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## Adjustments to amputation and artificial limb, and quality of life in lower limb amputees

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## **CHAPTER 7**

General discussion



## INTRODUCTION

The objectives of this study were to assess quality of life (QoL) in lower limb amputees, to study the adjustment to amputation and functioning and satisfaction with prosthesis, and to study the various factors influencing these in lower limb amputees, including the role of adjustment to amputation, and functioning and satisfaction with prosthesis on QoL.

In this last chapter, the main findings of the study will be presented and the four research questions posed in the introduction chapter answered. These findings in relationship with the outcomes from other studies in lower limb amputees will be discussed, and the weaknesses and strengths of this study with respect to study design, sample, instruments, etc. presented. At the end of this chapter, recommendations for future research and implications in clinical practice will be provided.

## MAIN FINDINGS

### **Systematic literature review**

We found 26 articles on QoL in lower limb amputees, which met the inclusion criteria for a systematic review. The studies were heterogeneous from the point of conceptualization of QoL, study objectives and the instruments being used to measure QoL, which limited the direct comparisons of outcomes across studies, and therefore, conducting meta-analyses. Also, studies were mostly carried out in the more developed countries. Gaps were found in the methodological study design of most of the studies. Study population characteristics were only partially provided in most of the studies. A lack of prospective longitudinal studies was noticed.

### **QoL in lower limb amputees**

QoL in lower limb amputees was found to be worse as compared to the general population in India as assessed by the MOS SF-36. Among all the socio-demographic, amputation and medical related factors, employment status was found to be the most important factor affecting QoL in amputees followed by daily prosthesis use. Amputees who were employed had better QoL. Those amputees who used their prosthesis also had better QoL. Co-morbidity and experiencing pain (stump and phantom) were associated with worse QoL.

### **Adjustments to amputation and artificial limb**

Psycho-social adjustment to amputation and prosthesis, and functioning with prosthesis, as assessed by the Trinity Amputation and Prosthesis Experience Scale (TAPES) revealed that younger age, being employed, more use of prosthesis on a daily basis, and non-use of assistive device were the factors linked with being more adjusted to the amputation and prosthesis. After controlling for socio-demographic, medical and amputation-related factors, better adjustment to amputation and prosthesis and functioning with prosthesis were found to be the most important factors associated with higher QoL of amputees.

## **DISCUSSION**

### **Characteristics of the study population**

Over more than 60% of amputees had undergone amputation as a result of trauma. This is in stark contrast with respect to the developed countries, where vascular complication is the primary cause of amputation.<sup>1-3</sup>

In the developing nations, trauma is the primary cause of amputation.<sup>4</sup> Besides differences in population structure, this is an important reason why the mean age of the study population in these countries would be younger when compared to the developed nations, where mostly people over 60 years of age undergo amputation.<sup>1</sup> The mean age of the current study population was 43 years. This stresses the importance of contextual factors playing a role in their lives, like employment, and which thereby influences their QoL, as compared to aged people of retirement age.<sup>5</sup> Older amputees suffering from causes other than trauma may have more co-morbidity and a lower life expectancy. In the current study, the recruitment of the respondents from limb fitting centers and rehabilitation center may have resulted in an over representation of younger traumatic amputees, since older patients with co-morbidities might use rehabilitation services less frequently as they may face barriers to access these services due to old age. It is also possible that patients not visiting rehabilitation centers or limb fitting centers are prosthetic failures, and might be using other modes of mobility, like wheelchair, crutches, or may be even bed-ridden.

Over 50% of the study population was unemployed, which is something of high consideration seeing the young age of the amputees. A similar high unemployment rate has also been found among amputees in Jordan.<sup>5</sup> Also, 60% of the study population had one or more comorbidities, which could be as a result of general health status of people and accessibility to healthcare as well. Schoppen et al.<sup>6</sup> reported

the presence of comorbidity in 44% of the amputees between 18 and 60 years of age, and van Eijk et al.<sup>7</sup> reported 53% multimorbidity to be prevalent in elderly amputees in the Netherlands.

The incidence of amputation can be said to be prevalent more in males than females, as the amputee population comprised of 88% males. The high representation of males has also been found in other studies.<sup>8, 9</sup> However, females are more prone to suffer psychosocial adjustment problems, and to exhibit more psychological symptoms, like anxiety and depression.<sup>5</sup> Thus, female amputees might be more vulnerable, and have more problems in coping with amputation than males, which in turn may affect their QoL more adversely.

### **Amputation related problems**

Phantom limb pain, stump pain and stump skin problems were reported by 22%, 28% and 17% of the study population respectively, and time since amputation was on an average 9 years and mean age of the amputees was 43 years. Desmond et al.<sup>10</sup> reported 57% and 50% of the amputees with phantom pain and residual stump pain respectively, and maximum amputees were amputated since 5 years and the maximum age of the amputees was in the age range 61-75 years. A higher incidence of stump-skin problem was reported by Meulenbelt et al.<sup>11</sup> and Schoppen et al.,<sup>6</sup> 63% and 76% respectively, despite the mean time since amputation being considerably high,  $20 \pm 19$  and  $19.8 \pm 12.9$  years respectively. The subjects in the study by Schoppen et al.<sup>6</sup> were aged 60 and above.

Stump-skin problem has been found to be less frequent in the above knee as compared to the below knee amputees. Furthermore, physical activity level and the use of prosthesis among such amputees is lower than among the below knee amputees.<sup>6, 12</sup> Other studies<sup>11, 13</sup> have also demonstrated that having a traumatic and trans-tibial amputation were positive determinants of the stump-skin problem. The present study also has a higher percentage of traumatic and trans-tibial amputees.

The prevalence of residual stump pain was found to be more than the phantom limb pain. This could be related to the study population, which comprised more of the below knee amputees. The prevalence of residual stump pain to be more in the below knee amputees, and that of phantom limb pain to be more in above-knee amputees has also been reported in other studies.<sup>6, 11</sup> Also, phantom limb phenomena has been found to be prevalent more in the new amputees.<sup>6</sup> Stump pain could have an

impeding effect on the use of the prosthesis, and therefore care should be taken to alleviate pain so as to ensure the effective use of the prosthesis.

More than 40% of the study population was using an assistive device, like canes and crutches. A similar percentage (40%) of the use of assistive devices was found by Narang et al.<sup>4</sup> in the Indian amputees in a study comprising of 500 amputees conducted in 1980-81. The use of an assistive device is not reported in many studies as most of the studies are conducted in more developed countries where the use of such assistive devices is not common. It could be that in these countries, patients who are prosthetic failures and very high level amputees would be getting motorized mobility vehicles, and the houses would be adapted to suit mobility with a wheelchair, whereas in developing countries, availability, accessibility and the use of such mobility aids in everyday life might not be as economically and environmentally supportive. A study recently conducted in trans-tibial amputees in India about the energy expenditure using prosthesis and using axillary crutches further testifies the common use of such assistive devices.<sup>14</sup>

### **Systematic literature review**

The findings of the systematic literature review on QoL in lower limb amputees hold clinical relevance and shed light on QoL in amputees to some extent. However, a lack of studies primarily focusing on QoL in amputees incorporating the multitude of factors surrounding the life of a person whose limb has been amputated was noticed. Such factors like contextual (possibilities of employment), use of prosthesis (which supposes the availability of and functioning with prosthesis, including both psycho-social and physical functioning) and co-morbidity are important factors to take into account to understand the QoL in lower limb amputees.

The study by Asano et. al.<sup>15</sup> could be considered somewhat comprehensive as it incorporated multitude of socio-demographics, amputation-related, activities of daily living and activities with prosthesis, and psychological factors, like balance confidence with prosthesis and depression factors. However, the study did not vividly account psycho-social adjustment and functioning with prosthesis in the society, as is measured by TAPES (Trinity amputation and prosthesis experience scale). In the current study, QoL in amputees was found to be poor when compared to the Indian general population.<sup>12</sup> This is in congruence with the findings from other studies.<sup>6, 16-20</sup>

In most studies QoL was used as an outcome measure to compare two or more different interventions, or to compare amputees with other diseased population. For

example, for comparing amputation versus limb salvage, or amputation versus arterial bypass surgery, etc.<sup>16, 21-27</sup>

A discrepancy in conceptualization of QoL and use of different instruments – as shown in Chapter 2, containing the systematic review – limits a comparison between studies. Some studies have also used parts of questionnaires being used in other diseased populations. A comprehensive analysis including diverse socio-demographic variables potentially affecting QoL was found to be limited in studies. So looking for explanations why QoL is worse in amputees or finding causal factors is difficult if such analyses are absent. Also, the studies do not often perform such analyses since their design is not longitudinal.

It was evident from the systematic literature review that research in this area has some limitations and methodological weaknesses. The most important problems are the design of the studies, i.e. most studies are not longitudinal, representativeness of the study population, inclusion of diverse factors that could potentially affect QoL, as well as diversity of instruments being used, which reflects the lack of instrument and a harmonized approach to assess QoL in lower limb amputees.

### **Adjustments to amputation and artificial limb in relation to QoL**

Our analyses show the importance of other factors – besides amputation – in relation to QoL. Being employed, non-use of assistive devices, more use of prosthesis, and absence of comorbidity, phantom-limb pain and residual stump pain positively influenced both the physical and the mental components of QoL.

Employment is the most important factor not only related to QoL, but also associated with psychosocial adjustment and activity restriction scales of TAPES. This indicates that people who are employed tend to be more physically active and more psychosocially adjusted. Coming to work and performing the job would require from the amputees to perform more physical activity as compared to a non-working person. On the other hand, employment means having a (constant) source of income and would be a boost at the psychological level, and would be helping the amputees to be more socially accepted, or could be that due to their better economic status, they are socially more adjusted in the society. This has a special relevance for a country like India where the social security is not available, or may be an insignificant amount to depend on it. This is in contrast to the developed countries where people can have financial support from the social security in case of disability.

An interesting finding is that a longer time with prosthesis had a negative influence on activity restriction. However, considering the time since amputation (almost 13 years) and the time since prosthesis use (almost 11 years), a large percentage of amputees still had stump-skin problem and residual stump-pain. These might be related to the activity-level, use, quality and fitting of the prosthesis, as more stress forces would be at play while doing vigorous activities or using the limb continuously without regular maintenance or repair, in which case the stump would be subjected to continuous unwanted pressure. Meulenbelt et al.<sup>11</sup> found younger age, being female, having diabetes as opposed to peripheral arterial disease, a higher frequency of washing the stump, more use of antibacterial soap and smoking to be related to a higher occurrence of skin-problems.

More use of prosthesis on a daily basis was found to be positively associated with psychosocial adjustment and less activity restriction. Presence of phantom limb pain was found to negatively affect the functional satisfaction with prosthesis. However, in a qualitative study,<sup>28</sup> the direct influence of phantom pain on well-being was found to be small.

### **Strengths and limitations**

Compared to other studies of a similar nature, our study has a comparatively larger sample size. However, as concluded from the systematic review of the literature, this study has similar limitations as most of the others: it has a cross-sectional design, while longitudinal studies are needed to unravel the role of socio-demographic factors, of health status, and of amputation and prosthesis related factors on QoL. On the other hand, it should be noticed that this being, to our knowledge, the first study on QoL in lower limb amputees analyzing the influence of socio-demographic, medical, and amputation related factors in India. The study was interview administered, whereas in western countries, the data is usually collected via postal surveys. Also, the role of employment is normally not studied in western countries, perhaps because of the social security system. Socio-demographic conditions might have a greater role to play in developing countries due to greater economic disparity in the society.

The study has analyzed the possible influence of multitude of factors on QoL of the amputees. A special feature of the study is that the QoL of amputees was compared to a cross-section of the Indian general population. Apart from this, the study has also analyzed the influence of psycho-social adjustment to amputation and prosthesis, and functioning with the prosthesis on QoL, which provides further prosthesis related insights affecting QoL of amputees.

One of the problems of such studies is sampling. Our study sample was not derived from a primary source, like a hospital, therefore the possibility that our study population comprises of only those people who are motivated and interested in their health and were able to receive rehabilitation cannot be totally disregarded. It can be estimated that the QoL of those amputees who did not approach the rehabilitation center/limb fitting center or did not have access to it, would be even worse than our study population. The cross-sectional study design also limits the knowledge about QoL of amputees over time. Prospective longitudinal studies are envisaged as it will provide in-depth knowledge of changes in QoL after amputation and the adjustment to amputation and prosthesis, and also rejection of prosthesis, if any.

This study used the face-to-face interview method as opposed to the postal method, as interview administration ensures higher response rate and more robust data collection.<sup>29</sup> Interviewers were properly trained, which led to appropriate conduct of interview(s), and anonymity offered during the data collection helped in preventing socially desirable answers. Postal administration method is not practically used in India, and studies predominantly use interview administration method for data collection, including for large health surveys. For self-reported health questionnaires, appropriately administered face-to-face interview with well trained interviewers is a robust and reliable way to collect data in the Indian setting; however, this method could possibly lead to a bias for medical related information, as there is a chance of recall bias.

One of the study strengths is that the sample was derived from three different sources, a rehabilitation center, a limb fitting center and several limb fitting camps. Approximately 90% of the study population comprised of males, and this high representation of males cannot be deemed to be a matter of chance. High representation of males has also been observed in other studies.<sup>12, 13</sup> This high representation is further reflected in the incidence of road traffic accidents, whereby males are the major casualties. This also brings a limitation due the low representation of females in the study, as the chance of type II error gets increased, and the power of the study is reduced for generalizing the results for this specific group.

Another strength of the study is that all the instruments used in the study were pilot-tested, and an adapted and translated version of MOS SF-36 was used in the study and its validity and reliability established in the general Indian population. TAPES is an amputee specific instrument, and its validity established in other studies. Therefore, it

was translated and pilot-tested for use in the study. Further, the analysis of TAPES indicated that most scales were reliable.

## **RECOMMENDATIONS**

### **Vocational rehabilitation**

The role of employment seems essential in relation to QoL in the study population. Therefore, it is important that the goal of rehabilitation should be re-integration in the society in the true sense, from work/employment perspective as well. The Indian work-force is more in the private and informal sectors than in the public sector. Public sector offers job security in the event of disability, and the provision of a job to a family member in some cases. Private sector may not have such provisions, and therefore the role of vocational rehabilitation becomes even much more important.

Social security may not be available like in the developed countries, and therefore it becomes more important for a person to be able to earn his/her living. In cases, where it would be difficult to continue with the earlier job as a result of body limitations, the job should be adjusted according to the body-functional capacity in co-operation with the employer with the help of medical social workers, or vocational training should be integrated in the rehabilitation program so that the chances of being employed are higher than otherwise.

Occupational therapists should also be involved in the procedure and long-term follow-up, so as to evaluate their body-function, advise them in maintaining their body-function and help them to optimally perform their work with their residual capacity. Care should also be taken that the amputees' functional capacities are maintained over-time. Public sector jobs have a reservation quota for disabled people; however, the number of jobs in the public sector is quite limited. There is a growing need to address issues at policy level to safeguard the interests of those in the private sector, and also to take care of people in the informal sector.

### **Use of prosthesis**

The use of prosthesis is another important determinant of QoL. Measures should be taken to ensure the use of prosthesis, which means ensuring a proper fit of the prosthesis and avoiding pain experience. This demands a regular check-up and control of the prosthesis, so that any undue pressure, which might have an impact on the stump could be relieved. This would also need patient education, as well as easy accessibility for these services. Effectively addressing phantom limb phenomena and

other comorbidities present just after amputation and during the rehabilitation program are of paramount importance to ensure wearing, use of the artificial limb, and good psycho-social functioning with the prosthesis by the amputees. These aspects need attention in the training of rehabilitation professionals.

### **Research**

From a research perspective, a prospective longitudinal study with the study sample recruited from hospital(s) is recommended, which will systematically provide information about adjustments to amputation and prosthesis, and changes in QoL over time. A study sample derived in such a way will also provide evidence about the probable causes of rejection and non-use of prosthesis, and the choice of other forms of assistive devices, like canes and crutches over prosthesis. Future research should try to unravel the cause(s) of residual stump pain, which has an important role to play in determining the QoL of amputees; as well as the cause(s) of stump-skin problem considering its high incidence as evidenced from this study. A qualitative research would be helpful in understanding the causal link.

Due to the dearth of scientific information available in the area of QoL in amputees, research towards this is highly recommended, especially for a country like India with growing incidence of amputations as a result of premorbid conditions, as well as in other developing nations. At the same time, there is a need for training on research conduct among physical rehabilitation professionals. This is particularly relevant in developing countries due to meager research budget and relative lack of research knowledge among physical rehabilitation professionals to be able to conduct such research studies to bring forth the scientific findings applicable in clinical practice.

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