the Mountain". An individual must endure this journey to attain one's dream. This researcher believed the song reflected the experience of the adolescents in the study. The adolescents in the study also embarked upon a journey of recovery and acceptance. Each adolescent was searching for their unique path as they were supported by family, friends, and others. As they traveled on this arduous journey, dreams and goals sustained them. Participant eight described her experience as, "... Like I can stand and talk about the fire and I won't cry....Because it's like ...I don't look at it as a sad thing. It was just

a little mountain I had to climb....And now that I'm up there I can help other people get up to where I am."

For the adolescent with a burn the lived experience is an arduous journey of struggles as each individual freely chooses a unique path to a new way of being. The adolescent desperately desires to leave the place of negative feelings related to their disfigurements. They have endured taunting and stares by others. Most realize this will be an inevitable occurrence throughout life. Each embarks upon a life journey to find a way to understand and react to these comments or behaviors. The journey is one of tremendous challenge. Physical adversity such as limited function or reconstructive surgery is ever present. Emotional turmoil abounds as they struggle to accept the challenges. Each chooses a unique path. All realize their hope for some level of comfort and acceptance will take time. Family friends and others support and guide the adolescents on their journey.

The lived experience of the burned adolescent is making difficult choices as cherished values are re-examined. They need to decide how committed they will be to the required therapy and if they will attempt to participate in previous activities. They actively decide to ignore the negative comments or respond in some positive fashion to the onlookers. They purposefully chose the attitude they will assume.

The lived experience of the burned adolescent is creating new images to transform the way of being. Most adolescents desire to be like their peers. Returning to pre-burn activities is valued immensely. Although they realize their appearance is forever changed, they develop a sense of normalcy as they return to previous activities and interact with peers.

The lived experience of burned adolescents is becoming empowered while rejoicing in accomplishments and abilities. The sense of accomplishment is essential to the adolescent's image of themselves. They treasure positive comments about their accomplishments. These accomplishments energize them to continue on their journey of living in the world with a burn injury.

Summary

Chapter six presented the themes uncovered when all interviews were analyzed as a whole as well as non-interview data sources. Four essential common themes were uncovered. Nineteen variations were revealed. All variations were within the themes of being on a journey, making choices, and being normal. Chapter six also presented non-interview data sources including personal experience, etymological sources, literature, art, and music. All data sources including the previously discussed interviews were then analyzed and the essence of the phenomenon revealed through phenomenological writing. The next chapter will discuss the findings.

CHAPTER SEVEN

Discussion of Findings

In this chapter the findings of a second literature review, as they relate to the lived experience of adolescents with a burn injury, is discussed. The findings will be linked to Rosemarie Rizzo Parse's theory of human becoming. In the previous literature review it was noted that many studies examined outcomes for burn victims such as quality of life. Studies varied considerably in their findings related to the quality of the outcomes achieved. Furthermore, some studies had contradictory findings. Few studies explored adolescents exclusively. No studies were found that described the lived experiences of burned adolescents.

Second Literature Review

An acute burn injury has been identified as one of the most traumatic injuries a human can endure. The resultant scars and other disfigurements can potentially have lifelong effects. The traditional burn literature has indicated a variety of both physical and psychological responses in children and adolescents to this event. Delays in the achievement of growth and development goals have been observed (Gilboa, et al., 1999; Meyer, et al., 2000; Patterson, et al., 2000). Psychosocial alterations have been encountered including problems with social re-entry, anxiety, depression, aggression, and self esteem disturbances (Herndon, et al., 1986; Meyer, et al., 2000; Molinaro, 1978).

The adolescents in this study were found to have experienced some of the same responses in the early months or years following the injury identified in the previous burn literature. For example, participants talked about limited function initially. When comparing their responses to the burn injury years later however, significant differences were observed between the adolescents in this study and previous studies. Eventually the six adolescents, who were able to give a description in this study, stated they engaged in activities as before and felt like their peers. They considered themselves like everyone else or normal. Most stated it took considerable time to be able to feel the way they ultimately did. One used the analogy of

“climbing a mountain” to describe this experience. All adolescents acknowledged that they met a variety of difficult challenges on their journey. Conscious choices had to be made such as ignoring the negative comments about their scars. The previous burn studies in contrast, did not reveal any specific information about feelings or meanings. In addition, these studies examined adolescent less than five years post-burn. It is quite possible these individuals had more burn related somatic problems making it difficult to compare them to the study group.

The traditional burn literature did not fully explain the findings in this study. Chronic illness studies particularly those focusing on the lived experience were thus reviewed.

Due to the lack of research on experiences of adolescents with burns, the second literature review explored the literature for phenomenological research involving adolescents with other chronic health conditions. Chronic health conditions are conditions that “interfere with daily functioning for more than three months in a year, cause hospitalization of more than one month in a year, or is likely to do either of these” (Hockenberry et al, 2003; p. 906). A burn injury with resultant scars or amputations is considered a chronic condition, therefore, the adolescent chronic illness literature would be valuable to understanding the findings from this study.

Eklund and Sivberg (2003) explored the meaning of the lived experience of adolescents with epilepsy. Thirteen adolescents aged 13-19 years who had been diagnosed with epilepsy for at least one year and were on an antiepileptic medication regime participated in the study. Individuals with mental retardation or cerebral palsy as well as epilepsy were excluded. Semi-structured and open-ended interviews were utilized to uncover the meanings. All the participants identified four strains that were part of their experience of epilepsy.

The seizures themselves were identified as strains. Concerns associated with them included anxiety, embarrassment, getting hurt, and loss of control. Seizures essentially made the adolescents with epilepsy different. The burned adolescents were also different because of scars and functional impairments.

I disgrace myself during the seizures. That is awkward. Throwing things around, not

being conscious about it, and saying strange things. It's no fun to have fits among others (p. 44).

A second strain, limitation of leisure activities, was a concern for all the adolescents in the study. They talked at length about the need to take care of themselves. Many were frustrated about being forbidden to do some things with their peers. The burned adolescents also wanted to be with their peers. Unlike the adolescents with seizures however, they were not usually forbidden by parents to engage in activities, rather they felt socially forbidden or left out because of their appearance.

I am not allowed to go out by myself, not even with friend, Mum wants to come with us. And I am not allowed to bike without a helmet so that I won't fall in the middle of the street(p. 45).

Medication side effects were significant strains for several adolescents. Side effects particularly troublesome were tiredness, sleeping disorders, problems with concentration, and memory impairment. Other problematic side effects included appetite changes, weight gain, hair loss, breathlessness, visual disturbances, and dizziness. Despite these complaints most adolescents realized the importance of following the medication regimens. Medication regimens were not a concern to the burned adolescents. Some spoke of restrictions when they had reconstructive surgeries, however, some were in the rehabilitation phase of burn injuries.

Feeling different was the fourth strain identified by the adolescents. Most participants desired to be seen like others but felt different; some expressed difficulties with classmates. Some wished for the epilepsy to disappear and thought about "what they would have been like without the epilepsy" (p. 45). Several adolescents feared future seizures. Burned adolescents acknowledged they were different but longed to be treated like other adolescents. All knew the permanence of their scars and developed ways to deal with their feelings about the scars.

And if you had been away from school, ill or something like that, all the teachers ask, "Has it to do with your epilepsy?" I have to tell them it's all right. It is as if they became scared. They don't have to be. It is as if they didn't get enough information about it. I suppose it would be easier if they had more information, the school nurse could inform them (p. 45).

I think it is more difficult for those who have diseases to make friends, they feel more

alone and as invisible persons (p.45).

Three major coping strategies were used by the adolescents to cope with the strains. These were described as finding support, feelings of control, and experimenting. The most common strategy uncovered was finding support. Support was found from family members, teachers, health care professionals, other adults, and peers. Peers were of particular importance. Adolescents wanted supportive persons to stay with them during a seizure and give them shelter. Burned adolescents also had many sources of support. These included friends, family, school personnel, burn care professionals, and other burned victims.

My mother always wanted to keep it in the family. She didn't want the school to know. But to me it wasn't hard. I think it's better people know. So I told my teacher at school (p. 45).

Adolescents stated they were less anxious if they felt they were in control, the second coping strategy. Knowledge about the disease, how to control it, and routine were helpful to some as it seemed to increase their self-confidence and sense of control. Some adolescents desired a more active role in their care; others believed a positive attitude helped. Burned adolescents seemed empowered when they would acquire new skills or would accomplish things. They exerted some control of their life through these activities.

I have changed doctors now. We didn't get on very well, I told my mother (p. 46).

Experimentation was the third strategy used by adolescents to cope with their epilepsy. Some skipped medication doses, others drank alcohol, and some engaged in activities which can cause seizures such as being on the computer too long. Through experimentation these individual learned the effects of their actions. Some stopped the risk taking behaviors, others modified them. The burned adolescents did not reveal risk taking behaviors as a means of dealing with their experiences however one did acknowledge injuries as a consequence of some of his behaviors.

I couldn't watch television or play games on the PC too long. I knew that I would get seizures. But I did it anyway (p. 46).

The researchers learned that the adolescents' strains influenced their coping strategies and vice versa. Coping strategies also influenced each other. Adolescents revealed that if strains increased, their feelings of control decreased. They also experienced a better sense of well being with less severe seizures. All adolescents in the study struggled to find meaning in the experience of epilepsy. Many were quite creative and gained valuable insights through this struggle. The study of the lived experience of adolescents with burn injuries also found that the young people were able to find meanings in their experiences.

Rydstrom, Englund, and Sandman (1999) explored the meaning of the lived experience of children with asthma. A phenomenological, hermeneutic method based upon the philosophy of Ricoeur was used. Fourteen children aged 6-16 years were interviewed using broad, open-ended questions. Two overall themes were identified from the meaning units; feeling that they participate in everyday life and feeling like outsiders in everyday life.

The theme "feeling that they participate in everyday life" was reflected in the narrative text as the study participants discussed how they managed to live normal lives. Sub themes identified within these narratives included feeling confident in one's own knowledge, feeling confident in other people's wishes to help, and feeling confident in medicine.

Well, cats, dogs, birds, all dust animals, I can't have them at home. There are animals I can have, fishes, turtles, elephants...can have pigs, they are not so dusty. They do not have so much hair and I can also have a snakes (p. 593).

They think of me and take showers and change clothes and everything.(p. 593).

I always keep it in my bags... I have a bottle in the locker too (p. 594).

The theme "feeling like outsiders in everyday life" was illustrated as the study participants discussed times when their illness restricted them or the usual supports failed. Four underlying themes were also uncovered: (a) feeling deprived, (b) feeling guilty, (c) feeling lonely, and (d) feeling anxious and fearful.

I miss not having dogs and cats and birds, that's what I miss, eh, we would have lots of animals, only animals, the whole house full of animal (p. 594)..

It's a good thing that my brother doesn't have asthma, because then my mother would have a lot of work to do (p. 594).

I don't want to. I manage, my friend upstairs, the computer...he and some of the others who don't play football (p. 594)..

It feels hard to breathe and you feel it's hard... and how much medicine dare I take?(p. 594).

The researchers stated the study found that children with asthma strove to lead normal lives. At times some became disillusioned during their efforts; others risked their health in their quest to be normal.

Several similarities were found between the adolescents with asthma and the adolescent with a burn injury. As the adolescents with asthma stated, the adolescents with burn injuries spoke at length about wanting to be "normal" or be like other adolescents. They yearned to engage in activities like others. They became empowered when they were able to engage in activities. The burned adolescents wanted to live normal lives.

In contrast, the adolescents with burn injuries did not use the terminology of outsider as the adolescents with asthma did. Adolescents with burn injuries did express feeling different; this difference was because of their appearance. Feelings of sadness or anger usually emerged in the burned victims when they were treated as outsiders.

Barbara Wise (2002) conducted a qualitative study to uncover the meaning of the lived experience of pediatric liver transplantation. Using the phenomenological approach of Max van Manen, Wise interviewed nine children aged 7 - 15 years who were at least one year post liver transplantation. Four overall themes were uncovered in the interviews with the children: (a) making connections - being the same and different; (b) the milieu of the hospital - ordinary and extraordinary experiences; (c) out of control - unpleasant experiences; and (d) parent responses.

The theme "making connections - being the same and different" described relationships before and after the transplant as well as what it meant to be different. Recipients desperately

wanted to "fit in with others" (p. 80) yet realized they were different. Furthermore, the children and adolescents in the study knew their lives were different after the transplant.

It wasn't until I got to middle school that I noticed I was different. Kinda like 50-50. I had some people that picked on me a little bit, maybe a handful. And I had some other people that protected me. Not really protect me. That was really cool. I basically had a lot of people that stuck up for me. It wasn't so bad (p. 80).

Participants revealed that they valued how they appeared to others more than how they appeared to themselves. Some attempted to make things appear normal in public areas such as at school, others attempted to hide their differences.

Why are you so dark? Are you dirty? NO, that is my complexion (p. 80).

Adolescent participants disliked the limitations imposed by their illness. These limitations prevented them from engaging in some common activities enjoyed by their age group. Furthermore, these restrictions often resulted in a limited peer group of friends. Despite these problems all valued having a good friend for support.

My best friends are Renee and Shana. We like to play basketball. We sit next to each other at exploratory reading. They like to help me. They help me do my math. And Shambolina helps me do my words. She helps me copy them from the board (p. 81).

Another theme uncovered in the study was "the milieu of the hospital". This theme revealed the meanings of the experiences the participants had as they encountered the hospital and members of the health care team. Most participants particularly the adolescents considered the hospital a commonplace experience. They experienced a level of comfort when there. Even threats to well being such as rejection episodes were downplayed.

When I have a little rejection, I take a bolus of steroids to get it under control. I don't want it to sound like I am taking it for granted but it doesn't dawn on me that I am going through a rejection episode. When I get a rejection episode, just like, okay I am going to deal with it (p. 83).

Unpleasant experiences particularly those which were painful or produced a sense of being out of control were central to the third theme identified in the study. Pain was universally associated with negative feelings. It was often anticipated thus producing more distress. Somewhat surprisingly, pain associated with procedures was more vividly described. Transplant

and surgical pain in contrast were discussed by few.

I threw up blood at home. One time I was bleeding in my throat and they tried to put this balloon thing down me. But I kept coughing it up. It was terrible. I felt like I couldn't breathe. I just threw up the tube. By then the bleeding had stopped. I wouldn't let them do that again (p. 86).

The final overall theme identified in the study was parental responses. This theme illustrated the importance of parental caring. Adolescents in the study were able to ascertain changes in their parents' mood that they perceived as increased concern. Participants revealed that they felt a sense of obligation to their parents to stay well.

I will never tell my Mom how I feel about anything. I don't think I would ever tell the truth because I would never want to upset her. I can just see the expression on her face. I know how she feels...she has been through so much stuff with me. I basically worry if she is all right instead of me.

Even with extreme hardship such as liver transplantation, children strive for normalcy. They accomplish this by focusing on the attributes they do have in common with well children and minimizing their differences and problems. Most perceived themselves as normal as long as they could participate in some common activities such as school, being with friends, and performing tasks. Participants identified physical appearance changes, frequent routine disruptions imposed by hospitalizations, and daily medications as deterrents to normalcy.

The adolescents with burn injuries had similar responses to their experience in comparison with the liver transplant children. For example, they also had a sense of same yet different. They knew that even if they did engage in activities with non-burned adolescents and were treated like other adolescents, they would always be different. All the adolescents with burn injuries expressed openly a concern about how they appeared to others. Not all participants however clearly stated if the opinion of others or their own was most important. Some of the adolescents with burn injuries had functional impairments which distressed them at times; all were able to overcome the limitations over time however.

Adolescents with burn injuries also revealed a level of comfort at the hospital. They knew the personnel and saw their fellow adolescent friends who also had burn injuries. It was a place of support. The adolescents had completed their acute burn care. Unlike their counterparts with liver transplant, physical discomforts were not reported except when elective reconstructive surgery was performed. Parent responses were also not revealed by the burned adolescents except in relation to offering support.

Three studies which examined lived experiences of adolescents with chronic illnesses were reviewed to discover possible explanations for the findings in this study, the lived experiences of adolescents with burn injuries. Numerous commonalities were identified between the three chronic illness studies and this study.

All three chronic illness studies uncovered a pervasive desire in the adolescents to have some sense of normalcy in their lives. Being able to participate in activities, be with their peers, and perform tasks tended to provide this sense of normalcy in most cases. The adolescent burn victims also verbalized problems in being able to perform favorite activities as very disturbing. Like their chronically ill counterparts, these individuals considered participating in activities a sign of normalcy. They desperately wanted to "be like other kids" and be involved in various activities. Some did this through sports.

Normalcy was further reinforced in the chronically ill adolescents, if the adolescent was in control of the disease. In the epilepsy group, less severe seizures was perceived as being in control and in the asthma group, being confident in the effects of their medications was perceived as being in control. Numerous strategies were employed to accomplish this. These included being knowledgeable about their illness, taking control of their treatment regimen, experimenting with the treatment plan, making treatment regimens a part of their daily routine, engaging supportive persons, and minimizing problems if they arose. All study participants recognized that they needed to actively participate in their health if any normalcy was to be achieved.

The adolescents with burn injuries had been through their acute burn treatment period and did not have extensive medication or treatment regimens as part of their daily routine. They did not, therefore, experience some of the issues encountered by the chronically ill. For example, medication side effects were not a concern. Some did mention repeated surgeries and clinic visits as a burden. The adolescents did not use all the same strategies for coping such as making treatment regimes a part of their daily routine.

The epilepsy and liver transplant studies demonstrated another similarity. Looking different was a major concern. The epilepsy group talked at length about their appearance during a seizure. Liver transplant recipients revealed concerns about their jaundice and distended abdomen. Limitations imposed by medication regimens or hospitalizations were additional areas of concern for these participants. These limitations interfered with their participation in common adolescent activities. Such impingements negatively affected their feelings of normalcy.

Like their counterparts in the chronic illness studies, the adolescents with burn injuries had visible reminders of their condition, the burn scars. Instead of controlling their disease with medications, the burn survivors made conscious choices about how they would respond to negative comments about the burns. Most chose to ignore the comments. Some used unique coping strategies such as humor. One individual believed the scars were unique characteristics that made her special.

Support persons were essential in all of the chronic illness studies. These individuals were there for the adolescent during the most difficult times. Parents and peers were most consistently identified as the key support person(s) however teachers, youth pastors, counselors, youth leaders, and others might also be supportive. The liver transplant group also revealed a level of comfort with the health care environment and personnel. Although they disliked the interruptions in their routine, they considered the experience commonplace and comfortable.

The adolescents with burn injuries also discussed at length the need for supportive persons. These individuals were always there for them. Sometimes the relationship was tense if the support person was actively encouraging them through difficult times such as therapy. As one young man stated, "she pushed me to my limits." Most burned adolescents mentioned family and peers as their supportive personnel. Burn care professionals, teachers, other burn patients and counselors were also mentioned. One young man, stated how important God was in his life.

Unlike the chronically ill study participants, the adolescent with burn injuries spoke about getting from one place to another. Not a physical place but rather a mental place in which they viewed themselves in a more positive way and felt like their peers. They needed to deal with the reactions of others over their appearance as well as their own reactions to others. They acknowledged that this took time. One young woman used the analogy of "climbing a mountain" to describe her experience.

Normalcy was a central theme in the chronic illness literature and this study. Both the subjects in the chronic illness literature and the participants in the study stated being like peers and engaging in activities like their peers was important; they associated these with being normal. For these individuals, QOL was associated with feeling normal. The WHO defined QOL as an "individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, personal beliefs, and their relationship to salient features of their environment" (WHO, 1997, p. 1). Normalcy was not addressed specifically in this definition however it might be proposed as an underlying theme. The definition identifies the importance of expectations, concerns, and social relationships. These factors influenced the meaning of normal for the individuals in the chronic illness literature and in this study. It can therefore be assumed that normalcy might be a criteria in

QOL.

Although the literature review did identify similar experiences between the adolescent with burn injuries and the adolescent with chronic illness, the literature did not adequately explain the findings in this study. The theoretical literature was thus investigated.

Theoretical Framework

After analyzing the data obtained through experiential descriptions of adolescent burn survivors, personal experience, etymological sources, literature, art, and music this researcher believed the theory of Human Becoming by Rosemarie R. Parse (1998) explained the findings of the study. Essential assumptions, principles, and concepts of the theory and their relationship to this study will be discussed.

Rosemarie Rizzo Parse's (1998) theory of Human Becoming is philosophically grounded in existential phenomenology and the human sciences. Parse also drew upon the work of Martha Rogers' theory of Unitary Beings. Synthesizing essential elements from these sources, Parse developed a unique nursing theory.

Parse believed the traditional natural science perspective employed by medical science and many nurse scholars inadequately captured the human health/illness experience. Research methods associated with this perspective were problematic to Parse. Parse believed reductionistic designs, the quantification of health and illness, and increased emphasis on causality produced an incomplete picture of the human experience. Furthermore, this perspective "virtually ignored" (Parse, 1998; p. 98) the concept of a human's active participation in health.

Nine foundational philosophical assumptions underlie the theory of Human Becoming (Parse, 1998). Each assumption addresses some aspect of human beings or health.

Assumptions

1. "The human is coexisting while coconstituting rhythmical patterns with the universe" (p.19). This assumption presumes that all humans exist with other humans and the universe. As

each human is existing, they are creating their own unique realities and patterns of relating one human can be differentiated from another or from the environment by the patterns they have created. Patterns are essentially unique fingerprints.

The findings uncovered from the lived experience of adolescents with burn injuries were congruent with assumption number one. For example, eight adolescents were asked to reveal their experiences following the burn injury. Although similarities were uncovered in their stories each adolescent possessed their own unique experiences and how they related to the world. Participant one knew that there would always be individuals who would stare or ask questions about his amputations. If he was to get along in the future he would have to develop an effective way to respond to these individuals.

Now when I see people look at me it doesn't bother me cause I know people are going to look.... Its, its not, the world is not just going to sit there and not look at you.... They have to look to learn.

Participant two knew he had residual functional limitations following the injury. He often compared his performance to others. He knew he would always be functionally different.

Like my brothers, they do some stuff that I can't do. Like...Like, uh, lifting weights. My brothers can lift weights. And I can lift weights but I can't lift weights like they can. And I can't do a whole lot of stuff like they can.

2. "The human is an open being, freely choosing meaning in situation, bearing responsibility for decisions" (p. 21). This assumption posits that all humans freely choose how they interpret and respond to a situation. In other words they freely choose their meanings of the lived experience. These choices may provide opportunities or impose limitations. Ultimately however each human is accountable for their choice.

The findings uncovered from the lived experience of adolescents with burn injuries were congruent with assumption number two. Adolescents in the burn study often had to make hard conscious choices about their care or how they would respond to various unpleasant experiences. Some of the choices may have opened up opportunities others may have restricted them. Participant four, like the other participants, had to face the unkind words of

others. Over time he assumed the attitude that unkind remarks would be more harmful to the perpetrators than to him. Although verbally and cognitively dealing with his situation with this choice, he still had the emotional burden to bare.

I mean, I used you know I used to get mad or whatever but after that I just realized that, uh, what they said, what they said to me about me is really not goin [sic]....it really didn't bother me at that time but when, you know, when I got away from it you know I think I thought about what they was saying and uh, you know it hurts a little bit but it's just like I told you.

Participant six knew that if she listened to the unkind remarks about her scars she would think about her unattractive appearance. Although difficult, she chose to ignore the comments.

Because it's just easier for me....Like, like if I ignore them I don't have to worry about them....Like, if I didn't ignore them I wouldn't look good.... You know, self-pity stuff.

Participant eight knew she and her sister had endured not only the fire but a life of poor foster care. She ascribed meaning to these experiences. She believed good had come out of adversity.

My belief is everything happens for a reason. So I think me, like me and my sister being burned in a fire, like that was a real bad thing.... But after, in the long run we got like a great reward for it. Like we got burned but we also got taken out of a bad situation, a bad environment....An some stuff with that and then we finally got adopted....And I'm loving it.

3. "The human is unitary, continuously coconstituting patterns of relating" (p. 21).

Congruent with Parse' belief in the irreducible, complex nature of humans, this assumption reinforces the concept that humans are more than the sum of their parts. Furthermore, humans are active rather than passive participants, as they engage with others in the world and create meanings. Unique patterns of relating to others and creating meanings result in unique distinguishing characteristics for each human. Humans can engage and relate in a number of verbal and nonverbal modalities.

The findings uncovered from the lived experience of adolescents with burn injuries were congruent with assumption number three. Participant eight utilized several unique strategies as she struggled with unkind remarks and a poor home environment. She used writing to express

herself when troubled. She used involvement with sports as a strategy for relating with others.

The most unique strategy however was humor.

I love to write. I write poems, I write books, I write short stories. Not books but like little long stories and short stories.... Writing helps me and music. Writing, music and basketball. I love basketball....It's like if I have something on my mind about the fire or about my birth parents or any event that has went on in my life....And if I'm not able to sit down and express myself to people....I can always go in my room and grab my pen and paper and write....And it comes out so easy. I don't have to worry about what someone is thinking while I'm talking because it's my paper and my pencil and it doesn't matter what anybody think about it because I wrote it. It just helps. It's like a therapy.

Several of the burn victims attended a burn camp and developed special relationships there. These were unlike any relationship developed in other settings.

They, they understood and then they just, I was part of them....When you go to our camp its like a brotherhood there. It's really a spiritual thing.

Oh it's like a second family thing going on, cause I see [sic], Like I come down for camp pretty much every year and I see most of these same people there.

4." The human is transcending multidimensionally with the possibles" (p. 22). This assumption posits the existence of a universe comprised of more than three dimensions. Furthermore, humans can experience more than one dimension at a time. As humans engage in the world and make choices, they do so by considering the whole perspective of the experience. For example, they consider the present, the pre-reflective, and the future.

The findings uncovered from the lived experience of adolescents with burn injuries were congruent with assumption number four. Many of the adolescents had no memories of the burn or their life prior to it, however some did. Often they would engage in thoughts about the "once was."

Um, it's hard. You know it makes me think back.

Feel, I feel real bad, and then I wish sometimes I say to myself I wish I never was playing with matches.

I mean like, it's not, it's really good but sometimes it's hard.... Cause I have a real strong memory and I remember my birth parents. And I remember the fire but it doesn't bother me. Like I can stand and talk about the fire and I won't cry.

5. "Becoming is unitary human-living-health" (p. 23). This assumption encompasses Parse's beliefs about health and highlights the somewhat bittersweet nature of the becoming process. Becoming is a dynamic process which evolves over time as the human interacts with others and the environment and are creating their health. Many choices are made and the human becomes more diverse and complex in the process. Choices made may open up possibilities for the human while eliminating others. Humans essentially create their own health.

Some of the findings uncovered from the lived experience of adolescents with burn injuries were congruent with assumption number five. As the adolescents developed strategies for reacting to remarks about their scars many difficult decisions were made. Some strategies required the adolescent to boldly face the adversity; others required the adolescent to assume a new perspective about themselves.

So when...now when I see people look at me it doesn't bother me cause I know people are going to look....It's, it's not, the world is not just going to sit there and not look at you. They have to look to learn.

Like if you watch a movie over and over and over....It gets boring to you right?.... And you still wanna watch it again, you know. Well that is how it is. People look and look and look. And you, it just doesn't bother you no more [sic]

I think, I think no one is normal....I think there is no definition of normal because if there were everyone would have to be the same to be normal....Not.. not even twins, they're not the same...So I, I feel ...I feel regular you know.... I feel like everybody else. I feel important, I feel wanted.

6. "Becoming is rhythmically coconstituting human-universe process" (p.24). Assumption six further defines the nature of the becoming process which is the human's creation of health. The energy exchange between humans and the environment as well as the ever-changing nature of this becoming process is explicated as well.

The findings uncovered from the lived experience of adolescents with burn injuries were congruent with assumption number six. As the adolescents told their stories many stated that the time period closer to the initial injury was very difficult. For example, encountering people

staring at their scars or making fun of them was problematic. It took time to get learn how to "deal" with these occurrences. Several individuals alluded to the ongoing nature of their experience and how they made changes to respond accordingly. This information was gleaned as a general theme throughout the interviews.

7. "Becoming is the human's patterns of relating value priorities" (p. 24). Parse believed a human's health encompassed their values and ideals. Choices an individual made in contrast reflected values, relating, and ways of being.

The findings uncovered from the lived experience of adolescents with burn injuries were congruent with assumption number seven. The belief systems of the adolescent burn victims greatly influenced their responses. It was explicitly stated, implied in their stories, and evident through their nonverbal expressions.

Yea, I mean whatever anybody say negative or anything positive you know I listen to positive people I don't listen to negative people....But if they say things negative, I will .. At right now I don't even pay no attention to it. I don't' ..I um let it try to get to me.

I took all my anger and negative energy and turned it around and.. how I did that I still don't know? I turned it into positive energy and I write things.

And uh I always I just think you know like said I just thank God for everything and he was with me for a long time. And I just say thank every you now thank everybody who helped me and, and just about everything.

8. "Becoming is an intersubjective process of transcending with the possibles" (p. 25). Assumption eight further explains the nature of the relationship between humans as well as humans with other elements in the universe. Whenever one human seeks to relate to another human, risks are taken. One cannot predict the nature of the relationship; the familiar is given up for the unfamiliar. Despite this uncertainty however, humans continue to relate, becoming more diverse and complex with each encounter.

The findings uncovered from the lived experience of adolescents with burn injuries were congruent with assumption number eight. As each adolescent encountered strangers and peers they took the risk of being taunted about their burns. Yet each individual in the study strove to

have friendships and engage in activities with others. Their lives were filled with the uncertainty of how these individuals would respond.

9. "Becoming is unitary human's emerging"(p.25). As humans engage in the process of becoming they continuously exchange energy with the environment and others. In this creative process humans create new ways of being further increasing their diversity and complexity. The humans can never return to a previous state.

The findings uncovered from the lived experience of adolescents with burn injuries were congruent with assumption number nine. All the adolescents expressed in a variety of ways how they changed. Many changed their attitude about how they felt about themselves. Others changed their viewpoint of others. Some tested their abilities and sought new challenges. All acknowledged they were different in some way.

Parse (1999) synthesized three overriding principles for the Human Becoming theory from the nine philosophical assumptions. These principles illuminate the fact that human becoming is characterized by paradoxical processes. The three principles contain the nine concepts imaging, languaging, valuing, revealing-concealing, connecting-separating, enabling-limiting, originating, powering, and transforming.

Principles

1. "Structuring meaning multidimensionally is cocreating reality through the languaging of valuing and imaging" (p. 6). As illuminated in the philosophical assumptions, humans are continuously relating through languaging to the other humans and the universe in a variety of ways. They continuously are making choices in creating their own realities based on personal values. Humans thus create their own meanings. These meanings change over time and in response to new experiences.

2. "Cocreating rhythmical patterns of relating is living the paradoxical unity of revealing-concealing and enabling-limiting while connecting-separating" (p. 7). As humans engage in the process of human becoming they create patterns of relating with the universe and others. These

patterns have unique paradoxical qualities. A human simultaneously reveals and conceals, as they are choosing to reveal some aspects of themselves they are also choosing to conceal other aspects. In connecting with others and the universe, at the same time they are separating themselves from others in the universe; creating a rhythmical pattern of relating. Ultimately as human relate and create unique patterns of relating, their way of being is both enabling and limiting.

3. "Cotranscending with the possibles is powering unique ways of originating in the process of transforming" (p. 7). As humans progress through their process of human becoming each selects a distinctive path. These paths may fraught with uncertainty. While humans become they strive to be their own unique person.

The findings uncovered from the lived experience of burned adolescents were congruent with Parse's concepts and principles. All the adolescents were on a metaphorical journey toward a new being. A being able to meet the daily challenges of appearance, and related taunting, and impaired or limited function. Each freely chose a unique path on this journey based on their values. Some paths offered enormous opportunity while limiting other opportunities. Many difficult choices were made on this journey however supportive people were always available.

Theoretical Structures

Further analysis of the themes uncovered using the lens of Parse's theory identified three theoretical structures: 1) languaging and enabling -limiting are powering for the adolescent with burn injuries, 2) originating emerges with the languaging of enabling-limiting and connecting-separating for the adolescent with burn injuries, and 3) imaging of being normal is transforming for the adolescent with burn injuries.

Theoretical structure one

As each adolescent traveled on their metaphorical journey they were faced with opportunities. Yet engagement in these opportunities limited others. Participant five for example,

enjoyed his visits to the burn center and burn camp. He valued the camaraderie of other adolescents with burns as well as the burn center staff; he felt comfortable and somewhat special. Yet these trips to the center or camp interfered with peer activities at home. When hospitalized for surgery, that would enable him to accomplish activities, he was limited further. Despite the potential for struggle, he was still energized by these experiences. Participant five also illustrated in a drawing of one of his scars. The drawing depicted a bird that resembled the mythical phoenix and was identified as such by the adolescent. Unlike the mythical phoenix however, the drawing evoked a sense of power and self-confidence. He revealed overcoming numerous challenges and acquiring new skills; he was powered by these experiences. Participant five also demonstrated power and self-confidence in his nonverbal communication. Participant eight was a prolific writer and loved to play sports. Both of these activities were modes of self-expression. These languaging activities were powering for her; she was "energized" after these activities.

Theoretical structure two

All the adolescents made conscious choices about how they were going to respond to negative comments. Several adolescents chose to ignore the comments. One viewed the scars as a unique characteristic that made her special. As the adolescents traveled on their journey they created unique relationship patterns. At times they were connecting with friends; at other times they were separating from onlookers who made negative comments. Often the adolescents cherished the friendships of other adolescents with burn injuries and the burn care personnel yet desperately sought relationships with non-burned individuals. They wanted to be like others but could not escape the reality of their burn scars and other physical limitations. Ultimately they languaged new possibilities through these relationships that were both enabling-limiting and connecting-separating. Originating emerged as a result of these experiences and relationships.

Theoretical structure three

The adolescents knew over time that their scars would never disappear. They strove to be normal like their peers and others. Participation in the same activities as peers and resuming pre-burn activities enabled most of the adolescents to feel like others, which they associated with being normal. Two adolescents redefined normal to include unique variations such as scars. All the adolescents transformed after they re-imaged the meaning of their scars.

The theory of Human Becoming explained the findings in this study. Adolescents were self-directed, freely choosing beings, and active participants in their health. These young people realized that the choices they made might afford them wonderful opportunities while limiting others. Yet these adolescent acknowledged their ultimate responsibility for their health.

Summary

This chapter discussed the second literature review involving chronically ill children. Commonalities and differences between chronically ill children and the adolescents with burn injuries were examined. The Human Becoming theory was discussed as well as its relationship to the findings in the study. The final chapter will discuss the conclusions of the study.

Chapter Eight

Conclusion

Exploring the lived experience of adolescents with burn injuries was the focus of this study. This chapter will summarize the study, discuss limitations, suggest practice implications, and make recommendations for future research.

Summary

This study was a qualitative study designed to examine the meanings and feelings of the life experience of adolescents following a burn injury. The hermeneutic human science phenomenological method of Max van Manen (2001) was utilized. This method enabled the researcher to gain a deeper understanding of the meaning of the life experiences from the perspective of the individual(s) experiencing the phenomenon. Data were collected using existential processes. Sources of data included: (a) the researcher's personal experience, (b) etymological sources, (c) experiential descriptions, (d) literature, (e) poetry, (f) the public media, (g) art, and (h) music.

Experiential descriptions were obtained from eight adolescents age 13-18 who had suffered a burn injury with residual scars, amputations, or other disfigurements. Creative and artistic works such as poetry were obtained from some participants, other burn victims, and the public domain. Data from literature, art, and other media were obtained following a thorough electronic search.

Adolescents interviewed were recruited voluntarily from a national pediatric burn center. Informed consent or participant assent and parent permission were obtained before each interview was initiated. The researcher conducted and audiotaped all interviews. Confidentiality was assured throughout the study

Following the interviews, each tape was transcribed. Hermeneutic phenomenological reflection was used to uncover the meanings of these individual experiences. The processes of (a) thematic analysis, (b) isolating thematic statements, (c) linguistic transformation, and (d)

identification of essential themes were utilized during this reflection. The researcher then read and re-read these accounts and reflected upon them to discover common essential meanings throughout the adolescents' experiences. These were identified and supported with quotes from the adolescents. The themes were: 1) the lived experience of a burned adolescent is an arduous journey of struggles as each individual freely chooses a unique path to a new way of being, 2) the lived experience of the burned adolescent is making difficult choices as cherished values are re-examined, 3) the lived experience of the burned adolescent is creating new images to transform the way of being normal, and 4) the lived experience of burned adolescents is becoming empowered while rejoicing in accomplishments and abilities. The essence of the phenomenon was then discussed.

The findings of the study were then linked to a theoretical framework, Rosemarie Parse's theory of human becoming, to explain the findings. Specific assumptions, concepts and principles from Parse's theory were discussed in relation to the findings. Three theoretical structures were identified when the data was analyzed: 1) languaging and enabling-limiting are powering for the adolescent with burn injuries, 2) originating emerges with the languaging of enabling-limiting and connecting-separating for the adolescent with burn injuries, and 3) imaging of being normal is transforming for the adolescent with burn injuries.

Limitations

Limitations were identified in this study. These limitations were related to participant recruitment, participant sample, the interview process, and trustworthiness.

Participant Considerations

Immediately prior to obtaining Institutional Review Board and site approval for this study, implementation of new regulations related to the Health Insurance Portability Accountability Act (HIPAA) was instituted nation wide. The implementation of this act and the subsequent individual institution application of policies related to the act adversely affected the recruitment of participants for the study and the sample that resulted.

Recruitment of participants for the study was very difficult. The site required a flyer be used for recruitment and forbade the staff to engage in recruitment. This flyer was to be placed in a visible location at the site for potential participants to pick up voluntarily. Subsequently, if interested in the study, the individual was to approach the researcher. This process did not work; no one picked up the flyers. When the staff was questioned as to why this was occurring, they replied that these individuals “are not used to being recruited in this manner.” As a result the researcher was forced to slightly modify the procedure by approaching potential participants with a flyer as they waited for their appointment; if interested they could then contact the researcher. A more diverse mix of participants would have been obtained had the restriction not been in place.

Sampling was also a problem. In a qualitative study, rich thick descriptions of life experiences are sought. It is adventitious therefore for a qualitative researcher to purposively sample and pre-screen participants so that a diverse sample can be obtained. Because of HIPAA regulations this researcher was not permitted to engage in either activity for recruitment of participants. Furthermore, staff members at the site were not permitted to identify potential participants. As a result, the sample was not too diverse across age when burned for the sample size and some participants did not fully reveal their experiences.

With this sample, a true glimpse of the lived experience of adolescents with burn injuries could not be fully obtained. All adolescents in this study provided confirmatory evidence indicating they no longer allowed negative comments about their burns to bother them, engaged freely in pre-burn activities, felt like other peers, had goals, and enjoyed friendships; an essentially positive experience. As a burn care professional however, this researcher knew that all adolescents did not have such positive experiences. Pre-screening would have permitted this researcher to include some of these individuals. Two study participants did not reveal their experience. Their interview material was essentially unusable despite volunteering to participate. Again pre-screening may have avoided this problem. Ultimately, problems related to

participant recruitment and sampling limited the holistic picture of the meaning of the experience.

Interview Process

Several aspects of the interview process impacted the quality of the data obtained. These factors included researcher expertise, interview questions, setting, and technical problems.

Although this researcher had 25 years of pediatric nursing experience and was the mother of four children, difficulties were encountered when interviewing these adolescents. During two of the interviews the adolescents were either shy or chose not to speak about their experiences. When this occurred, this researcher tended to lead the conversation. At other times, silence was excruciating for the researcher and again leading occurred. As a result, some the interview data had to be excluded. Following the interview, this researcher remained uncertain as to why the participant agreed to be in the study. One possible explanation was a perceived sense of responsibility to the burn center on the part of the participant.

The interview questions also contributed to the study limitations. A common problem for novice qualitative researchers engaging in interviewing is being too broad and fear of “leading” (Cohen, et al., 2000). Some of the adolescents in this study however, did not understand how to respond to the open-ended questions. Ultimately the researcher started to lead. One must question if the data obtained were sufficiently saturated to reflect the essence of this phenomenon. A more specific adolescent-focused set of open-ended questions may have produced richer, thicker data.

Five interviews were conducted in a room within the outpatient department; two in a board room in the outreach clinic; one in a patient room. Each room was in an area in which outside voices and noises could be heard. Interviews were in rooms that were not locked; staff interrupted two interviews. All of these factors affected the concentration of both the participant and the researcher. The room noise level made some of the conversations on the tape difficult

to understand. These disturbances may have affected the quality of the context of the interview. Sound quality difficulties may have resulted in incorrect transcriptions.

Actual limitations of the study were related to the ability to access participants, to obtain rich narrative data from them, and to analyze the data accurately. Participants for the study as noted previously came from the pool of patients currently within the burn center. Using patients from one center provided consistent and expert care however it may have resulted in an inappropriate mix of participants. Individuals treated elsewhere may not have received the same level of expertise and resources that may have affected their life experience. Participants self-selected to be in the study; only those willing to talk about their experiences participated. Those unwilling to participate may have had a different experience.

The researcher was limited to those individuals who were scheduled for admission or an outpatient visit during the study time period. A low number of admissions or outpatient appointments limited the researcher's access to potential participants. An adequate number of participants were enrolled to reach data saturation.

Once participants agreed to be in the study, the researcher was limited by the participant's willingness to fully reveal their life story narratively. A quiet, shy adolescent for instance, was hesitant to reveal personal stories to a stranger. Rich narrative data was not always obtained.

The primary investigator was conducting a qualitative study for the first time. A certain level of expertise and comfort with all the techniques of data collection such as in-depth interviewing must be attained by the researcher. Failure to do so impaired data collection. Although the researcher had much experience interviewing adolescents, the researcher was a novice at conducting a phenomenological interview.

Analysis of data was one of the most challenging aspects of the study. This was the first time the researcher was analyzing data from a hermeneutic phenomenological study. The linguistic transformation may not have captured the essence of the experience.

Trustworthiness

Numerous strategies were utilized by this researcher to enhance the trustworthiness of this study. As recommended by Guba and Lincoln (1981) four criteria should be used to judge qualitative studies: (a) credibility, (b) fittingness, (c) auditability, and (d) confirmability.

Credibility

Credibility refers to the confidence in the truth of the data. Guba and Lincoln (1981) emphasized the importance of prolonged engagement to enhance credibility. This can be accomplished by seeking to thoroughly understand the group being studied and building trust and rapport to gain a rich description of the experience.

This researcher had 25 years of pediatric burn experience and hence an excellent understanding of the group being studied. The researcher had not cared for some of these adolescents; the interview was a first meeting. Some of the other participants were known however it had been years since the researcher had cared for them. It was very difficult to build a credible relationship in one hour or less; trust and rapport however were difficult to ensure. The geographic distance between the participants and the researcher, and the time between the clinic visits made a follow-up interview impractical. Despite this fact thick, rich data were obtained from six of the eight adolescents. Furthermore the researcher believed a true rapport had been obtained with four of the eight participants.

The data from other sources added to the understanding and enhanced credibility. Artistic and literary works from two of the participants supported themes of facing challenges, it's a part of me, and climbing the mountain. Creative works from the public domain also supported findings. A painting by Linda Westlund (1993) for example, illustrated to themes of journey and rejoicing in abilities.

Fittingness

Fittingness refers to whether the data can be transferred to another group or setting by others upon reading the study may choose to do so. It also refers to how well the findings fit

within another context (Beck, 1993). The researcher did provide a thorough description of the: 1) setting, 2) researcher's role in the setting, 3) how the setting and role of the researcher affected data types, 4) adequacy of access, 5) study context, and 5) processes. After reading this information an outsider could make the decision about whether this information was transferable to other contexts: burn injured children and adolescents, others with visible scars or injuries resulting in physical limitations or chronic conditions. The researcher also included a table that described the relationship between individual themes and common themes uncovered in the data.

Auditability

Auditability refers to how objectivity and neutrality of the data. Traditionally this means that two or more independent individuals agree about the relevance and meaning of the data. This researcher had an expert read the data and determine if the interpretations of the researcher were congruent with the data. All interview transcriptions and analyses were given to the expert who had experience with qualitative research and pediatric burn nursing for review. The researcher and expert then collaborated to confirm meanings. The researcher maintained an audit trail, so that others could assess the techniques used.

Confirmability

Confirmability refers to the neutrality of the data (beck, 1993). This researcher utilized the expertise of the qualitative research expert to perform an inquiry audit and determine meanings. All supporting documentation was also given to the expert for review. Triangulation was employed to further enhance confirmability. Specifically, multiple data sources were used to compare themes found in the interview sessions. Confirmation of interview analyses with participants would have been beneficial however due to geographic distance this was not practical.

Practice Implications

Significant research has been conducted about the response of children or adolescents to a burn injury. The acute hospitalization burn care and early discharge period have been the focus of most research. Little has been done related to the long-term responses and needs. The findings from this study may provide ideas for improving the care of these clients long term.

All participants indicated some early difficulties dealing with negative comments. Most stated these comments induced feelings of self-pity, anger, or sadness. Practitioners must be aware that these reactions occur. They should provide information in advance about the possibility of occurrence to the adolescent. Furthermore the practitioner must be prepared to support the adolescents if these emotions arise.

Burn care professionals and other who work with adolescents with burn injuries might encourage artistic expression such as writing or drawing to facilitate expression of feelings particularly during difficult times. Adolescents might also benefit from viewing artistic works or reading literary works that reflect similar experiences. Such activities might provide an opportunity for the adolescent to express their emotions.

A common theme expressed by all adolescents was how hard this journey was. All had to chose a unique path to achieve their new sense of being. Burn care professionals and others might encourage verbalization of feelings as they endure this struggle. Individuals might be asked to identify factors that were making the journey difficult; interventions might then be planned to alleviate these difficulties. Other activities to assist the individual through these times might include expression of what the individual thought their new being would be like; this expression might be in the form of a narrative account or some artistic expression.

All the adolescents described difficult choices such as continuing difficult therapies or ignoring negative comments. Burn care professionals and others might offer the adolescents support when making decisions. The professional might assist the adolescent in identifying possible choices in the decision and the pros and cons associated with each. For example, the

ramifications of stopping therapy or elective reconstructive surgeries.

Most participants indicated that family members and others were helpful during these difficult times. Burn care practitioners must inform these support personnel as well as teachers and counselors about the potential needs of the adolescents. The support person(s) might then collaborate with the practitioner and adolescent to identify the best support strategy. Nurses and others need to assess how adolescents are doing at subsequent follow up visits. Other strategies might include role playing how to respond to negative comments, facilitating ways to express self, helping the adolescent identify their accomplishments, helping the adolescent recognize the challenges they may face, and having others share their journey. Community resources, an electronic support group, or specialty camps for those who had burns might also be beneficial.

A central theme uncovered in all the interviews was being normal. Burn care practitioners might encourage discussions with the adolescent about being normal early in the recovery phase of the injury. Adolescents might be asked to keep a written or verbal journal of their feelings about normalcy, the experiences associated with it, and what they think would make them feel normal.. Practitioners might then review the journal with the adolescent, identify problems, and develop interventions.

Participating in activities and accomplishing goals were factors that seemed to empower the adolescents and help them continue on their journey. During hospitalization, burn care practitioners might identify favored activities with the adolescent and focus rehabilitation efforts so that these activities might be resumed as soon as possible. After hospitalization, burn care practitioners and others might assist adolescents in becoming involved in activities and help them recognize their accomplishments.

Perhaps more than anything else, this study revealed the tremendous personal strength possessed by these adolescents as they faced the challenges and made the difficult choices. Practitioners must develop strategies that empower these young people to face these

challenges most effectively and to make the best choices

Quality of Life Considerations

Numerous studies in the past attempted to measure QOL in the adolescent population. Problems arose in relation to the adequacy of measurement, the dimensions to measure, age for participation, as well as other concerns. Although QOL was not the major focus of this study it was an underlying interest of this researcher. When questioned specifically about QOL however, some participants were unsure of the meaning, others gave answers that were inappropriate; less than half verbalized understanding of the concept. Despite this finding participants verbalized satisfaction with many aspects of their life situation such as peer relations. This was illustrated in verbal comments. In future studies, adolescents might be asked about life satisfaction when assessing QOL.

The WHO defined QOL as "individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, personal beliefs, and their relationship to salient features of their environment" (WHO, 1997, p. 1). The adolescents identified being like others and participating in activities like their peers as central to their well-being and normalcy. These findings support the WHO definition in some aspects. Goals and expectations relates to the adolescents' overall desire to be like others and participate in peer activities as well as the connection of these with normalcy. The social relationship dimension identified in the definition also was reflected in the study when the adolescents revealed the importance of participating in activities with others.

Previous QOL research also was supported to a degree in this study. This previous research identified personal -social factors (family relationships etc.) and personal-internal factors as some of the important dimensions in QOL. This study supported those findings. All adolescents identified friends as important to their lives; families were also identified as

important. Physical appearance and functional abilities were also important to the adolescents. When studying QOL in this population, researchers must include the social-personal dimension.

Recommendations for Future Research

This study, *The Lived Experience of Adolescents with Burn Injuries*, begins a new area of research for burn victims. Traditionally burn research has been outcome oriented. Studies have focused primarily upon physical treatments, functional outcomes, physical responses, and psychosocial responses. No research has examined the meanings of this experience. Clearly this phenomenon requires more exploration.

All adolescents revealed that they had gone from negative feelings about their burns to ignoring them or looking at them as unique features. Many expressed that the process took a long time. No participant could explain what process was used to help them get to that point; only one discussed why it took so long. Information is needed about the exact nature of the process, and why it takes so long. As patient advocates, nurses strive to decrease suffering in their clients. Increased knowledge in this area would enable us to decrease the time of psychological distress for these patients. Although not revealed in this study, some adolescents do not make that transition to their injury. Further research into understanding this process may enable health care practitioners to assist these individuals.

All adolescents in this study were burned at least five years prior to the interview. More than half of the participants did not remember the injury. They therefore had many years to learn how to respond. More research is needed to explore the experience during other time periods post-burn such as the immediate post discharge period and the 1- 3 year post-burn period. The experience during these times might be quite different.

Some of the adolescents in the study were burned as infants or young children who had no pre-burn memory; others were burned in later childhood and did have memories. Individuals burned when very young knew only a body with burn injuries. Those burned later could compare the nonburned body with the burned body. Although the study revealed a few differences such

as sadness over the loss of limbs or regret over causing the burn injury, more data are needed to fully understand the relationship between the age at time of injury and the experience.

Developmental level was also an area of concern. The age of the individual when burned determined the particular developmental stage(s) that was affected. What specific effect did the burn injury have on accomplishment of development goals at the different ages? Were there any cumulative effects if the individual had multiple developmental stages affected? How would the development for an adolescent with burn injuries differ for one without burn injuries?

One of the literary data sources revealed that an adolescent with a non-burn deformity had similar experiences to the adolescent with burn injuries. More research is needed to determine how adolescents define deformity and respond to it. Research is also needed to discover the experiences of adolescents with other disfiguring conditions.

One of the adolescents met inclusion criteria but most of his burn scars were not visible. The visibility of the burn scars may also have influenced the participant's experiences. Additional research is needed to discover if the type, extent, and location of scarring affects the reactions of others to the individual and the individual's response to the reactions.

The concept of QOL was difficult for some of the adolescents in the study to articulate. Further research is needed to determine how adolescents define and articulate QOL and how practitioners might facilitate the adolescent's expression of QOL. Despite the difficulties with expression of QOL by some adolescents in the study, others associated QOL with being like others, feeling normal, and participating in pre-burn activities. The adolescents with chronic illnesses expressed similar ideas. One can only wonder if adolescents without burn injuries or other health concerns associate QOL with the same factors. More research is needed to determine these factors and to compare and contrast the experience of QOL for these adolescents with adolescents who have other health concerns. QOL of life had been differentiated in the literature as NHRQOL and HRQOL. It would also be valuable to further investigate these concepts in the adolescent population to identify specific dimensions and the

relationship between the two.

The chronic illness literature revealed similarities between the adolescents with chronic illness experiences and the adolescents with burn injury experiences. Information about normalcy and the long process however was not revealed in the chronic illness literature. Individuals with chronic illness and others would benefit from research that examined if this process toward normalcy was present, the nature of it, and how the process can be hastened.

As more research is completed to fully understand the adolescent experience after a burn injury many interventions will need to be developed to assist adolescents on their journey. Research will need to test these interventions and evaluate their effectiveness over time. Burn care professional and others working with adolescents with burn injuries contribute to these research endeavors.

Summary

This hermeneutic human science phenomenological study was designed to explore the lived experience of burned adolescents. Study limitations, trustworthiness, practice implications, and suggestions for future research were discussed.

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Appendix A

Street Address
City, State zipcode
May 5, 2003

Physician Name, M.D.
Chief of Staff
Burn Center
Street Address
City, State zipcode

Dear Dr. Name,

I am a doctoral student at the University of Cincinnati. I am interested in conducting a study at your institution. My area of interest is life experiences of children after a burn injury. This study will be part of the requirements for my PhD.

The study will be a qualitative design using the phenomenological method of Max van Manen. Van Man describes his design as a hermeneutic human science phenomenology. I believe this type of research will help to enrich the knowledge we have about burned children post injury. The primary method of data collection will be in depth interviews. I plan to interview 10-15 children during the adolescent phase of development who are at least one year post discharge and have a burn which has resulted in visible scarring or skin discoloration (i.e. face, arms etc), amputation, or permanent gait or range of motion limitations.

I am asking your permission to conduct this research at Burn Center Name in City. If you agree to this study, I will forward a copy of the proposal. I also understand there is a complex process involving the national NAME headquarters, that must be completed along with IRB approval. Please respond in writing your decision about my request. Thank you for your time and consideration with this matter.

Sincerely,

Mary C. Kishman, M.S.N., R.N.
Doctoral Student
University of Cincinnati

Street Address
 City, State zipcode
 May 23, 2003

NAME
 Health Information Department
 Burn Center
 Street Address
 City, State zipcode

Dear NAME,

I am a doctoral student at the University of Cincinnati, College of Nursing. During the next year, I would like to conduct a study at the Burn Center, City. The study is entitled, " The Lived Experience of Burned Adolescents". I plan to use patients who have been burned at least one year and range in age from 13 through 18. The study will have approximately 10-15 subjects.

I am requesting a list a potential patients who might meet my inclusion criteria. If possible, I would also like their expected clinic or next admission date. After I receive this information, I will begin the study. When the patient arrives for their appointment or admission I will approach them about being in the study. If agreeable, informed consent will be obtained. Subsequently, I will conduct a limited review of the medical record to verify that they meet inclusion criteria. Permission to use this data will be obtained at the time of consent. Information I will require from this record include: 1) date of burn, 2) date of first discharge post-burn, 3) TBSA burned, 4) body areas burned, 5) cause of burn, 6) age, 7) range of data, 8) psychiatric diagnosis, 9) information about hearing impairment if present, and 10) grafting procedures.

Inclusion criteria

- a. Participant is age 13 years through 18 years.
- b. Participant sustained a burn and has at least one of the following:
 - 1) residual scarring to a visible area such as face, neck, hands/fingers, or forearms.
 - 2) one or more amputations of digits or limbs.
 - 3) permanent gait or range of motion alterations.
- c. Participant is at least one-year post discharge from initial hospitalization as an acute burn.
- d. Participant is a current patient (either inpatient or outpatient) of Burn Center, City.
- e. Written informed consent or parent permission and assent when applicable is obtained from participant and parent/legal guardian.

Exclusion criteria (for interviewed children)

- a. Participant is unable to communicate verbally.
- b. Participant is unable to speak and/or understand the English language.
- c. Participant is unable to clearly hear/understand verbal conversation even with assistive devices (hearing aid etc.).
- d. Participant has a serious emotional or psychiatric condition.
- e. Participant does not wish to participate in the study.

If you have any questions, please do not hesitate to contact me at (phone number) or mary_kishman@mail.msje.edu. Thank you for your cooperation with this project.

Sincerely,

Mary C. Kishman, MSN, RN
Doctoral Student

Appendix B

Announcement of a New Study

I am a doctoral student from the University of Cincinnati, College of Nursing who will be conducting a new study. This study will look at life experiences of adolescents after being discharged from the hospital. The study will also examine artistic and literary works produced by burned patients such as poems, drawings, and stories.

Adolescents age 13 through 18 who have been discharged at least one year since their initial hospitalization will be in this study. Study participants will be interviewed during a clinic visit or admission. The interview would be tape-recorded. There will be no treatments or invasive procedures.

If you think you might be interested in participating in this study OR would like to learn more about it please sign the form below and mail the form in the attached, stamped envelope. The student researcher, Mary C. Kishman, RN, MSN will contact you following her receipt of the form.

If you would like to discuss the study in more detail please contact the student researcher Mary C. Kishman, RN, MSN per phone at (H) (phone number) or (W) (phone number).

Signature of Interest

Yes, I _____ am
Print Name

interested in participating in this study. I may be contacted at the

following phone number _____.

 Signature

 Date

Appendix C

University of Cincinnati
 Consent to Participate in a Research Study
 College of Nursing
 Mary C. Kishman - Doctoral Student
 xxx-xxx-xxxx

**BURN CENTER NAME
 CITY HOSPITAL**

Informed Consent to Participate in a Research Study

Participant _____ Hospital # _____

Principal Investigator Mary C. Kishman IRB Approval Number _____

Principal Investigator Contact Information :xxx-xxx-xxxx(home) OR xxx – xxx- xxxx-(cell)
 24 hr Emergency Telephone Number

Sponsor Name _____ NA _____ Sponsor Study # _____ NA _____

Title of Project or Study Lived Experiences of Burned Adolescents

INTRODUCTION

Before you agree to participate in this research study, it is important that you understand the following information described in this form. It tells how and why the study is being done. It also tells about the good things that could be learned from the study. Possible risks or things that may hurt or be uncomfortable are described and explained.

Your participation in this research study is entirely voluntary. If you decide to participate, you can drop out of the study at any time and no one will be upset. It is important to know that no promises can be made about the results of the study.

This informed consent document is a brief written summary of what your study investigator is telling you. Please ask questions about anything that you do not understand before deciding whether or not to participate.

WHY HAVE YOU BEEN ASKED TO TAKE PART IN THIS RESEARCH STUDY?

You are being asked to take part in this research study because you: 1) are an adolescent age 13 through 18 years, 2) suffered a burn injury at least one year ago, 3) had burns which

involved one or more of the following areas: face, neck, hands, feet, or forearms, 4) have visible scarring, an amputation, or limited gait or range of motion, and 5) are a current patient of Burn Center Name – City.

WHO SHOULD NOT BE IN THIS RESEARCH STUDY?

You will not be asked to take part in this research study if you: 1) cannot speak verbally, 2) cannot speak and/or understand the English language, 3) cannot hear or clearly understand a verbal conversation even with a device such as a hearing aid, 4) are less than 13 or more than 18 years old, and 5) if you or your parent/guardian do not wish to participate in the study.

HOW LONG WILL YOU BE IN THE RESEARCH STUDY?

You will be interviewed on a single day for approximately one to two hours (not including breaks as desired). When the study is completed the researcher will share the results with you if you desire.

WHY IS THIS RESEARCH BEING DONE?

The purpose of this research study is to gain an understanding of the daily life experiences of adolescents after a burn injury. The researcher seeks to understand the adolescent's experiences through the adolescent's unique perspective. Through this understanding, the researcher hopes to discover the quality of life of for adolescents who have been burned.

WHO IS CONDUCTING THE RESEARCH STUDY?

The study is directed by Mary C. Kishman RN, MSN – a Doctoral Student at the University of Cincinnati, College of Nursing, the researcher.

HOW MANY PEOPLE WILL TAKE PART IN THE RESEARCH STUDY?

About 10-15 adolescents will take part in the interview portion of this study.

WHAT IS INVOLVED IN THE RESEARCH STUDY?

The researcher will Interview you about your everyday life experiences since being burned. You will be asked to talk about your life experiences and feelings

in your own words. The interview will take place in a non-threatening area such

a private room and will last no more than one to two hours (not including breaks as desired). Your parent/guardian may be with you during the interview if you desire. During the interview you will also be asked if you kept a journal, wrote poems, drew pictures or created any other artistic/creative work after your burn. If so, you will be asked if you want to include these works in the study. If these items are at your home, the researcher will pay for mailing. There are no experimental procedures used in this study. The researcher will study the interviews and write a report about adolescent life experiences after a burn injury.

WHAT ARE THE RISKS AND DISCOMFORTS OF THE RESEARCH STUDY?

During the interview as you are telling the researcher about your everyday life experiences and talking about feelings or emotions, there is a chance that you may become mildly upset and/or tearful. If this happens you will be allowed time to rest and if desired, talk about your feelings. You can decide if you want to continue the interview. Your parent (s) will be permitted to comfort you if you request this.

WHAT ARE THE RISKS OF STOPPING YOUR CURRENT TREATMENTS?

Not applicable.

WHAT ARE THE REPRODUCTION RISKS?

Not applicable.

ARE THERE BENEFITS TO TAKING PART IN THE RESEARCH STUDY?

If you agree to take part in this research study, there may not be a direct medical benefit to you. No promises are being made that you personally will benefit from this study. We hope the information learned from the research study will benefit other patients with burns in the future.

WHAT OTHER CHOICES FOR CARE ARE THERE?

This study is not giving a treatment but finding out information which might be

helpful to burn patients in the future. The alternative to this study is not to participate in the study.

HOW WILL INFORMATION ABOUT YOU BE KEPT PRIVATE AND CONFIDENTIAL?

Every effort will be made to maintain the confidentiality of your study records, according to applicable state and federal laws. The Institutional Review Board at the University of Cincinnati will be allowed to inspect sections of your research records related to this study. They are required to keep your records confidential. A report from the study may be printed in a scientific paper; however, you will not be identified by name or personally identifying information. Your identity will remain confidential unless disclosure is required by law.

WHAT ARE YOUR COSTS TO BE IN THIS STUDY?

There will not be costs to the study participants or to their parents/guardians in this study.

WILL YOU BE PAID TO PARTICIPATE IN THIS STUDY?

Neither you nor your parents/guardians will receive any cash, gifts, or other financial compensation for taking part in this study.

WHAT ARE YOUR RIGHTS AS A PARTICIPANT?

You may choose either to take part or not to take part in this research study. If you decide not to participate, there will be no penalty and you will not lose any benefits you would otherwise receive. If you decide to take part, you may change your mind and decide to leave the study at any time. Leaving the study will not result in any penalty or loss of benefits to you. No one will be upset if you end your participation in this study. You will continue to receive your usual treatment at Burn Center Name, City.

There are no consequences if you decide to withdraw from this research study.

If you wish to withdraw from this study, please contact Mary C. Kishman, MSN, RN at XXX – XXX - XXXX or XXX-XXX-XXXX or mary_kishman@mail.msj.edu

The researcher will tell you about new information that may affect your health, welfare, or willingness to stay in this study.

If the investigator feels that this study is not appropriate for you or that you have not followed directions you will be dropped from the study.

If you have questions about the study, you will have a chance to talk to one of the study staff or your regular doctor. Do not sign this form unless you have had the chance to ask questions and received satisfactory answers.

Nothing on the consent form waives any legal rights you may have not does it release the investigator, the institution, or its agents from liability for negligence.

WHO DO YOU CALL IF YOU HAVE QUESTIONS OR PROBLEMS?

If you have any question now or later about this research study or to report a research-related injury, you can contact the researcher Mary C. Kishman, MSN, RN at xxx – xxx–xxxx (H) or xxx-xxx-xxxx (W), her advisor Dr. NAME at xxx-xxx-xxxx., or Dr. NAME at xxx-xxx-xxxx (Burn Center).

If you have general questions about giving consent or your rights as a research participant in this research study, you can call the University of Cincinnati Institutional Review Board at 513-558-5784.

**BURN CENTER NAME
CITY HOSPITAL**

INFORMED CONSENT TO PARTICIPATE IN RESEARCH PROJECT OR STUDY

Participant _____ Hospital # _____

Principal Investigator Mary C. Kishman IRB Approval Number _____

Principal Investigator Contact Information XXX- XXX- XXXX (home) OR XXX – XXX- XXXX
(cell) 24 hr Emergency Telephone Number

Sponsor Name _____ NA _____ Sponsor Study # _____ NA _____

Title of Project or Study Lived Experiences of Burned Adolescents

Your signature, below, will indicate that you have read (or have read to you) the contents of the consent form and decided to volunteer as a research participant. It also indicates that you have been encouraged to ask questions and received answers to your questions. You will be given a signed copy of this form for your records and future reference.

Signature of Witness Date Signature of Participant

Date

Verbal assent was obtained.

Signature of Witness Date

.....
Using language that is understandable and appropriate, I have discussed this project and the items listed above with the participant and/or his authorized representative.

Signature of Principal Investigator or Co-Investigator Date

PERSON OBTAINING CONSENT:

I have read this form to the participant and/or the participant has read this form. An explanation of the research was given and questions from the participant were solicited and answered to the subject's satisfaction. In my judgment, the participant has demonstrated comprehension of the information.

Signature and Title of Person Obtaining Consent

Date

Identification of Role in the Study

Appendix D

University of Cincinnati
 Consent to Participate in a Research Study
 College of Nursing
 Mary C. Kishman - Doctoral Student
 xxx-xxx-xxxx

**BURN CENTER NAME
 CITY HOSPITAL**

Participant Assent to Participate in a Research Study

Participant _____ Hospital # _____

Principal Investigator Mary C. Kishman IRB Approval Number _____

Principal Investigator Contact Information xxx- xxx- xxxx (home) OR xxx – xxx- xxxx-(cell)
 24 hr Emergency Telephone Number

Sponsor Name _____ NA Sponsor Study # _____ NA

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About 10-15 adolescents will take part in the interview portion of this study.

WHAT IS INVOLVED IN THE RESEARCH STUDY?

The researcher will Interview you about your everyday life experiences since being burned. You will be asked to talk about your life experiences and feelings in your own words. The interview will take place in a non-threatening area such a private room and will last no more than one to two hours (not including breaks as desired). Your parent/guardian may be with you during the interview if you desire. During the interview you will also be asked if you kept a journal, wrote poems, drew pictures or created any other artistic/creative work after your burn. If so, you will be asked if you want to include these works in the study. If these items are at your home, the researcher will pay for mailing. There are no experimental procedures used in this study. The researcher will study the interviews and write a report about adolescent life experiences after a burn injury.

WHAT ARE THE RISKS AND DISCOMFORTS OF THE RESEARCH STUDY?

During the interview as you are telling the researcher about your everyday life experiences and talking about feelings or emotions, there is a chance that you may become

mildly upset and/or tearful. If this happens you will be allowed time to rest and if desired, talk about your feelings. You can decide if you want to continue the interview. Your parent (s) will be permitted to comfort you if you request this.

WHAT ARE THE RISKS OF STOPPING YOUR CURRENT TREATMENTS?

Not applicable.

WHAT ARE THE REPRODUCTION RISKS?

Not applicable.

ARE THERE BENEFITS TO TAKING PART IN THE RESEARCH STUDY?

If you agree to take part in this research study, there may not be a direct medical benefit to you. No promises are being made that you personally will benefit from this study. We hope the information learned from the research study will benefit other patients with burns in the future.

WHAT OTHER CHOICES FOR CARE ARE THERE?

This study is not giving a treatment but finding out information which might be

helpful to burn patients in the future. The alternative to this study is not to participate in the study.

HOW WILL INFORMATION ABOUT YOU BE KEPT PRIVATE AND CONFIDENTIAL?

Every effort will be made to maintain the confidentiality of your study records, according to applicable state and federal laws. The Institutional Review Board at the University of Cincinnati will be allowed to inspect sections of your research records related to this study. They are required to keep your records confidential.

A report from the study may be printed in a scientific paper; however, you will not be identified by name or personally identifying information. Your identity will remain confidential unless disclosure is required by law.

WHAT ARE YOUR COSTS TO BE IN THIS STUDY?

There will not be costs to the study participants or to their parents/guardians in this study.

WILL YOU BE PAID TO PARTICIPATE IN THIS STUDY?

Neither you nor your parents/guardians will receive any cash, gifts, or other financial compensation for taking part in this study.

WHAT ARE YOUR RIGHTS AS A PARTICIPANT?

You may choose either to take part or not to take part in this research study. If you decide not to participate, there will be no penalty and you will not lose any benefits you would otherwise receive. If you decide to take part, you may change your mind and decide to leave the study at any time. Leaving the study will not result in any penalty or loss of benefits to you. No one will be upset if you end your participation in this study. You will continue to receive your usual treatment at Shriners Hospitals for Children, Cincinnati Hospital.

There are no consequences if you decide to withdraw from this research study.

If you wish to withdraw from this study, please contact Mary C. Kishman, MSN, RN at xxx – xxx-xxxx or xxx -xxx -xxxx or mary_kishman@mail.msj.edu.

The researcher will tell you about new information that may affect your health, welfare, or willingness to stay in this study.

If the investigator feels that this study is not appropriate for you or that you have not followed directions you will be dropped from the study.

If you have questions about the study, you will have a chance to talk to one of the study staff or your regular doctor. Do not sign this form unless you have had the chance to ask questions and received satisfactory answers.

Nothing on the consent form waives any legal rights you may have not does it release the investigator, the institution, or its agents from liability for negligence.

WHO DO YOU CALL IF YOU HAVE QUESTIONS OR PROBLEMS?

If you have any question now or later about this research study or to report a research-related injury, you can contact the researcher Mary C. Kishman, MSN, RN at xxx– xxx–xxxx (H) or xxx-xxx-xxxx (W), her advisor Dr. NAME at xxx-xxx-xxxx, or Dr. NAME at xxx-xxx-xxxx (Burn Center).

If you have general questions about giving consent or your rights as a research participant in this research study, you can call the University of Cincinnati Institutional Review Board at 513-558-5784.

**BURN CENTER NAME
CITY HOSPITAL**

PARTICIPANT ASSENT TO PARTICIPATE IN RESEARCH PROJECT OR STUDY

Participant _____ Hospital # _____

Principal Investigator Mary C. Kishman IRB Approval Number _____

Principal Investigator Contact Information xxx- xxx- xxxx (home) OR xxx -xxx - xxxx-(cell)
24 hr Emergency Telephone Number

Sponsor Name _____ NA _____ Sponsor Study # _____ NA _____

Title of Project or Study Lived Experiences of Burned Adolescents

Your signature, below, will indicate that you have read (or have read to you) the contents of the consent form and decided to volunteer as a research participant. It also indicates that you have been encouraged to ask questions and received answers to your questions. You will be given a signed copy of this form for your records and future reference.

Signature of Witness Date Signature of Participant
Date

Verbal assent was obtained.

Signature of Witness for Verbal assent Date

.....
Using language that is understandable and appropriate, I have discussed this project and the items listed above with the participant and/or his authorized representative.

Signature of Principal Investigator or Co-Investigator Date

PERSON OBTAINING CONSENT:

I have read this form to the participant and/or the participant has read this form. An explanation of the research was given and questions from the participant were solicited and answered to the subject's satisfaction. In my judgment, the participant has demonstrated comprehension of the information.

Signature and Title of Person Obtaining Consent Date

Identification of Role in the Study

Appendix E

University of Cincinnati
 Consent to Participate in a Research Study
 College of Nursing
 Mary C. Kishman - Doctoral Student
 xxx-xxx-xxxx

**BURN CENTER NAME
 CITY HOSPITAL**

Parent Permission to Participate in a Research Study

Participant _____ Hospital # _____

Principal Investigator Mary C. Kishman IRB Approval Number _____

Principal Investigator Contact Information xxx-xxx-xxxx (home) OR xxx – xxx- xxxx-(cell)
 24 hr Emergency Telephone Number

Sponsor Name _____ NA Sponsor Study # _____ NA

Title of Project or Study Lived Experiences of Burned Adolescents

INTRODUCTION

If you are acting on behalf of an adolescent, the words “you” and “your” refers to your adolescent daughter, son, or guardian.

Before you agree to participate in this research study, it is important that you understand the following information described in this form. It tells how and why the study is being done. It also tells about the good things that could be learned from the study. Possible risks or things that may hurt or be uncomfortable are described and explained.

Your participation in this research study is entirely voluntary. If you decide to participate, you can drop out of the study at any time and no one will be upset. It is important to know that no promises can be made about the results of the study.

This informed consent document is a brief written summary of what your study investigator is telling you. Please ask questions about anything that you do not understand before deciding whether or not to participate.

WHY HAVE YOU BEEN ASKED TO TAKE PART IN THIS RESEARCH STUDY?

You are being asked to take part in this research study because you: 1) are an adolescent age 13 through 18 years, 2) suffered a burn injury at least one year ago, 3) had burns which involved one or more of the following areas: face, neck, hands, feet, or forearms, 4) have visible scarring, an amputation, or limited gait or range of motion, and 5) are a current patient of Burn Center Name – City.

WHO SHOULD NOT BE IN THIS RESEARCH STUDY?

You will not be asked to take part in this research study if you: 1) cannot speak verbally, 2) cannot speak and/or understand the English language, 3) cannot hear or clearly understand a verbal conversation even with a device such as a hearing aid, 4) are less than 13 or more than 18 years old, and 5) if you or your parent/guardian do not wish to participate in the study.

HOW LONG WILL YOU BE IN THE RESEARCH STUDY?

You will be interviewed on a single day for approximately one to two hours (not including breaks as desired). When the study is completed the researcher will share the results with you if you desire.

WHY IS THIS RESEARCH BEING DONE?

The purpose of this research study is to gain an understanding of the daily life experiences of adolescents after a burn injury. The researcher seeks to understand the adolescent's experiences through the adolescent's unique perspective. Through this understanding, the researcher hopes to discover the quality of life of for adolescents who have been burned.

WHO IS CONDUCTING THE RESEARCH STUDY?

The study is directed by Mary C. Kishman RN, MSN – a Doctoral Student at the University of Cincinnati, College of Nursing, the researcher.

HOW MANY PEOPLE WILL TAKE PART IN THE RESEARCH STUDY?

About 10-15 adolescents will take part in the interview portion of this study.

WHAT IS INVOLVED IN THE RESEARCH STUDY?

The researcher will Interview you about your everyday life experiences since being burned. You will be asked to talk about your life experiences and feelings in your own words. The interview will take place in a non-threatening area such a private room and will last no more than one to two hours (not including breaks as desired). Your parent/guardian may be with you during the interview if you desire. During the interview you will also be asked if you kept a journal, wrote poems, drew pictures or created any other artistic/creative work after your burn. If so, you will be asked if you want to include these works in the study. If these items are at your home, the researcher will pay for mailing. There are no experimental procedures used in this study. The

researcher will study the interviews and write a report about adolescent life experiences after a burn injury.

WHAT ARE THE RISKS AND DISCOMFORTS OF THE RESEARCH STUDY?

During the interview as you are telling the researcher about your everyday life experiences and talking about feelings or emotions, there is a chance that you may become mildly upset and/or tearful. If this happens you will be allowed time to rest and if desired, talk about your feelings. You can decide if you want to continue the interview. Your parent (s) will be permitted to comfort you if you request this.

WHAT ARE THE RISKS OF STOPPING YOUR CURRENT TREATMENTS?

Not applicable.

WHAT ARE THE REPRODUCTION RISKS?

Not applicable.

ARE THERE BENEFITS TO TAKING PART IN THE RESEARCH STUDY?

If you agree to take part in this research study, there may not be a direct medical benefit to you. No promises are being made that you personally will benefit from this study. We hope the information learned from the research study will benefit other patients with burns in the future.

WHAT OTHER CHOICES FOR CARE ARE THERE?

This study is not giving a treatment but finding out information which might be

helpful to burn patients in the future. The alternative to this study is not to participate in the study.

HOW WILL INFORMATION ABOUT YOU BE KEPT PRIVATE AND CONFIDENTIAL?

Every effort will be made to maintain the confidentiality of your study records, according to applicable state and federal laws. The Institutional Review Board at the University of Cincinnati will be allowed to inspect sections of your research records related to this study. They are required to keep your records confidential.

A report from the study may be printed in a scientific paper; however, you will not be identified by name or personally identifying information. Your identity will remain confidential unless disclosure is required by law.

WHAT ARE YOUR COSTS TO BE IN THIS STUDY?

There will not be costs to the study participants or to their parents/guardians in this study.

WILL YOU BE PAID TO PARTICIPATE IN THIS STUDY?

Neither you nor your parents/guardians will receive any cash, gifts, or other financial compensation for taking part in this study.

WHAT ARE YOUR RIGHTS AS A PARTICIPANT?

You may choose either to take part or not to take part in this research study. If you decide not to participate, there will be no penalty and you will not lose any benefits you would otherwise receive. If you decide to take part, you may change your mind and decide to leave the study at any time. Leaving the study will not result in any penalty or loss of benefits to you. No one will be upset if you end your participation in this study. You will continue to receive your usual treatment at Burn Center Name- City.

There are no consequences if you decide to withdraw from this research study.

If you wish to withdraw from this study, please contact Mary C. Kishman, MSN, RN at xxx-xxx-xxxx or xxx-xxx-xxxx (cell) mary_kishman@mail.msj.edu.

The researcher will tell you about new information that may affect your health, welfare, or willingness to stay in this study.

If the investigator feels that this study is not appropriate for you or that you have not followed directions you will be dropped from the study.

If you have questions about the study, you will have a chance to talk to one of the study staff or your regular doctor. Do not sign this form unless you have had the chance to ask questions and received satisfactory answers.

Nothing on the consent form waives any legal rights you may have not does it release the investigator, the institution, or its agents from liability for negligence.

WHO DO YOU CALL IF YOU HAVE QUESTIONS OR PROBLEMS?

If you have any question now or later about this research study or to report a research-related injury, you can contact the researcher Mary C. Kishman, MSN, RN at xxx-xxx-xxxx (w) her advisor Dr. NAME at xxx-xxx-xxxx, or Dr. NAME xxx-xxx-xxxx (Burn Center).

If you have general questions about giving consent or your rights as a research participant in this research study, you can call the University of Cincinnati Institutional Review Board at 513-558-5784.

**BURN CENTER NAME
CITY HOSPITAL**

PARENT PERMISSION TO PARTICIPATE IN RESEARCH PROJECT OR STUDY

Participant _____ Hospital # _____

Principal Investigator Mary C. Kishman _____ IRB Approval Number _____

Principal Investigator Contact Information xxx-xxx-xxxx(home) OR xxx-xxx-xxxx(cell)
24 hr Emergency Telephone Number

Sponsor Name _____ NA _____ Sponsor Study # _____ NA _____

Title of Project or Study Lived Experiences of Burned Adolescents _____

Your signature, below, will indicate that you have read (or have read to you) the contents of the consent form and decided to volunteer as a research participant. It also indicates that you have been encouraged to ask questions and received answers to your questions. You will be given a signed copy of this form for your records and future reference.

Signature of Witness Date Signature of Parent or Legal Guardian
Date

Signature of Witness Date Signature of Parent or Legal Guardian
Date

Verbal parent permission was obtained.

Signature of Witness for Verbal assent Date

.....
Using language that is understandable and appropriate, I have discussed this project and the items listed above with the participant and/or his authorized representative.

Signature of Principal Investigator or Co-Investigator Date

PERSON OBTAINING CONSENT:

I have read this form to the participant and/or the participant has read this form. An explanation of the research was given and questions from the participant were solicited and answered to the subject's satisfaction. In my judgment, the participant has demonstrated comprehension of the information.

Signature and Title of Person Obtaining Consent

Date

Identification of Role in the Study

Appendix F

CONSENT TO USE LITERARY OR ARTISTIC WORKPart One: Participant consent/assent:

I _____ creator of this literary/artistic work give Mary C. Kishman, M.S.N, RN, principal investigator permission to use my work in the study entitled “Lived Experiences of Burned Adolescents”. I understand that when the study is published or presented in some other public manner, no identifying information will be connected to the literary/artistic work **unless I explicitly direct Mary Kishman to do so**. I understand that submission of this work means I am giving consent for Mary Kishman to use the work in her study, presentations, and publications.

Part Two: Parent/Legal guardian permission

I _____ parent/legal guardian of _____ give Mary C. Kishman, M.S.N, RN, principal investigator permission to use my adolescent’s literary/artistic work in the study entitled “Lived Experiences of Burned Adolescents” I understand that when the study is published or presented in some other public manner, no identifying information will be connected to the literary/artistic work **unless I and my child explicitly directs Mary Kishman to do so**. My child and I understand that submission of this work means I am giving consent for Mary Kishman to use the work in her study, presentations, and publications.

 Parent/Legal Guardian

 Date
Questions or Concerns May be directed to:

Mary C. Kishman, M.S.N., RN

Doctoral Student

Street Address

City, State zipcode

(xxx) xxx-xxxx **home**(xxx) xxx-xxxx **work**mary_kishman@mail.msj.edu

Appendix G

CONSENT TO USE LITERARY OR ARTISTIC WORKPart One: Participant consent/assent:

I _____ creator of this literary/artistic work give Mary C. Kishman, M.S.N, RN, principal investigator permission to use my work in the study entitled "Lived Experiences of Burned Adolescents". I understand that when the study is published or presented in some other public manner, no identifying information will be connected to the literary/artistic work ***unless I explicitly direct Mary Kishman to do so***. I understand that submission of this work means I am giving consent for Mary Kishman to use the work in her study, presentations, and publications.

**Please include my name with my work _____

Participant

Date

Part Two: Parent/Legal guardian permission

I _____ parent/legal guardian of _____ give Mary C. Kishman, M.S.N, RN, principal investigator permission to use my adolescent's literary/artistic work in the study entitled "Lived Experiences of Burned Adolescents" I understand that when the study is published or presented in some other public manner, no identifying information will be connected to the literary/artistic work ***unless I and my child explicitly directs Mary Kishman to do so***. My child and I understand that submission of this work means I am giving consent for Mary Kishman to use the work in her study, presentations, and publications.

Parent/Legal Guardian

Date

Questions or Concerns May be directed to:

Mary C. Kishman, M.S.N., RN
 Doctoral Student
 Street Address
 City, State zipcode
 (xxx) xxx-xxxx **home**
 (xxx) xxx-xxxx **work**
mary_kishman@mail.msj.edu

Appendix H

Interview Guide

The adolescent will be asked a global introductory question/statement. Three questions/statements may be used.

- 1) Tell me about your life before the burn.
- 2) Tell me about your life since the burn.
- 3) Tell me about a typical day in your life.

As the adolescent speaks the researcher will refrain from “leading statements”. Some clarifications statements or questions may be used. For example:

- 1) Can you explain that further?
- 2) Tell me more.
- 3) How did you feel?
- 4) What did that mean to you?

If the adolescent is hesitant or unsure as to “where to begin” the researcher may say the following:

- 1) Lets start in the morning when you get up.

The adolescent will be free to stop at any time. Rest periods will be permitted and encouraged if the conversation lasts longer then 45 minutes.

Appendix I

Street Address
City, State, Zip Code
May 5, 2003

Name of Burn Care Professional

Name of Institution

Address of Institution

Dear *Burn Care Professional*,

I am a doctoral student at the University of Cincinnati in Cincinnati, Ohio. My area of interest is the quality of life of children after suffering a burn injury. In particular, I am interested in researching the personal experiences and life stories of these children from their perspectives. My dissertation is entitled "Lived Experiences of Burned Children". The study uses a phenomenological qualitative design.

Children and others have been known to express life experiences through drawings, poems, diaries, and other artistic works. To fully understand a burned child's experiences, it is essential to include these types of materials in the study. I am therefore seeking examples of artistic works created by burned children. If you have in your possession examples of such works (or know of where to obtain), I would like the opportunity to read or see it. If you have access to such materials, please contact me using one of the means listed below. We can then determine how I can best access the artistic work. I will reimburse you for any costs that might be incurred in this process. Please note that if the child artist is known, permission will have to be obtained from the child and parent/guardian using the form enclosed.

Thank you for your time and cooperation with my research endeavor. Please do not hesitate to contact me if you have any questions or concerns.

Sincerely,

Mary C. Kishman, M.S.N, R.N.

xxx-xxx-xxxx (home)

xxx-xxx-xxxx (Work)

mary_kishman@mail.msj.edu