

Abstract of Thesis

The Lived Experience of Caring for a Child with Lead Poisoning

Lead poisoning affects approximately 890,000 children in the United States every year. The effects of lead poisoning are irreversible and can result in lower IQ, learning disabilities, hearing loss, hyperactivity, impaired growth, seizures, and coma. In the United States 24,000,000 houses have lead paint and young children are living in 4,000,000 of these homes. This research is a qualitative phenomenological study using Parse's Theory of Human Becoming and research methodology to describe the caregiver's experience of taking care of a lead poisoned child. The data collection was completed using the technique of the unstructured interviews. From the interviews the concepts of The Story of Lead, Expectations of Others, Others towards the Caregiver, and Self, and Yielding to Powerlessness. This study will assist in education and the development of strategies to meet the needs of families, help to demonstrate the need for the provision of financial assistance to address lead hazards.

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October 15, 2006

The Lived Experience of Caring for a Child with Lead Poisoning

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MASTER'S THESIS RELEASE

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CHAPTER I

Background and Significance of the Study

Healthy People 2010 objectives 8-11 are to “eliminate elevated blood lead levels in children” (Healthy People 2010, 2000). Lead is a systemic toxicant with no health benefits and with no safe exposure. Lead poisoning affects approximately 890,000 children in the United States every year (Munro Cohen, 2001). The effects of lead poisoning are irreversible and can cause damage to the central nervous system resulting in lower IQ, learning disabilities, hearing loss, hyperactivity, impaired growth, seizures, and coma. Lead poisoning usually has no symptoms and often goes undetected and untreated (Center for Disease Control and Prevention: National Center for Environmental Health, 2004).

The largest source of lead is found in homes that were built before 1978 and painted with lead based paints. With renovations and over time the paint deteriorates and creates a lead dust. In the United States 24 million housing units have lead based paint with house dust that contains lead levels that are at greater than the acceptable level. Of these homes, 4 million have young children living in them (Center for Disease Control and Prevention: National Center for Environmental Health, 2004).

It is the role of the registered nurse to provide education to the family on strategies to reduce the lead blood level and the lead load in the home, nutrition, medical follow up, and referrals for Women, Infant, and Children (WIC), Medicaid, and Head Start if necessary (Roberts & Reigart, 2002).

Studies have looked at the success of educating parents to help control lead exposure of their children and engage in activities to lower the children's blood lead level. In June of 2002 Kass, Bisesi, and Khuder completed a study that assessed the lead management program for inner-city children. The study indicated that 1) chelation therapy and parent education are not always adequate to lower blood lead levels if exposure continues, 2) parents should receive more frequent and in-depth education, 3) residence of children in lead free homes remains the most effective way to lower blood levels.

Porter and Severtson (2000) conducted a descriptive study of parent's efforts to decrease their children's blood lead level. Only 30% of the parents documented the source of the lead exposure or the actions that they had taken to reduce the exposure. Parents also categorized their actions in relation to effectiveness and the study indicated that very few of the actions were effective. This research indicated that parents needed more education in identifying the lead sources and the actions to reduce the lead exposure to the child.

Research done in Shanghai found that parental education was very effective for mild to moderate lead poisoned children. Educating parents proved to be successful for changing habits that exposed children to lead, improvement in knowledge of lead prevention of exposure and poisoning, and it changed parent's attitudes towards lead poisonings (Shen, Yan, Shi, & Wu, 2004).

Statement of Problem

The purpose of this qualitative phenomenological study is to determine the lived experience of caregivers with a child or children with lead poisoning. A

review of past research done on lead poisoning did not indicate that any study had been done on the qualitative lived experience with a child with lead poisoning or the parent's perception of lead hazards, the cleaning protocol, and the education provided by case managers.

Theoretical Framework

Parse's research methodology is developed on the principles of the Theory of Human Becoming. "The Parse methodology is generically phenomenological in that entities for study are experiences as described by people who have lived them. These entities in the Parse method are to be universal lived experiences of health such as grieving, feeling, restricted-feeling free, and suffering. The participants are persons who can describe through words, symbols, metaphors, poetry, or drawings the meaning of the experience under study" (Parse, 1995, p. 153).

The use of Parse's theory allows the nurse to consider new meanings of a situation which in turn allows the nurse to go with the flow of the person's rhythms and allows the person to reach beyond the moment and illuminates their hopes and dreams (Hickman, 2002).

There are three main principles of Parse's theory. The first principle states that "Structuring meaning multidimensionally is co-creating reality through the languaging" (Hickman, 2002, p. 433). This means that a human being's reality is structured by their lived experience. Co-creating is the human-environment mutual participation and the patterns that it creates. Languaging is the reflection of values and images through the process of speaking and movement. Valuing

is the progression of living of cherished belief and adding to one's world view. Imaging is the knowing and this includes both the explicit and tacit knowledge. It is through this principle that Parse has identified the nursing practice of gaining meaning through discussion (Hickman).

The second principle states "Co creating rhythmical patterns of relating is living the paradoxical unity of revealing-concealing, and enabling-limiting, while connecting-separating" (Hickman, 2002, 434). This principle is the multidimensional universe that a human being creates while living a rhythmic pattern of relating and living a paradox. The paradoxes are revealing-concealing, enabling-limiting, and connecting-separating. The rhythmic patterns are not the opposite but exist together at the same time. In all relationships human beings reveal a part of them but also keep a part of them concealed. The nurse dwells with this process and moves with the flow of the family helping them to recognize the harmony in their own lived context (Hickman).

The last principle is "co creating rhythmical patterns of relating is living the paradoxical unity of revealing-concealing, and enabling-limiting, while connecting-separating" (Hickman, 2002, p. 435). This principle relates to the concepts of powering, originating, and transforming and Powering is seen as the energizing force which is the pushing and resisting that is an interhuman encounter. Originating is inventing new ways to conform or not to conform in the certainty and uncertainty of living and finding a personal way to live their life that creates personal uniqueness and the paradoxical rhythms of living all at once. Transforming is the changing of change and is seen as creating diversity

(Hickman). In this principle the nurse is guiding the family “to plan for the changing of lived health patterns” (Hickman, p. 435)

The Theory of Human Becoming is designed to guide research and practice. “Three theoretical structures are identified: 1) powering emerges with the revealing-concealing of imaging, 2) originating emerges with the enabling-limiting of valuing, and 3) transforming emerges with the languaging of the connecting-separating” (Hickman, 2002, p. 437).

With the first theoretical structure, Parse describes the process where the nurse family relationship enables the family to share their thoughts and feelings about the situation they are experiencing. This in turn reveals and conceals what they know about the struggle with their personal goals. When the significance of the situation is revealed then the meaning of the situation also changes for the family (Hickman, 2002).

The second theoretical structure is the nursing practice focus with the person or family that identifies ways of being alike and different from others in changing values. By combining rhythms, transcendence is achieved and the participants discover ways to be together and the choices result, according to Parse, in transcendence (Hickman, 2002).

The third theoretical structure allows for the illumination of relating ways for the nurse and the person or family to be together as different perspectives shed light on the familiar perspective but also identify new possibilities. Parse suggests that by relating the values to the nurse through speech and movement

the person or family's views change and by "mobilized transcendence the ways of relating change" (Hickman, 2002, 437).

Research Question

1. What is the lived experience of caring for a lead poisoned child?

Limitations

1. The findings of the study may only apply to these caregivers and may not be able to be generalized to other populations of caregivers of lead poisoned children.

CHAPTER II

Review of the Literature

Introduction

This review of literature will include Parse's Theory of Human Becoming and the research method used in phenomenological research, history of lead poisoning, followed by childhood lead poisoning and will look at the physiological effects and signs and symptoms of lead toxicity. Next the literature review will look at housing and lead paint and the role that it plays in lead toxicity of the young child. Case management, the role of the public health nurse, and the environmentalist, will be addressed in the managing of a child with an elevated lead blood level. This review will look at parental education for control of lead hazards and the effectiveness of this education in addressing the lead poisoned child.

Parse Theory of Human Becoming and Research Methodology

Caring for a lead poisoned child is a process that is really only understood by the caregiver of that child. Each caregiver and family are unique, bringing their own personal versions of what it is like to give care for that child. It is through the use of Parse's Theory of Human Becoming that the ability to understand the story of these caregivers is understood. The qualitative study the *Hope for American Women and Children* by Lynn Allchin-Petardi published in 1999 an excellent model of Parse's principles of Human Becoming Theory providing the framework for the sharing of human experiences and perceptions in their own unique way.

This qualitative study explored with a group of American women what hope was in their lives and for their children. Each of the participants had circumstances that made them different and unique. Some were married, divorced, single, worked, did not work, but all were mothers (Allchin-Petardi, 1999).

The first core concept in this study was envisaging the possibles and each participant expressed the possibles in terms of “what is” and “what will-be all-at once”. In Parse’s theory this would be considered the theoretical level of imaging and envisioning. The participants pictured alternative ways of becoming and spoke of the possibles that had not yet come. As every one of the mothers interviewed she shared what her situation was and what she hoped that it would be in the future. The participants spoke of their feeling and hopes of the “not-yet” and spoke of new ways of becoming in the “not-yet” (Allchin-Petardi, 1999).

In the second core concept, resolute perseverance, individuals moved from what is now to what goal they hoped to attain in the future. The participants clearly stated their perseverance goals while others discuss this in a more subtle fashion. In Parse’s Theory of The Human Becoming this is “powering”. This is the way the women moved from the “now” to the “not yet” (Allchin-Petardi, 1999). “In this study, participants viewed a variety of ways that their own situations could turn, but each looked to the not yet and what was desired” (Allchin-Petardi, p. 283).

The last core concept, formidable ambiguity, highlighted the individual’s ability to look at their difficult situation in more than one way (Allchin-Petardi,

1999). “The particular situation was unique for each participant, but all situations were identified as personally insurmountable and all –at –once surmountable as each participant knew there was more than one path to move beyond the ambiguity” (Allchin-Petardi, p.284). Enabling-limiting originating is the process of human being, moving in a direction, which will help them make a new way for themselves and their others (Allchin-Petardi).

“As participants viewed options and made choices, they were simultaneously enabled to move in one direction and limited to move in other directions in creating new ways of becoming. Participants gracefully acknowledged the fact that as they hoped for specific ways, other ways were, sometimes gladly, closed or lost to them” (Allchin-Petardi, 1999, p.284).

Parse’s theory and research methodology were used in the qualitative study of the Lived Experience of Restriction-Freedom in Later Life studied by Mitchell and published in 1995. The findings from this phenomenological qualitative study are situated within Parse’s theory of The Human Becoming (Mitchell, 1995).

The first core concept is *anticipating limitation*. Participants described the restrictions they are experiencing now such as not able to walk without a cane and considering future limitations such as moving from requiring a cane to needing a walker. (Mitchell, 1995). This has been linked to Parse’s theory as principle one “Structuring meaning multi dimensionally is cocreating reality through the languaging of valuing and imaging” (Parse, 1995, p. 6).

The next core concept is *unencumbered self-direction* was related to freedom and choice, free to do what they want and not to answer to anyone (Mitchell, 1995). This is linked with Parse's concept of originating "Cotranscending with the possibles is powering unique ways of originating in the process of transforming (Parse, 1995, p.7).

The third concept is *yielding to change fortifies resolve for moving beyond*. The participants learned to accept the loss of activities or abilities such as blindness and driving a car. The participants were able to make jokes about the loss of these abilities and replace them with new activities (Mitchell, 1995). This concept is linked to Parse's second principle "Cocreating rhythmical patterns of relating is living the paradoxical unity of revealing-concealing and enabling-limiting while connection-separating (Parse, 1995, p. 7).

"The restriction-freedom experience has been specified as *anticipating limitations with unencumbered self-direction while yielding to change fortifies resolve for moving beyond*. When linked to Parse's theory, restriction-freedom is imaging the originating of enabling-limiting" (Mitchell, 1995, p. 175).

The History of Lead Poisoning

Lead is a soft naturally occurring metal which is used in materials and products in manufacturing, burning of fossil fuels, and mining (Cohen, 2001). Lead poisoning was first identified in ancient times in 200 BC the Greek physician Dioscordies observed that "lead makes the mind give way" (Koller, Brown, Spurgeon, & Levy, 2004, p. 987). Lead was added to paint as far back as 1884 because it made paint more durable and adhesive. In 1921 General

Motors developed tetraethyl lead and added it to gas to decrease the amount of engine knock. Gasoline exhaust was considered the largest source of lead until it was phased out in 1970's. Today roadways and the soil areas around them remain highly contaminated with lead (Askari & McDiarmid Jr., 2003). The lead industry from the 1920s through the 1950's touted lead in it's' advertisements as "Lead... is contributing to the health, comfort, and convenience of people today as it did when Rome was a center of civilization" (Askari & McDiarmid Jr., p. 2). Lead poisoning was identified in the 1960's as a serious health threat in the United States. Banning the use of lead in paint in 1978 and in the use of lead in gasoline in 1986 has improved the health of Americans immensely (Askari & McDiarmid Jr.).

In 1971 The Lead Based Poisoning Prevention Act was passed which began the movement to reduce the amount of lead that was put into paint, gasoline, food cans, plumbing and house hold products. Lead poisoning has reduced from 88.2% in 1976 to 4.4% in 1994. Although extremely high levels of lead poisoning are rare low levels still continue to be a problem today (Cohen, 2001).

The Act: Section 1018 of the Residential Lead-Based Paint Hazards Reduction Act of 1992 (Title X of the Housing and Community Development Act of 1992) requires sellers, landlords, and real estate agents to warn potential buyers and tenants that the property dating to pre-1978 may contain lead based paint and lead-based paint hazards (Residential Lead-Based Paint Hazard Reduction Act Rules and Regulations, 1992).

Childhood Lead Poisoning

Elevated blood lead level is defined as “any blood level $\geq 10 \mu\text{g/dL}$ ” (Koplan, Richard, McGeehin, & Noonan, 2002, xix). Lead affects almost every system of the body and is ingested most commonly through swallowing. Lead impacts mostly children under the ages of six as it is easily absorbed into their bodies and interferes with the normal growth and development of their brains and organs. Children under the age of two are at the highest risk for the effects of lead (Alliance to End Childhood Lead Poisoning). Children readily absorb up to 50% of the lead they are exposed to, as contrasted to adults that only absorb 10% of the lead exposure. A single paint chip the size of a dime can have 50-200 mg of lead in it. Three of these paint chips ingested by a child daily would equal a 1,000 times the amount allowed for an adult daily (Cohen, 2001).

Medicaid considers the at-risk population to be “Children aged < 6 years (especially those aged 0-3 years), pregnant women who occupy homes constructed before 1978, and Medicaid enrolled and Medicaid eligible children. (This definition will be further refined on the basis of local conditions and data)” (Recommendations from the Advisory Committee on Childhood Lead Poisoning Prevention, 2004, p. 14).

High levels of lead exposure can cause mental retardation, coma, convulsion and death, however this is very rare. Children are more likely to have chronic low level exposure that results in reduced I.Q, shortened attention span, hyperactivity, learning disabilities, and other health problems (Alliance to End Childhood Lead Poisoning).

A child is considered to be lead poisoned with a BLL greater than 10 µg/dL. BLL of 15-19 µg/dL is considered moderate and at the level of 20-44 µg/dL is considered high. Levels that are 45 or higher are considered very high (Koplan, Richard, McGeehin, & Noonan, 2002).

A study done by Lanphear et al, 2000 indicated that even the lowest BLL concentrations were associated with deficits in cognitive functioning and poor academic achievement. The authors used data from the National Health and Nutrition Examination Survey, (NHANES III) that was done from 1988 to 1994. They assess the relationship between BLL and the results on Wide Ranging Achievement test arithmetic, and reading scores (WRAT) and the Wechsler Intelligence Scale for Children-Third Edition, (WISC-III). A total of 4,853 children between the ages of 6 to 16 years of age were tested. The Children had a mean BLL of 1.9 µg/dL, 172 of the children had BLL greater than 10 µg/dL. The results indicated an inverse relationship between BLL and scores on the cognitive tests.

For every 1 microg/dl increase in blood lead concentration, there was a 0.7 point decrement in mean arithmetic scores, an approximately 1- point decrement in mean reading scores, a 0.1-point decrement in mean scores on a measure of nonverbal reasoning, and a 0.5-point decrement in mean scores on a measure of short-term memory” (Lanphear, Dietrich, Auinger, & Cox, 2000). An inverse relationship was also seen for BLL that were below 5.0 microg/dL and arithmetic and reading scores (Lanphear et al., 2000).

Another study done by Lanphear, Dietrich, and Berger in 2003 indicated that there is not a discernable threshold for cognitive deficits as a result of lead exposure. As a result of this finding this group of authors stresses the importance of primary prevention and reducing children's exposure from residential lead hazards.

A study by Canfield et al., (2003) of 172 children had BLL measured at 6, 12, 18, 24, 36, 48, and 60 months and had the Stanford-Binet Intelligence Scale at the age of three and five years of age. The results of this study indicated that the effect of blood lead concentration was inversely and significantly related to IQ. In the linear model an increase in 10 $\mu\text{g}/\text{dL}$ had a 4.6 decrease in IQ ($p=.0004$). This study also found that blood lead had a greater effect proportionally on I.Q at lower levels of lead concentrations. The semi parametric analysis indicates a loss of 7.4 IQ points for a lifetime average blood lead concentration of up to 10 $\mu\text{g}/\text{deciliter}$. These findings suggest that the total lead-related impairment in this cohort is due largely to the initial I.Q. loss at blood lead concentrations of 10 μg per deciliter or less and that the linear model for children with peak concentrations of less than 10 μg per deciliter overestimates the lead-associated impairment (Canfield et al., 2003, p. 1524).

Many investigators question the findings that lead exposed children have decreased intellectual and cognitive functioning related to lead poisoning. The contention is that other variables such as social class, family size, maternal education, quality care, marital relationship in home, prenatal and postnatal

stressors and iron deficiency have a negative impact on cognitive functioning (Cecil, Lenkinski, & Villegas, 2001). Cecil, Lenkinski and Villegas (2001) investigated the effects of lead on the cortical gray matter of the brain using magnetic resonance spectroscopy, (MRS) to determine if there were any neurotoxic effects on the nervous system. By monitoring the brain's neurochemicals with MRS the investigators were able to measure the number of neurochemicals in the brain. The lead exposed individual's had a normal magnetic resonance imaging (MRI) scan however; they showed significant reduction in the levels of N-acetylaspartate/creatine and phosphocreatine ratios in the frontal gray matter. Diminished levels of these neurochemicals indicate a reduced level of neuronal viability, which was found to be significantly reduced in gray matter compared to the control group that had not been exposed to lead in a unpaired t test($P=.0345$). Both subjects and control individuals came from the same socio economic backgrounds and home environments. The only major difference between the groups was the elevated lead levels. The findings of this study seem to suggest that lead exposure does have some effect on cognitive and intellectual functioning. (Cecil, Lenkinski, & Villegas, 2001).

Housing

Housing has been identified as one of the largest sources of lead in the environment. Lead based paint was used in homes prior to 1978 until it was phased out. Lead base paint is defined as " paint or other surface coating that contains lead equal to or exceeding 1.0 milligrams per square centimeter or 0.5% by weight or 5,000 parts per million by weight (Recommendations from the

Advisory Committee on Childhood Lead Poisoning Prevention, 2004, 15). As the paint deteriorates the lead is released into the home environment in the form of dust. The recommendation for the prevention of childhood lead poisoning is the control of exposure to lead-based paint hazards in housing. Lead hazard is defined as “ accessible paint, dust, soil or other sources or pathway that contain lead or lead compounds that can contribute to or cause elevated BLLs” (Recommendations from the Advisory Committee on Childhood Lead Poisoning Prevention, 15). Approximately 40% of all American housing has lead based paint and 25% contain significant lead hazards (Recommendations from the Advisory Committee on Childhood Lead Poisoning Prevention, 2004). A lead hazard screen is “a limited environmental screening activity focused on visual assessment, which may include paint, dust and soil sampling and is usually performed in housing units less likely to contain lead-based paint hazards or as a preliminary step in the lead hazard assessment process” (Recommendations from the Advisory Committee on Childhood Lead Poisoning Prevention, 2004, p.15). A lead risk assessment is “an on site investigation of a residential dwelling to discover any lead based paint hazards and descriptions of options to eliminate them, which includes lead dust and soil sampling” (Recommendations from the Advisory Committee on Childhood Lead Poisoning Prevention, p. 15).

The CDC guidelines outlines that an assessment of environmental lead hazards needs to be completed when a child has a lead level that is greater than 15 µg/dL. This includes: 1) inspection of child’s home or sites where he or she spends a more than 6 hours per week, 2) history of exposure, 3) measurement of

environmental lead levels of house dust, paint that is not intact, exposed soil, other sources as necessary (Koplan et al., 2002).

The lead dust hazard standards have been set for 40 micrograms per square foot ($\mu\text{g}/\text{ft}^2$) for floors and $250\mu\text{g}/\text{ft}^2$) for interior windows sills. The standards for soil lead hazards has been set at 400 parts per million, (ppm) in play areas of bare residential soil and 1,200 ppm for the rest of the yard (United States Environmental Protection Agency, 1999).

Interim controls are “a set of measures designed to temporarily reduce human exposure to lead based paint hazards” (Recommendations from the Advisory Committee on Childhood Lead Poisoning Prevention, 2004, p. 15). Essential maintenance practices are “approved maintenance practices and procedures designed to control deteriorating paint and/or lead dust that are undertaken regularly to ensure a home is maintained in a lead-safe condition. These practices involve dust and paint chip containment using “wet” procedures and specialized cleanup” (Recommendations from the Advisory Committee on Childhood Lead Poisoning Prevention, p. 14). Clearance examination is the “visual examination and collection of lead dust samples by an inspector or risk assessor and analysis by an accredited laboratory upon completion of an abatement project, interim control intervention, or maintenance job that disturbs lead-based paint (or paint suspected of being lead-based) above the minimums levels” (Recommendations from the Advisory Committee on Childhood Lead Poisoning Prevention, p.14).

Lead abatement is a “procedure that eliminates lead-based paint hazards or lead-based paint. The four types of abatement methods are removal, enclosure, encapsulation, and replacement” (United States Environmental Protection Agency, 1999, p. 65). The EPA requires that a certified abatement contractor be used. If lead abatement is done incorrectly it actually puts the child at greater risk for lead poisoning. Lead abatement contractors can take steps to ensure that the home is protected so that lead dust is unable to accumulate. If done correctly lead abatement should significantly reduce lead hazards in the home (United States Environmental Protection Agency, 1999).

A study done by Pirkle et al., in 1998 which looked at the blood lead measurements of the Third National Health and Nutrition Examination Survey, (NHANES III) indicated that children ages one to five who lived in homes built before 1946 had a significantly higher BLL ($p= 0.040$), this same age group who lived in homes built between 1946-1973 had a BLL that was also significant ($p=.0021$), children who lived in homes built after 1973 did not have a significant BLL ($p=0$).

In January, 1995, the New York State Department of Health, (NYSDOH) assessed lead exposure of children to lead that resulted from remodeling and renovation in 1993 and 1994. Reviewing the records of 4608 children with BLL over $20\mu\text{g}/\text{dL}$, it was identified that 320 (6.9%) children lived in 258 households that were being remodeled and renovated. BLL that were in the $20\text{-}24\ \mu\text{g}/\text{dL}$ range included 117(37%) children, the $25\text{-}29\ \mu\text{g}/\text{dL}$ range had 76 (24%) children, in the range of $30\text{-}39\ \mu\text{g}/\text{dL}$ there were 87 (27%) children, $40\text{-}59\ \mu\text{g}/\text{dL}$ included

32(10%) children 60-79 µg/dL totaled seven (2%) children (Center for Disease Control and Prevention, 1997).

Breyse et al., 2004 in a two day workshop reviewed the relationship between housing and the health of children. They found in a review of literature that:

Studies report successful reductions in dust lead levels and in blood lead levels when initially >20 µg/dL. To date, the published data on the effectiveness of specific lead hazard control treatments have been too limited to draw conclusions about the relative effectiveness of specific lead hazard control approaches (e.g., window replacement, paint stabilization) (Breyse et al., p. 1585).

Case Management

According to the CDC the guidelines case management is recommended with a confirmed venous BLL greater than or equal to 20 µg/dL or two venous BLL taken two months apart that are greater than or equal to 15-19 µg/dL (Koplan et al., 2002).

Case Management is defined as “the follow-up care of a child with an elevated blood level. Case management includes a) client identification and outreach, b) individual assessment and diagnosis, c) service planning and resource identification, d) linkage of clients to needed services, e) service implementation and coordination, f) monitoring of service delivery , g) advocacy, and h) evaluation” (Recommendations from the Advisory Committee on Childhood Lead Poisoning Prevention, 2004, p.14). Case managers are usually

public health nurses who visit the home and coordinate all the services and the implementation of the plan. Case Management includes: 1) Home visit for visual inspection of the environment for factors that might impact on the child's BLL, 2) develop a written case management plan for temporary lead hazard reduction, permanent lead reduction, temporary or permanent family relocation if necessary, education of the family, plan for follow up medical care and testing, and referrals for Women, Infant, Children, (WIC) or Head Start, 3) education of family about lead and the reduction of exposure to hazards such as dust control, nutrition, hobby or occupational exposures, 4) referrals for services for WIC, Head Start or Medicaid, 5) evaluation of the plan to ensure it is successfully implemented (Koplan et al., 2002).

The environmentalist and the case manager must ensure that the interventions are completed in order to reduce exposure by: 1) concentrating on the control of lead hazards, 2) interim measures that are prompt, 3) safe work practices adhered to for lead control so there is no further exposure, 4) minimum removal of lead paint, 5) enclose or remove lead building components, 6) clearance test following lead reduction work, 7) occupants relocated until work is completed, 8) move children permanently if necessary to a lead safe house reduce exposure (Koplan et al., 2002).

Case managers must consider the elements of exposure when a child has an elevated blood lead level, (EBLL): 1) age and condition of the house, 2) duration of the child's habitation at the present site and a history of residences in the past year, 3) if the residence has been renovated, 4) other possible locations

of exposure, 5) lead hazards in the home accessible to the child such as window wells, sills, and other painted areas, 6) soil exposure, 7) dust and dirt control, 8) relevant child behaviors such as pica and hand to mouth activity, 8) care giver exposure such as hobbies or occupation, 9) miscellaneous such as water, mini-blinds, cultural practices, and new sources of lead (Koplan et al., 2002).

A study by Zierold and Anderson (2004), of the special supplemental nutrition program for Women, Infants, and Children, (WIC) surveyed WIC enrolled children BLL from 1996 to 2000. Although the findings were not significant, the study did show that BLL declined faster with children who were receiving WIC than children with BLL who were not receiving WIC supplement. WIC children had an average mean BLL of 7.89 $\mu\text{g/dL}$ (SD= 6.10) in 1996 and in 2000 had a mean BLL of 5.29 $\mu\text{g/dL}$ (SD=4.54). WIC children had a decline of .64 $\mu\text{g/dL}$ at the 95% confidence interval, (CI) = (.36, .91) per year. Non WIC enrolled children the mean BLL in 1996 was 5.51 $\mu\text{g/dL}$ (SD=4.79) and in 2000 the mean BLL was 3.70 $\mu\text{g/dL}$ (SD= 3.39). The average BLL decline of .42 $\mu\text{g/dL}$ at the 95% CI= (.19, .64). The WIC enrolled children's BLL declined more quickly than the non-enrolled WIC children but it was not significant ($p=.25$). When the ethnicity was compared with children receiving WIC black children had a significantly quicker decline in BLL than white children did ($p=.03$). The limitation to this study was they were unable to provide ethnic/ racial distribution of children not receiving WIC.

Parent Education for Lead Hazard Control

Education interventions were taught to parents to assist caregivers in reducing the exposure of children to residential and other sources of lead hazards (Koplan et al., 2002). Case managers “provide detailed instructions on intervention techniques, actually demonstrate the techniques, and then ask caregivers to perform the technique themselves” (Koplan et al., p. 101).

Parents are educated to control the lead dust hazards by: 1) vacuuming surfaces with HEPA filter-equipped vacuum, 2) wet clean areas with a solution of water and all purpose cleaner, 3) repaint lead painted surfaces, 4) repair friction and impact surfaces, 5) cover open soil areas with grass or limit access by child, 6) keep child’s hands wiped especially before eating and sleeping, 7) wash toys frequently, 8) block off areas with lead paint so they are not accessible to children (United States Environmental Protection Agency, 1999).

A study completed by Kegler, Crozier, Malcoe, and Lorraine, (2004) found that community education, provided by a lay health advisor to the Native American population, in preventative behaviors was significant in reducing children’s mean lead level and increasing preventative behaviors. The study population was divided into two groups because the Superfund County had been exposed to events in the community such as soil remediation and lead education by the Public Health Department which would influence the study outcomes. In the Superfund County BLL decline of from 6.0 µg/dL to 4.97 µg/dL ($p=.047$) after an educational intervention. In the Non-Superfund County the mean BLL went from 4.81 µg/dL to 3.34 µg/dL ($p< .001$) (Kegler et al.).

Four behaviors were targeted by the intervention: hand washing, playing on safe surface, damp dusting, and annual blood lead test. The proportion of Native Americans living in the Superfund County who received annual blood tests went from 14% to 29%, a significant improvement ($p=.019$). Use of a damp cloth also increased in this County from 1.34 to 1.64 after the educational intervention ($p=.015$).

This study also used a comparison population of whites and found that the mean BLL was not significant in difference between Native Americans and Whites. The mean BLL was 1.47 $\mu\text{g}/\text{dL}$ among Native Americans and .81 $\mu\text{g}/\text{dL}$ among Whites with a significance level of ($p=.238$). In the non Superfund County the only behavior that was significantly different was the damp dusting with a difference of .38 for Whites and -.09 for Native Americans ($p=-.004$). The study may suggest that the use of a lay health advisor contributes to the decline of BLLs and the adoptions of some the preventative lead-related behaviors but still require much more study (Kegler et al., 2004).

Lanphear, Eberly, and Howard in 2000 looked at the long term control of lead dust on the BLL of 275 children in Rochester, New York. These children and their families were randomly placed in a control or an intervention group. The intervention group received cleaning equipment and up to 8 visits from a trained lead hazard control advisor. After 48 months the intervention group was 5.9 $\mu\text{g}/\text{dL}$ (95% CI=5.3, 6.7) and the control group 6.1 $\mu\text{g}/\text{dL}$ (95%CI= 5.5, 6.9) and was not significantly different ($p=.73$). The findings of this study do not

indicate that control of lead dust is an effective method for prevention of childhood lead exposure. The authors of this elaborate on this theme to add;

These results underscore the fact that dust control, one of the primary strategies to control lead exposure for children with low to moderate elevations in blood lead concentration, does not seem to be effective unless it is performed by professional dust control teams. Taken together, these and other data indicate that we can no longer rely on dust control, as performed by families, as a panacea to prevent sub clinical lead toxicity in children (Lanphear et al., 2000, p. 4).

The purpose of this qualitative phenomenological study is to determine the lived experience of caregivers with a child or children with lead poisoned. Parse's Theory of Human Becoming as a research methodology will advance the understanding of the lived experience of lead poisoning children and their families, and educate those responsible for the development of programs and policies that impact on childhood lead poisoning prevention. Families with severely lead poisoned children are trying to cope and follow the cleaning protocols such as wet mopping in an effort to control the lead hazards in their child's environment. A review of literature indicates that even low blood levels impact on children's IQ and that children who reside in housing older than 1978 are at risk for lead poisoning with the greatest risk in housing stock built before 1950. Education interventions that attempt to teach preventative measures to address lead hazards do not appear to be successful in lowering children's BLL. Education that provides strategies for lead hazard control are also not effective in

lowering children's BLL. In order to provide quality case management of lead poisoned children, it is important to look at caregiver's perceptions of the experience of having a lead poisoned child or children and also explore what the perceptions of the caregiver are concerning the lead hazards. The information obtained from this study will assist in the education and the development of strategies to meet the needs of families with lead poisoned children. The findings may have an impact on local authorities who make the by-laws, enforce codes and provide financial assistance to address these lead hazards.

CHAPTER III

Methodology

Design

This is a qualitative phenomenological research study using Parse's research method to describe the caregiver's experience with a lead poisoned child or children.

"Parse's methodology is generically phenomenological in that the entities for study are experiences as described by the people who have lived them" (Parse, 1995, p. 153). Participants must be able to describe through words, symbols, poetry, drawings, and metaphors the meaning of their universally lived experiences of health (Parse).

The process of the method is:

1. Synthesizing the story that captures ideas about the study of the phenomenon (caring for a child with lead poisoning) from the participant's own words dialogue (Parse, 2006). The phenomenon will be described by the participant and the interview will be audio taped (Parse, 1995).

2. Extraction-Synthesizes is capturing the essences of the phenomenon from the recording of the interview and the transcription. These essences are the core ideas that the participant described (Parse, 2006).

3. Synthesizing-extracting is the essences in the language of the researcher. These essences are the ideas that were expressed by the participants but conceptualized at a higher level of abstraction by the researcher (Parse, 2006).

4. Formulating the language art from the participant's essence. This is a statement that is conceptualized by the researcher synthesizing the core ideas from the description of the participants (Parse, 2006).

5. Extracting-synthesizing the core concepts from the language art. All core concepts are written in phrases that portray the principal meaning of the language art (Parse, 2006).

6. Synthesizing is the structure of the lived experience of taking care of a child with lead poisoning. The structure is the statement that has been conceptualized by the researcher after the synthesis of the core concepts. The structure answers the research question (Parse, 2006).

Heuristic interpretation is the answer to the research questions that provides new knowledge and understanding of the lived human experience and adds to the nursing knowledge base (Parse, 1995). Heuristic interpretation is woven in with the principles of human becoming and moves the lived experience to a higher level of abstraction. The expressions of the participants bring to life the moments of what it is like to care for a lead poisoned child. The assumptions of human becoming are considered when analyzing the data. The assumptions of the Human Becoming Theory are:

1) The human is coexisting while coconstituting rhythmical patterns with the universe, 2) The human is an open being freely choosing meaning in situation bearing responsibility for decisions, 3) The human is a living unity continuously coconstituting patterns of relating, 4) The human is transcending multidimensionally with the possibles, 5) Becoming is an open process,

experienced by the human, 6) Becoming is a rhythmically coconstituting human-universe process, 7) Becoming is the human's pattern of relating value priorities, 8) Becoming is an intersubjective process of transcending with the possibles, 9) Becoming is human evolving (Parse, 1995).

Setting

The goal of understanding the lived experience of caring for a child with lead poisoning is to study the participant in their natural setting. The study was conducted in an area that the participant had identified they would be comfortable in, feel that they could openly talk, and free from distraction. The researcher went to the participant's home or a private room in the Northern Kentucky Health Department, as well as, telephone interviews for those participants who requested this venue. The interview process was completed face to face or by telephone interview depending on the preference of the participant.

Sample

The target population of interest was caregivers who had a child or children with a BLL that was greater than 15µg/dL. This study used purposive sampling to ensure that the subjects had experience with lead hazard control and children with a BLL that was greater than 15µg/dL, and ideally had received case management. The goal was to have caregivers describe their experiences of taking care of their child with lead poisoning. The study examined participants' experiences and understanding of the complex experience of a child with lead poisoning and parents' perception of the education process for management of

this environmental disease and the perception of what parents think “lead hazards” are.

The participants were chosen as they were referred to the case manager for the Northern Kentucky Childhood Lead Poisoning Prevention Program (CLPPP) and from the lead logs at the Northern Kentucky Independent Health Department in 2004, 2005, and 2006.

The size of the sample was determined by the saturation of data. “The number of participants in a qualitative study is adequate when saturation of information is achieved in the study area. Saturation of data occurs when additional sampling provides no new information, only redundancy of previously collected data” (Burns & Grove, 2005, p. 358).

Instrument

Demographic information of the participants was collected. Demographic information was also obtained on the lead poisoned child such as age diagnosed, duration of lead poisoning and interventions to control lead hazards and the blood lead levels (see Appendix A).

Data Collection

Data collection was completed using the technique of the unstructured interviews. An interview time and place was set up at the convenience of the participant and in a location that they indicated they were most comfortable and best able to talk. The consent form was read and signed and a copy of the consent was given to the participant and included the contact information of the chair of the research study. The contact information was provided in the event

there were any questions or concerns with the interview, the researcher, or research study. The informed consent included their permission to be audio taped. The audiotape machine was placed in an inconspicuous place so that it was not distracting. The participant was asked to confirm consent on tape, knowledge that they are being taped, and that they had the right to withdrawal from the study at any time for any reason.

The interview began with some basic questions to “break the ice” such as tell me about when your child was first diagnosed with an elevated lead etc... (See Appendix A). Only a few pre-developed questions were used by the interviewer. Demographic information was collected with the participants and the lead poisoned child/ children. The interviews continued until the data saturation point was achieved (Burns & Groves, 2005).

The interview process was conducted by two interviewers. Clients that had been previously case managed by this author were interviewed by a second interviewer so that they would feel comfortable to share any information that impacted on their experience of caring for their child with lead poisoning. This strategy was used so that participants felt free to speak openly about any issues including the case management process.

Protection of Human Rights

Qualitative research is considered noninvasive and talking is considered therapeutic and as a result this study should pose no apparent physical, psychological, economical, or social risk to the participants. Participants may experience some stress reliving the experience of having a lead poisoned child,

so the interviewer should assess with the participant the emotional demeanor of the participant and provide information for follow up and support (Munhall, 1993).

Approval was obtained from the Northern Kentucky University Institutional Review Board, the Northern Kentucky Independent District Health Department Review Board and the State of Kentucky Cabinet for Health and Family Services (CHFS) Institutional Review Board (IRB).

Consent to participate in the study was obtained from each participant before the interview began (see Appendix B). Confidentiality of all tapes and records was observed and the contents of the interview both audiotapes and transcripts will be kept in a locked draw and the key in the possession of the researcher. Anonymity and confidentiality was maintained so that the participants' name or any identifying factors were not used in the study results. The participants at any time had the right to stop the interview and were informed of this right before the interview began. The participants were given a small gift when attending the interview and their name was added in for a drawing for a \$100.00 gift certificate. The outcomes of the study will be shared with any participant who is interested in receiving the results.

Data Analysis

Transcripts from the audiotapes of the interview were typed and three copies made of each. One copy was locked in a drawer. The researcher listened to the tape, making notes in the margins of the transcript of discussion that was emotional, informational, or important (Burns & Grove, 2005).

The next step was immersion in the data that will involve the reading and rereading of the transcripts and listening to the tapes as the researcher becomes immersed in the data (Burns & Grove, 2005). In Parse's methodology this is known as "Extraction-Synthesizing that captures the essences of the phenomenon from the dialogue and the researcher is able to conceptualize the experience" (Parse, 1995, p. 153).

Next the data was reduced by "placing meaning to the elements of data" (Burns & Grove, 2005, p. 548). These elements were classified by their elements (Burns & Grove). Parse defines this part of data analysis as "Extracting the essences from transcribed descriptions participants' language" (Burns & Groves, 2005, p. 557).

The researcher assigned codes which are a "symbol or abbreviation use to classify words or phrases in the data" (Burns & Grove, 2005, p. 548). It is through these codes that the researcher is defining the area of interest in the study. Initially the categories will be broad but not overlap so that the most data can be collected (Burns & Grove). This part of Parse's research methodology is "Synthesizing essences researcher's language" (Burns & Groves, 2005, p. 557). Coding was done by using highlighter pens, and numbers. After each interview the transcript was analyzed for emerging themes.

During the next phase the researcher developed propositions and sorted them into categorizes. Propositions or essences evolve from the data collected as the relationship appears between the participants' lived experiences. Parse calls this part of the process "Extracting core concepts from the formulated

proposition of all participants” (Burns & Groves, 2005, p. 557). Often to verify these predictions and propositions, participants will be asked for their input into the accuracy of the predictions (Burns & Groves).

Finally, the researcher draws and verifies conclusions about the analysis that has taken place throughout the data collection phase. Parse labels this “Synthesizing a structure of the lived experience from the extracted concepts” (Burns & Groves, 2005, p. 557). The researcher may verify the results by counting what occurs most often. The researcher should avoid noting pattern and themes without seeking real evidence that they exist. The researcher may also do this by assuming something “fits” when there is no real evidence that it is so and clustering elements without truly considering alternative ways to cluster these elements. The use of metaphors with language helps to establish likeness in themes. (Burns & Groves).

The researcher ensures that the threats to research rigor are addressed. The first standard is to ensure that the researcher’s descriptions reflect accurately and with precise vividness “the description of the site, the subjects, sites, the experience of collecting the data, and the thinking of the researcher during the process needs to be presented so clearly and accurately that it gives the reader a sense of personally experiencing the event” (Burns & Groves, 2005, p. 628).

Another strategy to ensure rigor of the study is by using methodological congruence which addresses the rigor in documentation. This looks at whether the researcher presents all the steps taken in the research study. Procedural

rigor ensures that the researcher has applied the procedures correctly and has ensured that the data is accurately recorded. The author should also engage in self reflection in an effort to reduce researcher bias by critically looking at his or her potential biases. Ethical rigor requires the researcher consider and address the ethical implications of the study and actively consider the consent and data gathering process. Auditability helps to ensure the rigor of the study by the researcher reporting all decisions with a detailed account so that a second person using the same data can come to a decision that closely resembles the researchers (Burns & Groves, 2005).

Analytical preciseness is achieved by the researcher making an effort to identify and record the decisions that resulted in the transformation of the data into the theoretical schema. This should always be cross-checked by rechecking the data against the schema. This could be accomplished by having the participants provide feedback on the researcher's conclusions (Burns & Groves, 2005).

The use of triangulation and persistent observation are two techniques that were used in this study. Triangulation refers to the "combined use of two or more theories, methods, data sources, investigators, or analysis in the study of the same phenomenon" (Burns & Grove, 2005, p. 224). To achieve triangulation a research team was used that consisted of this researcher and two faculty members with experience in qualitative research. This group met after the first, third, sixth, and twelfth interview to discuss, interpret, and analyze the data. Transcribed copies of each interview were given to all team members for their

own analysis. The team members provided appraisals of the data which were then compared for consistency in categories and emerging themes. Significant information was considered in emerging concepts and theories. Thought and feeling that resulted from the interview process were explored. The resulting concepts were generated by the research team rather than just by one researcher.

Theoretical Connectedness is ensuring that the theoretical schema developed in the study is “clearly expressed, logically consistent, and reflective of the data and compatible with the knowledge base of nursing” (Burns & Groves, 2005, p. 630).

The research must have Heuristic relevance in that the reader must be able to identify with the phenomenon in the study, its significance, applicability to nursing practice and its impact on future research activities. Intuitive recognition refers to individuals recognizing the theoretical schema that is developed from the data and the realization that “it has meaning within their personal knowledge base” (Burns & Groves, 2005, p. 630). The existing body of knowledge, especially the theoretical perspective, should be compared with the findings of the study. Any differences from the existing knowledge base and the study should be explored. The reviewer will look for strong links between the existing knowledge base and the study. Lastly, applicability should be reviewed and nurses should be able to integrate the findings of the study into nursing practice and into their knowledge base (Burns & Groves).

Application of these five standards to the study ensures the quality, usefulness of the study, and the development of evidence based nursing practice based on the outcomes of this research.

CHAPTER IV

Data Analysis

Introduction

The purpose of this study was to explore the lived experience of caring for a child with lead poisoning. Participants were asked to share their lived experience in caring for a child with an elevated lead level, greater than 15µg/dL, the work that goes into attempting to control lead in the environment, and ensure that the child's BLL decreased. Results of this study will be the foundation for interventions designed to help policy makers and entities that work with children and families address issues of lead poisoning and understand the experience from a caregiver perspective.

Participant Demographics

A total of 12 participants were interviewed. Each participant was asked to complete a questionnaire before the interview (see appendix A). Of the participants interviewed 11 were females and one was male. The average age of participants was 32.72 years with the youngest being 21 years old, the oldest 51 years of age, and one participant refusing to disclose his/her age. Each participant was asked to list the age of the child or children that had been lead poisoned in their care. Among the 12 participants there were a total of 17 children in their care with an average age of 31.625 months with the youngest being nine months and the oldest being 72 months old. All of the homes that the children lived in were 50 years old or older with the oldest home being built in the late 1700's. Of the children, 12 lived in rented homes and five lived in homes

that were owned by their caregivers. The children's average initial lead level was 23.25 µg/dL with the average treatment time being 15 months.

The Story of Lead

When participants were asked to share their story of taking care of their children with lead poisoning they most often started with the story of how they found out their child had an elevated lead level. Statements such as "It was a shock", "I kind of got really stressed about it", "I was really freaked out at first", "It was a huge shock", and "I was really upset about it" were commonly used. One participant indicated that she did not realize that lead poisoning was even an issue today.

Participant # 1: *"It horrified me that there was still a chance of a child to be lead poisoned with all modern technology. It just, it just baffled me."*

Caregivers talked about learning about what lead poisoning is, what the side effects are, and what symptoms to look for. They also spoke about their concern for their children's health and the fear that it would permanently damage them for life.

Participant # 3: *"She almost acts kinda, she acts kinda slow sometimes and I don't know if it's from the lead or she just doing it to see how much attention she can get."*

Participant # 4: *"Oh yeah, so I was thinking so great now he's going to be developmentally delayed.....he is going to start out behind because he was exposed to this lead."*

Participant # 8: *"When they (preschool) first got her they had a really hard time with her. They had a lot of problem with her interacting with the other kids and all that."*

Participant # 9: *"I got a 3 year old who will be 4 and a 5 year old that take 10mg of Ritalin twice a day and 500 mg of Depakote a night so they can go to sleep and the Depakote don't do nothing for them due to the lead exposure for the*

Attention Deficit Hyperactivity Disorder (ADHD). My daughter, were still trying to find out if it's actually seizures she had because she sleeps with her eyes open and they roll back in her head when she's asleep and it's scary, it's really scary."

Participant # 11: *"I first noticed how my son's reaction was, he wasn't talking he was always running around it circles, jumping on beds very hyperactive. My daughter couldn't sit still for even a moment of time. Just very hyper."*

Participant # 12: *"I was worried because I had read up on it and stuff and I have seen a lot of different symptoms. I was worried you know if something might happen to my children."*

Others spoke of their children's behavior and the work of trying to manage these children and the resulting stress on themselves and the stress it created in the family.

Participant # 1: *"He got a hold of a knife and he told his sister "I'll stab you". If this is part of it God help us. Since we have been out of it (apartment) his lead level is considerably lowered."*

Participant # 2: *"It was a big burden on us. When we got this place it was a blessing. Totally uproot from one city to another even though it's a bridge away it is still a hassle. My daughter has post traumatic stress syndrome because of an incident that happened here we did not want to move back. The rent we pay here we could not pass up."*

Participant # 3: *"Yes, very hard on my nerves. And it's sometimes what have I got myself into. Maybe I should have not said anything and let them put them in foster care but when I got thinking about it I felt kinda bad and I thought no these are my grand kids and until I am physically unable to not take care of them I will do what I can."*

Participant # 9: *"I have to deal with a therapist myself over the things that are going on..... I am trying to get her (mother) to go to family counseling for all of us. She's at the point that she is so tried of going to doctors and stuff over it that she's in her own depression and she is not acknowledging that she needs to seek help for her own depression over it."*

Many of the participants spoke about their children's behavior and how it made the job of parenting much harder. That these children needed a greater amount of attention and care than their other children. Participants often

indicated that it was too much work for only one parent. Other participants talked about trying to find the balance between the normal development of the child and controlling them to reduce their exposure to lead and how that created self-doubt and guilt. Other participants talked about trying to balance the needs of the family and the needs of the lead poisoned child.

Participant # 1: *"It is very difficult, very difficult for any parent; it is the hardest job you will ever have. Raising three kids is hard enough but when you have a child with special needs whether they are in a wheel chair, mentally disabled, or whatever the disability is, you need an extra parent for that child."*

Participant # 2: *"It is challenging job. You're like sometimes surprised that you get your hair combed."*

Participant # 5: *"I am always fearful and I still do not like letting him crawl on the floor. An now I have to put him on a blanket and stuff and I can't let it ruin my life but it has caused a lot of stress that's for sure.....I can hardly wait for him to walk so he will not be on his hands so much. I am having a hard time teaching him to walk because I don't want him on the floor. It is a double negative. Oh yeah! I mean cause it has been lots of times that I feel I have hindered his development because I won't let him on the floor."*

Participant # 9: *"They didn't go to sleep until 11:30. My little boy woke up at 2:00 at 3:00 my little girl woke up and they didn't go back to bed until 6:00. And then my little girl got up at 8:00 and my son didn't get up until 10:00. That's no rest for them little kids at all and they both have been going all day. There is 2 parents here and both of us are run ragged. She (mother) is sleeping right now she is pretty much out, and it's my watch now. And in the night when I get my sleep she be keeping an eye on these kids."*

Participants also talked about their guilt feelings that they had put the children in this situation and they often were not able to change their living conditions because of financial restraints and other barriers. One participant also admitted to believing the family's activities to control the lead increased the lead levels in the house because of a lack of education and understanding.

Participant # 1: *"I was stupid, me I should have known but I was in a hurry to get out of an apartment complex so we took it because it was cheap, it was close. I was pregnant and I just wanted to get out of there."*

Participant # 1: *"I thought I had done something wrong, that it was my fault, I had put him in that situation."*

Participant # 6: *"You know I borrowed the HEPA vacuum and gone around, it was real flakey around the front door trying to suck that off. I think I loosened it and tracked it in. I can't think of another way it was worse (house lead load). I cried, I couldn't believe it was worse it was all we did for 2 weeks and it was worse"*

Participant # 12: *"I felt bad and I really didn't have anywhere else to really stay with the kids except to stay in this apartment and save some money so we would have a place."*

Another common theme with participants was "Watching the children and being vigilant". Many participants indicated that in order to keep their children safe in their homes they needed to be constantly vigilant. While lead is part of the environment watching the children and washing their hands, stopping them from putting things in their mouth, and chewing on things is paramount. All of these strategies were taught to caregivers and often they talked about learning to include these strategies in their daily lives and make it routine. Severely lead poisoned children often have behavioral problems that result in safety risks that caregivers talk about watching over constantly in order to ensure their safety.

Participant: # 2: *"If he got really sick or something like that or I saw a change in like a stool or um pretty much anything. I mean I keep a real close eye on them and stuff like that..... I am right there with them I never leave their sides because he likes to chew on things."*

Participant # 4: *"Now that his lead level is down I have been a little more relaxed. But I am like, no I mean, I am always in fear that is going to go back up again. If you don't pay, you know, if I don't be careful."*

Interviewer: *"It sounds like this experience in a lot of ways has changed your life hasn't it."*

Participant # 6: *“Oh yes it has most definitely, they say God works in mysterious ways, but I am not seeing how this is a good thing. It’s slowed me down a lot as far as , made me think more about how much closer you have to be and how much more attention you have to pay with what goes on with your kids. And what you acknowledge when it really first starts out and then you find out how something as small, something as small as dust can be as toxic as it is, you see what I am saying.”*

Participant # 11: *“With lead children they don’t sleep well, very poor sleep habits. They’ll go to sleep and later they will try to get out of the house. For some reason lead children need to wander, they can’t stand to be in one place. Always have to make sure that they are in the apartment. It is hard to get sleep with them.”*

Caregivers also talked about watching children for the first sign that lead poisoning has damaged their child.

Participant # 1: *“And they didn’t tell me anything I could do to help the situation, said that to watch him, here are the symptoms, attitude and behaviors, which we saw plenty of.”*

Participant # 3: *“I want to get her tested to see, you know, might be, you know affected her brain in any kinda way.”*

Participant # 4: *“I haven’t noticed any changes in him. I mean, he does everything that, or I think, I have a lot of co-workers who have new babies, and if anything I think that he is more advanced then some of them as far as his skills and everything. I am hoping that it is a short exposure to lead.”*

Participant # 5: *“And I know comparing one kid to another is not the thing either, but it seems that he is not behind in any way we are concerned about.”*

Participant # 6: *“They are different than their sisters at their age; their sisters knew their alphabet, could count a lot higher, and were just a little bit more on the ball.”*

Expectations

Expectations of Others

When caregivers were interviewed, they talked about when they first found out about their children being lead poisoned and how they expected that the

landlord, the city, the Health Department, or the Government would protect them and do something to address the lead problem and their child's health. Others expressed their disbelief that this was still a problem. The expectation was that the health and well being of Americans was being protected and addressed by the "Government". Caregivers talk about the expectations that they had that someone was responsible to make sure that the environment is safe and there are laws to enforce this. In the beginning caregivers also indicated that they thought there would be assistance to help clean up housing, enforce landlords to take responsibility for the lead contamination.

Participant # 1 *"There should be a big red sign on the side of the building that says this building contains lead stay away from it...I think that it should be documented any place that a child has high levels it should be documented somewhere either in papers in city hall where you can find out building information that there had been a lead poisoning at this address"*.

Participant # 4: *"We love this neighborhood, we love where we live, we like our house. We don't want to move but we feel like, oh my gosh, we feel like we almost need to move. And people should not feel that way; people should not have to leave their house because of it. There should be better way or should be, you know, more, more assistance and help for people whose children has been exposed to it. Ways to help and deal with it and assistance to get rid of it."*

Participant # 5: *"A lot of people who live in these neighborhoods and these types of houses, in this situation cannot afford to go out and spend two to three thousand dollars on new windows and make sure that the lead is cleaned up in the process. You need help with it and I am sure we are not the only ones who wanted to do something about it but just really couldn't do much about it."*

Participant # 5: *"If they know it's that bad, the cost of caring for a child who is mentally retarded for life because of lead poisoning is a lot great than the cost of caring for a child who is mentally retarded for life because of lead poisoning is a lot greater than the cost if they gave us a loan or grant to clean up our house. They never think about that if, that child is on Medicaid for the rest of their life or disability they don't think about what that only what it is going to cost to clean it up. It is money wasted in my opinion."*

Participant # 11: *“There are more buildings in Covington with lead than I have seen anywhere. People need to know that they need to test your children in Covington; parents need to get their children tested. Doctors don’t take it seriously over here. They just give the parents a pamphlet. I want to get help for my children. They need a special school to help teach them; otherwise what kind of adults will they grow up to be.”*

Participant # 12: *“But I feel that it was his fault because he’s the landlord and he should have made sure that the building was up to date and that it was safe for children and adults. My main concern is for my children but you know it should have been safe for everybody.”*

Participant # 12: *“It’s just time consuming to get it all out. Maybe the landlord could look out or make a rule for kid’s sake to make sure people; they are using non-lead paint not just if you’re on section 8. A rule that they got to have their testing done or something done because it’s harming children and it’s not fair to them.”*

Expectations of Others Towards Caregivers

Caregivers did not only have expectations of others but they also talked about the expectations that were placed on them from outside sources.

Participant # 4: *“I realize now I have to clean our floors every day in order to have, in order to have him crawl on the floor; it is kind of ridiculous.”*

Participant # 5: *“I told them I said, “we are not going to move, the way we bought the house is we have to stay here for a minimal of 2 years and we are in the process of remodeling”. And they said “well you need to stop.” I said “well we have to finish some of these projects” and then they told us “okay well then lets teach you how to be careful about how you are doing it.” And it got better but it was a strain and when you have people telling you, even though its about your own family, that their responsible. I was kinda stuck there was not really a whole lot that I could do. If I had brought the house from someone else I could have gone back and talked to them about it. But what am I going to do about my mother-in-law.”*

Participant # 6: *“I am thinking that the people around here cannot afford lead abatement you just can’t. And it is aggravating that a government agency will step in and tell you that your home is not safe and not help you with it.”... “There is a huge, old , old building and while this was going on, were driving by and watching workers scrapping clearly lead paint, because they showed me what it looks like, clearly lead paint all the way down onto the street for everyone to breathe not wet down, not protected in anyway. Anyone can do that, but you*

know, businesses can do that, the city can do that, but they can't help us to do anything right."

Participant # 6: *"They have only been home for a couple of weeks and I am afraid to bring them in to get tested and they test a point higher and start the whole thing all over again and be living under a bridge....."*

Interviewer: *"What is it that concerns you the most, is the levels are still high?"*

Participant # 6: *"That they comeback and start this all up again and I would lose custody of them (children) because I brought them home or I have choice between that and being homeless."*

Caregivers are educated and expected by the Health Department and health care providers to control their children's living environment for lead hazards. This also includes managing the normal developmental behaviors that put their children at risk for lead poisoning. The common strategies that are taught to caregivers by the health department and lead clinics were shared with the interviewer. These strategies were hand hygiene, keeping hands and toys out of children's mouth, cleaning toys, cleaning the house, the cleaning protocol, and being constantly vigilant "watch the kids".

Participant # 2: *"So I try really hard to keep things out of his mouth like keys and pretty much anything outside and I try to keep all their toys clean as much as possible you know sanitized. It is a hard job but I am doing it one room at a time you know ceiling to floor."*

Participant # 4: *"I just keep the windows closed so nothing comes in that way and I love fresh air, and fresh air is good for you child and here, now I am afraid to open up my windows"*

Participant # 5 *"Remembering to wash his hands and make sure he is not putting his toys in his mouth. And I would take his toys and dump them in the sink and just like rinse 'em and clean the all like that. And teaching him not to put things in his mouth although that is all he wants to do."*

Participant # 6: *"Then I went back and tried to get all the old accumulated dust out which I am probably still working on. It is a big complicated house and you*

are talking about every book on the shelf, every shelf, every piece of furniture, every spindle, every stair, the dust is every where, and it made me crazy because it is something that you cannot see. My kids are washing their hands more time then someone with OCD (obsessive compulsive disorder) does.”

One caregiver expressed that she thought the nurse was accusing her of letting the children eat dirt. The caregiver indicated that she became very upset.

Participant # 2: *“It’s irritating because you go to the health place and they take that (paper), and ask you if you feed your son dirt which we don’t do. I hate that when they ask you that its kina embarrassing.... Yes the first time I got asked I kind of got really stressed about it. They asked me the second time and my husband came with me and he went it and went off. Said “we don’t feed our kids dirt!”....it was a little embarrassing. I just pretty much ignore it now and try to keep my house clean.”*

Another caregiver indicated that others made statements that she was not watching her children and taking care of them.

Participant # 11: *“Everybody is saying “your child this and that, and you not taking care of him” when you are taking care of him.”*

Caregivers expressed how much work it is to control the lead in the environment and maintain the cleaning protocol. Many of the participants talked about how they had to change the family lifestyle in order to accommodate all of these protocols. Many caregivers expressed the concept that lead poisoning was equated with being a “dirty person”.

Participants # 2: *“I come from a real clean freak family. Having kids and stuff I do not get to clean as much as I want, but I try.”*

Participant # 4: *“I mean I am not like a dirty person, I mean we clean our house..... And our dog is supposed to be a family dog and now I can’t even let him in the house anymore because I am afraid he is going to track in dirt and then baby is going to get it on his hands.”*

Participant # 6: *“It is a huge house from the 1800’s it is big, complicated, hardwood floors, and it is impossible to wet clean twice a week. It is just impossible. As long as the lead source is still there on the outside that we cannot afford to take care of it is impossible.”*

Expectations of Self

Caregivers also expressed expectations of themselves that they would be able to help their children, attend to the living environment, and/or provide a safe place to live for their children. Often as parents attempted to do these very things, they were faced with a system that did not support them, time and financial restraints, and other barriers. Many expressed being increasingly frustrated and angry with a system that they could not navigate and their inability to provide a safe environment for their children.

Participants # 2: *“Like I said in the next five or six years we are going to try and buy us a house. So that we don’t have to go in there and do painting of lead and all that stuff or anything else.”*

Participant # 4: *“We have to move. That was my first instinct. We have to get out of this house. I can’t, I mean, I have control over what his lead levels are going to be and if it’s elevated I got to get him out of the house.... You think gosh, this is our home you think you would be able to let your child outside and be able to be a kid outside.”*

Participant # 11: *“It has mentally changed me. I get upset and stuff but I am determined not to give up on them.”*

Yielding to Powerlessness, Caregivers Must Move On

Many families when faced with the situation of caring for a lead poisoned child attempted to address the situations in ways that would bring about a reduction in the child’s lead level and improve the environment that they lived in. What many caregivers discovered was that there were limited resources and assistance for families with lead poisoned children. The system was complex and the laws that had been developed to protect children were ignored and not enforced. Parents also discovered that in order to address lead poisoning the

process was complex, required specialized and extensive training, was very expensive with no financial resources set aside for assistance to address housing. Families were expected to address the environment that their children lived in, lower their child's lead level but were often at the mercy of landlords, city codes and by-laws, state regulations, financial restraints, time constraints, and invisible lead hazards that were difficult to control. The control of lead hazards often proved to be very challenging not only because of limited knowledge and understanding about lead hazards but also because of the fact that lead is an invisible hazard.

Participant # 1 *"We were homeless for awhile. Because the landlord said "I am not fixing anything" and I said "I am not paying the rent". No one told me about escrow and just pay the rent that way. I did not know anything about it. So we became homeless, so I stayed with my friend and now were not friends anymore. So it was a big burden."*

Participant # 5 *"I didn't know where to begin and or what to do to clean up the lead or what we needed to do. And once we did get all the information it was very overwhelming too. Because it's like, where do we go from here, what do we do, and how do we do this. And all of a sudden I am realizing that it could cost us thousands and thousands of dollars to clean it up. We felt kinda trapped even then, even when we knew what to do, even when we knew what to do it was still hard to know where to start."*

Participants # 9: *"Legal Aid and they told me they couldn't do nothing for me. Um, then they said I needed to get the code enforcement and have them come through the apartment. And when code enforcement came through they condemned my apartment. And then I had to find a place for my kids. They gave me like 30 days to find a place."*

Participant # 12: *"I went to a lawyer to see what my rights was, he said, you know about my rights and stuff, he had somebody look into it and after the landlord found out and then he wanted us to move..... Yeah he wanted to evict me but he couldn't because I didn't do nothing wrong."*

Care givers of lead poisoned children expressed frustration and powerlessness when attempting to address the environment the children lived in.

Caregivers were dependent on landlords to perform lead abatement, to improve the environment or if caregivers were the home owners coming up with the money to fix the problem. Caregivers needed to protect their children but often had very few choices about how to improve their living conditions.

Participant # 6: *“Right now we can’t get out of it (house), at this point we couldn’t live in it, we couldn’t live in it, we couldn’t rent, and we couldn’t sell it. We just can’t abandon it, money is an issue for us, we just can’t do that.”*

Participant # 9: *“I just, we lived where we could afford to, you still have to eat and things like this.”*

Participant # 9 *“I talked to the landlord and let him know what was going on he said “all these places around here have lead in them.” He said “Well find out what needs to be done” and one lady that was there told us what basically needed to be done. I told the landlord that if he got what was needed I would do the work and I would help do it, you know just to make it safe for my kids. I gave him the lists. Three months in a row and he kept saying he lost them.”*

Participant # 10: *“It’s the only option that we have right now. I don’t have the funds to actually move out. We live with my brother.”*

Some homeowners were put under order by the state to fix the lead problems, were not allowed to do the work themselves but had to contract a certified lead abatement company. Parents struggled to get the funds and to find companies that would do the work in the state of Kentucky.

Participant # 6: *“So we found and called several places for lead abatement and they all said they used to do it in Kentucky but we don’t do in Kentucky. We do it in Ohio and Indiana and wherever because Kentucky’s regulations are too much to deal with. It is too much of a headache for them.”*

Caregivers not only talked about trying to control and fix the environment that their children lived in but how complex lead contamination was and how difficult it was to know where the sources were. They often talked about how lead was an “invisible” or a “hidden danger”. Caregivers talked about not having

the information they needed to protect their children from lead even if they wanted to.

Participant # 11: *"I didn't know about the dust, I knew about the paint chips but not the dust."*

Participant # 4: *"I figured that as long as he is not putting anything in his mouth like any paint chips that he be fine."..... "And I didn't realize that dust was such a huge part and soil levels was such a huge factor. And with our dog, tracks in all kinds of dirt."*

Participant # 5: *"I felt like we were living in poison and I felt like everywhere I went and every time I thought that something was safe I would find out that had lead in it too."*

Participants # 6: *"It makes you insane. You know the things that I have cleaned since all of this. I have dusted all the furniture, the knick knacks, you know dust is dust, dust appears. And now I don't see dust as dust anymore. I think it that toxic? It will make you insane. There is not a way you can keep all the dust off of everything."*

Five of the participants were homeowners and seven of the participants rented. Of all the participants who rented their homes only one was able to successfully have the home lead abatement for her children. This apartment was part of a program that was subsidized by a federal program and therefore had to address the lead hazards. Even with this, the participant indicated that she had to follow up to have the hazards addressed.

Participant # 7: *Then they (Health Department) talked to my landlord and her supervisor, and they are just now doing my balcony where I had the lead. I had to keep on calling to see when they were coming to do it and it took them more than a year to come."*

The other participants who rented did try to have the landlord address the lead hazards but eventually were unsuccessful or had to move to protect their children's health.

Interviewer: *“How long after he was lead poisoned did you move out of the house?”*

Participant # 1: *“When it was elevated up to the highest point it was probably two months when we moved....My landlord when we told him about it he said “What you expect me to do about it?”*

Participant # 2: *“The house that we lived before this one that paint was really bad also and the landlord did not want to do anything with the house so we had to move here, come here and just basically taking a day at a time.”*

Participant # 9: *“Well I had to move into a place that was 2 bedrooms, really small, we lost over half or less than one quarter of the stuff we had....due to the much smaller space we ended up in. We couldn’t bring everything we had, we lost a lot.”*

Participant # 10: *“Yeah, she (landlord) you know pretty much said she didn’t have money to help that right now and nothings been done.*

Participant # 11: *“I wanted to get out but I had just paid my rent with him promising to put us in a place and he didn’t. So we had to start all over again.”*

Participant # 12: *“No he told me that he would, he said to let him know what’s going on, and I did every time I talked to the Health Department. I told him, I would call him and say this is what is going on, when you find out something let me know. When it came time for the report everything was sent to him I didn’t hear nothing. Then he was like he wouldn’t put us in a place to stay while he was getting stuff done or then because there was mold there at the same time he didn’t want to do anything for us. Still today he has never done nothing for us for that.....I just moved because I didn’t want my kids in that kind of environment anyway.”*

Homeowners were not anymore successful then renters at being able to properly address lead hazards in the environment. Many blocked off parts of their house, only allowed children to live in certain areas of the house, or abandoned the house entirely. One homeowner even applied for an emergency homeowner’s loan from the city and the only response that the caregivers got was asking for the information all over again from city officials.

Participant # 4: *“I thought there is no way it could be that high. We don’t have lead and paint chips everywhere. So then, yeah pretty much, like upstairs, I don’t*

let the dog upstairs, so pretty much I felt like we are going to have to be upstairs for the rest of our lives and not come downstairs.”

Participant # 5: “When we remodeled the kitchen instead of tearing out like the plaster and re-insulating and everything else we wanted to do we covered everything up with new dry wall so now they said all the lead is gone, it’s behind the walls.....I know the parts of the house not to let her play that we haven’t been able to get to yet.”

Participant # 6: “So we moved the whole family into this little house, it was a 1bedroom house and there was 7 of us and we lived there for a year and a half trying to figure out what to do. Trying to get their lead levels down and got them down pretty low and eventually we were able to come up with enough money to encapsulate the outside paint on the window sills and the doorways.....There was a city loan program but the city made it impossible to get the loan and by the time, they just made it so hard.”

CHAPTER V

Discussions and Implications

Introduction

The findings of this study are built on the structure on Parse's Theory of Human Becoming. The lived experience of caring for a child with lead poisoning is the story of poverty, worry, disillusionment and frustration and of powerlessness. It is the story dealing with the expectations of others, of the caregiver, and expectations of self. It is conceptually integrated with the lived experience of caring for a child with lead poisoning. In yielding to the powerlessness, caregivers must move on. The concepts as described by all participants exist all at once as the lived experience of caring for a lead poisoned child. The concepts of the story of lead, the expectations of others, expectations of others towards the caregiver, and expectations of self coexist all at once in the lived experience and can be considered part of the same rhythm. The participant's discussions linked these two concepts together as they learned to be caregivers by anticipating and living with the expectations placed on them by others, their own expectations, and their expectations toward others. The third concept yielding to the powerlessness, caregivers must move on, coexists with the other concepts but this is the concept where the caregiver is creating a different way of becoming in transforming.

The Story of Lead

"Structuring meaning multidimensional is co creating reality through the languaging of valuing and imaging (Parse, 1995 p. 6). This is the story of lead

and learning to be a caregiver of a lead poisoned child. Caregivers when asked to tell their story most often started talking about when and how they found out their child was lead poisoned and what they initially thought that it meant for that child and them as a parent. As they participated with the lead case manager and were educated about lead poisoning their perceptions of their role as caregiver changed. Many talked about learning to control lead hazards, the environment, and also the new concerns for the health and well being of their children. Many before being educated about the effects of lead were unaware of the symptoms and long term problems. Caregivers shared their role of being vigilant and “watching the children to protect them” in a leaded environment. Caregiver’s worries and concerns were not just limited to their lead poisoned children but for themselves and the burden that it placed on them and their families. The participants not only reflected on how the lead poisoning was impacting on their families now talked about the worry they had for the future of their children. Many parents anticipated and watched for the symptoms that their children that had been the victims of permanent damage from lead poisoning. Many caregivers shared how they worried that their children would not have a future in which they could support themselves because they would be learning disabled. This concept can be related back to Parse’s assumptions that humans are open beings and they are trying to find meaning in the situation that they are in and bearing responsibility for the decisions that they make (Parse, 1995). This can also be related to Parse’s principle of Human Becoming Theory were caregivers through “pre-reflective-reflective knowing of imaging co create meaning and

changes the meaning of being a caregiver for that particular child who now is lead poisoned. This shows the evolution of the caregiver through the experiences of having a lead poisoned child.

Expectations

“Cocreating rhythmical patterns of relating is living the paradoxical unity of revealing-concealing and enabling-limiting while connecting-separating” (Parse, 1995 p. 7). Caregivers when interviewed expressed that they initially thought that there would be assistance from outside sources such as the Government, the Health Department, or city offices. Participants also expressed surprise that lead poisoning was an issue and thought that the well being of Americans was controlled through laws that would address the safety of housing, control landlords, and eliminate environmental hazards. Participants related how they attempted to get landlords and city officials to help them address the environmental living conditions of their children and to reduce their child’s blood lead level. Caregivers shared how they were enabled and limited at the same time by the barriers as they try to address their children’s illness. The biggest obstacle was getting landlords to address their housing. Caregivers also expressed that the expectations placed on them by others was difficult to achieve and often unrealistic. Caregivers told of how much work the lead cleaning protocol was and how the hazards were difficult to control. They shared their frustration of trying to control a hazard that was invisible. Participants talked of wanting to provide a safe environment for their children but were unable to manipulate the system so that they could do this. Many were restricted by

financial constraints and were unable to move or fix the lead hazards. Lead hazards were also identified as being invisible, hard to deal with, burdensome, both from time and financial barriers. The misconceptions surrounding lead hazards also made it difficult for parents to protect their children and yet they expressed that there were expectations from others that they should be able to successfully control all of these factors to lower their children blood lead level.

Caregivers lived in a rhythm of patterns of relating with outside others and their children. They were enabled and limited simultaneously by all the choices, opportunities, and limitations open to them. Caregivers were connecting and separating with the system to address their children's lead poisoning.

Yielding to Powerlessness, Caregivers Must Move On

“Cotranscending with the possibles is powering unique ways of originating in the process of transforming” (Parse, 1995 p. 7). After attempting to navigate the system set up for addressing lead poisoned children most of the caregivers abandoned it and took matters into their own hands; they moved on, many literally. In fact many caregivers were afraid to have children tested again in case it put them back into the system that was difficult to navigate with unrealistic expectations. Caregivers forged new paths either by moving out of their homes, blocking off portions of their homes and even becoming homeless in order to protect their children from a lead environment. They found ways to keep their children safe, for the most part without assistance from the system that was set up to address childhood lead poisoning. Caregivers demonstrated forging ahead-holding back, living with conformity by addressing their children's lead

poisoning but nonconformity by going around the system to protect their children. As this participants shared “We were homeless for awhile because the landlord said I am not fixing anything and I said I am not paying the rent.” Another participant stated “I don’t want to take away from the health issue. Just because we were put out, no one told us we had to get out of our house but we saw it as the only way. Their levels had to go down. What else can you do?” Certainty-uncertainty in moving to new housing or being homeless.

Implications for Research and Practice

Practice

The findings of this study have impact on the practice of health care professionals and agencies who work with caregivers of children with lead poisoning. Presently the system that supports these caregivers in Northern Kentucky is unable to truly address the housing that children live in and motivate landlords to rehabilitate housing so it is safe. It is a system that still puts the onus on parents to address the environment and control their children’s lead level when it is really lead contaminated and dilapidated housing that parents say needs to be addressed. Parents have indicated that they have been accused of not watching their children and not addressing behaviors such as pica. Bellinger & Bellinger (2006) explore the tendency for institutions such as real estate boards, banking systems and paint industry to place the blame of parents instead of housing.

Perhaps as a result of the historical emphasis in clinical medicine on the individual patient and host risk factors rather than on the broader social,

political, and economic contexts within which illness occurs, the responsibility for lead poisoning was placed on the victim and his or her family rather than on the dilapidated housing that caused it or on the institutions, policies, and regulations that permitted such lead hazards to exist. Parents, primarily mothers, received much of the blame. They were accused of providing inadequate supervision and nurturance, fostering pathological behaviors such as pica that caused children to ingest lead paint (Bellinger & Bellinger, 2006, ¶ 14).

The present system puts the emphasis on secondary screening and management of lead poisoned children. The difficulty with this philosophy is that the effects of lead are irreversible so the neurological damaging effects of lead have already occurred. The use of this method is essentially using children to identify lead hazards or to be “lead detectors”. Emphasis in this area needs to focus on not secondary prevention activities but primary activities such as addressing housing before it exposes children to lead hazards. The symptoms of lead poisoning are being treated instead of the root cause.

The findings of this study also support that resources be allocated to helping families address lead hazards through cleaning by professionals and the maintenance of /or abatement of lead hazards. Families are unable to adequately and safely manage this task on their own and it is putting both a financial and time burden on them not to mention a continuing health risk to children.

There are institutions, policies, and regulations that have been developed to address lead hazards in housing. At present these institutions, polices and

regulations are not being used properly or being enforced so that lead hazards continue to exist. Agencies are not working together for the common goal of reducing lead hazards in the environment. A commitment is needed by these entities to work together so that the enforcement and allocation of resources can be used to adequately reduce lead hazards. Until the laws are properly enforced in housing safety dilapidated housing and landlord behavior will continue to be an issue and children will continue to be lead poisoned.

This author believes that advocates should be retained to support and speak on behalf of these lead poisoned families as they are often the most economically and politically disadvantaged members of society. At present there are many laws and regulations that address lead hazards but time and time again families gave voice to the blatant disregard for these laws and the wellbeing of their children.

Research

Further research needs to be done to determine what the perceptions of lead hazards are by caregivers. Many of the participants spoke of not clearly understanding how lead was transmitted and what the sources of lead actually were. This is a concern to case managers who are working with families and are trying to help families control lead hazards to reduce exposure of lead to their children.

Secondly, families often leave high lead environments and move into housing that puts their children at the same level of risk. Research on how to effectively educate caregivers on recognition of lead hazards needs to be done.

Summary

The American Nurses' Association and Healthy People 2010 (American Nurses Association, 1994; Healthy People 2010, 2000) call for the elimination of health disparities among vulnerable segments of the nation's population including families and the control of lead through primary lead reduction activities and screening. This study listened to the participants' voice their feelings and experiences of having a lead poisoned child. It is the intent of this study to provide health care professionals and agencies working with lead poisoned children and their caregiver's insight into the lived experience of taking care of a lead poisoned child. Using these insights could give health care professionals the opportunity to tailor their practice to better meet the needs of caregivers and lead poisoned children. It may also provide the opportunity to shape future policy development in the area of lead hazard reduction and treatment of lead poisoned children. Finally, more research is needed to explore the relationships presented here and help to eliminate assault to children's health from the environmental hazard of lead.

Appendix A

Instrument

Ice Breaker Questions

1. How old was your child when he/she was diagnosed with lead poisoning?
2. What was your child's lead level?

Demographic:

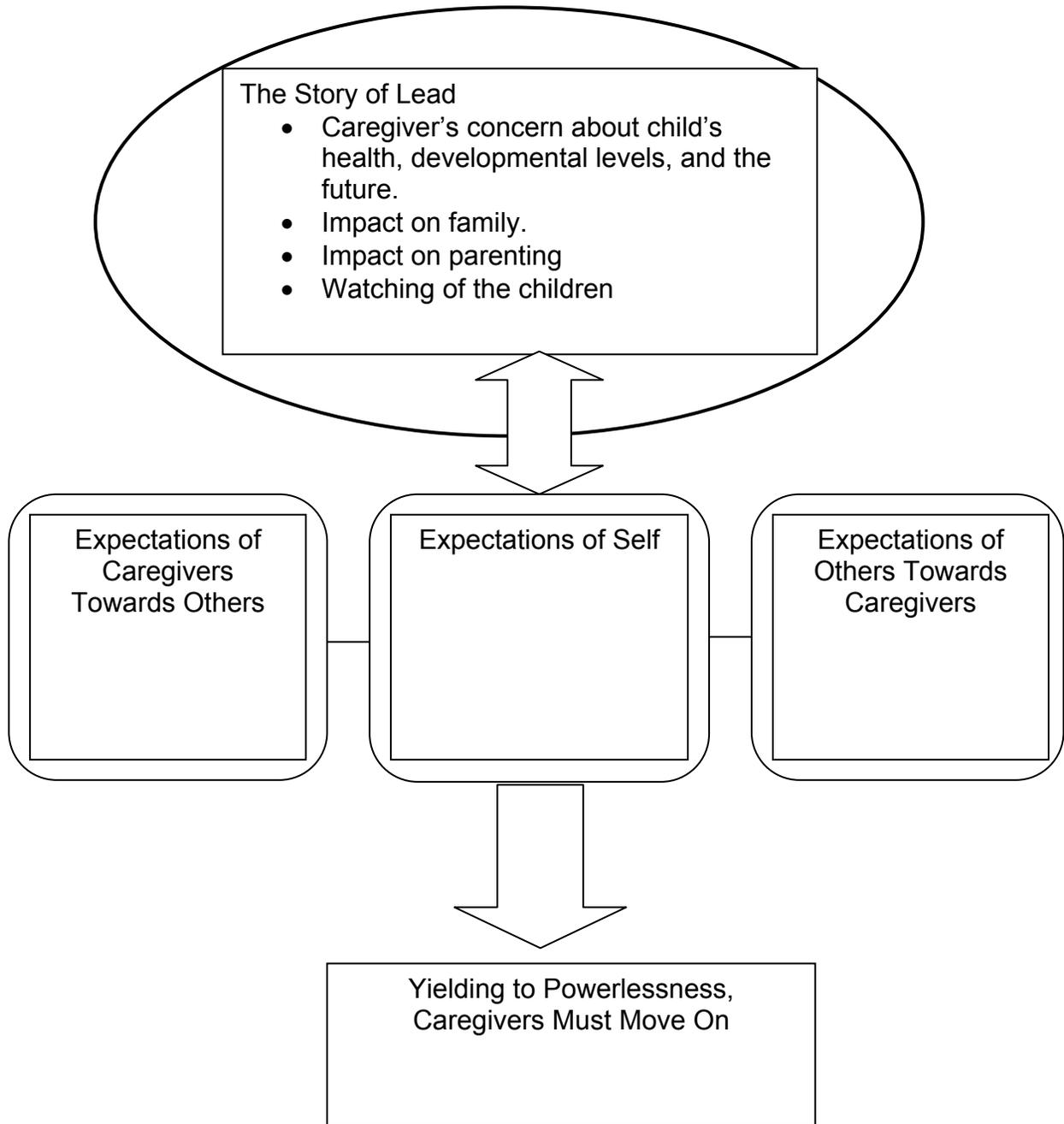
Participant:

1. age
2. gender
3. age of home
4. rent/own
5. number of people in family
6. number of adults

Lead poisoned child/children

1. age at diagnosis
2. lead level
3. duration of treatment
4. gender

Appendix B
The Lived Experience of Caring for a Child with Lead Poisoning



Appendix C

From: Lisa Davis-Roberts

Sent: Wednesday, October 18, 2006 8:58 AM

To: Ann Keller

Subject: Kim Dinsey Read IRB

IRB06-080

This email serves as confirmation of IRB approval of Kim Dinsey-Read's protocol for the project entitled "The Lived Experience of Caring for a Child with Lead Poisoning" for the period of March 2, 2006 to October 31, 2006.

Lisa Davis Roberts

Grants Administrator

Research, Grants & Contracts

AC 616

859-572-5137

davisroberts@nku.edu

Appendix D



**NORTHERN KENTUCKY
INDEPENDENT DISTRICT
HEALTH DEPARTMENT**

Linking People and Resources
for a Healthy Community

April 7, 2006

Kim Dinsey-Reed, RN, BSN
Northern Kentucky University
Masters Degree of Nursing Program
Highland Heights, KY 41076

Dear Ms. Dinsey-Reed:

We have reviewed your research proposal regarding children with lead poisoning. Even though you are no longer employed by the Northern Kentucky Independent District Health Department we feel our relationship with you and the information to be gained from this project is beneficial. We approve this research being done on our health department clients and will use the data collected in future planning.

Please contact me with the details of this project. We look forward to working with you.

Sincerely,

Gary E. Crum, PhD
District Director of Health

Jennifer Hunter, RN, BSN
Interim Assistant Director of Clinical Services

C: Dr. Ann Keller
file

one Health Center
35 Burlington Pike
rence, Ky 41042
859.363.2060 Fax: 859.647.3594
859.363.2061 Fax: 859.647.3850
859.363.2070 Fax: 859.578.3689

Campbell Health Center
12 East 5th Street
Newport, Ky 41071
859.431.1704
Fax: 859.655.6386

Health Education & Planning
2388 Grandview Ave
Covington, Ky 41017
859.578.7660
Fax: 859.578.7665

Grant Health Center
234 Barnes Road
Williamstown, Ky 41097
859.824.5074
Fax: 859.824.3220

Kenton Health Center
634 Scott Street
Covington, Ky 41011
859.431.3345
Fax: 859.655.6374

Administrative & Environmental Center
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Edgewood, Ky 41017
859.341.4264 Enviro 859.341.4151
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10 Medical Village Drive

Edgewood, Kentucky 41017

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www.nkyhealth.or

Appendix E



ERNIE FLETCHER
GOVERNOR

CABINET FOR HEALTH AND FAMILY SERVICES
OFFICE OF THE OMBUDSMAN
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WWW.KENTUCKY.GOV

MARK D. BIRDWHISTELL
SECRETARY
EXECUTIVE DIRECTOR

June 21, 2006

CHFS-IRB-DPH-FY06-84

Kim Dinsey-Read, RN, BSN
6899 Glen Arbor Drive
Florence, Kentucky 41042

Dear Ms. Dinsey-Read:

Your request for renewal of the approval of your research project titled "The Lived Experience of Caring for a Child with Lead Poisoning" was approved by the Cabinet for Health and Family Services Institutional Review Board (CHFS IRB) through the expedited review process on June 21, 2006.

In addition to all other requirements of 45 CFR 46.101-46.409, it is the responsibility of the researcher to:

- (1) obtain approval by the CHFS-IRB for any modification in the research protocol or design that may increase the level of risk to a subject or a subject's confidentiality prior to implementation;
- (2) advise the CHFS-IRB of any unanticipated problem involving a risk to a subject or another individual as a result the research activity as soon as possible;
- (3) submit to the CHFS-IRB an electronic copy of the final research findings and conclusions; and
- (4) obtain approval from the CHFS IRB prior to publication or public presentation of the findings and results of the study in order to assure human subjects protection and compliance with HIPAA regulations and confidentiality standards.

If you have any questions about any of the above, or need additional information, please contact me at (502) 564-7243 x3562 or Bob Blackburn, CHFS IRB Administrator, at (502) 564-5497 x4102.

Respectfully,

Douglas Thoroughman, PhD, MS
Department for Public Health
Co-Chair, CHFS Institutional Review Board

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Appendix F



NORTHERN KENTUCKY UNIVERSITY
RESEARCH
FOUNDATION

NORTHERN KENTUCKY UNIVERSITY RESEARCH FOUNDATION

Lucas Administrative Center 616 | tel 859.572.5136 | fax 859.572.6188 | rgc.nku.edu

November 22, 2005

Kim Dinsey-Read
6899 Glen Arbor Drive
Florence, KY 41042

Dear Kim Dinsey-Read,

Congratulations; Northern Kentucky University Research Foundation is pleased to award you a Graduate Student Research Grant (GSRG) in the amount of \$720 to complete your project entitled "The Lived Experience of Caring for a Child with Lead Poisoning". Your proposal was selected by the GSRG committee from the many proposals submitted from across campus.

Please contact Mark Santanello in the Office of Research, Grants & Contracts at (859) 572-5166 by December 9, 2005 to accept this award and set up a post award meeting. During this meeting you will learn how the funds will be administered and also be given feedback about your proposal. While you were successfully awarded a grant, you can use this feedback to improve your grant writing skills for future proposals.

Again, congratulations and I look forward to seeing a presentation of your results at the Celebration of Student Research and Creativity.

Sincerely,

Mary Ucci
Executive Director

cc: Dr. Ann Keller, Nursing and Health Professions
Dr. Margaret Anderson, School of Nursing and Health Professions

Appendix G

October 30, 2006

To the parents of _____,

I am a graduate nursing student at the Northern Kentucky University doing research on children with lead poisoning. I am also working with the Northern Kentucky Health Department on this project. After a great deal of study I found that there had been very little research done on what it is like to take care of a child with lead poisoning. This information is very helpful to others who help families with lead poisoning and make decisions about programs and other services to tackle this health problem.

In order to learn how families live with this I need to talk with parents who have had experience with a lead poisoned child or children. This would be a meeting that would take about one hour. This meeting can be anywhere that you feel at ease to talk in including your own home. Everything you tell me will be confidential and your name will not be used. A small gift of thanks for your time would be given to you after the interview and your name entered in a drawing for a \$ 100.00 gift certificate.

If you would be interested in talking to me about this or have any questions about this study please call 859-801-2269. Leave a phone number where you can be reached.

Sincerely,

Kim Dinsey-Read RN, BSN

Appendix H

Informed Consent for the Lived Experience of Caregivers with Lead Poisoned Children

Researcher: Kim Dinsey-Read RN, BSN,
Northern Kentucky University
Albright Health Center Room 236
Nunn Drive, Highland Heights
859-801-2269

Thank you for agreeing to participate in this study which will take place

(Date)

This form outlines the purposes of the study and provides a description of your involvement and rights as a participant.

The purposes of this project are:

1. To fulfill a course requirement for Nursing Research Methods II in Master's in Nursing, taught by Doctor Denise Robinson at the University of Northern Kentucky.
2. Families with lead poisoned children are trying to cope with the lead hazards and follow the cleaning protocols such as wet mopping in an effort to control the lead hazards in their child's environment. Education and support is provided through case management. In order to provide care of lead poisoned children it is important to try to understand the parent's experience of having a lead poisoned child or children.
3. It also helps to understand caregiver's perceptions of lead hazards so that education can be improved to meet the needs of families with lead poisoning.

Participant Selection:

You were chosen for this study because of the experience you have with a lead poisoned child and controlling the lead hazards in your home. Your experience will contribute to our understanding of lead poisoning and managing lead hazards in the home.

Voluntary Participation:

Your participation in this research study is strictly voluntary. You choose whether you wish to participate or not. If you choose not to participate all the services you receive from the case manager at the Health Department will continue. You are encouraged to ask any questions at any time about the nature of the study and the methods that I am using. Your suggestions and concerns are important to

me; please contact me at any time or the chair of the research study Dr. Ann Keller at 859-572-5248 or or the Cabinet for Health and Family Services IRB at 502-564-5497 x4102.

The methods to be used to collect information for this study are explained below. From this information, I will write the research study:

I will ask you to explain your experience with caring for a lead poisoned child so that I can better understand what it is like to have a lead poisoned child. We will pick a location that you are comfortable with and feel that you can talk openly about your experience. I will audiotape the interview and will try to place the tape recorder in a place that will be the least distracting. If you do not wish to answer a question you may say so and the interviewer will move onto the next question. No one else will be present unless you want someone with you. The information recorded is confidential and no one will have access to it except me, and the faculty assisting me in this research study. Your name or the names of others will not be used in the information. Everything you say will be typed into a transcript and I will try to look for similarities between your experiences with lead poisoning and other families with lead poisoning. I will use the information from this study to write the research study. This study will be read by the course instructor, and reviewed by different faculty members to ensure its accuracy. It will be published on the internet and placed on the shelf of the Northern Kentucky University Steely Library.

You are encouraged to ask any questions at any time about the nature of the study and the methods that I am using. Your suggestions and concerns are important to me; please contact me at any time or the chair of the research study Dr. Ann Keller at 859-572-5248.

Risks and Discomforts:

There is the risk that you may share some personal or confidential information that may make you feel uncomfortable. If you do not wish to share this type of information you do not have to answer questions or participate in the interview if you feel the questions are too personal or make you feel uncomfortable.

If at any time you feel you need support from any discomfort felt during your participation in the study you can contact Dr. Ann Keller at 859-572-5248.

Benefits:

There will no direct benefits to you but your participation will add to the knowledge that healthcare providers have and will assist in the treatment of lead poisoned children and help increase the education of their families.

Confidentiality:

I will be sharing your information only with of the research team of approximately three faculty members. All information that is collected will be kept private and locked in a draw with a lock and key. All information will have a number code on it. No names will be connected to the experiences you share. Only I will know what your number and name is.

Sharing Results:

If you wish you may have the results from the study and you can receive a summary of the study before it is published. The results will be published so that other healthcare providers can learn from this research study.

Right to Refuse or Withdrawal:

You do not have to take part in the research study if you do not wish to and can stop at any time you wish. All collected information and tapes will be returned to you.

Who to Contact:

If at any time you feel you have a question you can ask me. If you feel you have a question that you want someone else to answer you can contact Dr. Ann Keller at 859-572-5248 at the University of Northern Kentucky.

Certificate of Consent:

I have been invited to participate in the research study titled The Lived Experience of caring for a Child with Lead Poisoning. I understand that I will participate in an interview with the researcher. The researcher has informed me that the risks are minimal and I have been given the name, address and phone number of a researcher that I can contact. I am aware that there will be no benefits to me personally.

“I have read the foregoing information, or it has been read to me. I have had the opportunity to ask questions about it and any questions I have been asked have been answered to my satisfaction. I consent voluntarily to be a participant in this study and understand that I have the right to withdrawal for the interview at any time without in anyway affecting my medical care or my child’s medical care” (World Health Organization Research Ethics Review Committee, 2005, 4).

Do you grant permission to be quoted directly without being named?

Yes _____ No _____

Do you grant permission to be audio taped?

Yes _____ No _____

Do you wish a summary of the results? Address _____

Yes _____ No _____ _____

Print name of participant _____

Signature of participant _____ Date _____

I have accurately read or witnessed the accurate reading of the consent form to the potential participant, and the individual has had the opportunity to ask questions. I confirm that the individual has given consent freely (World Health Organization Research Ethics Review Committee, 2005, 4)

Print name of researcher _____

Signature of researcher _____

Date _____

A copy of this Informed Consent Form has been provided to the participant _____ (initialed by the researcher)

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Kim Dinsey-Read RN, BSN

Work Experience

Northern Kentucky Northern University School of Nursing and Health Profession

- 2005-to present Adjunct Professor of Nursing and Graduate Assistant

Northern Kentucky Independent District Health Department

- 2005-to April 2006 Lead Case Manager for Northern Kentucky

St Elizabeth Medical Center, Edgewood, Kentucky

- 2005-to present Registered Nurse-Business Health
- 2003-to present Registered Nurse-Acute Medical/Surgical Unit

Brockville Psychiatric Hospital Brockville, Ontario, Canada

- 1992-1994 Registered Nurse – Nursing Pool
- Dual Diagnosis- Registered Nurse
- 1988-1989 Rehabilitation / Community Unit- Registered Nurse

Kingston Psychiatric Hospital Kingston, Ontario, Canada

- 1986-1988 Acute Admission Ward- Registered Nurse

Volunteer Positions

- 2005-Rho Theta Nursing Honor Society Chapter of Sigma Theta Tau International Counselor
- 2003- Present Trustee on the Board of Trustee of Healthpoint Family Care in Northern Kentucky
- 2000-2001 President of the YMCA Belleville, Ontario, Canada.
- 1998-2000 Vice –President of the Belleville YMCA, Ontario, Canada.

Education

- 2006 Northern Kentucky University, Highland Heights, Kentucky
Enrolled in MSN-Masters in Nursing Education GPA 3.97
- 2004 Northern Kentucky University, Highland Heights, Kentucky
BSN- Summa Cum Laude GPA 3.94
- 2002 Loyalist College Belleville, Ontario, Canada
Health assessment, medication, 150 hour acute, medical, community clinical practice update- GPA 4.0
- 1988 Ottawa University Ottawa, Ontario, Canada
Healthy Aging Certificate
- 1986 St. Lawrence College, Brockville, Ontario, Canada
Health Science Diploma

Activities

- 2006 Northern Kentucky Nursing Research Collaborative
- 2006 Northern Kentucky Celebration of Student Research and Creativity
- 2005 Northern Kentucky Celebration of Student Research and Creativity

Awards

- Scripps Howard Center for Civic Engagement and Nonprofit Development Grant for Nursing Research Collaborative April 2006
- Graduate Student Research Grant Northern Kentucky University 2005
- Who's who among Students in American Universities & Colleges 2005
- Leadership in Excellence Award 2004, Northern Kentucky University 2004
- Sigma Theta Tau Nursing Honor Society 2004
- Who's who among Students in American Universities & Colleges 2003-2004
- Deans Scholar List 2003, 2004