10-15-2021

Quality of Life Disparities For The Rural Economically Disadvantaged

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QUALITY OF LIFE DISPARITIES FOR THE RURAL ECONOMICALLY DISADVANTAGED:

A PHENOMENOLOGICAL STUDY

by

April Westerfield

October 2021

A Dissertation Presented in Partial Fulfillment

of the Requirements for the Degree

Doctor of Education in Ethical Leadership

The Dissertation In Practice Committee for April C. Westerfield certifies approval of the following Dissertation In Practice:

Quality of Life Disparities for the Rural Economically Disadvantaged Phenomenological METHODOLOGY

DISSERTATION IN PRACTICE TITLE

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ACKNOWLEDGMENTS

I cannot imagine that anyone truly completes the doctoral process alone. I know I have benefited greatly from the support of others and would like to thank my family, friends, colleagues, and Olivet faculty who have supported me during this journey. First, thank you to Dr. Pauls. Your insights, patience and nudging kept me on track when, if left to my own devices, I most certainly would have derailed. To Dr. Perry, to say that I was intimidated to have you as my reader would be quite the understatement. I appreciate so much your wisdom, which you share in such a kind and nurturing way. In addition to my reader, as an instructor, I found you inspiring.

To my family, thank you for rolling with my ideas, my referencing every encounter to my research and always believing I would finish. Mom, thank you for an endless supply of "happies" while I trudged along and for your pride in me. Shelby and Aaron, thank you for asking questions along the way, showing interest in how things were proceeding, and believing in me. Shelby, specifically, thank you for talking me off every single ledge, every single time. Kage, thank you for always being ready for a debate on my unfolding research and how it applies to the lives of those we know or how we could help others based on what I found. Lola and Eastyn, thank you for being the best parts of me, for always being the light in every day, and never letting me forget what really matters. Tracy, thank you for always assuming I had this, your faith in my abilities, although at times aggravating, was also a constant reminder that I could do this.

To my friends, Heather and Julie, you both deserve at least honorary doctorates. I cannot thank you enough for all the impromptu Q &A's, the proofreading, listening to me rant, reminding me why I was doing this, celebrating every grade, and your unwavering support. Dr. Phelps, your positive energy, unofficial mentorship, authentic discussions, and overall enthusiastic faith in my abilities are more appreciated than I can begin to explain. To my cohort, Robin, Laura, and Hunter, our group texts made this experience enjoyable at times when it was anything but. I am so thankful for all of you and am blessed to have gained your friendship through this experience. To my buddy Jeff H., we started this journey together and there is no question, your support kept me here. You have been my biggest cheerleader from week 1 and I cannot thank you enough for reminders when you didn't see my posts, problem solving sessions, texts of encouragement, but most of all your humor.

A special thank you to the families who chose to share their life experiences with me in order for me to complete this study. Your transparency and willingness to participate is the only way this happens.

Lastly, to my younger self, thank you for hanging in there, for letting experiences turn to lessons, for striving to be better, and for getting me to this point.

ABSTRACT

Families who reside in rural communities and live in poverty often experience a lack of quality of life supports, which impacts their mental health and exasperates any special needs they may have. Research in regards to these concerns, has historically focused on southern states and or the impacts of poverty in urban settings. This phenomenological qualitative research study reveals quality of life supports that impoverished families living in rural communities in central Illinois often do without. This study further examines the families' perceived barriers to those supports. The following research questions guided this study: (1) What quality-of-life supports (employment, food assistance, mental health services, special education) do impoverished families living in rural central Illinois believe they lack? (2) What do rural families identify as perceived barriers to receiving quality-of-life supports? (3) How are rural families impacted by lack of access to quality-of-life supports? (4) How are the children in rural families impacted by lack of access to quality-of-life supports? Data analysis of interviews and questionnaire responses from eight families living in rural communities in central Illinois explained a need for mental and physical health supports, food assistance, quality special education services, and local employment opportunities. In turn, the research yielded the following barriers to these supports: lack of transportation services, community resources (including food banks and service agencies), stigma, specialized educational programming/training, and acceptance of state funded insurance. Recommendations for further research include, longer, longitudinal study, larger interview pool, and children specific interviews.

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CHAPTER 1

INTRODUCTION

Research has started to look for a connection between the lived experiences of the economic disadvantage and where those who are disadvantaged live as far as rurality. There are undeniable links between poverty and children's development. These links look different depending on whether the children live in cities, suburbs, or rural areas. How communities impact the situation is underrepresented in research. Results of one study show that children in poverty experience very different community contexts depending on whether they live in an urban or rural area; this context is then associated with differences in children's direct achievement and what they achieve through parenting (Miller, Votruba-Drzal, & Coley, 2019). Cree, Bitsko, Robinson, et. al (2018) summarized their study by stating, that poverty, in addition to health care, family, and community factors are associated with mental, behavioral, and developmental disorders (MBDDs) in children. Parents' report data from 2016 indicated that

> a higher percentage of children in lower-income households had ever received a diagnosis of an MBDD and a lower percentage had seen a health care provider in the previous year, compared with children in higher-income households. Most children in lower-income households were in families receiving public assistance benefits. (Summary)

The poverty rate in the United States showed an overall increase between 2000-2006. In rural communities this increase was between 5-6% higher than in urban areas.

Making the overall poverty rate increase 14% for rural communities. This increase mirrored the increase of food insecurity. There was an increase in food insecurity across the United States between 2000-2006. The rate grew from 8 or 9% to 11%. In rural communities this percentage grew to 12% in 2006 (Huddleston-Casas, Charnigo, & Simmons, 2008). Reschovsky and Staiti (2005), noted that mental health resources are scarce among low income families who live in rural communities (2005). Zanjani and Rowles (2012) began, by stating that barriers to accessing services in rural areas include geographical, economic, social and cultural factors. Local school districts in rural areas also face unique challenges. Provasnik, KewalRamani, and Coleman, (2007), report rural schools are different from their urban counterparts in many ways. For instance, rural schools have higher poverty levels and lower student to staff ratios (Provasnik, KewalRamani, & Coleman, 2007). Furthermore, special education services and qualifying students who need this service in rural schools are also a problem according to administrators in rural districts (Berry, Petrin, Gravelle, & Farmer, 2011; Mitchem, Kossar, & Ludlow, 2006). To put rural scholastics into perspective, Johnson, Showalter, Klein, & Lester (2014) shared,

> over 9.7 million students are enrolled in rural school districts, more than 20 percent of all public school students in the United States. More than two in five of those rural students live in poverty, more than one in four is a child of color, and one in eight has changed residence in the previous 12 months. (p.27)

The authors further detailed, "rural education is frustrating to those who wish it would conform to the oversimplifications that have long held sway in the discourse of policymakers and the public in general. Those oversimplifications do not stand in the face

of the mounting evidence that rural education is becoming a bigger and even more complex part of our national educational landscape. As that evidence mounts, it is becoming impossible to ignore the national relevance of these students, families, schools and communities" (p. 28).

As noted in one medical journal, by Zahnd, Mueller-Luckey, Fogleman, & Jenkins (2019),

> Current rural-urban measures, while indeed descriptive of the population size and geographic isolation of administratively-defined geographic units, may not fully capture the socioeconomic milieu of rural areas. Furthermore, when these measures are used in statistical analyses, they are not frequently considered as contextual factors to describe place, nor are they considered in conjunction with socioeconomic characteristics as appropriately as they could be (p. 76).

Statement of the Problem

Families who are in rural communities and live in poverty often experience a lack of resources such as transportation, school of choice, adequate special education programming, and food programs, which impacts their mental health and exasperates any special needs they have. Phillips, Harper, and Gamble (2007) stated the problem facing rural communities this way, "We have an idyllic view of summer in rural communities: fresh air, garden vegetables, Vacation Bible school, ice-cold lemonade, and playing outdoors with friends. But for many children living in rural areas, summers are empty bellies, hours of boredom, and unsupervised care" (p 65). They went on to share that 2.5 million children in rural America are living in extreme poverty (p 65). The authors also shared that the general public often thinks of poverty as being a city problem, but that the

child poverty rates in rural areas have been higher than the urban rates for several decades.

Background and significance

"Approximately 97% of the landmass in the United States is classified as rural and 19% of the country's total population lives in rural communities" (U.S. Census Bureau,2010).

Deleon, Wakefield, Schultz, Williams, and Vandenbos (1989) noted that there is a "general deterioration" in the quality of life of rural Americans that is affecting the quality of health and mental health services (p. 933). The authors further observe that in these rural areas the citizens are older, less educated, have lower incomes, and are less diverse in terms of race and ethnicity. They further suggested that Medicare and private insurance discriminate against rural services in their reimbursement procedures. As of 2014, 32.9% of the nations' schools are located in rural communities (Johnson, Showalter, Klein, & Lester, 2014). According to the New Freedom Commission on Mental Health in 2004, adolescents who live in rural communities have a higher suicide rate than their urban peers, but are less likely to have access to mental health services. Blackstock, Chae, Mauk, and McDonald (2018) wrote that 11.3% of American adolescents have mental health disorders with severe impairment. Fewer than half receive any treatment, and those living in rural areas have additional barriers to treatment that are specific to them. Poverty, limited resources, and additional stigma are just a few of those rural specific barriers. Robinson, Holbrook, Bitsco, et al., (2017) reported that some accessibility factors, such as lack of knowledge regarding behavioral health needs and support for treatments, lack of financing, limited transportation, and social isolation can

contribute to behavioral health service barriers for youths in rural areas. Gamm, Stone, and Pittman, as reported by Robinson, Holbrook, Bitsco, et al (2017) went on to explain, additional, rural specific barriers in regards to behavioral health care include social factors such as stigma, cultural beliefs, and values that are unique to the rural community. Additionally, "stigma and a lack of anonymity of behavioral health treatment in rural communities can contribute to delays in seeking care and underuse of care" (Angold, Erkanli and Farmer, Reported by Robinson, Holbrook, and Bitsco, 2017, para 4).

In 2014, 3.9 million persons experienced some form of food insecurity according to a 2007 United States Department of Agriculture (USDA) report. The U.S. Department of Agriculture (USDA) defines food insecurity as a lack of consistent access to enough food for an active, healthy life (2019). Food insecurities negatively impact school, home, health, and mental health. As Shanafelt, Hearst, Wang, and Nanney (2016) report, "The implication of food insecurity spans personal health, home, and school context" (p 472). As reported by Shaefer, Mattingly, and Johnson (2016), the problems that most poor people struggle to overcome are intensified in rural areas due to remoteness and lack of support services. For example, limited access to well stocked grocery stores including fresh fruits and vegetables creates food deserts in rural areas, especially in terms of the rural poor who have limited access to reliable transportation. To make matters worse, these often generationally poor rural areas exist far from the media and governmental hot spots in a metro focused nation which make it difficult for policy makers, the media, and the general public to see and understand the extent of rural poverty.

In regard to family participation in care for their children with emotional problems, Pullmann, VanHooser, Hoffman, & Heflinger, (2010) stated that families face

additional challenges due to rural environments; these include stigma, transportation, isolation, poverty, and lack of services. School officials from rural areas reported that, "administrators share they have difficulty hiring qualified special education teachers, especially those qualified to teach students with emotional and behavioral disorders (EBD) and they have equal difficulty retaining teachers once they do hire" Berry, Petrin, Gravelle, & Farmer, (2011); Mitchem, Kossar, & Ludlow, (2006) shed light on the academic piece by reporting from school officials, (p 4). This is even more disturbing when according to Lipscomb, Haimsom, Liu, et al. (2017),

> youth with intellectual disability and emotional disturbance are the most socioeconomically disadvantaged disability groups and most likely to attend lower-performing schools. Youth in these two groups are more socioeconomically disadvantaged than youth with an IEP overall based on several parent-reported indicators, including parents' income, education, employment, and marital status. For example, 72 percent of youth with intellectual disability live in low-income households, which is 14 percentage points higher than youth with an IEP, on average. In addition, youth with intellectual disability and emotional disturbance are nearly 10 percentage points less likely to have an employed parent than youth with an IEP overall (80 percent). One-third of students in these groups attend a lower performing school, compared with 27 percent of all youth with an IEP. (p.7)

There is evidence of growing mental health associated disabilities in United States' schools. Students in rural communities are reported to have higher incidence of mental health disorders than their urban peers as reported by Nichols, Goforth, Sacra, and

Ahlers (2017). The researchers include, there is not equal evidence of how rural schools are prepared to support these students, when rural communities are ill equipped to support mental health needs in general. Children with mental health concerns are frequently found eligible for special education services (George, Zaheer, Kern, & Evans (2018).

In terms of mental health services and support, Roberts, Battaglia, and Epstein, (1999) identified multiple barriers to quality care in rural communities nationally. Regardless of where the rural community is located, they share many of the same barriers. “Rural caregivers face serious clinical ethical dilemmas every day. Because of isolation and poor resources, rural clinicians commonly provide care without optimal supports, services, and safeguards for their patients” (p 499). Many of the difficulties that anyone living in poverty experience are intensified by rurality. One of the most alarming, is a persistent rate of suicide among those living in rural communities (Musgrove, Jackson, Belanger, et. al, 2017). This may be an unfortunate connection to the fact that rural communities experience considerable disparities in mental health supports as reported by Jensen and Mendenhall (2017), who included that research about this topic is limited; however, specifically speaking from the lens of family therapy, what is known about the disparities comes mostly from work in other disciplines, this information “points to three primary barriers that prevent rural communities from accessing high quality mental health care: availability, accessibility, and acceptability of services” (abstract). Parent programming to assist parents in proactive strategies to combat mental health concerns in their children is available in some rural areas. However, many of the same concerns mentioned before prevent them from being effective. Lack of staff or

retention of staff to implement the programs, poor buy in from families who struggle with childcare, transportation, and basic needs and frankly do not need one more obligation or concern, and the complications that accompany rurality keep the programs from being offered consistently and across communities (Smokowski, Corona, Bacallao, et al. 2018). Blackstock, Chae, Mauk, & McDonald (2018) found, research further showed an importance for schools to identify and provide supports for children with disabilities, even more so in rural areas where they may be the only access children have to those supports. Though under-researched, the research that has been reported showed fewer mental health supports for children in rural communities compared to those in urban communities. In addition, those children from rural areas who are seen for mental health concerns are more likely to receive medication in lieu of therapy.

A study by Casas, Charnigo, and Simmons (2008), found evidence of a relationship between food insecurity and depression in a sample of rural, low-income women. The researchers may be the first to examine the relationship between food insecurity and depression longitudinally. Casas, Charnigo, and Simmons (2008), noted that previous research demonstrated the two are closely related. The researchers discovered that barriers to alleviating food insecurities in rural communities included, high prices and lack of food stamps. Rural supermarkets charged higher prices for items than suburban areas markets. In addition, not all rural communities had grocery stores. This made transportation another barrier to alleviating the problem. Casas, Charnigo and Simmons concluded that if families cannot make it to the grocery store, they are not likely to have transportation to keep up with appointments at assistance program locations either.

An additional link to food insecurity and mental health was reported by Afulani, Coleman-Jensen & Herman (2020), when they stated in that their findings,

> food insecurity is associated with poor mental health and inadequate use of mental health services. Programs that provide food assistance could potentially serve as contact points for identifying adults with mental health problems and helping them access mental health care. Reducing food insecurity may possibly help reduce mental health issues. (Abstract)

Pollak and Wolfe (2020), reiterated what other research has stated in regards to poverty rate, implications of poverty on child development both psychologically and physically, and how this translates to adulthood in an unfavorable way. They echoed the data regarding children in poverty performing worse in school, from school readiness, to standard performance, to graduation rates, that children living in poverty have higher rates of mental health concerns, and often have higher incidence of emotional and behavioral problems. They questioned, what specifically causes the negative outcomes, specifically the physiological, cognitive, and social factors? Their study shed light on these questions, but the researchers shared that they still do not have concrete answers.

In a policy brief by Lauer (2016), inequalities or lack of access to education, housing, employment, and transportation for those living in rural poverty were addressed. This author shared that a shift has occurred from the number of people living in urban poverty to those living in rural poverty. Those living in poverty often use more than 40% of their income on housing and often find themselves unable to afford this or find themselves in less than desirable neighborhoods in order to provide shelter. Children in these families experience profound negative effects in regards to education, including

enrollment in AP courses, school engagement, GPA, test scores, and graduation rates. These outcomes have long-term consequences for the children who experience this and their communities. Lauer continued by addressing general economics and noted that once it was thought that working hard would allow for one to provide for their family, when in today's reality, often minimum wage has been unchanged for years and the hardest working are still left without means. He further mentioned,

> access to transportation is a fundamental component in escaping poverty. Without adequate transportation, individuals and families cannot access what is necessary to escape poverty, such as employment, education, health care, and human services. Transportation allows people to take advantage of opportunities not only in their own communities but in the broader regions in which they live (p.5).

Research Questions

The research questions that guided the current study were:

1. What quality-of-life supports (employment, food assistance, mental health services, special education) do impoverished families living in rural central Illinois believe they lack?
2. What do rural families identify as perceived barriers to receiving quality-of-life supports?
3. How are rural families impacted by lack of access to quality-of-life supports?
4. How are the children in rural families impacted by lack of access to quality-of-life supports?

Significance of the Study

While the mainstream media and social activist often bring to light the difficulties of urban poverty, little public attention is shown toward those living in rural poverty (Gurley, 2016). Living without is not easy for anyone. Gaining access to services in rural areas is a challenge that will be examined in the current study. The purpose of the current study is to explore the availability of, and access to, quality of life services in rural Midwestern communities in order to provide insight into strategies for improvement. According to Gibson and Barr (2017), children living in poverty across the United States face poor nutrition, frequent mobility, lack of health care, and toxic stress. In school situations these students have additional concerns such as, bullying, lack of quality education and educators. An underlying problem these children and their families must deal with is poverty bias. These authors reported that minimum wage jobs are not enough to keep families afloat. The research implies that higher education is key to above minimum wage, yet the research shows that children living in poverty are less likely to achieve higher education, and most likely to drop out, feeding the cycle of generational poverty. Hirano, Rowe, Lindstrom & Chan (2018) posed reasoning for lack of parental involvement in transition planning for their children with disabilities to include "stress, limited resources, lack of cultural capital, and low self efficacy" (p. 3445). They further explained that their research found three areas where barriers occur. The first is within the school itself and involve things such as discrimination and lack of accessible information for families as well as disregard for the families input. The second lies within adult based services and includes things such as low expectations for the student, lack of viable post-secondary options, and lack of regard for family input. The final overarching

area lies within the families and include, inability for self-efficacy, lack of resources, and lack of knowledge of how to improve or get support for these things. The authors included that regardless of the state and federal requirements for family involvement in school and after school planning, school-home collaboration and communication are often lacking, especially for families who are low-income and have cultural or language differences. Transition planning is one of the final phases of parent and school collaboration before students are expected to navigate post school life and yet the U.S Department of Labor (2019) released "In 2019, 19.3 percent of persons with a disability were employed, the U.S. Bureau of Labor Statistics reported today. In contrast, the employment-population ratio for persons without a disability was 66.3 percent. The unemployment rates for both persons with and without a disability declined from the previous year to 7.3 percent and 3.5 percent, respectively" (accessed 7/2/2020).

Families in need of quality mental health services, whose children need quality special education services, who do not have enough to eat, who have limited employment opportunities, and face unique barriers to these things due to rural living and economic disadvantage have stories to share. Their stories are important in understanding their situations, compelling others to help, and developing plans for support.

Overview of Methodology

The purpose of this phenomenological study was to explore the lived experiences of rural families with low socioeconomic status who experience barriers to quality of life supports. Participants consisted of no fewer than one member of five families and no more than three members of 15 families. The families lived in various rural communities within central Illinois. The families were chosen based on willingness to participate,

residence, and perceived need. The participants were from different rural midwestern counties in central Illinois. This researcher used a series of questions pertaining to quality of life supports (defined as food security, mental health care, employment opportunities, and quality special education services) and barriers to those supports. The researcher used a combination of unstructured interviews and secondary follow up questions after initial coding for this Phenomenological study. In addition, follow up surveys were used to ensure all responses were understood.

Sample interview question may be: Please circle the statement that best describes your experiences in working with your child's special education case manager.

a. I receive regular meaningful communication (phone call, text, email, or meeting no less than monthly that shares what he/she is doing at what level and progress toward goals, concerns, in meeting goals, etc.) directly from the case manager.
b. I receive a yearly notice to come to a meeting to discuss his/her plan.

Additional sample interview questions may be:

Please take 3-5 minutes to respond to the questions below regarding your experiences with mental health care in the past 3 months.

a. What has been the most difficult part of accessing mental health supports?
b. What are two things you feel would help with the above?

In addition to questioning, this researcher collected surveys to determine which supports are underrepresented in no fewer than 3 and no more than 5 rural Illinois Communities.

Once the underrepresented supports were identified, the researcher used the same methodology to determine what present barriers to those supports are reported by the family participants.

The data was recorded and aggregated into common themes. These themes were compared to the literature to determine what if anything has been done to focus on the barriers to the supports listed within the themes. This information was shared in the research and next steps will be suggested. Chapter II contains a review of related literature on rurality, quality of life disparities for those living in rural poverty, and barrier to supports.

Summary

A large majority of the United States population lives in rural communities. Living in rural areas presents unique challenges. When you compound those challenges with economic disadvantages those challenges become barriers.

The primary focus of this study was to shed light on the barriers that people of low socioeconomic status who live in rural areas face. There is a need to understand that disadvantage looks differently when compounded by rurality and that resources that are available for those in need may be unavailable for those in need who live in rural areas.

Description of Terms

Emotional/behavioral concerns: For the purpose of this study, emotional/behavioral concerns is defined as the educational diagnosis or reference for mental health concerns that impact a students' education, academically, social emotionally, or both.

Food insecurity: For the purpose of this study, food insecurity is defined as not enough food in the home to make two full meals for each resident every day of the week.

Quality of life supports: For the purpose of this study, quality of life supports is defined as needs such as food, employment, mental health treatment, and education.

Rural: As defined by the U.S. Census Bureau is everything not urban "less dense, sparse population, not built up, at a distance."

SNAP: For the purpose of this study, SNAP or SNAP benefits are benefits afforded to families in financial need. These benefits pay for food and in some instances food and money for monthly needs.

Socioeconomic status: For the purpose of this study, socioeconomic status is lifestyle allowed based on household income.

CHAPTER II

REVIEW OF THE LITERATURE

Introduction

According to the U.S. Census Bureau (2010) approximately 97% of the United States is classified as rural, and 19% of the country's total population lives in rural communities. This number equates to nearly 50 million people living in nonmetropolitan counties (Galambos, 2005). Twenty-four percent of the U.S students making up 32.9% of the schools are a subset of this population (Blackstock, Chae, Mauk, & McDonald, 2018). Rural, as defined by the United States Department of Agriculture, is a combination of open countryside, rural towns with fewer than 2,500 people, and urban areas with populations ranging from 2,500 to 49,999 persons that are not part of larger labor market areas.

Hartley (2011), shared that most research focused on urban environments more than rural ones in relation to health. Harley stated that physical environment, in addition to income and education, impacts physical health in rural communities. The USDA reported in 2004 that nonmetro poverty rate remained consistently higher than the metro rate. USDA further reported in 2004 that adult education levels were far below the national average for those living in rural communities.

Rural Communities Socioeconomics

Lichter and Ziliak (2017), began by pointing out that rural America is often left out of policy discussions as they are so far removed from the mainstream culture and

economics. The authors shared that approximately 46 million people living in the rural areas have been left behind while their urban counterparts thrive. Living in a poor or low-income household is a disturbingly common occurrence that many Americans will experience over the course of their lives. (Rank & Hirschl, 2015).

Huddleston-Casas, Charnigo, and Simmons (2009) wrote "Poverty is a significant problem in the USA that is associated with a number of public health concerns, including poor mental and physical health status and disparities in health care" (p. 1134). The authors reported that the national poverty rate increased between 2000 and 2006. In rural areas, the rate increased by 5 to 6% more than the national average. Mohatt, Bradley, Adams, and Morris, (2005) echoed this information as they noted lower paying jobs and greater childhood poverty in rural areas compared to urban. Pascoe, Wood, Duffee, and Kuo (2016) argued that children's development was impacted by the health of their parents and their immediate as well as extended family and the community in which they lived. They pointed out that children's development, parents' health and community was impacted by the family's social, financial, and health status.

Poverty poses another concern for these families in the form of food insecurity. In 2014, 10% or 3.9 million of U.S. families with children experienced a form of food insecurity (Shanafelt, Heartst, Wang, & Nanney 2016). According to the U.S. Department of Agriculture (USDA), in 2012 those numbers were more than 14% or 17.6 million households. Rural America is more likely to succumb to food deserts as the small-town groceries decrease and the distance between big chains increases (Piontak, & Schulman, 2014). Piontak and Schulman further reported that rural areas lacked resources such as mass transit and social services, like food pantries or soup kitchens, which their

urban counterparts may have to assist with food insecurities. The Food Access Research Atlas, developed by the USDA to track food insecurity trends, tracks population, grocery store location, and general food location. Piontak and Schulman shared, that the atlas clearly shows a discrepancy in resources. The atlas, shows large concentrations of hunger and lack of food in impoverished rural areas.

Thiede, Lichter, and Slack (2016) identified an increase in rural poor who are unemployed and that those who are employed are also at risk of poverty. The author's results pointed out a grim projection for the economic status of those in the rural workforce. Probst, Barker, Enders and Gardiner (2016), stated that "Rural counties are economically disadvantaged, leading to higher rates of poverty among rural versus urban children" (para 3).

Kelly-Reif, and Wing (2016) described the disparity between urban and rural as environmental injustice in their study. Their study stated that when one population benefits from the harm done to another population, it is unjust. The authors explained this typically happens in cases surrounding disparities in economic and political power and typically falls in line with dimensions of race and class. Kelly-Reif and Wing contended that urban-rural dimensions of this injustice do exist, claiming one example is urban populations benefiting from rural production while rural residence are left with pollutants and negatives of those productions without the financial gain. The researchers explained this as a "parasitic relationship between urban and rural communities because urban populations obtain most of their food and energy from rural areas and return their wats to rural areas" (p.1).

Rural Communities Mental /Physical Health

At least 15 million rural residents struggle with significant substance dependence, mental illnesses, and medical-psychiatric comorbid conditions (Roberts, Battaglia, & Epstein,1999). Rural mental health services and systems are plagued by a number of problems, including shortages of mental health professionals, budget constraints, stigma associated with mental illness, stigma for seeking help for such illness, and lack of collaboration between primary care and mental health care services (Jameson, Chambles, & Blank, 2009). Carpenter-Song, and Snell-Rood (2017) shared that "Entrenched poverty has long contributed to serious disparities in mental health and access to services for the 20% of Americans who live in rural areas" (p. 503). According to the U.S. Department of Health and Human Services (2017), approximately 62% of the identified mental health professional shortage areas are located in rural areas. In terms of physical health, the data is not much better, as noted by Bolin, et al. (2015). They reported that the US Census in 2010 showed 25% of the people living in rural communities, but only 9% of doctors and 16% of registered nurses practice there. In addition, the authors noted that there is a shortage of nurse practitioners, dentists, pharmacists, and specialty care in rural areas.

Findings from Bolin, Bellamy, Ferdinand, et al. (2015) included, "Rural health priorities have changed little in the last decade. Access to health care continues to be the most frequently identified rural health priority. Within this priority, emergency services, primary care, and insurance generate the most concern" (p. 326). According to Pascoe, Wood, Duffee, and Kuo (2016), poor families experience many stressors that inevitably impact their health. Two examples that impact childhood health are housing and food insecurities. A less -discussed health concern that arises as a result of poverty is relational

health. Crockenberg (1981) as cited by, Pascoe, et al. (2016), defined relational health in early childhood "as the ability to form secure attachments with engaged, responsive caregivers in a safe, stable, and nurturing emotional environment" (p. 2). The study delved further into physical and relational health and the negative impacts of poverty by pointing out how lack of finances can negatively impact relationships, therefore bringing additional stress into the home, which inevitably impacts children in the home in a negative way. Silva, Loureiro, and Cardoso (2016) reiterated these statements in their review of evidence regarding social determinants of mental health. The authors wrote "Higher rates of mental disorders are associated with social disadvantage, especially with low income, limited education, occupational status and financial strain" (para 2). They observed that lack of social support including poor neighborhood characteristics increase the risk of mental health problems and concluded by suggesting that in order to improve the mental health concerns, the needs of both the individual and the neighborhoods should be addressed.

Robinson, et al. (2017) reported on mental, behavioral, and developmental disorders (MBDDs) in their study on health care, community, and other factors surrounding mental health. The authors observed that mental health is a major component to physical health. They also stated that people who live in rural communities, in comparison to their urban peers, have health related disparities including worse health, risky health behaviors, and less access to resources. The researchers identified specific rural barriers to behavioral health care that included stigma, which is present everywhere, but often worsened in small communities due to lack of anonymity. This stigma often is a cause for delay in seeking care or utilizing care for mental health, lack of information

about treatment or options for treatment, and lack of access by way of finances, limited transportation, and limited providers.

Adverse childhood experiences (ACEs), which are traumatic events experienced by children before the age of 18, are directly linked to long term health and mental health consequences (Whiteside-Mansell, McKelvey, Saccente, & Selig, 2019). The authors echoed other studies that found children living in rural areas are at higher risk for health concerns such as obesity and developmental concerns. They also noted, as have others, that rural parents are less likely to be educated or have access to consistent full-time employment, as many urban parents do. The authors noted the above-listed factors contribute to health outcomes. In a unique study, Whiteside-Mansell, Mckelvey, Saccente, and Selig (2019), examined the environmental experiences, particularly ACEs and how they impact children in rural communities. Deighton, Neville, Pusch, and Dobson (2018), share that "Adverse Childhood Experiences (ACEs) are stressful and/or traumatic experiences that occur during childhood. Research has demonstrated a link between ACEs and risk of physical and mental health disorders, where early life adversity may become "biologically embedded" and have wide-ranging effects on various physiological systems" (p.1). As few as one ACE can begin to negatively impact a person's health. The researchers found that 41% of children from birth to 5 years old living in rural communities scored at least a 1 on ACEs, compared to 35% of urban children birth to 5 years old. Similarly, et al. (2018), shared specifically that childhood adversity such as abuse, neglect, and environmental instability, which make up the childhood experiences or ACEs, are associated with poorer physical and mental health as well as risky behaviors, and increased mortality. They note that low socioeconomic status

and lack of local services, among other things, contributed to the stable family environment. The authors pointed out that lack of resources is typically one factor already at play for many children living in rural communities.

According to the National Center for Health Statistics (2012), as cited by Hodgkinson, Godoy, Beers and Lewin (2017), there is a wide range of research linking poverty to lower ratings on measures of overall well-being across a person's life span. The study reported that children who come from lower socioeconomic situations have higher rates of parents with unsupported mental health needs. Based on the information shared by Cree, et al. (2018), childhood mental, behavioral, and developmental disorders, (MBDDs) are associated with adverse outcomes and can continue into adulthood. Early intervention can alleviate these outcomes and help with healthy development for all children, especially those living in poverty who are at increased risk for MBDDs and often have reduced access to supports. Based on survey results collected during the study, the percentage of children ages 2-8 with at least one MBDD was higher in lower income homes and the percentage who accessed early intervention was lower in lower income homes.

A closer look at mental health, specifically suicide, was examined in a study conducted by Fontanella, et al. (2015), the study showed a higher rate of suicide completion in men living in rural communities than those living in urban areas and more attempts by rural teens than urban teens. The authors concluded that youth suicide rates continue to be higher in rural settings, and suggested action was necessary to improve mental health services and supports in rural communities. Kegler, Stone and Holland

(2017) also found higher suicide rates in less urban areas and called for suicide prevention supports for those areas.

Jameson and Curtin (2015) focused on older adults who live in rural communities. They found that stigma in forms of both self and public, may be a large barrier to obtaining mental health supports. Compared to their urban counterparts, rural residents reported stigma as a barrier more often. The authors noted that the smaller community size made confidentiality more of a challenge. Olfson (2016) furthered the conversation on mental health in rural communities by offering that mental health care in rural settings can often be difficult and long periods between onset of illness and treatment negatively impact outcomes. Olfson noted many factors contribute to delayed treatment and barriers to accessing services. He also conceded that the unmet need for mental health care is mostly among, individuals who are working age, have lower socioeconomic status, live in rural communities, and lack health insurance (Wang, et. al 2005, Roll, Kennedy, & Howell, (2013), reported cited by Olfson, 2016).

The geographical factors surrounding mental health supports and rurality were discussed in an article authored by Andrilla, Patterson, Gaberson, et al. (2018). These authors noted similar statistics, in regards to need for mental health services. They shared that in 2015 out of over 43 million adults over the age of 18 in the United States, 17% had some type of behavioral health concern. They reported the difference in per capita expenses in supporting these needs based on census division. They shared a drastic difference in the percentage of counties without access to a psychiatrist between the New England Census Division, which reported a 6% need and the West North Central Census

Division whose need was 69%. Further emphasizing that rural counties lacked access to a psychiatrist.

Jensen, Wieling, and Mendenhall (2020) echo some of these insights and further explain that in their study, participants discussed ruralism as a culture. Within the rural culture people are often somewhat isolated and therefore, on their own to make things happen and are solely responsible if they don't. The authors translate this mindset as it relates to mental health and discuss how this way of thinking could be another obstacle to seeking and accepting help for mental health needs. They go on to explain that phrases such as I can handle this, or I will manage this on my own are common within those living in rural communities. A second point the participants made within this study was the lack of anonymity in small towns. They shared how everyone knows everyone and are often related to each other. This makes for easy gossip and an expectation to follow the local norms, which do not include seeking mental health supports. Some participants who were part of this study were mental health providers. They shared that availability, accessibility, and acceptability were barriers to services they witness in rural communities. They further explained that often they are the only provider for several rural communities. They shared that often highly qualified professionals do not want to leave metro areas and the amenities that are there. As far as accessibility, the providers shared that things such as transportation, cost, and distance keep rural clients from accessing the few services that do exist in their area. Lastly the providers shared that acceptability is another barrier to services. They reported that clients in rural communities seem more guarded, less accepting of services and often more stigmatized if they reach out for supports.

Probst, Barker, Enders, and Gardiner (2016) stated that even though rural and urban children are equally likely to be insured, rural children are proportionally higher recipients of Medicaid. The authors discovered that rural children are more likely to be overweight or obese than their urban peers. Rural children are less likely to come from households where preventative medical or oral health visits are a priority and that rural children are more likely to die by accident that their urban peers. Garcia, et al. (2017) observed that rural communities experience higher age-adjusted death rates and higher numbers of excess deaths from the five leading causes of death in the United States, which are, heart disease, cancer, unintentional injury, chronic lower respiratory disease, and stroke, compared to those in urban communities. These higher death rates are often due to interconnected societal, geographic, behavioral, and structural factors (p. 6).

Rural Mental Health and Education

More than 9 million students attend rural public schools in the United States, and more than 1.5 million of those students receive special education services (Snyder & Dillow, 2015). Rural school communities are different from their urban and suburban counterparts in that they have higher poverty levels and lower student -to- support -staff ratio, in this case support staff such as school psychologist. Students have lower rates of postsecondary education enrollment when coming from rural schools. In addition, rural schools have their own unique challenges when it comes to providing special education services to their students, particularly students who have emotional difficulties (Huscroft-D'Angelo, January, & Hurley, 2018; Tine (2019). Showalter, Hartman, Johnson and Klein (2010) have this to share regarding education in rural school districts.

> Nationally, the communities around schools in rural districts have an average household income 2.68 times (268%) that of the poverty line. Although only 1 in 200 rural school communities has an average income below the poverty line, 1 in 6 has an average income below 185% of the poverty line (which is the federal cutoff for reduced price meals). Students with IEPs require additional services only partly supported by supplemental federal funds, placing additional responsibilities on state and local funds. Poverty is consistently correlated with most educational outcomes, so it is essential that this report include some measures of poverty. Unfortunately, recent shifts in how discounted meal eligibility is reported make this a less reliable measure of poverty than it once was (p. 19).

The shortage of special education teachers is widely publicized and discussed with some regularity. What is sometimes missed is that this shortage is intensified in rural communities (Gregory, 2018). Azano, Stewart, and Thomas (2016) contended that, small class sizes and quiet rural living are not strong enough incentives to drown out poverty related student/family issues, isolation, and lower teacher salaries. Therefore, recruiting highly qualified teachers to rural schools remains a struggle. Tran & Smith (2020), shared these specifics in their study:

> Results from the most recent National Center for Education Statistics (NCES) Schools and Staffing Survey showed that 7.7% of all public school teachers left teaching in 2012–13. By community type, this attrition breaks down to 6.4% of town, 7.3% of suburban, 7.9% of city, and 8.4% of rural teachers. As can be seen, schools in the rural context experience higher rates of teachers leaving the

> classroom, which results in a greater need to hire new teachers. In addition, there is an association between poverty and teacher shortages. For example, 9.8% of teachers left the profession annually in schools with 75% or more of students approved for free or reduced lunch compared with 6.9% in schools with 34% or less of students approved for free or reduced lunch in 2012–13 (Goldring et al. 2014). Coupled together, high-poverty rural districts experience magnified teacher-staffing issues. Although "hard-to-staff" schools are prevalent in both rural and urban contexts (Taie and Goldring 2017), rural schools often do not receive comparable policy or scholarly attention when compared with their urban counterparts (Corbett and White 2014) (p. 447).

Behavior intervention plans can be a positive approach to working with students who exhibit troubling behaviors in school, according to Oram, Owens, and Maras (2016). Rural specific barriers to implementing these plans include the finding that rural residents are less likely to report a need for mental health services (Gamm, Stone, & Pittman, 2003 as cited by Oram, Owens, & Maras, 2016). This lack of reporting can lead to higher suicide rates (Centers for Disease Control and Prevention, 2014 as cited by Oram, Owens, & Maras, 2016). In addition, children living in rural areas are less likely to receive mental and behavioral health intervention (Calloway, et al., 1999 as cited by Oram, Owens, & Maras, 2016). This could be in part due to rural populations having less access to high-quality health care (Gamm & Hutchinson, 2003; Glasgow, Morton, & Johnson, 2004; Pande & Yazbek, 2003 as cited by Oram, Owens, & Maras, 2016). In addition to the difficulties in addressing the behavior plan specifically as a part of the entire plan, is the fact that there is little research on entire educational plans for students

with emotional needs in general, but in particularly in rural communities. Hott, et al. (2019) researched individualized educational plans (IEP) written for students with emotional/behavioral concerns who attended school in rural communities. They found the plans to be out of compliance. They found that rural special educators were typically isolated, lacked access to specialized colleagues, and often had to rely to remote professional development. Their study noted that to date, there is little research specific to rural special educator support or IEP writing, and compliance in rural areas. The researchers included that rural special educators are required to fulfill multiple roles and often have large caseloads due to less resources, included personnel. They encourage further research and plan development to assist those teaching students with special needs in rural settings. Atkins, et al. (2017) discussed mental health in regards to schools. In summary they found with the continual increase in mental health needs in young people, schools have become the only access to service providers for mental healthcare to which many families have access. However, access, does not equate to readiness to fill this need on the part of the school personnel. The authors noted that in order for children to be successful academically, they must be well emotionally. They stated that mental health providers have wanted to implement prevention and intervention services within the educational setting for a long time, but have made little progress toward this collaborative goal. Lastly, this study discussed the profound impact the stress has on the teachers and how impactful this is on the students. They recommended further research to investigate the latter in addition to the collaborative supports for student

Another educational concern for rural families concerns Autism Spectrum Disorder (ASD). According to a study by Antezana, Scarpa, Valdespino, Albright, and

Richey (2017), the prevalence of ASD in rural communities and urban areas is not drastically different, but access to resources for early diagnosis and intervention is not readily available for those in rural settings. Furthermore, Rhoades et al., 2007 as cited by Antezana, et al. (2017) reported that in addition to lack of access to basic care for rural areas, there is also a lack of evidence-based practices for identifying and providing services for those with Autism Spectrum Disorder. The study found that the combination of these factors led to poor outcomes for children in rural areas that include delayed screenings, diagnosis and interventions; the result was worse overall educational and functional outcomes for those who need those supports.

When speaking to the least restrictive environment (LRE) for educating students with disabilities, the law states that students with disabilities must be educated with non disabled peers to the extent possible. This requires an understanding of students with disabilities by not only the special educator, but the general education teacher as well (Illinois State Board of Education, 2020). Further detail regarding LRE and findings related to placement decisions of students with special needs were described by Kurth, Ruppar, Toews, McCabe, McQueston, and Johnston (2019).

> We were also concerned about factors IEP teams documented as considerations in making LRE decisions. According to IDEA (Sec. 612[29]), special education is defined as "specially designed instruction." IDEA further stipulates students are eligible to receive special education services if they (a) have a disability and (b) need special education services by reason of their disability (Sec. 612[3][A]). Yet, in our analysis, we found IEP teams justified removal of students with disabilities because of these criteria (i.e., having a disability and requiring specially designed

> instruction). We assert that this contradicts the LRE requirement of IDEA, in which students are assumed to both have a disability and require specially designed instruction to be eligible for IDEA services, and should only be removed from general education settings "when the nature or severity of the disability of the child is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily" (Sec. 612[5][A]). Relatedly, we found no LRE justification statements referring to the provision of supplementary aids and services, nor any discussion of how these were considered when making LRE decisions.

In addition, Finigan-Carr, et al. (2015) shared a report written by Reardon in 2013 based on data from 12 nationally represented studies that found the gap in standardized test scores of high- and low-income families has grown by about 40% over the prior three decades. Biddle, and Azan, (2016), reported that researchers had been trying for over a century to explain the complexity and uniqueness of rural schools. The authors observed that the need for change in rural schools is well documented as far back as Roosevelt's presidency when he was charged with the task of making rural America more appealing. One of the noted obstacles to that task was the state of rural schools (Biddle, & Azan, 2016).

Votruba-Drzal, Miller, and Coley (2015) discussed the impact of children living in poverty in rural America. Based on their research, the United States poverty rate in rural communities is equivalent to that of Bulgaria and Romania. The study sheds light on how poverty in early childhood life correlates to struggles in transitioning to school, less success in school, and lower educational attainment. The study points to resources

and stressors as guiding forces in the academic success for children of poverty. “Poverty is associated with children's early skills. In the United States, poverty-related disparities in cognitive skills emerge in infancy, and by kindergarten, children from low-income households score approximately 0.70 standard deviations lower than high-income children on core language, reading, and math skills” (p. 4). The researchers conclude their study by stating there is a need for a new approach to studying childhood poverty (Votruba-Drzal, Miller, & Coley, 2015).

In a 2019 study, Koricich, Chen and Hughes described the lack of rural students’ opportunity for college experiences as being an historic problem that has significant consequences for the students and their communities. As stated in the 1995, United States Development Program, “Poverty anywhere is a threat to prosperity everywhere.”

The differences between rural and nonrural schools were discussed in terms of organizational systems in the analysis by Johnson and Howley, (2015). The two explained that federal policies that pushed school improvement, including the distribution of funding, often adopted a cookie cutter model that does not allow for the differences rural schools face.

Conclusion

In conclusion, poverty is higher in rural areas. When discussing poverty in the United States, most researchers looked to urban areas; yet historically, rural areas have a higher poverty rate. At some points in time, the poverty rate in rural areas has been double that of urban areas. Data from 2015 shows that 16.7 percent of the rural population was poor, where as 13 percent of the overall urban population was reported to be classified as poor, with only 10 percent of the urban population that live in suburban

areas just outside of the larger city limits being classified as poor. Secondly, most new jobs are not in rural areas. Thieded, et. al (2017) reported, that most rural communities have yet to recover the jobs lost during the recession of 2007. Furthermore, census data shows that rural job market is 4.26 percent smaller than during the recession. Third, data from the American Community Survey, which is an annual government poll, shows that disabilities are more common in rural areas. The occurrence of disabilities in urban areas is reported at 11.8 percent to 15.6 percent in rural areas and 17.7 in remote urban areas. (Thiede, et al., 2017).

In an attempt to shed light on the lack of access to quality of life supports for the rural poor, the researcher of the current study conducted a phenomenological study. (Creswell & Poth, p. 121). As stated by Yiksel and Yildirim (2015), the purpose of phenomenological research is to share the reality of the individuals through narratives of their experiences. Mapp (2013) stressed that only those who live through an experience can truly communicate the experience to others. When researching phenomenological studies using Google Scholar, the majority of articles first shared are related to mental and or physical health and lived experiences of care workers and families of those impacted. Albert and Simpson (2015), reported on the experiences of being a care provider during a mental health crisis. Zhang, Yan, Barribal, While, & Liu (2015) used a phenomenological study to examine the increase of PTSD in mothers of children with autism. The benefit of using a phenomenological approach includes gathering information from individuals who are living the situation vs. deriving information from literature only or from perceptions of those who are removed from the problem at hand.

Summary

The purpose of the current study was to explore the lived experiences of rural families with low socioeconomic status who experience barriers to quality of life supports. In doing this exploration, the following research questions were addressed:

1. What are common quality-of-life supports rural families need access to?
2. What are barriers shared by rural families who are financially disadvantaged?
3. How are impoverished rural families in central Illinois impacted by lack of opportunity and access to quality of life supports?

CHAPTER III

METHODOLOGY

Introduction

Chapter III includes a description of the phenomenological methodology used to share the life experiences of families living in rural central Illinois communities who require access to quality of life services such as, mental/medical health supports, food, transportation, special education services and/or employment. Who face barriers to obtaining those services, and the additional barriers they face due to living in rural communities. Neubauer, Witkop, and Varpio (2019) explained "Phenomenology is a form of qualitative research that focuses on the study of an individual's lived experiences within the world" (p. 1). Teherani, Martimianakis, Stenfors-Hayes, Wadhwa, and Varpio (2015) added:

> Phenomenology can be defined as an approach to research that seeks to describe the essence of a phenomenon by exploring it from the perspective of those who have experienced it. The goal of phenomenology is to describe the meaning of this experience—both in terms of what was experienced and how it was experienced. (p.2)

The purpose of the current study is to explore the availability of, and access to, quality-of-life services in rural Midwestern communities in order to provide insight into strategies for improvement. This study will focus on the point of view of families who experience specific needs educationally, financially and emotionally. The researcher

conducted interviews with family members regarding supports they need for daily activity as well as any barriers they perceived to limit those supports. According to Korstjens and Moser (2017), “qualitative research takes into account the natural contexts in which individuals or groups function, as its aim is to provide an in-depth understanding of real- world problems” (p. 275). Korstjensand Moser (2017), had this to contribute regarding research questions, “to enable a thorough in-depth description, exploration or explanation of the phenomenon under study, in general, research questions need to be broad and open to unexpected findings”. “Depending on the research process, you might feel a need for fine-tuning or additional questions. This is common in qualitative research as it works with ‘emerging design,’ which means that it is not possible to plan the research in detail at the start, as the researchers have to be responsive to what they find as the research proceeds. This flexibility within the design is seen as a strength in qualitative research but only within an overall coherent methodology” (p. 275).

The following research questions guided this study:

1. What quality-of-life supports (employment, food assistance, mental health services, special education) do impoverished families living in rural central Illinois believe they lack?
2. What do rural families identify as perceived barriers to receiving quality-of-life supports?
3. How are rural families impacted by lack of access to quality-of-life supports?
4. How are the children in rural families impacted by lack of access to quality-of-life supports?

Research Design

Gerring (2017) explained that qualitative data are ideal for exploratory analysis. More generally, one might argue that social science knowledge typically begins at a qualitative level and then (sometimes) proceeds to a quantitative level. Second, qualitative data are likely to be more useful in so far as a study is focused on a single case (or event) or a small number of cases (or events). Dowling, Loyd, Suchet-Pearson (2016), pointed out that qualitative interviews – semi-structured or unstructured, with individuals or with groups – continue to dominate in the social and cultural geography subdisciplines. They expanded their explanation of qualitative research by sharing that an important characteristic of qualitative interviews over the past few years has been their use to shed light on issues of concern to other human geography subdisciplines, especially economic and political geography. Mauk (2017) reiterated these important aspects of qualitative research, "in contrast to quantitative research, qualitative research focuses on words instead of numbers, on understanding and giving meaning to a phenomenon or event." "Qualitative research is more exploratory and inductive, while quantitative research aims to reach conclusions by deduction and hypothesis testing." "With qualitative studies, researchers often discover those important aspects of inquiry that would be easily missed if the researchers had relied completely on quantitative data" (p. 222). This researcher selected qualitative research because it afforded the ability to tell the life experiences of families whose voices may not often be heard.

There are variations of qualitative research. The researcher chose a phenomenological study. As Moran (2000) states phenomenology is a "practice rather than a system…the attempt to get to the truth of matters, to describe phenomena, in the

broadest sense as whatever appears in the matter in which it appears, that is as it manifests itself to consciousness, to the experiencer" (p.4). Creswell and Poth (2017) add the focus of phenomenological study is on the individual participant's perceptions and often is referred to as the lived experience (Creswell & Poth, 2017). Additionally, Dodgson (2017), wrote the goal of phenomenological research is to understand the meaning that the particular topic of the study has for the study participant. Qualitative methodology served as the most appropriate vehicle for addressing this study's research questions and reporting on the participants' lived experiences. The participant perspectives are shared in the analysis and findings report in Chapter 4. Participants expressed their views on needs verses access to quality-of-life supports in their rural communities.

In this study, the researcher used purposive sampling to identify a specific group of participants who represented the population of interest (Berg, 2004). Lavrakas (2008) shared that a purposive sample is a type of nonprobability sample. The main objective of a purposive sample is to produce a sample that can be logically assumed to be representative of the population. Etikan, Musa, and Alkassim (2016) explained that purposive sampling requires the researcher to decide what information needs to be found and then find people who can and will provide the needed information through their experiences or knowledge.

The purposive sample chosen for this study was homogeneous sampling. The researcher sought to be purposeful in the participants chosen and wanted prospective participants to have access to the types of questions that would be asked and conversations that would be had in order to complete this study and wanted to ensure that

all participants shared at least one common trait, that of similar lived experiences (Creswell & Poth, 2017). Sharma (2017) noted these pros of using purposive sampling in qualitative research:

> Whilst the various purposive sampling techniques each have different goal, they can provide researchers with the justification to make generalisations from the sample that is being studied, whether such generalisations are theoretical, analytic and logical in nature. However, since each of these types of purposive sampling differs in terms of the nature and ability to make generalisations you should read the articles on each of these purposive sampling techniques to understand their relative advantages.
>
> Qualitative research designs can involve multiple phases, with each phase building on the previous one. In such instances different types of sampling techniques may be required at each phase. Purposive sampling is useful in these instances because it provides a wide range of non-probability sampling techniques for the researcher to draw on. For example, critical case sampling may be used to investigate whether a phenomenon is worth investigating further, before adopting an expert sampling approach to examine specific issues further.

Korstjens and Moser (2017) challenged,

> According to most qualitative researchers, the 'reality' we perceive is constructed by our social, cultural, historical and individual contexts. Therefore, you look for variety in people to describe, explore or explain phenomena in real-world contexts. Influence from the researcher on the context is inevitable. However, by

striving to minimalize your interfering with people's natural settings, you can get a 'behind the scenes' picture of how people feel or what other forces are at work.

Participants

This study will impact families of low socioeconomic status living in rural communities, educators, school administrators, and future researchers. Families with financial needs living in rural communities will be given a voice with which to begin further discussion on how to address the disparities they face. Educators and administrators will be given an additional lens to look through when working with and planning for families and children in their districts who share similar stories as those in this study. Future researchers have a foundation upon which to build.

Participants were assigned aliases for this study as have any school districts, contacts shared, and places of business. Families who participated in this study were compensated with a $25 gift card for their time. Once participants were chosen, they were told they would receive the gift card at the end of the interview process, and were assured that if for any reason they did not feel comfortable completing the interview process or could not complete the process for any reason, they would still receive the full gift card as promised.

In order to be eligible to participate in this study, participants had to live in a rural community in central Illinois; have or recently have had children that qualified as a dependent; live within the state guidelines for low income; and require access to quality of life supports such as special education services, mental health services, transportation, food, and/or employment. At the time this study was conducted, the U. S Department of Health and Human Services released the following poverty guidelines:

Table 1

2020 Poverty Guidelines for Illinois

Family Size	Poverty Guidelines
1	$12,760
2	$17,240
3	$21,720
4	$26,200
5	$30,680
6	$35,160
7	$39,640
8+	For families/households with more than eight people, add $4,480 for each additional person.

Note: These guidelines are effective Jan. 15, 2020.

After securing approval from the university Institutional Review Board, the researcher created a flyer with a phone number, qualifications for participation, and information regarding gift card to be shared with anyone who felt they would qualify (Appendix A). The flyers were hung in public places in different rural communities.

Participants were chosen based on geographic location, socioeconomic status, and need for quality of life supports. 11 families responded to the request for participants. After asking initial questions such as did they have children in the home, what services they utilize, if they face any barriers to utilizing those services, and if they lived in a rural community, eight families were chosen to participate in this study. (Appendix B)

Family one consisted of a single mother with one child. Living situation was stable and the majority of child's childhood the living situation was in rural central Illinois. The family utilized a state supported medical card, mother works. The family's needs included, mental health / drug counseling, specialized school services and medical supports. Family one dynamics further included a single mother who self- disclosed to past substance abuse issues in her family. She and her child lived in a rural community. The community had two grocery stores, more than one gas station, more than one restaurant and had a dollar store. The closest chain grocery store, even though, it was located in the same town that the family lived, was about 6 miles away from their low-income housing. The closest medical doctor was five to six miles, and the closest mental health professional was closer to 30 miles away. This mother had transportation of her own and worked two jobs. Her child needed specialized educational support. The mother noted that due to her own childhood, she was aware of services to support her mental health needs and physical needs and was proactive in seeking out and obtaining services. The school district for this town was divided between three kindergarten through fifth grade buildings and one sixth through eighth grade building. When the child is of high school age, she would attend the only high school in the town. Although the high school was also in the town in which the family resided, it was a different district than the other buildings mentioned for kindergarten through eighth grades. The closest elementary building was three miles from the family residence, the middle school was five miles from the family's residence, and the high school was seven miles from the family residence. There were two or more special education teachers for grades kindergarten through fifth grade per building and eight special educators for grades six through eight.

The elementary and middle school each had at least one social worker and at least one half to one psychologist per building. There were speech language pathologists in each building. The high school contracted with the regional special education cooperative for speech language services and for occupational or physical therapy as well as for school social work and school psychologist. The high school employed 13 special education teachers and relied on the regional special education cooperative for all other special service personnel.

Family two consisted of a two parent, unmarried, four children, blended-family home. Family two lived in rural central Illinois. The family was dependent upon SNAP (Supplemental Nutrition Assistance Program) benefits and state funded medical card. One child had special needs. Supports needed included, physical/neurological therapy, medical, mental health, alcohol treatment, transportation, and financial. Family two was comprised of two, unmarried parents, and four young children. Of the children, one had a diagnosed genetic disorder and belonged to both parents. The other three were under the age of 10 and were biologically related to mother only. The family lived in a rural community. This community had a local IGA for groceries, a hardware store, a liquor store, two health care clinics, and several gas stations. There was one mental health facility with the town limits. There were two to three clothing stores in the local, dwindling outlet mall within the town. None of the aforementioned business are within realistic walking distance from the family home. They are accessible via mobile transportation. The local school district was comprised of an elementary school serving 385 students raging from early childhood to fourth grade, a junior high school that serves grades five through eight and one high school. The district shared two social workers

between the three school buildings. The district employed one school psychologist. There are three special education teachers at the elementary level. The schools are not within reasonable walking distance from the family home and must be accessed via mobile transportation. The family had one vehicle and mom had a license. Dad, who was the primary wage earner, did not have a license.

Family three consisted of a mother and child. Family three lived in rural central Illinois. Family three's needs include medical, mental health, transportation, financial, and food. Family three is a mother and child. The family was dependent upon SNAP benefits as well as medical card and state supported daycare. They live in a rural community that has three chain grocery stores, three gas stations, four fast food restaurants, a dollar store, several liquor stores and a thrift store. The mother had some mental health concerns, mostly related to anxiety. The mother also required consistent medical assistance. The family disclosed a need for food supports. The closest chain grocery store was a 25-minute walk and the family did not have reliable transportation. The closest medical professional was 10 miles, on a four-lane high way, from the family residence. The closest mental health professional was five to eight miles from their residence. The child attends state supported daycare/pre-k while the mother goes to school and works.

Family four included a mother of two who was recently separated from her live-in boyfriend. This mother experienced needs and barrier in her younger adult life and again during the time of this interview after losing her job as a nurse due to injury. The family lived in a rural community with an estimated population of 221. The town did not have a gas station, a store, or a school within it. It was 15 miles to the closest town. The closest

town had one grocery store, one dollar store and multiple gas stations. The town in which the family lived did provide a monthly food bank for nonperishable items. The food bank is not within walking distance of the family home. The family has intermittent transportation and had utilized a lawn mower to get food from the food pantry as well as Dial-A-Ride mobility shuttle to get to the closest major city, which was 35 miles away, to donate plasma in exchange for money. The closest school district is two hours from the family residence. This district covers over 227 square miles, two counties and seven towns, according to the district website. The district has one elementary building for grades prek-5th and one Jr. high/high school building for sixth through twelfth grades. The district employs three special education teachers. One special educator for pre-k through fifth grade, one for grades six through seven (who is also the director of discipline) and one for grades eight through twelve. They have one Title 1 teacher, one speech pathologist and one psychologist. The children in the home did not have any special needs. The mother needs continual medical care and monthly prescriptions. She reported doing without both due to lack of transportation and lack of income. The family is awaiting disability income for the mother, but as of the time of this interview did not have a monthly income. The family did receive SNAP benefits as well as support with the electric bill by a local agency.

Family five was a married couple with five children. One of the children had a significant disability that requires specialty care. The closest specialist was a two to three hour drive for the family. The closest primary care physician for this child was a 35-minute drive. The family lived in a community where there were two chain grocery stores, multiple gas stations, and two dollar stores. The family lived in low-income

housing area. The distance from their housing to any aforementioned business was not within walking distance. The family did have transportation. The family utilized mental health supports for mom. The school district for this town was divided between three kindergarten through fifth grade buildings and one sixth through eighth grade building. The high school was also in the town in which the family resided, it was a different district than the other buildings mentioned for kindergarten through eighth grades. The closest elementary building was three miles from the family residence, the middle school was five miles from the family's residence, and the high school was seven miles from the family residence. There were two or more special education teachers for grades kindergarten through fifth grade per building and eight special educators for grades six through eight. The elementary and middle school each had at least one social worker and at least one half to one psychologist per building. There were speech language pathologists in each building. The high school contracted with the regional special education cooperative for speech language services and for occupational or physical therapy as well as for school social work and school psychologist. The high school employed 13 special education teachers and relied on the regional special education cooperative for all other special service personnel.

Family six was a single mother of three with a live-in boyfriend. The boyfriend works 40 minutes from the home, but does not have a license. The mother attends online classes from home and cares for her children. One child has a diagnosis of autism and receives supports through special education. Family four's needs included transportation, financial assistance, special education, physical and mental health. Family four is an unmarried couple living a rural community with the mother's three biological children.

One child receives special education supports for autism. The male in the home works 40 miles from the residence. The family has one vehicle with reliability concerns. During the initial contact with the family, the mother reported the family was staying with friends in the rural community where the male worked, rather than the family home, due to the family car being in disrepair. They were currently looking for a private person to rent a car from for a daily rate. The mother's friend asked that they leave as they had been there for some weeks, but they had no way to get the male to and from work. The family lived in a town with no grocery store and no gas station. The school where the children attended is a kindergarten through eighth grade building that was eight miles away from the family residence. There were two special education teachers for kindergarten through fifth and one special educator for sixth through eighth grades. The school contracted with the regional special education cooperative for speech language services and for occupational or physical therapy as well as for school social work and school psychologist. The high school was three miles from the family home. It employed one special education teacher and relied on the regional special education cooperative for all other special service personnel. The closest medical or mental health professional was 30 miles from the residence. The closest grocery store was 30 miles from the town in which the family lived. The closest gas station was eight miles from the family home.

Family seven did not have any children, however the husband struggles with spinal muscular dystrophy and as a result is a quadriplegic. This family of two live in a community that does not have a gas station, grocery store or food bank. The closest store is a 10 mile drive. The closest medical doctor is also a 10 mile drive and it is an additional 10 miles from the doctor to have prescriptions filled. The family is unsure how

far it is to the closest mental health professional. Educational information was not reported as there are no children in the home. It was noted that the husband did not become a quadriplegic until later in life and did receive services himself for a learning disability when he was in high school.

Family eight was made up of a married couple with three children. Mom has declining health and other disabilities. She is unable to work due to her condition. Two of the three children have disabilities and required specialized supports. The family resides in a town that does not have a gas station or grocery store. There is no public transportation. The closest grocery store was 18 miles from the family home. The closest gas station was 10 miles from the home. The closes doctor was 18 miles and the closest mental health support was 21 miles, but did not accept public assistance payments. Three out of the five family members required ongoing medical assistance at the time of this study. The children's schools were 10 miles from the home in a different town. The kindergarten through eighth grade building employed two special education teachers for kindergarten through fifth grade and one special educator for sixth through eighth grades. The school contracted with the regional special education cooperative for speech language services and for occupational or physical therapy as well as for school social work and school psychologist. The high school employed one special education teacher and relied on the regional special education cooperative for all other special service personnel.

Data Collection

Data collection for this study started with non-structured interviews. Moser and Korstjens (2018) reminded readers, "The qualitative research interview seeks to describe

the meanings of central themes in the life world of the participants. The main task in interviewing is to understand the meaning of what participants say" (p. 13). The two went on to explain that "most interviews are semi-structured. To prepare an interview guide to enhance that a set of topics will be covered by every participant, you might use a framework for constructing a semi-structured interview guide" (p.13). The researcher began with specific questions and allowed for follow up questions to naturally occur based on answers to the initial questions. The initial questions posed included:

Would you please share a brief family history with me? (i.e. did you grow up locally? Were both of your parents in the home?)

Do you and your family get regular medical/dental checkups?

What does a typical meal look like in your home?

How many meals do you eat at home each day?

Do you struggle with behavior concerns with your child? When did they begin?

Does your child enjoy school? Why or why not?

How often do you hear from the school? Regarding what?

How often do you travel to the nearest town? Why do you go there?

Do you know how to access mental health services?

Are you able to utilize the closest food bank? Where is it located? How often can you get there?

Mannerisms, expressions, voice inflection, and other pertinent information displayed thorough non-verbal communication will also be recorded. As stated by Creswell & Poth (2007), the purpose of interviews was to let our participants speak and their story be told. Rosenthal (2016) further explained that posing open ended questions

and following up with probes is how researchers gain a deeper understanding of participants 'experiences, thoughts, feelings, opinions regarding the situation and to learn what the participants know about their circumstances. Upon completion of the interviews, the researcher followed up with participants to ensure that responses were recorded correctly and that the participants were comfortable with the interpretation of the interview. The last aspect of data collection for the current study included a brief survey asking participants specific questions surrounding the research questions earlier presented.

The informed consent forms detailed that participation was voluntary, that participants could withdraw at any time, and that the dissertation advisor (Dr. Toni Pauls) and the researcher would protect the confidentiality of the participants (Appendix C). The study's research questions served as a guide for the construction of the interview protocol, and all interview questions used during the first round of interviews focused on exploring the specifics of quality of life needs the families have and access/barriers to those needs.

The researcher conducted the semi-structured interviews with the participants at locations selected by them; the majority of the interviews were conducted during evening hours in the homes of the participants. Each interview was conducted in one-on-one format, with only the caregiver(s) and researcher present. Interviews were audio recorded and transcribed to guarantee accuracy. A colleague reviewed all transcripts and recordings to confirm the accuracy of transcription.

Analytical Methods

For this qualitative study, the researcher used cross-case analysis to identify themes within the study. This type of analysis allowed the researcher to compare different cases across more than one setting or community (VanWynsberghe & Khan, 2008). This analysis included the use of Interpretative Phenomenological Analysis or IPA (Todorova, 2011) based on answers from semi-structured interviews. Pietkiewicz and Smith (2014) noted that IPA is a way to share how participants make sense of their personal truths. It is a way to report on the perceptions the participants have about their lived experiences.

The researcher reviewed relevant documents (such as initial correspondence for participation qualifications, child educational records, notes shared by families, etc.), transcribed field notes, and read and coded interviews to assess emerging themes. As recommended by Pietkiewica and Smith (2014), multiple readings and note taking was the first step for the analysis. This was followed by transforming the notes into initial themes. The third step, was to look for relationships among themes and cluster the themes.

This researcher chose a colleague to independently code all the notes and interviews. The researcher and independent coder met to discuss common themes and to ensure all participant perspectives/voices were shared within the cluster themes identified. Lastly, the researcher displayed the findings accentuating common clustered themes by using the participants own words.

Limitations

Limitations to the current study began with sample size. It was not easy to find families who wanted to admit they were struggling in the ways in which the current study

examined. For this reason, the researcher was limited to examining only a small percentage of the stories left to be told.

A second limitation to this study was lack of cross-county data. Champaign County encompassed such a large area that many of the rural towns were located in the one county. An additional limitation to the study is the definition of rural and which towns are considered rural. By definition, towns can be considered rural and still have many resources that other, more remote rural towns do not.

The third limitation to this study is that rural looks different from place to place. Some rural communities offer grocery stores, schools, and businesses. Other rural communities may have a post office as the only business in the entire town. A family without means, but who live in a rural community with a grocery store, may have a slightly different story to tell than a family without means who lives in the town with only a post office. It seems, using rural as a qualifier may still be too broad to get the clearest picture of the struggles some families experience.

Summary

Chapter III included references to the literature on qualitative methodology in order to explain the research design and analysis of this study. This researcher used cross-case analysis and Interpretative Phenomenological Analysis (IPA) to learn more about the perspectives of families who live in rural communities and struggle to gain access to quality of life supports. The chapter further described the participants for this study, how they were found, and how they were selected. The use of qualitative methods and data analysis will be the basis for generating a synthesis of each families lived experiences, which will be reported in chapter IV.

CHAPTER IV

FINDINGS

Introduction

This chapter includes a report of the findings from data collected through interviews and surveys. The purpose of this study was to investigate and share the life experiences of families in need who live in rural communities. Chapter IV is a presentation of the analyzed data collected during the semi-structured interviews with eight families located in rural communities in central Illinois. These interviews captured lived experiences from each family. Analysis of interview responses yielded patterns and themes which are outlined and summarized within this chapter.

The structured data analysis posed through this phenomenological study was that of induction. The researcher read the raw data compiled from the semi-structured interviews, derived commonalities found within the families' experiences and grouped those commonalities into specific themes regarding perceived quality of life supports and the barriers to accessing those supports.

The researcher, used phenomenological study practices, data collected from 8 families living in rural communities, who were financially challenged, and families' responses to questionnaires to answer the following research questions:

1. What quality-of-life supports (employment, food assistance, mental health services, special education) do impoverished families living in rural central Illinois believe they lack?

2. What do rural families identify as perceived barriers to receiving quality-of-life supports?
3. How are rural families impacted by lack of access to quality-of-life supports?
4. How are the children in rural families impacted by lack of access to quality-of-life supports?

These questions were established at the onset of this study; during research collection, it became evident that the responses regarding questions 3 and 4 were the same, or rather, the parents are speaking on behalf of their children as no direct children interviews were conducted. The children's voices, where applicable, are shared through their parent's responses.

Findings

The following, figure (1), is a concept map of excerpts from interviews with families regarding their perceived needs pertaining to quality of life supports and the barriers the families interviewed felt were present that kept them from those supports. The information on the top of the figure consists of quotes taken from interviews with families that share needs they experienced. The information in the bottom of the figure are additional statements shared by the families in regards to the barriers they see preventing them from meeting those needs. These quotes and statements, coupled with additional interview responses and survey results cumulated to answer the previously stated research questions as well as provided additional insight into the life experiences of those living in rural communities who are economically disadvantaged.

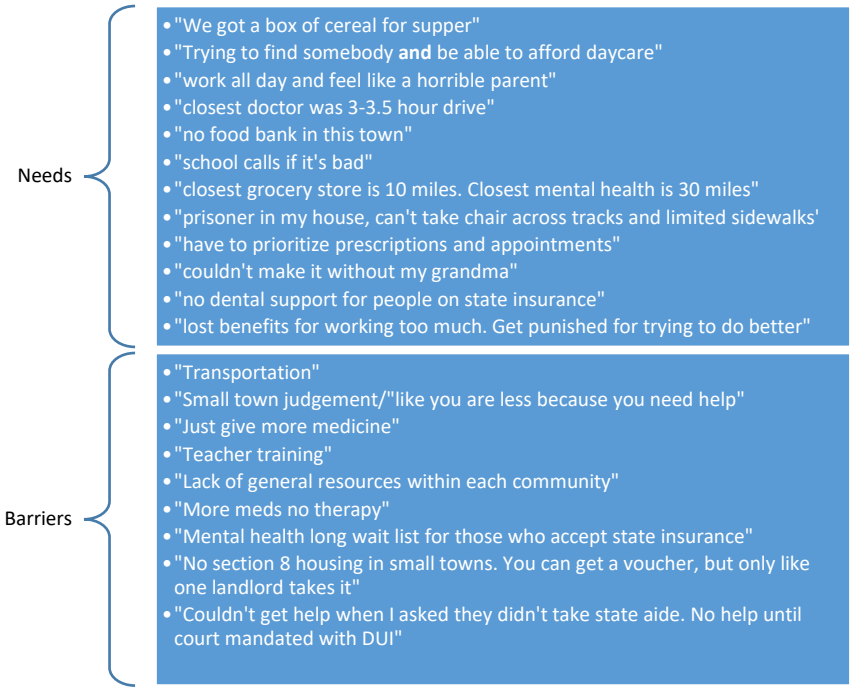

Figure 1. Concept map of major findings

Findings Related to Research Question One

What quality-of-life supports (employment, food assistance, mental health services, special education) do impoverished families living in rural central Illinois believe they lack?

Families spoke to the need for medical and mental health supports. Although these are not services that are specific to families living in rural communities, this researcher's earlier literary findings included higher rates of mental health concerns in rural communities. It is further documented that rurality combined with low socio-economic status impacts the need for these services.

Physical and mental health supports.

The first identified theme regarding quality of life supports, was the lack of mental/physical health supports within proximity to the families' homes. Eight out of the eight families interviewed shared that this is an ongoing need for their family. Seven out of the eight families shared that more than one family member requires these services on a continual basis. The family who has only one family member with this need, requires the support weekly. Seven of the eight families shared that the wait list for a mental health professional who accepts state insurance was up to six months. In one case, the family was repeatedly denied mental health services for depression and substance abuse using their state insurance. The mother in this family was eventually mandated by the court to receive these services as a result of a DUI.

Food insecurity.

The next quality of life support that families reported as lacking in their rural communities was access to supplemental food sources. Six out of the eight families shared that they heavily rely on community food banks to subsidize the state allowed food benefits for their families. Out of those six, three families had monthly food bank options in the town in which they lived. Out of those three, two lived in a town, that although rural, was large enough that the walk to the food bank and back was too far to carry many items. These two families shared that between the distance of the walk, and not having anyone to watch their children while they go, the food bank that is available is still not accessible for them in their situation. The third family reported using a neighbor's riding lawn mower to get to the monthly food bank in their town due to limited sidewalks and no way to carry the groceries once they got them.

The three families who rely on food banks, but do not have one within their immediate community, shared that they were allowed to utilize other banks within their county. As thankful as they reported being at the allowance of using these banks, there were still difficulties associated with this option:

> There is a couple of churches that do it. One in this town and one other town kind of close, about 10 miles, that will let you come from another town. They only do it once a month so that's difficult, but to find every other week, I gotta drive at least 30 miles and try to take three kids. By the time I load up three car seats, where am I going to put groceries? . . . Now I have four kids, I can't find daycare and if I can, I can't afford it for four kids to go get free food (Personal communication, Family two, November, 2020).

Three out of three of these families reported that the closest food bank to them is 10 miles or further from their home. Much like the other three families, the banks they access are afforded to the community on a monthly basis and do not include things such as meat, dairy, fruits or vegetables. The families reported that most of what they are able to get are more for snacks versus meals and may often be expired.

Out of the three families that must leave their town to find a food bank that they may access, one was headed by someone who is completely reliant on home health aides for all personal care and mobility. The family member is a quadriplegic and is unable to go anywhere independently. The state agency who provides his home health aides has passed a rule that the aides may not drive personal vehicles, this person requires his personal van in order to accommodate his chair. With the new rules, the aids cannot take him to the monthly food bank option.

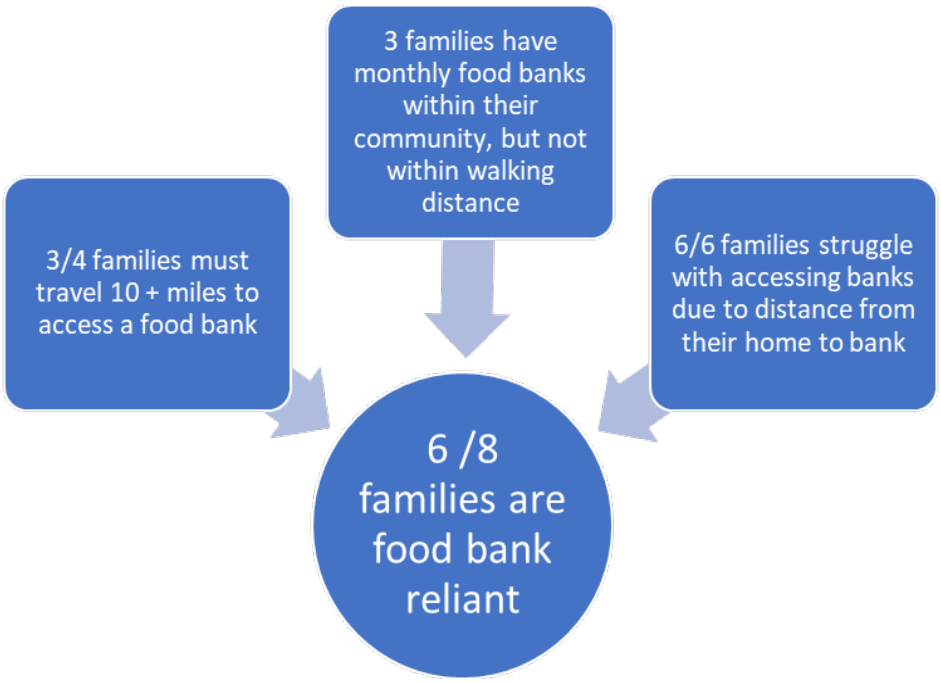

Figure 2. Food bank reliant family data.

Education.

Seven out of the eight families interviewed, which were all of the families who have children, noted lack of quality educational programs, specifically special education programming and supports, as a quality of life support they lack in their home community.

All seven families noted a general lack of communication from their child's school. These interviews were conducted during a pandemic. The families were asked specifically about their children's educational experiences before as well as during COVID 19. They reported the lack of communication had been an ongoing problem. Families further shared that their child's special educator was often the only special educator for multiple grades, that they did not always have access to their specialized supports staff, (speech language teacher, social worker, occupational therapist), as they

were often employed by the county cooperative and not the school, and they were physically in the child's school building on a scheduled day to meet student minutes only.

Seven out of seven of the families noted that during the pandemic, there were no specialized supports put into place for their children with special needs. They still had their same goals, but there were no options for tutoring, phone supports, or socially distanced meetings to assist their child with their unique needs.

It was further noted that out of the seven families who access specialized educational supports for their children, two of those families' children's school was located in the same town in which they lived. Five of the seven families noted a minimum of eight miles and up to 20 miles distance to the school their child attended. Six out of the seven families reported, that their children could not participate in extracurricular school activities due to distance. The distance was reported as being a source of friction between school administration and families for four out of the seven families, in that if their child received a consequence that required after school stay, the family would have to refuse to let them serve it. Families reported school administrator often made them feel like they didn't care about their child's behavior instead of realizing the distance they would have to travel to get them after bussing hours.

One of the seven families represented had a school district that housed specialized programming for children with extreme needs, this program was not in the child's home school, but could be found within the child's home district. For the other families, the closest alternate school programming was up to 30 miles away. If their child was placed in one of these alternate settings, families had to find a way to the placement school for meetings and family events.

Employment opportunities.

The final theme associated with quality of life supports that these families living in rural central Illinois feel they lack, is that of local employment opportunities.

Eight out of the eight families interviewed reported that they would rather work than rely on state assistance. Six of the eight families reported lack of local employment opportunities coupled with harsh benefit punishment for the reasons they cannot work; with two families reporting their personal disabilities keep them from working, even though they would rather be able to work. Harsh benefit punishment was reported by six families. This was explained to this researcher as follows: when a person who receives state assistance begins to work, the state support goes down drastically and quickly. Families seek job options due to the food allowance, housing allowance, and/or monetary allowance not stretching far enough for the family for a month. The family can't make enough at a part time job to pay both expenses and day care, but once they work at all they lose the benefits that they were getting. One family explained harsh benefit punishment like this, during summer session, when she had fewer courses, mom took on extra hours at work. This ended in her being cut from the daycare program and SNAP benefits she and her daughter relied on. "Then I'll get kicked off and yeah that was hard because I really just had enough to cover essentials even with the extra hours" (Personal communication, Family Three, November, 2020).

The following chart is a visual representation of the themes found in relation to the lack of supports the families discussed, as their needs, and how many of the families interviewed identified with that particular overarching theme.

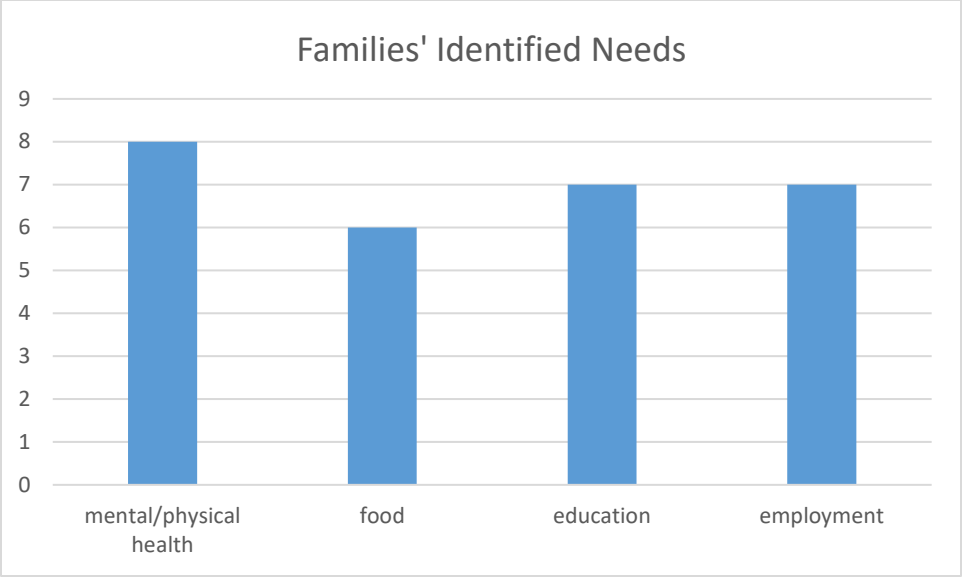

Figure 2. Families' Identified Needs

Findings Related to Research Question Two.

What do rural families identify as perceived barriers to receiving quality-of-life supports?

As presented within the concept map, quotes from interviews as well as via responses to the needs survey, there is a common perception regarding the barriers to receiving quality-of-life supports.

Lack of mental and specialty health providers who accept state supports.

Eight out of eight families shared experiences regarding a lack of mental and specialty health providers who accept state insurance. They unanimously noted this lack of acceptance as barrier for them accessing this quality of life support. Out of eight of these families, seven had more than one member of their family who relied on these supports on an ongoing basis.

> I would try to hide it from my kids well then that would just like build up inside me and I'd eventually like have to go hide and cry for a minute you know . . . I started drinking again I called to see someone and told them I'm trying to fix it before it makes it a bigger problem and they're all like okay well we'll try to get it approved by your insurance . . . I was on the state medical, the medical card and you know then they called back to tell me I was denied (Personal communication, Family two, November, 2020).

Six out of eight families shared that in their experiences with mental health, they were often referred back to family medicine where they were prescribed "one more drug." In each of these families, it was confirmed that they were offered medication before therapy and then again in lieu of therapy. For one family, the child's mental health became so extreme while waiting for an appointment that they had to admit her to inpatient therapy. In that case, the mother reported the outcome of the stay was not monthly therapy appointments, but rather additional medications.

Three out of eight of the families disclosed a need for specialty health care that is not covered under the state insurance by any providers within reasonable driving distance from their homes. One of these three families found a provider for their child's rare condition three hours from their home; however, the provider did not accept state insurance. The family had to fund raise for the money for a consultation and diagnosis, the family was then left to band-aid the illness as they could not afford the necessary treatments. In one of the eight cases, lack of providers who accept state insurance left the mother with limited use of her hand, which in turn, led to disability. "It's January when I started seeing him and I didn't get my first surgery 'til middle of July and I'd already lost

75% of my hand use . . . I should be on several medicines, but I can't afford them" (Personal communication, Family four, December, 2020).

Transportation.

A barrier that was shared by seven out of the eight families interviewed was a lack of transportation options. Even the families that reported owning their own vehicles, which were four out of the eight, noted that due to their remote living situation, transportation options would be considered a barrier for them.

Family eight reported having transportation, yet when the researcher asked, "in your own words, what would you say are the biggest barriers to quality of life supports (employment, food, services, medical, etc.) for your family?" The mother's written response was, "TRANSPORTATION! We pay an arm and a leg to make sure we can get to work and school and stores." She continued by adding, "We have to have working vehicles because we live so far away from everything. There are no taxis or busses where I live" (Personal communication, Family eight, January, 2021). These sentiments were echoed by the other three families who also reported having personal transportation.

The husband in family seven relies completely on personal assistants or family for all of his needs and shared that transportation is a barrier. He utilizes a specialized van due to his wheel chair. State insurance no longer allows personal assistants to drive client's personal vehicles, yet they do not provide one through their services. He further shared that the only transportation service available to him via his state insurance requires a 10-day advance reservation and pre-approval from his insurance before booking the reservation. This is not feasible for day to day activities and not practical for medical emergencies.

During the times of these interviews, three out of eight families admitted to displacing their immediate family to stay with friends or extended family in order to access appointments, part- time work, a partner's work, school activities, or food. These three families explained that this displacement may not have guaranteed them access to transportation, but may allow them to be within walking distance of some supports.

Lack of community resources.

When family eight was asked what services do you wish you could utilize, but can't? The mother responded, "We can't get grocery delivery, or any kind of food delivery here. We have no local gas stations or grocery stores. No transportation services if your vehicle breaks down. And no garage if your vehicle breaks down" (Personal communication, Family eight, January, 2021).

Eight out of eight families shared similar experiences when it came to lack of community resources. Six out of eight of these families lived in a community where there is nowhere to grab a loaf of bread or gallon of milk. They live in communities void of gas stations, convenient stores, dollar stores, food banks, schools or daycares. Seven out of eight of these families live up to 30 minutes from the closest government assistance agency. Four out of eight report not having regular access to a working phone or internet in order to access those agencies online and that at least some of their benefit appointments must be in person. For one family, the local supports the mother referred to the most were the human supports.

> There is nothing in town. I mean the cops have been here. There is a social worker from what I understand here in town sometimes, but they have never reached out. And every cop in town knows (daughter). I have had to call them because she's

> locked herself in my car with the keys and the car started. She's taken off and some stranger picked her up and took her to the police station, so they all know her but there's nobody that has reached out to help in any way. The resources here in town are none (Personal communication, Family five, November, 2020).

Three out of three families explained that their communities actually had some supports "within the town" (Personal communication, Family three, November, 2020), but that they were so far from their residence that they might as well been in a different town. This researcher noted that their lack of access to these resources could tie back to the transportation barrier discussed previously.

Stigma.

Seven out of eight of the families included in this research shared stigma as being a barrier to supports for them. When this researcher asked for further explanation each of the seven families shared that rurality makes it impossible to do anything truly confidential. The eighth family stated that due to his obvious disability, he would have stigma related issues regardless of where he lived, therefore he did not consider rurality to play into his personal case as much as his disability.

For the other seven families, who shared that rurality compounded the stigma for them, they shared some of their experiences to help the researcher understand. Five of the seven moms said, they feel these things anytime they have to cash in change at the local store or bank, when they have to pay for a loaf of bread with spare change, when they don't have enough gas to get their child to school some days. They shared that people literally watch and whisper and if they could get help for mental health locally, this would be a reason not to.

The mother for family three explained that she felt judged if she did better and judged if she didn't. She explained a time when she would have to walk eight city blocks one way to get to a support office for an appointment. She couldn't find a ride and it was extremely cold. She didn't want to walk that far with her daughter in the cold. When she called to reschedule she was made to feel like "if they are going to give me this food, you [sic] can at least get here." She further explained that during summer session in college she picked up more hours at her minimum wage job to save for a car, but once she started making more money, the state stopped helping with her child care and food benefits. So, because she was trying harder, "I can't get food and now I can't work because of no daycare and this is all because I am trying to build myself up and it's almost, it feels like a punishment." She continued by saying you are either judged for "staying in the situation and relying on the system" or "you try to build yourself up and then you can't make ends meet while you're getting there so you are judged for not being able to pay" (Personal communication, Family three, November, 2020). Six other families shared similar stories to this during interviews.

Six out of eight families shared lack of available, affordable, or state funded daycare as barriers to supports for them. One of the mothers interviewed shared that when she is able to find transportation to the food bank, she doesn't have anyone to watch her four children. By the time she puts four car seats into a borrowed vehicle she doesn't have any room for food. All four mothers agreed that if they were able to find a job, even locally, they still would not be able to go to work because they do not have any daycare options in their community.

Five out of eight families shared that stigma was a barrier to services as they did not know where to go or what services they could get because they were simply too embarrassed to let anyone know they were in need. In all five of these cases, the families live in the same small town in which their families had lived. People not only knew them, but they knew their parents, grandparents, aunts and uncles. These families feel that they would not only embarrass themselves, but their entire family if people knew they were struggling. They further shared that they had collectively been taught to keep your business, your business and that you should not rely on outsiders for help.

School Supports.

As noted earlier in this research, the families interviewed live in rural areas where specialized education may be limited and options for class assignment changes may be impossible (i.e. there is one special educator for the grade or in some instances for several grades).

In the words of family five, "school has been challenging." Some of the reasons behind this mother's initial statement included "when she really started acting up, I got called all the time to come and get her" (Personal communication, Family five, November, 2020). They just didn't know how to handle her. This child was eventually placed on homebound services.

Six out of the seven families interviewed noted that they reach out to the school to inquire about situations they heard about from their child's siblings or cousins who attend school with them. They each reported that the school does not initiate contact regarding issues that arise. Two out of the seven mothers reported an increase in school

communication after they set the bar, gave multiple ways for them to contact them and specifically stated that they expect to be contacted regularly.

> I am very active in her learning and in everything she does. I want to make sure I protect her and I'm guiding her, you know the right way . . . I think they (school) communicate well because of me. I don't think it is the school (Personal communication, Family one, November, 2020).

When asked what solutions come of any problems the children do have. Families shared that the parent's hands are tied because there is only one teacher for special education so it is their way or no way. One mom further explained that she sometimes has more luck dealing directly with the teacher, but the resources are limited even if that teacher is trying to help.

For three of the eight families, the schools their children attend are a result of multiple consolidations and are centrally located to several towns. It may be as far as a 20-mile drive from the family home to their school. If their children missed the bus in the morning, they could not go in late as there was no way to get there. If they misbehaved and earned a detention it would cause a lot of animosity between school administration and the family as they could not serve the detention because the family had no means in which to pick them up after.

The barriers shared by families via interview and survey reports are categorized in figure three, below.

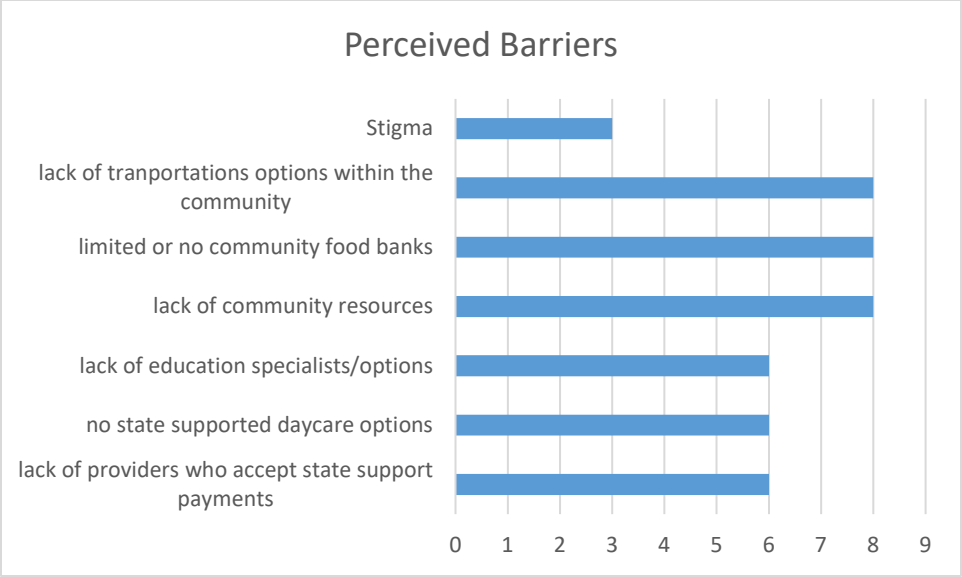

Figure 3. Perceived Barriers

Findings Related to Research Question's Three and Four

How are rural families impacted by lack of access to quality-of-life supports?

How are the children in rural families impacted by lack of access to quality-of-life supports?

As explained earlier, as interviews were conducted with only adults, the impact on the children were shared through their family, making the answers to questions three and four blend together. Some of the findings here are stated within earlier findings and will not be repeated as to avoid redundancy.

The response to these questions was first shared by the three families who circled back to the previous school discussion. They shared that opportunities for extra curriculars were limited to only participating in things that their children's friends from the same town did, and then only if their friends' family would take them with them. The seven families with children conveyed that due to the food bank situation, there were days when meals were more snacks and things such as after school snacks or bedtime

snacks were not an option. This left these mothers feeling depressed, and like they didn't deserve to be mothers.

For eight out of the eight families who have personal medical struggles, they are frustrated and depressed that lack of care is slowly creating worse problems. In some instances, lack of appropriate medication and possibly too much medication for mental health concerns combined with lack of therapy makes the families concerned for what this will mean for their families' long-term health.

In talking with family six, this researcher discovered that mom's depression has been significantly exasperated by the family's rural living situation. She feels helpless and worries a lot about what she would do if something significant happened to her children due to the distance to services. The family is limited in where they can live due to the use of the housing voucher and so few landlords accepting it as payment. She shares that her children are negatively impacted in many ways. There are three children in one bedroom. No one ever has a space to decompress. The children are limited in how many school supports are available which she worries will limit their likelihood of after school success. Her story is similar to five other families interviewed who had children.

Family one is unique in that this mother feels she has overcome most of the bad that her experiences brought. She is at peace with who she has become and is determine not to allow the cycle to continue with her daughter. She is able to work hard and allow her earnings to pave a way through many of the barriers. She is learning to not allow the stigma to stop her from the supports her family needs. She is still concerned about the lack of educational resources available for her daughter. She explained she will stay

active and involved, but she is not the educator and worries that her involvement will not be enough to ensure her daughter gets the education she needs.

The husband for family seven shared that the little independence he once had being taken away now that his personal assistance cannot drive his vehicle. This has made his depression more consistent. He is angry and resentful. He cannot leave his house for anything other than to sit outside in his chair. With no sidewalks or maneuverable railroad tracks, his assistant can't push his chair for walks. He lives in fear of that if something happens to his family, no one can drive him places in his accessible vehicle, even if on occasion. He is equally concerned about what he will do when his van, which already has over 100,000 miles on it, quits running and he will be an indefinite prisoner in his home.

Eight out of eight families shared that just navigating the red tape and systems to gain supports is enough to make you want to give up. They each shared their personal stories of how discouraged they become and how awful the feel as people. They stated common words such as depressed, frustrated, failure.

Three out of the eight families have children who need care that they cannot receive. One is due to lack of a provider who will take state insurance to make the formal diagnosis necessary for supports and the other is due to having a diagnosis that requires specific treatments that are not covered by state insurance, the third is due to lack of daycare or local supports.

The mother for family three became emotional when discussing these questions. She cried and said, that she tried to do the right thing, she went to college, she worked hard and just got further in debt and

> The part that sucks the most about being a low-income family is, you feel like you've missed out on so much because you're trying to provide for yourself so, like I didn't want some jobs and going to school was a job too. I remember working overnights and then put my child on the bus then go to school myself, get her off the bus. I would get to spend a little bit of time with her getting dinner done, but then I would have to go to bed around like 7:00 cuz I have to be at work at 11:00pm. You feel like you miss out on a lot, but when you work minimum wage jobs, you either miss nights with your kids or weekends, either way you miss a lot. Then if you start to get ahead, the state pulls your supports and you end up further behind. There needs to be a way to better yourself and slowly get off of services, not get two good pay checks then lose all help before you can get ahead some (Personal communication, Family three, November, 2020).

In speaking with family five, it became quickly evident that the family as a whole are negatively impacted by the lack of respite and specialized supports in their community. Mom feels overwhelmed and alone in providing services to her daughter. Her daughter has been removed from public education and all that this entails. The parent's marriage is strained due to the continual stress of their daughter's condition and lack of supports regarding it.

> A big toll on our marriage when it was first coming out she had a lot of separation anxiety. She was either in bed with me and my husband or I was in bed with her she had to sleep with one of us or both of us or she didn't sleep. If we went on date night, she was right there with us and she didn't care what she wore, if it was

her pajamas mismatch, her hair not done, whatever, she went with. (Personal communication, Family five, November, 2020.)

The family struggles financially, as one parent must be home at all times. The other children miss out on typical family outings, as they are not always possible due to their sister's condition. Mom reported that she and her oldest daughter left the home together for the first time in two years to spend time together and do some Christmas shopping. They had to leave a phone with the sister so she could video them as much as she wanted. This worked for a little while, but she soon started to become very upset so the two had to leave the store immediately and get home (Personal communication, Family five, November, 2020).

Figure four shows results from the survey in which the families participated. The survey responses represented in this chart, in conjunction with the interview responses, indicates questions three and four were answered.

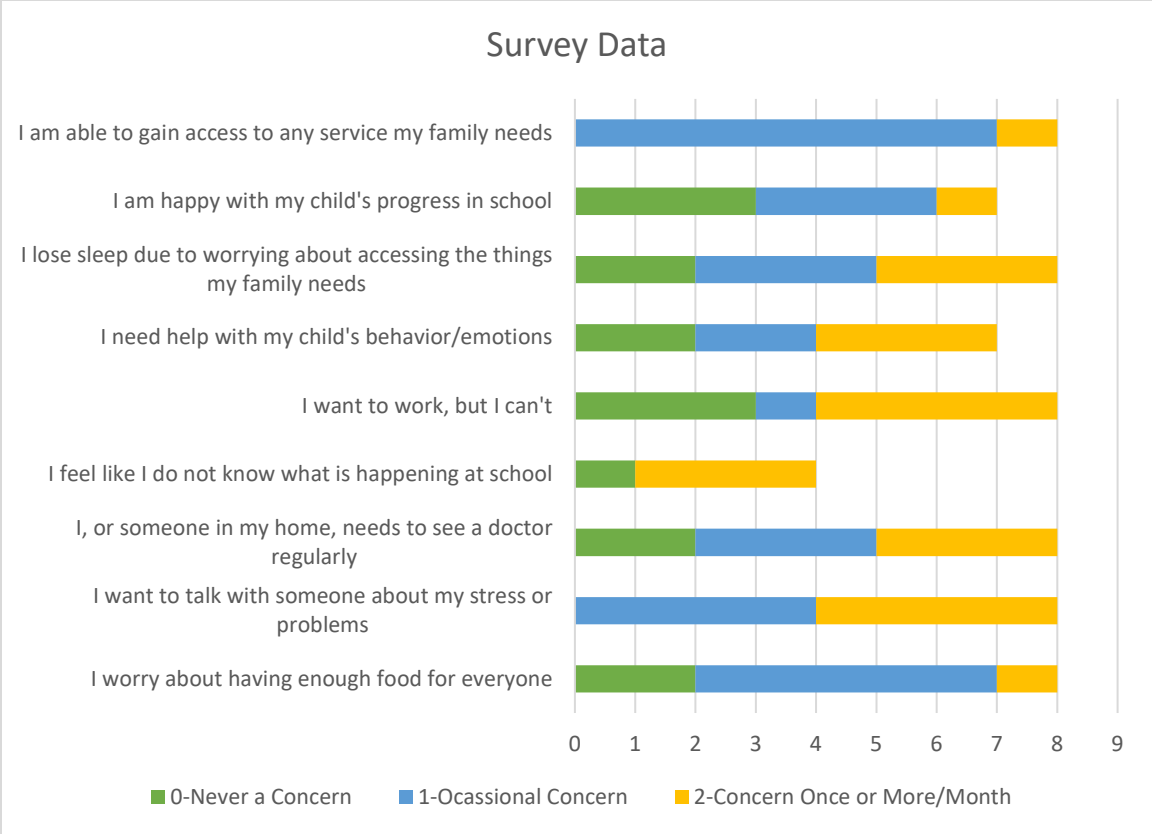

Figure 4. Survey Data

Chapter Summary

Chapter IV included a summary of the findings of this phenomenological study. The researcher explored lived experiences of eight families to better understand what quality of life supports they feel they need and what they perceive to be barriers to those supports. The research questions sought to be answered via this study included: (1) What quality-of-life supports (employment, food assistance, mental health services, special education) do impoverished families living in rural central Illinois believe they lack? (2) What do rural families identify as perceived barriers to receiving quality-of-life supports? (3) How are rural families impacted by lack of access to quality-of-life supports? (4) How are the children in rural families impacted by lack of access to quality-of-life supports? Analysis of raw data to find commonalities and differences within interview transcripts

led to coding of key words, phrases and rhetoric that became sub-themes and eventually themes based on the participants' lived truths. The researcher summarized the findings into 4 themes related to necessary supports which included: (1) Mental/physical health, (2) food, (3) quality education, and (4) employment. This study was two pronged in that the researcher aimed to find what supports were perceived as necessary for the families' quality of life as well as what barriers they felt impeded access to those supports. The researcher further noted 5 themes related to barriers to supports as: (1) Transportation, (2) Lack of immediate community resources (including food banks and service agencies), (3) Stigma, (4) Specialized educational programming, (5) Acceptance of state funded insurance.

The researcher described findings that emerged from personal interviews with families and answers to survey questions the families completed. The personal interviews allowed the researcher to identify themes in necessary quality of life supports as well as barriers to accessing those supports.

The researcher discussed interview data relative to emergent themes, as illustrated in Figure1, the concept map of the interview data. Families identified needs for monetary, social emotional, physical and educational supports. The needs factors related to monetary supports were, parents who wanted to work, but were unable to due to various reasons, lack of food, and parents who could work, having to work multiple jobs and hours that were not family friendly making them feel like less of a parent for their continual time away. Factors relating to the need for social emotional and physical supports included worrying about having enough to provide for their families, feeling like a prisoner in their home, being prescribed medication while denied therapy, and parenting

a child or children with special needs. The factors that relate to educational needs included, limited specialized services within their school and or district, negative or no communication initiated by the school, and the school having limited resources to service students with disabilities.

Overall findings presented in chapter IV indicate the need for intentional interventions in rural communities to assist families in gaining access to basic quality of life supports.

CHAPTER V

CONCLUSIONS AND RECOMMENDATIONS

Introduction

The purpose of this study was to investigate the lived experiences of rural families with low socioeconomic status who experience barriers to quality of life supports. The researcher conducted 1:1 interviews with a parent from eight families living in rural communities in central Illinois to gain their perspectives on needs they experience and the barriers they perceive to having those needs met. During the interviews, families discussed factors they thought contributed to both their needs and their lack of access to supports.

Upon completion of the interviews, the researcher reviewed survey responses the families completed related to their concerns regarding different quality of life supports. The survey responses were important as they acted as a reiteration of concerns that families may have mentioned during the interview, while categorizing concerns as frequent, not at all or sometimes a concern. Chapter V is summary of themes found within the interview and survey data, limitations of the research, and recommendations for further research surrounding the research questions.

Conclusion

In this study, families shared their lived experiences and what those experiences looked like in terms of quality of life supports they feel they require as well as what they

perceived to be barriers to those needs. At the beginning of the study, the researcher posed the following research questions:

> Question 1: What quality-of-life supports (employment, food assistance, mental health services, special education, employment) do impoverished families living in rural central Illinois believe they lack?

As noted in chapter IV, families interviewed for this study stated a need for mental and physical health supports beyond annual physical checkups. Seven out of eight families interviewed expressed some type of ongoing need for these services by one or more of their family members. They further expressed that these services were lacking in their community and that they must drive no less than 30 miles to access these services.

A second need expressed by the families was that of food assistance. Every family interviewed shared that they receive SNAP benefits from the state. Eight out of eight families noted that the closest grocery store was anywhere from 20 to 30 miles from their home community. In addition, seven out of the eight families shared that they required access to food banks to supplement the amount of SNAP benefits afforded to the family each month.

Out of the families interviewed, seven out of eight spoke to their children's educational experiences. Six out of the seven families who shared concerns surrounding limited school resources identified as having at least one child with a disability who required special education supports. Out of the families interviewed who had children, seven out of seven had concerns regarding school communication. six out of six families who had children with special needs, had concerns surrounding specialized resources and training for special education programming and educators.

The last thematic need which surfaced via interviews and survey results was that of employment. Out of the families interviewed one out of eight were gainfully employed and able to manage state benefits, full time work, a side business, had family support for daycare and transportation to get to and from work.

Seven out of the eight families noted that they would like to work or work full time, but could not. The reasons for their lack of employment included: having their own disability/state supports where if they worked too much they would lose their supports, but would not make enough to cover all of their family expenses; being fully disabled and having no feasible employment options within their community; extreme needs of their child(ren) with disabilities; lack of affordable daycare, and transportation.

Question 2: What do rural families identify as perceived barriers to receiving quality-of-life supports?

Families interviewed shared the most common barriers to receiving necessary services were transportation, "No, there are no mental health supports here, we can sometimes see the doctor, but then it's just another diagnosis and more medicine down her throat… The closest specialist is 3-3.5 hours away and doesn't take our insurance…The school sent her home every day, no one knows how to work with her…The resources here in town are none" (personal communication, Families 1, 2, 3, 4, 5, 6, 7, 8 December, 2020). Families interviewed stated that lengthy wait times and lack of providers who would accept their state assistance insurance deterred them from seeking necessary supports. Four of the eight families interviewed mentioned medication being offered in lieu of therapy leaving them to take medication that made them feel badly or do without mental health supports completely.

Families two, three, four, five, six, and eight shared lengthy wait list times for mental health supports due to lack of providers who accept state insurance, no, or limited, daycare options and inconsistent, if any transportation. Every family interviewed noted, no or limited community food banks, lack of community support offices, and lack of public transportation options as barriers to services and supports.

Families one, two, and three noted stigma as a barrier to supports. The mother in family one shared that she knows people in her similar situation who refuse to get help and would rather do without than to have others know that they need help. She said, personally she has gotten over this as she has gotten older and due to needing support for her daughter, but that stigma, especially in small communities where everyone knows what a state card looks like, is embarrassing. The mother for family two shared that she felt the stigma, not just for herself, but for her older family members. She noted that everyone knows her family so if she uses states supports, or walks into a mental health clinic, or takes change to the bank to cash it in, everyone knows about it and it causes problems for her with her family members who don't need the same supports, because she is an embarrassment to them. When the mother for family three spoke to stigma, she became very emotional and shared that she doesn't like that she needs assistance. She explained that she has made efforts to not need help, but the more she works, the less support she gets. Her employment is not enough to manage daycare, household bills, food, and insurance, but if she starts to work enough to get to where she can, she loses too much support at once and the cycle starts all over. She feels the system is set up to keep people who want to do better down and the stigma is unfair as not everyone who gets help wants to rely on it.

Questions 3 and 4: How are rural families impacted by lack of access to quality-of-life supports? How are the children in rural families impacted by lack of access to quality-of-life supports?

When speaking with these families, the researcher found that the answer to these two questions were often combined in their responses. I spoke with mostly mothers; seven out of eight families were represented in interviews and survey responses by the female head of the house. One out of eight was represented by the male, head of the house, where there were no minor children as part of the family.

The mothers, this researcher spoke with shared that lack of access to quality-of-life supports had various impacts on their family as a whole. One mother shared that she feels the lack of community resources and supports has contributed to a major strain on her marriage and her children's relationship with their sibling. She feels without respite or social service supports, she must manage her child's mental and physical health alone. She and her husband have limited, if any time to share together without their daughter, and her behaviors present. She further explained that her time with her other children is often compromised due to the needs of her daughter. Lastly, she shared that before the onset of difficulties with her daughter, she was gainfully employed full time which allowed her to better provide for her family and to have some adult time each day, but without community resources, she has lost all of these things. Her daughter is negatively impacted by lack of local specialists and being removed from education with her same aged peers. The other children in the home are negatively impacted by having less time as a family, little to no family outings, less income and more dependence on state supported programs. Mom also shared that the stigma discussed by other families, impacts her

children as they all attend the same schools their sister, who was removed, attended so everyone knows their situation (Personal communication, Family five, December, 2020).

The mother from family two, shared that she and her children are doing much better than they were. She feels one of the biggest impacts for them, impacted them as a family. She reiterated her situation where she could not get access to mental health supports, specifically for depression driven alcoholism. She was denied for this service repeatedly due to having state issued insurance. This led to a decline in her mental health and an increase in her drinking. She explained that this clearly bled over into her day to day life and caring for her children. She was eventually awarded help for this problem, after the supports were court mandated due to her getting a DUI. She feels this saved her and her family. She also explained that lack of daycare resources in her community equates to her not being able to work a steady job, as she would not make enough to pay for daycare. She further shared that lack of daycare supports also inhibits her ability to utilize many services, as the offices are up to 30 miles from her home and she cannot take four small children to these places and expect them to wait the hour or more to be seen.

The children in family four are negatively impacted by lack of community resources specifically when it comes to day to day schedules. Due to limited schooling options, the children must leave and return home up to four different times each day in order for their mother to transport siblings to and from different school programming. This does not allow time for necessary therapy appointments for the youngest child, or consistent nap times for the two youngest siblings.

The mothers in seven out of eight of the families interviewed shared that their children are negatively impacted by lack of specialized school programming and or

special educators in their community school districts. Out of those interviewed, three out of seven families' children's' schools were located within the community in which they lived. Out of those three families, none of the schools were within walking distance of the family home. Four out of the seven families had what they reported as "means" to get to their children's school if they needed to.

Recommendations for Future Research

This phenomenological study contributed to previous scholarly works regarding rural poverty and access to supports. It is unique in that the focus was overall quality of life supports and what barriers the families living the experiences feel are preventing them from those supports. The limitations discovered during this study were due to COVID 19, the mannerisms shared by families as they told shared their experiences were not able to be consistently observed by the researcher in person. Another limitation was that also due to COVID 19 and Illinois guidelines set forth, access to multiple family members and therefore multiple perspectives, including those of the children living within the home, was not possible.

The researcher provides the following recommendations for further research. First, this researcher suggests that future researchers add observational data to the interview and survey data. How a person shares their experience can hold important information that may otherwise be missed. Body language and emotion regarding responses to the questions posed may result in additional themes or sub themes.

Secondly, direct research questions to the children living within the homes, this may require some paraphrasing, reframing or simplification of the original questions. For this study, and due to COVID 19 guidelines, the researcher limited interviews to one

person from the family. Perspectives from the children may present additional information pertinent to research results.

Third, future researchers should include references to dental care for rural families with limited income as well as rural city ordinances involving side walk and rail road track accessibility for those with mobility concerns. As the anecdotal evidence brought these two topics to light for a small percentage of the families interviewed. A larger number of families interviewed could possibly yield more of those concerns.

This researcher suggests future studies focus on communities that have an objective definition of rural. As it stands, rural communities may vary drastically in size, amenities, services, etc. Using additional objective parameters to research rural communities with more commonalities may narrow findings and provide a more specific starting point for action to address those findings.

Lastly, the researcher recommends a larger interview pool, complete with perspectives from at least one adult family member and at least one child family member to gain deeper insights to both lived experiences. Additionally, a long-term study of three to five years following the same families to evaluate which families, if any, are able to overcome perceived barriers and what steps they take to do so. This information could assist in future studies regarding effective interventions to support breaking down barriers state wide.

Summary

Through the research data analysis process for this study, four main themes emerged in regard to necessary quality of life supports: (1) mental/physical health, (2) food, (3) quality education, (4) employment opportunities. This study allowed for

analysis of additional data in order to look at themes pertaining to perceived barriers to those supports. This analysis revealed 5 themes related to perceived barriers to quality of life supports: (1) Transportation, (2) lack of immediate community resources (including food banks and service agencies), (3) stigma, (4) specialized educational programming, (5) acceptance of state funded insurance.

This phenomenological study examined quality of life disparities for the rural economically disadvantage. The researcher reported on past and current literature regarding this population and noted needs. Developed guiding research questions, a family survey, and unstructured interview processes that were based on answering those questions. After analysis of the data, this researcher is confident the research questions have been answered.

Over all responses from all eight families in regard to question one revealed there are consistent quality of life needs each family seeks. Specifically, families reported the need for mental and physical health supports, food assistance, quality educational opportunities for their children, especially in terms of special education supports, and local employment opportunities.

The findings further showed that the family's lived experiences included similar barriers to accessing the supports they feel their family needs. These barriers included lack of transportation, including little, to no public transit for their communities, cost to use a personal vehicle due to the required driving distance to obtain services, and lack of means to own and, or maintain a personal vehicle. Families further shared the barrier of lack of community resources, noted as food banks, local support offices, and respite care/social supports. The third barrier families had in common was that surrounding

stigma. Although stigma associated with poverty, mental health, and disability, as reported by the families interviewed, is not rural specific. It is the experience of these families that stigma is intensified when living in a rural community where neighbors see your activity, hear your story, and note your situation regularly. The fourth common barrier that seven out of eight families interviewed, all the families whom have school aged children within their home, shared is that of lack of special education options for their children. It was reported that the rural districts discussed within this study, either have one special educator per grade and even as little as one per two to three grades. Often the school or district does not employee their own educational support specialists such as speech pathologist, social workers, physical therapist, occupational therapist, etc. In these cases, the district belongs to a larger, special education cooperative who employee these specialists and provide time to the district on specific days and times. Parents reported an overall lack of specialized educational supports as well as poor communication from their schools regarding their children with special needs. The final, common barrier shared by the families who were interviewed was lack of providers, especially specialty mental and physical health providers who accept state issued insurance. Parents shared that due to the lack of providers who accept their insurance, the providers who do accept it have very long waiting lists.

Due to COVID-19 regulations, the need to keep personal contact to a minimum was observed by combining the last two research questions. This did not impede the study in any way as parents were able to respond to how these barriers impacted the family as a unit. Common responses included that adults and children within the families interviewed are impacted by lack of quality of life supports in that the families rarely, if

ever, share three meals a day at home. Often times meals are replaced with snacks. School lunches provide one meal for the children during school months. Parents reported losing sleep due to worrying about the needs of their family. Five out of eight families reported emotional and or behavioral concerns regarding their children. Seven out of nine parents reported that they wanted to work, but could not for reasons ranging from disability, their child's needs, and lack of local job opportunities.

All participants involved in this study expressed a need for supports that they were unable to access or consistently access for themselves or a family member. Additionally, each participant spoke to barriers that they felt kept them from accessing the support their family needed. Every participant lived in a rural community in central Illinois. The size and available resources for every community varied as the definition for rural is a spectrum.

Conclusion

This phenomenological qualitative study explored the lived experiences of families who live in rural communities and who are economically disadvantaged. This research exposed quality of life supports that these families needed as well as perceived barriers to those supports. The findings captured via interviews and survey responses by the families allowed the researcher to gain insight into how rurality impacts quality of life supports and the additional barriers that being economically disadvantaged pose in regards to accessing those supports.

Analysis of the data collected during the interviews and surveys revealed common themes within all eight families included in the study (see Figures 1 and 2). Each

participant shared their truths without reservation as to what supports their families needed and what they found to be barriers to those supports.

Themes were found by reviewing data from each families' personal experiences. Findings were two-fold and addressed quality of life supports families felt they need access to as well as perceived barriers to those supports. In regard to quality of life supports, four themes emerged from the data: (1) Mental/physical health supports, (2) food, (3) quality education, (4) employment opportunities. As for the perceived barriers, the research revealed five common themes: (1) Transportation, (2)) lack of immediate community resources (including food banks and service agencies), (3) stigma, (4) specialized educational programming, (5) acceptance of state funded insurance.

The findings from this phenomenological, qualitative research study add to the scholarly literature regarding rural poverty and access to care. It expands existing research by discussing the lived experiences of those living in central Illinois, as many previous studies target southern states and communities for their frame of reference. This study will help educators to understand the need for seeking professional development and outside supports to assist them in not only meeting the needs of their students with special needs, but also by supporting them in ways in which their lived experiences may impact them. This study will be a support to future researchers by laying groundwork for future studies regarding families with low socioeconomic status who live in rural communities. This study will be a resource for policy makers when discussing programs, initiatives and other community topics.

Lastly, this study's hypothesis proved to be supported by the data. Families who are in rural communities and live in poverty often experience a lack of resources such as

transportation, school of choice, adequate special education programming, and food programs, which impacts their mental health and exasperates any special needs they have.

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APPENDIX A

FLYER

Wanted:

Who: participants for a dissertation study (allow student to interview you for the study)

Time Commitment: No more than 2 hours

Requirements: Live in a rural community, have a need to access services such as food bank, or transportation, or special education for children, or mental health supports, or employment or any combination of these. Do NOT have to need ALL.

Compensation: $25 gift card

Please text or call April Jackson (217-840-3367) by 1/10/2021 if interested.

APPENDIX B

TABLE 2

Table 2

Participant information at a glance

Q of L Support – Quality of Life Supports (Needs)

Family dynamics – member makeup

Perceived Barriers – What is keeping them from their supports?

Family	Dynamics	Q of L Supports	Perceived Barriers
Family one	Single mother/one child	Mental/medical health, Special Education	Stigma, school-initiated supports
Family two	Two parent, unmarried, blended family/four children	Food, mental/medical health, physical/neurological therapy, substance abuse counseling,	lack of local daycare, finances, wait list for therapy, and transportation
Family three	Single mother/one child	Mental/medical health supports, food, state supported daycare	Transportation, earning too much for continued support, but not enough to live on without the supports, waitlist for therapy
Family four	Single mother/two children	Medical/mental health supports, food, employment, financial	Transportation, insurance, no state assistance, limited food bank items and times
Family five	Married couple/five children	Medical/mental health supports, employment, respite, special education supports	Lack of community resources for respite support and understanding of medical/mental health conditions, lack of positive school collaboration
Family six	Two unmarried adults/ three Children who belong to mother	Medical/mental health supports, special education, employment, food	Transportation, consistent school communication, lack of community resources for general and mental health care, wait list for counseling

Family seven	Married couple no children	Medical/mental health supports, employment, food, physical assistant	Transportation, lack of community resources – PA, limited food bank availability within 10 miles
Family eight	Married couple with three children	Medical/mental health supports, employment, special education supports, food	Transportation, lack of local resources – foodbank, support services offices, specialists, special education interventions

APPENDIX C

INFORMED CONSENT

INFORMED CONSENT DOCUMENT

Project Title: Quality of Life Disparities for the Rural Economically Disadvantaged

Principal Investigator: April Jackson

You are being asked to participate in a research project conducted through Olivet Nazarene University. The University requires that you give your signed agreement to participate in this project.

The investigator will explain to you in detail the purpose of the project, the procedures to be used, and the potential benefits and possible risks of participation. You may ask him/her any questions you have to help you understand the project. A basic explanation of the project is written below. Please read this explanation and discuss with the researcher any questions you may have.

If you then decide to participate in the project, please sign on the last page of this form in the presence of the person who explained the project to you. You should be given a copy of this form to keep.

1. **Nature and Purpose of the Project:**

The purpose of the Quality of Life Disparities for the Rural Economically Disadvantaged is to share the life experiences of families living in rural central Illinois communities who require access to a variety of services, and who face barriers to obtaining those services, and the additional barriers they face due to living in rural communities.

2. **Explanation of Procedures:**

1-First we will go over this consent together to ensure you have the opportunity to ask any clarifying questions. Once you are comfortable you will sign the consent and we will begin the study.
2 – We will schedule an interview time that you feel will work best for you and settle on a location you feel most comfortable to meet at. (We will take COVID into consideration)
3 – Initial interview – I will keep this interview time to no more than an hour. I will begin by asking you basic questions about your family, job, children's school and as you answer, I will ask questions that build upon what you say. For example, I may ask how often you hear from your child's teacher. You may say rarely. I may then ask; would you say once a month? Once a year? What does he/she usually contact you regarding? We will do this related to school, meal planning, transportation, employment, mental or medical health services or whatever you feel is important to mention about the types of supports you utilize or would like to utilize.
4- I will then go back and complete initial transcription of field notes, read and code interviews to assess emerging themes. In other words, I will look at my notes and any things I noticed about our conversation, such as if something seemed to be upsetting or made you laugh. I will try to see if there are things in my notes that are similar or kind of fall under one umbrella.

5- I will then contact you via text/call to schedule a follow up interview. This one should not take as long, but can take as long as you feel comfortable in order for me to tell your truths about your experiences.
6- We will then meet for the follow up interview. I will share my interpretation of data, ask clarifying questions, give you an opportunity to add any information you wish to add or correct anything you feel I misunderstood.
7 – I will then leave to complete follow up transcription, read and code additional information to assess themes or place in existing themes.
8- I will let you know I have no further questions unless you do and will meet to give you your gift card as appreciation for your participation. (As noted before, if for any reason you do not want to continue, the gift card is still yours).

3. **Discomfort and Risks:**

I am unaware of any risks that may result from this study. I am aware that some of our subject matter/discussions could be uncomfortable to discuss.

4. **Benefits:**

You may benefit from having your story told. It can be validating to be heard and to know that you are not the only one experiencing a similar situation. This study could contribute to future studies or systematic changes in how supports are provided in rural communities.

5. **Confidentiality:**

All participant information will be held in the strictest confidence. Your identifying information will be replaced with an alias. All data will be stored on a thumb drive and kept in a locked drawer in a locked office. When it is time to share the information with my dissertation coach, I will do so through a private drive that only she has access to. If she downloads the information, she will keep it in a locked location.

6. **Refusal/Withdrawal:**

Refusal to participate in this study will have no effect on any future services you may be entitled to from the University. Anyone who agrees to participate in this study is free to withdraw from the study at any time with no penalty.

You understand also that it is not possible to identify all potential risks in an experimental procedure, and you believe that reasonable safeguards have been taken to minimize both the known and potential but unknown risks.

_____ _____

Signature of Participant Date

_____ _____

Witness Date

THE DATED APPROVAL ON THIS CONSENT FORM INDICATES THAT
THIS PROJECT HAS BEEN REVIEWED AND APPROVED BY
THE OLIVET NAZARENE UNIVERSITY INSTITUTIONAL REVIEW BOARD

APPENDIX D

SURVEY INSTRUMENT

Thank you for taking a few minutes to answer these questions.

0-never a concern

1-ocassional concern

2-a concern once or more each month

I worry about having enough food for everyone 0 1 2

I want to talk with someone about my stress or problems 0 1 2

I, or someone in my home, needs to see a doctor regularly 0 1 2

I feel like I do not know what is happening at school 0 1 2

I want to work, but I can't 0 1 2 (include reason why here

_____)

I need help with my child's behavior/emotions 0 1 2

I lose sleep due to worrying 0 1 2 (what do you worry about?

_____)

I am happy with my child's progress in school 0 1 2

I know how to get help for stress 0 1 2

I can get to any services I need to access 0 1 2

APPENDIX E

INITIAL QUESTIONS FOR INTERVIEWS

Questions:

These can be estimates like how many minute drive….

How far is the closest grocery store from your residence?

How far is the closest gas station from your residence?

How far is the closest grade school from your residence?

How far is the closest middle/high school from your residence?

How far is the closest doctor from your residence?

How far is the closest mental health support from your residence?

Does anyone in your family require ongoing medical attention?

If so, how do you manage this? Do you have supports? Who helps and how?

Do you have a local food bank in your community? If so, how far is it from your home?

Do you always have consistent transportation? What does your situation look like when you do not?

Does anyone in your family require specialized instruction or programming in school/have a different ability? If so, how well does the school supply those services? What do you like about the services? What would you like to see done differently?

Does the school your child(ren) attend communicate with you often? If so, how and about what? Do you think the communication, if positive/frequent is due to the school or due to your level of involvement?

Are you able to use resources such as SNAP or other assistance? If so, how close is the local office to your home?

How did you go about obtaining these services? How did you know how to get help? Was the process difficulty? Were there any barriers to you getting these services?

In your own words, what services do you wish you could utilize, but can't? What are the reasons you can't?

In your own words, what would you say are the biggest barriers to quality of life supports (employment, food, services, medical, etc) for your family?

Do you know how to get support for mental health needs? Would this be or was this difficult to access? Why or why not?

Thank you so much for your time and efforts.

Please return along with the survey at your convenience.