MJN

doi:10.31674/mjn.2019.v10i04.004

GOING BEYOND SKIN DEEP: LIFE AFTER LEPROSY

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ABSTRACT

Leprosy is a chronic disease wherein symptoms may appear after 5-20 years from infection of the bacteria Mycobacterium leprae wherein it causes irreversible physiologic effects. This study aimed to explore the experiences of individuals after being cured from leprosy. The methodology used was Husserlian phenomenology and Colaizzi's method during the analysis phase. A total of five (5) informants participated in the study. Three (3) themes emerged in this study. The first theme is Challenges and Difficulties in life with 2 subthemes, Social Disconnection; and Psychological Issues. The second theme is Uncertainty in Life with subthemes of, Feeling Lost; and Sense of Stagnation. The last theme generated is Regaining Clarity and Meaning of Life with the following subthemes of, Sense of Belongingness; Sense of Liberation; and Improved Quality of Life. Social Stigma took the lead as the cause of the difficulties and challenges leprosy survivors have to endure and the reason why the reintegration of leprosy survivors back to their communities of origin would fail. It is recommended that the leprosy survivors can form a well-developed community composed of good social networks with other survivors and their families.

Keywords: Leprosy, Leprosy Survivors, Lived Experiences, Phenomenology, Social Stigma

INTRODUCTION

Leprosy is a chronic disease wherein symptoms may appear after 5-20 years from infection of the bacteria Mycobacterium leprae (WHO, 2016; DOH, 2016). Although the disease is curable with multidrug therapy, it may cause irreversible damage to the affected individuals that were not immediately treated (WHO, 2016; DOH, 2016).

A total of 211,973 new cases of leprosy were recorded worldwide at the end of 2015 with 1,617 cases coming from the Philippines (WHO, 2016). The researchers went to Eversley Childs Sanitarium and General Hospital and gathered leprosy data from the hospital. It was reported that a total that there were 32 new reported cases for the year 2016 and the patients were currently on multidrug therapy; 16 are currently admitted due to complications; and a total of 95 cottages funded by the government for domiciliary care. In the past decades, the care management of leprosy has advanced greatly. However, there is much more to a disease than just the pathological processes. It does not only affect the physical aspects of the patients; but also, has social and psychological implications. The disease was feared resulting in negative impact. Leprosy patients were treated as outcasts in the society.

Furthermore, leprosy comes with a stigma affecting social functions. International and Local programs addressing the disease are focused on the prevention, treatment and its elimination (DOH, 2016; WHO, 2016) and much less on rehabilitation programs for those affected especially to ones with irreversible physiological damage. The researchers would like to further deepen their understanding on the lives of the people who were treated from the disease. The social stigma has always been the toughest as these people had to bear with the consequences. The researchers would also want to explore the problems of the stigma associated with such disease and its effects. With the information the researchers gathered, they aimed to find possible solutions that may help people who are affected with the disease.

METHODOLOGY

The study utilized Husserlian phenomenology, a qualitative phenomenological design. In this phenomenology, it is focused on experiences including its patterns and unique catalogue on ones encounters in his environment. Phenomenology records the subjective thought of a person's experiences to attain a narrative of the experienced; moreover, the data collected may lead to specific patterns that can be coded once being compiled with the experiences of other who are under the same situation (Behnke, n.d.). The research aimed to explore the lived experiences of individuals of leprosy survivors. The study involved the gathering of first-hand experiences of these people.

Locale

The study was conducted in a small community near Eversley Child Sanitarium located in Mandaue City, Cebu. This small community serves as a home for those people who were already treated with leprosy. As a leprosarium that houses former patients, this became a good setting for the researchers to conduct the study.

Key Informants

The informants of this study were people who are already treated with leprosy, who have visible body deformities. The informants were selected regardless of age and gender that are living in the same community. The study design was fully explained to the respondents and their participation was of their own will.

Sampling Technique

This study used theoretical sampling. Dudovskiy (2015) mentioned that theoretical sampling is a method where one will collect the data then code them. Analyzes was done collectively until one can create a concept. The researchers stopped data collection when data saturation was reached, and common themes have emerged during the interview phase.

Research Instrument

This study utilized a researcher made semi-structured interview guide with open ended questions. A semi-structured or open-ended interview will allow research informants to narrate their experiences with minimal limitations so they will be able to express thoughts more freely (Hesse-Biber, 2016).

The interview guide was available in English and Cebuano versions. The Cebuano version of the tool was the one utilized due to the limitations of the informants in the English language. An audio recorder was used to record interviews and was saved in the researchers' laptop.

Data Gathering Procedures

One time, face to face interviews were conducted by the researchers with the informants in their houses. The researchers used direct observation and made field notes for additional information during the interview while it was being recorded using an audio recording device. Informants were given a consent form that included details of the research. The researcher talked to them about the study in details and verbal consent was taken. A consent form was signed before the interviews started as a form of agreement that they participated in the study willingly.

Data Analysis

Data gathered after interview were transcribed and then translated to English by the researchers. Data were analyzed to determine patterns or similarities among the experiences of the informants of this study. Furthermore, a phenomenological approach was used since the purpose of this study is to describe and understand the lived experiences of individuals who experienced a particular phenomenon. Rigorous analysis of data constitutes the second component of the descriptive phenomenological investigation. Colaizzi's (1978) method was used to guide the analysis. The themes generated were shown to the key informants and they agreed with the results.

RESULTS AND DISCUSSIONS

Informants

The researchers reached data saturation after interviewing 5 informants. Interview data were then transcribed; translated and analyzed. Shown on the table below is the profile of the informants of this study utilizing 'pseudonyms' for their anonymity.

Table: Profile of the Informants

Key Informant	Biographical Data
Veronica	A 53-year-old woman who works as a janitress. She is married to another leprosy survivor. She is from the Southern part of Cebu Province. She has been diagnosed with leprosy at the age of 25. Her medical treatment lasted from 1985 to 1987. She went home to the province after being discharged. But came back immediately and settled in the leprosarium where she is still residing.
Joseph	A 63-year-old man working as a janitor. He is married with 2 children. He is a native of Northern Cebu while his wife hails from Samar. He was diagnosed with leprosy at the age of 36. His medical treatment lasted from 1989 to 1992. After being discharged, he went home to Samar to his wife and only child at that time. The whole family was then forced to relocate to the leprosarium and had been living in the community since they came here.
Magdalene	A 37-year-old woman that works as a janitress. She has a live-in partner and has 2 children. She is a native of the island of Bohol. She was diagnosed with leprosy when she was still 16 years old. Her medical treatment lasted from 1998 to 2000. She was able to work as a dietary staff in the hospital where she got treatment but left when she became pregnant with her first child and lived with her father. She worked as a janitress in Cebu but decided to come back and stay in the leprosarium after issues and concerns arose relating to leprosy.
Maria	A 69-year-old woman living in one of the cottages in the leprosarium. She is married and has 1 child but was never able to see her family after being diagnosed with leprosy (at the age of 56 in 2004). She is a native of Leyte but she was already living in her husband's hometown in Negros Oriental when she was diagnosed. Her medical treatment for leprosy started from 2007 and ended 2009. She has been living in the community since her confinement in 2007.
Peter	A 48-year-old man who is working as a janitor and a motorcycle driver. He is originally from Negros Occidental. He currently has a live-in partner who is also a leprosy survivor. He was diagnosed with leprosy at the age of 19. He was treated from 1987 to 1992 for his leprosy but extended for another year up to 1993 due to a broken leg. He was sent to school after his leg healed. He finished a vocational degree of furniture making in 1994. He went home in 1995 but came back after 2 years and settled back in the leprosarium.

Thematic Analysis

This part describes the findings of the interview data gathered from the informants on their experiences after they were treated from leprosy. Distinct and common experiences of the individual informants are also represented in this chapter. A total of 77 significant statements were recorded from the 5 informants. Out of these 77 statements, a total of 12 Formulated meanings were generated. With the use of content analysis, 3 main themes emerged. The first theme is (1) Challenges and Difficulties in life with 2 subthemes generated; namely, (a) Social Disconnection; and (b) Psychological Issues. The second theme is (2) Uncertainty in Life with subthemes of, (a) Feeling Lost; and (b) Sense of Stagnation. The last theme generated is (3) Regaining Clarity and Meaning of Life with the following subthemes of, (a) Sense of Belongingness; (b) Sense of Liberation; and (c) Improved Quality of Life.

Theme 1: Challenges and Difficulties in Life

Challenges and difficulties are evident even to those who are treated from leprosy. Social stigma plays a huge role regarding the problems experienced by the former leprosy patients that causes certain challenges and difficulties in their lives (Singh, 2012; Bergman & Britton, 2014; Abedi, Javadi & Naji, 2013; Peters., 2015).

Subtheme 1: Social Disconnection

According to Cornwell & Waite (2009) this refers to the lack of contact with others that can be related to having small network, rare social interaction, and the lack of participation in social events and norms. Former leprosy patients would often fail in the reintegration into their communities due to psychosocial issues like being socially isolated (Singh, 2012). The informants were able to express that their social networks were reduce up to the point that they can only interact with very few family members. Due to the reduced size of their social networks, they were no longer able to interact with community members and participate in social activities.

The informants mentioned that some of their neighbors and family members have started to avoid getting in contact with them.

"Lahi ra jud. Sa amo kay wala bitaw kay ka kaistorya-istorya. Imo rang mga paryente. Unya imo

mga silingan kay dili man moduol kay magkuan man, kanang naa mana siyay sakit (Things were indeed different. I cannot talk to anyone in my hometown except some of my relatives) (SS11) as verbalized by Veronica.

This did not only affect the informants; but also, immediate family members were avoided by the community around them.

Joseph also said that, *"O. Hasta akong anak kai nagduwa-duwa naman siya unya naa lage daghan mga bata magduwa-duwag traktrak. Singgitan naman sa mga silingan na, ila mga ginikanan nga, "Uli mo ngari kay takdan mo diha"* (Even my child was affected. Whenever he plays with the neighboring kids, the parents will immediately call them home; shouting, *"Come home before you get the disease."* Yes, even my child. He plays with other children around with toy cars. Once they notice, our neighbors would shout to their children, "Come home before you get the disease) (Ss30).

During the accomplishment of simple tasks, informants also experience the disconnection from their community.

"Kanang ang among tubig gud didto Sir, kay probinsiya manang amoa kana ra bang tabay bitaw ma'am. Kanang tubig bitaw nga mura siyag dako nga tubod. Pagpadong gud nako didto kay ang mga tao uban kay mahadlok, manghawa. Unya lain kaayo sa imong huna-huna" (Our source of water there was a deep well which is normal in the countryside. Every time I go there even when I was still on the way, people would be scared and leave the area. It was really upsetting) (SS67) as expressed by Peter.

It was evident among all informants that the people from their communities are trying to avoid and not to interact with them. It has been a common line among them that people are scared of them. With that, they are not able really able to socialize.

Subtheme 2: Psychological Issues

Psychological issues are evident among individuals who suffered from leprosy which can be related to the social stigma of the disease (Yang, 2014; Bergman & Britton, 2014; Santos *et al.*, 2015; Peters, 2015). Some of the issues like poor self-esteem and depression was found in the statements of the informants. The risk for psychiatric disorders like self-esteem issues and depression are high for those patients with leprosy (Singh, 2012; Bakare *et al*, 2015). People with poor self-esteem are likely to have social anxiety, low interpersonal confidence because they feel awkward, shy and conspicuous in interacting with society (McLeod, 2012).

There were statements made by the informants that would indicate that they experienced poor self-esteem like being shy due to what the disease had brought upon them.

"Kanang kalisod nga dili na ta kaskwela kay ma-uwaw naman ta." (It was also hard for me go back to school because I was already shy) (SS13) as stated by Veronica.

"Ambot. Wala nalang. Dili ko ganahan. Kay kanang, ma-ulaw bitaw ko. Sungogon, ingon ana" (It was also hard for me going back to school because I was already shy) (SS40) as stated by Magdalene.

Leprosy patients would continue to live with the emotional pain brought about by the degrading physical effects the disease has (Hoang & Yen, 2015). Certain statements expressed that the informants had undergone depression like being sad, hurt and stating several signs of being depressed.

Veronica said that, *"Mag-guol gihapon ka tungod sa kalisod kai dili man ka dawaton sa mga tao didto sa ato-a, sa amo. So, nakadesisyon nalang jud ko na ari nalng ko puyo"* (I felt sad because of the hardships and the rejection I received from my community. So, I decided to stay here) (SS14).

Peter stated, *"Di naman ko mokaon. Sige nag inom"* (There was a time when I was depressed and stopped eating and I became an alcoholic) (SS37).

Most of the informants expressed their sadness and feelings of being hurt due to the social reaction they received in the attempt to reintegrate with their communities. Despite attempts of explaining that they are already cured along with the presence of a medical certificate, social stigma will always outdo them. The social stigma took a great hit on the self-esteem of the informants and their mental health.

Theme 2: Uncertainty in Life

Uncertainty is linked to the phenomenological experience of anxiety arising from unpredictable future events. It happens when one is under a situation where he does not know what to do and how to face it (Grupe & Nitschke, 2013). It has been characterized by the informants of this study about how they were left with no other option in facing the issues they have regarding the disease they had. Most informants have been forced to leave their hometowns and return to the leprosarium as the only shelter in the current situation.

Subtheme 1: Feeling Lost

Feeling of lost is when people are being absorbed in a negative situation wherein they are left to wander in their mind. It happens when people are being confronted with circumstances where they do not know how to respond. Then people are usually in a pool of confusion wherein they ask "why" and they are usually ambiguous regarding certain situation they are in. They felt that they does not have anywhere else to go but to come back.

Joseph said, *"Wa lang. Mura silag motuo usahay ang uban. Ang uban sad kay dili. Pero ako sila gipasabot. Maayo ning maka-istorya ta usahay ug mga tarong-tarong na tao. Pag-uli ko ngadto mura kog si Robin Padilla lage. Pag-abot ko didto sa balay, sa una mo-agi gane ko kay manira ug bintana. Pag-abot nako daghan kaayo nag ingon nga naa na, naa na. Unya, una jud to nianha ang kapitan del barrio namo kay mao man tong nagpetisyon nako"* (When I went home, I was like a convict that people would shut their windows whenever I pass by their house. And I would hear them saying, "He's here, he's here." Until such time, our barangay captain approached me and petitioned to evict me from our community. Finally, they had a petition to evict me signed by my neighbors (SS35).

Peter also verbalized, *"Mao tong wa na jud koy lain kapuy-an mao ari nalang jud ko"* (It felt like I have nowhere else to go but to come back here) (SS73).

Subtheme 2: Sense of Stagnation

Stagnation happens when the one's life stops to progress and they are caught in a situation. This happened to the informants wherein they do not feel their lives are moving and are trapped to the remnants of leprosy. Moreover, their lives flow within the negative impact of leprosy and that they are not able to move forward with their lives.

"Lahi bah. Di ta ka suroy-suroy didto," (Things were different like I was no longer able to go out of the house and wandered around) (SS3) as verbalized by Veronica.

Mary said, *"Nangamatay naman pud sila. Akong ugangan. Ug buhi pa unta kay maka-uli ko. Unya kay dugay man sila kamatay kay naguol man to sila tungod nako. Pinangga man ko ato nila"* (My parents-in-law were already dead. If only they were alive that time, I might have had the chance of going home. They were sad about me. They really cared and loved me) (SS53).

Theme 3: Regaining Clarity and Meaning of Life

After experiencing stigma induced issues in life, the informant were able to stand up on their feet once again. It had been a difficult process for them, but they are happy and contented regarding their present situation. Most of them went home but came back while others opted to stay in the community they were presently living in. Slowly, they were able to work, build their own houses and a place where they can consider home. They found whatever they needed in the said community. They were able to find a community where they were considered to be a member, where they are able to interact with people without any restrictions. They were able to find their own means of living and have shelter.

Subtheme 1: Sense of Belongingness

The sense of belongingness happens when one feels to be an essential part of a group wherein he or she feels accepted. It is said that belongingness contributes to the overall happiness, health and a greater meaning in life (McConnell, 2013). The informants have stated that they were able to feel accepted in the community presently they are in and that they are living happily.

"Murag okay naman ko diri kay ang mga tao diri kay dili raman sad mahadlok. Murag kanang malipay ra gane ka kai gidawat ra gane ka imong….mga namuyo diri ba" (It was better here in Eversley since the people here are not scared of you. It made me happy because of the acceptance I get from the residents here) (SS6) as expressed by Veronica.

Joseph verbalized, *"O. Kaluoy sa Diyos murag ingon ana jud. Kung mangedaron na jud ko, gustong mopahuway okay na jud. Gisilayan paman kog trabaho. Trabaho ra pud ko hantod sa hantod. Murag nagtahod sila nako maong Tatay sugod ila tawag kay* *akoy kinatiguwangan. Maayo ra man sad ning ako mga kauban tanan. Wa man koy problema"* (Yes. In God's grace, I could say that. If I am already very old and would like to rest, I am okay with that. They are still giving me my job so I would work as long as I can. They respect me here and they even call me 'Tatay' being the oldest one. Everyone here is really good, and I don't have any problems with them) (SS38).

Mary also stated, *"Unya kanang mas maayo naa ko diri kay wala may magkuan nako. Di man mahadlok kay pareho-pareho raman mi"* (There is no judgement here because we are all the same here) (SS58).

Peter also mentioned, *"O kay mao nalang jud ako naingon didto. Sa ako sad paminaw nga kung ari ko diri kay mura sad ug diri ra gihapon ko natawo. Diri kay mas malipayon man ko kontra magtipon sa amoa kay ang mga tao kahibaw naman mo"* (It feels like I was even born here. I am happier here compared to my hometown where people know I was sick) (SS70).

Subtheme 2: Sense of Liberation

The sense of liberation is attained when one is being freed from the inevitable sufferings of life (Soka Gakkai International, 2011). The informants of the study have been imprisoned with the destructive effects that the social stigma of their disease. Upon returning to the leprosarium, they have expressed freedom from their problems.

"Dili na parehas sa amo ba nga maikog ka ug lihok-lihok ba. Diri kai okay raman ug kuan. Di naka mag lingo-lingo ba. Ang mga tao diri ba kai murag kaila na nimo tanan" (I feel free. And it seemed that I almost know everyone here) (SS9), as mentioned by Veronica.

Peter said, *"Ang uban didto wa mahibaw, ang uban, mahadlok sad ang uban. Dili jud ingon nga parehas diri ba nga mayano-yano ra nimo diri mga tao"* (Some people at home are unaware. Some are scared and some are not. But it is nothing compared to here where I can easily talk with people) (SS71).

Subtheme 3: Improved Quality of Life

Quality of Life is defined as a person's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of their environment (WHO, 1997). People with leprosy will tend to have a compromised quality of life due to the effects of the disease (Proto *et al.*, 2010; Santos, *et al.*, 2015). There were statements made by the informants that would indicate an improvement of one's quality of life.

Joseph verbalized, *"Pag-abot ko diri sa Cebu kay nakadesisyon ko nga diri nalang. Mas arang-arang na diri"* (We decided to stay here for good when we came back here. Things are better here) (SS31).

"Tukod ko dirig balay. Gitagaan man ko nilag kuan diha" (I built my own house when they gave me my own lot. Yes, they gave me my own space. I already have my own home) (SS74) as mentioned by Peter.

Exhaustive Description

Stigma is a major role player in the lives of leprosy survivors. The social stigma is always attached with the disease. The stigma caused certain issues that some survivors were not able to cope. The disease does not only affect people physically in general but psychologically and emotionally as well. After getting well with all the required treatment, the next problem that these survivors would confront would be the social response from the surrounding people making it difficult for them to reintegrated back to their communities (Singh, 2012; Abedi, Javadi & Naji, 2013; Bergman & Britton, 2014; Yang, 2014; Peters, 2015).

According to van Baarsen *et al.*, (2001) it was reported that people experiences social disconnection when people would have infrequent interaction with the society. It was also said that they may have a decrease participation with everything that is happening around them (Cornwell & Waite, 2009). This may be a result of the community members failing to communicate with them due to the stigma.

Former leprosy patients would often fail to reintegrate into their communities due to psychosocial issues like being socially isolated (Singh, 2012). The informants were able to express that their social networks were reduced up to the point that they can only interact to a few family members. Due to the reduced size of their social networks, they were no longer able to interact with community members and participate in social events.

Depression and other mental health issues can be found with former leprosy patients. These mental health issues were also associated with the social stigma (Yang, 2014; Bergman & Britton, 2014; Peters, 2015; Santos *et al.*, 2015) The stigma of the disease put the survivors of leprosy at a higher risk like issues with self-esteem, depression and societal interaction (McLeod, 2012; Singh, 2012; Bakare *et al.*, 2015).

Grupe & Nitschke (2013) mentioned that when one is experiencing uncertainty in life, the person would be on state of confusion on what actions to take regarding a certain situation in life. Persons who have had leprosy may experience the feeling of being pushed to certain decisions that they do not usually want to. The uncertainty may lead them to leave the problems they have with their communities and would tend to go back to their treatment centers where they feel welcome.

When reintegration with their hometowns fail and life is filled with uncertainty then leprosy survivors may be forced to go back to the leprosarium. Most leprosy patients would fail to reintegration back with their communities of origin (Chinguo & Duncan, 2011). They will start to build their lives back to normal. The effects of stigma would cause the decrease of the quality of life of these individuals (Proto *et al.*, 2010; Santos *et al.*, 2015). When one attains the sense of belongingness, he would become happy, experience a better health and a greater meaning of life (McConnell, 2013). One can attain liberation if he is relieved from all the sufferings that the stigma of the disease has caused (Soka Gakkai International, 2011). Quality of life would improve gradually with the assistance they find with their new community. WHO (1997) stated that one's quality of life increase when they experience improvement in their physical, mental and social health. It was evident that there was improvement in their lives once they were back on the leprosarium.

CONCLUSION

Social Stigma took the lead as the difficulties and challenges faced by the leprosy survivors. They have to endure and fight with the reasons they fail to reintegrate back to their communities of origin. Due to the stigma, leprosy survivors are being neglected and are treated outcasts of the society leading to poor social contact. Moreover, they experience self-esteem issues and depression. Although being cured from the disease, survivors would wonder about the experience they need to go through after being discharged making them feel lost and stagnated as they are trapped with the remnants of the disease. The solution they find is to return and stay in the leprosarium where they feel accepted and free. The people living in the leprosarium have formed a well-developed community composed of good social networks composed of other survivors and their families.

RECOMMENDATIONS

The programs made by the local Department of Health are mainly focused on the elimination of the disease. However, less importance has been made with regards to the rehabilitation, reintegration to home communities, health education and the de-stigmatization of the disease. The treatment, medication distribution and development of leprosarium should no longer be the focus of the government in today's age of leprosy. Moreover, the focus should now shift on how survivors of leprosy will be able to return to the usual living patterns similar to those who were not affected with the disease. Issues on how one can make rehabilitation programs for leprosy survivors should be addressed as this could be beneficial for them in making their own means of living. The focus should also fall on the de-stigmatization of the disease through health education especially in communities where the stigma of the disease is present or high. Once, the issue of social stigma is emphasized and given attention, solutions on how to increase the success rate of the reintegration of new survivors of leprosy may happen.

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