

Master of Science in Public Health



*Effect of chemotherapy induced hair-loss on
distress levels among cancer patients visiting
public and private hospitals of Punjab*

By

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*(Effect of chemotherapy induced hair-loss on
distress levels among cancer patients visiting
public and private hospitals of Punjab)*

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ABSTRACT

Background: Chemotherapy is used as an important component of multimodal approach in the management of various malignancies the estimated incidence of chemotherapy-induced hair loss is 65%. Anagen effluvium is the most common form of hair loss associated with cancer therapy and is usually noticed within 1–2 weeks of starting the therapy and becomes more apparent in the next 4–8 weeks of therapy. However, it is documented in the literature that chemotherapy-induced hair loss can result in anxiety, depression, a negative body image, lowered self-esteem, and a reduced sense of wellbeing.

Objectives: To determine the levels of chemotherapy induced alopecia on distress levels among cancer patients visiting public and private hospitals of Punjab.

To find out the relationship between demographic variables and chemotherapy induced alopecia distress.

Methodology: A cross sectional study was conducted in public and private hospitals of Punjab, over the duration of 6 months, from October 2021 to March 2022. A sample of 323 respondents with the age range 19-54 was obtained. Data collection tool was adapted version of chemotherapy-induced alopecia distress scale (CASD). It consisted of 25 items in five domains i.e. physical, emotional, daily activity, relationship and treatment.

Results: High distress level was 61% (n=196) while low distress level was 39% (n=127). Majority of the sample population consisted of participants belonging to age group 18-34 (n=146, 45.2%). Most of them were male 53% (n=173). Half of the participants 50 % (n=161) taken from public hospital while remaining 50 % (n=161) were taken from private hospitals. Majority of participants (n=206, 63.8%) were living in rural areas. Respondents diagnosed at stage 2 had low distress level (54%) as compare to respondents who were diagnosed at stage 3 and stage 4. Significant association (p-value ≤ 0.05) was found between Gender, family income, employment status, disease stage at diagnosis, number of chemotherapy cycles received and current active treatment.

Conclusion: Chemotherapy-induced alopecia distress was associated with all of five domains i.e physical, emotional, daily activities, relationships and treatment. It is necessary to develop specific interventions to minimize distress due to alopecia for patients with cancer. Health professionals should also provide culturally appropriate education or interventions for self-care strategies related to alopecia and lowered body image as well as psychosocial support.

Keywords: Chemotherapy induced hair- loss, Distress levels, Public and Private Hospitals, Punjab.

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TABLE OF CONTENTS

Chapter	Page
ABSTRACT.....	ii
ACKNOWLEDGMENTS	v
TABLE OF CONTENTS.....	vi
LIST OF TABLES	vii
LIST OF FIGURES	viii
CHAPTER I: INTRODUCTION	1
Objectives	4
Chapter II: LITERATURE REVIEW	5
Human anatomy and chemotherapy induced hair-loss	6
Psychological impacts.....	10
Prevention and management	17
Operational Definations	21
CHAPTER III: METHODOLOGY	22
CHAPTER IV: RESULTS.....	24
CHAPTER V: DISCUSSION.....	35
CONCLUSION AND WAY FORWARD.....	36
REFERENCES	38
Appendix A.....	42
Appendix B	45

LIST OF TABLES

Table	Page
Table 1: Demographic characters of respondents	25
Table 2: Effects of chemotherapy induced hair loss on distress level domain 1	26
Table 3: Effects of chemotherapy induced hair loss on distress level domain 2	27
Table 4: Effects of chemotherapy induced hair loss on distress level domain 3	28
Table 5: Effects of chemotherapy induced hair loss on distress level domain 4	28
Table 6: Effects of chemotherapy induced hair loss on distress level domain 5	29

LIST OF FIGURES

Figure	Page
Figure 1: Human anatomy and CIA	7
Figure 2: Molecular Pathway	9
Figure 3: Apoptotic Pathway	10
Figure 4: Coping with CIA	13
Figure 5: Prevention of CIA	15

Chapter I: Introduction

Cancer is the second most common cause of deaths worldwide. About 8.2 million people died due to different cancers in 2012. In Asia, the incident rate of cancer is expected to increase from 6.1 to 10.7 million in 2030, with an estimated increase in mortality rate from 4.1 to 7.5 million in 2030. Likewise, the rate of cancer is escalating in Pakistan; in 2012, of its 173 million people, 1.4 million were reported as cases of cancer, with an expected rise in the incident rate of 150,000 cases each year (Paus et al., 2017).

Cancer is a leading cause of mortality and morbidity all over the world and at present, it is witnessing an exponential growth in the number of malignancies. Chemotherapy is used as an important component of multimodal approach in the management of various malignancies. Hair loss due to chemotherapeutic agents is one of the most common cutaneous adverse effects and is rated as one of the most distressing side effects of cancer therapy. The estimated incidence of chemotherapy-induced hair loss is 65%. Anagen effluvium is the most common form of hair loss associated with cancer therapy and is usually noticed within 1–2 weeks of starting the therapy and becomes more apparent in the next 4–8 weeks of therapy. Even though chemotherapy-induced hair loss is very common and distressing side effect of the cancer treatment, we have very little insight and experience on its psychosocial impact on the patients. However, it is documented in the literature that chemotherapy-induced hair loss can result in anxiety, depression, a negative body image, lowered self-esteem, and a reduced sense of wellbeing (Saraswat et al., 2019):

Chemotherapy-induced alopecia is a distressing side effect common to certain treatment regimens in oncology. Unfortunately, chemotherapy-induced alopecia is an often overlooked or minor factor among our current research priorities and thus advances in amelioration have been minimal. This review offers a comprehensive examination of the clinically relevant basic science, clinical research, and current management options for chemotherapy-induced alopecia. We emphasize that hair loss secondary to chemotherapy is not as random or nonspecific in patterns or extent of disease, as one would initially

perceive. Patient support and education information and templates are provided to facilitate patient treatment (Chon et al., 2012).

Alopecia is a transient and usually (although not always) reversible consequence of systemic cancer therapy that can be psychologically and socially devastating. For some patients, the emotional trauma may be so severe as to lead to refusing or delaying treatment that might otherwise be beneficial (Del Mastro et al., 2020).

Alopecia, one of the side effects of the chemotherapeutic antineoplastic agents, is a problem frequently reported by 62.1% of the patients. Depending on the treatment protocol in use, chemotherapy-induced alopecia may induce partial to full hair loss. Besides its physical effects, the emotional impact of alopecia is also of great significance for the patients (Hindistan et al., 2016).

The alopecia developed 2–3 weeks after the first treatment application may be an important problem affecting physical appearance, self-confidence, family and social environment, and the patient's battle against cancer (Aktuğ & Gürsoy, 2018).

Negative impact of alopecia on body image is similar for both male and female participants, and the body image of the patients in both groups who experienced partial or complete hair loss was more negative than in the patients who did not develop hair loss. In the same study, because of the higher incidence of alopecia in females, the psychosocial well-being of females was found to be more affected than males. This may also be due to the fact that baldness is a socially acceptable phenomenon in men. (Erol et al., 2019).

Women with breast cancer experience significantly lower body image at the time of alopecia. Moreover, alopecia is associated with serious psychological consequences such as depression and anxiety. However, previous studies have evaluated the general association between alopecia and quality of life. Considering that patients may experience different levels of distress and body image depending on their internalization process and on the influence from peer and social environments, it is necessary to evaluate specific alopecia distress and its psychological burden. In addition, body image, which is a complex and multi-faceted construct encompassing perceptual, cognitive, affective, and behavioral

aspects of the entire body experience also should be examined in a more comprehensive manner in relation to CIA distress, as it is a key construct that impacts breast cancer patients' psychosocial health such as depression and sexuality (Erol et al., 2016).

Despite advances in the treatment of many side effects associated with chemotherapy, alopecia remains an issue that is difficult to resolve. Chemotherapy-induced alopecia (CIA) is a condition that can have profound psychosocial and quality-of-life consequences, resulting in anxiety, depression, a negative body image, lowered self-esteem, and a reduced sense of well-being. Patients who fear CIA may sometimes select regimens with less favorable outcomes or may refuse treatment. When supporting patients with CIA, health care providers should use an individualized approach with a focus placed on the actual moment of hair loss. Education, support groups, and self-care strategies are important components of any management approach. No treatment modality for preventing CIA has been clearly shown to be effective. Recent evidence suggests that new scalp hypothermic regimens may be safe and effective. There remains a critical need for effective new approaches to this problem (Schreier & Williams, 2018).

Chemotherapy and other appearance altering cancer treatments such as radiation or steroid hormones are emotionally, physically, and psychologically taxing and demonstrate the difficulty of being treated for a serious disease. Though there are different types of chemotherapy, the treatment itself can be broadly understood as a drug therapy that inhibits cell division or growth. One of the most common cutaneous side effects, meaning a side effect that affects the skin, is alopecia (Wackers et al., 2018).

Hair is often lost on all or most places the body has it, including the head, face, arms, legs, pubic area, and underarms. Understanding chemotherapy as a process helps bolster the argument for examining hair loss as a process (Erol, Can & Aydiner et al., 2017).

1.1: Objectives:

1. To determine the levels of chemotherapy induced alopecia on distress levels among cancer patients visiting public and private hospitals of Punjab.
2. To find out the relationship between demographic factors and chemotherapy induced alopecia distress.

Chapter II: Literature Review

2.1: Back Ground

In a study conducted on this issue with the participation of female patients, 47% of the patient's identified alopecia as the most traumatic side effect. In addition, in the same study, 8% of patients stated that they declined chemotherapy because of alopecia (Kluger et al., 2018).

In another study conducted women were afraid that their appearance due to hair loss would change, and some patients reported that chemotherapy-induced hair loss was worse than the breast loss. Since hair loss is like a symbol indicating that a person has cancer, it is expected that it negatively affects both male and female patients (Erol et al., 2016).

Many treatment approaches, such as surgical treatment, radiotherapy, chemotherapy, and hormonal therapy are used against cancer. Chemotherapy, which is one of these treatment approaches, prevents the development and proliferation of cancerous cells. However, it also prevents the development of hematopoietic cells, regeneration of gastrointestinal channel mucosa, and hair growth, and produces numerous side effects such as nausea, vomiting, mouth sores, fatigue, and alopecia (Hintistan et al., 2018).

The side effects of the cancer treatment and the perceived discomfort lower patient compliance, and cause them to falter in their expectations and plans for the future (Dedeli et al., 2019).

The chemotherapy treatment-related symptoms adversely affect patients' quality of life, leading to interruptions in the treatment process (Ovayolu & Ovayolu, 2017).

A diagnosis of cancer brings along with it ambiguity regarding the patient's future, and chemotherapy adds new fears due its side effects (Duran, 2011). Alopecia, one of the side effects of the chemotherapeutic antineoplastic agents, is a problem frequently reported by 62.1% of the patients (Hindistan et al., 2016).

Depending on the treatment protocol in use, chemotherapy-induced alopecia may induce partial to full hair loss (Lemieux et al., 2018).

Besides its physical effects, the emotional impact of alopecia is also of great significance for the patients (Dilek, 2020).

The alopecia developed 2–3 weeks after the first treatment application may be an important problem affecting physical appearance, self-confidence, family and social environment, and the patient's battle against cancer (Aktuğ & Gürsoy, 2014).

Numerous experts state that the presence of hair contributes to a positive physical appearance and body image, and symbolizes many factors such as charm and personality. Throughout history, hair has become an important part of body image in social, cultural, and political contexts (Erol et al., 2017).

For each person, his or her illness has a meaning and it affects them psychologically at varying degrees (Koszalinski & Williams, 2018).

For many patients receiving chemotherapy, hair loss is the biggest source of sadness. Although hair regrows after treatment, a study reports that even a temporary hair loss may have a major traumatic effect in patients (Irmak et al., 2019).

Although being mentally prepared, most patients have reported that they suffer from shock due to the bundles of hair lost in combs and on pillows. Patients who developed alopecia stated that they felt shame and that they try to camouflage it by wearing hats, scarves, and wigs, to hide their cancer (Erol et al., 2020).

A study reported that alopecia is important in social and sexual communication, and it causes patients to experience stress (Batchelor et al., 2017).

2.2: Human HF Anatomy and CIA Pathophysiology

To describe the potential utility of human HF analysis in assessing CIA, familiarization with the anatomy and physiology of this mini-organ is important, as is an understanding of the path mechanisms of this hair loss. Much of this detail can be found in Figure 1 In brief, HFs are composed of a series of concentric keratinocyte layers and ultimately function to produce a central hair shaft. Mature, terminal HFs can be divided into a permanent, non-cycling upper section and a lower section, which is continuously remodeled during the hair cycle (Lain S Haslan et, al 2019).

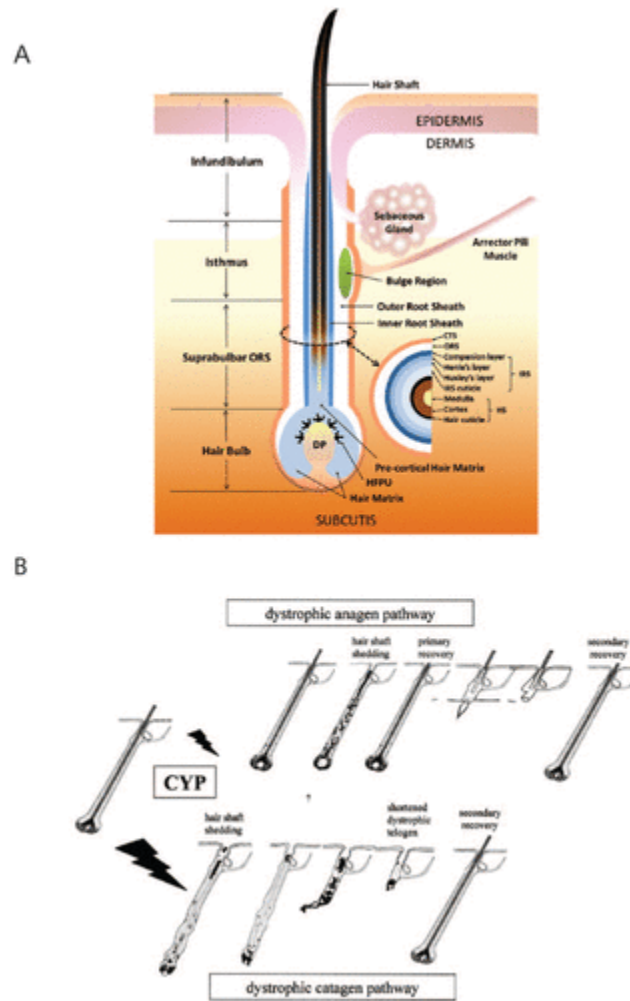


Figure 1. Human HF Anatomy and CIA Pathophysiology
(Lain S Haslan et, al 2019)

HF structure and the dystrophic pathways leading to chemotherapy-induced hair loss. (A) The upper region of the HF consists of the infundibulum and the isthmus, which meet at the insertion of the arrector pili muscle. The bulge region is located in the lower isthmus, at the origin of the arrector pili muscle, and contains epithelial and melanocyte stem cells. The lower region contains the hair bulb, housing the rapidly proliferating and chemotherapy-sensitive matrix keratinocytes. These matrix keratinocytes migrate and undergo terminal differentiation to produce the various cell lineages of the inner root sheath and the hair shaft. The outer root sheath is the external epithelial layer of the HF. The

dermal papilla, which is derived from the mesenchyme, invaginates the hair bulb and is responsible for controlling the size of the HF, the length and diameter of the hair shaft, and the duration of the growth phase of hair cycling. Source: Reproduced from Haslam et al. (B) On exposure to less severe chemotherapeutic insult, HFs undergo dystrophic anagen, whereby hair shaft production is paused but ultimately resumes, often with disturbed pigmentation and altered hair shaft structure. This leads to a poor-quality hair shaft being produced and a slow recovery as the hair follicles continue in this damaged anagen phase for a much longer period after cessation of treatment. Only on completion of catagen and telogen, at the onset of a new anagen phase, does new, healthy, fully pigmented hair shaft production resume (secondary recovery). In contrast, when the chemotherapeutic insult is more severe, HFs enter a dystrophic catagen phase in which regression is rapid and less well controlled, leading to sudden massive hair loss. Recovery is faster following this form of hair loss. Source: Modified after Hendrix et al.

HF, hair follicle; HFPU, hair follicle pigmentary unit; IRS, inner root sheath; ORS, outer root sheath; CTS, connective tissue sheath; HS, hair shaft; DP, dermal papilla.

2.3: Molecular Pathways and Structural Hair Alterations Associated With CIA

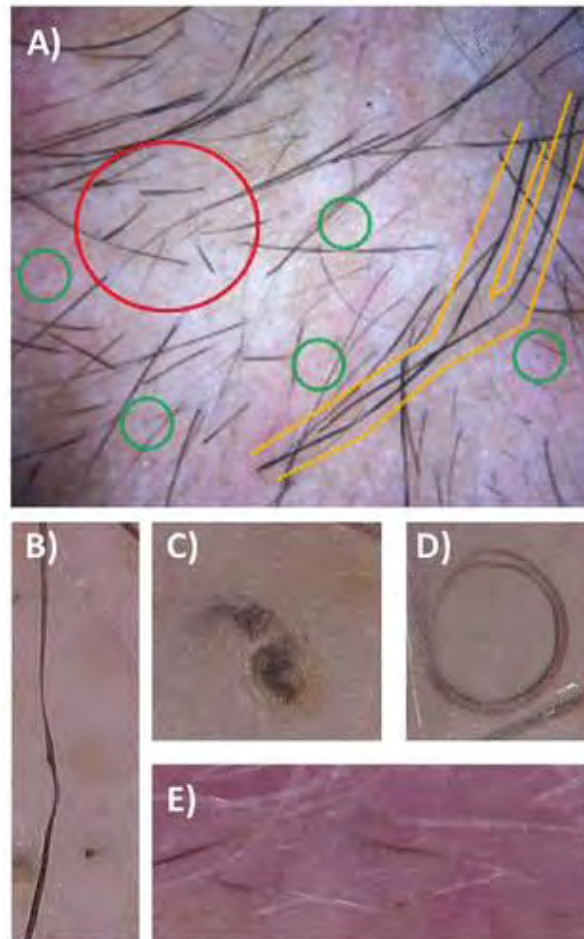


Figure 2 Molecular Pathways and Structural Hair Alterations Associated With CIA
(Lain S Haslan et, al 2019)

Trichoscopic features of chemotherapy-induced alopecia. Scalp of patient undergoing chemotherapy (A) showing Pohl-Pinkus constrictions (yellow lines), exclamation mark hairs (red circle), and black dots (green circles). Pohl-Pinkus constrictions are shown in more detail (B) with wave pattern of thickening and thinning within a single hair shaft. Examples of flame hairs (C) and circle hairs (D) are shown along with a black and white hair (E), where the hair shaft is depigmented except for the base where there is recovery of the damaged follicular melanocytes resulting in re-pigmentation(Lain S Haslan et, al 2019).

Apoptotic pathways

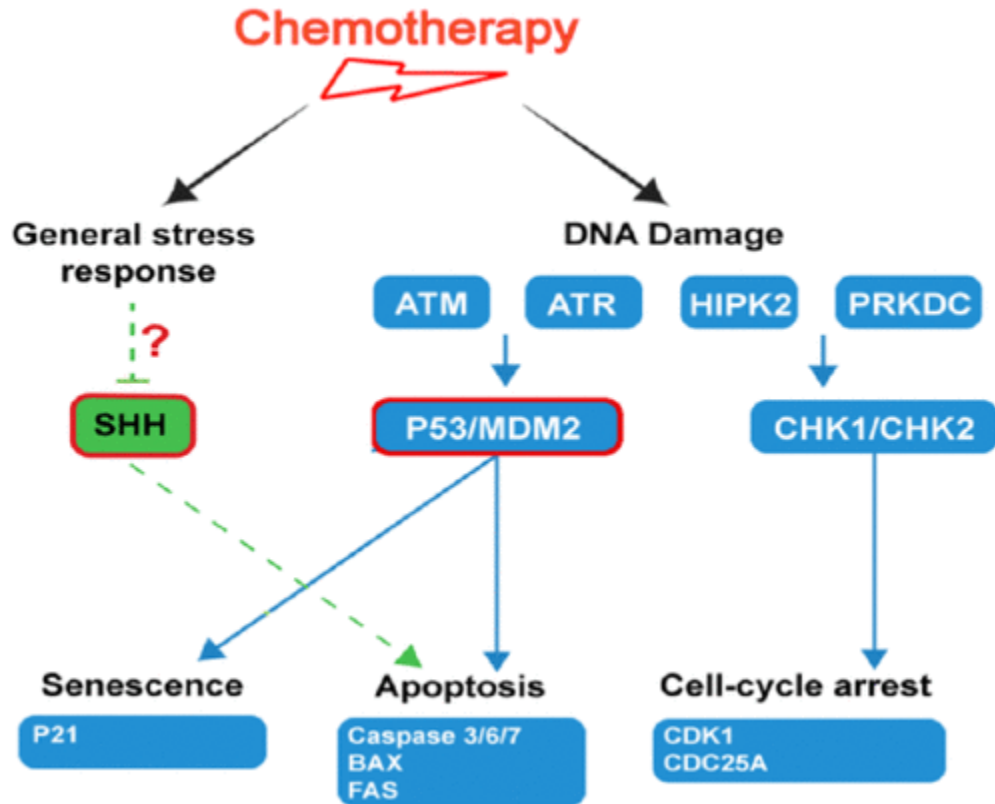


Figure 3 Apoptotic pathways

(Lain S Haslan et, al 2019)

Damage response pathways associated with chemotherapy exposure in hair follicles. Exposure of HF's to chemotherapeutic insult can cause DNA damage, with transducer molecules (ie, ATM, ATR) triggering cell cycle arrest (via CHK1/CHK2), P53-mediated apoptosis, or senescence (p21). In addition to these established pathways, induction of general or metabolic stress might also inhibit Shh signalling, leading to further apoptosis. Solid lines represent established connections, with dotted lines representing putative interaction (Lain S Haslan et, al 2019)

2.4: The Psychosocial Implications

The psychosocial ramifications of chemotherapy-induced alopecia must not be underestimated. Alopecia is the most traumatic effect of chemotherapy, according to 47% of breast cancer patients surveyed, 8% of whom said they would reject chemotherapy because of alopecia alone. Some women report that losing a breast due to a mastectomy would be less traumatic than losing all of their hair, Lacouture noted. (Paus et al., 2013)

Additionally, there is a gender difference in terms of the psychosocial impact of hair loss. Women are much more concerned about scalp alopecia, whereas men tend to be more concerned about body alopecia. Children undergoing cytotoxic chemotherapy tend to suffer social isolation as a result of alopecia, while people older than 60 years tend to be more affected by its psychosocial impact. Additionally, there is the issue of stigma; everyone knows the patient is receiving chemotherapy, which results in a feeling of loss of privacy. (Kapoor et al., 2020)

The relative impact of alopecia depends on tumor type and stage. It is the second most important toxicity in breast and lung cancers, whereas it is not even in the top 10 in gastrointestinal cancers or stage 4 disease. Chemotherapy-induced alopecia is graded by the Common Terminology Criteria for Adverse Events, but other grading systems have been implemented in the past few years, primarily led by Elise Olsen, MD, at Duke University Medical Center in Durham, North Carolina, one of the world's leading hair experts. She has devised a grading system in which a person has to lose more than 50% of his or her hair in order for other people to notice. "This is reassuring to patients," said Lacouture. "It also helps us to understand the severity of hair loss." (KOLAÇ & TAYLAN, 2021)

There is a lesser severity of alopecia with the use of targeted therapies. It is important to keep in mind, though, that patients exposed to epidermal growth factor receptor (EGFR) inhibitors develop a myriad of skin toxicities and infections. Therefore, alopecia is not only a mechanism-based effect; it can also be a consequence of infection. Patients can present

with alopecia that is actually an infection on the scalp, Lacouture explained. “The problem with this and what makes patients very upset,” he said, “is that once these patients have an infection on the scalp, it leads to a scar. And when there is a scar on the scalp the hair is never going to grow back there again. This is a very undertreated problem.” Patients on EGFR inhibitors who develop crust on their scalp should have the areas cultured; these patients are likely to have an infection that will need oral antibiotics, Lacouture advised. (Chon et al., 2012)

2.5: Persistent Alopecia and Its Consequences

“I’ve never seen patients as upset as those on cytotoxic agents whose hair never fully grows back, because these people were never told that this could happen,” said Lacouture. The incidence of persistent alopecia is unknown, but one group significantly affected is children who receive chemotherapy. In an analysis of over 40,000 patients from the Childhood Cancer Survivor Study, about 40% of children experienced persistent hair loss, which led to a higher risk of depression and anxiety when they became adults. “This is important for us to know since childhood cancer survivors are living longer and longer,” stated Lacouture. (Meg Barbor, n.d.)

“I favor the term ‘persistent’ because that connotes that there is something that can be done. If you see a patient and you tell them they have ‘permanent’ chemotherapy-induced alopecia that means there is probably nothing that can be done. I don’t think we know yet that there is nothing that can be done, and the histology does not support the notion that there is nothing that can be done,” he said. It is important to evaluate chemotherapy-induced alopecia at baseline and again every 3 months with standardized photos, tracheoscopies’, and, in some cases when inflammation or infection is suspected, with scalp biopsies. This allows for careful quantification, as patients who rely on memory can be very disappointed by their hair regrowth. (Meg Barbor, n.d.)

2.6: Coping with chemotherapy induced Alopecia

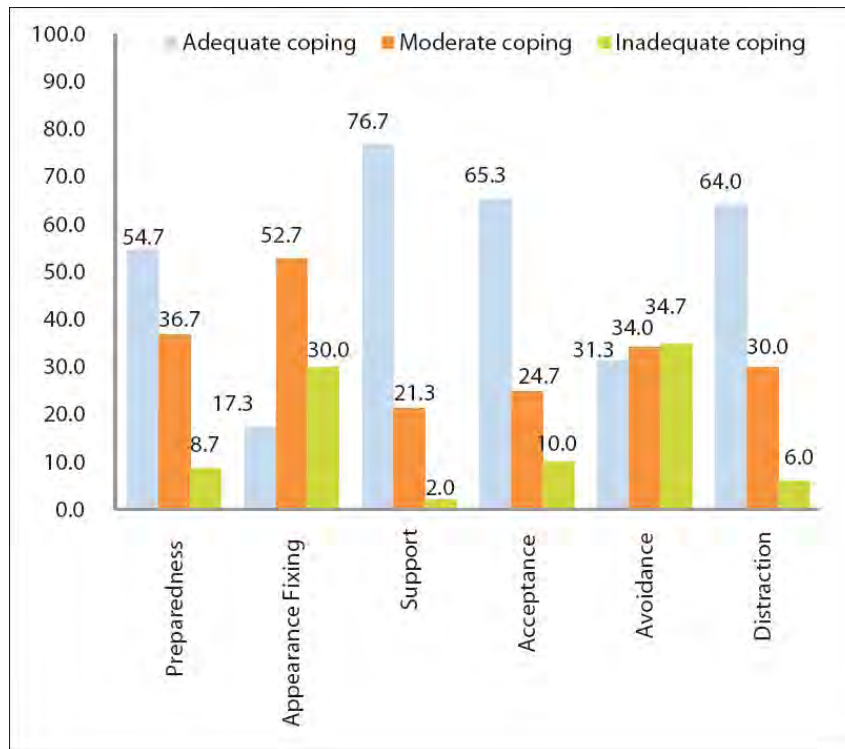


Figure 4 Coping with chemotherapy induced Alopecia
(KOLAÇ & TAYLAN, 2021)

2.7: Stigma:

The discomfort experienced by those who are stigmatized and those who perform the stigmatizing is described as an infinite regress of mutual consideration where a patient knows others are aware of her altered appearance and others sense the patient is conscious of their awareness. Keeping this regression of perception in mind, it is critical to generate empirical data examining the degree to which alopecia-related stigmatization, or the perception of being stigmatized, takes place throughout the course of treatment and how this informs how patients perceive their quality-of-life throughout the course of chemotherapy. Each person possesses at least one characteristic that sets him/her apart

from the social norm or what is considered yet the ways in which atypical traits are accepted or rejected is highly subjective and imbalanced. The construction and maintenance of what might or might not constitute a normative appearance, behavior, or value is historically contingent. In the context of research on women's health and side effect management, hair loss can be conceptualized as stigmatization because American society often interprets a woman's bald head as a sign of having cancer, a stigmatized condition (Rosman, et, al 2016).

The complex relationship between managing one's appearance and experiencing cancer is apparent when considering how the standards of "looking good" are culturally embedded. American novelist known for his critiques of the public sphere, demonstrates the intimate relationship between illness and aesthetics, arguing "we seem to believe it is possible to ward off death by following rules of good grooming." It is difficult to "properly groom" a body undergoing the intensity of chemotherapy, where drugs such as paclitaxel (taxol) cause alopecia, scalp irritation, nausea and vomiting, fatigue, loss of appetite, diarrhea or constipation, swelling, mouth sores, joint pain, and neuropathy, among others (oncolink.org, 2017).

2.8: Quality-of-life:

Cancer related depression is a pathological affective response to loss of normality and one's personal world as a result of cancer diagnosis, treatment or impending complications. Similar to Grief, depression presents with symptoms of sadness, fearfulness feeling of panic and yearning for lost objects. Depression is suspected when symptoms of sadness persist and are accompanied by increasing dysfunction, feeling of worthlessness, lowered self-esteem, suicidal preoccupation or inability to anticipate anything with pleasure.

2.9: Prevalence of chemotherapy induced Alopecia

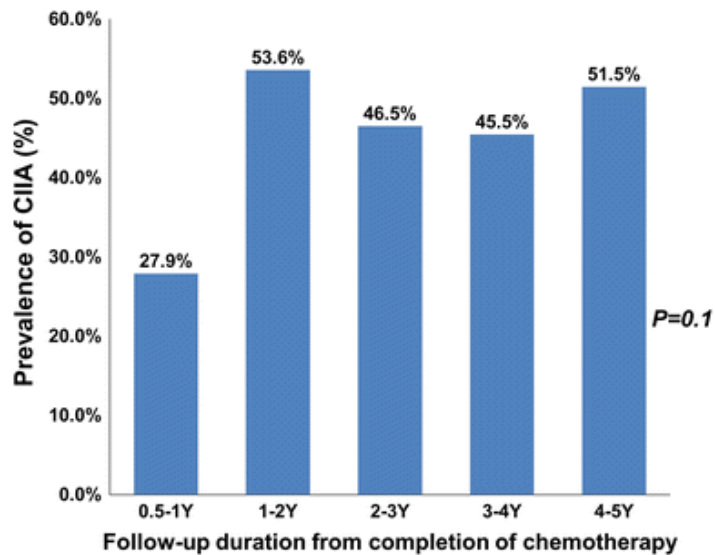


Figure 5 Prevalence of chemotherapy induced Alopecia

(KOLAÇ & TAYLAN, 2021)

2.10: Toxic agent that cause alopecia

The most common cancers expected to be diagnosed in 2015 include breast cancer, lung cancer, prostate cancer, and colorectal cancer. These cancers require different forms of treatment, which often depend on the stage and type of cancer in addition to several other patient specific factors. Cancer therapy can have adverse effects (AEs), often due to effects on healthy tissues and organs. Weight loss, vomiting, infection, nausea, and hair loss are ranked as the most feared AEs associated with cancer treatment (Kapoor et al., 2020).

Drug Class	Drug and Incidence of Hair Loss	
Antimicrotubules	Cabazitaxel (10%) Docetaxel (56%-76%) Eribulin (45%) Ixabepilone (48%) Paclitaxel (87%)	
Anthracyclines	Doxorubicin (n/a) Epirubicin (70%-96%) Idarubicin (25%-30%) Daunorubicin (>10%)	
Alkylating Agents	Cisplatin < 1% Bendamustine <1% Busulfan (17%) Carboplatin (2%-3%) Ifosfamide (83%-90%) Melphalan (n/a) Oxaliplatin (3%) Temozolomide (55%)	Frequency not defined Cyclophosphamide Lomustine Procarbazine Methchloroethamine Dacarbazine
Antimetabolites	Fluorouracil (dependent on rate/duration of therapy) Gemcitabine (15%-16%) Floxuridine (1%-10%) Capecitabine (6%)	
Targeted agents	Cetuximab Erlotinib Panitumumbab Sorafenib Vemurafenib	

Figure 6: Cytotoxic agents that can cause hair loss

(Lain S Haslan et, al 2019)

Approximately 65% of individuals undergoing chemotherapy will experience chemotherapy-induced hair loss, which is usually temporary and completely reversible when therapy ends. The use of molecularly targeted agents in cancer treatment has also

been associated with hair loss rates as high as 60%. Chemotherapy-induced hair loss has been shown to lower patient self-esteem and deprive patients of their privacy because the public commonly associates hair loss with cancer. Forty-seven percent of female cancer patients consider hair loss to be the most traumatic aspect of chemotherapy, with 8% of them stating they would decline treatment for fear of hair loss.

Hair loss associated with cancer treatment is related to the selected anticancer agent(s) and the treatment regimen. Chemotherapy-induced hair loss most commonly affects the scalp, although armpit and pubic hair, eyebrows, and eyelashes may also be lost. The hair loss can be seen within days to weeks of the initiation of therapy, with complete loss occurring 3 months after therapy has begun. Hair often begins to grow back in 1 to 3 months after therapy ends, with some patients experiencing differences in hair thickness, color, or texture upon regrowth.

Chemotherapy is thought to cause hair loss by attacking rapidly dividing cells in the body, including the dividing hair matrix cells, one of the fastest growing cell populations in the human body.⁶ The cause of hair loss associated with molecularly targeted agents has not been thoroughly investigated. Each chemotherapy agent has a different probability of inducing hair loss, and using a combination of agents may be more likely to cause hair loss compared with using 1 agent.

2.11: Prevention and Management

Many preventive measures have been attempted to reduce chemotherapy-induced hair loss. However, at present, there are no approved pharmacologic interventions to evade the hair loss associated with cancer treatment.⁷ Therapeutic approaches include decreasing drug delivery to the dividing hair bulb and pharmacologic interventions to block the hair loss effect. (Chon et al., 2012)

Preventing Hair Loss

Scalp-cooling and vasoconstrictors:

Scalp-cooling devices refrigerate the scalp with consequent local vasoconstriction and reduction of drug inflow to the hair follicles. It is largely used, and alopecia prevention rates are reported to be between 50% and 80%. Recently, this device was approved by the US Food and Drug Administration as the only efficient agent preventing CIA. Patient compliance is high, even though headache, discomfort, nausea, and xerosis may occur. This device is recommended in patients affected by solid tumors undergoing chemotherapeutic protocols associated with a high risk of developing CIA. Meanwhile, patients receiving platinum derivatives have severe peripheral neuropathies which limit their tolerance to cold for this reason scalp cooling should be avoided in these patients. Moreover, the risk of scalp metastasis prohibits the use of scalp cooling in cases of hematological tumors. Finally, this device is contraindicated in cold agglutinin disease, cryoglobulinemia, and posttraumatic cold injury because of the risk of triggering local or generalized attack (Can et al., 2018).

Soref and Fahl evaluated the efficacy of topical vasoconstrictors epinephrine and norepinephrine in preventing chemotherapy- and radiotherapy-induced alopecia in rats. Induction of hypoxia signal by local vasoconstriction preserves hair follicle cells and reduces the amount of drug reaching hair follicle. The use of vasoconstrictors 3 times a day leads to effective and long-lasting vasoconstriction (Erol et al., 2016).

In humans, when applied applied on nasal mucosae for a long time, topical vasoconstrictors could induce rhinitis medicamentosa that may present with inflamed, dry mucosa prone to bleeding, edema, and associated insomnia. It is reasonable to hypothesize that no risk of thinning and bleeding exists in cases of scalp application, since scalp is thicker than mucosa and has a different vascularization. Turkey Cancer Statistics, 2019).

The limitation of scalp cooling is that its action is confined to the application time, which usually coincides with the drug infusion. We know that the half-life of chemotherapeutic drugs is longer than their infusion time; for this reason toxic effects are prolonged too. Scalp refrigerating and consequent vasoconstriction limited to infusion time could not prevent toxic effects occurring during the weeks from one infusion to another. Meanwhile, daily topical application of vasoconstrictors could overcome this problem to ensure better

results in preventing CIA. Moreover, these drugs could be used also in patients who develop severe peripheral neuropathies after receiving platinum derivatives and who do not tolerate scalp cooling (Can et al., 2018).

Tropical Minoxidil

Topical minoxidil 2% and 5% is widely used, but clinical studies have reported disappointing results. In particular, Rodriguez et al reported severe alopecia in 88% and 92% of the patients treated with, respectively, topical minoxidil 2% and 5%. It was effective in shortening the period of baldness, and safety and tolerability were good. Duvic et al reported scalp pruritus in 60% and scalp folliculitis in 25% of the patients, and new hair growth on the face in 8 women. We would not recommend minoxidil for CIA prevention, not only because of its clinical inefficacy, but in particular because of the lack of a scientific rationale for its use (Schimdt et al., 2017).

Even if minoxidil's mechanism of action is still not completely clear, it is well known that it induces vasodilation by opening potassium channel localized on smooth muscular cells of peripheral arteries, with consequent slowing of circulation. This leads to a greater permanence of the anticancer drug around the hair follicle. Minoxidil, in addition, is able to induce angiogenesis by upregulating vascular endothelial growth factor expression, and to activate prostaglandin endoperoxide synthase 1, which is able to stimulate hair growth. This effect is exactly opposite to the scalp-cooling effect. Moreover, the final effects of minoxidil are the shortening of the telogen phase and extension of the anagen phase. Since the anagen phase is the most susceptible to drug insult, it is clear that this molecule cannot be used during chemotherapy administration (Turkey Cancer Statistics, 2019).

We suggest using minoxidil after chemotherapy discontinuation in order to obtain a greater regrowth. The best moment for introducing minoxidil should be evaluated considering chemotherapeutic drug half-life and monitoring scalp with trichoscopy and trichogram. Topical hydrocortisone could be associated with minoxidil topical application, acting as an anti-inflammatory agent but also helping follicular growth (Erol et al., 2016).

Prostaglandin Analogue

Another proposed molecule is the topical bimatoprost 0.03%, which is a prostaglandin analogue. Its efficacy was demonstrated with a randomized trial on 130 patients affected by chemotherapy-induced or idiopathic alopecia of eyelashes, which reported a clinical improvement in 37.5% of patients' vs 18.5% of controls. Bimatoprost works by protecting follicles in the anagen phase and improving follicular growth in anagen I. For these reasons it should be used with the same indications of minoxidil. (Turkey Cancer Statistics, 2016).

1,25-Dihydroxivitamin D3

Calcitriol (1,25-dihydroxyvitamin D3) has also been proposed as a CIA preventive agent. This molecule has several actions on keratinocytes, including DNA synthesis inhibition by blocking cellular cycle in G0/G1 phase, promoting cellular differentiation, and inhibiting Ki67 expression and cell growth. Initially calcitriol appeared effective in preventing CIA induced by cytosine but further studies conducted on patients in treatment with anthracyclines and cyclophosphamide showed no efficacy. Moreover, contact dermatitis was reported after prolonged topical application of calcitriol (Schmidt et al., 2017).

Topical application could be replaced by systemic administration of vitamin D3 in the postchemotherapy phase in order to take advantage of its effects on the hair follicle morphogenesis, enhancing the effects of simultaneous topical application of minoxidil and/or prostaglandin analogues. Dosage should be evaluated on the basis of vitamin D basal blood levels, weight, and height, ensuring blood concentration between 40 and 60 ng/mL, which is considered the optimal range (Erol et al., 2018).

2.1.2: Operational Definitions

Chemotherapy induced Hair-loss:

The partial or complete absence of hair from areas of body where it normally grows; baldness due to the chemotherapy (treatment of cancer by cytotoxic and other drugs).

Distress levels:

Distress is an unpleasant emotion, feeling, thought, condition, or behavior. Distress can affect the way of thinking, feel, or act, and can make it hard to cope with having cancer, along with dealing with symptoms, treatment, and side effects.

A score of 28 or above indicated high distress and 0-27 indicated low distress.

Chapter III: Methodology

3.1 Study design and duration

A cross sectional study was conducted over a period of six months.

3.2 Study Setting

Oncology Department of Public and Private Hospitals of Punjab

3.3 Study population

Inclusion criteria:

Age 18 years and above

Both male and female patients

Patients with at least 2 cycles of chemotherapy

Have either partial or complete hair-loss

Exclusion criteria:

Mentally challenged patients

Patients who have prior history of Alopecia

Patient who are non- responsive

3.4 Sample technique:

Convenient sampling.

3.5 Sample size: Sample size calculate through open epi software. At Margin of error 5%, 95% confidence interval and 30% prevalence (I. Baati et al., 2020) the sample size was 323.

3.6 Data collection tool

Data collection tool was an adapted version of chemotherapy- induced Alopecia Distress Scale (CADS) taken from previous study (I. Baati et al., 2020) It consisted of two section A and B.

Section A

Socio-Demographic variables (Age, Education, Profession....)

Section B

Chemotherapy-induced Alopecia Distress Scale (CADS) consisting up of 25 items in five domains which are physical, emotional, daily activity, relationship, and treatment.

3.7 Reliability and Validity

Questionnaire was translated in Urdu, pilot study was conducted to validate the questionnaire, followed by commencement of actual study.

Reliability was tested by calculating Cronbach's alpha by using SPSS 17.0. Cronbach's alpha was 0.8. Statistical significance was set up to $p \leq 0.05$.

3.8 Data analysis

Data analysis was done through SPSS version 17.0. All the data was cleaned after initial entry through frequency generation and data sorting techniques. Descriptive analysis for categorical variables was done through frequencies and percentages. Computation of variables was done to make final variable. Inferential analysis was done through Chi-square test for independence and 95% level of confidence was used for establishment of statistical significance and to find the association between independent and dependent variables

3.9 Variables

Independent variables:

Socio-demographic variables.

Dependent variable:

Distress levels.

3.10 Ethical consideration

Approval for study was taken from Ethical Review Board Al-Shifa School of Public Health and Quaid-e-Azam University. Informed Consent was taken from participants taking part in study. Confidentiality of participants was ensured.

Chapter IV: Results

4.1 Demographic characters of respondents:

Total sample of 323 respondents were included in the study. Regarding gender of respondents 53% were male and 47% were female. Majority of respondents were with the age of 18-34 (45%), 31% were with the age of 35-45, 6% were with the age of 55 and above. Regarding education of respondents; 27% were primary educated, 5% were matric, 37% were having high school education and 31% were professionals. Concerning respondent living area; 63% were from rural areas and 37% were from urban areas.

Out of 330; 54% were married, 31% were unmarried and 15% respond others. 37% of the respondents were working, 31% was retired while 32% was housewife/unemployed regarding employment status. Concerning family income 14% with less than 50000, 54% were with 50000-100000, 32% were with more than 100000. Out of 330, 69% of respondents were currently active treatment while 31% were not getting treatment. Detailed results given in table 1.

Table 1: Demographic characters of respondents:

Variables		Frequency	Percentage
Age	18-34	146	45.2
	35-45	100	31
	44-54	18	5.6
	55 & above	59	18.3
Gender	Male	173	53.6
	Female	150	46.4
Living area	Rural	206	63.8
	Urban	117	36.2
Employment status	Working	118	36.5
	Retired	101	31.3
	Housewife/unemployed	104	32.2
Education	Primary	87	26.9
	Matric	17	5.3
	High school	118	36.5
	Professional	101	31.3
Family Income	Less than 50000	45	13.9
	50000-100000	176	54.5
	More than 100000	102	31.6
Time from diagnosis	Less than 12months	46	14.2
	12-24 months	146	45.2
	More than 2 years	131	40.6
Disease stage at diagnosis	Stage-2	73	22.6
	Stage-3	46	14.2
	Stage-4	103	31.9
	Don't know	101	31.3
Current active treatment	Yes	224	69.3
	No	99	30.7
Number of chemo cycles received	1-2 cycles	46	14.2
	3-4 cycles	118	36.5
	5-6 cycles	131	40.6
	more than 6 cycles	28	8.7

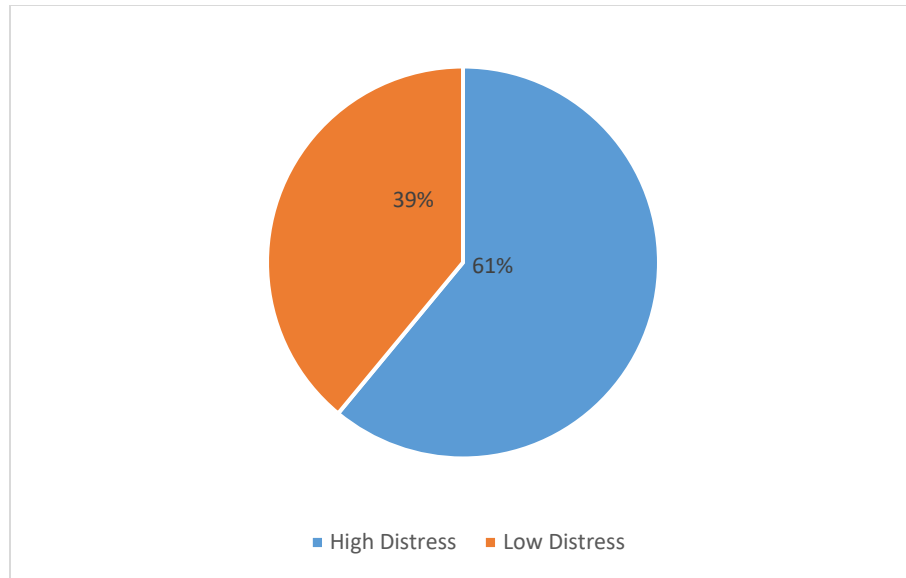


Figure 1 Effects of chemotherapy induced alopecia on distress levels

High distress level was 61% (n=196) while low distress level was 39% (n=127).

3.3: Effects of chemotherapy induced hair loss on distress levels

Physical domain

Regarding itching 6% strongly disagreed, 19% were disagreed, and 51% were neutral while 24% were agree. Concerning pricking 6% strongly disagreed, 31% were disagree, and 43% were neutral while 19% were agree.

About appearance 0.2% strongly disagreed, 26% were disagree, 31% were neutral while 42% were agree. Regarding mirror appearance 0.3% strongly disagreed, 18% were disagree, and 77% were neutral while 4% were agree.

Table 2: Effects of chemotherapy induced hair loss on distress levels physical domain

Variables		Frequency	Percentage
Itching	Strongly Disagree	18	5.6
	Disagree	62	19.2
	Neutral	166	51.4
	Agree	77	23.8
Prickling	Strongly Disagree	18	5.6
	Disagree	101	31.3
	Neutral	141	43.7

	Agree	63	19.5
Appearance	Strongly Disagree	1	0.2
	Disagree	186	26.6
	Neutral	100	31.0
	Agree	136	42
Mirror	Strongly Disagree	43	13.3
	Disagree	59	18.3
	Neutral	100	31.0
	Agree	121	37.1

Emotional domain

Regarding feeling awkward 0.3% strongly disagreed, 1% were disagreed, and 18.3% were neutral while 74.0% agreed. Concerning stress 0.7% strongly disagreed, 18.3% disagreed, and 44% were neutral while 36.8% agreed. About anxiety 0.7% strongly disagreed, 18.3% disagreed, 44% were neutral while 36% agreed.

Regarding loneliness 0.7% strongly disagreed, 13.3% disagreed, and 44.6% were neutral while 45% agreed.

Table 3: Effects of chemotherapy induced hair loss on distress levels emotional domain

Variables		Frequency	Percentage
Feeling awkward	Strongly Disagree	2	0.3
	Disagree	5	1
	Neutral	59	18.3
	Agree	251	77.4
		13	4.0
Stress	Strongly Disagree	5	0.7
	Disagree	59	18.3
	Neutral	140	44
	Agree	119	36.8
Anxious	Strongly Disagree	5	0.7
	Disagree	59	18.3
	Neutral	251	44
	Agree	13	36.8
Lonely	Strongly Disagree	5	0.7
	Disagree	43	13.3
	Neutral	140	44.6
	Agree	143	45
Confidence	Strongly Disagree	18	5.6

	Disagree	101	31.3
	Neutral	141	43.7
	Agree	63	19.5

Daily activity

Regarding bath and make-up 0.3% strongly disagreed, 18.3% disagreed, and 77.4% were neutral while 4% agreed. Concerning dressing 6% strongly disagreed, 31% disagreed, and 43% were neutral while 19% agreed. About leisure activities 0.9% strongly disagreed, 22% disagreed, 35% were neutral while 42% agreed.

Regarding shopping and restaurant 0.7% strongly disagreed, 13.3% disagreed, and 44.6% were neutral while 45% agreed.

Table 4: Effects of chemotherapy induced hair loss on distress levels daily activity

Variables		Frequency	Percentage
Bath and make-up	Strongly Disagree	2	0.3
	Disagree	5	18.3
	Neutral	59	77.4
	Agree	251	4.0
		13	
Dressing	Strongly Disagree	5	6
	Disagree	59	31
	Neutral	140	43
	Agree	119	19
Leisure activity	Strongly Disagree	5	0.9
	Disagree	59	22
	Neutral	251	35
	Agree	13	42
Shopping and restaurants	Strongly Disagree	5	0.7
	Disagree	43	13.3
	Neutral	140	44.6
	Agree	143	45
Working and reading	Strongly Disagree	18	5.6
	Disagree	101	31.3
	Neutral	141	43.7
	Agree	63	19.5

Relationships

Regarding relationship with family and friend 0.7% strongly disagreed, 13.3% disagreed, and 44.6% were neutral while 45% agreed. Concerning spouse relationship 0.5% strongly disagreed, 12% disagreed, and 52% were neutral while 34.3% agreed. About sexual relationship 1% strongly disagreed, 44% disagreed, 32% were neutral while 23% agreed.

Table 5: Effects of chemotherapy induced hair loss on distress levels relationships

Variables		Frequency	Percentage
Family and friend	Strongly Disagree	3	0.7
	Disagree	43	13.3
	Neutral	126	39.0
	Agree	154	47.7
Spouse	Strongly Disagree	43	0.5
	Disagree	59	12
	Neutral	100	52
	Agree	121	34.3
Sexual relationship	Strongly Disagree	5	1
	Disagree	59	44
	Neutral	212	32
	Agree	13	23

Treatment

Concerning treatment burden 0.7% strongly disagreed, 13.3% disagreed, and 44.6% were neutral while 45% agreed.

About treatment hesitation 5.6% strongly disagreed, 31.3% disagreed, 43.7% were neutral while 19.5% agreed.

Table 6: Effects of chemotherapy induced hair loss on distress levels (domain 5)

Variables		Frequency	Percentage
Burden	Strongly Disagree	5	0.7
	Disagree	43	13.3
	Neutral	140	44.6
	Agree	143	45
Treatment hesitation	Strongly Disagree	18	5.6
	Disagree	101	31.3
	Neutral	141	43.7
	Agree	63	19.5

3.4: Association of various demographic factors to on distress level to physical Domain:

There was a strong association between gender and physical domain 53% of male were physically stable had low distress level as compare to female χ^2 (df) 2.191(4), $p = 0.031$. Chi square showed significant association between family income and physical domain significant 56% of respondents having family income less than 15000 were physically unstable had high distress level as compare to high income χ^2 (df) 20.232(4), $p = 0.001$. A strong association between employment status and physical domain 36% of respondents who were unemployed were physically unstable had high distress level as compare to others χ^2 (df) 16.477(5), $p = 0.041$.

Chi-square depicted significant association between disease stage of diagnosis and physical domain 54% of respondents who diagnosed at stage2 were physically stable had low distress level as compare to respondents who diagnosed at stage3 and stage 4, χ^2 (df) 12.633(3), $p = 0.037$.

Table 7: Association of various demographic factors on distress level to physical domain

S.No	Variables	High	Low	χ^2	Df	p-value
1	Gender			2.191	4	0.031*
	Male	70(42.2%)	85(54.8%)			
	Female	100(53.2)	88(46.8%)			
2	Family income					

	<p>≤ 50000</p> <p>50000-100000</p> <p>≥ 100000</p>	<p>84(56.0%)</p> <p>78(51.3%)</p> <p>3(13.6%)</p>	<p>74(48.7%)</p> <p>66(44.0%)</p> <p>19(86.4%)</p>	<p>20.23</p> <p>2</p>	<p>4</p>	<p>0.001*</p>
3	<p>Employment status</p> <p>Working</p> <p>Retired</p> <p>Housewife/une mployed</p>	<p>69(62.7%)</p> <p>59(45.7%)</p> <p>23(36.5%)</p>	<p>41(37.3%)</p> <p>70(54.3%)</p> <p>40(63.5%)</p>	<p>16.47</p> <p>7</p>	<p>5</p>	<p>0.041*</p>
4	<p>Disease stage at diagnosis</p> <p>Stage-2</p> <p>Stage-3</p> <p>Stage-4</p> <p>Don't know</p>	<p>78(54.2%)</p> <p>30(49.2%)</p> <p>15(41.7%)</p> <p>11(22.9%)</p>	<p>66(45.8%)</p> <p>31(50.8%)</p> <p>21(58.3%)</p> <p>37(77.1%)</p>	<p>12.63</p> <p>3</p>	<p>3</p>	<p>0.037*</p>

Association of various demographic factors on distress level to Emotional Domain:

There was strong association between number of chemo cycle received and emotional domain 51% of respondents who received 1-2 cycles were emotionally stable had low distress level as compare to the respondents who received more chemo cycles χ^2 (df) 14.471(4), $p = 0.031$. Chi-square depicted significant association between disease stage of diagnosis and dependent variable 54% of respondents who diagnosed at stage2 were emotionally stable had low distress level as compare to respondents who diagnosed at stage3 and stage 4, χ^2 (df) 3.121(3), $p = 0.041$.

Table 8: Association of various demographic factors to emotional domain:

S.No	Variables	High	Low	χ^2	Df	p-value
1	<p>Disease stage at diagnosis</p> <p>Stage-2</p> <p>Stage-3</p> <p>Stage-4</p> <p>Don't know</p>	<p>70(42.2%)</p> <p>100(53.2)</p> <p>23(36.5%)</p> <p>3(13.6%)</p>	<p>85(54.8%)</p> <p>88(46.8%)</p> <p>40(63.5%)</p> <p>19(86.4%)</p>	<p>3.121</p>	<p>3</p>	<p>0.041*</p>
2	Current active treatment					

	Yes	78(51.3%)	66(44.0%)	18.23	5	0.002*
	No	3(13.6%)	19(86.4%)	2		
3	Number of chemo cycles received					
	1-2 cycles	69(62.7%)	41(37.3%)	14.47	4	0.031*
	3-4 cycles	59(45.7%)	70(54.3%)	1		
	5-6 cycles	23(36.5%)	40(63.5%)			
	more than 6 cycles	84(56.0%)	74(48.7%)			

Association of various demographic factors on distress level to Daily activities:

There was a strong association between gender and daily activities 53% of female were facing difficulties while performing their daily activities had high distress level as compare to male χ^2 (df) 3.191(5), $p = 0.021$. Chi square showed significant association between education and daily activities significant 48% of respondents who had primary education were facing difficulties while performing their daily activities had high distress level as compare to other χ^2 (df) 17.232(4), $p 0.004$.

Table 9: Association of various demographic factors on distress level to daily activities

S.No	Variables	High	Low	χ^2	Df	p-value
1	Gender					
	Male	70(42.2%)	85(54.8%)	3.191	5	0.021*
	Female	100(53.2)	88(46.8%)			
2	Education					
	Primary	84(56.0%)	74(48.7%)	17.23	4	0.004*
	Matric	78(51.3%)	66(44.0%)	2		
	High school	3(13.6%)	191(86.4%)			
	Professional	138(69%)	70(48%)			

Association of various demographic factors on distress level to relationships:

A strong association between employment status and relationship 36% of respondents who were unemployed had bad relationships with family and friends had high distress level as compare to others χ^2 (df) 14.477(4), $p= 0.031$. Chi-square depicted significant association between disease stage of diagnosis and relationship 54% of respondents who diagnosed at stage2 had good relationship status had low distress level as compare to respondents who diagnosed at stage3 and stage 4, χ^2 (df) 4.231(3), $p = 0.021$.

Table 10: Association of various demographic factors on distress level to relationships:

S.No	Variables	High	Low	χ^2	Df	p-value
1	Disease stage at diagnosis					
	Stage-2	70(42.2%)	85(54.8%)	4.231	3	0.021*
	Stage-3	100(53.2)	88(46.8%)			
	Stage-4	23(36.5%)	40(63.5%)			
	Don't know	3(13.6%)	19(86.4%)			
2	Employment status					
	Working	69(62.7%)	41(37.3%)	14.47	4	0.031*
	Retired	59(45.7%)	70(54.3%)			
	Housewife/une mployed	23(36.5%)	40(63.5%)			
			7			

Association of various demographic factors on distress level to treatment:

There was a strong association between living area and treatment 54% of respondents who were from rural areas were having low treatment utilization had high distress level had high distress level as compare to urban respondents χ^2 (df) 9.191(5), $p = 0.012$. Chi square showed significant association between family income and treatment 56% of respondents having family income less than 15000 were having low treatment utilization had high distress level as compare to high income χ^2 (df) 20.232(4), $p 0.001$.

A strong association between employment status and treatment 36% of respondents who were unemployed were having low treatment utilization had high distress level as compare to others χ^2 (df) 16.477(5), $p= 0.041$.

Table 11: Association of various demographic factors on distress level to treatment

S.No	Variables	High	Low	χ^2	Df	p-value
1	Living area					
	Rural	164(62.3%)	70(54.3%)	9.191	5	0.012*
Urban	176(66.7%)	40(63.5%)				
2	Family income					
	≤ 50000	84(56.0%)	74(48.7%)	20.23	4	0.001*
	50000-100000	78(51.3%)	66(44.0%)			
≥ 100000	3(13.6%)	19(86.4%)	2			
3	Employment status					
	Working	69(62.7%)	41(37.3%)	16.47	5	0.041*
	Retired	59(45.7%)	70(54.3%)			
	Housewife/unemployed	23(36.5%)	40(63.5%)	7		

Chapter IV: Discussion

Alopecia is a major issue related to body image. Hair symbolizes life and identity, plays an important role in social communication reflecting the social class, sex, profession and religious belief. Chemotherapy-induced alopecia is a condition that can affect psychosocial well-being and quality of life of a cancer patient resulting in anxiety, depression, a negative body image and lowered self-esteem. This study was designed to assess the level of distress in cancer patients experiencing chemotherapy-induced alopecia. Chemotherapy-induced alopecia distress scale was used to assess the level of distress and chemotherapy-induced alopecia.

This study found that the majority of the respondents (61%) had high distress level, which is in line with the study conducted in Turkey reported that 61.4 % (Turkey Cancer Statistics, 2016). On the other hand, this finding was higher than the study conducted in Europe 50.6% of respondents had high distress level.

The literature review shows that the significant factors associated with distress were gender, financial source for treatment, diagnosis, type of chemotherapeutic drug, number of cycles offered (Kapoor R et, al.,2020). This study revealed that 56% of respondents having family income less than 15000 had high distress level as compare to high income with p-value of 0.001, similarly 54% of respondents who diagnosed at stage2 had low distress level as compare to respondents who diagnosed at stage3 and stage 4 with p-value of 0.037.

Patients who were more concerned about their appearance and hair would be likely to experience distress due to alopecia compared with people who were not so concerned, and patients who had high CIA distress experienced two times poorer body image than patients who had low CIA distress (Batchelor et,al., 2017). In our study, participants reported about two times worse body image than that reported in studies of breast cancer patients in the USA or Europe.

This might be due to specific cultural, peer, and social factors in Korea, as Tiggeman conceptualized. In Korea, negative attitudes, stereotypes, and discriminating attitudes

toward cancer and people affected by the disease were very common and Korean breast cancer patients might experience high CIA distress and lower body image because of this. In a qualitative study in Korea, cancer patients with CIA felt uncomfortable being in public areas and had difficulties for daily activities such as grocery shopping or jogging because they were worried that people might recognize them as cancer patients. In this study 57% of respondents felt uncomfortable being in public areas (Kluger et al., 2018).

Similarly, in France cancer patients hid their alopecia because they wanted to protect their children and family members from people's attention. African American breast cancer patients in a rural area in the USA are also concerned about negative impacts of the CIA on their social and family relationships. Although Korean breast cancer patients might experience more CIA distress because of its specific cultural factors, it seems to be common that cancer patients experience more CIA distress when there are negative attitudes toward cancer patients. (Erol et al., 2020).

According to a recent qualitative study with Korean breast cancer patients, they lost self-esteem and felt sad and miserable when they look at the mirror with CIA. In our study, participants reported 56% of respondents felt sad when they look at the mirror with CIA.

4.1: Conclusion and way forward

Chemotherapy-induced alopecia distress was associated with all of five domains i.e physical, emotional, daily activities, relationships and treatment. High distress level was 61% (n=196) while low distress level was 39% (n=127). Majority of respondents were with the age of 18-34 (45%), 31% were with the age of 35-45, 6% were with the age of 55 and above. It is necessary to develop specific interventions to minimize distress due to alopecia for patients with cancer. Health professionals should also provide culturally appropriate education or interventions for self-care strategies related to alopecia and lowered body image as well as psychosocial support.

Strengths:

The study highlighted the impact of alopecia on the distress level of patients, as the mental health of a cancer patient is one of the crucial factor for successful outcome of treatment. It is expected that the results of this study will provide significant contributions to the literature of chemotherapy induced hair-loss on distress levels among cancer patients visiting public and private hospitals of Punjab, there is a scarcity of literature in this setting.

Limitations:

Study was conducted in few hospitals the results therefore cannot be generalized. The sample size was limited because of time constraints.

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Appendix A

Consent form and Questionnaire

EFFECT OF CHEMOTHERAPY INDUCED HAIR-LOSS ON DISTRESS LEVELS AMONG CANCER PATIENTS VISITING PUBLIC AND PRIVATE HOSPITALS OF PUNJAB

Dear Participant,

I am a research student in Al-shifa school of public health affiliated with Quaid-e-Azam University-Islamabad and currently conducting research on effect of chemotherapy induced hair-loss on distress levels among cancer patients visiting public and private hospitals of Punjab.

You can help me in my current research project by completing this questionnaire, which I think you will find quite interesting. I appreciate your participation in my study. It will take about 10-15 minutes of your precious time. I assure you that your responses will be held in strictest anonymity. Please keep in mind that the resulting data will be summarized on a general basis and not on an individual basis. If for any reason you do not want to participate in my study, please feel free to decline. If you wish to be informed of the findings of this study, the findings will be shared with you as a report discussing aggregated results only and will not disclose any raw data as this contravenes Al-shifa school of public health ethics guidelines.

Please read the instructions carefully and answer all the questions. There are no “trick” questions, so please answer each item as frankly and as honestly as possible. It is important that all the questions be answered.

I once again thank you for your assistance and cooperation in this academic pursuit.

Regards,

Dr. Muhammad Ali Alyalanz620@gmail.com

Confidentiality: Identities of respondents will not be disclosed to any one and the collected data will be used for academic research purposes only.

Please Tick the appropriate Box.

1: Demographic Data

Age: 01- 18 to 34 years 02- 35-44years 03- 44-54 years
04- 55 and above

Gender: 01- Male 02- Female

Living Area: 01- Rural 02- Urban

Employment Status: 01- Working 02- Retired 03- House
Wife/Unemployed

Education: 01- Primary 02- Matric 03- High school 04-
Professional

Marital status: 01- Married 02- Unmarried 03- others

Family Income: 01- Less than 50,000 02- 50,000-100,000 03-
More than 100,000

Religion: 01- Islam 02- Others

Time from Diagnosis: 01- Less than 12 months 02- 12-24
months 03- More than 2 year

Disease stage at Diagnosis: 01- Stage -1 02- Stage-2
03- Stage-3 04- Stage-4 05- Don't know

Current Active Treatment: 01- Yes 02- No

No. of Chemo Cycles Received: 01- 1-2 cycles 02- 3-4 cycles
 03- 5-6 cycles 04- > 6 cycles

Type of Cancer: 01- Carcinoma 02- Sarcoma 03- Leukemia
 04- Lymphoma

Prior Surgery(if any): 01- Yes 02- No

Prior Radiotherapy (if any): 01- Yes 02- No

Severity of Alopecia: 01- None 02- Mild 03- Moderate
 04- Severe

Intent of treatment: 01- Curative 02- Palliative

Questionnaire

Key for responses (Please tick the appropriate box against each statement)

1.Strongly Disagree	2.Disagree	3.Neutral	4.Agree	5.Strongly Agree
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Sr.	Statement	1	2	3	4	5
1	Is the area itchy?					
2	Is the area burning or prickling resulting in pain?					
3	Do you feel different from others?					
4	Do you feel uncomfortable and awkward to see yourself in the mirror?					
5	Are you dissatisfied with your appearance?					
6	Do you feel loss of confidence about future?					
7	Do you get irritated and stressed easily?					

8	Do you feel depressed?					
9	Do you feel anxious?					
10	Do you feel lonely?					
11	Do you face difficulties to do personal care such as bath and make-ups?					
12	Do you face limitations / difficulties to choose clothes?					
13	Do you experience limitations to do leisure activities?					
14	Do you feel sicker because of hair loss?					
15	Do you feel comfortable that people find that you have cancer because of hair loss?					
16	Do you feel difficulties to concentrate such as working and reading?					
17	Do you feel worried about that people would avoid you?					
18	Do you face problems to go out for shopping and restaurants?					
19	Do you talk to people about your hair loss?					
20	Do you always wear wigs or scarves to hide hair loss?					
21	Are you worried about relationship with family and friends?					
22	Are you worried about relationship with spouse or partner?					
23	Are you worried about sexual relationships with spouse or partner?					
24	Do you hesitate to receive chemotherapy because of alopecia?					
25	Do you feel burden of treatment/chemotherapy because of alopecia?					