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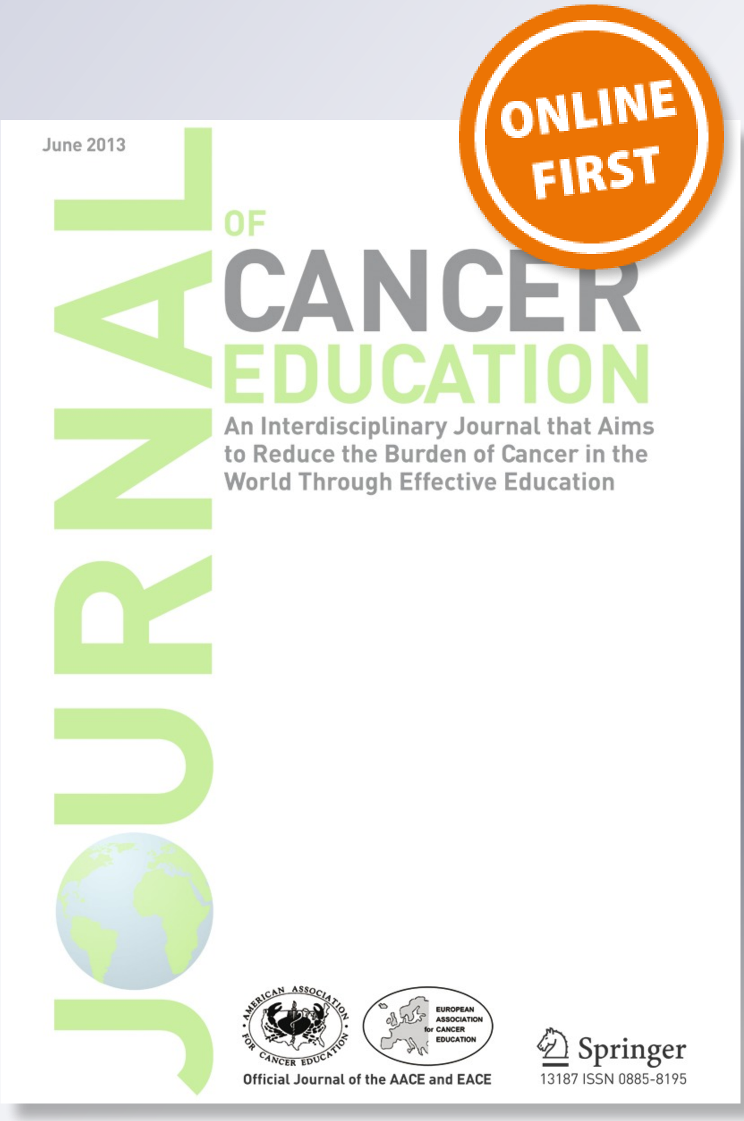
Journal of Cancer Education

ISSN 0885-8195

J Canc Educ
DOI 10.1007/s13187-013-0524-7



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Living with Cancer: A Qualitative Report of the Experiences of Leukaemia Patients in Lagos, Nigeria

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Abstract The study examined the qualitative, cognitive and psychosocial experiences of those living with leukaemia undergoing treatment at a teaching hospital. Twenty respondents who consented to participate were purposively selected from the cancer patients with leukaemia receiving treatment in the said teaching hospital. The in-depth interview method was used to collect data. The data was analysed using manual content analysis. Data showed that patients lack basic knowledge about leukaemia and had no beliefs regarding leukaemia. Some patients believed in God and a medical breakthrough for a cure, while for some, the hope of living was not certain. The ill-health condition had brought about financial predicament to both patients and family members and has limited their productivity in terms of income-generating activities. Good interpersonal relationships and support from their care providers aided their compliance to treatment regime and provided hope for living positively with their condition. The study concludes that there is a need to educate the patients on the causes of their condition. Financial supports should be rendered to those living with leukaemia, while health care providers should be encouraged to continue to maintain good interpersonal relationships with their patients.

Keywords Psychosocial Experiences · Financial Predicament · Interpersonal Relationship · Support · Leukaemia

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Introduction

About 715,000 new cases of cancer and 542,000 cancer deaths occurred in 2008 in Africa [1]. These figures are estimated to nearly double by 2030 to 1.28 million new cancer cases and 970,000 cancer deaths owing to ageing and growth of population. WHO [2] estimates that incidence of cancer in Nigerian men and women by 2020 will be 90.7/100,000 and 100–9/100,000 and death rates will be 72.7/100.000 and 76/100,000, respectively. At present, cancer accounts for 4.4 % of all deaths; the figure is projected to increase to 6.8 % in 2030. Leukaemia has been described as the most common blood cancer in Africa because it affects every sex and all age categories from 1–100 years. In 2008, an estimated 11,200 cases of leukaemia and an estimated 10,600 deaths were recorded for Africa [1]. The incidence rate for leukaemia in West Africa is estimated at 2.5 % for males, while death rate is estimated at 2.3 % for males and 2.0 % for females. There is no specific statistics of leukaemia in Nigeria, as studies show different locations. For example, Wiernik [3] found a 3.7 % prevalence rate for acute lymphoblastic leukaemia and acute myeloblastic leukaemia per 10^6 per year and 1.9 per 10^6 per year. Eze et al. [4] observed a high prevalence of leukaemic ophthalmopathy in the Enugu State of Nigeria.

Previous studies in Nigeria examined leukaemia from a biomedical perspective [5–7]. While in other places, studies have provided evidence of psychological, physiological and economic burden associated with the diagnoses and treatment of cancer and its symptoms [8–10]. Against this lack of studies on social and psychological dimensions in the management of leukaemia, this study examined psychosocial factors influencing the management of leukaemia among patients receiving treatment in a college hospital in Lagos, Nigeria. This is very urgent as it has huge financial costs on the management of leukaemia in Nigeria. According to medical experts, the management of an average cancer patient costs about two to eight million naira annually with an average of 100,000 new cases out of which 80,000 die from the disease. Survival after diagnosis of cancer is poorer in Africa than in the developed world for most cancer types. Late diagnoses or diagnoses at an advanced stage of the diseases limit treatment options, especially access to timely standard treatment, in Africa thereby limiting their chances of survival.

Method

The study was carried out in different wards and clinics of the Lagos University Teaching Hospital (LUTH), Idi Araba. There are basically two clinic days for leukaemia patients in LUTH, there is a general clinic for all the patients with blood-related ailments including leukaemia, which holds every Tuesday, referred to as haematology clinic. Tuesday clinic holds on the first floor of the Accident and Emergency building. The second clinic day is especially for leukaemia patients because they are seen by a specialist in the field of leukaemia cancer. Thursday clinic holds on the third floor of the same building. Respondents were selected from both clinic days. Also, there were inward patients i.e., patients who were admitted and were undergoing treatment in the hospital wards. There was no specific or particular ward allocated to leukaemia patients except in the case of the children's ward. The children's ward is a newly built building donated by a philanthropist and it's basically for children with all forms of cancers. From there, respondents were children and their parents or care givers.

In total, seven patients receiving treatment on admission (including one child and a parent) were interviewed and thirteen patients who came for treatment/clinic were interviewed, a total of 20 patients and one parent consented to participate in the study.

Data was collected using the in-depth interview method and case studies. Respondents were patients undergoing treatment for leukaemia in LUTH and care givers or parents during the period of the study. A total of 20 patients undergoing treatment for leukaemia at LUTH and one parent consented to participate in the study. The accidental sampling technique was used in the selection of the respondents. The respondents were selected because they had been diagnosed with leukaemia and were readily available, convenient and they consented to participate. Also, they were mentally sound to discuss with the interviewer without a third party aiding the individual to answer questions. Some respondents were approached during weekly clinic days in the hospital clinic waiting rooms, while waiting to see their physicians for consultation and then interviewed. Also, those receiving treatment in the wards were interviewed.

The Ethical Review Board of the teaching hospital approved the protocol for the study. Respondents voluntarily participated and there was no incidence of forced participation. The respondents were made aware of their right to discontinue the interview at any point and were briefed on the issues to be discussed before the interviews began.

Data Analysis

All interviews with the consent of the respondents were recorded on a voice tape recorder and transcribed verbatim. The data was analysed using manual content analysis by physically and manually identifying the themes and subthemes from each interview by three different research assistants before agreeing on a common theme to be used in the final analysis. In some cases, verbatim quotes from respondents were presented and used in the discussion.

Results

Table 1 shows that the age group with the highest number of patients in the study fell between the age range of 20–40, which constituted 35 % of the respondents. The respondents between the ages of 13–19 accounted for the lowest percentage of respondents i.e., 5 %. Those between 41–55 years accounted for 25 %. Those above 55 years constituted 20 %, while patients below 12 years made up the remaining 15 % of the respondents.

More than half of the respondents (55 %) were male, while 45 % were female. Among the respondents 55 % had tertiary education, 30 % had secondary education, while 15 % had primary education. The data shows that more than half of the patients interviewed were married and constituted 70 % of the respondents. Seven respondents had been diagnosed with leukaemia for less than 2 years and another seven between 6 and 10 years, while there were six patients who had been diagnosed for between 3 and 5 years (30 %). A total of 15 % of the respondents were unemployed, 10 % were civil servants, 20 % were retirees, 25 % were students, 25 % were traders while 5 % were teachers.

Knowledge and Perception of Leukaemia

The data shows that prior to diagnosis, the majority of the respondents never knew what leukaemia is all about. Very few knew it as 'blood cancer'. All the respondents attributed their basic knowledge of leukaemia to the information passed to them by their doctors at the time of diagnosis. The disease is generally perceived to be a 'horrible; one by the respondents. This was common in the responses of the respondents as shown in the following excerpts.

Table 1 Socio-demographic characteristics of leukaemia patients

Characteristics	Frequency	Percentage (%)
Age		
0–12 years	3	15
13–19 years	1	5
20–40 years	7	35
41–55 years	5	25
Above 55 years	4	20
Total	20	100
Sex		
Male	11	55
Female	9	45
Total	20	100
Religion		
Christianity	14	70
Islam	6	30
Total	20	100
Marital status		
Single	6	30
Married	14	70
Total	20	100
Duration of diagnosis		
Less than 2 years	7	35
3–5 years	6	30
6–10 years	7	35
Total	20	100
Educational attainment		
Primary	3	15
Secondary	6	30
Tertiary	11	55
Total	20	100
Occupation		
Student	5	25
Trading	5	25
Civil servant	2	10
Retired	4	20
Unemployed	3	15
Teacher	1	5
Total	20	100

> It is not a good cancer. I don't even pray for my enemy to have it (Adult male, diagnosed in 2011).
>
> Leukaemia is the cancer of the blood and it makes me sick, so I see it as a bad disease (Teenage female, diagnosed in 2009).
>
> Terrible! A very bad ailment (Adult male, diagnosed in 2003).
>
> I perceive it as a very bad health condition; but as a Christian, I have accepted my fate (Adult male, diagnosed 2010).

These responses show how horrified the patients were in dealing with such an ailment. The shock and grief in their tone could easily be noticed. The role of time interval becomes very important in shaping perception and even how they manage their condition. The data revealed that as patients managed the disease for longer periods, their perceptions darken on leukaemia. None of the patients laid claim to knowing what cause(s) leukaemia.

> I absolutely do not know what is responsible and no history of such illness in my lineage. But when I was first diagnosed, which was 9 years ago, I was not told what it really was but as time went on I was told and I also read about it on the Internet (Adult male, diagnosed in 2003).
>
> I honestly don't know what is responsible for leukaemia (Adult female, diagnosed in 2004).
>
> I don't know what is responsible for leukaemia. The doctor just said it is over crowding of the red blood cells by the white blood cells which result to malfunctioning of the body system and blood. (Male adult, diagnosed 2010)

However, in the bid to understand their exact causes of leukaemia, some patients decided to search the Internet for answers, as indicated by one of the patients: “I don't know what is responsible for it, but I went through the Internet and read about it” (Adult female, diagnosed 2010).

Personal Beliefs about the Illness

Various beliefs about the condition were expressed by the respondents. However, some patient claimed to have no belief about the illness, admitted not understanding why they were plagued with the illness and that people around them did not even understand what was going on: “I don't have a belief about it because I don't even know why I will have such a thing. People around me don't understand what is going on also (Teenage female, diagnosed 2009).

Not all patients shared the ‘no belief’ ideology. During interaction with an elderly patient this was realised

> Well, as an elderly man and a Christian, I don't think it is contagious or it is the work of evil doers. I just thought it was an elderly health condition but the doctors told me it is also present in children too and it has no specification or any kind of peculiarity to sex, age, gender, genotype or blood group. People around me initially thought it was spiritual, some thought it was contagious until I told them as I was told by the doctors that it wasn't contagious and I told anyone who cared to listen that it was leukaemia and they understood my predicament (Adult male, diagnosed 2010).

A number of things could be inferred from the patient's statement; firstly, information from his doctors helped shape his belief about leukaemia. Second, he tried to correct the perception and beliefs of the people around him that his ill health was not as a result of his general physiological peculiarities, that is sex, age, blood group, and so on. However, some perceived leukaemia slightly differently, as stated by a patient: ‘I believe it's deadly and God will take it away. I don't know what people think. Some feel it's HIV because of my weight loss and I even wish it was HIV/AIDS because this leukaemia is worse than HIV’ (Adult female, diagnosed in 2004). The length of time for which the patient had managed the ailment might have affected her beliefs of the illness leading her to categorise it as worse than HIV.

On the question of whether patients thought there could be possible curable vaccines, most of the patients viewed leukaemia as being incurable, a few of the respondents expressed hope and even expressed the desire for a miracle to cure it. However, one response stands alone: “Yes, I think they can [come up with curable vaccines]” (Teenage female, diagnosed in 2009).

Economic and Financial Burden of Managing Leukaemia

The respondents were from different social classes and, as such, had different occupational statuses ranging from traders, civil servants retired workers to students. For those who were students, they had no prior source of paid income and so were still dependent on their parents and family. None of the parents of these patients claimed to have lost his/her jobs on account of his/her child being diagnosed and living with leukaemia. However, they claimed that they had to increase their efforts in sourcing for more income to help provide for the needs of their wards adequately. However, some patients have to resign from paid work owing to their health condition, as shown below:

> No, [I haven't been out of job for the sake of my daughter's illness]. I have to do more jobs to get money to buy drugs (Mother of infant patient, diagnosed in 2011).
>
> No, I haven't [lost my job]. I'm still active in service (Adult male, diagnosed in 2008).

Some patients who had been battling with leukaemia for a long period, however, stated that;

> I had to stop working in 2008 because I was always falling sick (Adult female, diagnosed in 2004).
>
> I had retired before the diagnosis like I earlier said, but after the diagnosis, I stopped farming and reduced the kind of job and tedious things I used to do around the house due to fatigue, tiredness and swellings from my knee and different parts of my joint and body (Adult male, diagnosed in 2010).

Here, again, we see how the ailment had reduced the productivity of the patients and limited their ability to optimally provide for their financial needs on their own. This is not to say that there are no people living with leukaemia who still retain their jobs.

Financing Treatment and Impact of Ailment on Finances

On how the patients were financing their treatment, the data show that patients had not carried the burden alone. All of them stated that family members had been very supportive in providing whatever financial support they could afford. Some patients' religious bodies were involved in providing financial assistance towards their treatment.

As regards to the impact of the ailment on their finances, all the patients interviewed lamented on how the high cost of treatment and managing leukaemia had drained their purses;

> Yes! Of course, leukaemia is a very expensive ailment. The drugs are quite expensive, so it is financially draining. The money that is meant to go into some other benefiting things both personally and also for the family is being spent on drugs and so many things that concerns the ailment (Adult female, diagnosed in 2010).
>
> Yes it has affected my parents' finances and I pray God should always provide for them. They are both not earning big and I also have younger ones and the little they get goes to my treatment (Teenage female, diagnosed in 2009).
>
> The ailment is bad and it's very expensive to manage. So I will say yes a hundred times it has affected my finances. A sachet of drugs with 10 tablets is N15.000 and I use three in a day, so you think about it. The money I'm supposed to use for something else that will yield good things, I'm spending it on this leukaemia and even the government isn't coming to our aid, especially in LUTH. Because in some Federal hospitals like in Ife, most of these drugs are free but here in LUTH, we pay for everything and it's not fair. I can't be travelling to Ife because of free drugs. I'm too busy for that (Adult male, diagnosed in 2008).

These are separate views on how the ailment has affected the finances of the patients. There was an agreement among the patients that leukaemia is highly expensive to treat and manage. They felt that not much of their money should go into treatment of the ailment, as it could be used for other meaningful and profitable ventures and for other persons in their respective families. These responses highlight the fact that financing their treatment or their inability to be financially secure while handling this ailment is seen as a barrier to successful recuperation and proper management of their ailment.

Supports from Health care Providers and Communication

It is a common knowledge that people with life-threatening ailments are in dire need of special care and attention, especially in a developing country like Nigeria. They also need all the support that can be provided primarily from their health care providers. Information gathered from the interviews showed that the health care providers in LUTH have left no area untouched in providing adequate support for the patients, as stated by the patients:

> Yes they are trying in their own little way. They try to help me get blood, platelets and drugs. Not with their money oh, but these things are scarce so they help me get and secure them (Adult male, diagnosed in 2003).
>
> They are trying their best, just normal care and smiles from them (Adult female, diagnosed in 2004).
>
> The doctors are trying. That's why I prefer LUTH. They have specialists here. So they are trying especially Prof. Kehinde. He is a good man (Adult male, diagnosed in 2008).
>
> I get adequate support and care from everyone. The doctors attend to me very well when I come for my clinic because I'm not based in Lagos. I travel from Akure here. They do check up and do all necessary things for me. And as for my children, they support me in all ways (Adult male, diagnosed in 2010).

The patients did not make so much reference to other people when talking about support from care givers. They chose to focus on just the support and care being rendered by their primary care givers-the doctors. The input of the caregivers has led to a positive approach in handling the ailment and has helped in boosting their confidence in adequately managing their ailment.

Alteration in Normal Daily Activities

Normal life activities for most of the patients had been altered. Most of them complained about their reduced performances owing to their new fragile health. They hinted at having become weakened and easily fatigued by the ailment. The excerpt below reveals this:

> The ailment has affected my normal life activities because if I play too much, I get tired easily. I can't help my mummy in doing some housework and it has also stopped me from going to school regularly because I'm in SS1 and I should be in school but here I am on admission in the hospital (Teenage female, diagnosed in 2009).

The tone of the young girl is one of despair. This could possibly signify the emotional pain she suffers from not being able to do all that she really desires to be doing. The shortfall in productivity and activity in patients tends to weigh them down emotionally.

A queer and unique response as to alteration of normal activities owing to leukaemia was noticed in one patient:

> Not really, it [leukaemia] hasn't affected my life activities in any way. I still do everything I used to do before the diagnosis; even things I didn't do I have now started doing them. Although when I was just diagnosed, it affected me. I even had to bring my wife here to see the doctor so they can explain to her that it is not contagious because she was worried and scared. I reduced alcohol intake but I still take alcohol (don't tell the doctor, he added). I still have regular sex with my wife, I'm active at work, I eat anything I want. In fact, I have added more weight since the diagnosis because I don't want anything to get to me at all. So, the diagnosis has made me strong for my family because I am the breadwinner of the family and I can't afford to let anything get to me. I have to stay strong for them. But I don't do all the strenuous things. I try to avoid them (Adult male, diagnosed in 2008).

This patient exhibited the zeal and willingness to not give up on doing things to make him happy owing to the illness. He embraced the fact that he was sick but took up his responsibility in his family.

Suicidal Thoughts and Consideration of Death as Alternative to Living

Following diagnosis of terminal ailment, such as leukaemia, there is usually a swing of emotion and confusion which leads patients to a deplorable state of intense sadness, and sometimes, a desire for hastened death or suicide. From the findings of the interviews, no respondent owned up to have gone as far as considering the option of suicide; but there is a general admission of intense sadness and depression:

> No, I did not think of suicide within 2 weeks of the diagnosis, but I was depressed and sometimes I usually think of death especially when I'm on admission here (in LUTH) and I see my wife and kids suffering and running helter-skelter for me (Adult male, diagnosed in 2006).
>
> No, not really. Why suicide? Death will come so why hurry (Adult female, diagnosed in 2007).
>
> I didn't think of suicide at all before and after the diagnosis. The doctor explained very well that it doesn't kill at once (Adult male, diagnosed in 2005).

While the first two excerpts highlight the early mentioned findings on the issue of suicidal thoughts, the last excerpts gives an insight to a possible reason as to why the issue of suicidal thoughts may not have appeared in the minds of the patients. This factor could be the active role the doctors seemed to have played by explaining very well how leukaemia really affects them.

When the issue of considering death as the only solution to their ailment came up, most of the respondents said they had not considered death as such. This shows that the patients still harbour some sort of hope, however slim, to be able to continue living. For example a patient had this to say: No, I don't consider death as the only solution (Adult male, diagnosed in 2011).

This statement gives some hint on the subconscious thought of the patient, which borders on optimism; there could be a solution to being diagnosed and living with leukaemia. But not all patients share this optimism:

> Sometimes I do [consider death as the only solution]. Look at me now (directing question at the interviewer). Don't I look dead? I was very pretty before but look at me now (Adult female, diagnosed in 2004).

Although some patients mentioned that sometimes they consider death as the only solution to their predicament, this particular patient seems to be totally devastated with her plight. This can be noticed in her decision to liken herself to almost a dead person.

Thoughts on Being Liability to Others

Most of the respondents stated that they quite frankly feel like they are liabilities to others at varying degrees. One particular respondent felt so bad and had this to say: Yes, I feel like a liability even to myself (Adult female, diagnosed in 2004).

Feeling like a liability even to oneself can be an indication of severe depression and low self-worth and esteem. The major theme of responses regarding this particular issue highlighted some sense of indebtedness to close family members:

> Yes, I do feel like that [liability] sometimes, because my mum leaves her shop to always be with me and that sometimes stops her from selling and makes me feel bad and feel like a liability (Adult female, diagnosed in 2009).

However, some of the respondents did not consider themselves to be a burden to others.

> At all, at all, I'm not a liability. I am the head of my house and the breadwinner, so I don't feel like a liability. I have people I'm also taking care of. I'm just lucky my case hasn't become so bad for me to be in the ward here. Although I was in the ward when I was diagnosed (Adult male, diagnosed in 2008).

The above statement echoes similar traits found in the responses of patients who didn't feel like liabilities to others. They were male; considered themselves to possess pivotal roles in their immediate families; and that they were not bedridden yet.

Hope for Life and Getting Better

Despite their various battles with leukaemia, every single respondent in this research indicated inner strength to do whatever it would take to get better and remained hopeful of getting well at some point.

> Yes, I do have hope for life and for getting better…I make sure I take my medication though sometimes it is tiring swallowing drugs every time. So I skip sometimes, but I take them (Adult male, diagnosed in 2006).
> Well, I do have hope and with God, everything is possible…I try to use my drugs but when it is finished and there is no money, what do I do (Adult female, diagnosed 2004)?

Discussion

This research work examined the cognitive and psychosocial experiences associated with the management of leukaemia among patients receiving treatment in a teaching hospital. Although the patients recognised the disease as a deadly one, they exhibited poor knowledge and understanding of their ailment. Even though they were aware that it is the cancer of the blood as they were told by their physician, they lacked the basic knowledge of what causes leukaemia. This finding supports Ervik and Asplunds [11] assertion that cancer patients need varying information and support throughout the illness trajectory. This is very urgent in the study population, as there seems to be confusion about the onset of the disease. The respondents perceived the disease as a horrible health condition but hoped to thrive. They also hoped for some healing, be it by supernatural causes or even a medical breakthrough, although some seem to have resigned to fate. The belief in God, as expressed by the respondents as a way out of their health problem, agrees with studies that show that religious belief has an important role in helping individuals understand the cause of cancer and can help them sustain a sense of justice [12]. The finding on patients accepting their diagnosis of cancer without denial and subsequently being able to cope with the condition is supported by Edgar et al. [13] who claim that the emotional coping of patients with breast cancer improved during the years regardless of the intervention timing.

Living with the ailment has had adverse effects on the economic and financial status of the patients. Almost all of them had been dispossessed of their financial freedom. This affected their view of themselves as they had to dedicate almost all of their resources and even the resources of other family members to acquiring a considerably stable health status while managing leukaemia. This has, no doubt, affected their perception of themselves and limited their participation in revenue generation for themselves and their respective dependents. This is in line with Moradian et al. [14], who argue that cancer affects several aspects of the life of patients including financial situation, ability to work, family life, cost of treatment and psychosocial issues. Institute of Medicine [15] and Singh et al. [16] contend that economic barriers play an important role in limiting access to cancer care. The alteration in the daily activities of patients as noticed in this study is in line with Rowland's [17] categorisation of a universal set of cancer-related disruptions that occur across all adult age groups/life stages and throughout a continuum of care that begins at diagnosis and continues through phases of treatment and eventual transitions to off-treatment survival of the end of life. These disruptions are altered interpersonal relationships, issues relating to dependence/independence, achievement of life goals, concerns about body-sexual image and integrity and existential issues. These disruptions are generally noticed in daily activities, physical plan, diminished energy, changes to physical appearance, limitations in functional ability, and altered social relations, confrontation with mortality and existential issues and changes in one's sense of self, future and world.

This study shows that the health care providers have contributed their professional quota to ensuring that these patients remain stable and have some knowledge and desire to live healthy lives through support, interpersonal relationship and good communication channel. Such support has helped the patients to develop some self-efficacy and is able to adjust to living with the condition. This finding buttresses the claim of Helgeson and Cohen [18] that emotional support of love, respect, sympathy, understanding, listening, reassuring and comforting are particularly important for cancer patients. Other studies suggest that a good interpersonal relationship with their physician, characterised by caring, compassion, respect, and trust can significantly help cancer patients adjust better to their illness [19–22]. Furthermore, the recommendation that a physician should create a warm and trusting atmosphere in which the patient is treated as a "person" and feels that the physician shows interest in, and is sensitive to, his/her problems and feelings [20, 23] is reaffirmed by this study.

The diagnosis of leukaemia has altered the psychological and emotional orientation of the patients, as they were unable to continue to do the things that seemed to make up their normal lives prior to diagnosis. This has led some of the patients down the path of depression. Although there were no traces of suicidal longings or a desire for hastened death, the patients seemed to possess quite a good deal of psychological and emotional distress as the way they now see themselves has changed. This is in line with Hardwick and Lawson [24], who note that patients, relatives and family members need informational and educational support in order to find the strength they need in order to adjust to the new life situation, to continue to support the patient and to share the burden of the illness.

Conclusion

This research has shown that psychosocial factors play a defining role in the management of leukaemia. From the moment of diagnosis, the psychological orientation of the patient is altered. This, in turn, affects the patient's interaction with his/her environment and the people in it, including himself/herself. People living with leukaemia have special needs. A proper knowledge of their conditions needs to be made available to them and those close to them. Even the general public also need to be well armed with information regarding such sickness. This will aid proper understanding and encourage people to show their support to people living with this disease.

If these patients are to manage this disease well, they will need the continued support of their families and doctors and a constant reassurance from those around them so that they do not become emotionally and psychologically estranged. This will do a lot of good for the patients so that they do not spiral down the dark roads of a desire for hastened death.

Also, the issue of economic and financial strains on the patients shows that some sort of strain would be taken off their hands and minds if they are able to get less expensive treatments. This could be aided by donations to the treatment of leukaemia by the government and non-governmental organisations. Provision of adequate information about leukaemia, social and emotional support and financial interventions will aid effective management of this disease.

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