PERCEPTIONS OF HEALTH CARE FOR CHILDREN FROM CAREGIVERS IN
PERCEIVED POVERTY

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ABSTRACT

The purpose of this research study was to look into the perceptions of caregivers in Perceived Poverty, as they related to their children’s health care needs and familiarity with child life services. Parents expressed their perceptions through a self-report survey instrument and qualitative analyses were run. The results illustrated that a majority of caregivers met financial criteria for poverty, but only a limited number identified themselves as in poverty. A majority of respondents also claimed that their children’s healthcare needs were met, yet many responses yielded conflicting descriptions of what needs being met looked like. Altogether, respondents lacked knowledge of child life, and only a limited number of respondents expressed ever experiencing child life services. From these results, the researchers believe that additional factors play a role in the understanding and perception of poverty and healthcare needs for children and families. This research also began to illustrate the void in services provided to this population, illuminating an area of growth and expansion for child life. It is the hope of the researchers that this introductory study will initiate further research with this population and in the field of child life.
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CHAPTER I
INTRODUCTION

According to the United States Census Bureau (2015), in 2014 there were 46.7 million people living in poverty, which accounts for 14.1% of the total population. (Poverty – 2014 Highlights, 2015). Of these individuals living in poverty, 33% were children under the age of eighteen. While the poverty estimates found in this report were based entirely off of cash income prior to taxation, and did not include any noncash benefits, or other forms of supplemental assistance, these figures appear to portray a staggering number of individuals in the United States living below their means (DeNavas-Walt & Proctor, 2015).

In addition to the idea that 46.7 million people in the United States are living below the poverty threshold, these individuals are not only marginalized financially, but that this vulnerable population also appears to experience a lack of many other needs and services. Of particular concern are unmet healthcare needs, which refers to how often identified health related problems or concerns go unanswered or neglected (Newacheck, Hughes, Hung, Wong, & Stoddard, 2000). Such needs can include: dental care, prescription fulfillment, urgent care visits, physician check-ups, and a variety of other common medical services (DeVoe, Wallace, Selph, Westfall, & Crocker, 2011). These unmet healthcare needs are especially problematic for children, because of their potential
for long term consequences, such as the development of chronic health conditions later in life (Newacheck, et al., 2000).

Past research studies have looked to evaluate some of the barriers to care for children in poverty. DeVoe et al. (2011) examined the difference in insurance types and children’s health care needs. They found that those with public health care coverage felt they had limited access to providers, but that uninsured children faced the highest likelihood of having unmet needs. Other studies have evaluated parent perceptions of their children’s health care needs and areas of concern. Several studies found that although medical needs were met or addressed with their healthcare providers, information about their child’s development or psychosocial concerns were often unmet (Hickson, Altemeier, & O’Connor, 1983; McCunes, Richardson, & Powell, 1984). These studies highlighted that parents’ desired to understand and provide for their children’s psychosocial development while at the same time not having access to services that provided such information.

This is of particular interest for the growing field of Child Life, because a child life specialist is a member of the health care team that supports children and families through education, preparation, coping, and activities that support healthy psychosocial development. Child life specialists are primarily found in pediatric health care settings, with less of a presence in community clinics or other community agencies that serve underprivileged or impoverished communities.

The aim of this study was to fill the void left from limited research available in the field of Child Life about children in poverty and their healthcare needs. The purpose of this study was to evaluate parent perceptions of their children’s health care needs based on their past health care experiences, and the desired services they want for their
children. Further, the aim of the current study was to identify if parents in perceived poverty view their needs and concerns as being met, and how various professionals and agencies can meet these needs if they are not being met. While past research focused on parent perceptions strictly as they relate to the hospital or clinic settings, this study attempted to build upon this knowledge by expanding out to public and engaging them in community settings.

By capturing opinions from parents about their children’s needs, this study hoped to act as a cornerstone of knowledge for individuals and organizations that serve individuals in poverty. Also, this study hoped to understand the perceived needs of parents in poverty, while at the same time exploring how child life interventions could be facilitated to address the health care needs of children in poverty in order to better serve this population.
CHAPTER II
LITERATURE REVIEW

What is poverty?

In the United States, there are a variety of measures, that determine if an individual is considered to be in poverty. The first measure is that the Poverty Threshold. The Poverty Threshold is a statistical figure updated yearly by the Census Bureau, which uses income thresholds, according to family size and composition, to determine if a family is living in poverty; if a family’s total income falls below this established threshold, then all the members of this family unit are considered living in poverty (U.S. Department of Health and Human Services, 2014). For example, in 2014, a family of four, with two children under the age of 18 years-old would have a poverty threshold of $24,008, while a family of two, having one child under the age of 18 years-old would have a poverty threshold of $16,317. The poverty threshold is utilized as a determinant of poverty status, and as an aggregate measure of poverty for the population each year, but it has many shortcomings for determining a family’s level of need (United States Census Bureau, 2015).

Due to these shortcomings, the Department of Health and Human Services generates the poverty guidelines each year. These guidelines are a simplification of the Census Bureau’s Poverty Threshold and are based off of the consumer price index which is used to determine an individual’s eligibility criterion for a number of federal programs.
For example, the 2014 Poverty Threshold figure for a family of four was $24,008, while the 2014 poverty guideline was $23,850. However, this figure, like the Poverty Threshold, only looks at gross income prior to taxed cash income, and neglects the influence of non-cash benefits or other factors. For this reason, the Census Bureau has now created the Supplemental Poverty Measure (SPM) (Short, 2015).

The Supplemental Poverty Measure (SPM) was established as a macroeconomic statistic to understand the economic needs and trends of the population. This measure takes into account: 1) Additional unrelated individuals living in the home; 2) Mean expenditures on items such as food, clothing, shelter, and utilities, geographical housing cost adjustments; and 3) Cash income (including non-cash benefits) minus taxes, work expenses, out of pocket medical costs, and child support. The purpose of this measure was to be a supplement to the existing poverty figures, because it includes data from government programs that serve low-income families. For example, the 2014 SPM for a family of four with two children, was $25,844. Even though this figure is higher than that of the official Poverty Threshold, due to the other variables included in the SPM computation, SPM figures generally show an increase in the prevalence in poverty over the official poverty threshold figures. To explain this, in 2014 the official Poverty Threshold showed that 14.8% of the U.S. population was living in poverty. Comparatively, the SPM measure showed that in 2014 15.3% of the population was living in poverty (Short, 2015).

While each of these measures, the Poverty Threshold, the poverty guidelines, and the SPM, have a purpose and utility in understanding the definition of poverty, they are often difficult to understand. Due to the varying figures each measurement produces, it
becomes increasingly more complex and challenging to understand who actually is in
poverty in the United States, and what does attaining the status of in poverty truly mean.
The figures generated with the Poverty Threshold, the poverty guidelines, and the SPM
are formalized, economic, and statistical measures of poverty and might be seen as
concrete numbers that solely represent the financial definition of poverty, there are also
emotional aspects that can be accounted for with this population. These figures also don’t
account for an individual’s own assessment of his/her status, or whether an individual
sees himself/herself as being impoverished or in need of additional services.

With factors like emotional perceptions of poverty and individual’s in poverty
own validation of status, this current study attempted to capture these qualities with the
term “perceived poverty”. Perceived Poverty is a term coined by the researchers to
represent an individual’s own perception about his/her economic status. It is the belief of
the researchers that an individual may financially meet the status of living in poverty
without actually believing himself/herself to be impoverished, and vice versa. This term
is a qualitative measure, defined by each participant as it relates to his/her own perception
of his/her economic wellbeing. While the theoretical question posed above about the
definition and determination of poverty cannot be answered fully by this study, it is the
hope of the researchers that the importance of an individual’s perceptions will be taken
into account when using classifications such as “poor” or “impoverished.” Perceptions
play an important role in how individuals make judgements and opinions, which will be
evaluated further when looking at parental perceptions as they relate to their child’s
needs.
What are unmet health care needs?

Unmet health care needs can be defined as any existing health concern that goes without treatment or care. These needs can be considered strictly medical, such as unmet needs for physical care, dental care, prescription medications, and eyeglasses (Newacheck, et al., 2000), or they could be considered unmet psychosocial needs. Such unmet needs might encompass information relating to: discipline or parenting, child development, physical care, or nutrition (McCunes, Richardson, & Powell, 1984). Studies have found that parents are becoming increasingly more concerned with their children’s normative development, and are looking for psychosocial care to be provided as part of the health care experience (Hickson, Altemeier, & O’Connor, 1983).

A study by Garg, Butz, Dworkin, Lewis, and Serwint (2009) evaluated both parents’ and health care providers’ attitudes towards screening for social needs during health care visits. A majority of the parents in this study acknowledged the prevalence of a social need in their care, as well as agreed that they could seek assistance with this need from their provider. The providers in this study also believed screening for these needs were valuable, however, few reported that these needs were actually screened for at visits.

Other studies have also highlighted parents’ desires for psychosocial care to be incorporated into health care experiences. McCune, Richardson, & Powell (1984) found that 81% of concerns that parents had for their children’s physician were related to a psychosocial issue. Sharp et al. (1992) (cited in Young, Davis, Schoen, & Parker, 1998) also found that in 88% of health care appointments there was the possibility to discuss psychosocial concerns, but that in 60% of these experiences, the health care provider ignored or dismissed said concern. Young et al. went on to find that parents desired to
learn more about child rearing (i.e. newborn care, sleep patterns, toilet training, discipline, responding to a crying baby, and encouraging early learning). Parents in this study also believed that if pediatricians provided interventions that provided more educational information that a positive change in parent behaviors would ensue. These findings are important for any healthcare provider, or agency serving children and families, as it indicates that health care needs are shifting to include more than just basic physical care.

Poverty & Barriers to Access and Care

With much of the research on poverty having occurred in the past 40 years, the snapshot image of poverty has changed drastically. In the 1960’s, a large proportion of individuals in poverty belonged to the elderly. However, now the highest proportion of individuals in poverty belongs to the youngest members of society, children under the age of 18. The poverty rate of children in 2014 was 21.2%, as compared to the poverty rate for adults sixty-five years and older was only 10% (DeNavas-Walt & Proctor, 2015). In addition to this disproportionate reality is the idea that poverty is not evenly disbursed to all children. Children of minority groups, those living in single-parent households, and children of parents who have not completed high school are much more likely to be poor (Concoran & Chaudry, 1997).

Another concern when considering poverty and children is the duration of the poverty. Concoran and Chaudry found that one out of every three children spent a minimum of one year in poverty. While their research showed that most children spent less than five years in poverty throughout their childhood, there is an unfortunate group of children (5%) who will experience childhood poverty for ten or more years. These
findings show that the risk of poverty is widespread, and can occur as a transitory experience, or a long-term one.

One study that examined parents’ income as an influence on children’s access to certain health services was Porterfield and McBride (2009). They found that poor families were significantly less likely to use specialty services and prescription medications. While this study portrayed that insurance coverage did increase a family’s likelihood of accessing services, if the family had been uninsured for at least a month in the past year, they were less likely to access services. From these findings the researchers concluded that lower income parents lacked resources, or information about available health care services for their children, even if they had coverage for these services through insurance. This may point to the need for additional educational resources for both parents and children in poverty.

What are the effects of poverty & unmet healthcare needs (on children)

Brooks-Gun and Duncan (1997) found that the influence of poverty early in a child’s life had a greater effect on grade completion than did poverty during the school age years. This study also found that children who experience pervasive poverty over the course of many years had the worst outcomes, thus providing support for the importance of early childhood development, and the negative influence of early childhood poverty. Unfortunately, poverty is not only significant in the early years of a child’s life, but continues to impact child development across the lifespan. The negative outcomes of poverty accrue over the course of development, meaning that negative consequences at one stage of development can continue to influence later stages (Yoshikawa, Aber, &
Beardslee, 2012). For example, children whose childhood poverty was long term were more likely to be long-term poor as adults than were children whose childhood poverty was transitory (Concoran & Chaudry, 1997).

While past research generally looked at the psychological or psychosocial effects of poverty on children, recent research had begun to look at the biological effects of poverty on children. Yoshikawa, Aber, & Beardslee (2012; p.275) cited the following studies that found that parent stress due to poverty can create chronic biological stress activation in their children: Blair & Raver, 2012; Essex, Klein, Cho, & Kalin, 2002; Lupien, King, Meaney, & McEwen, 2000. Yoshikawa et al. also found that some genetic factors for certain developmental diseases can be activated and influenced by environmental factors (e.g., chronic poverty).

These recent findings help to support research that evaluates the effects of the environment on developmental outcomes, particularly for children. Wood (2003) examined the effects of family poverty on child development and concluded that many families living in poverty live in communities that lack public resources, opportunities for parental networking, or safe places for children to socialize and play. Due to this, children’s cognitive, affective, and physical wellbeing could be compromised.

Wood also reported that impoverished children are more likely to have deficient access to preventative care, have higher rates of hospital admissions, and higher rates of chronic health concerns. Brooks-Gun and Duncan (1997) further found that poor children are more likely to experience growth stunting, which is a marker of nutritional status, and lead poisoning, than non-poor children. This same study looked at emotional and behavioral influences of poverty on children. For example, persistent poverty was positively correlated with internalizing behaviors, like depression or anxiety, and that
current poverty was correlated with externalizing behaviors, such as fighting or peer conflict. All of the studies suggest that children are effected by poverty across various measures of development (physical health, cognitive development, school achievement, emotional-behavioral well-being, etc.), and that the effects appear to be mostly negative.

Parent Perceptions & Knowledge of Child Development

There has been research performed on parents’ knowledge of child development, parents’ perceptions of their children’s needs, and parents’ desire for additional interventions and resources, specifically as they relate to psychosocial care. Primary caregivers are the link between health care services and children’s needs being identified and met, therefor making parent education of needs, and parental perception of needs incredibly important when serving pediatric populations. To illustrate this point, a study by Wildman, Kizilbash, and Smucker (2009) noted that physicians were more likely to respond to parental concerns about their children’s behavior when the behavior was clinically significant, as well as when the behavior was causing personal psychosocial distress for the parent. While this gave credit to physicians listening to parental reporting, this study also found that 60.9% of the time when parents revealed psychosocial concerns about their child to the physician, the physician failed to address this disclosed information. This study suggested that while physicians do take parental reporting of concerns into account when distress is being experienced, not all parents received this level of care, leaving some children with unmet healthcare needs.

In order for children’s needs to be met, it is often necessary for the caregiver to identify the need, and then to disclose the need to a health care professional. In order for a need to be recognized and then reported, a general understanding of child development
is often helpful. If a parent were to score low in their knowledge of child development, it could be believed that they may not have the base knowledge to identify a necessary need to a health care professional. A study by McCunes, Richardson, and Powell (1984) found that there was a significant association between a parent’s income and their knowledge of child development. A majority of parents who made $18,000 or less a year scored low in their knowledge of child development. Other studies have also found a link between a parent’s education and their awareness of a specialty health care need for their child. For example, Porterfield and McBride (2009) found that mothers who had not completed high school were less aware of specialty service needs for their child as compared to mothers with college degrees.

Each of these studies seem to indicate that parents and caregivers play an important role in children’s needs not only being identified, but also in being met. These studies also give weight to the notion that caregivers have a desire for more information about their children’s psychosocial development, but also that some parents may need more information about their children’s development.

Child life’s role in serving children in poverty

Wildman, Kizilbash, and Smucker (2009), McCunes, Richardson, and Powell (1984), and Porterfield and McBride (2009) all have identified that parents rely heavily on their pediatricians and primary care physicians for such information about child development and psychosocial care. With healthcare trends turning towards a greater multidisciplinary approach to patient care, these findings give support for the utility of a child life specialist in non-traditional health care settings, such as primary care offices or community health clinics. The use of a child life specialist could help to address the
psychosocial needs parents disclose and provide additional education about these concerns that have been ignored or under supported by physicians in the past.

As stated previously, a child life specialist is a member of the multidisciplinary health care team that utilizes play, education, preparation, and coping to support the healthy psychosocial development of children and families. Child life specialists are often found in large and small pediatric facilities, particularly focusing on inpatient and outpatient care, emergency department care, surgical care, and intensive care (Child Life Council, accessed 2016). While the field of Child Life is growing and expanding to include coverage in additional health care settings, such as at primary care offices or community clinics, it is still relatively uncommon to find specialists in these areas. With this in mind, individuals who may only utilize physician offices or community clinics for their children’s care are unlikely to have ever met a child life specialist or received their services (Child Life Council, accessed 2016).

Previous research has identified that parents desire more information about psychosocial care, and this research has also identified what parents view as the most helpful sources of this information. McCunes et al. identified that parents found information directly from health professionals to be the most helpful, followed by information from relatives, and then finally from printed resources. This study also ranked parents preferred educational techniques, some of which included: educational pamphlets, planned discussions about specific areas of development, conducting group teaching sessions, having a consultant about child development available in waiting areas. While this study looked to see how physicians could fill the educational needs for parents, all of these desired educational techniques are within the scope of Child Life practice and competency.
There is currently no research available that examines if individuals in poverty are familiar with child life specialists, the services they provide, or have ever experienced child life care. It is the intention of the current study to begin to uncover this information. While past research has identified that this population generally lacks information and education relating to child development, it is the hope of this study to determine specifically what individuals in poverty identify as needs for their children, and how those needs could be met by child life services.
CHAPTER III
RESEARCH DESIGN AND METHODOLOGY

Participants

This study aimed to survey adult caregivers in perceived poverty about their perceptions and beliefs regarding their children’s health care. In order to reach this population, this study was conducted at various events hosted by a local residential housing association for people living in poverty. Participants included 23 adult caregivers of children receiving services from the residential housing association; there were nineteen mothers, one father, one grandmother, and two other caregivers. The original sample included 26 adult respondents, however 3 respondents were found to not being caregivers, thus excluding them from the final data pool.

Participants were recruited from various events and services associated with the residential housing association. The housing association provides various educational and social events to help promote independence and self-sufficiency for low-income families (Akron Metropolitan Housing Association, accessed 2016). At the onset of the study, the researchers provided surveys and informed consent forms to the housing association to recruit participants and collect data through individual case managers. The researchers also partnered with the housing association to recruit participants and collect data at a multitude of educational and social gatherings hosted by the housing association.
Procedure

Participants were approached by the researchers, or a member of the housing association, introduced to the purpose of the study, and asked to participate. Participants that agreed were given an informed consent form (See Appendix A) and a copy of the survey (See Appendix B). The survey instrument included open-ended and closed-ended questions. Demographic information was collected and broken down into two categories, general and household. The general demographics focused solely on the caregiver and included questions about gender, age, race, and educational level. The household demographics asked about: 1) The number of children in care; 2) The relationship to the child/children, 3) The number of individuals in the household, 4) Description of economic status, 5) Household income, 6) Family structure, 7) Health insurance type, and 8) Government assistance received. The remainder of the survey instrument focused on the health care needs of the child/children and information needs of the caregiver.

The health care needs and information needs portions of the survey was developed and modified from previous research questionnaires related to children’s health care needs (DeVoe, Wallace, Selph, Westfall, & Crocker, 2011; Garg, Butz, Dworkin, Lewis, & Serwint, 2009; McCune, Richardson, & Powell, 1984). The questions focused on what needs the caregiver felt were important for his/her child if these needs had been met, if there had been any delay in meeting these needs, and where these needs were met. A complete list of the health care needs can be found in Appendix B. There was one question that asked caregivers to rank their child’s care on a 10-point scale, (1 = “not at all” and 10 = “highly met”, and then explain their rating). All other questions fit a yes/no,
or ranking format, with the option for additional open-ended responses to allow the caregiver to explain their experiences.

One final section of the survey focused on information needs of the caregiver. This section assessed where caregiver’s sought and received health information, what questions they have for health care providers, what concerns they have about the medical system, and what their understanding or experiences with a child life specialist were. A complete listing of the information needs questions can be found in Appendix B. These questions were primarily open-ended, allowing for participants to explain their experience, perceptions, and concerns.
CHAPTER IV
RESULTS

General Demographics

As stated earlier, this study originally had 26 individuals who participated in completing the survey instrument. However, three of these participants were not primary caregivers to children, and thus were excluded. Out of the 23 participants that completed the survey, twenty were female and three were male. Of those 23, nineteen identified themselves as mothers, one identified herself as a grandmother, one identified himself as a father, and the remaining two choose not to respond to their relationship to the child. The age of the participants ranged from 21-62 years, with five participants choosing not to respond with their age. Twelve participants identified their race as black, one as Hispanic, two as multi-racial, five as white, and three participants choose not to respond. It should be noted that a majority of participants had some amount of education post high school with 34.8% (8) of participants reporting having some amount of college and 34.8% (8) reporting to have attained a college degree. Thirteen percent (3) of participants had some amount of high school, 8.7% (2) had attained a high school degree, and 8.7% (2) choose not to respond.
Household Demographics

Of the caregivers surveyed, the number of children in care ranged from 1-5 years. Concurrently, the number of people in the household ranged from 2-6 individuals. Everyone that completed the survey that chose to respond about their household income made less than $30,000 a year; 73.9% (17) of participants made less than $15,000 a year, 21.7% (5) made between $15,000-$29,000, and one participant choose not to respond. A majority of the caregivers reported being single parents/caregivers (65.2%, or 15 participants). The remaining participants’ family structure was as follows: four identified as being married, one identified as living as married, and three were divorced. All of the participants responded that they were insured, with the majority (78.3%, or 18 participants) having public health insurance; 17.4% (4) had private insurance, and 4.3% (1) had another form of health insurance.

For the qualitative responses, both researchers read all of the open-ended responses three times; the first reading was for content, the second reading was to discern the coded themes, and the third reading was to discuss the appropriate codes for each response. The researchers agreed upon each coded response with 100% reliability. Each of the codes were then transformed into numerical data and frequency analysis was performed in SPSS. Descriptive statistics were conducted, and frequency data was reported. The following results will break down each question asked on the caregiver survey.
Economic Status

As part of the household demographics caregivers were asked what their perceived economic status was. One of the primary focuses of this study was to understand the notion of Perceived Poverty, not just the government issued definition of financial poverty. This question was open-ended and gave participants the opportunity to describe their family’s status. Fourteen participants chose to answer this question. Of the 14 respondents, only three identified their status as “poor” or in “poverty”, however, by the 2014 Poverty Threshold figures, 12 participants could qualify as being financially “in poverty”, with two of the families possibly not meeting this standard. The 2014 Poverty Threshold Standard for a family of five with three children was $28,252, and the threshold for a family of three with two children was $19,073. Given that the household income question gave a range from $15,000-$29,000 for one of the responses, it is impossible for us to know with certainty if these two families in question fell above or below their specific poverty threshold for 2014. There also was the consideration of being defined as “near poor”, which according to the Orshansky definition is a family unit living within 133%-200% of their poverty threshold (Hegness, & Hokayem, 2013). However, even if these families do not meet the definition of living in poverty, or “near poor”, it stands to reason that caregivers primarily viewed their status differently than the government’s definition. This disparity gives way to the suggestion that the term poverty could be defined with additional qualities other than strictly financial parameters.
Survey Instrument Results

*Rate how well your child’s (children) health care needs have been met by your health care provider(s), and please explain why you chose the rating.*

This question looked to gain a quantitative and qualitative perspective as to how well parents believed their children’s health care needs were met, and why they believed this. Quantitative responses ranged from 5-10 on a 10-point Likert scale (1 being not at all, and 10 being highly met), with 82.6% (19) of participants rating their child’s needs being met as a 9-10.

For the qualitative analysis of this question, the researchers developed two major themes; 1) the theme of “credit”, and 2) the theme of “perception of care”. For the theme of *credit*, the researchers determined that all responses acknowledged someone or something for the child’s health care needs being met. Researchers determined that this theme required three codes for attributing credit: *personal credit, systematic credit*, and *other*. *Personal Credit* was determined to be any response that directly indicated or inadvertently attributed the health care needs of the child/children being met by the parent or caregiver themselves. Of the 23 respondents, 17.4% (4) were coded for personal credit. One caregiver responded, “I make sure he goes to all his doctor’s. appointments and provides all his medicine to keep him well.” This response seemed to highlight the theme that he/she takes personal credit for the child’s needs being met.

*Systematic Credit,* was determined to be any response that directly indicated or inadvertently attributed the health care needs of the child/children being met by a member of the medical team, or the medical system in general. Of the 23 respondents, 78.3% (18) were coded for *systematic credit*. Some examples of such responses included:
“With assistance my children are able to get checkups when needed and help with prescriptions.”
“Any situation or issue we as a family has or have our physician or health care provider take care of our needs.”

All other responses (4.3%, or 1 participant) that did not meet the criteria to be defined as personal credit or systematic credit was determined to fall into the code of other.

For the theme of perception of care, the researchers determined that all caregivers perceived their children’s health care needs being met, or not met, either due to a service or due to their judgements associated with care. Due to this, the researchers coded this set of data by three codes: service, judgements, or other. Responses that were coded as service were determined to include any answer that specifically named, or implied that the health care needs were met (or unmet) due to a service or procedure. Out of the 23 respondents, 56.5% (19) were coded for service. Some examples of these responses included:

“Same doctor since birth.”
“His providers provide resources, [and] helpful information on various topics.”

Responses that were coded as judgement were determined to include any answer that directly indicated an assessment of services due to the caregiver’s affective perception of the need being met. Out of the 23 respondents, 39.1% (9) were coded for judgement. One caregiver stated that “[his/her healthcare provider] went above and
beyond getting his needs met”.

All other responses (4.3%, or 1 respondent) that did not meet the criteria to be defined as “service” or “judgement” were determined to fall into the code of other.

*What health care needs do you feel are important for your child (children) (this can include physical, mental, dental, and emotional needs of any kind)?*

This question attempted to examine what needs caregiver’s perceived as important for their child’s wellbeing. From the results of this question, the researchers determined five different codes; *physical, mental, dental, emotional, and other*. *Physical* needs were defined as any response that explicitly stated or implied any services, procedures, or concerns that related to one’s physical health and wellbeing, such as getting regular check-ups or eating healthy. *Mental* needs were defined as any response that directly stated or implied any service or concern that related to one’s psychological health. *Dental* needs were defined as any service or concern that related to one’s dental care. *Emotional* needs were defined as any service or concern that dealt with one’s emotional wellbeing, such as regulating emotions. The code of *other* was used for any other response that did not fit into the previously explained codes; some examples of other responses included: “being healthy and happy” or “speech services”.

Of the respondents, 31.8% (21) mentioned the importance of *physical* needs, 22.7% (15) mentioned the importance of *dental* needs, 19.7% (13) mentioned the importance of *mental* needs, 18.2% (12) mentioned the importance of *emotional* needs, and 7.6% (5) mentioned the importance of *other* needs.
What have been your child’s (children’s) health care needs in the last 12 months?

This question sought to uncover what health care needs caregivers’ children had in the past year. The researchers coded all responses with the following five codes: physical, mental, dental, emotional, and other. The same definitions from the question “What health care needs do you feel are important for your child (children) (this can include physical, mental, dental, and emotional needs of any kind)?” were used in determining the codes for responses to this question.

Of the respondents, 41.9% (13) claimed their children had a physical need within the last 12 months, 22.6% (7) reported a dental need, 19.4% (6) reported a mental need, 12.9% (4) reported other needs, and 3.2% (1) reported an emotional need.

In the last 12 months, was there any time when your child (children) needed medical care, but did not get it?

This question sought to determine if there was a time in the previous 12 months that the caregivers’ children’s needs were unmet, and what that experience had been like for them. Of the participants that chose to respond, 95.7% (22) stated that “no” there had not been a time in the last 12 months that their children’s needs had been unmet. One caregiver did respond “yes” to this question though, with the following justification for this answer:

“Medication prescription was not followed up by physician.”

“Mental care was fixed with a band aid – [it’s] still very serious.”

From this response, it appears that while needs of the majority of the participants were met, not all caregivers in perceived poverty feel that their children are being
adequately cared for.

In the last 12 months, how many times did you take your child to a doctor’s office or clinic for care?

Responses to this question ranged from 1-20 visits to the doctor’s office within the past 12 months. The largest group of respondents (47.8%, or 11 participants) claimed to take their children to the doctor between 2-4 times in the year, 25% took their children less than 2 times, and 27.2% reported taking their children 5-9 times per year

Where do you primarily go to receive medical care?

Participants received medical care for their children from a variety of different hospitals, clinics, and health care providers. Some of the various establishments that the caregivers in this study utilized to meet their children’s health care needs Family Fall Practice, Child Guidance Family Solutions, Akron Children’s, and Access Point to name a few.

In the last 12 months, when your child needed care, how often did your child get care as soon as you wanted it?

All caregivers that chose to respond to this question responded that their child “always/usually” received care as soon as they wanted it. While on the surface this appears that every child received adequate and timely care, the qualitative explanations that parents provided for this question portrayed a different perspective. Some caregivers expressed these sentiments to highlight the nature of their care:
“His doctors are good about giving him the proper medicines and test he needs.”

“Just checkups and doctor’s visits, nothing major.”

While caregivers had the following experiences of getting care as soon as they wanted:

“If I couldn't get it, I took her to ER.”

“Many hours or days waiting for care.”

Given this range of explanations for “always/usually” receiving timely health care, it calls into question what the true definition of getting care as soon as wanted is for individuals living in perceived poverty.

*In the last 12 months has there been a time that your child was delayed in getting care due to cost?*

While in the last question participants unanimously stated to have gotten care for their child/children as soon as they wanted, the results for this question differed. A majority of respondents (91.3%) still claimed that there was not a time in the last 12 months that they were delayed in care due to cost. 8.7% of caregivers however did not feel this way. Some of these caregivers’ explanations for this barrier to care are as follows:

“Because insurance didn't cover the medicine.”

“I am paying out of pocket for good dental care.”
These qualitative responses, much like the responses from the last question, help to illuminate the perspective of parents in perceived poverty. While needs may be met by the health care system at hand, credit for needs being met may actually be due to the active participation from caregivers, and at financial expensive for individuals living financially below their means.

*Where do you primarily go to receive health/medical information?*

Previously in the survey, the researchers asked where caregivers received medical care (i.e. what medical institution or care facility did they go to). This question instead looked at evaluating where do caregivers receive health information. Based on the responses, the researchers evaluated responses based on 2 codes, *online resources* and *physical resources*. *Online resources* included any response that directly indicated that the caregiver utilized the internet, search engines, or any other online resource to gain health information. *Physical resources* were defined as any person or place that a caregiver might go to, or reach out to in order to gain health information (i.e. the doctor’s office, a specific family practice, etc.).

Of the respondents, 68% (17) claimed to utilize physical resources to attain health information, with the remaining 32% (8) utilizing online resources.
If a member of the medical team could give you all the time you needed today, what questions about raising your child would you like to talk to him/her about?

Previous research looking at parent’s psychosocial concerns for their children found that parents often did not feel there was enough time to adequately discuss or ask their health care provider about these concerns (Hickson, Altemeir, & O’Connor, 1983; McCune, Richardson, & Powell, 1984). With this in mind, this question was included in the survey in order to give caregivers the time and space to express any concerns they might have, or had, that they have not been able to vocalize to their provider. A majority of caregivers (40%) stated they had no questions or concerns at this time. Of the remaining respondents, their answers were coded with the following 4 codes: mental issues/concerns, physical concerns, caregiver needs, and other. Mental issues/concerns were defined to be any response that directly or indirectly indicated a mental health diagnosis or behavioral issue. Physical concerns included any answer that identified a physical ailment or typical physical health concerns (i.e. eating, sleeping, etc.). Caregiver needs were defined as any response that indicated that the caregiver had personal coping concerns related to their children’s development. The code of other was used for all other responses that did not fit into the previous three codes.

Of the respondents, 20% (5) indicated a caregiver need, 16% (4) indicated a mental issue/concern, 16% (4) indicated a physical concern, and 8% (2) indicated an other concern. Below are some examples of the various responses for each of the codes utilized.
Caregiver need:

“What’s the best way to adapt to my children growing up in life?”

“How to deal better with teen attitudes health moving forward to adulthood, and then taking care of themselves?”

Mental issue/concern:

“Are there natural ways to deal with certain behaviors instead of medicine?”

“Why can’t they help mental issues?”

Physical concern:

“How to get the young one to stop wetting the bed?”

“What is the cause for breathing (issues)?”

Other concern:

“Basic concerns”

“Is it normal for kids not to be want to eat?”

What are your concerns about the medical system, as it relates to your child’s care?

The intent of this question was to gain a broad spectrum perspective of caregivers’ beliefs about the medical system, as it relates to their children. From the responses attained, the researchers developed five different codes: no concern at this time, financial
concerns, insurance inconsistencies, physician approach to care, and frivolous procedures. The code of no concern at this time was used for any answer that specifically claimed they had no concern. Financial concerns were defined as any response that indicated the cost of care, or the inability to pay for care. Insurance inconsistencies was used to describe any response that indicated that insurance coverage dictated one’s child’s health care; this term was labeled as such to describe that the whole insurance system is inconsistent, as there are different rules of coverage for different insurance types. Physician approach to care was used to describe any response that identified that the provider’s philosophy and practice was of concern. The frivolous procedures code was used to describe any response that directly stated that medical tests or procedures were unnecessary or inconsequential.

Most of the respondents (70%) claimed to have no concerns for the medical system at the current time. Ten percent (2) identified having financial concerns, and 10% (2) identified concerns about frivolous procedures. Five percent (1) claimed that insurance inconsistencies were a concern, and another 5% (1) stated concerns regarding the physicians approach to care. Examples of each of these codes are provided below.

Financial concerns:

“When I get a job that pays more I will not be able to afford to take him to the doctor when needed.”

Frivolous procedures:

“So many tests leading nowhere but they made a lot of money.”
Insurance inconsistencies:

“I don't like how your doctor has your child on a medication for a very long time, and then because insurance doesn't want to pay, they want to change the medication, making them have to try a new medication.”

Physicians approach to care:

“So very book learn[ed] versus dealing with real life with patients. I can partially understand why. But what happened to the family doctor that knew the family [and] status of each member’s health without charts.”

Have you ever met a child life specialist/received child life care, and what do you think a child life specialist might do?

After finding out the caregivers’ perceptions of their children’s care, the researchers wanted to learn what these caregivers knew about child life services, and a child life specialist’s role. Parents were first asked if they had ever met a child life specialist. If they answered ‘yes’, they were then asked to describe that experience. If they answered ‘no’, they were asked to describe the role of a child life specialist, based on their best guess. A majority (82.6%) of the caregivers claimed to have never met a child life specialist before, with the remaining 17.4% stating they had received child life care in the past. See Table 3 to highlight what these individuals’ past experiences with child life specialists, and what caregivers in perceived poverty believed a child life specialist’s role was.
CHAPTER V
DISCUSSION

The objective of this study was to understand and uncover the perceptions that caregivers in perceived poverty had as they related to the health care needs of their children being met. With this in mind, the researchers hoped this study would give voice to a vulnerable population, while also drawing attention to a possible gap in care. From the results of this study however, there were quite a few differences in participants’ responses than what was expected based on previous research. The following section discusses the differences between the current study and past research, as well as some hypothesized insight into why these differences may have occurred. In addition to evaluating the various responses, this section will also discuss the unique incidents that occurred as a result of this study being conducted with its unique methodology. Some of these experiences can be considered limitations, and some as learning moments for future research.

Healthcare needs being met for children in Poverty

Given the previous studies conducted, past researchers appeared to believe that the healthcare needs of individuals in poverty may not have been met, either due to cost, insurance coverage, access to care, or other factors. However, the majority of caregivers in this study responded that their needs were met, they received care as soon as they
wanted, and cost was not a factor for delayed care. Also, a majority of respondents qualitatively gave credit to their healthcare providers in meeting their children’s needs. This finding is overall a positive one, as it portrays that the needs of most of the participants are being met, to some level or another.

One possible explanation for this increase in needs being met may be the recent changes in the health care system, not just in Ohio, but in the country as a whole. Seventy-eight percent of participants in this study claimed to have public health insurance, and 29.4% identified Medicaid as a form of government assistance they received. Medicaid has traditionally been a form of health care coverage that helps individuals in poverty (such as children, the elderly, and impoverished) to be able to afford basic health care needs. Prior to the Affordable Care Act, individuals and families qualified for Medicaid based on meeting 100% (or less) of the federal poverty level. With the passing of the 2010 Affordable Health Care Act, which went into effect in January 2014, Medicaid eligibility has expanded to anyone meeting 133% (or less) of the federal poverty level. This means, according to the 2015 poverty guidelines, that a family of four that annually makes less than $32,252.50 will meet the financial Medicaid eligibility criteria; there are some non-financial eligibility criteria, such as residency, immigration status, etc. that must be met on a federal and state level (Keeping America Healthy, accessed 2016).

With all of these changes and updated figures to the various guidelines, thresholds, and eligibility criteria for government assistance, it becomes increasingly more difficult to have an accurate representation of poverty in the United States. For example, the Census Bureau’s most recent publication of the Poverty Threshold, which is used to determine a statistical estimate of the number of Americans in poverty each year,
is from 2014. However, the U.S. Department of Health and Human Service’s Poverty guideline, which is used for “administrative purposes” such as “determining financial eligibility for certain federal programs”, has been updated for the year 2015 (U.S. Department of Health and Human Services, 2015). This inconsistency in up to date publications is further complicated by the fact that the Poverty guideline and the Poverty threshold do not equate to the same numerical value of “poverty”. To explain this, the 2014 Poverty Threshold shows that a family of three with two children is $19,073. The 2015 Poverty guideline for a family of three however is $20,090. While this $1,000 difference may seem miniscule, it complicates the general understanding of who is in poverty and who is not. By the 2015 poverty guideline, a family of three with a gross income is $20,000 technically meets the basic criteria to receive government aid. Yet this family would not be counted by the Census Bureau as being in “poverty” by the 2015 Poverty Threshold figures. By these inconsistent standards it is virtually impossible for anyone in the general population to conceptualize and understand what poverty is, what it looks like, and what it is defined as. The variability in each of these figures contributes to our communities not being able to empathize and understand the meaning of poverty; empathy requires the global community to be in solidarity with the experience of those in poverty, which cannot be attained without a “true” definition of poverty. The greater community cannot move forward towards acceptance and understanding of this population’s experiences and existence if the government agencies that determine these measurement tools are not even in agreement themselves.

Medicaid coverage does vary from state to state, with some states having additional cost-sharing programs that charge enrollees some out of pocket costs associated with their care, such as premiums, or co-pays. Every state also has the power
to determine their own “type, amount, duration, and scope of services” (Keeping America Healthy, accessed 2016), while meeting the federally mandated mandatory benefits of Medicaid. Some of the mandatory benefits included are: inpatient hospital services, certified pediatric and family nurse practitioner services, transportation to medical care, and physician services. Optional services, that each state is able to include or not in their Medicaid program, include: prescription drugs, dental services, eye glasses, hospice (Keeping America Healthy, accessed 2016). While it is outside of the scope of this study to critically evaluate the specific benefits each respondent had access to given their insurance type and Medicaid plan, it is clear to see that while many services are available, there still are many that are not. The essential physical needs children and families face are covered by the mandatory guidelines, but the remaining mental, dental, emotional, and other needs that caregivers stated as being important to their child’s wellbeing, are only optionally available. The results of this study might help to highlight a shift that healthcare communities have already experienced as a result of the Affordable Care Act, but more research is required.

Questions/Survey

Another major difference from the current study, compared to past research in the field, was that the current survey questions were aimed at parent perceptions of needs being met, not the magnitude of these needs being met. For example, many past studies (Young, Davis, Schoen, & Parker, 1998; DeCesaro, & Hemmeter, 2009) have looked for parents to rate their child’s health status (i.e. excellent, good, fair, etc.) as an indicator of needs. The current study instead wanted to see if a particular need was met or unmet, not how well it was met. With this in mind, it is difficult to assess and compare some of the
results with past research. Past research by Young, Davis, Schoen, and Parker (1998) indicated that children from low-income families are less likely to be in “excellent” health, which would indicate needs being unmet. However, the results of the current study showed that all children’s needs were met to some extent. While caregivers stated that needs were technically met, some stated paying out of pocket, waiting days for services, or having to take their child to the doctor over 20 times in the last year in order for these needs to be met. Due to these explanations, while needs may be “met”, one could come to believe the health status of these children truly may not be “excellent”, or that needs may only be satisfactorily being met.

Also, as briefly described in the results section, the definition of needs being “met” may vary from caregiver to caregiver. While every caregiver that responded to the question “In the last 12 months, when your child needed care, how often did your child get care as soon as you wanted it?” claimed to ‘always/usually’ get care when they wanted, not every caregiver claimed to have gotten the necessary medical care they needed in the past 12 months. This seemingly contradictory response may lead one to believe that “always/usually” receiving care as soon as one wants is not the same across the board for caregivers in perceived poverty. Due to this, it is challenging to get a clear picture if needs are actually met, how soon they are met, and to what extent the needs are met. However, given the majority of results, parents in perceived poverty appear to believe their children’s needs are met.

Knowledge and Use of Services in Poverty

While caregivers collectively rated their children’s needs as being met by their provider, past research calls into question the validity of these responses. McCunes, et al.
found that parents with incomes of less than $18,000 a year scored lower in knowledge of child development. Considering that 73.9% of respondents claimed to make less than $15,000 per year, it is plausible to consider they have less knowledge about child development, and specific health care needs than caregivers that have higher yearly incomes. With this in mind, while caregivers may have rated their child’s needs as being met, they may just be unaware of other developmental needs their children have.

If parents are unable to identify these needs, due to having less knowledge that needs exist, it is unlikely that providers are identifying said needs and meeting them for these families and children. Particularly in the realm of psychosocial needs, past research has already shown that physicians are less likely to address nonmedical needs with parents, even when parents are able to identify these needs themselves (Young, Davis, Schoen, & Parker, 1998). With this in mind, it appears impossible for caregivers who do not identify psychosocial needs as a concern, due to their lack of knowledge, to have these needs be met. Given all of this, while the current study may quantitatively show that caregivers in perceived poverty believe their children’s needs are met, this ultimately may not be the case.

In addition to knowledge of development being related to income, Porterfield and McBride (2009) found that level of education was a factor for identifying children’s specialty service needs. This study found that mothers who had not completed high school were less aware of specialty service needs for their child compared to mothers with a college degree. Given that a majority of the caregivers in the current study had received a college degree or some college education, it is conceivable that these caregivers were more knowledgeable of their children’s specialty service needs due to their educational attainment. Given these conflicting findings, it is still unclear if income
level or educational attainment account more strongly in regards to a caregiver’s knowledge of child development and specialty needs. However, even without this distinction, it is valuable to understand these external and generational factors play a role in parents’ ability to recognize and advocate for their children’s needs.

Knowledge and Experience with Child life

A majority (82.6%) of participants in the current study claimed to have never met a child life specialist or to have received child life services in the past. If one is to take into account all of the previously discussed assumptions that parents in perceived poverty, due to having a lower income, have less knowledge of child development, than a child life specialist could be an extremely useful resource for these families and children. As experts in child development and psychosocial needs of children, a child life specialist could be an advocate and educator for families in perceived poverty. The vision of the Child Life Council is to provide child life services to any environment that places children’s potential for growth and mastery at risk, thus including families in perceived poverty (Mission, Values, and Vision, accessed 2016).

Of these families that had never experienced child life services, the responses about the assumed role of a child life specialist varied highly. While every response, in some light related back to the role of a child life specialist, very few responses truly captured the services that child life could provide to these families. Some respondents believed that child life specialists:

“Help children with life crisis to overcome life's battles.”

“Help with any concerns we may have about her growing up.”
“Maybe someone that deals with patients that have illness and their life expectancy.”

Other respondents claimed to have “no idea”, or thought that a child life specialist might be “like a child guidance person”. It appeared that parents in perceived poverty from the current study had an incomplete understanding of the role of a child life specialist, and how that role could serve them.

As the field of Child Life is continuously growing and expanding, the results from this study may point to a need to promote child life services in areas where poverty exists. Previous research has already identified the risk to children who grow up in poverty, so in order to meet the vision of the Child Life Council, this is an avenue for future growth and research. Families did not identify child life as a service need or unmet health care need, but that is most likely due to the fact that most of the caregivers did not even know what a child life specialist was. Just as it is challenging to expect caregivers with limited child development knowledge to identify psychosocial needs their children may have, it is equally challenging to expect caregivers to know about a service they could benefit from if it is unavailable for them to ever have accessed or come in contact with.

Given the exploratory nature of this study, it is not possible to pin point the exact ways that a child life specialist could address and meet the needs of families in perceived poverty. However, given the responses that physical, dental, mental, and emotional needs are important to caregivers, a child life specialist could provide educational information, support, preparation, and play opportunities to address all of these needs in one way or another. These areas might be further explored in future studies within the field of Child Life discipline to attain a deeper sense of Child Life support, for this study
is merely the
beginning to a hopefully much greater avenue of future research. There is a great
potential for child life specialists to be able to serve those most in need in our
communities, but in order to assess the effectiveness and utility of child life services
with these populations, child life specialists must first be in these environments and
accessible to this population.

Methodological Challenges and Limitations

When reviewing the process of conducting this research study, there were a
number of challenges faced along the way. To begin with, finding an agency that served
this population and was able to coordinate with the researchers was a lengthy process.
While there are many agencies, non-profits, and government affiliates, both locally and
nationally, that serve individuals in poverty, finding one that could partner with the
researchers and support the current research was much more difficult than expected.

As in many businesses, there is a structural and organizational hierarchy that
oversees and approves of any collaborations between the business and any other person or
group. For many months at the beginning of this research endeavor, it was simply a
matter of understanding each agencies hierarchy and attempting to get in contact with the
correct individual. Once finding the correct contacts and presenting the intent of the
study, many locations opted out of the research partnership; one felt they could not get
the number of participants necessary, another felt the study would be invasive and
harmful to their population, and another discontinued conversing with the researchers
after months of follow up. After finally finding an organization that was not only
willing and able to help, it took many more months to then trickle down the structural
hierarchy and get in contact with the correct individuals that hosted the various events
the surveys
would be distributed at. While in the end the partnership that was formed was successful
and open minded to the researcher’s goals, it is noteworthy to understand the time that
was invested in this portion of the research process.

Researchers in child life who wish to collaborate with agencies can be
conscientious of time management and personal expectations of working with agencies
that serve people in poverty. There are many groups that are willing and capable of
collaborating, but it requires an open mind, patience, and effective communication skills
to make that possible. For example, when entering into a partnership with any company
of any size, it is good to be proactive with the personnel who are in charge, as well as to
build a connection with the personnel who are attending and facilitating any of the
events/focus groups. The researchers in the current study learned that the people
running/hosting the events for this population who can provide insight into successfully
carrying out the research objectives; these personnel know how to best approach
participants, what the best practices are for conducting surveys at certain events, and
other important logistical information about how the events are run. The researchers also
learned that navigating such a variety of personnel has its challenges; the larger a
company gets, being proactive and contacting everyone involved that you know at any
level helps to not only keep everyone in the loop, but helps to ensure forward progress.

In addition to the challenges associated with finding and forming a research
collaborative, there were also a number of challenges with the surveys and the
population. The researchers initially decided to utilize a survey tool to collect data with
the belief that it would be the most convenient type of data collection for the participants. In hindsight, while the surveys may have been convenient, their use produced a limited amount of qualitative data and explanations. Surveys were the least invasive and timely data collection tool that could have been used, but due to this, it was easier for participants to skip questions (usually the follow up qualitative questions), or to respond with short or single word answers. In order to get a richer and more full analysis of this population’s perceptions of poverty and health care, ideally an interview would need to be employed. However, given the population and the nature of the events that the researchers attended to facilitate the surveys, interviews would be impractical, if not impossible.

This predicament leaves those wishing to continue to do research in this field at a crossroad. How can one make the data collection efficient, convenient, and easy to use for the participants, while also producing opulent data for analysis? At this time, the researchers believe that convenience and incentives are the probable best courses of action. For example, at each event participants were given an index card with a checklist of different agencies or informational stations they needed to attend in order to get credit for their attendance at the event. If it would be possible to include the research station on such a checklist, this may help to recruit more individuals to participate in the study. By being required to at least visit the researcher’s station, while maintaining every freedom to reject participation, they would have an incentive to at least learn about the study. Another thought was to have a physical incentive, such as a gift card raffle. The thought behind this incentive plan was that any individual who participated could be entered for the chance to win a number of different gift cards, and that this material incentive may persuade individuals to want to take time to answer the survey. The only consideration
with this is that a grant may need to be utilized to cover the costs of such an incentive, which again would take time and effort to acquire and use.

One final consideration in regards to research with individuals in poverty was that it was important to remember that this population attends such holiday events to enjoy themselves, and not necessarily provide data rich information to researchers. However, everyone that the researchers encountered at the various social and educational events were helpful, kind, and open minded to participating. Yet, when surveys were later reviewed, some questions were blank or seemingly insufficiently finished. This was curious at first, seeing everyone was overtly interested in participating. However, it again needs to be remembered that these are real people, who were generous enough to take time out of their holiday celebration experience to fill out surveys for this research study. Some participants had multiple children present with them as they filled out their surveys, some participants were catching up with old friends or talking to those around them, some were trying to eat dinner and feed their children. Thus, given the intimate nature of the events utilized for the data collection, the participants cannot be faulted for seemingly insufficient responses. This was not a laboratory study, and it was not a convenience sample of college students, it was a community based assessment of actual people, at a community-family event. While the data may not have been as profuse as the researchers originally hoped for, the responses were honest and true to form for the lives that these individuals live. Just as it may be unrealistic and impossible to utilize an interview at these events, it may be unrealistic to expect lengthy and full responses to a questionnaire of this form with this population. The results obtained from this study may not have been what was originally expected, but they do open the doors for further questions and further
research. For all of this, the researchers are most grateful.

Future Research

In line with this current research project and methodology, a follow-up study might be one that utilized larger sample sizes, as well as samples from a variety of different major cities for comparison. A study of this nature could help to expand on the conclusions drawn from the current study, as well as add the additional factor of different locations to see if poverty and needs are perceived the same in various cities.

Another study might focus on evaluating the qualitative and quantitative definitions of poverty from individuals in various socio-economic status groups. The current study only recruited participants who utilized public housing as a resource, thus limiting the population to only include those in lower economic statuses. By expanding the population to include caregivers from all economic status groups, a broader understanding of the word “poverty” could be attained. This would also contribute to a greater understanding of parents’ perceptions of their children’s needs. This study was inconclusive in determining if economic status and/or educational attainment contributed to parents recognizing an unmet health care need.

By including a wider range of participants, with a broader range of experiences and status levels, this concept of unmet health care needs may be able to be understood more fully. Also, with a larger sample size, studying poverty related topics, and differentiating between specific variables can be better attained with higher level statistics. These studies can help make global, as well as specific changes to families in poverty.
Conclusion

From the current results, it is clear that parents’ perceptions of their children’s health care needs are more complex than simply being defined as met or unmet. While many participants assessed that their children’s needs were met, discrepancies among responses led the researchers to believe that additional factors of education, economic status, and knowledge of child development may play a role in a parent’s perception of needs being met. Having not accounted for these factors in the current study, it is impossible to assess if parent reports were accurate relating to their children’s needs being met. However, this consideration opens the door for further research in the field.

This study also found that this population of caregivers and children in poverty are altogether unfamiliar with the field of child life. It was found that 82.6% of respondents had never met a child life specialist, and the varied responses about the role of a child life specialist that were recorded further illustrated the void in services available to this vulnerable population. Caregivers in this study identified physical, mental, emotional, and dental needs as being important for their child’s well-being, all of which are areas that a child life specialist could address. Utilizing developmentally appropriate education, expressive/therapeutic activities, and psychological preparation before or after procedures are just some of the many ways a child life specialist could help to meet these needs.

This study acted as the first of its kind to begin to understand the needs and perceptions of caregivers in poverty, and how the field of child life can start to meet these healthcare needs and perceptions of caregivers in poverty. It is the hope of the researchers
that further research will branch off and continue to find ways to advance the well-being of this population of children and their caregivers.
REFERENCES


U.S. Census Bureau. (n.d.). Poverty Thresholds for 2014 by Size of Family and Number of Related Children Under 18 Years [Table].


APPENDICES
APPENDIX A

INFORMED CONSENT

Perceptions of health care for children from caregivers in perceived poverty
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Introduction: You are being invited to participate in a study pertaining to perceived health care needs of children. This study will be conducted by graduate student Samantha Polasky, under the advising of Dr. Scott Palasik this fall in the Department of Speech-Language Pathology and Audiology at The University of Akron. The goal of the study is to uncover the perceived health care needs of children from their caregiver’s perspective. This study has a specific focus on what these perceived needs are based on past health care experiences, and how interventions and services might address these needs.

Participants: Caregivers of a children in the Akron area, through the AMHA.

Exclusionary Criteria: Individuals who are not caregivers of children will not be able to participate.

Procedures: This study will involve filling out a questionnaire at a variety of AMHA sponsored events. The questionnaire asks basic questions about yourself and your family along with questions about your child’s (children’s) health care needs and if these needs have been met, your past health care experiences with your child, and questions relating to your economic and health care status.

The questionnaire should take approximately 10-15 minutes, depending on the length of answers to the questions. If you choose to participate, please sign this form below and return it to the researcher.

Contact: For any questions or concerns regarding this questionnaire, please e-mail Scott Palasik at: spalasik@uakron.edu or Samantha Polasky at: snp37@zips.uakron.edu

Risks and Benefits: There are no anticipated risks to this study. You can benefit by adding to our research pertaining to child life and health care needs of children.

Payment / Costs: Participation in this study is voluntary; there will be no financial payment for participating.

Confidentiality: Your personal information will be kept confidential. No identifying
information, other than your name on the consent form, will be collected. The consent form will be kept separate from the questionnaire to insure your anonymity. Results will be reported, but your name, your child’s name, and identifying information will not be reported.

Questions: If you have any questions you can contact Scott Palasik at 330-972-8185 (spalasik@uakron.edu). This project has been reviewed and approved by The University of Akron Institutional Review Board. If you have any questions about your rights as a research participant, you may call the IRB at (330) 972-7666.

Consent: I understand that this study is being conducted for the purpose for a graduate research honor’s project at The University of Akron. Through this document the researcher has explained how the study will be completed, what I will have to do, and how long my participation is required. I am aware that my full participation in this study is voluntary. I am fully aware that identifying information of myself, my child (children), or other family members will not be released or used in any manner. I am aware that no compensation will be provided for completing this questionnaire. By signing this form, I consent my participation in the study and will answer all questions to the best of my ability.

Participant Signature (Consent to Participate) 

Date
APPENDIX B
SURVEY INSTRUMENT

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GENERAL QUESTIONS

Gender (please check on):  □ Male  □ Female  □ Other________

Age: ________________

Race: ________________

Your Education level (please check one):

□ Some High School  □ High School Diploma  □ Some College  □ College Degree

HOUSEHOLD QUESTIONS

○ Number of Children in your care: ________________

○ Your relationship to the children in your care: ________________

○ Number of People in your household: ________________

○ How would you describe your economic status?

______________________________

○ Household Income (please check one):

□ Less than $15,000  □ 15,000 - $29,000  □ More than $29,000

○ Family Structure (please check one):

□ Married □ Living as Married □ Single Parent (caregiver) □ Divorced
o Health Insurance Type (please check one):
   □ Public  □ Private  □ Not Insured  □ Other __________

o Government Assistance (check ALL that apply to your household):
   □ SSI  □ Medicaid  □ Food Stamps  □ WIC
   □ Temporary Cash Assistance  □ Others________________________

HEALTH CARE NEEDS

o Rate how well your child’s (children) health care needs have been met by your health care
   provider(s).
      1 (not at all)  2  3  4  5  6  7  8  9  10 (highly met)

   Please explain why you chose the rating above:

o What health care needs do you feel are important for your child (children) (this can include
   physical, mental, dental, and emotional needs of any kind)?

o What have been your child’s (children’s) health care needs in the last 12 months?

o In the last 12 months, was there any time when YOUR CHILD (children) needed medical care,
   but did NOT get it? □ Yes  □ No

   If YES, please explain that experience below

o In the last 12 months, how many times did you take YOUR CHILD to a doctor’s office or clinic
   for care?

   Where do you primarily go to receive medical care?
In the last 12 months, when YOUR CHILD needed care, how often did your child get care as soon as you wanted it?  □ Always/usually  □ rarely/never  □ N/A

Please explain that experience below.

In the last 12 months has there been a time that your child was delayed in getting care due to cost?
□ Yes  □ No

If YES, please explain that experience below.

INFORMATION NEEDS

□ Where do you primarily go to receive health/medical information?

□ If a member of the medical team could give you all the time you needed today, what questions about raising your child would you like to talk to him/her about?

□ What are your concerns about the medical system, as it relates to your child’s care?

□ Have you ever met a child life specialist/received child life care?

If YES, please explain that experience below.

If NO, what do you think a child life specialist might do? (if you had to guess)

□ Are there any questions or comments you would like to express that we did not address above?

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APPENDIX C

HUMAN SUBJECTS APPROVAL LETTER

Office of Research Administration

Alton, OH 44025-2102
Phone: 330-972-5644
Fax: 330-972-4850
e-mail:sharon@kron.edu

NOTICE OF APPROVAL

Date: September 14, 2015

To: Scott Polachko PhD, CCC-SLP, School of Speech-Language Pathology and Audiology

From: Sharon McWhorter, IRB Administrator

IRB Number: 20150905

Title: Perceptions of Healthcare for Children from Caregivers in Perceived Poverty

Approval Date: September 14, 2015

Thank you for submitting your IRB Application for review. Your protocol represents minimal risk to subjects and matches the following federal category for exemption:

☐ Exemption 1 - Research conducted in established or commonly accepted educational settings, involving normal educational practice.

☐ Exemption 2 - Research involving the use of educational tests, survey procedures, interview procedures, or observation of public behavior.

☐ Exemption 3 - Research involving the use of educational tests, survey procedures, interview procedures, or observation of public behavior not exempt under category 2, but subjects are elected or appointed public officials or candidates for public office.

☐ Exemption 4 - Research involving the collection or study of existing data, documents, records, pathological specimens, or diagnostic specimens.

☐ Exemption 5 - Research and demonstration projects conducted by or subject to the approval of department or agency heads, and which are designed to study, evaluate, or otherwise examine public programs or benefits.

☐ Exemption 6 - Taste and food quality evaluation and consumer acceptability studies.

Annual continuation applications are not required for exempt projects. If you make changes to the study's design or procedures that increase the risk to subjects or include activities that do not fall within the approved exemption category, please contact the IRB to discuss whether or not a new application must be submitted. Any such changes or modifications must be reviewed and approved by the IRB prior to implementation.

Please retain this letter for your files. This office will hold your exemption application for a period of three years from the approval date. If you wish to continue this protocol beyond this period, you will need to submit another Exemption Request. If the research is being conducted for a master's thesis or doctoral dissertation, the student must file a copy of this letter with the thesis or dissertation.

☐ Approved consent form's enclosed

OHIO'S POLYTECHNIC UNIVERSITY
Uniting the Arts & Humanities with Science & Technology
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School of Speech-Language Pathology and Audiology

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Participant Signature (Consent to Participate) ___________________________ Date ___________