

## Lived Experience Among Patients With Allogeneic Stem Cell Transplantation: A Single Center Experience

Safaa M. Hassanein<sup>1</sup>, Zeinab. M. Elsayed<sup>2\*</sup>, Mohamed A. Samra<sup>3</sup>

<sup>1,2</sup>Medical-Surgical Nursing Department, Faculty of Nursing, Cairo University, Egypt;

<sup>3</sup>Medical Oncology Department, National Cancer Institute, Cairo University, Egypt.

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### Abstract:

**Background:** Allogeneic stem cell transplantation (SCT) is dramatically increased all over the world, and qualitative study is a method which highlights the lived experience of patients' difficulties after allogeneic SCT in order to develop a continuous support system for these patients in the future.

**Aim of the current study:** Was to describe the lived experience among patients with allogeneic SCT at Nasser Institute Hospital for Treatment and Research", Cairo, Egypt.

**Design:** Mixed "Phenomenological-Exploratory" method. This refers of "mixing" both quantitative and qualitative data within a single study.

**Research questions: Q1:** What is the lived experience among patients with allogeneic SCT?

**Q2:** What are the themes of the lived experience among patients with allogeneic SCT?

**Participants:** Purposive typical sample was utilized until saturation achieved as adult participants who underwent Allogeneic SCT were intended to be recruited if they have been matched with the inclusive criteria. By the end of the study (20 participants were recruited)

**Tools: I:** Personal data which consisted of I-Demographic data covered variables such as age, gender, marital status, and working. 2- Medical data included history of cancer, current cancer diagnosis, medical therapy received ...etc.

**II:** Open-ended questions to highlight the lived experience for patient undergoing allogeneic SCT, included (six open-ended questions); two sessions were accomplished for each participant, which took 30 to 40 minutes /session.

**Results:** The study results concluded that participants' age was 34.15+7.86. Most of the participants had acute myeloid leukemia. The founded themes were (Ambiguous view, Traumatic experience. Locked inside Post SCT cautions /carefulness. And became closed to God).

**Conclusion:** SCT nurses play an integral role in ensuring optimum care for recipients therefore; description of allogeneic SCT lived experience is very essential for nurses and other health care staff. Also the current research findings can be used clinically for the development of supporting interventions, and giving appropriate advices for allogeneic SCT recipients' as well.

**Key words:** Qualitative study, Phenomenological-Exploratory, Allogeneic stem cell transplantation.

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### I. Introduction

Cancer diagnosis is always accompanied with stress and it can create constant or temporary physical and psychological changes in patients. Those changes may lead to hopelessness, intolerable pains, fear and even death (Arslan, Celebioglu, Tezel, 2009). Allogeneic stem cell transplantation (SCT) offers effective control and potential cure of hematopoietic malignancies (Pidala, Anasetti & Jem, 2009).

In the treatment of hematological malignancies, the number of allogeneic stem cell transplants (SCT) increases each year. Also, the number of indications for which SCT is considered appropriate expands, for instance to older patients and patients with co-morbidities. SCT has become standard care for many patients. Around 50,000 SCT-procedures for hematological disorders were performed annually worldwide. Although these intense procedures lead to improve long-term survival, they are associated with physical morbidity and psychological distress, potentially threatening patients' quality of life. (Braamse et al, 2011).

Hematopoietic stem cell transplantation (HSCT) has revolutionized the treatment of hematologic malignancies, bringing essential improvements to survival outcomes for many patients. However complications as infection, graft-versus-host disease (GVHD); these complications consider the most challenging sequelae to address and to improve the outcomes of all patients after allogeneic transplantation (Cruz & Bollard, 2015). Furthermore the HSCT is a long-term process during which patients receive chemotherapy and suffer chemotherapy-related toxicity, and HSCT complications. As a reason, patients experience various physical, social, psychological and emotional stresses and become vulnerable. The HSCT patients suffer from serious consequences of HSCT along with uncertainty in survival. In this situation, the patient is unable to determine or assign a definitive value to illness-related events or is not able to accurately predict outcomes (Zamanzadeh,

Valizadeh, Sayadi, Taleghani, & Jeddian, 2013). In addition, those patients category may experience guilt, anxious feeling of having children in the future, loneliness as distress caused by dependability. Recently a qualitative study revealed that most HCST/SCT patients experienced changes in their economic status, their roles in the family, the workplace might be deteriorated; and their relationships with friends as well, also they experience other difficulties, such as social stigma. Even many patients have been stated that they had to be retired early owing to medical treatment or that they had reduced their work hours because of their physical condition (Liang, Lin, Yeh & Lin, 2014)

So, assessment and describing the state of allogeneic HSCT/SCT patients and considering that in practice will be effective in reducing the complications and enhance the allogeneic SCT success. Beside that the majority of SCT researches were focused only on medications complications as chemotherapy & radiotherapy. Researchers found that it is valuable to conduct both a qualitative and quantitative research in this field. Evaluation of the patients' experience can further clarify the state of patients and problems they have in this process. Moreover assessment of patients' experiences can help to explain their status and problems which also may guide the transplant team in determine patients who need extensive explanation during the journey of allogeneic SCT and to highlight what kind of care those patients require. Apparently a multidimensional study of the experiences of patients undergoing allogeneic SCT from the patients' perspective is tremendously essential for improving health care personnel's understanding of patients' approach. Thus, this study was conducted to describe the lived experience among patients with allogeneic SCT at Nasser Institute Hospital for Treatment and Research", Cairo, Egypt.

### **Significance of the study:**

Entirety of 17 SCT programs exists in 9 countries of the Eastern Mediterranean (EM) region. A total of 7617 SCTs have been performed by these programs including 5701 allogeneic SCTs. One of the biggest centers is at Nasser Institute-Egypt which contains 20 cabins equipped with high efficiency particulate air (HEPA) filters, positive pressure and vertical laminar air flow; at that center around 170 transplants were performed per year; 80% of the transplants are allogeneic. (Mahmoud, et al, 2008 & Aljurf, et al, 2009).

Most of the conducted researches related to this area in Egypt from nursing outlook were focusing more on the quantitative findings specially the physical perspective rather than the patients' holistic lived experience; so it was crucial to conduct a mixed research method (qualitative and quantitative) for patients/participants undergoing SCT, Additionally; the experience of the patient, psychologically and physically is not the same after transplant as patients undergoing allogeneic SCT; receive high doses of both chemotherapy and radiotherapy and could experience graft rejection. All these factors definitely boost the negative impact on those patients' living experience. Subsequently, it is valuable to dig down inside their lived experience to highlight the themes of their experience in order to set a model/diagram of their real life following the allogeneic SCT. Also, it is beneficial to combine the quantitative with the qualitative perspectives side by side to enrich the trustworthiness of such study.

It is essential for the health care professional team to understand the lived experience which their patients have undergone. Dramatically this will enhance a greater depth of nursing management in the future of care for patient with allogeneic SCT as well. Thus, the aim of the current study was to describe the lived experience among patients with allogeneic SCT at Nasser Institute Hospital for Treatment and Research", Cairo, Egypt.

## **II. Material & Methods:**

### **The Aim:**

The aim of the current study was to describe the lived experience among patients with allogeneic SCT at Nasser Institute Hospital for Treatment and Research", Cairo, Egypt.

### **Research Questions:**

**Q1:** What is the lived experience among patients with allogeneic SCT?

**Q2:** What are the themes of the lived experience among patients with allogeneic SCT?

### **Research design:**

The utilized design to accomplish the current study was mixed "Phenomenological-Exploratory" method. The term "mixed methods" refers to an emergent methodology of research that advances the systematic integration, or "mixing," of quantitative and qualitative data within a single investigation. In other word, a mixed method is used when a single study uses multiple or mixed *strategies* to answer the research questions and/or test hypotheses. The basic principle of this method is that such combination permits further synergistic utilization of data than carrying out quantitative or qualitative data collection and analysis separately. The imported strategy

cannot stand alone, but instead it is imported to support the primary data collection strategy. (Driessnack, Sousa & Mendes, 2007).

The core characteristics of the designed mixed methods study in the current research included the following:

1. Collecting and analyzing both quantitative and qualitative (open-ended) data.
2. Integrating the data during the process of collection, analysis, or discussion.
3. Using procedures that implement qualitative and quantitative components concurrently with the same sample. (Wisdom & Creswell, 2013).

**Setting:**

The study was conducted at “Nasser Institute Hospital for Treatment and Research”, Cairo, Egypt.

**Participants:**

Purposive typical sample was utilized until saturation achieved as adult participants who underwent Allogeneic SCT were intended to be recruited if they have been matched with the inclusive criteria.

*\*The researchers utilized participant term instead of "patient term" as in either for mixed research method or for only qualitative method; participant term is scientifically utilized.*

**Inclusion criteria:** Adult participants (>18 years old) who underwent allogeneic SCT 15 days later after SCT were included, fully conscious, willing to interact, no major health problem might interfere researchers/participant interaction. The interview carried out inside participants' rooms.

**Time of the study:**

By the end of the study, 20 participants over 3 consecutive months (from February to April 2015); were recruited to the study.

**Data Analysis:**

Phenomenological method was followed until reach the themes step in order to analyze the data of the qualitative parts; while SPSS Version 18 was utilized for the quantitative results (descriptive & inferential tests).

**Tools:**

To achieve the purpose of the research two tools were utilized to gather data relevant to the study variables as follows:

**Tool I:** Personal data which consisted of **1-** Demographic data covered variables such as age, gender, marital status, and work. **2-** Medical data included history of cancer, current cancer diagnosis, medical therapy received...etc.

**Tool II:** Open-ended questions to highlight the lived experience for patient undergoing allogeneic SCT, included six questions which covered the following perspectives: first one was broad question which covered the general patients' expectation of having SCT; the another four open-ended questions covered patients feeling regarding their physical, psychological, social and spiritual status. Finally the sixth question focused on their general opinion about suggesting SCT as a treatment option for another patient.

**Ethical consideration:**

An official permission was taken from the hospital administration. Each participant was informed about the nature and purpose of the study. The researchers emphasized that participation in the study is entirely voluntary; anonymity and confidentiality are assured though coding the data. Then a written informed consent was obtained from all participants for participation in the study.

**Pilot study**

Once permission was granted to proceed with the proposed study, a pilot study was carried out before starting data collection on 3 of the targeted participant to evaluate the clarity, feasibility and applicability of the tools as well as estimate the time needed to collect data. Finally more modification and clarification was done on the used research tools. Data obtained from the pilot study was excluded from the study results.

Also, a panel of juries' expertise in SCT field reviewed the utilized tools for its validity; lastly a few modifications were performed on the tool of quantitative data sheet to make it more comprehensive. Also, reformulation of some qualitative questions was done.

### **III. Procedure:**

**Data Collection:**

Participants who fulfilled the inclusion criteria were interviewed individually in a private quiet room for 30 to 40 minutes started by fully explanation of the aim and nature of the current research. Around 10

minutes of rest in the middle of each interview for every patient/session was given. Each participant received the following directions:

- You have the right to stop the conversation at any time you fell exhausted.
- Each participant's name and data are confidential.
- Such study aimed to improve the effectiveness of allogeneic SCT by getting the real lived experience of participants.

In order to fell out the intended tools; two sessions were accomplished for each participant. The researcher started by collecting the data pertinent to demographic and medical data, which was collected once, followed by Semi-structured individual interview which repeated after another two weeks Paper and pencil was used to write down the main ideas. Also researchers were utilized diary technique (not in front the participant) to avoid participants' apprehension.

After the first three participants' data collection, the researchers started the coding process for the studied sample and during the coding process the researchers used both the quantitative & the qualitative methods in order to enrich the study as follows:

**Quantitative method** was utilized to analyze the Demographic-Medical data part and convert all patients'/participants' open-ended questions into number & percent to test its frequency; in addition to the related inferential tests (*section I, II & III*).

**Qualitative method** was operated by driven the four themes (*section IV*) which also was based on the open-ended questions as it was inducted depending on patients repeated words, expressions, complains, experiences and suggestions which was based on Streubert, Rinaldi & Carpenter (2011) as the researchers followed the phenomenological steps/phases and put it into application as follows: (1-Intuiting step: Verbal interaction between researchers & participants to discover what is known about that phenomena from the participants, 2-Analyzing step: Analysis is ongoing process from the beginning of the research until its conduction in order to explore the collected data simultaneously 3-Describing step: Researchers converted what was participants mention into clear word, 4-Phenomenological of essences step: Understood the phenomena under investigation and started to formulated into a conceptual categories/essences, 5-Phenomenological appearance step: Transform these essences into a written document, 6-Constitutive phenomenology step: *This is the fruitful end outcome* which comes out from the phenomenological research as in this step the phenomena is fully clear and the researchers write the themes into an understanding form and used some participants own expression "verbatim" which presented in (*section II*) Finally 7-the researchers have been compare what they concluded with the existed recent review and other researches which is clear in *the discussion section*). Moreover the researchers declared that each participant was reviewed individually; as they were compared the interviews of each participant {2<sup>nd</sup> interview compared to their primary stages 1<sup>st</sup> interview} so that the process of changes in perceptions and experience of the participants could be specified. Also the researchers reviewed the existing meaning of the data for instance.

Saturation of the sample started almost by the participant's number twelve, but to ensure credibility; the researchers continue data collection until the participant number 20. As the researchers intended to draw conclusions based on both quantitative and qualitative methods side by side so it was crucial to enlarge the sample/participant size to be up to 20 participants which significantly a larger sample for a phenomenological study comparing to other researches in the similar perspective.

#### **Trustworthiness:**

Trustworthiness of data has been met by means of the criteria which established by Lincoln & Guba, (1985) In Robort (2008) & Corbin & Strauss, (2008) for credibility, transferability, dependability, and conformability as they mentioned. –**Credibility:** Focus on the confidence in the 'truth' of the findings. – **Transferability:** Showing that the findings have applicability in other contexts. –**Dependability:** Means that the findings are consistent and could be repeated. –**Confirmability:** Stands for that a degree of neutrality or the extent to which the findings of a study are shaped by the respondents and not researcher bias, motivation, or interest.

Thus in order to achieve the trustworthiness the researchers did the following: Conduction of all interviews was done by the same researchers to sustain consistency of the interviews. Also to ensure trustworthiness; in the second session the researchers gave feedback to each studied sample about the first session to guarantee researchers/participants fully data understanding then proceed in the second session in order to clarify any uncertain point from the side of the researchers. Each transcript was cautiously checked to guarantee the accuracy of the transcript. Also the use of controlling conditions and variations in the sampling analysis of a large volume of qualitative data established transferability. Dependability was validated by means of a peer review analysis process. Again all the participants were also invited to verify the findings.

**Operational definition:**

- Lived Experience: Understanding of each participant situation or lived experience of allogeneic SCT.
- Patients with allogeneic SCT: It referred to 15 days after stem cell grafts.

**IV. Results**

The results will be presented into four main sections: **Section I):** Illustrated the Demographic & data pertinent to the medical diagnosis. **Section II):** Showed up the related inferential tests of the allogeneic SCT's participants. **Section III):** Highlight the lived experience's interviews results of patients with allogeneic SCT. While **Section IV):** Concluded themes of the lived experience among Patients with allogeneic SCT. Both section II&III will be presented into consecutive interrelated form in order to clarify the lived experience of the studied participants.

**Section I):** Illustrated the demographic & medical data pertinent to the medical diagnosis.

**Table (1): The demographic results: (Participants No. =20)**

Characteristics	No.	%
<b>Age: Mean + SD= 34.15+7.86</b>		
- > 25	2	10%
-25 -> 35	8	40%
-35 -> 45	7	35%
-45 -≥ 55	3	15%
<b>Gender:</b>		
-Male	18	90%
-Female	2	10%
<b>Working:</b>		
-Employee	16	80%
-House wife	2	10%
-Does Not Work	2	10%
<b>Marital Status:</b>		
-Single	5	25%
-Married	15	75%
<b>Educational Level:</b>		
-Can read & write	2	10%
-Bachelor degree	18	90%
<b>The payment party:</b>		
-The Government	11	55%
-On patient budget	9	45%

The mean participants' age was 34.15+7.86. It was found that 90% of them was male, 80% was employees. 75% was married. 90% was taking the bachelor degree and only 55% was treated on the expenses of the government financial plan.

**Table (2): Medical data results: (Participants' No. = 20)**

Characteristics	No.	%
<b>Cancer history in the past</b>		
-No	20	100%
<b>Current Cancer Diagnosis:</b>		
- Acute Myeloid Leukemia (AML)	13	65%
- Myelodysplastic Syndrome (MDS)	1	5%
-Acute Lymphocytic Leukemia (ALL)	2	10%
-Severe Aplastic Anemia (SAA)	2	10%
-Fanconi's Anemia (FA)	2	10%
<b>Duration of cancer (By years):</b>		
- > 1 y	10	50%
-1y > 2 y	6	30%
-2 y > 3 y	3	15%
-3 y ≥ 4 y	1	5%
<b>Receiving chemo/radiotherapy therapy (Before SCT):</b>		
-Chemotherapy only	10	50%
-Radiotherapy only	0	0%
-Chemo & Radiotherapy	10	50%
<b>For how long received chemo/radiotherapy By Months (M):</b>		
- > 5 M	4	20%
-5 M > 10 M	12	60%
-10 M > 15 M	2	10%
-15 ≥ 20 M	2	10%
<b>Since when patients had the SCT By days (D):</b>		
-15 > 25 D	1	5%
-25 > 35 D	10	50%
-35 ≥ 45 D	9	45%

It was found that 65% had acute myeloid leukemia, 50% was diagnosed with cancer for more than a year up to 4 years, 50% was treated with both chemo & radiotherapy prior receiving the SCT. 70% have been received the medical chemo/radiotherapy between 5 > 15 months. 50% of the sample joined the study between 25 > 35 days after receiving the SCT.

**Section II):- Highlight the related inferential tests of the allogeneic SCT's participants (No=20).**

**\*P Value ≤ 0.05**

-It was found that there was a significant mean of difference between participants' age & their diagnosis; chi square=9.17

-Also there was a significant moderate correlation between duration of cancer and both (Since when patients had the allogeneic SCT & the overall period of receiving chemo/radiotherapy;  $r=0.41$ ;  $0.55$  respectively.

*\*N.B. Section III: All open-ended questions which the researchers have been utilized in the interview; have been converted into number and percentage in order to give objective/purposive meaning in the following quantitative part.*

**Section III): Highlight the lived experience's interviews results of participant with allogeneic SCT's participants (No=20).**

**-General participants' expectation of having SCT:**

It was found that 25% expected that procedure is blood transfusion alike; 15% was thinking that all their complaining will disappear; while 25% anticipated that they will be cured from cancer completely. On the other hand 30% had no prospect and had information that they will have chemotherapy complications alike. 5% was expecting great complications.

**-Participants feeling regarding their physical status:**

The researchers found that 35% of the sample reported that their physical complications were severe specially regarding nausea & vomiting and even cannot go to the bathroom. 25% of them wish if that they did not have SCT and take only the chemotherapy. 10% complained that SCT was worst than chemotherapy complications. 30% of the sample had feeling that SCT post complications are like poisoning and wish if they die. While the whole sample reported that they cannot do any of the activity of daily living.

**- Participants feeling regarding their psychological status:**

It was found that 45% of the sample feels like that there were looked as prisoners inside their rooms. 10% had nightmares of death. Also 10% of them afraid to die during sleep. While another 10% feel that they had no connection with the medical staff. 25% of them always think about their family and how they will do specially those patients are the responsible about their family. The entire sample was afraid of sudden death because of the worst complications following the SCT and also mentioned that they had depression.

**- Participants feeling regarding their social status:**

80% of the sample was worry about what they will do after discharge in order to feed their family. 15% was expressed that even they missed the face-to-face meeting with family & friends but at the same time they did not like others see them during such bad condition. 5% wished if the government can draw a working law particularly for patients with cancer. The whole sample mentioned that they communicated with their family & their friend via cell phones.

**- Participants feeling regarding their spiritual status:**

The researchers found that 80% of the sample reported that their current condition make them more close to God. While 15% reported that they always ask God either to cure them or let them pass. However 5% mentioned that they do not know and as the condition get worst and he cannot do any activity or even think.

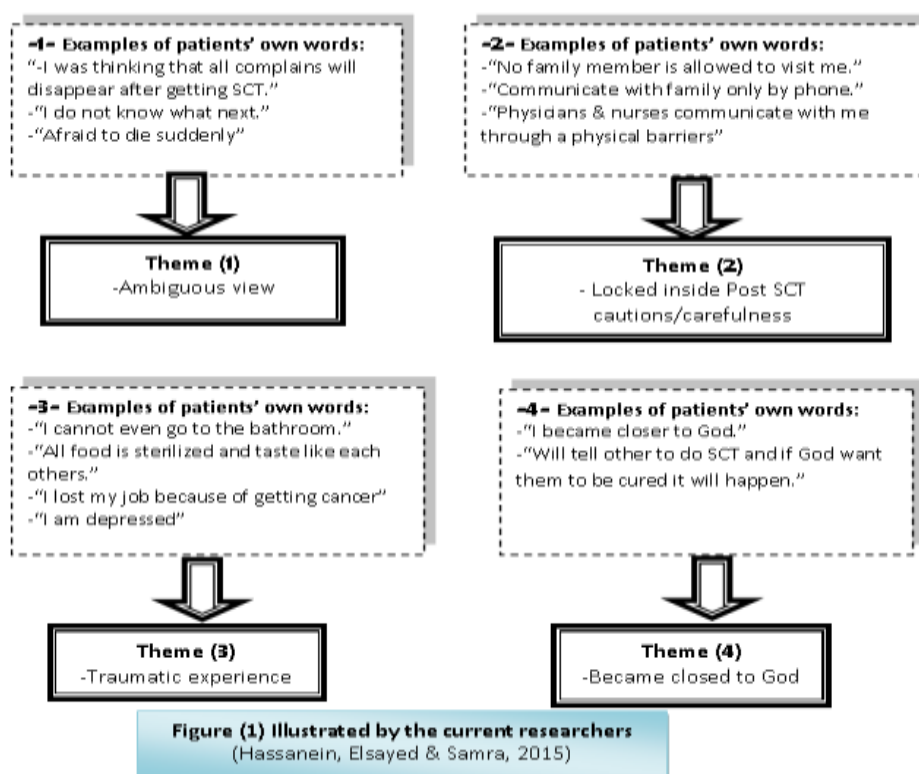
**-Their general opinion about suggest the SCT to another participant:**

Regarding this point 75% out of the sample focused that each **participant** prior getting the SCT procedure must be fully oriented about post SCT complications then let him/her decide either do it or not. However, only 25% mentioned that they would never suggest any other participant to do it.

**Section IV): Themes of the Lived experience among participants with allogeneic SCT.**

Based on the entire results; and after coding; data reduction and categorizations step; finally the researchers draw the (4) themes which highlight Lived experience among Patients with allogeneic SCT at Nasser Institute Hospital.

Figure (1) illustrates the founded themes and gave examples based on participants' own words, which directed the researchers to draw the themes' diagram.



## V. Discussion

Recently Stem Cell Transplantation (STC) is the golden solution for many patients, who suffer from chronic disease as cerebrovascular stroke, diabetes...etc. but; all manipulation still under the umbrella of the experimental trials in order to ensure its effectiveness and its reliability. Allogeneic SCT for patients with cancer especially who suffer from leukemia became a wise choice worldwide for several cases. Egypt is one of the pioneer countries, which apply such procedure in different medical governmental and nongovernmental centers. Most of the conducted studies focused only on the quantitative part of patient with SCT in Egypt; so this study hopefully will give more attention on the qualitative part from the view of the SCT recipient patients in order to highlight the qualitative lived experience part of those participants which might improve the effectiveness of this procedure side by side with the quantitative part.

*The following discussion will combine between the quantitative & qualitative finding in order to enrich the study and clarify the lived experience of the participants with allogeneic SCT.*

**Primarily this section will discuss demographic & medical findings in addition to the related inferential tests of the studied participants who underwent allogeneic SCT.** The researchers found that around three quarter of the participants their age was ranged between 25 up to 45 years old; which was expected as that age is preferable to perform the allogeneic SCT; also the youngest participants/patients' age could afford physical side effects as their response becomes positively to SCT. A study done by Zittoun, Mandelli, Willemze, et al (2015) on 446 patients to analyze the risk factors after allogeneic SCT supported the same current research finding as it found that patients' complications following SCT became less for patients with age less than 40 years old.

Most of the sample was married. Also was noticed that most of them was male; this is might be an indicator that blood cancer is higher for males than females and even males have awareness about taking the treatment as the majority of them had bachelor degrees. Cancer Treatment Centers of America, (2015) revealed that men are more likely to develop chronic myeloid leukemia (CML), chronic lymphocytic leukemia (CLL) and acute myeloid leukemia (AML) than women. In addition it was strange to find that the majority of the sample was employees but only found that around half of the sample was taking the treatment under the umbrella of either the health insurance or taking the approval of the free treatment by taking "A governmental decision letter" while the rest of them afforded the treatment on their own budget.

The current study revealed that no one had history of previous cancer; most of the participant/sample suffered from acute myeloid leukemia (AML) and half of the sample was diagnosed with cancer only a year ago before starting taking SCT treatment. American Cancer Society, (2013) stated that Allogeneic SCT transplant is most often used to treat certain types of leukemia, lymphomas, multiple myeloma, myelodysplastic syndrome, and other bone marrow disorders such as a plastic anemia. Also in the current study it was found that half of the sample was receiving chemotherapy before the SCT and the other half of the studied sample was receiving both chemo and radiotherapy treatment before preceding the SCT. The American Cancer Society, (2014) mentioned that chemotherapy must be used with higher doses to kill the cancer cell also Radiation is sometimes given as well. Moreover merely around three quarter of the studied sample have been received the chemo/radiotherapy for between five to fifteen months. The American Cancer Society, (2015) clarified this management as myeloablative transplant; as in this case the physicians give higher doses of chemo (sometimes along with radiation therapy). This is because after getting high-dose chemo treatment, the patient receives a transplant of blood-forming stem cells to restore the bone marrow. However there is a limitation in the uses of such management as it would severely damage the bone marrow where new blood cells are made in the future. In addition half of the sample was join the current study between the twenty five and the thirty five days after the SCT and this was one of the inclusion criteria the researchers have been included as they must be enrolled in the study 15 days after the allogeneic SCT as the immunity started to be engrafted and complications became in progress. This finding congruent with Negrin (2014) who found that Engraftment is measured the Neutrophils counts as a type of white blood cells that are a marker of engraftment. This can occur as soon as 10 days after transplant, although 15 to 20 days is common for patients who are given bone marrow or peripheral blood cells. Platelet counts are also used to determine when engraftment has occurred.

Moreover it was found that there was a significant mean of difference between participants' age & their diagnosis as one third of the studied participants who their age was from the twentieth category was suffering from acute myeloid leukemia; which means their suffering was boosted. As it was expected that this age category is the most energetic life time; nevertheless instead they do their future life plan they were jailed inside the disease and the allogeneic SCT precautions which might reflect negatively on their allogeneic SCT lived experience. Also there was a moderate correlation between duration of cancer and both (Since when patients had the allogeneic SCT & the overall period of receiving chemo/radiotherapy). Based on this correlation and based on the initial current research finding which found that the majority of the participants received chemo/radiotherapy for more than five months and also have been experienced the allogeneic SCT side effects for more than twenty five days; the researchers represented a logistic explanation that as much as the period of (diagnosis, chemo/radiotherapy & allogeneic SCT) was increased as much as those participants would have negative allogeneic SCT experience and this have been clearly evidenced on their responses in *the qualitative finding & the drew themes at (section IV)*.

A study conducted by Cheng, Hourigan & Smith (2014) on patients/participants with acute myeloid leukemia receiving chemo/radiotherapy & allogeneic SCT was congruent with the above current research finding as it concluded that AML remains one of the more common hematologic malignancies among adults. And for survivors who achieved complete remission after months of rigorous treatment, they will enter another time of physical, emotional, social, and role adjustment. Also they added that Adult AML survivors after durable rigorous months of induction and consolidation therapy suddenly transition into a period of “watchful waiting”—integrating back into life while not knowing if and when their cancer may recur. Survivors also face disease and treatment sequelae manifesting as medical complications, deficits in activity of daily living and daily function, and persistent symptoms as well.

**Secondly /While this section will discuss the themes of the Lived experience among patients who underwent allogeneic SCT** which inducted based on both the quantitative & the qualitative research methods which founded earlier on the results (section III & IV) of the current study. The researchers will shed light on those four themes which revealed from the study: Theme (1): Ambiguous View. Theme (2): Locked inside Post SCT cautions/carefulness. Theme (3): Traumatic experience. Theme (4): Became closed to God.

**Theme (1):** The researchers found that the studied sample had a general **Ambiguous view** about the nature and the process of the SCT. Quarter of the participants/patients was anticipated that Allogeneic SCT procedure is similar like the blood transfusion in its administration which is actually true to some extent however the whole process is different; while some of them had no expectation or information at all as they mentioned “*I do not know what is next*”. Also few participants of the studied sample were thinking that they have great complication after the SCT. Even some patients reported that they were afraid to die alone and even they stay the whole night awaken they stated “*I am afraid to die suddenly*”. Even quarter of the studied participants had a high expectation of full cure directly after taking the SCT they said “*I was thinking that all complains will disappear after getting SCT*”. Based on the finding related to theme (1); the researchers point of view that there was no doubt that specialized physicians and nurses had a session or more of talking and explaining to participants/ to some extent about the nature of the SCT procedure as some of the studied sample



mentioned that *"it is blood transfusion alike"* and also they mentioned that they would have chemotherapy complications alike; but it is clear that this session(s) is not quite enough as it did not clarify the exact process as many patients afraid to die and even think they will be cured immediately after the SCT. Jim, Quinn, Gwede, Cases, Barata, Cessna, Christie, Gonzalez, Koskan & Pidala (2014) when study Patient education in allogeneic hematopoietic cell transplant; they investigated 24 participants about what wish they had known. An exception noted by only three participants which was the better description of the transplant itself (i.e., the infusion of the blood product). Another participant suggested that education should include practical tips from nurses and other patients. While other participants reported that they hopefully to be well prepared for the acute transplant process. While the majority of suggestions for patient education focused on the late complications and how they can deal with.

**Theme (2): Locked inside Post SCT cautions/carefulness.** Many participants reported that directly and following the allogeneic SCT they had feeling that they are *"like prisoners"* as the medical staff talk or deal with them behind shelter (gown, gloves and glass borders). Also they added that they miss dealing and talking with their family members and friends and *"the only connection was by phone"*. And even all of them mentioned that *"All food taste like each other's"* as all food type must be cooked and sterilize it before serve it to those participants in order to kill the micro-organisms. From the researchers perspectives all the above findings related to theme(2) was expected as a protective measures for those participants was important so they needed extensive protection against micro-organisms, however the researchers noticed that each room was equipped with television, cell phone was allowed, nurses and physicians were allowed to enter their rooms and communicate with them but apparently it was not enough as those participants needed more physical & social interaction to minimize their anxious level.

Farsi, Nayeri & Negarandeh (2013) assessed the perceived threat in adults with leukemia undergoing hematopoietic stem cell transplantation mentioned that, the participants must be isolated in a room for doing chemotherapy and transplantation. Feeling of being in prison, and negation of freedom, fear of disconnection from the outside of isolation room, lack of some required facilities such as direct phone line were the issues which had made passing time difficult for some participants. most of them were suffered of their family members and a companion in conversation. So; they compared themselves with prisoners as they described prison as the worst torture for human and saw themselves imprisoned in the place for torturing: One of their verbatim was "You know, especially loneliness is the worst torture for a prisoner, negation of freedom is really hard and to have this disease is more difficult".

**Theme (3): Traumatic experience.** Almost all the studied sample reported that their physical experience of allogeneic SCT was chemotherapy complications alike as nausea & vomiting, fatigue, weakness...etc and even some of them mentioned *"It is like poisoning"* and even they went to the bathroom hardly and few of them cannot do any of the activity of daily living because of both fatigue and isolation. In addition few of them reported that their psychological status deteriorated and they had nightmares of death and on the other hand the whole sample was afraid of the sudden death. It was crucial to mention that during the data collection phase the researchers faced some hard time as at least two participants started to talk with the researchers with difficulty as they completely depressed with worse physical side effects especially severe diarrhea. While regarding social status the majority of the sample was worry about the future as most of them were the responsible person on expensed money for their family and they were afraid of intolerant working time after hospital discharge. From the point of view of the researchers they found that it will be so helpful for such participants category to connect them with special program which could allocate them to new job based on each participant capability to guarantee for them reasonable income and to minimize their traumatic feeling and this probably might have a positive impact on their general physical-social status and such program must be establish to support those categories on a wide level within the country. This result is compatible with Ovayolu, Ovayolu, Kaplan & Karadag (2013) who studied the participants symptoms before and after stem cell transplantation in cancer, show that they had increased mean scores of fatigue, nausea, depression, anxiety, decreased sense of well-being and decreased physical mean scores after the stem cell transplantation as compared to before transplantation. The changes in the symptoms such as anxiety was found to be highly significant ( $p < 0.05$ ). Also another study was conducted by Rahemi (2006) which is in line with the current study's results, As reported that participants who suffering from cancer does not think about the nature of the disease too much but they care more about its effect on their life, the changes regarding continuation of their activities, job, their family and losing hope for the future.

**Theme (4): Became closed to God.** The majority of the studied sample reported that their health status let them more closed to God and pray a lot; however only few of them mentioned that they ask God *"Either cure me or let me pass away"*. So the researchers found that the majority of the sample became closer to God in order of seeking health and this considered a coping strategy. Apparently the hard time as chronic illness let human to be closer to God. A study conducted by Farsi, Nayeri & Negarandeh (2013) supported this finding as

they revealed that Leaning toward religion, looking for social support, behavior modification, reflection and patience were the most important coping strategies used by the patients at this stage in order of coping.

Generally the majority of the studied sample wish if each participant get a full explanation about the benefits and the side effects of the allogeneic SCT in order to let them take a decision either do it or not. But based on the researchers perspective it is too hard for any participant to decide to do the allogeneic SCT or not do it based only on the mentioned allogeneic SCT hazards; as few of the studied sample mentioned "*Patient is hanging in any hope*". However it is still so important to clarify both the broad benefits and the expected side effects following the allogeneic SCT for each participant prior proceeding in such procedure; firstly to gain their cooperation in taking decision, secondly when they have an overview about what is next this might lower their worry level to some extent.

**To conclude;** by knowing that few qualitative researches could be found in allogeneic SCT perspectives; the current research could have an effective role in clearing ambiguities during providing the health care; and might be a corner stone in the mixed design research (quantitative & qualitative) in the allogeneic SCT field. Moreover Hematopoietic Stem Cell Transplantation (HSCT) nurses play an integral role in ensuring optimum care for recipients therefore; description of allogeneic SCT lived experience is very essential for nurses and other health care staff. Also the current research finding can be used clinically for the development of supporting interventions, and giving appropriate advices for allogeneic SCT recipients' as well.

## VI. Recommendation Of The Study:

-Replication of the study on another sample/participant with Allogeneic stem cell transplantation in other different SCT units.

### Nursing implications:

- Nurses should help patients/participants to express their expectations and beliefs, to clear their mind, and to discover meaning in experienced events to help them reflect on the nature of life.
- Nurses should discuss disease progression with the medical team, in order to help patients in making plans of returning back to work or to school...etc and implementing their plans step by step.
- Each member in the medical health team must provide sufficient information prior proceeding in the allogeneic SCT in order to clarify and answer patients/participants questions.

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