

Experiences of pediatric cancer survivors



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Exploring the experiences of pediatric cancer survivors in Karachi, Pakistan.

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This chapter presents the study design, its setting, the sampling technique, the data collection process and the details of data analysis. In addition, the ethical considerations and study limitations are also discussed in the chapter.

Methodology

Qualitative methods are utilized to generate knowledge about a new area of interest. Qualitative research methods are mostly descriptive in nature to bring out the subjective meaning of behaviors and attitudes (Polit & Beck, 2008). As there is no documented evidence for the issues encountered by cancer survivors in Pakistan, the researcher felt that the question about the experiences of cancer patients and their needs for care could be best upraised by following a naturalistic inquiry using a qualitative methodology.

Study Design

The descriptive explorative qualitative design was used in this study to explore the experiences of survivors of pediatric malignancies. In the process of developing new knowledge one or more characteristics of a specific population can be examined by utilizing descriptive designs whereas, exploratory designs are used when an in-depth exploration of a single process, variable or concept is required (Wood and Ross-Kerr, 2011). Hence, in order to delineate the characteristics and conduct an in-depth exploration of the phenomenon of survivorship, the descriptive exploratory design was

employed for the study. This design offers flexibility to generate knowledge by ensuring less control of the researcher over the variable and allowing the manifestation of subjective experience of the cancer survivors.

Study Setting

There is substantial amount of evidence that over the past decade the incidence of lymphoma is on the increase in Karachi, (Bhurgri, 2004), and this is equally applicable to all pediatric cancers. Karachi is a metropolitan city with a population, representative of diverse cultural, socioeconomic and educational backgrounds from all over Pakistan. The study site, the Aga Khan University Hospital (AKUH) is located in Karachi and it receives patients from diverse financial and geographical backgrounds from all over Pakistan. These characteristics make AKUH suitable as the study setting.

Study population

The pediatric oncology follow-up clinics of AKUH were identified as suitable places to study a variety of individuals who had survived pediatric cancers. All pediatric patients registered with the department of pediatric oncology AKUH were the study population. The study participants were the follow-up patients in the remission period who survived pediatric cancer and were discharged from the oncology clinic after completion of their anti-cancer treatment.

Sampling Technique

The purposive sampling technique is used in the present study. Despite the fact that a non-probability sample is less likely to be a representative of each

individual of the population, in order to develop a rich and holistic understanding of survivorship, the sampling decision would be based on the informational and theoretical needs of the phenomenon of interest (Polit & Beck, 2008). Therefore, based on the researcher's prior knowledge about the population, participants who were particularly knowledgeable about the issue under study were chosen purposefully. Purposive sampling that deliberately reduces variation and permits a more focused inquiry for typical cases (Polit & Beck, 2008), such as previously treated pediatric cancer patients (in remission), would bring qualitative information enriched with their lived experiences about cancer and its treatment.

Sample Size

Recruitment of the participants continued until theoretical saturation became apparent. Theoretical saturation is a point in time achieved in data collection process when no new relevant concepts are recognized in comparison with the data already produced; and researcher may only find repetition of previously collected data (Burns & Grove, 2009; Gerrish & Lacey, 2010). Male and female participants were randomly chosen at the pediatric oncology follow up clinics. Eight participants, four male and four female were interviewed after taking informed consent at pediatric oncology follow-up clinics. Ages of the patients ranged between 08-25 years. The length of time since completion of chemotherapy and radiation therapy was one year. The selected patients were in remission after having completed anticancer treatment for at least one year so that research would reveal the rich experience of the individuals who were treated and were disease free

after the treatment regimen. Patients were cognizant about their diagnosis and the treatment and subsequent after the treatment.

Inclusion Criteria:

- Both male and females cancer survivors
- Children Age 08-16 years
- Diagnosed as having had Pediatric Cancer
- Have had completed anti-cancer treatment regimen
- In remission for at least one year after treatment

Exclusion Criteria:

- Children who are on active treatment or relapsed after completion of treatment
- Children who did not sign voluntary informed consent

Data Collection

In-depth interviews are used when the researcher has a list of topics that are needed to be explored. Interview Guides are the list of areas or questions to be covered with each participant. These guides may be pilot tested before embarking upon the actual data collection (Polit & Beck, 2008). For the study under discussion, the researcher has prepared a written interview guide with Urdu translations that are attached as Appendix A. While preparing the interview guides a previously developed questionnaire for oncology was referred to (FACIT, 2010). The prepared interview guides were sent to the committee members for their opinion. The interviews allowed the researcher to explore the research topic in a broader way. The venue for the interview was an allocated room at pediatric oncology clinic at AKUH. In addition, the <https://assignbuster.com/experiences-of-pediatric-cancer-survivors/>

technique of interview permitted the researcher to probe on the issues which needed further exploration and clarification more in detail at the same time of interaction with the participant. Immerging ideas were also incorporated in the future session of data collection to enhance the richness of the data. It allowed the respondents to recall their memories and bring out the rich experiences in detail. The respondents expressed their feelings and perceptions in the context of the topic under discussion. These first hand reports of the participants, probing of the researcher during interview and researchers own reflections for nonverbal clues helped in collecting enriched data from the survivors of pediatric cancers.

Each interview took about 30 to 45 minutes. A female moderator conducted the interviews for female pediatric cancer survivors. Interviews were recorded on an audio recorder with pseudo names. The pseudo names were used at transcription process to certify confidentiality. Demographic information e. g. age, gender, native area, history of ailment like diagnosis and treatment, length of treatment and treatment modalities used during the treatment process were also recorded at the beginning of the interview. The interviews were transcribed verbatim in Urdu Language and translated by the researcher in such a way that no meaning was sacrificed.

Data Analysis

The audio-taped interviews in Urdu were transcribed word by word and analyzed manually. The interview generated codes, categories and/or sub categories and then themes, which in qualitative research are said to be broad units of information that consist of several codes aggregated to form a

common idea (Creswell, 2013). The researcher listened to the recordings several times in order to assimilate the data to generate accurate transcription. To analyze the collected material during data collection, the recorded interviews were transcribed in the form of a formatted document for manual thematic analysis. The researcher then reverberated in the data to take similarities and differences of ideas. By doing this various specific ideas were identified which were labeled as codes. The codes were put under the sub categories and categories. The ideas or codes were marked very carefully in a way that prevented the researchers own frame of mind from affecting the interpretation of the collected data to reduce bias and ensure bracketing (Tufford & Newman, 2012). Careful reflections were made to keep researchers own thoughts and understandings from affecting the analysis (internal validity). Various identified ideas were then grouped together by axial coding in order to make tentative categories of themes. As the process of analysis proceeded, these tentative codes or categories were merged to form common themes under the guidance of the research supervisor to avoid gaps in qualitative inference of the data. The valuable input of the research supervisor also shielded the analyses process form the personal reflexivity (biases in analysis due to personal assumptions, values and beliefs) of the novice researcher. To ensure the credibility and consistency of the analysis, constant input from the external supervisors (committee members) were also incorporated. A chronological record of all the activities of the study was made by the investigator in order to ensure the dependability/audibility of the study. To safeguard the transferability of the research, the study settings, context of the study and demographics of the

patients with their diagnosis and treatment modalities were noted to enable the future investigators to replicate the study (Polit and Beck, 2008).

Ensuring trustworthiness and quality of the study

Rigour in the qualitative researches is defined as the means by which the researcher shows integrity and competence (Aroni et al., as cited in Holloway & Wheeler, 2010). Trustworthiness to maintain rigour in the study was maintained ensuring credibility, dependability, conformability and transferability (Lincon & Guba, 1985).

Credibility

Credibility is the extent to which the data and interpretation of the research are grounded in the events rather than the inquirers personal construct (Lincoln & Guba, as cited in Polit & Beck, 2008). In other words credibility of a study is ensured when it presents such faithful interpretations of participants' experiences that they are able to recognize them as their own (Hall & Stevens as cited in Long, & Johnson, 2000). A conscious attempt was made by the researcher to maintain credibility during the study. The researcher tried his best to remain involved with the participants during interviews rather than being with them only to ask questions and record the answers. It was done by helping participants to elaborate their lived experiences and allowing them to recall the events that occurred during the diagnosis and treatment. Triangulation was done by taking notes during the interview, recording of the demographics and cross checking of the data by the research supervisor.

Dependability

Dependability refers to the reliability of the collected data over time and over conditions in which the research is done (Lincoln & Guba as cited in Polit & Beck, 2008). It determines whether the process of study was consistent and reasonably stable over time. The researcher attained this by working on the research plan with the research supervisors and committee members, by taking approval from the ethical review committee of the institute and by submitting the updates of the research process to the supervisor and the committee members. The researchers' personal record, notes during the interview and transcription records were kept chronologically so that the process of the study can be traceable.

Conformability

Conformability refers to objectivity to verify the quality and adequacy of the results and interpretation. The accuracy, relevance and meaning of the data are appraised by two or more independent people for congruence (Polit & Beck, 2008). Conformability is achieved by having the input of the supervisor and the committee members at every step of the research. All the interviews and their transcript were cross checked by the supervisor. The thematic analysis by the researcher was cross checked by the supervisor for congruency and objectivity of the outcome. The researcher also maintained the records of unrefined data, transcriptions of the interviews, and also the records for synthesis and analysis of data.

Transferability

Transferability refers to the generalizability of the data and the results that came out as a result of subsequent analysis ((Polit & Beck, 2008). In order to make the result applicable to other settings, the researcher interviewed male and female cancer survivors at the follow up clinic of the pediatric oncology. The demographics of the participants, who had different socio-economic status showed that they were from different backgrounds as they belonged to the provinces of Khyber Pakhtoon Khwa, Sindh, Baluchistan and lower Punjab. To maintain homogeneity, four male and female were interviewed. Therefore, the consumers of this research can use the results at different places in similar context.

Ethical Consideration

World Medical Association has put forward a statement of ethical principal as Declaration of Helsinki to guide medical research involving human subjects (World Medical Association, 2014). To fulfil the requirement of the article 22 and 23 of recently revised document of Declaration of Helsinki, a research proposal was made and submitted to the Ethical Review Committee (ERC) of AKUH. Approval from the Director of Nursing Services (DNS) and also from the Medical Director (MD) of AKUH was taken to conduct the study and was submitted to the ERC with the research proposal. Approvals from the DNS and the MD are attached as Appendix C and Appendix D respectively. The participants' right of autonomy was maintained by having a consent form signed by the participant and the parent of each participant after giving complete information about the study and its significance. Assent form with Urdu translations is attached as Appendix B and Appendix D respectively. A confidential ID number for further identification was assigned to each

participant and to the corresponding data. As research thesis is one of the requirements of MScN program for Aga Khan School of Nursing and Midwifery the fund for the study was already allocated in the Master's program budget. The thesis budget is attached as Appendix G. A formal approval was granted to conduct the study by ERC of Aga Khan University.

Summary of the chapter

This chapter presented the methodology for the study, giving a brief description of the study design, study setting, and sampling technique. The chapter also included the data collection and data analysis plan. Ethical considerations for conducting the study are discussed in the end.

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