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

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# **CHAPTER 1**

Lower limb amputation and quality of life: an introduction



## BACKGROUND

Amputation is the removal of one or more parts of the body and can be as a result of unprecedented havoc or natural disasters; like accidents, earthquakes of major intensity, terrorism and war, or carried out due to medical reasons with the motive to improve health outcomes and quality of life (QoL) of patients. In cancer patients, it is performed as a lifesaving procedure to protect them from further malignancy of the body part or to other parts of the body. In debilitating vascular conditions of the extremities, limb gangrene, leprosy, etc., it is performed to prohibit further progression or to restore functions of that body part by making it amenable for prosthesis, and thereby making the person mobile. Inadequate treatment of diabetic foot ulcers are also precursors of lower limb amputation.

Irrespective of the cause of amputation, it brings a significant and drastic change in a person's life, and one goes from a stage of shock, to acknowledgement, and finally adjustment.<sup>1</sup> Horne et al.<sup>2</sup> referred to amputation as triple insult, as it brings loss of function, loss of sensation, and loss or change of body image. This dramatic change has an effect on the QoL of the individual due to the physical activity limitations immediately after amputation as well as has longer-term implications in varied facets of life.<sup>3</sup> It also affects the individuals at psycho-social level, and can have long-term economic implications on the life and opportunities for employment.<sup>3</sup> Outcomes and long term functioning after amputation can also have an influence on the individual's contribution to the society. A significant positive relationship has been observed between higher QoL after amputation and better physical functioning.<sup>4</sup> Also, better social and psychological functioning are related with better QoL.<sup>4</sup> Social support, effective rehabilitation and appropriate prosthetic treatment can help the amputees in coping and overcoming the triple insult, and improving their QoL.<sup>2</sup>

## LOWER LIMB AMPUTATION

This study is aimed at the lower limb amputee population. As compared to the upper limb amputees, the lower limb amputees experience more changes in their life after the amputation.<sup>5</sup> Incidence of lower limb amputation is also greater than the upper limb.<sup>6</sup> A worldwide overview regarding the prevalence of lower limb amputation does not exist. The annual incidence of major lower limb amputation per 100,000 inhabitants is 18-20 in the Netherlands<sup>7</sup> and 6.6 in France<sup>8</sup> respectively. Regarding prevalence in the United States of America, 500 per 100,000 people had had an

amputation,<sup>9</sup> and it is estimated that 1.7 million people in the United States of America are living with a limb loss.<sup>6</sup>

There is an association between age and cause of amputation as a result of its higher morbidity in the older age population. In the population up to 60 years, trauma and cancer are the major causes of amputation.<sup>10, 11</sup> In the Western world, peripheral vascular disease with or without diabetes accounted for 80-90% of all amputations,<sup>7, 12-19</sup> and the mean age of amputation for this population was 70 years.<sup>14, 18, 20</sup> Similarly, in the United States, vascular problems accounted for 82% of all amputations.<sup>19</sup> Traumatic accident rates have either been constant or declining in these countries.<sup>10, 12, 13</sup> On the other hand, in developing countries, trauma is the main cause of amputation,<sup>10</sup> and males are more prone to traumatic accidents than females.<sup>17</sup> In countries where landmines exist, they also lead to a further incidence of lower limb amputation.<sup>21-24</sup>

Challenges for old age patients who need to be amputated would be mainly towards adjustment in activities of daily living, personal care, recreation and social participation, as with age individuals settle in their personal as well as professional lives. However, rehabilitation for them could be challenging and might take more time, because of age, increased number of comorbidities and related to the cause of amputation. On the other hand, young people would also have issues of employment, civil relationship and financial issues in their life, particularly if social security or other means of financial security is not available from the state, or available financial help is insignificant to be able to lead a normal life. They would also be a burden to the family, or societies where the youngsters are supposed to take care of the elderly. Younger age, non-white race, poor sense of self-efficacy, poor physical functioning, poverty and limited social support has been found to be associated with psychological disorder in severely injured lower limb patients.<sup>25</sup> It would also be a loss for the state, as young people constitute a productive workforce, and potential contributors to the economy.

## **LOWER LIMB AMPUTATION IN INDIA**

There is meager data regarding the overall incidence and etiological background of lower limb amputation in India. According to World Health Organization, India has the highest number of road accidents in the world with 16.8 fatal injuries per 100,000 population, and 38.9 non-fatal injuries per 100,000 population as per the data from 2006.<sup>26</sup> From these figures, it can be postulated that traumatic road accidents would be

a significant cause of lower limb amputation. A cross-sectional study reported vehicle accidents as the major cause of amputation.<sup>27</sup> Apart from road accidents, train accidents especially due to over-crowding, and other traumatic injuries due to infrastructural challenges posed by increasingly growing population and rapidly expanding economy would be contributing towards this. An optimum access to healthcare within the stipulated time that the injured limb could be saved from infection is crucial. However, delays due to civil formalities in case of accidents and the quality of treatment being received by the individual may determine the outcomes after amputation.

Following traumatic accidents, diabetes mellitus is the second major cause of lower limb amputation in India. As a matter of fact, India is the diabetic capital of the world, and by 2030; India will have the highest number of diabetic people in the world (WHO). As per the estimates of the World Diabetes Foundation, about 40,000 lower limb amputations are performed each year in India due to diabetic complications.<sup>28</sup> Studies conducted by Viswanathan et al.<sup>29, 30</sup> about diabetic foot complications in India projected that almost 90% of the people had diabetic foot infection, 30% of which underwent a major amputation, and 70% a minor amputation. It has also been reported that primarily socio-cultural practices are a cause of diabetic foot infection in India.<sup>31</sup> Also, vascular problems are on rise due to ageing population. Related to all these, socio-economic inequities, a considerably high illiteracy rate which may influence the lifestyle, and inaccessibility to optimum healthcare by all would further be contributing to the problem.

Only a very few studies have been done recently in amputees about diabetic foot ulcers leading to amputation<sup>32</sup> and about depression and psychiatric issues in the amputee population.<sup>33</sup> Malik et al.<sup>34</sup> found QoL to be poor in traumatically handicapped patients, and found it to be worse when they had psychiatric morbidity. Narang et al.<sup>10</sup> studied functional capabilities in lower limb amputees, and found age to be negatively influencing functional independence, and below-knee amputees to be functionally more independent than the above-knee and bilateral amputees. Paul et al.<sup>35</sup> studied a small sample (n=25) of bilateral amputees and found the activities of daily living scores of prosthetic users to be significantly higher than the non-users, and less than half of the amputees (n=11) to be prosthetic ambulators at a mean of 6.6 years follow-up, out of which half were trans-femoral amputees. The study population comprised 12 trans-femoral amputees. From these perspectives, it is imperative to understand amputees' adjustments to amputation and prosthesis, and satisfaction with prosthesis, as it could have an effect on the use of prosthesis and thereby their QoL.

## THE IMPORTANCE OF QUALITY OF LIFE

Quality of life has been advocated as an outcome measure for assessing the effect of treatment and quality of care. QoL is described as a multidimensional concept<sup>36-38</sup>, and as an emotional and cognitive judgment about the persons' well being, life satisfaction, and happiness and as such may be best assessed by the person himself.<sup>39</sup> Therefore, a multitude of facets need to be taken into consideration to comprehensively assess QoL. Assessing QoL in its entirety is challenging because of its multifaceted nature. At the same time, the instrument being used to assess QoL should not be too long which will make its administration time-consuming, and at the same time, it should not be too short, so that it does not adequately capture the essence of QoL. Also, the meaning of QoL and what it implies might vary for different individuals. Nevertheless, QoL instruments have been developed and they encompass the domains that have been demonstrated to be important for the majority of the population. Due to this, QoL assessment is a useful means to measure the health and well-being in a population.

Most QoL instruments were developed encompassing domains, such as physical, psychological, mental, social, etc., and have come to be known as general QoL instruments, such as SF-36,<sup>40</sup> WHOQOL,<sup>41</sup> Nottingham Health Profile (NHP),<sup>42</sup> SF-12,<sup>43</sup> WHOQOL-BREF,<sup>44</sup> among others. A visual analog scale is also being used to measure QoL.<sup>45</sup> These scales have been extensively used for research purpose, particularly the WHOQOL and SF-36. SF-36 and WHOQOL were further translated and validated in different languages, which further propagated their use for research purpose and population surveys.

It is important to comprehensively assess the factors which play a role in influencing QoL in a certain population. Diverse socio-economic and socio-cultural factors, personality characteristics and medical factors (like comorbidity or complications) may play a role in influencing QoL as is implicit from the International Classification of Functioning, Disability and Health framework of WHO.<sup>46</sup> Adjustments to the amputation and prosthesis; physically and psychologically, are reported to be associated with QoL in people with amputation.<sup>47</sup>

The study population has been derived from India. However, the study results would be applicable to amputees worldwide, except those pertaining to socio-economic factors, as it may differ country-wise. Therefore, on one hand the study results would be broadly applicable to the amputee population, and on the other hand, the

contextually relevant study results would be applicable specifically to Indian amputees and other countries with similar contextual situation.

## RESEARCH QUESTIONS

The objectives of this study are threefold, i.e. to assess 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 socio-demographic and amputation related factors.

The research questions that will be answered in this thesis are:

1. What is known in scientific literature about the QoL of people with lower limb amputation?
2. Is the health-related QoL instrument (adapted and translated in Hindi for this study) reliable and valid to be used in India?
3. Which background (socio-demographic and medical) and amputation-related factors are related to the adjustments to amputation and prosthesis?
4. Which factors (socio-demographic, medical, amputation-related and psycho-social adjustment to amputation and functioning with prosthesis) are important in predicting QoL in lower limb amputees?

## OUTLINE OF THE THESIS

The introduction chapter provides a general background about the study population and prevalence of amputation. Lastly, the research questions are posed.

The above-mentioned research questions will be answered in five consecutive chapters. Chapter 2 will aim to answer the first research question about the available scientific information about the QoL of people with lower limb amputation by conducting a systematic literature review (SLR). The SLR results will be discussed and overview of the results presented.

Chapter 3 will cater to answering the second research question by investigating the validity and reliability of adapted and translated MOS 36-Item Short Form Health Survey (SF-36)<sup>40</sup> in Hindi for use in India. Psychometric analyses will be performed and results investigated with the prescribed measures of reliability and validity. Deviations (if any) will be discussed, and considered for use in India.



Chapter 4 will be focused towards studying the psycho-social adjustments to amputation and prosthesis, and the use and satisfaction with the prosthesis using a translated version of Trinity amputation and prosthesis experience scales (TAPES)<sup>48</sup> in Hindi. Also, the relationship between the different background, medical and amputation-related variables, and the adjustments to amputation and prosthesis will be studied, thereby, answering the third research question.

The last research question will be answered in two steps. Firstly, by studying the QoL in amputees, and the role of different background (socio-demographic and medical) and amputation-related factors in determining their QoL. The QoL in amputees will also be compared to the QoL in the Indian general population. This will be presented in Chapter 5. Secondly, in Chapter 6, the influence of different background, amputation-related factors, and the role of psycho-social adjustments to amputation and prosthesis and functioning with prosthesis on QoL of amputees will be studied.

In Chapter 7, the main findings of the study will be presented. These findings will be discussed in relationship with outcomes of other studies, and the weaknesses and strengths of this study with respect to study design, sample, instruments, etc. will be presented. Finally, recommendations for future research and implications in clinical practice will be provided.

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