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Review Article

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Life after Lower Limb Amputation: A Meta- Aggregative Systemic Review of the Effect of Amputation on Amputees

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ABSTRACT

Purpose: To explore the lived experience of lower limb amputees with respect to their lives following amputation, both before as well as after using prosthesis. **Materials and Methods:** Meta-aggregation of qualitative studies in the field of lower limb amputation was conducted utilizing the Qualitative Assessment and Review Instrument (QARI) designed for the synthesis of qualitative research by the Joanna Briggs Institute, 2011. The searches were carried out between September to November 2019. The reviewed studies had samples consisting of adult having lower limb amputation and prosthesis use. A total of 68 potentially relevant papers published in the period starting from 1978 to November 2019 were identified and finally eight papers were included for the meta-aggregation. **Result:** The meta-synthesis of the findings from the eight studies considered derived three major themes, i.e., amputation as a sense of exclusion from life, embodiment of new self-identity and prosthesis enabled identity. **Conclusion:** Lower limb amputation affects the physical as well as psychological well-being of an amputee. This review also features the importance of prosthesis in the life of lower limb amputees in reviving them from the negative impacts of amputation.

*Keywords: Phenomenological study, lived experience, lower limb amputation, prosthesis, qualitative study, embodiment of amputation_*

INTRODUCTION

Amputation of limb is a medical procedure in which there is partial or complete removal of a limb. The various reasons of amputation include tumours, gangrene, and intractable pain, crushing injury or uncontrollable infection (Fremgen & Frucht, 2009). It has been estimated that there are roughly 0.62 amputees in India per thousand populations (Mohan, 1986). This translates close to one million individuals with amputations in the country. Lower limb amputation accounts for 94.8% of all amputations. According to the guidelines and gazette notification issued by ministry of social justice and empowerment on December 23 (2011), permanent physical impairment (PPI) for person with lower limb amputation corresponds to a disability level of 70% or above in case of below knee amputation and 85% or above for above knee amputation. Lower limb amputation not only affects a person's ability to walk, but may also decrease his participation in other important and valued activities.

Amputation is an extremely stressful psychological experience and the prevalence of psychiatric disorders among amputee's ranges from 32% to 84 % including depression rate of 10.4%-63%, post-traumatic stress disorder 3.3%-56.3% (Sagar et al., 2016), compared to 10-15% in the general population (Williams et al., 2004). This condition is likely to have adverse psychological impact like lowering his self-confidence due to a feeling of inadequacy, developing a negative self-concept with a disturbed perception of his body image, and on the whole, affecting his quality of life (Williams et al., 2004). Research in the field of amputation reported that traumatic loss of a limb is typically equated with loss of spouse, loss of one's perception of wholeness, symbolic castration, and even death (Behrouz et al., 2013). This may result in the patient being severely affected emotionally and thereby lowering her/his quality of life. Depressive disorders resulting mainly due to multiple factors such as feelings of loss, self-stigma, and difficulty in coping up with the impairment are common among these individuals (Behrouz et al., 2013; Williams et al., 2004). The person's distress is not only due to the loss of a body part but also due to the role limitation and the need for adjustment to the changed lifestyle options. Amputation makes people to face with severe physical and mental and social challenges such as impaired physical function, pain, change in employment and job status, consequently affecting their emotional well-being.

Amputees may have a negative self-image or self-esteem due to their perceived inability to contribute to the society, and the resultant feeling of worthlessness, though many of them have

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overcome their disability by living a life with minimum dependence on others with the use of artificial aids. According to the WHO's report (Geneva, 2011) on disability, assistive devices are powerful element in improving an amputee's independence and thereby enhances participation in society. Prosthesis is one such effective assistive device. According to International standards organization (ISO 8549 Part 1, 1989), prosthesis or prosthetic devices are externally applied devices used to replace wholly or in part, an absent or deficient limb segment. Lower limb prosthesis facilitates mobility, independence and capability for an active life in a disabled person (Jarnhammer et al., 2017). This sense of independence certainly enhances an amputee's self-esteem and self-image (Khademi et al. 2011; Mosaku et al. 2008). Another study by Andregard, and Magnusson (2017) also supports the fact that prosthetic devices are vital for persons with disabilities as they perk up their dignity. But it is not clear whether prosthesis use can wipe out all the negative impacts of amputation.

A body of quantitative research related to amputation and its effect as well as challenges has now been accumulated which provides statistical details in this area. However, these approaches do not provide an understanding of what it is like to live with lower limb amputation and prosthesis use there after (Horgan & MacLachlan, 2004). It is not possible to summarize human phenomena in the form of mathematical formulas (Speziale & Carpenter, 2007). Therefore, to achieve deep inner reality of human beings, more appropriate qualitative research strategies are required. In fact, qualitative approach to research methods facilitates the analysis of human experience, in relation to their culture and social phenomena (Jorden et al., 2006). The present systematic review intends to synthesize the findings of eight qualitative research studies that have examined the impact of lower limb amputation and subsequent prosthesis use in adult samples. For obtaining a holistic picture from eight discrete studies we chose to use the technique of Meta synthesis. Meta syntheses or meta-aggregation of qualitative studies have been found to be helpful in integrating the findings of different qualitative studies, particularly for informing important aspects of evidence-based healthcare in a practical decision-making context (Lockwood et al., 2015). The present paper posed the following questions: (a) what are the difficulties faced by lower limb amputees after amputation, and (b) what is the effect of prosthesis use on the life of lower limb amputees. The recommendations derived from these meta-aggregations aim to identify the key implications for the design, organization and delivery of health rehabilitation services to meet the needs of this population.

Phenomena of Interest

The present review is undertaken to focus on the lived experiences of lower limb amputees after amputation, both before as well as after prosthesis use.

METHODS

This study utilizes meta- aggregation to collate the findings of some qualitative studies published in different journals. We used the method outlined in the Qualitative Assessment and Review Instrument (QARI) designed for the synthesis of qualitative research by the Joanna Briggs Institute (2011). This incorporates a critical appraisal scale, data extraction forms, a data synthesis function and a reporting function.

A total of 68 potentially relevant papers published on amputation in different journals during the period starting from 1978 to November, 2019 were identified (searched between September to November 2019) out of which 38 papers were excluded after initial evaluation of abstract and 13 were excluded after more detailed scrutiny as they were not within the area of interest. The remaining 17 papers were critically appraised and nine were further excluded on the basis of method of study they employed. Finally, eight papers were included for the meta aggregation. The total procedure of selection of papers is shown in the Figure 1. The steps involving the inclusion and exclusion of papers are described below.

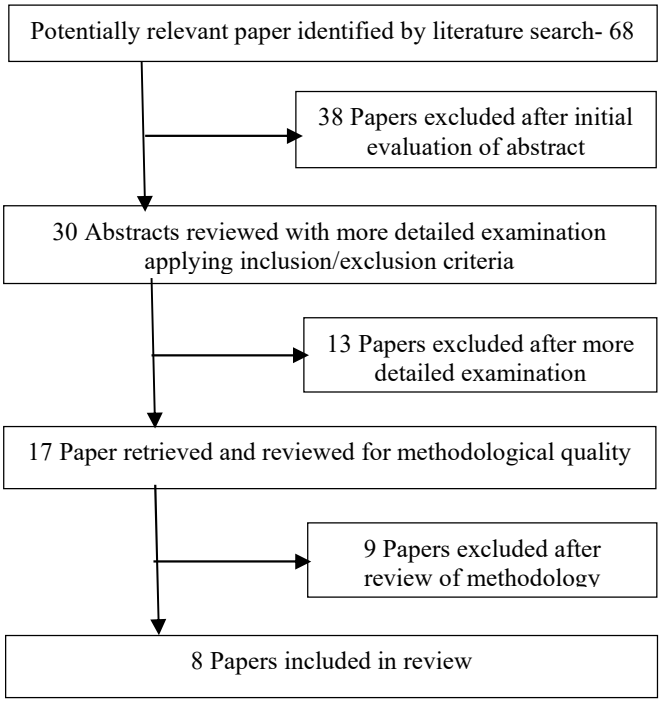

FIGURE 1. FLOW DIAGRAM FOR INCLUSION OF PAPERS IN THE METASYNTHESES

INCLUSION CRITERIA

Types of Studies: This review considered studies that focus on qualitative data, including but not limited to designs, such as phenomenology, grounded theory, ethnography and hermeneutics.

Participants: The reviewed studies had sample consisting of adult having lower limb amputation and prosthesis use. The studies included participants with varied etiology and level of amputation.

EXCLUSION CRITERIA

Papers which focused on the experience of phantom pain only or dealing primarily with patient's evaluation of the service and studies conducted on both people with and without amputation were excluded from this review.

Search Strategy

The search strategy included electronic search engine database: Pubmed and Google Scholar. The key words for the search were phenomenological study, lived experience, lower limb amputation, qualitative study, embodiment of amputation, prosthesis. The searches were carried out between September to November 2019. Searches were independently conducted by authors. In addition, further studies were identified from the cross references. Unpublished material and non-peer reviewed material were not included as a part of the review, nor were hand search of libraries conducted. The aim of the search strategy was to obtain all qualitative studies published in peer-reviewed English language journals.

Quality Appraisal

All studies that met the criteria for inclusion were selected for retrieval. They were then assessed by two independent reviewers for methodological validity using "The Joana Briggs Institute Critical appraisal instrument" prior to inclusion in the review. This enabled the reviewers to determine which studies were of suitable methodological rigor and whether they had been granted ethical approval for inclusion in the review. No disagreement arose between the reviewers and therefore, there was no need for these to be resolved by a third reviewer. Had a disagreement been occurred, a third reviewer would have to resolve this.

Data Extraction

Data extraction in meta-aggregation is a multi-phase process. First, the general details of the studies including the citation detail, the population, phenomena of interest, context, methodology, methods, settings and cultural information were extracted. Then each extracted finding was accompanied by an illustration from the same study. Findings of the studies were categorized as unequivocal, equivocal or unsupported. Unsupported findings did not appear in the review. Studies with unequivocal and equivocal findings shared equal recognition in the synthesis. Regular meetings of the two reviewers were held to cross-check the data and provide a decision trail for the review with minimized errors (Pearson et al., 2004; The Briggs Institute, 2011).

Data Synthesis

Meta-aggregation uses a three-step approach to thematic analysis. First, extraction of all the findings from the included studies was done. Then in the second stage, all the findings were categorized in such a manner that at least two findings in each category could be developed. Finally, meta syntheses of all the equivocal and unequivocal findings were done and organized according to themes (The Briggs Institute, 2011).

Result

From the review of eight finally selected studies, a total of 55 different types of participant responses could be identified which were again classified into seven categories. These categories of responses were discussed under three broad themes, for example, immediate emotional reactions following amputation, gradual acceptance of their new identity as amputees and an enabled identity following prosthesis treatment.

Theme 1 Amputation - A Sense of Exclusion from Life: During the pre-amputation phase and within a few days to several weeks following amputation, the lower limb amputees generally experienced a high degree of fear and uncertainty related to their future. Although they intellectually accept and appreciate that amputation was the best medical option, they struggled to accept the decision emotionally. They felt a sense of exclusion from normal life, as suddenly their future perspectives get scattered in the circumambient darkness of uncertainty. The review documented a total of 11 different experiences mentioned by the participants which suggest a sense of exclusion from life, mainly resulting from the amputee's disturbed relationship with his world. However, this feeling may develop in two stages, first comes a feeling of denial and helplessness followed by a sense of social rejection and isolation.Before discussing the themes of findings, below is given a summary of the qualitative studies considered for this meta-synthesis in Table 1 which also provides information relating to the research objectives, design and method followed as well as participants' characteristics of each study.

Category 1.1- Feeling of Shock Unreality, Helplessness and Fear: Loss of limb is a huge trauma and amputee feels his life has totally crumbled and crushed (Sjodahl et al., 2004). The sudden change from being healthy to being seriously injured or ill is drastic and overwhelming. Lower limb amputation is followed by a feeling of hopelessness, helplessness, vulnerability, anxiety and exhaustion as they don't have control over the current situation (Sjodahl et al. 2004; Williams et al. 2010). Amputation is perceived as a shock and the amputees have feelings of unreality, helplessness and fear (Senra et al., 2011; Sjodahl et al., 2004), sadness, insurgence, non-acceptance of the situation, anger, and suicidal thoughts (Senra et al., 2011).

Category 1.2- Sense of Isolation and Social Rejection: The immediate shock reaction is associated with avoidance and denial. The amputees felt physically helpless and dependent on help from others (Liu et al., 2010; Sjodahl et al., 2004). There were changes both in the inner and outer relational life. There was loss of independence, inability to perform basic skills and daily activities (Senra et al., 2011), inability to return to professional life and change in their affective sexual life. All these leads to various emotional reactions, such as anger, anxiety, depression, fear, sadness and sorrow (Liu et al., 2010; Sjodahl et al., 2004). This new situation implied feeling of frustration which was a source of irritability (Senra et al., 2011). They even sometimes felt mutilated (Sjodahl et al., 2004).

All these lead to a sense of endless suffering, social loneliness leading to emotional collapse (Liu et al., 2010). They had difficulties in expressing their feelings to their family and friends, as they presumed that their suffering cannot be understood by anyone else. These unexpressed emotions and grief lead to a feeling of isolation abandoned by others and social rejection.

Theme 2- Embodiment of New Self-Identity: The post amputation period is a phase of transition in terms of embodiment of new self-identity. This transition is between being identified with impairment and negotiating with their new identity (Senra et al., 2011). To accomplish this new identity the amputee endures psycho-social and physical challenges and adjustments. The adjustment process includes change of self-image, social isolation, despair and struggle to accept this new identity as physically impaired (Norlyk et al., 2013). The studies reviewed recorded 26 different statements which indicate the participants' difficulties in accepting their new identity of a disabled person. The rehabilitation process should be directed towards addressing this phase by proper counseling, so that the amputee is able to accept the embodiment of amputation. This theme again could include three categories of feelings.

Category 2.1- Living with Reduced Body/Immediate Practical Problems: Loss of leg leads to limitation of action space, loss of freedom and disruption of amputee's social world. The world around him suddenly became different (Norlyk et al., 2013). Everyday actions, which were formerly taken for granted, presented themselves as a challenge due to the reduced body (Norlyk et al., 2013; Sjodahl et al., 2004). Trivialization and negative attitude from others in the community towards their impairment further narrows their outlook (Bragaru et al., 2013; Oaksford et al., 2005). Approaching the world with a lost limb is a struggle which requires constant and continuous effort in order not to give upon life (Norlyk et al., 2013; Senra et al., 2011). A more holistic approach is needed to address the consequence of losing one's mobility. The amputee had lost the ability to live the body unreflectively and therefore viewed the world through their reduced body.

Category 2.2- Negotiating with the New Identity: The initial phase of struggling with a reduced body is gradually replaced by a phase when the person tries to negotiate with his new identity (Senra et al., 2011). Family and friends played a major role in motivating the amputee and accepting the amputation (Bragaru et al., 2013). They were forced to learn to live with amputation, although they still could not accept it (Norlyk et al., 2013). The transition of accepting the new identity as a lower limb amputee is accomplished with uncertainty for the future (Ostler et al., 2014).

Category 2.3- Positive Reframing and Psychological Growth: One of the most important coping strategies in everyday life is downward comparison. The amputees used to compare their life to the more ill or more unfortunate as a coping strategy (Sjodahl et al., 2004). The possibility of sharing experiences with others having amputation helped in positive reframing and psychological growth (Bragaru et al., 2013; Sjodahl et al., 2004). The degree to which these coping strategies are affirmed by the amputees may vary depending on the length of time elapsed since amputation. The positive reframing and psychological growth prepare the amputees to face the life after amputation with a more realistic and optimistic approach.

Theme 3- Prosthesis Enabled Identity: The loss of limb is associated with potential loss of a sense of physical wholeness. After two- or three-months post-surgery, wearing of prosthesis ignites a gleam of hope in the amputees (Järnhammer et al., 2017; Liu et al., 2010). Though lower limb prosthesis may not help in restoring physical wholeness, but it is appreciated for restoring aesthetics which has a positive effect on self-esteem (Liu et al., 2010; Senra et al., 2011). Walking independently not only helps in restoring independence of performing basic skills and activities of daily living but also provides hope for employment. The ability to earn his livelihood by the use of prosthesis has a positive effect on self-image. The level of independence influences body image (Järnhammer et al., 2017) and self-esteem. Thus, prosthesis enhances independence and self-identity of lower limb amputees. A total of 18 findings lead to the development of two categories, which were further synthesized in to prosthesis enabled identity.

Category 3.1- Prosthesis Restores Physical Independence: The loss of mobility reduces the life-world of the amputees. The most significant expectation of a lower limb amputee is returning to normality, which can be described as being able to walk. The prosthesis helped them in being more mobile and regaining independence to a great extent (Ostler et.al 2014; Sjodahl et al. 2004). The use of prosthesis is associated with restoration of maximum independence(Liu et al., 2010). The use of prosthesis ignited hope and became a lifeline to resume their former active life. The amputees were able to walk again and become independent and returned to the previous life (Järnhammer et al., 2017; Norlyk et al., 2013; Senra et al., 2011).

Category 3.2- Prosthesis for Re-Establishment of Meaningful Role in Life: The use of prosthesis provided amputees with an opportunity to develop skills for suitable employment and an income. Using prosthesis and being mobile re-established the amputee in different spheres of life. The amputees became able to travel and participate in social events once again (Järnhammer et al., 2017). They were able to participate in sports and leisure related activities (Bragaru et al., 2013). Prosthesis enabled the user to sustain a qualitatively better life with a respectable position in family as well as in society, thus, living a meaningful life.

Below is given a summary of the qualitative studies considered for this meta-synthesis in Table 1 which also provides information relating to the research objectives, design and method followed as well as participants' characteristics of each study.

Table 1. Summary of Information of the Studies Included in the Metasynthesis

Author/s of the Study and Country	Research question/ Objectives	Methodology	Participants
Author- Sjodahl, Gard, &Jarnlo (2004) Country- Sweden	1. To describe and understand the experiences of relatively young TF amputees. 2. To know their coping strategies in the acute phase and over time	Design- Phenomenological approach Method – Single Semi structured interview were conducted	Sample - 11 TF amputees;Age- 16-30 years (median age 33.5);Cause of amputation: 5 females & 1 Male- Tumour, 3 males- motorcycle accident, 1 male- accident in grinding machine; Amputation was done in median 7.5years before the interview.
Author- Oaksford, Frude, Cuddihy, (2005). Country- South Wales, U K.	1. To explore how individuals, cope with a lower limb amputation. 2. To examine the influence of positive coping on their stress-related psychological growth on adjustment.	Design- Grounded theory Cross-sectional design Method- Single semi-structured interview was conducted.	Sample - 12 Lower limb amputees; Age- 51-83 yrs (mean = 67yrs); 2 females 10 males Cause of amputation: vascular, Diabetes mellitus, Trauma
Author- Liu,Williams, Liu,Chien,(2010) Country-Taiwan	To understand the lived experience of Taiwanese people with lower extremity from pre-amputation phase to six months after surgery.	Design-Phenomenological analysis.Method- Two-in depth open-ended interviews with each participant were conducted.	Sample - 22 amputees; BK amputee- 77.3%; Mean age- 70.6 years (SD- 8.09 Range- 56-84); Male- 68.2% Cause of amputation- not mentioned
Author- Senra,Oliveina, Leal, Vieira,(2011) Country-Portugal	To explore the experience of lower limb amputation with a special focus on the change in individuals' self-identity	Design- an exploratory cross-sectional using qualitative methods Method-Two face to face interviews were conducted.	Sample - 42 adults (35 males, 7 females); Mean age 61 yrs. (SD=13.5); 61% TT amputation; Cause of amputation- Vascular disease in 83% sample, Oncologic disease and trauma
Author- Norlyk, Martinsen, Kjaer-Petersen, (2013) Country- Denmark	To explore the lived experience of losing a leg as described by the patients themselves after discharge	Design- Reflective life world research Methods-Two in-depth interviews with each participant.	Sample -12 participants (8 males 4 females); Age- 33-87 yrs. 8- TF amputation 4- BK amputation
Author- Bragaru, Wilgen, Geertzen, Ruijs, Dijkstra, (2013) Country- Netherland	To identify the barrier and facilitators that influence participation in sports for individual with lower limb amputation.	Design- Phenomenological approach Methods- one Semi-structured interview	Sample - 26 participants Male 1(non- athletes) Female 3(non-athletes) Male 9(athletes) Female 4(athletes) Cause of amputation- not mentioned.
Auther- Ostler, Ellis-Hill,Hall (2014). Country- Southampton, UK	To explore the expectation of patient immediately after undergoing lower limb amputation regarding the prosthetic limb, rehabilitation process and the outcome of rehabilitation	Design- Qualitative approach Method- Single interview was conducted	Sample - 8 participants (6 males 2 female); Age- 22-77 yrs. (mean-51 yrs.) 2 TF, 6 BK; Cause of amputation- dysvascularities.
Author- Jearnhammer, Andersson, Wagle, and Magnusson, (2017). Country- Nepal	To explore the experience of persons in Nepal using Lower limb prosthesis in relation to specific articles in the convention on the right of persons with disability that consider mobility, education, health, rehabilitation and work and employment.	Design- Qualitative method. Method- One semi-structured interview was conducted	Sample - 16 persons with lower limb amputation (6 females, 10 males) 11- TT amputation 4-TF amputation, 1 -KD Mean age- 38yrs (range-21-67 yrs) Average time since amputation 10 years Average age duration of prosthetic use 7 years; Cause of amputation- Not mentioned

NB: BK- Below Knee, TT- Trans-tibial, TF- Trans-femoral, KD- Knee-disarticulation

DISCUSSION

The finding of this systematic meta-aggregation of reviews highlights a set of related issues of key concern for people who undergo a lower limb amputation. The derived themes from this meta-synthesis include: amputation as a sense of exclusion from life, embodiment of new self-identity and prosthesis enabled identity. Regardless of etiology, lower limb amputation disturbs physical, psychological and social functions (Davidson et al., 2002; Sjodahl et al., 2004). The acute stage of recovery after amputation is marked by an attempt to cope with the fear and anxieties relating to the impacts of amputation and associated changes in life thereafter. High level of uncertainty, perceived loss of control over their life and lack of knowledge about prospects of a better life with the use of prosthesis contribute to the psychological distress among amputees. According to our review this immediate effect is followed by a sense of isolation and social rejection. They become hypersensitive to other people's negative remarks. People with lower extremity amputation feel embarrassed by their impaired physical appearance and assuming that they would be socially rejected isolate themselves from the society. This is congruent with the findings of previous research (William et al., 2004) which also evidenced physical, psychological and social repercussions of social isolation due to amputation using different method other than the reviewed studies. The amputee slowly starts embodiment of his new self–identity through a changing bodily awareness. A loss of leg can be felt as a bodily dissonance characterized by a conflict between wanting and not being able to do (Dahlberg et al., 2009). The amputee gradually develops awareness and acceptance of his or her new physical appearance, functional limitations, available social support and possibility of leading a quality life. (Bosmans et al., 2007; Murray & Fox, 2002; Williams et al., 2004). The amputee with time starts accepting and adjusting with amputation. According to Murray (2012) amputees over time develop ways of adjusting to or coping with their amputation. This finding is also supported by researchers (Sagar et al., 2016) who are of the opinion that psychological issues are gradually resolved over course of time.

Using prosthetic limb promotes physical as well as financial independence of lower limb amputees, increases their dignity, and enhances their self-identity. The findings are in consonance with previous studies (Andregard & Magnusson, 2017; Liu et al., 2010; Murray 2009). WHO (2011)in its report on disability, also has mentioned that assistive devices such as prosthesis have been proven to be improving independence and participation in society.

An interesting observation from this present meta-aggregation is that some patients, particularly those in whom amputation has been done as a life saving measure due to cancer or any other fatal condition, appraised the amputation positively and reported fewer losses and changes in their self-identity (Senra et al., 2011; Sjodahl et al., 2004). It may be due to their realization that but for amputation, anything worse could have happened.

CONCLUSION

The present Meta synthesis focused on the qualitative findings of eight papers on persons with lower limb amputation with respect to their lived experiences following amputation, during pre- as well as post-prosthesis use period. Three themes emerged which could be understood to be occurring in three phases. These themes have been described as an alienation from life, acceptance of new self-identity and prosthesis enriched life. The amputees may experience Kubler-Ross's five classic stages of grief which includes- denial, anger, bargaining, depression and acceptance (Bhuvaneswar et al., 2007; Kublers-Ross, 1975; Parkes, 1971). These findings provide a firm base from which suggestions can be made regarding the design, organization and delivery of health rehabilitation services that can meet the needs of this population. Considering the physical as well as psychosocial impacts of amputation, the rehabilitation of lower extremity amputees should emphasize on multi-dimensional approach comprising of psycho-social education and counseling for better adaptation to the new identity as amputee and inclusion into the society. The review also features the importance of prosthesis in the life of lower limb amputees, which becomes the 'life-line' for the amputees. It is expected that the earlier the intervention is given; the better will be the impact on their psychological status and re-integration into the society.

IMPLICATION OF FINDING FOR PRACTICE

Clinical guidelines suggesting for working with adult with lower limb amputation include:

- Listening to and respecting their thoughts, needs and fear in the acute post amputation phase.
- Counseling them about the life after amputation.
- Educating their family and peer about the life of the amputee which can be normalized after prosthesis use.
- Conducting social interaction events with other amputees who have succeeded in their life.
- Encouraging them to think positively and discussing with them their plans for the future
- Discussing, the other prospects with prosthesis which include involvement in sports and recreation.
- Providing them with vocational training to earn for themselves and becoming a productive part of the society.
- Conducting social awareness programs which will help illuminating the negative illusion of amputation.

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