Amputation in the case of cancer: a case study

Narelle Warren, Lenore Manderson & Peter Disler Monash University

Most clinical and research literature investigating decision-making about amputation following a cancer diagnosis has been concerned with doctors' perspectives. In particular, clinical information addresses when amputation should occur – that is, for what types of tumours and how, and at what level (e.g. above knee, below elbow). Amputation following bone sarcoma or soft tissue sarcoma is often performed in instances where, for various reasons, limb salvage or reconstruction is either not performed or has been performed unsuccessfully (Wafa and Grimer 2006). Ghert and colleagues (2005), for example, found that medical specialists consider the location and extent of the tumour when deciding whether to perform an amputation, although they also take into account the physical functioning of the affected limb post-surgery. International research (Zahlten-Hinguranage et al. 2003) has shown that people's quality of life and subjective wellbeing is similar regardless of the type of treatment (limb salvage or amputation) and thus the clinical decision-making is based on oncological factors (i.e., associated with the cancer itself).

There is little information, however, in research or clinical guidelines, about what the person diagnosed with cancer takes into consideration or how they feel during decision-making concerning amputation. In this short article, we offer a case study of decision-making for a man we call Charles (not his real name). Although osteosarcoma is most common in younger people (Tebbi and Gaeta 1988), Charles was diagnosed when he was 75 years old. His decision-making therefore was based on factors different from those that might be considered by younger people. Charles participated in an in-depth interview with us at the end of his inpatient rehabilitation, as part of our larger study (described in previous issues of Amplified) exploring the social aspects of amputation.

Charles experienced unexpected, sudden and long-lasting pain, after which his symptoms progressed rapidly. As a result, he had to decide quickly whether or not to undergo amputation. Overall, eight weeks elapsed between the onset of symptoms and his amputation. In the following quote, he described the choice that he was given:

[My doctor] didn't really tell me I had to have the amputation. He gave me a choice. They do leave it to you because you have to agree. He gave me three alternatives. He said, "You can get up and walk out of here… [or] I can try to remove the tumour and leave a big hole in your leg. But then you will still have a leg and I can't guarantee I will get all the tumour. Or you can have an amputation, which would probably get it all". The first one was eliminated because I wasn't going to get up and walk out [because] the thing would take over and kill me in a comparatively short time because of the aggressive nature. The second alternative [was] to have it operated on and removed. It was rather large, eight inches by two inches wide, but he couldn't

guarantee success. So… he recommended [that] I go away think about it and come back in a couple of days. So I decided that I had to have [the amputation]… I guess in my own heart, I knew that radical treatment had to be performed. I accepted it. I didn't like to accept it but I had to accept the fact that this was going to happen. There was no trying to hide away from [the decision to have an amputation]. It was going to happen. It was a bit of a shock, I suppose, but I had to make my mind up quickly. So, yeah, I accepted that things were going to be a little bit life changing.

As he explained, Charles made his decision in a similar way to his medical professionals and, in doing so, was concerned with what type of treatment (i.e., what procedure) offered the highest chance of success. He conceptualised success around three factors: which procedure would remove the entire tumour, which procedure would cause the least trauma to his body and which procedure would maximise his chances of recovery. Given the size of the tumour, amputation offered the best opportunity for success of these three factors. Indeed, he believed that amputation offered the *only* way to adequately treat his cancer.

Ideas about success were not the only considerations Charles made, however. Family support was important, and he discussed his treatment options with his wife and children. Pain relief was also important:

[Over] the eight weeks. I was getting sorer. Before the operation, the pain level was acute, and I mean acute. There was no sleep; there was no relief. The only slight relief I got [was when] I went back to the surgeon and said the pain is absolutely driving me mad. He could see I was in a lot of pain and he gave me a medication. I think it was a mild dose of morphine, which sort of subdued it a little bit and then I had the operation.

Although cancer treatment often involves chemotherapy, this was not the case for Charles. He chose not to have chemo because he was extremely worried about the side effects. His concerns about these were partly involved in his choice to have an amputation rather than limb salvage surgery.

During his interview, Charles described how he based his decision on cancer-related factors (getting the tumour and reducing pain), centred on what would cause the least disruption to his lifestyle. In this way, his decisions resembled those of the medical professionals and were pragmatic in nature.

This provides a brief snapshot of his story, however his pragmatism was an important finding. Our other data indicates that people who have an amputation for other reasons emphasise how social factors play an important role in their decision-making. For example, the decision to have an amputation is often made after ongoing consultation with family members or, when the amputation occurs due to a medical crisis, is made by the family members. This may relate to the perceived options available. Where multiple treatments are seen to be available, considerable negotiation occurs within the family and wider social network. However, this was not

the case for people such as Charles. At the same time, social support and participation were important to all recent amputees, regardless of the reason for their amputation. This suggests that information pre-amputation and social support post-amputation need to take different underlying health conditions and reasons for amputation into account.

References:

Ghert MA, Abudu A, Driver N, Davis AM, Griffin AM et al. (2005). The indications for and the prognostic significance of amputation as the primary surgical procedure for localized soft tissue sarcoma of the extremity. *Annals of Surgical Oncology, 12(1)*: 10-17.

Tebbi CK & Gaeta J (1988). Osteosarcoma. *Pediatric Annals, 17(4)*: 285-300.

Wafa H & Grimer RJ (2006). Surgical options and outcomes in bone sarcoma. *Expert Review in Anticancer Therapies, 6(2)*: 239-248

Zahlten-Hinguranage A, Bernd L & Sabo D (2003). Amputation or limb salvage? Assessing quality of life after tumor operations of the lower extremity. *Orthopade, 32(11)*: 1020-1027.

limbs4life

1300 782 231