



"Five minutes can make a difference": a narrative analysis exploring amputees' experiences of support and community reintegration post limb loss

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ABSTRACT

More than one billion people in the world live with some form of disability. Nearly 200 million experience considerable difficulties in functioning (World health organisation, 2011). This has provided a motive for researchers to explore what difficulties disabled individuals experience, with a view to improve their lives. One area of study has been on individuals with limb loss, which is referred to as the ‘experience of parting with a limb of the body’ (Cosby & Miller, 1999). This is a difficult experience for the amputee but also to their family and social system. This qualitative study aims to explore the challenges amputees face when reintegrating into the community. Previous research specifically examining this subject has largely focused on the factors that impact upon adjustment following amputation (Atherton and Robertson, 2006). This study seeks to examine this further by exploring the challenges faced by amputees and the ways in which they can be supported in terms of social and psychological support to ensure successful reintegration which can maximise their independency. Six participants were interviewed using semi-structured interviews lasting for one hour each. Interviews were recorded and subjected to narrative analysis. From this three significant themes were identified; a different life, ‘they all rallied round’ and ‘it’s all from books’.

KEY WORDS:	AMPUTATION	CHALLENGES	SUPPORT	NARRATIVE	INTERVIEW
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Acknowledgements

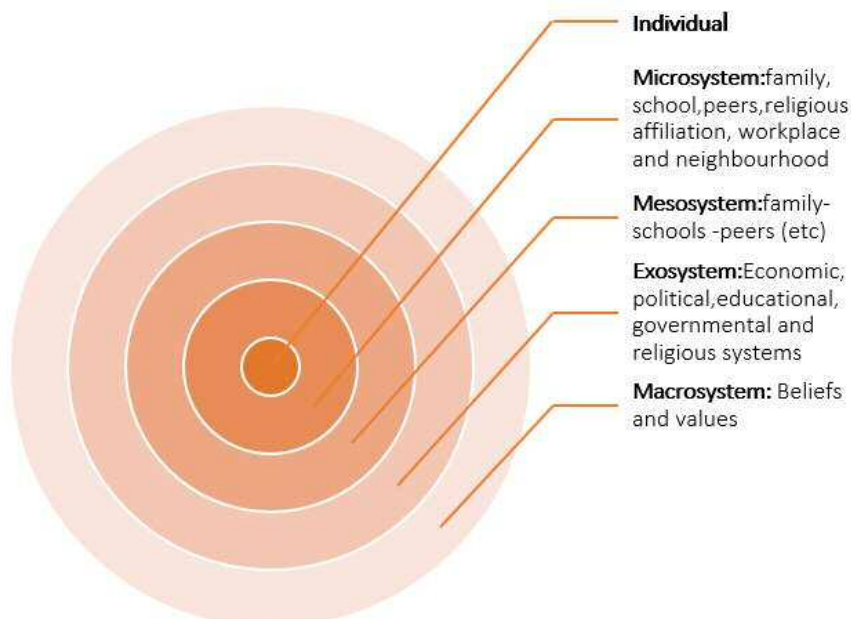
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Introduction

“More than one billion people in the world live with some form of disability, of whom, nearly 200 million experience considerable difficulties in functioning. In the years ahead, disability will be an even greater concern because its prevalence is on the rise” (WHO & World Bank 2011:11).

This has provided a motive for many disability researchers to explore the kinds of difficulties disabled individuals experience on a day to day basis. Looking at relevant disability literature, it is evident there is no firm agreement on how disability should be described (Edwards,1997; Oliver,2009; Boorse,2010). As opposed to this, competing definitions are proposed by some key models, such as the medical model (Brisenden,1986). This model assumes that limitations faced by disabled individuals are ‘resulting primarily from their impairments’ (Altman,2001:2). In contrast, social model of disability postulates ‘it is society which disables the physically impaired’ (Oliver,2004:2) and ‘disability is something imposed on top of our impairments by the way in which we are excluded from full participation in society’ (UPIAS 1976:14). However some theorists argue disability is a multifaceted issue as it can equally affect disabled individual’s social system (Maki and Tarvydas,2011). A relevant framework in support of this assumption is Bronfenbrenner’s(1979) ecological systems theory. According to Bronfenbrenner (1979), the environment is comprised of five nested structures which ‘interact in complex ways and can both affect and be affected by the individual’(Johnson,2008:2). These five structures include the individual, microsystem, mesosystem, exosystem and macro system (Skinner, 2010) (Figure 1).

Figure 1. Ecological systems theory (Bronfenbrenner, 1979)



This study makes use of Bronfenbrenner's (1979) model as a way of conceptualising the impact of limb loss on an individual and the individual's social system. In addition this study uses this model as a way of understanding how individuals with limb loss can be supported.

Background: Limb loss

Limb loss refers to 'experience of parting with a limb of the body' (Cosby & Miller,1999), and has been defined as 'removal of a body extremity by surgery or trauma' (Mohammed and Shebl,2014:1). Desmond et al.,(2012) outline pathways that may lead to limb loss; traumatic injury, disease (e.g.diabetes, malignant tumours, peripheral vascular disease) as well as congenital causes.Not only can limb loss be a difficult experience for the individual but it can also affect family and the social system around the individual.In certain situations amputation seems unavoidable, as it may need to be carried out for medical reasons to improve health and quality of life' (Sinha,2013:4).Kulkarni et al.,(2014) argue that although amputation may be regarded as lifesaving, individuals often experience long term negative psychological consequences 'which restrict them from reintegrating themselves into the society and living normal life '(Hagberg,2006:5).Behel et al.,(2002) outline that individuals with limb loss are faced with a number of physical, psychological and social barriers including issues with body image, changes in close relationships, occupation, lifestyle and having to deal with existing medical problems (Atherton & Robertson,2006).

Psychological well-being

Amputation can be a distressing experience likely to pose considerable challenges in terms of psychological and social adjustment (Cater,2012;Coffey et al.,2009).In terms of psychological well-being,Cavangh et al.,(2006) argued that depressive symptomatology is commonly experienced by amputees.Horgan and Machlan(2004) found that depression was reported by patients as being the reason for reduced levels of mobility and decreased use of their prosthesis.Also among individuals with long term amputations, studies have found a strong association between depressive symptomatology and factors such as high levels of activity restriction and feelings of vulnerability(Behel et al.,2002).Another factor that has been found to have an impact on amputee's psychological well-being is phantom limb pain (Helm et al.,1986), a 'painful sensation perceived in the amputated body part'(Ehde and Wergener,2008:1). In addition, phantom limb pain has been linked to a number of other cognitive and emotional outcomes such as stress (Jensen et al.,1983).

Body image anxiety

Furthermore limb loss has been found to dramatically change a person's sense of body image, which can consequently have an impact upon the amputee's quality of life and social adjustment (Saradijan et al.,2008). Early studies have discussed the occurrence of body image anxiety among individuals who have had amputation (Marshall et al.,1992;Freidman,1978).Subsequent studies have since found that there is a significant correlation between body image and life satisfaction, suggesting that the more negative an amputee feels about their body image the less satisfied the

individual is about their life (Breakey,1997).This decreased satisfaction has been attributed to the limitations in performing professional, leisure and social activities (Atherton and Robertson,2006).In addition qualitative studies have revealed that the desire to appear 'normal' in the eyes of others emerged as a dominant theme (Desmond et al.,2012). Murray(2005) also found that for prosthesis to be accepted it must have a 'pleasing appearance', which has been positively associated with increased social integration and absence of emotional problems.

Social support

Regardless of the impact amputation may have on the individual's psychological well-being research has also looked into the impact of various modes of support.Meier(2014) argued that support systems play a significant role in the reintegration of the disabled, and more specifically for amputees to reintegrate themselves into the community.Schoppen et al.,(2003) mentions that adaptation to limb loss is greatly influenced by the level of support and social care provided by a close network of friends and family.The importance of this support has also been emphasised by rehabilitation specialists, specifically during the post amputation phase (Frust and Humphrey,1983).Early Studies have revealed that high quality support after amputation is likely to enhance the psychological wellbeing of the individual by providing the emotional support needed to come to terms with this life changing experience(Elliot & Gramling,1990).These findings support Mosaku et al.,(2009) who argued that people who encounter a stable relationship, caring partner/spouse and a family with strong social support and affiliation will experience a decrease in the negative implications surrounding amputation.

Psychological support

Besides social support, research has also looked into psychological interventions such as counselling for individuals who have experienced limb loss.Wegener et al.,(2008) argues that attention to the psychological needs of persons with limb loss and their families is a vital part of comprehensive rehabilitation.However, there appears to be very little research exploring the experiences and importance of counselling for amputees. Price and Fisher(2002) found that counselling offered in the early weeks post amputation indicated a positive effect on the experience of practical problems.

Drawing on the wider literature, it has been argued that when looking at disability it is important to consider that 'having a disability does not necessarily imply having an emotional problem' (Oliver:1995:1).The assumption that becoming disabled can be psychologically devastating also infers that those who are disabled will therefore need counselling to come to terms with their 'losses' (Lenny,1993).However not all disabled individuals will take counselling (Crisp,2002) ,but those who wish to seek help from a counsellor want access to counselling which meets their perceived needs (McKenzie,1992).Nevertheless it is important to understand that those living with a disability may have other difficulties which they may wish to resolve through counselling such as the experience of living in a disabling society (Keith,1996).

The current study therefore aims to contribute to the qualitative literature by exploring the challenges amputees face when reintegrating into the community and to understand the importance of social and psychological support for amputees.

Research question

1. To explore the factors that hinder and facilitate the reintegration into the community after amputation surgery.

Research Aims

1.To gain an understanding of the various challenges that restrict amputees from reintegrating themselves back into the community and living their lives.

2.To explore how individuals who have experienced limb loss perceive their experiences of support after amputation in relation to psychological or social interventions that may have occurred.

3.To formulate a model of support for amputees from the participants feedback.

Methodology

Design: Qualitative design

A qualitative approach was taken to conduct this study which can be defined as a form of research 'that produces findings not arrived by its statistical procedures or by other means of quantification'(Strauss & Corbin,1998:11). The qualitative paradigm seeks to interpret and understand the world out there by accessing people's experiences (Atieno,2009) which enable us to explain phenomenon from the 'inside' (Flick,2007:36) .Limb loss is a life changing event that is likely to pose considerable challenges for the individual(Desmond et al.,2012), and therefore by using qualitative methods the researcher was able to gain a deeper insight into the meanings attached to individual's experiences, emotions and behaviours.

Narratives and disability

A narrative inquiry has been used to gain an understanding of the challenges faced by amputees and the kinds of support needed to facilitate their reintegration into the community. Telling and listening to people's stories has been considered to be the most powerful instrument we have for sharing our experiences and knowledge (Hyden and Antelius,2011). Stories can be referred to as a unique way of allowing us to see and experience the world through the subjective eyes of the participant (Bamberg,2010). Therefore stories are key tools for 'establishing, confirming and negotiating shared worlds'(Hayden and Antelius,2011:2). This method has captured the interest of researchers as it has facilitated voices of often underrepresented groups to be heard (Petalas et al.,2009). Recently researchers have argued that narrative forms of research can be of significant interest in the area of disability (Goodley and Tregaskis,2006).Smith and Sparkes et al.,(2008) mention that by gathering and examining the stories from individuals with a disability, it enables us to appreciate and describe the experiences as well as to contextualise it further in a political or cultural sense.

Participants

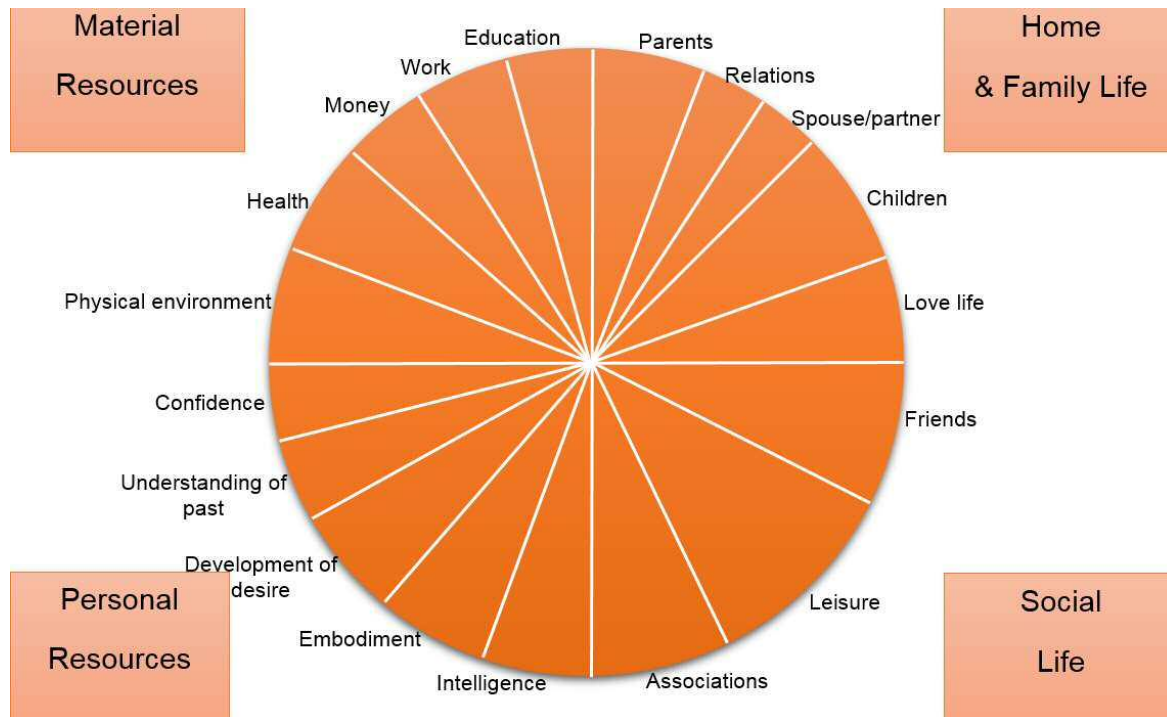
Six amputees were recruited; three of whom had amputation due to a disease, two because of trauma and one had congenital limb deficiency. Notably in qualitative research small numbers are more desirable (Baum,2002) and generally preferred because it allows the researcher to delve deeply into the individuals experiences(Alder,1987). Participants were recruited through a snowball sampling technique which yields a sample through the referrals made among people who share or know others who possess particular characteristics that are of research interest(Biernacki,1981). This aided the researcher in the recruitment of the participants who had experience of limb loss. Through a information leaflet of an amputee support group, the researcher was able to identify a possible group of participants who attend a local amputee support/fitness group meetings. Before proceeding further, permission was obtained from the gatekeepers of both groups (Appendix 1 and Appendix 2).

Data collection

Semi-structured interviews

Six one hour semi-structured interviews were carried out using an electronic recording device. Semi-structured interviews are executed using an open framework(King and Horrocks,2010) and tend to 'unfold in a conversational manner offering participants the chance to explore issues they feel are important'(Longhurst,2012:103). This method has been widely used to explore various issues in psychology such as the experiences of living with dementia(Mazaheri et al.,2013). This method was chosen because it provided the participant with the freedom to express their views in their own terms (Cohen,2006) which enabled the researcher to gain a deeper insight into the 'Psychological and social world of the respondent' (Smith, 1995:12).

An interview schedule (Appendix 3) was designed which consisted of key areas that were grouped thematically to be used as prompts. These served more as a guide rather than something that was strictly adhered to during the interview (Turner,2010). In order to devise the schedule, background research was used (Gibbs,2010) to aid the generation of open-ended questions related to the research topic (Laforest,2009). In addition, Smail's(2005) 'power mapping' technique (Figure 2) was adopted to help structure the interview schedule in terms of the areas that were intended to be explored when interviewing the participant (eg.relationship with family). This is a popular tool used in clinical settings whereby the client is encouraged by the therapist to recognise potential sources of social power in their lives and to access these resources as a way of reducing distress(Hagan and Smail,1997). Interviews took place at the site where the participant attended support group meetings or fitness sessions. According to Lindlof (2011) familiarity of the surroundings can put the interviewee at ease with psychological comfort.

Figure 2. Power Mapping (Smail, 2005)**Data Analysis****Narrative analysis**

Each interview was transcribed (Appendix 4) and a narrative analysis was used to analyse the data gathered. Narrative analysis can be described as a 'family of approaches to diverse kinds of text, which have in common a storied form' (Riesman, 2005:1). This method 'attempts to systematically relate the narrative means deployed for the function of laying out and making sense of particular kinds of, if not totally unique experiences' (Bamberg, 2012:78). This approach to analysis has been used to study areas such as organisational change (Beech, 2000) and more recently Vyver (2013) adopted the method to explore user perceptions of digital technology. This method allowed the researcher to 'construct and communicate meaning', as well as to 'capture the complexity of meaning embodied within stories' (Mitchell et al., 2003:3).

To analyse the transcripts Crossley's (2000), six analytic steps were implemented (Table 1). The first step involved reading through transcripts; familiarizing with material and to then identify any significant themes. Secondly, it is important to get a grasp of the principal concepts emerging from the transcripts. Mc Adams (1993 cited in Lyons and Coyle, 2007) suggests that these concepts can be identified by exploring the narrative tone, imagery and even themes. Crossley (2000) argues that narrative tone can be identified by looking at both what the individual has reported in relation to their experiences and also the way in which they have done so. In addition to the tone Crossley (2000) mentions that it is useful to look for both imagery and themes together

as certain kinds of imagery tend to be indicative of particular themes .After constructing a map of the various images, themes and tones from the data, the final step involved weaving all of this into a coherent story.

Step 1:	Reading and familiarising
Step 2:	Identifying important concepts to look for (specifically tone, imagery and themes)
Step 3:	Identifying 'narrative tone'
Step 4:	Identifying narrative themes and images
Step 5:	Weaving all of this into a coherent story
Step 6:	Writing-up as a research report

Table 1. Six analytic steps in narrative analysis

Ethical Considerations

Ethics refer to evaluation of behaviour in terms of right or wrong (Keith-Spiegel & Koocher,1985) and must be addressed at all stages of the research process when using human participants (Evans and Fitzgerald,2007). Prior to the research project an application for ethics approval form(Appendix,5) and an Ethics Check Form (Appendix,6) was completed and referred to the psychology ethics panel at Manchester Metropolitan University. This study adhered to the 'Code of Ethics & Conduct' set by the British Psychological Society (2010:10). When conducting qualitative research, there are a number of ethical considerations; informed consent, no deception, right to withdraw, debriefing and confidentiality (Willig,2008). Each participant was given a research invitation(Appendix,7) and an information sheet (Appendix,8).

Participants were informed that withdrawal during research was acceptable, and consent would be taken from them(Appendix,9). However, due to the sensitive nature of this research 'process consent'(Ramos,1989) was used instead of informed consent. This is because one-off informed consent is usually not acceptable in qualitative interviewing (King and Horrocks,2010). Participants were also told that their information would be partially confidential as data would be shared with the researcher's supervisor and would be stored safely on an external device to avoid accidental disclosure. Also data was anonymised using a unique personal code to ensure that identity was protected. After completing interviews all participants were

debriefed (Appendix,10). Moreover, an attempt to minimize psychological distress was considered as some of the topics in this study were sensitive and the way in which interview questions were framed was taken into account.

Social ethics

Various kinds of approaches to research determine their understanding of ethical practice which depends on what theoretical, cultural and moral ideology is used. This is why some researchers have been engaged in using social ethics (Code,1991). This form of ethical practice emphasises the importance that participants have in how research is conducted and may play a role in undertaking of the research(King and horrock's,2010).For example, one of the aims of the study was to formulate a model of support for amputees using feedback gathered during interviews. This makes research into social action with researcher and participants 'acting in the best moral interests' (shaw,1999) of both individual and community.

Analysis & Discussion

Narrative analysis provided a rich understanding of challenges faced by individuals who have experienced limb loss and different forms of support needed to facilitate an amputee's reintegration into the community. It revealed three significant themes: a different life, 'they all rallied round' and 'it's all from books'. Some of the themes have been divided into sub-themes which will be discussed with the use of excerpts taken from participant's accounts and discussed in relation to existing literature.

Narrative theme 1: A Different Life

'it stopped me from having a better life with my family'

Findings from this study suggested that living with an amputation may bring about several changes in one's life. Some participants expressed how their amputation was a 'barrier' to having a better life by not being able to engage in activities with their family. This was inferred from the way in which both P2 and P6 used language that connoted a barrier to participating in family life or to having a better quality of life, such as 'stopped' and 'obstacle'. This is illustrated in evidence provided below:

'... it stopped me from having a better life with my family to be quite honest with you like going on trips and days where we can do some walking...'(P2,L:212-213)

'...my amputation has been an obstacle for me from not being able to do many things with my family...'(P6,L:55-56)

This finding can be supported by past literature that suggests that families that are affected by a disability commonly experience a host of relational and recreational challenges(McDaniel and Pisani,2012;Rolland,1994). Both P2's and P6's experiences also support the findings from research exploring psychosocial adjustment to amputation which suggest that due to decreased functional mobility amputation can

have an impact on the individuals participation in activities of daily living and activities they enjoyed in their free time (Burger and Marineck,1997; Hamil et al.,2008). Also in terms of narrative tone a sense of frustration emerged from the way in which participants were narrating the challenges they had experienced with their family. For example P6 expresses how sometimes he would 'easily get angry' or feel 'down' because he was unable to interact with his daughter like a 'normal parent' which he found extremely difficult(P6,L:44-48).This supports Rolland (1999) who argued that when an illness or disability strikes a parent in the childrearing phase of life, serious strains can develop because the possibilities for meeting usual individual and family goals can become skewed.

Similarly P2 also expresses feelings of frustration but unlike P6 he discusses how he wishes to go abroad but mentions that his wife won't take him as she feels it would be 'too much trouble', suggesting loss of his limb may have become a burden upon his wife which in turn had an impact on his quality of life(P2,L:89-93). From P2's excerpt it can be inferred that limb loss not only has an impact on the individual but can also affect psychological well-being of the caregiver(Acton and Kang,2001).These findings also tie in with assumptions of Bronfenbrenner's ecological systems theory(1979) which postulates that individuals do not live in isolation and instead exist within systems such as their family(Orford,2008).Therefore amputation can be considered as a phenomenon not only unique to the person suffering but affects those involved with that individual.

Judgement

Another predominant theme that emerged throughout the participant's narrative was the impact limb loss had on the individual's body image and the awareness of physical difference to others. Although none of the participants raised any issues about their appearance, it was apparent that P3 in particular was concerned about her body image.

'...I think a lot of the confidence has got a lot to do with body image...you're aware that if you walk across some space people do look at you...'(P3,L:114-116)

'...it just doesn't look like a normal leg ...' (P3,L:100-101)

In contrast P1 held a very different viewpoint.

'...if people want to look they look...I'm not bothered about what other people think...'(P1,L:241-243)

Despite the mixed reactions regarding body image,P3's excerpts can be supported by the past literature which suggest that limb loss can change a person's sense of body image (Saradijan et al.,2008).It was also interesting to note how P3 used the word 'normal'(P3,L:101)When discussing about her appearance, which was also mentioned by P6 in the previous theme. It could be argued that perhaps participants are basing normality on the individuals around them or on what society construct as normal.

Serres(2001) mentions that the culture of normalcy demands disabled individuals to meet many unrealistic expectations, which can perpetuate the oppression of disabled communities by viewing them as individuals outside the norm(Madriga et al.,2011;Goodley,2007). The evidence also supports studies which have revealed that the desire to appear 'normal' and the awareness of difference in appearance emerged as a dominant theme (Desmond et al.,2012; Saradija, 2008);and that the appearance of the limb can play an integral role in establishing a positive body image (Gallagher and MacLachlan,2001). P3 also mentions that although she feels anxious about her body image she tries to 'compensate by trying to dress nicely' and 'put make up on'(line,L:102-107).This finding can be supported by Saradigan et al.,2008) who found that participants would use positive coping strategies in order to minimize the sense of difference. In addition, unlike the other participants P3 expresses how her body image had an impact on other people which can be inferred from the way she states 'real realisation':

'...I got up and they got up they just said 'ohhh' and just walked off...that was the worst thing ...that was the real realisation about what affect it can have...'(P3,L:76-78)

Novonty (1991) argues that the experiences of one's own body are the basis for all other life experiences, hence the disruption of body image caused by amputation can also have a significant and long lasting impact on the interactions with others (Desmond & MacLachlan, 2002; Rybarczyk et al.,1995).Based on the findings it can be inferred that disturbance to one's body image due to limb loss can have a significant impact on one's life. Also it is evident that not all amputees may experience issues with their body image which can be seen by the excerpts above. This can be supported by Rybarczyk and Behel (2008) who argue that for some, the transformative impact of amputation on body image may be tolerated with minimal distress while for others it results in long-lasting negative views about their body image.

'It's just difficult'

Participants continually throughout their narrative make a reference to some of the difficulties they faced as a result of the physical barriers in the environment. Through the participants experiences it was interesting to see how they created a world which was unique to them.It emerged that the participant's relationship with the outer world appeared to be disturbed by the barriers they faced in society which was experienced as a sense of exclusion from social activities.

'...there are no hand rails and if I do go down those steps and take a tumble I'm going to probably land in the pool...'(P5,L:154:155)

'...the gym hasn't been designed for us...'(P6,L:199-200)

Talley and Crew (2012) argue that problems related to having a disability often have as much to do with the deficiency in the environment as with the physical impairment itself. It can be argued that the participants above draw on the social model of disability(Lang,2007).In the context of amputation the social model of disability would

argue that limb loss does not determine disability, but that disability is rather caused by 'externally imposed disadvantage and social restriction'(Oliver and Barnes,1998:18). For example P5 builds a striking image of what could happen if he walks down the steps due to the absence of hand rails, which creates a sense of humiliation and embarrassment. The use of strong imagery emphasises the impact physical barriers can have on disabled individuals. Also the notion of social exclusion appears to emerge strongly through the experiences described by the other participants. Burchardt et al.,(1999) argues that social exclusion can take place when individuals who would like to participate in the 'normal' activities of society find that they are prevented from doing so due to the factors beyond their control.

'...we are trying to go to the normal gyms to make our self better but the government ...now they are saying no we can't do that now we cannot afford... so now where do you put them (pause) you want to help them be part of society and then start making cuts...these are the barriers...'(P6,L:169-172)

'...I feel that if I get these facilities then I can feel like any able bodied person and I think more needs to be done...'(P6,L:316-317)

From P6's excerpt a sense of anger also emerges as the cuts being made by the government and council to public services such as the gym are marginalising their efforts to become part of society. Therefore it can be concluded that more efforts should be made in order to prevent the marginalisation and exclusion of people living with a disability such as limb loss. Furthermore it was apparent that some of the participants experienced a sense of exclusion within their friendships.

'...you find that what used to be your friends err back off a little bit...'(P1,L:89)

'...my worst experience ...is that when people talk to you and when you're sat down and they think ...you're able bodied and then when you get up and walk away their attitude changes...'(P3,L:43-46)

Weiner and Freedheim(2003) found that when an individual suffers from an illness or disability the nature of most of their social relationships in which he or she is engaged to changes dramatically. This can be seen from the way in which P1 and P2 expressed how they felt that their friends had 'backed off' or 'pushed them to one side'(P2,L:117). In support of this, studies looking at amputation and relationships found that individuals with an amputation were given significantly greater social distance and were treated differently by those without an impairment. Studies within the disability literature have suggested that one of the most disabling aspects of physical difference is the change in attitudes of others towards disabled individuals (Winchell,1996), which supports the experience described by P3 above. Based on these findings it can be inferred that although the individual is having to cope with the loss of their limb, loss is also experienced in the form of being excluded from society and in social relationships.

Narrative theme 2: 'they all rallied round'

Regardless of the challenges amputees face after their amputation, the study revealed interesting findings about the participant's experiences of support. Within the participant's narratives stories of support emerged which highlighted the importance of social support from friends and family.

'...I think family support is very important because without that I don't think you'd be able to do anything well that's for me but I think by having strong support from your family can make a huge difference...'(P1,L:371-373)

'...I had terrific support and I think that support from my friends helped me a lot...'(P5,L:186-187)

The evidence appears to be consistent with the literature which suggests that support systems can play a significant role in the integration of amputees into the community (Meier,2014). The importance of the support provided by friends and family during the post amputation phase has also been emphasised by rehabilitation specialists (Frust and Humphrey, 1983; Schoppen et al.,2003), as the presence of high quality social support is likely to enhance psychological well-being by providing the person with the emotional support needed to come to terms with this life-changing event (Williams et al.,2004). The participants also spoke about how by speaking to other amputees through a local association for amputees had helped them, as it allowed them to share information and learn from each other's experiences.

'...we all speak to one another and if there are any problems we help each other and that's how we get a lot of our information really...'(P1,L:344-345)

'...it's surprising what you learn when you come here talking to everybody whose an Amputee...'(P2,L:318)

The experiences described above, supports Liu et al.,'s(2010) finding that peer support for amputees can be helpful in providing relief from emotional distress and reducing isolation. Also the evidence appears to be consistent with Damen et al.,(2000) who concluded that peer support provides complementary sources of support through information sharing that allows both educational and emotional support for individuals. In addition, some participant's emphasised how peer support made things a lot easier as their peers were coming from a point of their experience (P4,L:157-162). P4 also explained how someone who attended a support group meeting had expressed how he felt that he learnt more by attending the group than from what he had learnt from the health care professionals (P4,L:288-290). Mead and McNeil(2006) argue that peer support is tremendously important as people who have similar experiences can better relate and can offer practical advice and suggestions that professionals may not be able to offer. This highlights the importance of forming relationships with others who have been in the same situation (Grech and Debano,2014).

Furthermore it is interesting to note how the participants expressed the need for support provided to the family prior to and after amputation. Participants emphasised how the caregiver which in most cases was the wife should be involved in the rehabilitation of the individual who had amputation(P4,P2,P3).Also it emerged that social interventions such as support groups for amputees were beneficial to the family members.

'...it was like my wife (pause) they never told her anything about it err how to cope with it and things like that (pause) it were like people like B's wife who spoke to my wife and B spoke to me (pause) but that helped us a lot ...'(P1,L:102-104)

P4 describes that the reason for setting up the amputee support group was due to the lack of support provided for the family or caregiver of the amputee:

'... when I met big S and one or two more and I was talking to his wife and she was telling me that when S had his amputation at NM err nobody said a word to her an I mean nobody ...personally I think err I thought to myself people should be supported ... because the spouse has to do things that she may not want to do...'(P4,L:132-137)

Gallagher et al.,(2011) argued that amputation can have a significant impact on the amputee's family and therefore we must consider the role and well-being of the amputee's carer. Research also indicates that caregivers are often in need of social support and may benefit from the association with people who had similar experiences (Schinking et al.,2014;Tang,2008).Similarly Washington(2013) suggest that support groups for amputees are a valuable source of support as they provide opportunities for the individual and their family to network with others with similar problems and experiences.

The evidence also supports findings from recent studies of ecological analysis and disability which contextualise the individual within a series of nested and interconnected structures (Michailakis,2010;Bronfenbrenner,2005) such as the family who are equally affected. Also from the way P4 describes how 'the spouse should be supported because it's a joint thing' (P4,L:136-138) highlights the importance that the caregiver has in the care of the amputee. In addition it is interesting to note that the kind of family support the participants constructed within their narratives is not the formal support you would expect from a professional, but is the more social support based on groups which involves strengthening ties within networks (e.g. with the wife). Therefore this suggests that more must be done to address the importance of social support for the family/care-giver of the amputee to facilitate successful rehabilitation.

Narrative theme 3: 'it's all from books'

Throughout the narratives it emerged that none of the participants had received any counselling but said that if it was offered to them they would have happily taken the support. In addition they had also expressed that they could have benefited greatly from access to counselling and emotional after care at an early stage.

'...I definitely think that at the beginning I could have done with a bit of you know somebody to talk to...'(P1,L:310-312)

'... it would have helped me...especially on that day when the doctor came err the consultant turned round and said you are going to lose your leg and then turned and walked out with no explanation....that was really hard...really hard'(P4,L:281-283)

This supports McKenzie(1992) who studied the need of counselling for the disabled and found that majority of the participants felt that they could have benefited from counselling at a very early stage. Participants also perceived that other professionals such as doctors or nurses were important sources of psychological support. They expressed that it would be helpful if professionals take time to talk to them after their amputation (P4,L:337-338). Also it is interesting to note how P4 repeats the phrase 'really hard' when narrating his experience at the hospital when the doctor had not given any explanation regarding his amputation. The use of repetition allows us to visualise how frightening it must have been for P4 when he found out that he would be losing his leg, and especially when the doctor had not provided any emotional support. This supports Eldar and Jelic(2003) who emphasised the importance of early involvement of rehabilitation health professionals who can provide useful advice and support. Although it was apparent that participants would have benefited from counselling or emotional support, it was interesting to note how most of the participants felt that they would rather be counselled by someone who had been through a similar experience.

'...if counselling is offered I think it should be offered from someone whose been through it ...'(P5,L:329-330)

Participant 6 also held a similar viewpoint, but describes how a counsellor who hasn't gone through the same experience will not be able to relate to them properly.

'...it's just like training someone to swim you have to be able to swim to teach people to swim...someone who has never taken the journey of like going through trauma and you want them to speak to someone who hasn't been through trauma is different because you don't understand how I might feel...'(P6,L:297-300)

It is evident that participants feel that a counsellor would have little understanding of the problems that may arise after amputation. It was also interesting to note how participants referred to the counsellor as 'someone who just gets everything out from the books' (P6,L:293-296). This particular reference made by the participants embodies the notion of subjectivity vs. objectivity. It can be argued that the participants perceive the counsellor as a professional who may be too objective or too distant, by not having that area of subjectivity or personal experience of disability. Also the counsellor is being viewed as someone who won't be able to understand what it is like

to be disabled and therefore unable to understand the needs of this particular client group (Oliver,1995).This can be seen from the way P6 describes his amputation as a 'journey', perhaps suggesting that to be able to relate to someone who has been through trauma you must be able to understand what it is like to go through trauma .Another interesting finding was that some of the participants felt that it was important for the professional or counsellor to understand that every amputation is different(P6,P5).

'...I believe that every amputation is different because no two amputations are the same and maybe that needs to be considered...'(P4,Line:293-294)

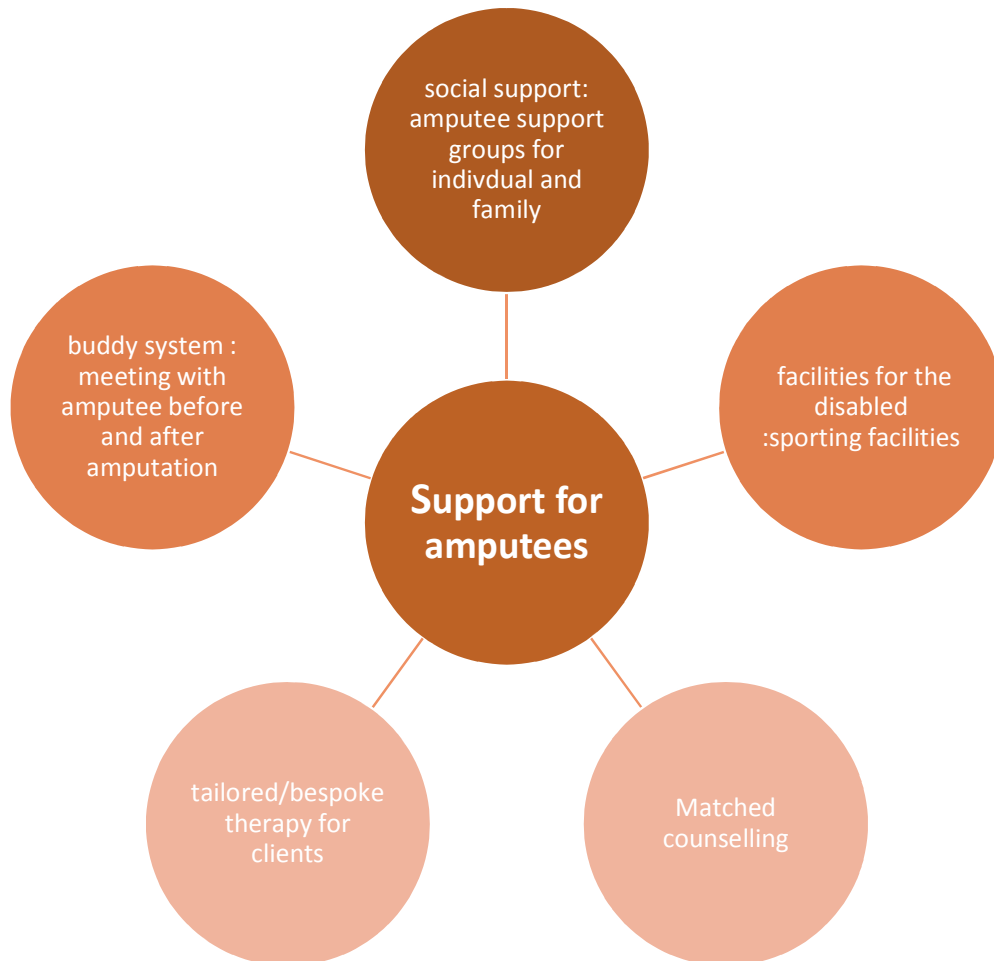
From the excerpt it can be inferred that the participants would like to be considered as a unique individual with a unique experience. Based on this finding it is interesting to note that the kind of psychological support they are describing places an emphasis upon looking at the individual as a whole in understanding individual differences within a particular context,as opposed to operating with diagnostic systems (McGartland and Polgar,1994;Crisp,2002). This draws on another major dimension of this debate, formulation vs. diagnosis. Crisp(2002) argued that typically most professionals work with patients in an objective way within the medical model. However not all professionals practice within this model and instead work from the clients story by focusing on the insider's perspective in which the individual is also regarded as a contributor in the rehabilitation process (Wright,1983;Zimmerman and Warschausky,1998). This also emphasises the importance of formulation, an approach commonly used in psychotherapy which involves making sense of a person's difficulties in the context of their relationships, social circumstances and life events (Johnstone,2006). In terms of amputation this could suggest that the participants want the human side of their amputation to be recognised by focusing on the whole individual, rather than focusing on their limb loss alone which is connected to other aspects of their life.

Model of support

From the participant's feedback, a model of support was constructed to understand what kinds of support would be beneficial for individuals with limb loss (Figure,3).What became clear through all the interviews was the importance of social support for both the individual and family/carer, as participants had strongly expressed the need for more support groups/societies for amputees.Secondly some of the participants pointed out the need for more fitness facilities exclusively for them which would not only improve their mobility but would contribute to their psychological well-being.In terms of psychological support it was apparent that even though participants felt that counselling would be most useful during the early stages after amputation, the need to talk to someone who had been through a similar experience was strongly expressed. For example P5 mentioned how a below knee amputee should speak to someone who also had a below knee amputation(L:347-349), suggesting that patients would benefit by having a meeting with a 'matched' user. Similarly participants suggested the usefulness of a 'buddy system', which would involve speaking to an amputee prior to and after the surgery.From this feedback it is evident that support given by other amputees may possibly play a vital role in the rehabilitation

process. Another point which was raised was the need for health professionals to be more compassionate towards them and to take time to talk to them before and after their amputation. In terms of recommendations perhaps future training for health and allied professionals should incorporate disability awareness training.

Figure 3. Model of support designed using participants' feedback



Reflexivity

Reflexivity is essential in qualitative research as it allows the researcher to justify their assumptions based on their positionality (Mauther and Doucet, 2003). The whole conceptualisation of this project arises from my engagement with communities of individuals who have experienced limb loss both here and in India. My exposure to individuals who have experienced limb loss and helping them in the community has also influenced the concept of this project as one of the aspects this project explored was how the participants perceived their experiences of support after amputation. Also I feel that this pre-established knowledge and involvement with amputees had sensitized me to the topic areas that were being discussed during the interviews, which influenced the way particular questions were asked. In addition, a rapport was developed prior to the study by attending several support group meetings. It was also very heart-warming to hear participants express that they found the interview very

therapeutic, perhaps this had given them an opportunity to voice their own experiences and emotions in relation to limb loss. Furthermore one thing that was noticeable was that most of the participants were males and maybe this could be an area of exploration for future research which could look into the experiences of limb loss and the importance of support for women who have had amputations. Overall this research has shed light on interesting evidence and has provided me with new understandings of the challenges faced by individuals with limb loss and the importance of both social and psychological support.

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