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The role of social support systems in enhancing community participation of individuals affected by leprosy: Insights from family networks, community groups, and self-help initiatives

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Abstract
Leprosy continues to be a significant public health issue in many low-income countries, including Mozambique, where it causes deep social and economic challenges. This study explored the socioeconomic factors and Participation of people affected by leprosy in community projects in Montepuez District, Cabo Delgado Province. The study specifically aimed to examine the causal relationship between demographic factors-such as age, education, gender, and marital status, and levels of community participation; to assess the extent to which income, employment, and access to resources influence community participation participation; to determine how disease-related characteristics like duration, visible impairments, and disability levels affect participation in community life; and to examine the contribution of social support systems, including family networks, community groups, in facilitating community participation among leprosy affected individuals. Guided by the social exclusion and health belief model theories, the study targeted, 1,200 individuals, including leprosy-affected individuals, community leaders, healthcare providers, and support group members. Using Krejcie and Morgan's (1970) sample size formula, 291 participants were selected. Data were gathered through structured questionnaires with 142 leprosy-affected individuals, 18 interviews with community leaders and health workers, and four focus group discussions with 28 individuals. Findings revealed generally low community participation. However, younger individuals (18-34 years, OR = 2.67, p = 0.014), those with secondary education or higher (OR = 3.45, p = 0.005), those earning above 1,000 MZN (OR = 3.12, p = 0.012), and employed participants (OR = 2.56, p = 0.017) had significantly higher participation levels. Stigma was a major barrier ($r = -0.52$, $p<0.001$), while strong social support encouraged involvement. Qualitative insights showed that self-help groups promoted empowerment, while poverty, disability, and discrimination limited participation. The study recommends strengthening community-based care, expanding economic empowerment initiatives, reducing stigma, improving rural access to services, and tailoring interventions to meet demographic needs.

Keywords: Leprosy, social support systems, community participation, self-help initiatives

Introduction

Background to the Study

Leprosy is one of the chronic contagious diseases that presents problems around the world particularly in underdeveloped areas. Even after improvements in treatment and management strategies, the disease continues due to a concurrence of medical, social and economic factors. To date, Leprosy remains the significant public health issue, as more than 200,000 new cases emerge annually (World Health Organization [WHO], 2023). In Mozambique, particularly in Montepuez, traditional beliefs about leprosy and gender roles further compound barriers to effective participation in care and treatment. The disease disproportionately affects individuals in low-income, resource-limited settings (Lockwood *et al.*, 2020) [17].

Poverty is one of the few reasons why the socioeconomic condition of people with leprosy is hampered. Being poor will increase the vulnerability of people to leprosy since they will not have access to healthcare services such as diagnostic facilities and treatment methods. Further, people living in poor circumstances have the disadvantage of having to deal with transportation expenses and sheer wages which prevent them to consult. Experience indicated that poverty has been linked with delayed leprosy diagnosis and treatment process which results into more advanced stages of the disease with worse treatment outcomes (Tiendrebeogo *et al.*, 2020) [38]. The leprosy burden in Nigeria is also on a high level, and such a problem as poverty and inability to access healthcare services is a major issue as many cases just remain undiagnosed or untreated (Idogdor and Owoaje, 2021). In the Democratic Republic of Congo, the factor of poverty and existence of poor healthcare structure is associated with the persistence of leprosy burden as well (Lambrecht *et al.*, 2021).

One of the major community participation features for persons with leprosy is the presence of support networks and self-help groups (Peters *et al.*, 2019) [21]. Through these groups, the affected people get a platform where they can pool in the years of experience in overcoming the challenges posed as a result of leprosy. By providing a platform for self-help and solidarity, the self-help groups are contributing to the empowerment of the affected survivors and their fight against stigma and discrimination. Furthermore, community engagement in activities such as social and economic integration of the leprosy-affected into society at large. It could be things like vocational training, micro-finance projects and job creation training programs, which are relevant to the needs of the population living with disabilities due to leprosy. Some initiatives also at hand can help to bring the affected people back to their feet and to make them independent till they become an asset to the society by directly affecting their economic empowerment and to be included within the social circle.

Justification of the Study

Leprosy remains a significant public health challenge in Mozambique, particularly in Cabo Delgado Province, where the disease continues to affect vulnerable populations. Despite the availability of treatment, individuals impacted by leprosy face severe social, economic, and cultural barriers that hinder their full participation in community life. Previous research has primarily focused on the medical aspects of leprosy, with limited attention given to the socioeconomic factors that influence inclusion of the affected individuals. This study is justified by the need to fill this research gap, particularly in the Montepuez District, where leprosy prevalence is high, and the exclusion of those affected is pronounced.

There are many reasons for knowing the factors that determine participation in the community for people affected by leprosy in the area. Second, targeted intervention, which takes into account the impact of income generation, social and cultural contexts, physical disabilities and support programs to improve participation within their communities can be performed in greater detail. Such insights would be critical in the design of programs that will respond to the health needs of such persons while also working to integrate them within their social, economic setting, and thus minimizing the stigmatization of such persons and improving their quality of life.

Significance of the Study

It was relevant because this type of research helped improving the health and wellbeing of leprosy patients in Montepuez District, Cabo Delgado Province, because of their improved understanding related to the impact of socioeconomic factors on their participation in the community activities. This study was useful at various levels and had practical implications for its different stakeholders. Community health workers and health professionals have been able to gain more insight into the socioeconomic circumstances that functioned as a barrier to the retention of their patients in treatment programs and the community continuing efforts. Dedicated social services which gave promises to provide in good time a suitable help, and the personalization of interventions involving medical and social care in leprosy, were the necessary elements to literate care and the universalization of leprosy.

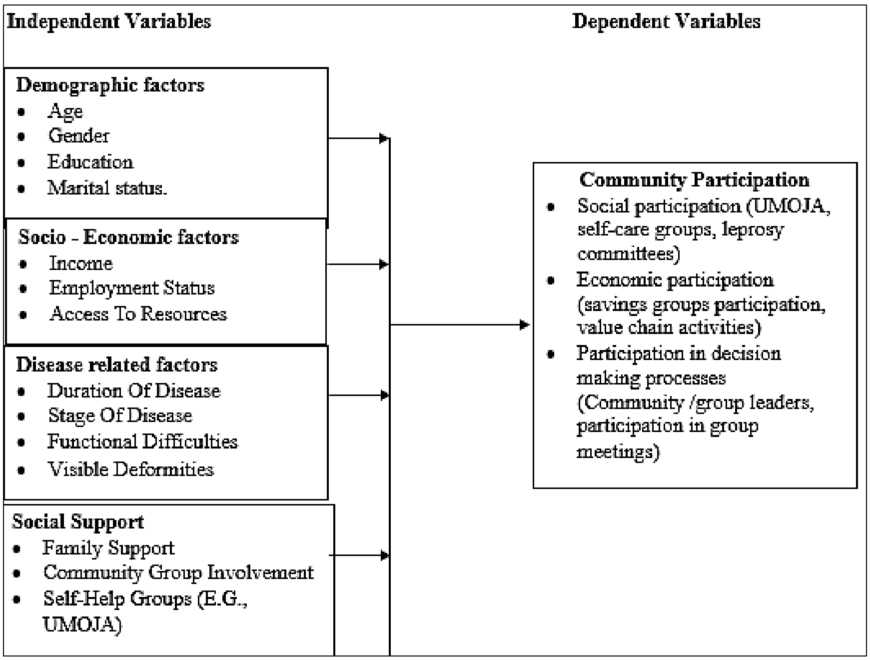
Also, the findings were extrapolated to health care authority and program management levels for incorporating socioeconomic status of the target population in health care facility layouts and delivery. This not only changed how decisions are made at facility levels, but also that these administrative levels not only care for the data, but also for the human aspect of people living with leprosy; such as poverty, availability of resources, and social marginalization. This in turn facilitated greater access to services of care and support and the coordination of greater access to community-based health care.

The information gathered by the NGOs and the local organisations working with the leprosy affected people was also used for formulating better support programmes. In so doing, these organizations have utilized the insights acquired at each of the articulations into socioeconomic issues in constructing their diagnostic interventions, meant to impact the fabric of the patients and their families. This was especially in areas for vocational training, micro finance activities and support groups, which have become important vehicles to break the cycle of poverty and dependency in relation to the disease. Further, these findings showed organizations increased their strategic allocation of resources, community engagement planning, and sustainability of programming by engaging the community in their work.

These analytical results were interpreted at district and provincial levels in order to make formulation of evidence based policies which would be favorable, among other resources, for the social inclusion as well as wealth empowerment of victims of leprosy. It could have been a step of new standards of social protection, more appropriate resource distribution, or even implementation of some programs aimed specifically in the opposite direction at obstacles on the socioeconomic level. The evidence produced by the research could be used by the policymakers to promote the change in healthcare financing, social insurance, or rehabilitation services that would consider the experience of practicing people with leprosy. Moreover, this type of research helped to establish a stronger evidence base that is required to compose long-term plans and inter-sectoral partnerships in the health, social welfare, and economic aspects.

The results also came in handy to the community leaders and social workers who also gave evidence-based information on how much better they could advocate and assist the leprosy-affected people in their communities. That resulted in more successful sensitization activities in their home communities, reduced stigmatization, and increased integration into society. The possibility to refer to localized data gave community influencers a chance to develop more appealing messages and enabled them to converse with the community to change attitude and promote their inclusion in practices. They helped decrease the discrimination and integration of the affected people into the day-to-day life of a community through enhanced awareness and mobilization of people in the community.

Conceptual Framework



Literature Review

Social Exclusion Theory: The Social Exclusion Theory developed by Levitas *et al.* (2007) [39] is done in such a way that it explains how both individuals and a whole social group can be moved to the periphery of the society and deprived of resources, opportunities along with rights that are vital in the full immersion in economic, social, cultural and political life. The theory points out that exclusion is not about poverty and other aspects of material deprivation- it is a multidimensional process and is determined through complex interpolations of structural inequalities, institutional practices, and attitudes of the society (Silver, 1994) [40]. It especially addresses the outcomes of stigma, discrimination as well as the unequal power relations that hinder a person and his or her potential or meaningful contribution to the life of the community (Room, 1995) [41]. This paper consists of the analysis of the aspect of the leprosy-affected population in Montepuez District, view in relation to Social Exclusion Theory and the way in which the affected people experience the different forms of exclusion that affect their participation in the life of the community and exposure to economic and social opportunities.

In this context, the theory works as a prism through which the processes causing the leprosy-affected persons to be excluded and denied access to direct participation in important spheres or education, workforce, and health care, and civic life can be analyzed. Negative stereotypes are usually formed based on stigma towards leprosy, cultural misunderstanding and physical deformation, which leaves them poorly mobile and with poor self-identity, depriving them of accessibility to networks and the societal gathering places. These processes are not only perceptible at the interpersonal level but they are also strengthened by the institutional level of service delivery systems, which might not be inclusive or open to the special requirements of the victims. With the help of this theory, the paper can narrowly define and trace the social, economic and policy-related conditions that lead to the marginalization of people affected by leprosy in the greater context of structural exclusion.

In addition, the Social Exclusion Theory happens to be highly applicable when it comes to a determination of the adequacy of individuals who have become affected in terms of their capabilities to make use of the available resources as well as invoking the community support systems. The theory justifies a detailed investigation on the effect of the factors like community stigma, limited access to education or employment, and lack of fit in the community groups, which determine the lives of the leprosy affected individuals. This allowed the study to identify the major obstacles which restrict the participation as well as the areas in which interventions may be sought.

Role of Social Support Systems: Social support, in the form of self-help groups and the support of family networks, has been repeatedly defined as an enabler of participation. Deepak *et al.* 2021 [8] showed membership of self-care groups enhanced self-esteem and adherence to treatment as well as social acceptance. Similarly, community-focused organisations (CFOs) in Nigeria were also mentioned to play a crucial role in reducing stigma and empowerment through advocacy and capacitation (Ezenduka *et al.* 2012) [42].

Peer support models are effective in reducing psychological distress, and in enhancing integration within communities (Lusli *et al.*, 2015) [43] in Asian settings. However, empirical evidence from Mozambique is still very limited. The few existing literature in the field suggests that low institutional quality and cultural norms impact the efficiency of the mechanisms (Abdela, 2019) [1].

Disease-Related Characteristics

Disability level of the person and deformities have been found to adversely affect the level of participation. Van Brakel and al. (2019) [33] concluded that use of community was significantly constrained for persons with severe physical impairments, both because of functional limitations and their incorrect attribution of stigma. Furthermore, Putri, *et al.* (2022) [44] describes that leprosy reactions, including painful inflammation, interfered with employment and daily activities, making them less likely to be active participants in social life.

Support Programs and Community-Based Interventions

Community-based rehabilitation and awareness campaigns have proven effective in reducing stigma and improving participation. Barbosa *et al.* (2019) [45] in Brazil found that integrated rehabilitation programs enhanced both economic prospects and psychosocial well-being among participants. Similar findings were reported by Sermrittirong *et al.* (2020) in Southeast Asia, where participatory approaches improved knowledge, reduced discrimination, and strengthened social cohesion.

However, sustainability remains a challenge. Short-term donor-funded programs often lack continuity, limiting long-term impact (Lusli *et al.*, 2015) [43]. In Mozambique, Abdela *et al.* (2019) [1] highlighted the need for institutionalized support mechanisms and integration of leprosy programs into national health and social protection systems.

Social Conditions of People Affected by Leprosy

Leprosy is still an important civic problem in quite a number of areas of the globe and social consequences are deep-rooted. Additional to the physical signs of the disease, people who are afflicted with leprosy are likely to have to experience harsh social deprivations of severe stigma, discrimination and ostracism. Such social factors not only enhance the misery of leprosy patients but also have huge implications on their psyche, socioeconomic levels as well as the quality of life. Social consequences of leprosy are matters of various studies and the overall picture is that they have generated much light over the sophisticated mannerisms by which the disease affects social health.

Social stigma surrounding the leprosy disease is closely connected to the mental health of the persons experiencing the disease. The study of Somar *et al.* (2020) [46] entailed a review of mental health outcomes of individuals with leprosy and their relatives. The review showed that the price to pay in terms of the psychological burden is exacted by leprosy: people with this disease have anxiety and depression levels that are much higher than those of the general population and a range of other mental disorders. Stigma and discrimination together with leprosy brings about social isolation and feelings of worthlessness thereby worsening mental problems.

Besides the mental health, the subject of lived experiences of those affected by leprosy can give insight into the greater social problems experienced by people with leprosy. A systematic review and a qualitative synthesis of the experiences of people to manage leprosy conducted by Abdul Rahman *et al.* (2022) were done. The research concluded that the social stigma and discrimination are widespread, which results in serious marginalization of the social and economic kind. Leprosy victims usually feel excluded in communal activities, schooling and jobs thereby further deepening them in social seclusion. The review points out that it is relevant to take care of the underlying causes of social exclusion and social inclusion with the help of specific measures. Such findings, in particular, in the context of Mozambique, where leprosy is still very common, highlight the necessity of comprehensive approaches to dealing with the problem that will take into account the social as well as the financial barriers affecting people with leprosy.

A historical look at the psychological effects of leprosy would tell us that social issues that people with the disease have to cope with are not recent. Literature review on the history of leprosy and focus on its psychological impact on various cultures and different eras was done by Achdiat *et al.* (2021). The research established that leprosy has been linked with social stigma and discrimination and the resultant deep psychological effects experienced by the victim is related to social isolation and low self-esteem. Such patterns of stigmatization in the past are still comparable to the current life of leprosy victims.

Social realities of the leprosy-affected households are further complicated by the socioeconomic situation in their households. The study of Kumari *et al.* (2021) [14] determined the socioeconomic conditions of households affected by leprosy in India in terms of access to education, healthcare, and clean water. The research showed that most of the households that were affected by leprosy were below poverty so that they experienced great difficulties in receiving the essential services especially in the rural. These households continue to be trapped in poverty and social marginalization due to their low level of education, awareness and economic wealth. Leprosy not only has a socioeconomic implication in India but the same situation has been reported in Brazil.

The study conducted by Fonseca *et al.* (2020) analyzed the socioeconomic consequences of the experience of leprosy among the affected in Brazil with the emphasis placed on the impacts on the population with modeled deformities or unconcealable disabilities. It was observed in the study that these people are less likely to lead a socioeconomically unprivileged life due to social factors such as low income, unemployment, and poor access to medical treatment because of visible deformities of the body.

This study by Dadun *et al.* (2018) [5] is qualitative research carried out in Indonesia to determine the social situation of the leprosy-affected people who were sought with more attention to their experience of the stigma, discrimination, and social exclusion. The researchers found out that most of their respondents found it difficult to live a normal life and stay connected with other family members and friends mainly because of the leprosy stigma. Moreover, the respondents complained about having substantial difficulties gaining access to education and jobs thus being socially isolated even further.

Social factors further complicate the social conditions of victims affected by leprosy through delays in the detection of the cases. Urgesa *et al.* (2022) studied potential contributors to the delays in the detection of leprosy in a hotspot of leprosy in Eastern Ethiopia. In the program, the study revealed that the social stigma and a general absence of awareness among the society were some of the most influential factors that contributed to such delays and, as a result, brought negative effects to the health of the affected individuals. The results indicate fixing of social stigma and community awareness as important in uplifting early diagnosis and treatment of leprosy. In Mozambique, where comparable issues in identification of the cases prevail, the mentioned insights highlight the necessity of a community-based intervention that has to target the social factors that lead to the delay in diagnosis and treatment.

Support Programs for People Affected by Leprosy

Support programs are very necessary in solving the social, economic and psychological problems experienced by people infected by leprosy. The purpose of such programs is to improve the health, social integration, and community life of the people affected by the condition. Side effects of the various support programs and how well they have or have not worked in the lives of a leprosy-stricken person have been subjected to different studies.

The support programme of the leprosy-affected individuals has also been discussed in various perspectives showing its relevance in the reduction of the social and economic impacts of the disease. In their systematic review, Lusli *et al.* (2015) [43] also emphasized the necessity of the comprehensive support programs as a way of mitigating the long-term socioeconomic consequences of leprosy on the affected individuals, their families and communities. The review focused on the importance of support programs in dealing with complex issues of persons who are affected by leprosy especially in encouraging them to take part in community life and eliminate stigma surrounding the ailment.

In the investigation of the role of community-based organizations, Ezenduka *et al.* (2012) [42] observed the conclusion that these organizations are significant in achieving the effort of supporting people with leprosy in Nigeria. It was identified that community-based organizations played a critical role in increasing awareness, minimizing stigma and offering necessary support service like counseling and vocational training. The cooperation of these institutions with other players was noted as a major contributor towards successful implementation of support programs to meet the needs of leprosy affected persons.

Effect of community based rehabilitation programmes on the life of the people affected by leprosy has also been noted. Barbosa *et al.* (2019) [45] conducted a study on community-based rehabilitation in Brazil and revealed that this initiative positively affected outcomes of participation and quality of life among the individuals with leprosy. The program was comprised of various programs in terms of support service provision including counselling, vocational skills training and social reintegration initiatives one which were beneficial in increasing the social inclusion and empowerment of the participants economically. Barbosa *et al.* (2019) [45] affirmed the significance of put together and wholesome support programs that meet the various necessities of leprosy influenced people and help them be independent once more and take part in their society.

Special kinds of support programs focused on the cultural and socioeconomic environment of leprosy-affected people have been perceived to be effective. As an example, Gourvennec *et al.* (2021) [47] qualitative study performed in Mozambique aimed to assess their experiences and opinions about the provided support systems regarding persons with leprosy. The research found that the support programs which were very much associated with the cultural aspects and economic environment of the local population were more effective in facilitating social inclusion and elevating the quality of living of affected people with leprosy. The results stressed that it is necessary to have culturally sensitive and context-specific support programs that can adequately target the specific issues of this group of people.

All this research points to the importance of support programs in enhancing the lives of the leprosy affected individuals. An efficient support program should not only help resolve social and economic problems of these people but will also help in cutting down on stigma and discrimination of the disease. The results highlight the necessity to provide broad, specific, culturally-tuned support programs that may potentially contribute to the social integration of the people with leprosy and to their economic prosperity. Such support programs are vital in enhancing community involvement and improving the overall welfare of individuals affected with leprosy in areas where the disease tantamounts to a major public health issue such as the case in Mozambique.

Research Methodology

Research Design

The research was conducted using triangulation mixed methods research design, which combines both qualitative and quantitative approaches. The qualitative and quantitative design was chosen to allow comprehensive analysis by collecting statistical data through surveys and gaining deeper insights through interviews and focus group discussions, ensuring validity and reliability of findings. The quantitative aspect of the research employed the analytical cross-sectional methodology that aimed at analyzing the correlations between several variables (demographic, social, and economic factors) and the pattern of participation among individuals with leprosy at a certain instant.

It is completely suitable to use this design, specifically, because it was optimal in collecting and analyzing the data and examining several exposures and outcomes at once (Setia, 2016) [48]. The procedure allowed determining the possible relations that exist among different socioeconomic factors and the levels of community participation, as well as allowing taking a picture of the reality confronting people with leprosy regarding their communities.

The qualitative part used phenomenological study design to obtain an in-depth picture of the life lived and views of stakeholder working with the leprosy-affected people. This methodology was especially helpful in terms of enabling the researchers to learn how the stakeholders experience life and comprehend its nature by deeply interviewing them and carefully examining their stories (Neubauer *et al.*, 2023) [49]. Phenomenological inquiry helped to cover a diverse set of phenomena of stakeholder interactions and experiences and control the field to their respective lived experiences of participants in the work with the people with leprosy.

Study Area

The research was done in Montepuez area of Cabo Delgado province which is located in the Northern part of Mozambique, approximately 200 km west of Pemba, the provincial capital of Cabo Delgado, and about 1,800 km north of Maputo, Mozambique’s capital city. The nearest airport is Pemba Airport, from which Montepuez can be accessed via a 3-hour road journey. Cabo Delgado was one of the most leprosy-affected provinces in the country and it has had a substantial contribution to the burden of leprosy in Mozambique (MISAU, 2017).

The study area was chosen as Montepuez District because of a few reasons.To begin with, it was an area with a high prevalence rate of the leprosy cases with a good number of the people in the district having the disease. The burden of diseases outlined the necessity of special involvement and better comprehension of sociobonomic packages, which affect the community involvement in the area. Second, the area of Montepuez District was a unique cultural and geographic terrain which could have influenced the lives of leprosy-stricken people.

It has different ethnic groups in the district with different cultural beliefs, practice and attitude towards leprosy. These cultural subtleties were paramount in the endeavor to arrive at culturally focused interventions and embrace community integration. Besides, Montepuez District was mainly rural and most of the people were located in different areas, very far apart and difficult terrain. Such geographical distribution acted as a major obstacle in receiving medical treatment, rehabilitation programs, and community support systems which may further translate to the socio-economic problems experienced by those with leprosy.

Target Population

A total of 170 individuals (people with leprosy in the Montepuez District, Cabo Delgado Province, Mozambique) became the target population. These people were diagnosed with leprosy, who were under treatment, some with disability and visible impairments. In order to understand as much as possible about the context of the target population, the research accessed significant individuals who participated tremendously in the care of people with leprosy and community development. The healthcare providers who formed part of these key informants were doctors, nurses, and community health workers who provided direct care in leprosy diagnosis, treatment and management in Montepuez District.

The directors of the hospitals that were in charge of the healthcare facilities and formed the policies of the leprosy caring were also the significant informants. The researcher also interacted with community-based organizations and community support groups that dealt with individuals living with leprosy, and also the alternative healthcare providers in the district who were the traditional healers. Other key informants were community leaders such a village chiefs and religious leaders who commanded influence on issues affecting social life in the community. The healthcare providers included 4 healthcare workers, and 10 community health workers. These key informants were selected purposively based on their direct involvement in leprosy diagnosis, treatment, and management. The experiences presented by these stakeholders gave proper contextual information pertaining to the socioeconomic activities and the community engagement mechanisms of leprosy in the Montepuez District.

Sample Size and Sampling Procedures

The study employed stratified random sampling for quantitative respondents and purposive sampling for qualitative respondents, ensuring representation from different demographic categories and community groups. An effectively structured sampling strategy allowed the study findings to be representative and reliable. Since depending on the mixed-methods approach the study had both quantitative and qualitative parts, each one of them had to consist of particular sample size and sampling practices that represented the nature of data along with the specific attributes of the target population. Sample sizes were determined using statistical formulas for representativeness, and quality sample adequacy was guided by data saturation principles. The plan was adapted to the reality of Montepuez district, and the action was based on the assessment of people with leprosy and variety of stakeholders concerning their care and integration into the communities.

Quantitative sample size and sampling approach

The study used cluster sampling to identify the respondents, that is, a total population of 305 persons who had been infected with leprosy in Montepuez District. Cluster sampling was used in dividing the population into different clustering groups or categories then picking out some of the clustering with elements of random sampling. This approach guaranteed that the sample was representative of the various opinions and experiences of the population. It entailed the determination of these clusters that were comprised of healthcare workers, hospital directors, community groups, traditional healers, community leaders, and patients.

After provision of the clusters, a random sample of the clusters was taken, and any individual under the sampled cluster was considered to be a part of the sample. The specific samples within each cluster were selected by randomly choosing the clusters. Then, all individuals within each selected cluster were included in the study sample without further sampling. To determine the sample size for the quantitative component, the formula proposed by Krejcie and Morgan (1970) was used [13]:

$$\text{Sample Size} = [X^2 \times N \times P \times (1-P)] / [d^2 \times (N-1) + X^2 \times P \times (1-P)]$$

Where: $X^2 = 3.841$ (chi-square value for 1 degree of freedom at 95% confidence level)

- $N = 305$ (total target population)
- $P = 0.5$ (population proportion)
- $d = 0.05$ (margin of error)

Applying these parameters: Sample Size = 170

From the list of persons affected by leprosy in Montepuez district, the researcher will select 170 participants using systematic random sampling.

Qualitative Sample Size and Sampling Approach

Regarding the qualitative component, in-depth interviews (IDI) were conducted with healthcare workers, hospital directors of the district, leaders of community groups (supporting leprosy-affected individuals), traditional healers, and community leaders. In addition, focus group discussions (FGDs) were conducted with people living with leprosy and selected members of self-care groups. The qualitative sample included 18 key informant interviews and 4 focus group discussions with a total of 28 participants). Table 2 summarized the qualitative data collection approach by respondent group.

The IDI respondents were purposively sampled. Only people in these stakeholder groups who had been working with people affected by leprosy were interviewed. Regarding FGDs, purposive sampling was conducted to ensure two homogenous discussions with people affected by leprosy- one FGD with individuals participating in at least one group and another with those who did not participate in any group. Self-care group FGD participants were also purposively selected, ensuring that only those with significant experience interacting with people living with leprosy were included. Each FGD comprised 6-10 participants.

Data Collection Instruments

This study utilized a combination of data collection instruments tailored to meet the specific needs of both quantitative and qualitative research components. The tools were developed to gather detailed information on participants' demographics, perceptions, experiences, and levels of community participation. Careful attention was given to ensure that the instruments were contextually appropriate, culturally sensitive, and methodologically sound, allowing for the collection of accurate and meaningful data relevant to the study objectives.

Validity of the Instrument

The questioning (questionnaire and interview) was meant to generate detailed information in all the major areas and, work on initial versions of the questionnaire and the interview were sent to the panel of researchers, to review and align them with the study objectives. The panel feedback was used to acquire the level of instrument clarity and relevance. The validity of these data collection tools was maintained by carrying out field tests to point out any ambiguities then solve them before carrying the actual data collection as explained in 3.5.2.

Also, as a measure to ensure content validity, need to observe that they used proper literature review since ensuring that the question and the constructs were aligned with the tool that has already been well tested in a similar study. The construct validity was also enhanced by ensuring that the questions contained in the instrument were directly related to the conceptual framework of the study. This combination of measures warranted the analysis of the variables under investigation using the instruments appropriately and assisted in the objective of the study which is to make meaningful and actionable conclusions.

Reliability of the Instrument

Cronbach alpha coefficient of reliability was used to determine this in terms of the consistency and repeatability of measurement taken using the instrument. This coefficient measured whether items in sections of a construct or subscale were measuring the same thing in common in that section rather than they were a relationship of chance.

The data collected through the pilot test responses was used in computing the Cronbach alpha where the researcher had an opportunity to isolate items contributing to low internal consistency. Revisions or removal of items wherever necessary was done to enhance reliability. It was established that, a Cronbach alpha of 0.7 and above would be acceptable in this study due to adequate internal consistency. It is through this process that the final instruments would give reliable results under similar settings and similar respondent populations, enhancing the final credibility of the data to be collected.

Data Collection Procedure

The data collection exercise has taken a systematic direction so as to make the information collection more ethical and inclusive. To begin with, the relevant approvals and the necessary permission should be received form the authorities and the community gatekeepers to create legitimacy and access the target population with ease. Field enumerators were trained in ethical and cultural sensitivity. Random and purposive sampling were then used to identify and recruit the subjects to be used in the quantitative and qualitative parts respectively. This mixture created a representative quantitative sample in terms of generalizability of the results and a qualitative sample included people who are most relevant to the goals of the research.

All the participants were requested to give an informed consent before data was collected. This was done by explaining with much authority the purpose of the study, risks and benefits associated with it and emphasis was made that participants were free to bow out of the study any time without any repercussions. This made it such that the relationship between the participants and the researchers was one that can be described as well informed and not coerced into participating.

In quantitative survey, questions were done in a face to face interview using interviewer-administered questionnaires in a place comfortable to the participant in order to make him/her feel comfortable and free to respond truthfully and freely. In case the interviews could not be conducted face-to-face, telephone or video call interviews were organized. The interviews were of a semi-structured, questionnaire-based format, and the quantitative data continues to be electronically obtained with the help of the KOBO application.

The qualitative element consisted of intense interviews (IDIs) and focus group discussions (FGDs) with the directive of the IDI and FGD protocol. IDIs were carried out both in-person and on online basis according to preference of the participant whereas FGDs were carried out face to face by the investigator with the help of a note taker. The investigator identified the research team followed by provision of the purpose of the discussion and the request to introduce yourselves at the very beginning of each FGD followed by informed consent. All the qualitative interviews and FGDs were recorded with the participants and further notes were made in order to familiarize the data. The research team also observed ethical standards during the process of data collection, which included being confidential and anonymous but focusing mostly on the rights and welfare of the participants to obtain complete and valid data.

Data Analysis Techniques

Analysis of the data was done in a step by step manner so that the information gathered would have a great meaning in the interpretation of the analysis. It consisted of two key parts quantitative assessment of the answers in the questionnaires and qualitative assessment of the data of interviews and focus group discussion (FGD). In the case of the quantitative data, descriptive and inferential statistics were used. This was started by using descriptive statistics mean or medians (Again depending on how data is distributed) and frequency distributions) as a way to give a clue or description of the told in the data, the central tendencies and patterns in the particular data.

Following the descriptive analysis, inferential statistical techniques were employed to examine relationships between variables. Bivariate analyses were conducted to assess associations between individual independent and dependent variables. At this level, the researcher utilized correlation analysis, cross-tabulations with the Chi-square test, and binary logistic regression where appropriate. Consistent with prior research (Bursac *et al.*, 2008), variables demonstrating a p-value of less than 0.2 in bivariate analyses were retained for further examination in multivariate analysis.

Multivariate analysis primarily involved regression modeling to explore the combined effects of multiple independent variables on the dependent variable.

Ethical Considerations

To mitigate the risk of going against the ethical standards during the research and especially since the target population was vulnerable some thorough measures were applied. To begin with, before the study was undertaken it sought ethical approval of the relevant institutional review boards or ethics committees. This consent was in a bid to make sure that the research complied with existing ethical standards and policies. The informed consent proved to be a very crucial element of the research.

All the participants were informed in a detailed but understandable way about the purpose of the study, the risks involved, the benefits of the research and that they had the freedom to drop out at any time without any penalty. Particular emphasis was made on helping the participants especially the physically deformed or those with any other serious health complications be fully aware of the information passed across to them. A trained researcher would be on-hand to assist in explaining the study and obtaining consent of participants with communication challenges or physical limitation.

Data was kept confidential and anonymous with the help of codes or pseudonyms as well as safely stored. This was to safeguard privacy and guarantee confidentiality of identity of the participants. Since the information is sensitive in nature and stigmatizing, additional measures were observed to protect personal information especially to individuals with visible deformities or other outstanding features. The interviews were done in safe confidential settings in order to reduce risks and make people feel comfortable. In case the participants were in an emotional or psychological distress, they were offered counseling and support services. Moreover, the research team was equipped with methods of dealing with sensitive interactions with a lot of caution offering support and understanding during the data collection procedure.

The cultural norms and protocols were also respected since the community gatekeepers were consulted in order to study and apply cultural sensitivities to the research process. Cultural competence was regarded in every encounter between them and the participants since they wanted to treat them in a respectful and appropriate manner. Special arrangements were done to accommodate participants with physical deformities or other weaknesses. The interviews were carried out by the person who is a dedicated researcher and has experience working with people with similar conditions.

The researcher was socialized to handle delicate matter with care as well as to make sure that each participant was respected and dignified. Other steps which were offered to support the inclusion of those with special needs included special ways of communicating and fitting the environment into the needs of specific people. Fairness and equity were transgressed towards all the participants irrespective of their social and economic stature, gender or other traits. In this way, the contribution of any of the participants was appreciated equally and the study was carried out in a responsible, respectful, and trustworthy way. With these ethical considerations, the research will strive to keep the research process intact, in the process upholding the interest and rights of all the participants.

Data Analysis and Results

Data Quality and Response Rate

The sample size consisted of 291 respondents in general, including 150 people affected by leprosy, four community leaders and four health workers. A total of 28 participants were involved as the FGDs were done among 6-8 individuals with leprosy in each group four times. A majority (39.4%) of the sample fell in the middle-aged category (35 to 49 years), and 54.9 percent were males compared to 45.1 percent of females. The level of education was low where 43.7 percent were not educated and 40.8 percent attained primary education.

Questionnaire survey was aimed at 150 leprosy affected individuals and 142 valid questionnaires were received hence response rate of 94.7%. To guarantee the quality of data, eight questionnaires were avoided during the analysis due to incomplete or uneven answers. In relation to the qualitative research, 10 out of the 10 scheduled IDIs were completed achieving a 100 percent response rate comprising of five community leaders and five health workers. There were four FGDs conducted consisting of 6-8 participants who were leprosy-affected per group making a total of 28 participants. The high response rates in both phases reflect robust data collection activities, underpinned by community buy-in and the use of trained enumerators who were conversant with local languages (Portuguese and Macua). Data quality was also ensured by putting the data through rigorous validation processes, including double-entry of quantitative data and transcription verification for qualitative data, minimizing errors and making the results more reliable.

Social Factors' Role in Community Participation

The third objective examined the influence of social factors, including stigma, social support networks, and community attitudes, on community participation. Stigma was measured using a 10-item scale adapted from the literature (e.g., Peters *et al.*, 2019) [21], with scores ranging from 0 (no stigma) to 10 (high stigma). The mean stigma score was 6.4 (SD = 2.4), indicating moderate to high levels of perceived stigma. There was a strong negative correlation between stigma and the composite participation score ($r = -0.52$, $p<0.001$), such that more stigma was associated with less participation, as ascertained by a Pearson correlation test.

Social support was assessed by questionnaire items of family, friend, and community group support availability, which was graded as low, moderate, or high on the basis of a composite score. Table 4.5 indicates the distribution of social support levels and their correlation with participation.

Table 1: Social Support and Community Participation

Social Support Level	Frequency	Percentage (%)	Mean Participation Score (SD)
Low	52	36.6	2.6 (1.5)
Moderate	60	42.3	4.3 (1.8)
High	30	21.1	6.5 (1.9)

Source: Research data, (2025)

Individuals with high social support had a significantly higher mean participation score (6.5, SD = 1.9) compared to those with moderate (4.3, SD = 1.8) or low support (2.6, SD = 1.5). A one-way ANOVA also confirmed group differences (F = 16.89, $p<0.001$), illustrating the positive effect of social support on participation.

Qualitative data added richness to the understanding of social determinants. FGDs highlighted participation in self-help groups as a significant enabler, creating a sense of belonging and reducing loneliness. One participant, a 38-year-old male, reported, "In UMOJA, we encourage each other to attend village meetings. It is like family." Conversely, stigma was a pervasive barrier, and participants reported exclusion. A 50-year-old female respondent reported, "People tell me not to attend church because I have leprosy, so I remain home." IDIs with leaders described entrenched negative attitudes, one of whom reported, "Some villagers think leprosy is a curse and avoid patients." But healthcare providers cited effective stigma reduction through community education, with one nurse reporting, "Since our talks, some families now invite patients to celebrations." These narratives are congruent with the quantitative findings, illustrating the mixed influence of social facilitators and barriers on attendance.

Discussion of the Results

The research findings on the facilitators and barriers of community participation of leprosy-affected individuals in Montepuez District revealed overall low levels of participation, consistent with global trends described by Van Brakel *et al.* (2019) [33]. The quantitative results displayed a high proportion of respondents with low levels of participation in community meetings, self-help groups, or decision-making, while qualitative feedback from focus group discussions revealed the empowering influence of organizations like UMOJA. Participants described that these groups facilitated confidence in participating in village activities, an observation health workers corroborated through reporting more social integration among members. However, physical impairment and rural isolation, frequently mentioned in focus groups, aligning with Peters *et al.* (2019) [21], limit participation in Montepuez's geographically dispersed communities. This suggests that while self-help groups are effective, more widespread interventions facilitating accessibility are crucial.

Socially, stigma was a considerable barrier, with strong negative correlation with engagement, which is consistent with Dadun *et al.* (2018) [5]. Focus group participants recounted exclusion from community events, driven by misconceptions about leprosy’s contagiousness, as community leaders confirmed. Conversely, social support from self-help groups significantly enhanced engagement, consistent with Peters *et al.* (2020) [23], fostering resilience and belonging. Economically, higher income and employment facilitated participation by easing financial constraints, supporting Chukwu *et al.* (2021). NGO personnel highlighted the role of vocational training in enabling community engagement, while poverty was a limiting factor, particularly in rural areas, as Kumari *et al.* (2021) [14] prescribed. The mixed-method method bettered these results, and quantitative correlations were complemented by qualitative depths highlighting the necessity of strategic interventions to approach stigma, economic exclusion, and demographic diversity in the rural Montepuez setting.

Conclusion and Recommendations

Summary of Findings

The study revealed that patient participation in activities in Montepuez District is typically limited, and the majority of individuals participated minimally through activities such as meetings, self-help groups, or decision-making. The mixed-method approach provided an adequate understanding of the predictors of participation by combining statistical correlates derived from questionnaire data with contextual data from in-depth interviews and focus group discussions.

Demographics, and specifically age and education, were seen to be key determinants. Young adults and those who had higher levels of education were more active, one assumes due to being more alert and capable of physical effort. Gender, marriage, and where one lived had less severe impacts, although living in the country posed practical barriers to becoming active.

Social influences, including stigma and social support, were crucial. The salient barrier was stigma, which causes the social exclusion and low engagements and active social support networks, especially self-help groups, have offered a sense of belonging and have encouraged active partnership. Responses in the community were mixed with deep-rooted beliefs about leprosy in some individuals excluding them.

Economic-related factors were also significant like employment and income. People with higher levels of income and with stable lives had better chances of participating because this offered access to activities at the community level due to their higher income. Participation in income generating activities also enhanced participation, unemployment and poverty on the other hand worsened exclusion.

These discoveries help to explain how rich the dynamics of community engagement are since it touches upon the relations between demographic, social, and economic barriers and facilitators. The qualitative testimony completed the quantity of outcomes with the richer description of the perceived world of individuals who are victims of leprosy in Montepuez District.

Conclusions: The study concludes that leprosy in Montepuez District is influenced by a complex mix of demographic, social, and economic factors, which also reflect broader issues of social inclusion. Low community participation among those affected by leprosy highlights the need for targeted, evidence-based interventions.

Participation is hindered by physical limitations, social stigma, and economic hardship. Self-help groups like UMOJA play a key role in promoting inclusion, but broader community-based strategies are needed. Demographics strongly influence participation. Young and educated individuals are more involved due to mobility and awareness, while older and less educated people face more barriers. Rural residents also experience access challenges, though men and women are equally affected.

Social stigma is a major barrier, leading to isolation and reduced engagement. Misconceptions about leprosy persist, but support networks can counteract this by fostering resilience. Combating stigma requires both education and stronger social support systems.

Economic exclusion is another key factor. Employment and income enhance participation by reducing logistical barriers. Economic empowerment initiatives like vocational training and savings groups are essential, especially in rural areas with limited opportunities.

Overall, the study calls for multidimensional programs that address these interlinked barriers. Strengthening self-help groups and community-led efforts can enhance inclusion and improve the quality of life for people affected by leprosy in Montepuez and beyond.

5.4 Recommendations

To address the barriers to community participation among leprosy-affected individuals in Montepuez District, a set of integrated, multi-sectoral recommendations is proposed for stakeholders, including policymakers, medical professionals, NGOs, and community leaders. Additionally, each recommendation includes specific implementation steps, resource needs, and potential community-based strategies to overcome cultural resistance.

Self-help groups should be expanded in rural areas and made more accessible through transport support and inclusive venues. Special attention should be given to older adults, people with disabilities, and women, with gender-sensitive policies and childcare support. Adult literacy programs targeting the elderly and less educated should also be introduced to enhance engagement.

Economic participation can be improved through vocational training in local skills (e.g., farming, tailoring), supported by microfinance, savings groups, and financial literacy training. Collaboration with the private sector should promote inclusive employment, while improved transport options like subsidized travel or community shuttles would help people access services and activities.

Health interventions should include psychosocial counseling to address stigma and isolation, and decentralized treatment via rural clinics and mobile outreach. Assistive devices like prosthetics and wheelchairs should be provided to improve mobility and participation.

To reduce stigma, awareness campaigns led by trusted community and religious leaders should correct misconceptions about leprosy. Health workers must be trained in inclusive care, and families and neighbors involved in educational efforts to foster supportive environments.

Finally, leprosy-affected individuals should be empowered to advocate for their needs through participation in community councils and leadership training. These combined efforts address the demographic, economic, medical, and social barriers identified in the study, and can foster a more inclusive, equitable society.

Directions for Future Research

To build on the results of the study, several directions for future research are indicated. Longitudinal designs would examine the causal pathways between socioeconomic attributes and community engagement, with data on how interventions impact engagement longitudinally. Analysis of the effectiveness of single interventions, such as vocational training programs or stigma reduction interventions, would give stakeholders helpful recommendations. Multisite comparison within leprosy-endemic districts in Mozambique or elsewhere might elucidate differences between regions and lessons learned, increasing external validity of findings. Also, research on use of technology, for example, mobile health apps or virtual support groups, may examine novel mechanisms for increasing participation, particularly for those in rural areas. Finally, research on opinions of family members and leaders of communities could provide a truer understanding of social dynamics underlying participation.

5.6 Implications of the Study for the Profession

Through this study, very important observations with profound implications have been discovered in terms of the field of project planning and management, especially in fields of community development and in the field of public health. This can be understood by looking at the issues that affect the participation of people affected by leprosy in the community, and that way the results of such enquiry form a good source of evidence when building interventions that are responsive and inclusive. Giving directions on evidence-based program design is one of the significant contributions. The presence of the socio-economic barriers and demographic barriers provide a platform on which the project managers can customize the interventions among the leprosy-affected population in a manner that interrupts an immediate response to the needs and constraints of such populations. The method improves the relevancy, effectiveness, and overall influence of community-based projects.

Further, the analysis highlights the financial aspects of participation, proving that the income and employment factor plays an important role in participation in the life of a community. It is useful with regard to how we can incorporate elements of economic empowerment, including vocational training and microfinance projects into large-scale projects. In this way, the ability of the marginalized people to actively engage in development initiatives will be expanded by the project managers, who will, at the same time, encourage economic resilience and self-reliance.

Summary

This chapter summarized the study’s findings on the socioeconomic and demographic factors affecting community participation among people affected by leprosy in Montepuez District. It concluded that participation is generally low due to key barriers such as social stigma, poverty, limited education, and poor access in rural areas. Younger, more educated, and economically stable individuals are more likely to participate in community life.

Recommendations include expanding self-help groups, providing vocational and adult education, improving healthcare access, and conducting stigma-reduction campaigns. Empowering individuals through leadership training and advocacy is also crucial.

The chapter suggests future research on long-term impacts of interventions, regional comparisons, and the use of technology in rural settings. Finally, the study has important implications for community development and public health, emphasizing the need for inclusive, evidence-based project planning that addresses the specific needs of leprosy-affected populations.

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