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EXPERIENCES OF PARENTS HAVING CHILDREN WITH LEUKEMIA: A QUALITATIVE STUDY FROM PESHAWAR, PAKISTAN

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ABSTRACT

Background: After cardiovascular diseases, cancer is the second largest cause of death worldwide and a serious issue. There are many different kinds of cancer, but leukaemia is one of the more common forms in children that has a significant impact on the patients as well as their families. Literature has demonstrated that leukaemia carries a heavy weight in terms of morbidity and mortality, causing physical and psychological suffering for both patients and their families.

Aim: The purpose of this study was to investigate the experiences and coping strategies of parents in KPK Peshawar who were caring for children with leukaemia.

Methodology: The study design employed in this investigation of the experiences of parents of children with leukaemia was phenomenological. In the study, eight parents from Peshawar's public and private hospitals made up a purposive sample. Verbatim transcriptions of semi-structured, guided, in-depth interviews were made on tape. The information was manually coded and arranged. Thematic analysis was used to examine the data.

Results: From the data that was gathered, four major themes emerged. These themes were classified as the parents' psycho-social, spiritual, or religious struggles during their course of therapy, as well as their lack of resources. The results revealed a number of illnesses, such as melancholy, worry, grief, unpleasant emotions, irrational hope, helplessness, delayed diagnosis because of financial difficulties, insufficient knowledge of the side effects of chemotherapy, and co-morbid leukaemia.

Conclusion: The study's conclusions show that parents of leukemic children encountered certain issues that needed to be successfully handled. In order to address these illnesses and issues, it is necessary to provide them with the necessary information and counselling on the true nature of the sickness, its effects, and its treatment.

Keywords: Leukemia, Children, Parents, Experiences, Challenges, Awareness, Parents Needs

CHAPTER-1

INTRODUCTION

Introduction to the study

Following cardiovascular illnesses, cancer is the second largest cause of death worldwide and one of the main causes of concern.1. Leukaemia is one of the more common types of cancer detected in children, and it has a significant impact not only on the patient but also on their close family. Cancer can be diagnosed in individuals in many different ways. Leukaemia is a kind of blood cancer that progresses over time, affecting the bone marrow and producing more immature leukocytes, which can cause anaemia and other symptoms. Acute lymphocytic leukaemia, acute myeloid leukaemia, acute lymphoblastic leukaemia, and chronic lymphocytic leukaemia are the four different forms of leukaemia.2. Leukaemia frequently manifests as fever, tiredness, malaise, and exhaustion, as well as anaemia, bleeding disorders, vomiting, and weight loss. Approximately 76% of leukaemia patients die, according to stated mortality rates 3. Sepsis, weakened immunity, chemotherapeutic side effects, limited treatment options for co-morbid conditions in rural locations, poverty, and unsanitary food and water sources are the primary causes of leukemia-related deaths. It's not easy for parents whose children have leukaemia to cope. One way to maintain and manage challenging circumstances without sacrificing vital bodily and social functions is through one's own ability to cope. Sometimes a parent's condition is intolerable and they become more likely to experience panic attacks, which are detrimental to the family and the community. According to studies, parents of leukaemia patients consider having no more children if they are already dealing with a child's long-term treatment4. Their thoughts stray to other facets of existence. According to a US study, managing a child's long-term care when they have leukaemia is an agonising and hopeless experience, and parents run a serious danger of losing their jobs. 5. When a kid is diagnosed with leukaemia, the parents first experience shock and denial before facing the truth and looking for coping mechanisms and emotional support. 6. When their children are being treated for leukaemia in a paediatric unit, parents take a passive role. When their children are being treated, they require exceptional emotional support and assistance with communication 7. Research from Pakistan reveals that typical issues include For families caring for children with leukaemia, the main outcomes are depression, loneliness, anxiety, and lifestyle changes. 8. The variety of factors parents deal with when raising their kids. The fact that they had to wait several years without knowing if their leukaemia would fully heal is the most important. Recurrence is another important factor in leukaemia. 9. Refusal to receive treatment can occur when an illness progresses, but laypeople are unable to comprehend this, and as a result, the family may face additional difficulties and issues. The main causes of mortality for children with leukaemia, infection and co-morbidity, are increased by low socioeconomic level. Children with leukaemia also have several infections as a result of poor hygiene because their immune systems are weakened. 10. Pakistani residents frequently experience poor hygienic conditions, low-quality food, and poor water quality, particularly in areas with murals. Regretfully, Pakistan lacks a central database registry to keep track of the incidence and prevalence of cancer at the provincial, district, and city levels. While some province-specific databases, like as the IRNUM and SKMCH databases, record approximately 50% of adult cases of leukaemia, 64% of paediatric patients are from KPK, and the other patients are from throughout the nation 11,12 This situation contributes to the nation's inadequate management and control of cancer. In addition, the government finds it challenging to plan for and provide a new cancer hospital and diagnostic facility.

Leukaemia has been the subject of some research, but studies on psycho-social, spiritual, and other issues were not well covered in those earlier investigations. A study that was carried out in Lahore focused on depression associated with financial issues rather than directly on child care.13. The primary worry of parents has been quantitatively underlined by another study carried out in Abbottabad; nevertheless, the qualitative nature and phenomenology of leukemic children have not been investigated.14 In this sense, the current study is closely related to the investigation of the fundamental phenomenology of parents caring for their leukemic children both at home and in the hospital throughout treatment. In this area, little is known about the fundamental experiences of parents whose children have leukaemia. This study aims to close the information gap by investigating the emotions, feelings of sadness, melancholy, anxiety, anger, and other aspects that parents of leukemic children experience while caring for and treating their children. The purpose of this study was to investigate the real-life experiences of parents in Peshawar, Pakistan, who had children with leukaemia. Additionally, the following goals were particularly targeted to be accomplished by this study.

1. To investigate the experiences of parents whose children were given a leukaemia diagnosis.
2. To find coping strategies used by parents whose children have been diagnosed with leukaemia.

MATERIALS AND METHODOLOGY

Study Design

For this investigation, a qualitative descriptive phenomenological study design was adopted. The most detailed explanation of life events, perception, assumptions, and emotions is provided by descriptive phenomenology15. Given that the purpose of the study is to examine the experiences of parents whose children have leukaemia, a qualitative phenomenological technique was deemed to be the most appropriate design for the current investigation.

The Hayatabad Medical Complex and the Rehman Medical Institute Peshawar are two of the province's hospitals that were chosen as the study's research settings. Hayatabad Medical Complex is a public hospital that offers tertiary care, including a paediatrics oncology section that offers free services to patients. Rehman Medical Institute, on the other hand, is a hospital in the private sector that has the capability to treat children with leukaemia.

Sample quantity and sampling methodology

Using a non-probability purposive sampling technique, the research phenomenon's features were taken into account. The study's tentative sample size of 12–15 parents was calculated, but 8 sample sizes were needed to reach data saturation. When certain themes, notes, behaviour, and overall information are reached, saturation of data is typically reached.16 When gathering data for the current investigation, the same saturation pattern was taken into account. In order to obtain diversity and enhanced data, several groups of parents were chosen based on considerations such as education, phenomenology, living conditions, perception, environment, and distinctive experiences of parents from different societies. Parents whose children attend both public and private institutions were chosen for the current study because purposeful sampling made it possible to choose a diverse group of participants, preserving the originality and diversity of the data collected from parents.

The study's *inclusion criteria* were: Parents whose children were diagnosed with leukaemia at any stage or whose children were diagnosed with the disease at least six months prior.

Exclusion criteria: Parents whose children were diagnosed with cancer other than leukaemia Parents whose children were diagnosed with leukaemia but were not KPK residents. Parents who declined to participate were excluded, as were patients receiving palliative care and DNR.

Data collection

Extensive in-person interviews were carried out to get the necessary information. Additionally, demographic information was collected during the data collecting process, including gender, the education and qualifications of couples, living situation, income, and associated details. The participant received all the information required for their voluntary participation. 2018's data collection period ran from July 25 to August 25. The ERB-K.M.U., AS&RB, concerned hospital directors, department heads, and participants all gave their consent. Following the participant's consent to participate, the interview was scheduled and the date and time were determined based on the participants' availability. Interviews were conducted in accordance with the preferences of those who were approachable and eager to be interviewed first. Parents were allowed to choose the interview location with the least amount of disruption to the data gathering process. Professional reviewers of qualitative research conducted interviews with interview guides. The prior research served as the foundation for the structure of these inquiries. Furthermore, prior to the interviews, each participant-related question was thoroughly clarified. In order to satisfy the participants, every question was addressed. Every parent participated in a face-to-face, in-depth interview lasting between 60 and 75 minutes. The person was interviewed in a semi-structured manner. Data was first collected using a semi-structured interview guide that was self-generated. Participants were able to readily convey their feelings during the semi-structured interview. Every area where participants could freely discuss their feelings and experiences was facilitated. Five open-ended questions with prearranged and impromptu inquiries made up the interview guide. Furthermore, it was observed that the field notes captured both the participants' nonverbal cues and facial expressions. Parents participated in a preliminary study of the interview guide, and additional questions and probes were added as needed. Interviews were held in Urdu, or the participant's preferred language, such as Pashto or English. With the participants' permission, interviews were tape taped, and qualified transcriptions wrote up the verbatim transcriptions. All text in Pashto and Urdu was translated directly into English prior to transcription. The tape recorder was used to verify the transcriptions. Where necessary, follow-up interviews were held to validate, clarify, and corroborate the information provided by the participants.

Data Analysis

According to the methodology of qualitative research, data gathering and analysis would begin at the same time.17 As a result, the data analysis process began as soon as it was collected. All of the interview audio files were stored in the system and given pseudonyms for anonymity. Interviews were verbatim transcribed. Relevant concepts, whether latent or manifest, were found by reading and rereading the transcriptions of the interviews multiple times, word by word and phrase by sentence.17 Second, all pertinent information was taken from the transcripts in accordance with the questions posed during the interview. The Morse and Richard axial, open, and thematic coding approaches were used in the data processing process.17 Key words, sentences, and phrases were underlined or labeled for coding. Subcategories and categories were created based on the concepts, meaning, and relevance of the codes. Ultimately, a table and plain text version of the data were shown.

The data was analysed using the following steps in order to create a summary.

1. Transcription: the process of turning audio into text
2. Coding: The process of designating significant data
3. Categories: Groups based on the key information in the data.
4. Themes: Subcategory and category essences, the report's overall theme, the primary notion of the data, and the categories' essences.

Examine Strictness

Study rigour are crucial for maintaining research quality, and Lincoln and Guba's (1985) criteria were adhered to in order to preserve trustworthiness, conformability, and Transferability.18 Credibility is predicated on the idea that accurate data collection and interpretation are essential to the generation of knowledge.15 Conformability refers to the degree of objectivity present in a study. Additionally, it represents the actual opinions of research participants without any inspiration being given or not, and whether or not the researcher's opinions or judgement have an impact on the results.16 The current study maintained study rigors by taking steps to ensure trustworthiness, conformability, and Transferability.First and foremost, the participant interviews were conducted in a workable setting with strict adherence to the time limit. In addition to conducting in-depth interviews, brief field notes were kept on participant expressions during the process. For the purpose of interpreting the data that was gathered, real participant presence was guaranteed. The real study participant's presence is crucial for information accuracy and quality control in cross-questionnaires used in qualitative research.19 Secondly, reflective logs were kept to have distinct perspectives from each participant in order to guarantee the conformance of the research effort. Thirdly, consideration was given to Transferability when attempting to generalize the findings in light of the other discoveries. Transferability is the degree to which findings from qualitative research can be extrapolated to another context or environment and the amount of information that would be pertinent or similar.15In order to achieve a high level of research rigour in the current study, conformability, Transferability, and trustworthiness were carefully considered and evaluated throughout the analysis process.

Ethical consideration

The Advance Research & Scientific Board of Khyber Medical University (AS&RB), Peshawar, Pakistan, provided approval prior to data collection. HODs of the relevant departments and the hospital director were consulted for additional authorization. Before the interview began, the parents of each patient provided their informed consent. Each participant received a pre-interview information document, which they were asked to thoroughly read. The information sheet covered everything from the goal of the study to its benefits and drawbacks, as well as the rights to participate in it or to decline without consequence, as well as the confidentiality and anonymity of data collected both during and after the study. Each participant in the study was given a pseudonym and code to ensure their privacy and anonymity. Access to the data was restricted to the study supervisor only. The study's findings will be shared without revealing the participants' names or any other personal information. After usage, unprocessed and random data will be discarded. To put it briefly, every ethical concern was carefully considered in order to safeguard the study participants' rights.

OUTCOMES

This chapter's main objective is to describe the study's findings about the experiences of parents whose children have leukaemia. In order to better understand and explain the experiences, emotions, difficulties, and issues parents had when treating their leukemic children, eight in-depth interviews were done. Every parent's experience and emotion was directly stated, complete with codes and classifications. Ultimately, all themes and extracted data were formatted, and the study's findings are covered in detail below.

Following a thorough investigation, themes were identified in the data transcription. In the beginning, categories were created using an open coding technique to classify the data. To further categorise the data in succession, open coding was followed by axial coding. The psycho-social viewpoint of parents, the importance of religious or spiritual healers in curing leukaemia, the difficulties parents confront during treatment, and the lack of resources were all recognised as the four primary issues.

THEME-1: PSYCHOSOCIAL PERSPECTIVE
THEME-2: ROLE OF RELIGIOUS/SPIRITUAL HEALER TO CURE LEUKEMIA
THEME-3: CHALLENGES FACED BY THE PARENTS DURING THE TREATMENT
THEME-4: SCARCITY OF RESOURCES

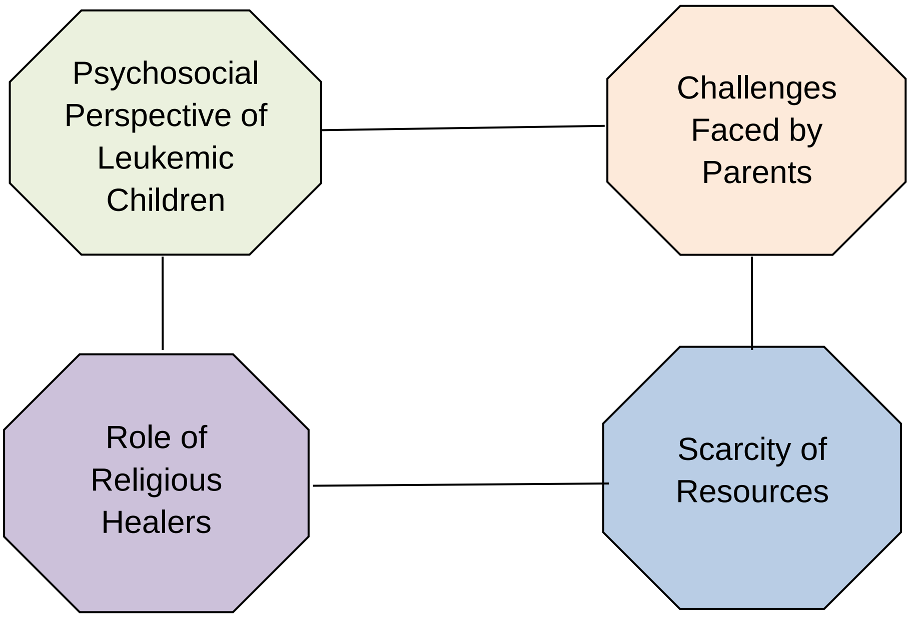

Figure 1: Major themes of the study

THEME-1: PSYCHOSOCIAL PERSPECTIVE

Following the parent interview, it was determined that parents found it extremely challenging to comprehend the nature of treatment while caring for their ill children. Whether receiving care in a public or private healthcare facility, parents were anxious and dissatisfied with the situation involving their kids. The parents dealt with a number of the psycho-social problems listed, explained, and quoted below. For several reasons related to exploration, the parents were not happy. The majority of the justifications lacked a sound or genuine reasoning. They claimed that we had heard somewhere that leukaemia is extremely dangerous, that it is extremely difficult to treat, and that there is a chance that their children won't live. A few of them reported seeing some of these individuals die right in front of their eyes.

"This disease is not curable," one of the parents stated.

They also learned that the illness was extremely dangerous and that there was no cure, so they lost hope for the people in their social group. They become more vulnerable to various psycho-social problems as a result, including social stigma, stress, rage, frustration, disturbed life patterns, and many other negative aspects of society and norms.

"Environment, society, and uncertainties in life have badly affected us in our timely decision making," said two of the parents.

The statement demonstrates how a variety of circumstances influence parents' ability to make wise decisions regarding the future planning and treatment of their leukemic children. A participant shared that he lost his employment due to his child's leukaemia, which prevented him from continuing. He went on to say that he had no choice but to battle for his leukemic child's life. Young parents reported that they had cut themselves off from all social interactions, including games, get-together, festivities, and other family members. However, four of the individuals later acknowledged receiving social assistance from their neighbour.

"People in our immediate vicinity, especially our neighbour, provided us with some emotional, moral, and ethical support."

These remarks demonstrated that people are still sensitive to others' issues and are willing to provide a helping hand when circumstances call for it, which lessens the psychological load on parents. They said that our neighbour took care of our houses while we were away so that our kids could be taken care of. Even though it was unable to cure our child, this helped us during a trying period. We always offer prayers and our warmest regards to everyone who has helped us throughout trying times, both emotionally and morally.

"When I heard about this disease, I was about to pass out and start crying about the child's health."

The sentiments that parents hold closest to their hearts were captured in the lines spoken above. That was also observed when parents were crying and sharing their emotions during the interview. Their voices were rife with anguish, heartbreak, and grief.

As far as individuals are concerned, this sickness is quite deadly.

The voice recording of five participants' perspectives was filled with sadness, despair, social breakdown, and depression. *"I was very afraid, felt grief and pain-full feeling when heard about the nature of the disease,"* the person was quoted as saying. Each of these individuals was speaking the truth about their experiences. Because it was a significant and unforgivable incident in life, even though some of them had already overcome many obstacles in life. One of the participants said he had already experienced the suffering of cancer treatment and his father's death from the disease. His child is currently suffering from leukaemia, and this is the worst circumstance he has ever been in. As was previously mentioned, social and psychological viewpoints are crucial to an individual's existence. Stigmatization and loneliness were psycho-social problems that half of the participants had to deal with. These problems were excruciating and contributed to many societal ills. The participant said,

"We have been kept alone in society due to social stigmatization."

One member said,

"This child has completely changed the way I live my life." My other children are suffering since I am dedicating all of my time to the child's treatment".

Being stigmatized is a highly humiliating situation for anyone who is a parent. They found it extremely challenging to survive in society. It was really stressful and difficult for me to manage all the problems during the therapy, especially since I was the only family member left to support and assist them at all costs. According to one mother,

"*We are fighting with everything in life."*

However, while feeling as though they were not alone in society, half of the participants were experiencing agony and grief. They said,

"Our relatives, neighbour, society, and other villagers helped us a lot in terms of morality, ethics, and all other areas."

Similarly, parents faced a variety of challenges in their daily lives; some received support from various individuals, while others received little or no support from the community. Stress was the more prevalent psychological and social element. Every individual showed signs of stress and despair. Although many parents discussed their worry and anxiety during this awful period, the study was not specifically dedicated to measuring stress or depression.

"We are sad, depressed, and have fear because of the long treatment and other difficulties in the treatment of our child," one of the parents said.

Throughout the conversation and interview, a few of the parents talked about their feelings, including rage. Five of the participants reported that we were taught various techniques to control our emotions and feelings during the course of the treatment. A variety of psychology sessions were scheduled to help us learn how to manage our depression and anxiety. According to the participant's statements, anger management techniques were given to us in order to gain control over our emotions, anxiety, and depression because we were observed to be acting in an angry and depressed manner in certain situations.

It is crucial that parents overcome this protracted, agonizing, and depressing phase of life with fortitude and bravery because failing to do so could negatively impact their child's behaviour. Stress was discovered to be a prevalent issue among the parents caring for their leukemic children. The most stressful times in their lives occurred when they were admitted to the hospital for an infection, along with vomiting and other side effects from the chemotherapy. Five participants reported that they experienced unmanageable stress when researching the health status, treatment, and management of diseases affecting children.

"I am stressed because of the care of my child at home, financial problems, and their effect on my other children," stated a different participant.
All of the aforementioned factors were identified as the most frequent and widespread ones affecting and impeding the parents' everyday routines while they were caring for their children at home and in the hospital.

THEME-2: ROLE OF RELIGIOUS/SPIRITUAL HEALER TO CURE LEUKEMIA

Parents of leukemic children were always hopeful and looked forward to things throughout treatment. Since half of the parents said, *"My child will receive shifa from Allah,"*

Parental expectations were well-founded since they firmly believed in Allah's blessings. They had faith that their kids will soon return to living regular lives like other kids.
Conversely, half of the parents expressed their disappointment with the circumstances, saying things like *"Cancer is a name of death" and "He or she is going to die too."*

A few participants stated that it was impossible to overlook the influence of religious healers in curing illnesses. Numerous individuals used various ways to communicate their thoughts and feelings about religious perspectives. The majority of those in attendance said
"In addition to using religious practised like tweeze, reciting the Holy Quran, zikr, and prayer to aid with the continuation of treatment."

Religion is important in life, and nearly all of the participants shared the belief that their religious activities and practices make them feel better. They went on to say,
"We are praying to Allah for relief and ease with the disease and its consequences because we are believers that everything comes from Allah."

The majority of participants said that the illness's origin and treatment were like an exam from Allah, the universe's creator. One participant is reported to have said,
*"We are tested by Allah in the form of such diseases."Zikr of Allah and the spiritual support made me strong while fighting with such a deadly disease",*stated a participant who was cited by another.
These were some of the participant's statements regarding how engaging in religious and spiritual activities strengthened us and helped us to form new beliefs and hopes. The participants went on to say that having these kinds of ideas makes us more optimistic. We experience a moment of relaxation during treatment anytime we discuss our Islamic and religious beliefs. *"We always believe in Allah and remain positive for Allah's blessings in all aspect and matters of life,"* the participants declared.
Therefore, we hold no one accountable for our child's condition, his illness, or any of the other problems we are currently dealing with. As they returned their attention to reality and the meaning of life, one of the participants cited;
"Everyone must die; it is the ultimate destination, regardless of illness or other disaster, but we always ask Allah for His blessings and miracles."

THEME-3 CHALLENGES FACED BY THE PARENTS

Throughout their children's treatment, the parents had to deal with a lot of difficulties. Throughout this arduous tenure, they faced many challenges, but some of them were quite unpleasant and will never be forgotten. Numerous parents were crying as they described the difficulties they had encountered. Nearly half of the participants said that receiving a late medical diagnosis was a barrier to their ability to recover from the illness because they were ignorant of the condition and its nature.
“The disease was not diagnosed in a timely manner due to a lack of services and unawareness.”
The other half of the participants went into great detail about how various factors delayed their children's leukaemia diagnosis or medical diagnosis. They said that there was a lack of radiology and laboratory services available at the Tehsil and district levels. We had to travel to the capital of

KPK, Peshawar, for a little test. An other factor was the availability of knowledgeable physicians to provide a prompt leukaemia diagnosis. Two parents shared that they had been turned down for free treatment at a reputable hospital because of our children's delayed diagnosis. One of the parents said,

"The doctor prescribed medication, but there was no accurate diagnosis of the disease in the local clinic."

My toddler had a temperature and was sweating and perspiring. *The doctor diagnosed him with typhoid fever. When there was still no progress, I took my child to Mardan Medical Complex for additional care. There was a suspicion of anaemia. Finally, in Peshawar, leukaemia is diagnosed.*

These words Clearly showing that the correct diagnosis was not completed in a timely manner, they brought their infant to the Mardan Medical Complex before being directed to Peshawar, the capital of KPK. A second person made a similar response. The participant started crying as she related the story and said,

"My child could live longer if it were diagnosed in a timely manner."

Another person related what had happened to him in the similar way:

"First of all, we were not given a clear status for our child by the doctors in Swat and Timergara. They informed us that the child's illness is caused by a microbe. Then, following a few tests conducted in Shaukat Khanum, we discovered that this is cancer.

The scenario shows that the parent had some issues throughout the diagnostic process. Due to the inadequate basic level facilities, they were unable to accurately diagnose their children and as a result, their treatment of the children was delayed.

The parents also raised concerns and shared their perspectives over the lengthy course of treatment that involved divided chemotherapy cycles. Since cancer patients receive different treatments depending on their unique circumstances. Sometimes the entire course of treatment takes two or three years.

Four research participants stated that *the length of their treatment was excessive, stating that it "created more difficulties in their lives."*

The parents' statements suggest that the lengthy course of treatment came with a number of difficulties, one of which was its length. A lengthy course of treatment can lead to a variety of issues, including worries about money, tension, curiosity, worry, despair, and the possibility of losing their work. The following is a quotation from one of the participants: *"We had various financial and mental issues as a result of our child's lengthy hospital and at-home care. as a result of which other family members experienced.*

The majority of parents were concerned about the long treatment duration, which has an impact on them in various financial, social, and psychological domains. In addition to financial concerns, parents' careers and schooling were also impacted; one participant said, *"I wasted two years of my study due to my child's disease."*

The parent had to deal with this differently. The participant was doing his M Phil study while working in one of Pakistan's largest cities. His kid was given a leukaemia diagnosis. Initially, neighbour and family handled all treatment-related problems, but because of the prolonged course of treatment, he was forced to give up his work and pursue his studies. Thus, he had been raising his child for the last two years and had encountered difficulties ever since. The participant went on to say that it was a very tough and demanding effort for me to act bravely in this circumstance. However, I was abusing our health system and felt alone and heartbroken on the inside. If the health system had helped me sooner, things might not have turned out the way they did.

Chemotherapy side effects were another prevalent issue and difficulty faced by parents caring for their children. Chemotherapy side effects that were most frequently reported included nausea, vomiting, diarrhoea, alopecia, and mucous membrane inflammation. The majority of parents discussed this issue frequently, and some of them also frequently expressed their worries and stress over it. *"We are in stress and anxiety due to the longer period of treatment and the problems associated with the chemotherapy," stated six of the participants.*

As a result of chemotherapy, patients typically experience low ANC count, diarrhoea, vomiting, and febrile neutropenia. While some patients may experience all of the issues in a severe manner, others may only experience mild issues. Another possible explanation for this could be that they weren't adequately informed about the dangers of chemotherapy. According to the results of the current study, most parents had never heard of these difficulties before and were unsure of how to express their worries to medical professionals. Both at home and in the hospital, they were unable to control the negative effects of chemotherapy.

Nearly all of the parents shared their opinions, saying that despite the numerous obstacles and issues we face, we continue to work towards preserving our children's life. The majority of participants cited, *"We are fighting for our child's life."*

THEME-4: SCARCITY OF RESOURCES

When it comes to secondary care, resources are thought to be the most important factor in ensuring the best care and early leukaemia diagnosis. Pakistan is a developing nation with a relatively small budget for healthcare, and conditions for cancer patients in particular are appalling. According to the government, there is no advanced technology accessible to diagnose cancer in its early stages, such as modern radiology or oncology laboratories. According to three participants from rural locations:

"the disease got delayed in its diagnosis on time due to improper facilities".

This highlights the critical role that resources have in early disease detection. The participants' expressions show that their inadequate access to resources at the primary and secondary levels resulted in subpar diagnosis. There were no adequate laboratories available to determine the precise and advanced stages of leukaemia. Advanced radiography and haematology labs are essential for determining the precise nature of diseases; but, according to the results of the current study, most parents were unable to locate these labs in time for their children to receive a leukaemia diagnosis. Due to inadequate resources, the diagnosis, additional therapy, and admission of the youngster were delayed. Second, it was brought out in the discussion that secondary level of treatment lacked medical experts with experience in oncology. According to the participant, the secondary level hospital was determined to be in a dismal and poor state. One other significant point that was frequently mentioned by the participants concerned the financial difficulties and limitations. The importance of financial position was particularly felt during cancer treatment. Cancer treatments are exceedingly expensive, regardless of other medical interventions. When asked about their financial concerns for their children's care, the majority of parents mentioned them. Six individuals mentioned this:

"Due to our financial situation, we are under pressure and extremely sad."

The majority of participants were from rural areas, and they expressed concern about how their lack of financial stability affected their ability to treat their children, access to hospitals, availability of appropriate diagnostic tools, and availability of enough staff to provide them with basic management guidance. Sadly, one of the parents claimed that:

"It is a great misfortune for me that I did not provide my child with adequate care because I was poor."

The participant's account of how the child reached his lowest point due to a lack of financial arrangements was heartbreaking to hear. Other interviewees voiced their concerns about the hospital's extremely subpar services and lack of resources, with the exception of few private hospitals. how I understood it from the viewpoint of the parents:

"The hospital's inadequate diagnostic equipment prevented the care from being delivered effectively."

It was noted that public hospitals were failing to properly research the illness in order to effectively manage it. Chemotherapy was not handled properly when it was completed. Numerous participants voiced issues regarding extravasation, which they believed to be the result of improper chemotherapy administration. It was also communicated that the same I/V line and single line chemotherapy was administered for several cycles. We had to buy medication related to chemotherapy from a location other than the hospital. Additionally, we've heard that improper chemotherapy administration can also result in various forms of leukaemia

Parents have stated that when they asked medical and other staff questions, they were told that we are overburdened with patient flow and that we lack supplies and medication. However, just three of the eight individuals expressed satisfaction with the way chemotherapy was handled and treated. It was noted that three of the participants had received care from a private hospital. They stated that proper care was used when managing chemotherapy. All pertinent care was provided in compliance with the policies and procedures.

The parents also expressed concern about the fact that no government agency, authority, or non-governmental organization had assisted them in any way while their child was being treated. at any stage of the course of therapy. Four participants reported that despite their repeated requests and efforts, none of the above parties offered them any support.

"At no point did any government agency or non-governmental organization (NGO) assist us".

Participants disclosed that we had gotten in touch with numerous NGOs to ask for financial assistance or to send medication both before and after treatment. They constantly express hope but never follow through on their promises. We spoke with a number of senior administrators at the government hospital, but sadly, they let us down. We made contact with numerous other neighbourhood NGOs and benefactors, but we didn't look elsewhere for help. Parents reported that they dealt with a variety of concerns and problems during their children's complete treatment. The participants also emphasized the need for suitable help to be provided in these appalling circumstances and the establishment of more hospital settings with cutting-edge technology in order to stop children in the future from suffering from these kinds of appalling diseases in a province like KPK. According to what the parents said:

"More hospitals are needed in the area to support the sick children with such deadly diseases with adequate care".

In spite of the difficulties, hardships, and sufferings they endured, this statement suggests that well-equipped hospitals should be available to treat these patients with more advanced care in order to raise the standard of care for leukemic children in the future.

According to the overall findings on the four primary themes, it was estimated and judged that all points of view must be taken into account while interacting with parents and children who have been diagnosed with leukaemia. The themes that the parents were asked to explore for all of their experiences and challenges towards the investigation and treatment of their leukemic children were the psycho-social perspective of parents, the role of religious or spiritual healers in curing leukaemia, the challenges faced by the parents, and the lack of resources.

DISCUSSION

This study was carried out in a public and private hospital in Peshawar, Pakistan, to investigate the experiences and difficulties faced by parents whose children had leukaemia. In general, the study involved interviewing participants to learn about their thoughts, feelings, experiences, challenges during treatment, and other related issues they had encountered, such as psycho-social obstacles, diagnosis, treatment procedure, treatment facilities, problems during caring for their children in the hospital, and challenges during chemotherapy cycles. In the end, four themes emerged from the information. The data from axial coding, open coding, and transcription were analysed to identify themes. Every theme was examined individually in the context of the interview, the literature review, and pertinent findings that were paralleled and contrasted with potential explanations. Every theme was thoroughly examined from every angle to determine the real opinions and findings based on the research that was done.

Psycho-social Perspective of Leukemic Children Parents

The psycho-social viewpoints when caring for the sick children with leukaemia in the region of Khyber Pukhtankhwa were the fundamental issues found in the study. The parents were discovered to be managing their leukemia-diagnosed children despite leading chaotic, depressing psychological and social lives. Stress, social isolation, hopelessness, and a lack of social support were the primary issues that the current study found. A few other earlier research have addressed these psycho-social issues. According to a study by Cornelio, Nayak, and George (2016), mothers of children with leukaemia face similar difficulties and experiences. Their psychosocial lives were characterised by similar challenges.[20] Another study by Lau et al. (2014) investigated the difficult and disrupted life patterns that the majority of parents of leukaemia patients had to endure. Subsequent research revealed that parents were experiencing loss, pain, deplorable circumstances, and other socially and mentally disrupted methods of living.[21] According to a study by Kholasehzadeh et al. (2014), parents who were caring for their leukemic children experienced stress, worry, and depression. The current study also shows that the families did not receive any education or awareness-raising programmed to help them deal with their psycho-social problems.[22]

Role of Spiritual and Religious Healer to Cure Leukemia in Parent's Perspective

Since ancient times, there has been a connection between religion, medicine, and health care across all population groups.23 Spirituality is the commitment to religious principles that provide a person with a profound awareness and comprehension of life. There are numerous connections between the concepts of religion, spirituality, and health. People often question the meaning and purpose of existence when faced with life-threatening situations. It has been noted that spirituality and religion can be extremely important to providing patients with high-quality care since they give their parents solace and solace. It provides parents with a sense of fulfilment and well-being and serves as a cornerstone for them to overcome their melancholy. According to the study's findings, parents believe that we are put to the test by Allah and that it is our responsibility to prepare our children for life. Our steadfast belief that Allah is the source of both health and illness has made it simple for us to care for our children and carry on with customs and daily life. Similar ideas and opinions have been documented in a few earlier research that are related to the one that was done.

Families, religious leaders, and medical professionals ought to collaborate when making decisions. Religious leaders have the ability to mediate disputes between parents and doctors. Spirituality is for mental & soul peace; medication is for physical wellness. According to the participants, religious and spiritual healers are an effective way to help people overcome their fear of dying and moving on, as well as to instill a sense of fulfilment and optimism. Spiritual cures are highly sustainable for parents and their children in order to maintain a good balance in life between anxious perceptions and fears. The fundamental motivations for directing positive or negative associations in treatment concerns are beliefs and faith, which are linked to positive and negative associations of emotions with feelings in order to attain or set destination of children's life.24 According to the findings, there are both positive and negative associations, and participants' perspectives on illness and treatment were clarified.

Challenges Faced by the Parents During the Tenure of Treatment

Parents are the most important people in the lives of young children. Parents provide the example for their children's general wellbeing. Parents are always concerned about their kids' health. While their children are receiving leukaemia treatment, they may feel depressed, guilty, stressed, anxious, confused, have social difficulties, financial difficulties, and many other issues. According to a study, parents of leukemic children face a variety of challenges and difficulties, some of which are medical in nature. These difficulties include job loss, parent-child separation, depression, the desire to have no more children, and other social issues.25 Parents need to keep up with the latest information on diagnosis, medicine, and treatment plans in order to be informed about the health of their children. This phenomenon is particularly potent in industrialised nations; unfortunately, in Pakistan and the surrounding areas, pre-diagnosis education is nonexistent, and parents are not provided with basic and primary education.The expense of treatment for leukaemia patients might be concerning; in addition, the cost of medication and doctor visits adds to the parents' financial strain. Considering the circumstances in KPK, it can be seen that parents face financial hardships, lack of access to counselling, and lack of education, all of which worsen their circumstances. On the other hand, before to and throughout the course of treatment, parents and individuals in industrialised nations are fully informed.26 The fear element associated with chemotherapy remains in parents' lives even in cases when their child no longer requires medical attention or treatment.

Siblings' needs must also be appropriately met; leukaemia sufferers are not the only ones with parenting duties. The majority of families and parents make an effort to balance providing for their leukemic child with their own needs, but they eventually give in to and become tired of their hectic daily schedules. Parents are unable to participate in family events and social gatherings. Both parents' and children's social lives are negatively impacted, and parents avoid inviting strangers into their homes to prevent infection in their kids. Because chemotherapy suppresses the immune system, side effects from the drug exacerbate the issues. Parents and families face confrontation and societal shame as a result of this. Parents' social and personal lives are completely ruined because of the extra care required to shield a child from unnecessary infections and hospital stays. These factors put additional financial strain on parents, the hospital, and the family. Little children encounter difficulties in addition to their parents. Similar circumstances and conclusions that harm parents and cause them suffering are evident in earlier research and literature as well.

Scarcity of Resources

Resources scarcity is a major issue in practically every society, but it is particularly problematic in emerging nations' rural areas. The study's findings indicate that the issue with early diagnosis was one of the critical components. Early diagnosis has been found to be essential for timely therapy initiation. The lack of well-equipped labs and screening tools in rural hospitals is a primary cause of this diagnosis delay. Relocating patients from rural to urban areas is another time-consuming procedure that postpones an early diagnosis. As the condition progresses, further expenses are anticipated to manage the patients. On the other hand, things are different in industrialised nations where the healthcare system offers resources for prompt leukaemia diagnosis, which improves the disease's prognosis and has less of an impact on the parents.27 A UK study found that with proper facilities, children received prompt diagnoses that improved their prognosis and eased the worries and difficulties faced by their parents and other family members. Second, parents regularly visit the hospital for the treatment of their child's chemotherapy side effects due to a lack of knowledge about these symptoms, which further entails keeping them in financial difficulties and limiting their access to medical specialists.28

In Pakistan, health care services receive only 3% of the budget, which places an additional financial strain on the individual. Western nations, in comparison, have well-organized health care systems for all diseases, including prompt diagnosis and reporting systems, and a significant portion of their budget is set aside for the health sector.

Conclusion

The primary goal of this study was to investigate the difficulties and experiences faced by parents of children with leukaemia. The study's results and findings delved deeply into the worries, dilemmas, and challenges that parents had when caring for their children who had leukaemia. Different experiences were discovered, impacting the parents in many domains. In terms of their psychological state, they were discovered to be painfully unhappy, tense, nervous, and melancholy when caring for their kids. They had various social setbacks as well, and they lacked the necessary assistance to effectively manage their social lives. The majority of parents experienced loneliness as a result of having to battle their illnesses alone without sufficient social support. Along with these issues, the families and parents were also made aware of the ambiguity surrounding the condition, the negative effects of chemotherapy, and the need to manage their child's side effects. It was also determined that the parents were not receiving the appropriate counselling sessions necessary to move forward with their children's care and improvement. Certain parents faced greater difficulties in managing their issues, but others managed to cope to some degree by using coping mechanisms to manage their children's lives. It was also a terrible experience for them to not have access to an updated medical facility for an early leukaemia diagnosis and to financial restrictions. The difficulties they faced when their child was admitted to the hospital for various treatment sessions were horrific. The difficulties of treating chemotherapy side effects and providing for the needs of hospitalised and at-home children are exacerbated by a lack of finances. They disclose that every coping strategy they use is connected to a religious or spiritual approach to lessen and overcome obstacles in their children's lives. Pakistan is a developing nation where there is a dearth of knowledge about leukaemia and cancer, and parents often view disease as an indication of impending death. Thus, appropriate counselling, prompt diagnosis, affordable treatment, and raising knowledge of the illness may all contribute to lessening the suffering, obstacles, and challenges faced by parents of children with leukaemia.

Strengths and Limitations

The baseline data for future investigations into the experiences of parents of children with leukaemia were generated by the current study. According to participant statements, the degree of anxiety, sadness, and mood disorders was not specifically examined or covered, but rather a generic perspective was adopted. Neither gene study correlations nor genetic factors were investigated. None of the participants received any kind of interview education or session to shape their experiences and mindset. Although they were mentioned from the outset, inheritance and environmental factors also contribute to leukaemia; nevertheless, these aspects were not directly explained as a significant portion of the study. This study is noteworthy because it collects data from an underprivileged area of the nation where leukaemia cases are reported at a higher rate than in other regions. For more insightful results, data was gathered from KPK Peshawar's public and private hospitals. To investigate the fundamental and actual events and experiences of parents throughout the treatment and care of their leukemic children, the study solely relied on phenomenology. The study's primary goal was to investigate the common experiences, difficulties, and coping strategies of parents of leukaemia patients, as well as how to modify lifestyle choices to better meet the requirements of their children. The results were presented implicitly in the form of themes and categories. Ethical concerns were successfully met.

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