

Rural Childhood Cancer Patient and Survivor Risk for Financial Difficulties: A Systematic

Literature Review

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Introduction

In the United States alone, cancer is a leading cause of death among children aged fifteen and younger (Centers for Disease Control and Prevention, 2015). The odds of a child in the United States developing cancer before his or her twentieth birthday is 1 out of 285 (American Cancer Society, 2014). Incidence rates for children developing cancer have steadily increased by 0.6% since 1975 (National Cancer Institute, 2015; National Cancer Institute: Surveillance Epidemiology and End Results Program, n.d.). Despite this increase in incidence rates, survival rates, specifically five year survival rates for children with cancer have increased from 60% in the 1970's to 86% (National Cancer Institute, 2015).

More children surviving cancer is a positive finding; however, 60% of children surviving cancer will suffer from one or more late effects due to their cancer treatments (Cure Search: For Children's Cancer, n.d.). A study by Hudson et al. (2013) revealed by the time childhood cancer survivors reach age 45, their cumulative prevalence for developing any chronic health condition is 95.5% and their chance of developing a serious, disabling, or life threatening condition is 80.5%.

Increased risk for additional health problems creates a potential financial strain on childhood cancer survivors and their families. Additionally, the cost of paying for cancer treatments does not end once the person recovers. In 2012, the condition related expenditure total for cancer ages 18-64 was \$52 billion (Agency for Healthcare Research and Quality: Medical Expenditure Panel Survey & Soni, 2015). The purpose of this literature review was to examine if the financial burden is heavier on childhood cancer families living in rural areas due to lack of available resources as opposed to children

with cancer living in urban areas with available resources. The specific research question formulated was: Do rural children with cancer and their families experience a higher financial burden and unequal access to healthcare compared to urban children with cancer? Three hypotheses were created from this research question.

Hypothesis one asserted families and their children with cancer or whose children have survived childhood cancer living in more rural areas are less likely to attend regular checkups with their primary oncologist or receive appropriate follow-up care once cancer treatments are over due to travel costs. Hypothesis two stated childhood cancer patients living in more rural areas are more likely to utilize Emergency Medical Transportation Services or Emergency Room services. Hypothesis three stated childhood cancer patient mothers are more likely than fathers to become the ill child's caregiver regardless of the mother's educational background and occupation.

Methods

Inclusion criteria consisted of the articles being scholarly peer reviewed articles, the articles related to rural childhood cancer patients or survivors and one of the three hypotheses, and if the articles were published between the years of 2003 and 2017. Studies were excluded if the child was diagnosed with cancer after the age of twenty-one. Databases, search strategies, and filters used to generate articles are listed in Table 1.

Miscellaneous

The following articles by these authors were pulled from the reference sections from other articles. The journal article by Youlden et al. (2011) was retrieved from the reference section of the article by Lindley and Oyana (2016). The article by Miedema,

Easley, Fortin, Hamilton, and Mathews (2008) was identified from the reference section of the article by Warner, Montenegro, Stroup, Kinney, and Kirchoff (2014). The article by Tsimicalis et al. (2013) was found in the reference section of the article by Fluchel et al. (2014). Articles by Klein-Geltink, Pogany, Barr, Greenberg, and Mery (2005) and Mader et al. (2016) were retrieved from the reference section of the article by Miedema et al. (2008). The article by Erdmann et al. (2014) was retrieved from the reference section of the article by Erdmann et al. (2016).

Table 1

Search Strategy/Key Terms	Databases	Filters	Number of Results	Articles Used
Cancer Survivors AND rural health	University of Georgia Library Multi-search	Scholarly peer reviewed articles, published between 1889-2018, geography included: United States of America, England, Great Britain, Washington DC, Virginia, North America, New York State, New York City, Canada, Australia, and Europe.	1424	Warner et al. (2014)
childhood cancer survivors AND rural health	University of Georgia Library Multi-search	Scholarly peer reviewed articles, published between 1889-2018	29	Lindley and Oyana (2016)
rural health AND childhood cancer	University of Georgia Library Multi-search	Scholarly peer reviewed articles, published between 1889-2018	599	Kong et al. (2010)
rural AND (childhood AND cancer)	University of Georgia Library Multi-search	Scholarly peer reviewed articles, published between 1889-2018	868	Warner et al. (2014)
rural AND (childhood AND cancer)	University of Georgia Library Multi-search	Scholarly peer reviewed articles, academic journals, published between 2003-2016	828	Ospina, Portilla, Bravo, and Ramirez (2016)
rural	University of Georgia Library Catalog of Journals	Journal of Pediatric Blood and Cancer	227	Erdmann et al. (2016) Mueller et al. (2016)

Results

Three hypotheses were formed based on the research question of this review. The three hypotheses were: families and their children with cancer or whose children have survived childhood cancer living in more rural areas are less likely to attend regular checkups with their primary oncologist or receive appropriate follow-up care once cancer treatments are over due to travel costs; childhood cancer patients living in more rural areas are more likely to utilize Emergency Medical Transportation Services or Emergency Room services; and mothers of rural childhood cancer patients are more likely to become the ill child's caregiver over the father regardless of the mother's educational background and occupation.

Hypothesis One

Hypothesis one asserted that families and their children with cancer or whose children have survived childhood cancer living in more rural areas are less likely to attend regular checkups with their primary oncologist or receive appropriate follow-up care once cancer treatments are over due to travel costs. Supporting articles for hypothesis one consisted of articles by Fluchel et al. (2014), Miedema et al. (2008), Klein-Geltink et al. (2005), Mueller et al. (2016), Kong et al. (2010), Youlden et al. (2011), and Tsimicalis et al. (2013). Three articles refuted hypothesis one: Warner et al. (2014), Erdmann et al. (2014), and Erdmann et al. (2016).

Supporting articles. Fluchel et al. (2014) conducted a cross-sectional survey at the oncology clinic at Primary Children's Hospital (PCH) in Salt Lake City, Utah. In this study two independent variables were observed in regards to location: travel time and

rural residence. The majority (66%) of rural childhood cancer patients sought and received cancer related care from a physician other than their primary oncologist at PCH at least once. Children with cancer living in urban areas were less likely (46%) to seek outside care from their primary oncologist at PCH. For travel time 70% of families with a child with cancer living over two hours away from PCH received care from a medical facility other than PCH compared to 43% for families with a child with cancer living under two hours away from PCH. Average costs per hospital stay for rural families was \$138 versus \$42 for urban families. Families rated their perception of the financial burden which resulted from their child's cancer diagnosis from 0-100. Zero signified no burden and 100 signified the greatest burden possible. The entire cohort's financial burden perception was 66. Through multivariable models a significantly greater burden was shown for rural families and families traveling over two hours to the hospital with adjusted mean differences of 9.6 and 8.9 (Fluchel et al., 2014). This study strongly supported hypothesis one.

Miedema et al. (2008) performed a cross sectional survey in three rural provinces of Canada: Labrador, Newfoundland, and New Brunswick. In the study parents of children currently with cancer, parents of children who had survived cancer, and parents who had lost their child to cancer were observed. Travel costs for cancer treatments and follow-up care were a significant financial restraint on families from these rural areas of Canada. Of the 28 families interviewed, 25 families reported having to travel to other cities or out of province to seek care for their child with cancer. Parents reported lodging and food expenses accumulated quickly when their child was admitted for inpatient care (Miedema et al., 2008). This study strongly supported hypothesis one in regards to the

issue of travel costs for rural childhood cancer families, although documentation of visits to a primary oncologist were not included in this study.

Klein-Geltink et al. (2005) observed wait times to receiving medical care for children with cancer in the Canadian Childhood Cancer Surveillance and Control Program's Treatment and Surveillance system. A total of 2316 children were observed. Out of the 2316 children, 34% lived more than 100 km away from a pediatric oncology treatment center. Children residing up to 500 km away from a pediatric oncology treatment center represented 5% of the sample population. As distance from a pediatric oncology center increased, the likelihood of seeking care from a physician other than the primary oncologist increased. Children living over 500 km away from a treatment center used a general practitioner for care 51.9% of the time and an Emergency Room physician 29.6% of the time. Children who lived within 24 km of a pediatric oncology treatment center utilized a general practitioner for care 37.9% of the time and an Emergency Room physician 36.1% of the time instead of their primary oncologist (Klein-Geltink et al., 2005).

Klein-Geltink et al. (2005) observed children aged 10 to 14 who lived the furthest away from a treatment center were the first to seek care after initial onset of their cancer symptoms when compared to other age groups. Children diagnosed with leukemia who lived within 25 km away from the treatment center waited one day to see a pediatric oncologist or surgeon, whereas children diagnosed with leukemia living more than 100 km away from a treatment center waited three days to see a pediatric oncologist or surgeon. Children with renal tumors waited on average of one day to see a pediatric oncologist or surgeon if they lived within 25 km of a treatment center, and up to four

days if they lived over 100 km away from a treatment center (Klein-Geltink et al., 2005). Although this study did not mention direct travel costs, the study supports hypothesis one regarding children with cancer living in rural areas being less likely to attend checkups or follow-up care with their primary oncologist.

Mueller et al. (2016) noted children with cancer living in rural areas potentially face more difficulties in regards to traveling for their cancer treatments. Children living in rural areas were more likely to experience lodging costs, higher traveling costs, and transportation issues compared to children with cancer living in urban areas. Mueller et al. (2016) stated these financial costs may attribute to longer hospital stays for rural children with cancer following an emergency room visit to ensure the child is in a stable condition before returning home. This study provides further support for hypothesis one by demonstrating higher travel costs for rural childhood cancer patients and survivors, and subsequently longer hospital stays which could be attributed to not attending regular checkups with a primary oncologist.

Kong et al. (2010) performed a retrospective cohort study on socioeconomic status and childhood cancer mortality in South Korea. Risk of childhood cancer mortality was significantly greater for children living in rural areas of South Korea when compared to children living in other city types with a risk ratio of 1.22. Childhood cancer mortality for families of low socioeconomic status was consistent for all age groups with no major statistical differences (Kong et al., 2010). This study does not strongly support hypothesis one, but one could attribute higher childhood cancer mortality in rural areas to high travel costs for medical care.

Childhood cancer survival rates in regards to rural residents and socioeconomic status were observed in Australia by Youlden et al. (2011). In the study, 93% of the sample population of 6576 were at risk for mortality. The five-year survival rate was highest among children living in cities at 82%. Five year survival rates for all cancers combined were lowest for children living in remote areas at 73% with an Adjusted Hazard Ratio of 1.55. Fifty-five percent of children with cancer from remote or very remote areas were more likely to die within five years from their cancer diagnosis compared to children with cancer living in major cities. The five year survival rate for children from most disadvantaged areas in Australia was 78% compared to 81% for least disadvantaged areas (Youlden et al., 2011). This study does not strongly support hypothesis one; however, survival rates from the study do show children with cancer in rural areas are more likely to die from cancer which could be attributed to the significant travel costs to receive appropriate cancer care.

Tsimicalis et al. (2013) examined the direct costs of having a child with cancer for Canadian families. The majority of the population was from urban areas (86%). The average total direct cost of childhood cancer on each family was \$539,185. Rural versus urban direct cost differences were not explicitly stated. Travel accounted for 56% of this cost, food 18%, and domestic labor such as a babysitter or at home nurse 5%. The most expensive items consisted of travel costs such as traveling via car to the hospital at \$1797. Having a car to use or buying a new car was \$35,000 and plane tickets for when air travel was needed were \$1300. The most frequently represented cost categories and items were travel regarding mileage and parking, food, at home help such as a babysitter, prescription medication and over-the-counter medication cost, and non-medically related

supplies such as clothing, gifts and equipment like wigs. Regarding travel, 53 parents reported accumulating costs from traveling back and forth from their home to the hospital. Parents without access to a car had increased expenses due to travel because of taxi and bus fares (Tsimicalis et al., 2013). This study strongly supported hypothesis one in demonstrating the financial costs of travel for rural childhood cancer families; however, this study did not document actual visits with a primary oncologist.

Refuting articles. Warner et al. (2014) surveyed childhood cancer survivors who stated they did not mind driving long distances to see specialist doctors for follow-up care. A study by Erdmann et al. (2014) did not find differences in access of care for rural childhood cancer patients or survivors; however, Germany has a public health insurance plan for all its citizens. Because of Germany's public health insurance plan equal quality care for all citizens is guaranteed regardless of a patient's geographic location (Erdmann et al., 2014). Erdmann et al. (2016) observed survival rates for children with cancer in Denmark. Childhood cancer survival rates in Denmark were higher for survivors living in the most rural areas; however, authors of this study noted very few children resided in extremely rural areas of Denmark potentially skewing the data (Erdmann et al., 2016).

Hypothesis Two

Hypothesis two stated childhood cancer patients living in more rural areas are more likely to utilize Emergency Medical Transportation Services or Emergency Room services. Supporting evidence for hypothesis two consisted of one article by Fluchel et al. (2014). One article refuted hypothesis two by Mueller et al. (2016).

Supporting articles. Fluchel et al. (2014) surveyed primary caregivers of childhood cancer patients at Primary Children's Hospital (PCH) in Salt Lake City, Utah. Rural residence and travel time to PCH were the independent variables. No difference was found between rural and urban caregiver ambulance use; however, caregivers who lived over one hour away and over two hours from PCH had an increased risk of needing an ambulance with adjusted risk ratios of 1.6. Caregivers who lived in rural areas were strongly associated with use of emergency air transportation at 23% compared to 5% for urban caregivers. Specifically, caregivers living over one hour away from PCH had an adjusted risk ratio of 3.8, and families living over two hours away from the children's hospital had an adjusted risk ratio of 7.2 for using emergency air transport (Fluchel et al., 2014). This study supported hypothesis two through the examination of emergency transport services by distance from the hospital rather than specific rural location.

Refuting articles. Mueller et al. (2016) conducted a retrospective cohort study of children with cancer who utilized emergency room services in thirty-nine children's hospitals throughout the United States. The majority of children observed were from urban areas at 86% of the sample population. Children residing in rural areas represented 14% of the sample population. Children who lived in urban areas made up the majority of children who utilized emergency room services at 86.1%. The study by Mueller et al. (2016) refuted hypothesis two in regards to rural children with cancer utilizing Emergency Transportation Services or Emergency Room use; however, the study by Mueller et al. (2016) did demonstrate children with cancer living in rural areas were more likely to be admitted to the hospital following an Emergency Room visit.

Hypothesis Three

Hypothesis three stated mothers of rural childhood cancer patients are more likely than the father to become the ill child's caregiver regardless of the mother's educational background and occupation. Supporting evidence consisted of two articles by Miedema et al. (2008) and Ospina et al. (2016).

Supporting articles. Miedema et al. (2008) surveyed mothers of children with cancer from provinces of Canada, specifically Newfoundland, New Brunswick, and Labrador. Rural mothers had a higher percentage of work hour changes at 86% compared to rural fathers at 61%. Out of 24 rural mothers and 22 rural fathers who were working fulltime or part-time, five mothers left their jobs, eight mothers took paid leave time, eight mothers took unpaid leave time, and two mothers took parental leave (Miedema et al., 2008). Seven fathers took reduced hours at work compared to only three mothers. However, zero fathers quit their jobs to take care of their child, four fathers took paid leave, two fathers took unpaid leave, two fathers were laid off, and one father used vacation time. One mother tried to use sick leave time to care for her child, but was denied because she herself was not sick. Overall, mothers were more educated than fathers. Mothers held the majority of graduate or professional degree at 32% versus zero for fathers. The percentages of both mothers and fathers with undergraduate degrees were equal at 25%. The percentage of mothers with high school diplomas or lower levels of education was 14% compared to fathers at 18%. One father reported having too many projects to quit his job, but his wife was a nurse and the child's mother, therefore she should be the one to quit her job to care for their sick child (Miedema et al., 2008). This

study provided strong support for the hypothesis of rural mothers of children with cancer becoming the primary caregiver over the father regardless of education background and occupation.

Ospina et al. (2016) observed caregivers of children with cancer in Cali, Columbia. Mothers were the primary caregivers at 87%. Education levels were not differentiated between mothers and fathers in this study. The highest level of caregiver education was classified as low education or a completion of primary education with some secondary education at 45%. Occupation was divided into three groups: farmer, other qualified workers, and unqualified workers (defined as housekeepers, mineworkers, construction workers, etc.). Ospina et al. (2016) did not define the jobs listed under the ‘other qualified worker category.’ The majority of caregivers were in the other qualified workers category at 47%. Of the caregivers surveyed, 42% reported being from rural regions of Columbia (Ospina et al., 2016). This study did not support the hypothesis as strongly as the one by Miedema et al. (2008), but the study did demonstrate almost half of the mothers who acted as the primary caregiver were from rural areas of Columbia.

Refuting articles. Refuting articles for hypothesis three consisted of one article by Mader et al. (2016). Mader et al. (2016) observed no correlation between mother caregivers and rural location. However, mothers were the primary caregivers regardless of education level and salary.

Discussion

These findings demonstrate hypothesis one as having the most support. Children with cancer and childhood cancer survivors living in more rural areas do struggle more financially than urban children with travel expenses in regards to appointments and follow up care.

Hypothesis two was not well supported. Surprisingly, urban children with cancer were more likely to utilize Emergency Room services (Mueller et al., 2016). The presumption behind hypothesis two was children with cancer living in rural areas would be more likely to utilize Emergency Room services. This presumption was held because of the longer distance for rural families to travel to attend regular checkups with physicians. Because of the longer distance, rural families of children with cancer may not be aware of complications of their ill child's condition as families living in urban areas with easily available access to physicians and would utilize the Emergency Room services. This presumption was disproven by the research.

Hypothesis three did not have enough supporting evidence to confirm rural mothers of children with cancer were more likely than fathers to become the primary caregiver of the child with cancer regardless of education level and career. Only two studies analyzed the caregiver relationship to rural childhood cancer patients and survivors; however, the two studies analyzed did show overwhelming evidence of mothers being the primary caregivers of children with cancer instead of fathers. This evidence was observed directly in the studies by Mader et al. (2016), Ospina et al. (2016), Miedema et al. (2008). Female

caregiver roles were observed in the study by Kong et al. (2010), although female caregivers were not the direct purpose of the study. Mothers becoming the primary caregiver for children with cancer over fathers could provide a basis for further research in traditional gender roles and society.

Strengths

Studies pertaining to rural childhood cancer health were observed from the perspectives of several different models of healthcare implementation. This proved insightful regarding rural childhood cancer health due to the variety of healthcare implementation models used in countries such as Canada, Germany, and Denmark where there is government provided healthcare for all citizens. Through further examination of other countries' public healthcare systems and implementation models, better care for American children with cancer can be achieved both in urban and rural areas. This literature review also reveals the extreme financial burden of travel costs for rural childhood cancer families.

Weaknesses

There was a limited amount of research pertaining to rural childhood cancer health. Several of the studies pertaining to costs of rural childhood cancer diagnoses and survivorship were performed in other countries with separate healthcare systems such as Germany, Canada, and Denmark. The results from these studies included in this literature review regarding costs of care are not externally valid in regards to the population of United States rural children with cancer, their families, and rural childhood cancer survivors. Additionally, this literature review was not all encompassing of every study

performed on rural childhood cancer survivors, but sought to give an overarching review of access to care for rural childhood cancer patients and survivors.

Implications for future research

More research should be performed to examine access to care and the financial burden of childhood cancer care on families living in rural areas of the United States. The majority of studies in this review were performed in other countries such as Canada, Denmark, and Germany. The United States is unique in its healthcare system compared to the rest of the world. A true analysis of the burden of care placed upon families in the United States would provide better grounds for examining disparities in regards to access for rural families. Gender roles of caregivers for rural childhood cancer patients and survivors is also a phenomenon to further observe.

Conclusion

This review examined the financial burden of childhood cancer placed on rural families. Three hypotheses examined this financial burden. Hypothesis one stated families of rural children with cancer or childhood cancer survivors are less likely to attend regular checkups with their primary oncologist or receive appropriate follow-up care once cancer treatments are over due to travel costs. Hypothesis two stated childhood cancer patients living in more rural areas are more likely to utilize Emergency Medical Transportation Services or Emergency Room services. Hypothesis three stated childhood cancer patient mothers are more likely than fathers to become the ill child's caregiver regardless of the mother's educational background and occupation. Of the articles analyzed in this review, hypothesis one had the most supporting evidence from the

literature. Hypotheses two and three did not garner the same amount of supporting evidence as hypothesis one, but a limited amount of studies included information pertaining to hypotheses two and three. In conclusion rural childhood cancer health is still an understudied topic. Access to care, especially in regard to transportation, is still a major issue for rural childhood cancer health.

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