Amputation and Non-Functioning Limb Salvage: Cultural Stigma of Limb Loss

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Amputation is usually the last resort for treatment of non-salvageable limbs due to various indications such as trauma, infection and malignancy. However, some patients still refuse surgery and reconstruction. Instead, they insist on keeping their limbs despite knowing the negative consequences including a limited or non-functioning limb.

We present three cases who refused amputations: The first was a nine-year-old boy involved in a motor vehicle accident (MVA), with a left femoral midshaft open grade IIIb fracture; the mangled extremity severity score (MESS) was five. The second was a 16-year-old girl sustained a left leg crush injury, a fractured left fibula and an injury to the anterior tibial artery following an MVA; her MESS was 12. The third was a 60-year-old left-handed tractor driver presented with a five-year history of a slowly enlarging fungating growth over the dorsum of his left hand; biopsy confirmed basal cell carcinoma (BCC).

We explore the cultural and religious reasons behind this stigma of amputation in a multiethnic community. It will help clinicians to manage these challenging situations according to the principles of medical ethics.

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Amputation has a significant impact on patients' life, economy and family. Post-amputation rehabilitation and prosthesis have allowed amputees to return to the community. However, the negative perception remains. It is considered a taboo in some tradition or religion, resulting in patients declining surgery[1]. This poses a clinical and ethical dilemma to surgeons.

The aim of this report is to highlight the perceived stigma and cultural features of limb amputation in South-East Asia, where we discuss the rationale behind why some patients would rather live with a non-functioning limb than a functioning prosthesis.

THE CASES

Case 1

A nine-year-old boy involved in a motor vehicle accident (MVA), sustained a circumferential degloving injury over his left thigh with a left femoral midshaft open grade IIIb fracture, see figure 1 (A to C). Angiogram revealed no deep vascular injury. His mangled extremity severity score (MESS) was five. A high above knee amputation (AKA) was advised, but his father refused for fear of having a "disabled child". Surgical debridement was done followed by femoral plating. He was referred to our center for further management of the soft tissue injury.

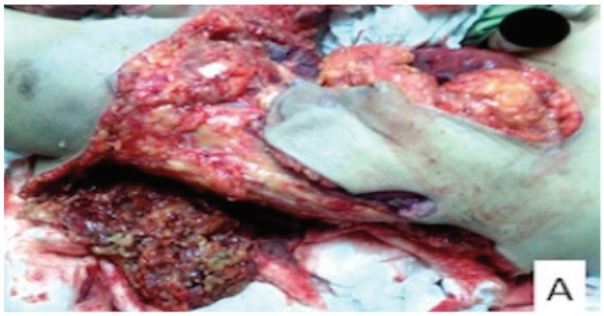

Figure 1 (A): Initial Injury

Figure 1 (B): During Wound Bed Preparation (WBP)

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Figure 1 (C): Post Superficial Split-Skin Graft (SSG)

Case 2

A 16-year-old girl sustained a left leg crush injury, a fractured left fibula and an injury to the anterior tibial artery following an MVA, see figure 2 (A to C). Her MESS was 12. Initial treatment included a fasciotomy and resection of the fractured fibula. She was advised high above knee amputation (AKA) as there was a high risk of osteomyelitis. Her father refused, claiming "No one will marry her if she became an amputee".

Figure 2 (A): Initial Injury

Figure 2 (B): During Wound Bed Preparation (WBP)

Figure 2 (C): Post Superficial Split-Skin Graft (SSG)

Case 3

A 60-year-old left-handed tractor driver presented with a five-year history of a slowly enlarging fungating growth over the dorsum of his left hand, see figure 3 (A to C). He was reluctant to seek medical advice except after his family's insistence. MRI revealed a tumor invading adjacent tendons and muscles. Biopsy confirmed basal cell carcinoma (BCC). The patient was advised a wide local excision with possible forearm amputation. He pleaded to keep his hand because having 'a fake hand' was considered 'shameful'. A wide local excision and decortication of third to fifth metacarpals were performed.

Figure 3 (A): Preoperative Image

Figure 3 (B): During Wound Bed Preparation (WBP)

Figure 3 (C): Post Superficial Split-Skin Graft (SSG)

All patients had superficial split-skin graft (SSG) for wound coverage after cycles of negative pressure wound therapy (NPWT) and adequate WBP (Figure 1B, 1C, 2B, 2C, 3B, 3C).

During follow-up, the affected feet in both children were fixed in semi-plantar-flexion. They were unable to weight-bear on the limbs and required walking aids. The elderly man's palmar grip and pincer grasp were weak; he had difficulty with basic daily activities such as holding objects and dressing up. Nonetheless, all three were content with the outcome of the surgery especially being able to keep their limbs despite its lack of function.

DISCUSSION

Trauma and malignancy are common indications for limb amputation. In these cases, one patient and the fathers of the two children below the age of consent were adamant to preserve the limbs. In trauma, MESS of seven or more can be used as the threshold for amputation[2]. However, for case one, though the MESS score was five, in view of severe circumferential open degloving injury, the surgeons advocated amputation to prevent infection, achieve optimal recovery and early return of function.

The reason for refusing amputation is multifactorial. Apart from the fear of rejection by the public, superstitious beliefs also plays a role. History, culture, and religion form an integral part of this belief. In the eastern world, amongst the Chinese, amputation is considered taboo. The Hmong people believe that amputation may affect reincarnation and life in the afterworld[3]. Under the name of Islam, the Taliban regime in Pakistan prohibits medical amputation[1]. In the west, many Native American tribes believe in keeping complete body parts while for some African-American, amputation implies losing control over their bodies, akin to the African slaves in history[4,5].

The psychological impact of amputation could be detrimental. If planned, patients may experience phases of grief, which may result in depression or anxiety before acceptance[6]. However, during an emergency, patients usually do not have time to digest all the information. Post-traumatic stress disorder (PTSD) and major depressive disorders (MDD) are common, especially if amputation performed at young age[7]. In some patients, 'mutilation anxiety' can affect sexual function. Men feel 'castrated' and women haunted by sexual guilt for misconducts that could be real or imaginary[6]. That requires psychiatric assessment and treatment besides psychosocial support from the family.

The role of surgeons in such situations is not to be autocratic. The evolution of a doctor-patient relationship from paternalism to enhanced autonomy implies that patients' wish should be respected[8]. The indication for amputation may be evidence-based from the surgeon's perspective, but if the patients refuse, the concepts of 'beneficence' and 'non-maleficence' should be adhered to. Doctors should always act in the patient's best interest and not cause any harm, as there are many non-measurable factors that can affect patient's satisfaction[9].

Patients with a sound mind should be allowed to decide what happens to their bodies. The fathers in the cases above decided the fate of their children. If the children did not agree, 'Gillick competence' allows a child especially between age 14 to 16 to give consent provided that they are deemed emotionally and intellectually matured by medical professionals[9].

Clinicians should not overlook the cost-effectiveness of such treatment. The children had prolonged hospital stay, three and six months respectively; they required multiple wound debridement and surgery, and long-term antibiotics for osteomyelitis. A psychiatrist was consulted to help them cope with depression. In addition, their education was also halted. The boy took two years before he could ambulate and was out of school during that period. Similarly, the girl had not returned to school four months after discharge. These aspects should be addressed delicately through discussion with patients.

CONCLUSION

Limb amputation has significant social, psychological and spiritual impact on patients apart from the clinical impact. Decision of treatment is a dynamic process between doctors and patients. Whilst evidence-based medicine is the foundation of our practice, it may contradict patients' values. Hence, doctors should be aware of local sensitivities; facilitate decision-making by providing adequate information and manage patients based on sound medical ethics.

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