

## WHAT IS THE VALUE OF A LIMB?

### Introduction

“I’d rather die than amputate my leg” was what Mdm Tay said when facing the news of a malignant sarcoma at her knee. The mantra “life before limb” has been deeply ingrained into orthopaedic practice, yet many of us have encountered patients who defy this mantra and prioritise their limb over life. The existence of this divergence has prompted me to ask myself, “what is the value of a limb?”

In pursuit of trying to understand the value of a limb, I have found our core orthopaedic textbooks rather insufficient and a philosophical discourse rather theoretical. Instead, the reflections and writings of amputee survivors have been particularly insightful. I would like to explore the value of the limb by presenting four aspects of an amputee’s journey: The decision making process, the changes in personal identity and normality, the changes in social identity and the experience of the process.

### The decision making process

*“You just get on with it, it’s all you can do. It’s either that or you just crawl into a hole somewhere and make your life miserable - it’s not worth it. I am positive; I do whatever I can, just live independently.”<sup>1</sup>*

*“If you’d had said to me before the accident, you’ll lose a leg, I’d think I would have said I’d rather be dead. Prior to it happening, it sounded like such a horrendous prospect & would never have thought I would have coped at all. but I think people are just pretty good at coping with whatever is put in front of them, You don’t really have a lot of options. I now see having a prosthesis as inconvenience.”<sup>1</sup>*

*“I want to live, but provided that it does not cause trouble to my family. If I cause trouble, I prefer to leave. I don’t want to leave (die).”<sup>2</sup>*

Experiencing an amputation implies an experience marked by bio-psycho-social and cultural change, loaded with stigma. The experience consists of feelings that are mixed and permeated by reason on one hand, which visualises surgery as necessary, and emotion on the other, which does not accept the loss of a limb or life after loss.<sup>2</sup> Opposite but mutually united feeling and sensations coexist in one and the same scenario.

*Shock leaves “the individual emotionally and intellectually numb and is manifested by disruption of organized thinking. The individual has no plan of action and is essentially without psychological resources. The reality of the situation is too much to handle, resulting in overall helplessness.”<sup>3</sup>*

This state of shock often affects a patients decision making process. They may be subjected to a flood of information in a short time amidst a wide range of confusing emotions. Thus, it is imperative that the decision to amputate must be presented to the patient in the most simplistic manner possible . It is important that we intermittently reinforces that we are making every possible effort to avoid amputation surgery, but if it is unavoidable , that we reassure the patient's postoperative level of function. A wavering surgeon would be unacceptable. Delay in amputation may sometimes be necessary but also often fosters depression, suicidal urges, and universally a fear of death.

Perhaps the decision making process is easier in patients who are in pain or find the limb a “damn nuisance”. Patients may perceive amputation as a source of hope to return to the world. Pain is discouraging, unbearable, sad and limiting, and any attempt to relief pain is considered positive.<sup>2</sup>

*“...not sleeping for six months is hard....it hurt when I lay down, when I stood up, its hard, its sad, I suffered so much, so much, so much. Now, if I had to do it again, I’d do it again, because all the suffering ends...”<sup>2</sup>*

*"I haven't been able to walk properly for two years now because of pain. In the end I didn't have a life. I was in constant pain and finally I was afraid of going to bed because I would wake up in a few minutes in a lot of pain. It was a nightmare in the end... something had to be done."*<sup>4</sup>

The surgical experience shows its possibilities to the patient, as it makes possible, a different existence. Patients can see the perspective of an incomplete existence, as a body part loss, or simply from the perspective of standing open to new experiences, free (hopefully) from pain and from the deformed part.

### **Changes in Personal Identity and normality**

The value of the limb is not only in the physical presence of a body part but more importantly in the functions we can perform because of it. As Merleau-Ponty has mentioned "The body is the vehicle of being in the world. Thus we do not *have* a body, we *Are* our body and consequently, the body connects us to the world.<sup>1</sup> Through the body, the surrounding world becomes meaningful". An amputee often faces the realisation that he is no longer has the ability to engage the world in a habitual way and is in conflict of "wanting and not being able to".<sup>1</sup> An infinite range of feelings is involved in the change process of the body.

*"I felt very angry ...I stopped making love to my wife ...I became more isolated from my colleagues and friends, and more dependent on my family ...I was feeling very sad depressed ... it was a shock to me!"*<sup>5</sup>

*"You would expect it in your own mind that you without the leg, you are not a whole human being, that's the way I look at it."*<sup>1</sup>

*"I was a complete sun worshiper and I would walk for miles for the perfect beach... I was in heaven, miles and miles of beautiful beaches and I used to walk, park the car, walk across fields and tracks to get there and it was just great but that's all gone, I'm not that person anymore."*<sup>1</sup>

*"It is my goal to get back to work again... It may not be realistic, but you need a goal... if you don't have goals, you might as well give up"*<sup>4</sup>

Individuals who have lost a limb face the unavoidable renegotiation of personal identity. Regardless of the specific concerns of an individual, the unifying theme is that of maintaining or renewing a personal and unique normality: Get me back to "me". Normality is a personal thing.

*"When I tuck in my small son, that's upstairs, and he wants a glass of water... I can't fetch it for him. I can't walk on crutches with a glass of water in my hand."*<sup>4</sup>

*"I can easily watch the tv and read and move about the house... but you are confined to these four walls."*<sup>4</sup>

The central theme of normality is not concerned with conforming to a uniform or comparable version of other people but to regain or maintain a sense of individual normality. For some this may prioritise function over aesthetic appearance, put greater emphasis on a particular ability, allow for adjustment or compromise in one area over another.

*"I used to run around in 3 and a half inch heels, never ever did I wear flat shoes and so the only cause of my grief was losing my lovely shoes."*<sup>1</sup>

### **Changes in Social Identity**

The value of a limb extends to its impact on a person's social identity which is defined as how individuals see themselves within a social setting and the way in which others may react to them. The

way an individual feels they “fit” in a social context is of key importance within the experience of limb loss.

*“You don’t want to stand out from the crowd – nobody does I don’t think.”<sup>1</sup>*

*“It bothers you, you know. Perhaps the person helps you now, then you call him again. Perhaps he comes to you with the same good will as the first time, but you don’t think like that in your head. I think like, I’m causing too much trouble... it gets difficult... but what can you do?” (silence)<sup>2</sup>*

Losing control seems to be a recurrent theme in losing a limb. From the diagnosis and decision making process, to the loss of control over personal identity and function, to the loss of control in a social setting. Helplessness, dependence and being a burden are genuine concerns in the setting a living without a limb.

*“I was buying some toothpaste which was placed fairly high up, so I got up (from my wheelchair) and people started staring... I could sense people thinking... “Gosh... can a handicap person really do more than just sit in a wheelchair?””<sup>2</sup>*

*“I could get a disabled space outside but I don’t want to just because it’s like... I don’t want attention drawn to the fact.”<sup>1</sup>*

Intentionally avoiding the use of an entitled disabled parking space illustrates the longing for social integration and the priority this takes over convenience for this amputee.

One way for amputees to regain some normality and social integration is through the use of a prosthesis. Whilst Orthopaedic training has always emphasized the importance of the prosthesis to aid ambulatory function, perhaps the importance of the aesthetic function of a prosthesis should not be overlooked.

*“I think most of the time people have more of a worry about it than their family would. I remember one guy saying to me : I don’t want this (missing leg) to spoil my daughter’s wedding photos and I kind of thought: Your daughter will be quite delighted that you’re there , never mind the fact that you had to use your wheelchair because you got tired.”<sup>1</sup>*

The prosthesis here fulfils the purpose of allowing him to continue to present a non-amputated appearance. The sense of achievement at being able to hide his amputation gives an insight into the level of importance aesthetics holds. The success of the prosthesis seems to be determined on its ability to allow the individual to continue to integrate as a fully functional individual in society with little or no differentiation from able-bodied persons and not only an ambulatory function.

## **The experience of the process**

*“I would appreciate just to feel that someone was caring for me - was actually leading looking after me.”<sup>1</sup>*

One aspect of care that is often lacking is the perceived lack of a holistic experience. Patients identified the need to feel fully cared for in a continuous manner rather than each specialty dealing with only “parts” of the patient as dictated by their particular profession.

*“A lot of time has passed and I’ve been in this sort of purgatory, the land of no-where. I’m not blaming anyone but there is no holistic overview, that’s what I’m getting at. I seemed to have been.....yes, the cardiovascular people, yes they do a great job. You are passed, somebody else does not such a great job - you’re passed - you go on, you’re passed to someone else. The cardiovascular people are specialists, they are not diabetic specialists. The orthotics people are specialist but they are not diabetic specialists.”<sup>1</sup>*

A multi-disciplinary team has been shown to improve the quality of care by including the perspectives of different professionals into the service to provide holistic care. However, without adequate leadership and coordination, fragmented care ensues.

*“With regard to improving the service I receive, I wish they were more able to think outside the box and offer me solutions to problems rather than me having to lead.”<sup>1</sup>*

I am guilty for contributing to this problem of care fragmentation. Thinking back on all the amputations I have done in orthopaedic residency training, there are very few patients where I have counselled for amputation, journeyed with them through the amputation process and followed-up through the prosthesis fitting and rehabilitation back to their community.

### **Cost of a limb**

An alternative perspective of the value of a limb would be the monetary value. The Ministry of Health estimates that four amputation procedures are carried out daily in Singapore. The mean cost of an amputation including inpatient hospital stay is \$5000. Prosthetic limbs cost between \$1,300 for a basic below-knee prosthesis to more than \$50,000 for a high-end bionic leg, which has artificial intelligence to detect movements of the leg. With regards to monetary compensation for a limb loss in Singapore, the percentage impairment from the loss of a lower limb ranges from 65-75%. The monetary compensation however is varied depending on the age and salary of the patient.

### **Limitations**

A large determinant of the value of a limb also hinges on cultural and religious beliefs. However, the discussion of various religious beliefs are beyond the scope of my reflection.

### **Conclusion**

The concerns of any patient facing the thoughts and consequences of an amputation are highly varied. The value an individual places on a limb are heavily influenced by their bio-psycho-social circumstances and are certainly not universal. Whilst Orthopaedic principles of relieving pain and restoring function (and saving lives in certain situations) still hold true in the setting of an amputation and are universal, perhaps we should also consider a patient’s well-being on an existential level i.e. what does this mean to the individual in such terms as freedom and vulnerability in order to understand the challenges and consequences our patients face.

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