

Health related quality of life amongst people affected by leprosy in South Ghana: A needs assessment

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Accepted for publication 27 February 2013

Summary

Aim: This study examined Health Related Quality of Life (HRQOL) among leprosy-affected elderly people at three leprosoria located in South Ghana.

Methods: Seventy elderly people who have been cured of leprosy but were undergoing socio-economic rehabilitation at three selected Leprosoria in the southern part of Ghana, were involved in this study. They comprised 31 female and 39 male adults with leprosy-related residual impairment and disability. The main outcome measure was a standardised HRQOL questionnaire which comprised physical functioning, role functioning, social functioning, cognitive functioning, health perception and pain. Descriptive statistics of mean and standard deviation were used to summarize the data whilst relationships and comparisons among and between the variables were evaluated using linear regression analysis and independent *t*-test respectively. Alpha level was set at $P < 0.05$.

Results: The mean age of the participants was 59.7 ± 13.5 years. The overall mean score of the subjects (40.9 ± 7.6) on the six domains of the questionnaire was below average. The highest and lowest mean scores were obtained in social functioning (56.9 ± 20.1) and physical functioning (15.0 ± 25.1) domains respectively. All the domains were significantly and positively correlated ($P < 0.05$) with the overall HRQOL scores. Age had no significant relationship ($P > 0.05$) on any of the domains and the overall HRQOL scores. Male participants scored significantly higher ($P < 0.05$) than their female peer on cognitive functioning and HRQOL.

Conclusion and implication: This study demonstrated low QOL among the sampled elderly people affected by leprosy at the selected leprosoria, thus stressing the need for measures that could improve their health and socio-economic status within the settlements.

Introduction

Leprosy is regarded as a special public health problem because permanent disabilities could develop if intervention is delayed or poorly implemented. An equally important aspect of the disease is its attendant social consequences including discrimination and stigma. The psychosocial impact of leprosy on those affected was so profound that the World Health Organization formulated three cardinal management strategies to curb its incidence and the residual effects.¹ These strategies included interrupting the transmission of the disease, prompt treatment of patients and preventing development of deformities. Although advances in medical care have reduced the incidence of leprosy drastically in developing nations, its effects still linger on indefinitely due to the residual permanent impairments and progressive physical disability precipitated by the disease.² The negative psychosocial experiences occasioned by residual disability may have far reaching influence on the quality of life (QOL) of people affected by leprosy (PAL).

While considerable efforts have been made to reduce the development of disability in leprosy patients, there are still large numbers of cured leprosy patients with residual deformities.³ In India, for instance, it is estimated that there are 1 million individuals with disabilities attributable to past and present leprosy.⁴ In view of the large number of people with leprosy-related disabilities and the limited available resources in developing countries, it is important to devise management programmes that are targeted towards those in greatest need. Indeed, the socio-economic impact resulting from the physical and psychological disabilities of leprosy continues to be a burden in endemic countries where 25% of leprosy patients have some degree of disability.⁵ Consequently, the concept of socio-economic rehabilitation (SER) as an essential component of community-based rehabilitation was introduced to improve the QOL of PAL so as to ensure re-integration into their communities. Evaluation of SER projects in Nigeria have been found to be very beneficial.⁶ In Ghana however, rehabilitation services are largely institution-based thereby presenting the need to maximize the available essential services and make it available to those who need it, as enshrined in the United Nations declaration on the Equalisation of Opportunities for people living with disabilities generally.⁷ One such paramount area of rehabilitation that could ensure attainment of optimal health status is the prevention of disabilities (POD) which has yet to be fully introduced in most developing countries including Ghana.

Assessments of people affected by leprosy prior to initiating any rehabilitative process should include evaluation of health-related quality of life (HRQOL) before and after intervention as a key outcome measure. Previous studies that have compared QOL of people affected by leprosy and that of control in the general population in India, Bangladesh, Brazil and Nepal reported worse QOL among the former than their healthy counterparts in general populace.^{5,8-10} Studies evaluating HRQOL in patients with chronic diseases to establish the need for modification of health care delivery are not yet documented in Ghana. Measurement of Health-Related Quality of Life in disabling diseases is particularly necessary as a starting point in situations where management is largely focussed on palliation and restoration of functions rather than cure. This study thus aimed to provide an insight into HRQOL among people affected by leprosy at three leprosaria located in the Southern Region of Ghana with a view to adopting a more pragmatic approach towards alleviating the suffering of leprosy-affected elderly patients who have been under institution-based care.

Materials and Methods

PARTICIPANTS

The study population consisted of the beneficiaries of prevention of disability and socio-economic rehabilitation programmes between the ages of 30 and 90 years. Participants were people affected by leprosy who originated from various communities and were under the care of a Catholic mission agency at three selected leprosaria in the Southern Region of Ghana for promoting appropriate rehabilitation services. The majority were elderly people who had been cured of leprosy but still had leprosy-related impairments and disabilities as a result of peripheral nerve damage. Most of them also needed assistance with regard to the means of earning a living. The Catholic church in collaboration with governmental (Ghana Leprosy Service) and non-governmental agencies provides them with shelter, and support from technical staff and engages them in petty trading so as to discourage begging in the street. Specifically, the young participants are normally given welfare packages to engage in small scale trading such as buying and selling at their respective homes following their exit from the settlements. Other rehabilitation services include provision of soft in-sole footwear and walking aids as well as wound care programmes. The young and active individuals are discharged to their various communities once they are certified fit on health grounds, while the older and incapacitated adults are kept in the leprosaria under the care of these agencies.

The sampling process began by visiting the three selected leprosaria namely Weijah leprosarium in the Greater Accra Region, Ankarful leprosarium in the Western Region and Ho lepers' village in the Volta region. Participants were recruited through purposive sampling techniques in this cross-sectional survey design. They were enrolled into the study based on the following: leprosy-related impairments and disabilities, leprosy-affected residents in leprosarium and presence of Grade II disabilities, defined as presence of visible impairments.⁸ Leprosy-affected people with the following attributes were excluded: Newly detected leprosy in the leprosarium, Grade I disabilities (presence of non-visible impairments) and non-resident clients in the leprosarium.

SURVEY INSTRUMENTS

1. *Data capturing form*: This was designed by the researchers and used to obtain information relating to biodata of participants such as age, sex and level of education.
2. *Short Form-20 health survey*: Developed by McDowell and Newell, this was used to evaluate quality of life of participants.⁹ It contains 20 items that are grouped under the following domains: physical functioning (6 items), social functioning (1 item), role functioning (2 items), cognitive functioning (5 items), health perception (5 items) and pain (1 item). The instrument has been found to be internally consistent (Cronbach's alpha value = 0.81). Comparison of HRQOL with Dartmouth co-operative charts using a multitrait-multimethod analysis revealed convergent correlations ranging from 0.45 to 0.75 while the average divergent correlation were 0.39 and 0.32.^{9,10} It can be used either as self-reported survey instrument or Researcher-administered questionnaire.

Owing to poor understanding of the English language by the participants, the questionnaire was translated into the Twi language, being the most popular language spoken by Ghanaians. Back translation was also done to ascertain the validity of the questionnaire. Criterion validity of the questionnaire was performed by administering each version to 11 apparently healthy

Ghanaians at two different occasions. Following this procedure, good agreement was found between the responses from the original English version and that obtained from Twi version ($r = 0.76$). It took about 20 min to complete the questionnaire for each participant. The instrument was scored according to the recommended procedures, with raw scores ranging between 0 and 100. A high score on any functional domain represents a high or healthy quality of that particular functioning.

PROCEDURE

Ethical clearance was sought and obtained from the Ethics Review Committee of the School of Allied Health Sciences, University of Ghana to conduct the study. Permission was also sought from the authorities at the selected leprosaria. Informed consent of the participants was obtained after the study protocol had been well explained to them. The Researchers visited the facilities prior to data collection and educated the participants and the authorities about the intent of the study. Each participant was interviewed with Short Form-20 health survey using the translated version.

DATA ANALYSIS

Data was analysed using SPSS version 16.0. Mean and standard deviation were computed to summarize scores on the six domains of the questionnaire. Comparison of male and female on overall QOL and domain scores was done using independent *t*-test. Linear regression was performed to determine the relationships between the following:

1. Age and domain scores of the participants
2. Age and QOL scores
3. QOL scores and domain scores

Level of significance was set at $P < 0.05$.

Results

A total of seventy (70) people affected by leprosy (PAL) aged between 30 and 90 years (Mean = 59.7 ± 13.5 years) participated in this study. Assessment of the educational attainment of the respondents indicated that 90% of the PALs in this study had no formal education. Only 10% had formal education with 1.4% attaining the tertiary level as shown in Figure 1.

The mean length of stay at the three leprosaria was 14.5 ± 3.7 years (Table 1).

The main scores on each domain were presented in Table 2. The highest score was recorded on social functioning domain (56.9 ± 20.1) while the lowest score was obtained on physical functioning (15.0 ± 25.1) domain. The overall mean score for health related quality of life (HRQOL) of the PAL was 40.9 ± 7.6 .

Age was not significantly correlated ($P > 0.05$) with any of the domain scores. An inverse and non-significant relationship was observed between age and the participants' health perception (Table 3.).

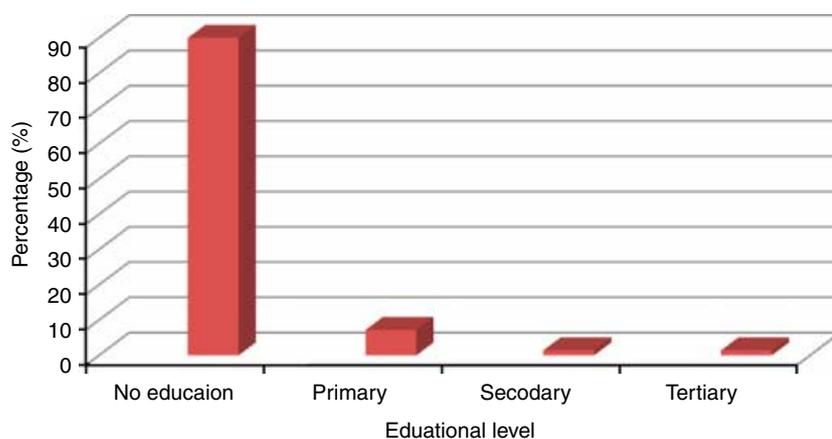


Figure 1. Educational attainment of the participants.

Physical functioning (PF), role functioning (RF), social functioning (SF) and cognitive functioning (CF) domains were significantly and positively correlated with the overall scores ($P < 0.05$) with the strength of relationship following the order $CF > RF > SF > PF$. Results were presented in Table 4.

Male participants scored significantly higher than the female counterpart on cognitive functioning (48.9 ± 8.5 years vs 45.1 ± 7.0 years; $P = 0.046$) and overall health-related quality of life (42.5 ± 7.7 years vs 38.9 ± 7.1 years; $P = 0.049$) respectively (Table 5).

Discussion

The need to ascertain the quality of life among leprosy-affected persons presenting with leprosy-related residual impairments and disabilities forms the purview of this study. The Quality of Life (QOL) of the participants was determined on different domains of Health Related Quality of Life (HRQOL) questionnaires, while the relationship between the age and each domain was examined. Participants' mean score on overall HRQOL (40.9 ± 7.6) was below the threshold (50) set for this study thus indicating the debilitating effects caused by leprosy and its sequela. The ages of the participants also have no bearing on their QOL).

Participants scored highest (56.9 ± 20.9) on social functioning in this study which was above average. This outcome is at variance with the findings of Tsutsumi *et al*, whose score

Table 1. Socio-demographic profile of the participants

Socio-demographics	Male ($n = 39$)	Female ($n = 31$)	Total ($n = 70$)
Age (years)	60.6 ± 13.6	58.71 ± 13.6	59.76 ± 13.6
Vocation			
Unengaged	38 (54.3%)	27 (38.6%)	65 (92.9%)
Engaged	3 (4.3%)	2 (2.8%)	5 (7.1%)
Duration of residence (years)	16.1 ± 2.6	13.5 ± 1.5	14.2 ± 3.7

Table 2. Mean domain scores and quality of life of participants

Domains	<i>n</i>	Mean score	SD
Physical functioning	70	15.0	25.1
Role functioning	70	21.1	21.0
Social functioning	70	56.9	20.9
Cognitive functioning	70	47.2	8.1
Health perception	70	42.7	10.9
Pain	70	55.5	19.4
HRQOL		40.9	7.6

Key: HRQOL = Health related quality of life. *n* = Total number.

on social functioning was below average due to reported incidence of discrimination against the sampled population.⁵ The variation in the outcomes of the present and previous studies may be linked to different selection criteria of the participants. Participants in the present study, a majority of whom were elderly people, have become resigned to their situation in the leprosaria and enjoyed healthy interactions among themselves thereby largely curtailing the incidence of discrimination as a result of stigma. On the contrary, the leprosy-affected persons in the previous study were sampled from their natural communities among the general populace with reported appalling levels of discrimination in terms of employment, social interaction and leadership role.

In the same vein, participants scored least (15.0 ± 25.1) on physical functioning domain in this study, which indicates a high level of disabilities among the sampled population. This finding agrees with previous studies where the authors also recorded very low scores on physical functioning scale.^{5,9,10,11} The previous authors corroborated the understanding that negative impact of physical deformities with regard to engagements in physical activity among the participants predisposes them to an altered role in the society. The mean score of the participants on the pain domain was above average which confirms the likely presence of associated musculoskeletal disorders including joint stiffness and other bodily dysfunctions. This result is not unexpected given the inadequate implementation of prevention of disability (POD) programme at the three selected leprosaria occasioned by inadequate number of personnel. The high impact of pain on these patients as regards reduced mobility might have contributed to the low physical functioning in this study. This outcome is in tandem with fear-avoidance model of pain by Linton and Shaw in which pain from any forms of impairment

Table 3. Relationship between age and domain scores and quality of life

Domain	Correlation coefficient (<i>r</i>)	<i>P</i> -value
Physical functioning	0.020	0.872
Role functioning	0.052	0.671
Social functioning	0.284	0.170
Cognitive functioning	0.063	0.606
Health perception	-0.043	0.726
Pain	0.132	0.277
HRQOL	0.142	0.240

Key: HRQOL = Health related quality of life.

Table 4. Relationship between quality of life and domain scores of participants

Domain	Correlation coefficient (<i>r</i>)	<i>P</i> -value
Physical functioning	0.311	<0.001*
Role functioning	0.589	<0.001*
Social functioning	0.472	<0.001*
Cognitive functioning	0.641	<0.001*
Health perception	0.411	0.05
Pain	0.555	0.05

* = Significant at $P < 0.05$.

may result in fear which could lead to avoidance of certain movement or engagement in certain physical activities and subsequent altered role performances.¹²

Age was not significantly related to any of the domains implying that age was not a strong predictor of functioning and quality of life among leprosy-affected individuals. This outcome is consistent with the previous findings in which the overall QOL in patients generally was reported to be minimally influenced by the age.¹³ An inverse and non-significant relationship was also observed between overall HRQOL and health perception in this study indicating that as one ages there is likelihood of decline in the perception of health.

The overall HRQOL of the participants was significantly and positively correlated with physical functioning, social functioning, role functioning and cognitive functioning of the participants. Previous studies have also reported similar findings on these domains.^{5,13,14,15} However, the strength of the relationships in each of the above mentioned studies varied from place to place. While the study by An *et al.*¹⁵ showed a stronger relationship between HRQOL and cognitive domain as well as social domain, the present study showed a stronger relationship of HRQOL with role functioning and cognitive functioning domains. A possible reason for this disparity could be traced to socio-cultural demands on people in terms of health and functional roles in different geographical locations. The importance of culture as a crucial factor in the analysis of health care planning has been documented.¹³ In spite of these reported relationships, Frank–Stromberg has indicated that more is involved in the perception of QOL other than functional abilities of the patients.¹⁴

Male participants scored significantly higher on cognitive functioning and overall HRQOL than their female counterparts. On the contrary, previous studies reported a lower quality of

Table 5. Independent *t*-test comparison of domain scores and quality of life between male and female participants

Domain	(Female <i>n</i> = 31) Mean ± SD	Male (<i>n</i> = 39) Mean ± SD	<i>t</i> -value	<i>P</i> -value
Physical functioning	10.2 ± 17.5	18.8 ± 29.4	−1.5	0.134
Role functioning	17.7 ± 20.6	23.7 ± 26.2	−1.1	0.290
Social functioning	55.9 ± 19.9	57.7 ± 21.9	−0.4	0.724
Cognitive functioning	45.1 ± 7.0	48.9 ± 8.5	−2.0	0.046*
Health perception	43.1 ± 10.9	42.3 ± 11.1	0.3	0.781
Pain	53.7 ± 20.5	56.8 ± 18.6	−0.6	0.519
HRQOL	38.9 ± 7.1	42.5 ± 7.7	2.0	0.049*

Key: HRQOL = Health related quality of life.

* = Significant at $P < 0.05$.

life score in males than females affected by leprosy.^{11,15} Socio-cultural orientation and role expectations in different countries and societies might have accounted for this variation. In Bangladesh, the Gender Development Index (GDI) of 0.47 was reported.¹⁶ Owing to their more active involvement within the society, the social relationships of male individuals might be more impacted by leprosy within the society compared with those of women who are more restricted. Therefore, the social relationships domain of women may be similar regardless of whether they have the disease or not. On the contrary, GDI in Ghana was 0.56 in the same year indicating that there are fewer restrictions in female relationships making them to be more involved in society, hence the marked changes in the QOL of female PALs in this study.^{16,17}

The findings in this study clearly show a close and direct link between quality of life of leprosy-affected people and their level of disabilities. It thus suggests the need for more emphasis on the prevention of disability and socio-economic rehabilitation programmes either through community-based or institution-based approach in Southern Region of Ghana. This could be accomplished by requiring the health care and social services personnel to engage more in patient-centred management approach. One of the main concerns troubling health care providers and organizations seeking to rehabilitate those affected by leprosy is how to find a balanced approach which is caring yet encourages people to manage their own lives, either in the wider community or – when appropriate – within a sheltered residential community if they have long made them their home. Socio-economic rehabilitation and prevention of disability are important requirements for rehabilitation activities in leprosy where the disease impact is far-reaching. Thus, this approach will serve as a means of overcoming the restrictions imposed by leprosy-related disabilities, particularly in developing countries where the demand for rehabilitation service still outweighs the supply in terms of personnel.

Our study design was limited by the lack of control group with which to compare the quality of life of the participants. It is difficult to identify another segregated residential community, comprising non-leprosy-affected people as a suitable source of controls with which to compare these subjects. They might have been compared with leprosy-affected people who had never been admitted to a leprosarium. Another limitation of the present study is the single-contact measurement procedure. Early contact and monitoring of the participants over a period before and after intervention with regard to their QOL might have been more informative. The instrument used, though standard, has not been validated to suit Ghanaian environment, thus could also form a further limitation in the study, although we did test it among a group of healthy Ghanaians. These observations could be the focus of future studies concerning socio-economic activities of elderly people affected by leprosy living in leproseria with regard to their quality of life.

Conclusion

This study has demonstrated low overall quality of life among people affected by leprosy in the three selected leproseria in Southern Region of Ghana. The observed overall HRQOL has been shown to be influenced by many factors including inability to engage in social and physical activities, altered role functioning and poor mental health. It is recommended that more a pragmatic measure, in the forms of prevention of disability and socio-economic programmes, be put in place to improve the health and socio-economic status of leprosy-affected people within the settlements.

Acknowledgements

We acknowledge the support of the staff and the participants at Ho, Weijah and Ankarful leprosaria for their interest and participation in this work. Especially, Ghana Leprosy Service that oversees all activities related to Leprosy in Ghana.

References

- ¹ WHO. Report on third meeting of the WHO technical advisory group on elimination of leprosy. Geneva: WHO, 2002. WHO/CDS/CPE/CEE/2002.29
- ² Calcraft JH. The effects of stigma of leprosy on the income generation of the leprosy affected people in the Terai Area of South-East Nepal. *As Pacif Dis Rehabil J*, 2006; **17**: 73–89.
- ³ Vaz M, Diffey B. Should nutritional status evaluation be included in the initial needs assessment of leprosy patients with disability prior to Socio-Economic Rehabilitation. *Lepr Rev*, 2001; **72**: 206–211.
- ⁴ WHO. Leprosy disabilities: magnitude of the problem. *Weekly Epidemiol Rec*, 1995; **70**: 269–275.
- ⁵ Tsutsumi A, Izutsu T, Islam AM *et al*. The quality of life, mental health, and perceived stigma of leprosy patients in Bangladesh. *Soc Sci Med*, 2007; **64**: 2443–2453.
- ⁶ Ebenso B, Fashona A, Ayuba M. Impact of socio-economic rehabilitation on leprosy stigma in northern Nigeria: findings of a retrospective study. *As Pacif Dis Rehabil J*, 2007; **18**: 98–119.
- ⁷ United Nations (1993): Standard Rules on the Equalization of Opportunities for Disabled people: <http://www.un.org/documents/ga/res/48/a48r096.htm>
- ⁸ Joseph GA, Rao S. Impact of leprosy on the quality of life. *Bull World Health Organ*, 1999; **77**: 515–517.
- ⁹ Martins BDL, Torres FN, Oliveira ML. Impact on the quality of life of patients with Hansen's disease: Correlation between Dermatology Life Quality Index and disease status. *An Bras Dermatol*, 2008; **83**: 39–43.
- ¹⁰ Brouwers C, van Brakel WH, Conielje H, *et al*. Quality of life, perceived stigma, activity and participation of people with leprosy-related disabilities in South-East Nepal. *Dis, CBR inclusive develop*, 2011; **2**: 16–34. Available at <http://www.dcidj.org> DOI 10.5463/ DCID.v22i1.15
- ¹¹ Rao VP, Rao IR, Palande DD. Socio-economic rehabilitation programmes of LEPRO India: Methodology, results and application of needs-based socio-economic evaluation. *Lepr Rev*, 2000; **71**: 466–471.
- ¹² Linton SJ, Shaw WS. Impact of psychological factors in the experience of pain. *Phy Ther*, 2011; **91**: 700–711.
- ¹³ Jegede AS. The Yoruba cultural construction of health and illness. *Nordic J Afr Stud*, 2002; **11**: 322–335.
- ¹⁴ Frank-Stromberg M. Single instrument for measuring quality of life. In: Frank-Stromberg M (ed). *Instrument for clinical nursing research Norwalk*. Appleton and Lange, Conn, 1998.
- ¹⁵ An JA, Ma JH, Xiao S-X, Yang F. Quality of Life in Patients with Lepromatous Leprosy in China. *J EADV* Doi:10.1111/J.1468—3083.2009.03534.x
- ¹⁶ United Nations Development Program. Human development report 2002. New York: Oxford University Press
- ¹⁷ WHO. 'Leprosy disabilities: magnitude of the problem'. *Weekly Epidemiological Record*, 1996; **70**: 269–275. PMID 7577430.
- ¹⁸ McDowell I, Newell C. *Measuring Health*. Oxford University Press, New York, 1996; pp. 380–473.
- ¹⁹ Osoba D, Aaronson NK, Muller M *et al*. Effects of neurological dysfunction on health-related quality of life in patients with high grade glioma. *J Neuro-Oncology*, 1997; **34**: 263–278.
- ²⁰ Lu W, Cui Y, Zheng Y, *et al*. Impact of newly diagnosed breast on Quality of life among Chinese women. *Breast Cancer Res. Treat.* 2006 (Epub ahead of print).