



# The Lived Experience of Patients with Leprosy at Kagando Hospital, Uganda

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**Abstract:** Though the world health assembly passed a resolution to “eliminate leprosy as a public health problem” by 2000, the disease is still common in many countries worldwide. Leprosy deforms and disables but seldom kills so that those who have been crippled live on getting steadily worse. Thus, the researcher was prompted to explore the lived experiences of patients with leprosy. A descriptive phenomenological qualitative approach was used for this study, to explore lived experience of patients with leprosy. In-depth audio taped interviews were conducted with six participants, data was analyzed using Colaizzi’s framework and Watson’s Human caring theory directed the study. The process of analysis identified five central themes: Living with physical disability, living with social dilemmas, living with economic hardships, relative social acceptance, and living in harmony with self and God. Notably, physical disabilities push patients with leprosy to the extreme of poverty. Failure to meet the basic human needs increase their susceptibility to chronic ulcers and an enduring hospitalization. Ability to meet the basic necessities of life was seen to increase social acceptance and respect from community members who are not affected by leprosy. Thus, economic rehabilitation is the most preferred solution to overcome the agony faced by patients with leprosy.

**Keywords:** Experience, Patients, Leprosy, Uganda

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## 1. Introduction

Leprosy is a chronic infectious disease caused by mycobacterium leprae and if treated poorly can result in clawing of fingers and toes, loss of fingers or hands, toes or feet, blindness and facial disfigurement [1, 2]. Though the world health assembly passed a resolution in 1991 to “eliminate leprosy as a public health problem” by 2000 the disease is still common in many countries worldwide; in the temperate, tropical and subtropical climates. The global prevalence of leprosy at the beginning of 2011 was 192, 246

cases, while the number of new cases detected during 2010 was 228, 474; excluding the small number of cases in Europe [3]. In the United States, approximately 100 cases of leprosy are diagnosed per year and most cases are in the south, California, Hawaii and U. S Islands [4]. India, six years after officially declaring eliminating leprosy remains the biggest contributor to the global burden of new leprosy cases, contributing 65% of new cases [5]. Pockets of high endemicity still remain in some areas of Angola, Brazil,

Central African Republic, Democratic Republic of Congo, India, Madagascar, Mozambique, Nepal, and the United Republic of Tanzania [4].

Uganda achieved the elimination of leprosy in 2004. However a total of 1500 new cases were notified in the period 2006 to 2009 and the proportion of new cases with visible disability showed increasing trend from 10% to 19% in 2005 and 2009 respectively. The proportion of multibacillary patients, who are at greater risk of developing disabilities, is on the increase. Uganda is facing a challenge of ensuring the sustainability of leprosy control services in order to avoid a reversal of the trend [6]. According to the National Health Information System Kagando hospital registered 17 new leprosy patients in the year 2010/2011. Ideally, after controlling the distressing symptoms of the disease and the patient is no longer infectious to others, the patient with leprosy can be discharged back to the community. At Kagando hospital patients with leprosy are hospitalized for months and have been named 'long stay patients' and when it comes to the time of discharge some are reluctant to go back to their residential homes. The factors behind their apparent institutionalization remain poorly understood, thus the researcher was prompted to explore the lived experiences of patients with leprosy so as to provide a basis for studying related phenomena aimed at improving the plight of patients affected by leprosy [7]. This study is in keeping with Jean Watson's theory basing on the following care-linked factors: Provision for a supportive, protective and /or corrective mental, physical, socio-cultural and spiritual environment, assistance with the gratification of human needs and allowance for existential-phenomenological forces.

The objective was to explore the lived experiences of patients with leprosy at Kagando Hospital. The information that will be generated from this research may be used by health practitioners to develop new strategies of caring for patients with leprosy. The information that will be obtained by this research may contribute to the identification of gaps in the theory and practice for the care of patients with leprosy that may require special attention by tutors/ lecturer and students in health institutions to come up with new innovations in the care of patients with leprosy.

## 2. Materials and Methods

### 2.1. Study Design

A qualitative research method based on phenomenological approach was used to explore the lived experience of patients with leprosy.

### 2.2. Study Area

The study was conducted in the clinical area, the Leprosy ward of Kagando Hospital where patients with leprosy and its complications are admitted and cared for. Kagando Hospital is a rural community hospital, located in Kagando, Kasese District, and Ruwenzori sub region, Western Uganda

at the foot hills of the Ruwenzori Mountains and close to Queen Elizabeth National Park. The hospital was established in 1965 by the African inland missionaries and was primarily treating patients afflicted with leprosy.

### 2.3. Sampling Strategies

The researcher purposively selected individuals with leprosy as participants because they were undergoing or had undergone the experience of being patients with leprosy. Purposive sampling is designed to enhance understanding of selected individuals' experiences [8]. Thus, the researcher accomplished this goal by selecting "information rich" participants to provide the greatest insight into the phenomena. The study involved 6 participants. In phenomenological studies, owing to the large amount of data generated which is complex to analyze participants lie within a range of 5 to 25 as determined by saturation point [8].

#### *Study population:*

The participants were patients with leprosy who met the inclusion criteria shown below

- i. Inclusion criteria were
  - Patients above 18 years
  - Patients admitted on the Leprosy ward
  - Patients who consented to participate in the study
  - Patients who were able and be willing to narrate their experience of living with leprosy
  - Patients who were once discharged into the community and readmitted back to the hospital
  - Patients who were able to participate in one to one audio tape interview each lasting between 30 between 45 minutes.
- ii. Exclusion criteria
  - Eligible participants who declined to consent.
  - Eligible participants with mental health problems which would exacerbate emotional feelings, particularly distress during the interview.
  - Eligible participants with speech and hearing impairment.

### 2.4. Rigors of Research

Rigors relates to establishing the trustworthiness of the data and study [9]. Trustworthiness of this research will be demonstrated as stated below.

#### 2.4.1. Credibility

Credibility aims at increasing the truth and value relating to the findings of the study and presentation of these and is achieved through Member checks and prolonged engagement in the field. One of the essential ways of establishing credibility is prolonged engagement with participants. In this study, the researcher achieved credibility using one-to-one in-depth interview which allowed participants reveal their independent experiences of living with leprosy. Participants were allowed to take their time narrating their experiences. In addition, use of tape recordings of the interviews and transcription of the verbatim increased the accuracy of

description of the participants' experiences, hence increased credibility of the findings. During this prolonged engagement the researcher was passively active, more of a listener while taking note of the verbal and non-verbal cues and only engaged by asking probing questions so as to ensure that the data generated is true and consistent with participant's views.

#### 2.4.2. Dependability

Kock suggests that one of the ways of ensuring dependability is to engage in regular auditing of the research process [10]. In this study, the researcher transcribed each participant's verbatim of the audio recorded information and continued listening to the audio recorded data for clarity. The generated information was correlated with the available literature, so as to provide sufficient information and produce evidence that can be laid open to external scrutiny. Also, the researcher being a novice researcher kept updating his research supervisor about the progress of his research proposal and dissertation for guidance to ensure that the research question, methodology, ethics, trustworthiness, and other research issues that underpin this study were observed and a faithful description of the research process was observed.

#### 2.4.3. Comfirmability

Confirmability is achieved through audit trail and reflexivity [11]. The researcher derived findings and conclusions from the participant's narrative. This was achieved through interviewing participants, coding and audio recording each participant's verbatim. There after listening to each participant's verbatim while jotting down important points on each participant transcript and analyzing data using Colaizzi's framework. In the process of data analysis the researcher suspended his own preconceived ideas and beliefs about patients with leprosy and concentrated on the information that was given to him by participants to avoid misinterpreting the phenomena

#### 2.4.4. Transferability

Finley argue that Transferability is achieved through thick description of setting and or participants and encourages qualitative researcher to provide detailed portrait of the setting in which the research is conducted [11]. The aim here is to give readers enough information for them to judge the applicability of the findings to other settings. To capture rich and detailed information in this study the researcher allowed each participant to tell his or her independent experience exhaustively, until no new information was aired out and quotations from participants were used to support the data as suggested by [12].

### 2.5. Data Management

This include tools of data collection; methods of data collection, data processing and data analysis.

#### 2.5.1. Tools of Data Collection

The researcher collected information using

- Unstructured in-depth participant interview guide which

engaged participants with the interview

- An audio recorder which helped the researcher to concentrate on the conversation.

These are regarded as the appropriate tools that can be used to generate detailed information of lived experiences since they don't impose a rigid direction in the interview [13].

#### 2.5.2. Methods of Data Collection

(1) Data was collected using unstructured interview guide and audio tape recorder while employing face-to-face and one to one technique and each interview lasted 30 to 45 minutes.

(2) Data was collected for a period of three days

(3) The researcher provided participants with information about the study which included: the purpose of the study, methods of information collection, what sort of information was expected from them, assurance of confidentiality and anonymity, level of risk and their right to withdrawal from the study without prejudice.

(4) The researcher requested each participant to sign a consent form at the beginning of the interview.

(5) The researcher requested for permission from participants to use an audio recorder for capturing the information.

(6) The researcher tested the recording equipment and the suitability of the venue [14].

(7) The interview was conducted in a side room on leprosy ward so as to avoid noise, disruption and ensure participants' convenience and privacy.

(8) The interview begun with one main open ended question translated in the language that a participant understood most. The central question that informed the interview process was "What is your lived experience because of having being infected by leprosy"?

(9) The researcher clarified sections of the question that seemed unclear to a participant and probing questions to encourage a participant to elaborate and clarify their experience were employed.

(10) During the interview the researcher provided participants with both time and space to explore their world of experience within the atmosphere of personal respect and humility

(11) The researcher allowed a participant to express his or her emotions like one cried, the interview was stopped and continued after the participant had ventilated her feelings.

(12) During the interview the researcher took note of the verbal and non-verbal cues indicating that a participant is tired or has finished the description, consequently the interview terminated.

#### 2.5.3. Data Analysis

The researcher analyzed the data using Colaizzi's framework as follows;

##### *Transcribing all participants' descriptions*

Each day after data collection the researcher listened to each participant's audio recorded verbatim while writing down what the participants spoke on each participant's

transcript

*Extracting significant statements/familiarization and coding*

The researcher read each participant's verbatim transcript carefully several times to identify meaningful statements about the description of the phenomena; underlining and extracting meaningful statements that directly relate to the lived experience of patients with leprosy.

*Creating formulated meanings:*

The researcher formulated more meanings from each significant statements and phrases.

*Aggregating formulated meanings into themes and sub themes:*

The researcher grouped the formulated meanings into clusters of themes while ensuring that these statements are original and not changed to fit into the theme. Colaizzi recommends that the formulated meaning can be organized into groups of similar experience.

*Writing an exhaustive description of the phenomena:*

The results of the data analysis was integrated by the researcher into a description of the phenomena of the lived experience of patients with leprosy ensuring that the participants views are described accurately and appropriately. The researcher maintained validity by referring themes back to the original descriptions and repeated examination of the significant statements.

*Literature review to understand the phenomena.*

The findings of the study were reviewed in relation to the available literature on the lived experience of patients with leprosy and based on the variables identified in the conceptual framework adapted from Watson's Human caring theory.

## 2.6. Limitations

The researcher encountered the following challenges;

The participants expressed expectations of financial assistance from the researcher and rehabilitative benefits following the dissemination of findings. The researcher overcame these by explaining to participants the purpose of the study and assured them that there is no any benefit following dissemination of the study findings.

## 2.7. Ethical Considerations

The researcher accorded human respect to participants by taking into account ethical issues that underpin this study as follows;

The researcher sought permission from the Faculty Review Ethical Committee (FREC) MUST. The researcher was offered letter from the head of nursing department introducing him to authorities of the research setting. The researcher presented the introductory letter to the Director of Kagando Hospital who endorsed the study and instructed the PNO to introduce the researcher to SNO medical department. The SNO medical department introduced the researcher to the In-charge leprosy ward who introduced the researcher to the participants. This was done so that ethical principles are

adhered to and participants are protected from potential source of harm [15]. Each participant was administered consent form before collecting any data as well as each participant given a code to ensure confidentiality of the data collected.

## 3. Results

This chapter contains themes, categories and responses from the participants. The data generated from participants and the emerging categories were scrutinized to accurately and meaningfully describe the lived experience of patients with leprosy.

### 3.1. Demographic Characteristics of Participants

A total of six (6) patients admitted on leprosy ward were the participants of this study. Three were males and the rest females within the age range of 18 – 65 years and had lived with leprosy for a period of 1 to 20 year. All the participants did not go beyond primary education. The three male participants were married and stayed with their wives and children in well-established settlements in communities with other people who are not affected by leprosy. Of the three female participants two were widows and one a single mother; two did not own land or a house. Most participants were surviving on petty businesses. The participants were given codes from B/1, C/2, D/3, E/4, F/5 and G/6

### 3.2. Lived Experience of Patients with Leprosy

Participants were asked to narrate what their lived experience was because of being infected by leprosy so as to generate the lived experience of patients with leprosy. In their narrative five themes emerged as follows: living with physical disability, living with Social dilemmas, living with economic hardships, relative social accepted and living in harmony with self and God

*Theme 1: living with physical disability*

This theme emerged from 3 categories namely: Symptoms before treatment, symptoms after treatment and aggravating factors of the disease

Category 1: symptoms before treatment; participants reported that they had experienced unbearable symptoms before accessing treatment like, loss of sensation, severe body pains, paralysis of fingers, loss of fingers and toes as narrated;

B/1 said, "...after injury I could realize blood oozing without feeling any pain and three months after treatment I started feeling pain"

C/2 said, "...I suffered feeling severe body pains, paralysis of the fingers, lost fingers and toes before treatment"

Category 2: Symptoms after treatment; Participants pointed out that the course of treatment changed their life. They were relieved of some symptoms though they developed non painful skin blisters and the occurrence of ulcers reduced but not totally dealt with, as narrated;

B/1 said "...I developed these non-painful skin blisters

*after commencing medication”*

C/2 said “...after treatment I started feeling the pain of an injury and skin patches disappeared”

G/6 said, “ ... though other symptoms disappeared following treatment, I do experience episodes of traumatic wounds on the legs that take long to heal which cost me many months of hospitalization, like I have been hospitalized for three months ”

Category 3: Aggravating factors of symptoms; participants reported that symptoms become severe following child birth or after abstinence from treatment as narrated;

B/1 said, “...these patches and nodules you are seeing reoccurred immediately after child birth”

E/4 said, “...I lost one of my fingers when I stopped taking medication for one month because drugs were out of stock in the hospital”

#### *Theme 2: living with Social dilemmas*

This theme emerged from three categories namely: Rejection and isolation, Divorce, Denied sex by wife and dropped out of school

Category 1: Rejection and isolation: some participants take the hospital as place of solace because of the mistreatment they undergo while in the community, as narrated

C/2 said, “...I feel I have peace while I am here at the hospital because in the community there people who mistreat me; imagine my blood relatives are well off but none of them cares about me”

B/1 said “... I have been here for six months but none of my relatives has ever visited me, you will never be accepted when you are sick, people don't want to interact with you”

D/3 said, “...my brothers used to visit me and we could plan together but none has ever visited me since I was declared a patient with leprosy”

Category 2: Divorce: A participant reported that after her husband realized that she had leprosy he divorced her, as narrated

F/5 said, “... My husband forced me to go back to my parents for treatment and assured me never to go back to his house anymore”.

Category 3: Denied sex. A participant spoke of his wife denying him sex after realizing that he had leprosy, as narrated

D/3 said, “...my wife, when she realized that I had a skin infection which was leprosy she refused me having sex with her any more for fear that I will infect to her.”

Category 4: School dropout for patients with leprosy; participants reported dropping out of school due to unfair treatment by teachers and by their fellow learners, as narrated

C/2 said, “...I dropped out of school because I was isolated from other pupils; my teachers allocated me the last bench behind in class and no pupil ever interacted with me, instead my fellow pupils used to laugh at me and if it was not the case I would have continued with my studies regardless of the sickness ”

#### *Theme 3: Living with economic hardships*

This emerged from 3 categories as follows; Impact of long hospitalization, lack of economic rehabilitation and education

for children of patients with leprosy

Category 1: Impact of long hospitalization. Participants reported that long hospitalization deprive them of opportunities to fend for themselves and their families, as narrated;

B/1 said “...I had a small supermarket before admission to the hospital; it is now for four (4) months in the hospital everything is in a mess”

C/2 said, “...I used to sell cabbages and dry fish before I was admitted to the hospital and I could also cultivate cotton during the season and earn when I sell my cotton harvest. Now I cannot earn anything because I have been hospitalized for more than three months, even the clothes I came with are in rags and I wish our wounds were cleaned at home”

Category 3: lack of economic rehabilitation; a participant aired out that lack of financial support is responsible for the economic challenges they face, as narrated;

C/2 said, “... I wish we were supported financially to own land, start small income generating activities, anyway if I had my own land I wouldn't be begging though I have deformities I can dig”

Category 4: school dropout for children of patients with leprosy; participants' spoke of their children dropping out of school due financial constraints, as narrated

E/4 said, “...Children of people affected by leprosy don't progress with education because we leprosy patients are very poor due the disabilities we cannot work”

D/3 said, “... my children have already dropped out of school because my hands are paralyzed I can no longer work to earn money”

#### *Theme 4: Relative social acceptance*

This theme emerged from three categories as follows: Married while infected with leprosy, respected in the community and fair treatment at social gathering

Category 1: married while infected with leprosy; a participant reported being lured into marriage by individual who was not infected with leprosy

C/2 said, “...I got married when I had leprosy deformities; when he proposed to marry me I asked him that there are very many young girls who are normal and why have you come for somebody without fingers and toes, anyway it is only his death which separated us”

Category 2: socially respected in the community. Some participants reported being treated with respect in their communities to the extent of being leaders of people who are not infected with leprosy, as narrated

E/4 said, “...At a party I am offered a sit like any other person and saved food in the same way and wherever I go I am always a leader”

G/6 said, “... I am a chief in my community, I have men who pay me taxes and after discharge I will go back to my home and join my wife, children and community members”

Category 3: fair treatment at social gathering. A participant spoke of being treated like any other human being at social gatherings; parties and places of worship, as narrated

E/4 said, “...at a party I am offered a sit, sit amidst other people and served food like any other person and at my place

*of worship I sit amidst other people”*

*Theme 5; living in harmony with self and God*

This theme emerged from: taking self as of value and according God his respect as the giver of life, as narrated;

E/4 said, “...I see myself still breathing, I know there are very many health people who have ceased to live and I don't regret to why I am still alive. In fact I give God his respect since he has sustained my life through all these years though I have been with the deformities for 20 year I count my self-health”

F/5 “...though may peers isolate from me on the way to the church and at church I still go to church to pray”

## 4. Discussion

This chapter presents the discussion of the lived experience of patients with leprosy. Five themes emerged: living with physical disability, living with social dilemmas, living with economic hardships, relative social acceptance, and living in harmony with self and God. Participants in this study spoke of the symptoms endured being responsible for their disabilities. Although the degree of disability varied for each of the participants, it was very much correlated with the severity of the symptoms. The experience of symptoms was reported in three categories, that is, before treatment, after treatment and aggravating factors. Participants spoke of symptoms like inability to feel pain, clawing of fingers and toes, or loss of fingers or toes may occur before treatment. This is true as mentioned by Cookson and Rhodes that leprosy is characterized by loss of ability to feel pain and injury and clawing of fingers [16]. Notably, in spite of treatment participants reported occurrence of chronic traumatic ulcers which result in loss of finger and toes and these ulcers are the main reason for their hospitalization even after treatment. Similarly, Cookson and Rhodes affirmed that leprosy attacks nerve endings destroying the ability to feel pain and injury increasing the susceptibility to ulcer [16]. On the other hand it was noted that missing medication and child birth aggravated the symptoms culminating into mutilating deformities like loss of fingers, as on participant narrated “...I lost one of my fingers when I stopped taking medication for one month because drugs were out of stock in the hospital”. Intermittent drug supply is the cause of irreversible complications and the likelihood of leprosy relapse increases during pregnancy and lactation [17].

For some participants the course of leprosy infection changed their social life to being victims of social rejection and isolation, divorce, denied sex and dropping out of school. Rejection and isolation meant that even their blood relatives disowned them or denied them any assistance or could not pay them any visit even while in the hospital, similarly Kent and Tsutsumi explained that the person affected by leprosy experience unsympathetic reactions, hate and rejection from the society [18, 19]. Divorce meant that a partner especially a female partner was shunned by the husband and forced to divorce, this in similarity to Shieh et al stating that leprosy can disturb sexual intimacy and act as a barrier to

manifestation of affection such kissing and caressing [17]. Participants reported dropping out school due to inhumane treatment by both teacher and fellow learners Van Brakel asserted that the social stigma attached to leprosy compromises the education of people affected by leprosy [20]. In spite the efforts made to help patients with leprosy to reintegrate into the society, the stigma affecting patients still persist [21].

Participants spoke of the long hospitalization, lack of economic rehabilitation and their children dropping out of school as pertinent issues that relate to their economic abilities. All participants elaborated clearly that they depend on none sustainable small scale domestic income generating activities Leprosy affect extremely poor people and even the cured keep at the margin of society [21]. A participant emphasized that lengthy hospitalization exacerbate their existing precarious economic situation by saying that “...I used to sell cabbages and dry fish before I was admitted to the hospital and when I would also cultivate cotton during the season I used to earn money. Now, I cannot earn anything because I have been hospitalized for more than three months, even the clothes I came with are in rags and I wish our wounds were cleaned at home” Scott noted that lengthy hospitalization has a negative effect on leprosy patients such as loss of income [22].

Social and economic rehabilitation for patients with leprosy is recommended because it empowers the affected individuals to contribute to the economy of their communities. All the participants noted with concern that their children drop out of school at infancy as a results of failure to get financial resources to sustain them in school. Notably this situation is exacerbated by physical incapacitating disabilities which deprive them of the ability to effectively carry out manual work that would earn them money; this is true as leprosy patients with deformities like severe clawing of hands and feet remain dependent in order to survive [23]. On the other hand, Chens et al challenged the notion that providing handouts can improve the well being of patients with leprosy by conclusively stating that the economic situation of patients with leprosy can only be improved by economic rehabilitation [24].

For some participants getting infected by leprosy did not threaten their social life, thence, they continued enjoying the privileges of human socialization in form of marriage, respect from the community and fair treatment at social gathering [24].

In this context an individual with leprosy deformities was lured into marriage by individuals who had no leprosy ending up with successful marriage, a participant narrated; “I got married when I had leprosy deformities, it is only his death which separated us” this is true as stated by Proestges (2011) with enlightenment people who do not have leprosy can freely interact with people with leprosy [25]. A participant expressed appreciation to the almighty for sustaining his life through the years of having the disease. This is true as reported by Awofeso and Van Den Broek et al who stated that some patients take leprosy as the will of God [26, 27].

Though patients with leprosy are treated as alien at social gathering they still go to places of worship to worship their God. This concurs with Van Brakel who noted that people affected by leprosy resort to offering to God as a means of treatment and Sheih *et al* revealed that prayer and attendance at religious services enabled patients with leprosy find emotional peace [17, 20].

## 5. Conclusion

In conclusion, the study explored the lived experience of patients with leprosy. The experience of a patient with leprosy emerged as characterized by living with physical disability, living with social dilemmas, living with economic hardships, relative social acceptance and living in harmony with self and God. Notably, deformities deprive patients with leprosy the ability to perform manual activities hence pushing them to the extreme of poverty. Failure to meet the basic human needs for themselves increases their susceptibility to chronic ulcers and an enduring hospitalization. The education progress of children is curtailed from a family where the bread winner is a patient with leprosy thus children end up dropping out of school at infancy. Conversely, it emerged from this study that as much as some patients experience negative consequences of the disease some continued to enjoy self-worth and respect from their communities. The experience of patients with leprosy is worth to understand in order to appreciate their mental, physical, socio-cultural and spiritual life. Leprosy is a dreadful disease associated with stigma to the extent of even the closest relative shunning the sufferer. Nurses should appreciate the fact that patients with leprosy needs holistic care which can only be achieved by a multidisciplinary team of professionals comprising of community development officers, social workers and health care provider in order to harmonize the physical, social, psychological, spiritual and economic aspects of the patient.

## Recommendations

Owing to the disability associated with leprosy, an individual treated for leprosy should be followed up by health care providers for quite a long time and if resources allow even for life in order to anticipate and treat complications that may arise. Health care provider at the lowest facilities should be trained in the care of patients with leprosy to avoid patients travelling long distances in search of specific treatment centers. A multidisciplinary team of professionals ranging from social workers to health workers should be involved in the care of patients with leprosy in order to meet the physical, social, psychological, spiritual and economic needs of the patient. It is evident, that patients with leprosy live in abject poverty due disabilities thus government, aid and charitable organization should support the economic rehabilitation of patients with leprosy, their families and meet the education needs of their children unconditionally.

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