

Holistic Understanding On How Individuals Manage Change Post Amputation

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Declaration

Declaration

‘I declare that this thesis that I have submitted to Dublin Business School for the award of BA (Hons) Psychology is the result of my own investigations, except where otherwise stated, where it is clearly acknowledged by references. Furthermore, this work has not been submitted for any other degree.’

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1: Abstract

Previous research into different causes of why patients need amputations focuses primarily on occurrence of change in a physical form after the procedure. However, how patients manage these changes has been overlooked. With reports indicating rising levels of vascular diseases and a statistical increase on the number of amputations occurring weekly. This study aims to gain a deeper understanding of individuals managing these changes in a holistic approach. The study sought to explore key areas of change and how these changes were being managed. Qualitative research was carried out with four patients who had an amputation, Data was collected using a semi structured interview process. Thematic analysis of interview transcripts generated Three themes reflecting: (a) The Body, (b) The Mind, (c) The External Supports. Implications of these themes focused on the Physical, Mental and Social needs of patients, incorporating these needs into treatment plans could be of benefit to healthcare professionals.

2.Introduction

2.1 Amputations

Amputation (AMP) is the surgical procedure to removal of all or part of a limb or extremity such as an arm, leg, foot, hand, toe, or finger. It is believed that amputations were performed as far back as Neolithic times, from evidence of saws made from stones and what appears to be remains of amputated bone stumps in skeletons. Until 100 AD. amputation had been performed as a treatment method for gangrene, which is a horrible condition where body tissue dies due to a loss of blood supply. During the 14th century the advent of gunpowder, with its conception of weapons, increased the frequency of amputation cases that came to the military surgeon. In the mid-16th century, a French army doctor named Ambroise Pare, A major consequence associated with amputation at the time was the loss of blood, Pare introduced the use of ligatures, using a lengthy wire like material to wrap around the limb and constrict a patient's blood flow to the damaged area. This surgical technique, greatly reduced patients' blood loss, (Hernigou, Philippe (2013)). It's not surprising that in the eyes of the general population amputations are seen as a result of trauma (ie war wounds or accident related injuries) Wamen and Kihn (1968) have reported that 76% of 1964 amputees who received treatment at the Veterans Administration Hospital were amputation cases caused by vascular insufficiency, however this is far from the truth as in 2008 (Ziegler-Ghram K et al 2008) found in Estimating the Prevalence of Limb Loss in the United States: 2005 to 2050 that nearly 2 million people are or will be living with amputation limb loss in the United States, of which the main causes are vascular disease (54%) – Mostly diabetes and peripheral arterial disease – trauma (45%) and cancer (less than 2%) .The United States Centre for Disease Control and Prevention, National Centre for Health Statistics; 1998 revealed that roughly 185,000 amputations occur in the United States each year which equates to 300-500 amputations per day.

2.2 Vascular amputation and peripheral arterial diseases

In an attempt to quantify the global variations in the incidents of lower extremity amputations as a result of the rapidly increasing rates of Diabetes Mellitus, P. W. Moxey et al (2011), ran a Meta-Analysis for incidences of lower extremity AMP, gathering data through electronic search using the databases from EMBASE and MEDLINE between the years 1989 and 2010, the results showed Incidence of all forms of lower extremity amputation ranges from 46.1 to 9600 per 100 000 individuals in the population with diabetes as compared with 5.8–31 per 100 000 individuals in the total population. Ethnicity and social variables played a significant role, but it was the role of diabetes and its harm to the body that was the most influencing factor. Research in Sweden by Hansson (1964) studied 856 individuals who received amputation surgery in from 1947 to 1963, 85% of lower limb amputations were because of peripheral vascular diseases, and that rates of amputations would increase yearly as rates of vascular disease increased. A 25-year review of total amputee services in Dundee Scotland but Stewart and Jain (1993) reported that the majority of amputations were as a by peripheral vascular disease, especially arteriosclerosis. In 2015 Diabetes UK using public health data from England revealed that the number of diabetes-related amputations weekly in England had now reached the all-time record high of 135 according their analysis. The figures showed that more than 7,000, compared to the previous figure of 6,677. This meant an increase of seven more amputations per week, which helps support the International Diabetes Federation (IDF) predictions that the global occurrence of diabetes will increase from 285 million to reach 435 million by 2030. The prevalence of diabetes mellitus globally is slowly reaching critical status and will drive an increase in future rates of peripheral arterial occlusive disease (PAOD), neuropathy and soft tissue sepsis (Beckman JA 2002, Newman AB 1993), The vast majority of lower limb amputations is caused by this trio and patients with diabetes have a 30 times greater lifetime risk of having an amputation than patients without diabetes (Calle-Pascual AL et al 1997, Ebskov B et al 1996, Tentolouris N et al 2004)

2.3 Trauma related Amputations

There has been great technological advancement in the 20th and 21st century across the health care professions, but despite all the advancements made in medical and surgical techniques, amputation remains a commonly required procedure in the management of not just military trauma but also civilian. Trauma related amputations remain one of the most emotionally difficult and disturbing of wounds that doctors have to deal with, often used in Hollywood movies to highlight the horrific damage caused by war, it can make such things seem almost fictional and distant from everyday life, however traumatic AMPs remain common injuries, with many survivors requiring limb amputations to save their life. Most public general hospitals see traumatic amputations as a result of accidents occurring during everyday life, Livingston et al(1994) reported on incidences of traumatic AMPs caused by Motor vehicle accident (42.9%), Industrial (26.2%) , Motor cycle accident (21.4%) and other incidences (9.5%), with many of these patients receiving hospital care relatively urgently the survival rates tend to be quite high. Unfortunately Traumatic AMPs are sometimes required on children also, Loder (2004) reported that during a 20 year span across the Midwest of the United States, that of the 256 AMPs in children 193 cases were major AMPs occurring above the ankle or wrist , due to mostly everyday instruments, lawnmower (69) , fireworks(10) and even gunshot (7).As the stats show traumatic AMPs are somewhat common, but are rarely treated by majority of surgeons, a highly skilled and attentive surgeon is necessary for the best possible outcomes, but even taking into consideration a variety of post-operative care guides, Amputations due to trauma can be riddled with obstacles due to the random nature of the wound and internal damage, as a by product of this randomness majority of traumatic AMPs require multiple trips to the operating theatre, Harris AM et al(2009) Lower Extremity Assessment Project (LEAP) conducting research on post amputation complications found that over 85% of 520 patients who had severe lower-extremity traumatic AMPs had a complication, their finding supported the research of Pierce RO Jr et al (1993) that of their 61% of patients who had traumatic AMP over

half of those had postoperative complications to deal with. In addition to the aforementioned physical complications, Abeyasinghe N. L et al (2012) reported the increase in prevalence of Post-Traumatic Stress Disorder among soldiers with amputation of a limb or spinal injury, from a sample of 96 males 41.7% were compatible with the diagnosis of Post-traumatic Stress Disorder.

2.4 Cancer related Amputations

It is projected by 2020, 1 in 2 people in Ireland will develop cancer during their lifetime. In Ireland more 40,000 new cases of cancer or related tumours are diagnosed each year The National Cancer Registry (NCRI) highlight breast cancer as the second most common cancer affecting women in Ireland with over 3,100 women being diagnosed with the disease every year. The average age being 50-64 (41%), but younger women are also affected, with 23% of diagnosis occurring in women under 50. According to Aebi S et al (2011) Primary breast cancer: Clinical Practice Guidelines for diagnosis, treatment and follow-up, The basic rule for treatment process in the early stages of breast cancer is primary application of surgical interventions combined with post-surgical radiotherapy (RTH), depending on the indications. Two types of surgical procedures are used in course of breast cancer treatment: breast conserving treatment (BCT) and mastectomy (breast AMP). Kaminska M et al (2015) conducted a study to Evaluate the presence of symptoms of anxiety and depression in women treated for breast cancer who underwent surgical procedure using one of the previously mentioned methods, either breast AMP or breast conserving treatment (BCT), researchers used questionnaires like Hospital Anxiety and Depression Scale (HADS), Beck Depression Inventory (BDI) and depression degree evaluation questionnaire, the results were statistically significant for HADS, a statistically significant difference was found between the methods of treatment and they also found a negative correlation between anxiety and depression, this study showed that levels of anxiety and depression experienced during breast cancer treatment is largely dependent on types of treatment methods and not demographic variables. The results of this study confirmed that a higher level of anxiety and depression occurred in patients who had

undergone mastectomy. Lim CC et al (2011) conducted a systematic review on anxiety levels in women undergoing breast cancer treatment demonstrates that patients who had undergone BCT were characterized with a lower level of anxiety and depression than patients after breast AMP, possible reasons for this could be that after breast amputation, apart from physical changes, the patients also reportedly experienced negative psychological changes to their mental health. Decrease in self-esteem levels due to the loss of the breasts, results in a lack of own body acceptance and can increase levels of anxiety about the perceived loss of femininity.

2.5 Patient Experiences

In the case of Trauma patients, they rarely get the time to consider the situation an accident may have placed them in, and more often than not their first initial realization comes after the AMP has been carried out and they wake up in a hospital bed. The choice of having the AMP done is taken away from them. McCarthy ML et al (2003) investigated the Psychological distress associated with severe lower-limb injuries. Psychosocial Impact of Amputation, the findings of the LEAP study group have heightened the awareness of the psychosocial disability that individuals experience after a lower-extremity amputation (MacKenzie EJ et al (2004)). McCarthy found that 48% of the sample tested positive when screened for a psychological disorder post AMP, Traumatic AMP was the biggest cause of life stressors up to three months after the AMP and 42% showing signs of psychological disorders up to twenty-four months later.

In the case of Cancer related AMPs, the threat of possible reoccurrence of the cancer, side effects of chemotherapy and possible return visits to the operating theatre, patients experience a loss of control as they feel unable to maintain a control on their life. Cancer can present a constant sense of impending doom to the patient's life, which will inevitably result in higher levels of anxiety, depression and lower levels of self-esteem, it's important to remember that these factors are just as important as the physical changes. It seems almost certain that given these associated challenges and adjustments required that individuals will experience a change in their quality of life (QoL)

(Weiss et al. 1990). The majority of the previous research and literature to date has focused primarily on the physical aspects of the adjustment after amputation (Gallagher and MacLachlan 2002) Individuals with AMPs can experience multiple challenges which can range from learning how to care for their amputated limb, how to move, and how to adjust mentally and cope with their limb loss. Patients can be hospitalized from five to 14 days or more depending on the surgery or complications. Depending on the limb or extremity being amputated and the patient's general health the procedure and recovery time may vary accordingly. It seems almost certain that given these associated challenges and adjustments required that individuals will experience a change in their quality of life (QoL) (Weiss et al. 1990). The majority of the previous research and literature to date has focused primarily on the physical aspects of the adjustment after amputation (Gallagher and MacLachlan 2002)

2.6 Current Study Rationale

Recently researchers have begun to pay attention to any psychosocial changes occurring with lower limb amputations (Horgan and MacLachlan 2004) and other forms of AMP. Given the increase in the number of individuals experiencing amputation (Owings and Kozak 1998), Researchers have noticed a gap in a more holistic inquiry into the factors impacting QoL after AMP. The focus of this current study will be, Understanding how individuals manage change post amputation in a holistic approach, The study will explore changes to physical behavioural, psychosocial and mental health needs experienced by patients post AMP, firstly by understanding how individuals are adapting to their change in physical behaviour, and adapting to the new physical demands placed on the body the study aims to shed light on previously overlooked area of patient needs. secondly is support available for patients from relationships such as friends/family/partner/workplace and is their support purely physical assistance or mental health oriented and finally is there any use of coping strategies which have helped patients overcome issues like that of depression and anxiety as mentioned in previous sections, whether or not spiritual

belief in anyway played a role in managing any changes will also be explored. The study will examine in detail the post AMP experiences of patients to answer the research question which are as follows:

- 1. Understanding How individuals managed changes in their physical needs*
- 2. Understanding How individuals managed changes in their social aspects of life*
- 3. Understanding How individuals managed any changes in their mental health*

With increase in life expectance levels globally and as rates of peripheral arterial diseases increase as highlighted by organizations such as Diabetes Uk amputations are becoming far too common. This study aims to highlight areas of need which should be considered by healthcare professionals in developing post AMP care plans for future patients.

3. Methods

3.1 Participants and recruitment

Participants were a purposive sample of 4 volunteer patients who met the criteria of being over the age of 18 and who have had any kind of amputation procedure, After obtaining a letter of introduction (Appendices A) from Dr. Pauline Hyland Head of Undergraduate Psychology Research in Dublin Business School, contact was made with Vascular surgeon Mr. Madhavan a consultant in an Irish Hospital, the name of the hospital will not be named so as to ensure patient anonymity. After approval from the hospital and support from Mr. Madhavan (*A letter of approval was tainted from the hospital but will not be presented in this study so as to ensure anonymity of all participants*) his team were able to pass on the information sheet (Appendices B) regarding this study and those patients who wished to participate in interviews made their intentions known to the medical team and were subsequently contacted to arrange an interview.

3.2 Design

To gain a deeper understanding into AMP patients experiences, this study employed a qualitative research design, With relation to the sensitive nature of the topic a one-to-one semi structured interview format mapped out to last a maximum of 30 mins per interview focusing on the research questions was seen to be the best option so as to avoid any distress on the patients. Conducting in-depth interviews is one of the best and most common qualitative research methods. It is a personal conversational method that invites opportunities for the volunteers to give in dept details and allows for follow up questions in real time while giving the participants the opportunity to describe their perspectives and relate their experiences after the AMP. Each interview was transcribed and as per Braun and Clarke (2006) “A method for identifying, analysing and reporting patterns within data.” thematic analysis was carried out on the transcripts to answer the research question. Some sample questions from holistic health and

wellness survey relating the key areas of interest for this study were obtained from online sources, this meant the interviews were structured in a way to allow the researcher to maintain focus on the key areas of interest. These included: changes in physical behaviour, and the new physical demands placed on the body, the role of relationships with family and friends, if there any use of coping strategies being implemented and lastly if spiritual belief played a role in managing changes in anyway. More sample questions can be found in the appendices section. (Appendices C)

3.3 Materials and Apparatus

The initial materials used were designed to recruit patients and to present the research proposal to hospital ethics committee. Each participant received the information sheet containing details of the research and signed a detailed consent (Appendices D) form to partake in the study. After each interview was concluded a de-brief sheet was given to each interviewee. (Appendices E) The interviews were recorded using iPhone voice memos app and transcribed into word document format. The data was analysed, and a model of themes were created using NVivo 12 Software obtained from DBS.

3.4 Procedure

Upon receiving ethical approval from DBS Ethics Board and approval from the hospital, permission was granted by Mr. Madhavan and the hospital for the recruitment process to take place, he was provided with and gave the patients the information sheet containing all relevant information pertaining this study. On receiving information regarding the objectives of the study, any risks of participation and their rights to withdraw, participants were asked to volunteer. Only those participants who were over the age of 18 were approved for interviews

and were asked to sign an in-depth consent form prior to participating. The participants were also informed that their information would be anonymous.

3.4.1 Interviews

The interview method used for this study was the frequently used semi structured method of qualitative research (Doody & Noonan, 2013). As the aim of the study was to explore and understand experiences of individuals managing post AMP, one-one interviews were chosen as the most suitable method due to the sensitive nature of the topic. The design of the interview included mostly opened ended questions, but some impromptu questions intended to elicit information regarding experiences related to the research questions.

3.4.2 Protocol

Interviews took place in private rooms, to allow for patient comfort and freedom to speak openly. Each interviewee was welcomed to the room by the researcher, the researcher then took time to go over the purpose, motivation and time line of the interview to establish a rapport. Interviews were semi structured (Appendices F) allowing the researcher to use probing questions to gather as much information as possible. Trying not to interrupt participants but only to steer the conversation towards the areas of interest. At the closing of the interview, patients were provided with a de brief sheet and thanked for their participation. The interviews were then recorded and transcribed, the key areas discussed in all interviews can be found in the interview outline (Appendices F) To maintain patient anonymity, each interviewee was given an ID number to ensure that transcriptions were not identifiable.

3.4.3 Thematic data analysis

Due to the qualitative design of this study Thematic analysis was chosen because it is simple to use which lends itself to use for novice researchers who are unfamiliar with more complex types of qualitative analysis. It allows for flexibility in the researchers' choice of

theoretical framework. Through this flexibility, thematic analysis allows for rich, detailed and complex description of the data. Thematic analysis is a commonly used method of analysis in qualitative research. In 2006 Braun and Clarke published an article that aids novice researchers on how to use thematic analysis through a step-by-step process. Firstly, the process involves the researcher to become familiarized with the data, secondly once the transcripts have been recorded, they are analysed to create the initial codes, Braun and Clarke outlined the use of the research questions to highlight the initial themes. Upon reviewing the initial themes, the researcher then revised these themes according to their relevance in relation to the research questions when it came to analysing the data, themes were identified inductively and driven by the data obtained from interviews. Braun and Clarke outline the importance of reviewing these themes more accurately before producing the final report. Themes were generated on NVivo and by coding the responses in the data set as literally as possible meant that the language from the dataset was as closely related to the experiences of the participants as possible, In this way when the themes are reported they stay within the “explicit meanings of the data” (Braun & Clarke, 2006)

3.4.4 Ethics

Preceding any actions taken with this study, a research proposal was submitted and approved by a DBS ethics committee. Psychological Society of Ireland (PSI, 2010) guidelines had to be considered before proceeding with the study. As the research aimed to work with a vulnerable sample in a hospital/clinical setting, it was vitally important that DBS and the hospital were able to review ethical concerns.

Firstly, the principle of Do No Harm was addressed, of all the principles associated with research ethics, it is safe to say that this is the cornerstone of ethical conduct. There was a reasonable expectation from both the DBS and hospital ethics committee and by those participating in this study that individuals will not be involved in any situation in which they

might be harmed or put into a state of distress during the interview process, this issue was addressed by providing a safe space to conduct the interview and allowing participants to withdraw from the study at any point they may feel uneasy.

Secondly issues of Confidentiality, any individual participating in the research study had a reasonable expectation that the information provided will be treated in a confidential manner. Consequently, the participant is entitled to expect that such information will not be given to any third-party individuals, this was addressed by keeping all voice recordings and notes passwords protected and locked for safe keeping.

Thirdly, Informed Consent, Individuals participating in the research study had a reasonable expectation that they will be informed of the nature of the study and may choose whether or not to participate. They also had a reasonable expectation that they will not be coerced into participation. Volunteers might feel that they cannot refuse when asked. There might be pressure placed on them by superiors or in the case of this study by Doctors in the hospital. This was addressed this by offering a consent and information sheet to participants before conducting any interviews and informing the participants of their right to withdraw at any point.

Fourthly individuals participating in the research study had a reasonable expectation that the conduct of the interview maybe intrusive. Intrusiveness can mean intruding on their time, intruding on their space, and intruding on their personal lives due to the sensitive nature of the topic which can bring about feelings of unease, this was addressed upon completion of each interview each participant was provided with a de brief sheet containing contact information for helpful services and provided with some information as to the nature of the study.

Lastly Data use and Interpretation, a researcher is expected to analyse data in a manner that avoids misstatements, misinterpretations, or fraudulent analysis, this concern was addressed by de identifying all participants and focusing on the themes gathered during analysis so as to

avoid any biases towards any participants, Participants were also informed that they may be quoted but not identifiable in the final report.

4: Results

4.1 Thematic analysis

This study implemented the use of thematic analysis as outlined in Braun and Clarke (2006) to gain a better understanding of how individuals manage change post AMP in a holistic approach. The objective was to explore this previously overlooked area in research, aiming to describe patients' experiences as accurately and detailed as possible. Through semi-structured 25-30-minute interviews with four participants who had an AMP procedure. Thematic analysis allowed for a detailed breakdown of the interview transcripts and allows for easy identification of patterns and themes which emerge from the data. The data corpus was collected and transcribed first hand by the researcher, according to Braun and Clarke (2006) this is the most crucial stage step in the thematic analysis process because it aids in familiarization of the data through the interview process itself and by giving the data close attention, the researcher can then form more reliable interpretations and analysis. This is important when using transcripts to generate initial codes with relevant content related to the research questions. Coding was done using NVivo 12 software. Following transcription, initial codes were then generated using the entire data set of interviews and additional qualitative questions.

4.2 Transition from codes to themes

The third phase of thematic analysis involved generating potential themes from gathering and organizing the initial set of codes and relevant data. After the initial codes were categorized into each theme. Sub-themes were created based on the relevant codes and their relationships to each theme, this helped the researcher to spot patterns within the data. Initial

themes were then reviewed to ensure that they accurately represented the coded extracts and data set. The initial and sub themes were again examined as part of ongoing analysis to general clearer and more defined themes, A thematic model was created using these themes and sub-themes. Each theme was detailed and outlined by the researcher's interpretation of the data. On completion the themes were related back to the research questions and key areas of interesting of the study for the final report.

4.3 Themes

The step by step process of thematic analysis outlined by Braun and Clarke (2006), the researcher was led to the extraction of three overarching themes which serve to outline how individuals have managed the experiences in their post AMP. Within each of the three themes are a number of sub- themes which combine in supporting the main theme (See Figure 1)

Table 1

Summary of Themes

Themes	Sub-Themes
The Body	<ul style="list-style-type: none"> • Physical Behaviours • Fitness • Nutrition • Prosthetics • Mobility
The Mind	<ul style="list-style-type: none"> • Self-Esteem • Motivation • Emotions

	<ul style="list-style-type: none"> • Attitudes • Self-awareness • Contemplative • Spiritual
<ul style="list-style-type: none"> • The External Supports 	<ul style="list-style-type: none"> • Relationships • Family • Friends • Work

Figure 1: Summary of Themes and Sub-themes

4.3.1 Theme 1: The Body

As was expected due to the nature of the topic, the first theme which featured across all participant interviews was ‘The Body’ and its many sub themes. This referred to any of the change’s participants experienced regarding their physical behaviour’s importance of these needs cannot be understated, as patients became accustomed to their new body. As Participant number 2 noted

“I always sleep on that side and used that leg to support the other leg while I sleep, that’s the biggest change I’ve noticed that I can’t roll around the bed.”

For the majority of the general population this may have never crossed their mind, but post AMP individuals are in a situation where they must re learn certain habits and physical behaviours and adjust to the apparent loss of freedom, a sentiment echoed by

Participant 1 “It takes away your freedom, that’s what it does” “you can’t just go where you like, know what I mean? like I was a goer, like cycle and that kind of thing and that came to a full stop when I had my leg amputated. so that was a BIG blow to me”

Many of the participants noted their desire for the use of prosthetics too overcome these new physical barriers, the participants felt confident in their ability to overcome these changes when asked if they feel they are being held back by the AMP.

Participant 3 “no, I want to get out there, try and get prosthetic legs and things like that”

Participant 2 “I want my prosthesis so I can get out of the wheelchair and nobody will know if it’s a false leg or not.”

This desire for mobility and freedom of movement was seen throughout the interviews, during post AMP care in the hospital the participants emphasized the role of physiotherapy as an important part of the process of re adjusting.

Participant 4 “I had a little physio. I swam through the treatment and that helped me actually. I’m almost back to my fitness levels.”

Participant 3 “I did do physio for a good while and then they stopped they said I was way ahead of them.”

One participant had never partaken in physical exercise like a gym, but after the AMP this has changed the motivation “I’m on the wheelchair and using these arm muscles I have to bulk up to get going, get physically fit enough to use the prosthetic leg”

Changes in the body aren’t just physical and can’t always be addressed with prosthetics, an unexpected change for participants was nutrition based, participants reported a change in sinuses and more importantly appetite.

Participant 4 “because of the chemo the taste of food really changed. the appetite was there but just couldn’t taste it”

Participant 1 “I don't have the same taste for food, I still want food but don't have the same taste for it,”

Participant 3” food tastes differently”

While each Participant had undergone a different type of AMP, ranging from Vascular to cancer related AMP, the experiences to physical changes was that of restricted freedom and the desire for mobility, a sentiment best summed up by

Participant 1 “when I got my wheelchair I couldn't believe I could move it myself, which meant that if there was something there I could get it myself and wouldn't need to ask somebody to get it for me, it was a big thing in my life again, the freedom to move without assistance from anybody”

While participants 1-3 had assistive technology such as prosthesis and wheelchairs as viable options, *Participant 4* underwent breast cancer AMP which requires chemotherapy during treatment, unlike other participants she reported a troublesome experience regarding her femininity and sexuality, *“that was due to the fact I had chemo and I had lost all my hair, you wear hats and stuff but the eyebrows go as well, that was the worst thing for me actually”*

The need to maintain physical aspects of womanhood *“I think it's a big part of your femininity your hair and sexuality you know. more than the scars on my chest, they didn't affect me as much as the hair lose, and people look at you and they point”* *Participant 4* focused on the importance of the psychological toll her physical changes brought.

4.3.2 Theme 2: The Mind.

While participants believed that prosthetics and physiotherapy were important factors dealing with physical changes or changes to the body, there was a strong emphasis throughout

the interviews on psychological factors such as patient self-awareness, self-esteem, attitudes and motivation that has influenced their experiences,

Participants self-awareness and attitude can set the tone for the recovery process,

Participant 4 "being a doctor makes it worse, it's very hard to reassure me, because the other day my mammogram gave the all clear, but I know the ins and outs, so I doubt if I'm really in the all clear."

Participant 2 "if I was a pessimist, I would will that other leg bad. We fixed the bad leg, move on. Get the best use out of the remaining leg now."

As previously mentioned in the introduction many AMP patients many not be in a position to choose whether or not they have the procedure.

Participant 1 "I didn't get time to think, I don't remember much about it, and I was in hospital and they found a clot, so I don't remember that time very much"

Participant 2 in order to alleviate pain and prolonged suffering made the decision

"I said there was no point in trying to save that leg, and I prefer at this stage to just take it off"

"oh yes I made the call to remove it"

The participant demonstrated high levels of self-awareness and positive attitudes, *"I didn't look at the implications, I get up in the morning and even if I get up in a wheelchair, I'll just go up the road for a walk or whatever"*

Participant 3 "I think it depends on the person them self, for a while I didn't want to get the amputations done, but it got to a stage where I was crying to get them done"

Participant 3 did have hesitations, but did in-fact decide to have the AMP and just like the other participants they felt the worst was behind them and they maintained a positive outlook and most reported no apparent change to self-esteem either. *Participant 2* experienced a situation with a lady walking passed him in which he felt different for the first time “*she looked up, she saw the wheelchair first and then my leg then she said sorry to my face, I said to myself get use to this, people will look at me different*”

How patients react to being seen differently varied across participants,

Participant 3 “*I don't think it's changed how people look at me*”

Participant 1 “*I'm still the same me*”

While some had no experienced change, In the case of *Participant 4* there were negative experiences “*for me the physical stuff was nothing compared to the psychological side of it, the anxiety and panic were the worst*”

This sentiment of psychological difficulties weighing heavier than any physical challenges was echoed by *Participant 2* when asked about difficulties and reflection upon the experiences “*nothing really, not bad, the awful thing was the isolation in the hospital, feeling like left alone, frightening*”

participant was facing a different set of difficulties, from loss of hair and anxiety in *Participant 4* to feeling isolated during treatment in *Participant 1*, The researcher took time in the interviews to probe these issues further in an attempt to explore any coping mechanisms and or spiritual beliefs the participants may have had as support during such difficult times.

Participant 1” *oh yea my prayers, I go to mass, I never gave that up, that keeps me going, my spiritual belief keeps me going*”

Participant 4 "it's interesting that before all this I wouldn't have believed anything, but a few very precious nice things happened along the way, it probably has changed me a little bit, I really wished I had a really strong faith because I think it would really help you"

Participant 4 "oh yea I've done bit of mindfulness and relaxation. my biggest problem throughout the process was anxiety, I had a couple panic attacks, I would go through chemo again to avoid the anxiety"

Participant 3 "yea I feel calmer going to prayer. I don't know what is, but nothing has ever hit me as in shock wise that my legs are gone. it hasn't held me back"

Through the data analysis the researcher noted the presence of these supports were not prominent in all participants, possibly as result of varying levels of belief. *Participant 4* referenced her mother's strong belief as a source of comfort for her, *Participant 2* also came from a family with strong beliefs and referenced his wife as having a strong faith, but it did not "fit" for him personally.

4.3.3 Theme 3: The External Supports

Human beings are social creatures and during times of hardship individuals turn to those closest to them for support whether that is family, friends or a partner, Participants were asked about these factors and how it influenced their experience post AMP.

Participant 2 " Oh yes , my wife is so good to me in a sense that I take her for granted, if something happened to me I know that she's there, she's been there through the thick and thin, I didn't realize I was putting her under so much pressure, and she cried for me, but I didn't cry for me, for me it was just another part of life I was going through"

Participant 3 " they have always been there for me, every time I see them, I'm in a very happy humour, obviously get upset when they leave because I can't go with them. family have been there for support"

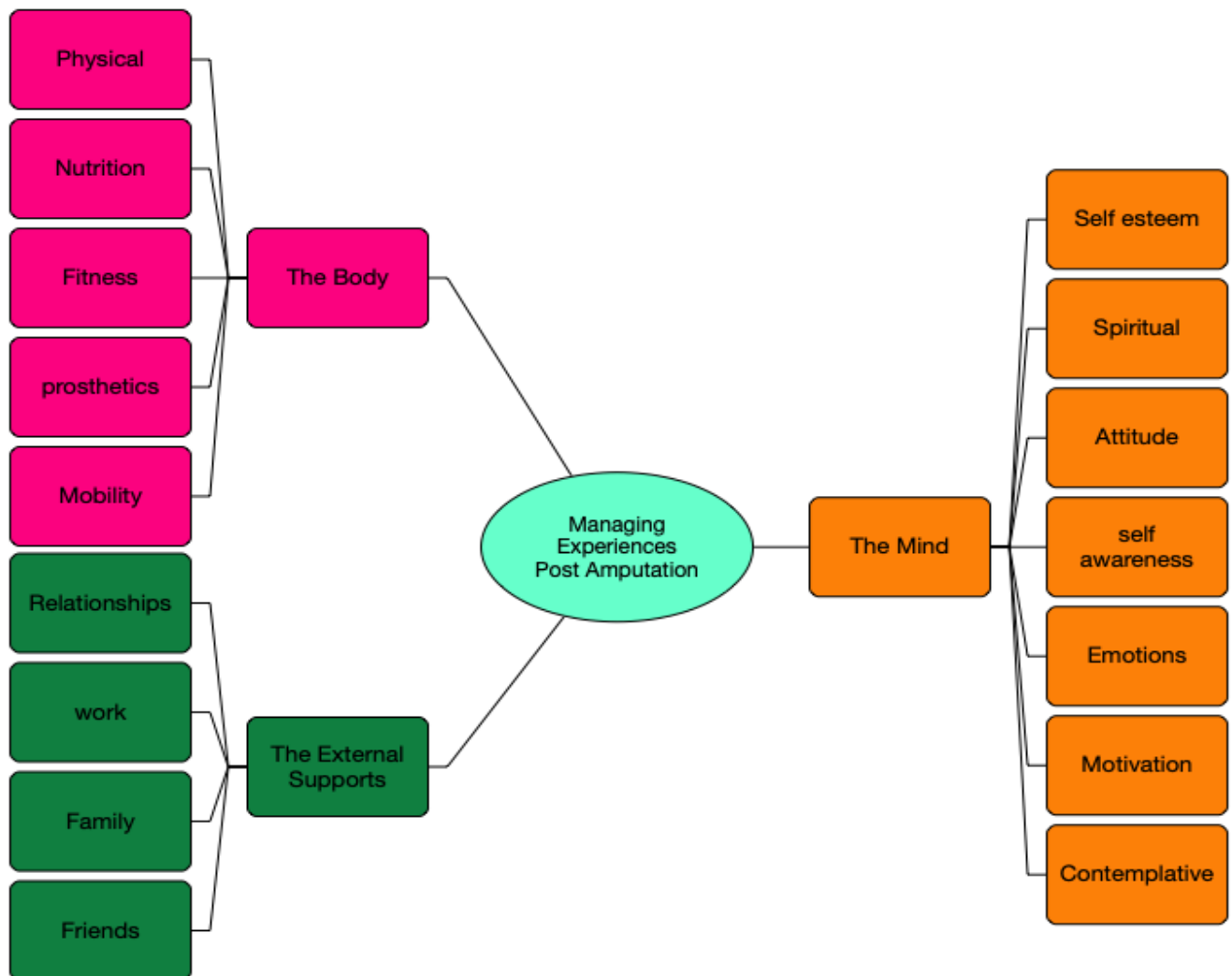
Support from family was the big motivating factor for participants to get well enough to leave the hospital and get home as soon as they could, It is important to note that *Participant 1-3* were retired so they did not experience issues leaving a busy working life due to the AMP, however this was not in the case of

Participant 4 who is a doctor in her profession and raised an important point, "the roles changed, that didn't come easily I didn't really like it". "it was hard for me because I was working full time 4 kids a husband so busy busy busy, and running around and all of a sudden I was needing bit of help" The role reversal from career of patients to becoming a patient herself was challenging obstacle for her

Participant 4 also reflected on her marriage "I'm really glad I'm in a relationship married for 20 odd years with kids, I think it would be really difficult for younger women who have had a mastectomy it must be really hard to get into relationships"

To summaries, all participant found the interview process and experience a positive one and saw value in exploring this research. The themes generated through the data analysis highlighted areas that individuals themselves felt were off importance, but certain themes were found more consistently in the data. "The Body" and its changes are being managed with prosthetics where possible, but more than that the psychological challenges associated with these changes have been managed through self-awareness and positive attitudes and in some cases spiritual beliefs. Lastly external support from social factors such as friends and family have been the biggest contributor for helping patients manage isolation and anxiety. A model

of the themes and sub-themes can be seen in Figure 2 below



5. Discussion

The current study looked at areas which had been previously overlooked in relation to how individuals have managed changes post amputation, this research aimed to qualitatively explore these changes to gain an understanding in this area to inform health care professionals in developing possible treatment plans for patients. Using semi-structured interviews, 4 participants were asked to share their experiences in relation to the AMP. The interviews were analysed, and information gathered was used to generate themes which were supported by direct quotes. Three themes and multiple sub-themes appeared to represent the key aspects of individuals lives which ranged from areas of difficulties to support.

5.1 Implications

5.1.1 Theme 1: The Body

While previous research has focused on physical rehabilitation outcomes in relation to health profiles (Pezzin LE et al 2000), In this current study, the aim was to explore how the individuals are managing the changes and not just the occurrence of changes. The results showed changes to the physical behaviour were multifaceted across multiple areas related to physical health needs, Participants experienced difficulties with the loss of mobility and sense of freedom *“It takes away your freedom, that’s what it does” “you can’t just go where you like”* This implies that the desire for prosthetic assistance in most cases is due to the physical need to move from place to place. The implication of these finding could prove useful for health care professionals because all patients may not be eligible for prosthetics due to the differing types of AMPs, In incidences of breast cancer amputation prosthetics would serve a more aesthetic role, but due to the chemotherapy during treatment many patents turn to wigs as a way to deal with hair loss, facilitating these need for physical mobility and physical aesthetics through alternative methods should be explored.

5.1.2 Theme 2: The Mind

While participants believed that prosthetics and physiotherapy were important factors dealing with physical changes or changes to the body, this study found there was a strong emphasis throughout the interviews on psychological factors such as patient self-awareness, self-esteem, attitudes and personal motivation that has helped patients manage their experiences. *“I think it depends on the person them self, for a while I didn't want to get the amputations done , but it got to a stage where I was crying to get them done”* Three of the participants made the choice to have their AMP procedure and only one was unable to make decision due to other medical complications, but still showed a positive attitude, the patients

positive outlooks could be explained by their awareness and their choice to have the AMP done, they were aware of the process and prepared to deal with it, *Participant 2* “*I didn't look at the implications, I get up in the morning and even if I get up in a wheelchair I'll just go up the road for a walk or whatever*” .While some had not experienced any negative psychological change, In the case of *Participant 4* there were negative experiences “*for me the physical stuff was nothing compared to the psychological side of it, the anxiety and panic were the worst*”

This sentiment of psychological difficulties weighing heavier than any physical challenges was echoed by *Participant 2* when asked about difficulties and reflection upon the experiences “*nothing really, not bad, the awful thing was the isolation in the hospital, feeling like left alone*” “Each participant was facing a different set of difficulties, from loss of hair and anxiety in *Participant 4* to feeling isolated during treatment in *Participant 1*. *Participant 4* reported negative emotions in relation to the loss of her sexuality and femininity which resulted in anxiety and panic attacks, the participant was able to manage these emotions through mindfulness techniques and help from a psychologist “*I told them I felt embarrassed I was so upset about my hair, and they helped me through that.*”. The implications for the findings throughout this theme showed the importance of psychological support needed by patients, health care professionals should focus on supporting patients mental health needs especially through the early stages of treatment, patients reported of isolation and being looked at differently, early stage treatment plans should account for these circumstances so as to avoid patients feeling isolated and feeling anxious regarding biological aesthetics and sexuality in the case of breast AMP.

5.1.3 Theme 3: The external Supports

A common thread throughout the interviews was patients' relationships with family partner and work, Participants were asked about these external and more social factors and how it influenced their ability to manage changes post AMP. Presence of family and support from a

partner was the big driving factor for participants to get well enough to leave the hospital and get home as soon as they could, *Participant 2* is retired and enjoyed sight-seeing and exploring new towns with his wife as a hobby before the amputation and was adamant to continue doing such activities after the procedure, *Participant 1* found difficulty with isolation initially and felt there was not enough information provided in regards to post-surgical care, but was helped by frequent visits from friends and socializing with staff *“I love people I love chatting”*

It is important to note that *Participants 1-3* were retired so they did not experience issues leaving a busy working life due to the AMP, however this was not in the case of *Participant 4* who happens to be a doctor. For her the role reversal from caregiver to receiver was difficult and due to her extensive knowledge of the human body she reported *“being a doctor didn’t help because u know all the complications and things that can go wrong , so I was anxious about it” “think being a doctor makes it worse, it’s very hard to reassure me”*. These findings imply there could be a review into how much information is given to patients so as not to induce anxiety and panic but enough relevant information to avoid patients feeling left in the dark regarding what is happening to their body. Each participant referred to the positive influence from family and friends. These finding should be used by health care professionals to implement external support programs related to factors within *Theme 2* and psychological needs which include patients’ families, aiming to avoid the reported feelings of anxiety, isolation.

5.2 Strengths and limitations

The current research looked in depth at patients reported experiences in managing change post AMP. Previous research focused primarily on the physical aspects of the adjustment after amputation (Gallagher and MacLachlan 2002),The aim of this study was to focus on how individuals managed change post AMP in a holistic approach, A major strength of this study

was the one-one semi structured interview process which allowed participants to freely express themselves. The limitations of the study were, due to the small sample size may not have represented the experiences of the larger population of patients.

5.3 Future Research

Future research of a wider and more varied sample including qualitative questionnaires could provide more in-depth analysis. In addition to modifying the sample, a more Longitudinal study relating to the research questions evaluating how the patients' needs change over time would provide healthcare professionals the opportunity to create programs according to a timeline. Two areas which could be of particular merit in further research are the 'Prosthetic needs' and 'changes to body image'. Research investigating types of prosthetics has been previously conducted but a study to examine the changes in body image and how individuals may have difficulties adjusting to the aesthetics of the prosthesis could be combined with support programs during early stages of treatment and rehabilitation.

5.4 Conclusion

The current study found mostly positive experiences reported by individuals managing change post AMP. The three main themes that developed from the data had consistent links to the research questions and managing changes in Physical needs, Mental health needs and Social needs. Highlighting that these areas should be considered by health care professionals when developing post AMP treatment plans in the future.

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Appendix A



Psychology Department
School of Arts
Dublin Business School
Castle House
73-83 South Great George's St.
Dublin 2

17th October 2018

Dear Mr. Madhavan,

Re: Permission to conduct research

Hamza Razaq is enrolled as a final year BA (Hons) Psychology student at Dublin Business School. DBS psychology students are required to complete an independent research project during their final year of study. Hamza wishes to conduct research to understand how individuals manage change post amputation, with the use of semi-structured interviews.

All research conducted by final year students is done for the purpose of meeting course requirements. All results obtained will be de-identified, and will be used for assessment of the researching student's qualifications for receipt of a BA in Psychology. Hamza is currently seeking formal ethical approval from DBS Ethics Committee for his research project and is requesting written permission, to collect research data on some of your patients who have had an amputation.

Please feel free to address any questions regarding this research to Hamza (Email: 10339894@mydbs.ie) or myself. Hamza can also provide further details about how he will conduct his research study. Thank you for your time.

Yours Sincerely,

A handwritten signature in black ink that reads 'Pauline Hyland'. The signature is written in a cursive style.

—
Dr Pauline Hyland
Psychology Lecturer
Head of Undergraduate Psychology Research

Appendix B

Information Sheet for a study on
Understanding how individuals manage change post amputation in a holistic approach

You are invited to participate in a research study that will form the basis for an undergraduate thesis. Please read the following information before deciding whether or not to participate.

What are the objectives of the study?

How individuals are adapting to their change in physical behaviour, and the new physical demands placed on the body, Is support available from relationships such as friends/family/partner and is the support purely physical assistance or mental health oriented,Is there any use of coping strategies or goal management strategies being implemented

Has spiritual belief in anyway played a roll in managing changes.A complete debriefing will be offered after participation, where any further questions will be answered.

Why have I been asked to participate? I would like to collect information from different people from all backgrounds who have had an amputation procedure.

What does participation involve?

Right to withdraw Participants have the right to withdraw from the research at any time until the data has been submitted ,for whatever reason.

Are there any benefits from my participation? While there will be no direct benefit from participation studies like this can make an important contribution to our understanding of some of the holistic changes experienced by amputation patients, the findings from this study may be presented at national and international conferences and will be submitted for publication in peer-reviewed journals. Interim and final reports will be prepared. However no individual participant will be identified in any publication or presentation ever and the audio files from interviews will not be presented. Individuals will not be offered any monetary or other rewards for their participation.

Are there any risks involved in participation? There are no risks associated with participation. Any inconvenience involved in taking part will be limited and a debrief sheet will be provided.

Confidentiality All individual information collected as part of the study, will be used solely for research purposes. They will be stored safely and will not be publicly displayed or published.

Contact Details

If you have any further questions about the research you can contact:

Researcher:

Supervisor:

Appendix C

Sample Questions

(Transition: Let me begin by asking you some questions about your experiences in relation to physical well being)

(Steer the conversation to focus on-Fitness - Behaviour - Nutrition areas)

- Tell me about your experiences in relation to physical behaviour
- Tell me about your nutrition
- Tell me about your fitness

(Transition: Let me ask you some questions in relation to your internal well being, motivation and self-awareness)

(Steer the conversation to focus on - Attitudes - Emotions - psychological well being - Mindfulness)

- Tell me about your feelings in relation to the amputation.
 - Tell me about your outlook,
 - Are you motivated to make any productive, healthy changes in your life if needed.
 - Have you experienced any changes to your self esteem (giving yourself more supportive messages than critical ones)
 - Tell me about any spiritual experiences if any(taking time for prayer, meditation or reflection)
- (Transition: Let me ask you some questions in relation to your external relationships)*

(Steer the conversation to focus on relationships with family, friends, work)

- Tell me a bit about the role your family, friends and work colleagues have had
- Are you likely to speak openly with another individual in your daily life
- Are there playful and humorous aspects of your daily life
- Tell me about any experiences of Difficulties
- Does truthfulness play a role in all your interactions with others?

Appendix D**Consent Form**

I have read and understood the attached Information Leaflet regarding this study. I have had the opportunity to ask questions and discuss the study with the researcher and I have received satisfactory answers to all my questions

I understand that regardless of whether I consent to partake now, I can pull back whenever or decline to answer any question with no outcomes of any kind.

I understand that I am free to withdraw permission of data usage within two weeks after the interview, in which case the material will be deleted.

I understand that participation involves a min of 30 minute one to one interview.

I agree to my interview being audio-recorded.

I understand that all information I provide for this study will be treated confidentially.

I understand that in any report on the results of this research my identity will remain anonymous. This will be done by changing my name and disguising any details of the interview which may reveal my identity or the identity of people I speak about.

I understand that disguised extracts from my interview may be quoted in dissertation, conference, presentation, published papers etc

I agree to take part in the study

Participant's Signature: _____ Date: _____

Participant's Name in Print: _____

Appendix E

De Brief sheet for a study on
Understanding how individuals manage change post amputation in a holistic approach

Thank you for your participation in this research, The goal of this study was to Understand how individuals manage change post amputation in a holistic approach.

During the interview you were asked some semi structured questions and invited to share as much information as you were comfortable doing. The aim of the research was to identify areas outside the usual physical and biological changes which occur after amputation but to focus more on the holistic aspects.

Your participation is not only greatly appreciated by the researchers involved, but the data collected could possibly shed some light on a much neglected aspect of amputees lives. If you are feel uneasy or stressed.

If you need to talk to someone, here are a number of helplines you can contact for confidential non-judgemental support, you can make contact with one of the following:

Most helplines will provide a listening service, give information and advice, provide emotional support and point you in the direction of other services. They are often free-phone services which are staffed by trained volunteers or employees.

The Samaritans
The Samaritans
www.samaritans.ie
Tel: 116 123

Text: 087 2 60 90 90

Email: jo@samaritans.ie

Aware (Depression & Bi-Polar Disorder)
www.aware.ie
Tel: 1800 80 48 48

Email: supportmail@aware.ie

Irish Council for Psychotherapy (Counselling & Psychotherapy)
www.psychotherapycouncil.ie
Tel: 01 905 8698

If you have any questions about this study, please contact me
Researcher :
Or My Supervisor .

Appendix F

- Experiment Protocol
 - Patients in the hospital/clinic will be provided information sheets and consent forms
 - Those patients who wish to take part in the study will be invited to come forward
 - Those Participants will be welcomed to a private room for interview after signing consent forms.
 - Introduce myself, point out the listening audio device to the participant and make sure they're working. Ask warm-up or demographic questions first; then keeping the key interests in mind move on to more focused questions but allow flexibility in the dialogue.
 - Use probing questions to gather as much information as possible. Try not to interrupt participants; make a note and come back to the idea later.
 - If a participant gives an answer relating to a question you have not yet asked, record the answer and avoid repeating the question later.
- Keep the conversation focused on the main domains, avoiding tangents. Time is limited, so completing the entire interview guide may not be necessary. Instead, spend time on key factors, including what the participant is interested in speaking about.
- If time permits, ask the participant if there is anything else they'd like to share. Turning off the recording device before asking this question may lead to a different response.
- Thank the participants at the end of the interview
- Provide participants with the De-Brief sheet.