

# The Impact of Living With Severe Lower Extremity Lymphedema

## A Utility Outcomes Score Assessment

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**Background:** Debilitating lower extremity lymphedema can be either congenital or acquired. Utility scores are an objective measure used in medicine to quantify degrees of impact on an individual's life. Using standardized utility outcome measures, we aimed to quantify the health state of living with severe unilateral lower extremity lymphedema.

**Methods:** A utility outcomes assessment using visual analog scale, time trade-off, and standard gamble was used for lower extremity lymphedema, monocular blindness, and binocular blindness from a sample of the general population and medical students. Average utility scores were compared using a paired *t* test. Linear regression was performed using age, race, and education as independent predictors.

**Results:** A total of 144 prospective participants were included. All measures [visual analog scale, time trade-off, and standard gamble; expressed as mean (SD)] for unilateral lower extremity lymphedema ( $0.50 \pm 0.18$ ,  $0.76 \pm 0.22$ , and  $0.76 \pm 0.21$ , respectively) were significantly different ( $P < 0.001$ ) from the corresponding scores for monocular blindness ( $0.64 \pm 0.18$ ,  $0.84 \pm 0.16$ , and  $0.83 \pm 0.17$ , respectively) and binocular blindness ( $0.35 \pm 0.17$ ,  $0.61 \pm 0.28$ , and  $0.62 \pm 0.26$ , respectively).

**Conclusions:** We found that a sample of the general population and medical students, if faced with severe lymphedema, is willing to theoretically trade 8.64 life-years and undergo a procedure with a 24% risk of mortality to restore limb appearance and function to normal. These findings provide a frame of reference regarding the meaning of a diagnosis of severe lower extremity lymphedema to a patient and will allow objective comparison with other health states.

**Key Words:** lymphedema, lower extremity, utility outcomes

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Utility outcome scores are established standardized objective measures that are derived from the value attributed by individuals to a specific health state and have been described in fields of various medical specialties as well as plastic surgery (eg, severe breast hypertrophy, face transplantation, and aging neck).<sup>1–25</sup> Utility scores allow having a comparable quantitative value for health economic decision analysis on behalf of individual health states when deciding on how to assign health resources for research and treatment.<sup>8,9,23</sup>

Previous studies have investigated and identified many of these measures which can be helpful in comparison of many of these

health states such as end-stage renal disease requiring hemodialysis, renal transplant,<sup>10</sup> human immunodeficiency virus stage II,<sup>13</sup> diabetes mellitus type I,<sup>12</sup> erectile dysfunction,<sup>14</sup> severe breast hypertrophy,<sup>21</sup> and obstructive sleep apnea syndrome.<sup>18</sup> These scores [range, 0 (death) to 1 (perfect health)] are a standardized tool which help objectify health states and diseases. Utility outcome measures allow a comparable quantitative value for individual health states that can be used in health economic decision analysis.<sup>7</sup> The use of more than one utility outcome tool minimizes weaknesses of any individual tool: standard gamble (SG),<sup>5</sup> time trade-off (TTO),<sup>7</sup> and visual analog scale (VAS).<sup>6</sup> Utility outcomes can be measured from a sample of the general population based on a case presentation of the health state in question.<sup>21,24</sup> In this study, we use utility outcome scores to objectify the health burden of living with a significantly enlarged lower extremity caused by lymphedema.

Lymphedema is a potentially debilitating condition associated with abnormal accumulation of lymphatic fluid in the interstitial space. This condition can be either congenital (primary lymphedema) or acquired (secondary).<sup>26</sup> Primary lymphedema includes Milroy disease, lymphedema praecox, and lymphedema tarda. Acquired lymphedema is most commonly seen in the upper extremities of breast cancer patients particularly after radical mastectomy with adjuvant radiation of the axilla or in patients after axillary lymph node dissection.<sup>25</sup> The current trend of sentinel lymph node dissection as an integrated part of the treatment of breast cancer may reduce the occurrence of symptomatic lymphedema.

Lymphedema, if left untreated, may lead to severe swelling of the extremity that is associated with fibrosis of the subcutaneous tissues as well as recurrent episodes of infection. Initial treatment is usually conservative. When these measures fail, surgical management may be considered.

Multiple surgical procedures have been proposed.<sup>27–29</sup> Physiologic procedures such as lymphatic anastomoses aim to restore lymph flow, whereas excisional procedures aim at resecting the diseased tissue.<sup>29</sup> These procedures can be associated with significant cost and associated morbidities.<sup>30</sup> There is still debate regarding whether the long-term benefit of surgical treatment of lymphedema outweighs the perioperative and postoperative costs and risks. Questions such as these are difficult to answer without an objective measure of living with such health states.

Our study's primary objective was to identify and compare the health state utility assessment of living with unilateral lower extremity lymphedema to monocular and binocular blindness using 3 separate tools for measurement of utility outcome scores (SG, TTO, and VAS) in a sample of the general population and medical students. We also aimed to determine whether the utility outcome assessments of living with lower extremity lymphedema varied with age, race and education.

## METHODS

The McGill University Research Ethics Board in accordance with the Declaration of Helsinki ethical guidelines for human subject research approved this study. All volunteers signed an electronic

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