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Research paper

# THE LIVED EXPERIENCE OF PERSONS WITH AN AMPUTATION

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**Abstract.** This paper presents an exploratory study of Maltese persons living with an amputation. Semi-structured interviews were conducted with four participants. Three of the participants had a lower limb amputation, while the fourth had an upper limb amputation. Interpretative phenomenological analysis (IPA) was used in the analysis phase. The three core superordinate themes that emerged from the data revolved around the emotional reactions towards the amputation, the numerous changes it brought to the participants' lives, and the support which enabled amputees to cope with their situation. The study highlights the range of emotions experienced by the participants on having an amputation and the changes in their lifestyle. Support from family, friends, health professionals and other amputees was identified as a factor that helped participants cope and adapt to their new condition.

**Keywords:** amputation, lived experience, prosthesis, social support, qualitative research, interpretative phenomenological analysis

## 1 Introduction

Limb amputation is considered to be one of the oldest surgical procedures with a history of more than 2,500 years (Van der Meij, 1995). It is defined as a medical procedure in which there is "partial or complete removal of a limb for a variety of reasons, including tumours, gangrene, intractable pain, crushing injury or uncontrollable infection" (Fremgen & Frucht, 2009, p.10). Amputation is usually considered as a last resort in the case of life endangerment (Paudel, Shrestha & Banskota, 2005), since it brings about drastic social, economical and psychological changes to both the amputees' and their families' lives (Sinha, van den Heuvel & Arokiasamy, 2011). Local statistics indicate that there were approximately 88 Maltese patients who had undergone one or multiple major amputations over a one-year time frame, between 1st June 2011 and 31st May 2012 (Cassar, 2012). Fortunately, the number of major limb amputations above or below the knee in Maltese patients has decreased by around 33% between 2003 and 2010, as a result of early detection, timely intervention and improvement

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in hospital and medical facilities (Government of Malta, 2011).

Various studies on the experiences of amputees (e.g. Desmond & MacLachlan, 2006; Liu et al., 2010; Senra et al., 2012) focus on three broad aspects: the psychological impact, the processes of adjustment linked to the change in physical image and pain, as well as the impact of social factors such as social support and education. Furthermore, most of the available research (Horgan & MacLachlan, 2004; Senra et al., 2012) focuses on the lived experience of persons having an amputation of the lower limb. This study aims to contribute to this literature by exploring the lived experience of Maltese individuals with a lower or upper limb amputation.

## 2 Methods

### 2.1 Participants

Four Maltese participants were interviewed regarding their lived experience of being an amputee. Interpretative phenomenological research is usually conducted using small samples (three to six participants) since a detailed analysis of each case is necessary (Smith, Flowers & Larkin, 2009). The purposive sample consisted of two male and two female amputees whose ages ranged between 30 and 80 years. Participants were recruited from the Amputees4Amputees Association, which is a support group for Maltese amputees. They were informed about the study by the Association through an information letter which contained details on the nature, aims and requirements of the study. Those persons who were willing to participate informed the designated Association member, who then forwarded their contact details to the first author. Criteria for inclusion in the study included being over 18 years of age and having had an amputation for at least 4 years prior to the study, to ensure that emotional distress levels would have returned within the norm (Horgan & MacLachlan, 2004). A profile of the participants is presented in Table 1.

### 2.2 Data Collection

The interview schedule consisted of ten semi-structured and open-ended questions. Questions were open-ended to provide participants with an opportunity to elaborate on their responses. Their semi-structured nature allowed for probing and a more conversation-like interview, rather than a rigid question-and-answer approach (Langdrige & Hagger-Johnson, 2009). The participants could opt to be interviewed in Maltese or English. In fact, all opted for the Maltese language. The duration of the tape-recorded interviews was 40-60 minutes and took place in a

Table 1. Participant characteristics.

Pseudonym	Gender	Status	Type of amputation	Reason
Jessica	Female	Single	Below the knee	Birth defect - limb malformation
Maria	Female	Married	Above the knee	Gangrene
Joseph	Male	Married	Upper Limb	Accident
Mario	Male	Married	Below the knee	Accident

Note: Participants' ages are not included in order to preserve their anonymity.

Table 2. Super-ordinate themes.

Super-ordinate themes	Sub-themes
An emotional reaction	Impact on self Feelings of significant others
A different life	Changes in lifestyle Prosthesis and discomfort Searching for meaning
Social connections and support	Family and friends Professionals as a source of information and care

setting suggested by the interviewee. Three core areas were explored, namely participant pre-amputation and post-amputation experiences, as well as external factors such as social support and social integration. Interviews were conducted by the first author between December 2012 and January 2013.

## 2.3 Data Analysis

Interpretative phenomenological analysis (IPA) was used, following procedures outlined by Smith et al. (2009). This approach was found to be the most suitable to examine personal experiences as it involves a detailed analysis of each case (Smith et al., 2009), and therefore the researcher must take on the role of an interpreter (Smith & Osborn, 2003). IPA aims to engage with people's reflections on their subjective experiences, paying particular attention to what the experience was like for every participant and how s/he made sense of it (Smith et al., 2009). Studies using IPA are often concerned with existential issues in relation to major life-changing or threatening events, as in the case of the loss of a limb (Smith, 2004).

## 2.4 Ethics

Ethical approval to conduct this study was obtained from the University of Malta Research Ethics Committee (UREC). All participants were asked to sign a consent form prior to the study. They were informed that they could terminate the interview at any point, or decline to answer any question without the need to provide a reason. Pseudonyms were assigned to each participant, and transcripts and audio-recordings were stored in a locked cabinet to safeguard participant confidentiality.

## 3 Results and Discussion

Three super-ordinate themes emerged from participant accounts. These were: a) the Initial Emotional Reaction, b) a Different Life and c) Social Connections and Support. In the following sections, each super-ordinate theme is divided into sub-themes, which are discussed with the use of excerpts from participant accounts and compared to existing literature.

### 3.1 An Emotional Reaction

Participants gave details of their own personal reactions to the amputation, as well as the reactions of family members and significant others.

#### 3.1.1 Impact on self

Most of the research available on the experience of amputation is related to one's reaction to his or her own amputation, which is dependent on a number of factors such as age, level (below or above the knee/elbow) and time since amputation (Horgan & MacLachlan, 2004). The participants in this study described their initial reaction to their own amputation, occurring as a consequence of an accident or gangrene, in a negative manner. Mario explained:

*"Initially it was a huge shock. I was crushed!"*<sup>1</sup>

Maria stated:

*"I really cried!"*<sup>2</sup>

Similarly, participants in a study conducted by Senra et al. (2012) expressed feelings of sadness, shock and surprise. However, Jessica, who had her limb amputated due to a malformation in her leg (birth defect), perceived it in a positive light, as exemplified in the following excerpt.

*"The iron rods around my [malformed] leg were so ugly and so uncomfortable. In fact, the first thing I asked her [my mother] as a child, was whether the amputation would allow me to wear heels and any kinds of shoes. In that aspect I can say it was more of an improvement for me."*<sup>3</sup>

This demonstrates that the cause of an amputation may influence one's reaction towards it (Horgan & MacLachlan, 2004). Participants in this study denied experiencing any long-lasting emo-

<sup>1</sup>*"Ghall-ewwel kien xokk kbir. Kont imfarrak!"*

<sup>2</sup>*"Tghidx kemm bkej!"*

<sup>3</sup>*"Il-hadid li kelli ma' saqajja [l-isfurmata] kien vera ikrah u skomdu. Infatti, l-ewwel haga li staqsejtha [lil ommi], ta' tifla li kont, kienet jekk inkunx nista' nilbes takkuna u zraben li rrid. Jigifieri minn dak il-lat jiena kelli improvement."*

tional distress such as depression and anxiety, even though psychopathological symptoms following amputation are commonly cited in the literature (see Hamill, Carson & Dorahy, 2010). This could be due to “heroic cheerfulness” and denial of any problems (Thomson & Haran, 1984, cited in Horgan & MacLachlan, 2004). Another possible reason could be the presence of sufficient support, a possible mediator between amputation and the psychological outcome (Hamill et al., 2010).

All the amputees in this study voiced their preoccupation that the loss of a limb would affect their physical appearance. A research study by Miller and Deathe (2004) highlighted the effect of an amputation on aesthetics. The ability to sustain femininity and wear heels and skirts, was also of particular importance to the females interviewed in this study. In contrast, male participants seemed to be more concerned over the loss of their breadwinner status.

*“Even aesthetically, as a woman, I want to make sure that it [the prosthesis] looks good, especially if I’m wearing a dress.”<sup>4</sup> (Jessica)*

Joseph also described how the amputated limb affected his self-pride.

*“... it made me feel inferior, because I could no longer be my family’s breadwinner.”<sup>5</sup>*

This concern finds support in the literature. Men place more importance on the functional aspect of the limb and their ability to financially provide for the family (Murray & Fox, 2002). During each of their interviews, participants expressed similar opinions that certain character traits such as courage, confidence and being positive helped them to cope, as exemplified by the following excerpt.

*“... but every human mind is different, not everyone thinks alike. Some people get disheartened ... There were some who gave up and passed away within a fortnight.”<sup>6</sup> (Maria)*

In a study about positive adjustment to lower limb amputation, Unwin, Kacpersek & Clarke (2009) suggested that positive mood was a strong contributor towards a good early adjustment.

### 3.1.2 Feelings of significant others

Participants also described the emotional responses of significant others in their lives. Maria reported how her granddaughter, with whom she had a close relationship, reacted to the amputation. She explained how initially her granddaughter appeared to be afraid of her, but soon realised that her grandmother was still the same person. Jessica, who had undergone her amputation during childhood, mentioned how preoccupied her mother was about the comments and judgements of others, especially children’s. Mario described his experience in the following way:

*“... they [my parents] took it really badly. Especially my father, who had never wanted me to ride a motorcycle [for fear of an accident].”<sup>7</sup>*

The emotional difficulties that parents endure as a result of their child’s amputation were also highlighted in a case study on child amputation (Judd, 2001). In this study, the participant describes the distress experienced by his mother in the following way: “Mum... every time I cry she cries with me.” (p.50)

<sup>4</sup>*Anke estetikament bhal speċi mara, nara li nkun irridha [il-prosthesis] pulita, li jekk jien ha nilbes libsa, tidher pulita.”*

<sup>5</sup>*“... bdejt inhossni inferjuri jien, għax speċi I’m not the breadwinner.”*

<sup>6</sup>*“... imma l-moħħ tal-bniedem, mhux kulhadd jahseb l-istess. Min jaqta’ qalbu... kien hemm min qata’ qalbu u fi hmistax miet.”*

<sup>7</sup>*“... ħaduha [il-ġenituri] bi kbira hafna. Speċjalment missieri, li ma riedni qatt bil-mutur [għax jibza’ li jkollu xi incident].”*

## 3.2 A Different Life

Findings from the present study showed that living with an amputation may bring about several changes in one’s life. The following section provides details on the participants’ perceived changes in their life, as a result of their amputation.

### 3.2.1 Changes in lifestyle

All participants had similar views on the fact that the amputation had an effect on their independence, posing certain limitations and at times making them dependent on others.

*“... It’s very difficult! You have to depend on many people. I hate it when I can’t do something myself.”<sup>8</sup> (Joseph)*

Changes in lifestyle were specifically cited by participants who previously enjoyed sports and physical activities.

*“... certain things like running, sports and football... The worst thing of them all is not being able to run and play with my children.”<sup>9</sup> (Mario)*

According to Asano et al. (2008), mobility was the second best predictor of quality of life among individuals who had a lower limb amputation. In this study, participants highlighted the changes in their everyday life brought about by the amputation. Similar to what was reported by Liu et al. (2010), three of the participants described feelings of frustration as a result of their loss of independence and increased dependence on caregivers.

Another participant, Maria, described the change in her intimate relationship with her husband following her amputation. She explained that her husband had a fear of illness and was greatly upset by her amputation. This in turn affected their sexual relationship.

*“It took a very long time until we were able to be sexually intimate again, as a married couple. When he started to initiate intimacy again, I used to just cover it [the stump].”<sup>10</sup>*

The research literature on sexuality in amputees is limited. However, the present study corroborates the findings of a prominent investigation on the topic by Williamson and Walters (1996), which suggested that sexual activity in a couple was influenced by the perceptions of the spouse regarding the stump or prosthesis.

Two of the participants explained that while reactions from people whom they had dated were mostly positive, the parents of such individuals seemed to think otherwise.

*“Some mothers didn’t want their daughters to date me. One of them even paid for her daughter to move to Australia.”<sup>11</sup>*

Mario, however, also described how he managed to take advantage of having an amputation.

*“... they [females] felt more comfortable approaching me themselves, because they felt sorry for me. Rather than having to approach them myself, they would come to me ... I would then choose the best one!”<sup>12</sup>*

<sup>8</sup>*Diffiċli hafna! Tiddependi minn hafna nies. Jiena jdejquni affarijiet li ma nistax naghmlhom jien.”*

<sup>9</sup>*“... ċertu affarijiet bhal ġiri, sport u futbol... L-aktar li thoss illi ma tistax tiġri u tilgħab mat-tfal.”*

<sup>10</sup>*“Dam voldieri ma kellniex x’naqsmu flimkien bħala miżżewġin. Imbagħad meta beda jerġa’ jersaq lejja, din [is-sieq maqtugħa] kont nġhattiha.”*

<sup>11</sup>*“Ftit ommijiet ma ridux lil binthom toħroġ miegħi. Wahda minnhom hallsitilha [lit-tifa] b’ax titlaq l-Awstralja.”*

<sup>12</sup>*“... bdeu ihossuhom komdi iktar it-tfajliet jiġu fuqi huma, u kienu jaqdbu miegħi huma milli kont immur jiena fuq tfajla... u naghzel lil-ahjar wahda!”*

### 3.2.2 Prosthesis and discomfort

All participants described how the use of a prosthesis involved a process of acceptance and adjustment, as demonstrated in the following two excerpts.

“... you start adjusting to the prosthesis by wearing it for half an hour. Then you start going for very short walks.”<sup>13</sup> (Mario)

“... You must trust your body, you must trust the leg so that you can stand on it and walk. You can't remain dependent on crutches or a wheelchair.”<sup>14</sup> (Jessica)

These comments highlight the importance of the adjustment process of the amputee to his/her prosthetic limb. Saradjian, Thomson and Datta (2008) showed that adjustment to a prosthesis is a personal and individual process. All the participants had different ways of adjusting, with some even customising their prosthesis to suit their own personal needs or wearing it initially for short periods of time. Participants also complained about the discomfort and increased sweating induced by wearing the prosthesis in the hot Maltese summer, as well as the burden of its weight. The former factor was also cited in Saradjian et al.'s (2008) study, in which amputees spoke about the sweating and skin sores caused by wearing a prosthesis in warm temperatures. Although the amputees in the current study did not mention any phantom limb pain, they complained of residual pain and pain in the lower back. Ehde et al. (2000) state that this could be due to altered gait patterns to accommodate the prosthesis.

### 3.2.3 Searching for meaning

Participants were consistent in reporting that the amputation had resulted in a change in how they viewed their own lives. They explained how they had begun to appreciate life and had learned to live on a day-to-day basis, rather than focusing on the future. This was even more evident in those participants who had lost their limb in an accident, as exemplified by the following statement.

“Nowadays, I don't take anything for granted ... because I know I could leave here in five minutes, a minute or a second, and my life could end, and so your priorities do change.”<sup>15</sup> (Joseph)

A common question asked by all the participants was “Why me?”, representing an effort to understand why the amputation had happened to them. Similarly, Dossey and Dossey (1998) had identified the need for participants in their study to arrive at an understanding to this question. This was reported to often result in spiritual discomfort, which could in turn lead to the complete negation of God in some amputees (Dossey & Dossey, 1998). This was clearly evident in Mario's statement.

“I don't believe in anything anymore. When I look at people going to church nowadays, they remind me of when we used to watch Red Indian movies, in which people adored wood or stones. . . People go there because

<sup>13</sup>“... sakemm tibda tidraha [il-prosthesis] just kemm tilbisha toqghod nofs siegħa biha. Imbagħad mixja minn hawn s'hemm u lura . . .”

<sup>14</sup>“Inti trid tafda lil ġismek, trid tafda lis-sieq, li inti trid tinfes fuqha u timzi. Ma tistax tibqa' tiddependi fuq il-crutches, fuq il-wheelchair.”

<sup>15</sup>“Illum il-ġurnata ma sirt nieħu xejn for granted. . . Ghax naf li jiena nista' noħroj minn hawn hames minuti, minuta jew sekonda oħra u hajti tispicċa, u allura qisek il-prijoritajiet tiegħek se jinbidlulek.”

they are obsessed and blind.”<sup>16</sup>

Conversely, Maria described a very different experience.

“It [the experience of an amputation] brought me closer to God. It made me realise God was by my side all along.”<sup>17</sup>

Maria goes on to explain how her experience encouraged her to join her local parish group. A relationship with God/higher power has been demonstrated to offer security and strength (Baldacchino et al., 2013) and to serve as a means of positive coping. Joseph also described how his initial reaction was that of anger towards God. However, over time he realised that God had nothing to do with the incident that befell him.

## 3.3 Social Connections and Support

Participants all highlighted the importance of social support, be it from family and friends, from professionals and staff at hospital, or from other amputees. Furthermore, the importance of support from family and friends was highlighted as one of the most important aspects in their experience.

### 3.3.1 Family and friends

Participants did not report any change in the way they interacted with others. However, they highlighted the importance of re-integration and remaining socially active by joining organisations, or simply by spending time with friends and family. Williams et al. (2004) reported that this is an important aspect of adjusting to life after the loss of a limb. As explained by Mario:

“The way you re-integrate in the first few months. . . if you take long to re-integrate, yes, I think you'll suffer. I was meeting my friends and going to the disco when I was still in a wheelchair. Maintaining your social life is very important!”<sup>18</sup>

Furthermore, family members also served to encourage the amputee during the rehabilitation process. For example:

“You need to let go. You need to let go of your walking aids. In fact, the more time passed, the more I felt pressured by those around me [to trust the prosthesis].”<sup>19</sup> (Jessica)

Other family members improvised ways of enabling the amputee to cope in his/her situation, as described by Joseph:

“I was really lucky that my son was able to modify my prosthesis. . . he attached an electric motor which helps me a lot.”<sup>20</sup>

Although support from family and friends is considered to be of importance following an amputation (Liu et al., 2010), at certain times, participants felt that they were being over-protected by their families. For instance, Jessica recounted the following episode.

<sup>16</sup>“Anqas għadni nemmen f'xejn. Meta nħares lejn in-nies imorru l-knisja llum il-ġurnata jien nistħajjilhom meta konna naraw il-films tal-Indjani, jaduraw xi injama jew ġebħa. . . In-nies imorru hemmhekk għax ossessjonati u għomja.”

<sup>17</sup>“Ġabitni [l-esperjenza tal-amputazzjoni] aktar viċin tal-Mulej. Ġegħlitni nirrealizza li Alla kien miegħi l-ħin kollu.”

<sup>18</sup>“Kif tintegra l-ewwel ftit xhur. . . jekk inti ddum biex terġa' tintegra, iwa, naħseb li tbat. Jiena kont niltaqa' ma' shabi u mmur id-diskow, kont għadni bil-wheelchair. Importanti hafna li żżomm social life!”

<sup>19</sup>“Inti trid you let go. Li inti dawn l-aids you let go of them. Aktar ma beda jgħaddi ż-żmien iktar hassejtha l-pressure minn dawħ ta' madwari [biex nafda l-prosthesis].”

<sup>20</sup>“Jiena kont lucky hafna wkoll illi kelli t-tifel kien għenni biex irrangajna l-prosthesis. . . għamilieħi bl-electric motor u tghinni hafna jġifieri.”

*"Last time my mum saw me climbing up the ladder, to change a light bulb. She started panicking and asked me to get down [due to fear of a fall]."*<sup>21</sup>

The participants in Hamill et al.'s (2010) investigation similarly identified this over-protective behaviour as frustrating for amputees.

The amputees in the current study spoke about the need to form relationships with others in the same situation as themselves. They also highlighted the importance of being able to share and encourage each other throughout the experience. One of the participants had been introduced to another amputee her age before the amputation.

*"When they introduce you to an amputee who is already walking, you get to see the final results."*<sup>22</sup> (Jessica)

Similarly, Joseph explained:

*"That [meeting another amputee] helped me so much, because automatically, when you see someone who has been in the same situation, you can't help listening to them."*<sup>23</sup>

Other participants managed to meet up with other amputees through information meetings and sessions held by local associations for amputees or when visiting the Orthotic and Prosthetics Unit or Physiotherapy Outpatients Department following their amputation. These experiences tie in with Liu et al.'s (2010) finding that peer support is helpful in providing relief from emotional distress, and reducing isolation.

### 3.3.2 Professionals as a source of information and care

Health professionals, such as doctors, nurses and physiotherapists, were also perceived as an important source of support. Participants seemed to mention different aspects of support when describing their experience in hospital. Joseph described the support that he received from hospital staff as follows:

*"I cannot complain about anything. When I was in hospital, I had good support because I had doctors, nurses... they were all supportive. They were always there to help change my dressings [following the amputation] and provided for my needs."*<sup>24</sup>

In contrast, Maria held a very different viewpoint.

*"Nothing! While in hospital I found no emotional support at all. They give you no information on the procedure, the way it will affect your life and how to cope."*<sup>25</sup>

Despite the mixed reactions regarding the support given during their stay in hospital, all participants agreed on the quality of support given at the Physiotherapy Outpatients Department and the Orthotic and Prosthetics Unit, which they had been making use of following their amputation.

<sup>21</sup>*"L-ahhar darba ommi ratni tiela' fuq sellum, biex inbidde bozza. Bdiet tippanikja u tghidli biex ninzel [ma mmurx naqa]."*

<sup>22</sup>*"Inti meta jlaqqghuk ma' xi hadd li digà qed jimxi, inti qiegħda tara l-final results."*

<sup>23</sup>*"Dik ghenitni hafna, ghax inti qisu awtomatikament meta tara lil xi hadd fl-istess sitwazzjoni, tismagħhom bla ma trid."*

<sup>24</sup>*"Ma nistax ingerger. Mindu kont l-isptar kelli support taj-jeb ghax kelli t-tobba, kelli n-nersis... kollha kienu ta' support. Dejjem kienu hemm biex ibiddluli l-faxex [wara l-amputazzjoni] u jipprovduli li kelli bżonn."*

<sup>25</sup>*"Xejn! L-isptar ma sibt l-ebda support emozzjonali. Ma jagħtuk l-ebda informazzjoni dwar l-operazzjoni, kif se taffettwalek hajtek u kif tista' tikkowpja."*

*"They all give their 100% to see you satisfied... they provide the support that you need. They see you as a person and not a number."*<sup>26</sup> (Maria)

In their review on rehabilitation following major traumatic amputations, Eldar and Jelić (2003) mentioned the importance of early involvement of rehabilitation health professionals who can provide useful advice on rehabilitation, prosthetic options and ways on maintaining muscle strength, as well as self-care skills.

## 4 Limitations

The present study addresses the lacuna in local literature on the lived experiences of persons with lower and upper limb amputations. There is, however, a need for further research which is longitudinal in nature and explores the lived experiences of study participants over a period time. The limited time frame for this study posed limitations on the number of participants with whom interviews were conducted, and on the possibility of second interviews. Also, the fact that only one of the four participants had an upper limb amputation limits the ability of this study to delve into the experience of amputees of the upper limb. A more diverse sample that included more upper limb amputees would have allowed further understanding of the experiences of persons having different types of amputation.

## 5 Conclusions

This study explored the lived experience of four Maltese amputees. It identified the various reactions and changes which occur following the loss of a limb. Being specific to the Maltese population, it contributes to a better understanding of the experiences of persons with an amputation in the local context. It also explores the needs of amputees in Malta as well as the type of services provided. Furthermore, it highlights the importance of family members' and friends' psychological and physical support as an essential part of individuals' adjustment to their new life as amputees and the use of their prostheses.

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## 8 Conflicts of Interest

The authors report no conflicts of interest.

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<sup>26</sup>*"Kollha jagħtuk il-100% biex jarawk sodisfatta... jagħtuk kull support li hemm bżonn. Jarawk bhala persuna u mhux bhala numru."*

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