

Caregiver Distress and Burden among Parents of Children with Cancer; A Qualitative Study of the Sociocultural Context in Punjab, Pakistan



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Abstract: *Cancer is a life-threatening disease worldwide and it is still considered having minimal chances of recovery in low-income countries. During the recent decades the cancer increasing rapidly among children in Pakistan and have multidimensional impacts on patients and their families. This study explored the socio-economic impacts of cancer on the parents of the children diagnosed with cancer. The study was qualitative in nature and in-depth interviews were done from parents and guardians. The sample selection criteria comprised of parents of the children who were under treatment in Children Hospital Lahore Punjab, Pakistan. The data was interpreted through thematic analysis and results of the study showed that parents economic, social and psychological problems and their social life was greatly affected due to parenting of a child with cancer. The findings indicated that the parents suffered from work place disturbance, psychological shock, depression social isolation, family relations breaks, sleeping disorder, financial crises and inaccessibility of leisure moments owing to their commitment with their child regarding illness of children. The study suggested that there should be a comprehensive counselling session for parents regarding their problems in social and economic aspect, and the government should include views of parents in her policy regarding cancer among children prevention and treatment.*

Keywords: *Parenting in Distress, Parents as a Care Taker, Child with Cancer, life-threatening disease*

Introduction

The diagnosis of cancer in childhood is often a source of significant stress and trauma, particularly for parents. This diagnosis brings forth a myriad of challenges, from the uncertainty of the disease's outcome to the financial burdens associated with treatment, potentially leading to the disruption of family life. Depression and anxiety commonly afflict parents of children with cancer, as the impact of the illness extends to the entire family (Bajjani et al., 2019). Parents often grapple with feelings

of helplessness, sadness, and grief upon learning of their child's diagnosis, realizing that their lives will never be the same. The loss of normalcy, dreams, and expectations for their child's future contribute to their emotional turmoil. Although moments of clarity may alleviate feelings of panic and fear, these emotions frequently resurface throughout their child's treatment journey (Rao et al., 2022).

The functional limitations of the child, behavioral issues, and frequent hospitalizations further exacerbate parental distress, with past

life events and lack of social support adding to their burden (Mack et al., 2020). Employment concerns have also been identified as a significant factor contributing to parental depressive symptoms. While advancements in diagnostic practices may partly explain the rise in reported cases of childhood cancer, skin cancers among children have seen a notable increase, suggesting the need for continued vigilance and research in this area (Toledano et al., 2021)

The absence of a peak in cancer rates among white populations in the early 20th century, followed by the emergence of such a peak in Britain and later in the US, suggests the influence of unknown environmental factors in driving this change (Barrera et al., 2020). Higher the rates of acute cancer among children's of South Asian descent, prompting questions about potential genetic susceptibilities to cancer among certain racial groups. It is also identified occupational exposures of parents as potential risk factors for childhood cancer. For instance, children whose parents work in the agricultural industry face an elevated risk of cancer (Yeung et al., 2021). Specific attention has been given to the association between parental occupational exposure to agricultural pesticides and fertilizers and the incidence of brain tumors in children. Cancer remains one of the most perilous diseases affecting humans, often manifesting from birth and impacting various organs of the body (Grant et al., 2020).

In a little percentage of childhood cancer, biological factors are thought to be main causes of cancer in children. Moreover, a little ratio of cancer in childhood has seen also ecological cause (Magni et al., 2021). However, some studies have explored that biological factors make a small contribution to major types of cancer. For example, 44,788 pairs of twin children were studied to find the relation role of genetics and environmental factors causing cancer. It was found that majority of childhood cancers remained little understood and causes were not known. This is through the findings by physicians when a new case of childhood cancer is diagnosed that causative factors are explored. It is obvious that there is a combination of factors that act concurrently and sequentially with any individual case of childhood cancer (Karami, 2019).

Parenting is a profound journey that begins even before a child is born, encompassing prenatal care and continuing through birth, nurturing, and guidance into adulthood. It entails more than just love and affection; it involves providing basic care, emotional support, safety, guidance, and setting boundaries in life. Additionally, parenting encompasses ensuring the child's health, economic well-being, and overall security (Yeunget al., 2021). However, when a child is diagnosed with a chronic illness like cancer, the demands of parenting become significantly more challenging. Parents of children with cancer often experience high levels of stress, including fear, anxiety, depression, and sleep disorders (Bodryzlova et al., 2022). The diagnosis of such a life-threatening disease places serious responsibilities on parents as they navigate the complexities of treatment and care for their child.

The diagnosis of life-threatening chronic diseases such as cancer disrupts the routines and functioning of families, impacting them psychosocially and economically (Michel et al., 2020). Unlike adults, childhood cancer patients involve the entire family in caregiving, including parents and grandparents. Families, especially parents, endure significant social and economic challenges during their child's cancer treatment, highlighting the profound impact of childhood cancer on familial dynamics (Bon et al., 2022).

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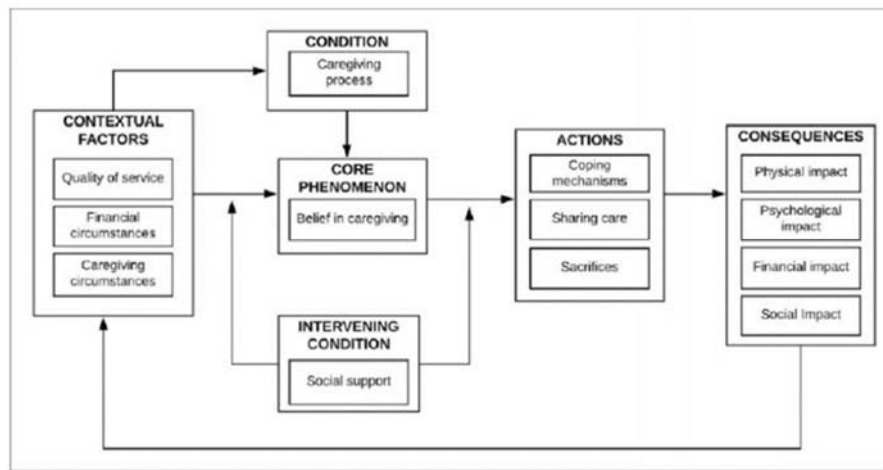


Figure 1: Family care givers model

The survival duration of children with cancer has significantly increased over the last few decades due to the availability of multimodal cancer therapies. Therapies once provided exclusively in cancer patient hospitals are now commonly administered in outpatient hospital settings.

Cancer patients have weakened immune systems due to the chemotherapeutic medications used in their treatment. Consequently, they are more susceptible to a variety of diseases, including bacterial, viral, and fungal infections. These infections can be life-threatening and contribute to higher disease rates and mortality among cancer patients. This situation poses significant challenges for the parents of children diagnosed with cancer (Tocut et al., 2018).

The shift in long-term survival of cancer patients has increased the expressive and caregiving duties of the primary family members, particularly parents, for the child diagnosed with cancer. Thus, descriptions of pediatric cancer having an impact on immediate family caring for their children are well cited in the literature (Wojtukiewicz et al., 2021).

The study aimed to contribute to the existing literature by providing insights into the experiences of mothers and fathers raising children with cancer, focusing on their personal transformations and the challenges they face. Living with the uncertainties and challenges of their child's illness often leads to profound

changes in the parents' thinking and perspectives. Having a child with cancer not only affects the child's well-being but also significantly impacts the entire family, evoking feelings of denial, fear, and sadness among parents. In the context of Pakistani society, where cultural and socio-economic factors play a significant role, parents encounter various difficulties when caring for a child with cancer (Imran et al., 2020).

Despite the importance of understanding these challenges, limited research has been conducted on parenting children with cancer in Pakistan, particularly in Punjab. Therefore, this qualitative study aims to explore the specific challenges faced by parents in such circumstances (Imran et al., 2020). Through narrative analysis, the study seeks to provide a deeper understanding of the issues and concerns faced by parents in raising and caring for a child with cancer. By shedding light on these experiences, the research aims to contribute to the development of support systems and interventions tailored to the needs of families navigating the complexities of childhood cancer in Pakistani society.

In Pakistan, approximately 7,000 children are diagnosed with cancer annually, with a concerning 50% of them passing away before receiving any medical attention (Rao et al., 2022). Tragically, the government does not provide free medication for pediatric cancer, placing the financial burden squarely on the shoulders of parents, particularly amidst the

backdrop of longstanding poverty issues documented in the country. Parents of children with cancer face significant emotional and financial strains (Imran et al., 2020). In response to these challenges, recent medical advancements have begun to prioritize support for families of cancer patients, recognizing the holistic impact of the illness on the entire family unit. Research in this area aims to offer valuable insights that could benefit parents, families, and communities, as well as contribute to the advancement of counseling psychology and related mental health fields.

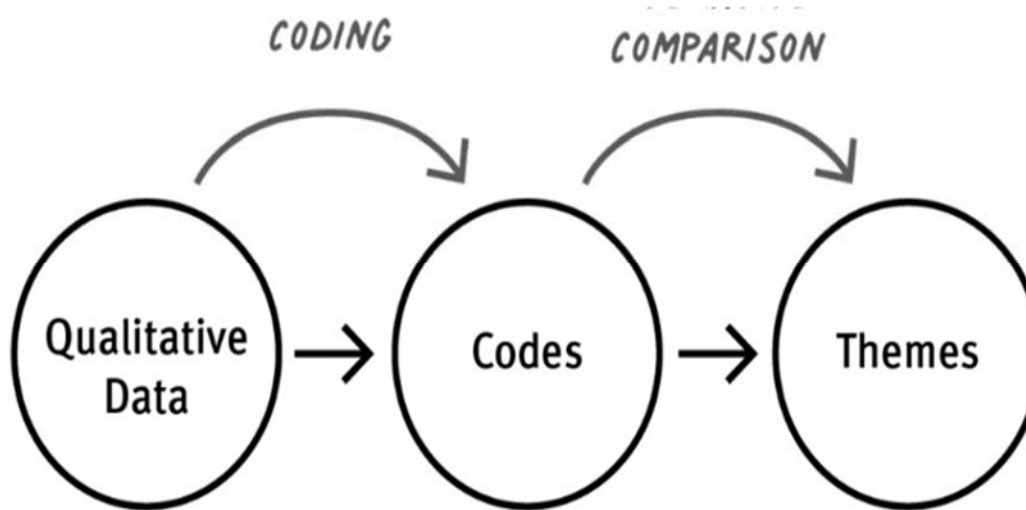
Research Objectives

- To assess the Psycho-social, physical and demographic aspects of parents having a children with cancer
- To understand the economic challenges and its impacts faced by parents of children with cancer.
- To explore the social and health care policies and their practical implications for the parents and children with cancer.

Research Methodology

The study conducted in-depth interviews with thirteen parents of children diagnosed with cancer at The Children's Hospital in Lahore, Pakistan, aged between 7 to 18 years. The research design followed a constructivist approach, aiming to analyze social challenges and socioeconomic issues faced by parents of children with cancer. Respondents were selected through varied approaches, each providing informed consent. Detailed vocal descriptions of consent were recorded to safeguard information. Unstructured discussions were the primary data collection method, tape-recorded to capture nuances, with transcripts made available for review. This facilitated thorough data collection and active participant engagement.

Data was categorized into coded themes, topics and sub-themes with a continuous procedure in which the starting thematic framework was continuously refined and data were compared for differences and similarities in accordance to the statements of the respondents. In this way data themes were maintained or changed to obtain a good quality within the data and to constitute data features as completely understood.



Theme1: Socio-psychological shift in parents life

Results and Major Findings

The interviews with parents of children with cancer revealed a narrative depiction of how the disease disrupts their lives, impacting their self-identity and parenthood roles. Parents

experienced a shift i control and a redefinition of their identities post-diagnosis, adapting to the demands of childhood cancer care while navigating societal expectations. This ongoing process reshapes parental self-identity, affecting

emotional and caregiving roles, despite not being directly afflicted by cancer themselves. The study found a noteworthy impact of cancerous children on parents. The impact of Cancer was on the most on economic conditions of parents and remained a prevailing subject. Parents communicated feelings of tension, dissatisfaction and defenselessness over their disease of children. One of these respondents said;

„To see them (children with cancer) presses me inside (internal feelings). They are just kids and have been suffering from harmful disease. I wish to have this disease myself except my child“.

This concern shows that parents were struggling to have best treatment, for cancer disease of their child and they were trying to relieve burden over their children. Similarly, another respondent shared the feelings in these words;

„We are in stress since we got it (cancer diagnosis). The blood cancer destroys the body of the child, so we are generally worried about her situation.“

Specialist assessments highlighted the profound social and mental impact of cancer on children, leading to significant disruptions in their lives and schooling due to treatments and blood transfusions. Parents faced substantial financial burdens, often leading to career sacrifices and struggles with medical expenses, impacting their lifestyle. Concerns about the social and mental isolation of children with cancer were prevalent among parents, who advocated for their children's normalcy while concealing their condition from others. For instance, one respondent said;

„This is in fact the smaller age, and kids get sense of incompleteness. When my child was a little girl, I used to tell her that does not tell everyone that you are suffering from cancer disease; no one is going to know“.

Theme2: Socio-cultural blocks to health care access

Guardians recounted specific experiences highlighting barriers in accessing cancer treatment, such as navigating insurance hurdles and language barriers in understanding medical

instructions. Common obstacles included transportation issues and language barriers, particularly for non-English-speaking parents struggling with medical terminology. Data analysis revealed a focus on practical challenges rather than solely social barriers, emphasizing the importance of addressing logistical hurdles in cancer care. For instance, a children countered a postponement in the treatment in spite of advancement of the disease spread on is body narrated one the respondents and said;

„Some doctors referred the child to a child specialist, I've never observed anything like these symptoms and I thought perhaps this is simply blood problem and the child needs blood related treatment“.

A comparable issue is lack of information about cancer in people from the more far off family who have given false impressions that additional to the parental and social torments. Guardians confronted a general sentiment of absence of social help from individuals outside their nearby family. For example one of the respondents replied;

“My close relatives, they knew everything. In any case, my relatives believe that cancer is a life taking disease and other children may also contact cancer if they inter act with our child affected with cancer”

The parents of children with cancer were stressed over the capacity of their kids to be happy in the marriage and to have their very own families. Hence the parents communicated their war in essay out the late diagnosis of cancer in their children because of lack of proper medical facility. In one of the case, the parents were express such feelings in following words;

“Since the duration the child is getting treatment I the one who is supporting the whole family. Although treatment is free in this hospital but I have to support other family members. But it is impossible to be in hospital with the child patient and to work at the sometime. It becomes more tragic when no family member or relative help or support you”.

Theme3: Spiritual Approach

Parents of children with cancer sought support from medical professionals and cancer support groups, while also relying on close family members for emotional stability outside of medical settings.

"The doctors treated my child in an excellent way and my kid got well from this dangerous disease. After the treatment my kid is healthy. I think this is the blessing of Allah. But this happiness last only for nine months approximately. The same problem happens again and we directly came back to this hospital and this time the problem was much severer. This was second attack and this thing broke us down completely and but still we were having hope with this institute. Besides going to the hospital we also went to some BABA who does something spiritual work but it also wasn't helpful either"

Parents discussed the sense of shared hope and support within their families and for their children battling cancer.

"I never thought that my child would have cancer. She was raised as a normal kid. I told my family members, 'You don't need to feel sorry for my child.' Even as a baby, despite her illness, I kept educating her. It wasn't easy for her, but she has excelled in school despite the situation."

It was likewise regular for parents to adapt through various difficulties of life due to disease of their child and the parents were counseled for upgrading their medical caretakers. One respondent told;

„We came in this hospital and doctors told that your kid is suffering from the tumor cancer. I cannot describe my feelings in those moments. This further hurt me when the doctor said that we are very late for treatment and they will do their best. Doctors operated and the problem of tumor swelling was cured. However, the root of the disease still existed. But now we were receiving regular treatment of the child and this is on recovery stage“.

Besides, it was discovered that guardians were eager to update and educate others about their

child's disease and treatment. One of them explained:

"The doctors told us that have a blood test for your child. Mostly Pakistanis have cousin marriages, you know. If in your immediate family, there is existence of this disease child may have genetic causes for cancer.“

Theme4: Emotional impact on parents

Most of the parents of children with cancer experienced emotional impacts due to their child's illness. They mentioned mental stress, dissatisfaction, anger, and self-blame in their lives. For example, one respondent explained:

“When we experience this kind of dreadful situation of life, it feels like we will never be back on the normal situation. In the back of your mind there is continuous stress that looks not going to return“

Another father of a child shared same concern whose child was suddenly diagnosed with cancer;

“After conducting some medical tests doctor told that the boy may be having cancer and they did not have medical facility for cancer. Doctor recommended that take your child to The Children's Hospital in Lahore. I am a laborer and I could not afford to go for treatment in a big hospital. But I have taken my savings and some help from friends and have come to children hospital. At the start, the doctors performed some medical tests and have confirmed the blood cancer. This was very difficult time for us.“

Theme5: Shift in daily activities of parents and financial crises

The cancer diagnosis of their children had a negative impact on the daily lives of parents, affecting tasks like caregiving, dressing assistance, maintaining cleanliness, and providing food. Many parents reported experiencing mental stress while caring for their child with cancer, with limited time for recreational activities. Additionally, their leisure pursuits were significantly influenced by their child's illness. The mother of a child with cancer described;

"I have returned to a stage of child-rearing similar to many years ago. Due to my child's illness, I find myself confined to the house most of the time. Sometimes I feel frustrated and helpless because I can't go outside like I used to before my child's illness."

Some respondents noted how their own work was impacted by their child's illness, leading to challenges and necessitating changes in their employment, even switching professions, causing financial strain for families. The mother of a severely affected patient expressed extreme helplessness.

„I could not work with hard work and earn. My ailing child requires care and time so the disease of my kid has become great responsibility for me"

The financial strain of their child's cancer led one parent, despite a lucrative job, to leave work, with their spouse also leaving full-time employment. They rely on financial and social support from parents but struggle to sustain themselves without working.

“Our salary and savings is spent on child's caring and medicine costs. These include a heavy bill every month for key expenses."

A few parents organized alternative treatments as indicated by their physicians. This indicates a few formulas are not satisfied or consistency with prescription by the doctor. For example,

"There are different types of medicines that we need to buy from medical stores from our own pocket and these are too costly. The care, food and living facilities for a patient child also need money but we do not have enough income. We depend on our earning of other children for bills payment."

Theme6: Response of relatives and change in social life

The larger part of family and relatives showed the absence of support the parents of the children. Parents regularly felt that others couldn't understand what they are facing, and difficulty in medical care of the child's disease. One respondent described:

„Most of the time people do not want to listen.

None of my brothers and sisters have visited us. No one of them support us the in-care giving of our child. I feel they all are selfish even, they blame us for disease of the child."

Majority of the parents explained their acute capacity to manage and spend time for the treatments of the child's cancer. The parents similarly told that they have troubles and difficulties to get ready for special occasions such as family visits. They also complained that they have lost so much time to go to relatives and family functions like marriage and funerals. One of the respondents asserted that;

„I am sometimes irritated when I am out of control of the situation. I do not have the capacity to manage all things of the home at the same time. I am unable to go to my friends in their homes since I cannot give the men enough time for visits and dinners"

Theme7: Impact on health of parents

Parents of children with illness experienced significant negative impacts on their sleep and mental health, with some reporting disorders and feelings of depression. One mother of a child with schizophrenia described persistent mental stress and sleep deprivation despite medication, while another parent of a child with cancer expressed internal anguish but continued dedication to their child's well-being.

Theme8: Satisfaction with treatment of health facility

Most fathers of children battling cancer expressed satisfaction with the healthcare system, noting the availability of free medical diagnosis, treatment, and medicines. However, they occasionally had to purchase medicines not provided by the hospital, although free food was generally available within the facility. For instance, one respondent stated,

"We have come directly to this hospital. So far, all expenses for the child's medical tests and medicines have been covered by the hospital, except for a few blood tests. We haven't paid anything for treatment in this hospital, and the doctors provided every support we needed without any cost."

This story underscores the comprehensive care, treatment, and medical assistance provided by the medical facility where the study was conducted. Similarly, another father informed the interviewer,

"Since the child's cancer diagnosis, we haven't received any financial support from relatives or friends, but we do receive free treatment from this hospital. There is no other organization, government or non-governmental, from whom we seek assistance. This hospital provides us with free treatment, medicines, and all laboratory tests, along with food and other assistance we need, and we are fully satisfied with their service."

Likewise, a mother responded positively regarding medical help from the same hospital, stating,

"We are completely satisfied with this institution's service. All treatment and medicine expenses are covered here, reducing our financial burden. The hospital also provides us with food and psychological support."

Similar levels of satisfaction were expressed by another mother whose child was also diagnosed with cancer in the same medical facility, saying,

"The hospital supports us in every matter, providing everything free of cost, including food and other facilities."

Another parent praised the medical facility and treatment, stating, "The hospital provides us with free treatment, medicines, and every kind of help and support we need, along with food and accommodation."

The study's results indicate that almost all parents expressed high satisfaction with the provision of medical treatment, accommodation, food, and medicines free of cost. One parent mentioned,

"Until now, there have been several medical tests and x-rays for the treatment, but we have not paid any cost or fee for these tests."

However, one mother reported never receiving any financial accommodation or food assistance from any government or private organization.

On the other hand, another parent expressed dissatisfaction with financial and medical assistance from anywhere, stating,

"I have not received any kind of help from any government or non-governmental organizations. I don't even know where and how I can seek help in times of difficulty."

Discussion

The study, conducted at Children's Hospital Lahore, focused on parents of children with cancer across Punjab, utilizing qualitative in-depth interviews to derive generalizable findings regarding their experiences and perspectives. Themes and sub-themes were employed to synthesize the collected data and draw meaningful conclusions.

The analysis explores how the parent-child interaction and relationship influence parents' concerns and reflections, shaping their experiences in caring for ill children. It suggests the importance of considering overlooked literature and parental perspectives to address challenges faced by parents of children with life-threatening diseases like cancer. The results highlight the significant role of caregiving in parenting children with cancer, underscoring the importance of social construction in understanding parents' firsthand experiences and their relationships with medical and paramedic staff. These results are in line with the previous studies (Ahmadnia, Ghalibaf, Kamkar, Mohamadzadeh, & Ghalibafian, 2021; Cheung et al., 2021; and Polanco et al., 2022).

The study examined that most parents believe caring and supporting their children during treatment is their most important responsibility, exerting utmost effort to provide comfort. Parents in this study pointed out how stress during the illness and treatment significantly increased their child's need for comfort. In interviews regarding who would have this responsibility, most parents emphasized the special contribution of mother-child interaction in providing comfort to the child as discussed in the previous studies (Tillery et al., 2020; Glick et al., 2021; and Rao et al., 2022). The presence of parents close to the child serves as a source of

comfort for the ill child. Parents desire to witness the normal movements of their child as part of their caregiving responsibility. They seek a distinction between care provided at the hospital and care administered at home.

It can be argued that caring for children entails excessive expenditures for parents, especially in pre-diagnosis conditions, due to various needs and responsibilities. Many parents reported spending nights in open areas, such as hospital parking lots, to manage their emotions, with some expressing feelings of suffocation while staying with their child in the hospital. Main parental struggles were associated with staying in the hospital, as mothers recounted sleeping on camp sheets beside their children or in open areas within hospital wards, highlighting poor conditions and privacy concerns the findings supported the subsequent literature (Bradshaw et al., 2019; Dawson et al., 2020; Martinez et al., 2022; and Bodryzlova et al., 2022).

Moreover, findings of the previous studies also documented that the parental concerns regarding the level of support and comfort required by their ill child, particularly impacting parents with other teenage children at home. Absence from home due to caring for the sick child engenders guilt and role strain among parents, especially those who are working and have young children at home. This highlights the interplay between role expectations and strain observed among parents in caregiving roles (De Oliveira et al., 2018; Borjalilu et al., 2020; and Toledano et al., 2021).

The study's findings provided a conceptual understanding of the distressing challenges faced by parents of children with cancer, revealing diverse perspectives among parents regarding their situation. By delving into various parental issues, the study aimed to shed light on the current circumstances of parents with infants facing advanced-stage cancer.

Limitations

The study's limitation lies in its exclusive focus on younger children, neglecting potential differences in experiences between boys and girls facing cancer. Additionally, it overlooked the perspectives of family members, relatives,

and friends, who may offer valuable insights into the parents' experiences and the child's illness. Nonetheless, the study delves into in-depth case experiences of the child's parents and guardians.

Recommendations

There should be awareness programs at the school, college, and university levels to educate individuals about the symptoms of cancer in children.

Awareness should be provided to people that cancer is not an infectious disease that transfers from one generation to the next genetically.

The government should establish public facilities dedicated to cancer patients at the district level to save the time and money of parents who travel from remote areas for treatment in big cities.

The government should provide social security to parents who have left their private and government jobs due to the disease of their child.

REFERENCES

- Ahmadnia, S., Ghalibaf, A. K., Kamkar, S., Mohamadzadeh, Z., & Ghalibafian, M. (2021). Survivor and parent engagement in childhood cancer treatment in Iran. *ecancer medical science*, 15.
- Bajjani-Gebara, J., Hinds, P., Insel, K., Reed, P., Moore, K., & Badger, T. (2019). Well-being, self-transcendence, and resilience of parental caregivers of children in active cancer treatment: Where do we go from here? *Cancer nursing*, 42(5), E41-E52.
- Barrera, M., Alexander, S., Atenafu, E. G., Chung, J., Hancock, K., Solomon, A., ... Mills, D. (2020). Psychosocial screening and mental health in pediatric cancer: A randomized controlled trial. *Health Psychology*, 39(5), 381.
- Bodryzlova, Y., Kim, A., Michaud, X., André, C., Bélanger, E., & Moullec, G. (2022). Social class and the risk of dementia: A systematic review and meta-analysis of the prospective longitudinal studies. *Scandinavian Journal of Public Health*, 14034948221110019.
- Bon, S. B., Wouters, R. H., Hol, J. A., Jongmans, M. C., van den Heuvel-

- Eibrink, M. M., & Grootenhuis, M. A. (2022). Parents' experiences with large-scale sequencing for genetic predisposition in pediatric renal cancer: A qualitative study. *Psycho-Oncology*.
- Borjalilu, S., Sharif, Z., Sabbagh Bani Azad, M., Afzali, M., & Koochakzadeh, L. (2020). The information needs of parents of children with cancer: A qualitative study. *Journal of Qualitative Research in Health Sciences*, 6(3), 228-237.
- Bradshaw, S., Bem, D., Shaw, K., Taylor, B., Chiswell, C., Salama, M., ... Cummins, C. (2019). Improving health, wellbeing and parenting skills in parents of children with special health care needs and medical complexity—a scoping review. *BMC Pediatrics*, 19(1), 1-11.
- Cheung, A. T., Li, W. H. C., Ho, L. L. K., Chan, G. C. F., & Chung, J. O. K. (2021). Parental perspectives on promoting physical activity for their children surviving cancer: A qualitative study. *Patient Education and Counseling*, 104(7), 1719-1725.
- Dawson-Hahn, E., Koceja, L., Stein, E., Farmer, B., Grow, H. M., Saelens, B. E., ... Pak-Gorstein, S. (2020). Perspectives of caregivers on the effects of migration on the nutrition, health and physical activity of their young children: a qualitative study with immigrant and refugee families. *Journal of Immigrant and Minority Health*, 22(2), 274-281.
- Oliveira, C., Weir, S., Rangrej, J., Krahn, M. D., Mittmann, N., Hoch, J. S., ... Peacock, S. (2018). The economic burden of cancer care in Canada: a population-based cost study. *Canadian Medical Association Open Access Journal*, 6(1), E1-E10.
- Glick, A. F., Goonan, M., Kim, C., Sandmeyer, D., Londoño, K., & Gold-von Simson, G. (2021). Factors Associated With Parental Participation in Family-Centered Rounds. *Hospital Pediatrics*, 11(1), 61-70.
- Grant, C. J., Doig, L. F., Everson, J., Foster, N., & Doig, C. J. (2020). Impact of patient and family involvement in long-term outcomes. *Critical Care Nursing Clinics*, 32(2), 227-242.
- Imran, N., Aamer, I., Sharif, M. I., Bodla, Z. H., & Naveed, S. (2020). Psychological burden of quarantine in children and adolescents: A rapid systematic review and proposed solutions. *Pakistan journal of medical sciences*, 36(5), 1106.
- Magni, G., & Reynolds, A. (2021). Voter preferences and the political underrepresentation of minority groups: lesbian, gay, and transgender candidates in advanced democracies. *The Journal of Politics*, 83(4), 1199-1215.
- Martinez-Santos, A. E., Fernandez-De-La-Iglesia, J. d. C., Sheaf, G., & Coyne, I. (2021). A systematic review of the educational experiences and needs of children with cancer returning to school. *Journal of Advanced Nursing*, 77(7), 2971-2994.
- Michel, G., Brinkman, T. M., Wakefield, C. E., & Grootenhuis, M. (2020). Psychological outcomes, health-related quality of life, and neurocognitive functioning in survivors of childhood cancer and their parents. *Pediatric Clinics*, 67(6), 1103-1134.
- Phiri, P. G., Chan, C. W., & Wong, C. (2020). The scope of family-centred care practices, and the facilitators and barriers to implementation of family-centred care for hospitalised children and their families in developing countries: an integrative review. *Journal of Pediatric Nursing*, 55, 10-28.
- Polanco, A., Al-Saadi, R., Tugnait, S., Scobie, N., & Pritchard-Jones, K. (2022). Setting international standards for patient and parent involvement and engagement in childhood, adolescent and young adult cancer research: A report from a European Collaborative Workshop. *Cancer Reports*, 5(6), e1523.
- Rao, V. N., Anantharaman Rajeshwari, R., Rajagopal, R., & Normen, M. (2022). Inception of a pediatric cancer caregiver support group guided by parental needs. *Cancer Reports*, 5(6), e1469.

- Tillery,R., Willard, V.W.,Howard Sharp, K. M., Klages, K. L., Long, A. M., & Phips,S.(2020).Impact of the parent-child relationship on psychological and social resilience in pediatric cancer patients. *Psycho-Oncology*,29(2),339-346.
- Toledano-Toledano, F., Luna, D.,Moral de la Rubia, J., Martínez Valverde, S., Bermúdez Morón, C.A.,Salazar García, M., & Vasquez Pauca, M. J. (2021). psychosocial factors predicting resilience in family caregivers of Children with Cancer: A Cross-Sectional study.*International Journal of Environmental Research and Public Health*, 18(2),748.
- Wojtukiewicz, M.Z., Rek, M.M., Karpowicz, K.,Górska,M.,Polityńska,B.,Wojtukiewicz, A.M.,. Honn, K. V. (2021). Inhibitors of immune checkpoints-PD-1,PD-L1,CTLA-4- new opportunities for cancer patients and a new challenge for internists and general practitioners.*Cancer and Metastasis Reviews*, 40(3), 949-982.
- Wong, P., Redley, B., & Bucknall, T. (2021). Families' control preference for participation in patient care in adult intensive care. *Intensive and Critical Care Nursing*, 62, 102953.
- Ye,Z.J.,Cheng,M.H.,Zhang,X.Y.,Tang,Y.,Liang,J.,Sun,Z,...Yu,Y.L.(2021).Treatment decision making and regret in parents of children with incurable cancer.*Cancer Nursing*,44(3),E131-E141.
- Yeung,N.C.Y.,Cheung,K.C.,Chau,H.C.,Leung,A. W.K., Li,C.K.,Lam,T.T.N,...Cheung,Y.T.(2021). Transition from Acute Treatment to Survivorship: Exploring the Psychosocial Adjustments of Chinese Parents of Children with Cancer or Hematological Disorders. *International Journal of Environmental Research and Public Health*, 18(15),7815.