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From Injured Body to Changes in Self-Identity: a research on adults with acquired physical impairments

Hugo Renato Carreira Gomes Senra

Thesis submitted as a partial requirement of the PhD in Psychology
Specialization in Clinical Psychology

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To all Patients

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“*If anything at all, perfection is finally attained not when there is no longer anything to add, but when there is no longer anything to take away*.”

Antoine de Saint-Exupery

Key Words:

Vision Loss; Lower Limb Amputation; Adjustment; Self-Identity; Depressive Levels.

Palavras Chave:

Perda de Visão; Amputação de Membro Inferior; Ajustamento Identidade; Níveis de Depressividade.

PsycINFO Classificaion Categories and Codes:

- 3200 Psychological & Physical Disorders
  - 3290 Physical & Somatoform & Psychogenic Disorders
    - 3295 Cardiovascular Disorders
    - 3299 Vision & Hearing & Sense Disorders

ABSTRACT

Background: The experience of becoming physically impaired, especially in lower limb adult amputees and in working-aged patients with vision loss, has deserved little attention by research in general. The weight of some variables associated with these experiences on depressive levels has been stressed by some studies. However, little is known about it.

Aims: The current dissertation aimed at filing in the knowledge gap regarding these topics. We intended to explore the experience of acquired physical impairment, focusing on changes in self-identity, in two groups: working-aged adults with vision loss; and adults who suffered a lower limb amputation. In addition, we aimed at exploring a possible connection between the most relevant emerged variables of these experiences and the depressive levels: the self-awareness of impairment; and the self-identifications with the impairment.

Method: Two independent studies were performed, both was cross-sectional and using mixed-methods: study 1 was on the experiences of vision loss of 38 patients at rehabilitation setting (mean age of 42.7; SD=14.5); and study 2 was on the experiences of lower limb amputation in 42 patients (mean age of 61; SD=13.5) followed-up at a general hospital's rehabilitation medicine unit. Qualitative data on the experiences of impairment was collected by two semi-structured interviews for each patient. The interviews were performed by an independent and trained psychologist, under the supervision of a senior psychologist and psychotherapist. 87 interviews were conducted in study 1 and 85 interviews in study 2. Depressive levels were assessed using CES-D. The content analysis was performed using the Categorical and Coding analysis proposed by Bardin.

Results: Qualitative data from the study 1, on the experiences of vision loss, retrieved seven themes, most of them focused on changes in self-identity. These results supported a new model for the adjustment process to vision loss, based on patients' self-awareness of impairment and self-identifications with the impairment. 39.5% (n=15) of patients met CES-D criteria for depression. Higher depressive levels ($P<.05$) were found in patients who: lost vision for longer; begun their rehabilitation later; were more aware of their impairment; and those who reported an inadequate social support ($P<.01$). A positive correlation was found between CES-D scores and vision loss evolution (.333; P=.036), and between CES-D scores and rehabilitation time (.335; P=.035). In study 2, eight themes emerged from the interviews. Qualitative results supported a theoretical model for the changes in self-identity related to lower limb loss beyond the body image. 31% (n=13) met CES-D criteria for Depression. Higher depressive levels (p<.05) were found in those who showed: greater self-awareness of impairment; lower identification with the impairment; and worse appraisals towards the prosthesis, social support and well-being.

Conclusions: In both studies the changes in self-identity, especially in terms of self-awareness of impairment and self-identifications with the impairment, arose as core milestones of the adjustment process to the impairment. The relationship found between the variables related to the experience of impairment and depressive levels suggests two conclusions: the changes in self-identity caused by the impairment might be one of the important causes for the rising of depressive levels; the increase in depressive levels in these populations might be, at first, the reflex of the adjustment process to the many personal losses and therefore, do not necessarily reveal a bad adaptation to the impairment nor a mental health problem.

SUMÁRIO

Enquadramento: A experiência de amputação de membro inferior em adultos, e a experiência de perda irreversível de visão em adultos não idosos, são dois temas que têm tido pouca atenção por parte da investigação científica. O peso desta experiência ao nível da identidade dos sujeitos e a relação dessas variáveis com os níveis de depressividade são temas considerados relevantes, embora ainda pouco estudados.

Objectivos: A presente dissertação veio no propósito de produzir alguma evidência acerca dos tópicos referidos. Com estes estudos pretendemos explorar as experiências incapacidade física adquirida e as suas implicações para a identidade dos sujeitos em dois grupos de sujeitos: adultos que tenham sofrido amputação de membro inferior; e adultos não idosos com perda irreversível e severa de visão. Outro dos objectivos destes estudos foi a investigação preliminar de potenciais relações entre variáveis como a auto-consciência de incapacidade e as auto-identificações com a incapacidade e os níveis de depressividade.

Método: Para atingir os objectivos do nosso estudo, delineamos duas investigações independentes. Estudo 1: 38 sujeitos com perda irreversível de visão (média de idades de 42.7 anos; desvio padrão de 14.5), todos eles em fase de reabilitação. Estudo 2: 42 sujeitos amputados (média de idades de 61; desvio padrão de 15.6), todos eles em seguimento na consulta de medicina física e de reabilitação num hospital geral. Em ambos os estudos as experiências de incapacidade foram recolhidas através de uma metodologia qualitativa, com recurso a entrevistas semi-estruturadas realizadas individualmente a cada sujeito. No total foram realizadas 87 entrevistas no estudo 1 e 85 entrevistas no estudo 2. Cada entrevista foi realizada por um investigador independente, formado em Psicologia e com experiencia clínica com este tipo de populações. As entrevistas foram supervisionadas por um Psicólogo e Psicoterapeuta Sénior. Os níveis de depressividade foram avaliados usando o CES-D. A análise do conteúdo das entrevistas foi realizada com base no método de codificação categorial não indutivo de Bardin.

Resultados: Os resultados qualitativos do estudo 1 (perda de visão) revelaram sete temas, a maior parte dos quais acerca das alterações ao nível da própria identidade. Esses resultados suportaram um modelo compreensivo para o processo de ajustamento à perda de visão, com base na auto-consciência de incapacidade e nas auto-identificações à incapacidade dos sujeitos estudados. As pontuações no CES-D de 39.5% (n=15) dos sujeitos cumpriram os critérios para depressão clínica. Maiores níveis de depressão ($P<.05$) foram encontrados nos sujeitos que: tinham perdido a visão há mais tempo; começaram a reabilitação mais tardiamente; estavam mais conscientes a sua incapacidade; e percepcionaram um pior suporte social ($P<.01$). Foi encontrada uma correlação positiva entre as pontuações dos sujeitos no CES-D e duas variáveis: o tempo decorrido entre o primeiro diagnóstico da doença responsável pela perda de visão e o momento em que o sujeito ficou clinicamente com baixa visão ou cego (.333; P=.036); o tempo de reabilitação (.355; P=.035). No estudo 2 emergiram oito temas sobre a experiência de amputação. Esses resultados suportaram também um modelo teórico compreensivo para as alterações na identidade dos sujeitos, decorrentes da situação de amputação. 31% (n=13) dos sujeitos apresentaram pontuações no CES-D que cumpriram os critérios para depressão clínica. Maiores níveis de depressão ($P<.05$) foram encontrados nos sujeitos que apresentaram: maior auto-consciência de incapacidade; menor identificação à incapacidade; pior relação com a prótese; pior percepção do suporte social; e pior percepção do bem-estar.

Conclusões: Nos dois estudos a auto-consciência de incapacidade e as auto-identificações com a incapacidade surgiram como duas variáveis chave do processo de ajustamento à incapacidade, demonstrando o potencial efeito transformador destas situações de incapacidade para identidade dos sujeitos. A associação encontrada entre as variáveis relativas à experiência de incapacidade e os níveis de depressividade parece sugerir duas conclusões: as alterações na identidade decorrentes da situação de incapacidade física adquirida poderão ser uma das importantes causas do aumento dos níveis de depressividade; o aumento dos níveis de depressividade poderão ser, num primeiro momento, reflexo do processo de ajustamento às perdas sofridas e não traduzir, necessariamente, uma má adaptação à situação de incapacidade, nem um problema de saúde mental.

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BACKGROUND

1. INTRODUCTION

The main purpose of the current dissertation came from a set of ideas and hypotheses retrieved both from the state of art and from our previous clinical experience. We have worked, for several years, with patients with acquired and congenital physical impairments, especially with visual impairments. The work we've developed includes: psychological assessment; psychotherapeutic follow-up; counselling for rehabilitation program; early intervention; promotion of educational inclusion; and community awareness and support work.

In the case of patients who lost their vision in adult ages we could see a different set of behaviours, expectations, and fears that regulated their rehabilitation commitment, motivation and outcomes. A great portion of these patents tended to resist to the rehabilitation program, and especially to the white cane. They were often focused on their own loss and on its implications for their lives in terms of who they were, and who they become now. Moreover, they were not prepared to improve and adapt functional skills to deal with their loss, because they were refusing anything that represented this vision loss or blindness.

Frequently, a set of strong and overwhelming emotions emerged from adult patients' verbalizations of how dealing with vision loss was going on. During our experience of supporting these patients, we realized that, as long as they could not minimally integrate vision loss in their Self and be willing to overcome their new condition, any effective rehabilitation work was not viable. It seemed that we had to give time to these patients, and be patient with their refuses to be helped and rehabilitated. When we respected the patients' timings on their loss experience, and at the same time promoted their emotional verbalizations, they started to become more willing to be rehabilitated, and became less emotionally distressed. The goal was to potentiate their ability to verbalize and to think about their emotions, ideas and expectations about vision loss. This potentiated patients' toleration towards vision loss, instead of keep hiding it from others and from themselves. In a certain way, we realized that we could get them to think about vision loss in terms of something they could overcome sharing it with us.

During our experience with these patients we realized that both cognitive-behavioural and grieving approaches were not powerful enough to explain these behaviours and the mental functioning behind them. Moreover, the last studies on this field suggested different approaches for adjustment to vision loss and for intervention with these patients (1,2). Therefore, we concluded that more knowledge was needed in this field.

Although these findings from our clinical practise appeared to be innovative and suggesting new assessment and intervention approaches, we had to develop new systematic studies in order to better understand those processes. Our parallel work with patients with other physical impairments and the state of art (3), also suggested that in the case of adults with lower limb amputation, similar questions have been raised.

Our dissertation arose from these clinical and research questions and had the main purpose of offering a relevant contribution to the creation of new approaches on understanding and supporting patients with vision loss, or lower limb amputations.

2. THE IRREVERSIBLE VISION LOSS IN ADULTHOOD

2.1. Epidemiology and Overall Implications

According to the World Health Organization (4), a person has visual impairment when his visual acuity is worse than 3/10 and equal or better than 1/10, and is blind when his visual acuity is worse than 1/20. About 314 million people are estimated to be living with visual impairment worldwide, 45 million of them with blindness (4-6). According to the last Portuguese censuses 6.1% of the all population are impaired, and 25.7% of them are blind or partially sighted (7).

Most of visually impaired people are older and live in developing countries (5-6). Females are more likely to have vision problems (5,6). The leading causes of blindness are: Cataract; Uncorrected refractive errors; Glaucoma, age-related macular degeneration; and metabolic diseases such as diabetes (4,5). Cataract is on top of the leading causes of blindness globally, except for the most developed countries (4-6).

These numbers pose visual impairment as a worrying public health issue that deserves a special attention, especially in adults. Personal and social implications of visual impairment vary according to many variables such as (8-10): age at loss; if it was congenital or acquired; personal history of ophthalmological problems; type of sight loss (progressive or sudden); severity (low vision or totally blind – having or not having light perception); premorbid mental health problems; and other personal and social factors.

In adults, vision loss has been related as a serious decrease in individual's well-being, quality of life and functioning (10-12). Stop working, driving, reading, or walking are frequent consequences of becoming blind or with acquired low vision.

Therefore vision loss is a potentially overwhelming event which often causes loss of independence, self-esteem, and a great change in the individual's life (11-12).

2.2. Vision Loss and Emotional Distress

Many authors have referred the high frequency of emotional distress in patients with sight loss (13-15). Affective and mood disorders like depression and anxiety are the most common psychological disorders associated with the acquired visual impairment (13-18). However, post-traumatic stress disorder, suicide thoughts, phobia, paranoid ideation, psychoticism, and sleep disturbance are also described as possible psychopathological consequences of the vision loss (19-21). All of these implications disclose several mental health problems in visually impaired subjects, which tend to increase with age (11,22). Furthermore, these mental problems are an additional hindrance for patients' adaptation to vision loss, rehabilitation outcomes, and social reintegration (23-25).

Frequently, depression becomes a chronic or a long-term problem in many visually or physically impaired patients (26,27). It is caused by multiple factors such as (9,14,16,28,29): decrease in visual acuity; perceived functional problems; perceived environment barriers; perceived social support; other serious comorbidities; self-concept; resilience and coping style.

2.3. The Personal Experience of Vision Loss

Qualitative and mixed methods studies have often addressed patients' experience of vision loss, underscoring the role that specific meanings and subjective variables play in this experience. From most of these studies, common key themes have emerged about the overall experience of becoming visually impaired (30-35): the diagnosis experience and its depressive meanings; changes caused by vision loss, such as the loss of independence, self-esteem, and basic skills; isolation; fear of accidents; coping with impairment; and the end of life. Furthermore, these studies have emphasised the patients' demanding process of having to deal with the assistive devices, especially the white cane.

Wong's (22) work with fifteen patients, with age-related macular degeneration, found six main themes about their experiences of vision loss: understanding their medical condition; inferiority feelings; asking for help; feeling of failure; coping and acceptance; and rehabilitation. Among these themes patients expressed feelings of isolation, not being understood, ashamed of using the white cane, or the benefits of having family or friends' support.

In the same way, Wang and Boerner (36) stressed patients' social re-establishing of relationships, following vision loss, as a main theme for the experience of vision loss and the adjustment process. Most patients reported problems in social relationships after vision loss and associated it with feelings of being isolated and abandoned by others. Another study found death feelings associated with the experience of becoming visually impaired (37). In this study patients expressed their impairment meaning the end of life as they knew it before the vision loss.

In Teitelman's qualitative study (38) the themes retrieved were more focused on the emotional changes and the indicators of emotional adaptation. Self-perceptions and coping emerged associated to patients' verbalizations of how they were dealing with their impairment and with themselves as different persons. Feelings of abandonment, rejection and not feeling understood by others appeared associated with patients' relation with others, whereas feelings of ambivalence, refuse, or acceptance and hopefulness emerged associated with the theme “rehabilitation”.

Recent mixed methods studies with adults with retinitis pigmentosa (2,33) pointed out the experience of sight loss as a process of transition from sight to blindness. According to Stanford, this is a process where patients will progressively cope with their loss, towards the acceptance of the white cane, of the lifestyle changes, and of the rehabilitation process.

In the same way, Hayeems and colleagues (1) found that adults that were more identified with their impairment were those who: exhibited a greater independence; were more likely to reveal their impairment; were more suitable to make lifestyle changes; accepted specialised help. These findings were confirmed in a later qualitative self-study by Fourie (39), where the understanding of the identity changes caused by vision loss is stressed as an issue that needs more research and comprehension, especially to change practises in clinical and rehabilitation settings.

Another recent study by Dale (40), places the focus on questions associated with living in a society of sighted people, dominated by sighted relationships and expectations. Therefore, patients’ negative changes caused by vision loss arose related to their confrontation with a society whose appraisals to vision loss tend to be negative. In the author’s experience of counselling these patients, addressing that negative impact and facilitating their emotional verbalizations appeared to be a good practice to promote their adjustment to the impairment.

Although the experience of vision loss has been explored in some studies, more knowledge is needed on this topic. Most of studies are on elderly patients and therefore this experience on working-aged adults is understudied. A recent study by Boerner and

Wang (41) compared the reported life changes between working-aged adults and elderly individuals. The overall results showed that middle-aged adults tend to report more changes in personal achievement, personal goals, and relationships. These changes were perceived as being more disruptive by the younger group and therefore they were at risk of suffering more negative consequences regarding their vision loss when compared with the elderly patients.

Nevertheless, we still know little on which mental processes can operate after vision loss, especially in working-aged adults.

2.4. Adjustment to Vision Loss

Due to the demanding situation caused by vision loss a person often has to adapt to the new condition and perform several life-changes. During this process, called the adjustment process, each person experiences the vision loss in a certain way with their own feelings, reactions, behaviours and outcomes.

As we address further in this dissertation, several factors are behind the variety of adjustments between people who lost their vision.

2.4.1 Overall Factors for Adjustment

Fitzgerald (42) and Dodds (43) conducted the first systematized studies about factors for psychological adjustment to vision loss. Based on a longitudinal study, Fitzgerald stressed the importance of personal and family factors for the adjustment process. According to the author, patients who are in a disadvantaged social class, have a family history of blindness and have a poor health, are more likely to present greater emotional distress and a worse adjustment to vision loss.

Dodds' studies (43,44) were focused on patients' attitudes and attributions towards vision loss. This research integrated social, cognitive and emotional factors. Findings showed that patients' perceived self-efficacy was affected by vision loss and, therefore, they were more likely to have self-worth problems. Factors that appeared to be relevant for patients' self-efficacy were: failure and success in daily living activities; how other visually impaired people and their behaviours are perceived; distress caused by patients' attempt to perform some tasks; and how others perceived patients' failures and successes in performing some tasks.

Thereafter, other adjustment factors have been found. The emotional distress, particularly depression and anxiety have been described as common problems after vision loss, causing additional problems in patients' adjustment (45,46). Moreover, depression has also been described as having its own value as factor in the patients' disability (47).

Several authors have emphasized the importance of the variables related to life satisfaction and social and family support for the adaptation to sight loss (28,48-51). A good social, family, and other caregivers' affective support has been described as a good facilitator for patients' adjustment to their impairment, decreasing the emotional distress and social isolation. Nevertheless, some of these studies have also stressed the counter-productive effect that social support may assume for the adjustment process (28,50). Subjects' perceived overprotection has been described as a factor for emotional distress, lower levels of functioning, and poor outcomes (28,50). In the same way, a recent study by Weber (48) found that a correct balance of support and confidence appeared to enhance the adjustment process in terms of functioning and outcomes.

In terms of ethnical variables, studies on this field did not find any potential factors for adjustment to visual impairment (52,53).

2.4.2. Coping Strategies

Regarding the coping strategies, the instrumental and problem-focused have been described as more likely to produce positive changes in stressors and to promote the adaptation to sight loss, than the emotional-focused coping, as a ruminative style of dealing with the impairment (54,55). Strategies like refocusing their attention, seeking alternative ways and aids were more related to a greater adaptation to vision loss and lower levels of depression (54-56).

Lindo and Nordholm (57) studied positive and negative adaptation strategies to cope with low vision. This study adopted the Persson's strategies model [cit by Lindo & Nordholm (57)]. Strategies like revaluation, minimization and control seem to be more related to better levels of adjustment and well-being, while strategies like helplessness, isolation, shame, resentment and trust are associated with activity problems in patients with low vision.

Works by Horowitz (11,37) and by Brennan and colleagues (55), have shown the relevance of positive personality, as well as attitudes of acceptance and independence, for the adaptation to visual impairment. The great use of acceptance coping, family and friendship support, the lower use of wishfulness coping, and the lower endorsement of chance locus of control, proved to be the best predictors of a good adaptation to vision loss (56). According to authors, these coping strategies are also associated with lower emotional distress, especially with depression.

Other authors have emphasized the negative effect of coping strategies such as escape-avoidance, neuroticism and lack of planful problem solving, on the patients' adaptation to their impairment and global recovery (58,59). On the other hand, coping strategies such as positive reappraisal, optimism, distancing, self-control, seeking social support and cohesion have been associated with optimal adjustment to sight loss (58,59).

Lee and Brennan’s (60) qualitative study with adults with vision loss, explored stress constellations and coping style codes that emerged from their narratives. Five stress constellation groups, and five cluster solutions were yielded. The stress constellation groups that emerged were: stoics; complainers; taciturns; sentimentalists; and articulates. In terms of cluster solution, the following categories emerged: mavericks; autonomous; pragmatists; hermits; and nonchalants. The majority of patients were classified as taciturn and nonchalant. Patients’ self-reports demonstrated a tendency for expressions of negative thoughts and feelings, occurrence of negative social interactions, and loss of functional abilities to perform activities daily life.

Spirituality and religious well-being have also been studied in the adaptation process. Yampolsky and colleagues (61) demonstrated that high levels of religious well-being proved to be a good predictor for patients’ adaptive coping behaviours.

Other studies have also stressed the importance of behaviour coping skills, like using adaptive and assistive devices, including rehabilitation programmes, for the success of patients’ adjustment (62,63).

2.4.3. Comprehensive Conceptualizations of the Adjustment Process

Based on several studies, some authors developed a conceptual model for adjustment to vision loss.

The first studies conceived the adjustment process as being composed by several stages of emotional and non-emotional reactions. Cholden (64) developed the first studies to conceptualize this process and created a three-phase adjustment model. The first phase begins with shock, the second stage is when the patient starts to react emotionally and to be depressed, and the last phase is when patient accepts his/her impairment.

Based on Cholden's model, other models were developed. Whereas Fitzgerald (65,66) added one more stage to Cholden's model, stressing patients' emotional distress and self-esteem, Dodds (44) integrated social, emotional and cognitive factors into the adjustment model. This model emphasized the role of other patients' factors in their adaptation such as: anxiety; depression; self-worth; self-efficacy; locus of control; attitudes toward visual impairment; self-acceptance of the impairment; and attribution style.

Tuttle (67) reformulated this process into a seven stage model. His perspective describes the sight loss experience as a sequential, continuous, dynamic and non hierarchical process, which does not necessarily suppose a final adaptation. Patients might float through any phase if they need because it is common for them to have new challenging situations to solve over time. Tuttle's phases are (67,68): Trauma, Physical or Social; Shock and Denial; Mourning and Withdrawal; Succumbing and Depression; Reassessment and Reaffirmation; Coping and Mobilization; Self-Acceptance; and Self-Esteem.

Although in a different perspective, a recent qualitative study based on adult patients' narratives about their experience of being visually impaired, presented a model with some similarities to the first stages theories. In this study Thurston and colleagues (2) stressed the transition experience, from being sighted to being visually impaired, as an important part of the adjustment process. Based on these findings, authors proposed a model of stages that translates the evolution of patients' acceptance of the impairment. During the first stage subjects tend to hide their impairment, refusing help. In the second stage they start to enforce their lifestyle change towards their loss. In the final stages they tend to accept the situation and to reconceptualise themselves as different people.

Despite the value of stage models in the understanding of the adjustment process, other recent studies have stressed different variables and courses of the adjustment. Stanford and colleagues (32) developed a longitudinal and qualitative study about psychosocial adjustment in patients with age related macular degeneration in their first contact with clinical services. In this study, patients' narratives did not reveal much improvement over the years in terms of their well-being and acceptance. Contrariwise, they remained vulnerable and kept having many difficulties in coping with their new condition. According to the authors, even though these narratives did seem to resonate with the grieving process described by Klüber-Ross (69), in which the patient shows feelings like denial, anger, bargaining, depression and acceptance of loss, it does not offer a satisfactory explanation for this process. The reason is that this process results from a subjective, complex and differentiated experience.

Aware of this complexity, Hayeems and colleagues (1) studied the importance of other personal variables involved in the adjustment to vision loss in adults with retinitis pigmentosa. Findings disclose that patients'self identification as disabled or not disabled is the core of the adjustment process and patients' independence levels. Patients who were identified as visually impaired proved to: be the most motivated to attend a rehabilitation program; have the best disability adaptation levels; be more able to use assistive devices; and to be the most independent people. However, those who continued to identify themselves as sighted tended to hide their impairment, avoid assistive devices and be more dependent on others. Patients who appeared to be in transition between the referred courses were more likely to seek help and to develop better skills to become independent, than those who are identified as sighted. According to the authors, patients during the transition process are likely to change their behaviour through the following stages: precontemplation; preparation; contemplation; action; and maintenance. Through these stages, patients exhibit their course of behaviour changes, towards a stronger identification with visual impairment.

2.5. Rehabilitation and Intervention

Usually, a rehabilitation programme provides integrated services as: orientation and mobility; occupational therapy; psychomotricity; Braille; adapted computer technologies; activities of daily living (ADL); counselling and psychotherapy. The recovery areas addressed are: functional vision training (for low vision patients); activities of daily living (basic and instrumental); mobility; communication skills (computer and Braille); new skills to use residual vision; new skills to return to work; coping with sight loss; and mental health (70-73). Instrumental Activities of Daily Living (identifying clothing; locating and identifying food; handling and identifying money, or writing checks) tend to be more impaired than ADL (transfer, use a toilet, bath oneself, dress and undress oneself, or walk across a small room) (9).

In a recent onset of visual impairment, most visually impaired patients tend to be more focused on understanding their visual impairment (give meaning to) than using the existent assistive devices (29,58,74). While some patients perform and accept their rehabilitation, other patients still refuse or resist it as a helpful resource. They are usually socially isolated, focused on their illness and less motivated to learn new skills or make friends (75,76). One of the reasons for this avoidance is that rehabilitation and other aids are sought only when sight loss is minimally accepted and embodied as part of the patient (1,77). Thus, assessing avoidance and the way patients are dealing with their impairment seems to be a good practise for primary care services, in order to plan the referral of the patient to a rehabilitation service (78).

Boerner and colleagues (62) have demonstrated the changing effects of rehabilitation interventions on individuals' coping patterns. Patients who concluded their rehabilitation tend to use various types of assistive devices, having more an instrumental coping than an emotional-focused coping. Decreasing depression levels, increasing adaptation to vision loss and well-being are other positive effects of the rehabilitation intervention (62,79).

Other studies (25,74,80) have also proved the importance of rehabilitation for visually impaired patients, in terms of reducing depression levels, promoting adjustment with great levels of social participation function and well being.

Wang and Boerner (36) interviewed 58 adults with visual impairment about relationship changes related to their vision loss. Patients verbalized their tendencies toward maintaining or disinvesting relationships after vision loss. Moreover, patients' relationship challenges seem to be linked to functional challenges, which usually are the priority target of rehabilitation programmes. The authors (36) emphasized the importance of addressing patients' relationship competences and strategies in rehabilitation services, because it will improve patients' outcome and social reintegration.

In the same way, a study from Cimarolli and colleagues (70) explored patients' (young and middle-age adults) perceptions about their life goals and vision of rehabilitation services. Results stressed the patients' need for health-related goals such as: improving and maintaining vision related health; maintaining or getting a job, remaining independent and being able to move around.

Concerning the psychological intervention, it is a helpful and fundamental resource both to promote individual adaptation to vision loss and to improve the rehabilitation outcomes (14,75,81). It might be a valuable tool to help patients in: reframing their experience of loss; restoring their self-esteem and mental health; finding new life meanings; regaining their sense of control of the main life domains; and to accept new compensatory aids which will allow their social reintegration (79,82,83). These aims are achieved by several psychological techniques and methods, which are usually focused on: patients' coping, experience of loss, social and family support, and functional resources (37,83,84).

Individual and group psychotherapies, support groups, counselling, psycho-educational groups, and other resources have been used by rehabilitation psychologists working with visually impaired people (85-88). Support groups are described as a good facilitator to promote patients' sharing of experiences, feelings and doubts about their new situation (89). Counselling has also been tested as a useful tool to improve: adjustment to vision loss; the use of assistive devices; rehabilitation goals; skills for returning to work; and decisions in vocational rehabilitation (33,86,90).

Another helpful resource in the rehabilitation setting is the Peer Group (37). According to these authors, it improves the patient's functional independence and well-being through: reducing feelings of isolation; promoting opportunities for sharing experiences related to vision loss; understanding that each case of vision loss is not unique; promoting social networks and friendships; and promoting rehabilitation goals.

The Self-Confrontation Method (SCM) can also be a useful instrument to help patients to deal with their disability (91). The main aim of this method is to give meaning to the consequences of the subject's impairment. The patient asks himself questions in order to give new meanings to His / Her new condition.

One of the psychotherapeutic most used techniques, in the rehabilitation setting, is the Cognitive Behavioural Therapy (CBT), which is focused on: changing distorted perceptions such as those related to the depressive disorder; not adjusting behaviours associated to refusing rehabilitation or functional aims; patients' coping strategies; patients' return to work; and patients' well-being (54,86,92).

These aids are fundamental to provide a global rehabilitation program and to stimulate patients' functioning recovery and autonomy (37).

Hence, rehabilitation and its specific methods represent one of the best instruments to reduce disability levels associated to vision loss and to promote individual's social participation and reintegration. Linking functional recovery, personal goals and expectations seems to be a good practise in rehabilitation settings; particularly when the psychological intervention is focused on a patient's experience of loss, meanings, coping and aims. The point is to look at person holistically, without neglecting any of the individual's functional areas (93).

2.6. Overall State of the Art

The current state of art points out the vision loss as a potential painful and complex process of change in several domains of the individual's life. Many studies have been developed in the field of the psychological implications of vision loss and the rehabilitation process as well.

Table 1 (see appendix A) summarizes the main studies developed on the experience of vision loss and its adjustment process, since 1994. Papers on this table were retrieved from several databases: EBSCO-host; PsycInfo; PsycArticles; Library, Information Science & Technology Abstracts; Academic Search Complete; Psychology & Behaviour Sciences collection; Medline; and PEP archive. The search was based on the following key words: adjustment to vision loss; experience of vision loss; vision loss; sight loss; visual impairment; acquired visual impairment; and low vision. As can be seen, since 1994, only 16 studies were performed on the experience of vision loss in adult ages. From these 16 papers, only four were on working-age adults. Thus, the experience of vision loss continues being a topic where more research is needed, especially on middle age patients. This lack of knowledge is extended to the particular meanings of becoming impaired which are related to the changes in self-identity, as the papers of Hayeems, Thurston, Dale and Fourie have suggested.

In terms of emotional distress, several papers have demonstrated its high prevalence in this population and some clinical and demographical associated factors. However, most studies did not address connections between depressive levels and some particular variables involved in the experience of vision loss, such as the self-awareness of impairment, and the self-identifications with the impairment. These variables, and others related to the process of experiencing vision loss, need to be more researched on their relation with depressive levels. This will enable a better understanding of what can be on the origin of the depressive levels in these patients.

Therefore, at least three topics need further research on the experience of vision loss: the working-aged adults' particular experiences; the processes of changes on self-identity related to this experience; and the potential relation between intrapersonal variables related to this experience and depressive levels.

3. THE LOWER LIMB AMPUTATION IN ADULT AGES

3.1. Epidemiology and Overall Implications

A lower limb amputation is a surgical procedure that results from a serious medical condition. An amputation is considered major when it is transfemoral, transtibial, or through-knee (94).

According to the last epidemiological data from England, there were 57,153 lower limb amputations between the years of 2003 and 2008 (94). During this period the major amputation's rate was of 5.1 per 100,000 (94). Diabetes (39.4%) was found to be the main cause for major amputations in England, followed by trauma (13.9%), and neoplasm (2.2%) (94).

In United States, the last estimates accounted 1.9 million of adults with limb loss, most of them with lower limb amputation caused by vascular disease (95).

In Portugal, diabetes is also the main cause for lower limb amputation, being responsible for 1,552 cases in 2007, and 1,599 cases in 2008 (96).

The lower limb amputation has been described as an event usually associated with several changes in one's personal life, affecting the individual's (97-103): body-image; well-being; relationships; sexual life; and autonomy. Several studies have stressed the negative impact that the amputation might have on the individual's quality of life, even after the rehabilitation process is complete (102,103). Therefore, it is considered a challenging process which implications depend on patient's emotional resonance, inner resources, coping strategies, social support, and environmental facilitators (104-109).

3.2. Lower Limb Amputation and Emotional Distress

There are a lot of studies on the emotional distress related to a situation of lower limb amputation. Depression, anxiety (especially body-image anxiety), and, in some cases, Post Traumatic Stress Disorder, are the most frequent emotional distress manifestations pointed by literature on lower limb amputation (110-113). Due to its frequency and associated problems of poor outcomes and well-being, depression has been the most studied manifestation of emotional distress.

In terms of frequency of depression in this population, different rates have been found in previous studies. While some studies argued that the prevalence of depression in amputees is not higher than in the general population (114,115), other studies found greater depression rates varying from 10% to 30% of the amputees (116-118).

Regarding the incidence of depression, some authors have pointed out the highest levels of depression during the first year after the amputation (113), whereas other studies found a significant drop in its incidence by the time of discharge from rehabilitation (116,117). Singh and colleagues (116,117) found a rapid resolution of depression and anxiety after rehabilitation. The authors argued that the possible reasons for this drop might be: the positive effect of rehabilitation in terms of independence restoration; and the changes in amputation appraisals and future outlooks. However, consistent with other previous literature (113), Singh's research also found a re-rising of depression after the second year subsequent to the amputation and that it tends to persist for a long time.

The main factors pointed for the higher rates of depression in amputees are: negative coping (118-121); catastrophizing (118,121); having other comorbidities (116,122); public self-consciousness (123); social discomfort (124); appearance-related beliefs (112); perceived functioning level (109); and having a poor social support (123,125,126). On the other hand, positive appraisals of amputation have been associated with better psychosocial adjustment to amputation and less emotional distress (127).

3.3. The Experience of Lower Limb Amputation

The individual experience of becoming a lower limb amputee is not an over-studied topic, and it needs further scientific exploration. The current available research on this topic is based on qualitative and mixed methods designs which appear to be an appropriated way of acquiring true life stories. Most of these studies had focused on particular features of the adjustment process such as: the body image (128,129); the prosthesis wear and its embodiment (3,130); and the phantom sensations, or pains (101,131). Nevertheless, other personal meanings for amputation emerged in these studies. Coping with loss, relations with the own body, feelings of vulnerability, resilience, well-being and the need for social and emotional support were other core themes that emerged from studies on the experience of amputation (101,132-134).

The experiences of sixty lower limb amputees were studied by Bosmans and colleagues (101) using semi-structured interviews and two visual scales. The results stressed a set of factors for patients' well-being, such as: the medical history; the phantom sensations and pains; the daily activities; the received social support; and the factors inter-influence.

Murray's studies (128,134) gave a special emphasis to the body-image implications of the lower limb loss. In a qualitative study with 35 lower limb amputees (134), three core themes were found: "meanings surrounding prosthesis use"; "being like everybody else”; and “passing, telling, and getting away with it”. The first theme was linked to the positive resonance regarding the prosthesis in terms of functional and autonomy levels restoration, this is when patients become aware of the specific gains of using prosthesis. The other two themes had to do with a great decrease of the body-image anxiety, due to the prosthesis’ use. Patients stressed how their body-image was repaired after they started using the prosthesis, and the potential disguising effect that prosthesis might offer, in terms of public self-consciousness.

Another study by Murray (3) explored the experience of amputation focused on the prosthesis’ embodiment process. Using a phenomenological analysis, this study retrieved six themes: “adjustment to a prosthesis”; “the balance of the body”; awareness of the prosthesis”; “the knowing body”; “the phantom becomes the prosthesis”; and “the prosthesis as a tool”. From these themes, two main findings were retrieved. One is that the awareness of prosthesis tends to decrease overtime. The other important finding is that the resistance or refusal of the prosthesis arose as part of the initial adjustment process. Thus, that rejection was frequent in the initial period of the adjustment in patients successfully adapted to the prosthesis.

Besides these referred variables on the experience of limb loss, little is known about its particular implications on self-identity, beyond the body image. A review from Horgan (113) pointed out the need for research on this topic and referred only one article where the changes in self-identity related to limb amputation were addressed [see Parkes (135)]. In the most recent literature we found only two papers addressing the identity implications beyond the body image. Saradjian (136), in a qualitative study with upper limb amputees, stressed the importance of both the individuals’ awareness of physical difference and their ability to integrate the prosthesis, for the recovery process.

Hamill and colleagues (137), in a qualitative study with eight lower limb amputees, found an interesting theme associated with their self-identity changes: the renegotiation process of the new identity. According to the study, this process represents the patients' transition to a new identity, which causes an initial resistance and is mediated by decisional, informational and social factors.

3.4. The Adjustment Process

The adjustment process to lower limb amputation has been mainly studied on five topics: the adjustment to prosthesis and the body-image anxiety/restoration; the phantom limb sensations and/or pain; the emotional distress, especially depression and anxiety; the social support; and the coping strategies. Although it is a topic where the rehabilitation psychology field has developed many research, there are few deep explanations in models that conceptualize the adjustment process.

During all the adjustment process to amputation, several factors can play an important role. In terms of demographical variables, females and elderly people are more likely to have body-image anxiety and poor adjustment to limb loss (100,138). Other studies (106,139,140) found that an amputation caused by trauma is more suitable to display denial and avoidance, whereas an amputation caused by vascular disease is more likely to display anger and hostility in the initial phase of the adjustment.

A longitudinal study developed by Kratz and colleagues (140) found no differences in terms of emotional distress (post-traumatic stress) between non-traumatic amputees and traumatic amputees. Nevertheless, this study found that the traumatic amputees may experience more changes than the other group, particularly during the first year after the amputation.

In terms of elapsed time after the amputation, literature suggests that a longer elapsed time may represent better outcomes and functioning (138,141,142).

According to previous literature, having other medical comorbidities, having back pain, and a greater level of activity restriction, are moderate risk factors for a poor adjustment to limb loss (110).

Phantom limb pain and stump pain have also been referred as factors for psychosocial adjustment, because they are associated with greater stress levels and problems in well-being and outcomes (141,143,144). In the same way, the prosthesis use is related to the adjustment process, because it mediates the subject's relation with his own impairment. Moreover it plays an important role against body image anxiety (98,130,145).

A longitudinal study with 89 adult amputees, by Williams and colleagues (146), found high levels of social integration during the two years of the study. Although these levels of social integration have been stable during the two years of the study, they were lower than the control group of people without disabilities. According to authors the patients' perceived social support was a good predictor for: pain interference; life satisfaction; and mobility. Furthermore they are also strongly influenced by demographical and clinical variables (146).

Other frequently studied factors are the coping strategies for limb loss. Excessive avoidance, catastophizing, not seeking social support and being pessimistic/fatalistic, are some of the referred negative coping strategies that may cause a worse adaptation to limb loss (106,120,144,147). Humour regarding the disability, downward comparison, support seeking, optimism, or practical coping have been associated with better improvements in well-being and adjustment (115).

Based on literature findings Horgan and MacLachlan (113) described the adjustment process to lower limb amputation in four periods: pre-operative; immediately post-operative; during rehabilitation; and long term. First period is when the individual knows that the amputation is required. Obviously, this period has less or no impact on patients whose amputation results from a sudden event, like a car accident. The second period has to do with the critical phase in which the patient can experience emotional distress and begin to deal with his new condition of becoming an amputee. The third period is when the patient is faced with the real impairment and its implications. It is a learning period to acquire new skills and to cope with his/her own impairment, including the prosthesis wear and use. Therefore, the patients can experience either negative or positive feelings or expectations about their own impairment. The last period is following the discharge from a rehabilitation ward, when patients tend to achieve several improvements in their overall functioning and well-being.

3.5. Rehabilitation and Intervention

In most rehabilitation centres for lower limb amputees, the rehabilitation work is mainly focused on wearing and using the prosthesis, and on the overall functional restoration. Nevertheless, other features of the adjustment process are often addressed, such as the emotional status, the coping strategies, the social support, the daily life activities, and the social reintegration. Usually, these rehabilitation teams are composed by several practitioners with different specializations: rehabilitation medicine; occupational therapy; physical therapy; psychology; nursing; and social work.

Usually, the role of psychology in rehabilitation settings for amputees covers a set of tasks such as (104,141,147): psychological assessment of coping strategies, emotional state, perceived social support, history of other mental health problems, including addiction; neuropsychological assessment, when needed; psychotherapeutic interventions – individual and group; monitoring the rehabilitation adherence; counselling; interdisciplinary work to monitor the patient's rehabilitation and outcomes.

Generally, rehabilitation produces a positive effect on the patient's overall adjustment (117,141). It can promote: changes in coping style; the reduction of depressive levels, body-image anxiety and pain interference; and patient's well-being and quality of life.

Due to the frequent resistance to prosthesis use, especially during the initial rehabilitation period, it is extremely important to prevent possible drop outs from the settings, or drop outs in using prosthesis. Even in well-adapted patients, an initial refusal of the prosthesis is usual, becoming part of the adjustment process, and therefore has to be carefully addressed by practitioners (98,128). This refusal frequently appears associated to pain interference, especially to stump pain. It is common for the prosthesis not to fit well with patient's body at first and therefore cause pain and disappointment. An intervention focused on enhancing patients' tolerance to these first experiences and focused on promoting strategies to deal with it, is considered a good practise at rehabilitation settings for amputees.

In terms of pain, especially the phantom limb pain, some studies have presented specific (psychotherapeutic) treatments that appear to be effective, in some cases (148-150). The mirror treatment is one of the most used tools to attenuate phantom pain. It is a procedure that consists in using a box with a mirror in order to create the illusion of patients having two intact limbs. Using a series of limb movement exercises, patients can experience a reduction of phantom limb pain. Even though this treatment is broadly used in upper limb amputees, some authors have already proved its value for patients who suffered a lower limb amputation (148).

Works by Murray and colleagues (149,150) tested a different approach for treating phantom pain. The method is called Immersive Virtual Reality which consists in offering a virtual experience of body movement with both limbs. Results showed great improvements in pain frequency after 3-week of sessions. Even being a preliminary study, findings suggest the need for further research on this topic.

Studies from Singh (116,117) found a significant decrease in patients' symptoms of depression after discharge from a rehabilitation ward. This longitudinal study found the rehabilitation work as being a promoter of a rapid resolution of depression and therefore improving patients' adjustment and well-being.

In terms of psychotherapeutic work, several authors (110,151-153) have stressed the importance of modifying patients' behaviour and coping strategies, when they are negatively interfering with their adjustment, well-being, and rehabilitation outcomes. Promoting prosthesis adaptation, life-style changes, a better use of their social support are some of the core target for psychotherapeutic interventions in this field. In addition, a psychotherapeutic intervention must also be focused on patients' changes in self-identity, mental functioning and relational world, because they are crucial features of how patients experience their impairment.

Due to patients' mental functioning particular relevance for the adjustment process Oliveira (104,147) stressed its value both for assessment and for therapeutic intervention. From a psychodynamic perspective (147) the author points out some mechanisms of mental functioning to consider for psychotherapeutic work: how the patient organizes himself to deal with his external and internal reality, in terms of his inner conflicts and real problems. The patient's real problem is not only how to deal with his loss, but also how to interiorize this loss, his history, and his foreseeable future. In this way, psychotherapeutic work with rehabilitation patients, must addresses individual's inner and relational world, because these dimensions represent core issues for subject's adjustment and for rehabilitation outcomes.

Concerning other psychotherapeutic interventions, several authors (154-157) have proven that group psychotherapy and the mutual aid based groups, can be valuable resources to promote patients' adjustment to their impairment. Sharing their experiences and feelings and creating new meanings for being impaired can promote a great transformation in patients' life, self-identity and overall adaptation process. According to Page (157) there are some personal aspects that are usually addressed by physically impaired patients in non-structured groups: the authority; the own group; the impairment; relationships; and the employment. Working on these themes appeared to be an effective way of promoting patients': adherence and motivation towards rehabilitation; adjustment in terms of well-being; coping with disability; coping with relationships and with their own new body; managing emotions; and finding new ways for work reintegration.

In conclusion, the rehabilitation work with amputees, as with other physical impairments, should be adapted to individual goals, expectations and needs. An integrated set of health services, including the psychotherapeutic work might be a good practise. The main goal is to promote the patients' (inner and external) resources to deal with their new condition, beyond the merely functional restoration.

3.6. Overall State of the Art

Most literature on the psychological features of the lower limb amputation has reported it as a serious medical situation often causing many losses beyond the functional limitations. Losses in self-worth, emotional state, relational life, employment, and in the overall autonomy, even when they are provisory, justify a special attention from all health and rehabilitation practitioners. Several studies have conceived the adjustment process to limb loss as being a period in which the patient might be more vulnerable and at risk for mental health and functioning problems.

The body image anxiety and the process of prosthesis embodiment have been broadly explored in the literature. They are important topics on the experience of amputation and its adjustment process. However, as Horgan (113) referred in an extensive literature review, there are other changes in self-identity related to this experience that deserve more attention by researchers. Until this review, only one article had addressed this topic (135). Since Horgan's study (in 2004) (113), and as far as our knowledge goes, only two studies did an approach to this topic: the study from Saradjian and colleagues (136) with upper limb amputees, and the study from Hamill and colleagues (137) with lower limb amputees.

Other topic that has been understudied is the relation between the experience of limb loss and the emotional distress, especially the depression. Most of studies have been focused on other variables, particularly the clinical and socio-demographical. In this way, little is known on the intrapersonal variables potentially associated to the experience of becoming amputee, especially besides the body image anxiety and the prosthesis embodiment.

For that reason, at least two topics need further research on the experience of lower limb amputation: the processes of changes on self-identity related to this experience, especially beyond body image and prosthesis embodiment; and the potential relation between intrapersonal variables related to this experience and depressive levels.

4. BRIEF CONSIDERATIONS ON THE SELF-IDENTITY AND ITS RELATION WITH THE ACQUIRED PHYSICAL IMPAIRMENT

The conceptualization of human body, the construction of its image and its relation with identity has deserved many conceptual approaches from several authors. In a brief explanation we can address some relevant conceptualizations about identity and its developmental process.

Sigmund Freud was one of the first authors who develop a powerful conceptualization on how the subject's mind processes a significant situation of loss. According to him, "the Ego is first and foremost a bodily Ego; it is not merely a surface entity, but is itself the projection of a surface" [Freud (164), pp. 26]. In his work on Mourning and Melancholia, Freud (165) argued that the mourning work is characterized by the Ego's efforts to integrate the experience of loss. During this process, it is expected that the individual performs an over libidinal investment in the lost object(s).

Jacobson (158) conceptualized the process of identity construction during childhood in four phases: the Oneness phase, in which the Self is not differentiated from the object; the Sameness phase, when the Self has a mimetic relation with the external objects; the Likeness phase, in which the Self idealizes the object; and the Closeness phase, where the Self is completely differentiated from the object. This progressive process of differentiation of the Self is composed by several dimensions in terms of time, space, gender (sexual identity), own body (bodily identity), and in terms of differentiated identity (159). According to Bergeret (159), this developmental process is strongly dependent on the formation of one's own mind and consciousness.

Grinberg and Grinberg (160) proposed a theoretical approach concerning identity, based on the conceptualization of the three distinct integration links: spatial;

temporal; and social. According to the authors the identity results from the relation between these three integration links. The spatial link refers to the relation between the different parts of the Self, including the Bodily-Self. This relation is responsible for the Self's cohesion and allows the comparison and the differentiation between Self and non-Self. The temporal link is defined by the authors as being the link between the different Self representations in time, and establishing the feeling of oneness. The social link concerns the identity's social connotations and includes the relation between the Self and objects, by projective and introjective identification mechanisms.

In a different approach, Damásio (161,162) conceptualises the Self based on the three individual instances: the *Proto-Self*; the *Core Self*; and the *Autobiographical Self.* The *Proto-Self* refers to a set of non conscious representations of the multiple dimensions of the current organism's state. The *Core Self* is defined as a transitory and conscious reference for what is happening at the moment. It refers to the individual's sense of "here" and "now" that are included in the subject's *Core Consciousness.* Mediated by the *Autobiographical Memory*, the *Core Self* will be an important base for another type of Self which Damásio called of *Autobiographical Self* (161). The *Autobiographical Self* is based on the *Autobiographical Memory* and is part of the *Broad Consciousness* where the past and present experiences and memories are included; it comes from the Proto Self and form the Core Self. In addition, the *Autobiographical Self* includes another important part of the individual's Self, which is the way the Self is projected in the future, this is, the anticipated future and the individual's expectations.

In terms of construction of the body image, Damásio (163) argued that our brain produces two distinct kinds of body images: the images of our flesh that concern to the images of the interior of our body - these images are based on the representations of our entrails and internal environment’s structure and state; and the specific body components that provide images based on the peripheral organs of the special senses like hearing, smell, taste or sight. In this way, it is understandable that an event like a lower limb amputation or an irreversible sight loss can produce significant changes in body image, and mostly in self-identity.

Besides the works that we already referred from Hayeems (1), Thurston (2), Parkes (135), and Murray (3), the self-identity in acquired physical impairment also aroused the interest of authors who developed different approaches on this topic. Due to its relevance for the study of the experience of becoming impaired, we will briefly address these works.

In a similar approach, Oliveira (147) stressed the acquired physical impairment as an event where an affective regression may occur. It is a situation of many potential losses for the individual’s Ego that originates a mourning process. This means that the impairment can be a disruptive event for the Self’s oneness. According to the author, the inherent changes and losses caused by the impairment can be reflected in dimensions like the relation with the own body, the own Self, and the affective relationships. These changes are often accompanied by a set of negative feelings such as: insecurity; inferiority; shame; envy; being different from others; or lack of control.

In another work, Oliveira and colleagues (104) stressed the incongruence of the “new Self-Image” against the former and ideal Self. In their qualitative study on patients mostly diagnosed with spinal cord injury, results show five main themes related to the experience of becoming impaired: the mourning process; the loss of self-awareness; the aggressiveness; the emotional liability; and the medium level of motivation towards treatment.

In a different proposal, Thomas & Siller (167) conceptualized the physical disability experience based on the Ego’s experience of loss. Authors proposed that narcissism can be a general factor in reactions to disability. This approach places the subject’s experience as being influenced by his/her type of object relationships. Five levels of narcissistic regression were proposed, ranging from a basic object cathexis to a basic narcissistic cathexis: individuals who have attained mature object relationships; individuals who have attained object relationships based primarily on physical appearance or *physique* (type I); individuals dominated by castration anxiety; individuals who have attained object relationships based primarily on physical appearance or *physique*; and individuals with a basic defensive narcissism. Authors proposed that individuals at type I (those who have attained mature object relationships) would have a better adaptation and resources to adjust to disability than individuals with a basic defensive narcissism.

Another approach that has also aroused some interest in authors from this field is the Somatopsychological model, developed by Dembo (168). According to this approach, the adjustment to physical loss is conceptualised as involving changes in the person’s value system that would promote the individual’s coping with the situation, in terms of the mourning process and in terms of handling the damages in self-worth caused by the physical injuries (in body-image and functional skills). The author proposed four areas related to the individual’s value changes (167): enlargement of scope of values; subordination of the *physique*; containment of disability effects; and transformation of comparative values to asset values.

Wilson (169), in an interesting approach on the experience of sight loss, stressed the transitional character of the adaptation process to impairment. According to the author, the experience of sight loss often ends as an eternal transitional process in which the patient never reaches a complete acceptance. The author designated three types of defences against the anxiety triggered by the threat caused by the impairment: the rejection of the impaired person by the family/community; denial of the impairment by the person and/or the environment; and the impairment perception as a transitional phase that could disappear in the future. The author's experience with these patients (psychotherapeutic work) showed that one of the most important steps in the adjustment process is the possibility of linking the own state with other blind people.

Other recent approaches have also emphasised several aspects of the Self that can be changed by a serious acquired medical condition. A study by Goetzman (170), with patients who had a lung transplant, stressed that the psychological crises after the transplant was conditioned by "safe" and "unsafe" internal object relationships, in the sense used by Sandler (171). According to Goetzman (170), it is the particular case of patients who had a traumatized object relationship and/or relevant losses before the transplant that display (after the transplant) a psychological crisis, as a crisis of affective regression.

In a similar view, Kaplan-Solms & Solms (172) and O'Gorman (173), with patients with acquired brain injury, address a link between the loss of physical capacities and the narcissistic loss. According to the authors these patients were described as having suffered a particular combination of physical, neurological and narcissistic injuries. These patients frequently reported a lack of awareness (and memory?) of the impairment (172,174-176), that has raised an interesting question: is this lack of awareness, a neuropsychological deficit or a narcissist defence (or both)? One possible answer according to Kaplan-Solms & Solms (172) is that these patients could unconsciously use defences to protect themselves from the awareness of loss and its associated depressive affects. Regarding this, O'Goorman wrote (173): "The strength of the narcissistic defence depends on factors such as ego strength, and the containment provided, or not provided, by early object relationships..." (pp. 135); and "the accident was, in part, a reactivation of this undigested/unmentalized trauma" (pp. 143 - regarding patients with traumatic brain injury). In this way, the author stressed the importance of the concept of "Mentalization", developed by Fonagy (177), to understand why some patients appear to be more able to be aware of their own impairment and to overcome the new condition, whereas other patients are not.

In summary, the experience of acquired physical impairment can affect the individual's identity and generates changes in several domains of the individual's self-image. This process appears to be very complex insofar as can hold a painful grieving process in which the inner and the external resources of the subject will be tested. Due to the importance of better understanding this complex process and to produce new knowledge on the experience of acquired physical impairment and on the adjustment process, more research is needed.

5. LOOKING FOR QUESTIONS

5.1 Why visual impairment and lower limb amputation?

In the previous chapters the main findings from several recent studies on vision loss and on lower limb amputation were presented and discussed. They are two clinical situations of acquired physical and functional impairment where other personal losses and transformations are at stake. Even though they are two different kinds of physical impairment, some common denominators may be considered in terms of the personal experience of becoming impaired.

Murray (3), in the introduction of his study with amputees, using a phenomenological analysis, pointed out some particular links between these two impairments. The author presented a phenomenological approach in which the body image conceptualization is based on the embodiment of the perceptual experience of the body. In that approach, the author stressed the perspective from Merleau-Ponti (158) that “the cane is an extension of the senses realm, with touch being transferred from the hand to the end point of the cane” [Murray (3), pp. 964]. The author (3) places the “tool’s” incorporation (cane or prosthesis) as a fusion process between the body and the cane / prosthesis, based on Leder’s concept of “phenomenological osmosis” [cit by Murray (3)]. Therefore, in a certain moment of both experiences (vision loss and amputation) – when the individual has to embody the “tool” - there is an experience with potentially common meanings. The sensorial/perceptual, or physical prosthesis (cane/artificial limb), will be the main mediators for the patient’s functional re-establishment, in terms of autonomy and in terms of relation with his/her inner and external reality.

That perspective of the embodiment process, and the fact of both clinical situations being related to a particular condition of loss (physical/functional), appears to justify our choice in terms of our study's population. Moreover, as we saw in previous chapters, much literature has found similar implications between them regarding the emotional impact and some features of the adjustment process.

In this way, our first challenge was to consider, independently, these two different populations on the experiences of becoming impaired. Our starting point was that both need a special attention and further research. Therefore, two independent studies were performed: one on the experience of vision loss and depressive levels; and other on the experience of lower limb amputation and depressive levels.

Following the main questions and aims of our study are presented and justified.

5.2. Studies' Problems, Rationale and Hypotheses

5.2.1. Study 1 – Vision Loss

The previous literature review showed that, although there is previous relevant research on the experience of vision loss, it is a topic that continues to be understudied, especially in working-age adults. In terms of the intrapersonal variables related to this experience, the patients' self-awareness of impairment and self-identifications with the impairment are two psychological processes that deserve more research. They are variables that arise strongly associated with changes in self-identity which is an understudied aspect of the adjustment process to vision loss.

Regarding the depression which is the most frequent manifestation of emotional distress in adults with vision loss, the literature review showed that the potential connection between depressive levels and variables, involved in the experience of vision loss, is an underexplored topic. Some previous studies, especially from Malec and colleagues (159,160), with patients with other physical impairments, proved that depression can be linked to self-awareness of impairment. Therefore, more knowledge is needed on whether some intrapersonal variables, as the self-awareness of impairment, might be related to depressive levels in this population.

Thus, our two main questions were:

Question 1: “How do working-age adults experience vision loss?”

Question 2: “Can some intrapersonal variables, related to the experience of vision loss, be linked to depressive levels?”

For **question 1** two hypotheses were defined:

a) There is an experience of vision loss in working age adults that might present distinct meanings and implications associated with that ages and with changes in self-identity;
b) The self-awareness of impairment and the self-identifications with the impairment are two relevant variables, linked to changes in self-identity that are involved in the overall experience of vision loss.

For **question 2**, two hypotheses were defined:

a) There are intrapersonal variables that might be linked to patients’ depressive levels;
b) Self-awareness of impairment and self-identifications with the impairment are two intrapersonal variables that might be linked to patients’ depressive levels.

5.2.2. Study 2 – Lower Limb Amputation

Our previous literature review on this field showed that there are some specific topics where more research is needed. The experience of limb loss is mainly studied in terms of implications in body image and prosthesis embodiment, and we continue to have little knowledge on other personal implications such as the changes in self-identity. This topic is useful to get a deeper understanding of the adjustment process to limb loss and to design new intervention approaches and targets.

Another topic identified as under-studied on lower limb amputation is how the experience of becoming amputee might be linked to depressive levels. As in Study 1, we considered the self-awareness of impairment and the self-identifications with the impairment as being two relevant aspects to study on the experience of becoming impaired.

Thus, our two main questions were:

Question 1: "How do adults experience lower limb loss?" and "What are the self-identity changes caused by limb loss that occurs besides the ones concerning the patients' body image?"

Question 2: "Can some intrapersonal variables, related to the experience of amputataion be linked to depressive levels?"

For **question 1** two hypotheses were defined:

a) Patients experience the lower limb loss beyond the changes in body image and prosthesis embodiment, and reveal other core changes in self-identity;

b) The self-awareness of impairment and the self-identifications with the impairment might be two variables associated with changes in self-identity as consequence of the lower limb loss.

For **question 2**, two hypotheses were defined:

a) There are intrapersonal variables that might be linked to patients' depressive levels;

b) Self-awareness of impairment and self-identifications with the impairment are two intrapersonal variables that might be linked to patients' depressive levels.

5.2.3. Overall Rationale

The main questions of our dissertation are:

- How do adults experience becoming physically impaired?
- How these experiences influence the changes in self-identity?
- Might the experience of becoming physically impaired be linked to depressive levels?

5.3. Aims

5.3.1 Study 1 – Vision Loss

In sequence of our previous study problem, rationale and hypotheses, the following aims were defined:

- To explore in depth how working-aged adults experience their vision loss;
- To explore that experience in terms of changes in self-identity, especially the self-awareness of impairment and the self-identifications with the impairment;

- To explore possible links between some intrapersonal variables related to the experience of vision loss and depressive levels – especially the self-awareness of impairment and the self-identifications with the impairment.

5.3.2 Study 2 – Lower limb Amputation

Considering our previous questions and hypotheses to be tested, three aims were defined:

- To explore, in depth, how adults experience becoming lower limb amputees;
- To explore that experience in terms of changes in self-identity, especially the self-awareness of impairment and the self-identifications with the impairment;
- To explore possible links between some intrapersonal variables related to the experience of amputation and depressive levels – especially the self-awareness of impairment and the self-identifications with the impairment.

5.3.3. Overall Aims

The main aims of the current dissertation are:

- To explore both experiences of becoming impaired, especially in terms of changes in self-identity;
- To find common denominators and meanings between both experiences;
- To find preliminary links between the experience of becoming impaired and depressive levels. For this topic only preliminary findings were searched, because our study design is cross sectional (see chapter 5 and papers).

6. LOOKING FOR ANSWERS

In order to answer our questions, two studies were performed, as referred previously: one with adults with vision loss; and the other with adults with lower limb amputation. Details on each research's method are presented in the papers section of this dissertation. Following, our research design is summarized and the guidelines to find our research answers are presented.

6.1. Study 1 – Adults with vision loss

To explore adults' experiences of vision loss and depressive levels, a cross sectional research using mixed methods research was adopted. The sample was composed by 38 working-age adults, all of them in a rehabilitation setting for visually impaired people: Nossa Senhora dos Anjos Rehabilitation Centre; and Ophthalmological Hospital Instituto Gama Pinto. The inclusion criteria were: to be between the ages of 20 and 65; having lost their vision after the age of 18; to have vision loss due to an acquired ophthalmological disease; and to be in a rehabilitation setting. The following patients were excluded: under the age of 20; with a serious congenital ophthalmological condition; HIV positive; and with any confirmed neurological or cognitive impairment. Patients with different types of visual impairment (severe low vision and blindness) were considered.

The following measures were used: a simple questionnaire for socio-demographical and clinical variables; a semi-structured interview to explore patients' experience of vision loss (see details in the papers 1 and 3); and the Centre for Epidemiological Studies of Depression Scale (CES-D) (161), to assess depressive levels.

Two interviews lasting between 45 and 60 minutes were performed for each patient. The last 15 to 20 minutes were used to collect socio-demographic and clinical data and to assess depressive levels.

Qualitative data was recorded, transcribed verbatim and analysed by two independent researchers. The content analysis was performed using the Thematic and Categorical Analysis proposed by Bardin (162).

6.1.1 Papers for Study on Vision Loss

Due to the fact of this research had approached two different kinds of patients' data (qualitative and quantitative), it contains two distinct aims that we have decided to separate it into two papers:

- One paper addressing a qualitative study on the working-age patients' experiences of vision loss;
- Another paper on depressive levels and the experience of vision loss, combining our retrieved qualitative data (used in the previous paper) and the results from CES-D.

6.2. Study 2 – Adults with lower limb amputation

To explore adults' experiences of lower limb amputation and depressive levels a cross sectional research, using mixed methods, research was adopted. The sample was composed by 42 adults, all of them being followed up at the rehabilitation medicine department from Hospital de Santa Maria (a public general hospital in Lisbon).

The inclusion criteria were: being at least 20 years old; lower limb amputation performed after the age of 18; and being followed up at a rehabilitation medicine unit. Patients, who did not meet the inclusion criteria and/or had neurological or cognitive impairment, were excluded, as it could interfere in the patients' outcomes. Patients at two different stages of rehabilitation were selected: those who were performing their rehabilitation; and those who had already finished it but continued to be followed up by this unit.

The following measures were used: a simple questionnaire for socio-demographical and clinical variables; a semi-structured interview to explore patients' experience of limb loss; and the Centre for Epidemiological Studies of Depression Scale (CES-D) (161), to assess depressive levels.

Two interviews lasting between 45 and 60 minutes were performed for each patient. The last 15 to 20 minutes were used to collect socio-demographical and clinical data and to assess depressive levels.

Qualitative data was recorded, transcribed verbatim and analysed by two independent researchers. The content analysis was performed using the Thematic and Categorical Analysis proposed by Bardin (162).

6.2.1. Papers for Study on Lower Limb Amputation

Due to the fact that this research had approached two different kinds of patients' data (qualitative and quantitative) it contains two distinct aims that we decided to separate it into two papers:

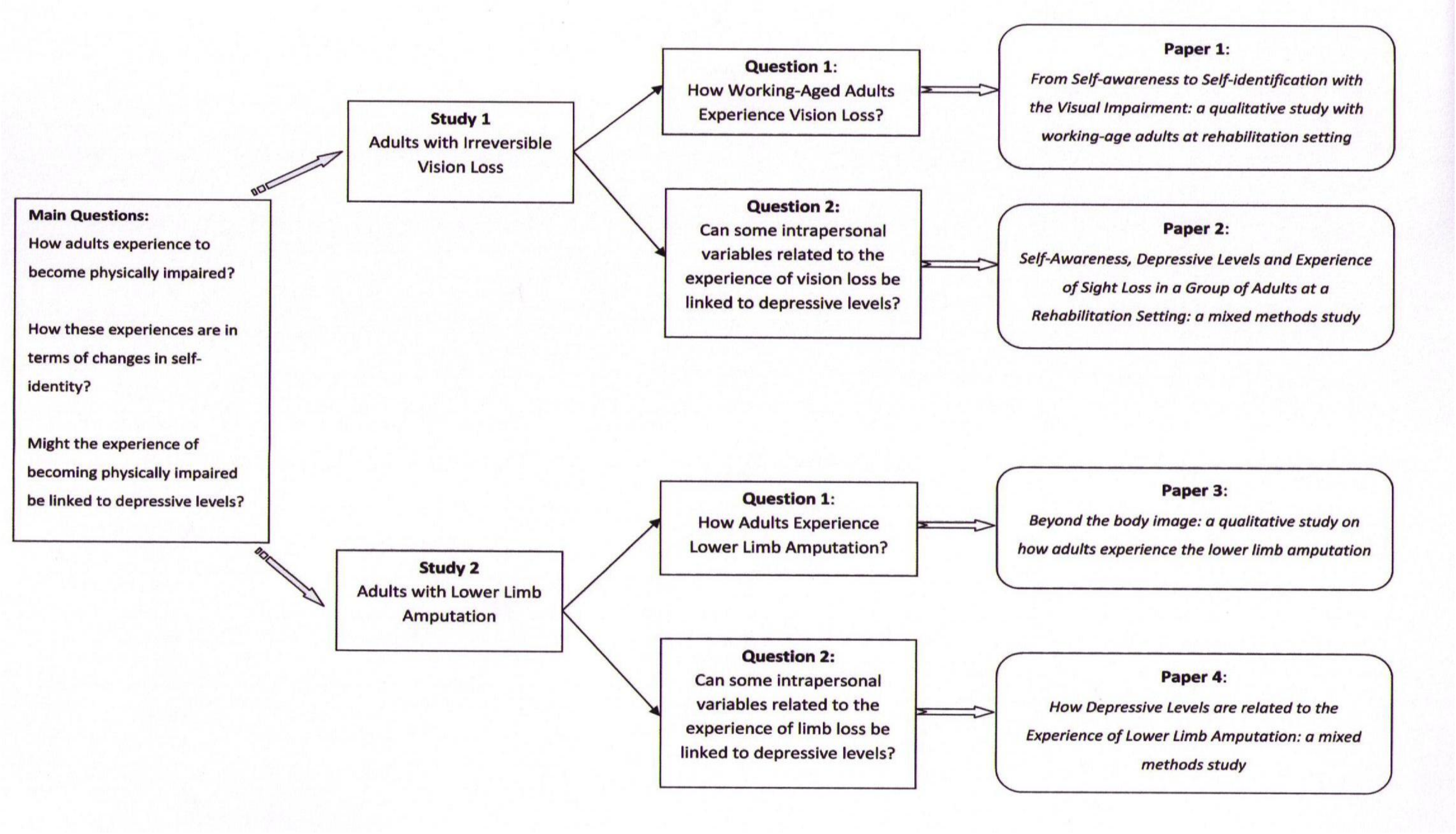
- One paper addressing a qualitative study on the patients' experiences of lower limb amputation (n=42);
- Another paper on depressive levels and the experience of limb loss, combining our retrieved qualitative data (used in the previous paper) and the results from CES-D, and using all of our recruited patients (n=42).

6.3. Overall Scheme of our Dissertation’s Papers

To answer our study’s questions, two studies were performed, each of one generating two papers. The purpose of each paper was to answer to each study question. Figure 1 illustrates how we designed our research structure and study’s answers.

Regarding the second paper from both studies, a cross-sectional design was adopted, as in many previous similar qualitative and mixed methods studies in this field. Therefore, we cannot argue anything about causality between depressive levels and intrapersonal variables. However, they are studies that also offered a wider picture of the experience of vision loss/amputation in patients, in different periods of time after they become impaired.

Figure 1 – Structure of the Research Design



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STUDY 1:

VISION LOSS IN ADULT AGES

The Experiences of Vision Loss in Working-Age Adults

PAPER 1

TITLE:

From Self-awareness to Self-identification with the Visual Impairment: a qualitative study with working-age adults at a rehabilitation setting.

ABSTRACT

Objective: To explore the experience of vision loss focusing on working-age adults' self-awareness of impairment and self-identifications with the impairment.

Design: A cross-sectional and qualitative study, using semi-structured interviews.

Setting: A specialised rehabilitation centre and a low vision unit from a public hospital.

Participants: A convenience sample of 38 patients between the ages of 20 and 65, with sight loss caused by a serious ophthalmological condition acquired after the age of 18, and doing their rehabilitation.

Main outcome measures: A semi-structured interview, addressing 3 core areas: the emotional impact of vision loss; the adjustment; and the social support. Interviews were transcribed, coded and analysed by two independent researchers.

Results: Seven themes emerged from interviews. Changes in subjects' identity, achievement and future life projection arose as being the main transformations caused by vision loss. Self-awareness of impairment appeared associated with the subject's first contact with his/her loss, while the self-identifications with the impairment arose connected with the later embodiment process of the vision loss.

Conclusions: Patients' self-awareness and self-perceptions of impairment appear as two important milestones of the adjustment process to vision loss. Their assessment and monitoring over the rehabilitation period might help to promote the impairment acceptance and the rehabilitation outcomes.

INTRODUCTION

According to the World Health Organization, most of the visually impaired people worldwide are adults and elderly, and live in developed countries (1). Due to its implications on the subject's activities of daily living and functioning, vision loss has been reported as a potential cause for other individual losses. Stop working, driving, reading, or writing, might be consequences of vision loss, which often cause an important loss of independence and self-esteem (2,3). Nevertheless, it is a fact how subjective the experience of vision loss may be and the different meanings it may have for a person. After vision loss people show different kinds of adjustment courses and achieve different levels of rehabilitation outcomes. Therefore, the personal experience of vision loss has aroused interest in some authors, especially those using qualitative studies.

Loss of independence and mobility, isolation, fear of accidents, depression, and the end of life are some of the key themes stressed by adults and elderly who lost their vision (4-9). According to these studies, patients addressed their greater losses caused by vision disease, emphasizing feelings of sadness and of vulnerability. These feelings appeared also associated with their great challenges during the adaptation process, such as to use the assistive devices, especially the white cane.

In terms of social functioning, a study from Wang & Boerner (10) underscored how challenging it may be the re-establishment of relationships after vision loss. In this study patients stressed their feeling of being little understood by others and their difficulties due to the lack of visual cues as main relationship-related challenges after vision loss.

Concerning the social support some studies have associated an overprotective or a conflictive and controlling social support with worse outcomes during the adjustment process to vision loss (11,12).

Recent researches have addressed new intra-personal variables in patients' experience of impairment. Mixed methods studies form Thurston (7,13) emphasized patients' experiences of changed perceptions of self as being associated with the adjustment process of transition from sighted to blindness. During this process, patients will progressively cope with their vision loss. The impairment will no longer be hidden and the white stick and the rehabilitation begin to be accepted.

In the same way, Hayeems and colleagues (14) found that subjects who are more identified as being visually impaired were more likely to reveal their disease, to make life-style changes, to use assistive devices and, consequently, to be more autonomous. Although these studies are only with patients with retinitis pigmentosa, they addressed an under-studied intra-personal variable, the self-identifications with the impairment. Another interesting intra-personal variable was addressed by two studies with patients who suffer a traumatic brain injury or orthopaedic injuries (15,16). These studies linked the self-awareness of the impairment with early and late depression. Despite the relevance of this intra-personal variable, there are no studies on visual impairment that addressed subjects' self-awareness of the impairment. It would be interesting to explore how this variable is related to the adjustment process in visually impaired patients. Thus, both self-identifications with the impairment and self-awareness of impairment appear as new and under-studied intra-personal variables that deserve further research. Furthermore, the experience of vision loss continues to be a less studied area, especially in working-age adults (17). Practitioners can benefit from this knowledge, especially to promote new target interventions and to prevent patients' dropout of rehabilitation settings.

Our study intends to explore the experience of vision loss on working-age adults in a rehabilitation setting, focusing on the patients' self-awareness of the impairment and patients' self-identifications with impairment.

METHOD

To perform this research, an exploratory and cross-sectional design using qualitative methods was adopted.

Adult patients were recruited from two specialised centres: a rehabilitation centre for visually impaired people; and a low vision unit from a public hospital. Inclusion criteria were: to be between ages 20 and 65; having lost vision after the age of 18; to have vision loss due to an acquired ophthalmological disease; and to be in a rehabilitation setting. The following patients were excluded: under age 20, or above age 65; with a serious congenital ophthalmological condition; with HIV positive; and with any confirmed neurological and cognitive impairment. Patients with different types of visual impairment (severe low vision and blindness) were considered. The criteria to classify the patients' type of impairment were based on medical report and according to the World Health Organization's classification for low vision and blindness (18). Patients at different stages of rehabilitation were selected: subjects who were in the first 3 months of their rehabilitation; and subjects who were more advanced (more than 3 months) in their rehabilitation. In both centres, patients' rehabilitation includes integrated multidisciplinary services such as: mobility and orientation; psychological support; Braille; adapted computer technologies; and educational support. In the rehabilitation centre patients also have physical education and art-therapy. In the low vision unit, patients are followed by a physician specialised in low vision. The rehabilitation's turnaround time is between 4 and 6 months, depending on the patient's needs. Ethical procedures were adopted following the institutional protocol, and using an Informed Consent Form.

Data collection

Our sample's data were collected through an assessment protocol composed by two interviews for each patient, lasting between 45 and 60 minutes. This protocol was designed to collect the maximum data about their experiences. Thus, a second interview facilitates patients' reports about their feelings and attributions to vision loss. The process of selecting and inviting patients to participate in our study was performed in partnership with the centres' practitioners. Then, they were directly invited to be interviewed. A total of 50 patients were invited and 38 accepted or fulfilled all inclusion criteria.

Qualitative data were collected using a semi-structured interview, which was conducted through open-ended questions. These questions were designed to address patients' experience of sight loss, including patients' self-awareness of the impairment and self-identifications with the impairment. Thus, three core areas were defined to be addressed: the emotional impact of vision loss; the adjustment process to vision loss; and the perceived social support. The questions were created to be bias free, to allow for any kind of narrative about each theme and to facilitate the fluency of participants' narratives about their experiences (see appendix1). All interviews were conducted and recorded by the same researcher (HS) who had no previous relationship with the participants. This researcher was supervised during the whole study by another researcher (RAO).

The interviews continued being conducted even after researchers felt saturation had been reached, in order to get the maximum variation of sample's characteristics. A total of 87 interviews were conducted for all 38 participants (n=38). As can be seen in table 1, the mean participants' age was 42 (SD= 14.5) and 18 were women. Most of them (65.8%) were blind and the remaining patients had severe low vision. The main aetiology of the impairment was glaucoma (n=13). Patients who lost their vision faster (n=17), or progressively (n=21) were assessed. Patients' rehabilitation time varied between 1 to 12 months.

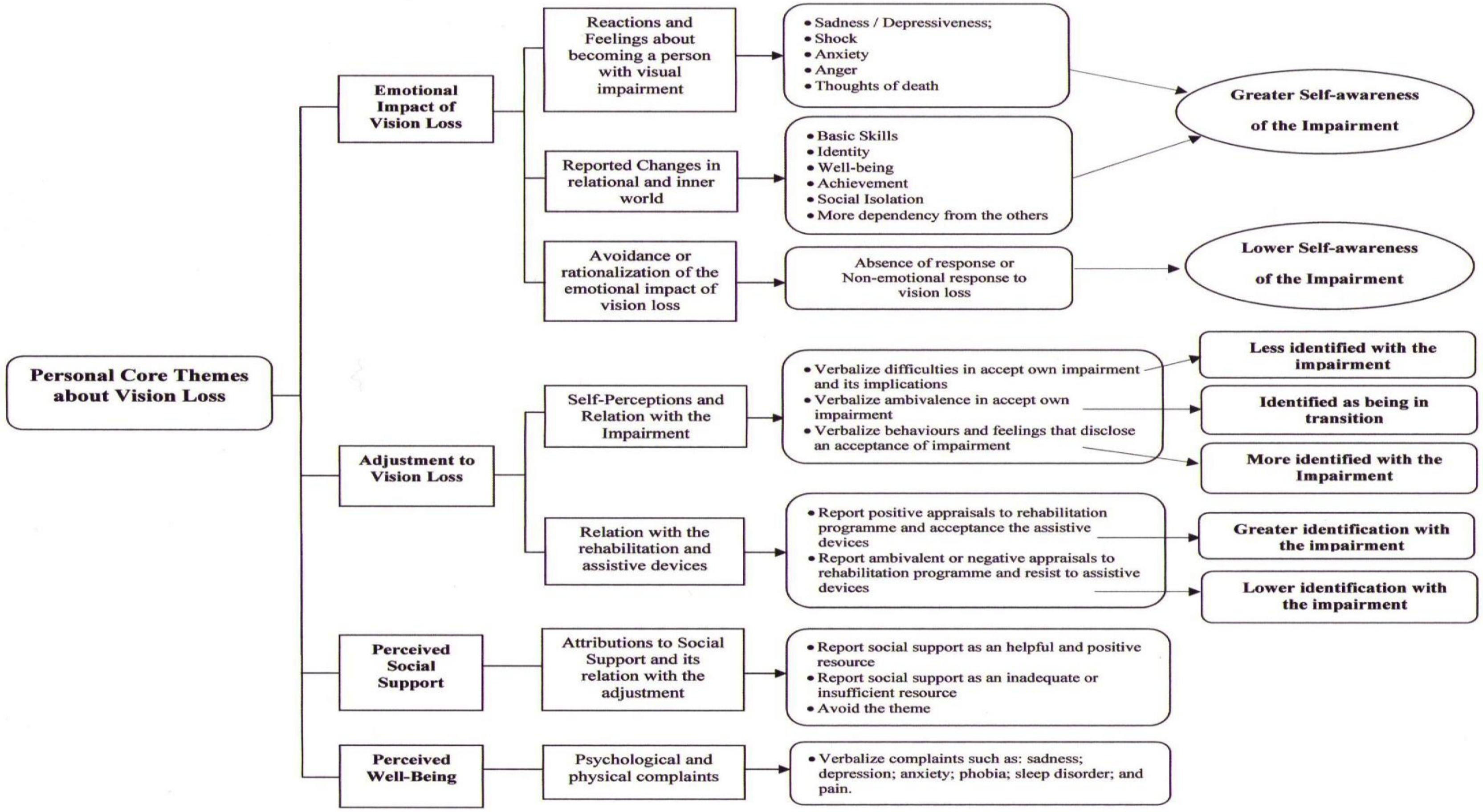
Data Analysis

After the interviews were recorded, they were transcribed verbatim. Then, they were analysed using the Thematic and Categorical Analysis proposed by Bardin (19). In this method, an induced analysis modality with an open coding technique was adopted (20,21), because we did not have any previous ideas or conceptualizations about the patients. The content analysis was conducted by following these steps: transcriptions were read at least twice, line by line to infer global and specific meanings, and structure; each narrative's specific meanings that generated open codes (semantic criteria) were identified and labelled; codes were gathered by sharing common themes; themes were reanalysed and reviewed in order to be labelled and regrouped in thematic categories; thematic categories were validated by returning to the data through the patients' direct quotations. This procedure was performed by two researchers (HS, RAO) who made an exhaustive discussion and reflexion about each meaning and defined criteria for each themes categorization, during all the analysis' steps. There was a high consensus between researchers, and disagreements were solved by returning to the transcripts.

Table 1 Characterization of the sample

Variable	**Variable Groups**	**N**	**Valid %**
Age (M=42.7 / SD=14.5 / Min:20; Max:64)	20-40 years	18	47.4%
	41-65 years	20	52.6%
Gender	Male	20	52.6%
	Female	18	47.4%
Education Level	Up to 9 years	28	73.7%
	> 9 years	10	26.3%
Age at vision loss (M=39.2 / SD=14 / Min:18; Max:64)	18 to 40 years	21	55.3%
	41 to 65 years	17	44.7%
Type of Acquired Visual Impairment	Blindness	25	65.8%
	Severe Low Vision	13	34.2%
Main Pathologies that causes vision loss	Glaucoma	13	34.2%
	Retinitis Pigmentosa	7	18.4%
	Retinopathy	7	18.4%
	Physical Trauma	3	7.9%
	Cataracts	2	5.2%
	Others	6	15.7%
Time between first diagnosis and vision loss – evolution (years) (M=7.3 / SD=8.4 / Min:0; Max:34)	0 to 3 years (fast)	17	44.7%
	> 3 years (progressive)	21	55.3%
Time between vision loss and Interviews (years) (M=3.3 / SD=2.9 / Min:1; Max:16)	0 to 2 years	20	52.6%
	> 2 years	18	47.4%
Rehabilitation Time (months) (M=4 / SD=3 / Min:1; Max:12)	0 to 3 months	19	50%
	>3 months	19	50%

Figure 1 Categories, Themes and Subthemes emerged from interviews



RESULTS

The three core categories addressed by the interviews generated seven themes, each one with specific sub-themes extracted from patients' verbalizations. As can be seen in figure 1, the three themes related to the category "emotional impact of vision loss" allowed obtaining the patients' self-awareness of impairment. The two themes that emerged from the category "adjustment to vision loss" enabled the exploration of the patients' self-identifications with visual impairment. The perceived social support generated themes related to its attributions and its relations with the recovery process. Besides these categories, patients also approached another one which theme was their well being perceptions.

Self-Awareness of the Visual Impairment

Patients more Aware of their Impairment

A large portion of patients (n=26) showed greater emotional responsiveness to vision loss and greater self-awareness of their impairment. These patients verbalized the following feelings associated with becoming impaired: sadness; depressiveness; anguish; anxiety; shock; non-acceptance of the impairment; anger; and thoughts of death. Also all of them acknowledged some implications of vision loss in their lives. They reported changes in the inner and relational world, such as in: basic skills; identity / personality; psychological well-being; academic or professional achievement; and social and affective life. Stop doing the daily life activities and working; giving up on some future life plans; being a more dependent person; being more isolated from the others; being abandoned by others; and losing friends and trust in others, were some changes pointed out by the patients.

- *It was something that disturbed me very much! I was shocked and down and lost a lot of weight... up to 59 Kg! I was very depressed... I didn't want to live anymore... I felt very sad...* (Participant 19);
- *The hardest part was having to stop working... I lost my job and stopped doing many things such as driving, reading, walking alone... I became sadder... before the loss I was happier and more satisfied with my life.* (Participant 39);
- *Others told me that I wasn't the same person... I was happier... today I'm feeling sad... I isolated myself at home, because I lost my interest in everything! Moreover, nobody understands me! Few people want to accept a blind person and have her as a friend! On the other hand, it's very hard to depend so much on others!* (Participant 32).

Patients less aware of their impairment

Other patients (n=12) showed a non-emotional response or an absence of response to vision loss, and a lower self-awareness of their impairment. Most of these patients devaluated or refused the theme, and did not report any change in their lives caused by vision loss. Frequently, they changed the theme to other matter not related to vision loss. In the few cases of some responsiveness to vision loss, patients rationalized the theme and devaluated any major limitation related to the impairment.

- *I loved working in my farm, because I had an active life, but today I'm not a poor little thing... Things happen and we have to deal with it! Life goes on...* (Participant 30).
- *I had no problem with it! I know, some people feel down... but you don't know me! I never back down in my life!* (Participant 10).

- *I know there are some things that I cannot do, but it's temporary! I know I will see again soon! No, I never felt sad or depressed with this! I'm very strong, and I know it will change!* (Participant 24).

Self –Identifications with the Visual Impairment

Patients more identified with their impairment

Twelve patients exhibited narratives about themselves and their vision loss where they appeared to be identified with their impairment. In these cases, the impairment was addressed as being part of them, and the rehabilitation and the assistive devices were appraised as being helpful and positive resources. The white cane was frequently addressed as being part of the new life style and a useful device to begin to walk alone again. In some situations they also showed to have future plans associated with the rehabilitation program, such as to return to work.

- *Before rehabilitation I hid my problem and hid myself... I was isolated... Today I found a new life... I have new friends... I take better care of myself! The stick has helped me so much; I can walk alone to many places where I couldn't before. The rehabilitation has helped me so much. I adore my teachers! They have been so understanding with me! I never thought I would find a place like this centre!... I'm discovering new skills in me. I'm planning on returning to school...* (Participant 35).

Patients identified as being in transition

The majority of our participants (n=20) presented an ambivalent narrative about themselves, their impairment and about the rehabilitation progresses. Even partially resisting to some assistive devices and lifestyle changes, feeling ambivalent about the white stick and the rehabilitation's value, these patients already have some identification with their impairment. Therefore, there already is a partial acceptance of their condition and the related adaptive aids. In these cases patients appeared to be in transition between being identified as a person without visual impairment and a visually impaired person.

- *I like to be here (in the rehabilitation)... I've learned a lot of new things that help me... I returned to doing many things... However... I still have problems with the cane, because it draws attention and people say: "look at the blind!" I know I am blind, but it's still hard to hear it!* (Participant 2).

Patients Identified as being a person without visual impairment

Other patients (n=6) verbalized that they did not need or did not like the assistive devices, refusing help, resisting rehabilitation, acknowledging the white stick as a bad or a useless thing, and in some cases, referred to themselves as being sighted. In these cases, the rehabilitation was frequently appraised as being an inadequate resource that is not helpful for their individual needs. These verbalizations show that patients are *not identified as impaired* and keep on being identified as sighted:

- *I'm very well... I don't have any problem with it... I know there are people that are traumatized, but you don't know me, I'm strong!!... I don't use the stick because I have my wife... she helps me... I think that maybe rehabilitation is being too long for me... I have to work... I've been thinking about quitting!* (Participant 8: <3 months of rehabilitation).

Perceived Social Support

Fifteen subjects appraised their social support as being a good and a helpful resource. These patients valued the role that their friends or family have in their adaptation and recovery.

- *When I went blind the world broke down... It was a big shock... I was very lost because it was unexpected and I'd never thought that it could happen to me and I still do not understand... However, today I feel better... thanks to my family... my husband! They have been the main reason for my staying here.* (Participant 32).

Other patients (n=21) reported an inadequate or insufficient social support. These patients referred a lack or an absence of support from their family or friends, frequently verbalizing feelings of loneliness and abandonment.

- *They try to help me but they don't understand me... they still believe that I can do many things that I can't... however, they have improved lately!* (Participant 25).
- *After I became blind, nobody cared about me... People must think I have a contagious problem or that I'll be a lot of work and trouble for them!* (Participant 13).

Problems in Well-being

A great part of our participants (n=25) also verbalized current problems in well-being, through physical and / or psychological complaints. The most mentioned complaints were mood changes (depressive and sadness), sleep disturbances, and anxiety and somatic compliments:

- *I'm feeling very sad... I cannot sleep and I'm less motivated to do anything. I'm feeling bad with this!"* (Participant 16).

Experience of vision loss in different groups of patients

As can be seen in table 2, results point to higher occurrence of patients who are more identified with visual impairment in the group of those who have been at rehabilitation for longer. In terms of the type of impairment, the data shows no relevant differences between the two groups (table 3).

Table 2 Frequency of emerged themes by two phases of the rehabilitation

Experience of Vision Loss		**Rehabilitation Time**	
		0-3 months (n=19)	>3 months (n=19)
Self-Awareness of the Impairment	More aware	13 (68.4%)	13 (68.4%)
	Less aware	6 (31.6%)	6 (31.6%)
Self-Identifications with the impairment	As sighted	4 (21.1%)	2 (10.5%)
	As in transition	11 (57.9%)	9 (47.4%)
	As visually impaired	4 (21.1%)	8 (42.1%)
Perceived Social Support	As a good resource	7 (36.8%)	8 (42.1%)
	As inadequate or insufficient	11 (57.9%)	10 (52.6%)
Perceived Well-being	Report problems / complaints	11 (57.9%)	13 (68.4%)
	Did not report problems / complaints	8 (42.1%)	6 (31.6%)

Table 3 Frequency of emerged themes by type of visual impairment

Experience of Vision Loss		**Type of Acquired Visual Impairment**	
		Blindness (n=25)	Low Vision (n=13)
Self-Awareness of the Impairment	More aware	17 (68%)	9 (69.2%)
	Less aware	8 (32%)	4 (30.7%)
Self-Identifications with the impairment	As sighted	3 (12%)	3 (23.1%)
	As in transition	14 (56%)	6 (46.2%)
	As visually impaired	8 (32%)	4 (30.7%)
Perceived Social Support	As a good resource	10 (40%)	5 (38.5%)
	As inadequate or insufficient	13 (52%)	8 (61.5%)
Perceived Well-being	Report problems / complaints	15 (60%)	9 (69.2%)
	Did not report problems / complaints	10 (40%)	4 (30.8%)

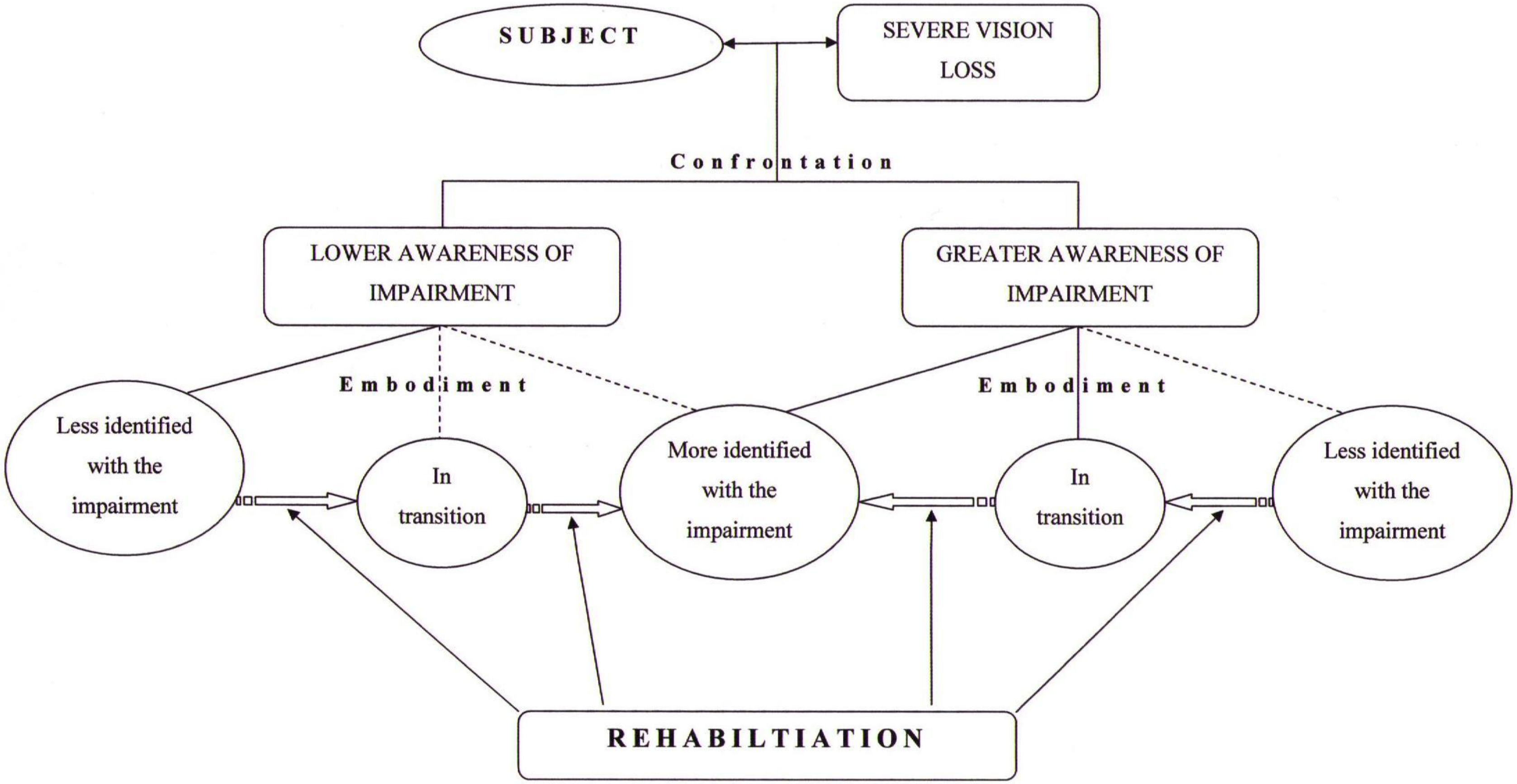
Discussion

Our study retrieved a set of themes on the experience of vision loss which are, apparently, similar to those that emerged from previous qualitative studies (4-7). Verbalizations such as the depressive reactions, feelings of loneliness, changes in basic skills and autonomy, and some difficulties with the rehabilitation, were the most similar findings, in comparison with studies with older adults (5,6,8,9). However, the themes from our qualitative data contain mostly a set of verbalizations associated with characteristic issues of working-age patients. For this reason, our patients' narratives reflected different approaches to vision loss implications when compared to older adults in a similar condition. In terms of the emotional and personal impact of vision loss, patients were more focused on losses in their professional course and achievements, on changes in their identity, and/or in their marital life. Generally, the depressive feelings were associated with these life transformations, this is the emotional impact of vision loss in our sample appears associated with two main losses: who the subject was/is (the identity); and who the subject will be (the future projection). In the sense used by Damasio (22), these transformations caused by vision loss could assume a potential change in the subjects' *Autobiographical Self,* both in terms of their body and global image, and in the future projection of this image. Furthermore, other authors have also found some changes in individual's spatial and temporal sense and his relation with objects after vision loss (23-26).

In terms of the adjustment process, our sample also focused on different themes of their recovery process in comparison with the older adults previously studied. Most of rehabilitation goals were not only focused on the basic skills and autonomy recovery, but especially to acquire new skills to return to work, and to concretize a new project for future life.

Due to the significant changes caused by vision loss in the subjects' life, this experience appeared as an event potentially hard to overcome and to accept. At first, facing vision loss, each of our patients coped by accepting more or less their own reality, and reacted according to their acceptance. Therefore, patients with different self-awareness of the impairment were found. After this first confrontation with impairment, patients reported an adjustment process in which they made several efforts to embody the impairment and reach a more or less adaptive course. Thus, the three types of identification, that our sample showed, seem to be associated with the embodiment of the visual impairment, which is part of the adjustment process.

Figure 2 Model of the adjustment to vision loss



--------- Less likely to occur

In terms of the influence of the rehabilitation and the type of visual impairment, the results suggest a positive interference of the rehabilitation in the adjustment process and no influence of the type of impairment.

These findings suggest a model for the adjustment process to vision loss, in which the self-awareness of impairment and the self-identifications with the impairment appear to be important milestones of the evolutionary process of adaptation to vision loss (figure 2). In this model the self-awareness of impairment initiates the adjustment process through the subjects' confrontation with their new condition. A lower awareness will make the subject more susceptible to be less identified with his/her visual impairment, whereas a greater identification with the impairment will be more likely to occur after a greater awareness of the impairment is achieved. In other words, the impairment's embodiment appears to be influenced by how much the subject is aware of his/her situation. Rehabilitation provides a positive interference in this process, because it facilitates the patients' self-awareness and embodiment progresses.

A part of this theoretical framework is supported by other qualitative studies (7,13), especially Hayeems' one (14). Alike this study, our findings stress the importance of the patients' self-perceptions and self-identifications with the impairment in the adjustment process. Moreover, Hayeems also purposes that the self-identifications might be associated with rehabilitation outcomes. However, our model goes further in terms of the beginning of the adjustment process, because we explored which intra-personal variables could be behind the impairments' embodiment process.

Consistent with previous studies our results also showed other variables that seem to influence how subjects experience their vision loss: the quality of patients' perceived social support (12) and well-being (27). The only reason for these variables not appearing in our model is that we do not know their relation with patients' self-awareness and self-identifications. We just know that some previous studies found an association between these variables and patients' levels of emotional distress, well-being and outcomes (27-29).

In terms of clinical practise, these findings bring some innovative cues for the assessment and intervention work. During the follow-up of these patients, an assessment protocol, which includes the monitoring of the patients' self-awareness and self identifications, will help to identify in which phase of the adjustment they are. This information is helpful to understand certain patients' reactions and behaviours, such as: why the patient is refusing rehabilitation, an assistive device or a specialised aid; why the patient is conflicted with peers or with practitioners; or why the patient's expectations do not match his/her reality. A good diagnostic of the intrinsic causes of patients' courses and behaviours, during the rehabilitation process, will be valuable for individual intervention plans, and especially for a more effective psychotherapeutic work.

Although our study supports some previous findings from literature and presents a model for the adjustment process, some limitations need to be acknowledged. First, even though our sample size is big enough for a qualitative study, it is a selected sample composed only by subjects who are going through rehabilitation.

Second, despite the fact that patients at the beginning of their rehabilitation were included in our sample, the rehabilitation's effect was not completely controlled. Therefore, it would be interesting for future research to compare patients who have not started their rehabilitation with those who are doing it, in terms of the vision loss experience.

Third, the interviews were only semi-structured. Even though the interviews were conducted with the concern of being bias free, three core areas were pre-defined to be addressed in interviews. Thus, interviews tended to be steered to these areas and therefore they could have biased the results.

Fourth, due to the fact of our study being a cross-sectional study rather than a longitudinal study, the evolution of patients' adjustment to vision loss overtime was not assessed. It would be interesting to perform it in future studies.

Finally, our proposed model cannot be generalized to other samples and only reveals the experiences of vision loss of our studied patients. It indicated only relevant clues to take into account in clinical practise and future research.

CLINICAL MESSAGES:

- The experience of vision loss in working-aged adults appears related to changes in patients' identity, achievement, and future life projection.
- To assess the patients' self-awareness of impairment and self-identifications with the impairment it might help to identify their adjustment course, behaviours and reactions over the rehabilitation period.

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Appendix 1 – Core Questions for Patients' Interviews

1. Beginning of the Interview:
    a. I would like to know more about you, your history, what's happened with you, your feelings, how did you come here...?
2. The Emotional Impact of Vision Loss
    a. What's happened with you? How did you know that you were having problems with your vision?
    b. How did you react to your vision loss? Which thoughts occurred to you? How did you deal with it?
    c. Did the vision loss lead to any significant change in you and your life? Was there a life or a person before and another after the vision loss? If so, what changed?
3. Adjustment to vision loss
    a. How did you come here (to rehabilitation)?
    b. How are you doing your rehabilitation? Has it been helpful? Have you had some particular problems with any area? What do you think about the stick?
    c. What personal aims do you have in the rehabilitation?
4. Relation with the social support
    a. How did your family and friends react to your vision loss?
    b. Have you had some significant support from your family, friends, or others?

PAPER 2

Self-Awareness, Depressive Levels and Experience of Sight Loss in a Group of Adults at a Rehabilitation Setting: a mixed method study.

ABSTRACT

Objectives: To explore the connection between self-awareness of impairment, self-identifications with the impairment and depressive levels in adults at a rehabilitation setting.

Participants: A convenience sample of 38 adult patients aged between 20-64 years, with sight loss acquired after age 18, all of them participating in a rehabilitation programme for visually impaired adults. Both patients with acquired severe low vision and patients with acquired blindness were assessed.

Method: A cross-sectional study was designed using qualitative and quantitative methods. The qualitative data was retrieved from ours previous qualitative study on the experience of vision loss in working-age adults. The Centre for Epidemiological Studies Depression Scale (CED-S) was adopted to assess depressive levels.

Results: Higher depressive levels were found in patients who: lost vision for longer; begun their rehabilitation later; were more aware of their impairment; and those who reported an inadequate social support. A positive correlation was found between CES-D and vision loss evolution, and between CES-D and rehabilitation time. No relation was found between CES-D scores and the self-identifications with the impairment.

Conclusions: Self-awareness of impairment showed to have more importance for the experience of vision loss and for patients' outcomes, than the severity of the impairment. Depressive levels appeared to be part of the adjustment process to vision loss and not only a sign of maladjustment.

INTRODUCTION

The depressive and anxiety disorders have been described as the most frequent sign of emotional distress after vision loss (Brody et al., 2001; Huang, Dong, Lu, Yue &Liu, 2010; Karlsson, 1998; King, Sarah & Peveler, 2006). According to previous studies, these disorders are more likely to occur in elderly visually impaired than in the non-impaired peers (Evans, Fletcher & Wormald, 2007; Horowitz, 2003). Its prevalence rate varies between 25% and 45% (Brody, Roch-Levecq, Kaplan, Moutier & Brown, 2006; Burmedi, Becker, Heyl, Wahl & Himmelsblach, 2002; O'Donell, 2005). Studies with working-age adults found more depression in patients with high levels loneliness and lower levels of quality of life (Nyman, 2010; Scott, Schein, Feuer, Folstein & Bandeen-Roche, 2001; Upton, Bush & Taylor, 1998). Depression after vision loss has been associated with poor functioning (Boerner, Wang & Cimarolli, 2006; Crews, Valluru & Campbell, 2005; Upton et al., 1998), long-term emotional distress (King et al., 2006), problems in well-being (Nyman, 2010; Owsley & McGwin, 2004), and problems in health and in social participation (Jones, Rovner, Crews & Danielson, 2009). Other authors have also stressed depression as being a supplementary factor for patients' disability levels (Casten, Rovner & Edmonds, 2002; Casten & Rovner, 2008).

Several factors have been identified as causes of the comorbidity between depression and vision loss. To have a chronic condition such as visual impairment (Huang et al., 2010), with a reduced visual acuity which implicates several functional limitations (Augustin et al., 2007; Bandello, Lafuma & Berdeaux, 2007), have been pointed as two potential factors for depression. However, a recent study from Dreer, Elliott, Berry, Fletcher, Swanson and McNeal (2008) has found no direct relation between visual acuity and depression. According to this study, depression appeared directly associated with intra-personal factors, such as cognitive appraisals of interference and tolerance to vision loss. Higher levels of emotional distress were found in patients with lower tolerance to vision loss, and in those who perceived a greater interference of vision loss on their goal-directed behaviour and expected activities (Dreer et al., 2008). Within the intra-personal factors for depression, other variables can also be found in literature. Feelings as loneliness, fear of dependence, lack of self-worth and feelings of changes in identity can increase the patients' susceptibility to becoming depressed (Nyman, 2010; Verstaten, Brinkmann, Stevens & Schouten, 2005). Regarding to coping strategies, emotional-focused coping, as a ruminative style of dealing with the impairment, has been referred as more related to adjustment problems and to greater levels of emotional distress (Horowitz & Reinhardt, 2000; Reinhardt, Boerner & Horowitz, 2009).

The majority of studies on emotional distress in visually impaired patients have stressed depression as a predictor of poor adjustment to vision loss. However, a recent study from Tabrett (2010) addresses depression as part of the adjustment process to vision loss rather than a serious comorbid psychological condition. In the same way, studies from Malec (2000; 2007) with other physically disabled patients, found an interesting association between depression and self-awareness of impairment. In these studies patients' self-awareness of impairment appeared strongly associated with early and late depression after physical impairment. Despite the relevance of this finding, as far as our knowledge goes, no study on visual impairment addressed this variable or some similar feature of the patients' experience of vision loss.

The main purpose of our study is to understand the role that depression plays in patients' experience of sight loss. We want to know if the individual's self-awareness of impairment, and self-identifications with the impairment are associated, or not, with the depressive levels. New knowledge on the intra-personal variables related to depression might raise a new assessment and psychological intervention approaches in clinical practice.

Our study's hypothesis is that there is a connection between these variables related to the experience of vision loss (self-awareness of impairment and self-identifications with the impairment) and depressive levels. Our main aim is not to find any causal relations or predictions for depressive levels, but just to explore possible connections which might point to helpful cues for further research.

METHOD

DESIGN

To perform this research, a cross-sectional design, using qualitative and quantitative methods, was adopted.

SAMPLE

Sample and qualitative data on patients' experience of vision loss were retrieved from other ours previous study (Senra et al., in press). The participants were adult patients with acquired visual impairment, recruited from two rehabilitation centres for visually impaired adults. The inclusion criteria were: age between 20 and 65 years old; have suffered vision loss after being 18 years; vision loss caused by an ophthalmological disease; being severely visual impaired according to the World Health Organization's criteria (World Health Organization, 2008); to be at rehabilitation setting. Patients with other serious medical comorbidities or with cognitive impairment were excluded. Of the 50 patients invited to participate in the study, 38 accept of fulfil the inclusion criteria (n=38). The mean age was 42.7 (SD=14.5). 25 (65.8%) of these patients were blind and 13 (34.2%) have severe low vision. All of patients had vision loss caused by ophthalmological diseases. The main causes were Glaucoma (34%) and Retinopathy (18%). Ethical procedures were adopted following the institutional protocol, and using an Informed Consent Form. [see Senra et al. (in press) for more sample details].

In our two rehabilitation centres, the rehabilitation's average duration is from 4 to 6 months, depending on the patient's needs. The programme provides integrated care services, which include: medical and psychological follow-up; mobility and orientation classes; activities of daily living; psychomotricity; Braille; computer adapted technologies; and art-therapy. Each patient's rehabilitation is previously discussed by the team and is adjusted to the individual's needs.

DATA COLLECTION

The assessment protocol to collect qualitative and quantitative data included two interviews per patient, lasting 45 to 60 minutes. Qualitative data was collected using a semi-structured interview [see Senra et al. (in press), for more details]. The interviews were conducted by an experienced psychologist in interviewing visually impaired patients. This interviewer had any previous relation with patients. The last 20 minutes were used to collect demographical and clinical data and to assess depressive levels.

Demographical and clinical data was collected using a general questionnaire with simple closed questions. The Centre Epidemiologic Studies Depression Scale

(CES-D) (Gonçalves & Fagulha, 2004) was chosen to assess depressive levels. CES-D is a self-rating scale, whose final score ranges from 0 to 60. A cut score of 23 was defined for CES-D as the instrument’s authors suggested.

QUALITATIVE DATA ANALYSIS

Qualitative analysis was performed using the Thematic and Categorical Analysis proposed by Bardin (2008). Two independent researchers performed the analysis and coding procedures. A high consensus was achieved. Disagreements were solved by returning to the transcripts. The criteria for coding patients’ self-awareness of impairment and self-identifications with the impairment are summarized below.

Regarding the patients’ self-awareness of impairment, the previous study (Senra et al. in press) retrieved 26 patients more aware of their impairment, and 12 with less awareness. Those more aware of their vision loss verbalized reactions and feelings about becoming impaired and recognized some implications of the vision loss in their lives. The others 12 patients (less aware of their impairment) avoided or rationalized the emotional impact of vision loss and its implications for their lives.

In terms of self-identifications with the impairment our previous study retrieved 26 patients more identified with the visual impairment, and 12 less identified with the impairment. Those who were more identified with the impairment talked about themselves as being a person with blindness or low vision, were more social active, and showed a better acceptance of the assistive devices and rehabilitation. The other patients less identified with the impairment, talk about themselves as being sighted or in transition between sighted and visually impaired, reported problems in accepting the assistive devices and rehabilitation, and in making changes in life-style.

STATISTICAL ANALYSIS

Considering that the dependent variable (depressive levels) showed a normal distribution with homogeneity of the variances between the analysed groups, the Pearson correlation test was adopted to correlate depressive levels with the following variables: time between the diagnosis of a serious medical condition and the moment that patient became visually impaired; and rehabilitation time.

T-Student Test was chosen to compare mean scores on CES-D for each independent variable: the elapsed time between vision loss and interview; the elapsed time between vision loss and the beginning of rehabilitation; the patients' awareness of their vision loss; and the patients' self-identifications with the impairment. A 95% confidence interval was chosen.

Where results were statistically significant, Cohen's d to measure the effect size was used. According to the Cohen's criteria (Henson, 2006): a *d* value around 0.2 is considered a small effect; a *d* value around 0.5 is considered a medium-sized effect; and a *d* value of 0.8 or higher is considered a large effect.

RESULTS

The results for CES-D showed a large portion of patients (n=15; 39.5%) scored above 23 and met CES-D criteria for Depression.

Pearson correlation test results showed (n=38): a positive correlation (.333; p=.036) between depressive levels and the time between the diagnosis of a serious medical condition and the moment that patient became visually impaired (vision loss evolution); and a positive correlation between depressive levels and rehabilitation time (.335; p=.035).

T-Student test (table 1) showed significantly higher depressive scores in those who: had lost their vision for over two years ($P \leq .05$); begun their rehabilitation more than three years after vision loss ($P \leq .05$); are more aware of their impairment ($P \leq .05$); and reported an inadequate social support ($P \leq .01$). Between patients with different self-identifications with the impairment T-Student test found no significant differences for depressive levels.

Concerning the type of visual impairment (blindness and low vision), no significant differences were found between groups for depressive levels ($p=.611$, $p>.05$).

DISCUSSION

Results support the previous hypothesis of being differences in depressive levels between patients with different self-awareness of impairment, but not between patients with different self-identifications with impairment. Therefore, we can confirm partially our study's hypothesis.

A similar frequency of depression (39.5%) was found when compared to the rates retrieved from previous studies (Brody et al., 2006; Burmedi et al., 2002; O'Donell, 2005).

Generally, the statistical results appeared to strengthen the idea of a connection between some variables related to the experience of vision loss and depressive levels. Concerning the patients' awareness of the impairment, the highest depressive levels were found in those who appeared to be more aware of their vision loss. This means that patients' who were more aware of their impairment showed also higher depressive levels than those who were in denial.

Table 1 *Differences in depressive levels between each variable group*

VARIABLE	CES-D – M(SD)	*p*	*t(38)*	*D*
Type of Acquired Visual Impairment		.611 (TST)	-.513	-----
Low Vision (n=13)	20.5 (13.6)			
Blindness (n=25)	18.3 (12.8)			
Elapsed time between vision loss and interview (years)		**.032 (TST)***	**-1.911**	**0.63**
0 to 2 (n=20)	14.9 (12.7)			
> 2 (n=18)	22.7 (12.1)			
Elapsed time between vision loss and the beginning of rehabilitation (years)		**.04 (TST)***	**-1.804**	**0.60**
0 to 3 (n=23)	15.6 (12.6)			
> 3 years (n=15)	23.1 (12.3)			
Self-Awareness of the Impairment		**.049 (TST)****	**2.042**	**0.73**
More aware (n=26)	21.4 (12.7)			
Less aware (n=12)	12.6 (11.4)			
Self-Identification with the Impairment		.168 (TST)	**-1.717**	-----
Less identified (n=26)	20.6 (13.6)			
More identified (n=12)	14.3 (10.3)			
Perceived Social Support		**.003 (TST)*****	**-3.204**	**1.099**
As good (n=15)	12 (10.5)			
As inadequate (n=21)	24.4 (12)			
Perceived Well-Being		.296 (TST)	**-1.059**	------
As good (n=14)	15.7 (14.8)			
With complaints (n=24)	20.3 (11.6)			

* Significant differences between groups for p (1-tailed) ≤.05; ** Significant differences between groups for p (2-tailed); *** Significant differences between groups for p (2-tailed)) ≤.01; CES-D= Centre Epidemiologic Studies Depression Scale; TST= T-Student Test.

Regarding the patients' self-identification with the impairment, results suggested no connections between this variable and depressive levels. Our previous study (Senra et al., in press) suggested that while the self-awareness has to do with the patient's awareness of having lost his/her vision and therefore other important things and capacities, the self-identifications arise after patient has been aware of the impairment and as being a resolution process of accepting the impairment. Therefore, it is expected that patients becomes more depressive after being aware of his/her losses and of the strong changes caused by vision loss in own life. Probably the self-identification process not arose related to depressive levels because patients were still highly depressed when they were at this stage. The adjustment process to vision loss has been described as a hard and painful change situation to overcome, and in many cases patients remain depressed for a long time (King et al., 2006).

Consistent with previous studies on this field (Cimarolli, 2006), our results suggested more depressed patients within the group of those who reported a bad social support. As can be seen in our previous study (Senra, et al., in press), patients reported family and friend supports that were perceived as both insufficient (lack of support) and overprotective. Therefore our results strength the previous idea that the perceived social support can be one of the causes for the depressive levels rising in these patients.

Although the previous literature have found a connection between problems in well-being and depression in this population (Nyman, 2010; Owsley & McGwin, 2004), our study found no differences in CES-D for the perceived well-being. One of the causes for this discrepancy might be related with two hypotheses: our sample is biased by a small size which was not big enough to show variances; the vision loss is a powerful limitation that often affects the subjects' well-being, even after the rehabilitation is concluded.

Concerning the clinical variables, the highest depressive levels were found in those who had lost their vision for longer and progressively. More elapsed time since the impaired might implicate more time in contact with the negative effects and restrictions of visual loss. All this time will inevitably enhance the patients’ awareness of the impairment, because its interference in self-perceptions and in daily life tends to improve over the time. For those who lost their vision suddenly, the changes caused by vision loss might be harder to overcome, and cause a disruptive effect in the subjects’ life and expectations. Therefore, these subjects are more likely to display denial and resist assistive devices. On the other hand, a more progressive vision loss appears to make the subjects face with their impairment for a longer period of time and with the fear of becoming totally blind. Therefore these patients are more likely to be more aware of their impairment. Thus, the positive correlation between the vision loss evolution and depressive levels strengthens the idea that those who are more aware of their impairment tend to have higher depressive levels.

Concerning the effect of rehabilitation on patients’ adjustment to vision loss, previous studies have stressed the benefits of rehabilitation both for patients’ well-being and emotional distress (Bragg, 2005; Heyl & Wahl, 2001). However, it can also assume other roles in the patients’ adjustment. Usually rehabilitation promotes patients’ use of the assistive devices such as the white cane and socializing with other visually impaired persons. When they are at rehabilitation, they are usually forced to face their own impairment and become more aware of it. In this way, the rehabilitation can also be conceptualized as a promoter of the patients’ self-awareness of impairment. Therefore, this rehabilitation’s role justifies why patients’ who spend more time without rehabilitation, or are beginning, tend to have lower depressive levels.

The relation between depressive levels and the type and severity of the visual impairment (blindness and low vision) strengthen the previous idea that depression appears to be more connected with intra-personal variables than with the impairment severity (Dreer et al., 2008). The same is valid for self-awareness of impairment, where the absence of a relation between this variable and the type and severity of the impairment was found.

The overall results from the current research are consistent with the previous finding from Malec and colleagues (2000; 2007), where depressive levels appeared also strongly associated with the self-awareness and self-assessment of impairment in patients with acquired physical impairments. Therefore, it would be interesting to explore more the connection between self-awareness of visual impairment and depressive levels in future studies. It seems that the rise of depressive levels might be an indicator of a specific mental mechanism related to the adjustment process to vision loss.

Although our research found relevant features on depression links with some patients' clinical and intra-personal variables, it has some limitations that must be acknowledged. Even if the statistical data derives from powerful parametric tests, and relatively medium-high effect sizes, the tested groups were small, the correlation coefficient was moderate, and the study's design is cross-sectional. Therefore we cannot argue solid causal relations between variables. We just have explored some potential links between intrapersonal variables and depressive levels in order to point to some relevant cues and further research.

Finally, although our sample was composed by patients at different phases of rehabilitation, those who had not started yet their rehabilitation were not addressed by our study. It would be interesting to compare both groups in terms of depression and adjustment in future studies.

Our findings point to the possibility of high depressive levels being not only a symptom of emotional distress, but also a sign of the individual's awareness of his/her new condition and losses. Therefore, the increase of the depressive levels appears, also, as part of the adjustment to vision loss and reveals the individual's response to a new, hard situation of change.

These findings can generate helpful clues for the assessment and intervention work with visual impairment patients. An intervention oriented to follow the increase of the depressive levels as an adaptive phenomenon, respecting patients' feelings, and at the same time preventing a chronic condition, seems to be a good practice.

In terms of future research, this study can be useful to provide new variables to address both in longitudinal studies about the adjustment process, and in other studies on the best predictors for depressive levels. One interesting goal for future studies would be to compare patients who become more depressed after vision loss, but that improved after achieving better levels of functioning and independence, with those who continue to be depressed for a longer period, as a previous study suggested (King et al., 2006).

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STUDY 2:

LOWER LIMB AMPUTATION IN ADULT AGES

The Experiences of Lower Limb Amputation in Adults and Elderly

PAPER 3

TITLE:

Beyond the body image: a qualitative study on how adults experience the lower limb amputation

ABSTRACT

Objective: To explore adults' experience of lower limb amputation, focusing on the changes in self-identity related to the impairment.

Design: A cross-sectional and qualitative study, using semi-structured interviews. Interviews were transcribed, coded and analysed by two independent researchers.

Setting: A rehabilitation medicine service from a general public hospital.

Participants: A convenience sample of 42 patients with lower limb amputation performed after the age of 18 and followed up in a Physical Medicine and Rehabilitation Department from a general hospital.

Main outcome measures: A semi-structured interview, addressing 3 core areas: the emotional impact of amputation; the adjustment process; and the relation with the external resources.

Results: Eight themes emerged from interviews: reactions and feelings about becoming amputee; changes in own life; problems in well-being; relation with the prosthesis; self-perceptions; relation with the rehabilitation; aims related to the rehabilitation and future plans; and the perceived social support. These results supported a theoretical model for the self-identity changes related to limb loss.

Conclusions: The self-identity changes after a lower limb amputation appear beyond the patients' body image and functioning, affecting the patients' awareness of the impairment, biographical Self and its future projections. Their assessment and monitoring over the rehabilitation and follow-up period might be a good practise.

INTRODUCTION

A lower limb amputation is a surgical procedure that results from a serious medical condition such as: Diabetes; trauma, and neoplasms (1). It has been described as an event usually associated with several changes in one's personal life, affecting the individual's well-being, quality of life, and autonomy (2-6). Anxiety, depression, body-image anxiety, and social discomfort have been pointed out as frequent consequences of a lower limb amputation (7-11). Both, these consequences and the adjustment process to limb loss, will depend on how the individual experiences the amputation (3,7,12) and how his/her social support and rehabilitation are perceived (13-15).

Several studies have been developed to better understand the experience of lower limb loss in adults. The main personal areas focused by these studies were: the body image (16-18); relation with the artificial limb (5,7,19); the phantom limb sensations and pain (20-22); the coping strategies (12,23,24); and the perceived well-being (3). Regarding the qualitative studies developed in this field, several themes associated with this experience have been found (5,10,12,25-27): meanings of being an amputee; identity changes; meanings of using a prosthesis; coping with the loss; relation with own body; relations with the prosthesis and embodiment of an artificial limb; phantom and stump pain; feelings of vulnerability; resilience characteristics; social support changes; and need for emotional support.

In the majority of the studies on the adjustment to limb loss, two main changing processes of the patients' identity have been addressed: transformations in the individual's body image; and the embodiment process of the prosthesis. Although they are two important milestones of the adjustment process, the limb loss may also include other self-identity implications beyond the body-image and the prosthesis embodiment (28,29).

In 2004, a comprehensive literature review by Horgan and MacLachlan (29), stressed the implications of limb loss in self-identity as a practically non-explored subject. As far as our knowledge goes, since this review until now, ten studies were developed on the experience of limb amputation (3,5,12,19,23,25,26,30-32). Only two of them (25,31) addressed the self-identity changes related to limb loss. Saradjian's study (25) stressed the importance of the individual's awareness of physical difference and the ability to integrate the prosthesis for the recovery process. Hamill and colleagues (31), in a qualitative study with eight lower limb amputees, found an interesting theme associated with their self-identity changes: the renegotiation process of the new identity. According to the study, this process represents the subjects' transition to a new identity that cause an initial resistance and which is mediated by decisional, informational and social factors.

In this sense, it is a fact that the self-identity changes are beyond the body-image changes and the prosthesis' embodiment. It is, therefore, a complex phenomenon that needs more attention and further investigation.

The current research aims at filing in the knowledge gap regarding the self-identity changes related to the lower limb amputation. The main goal of our study is to explore how adults' experience the lower limb amputation, with a special focus on the individuals' self-identity changes caused by limb loss.

METHOD

To perform this research, an exploratory cross-sectional design, using qualitative methods, was adopted.

A convenience sample composed by 42 adult patients, followed up at a rehabilitation medicine service of a general public hospital, was used in this study. The inclusion criteria for patients were: being at least 20 years old; lower limb amputation performed after the age of 18; and being followed up in the rehabilitation medicine unit. Patients, who did not meet inclusion criteria and/or had neurological and cognitive impairment, were excluded, as it could interfere in the patients' outcomes. Patients at two different stages of rehabilitation were selected: those who were performing their rehabilitation; and those who had already finished it but continued to be followed up by this service, to monitor the health condition and to evaluate functional progressions. In this hospital's service, the rehabilitation programmes are focused on enhancing the patients' functional skills and on restoring their independence, through physical and occupational therapy. In general, no psychological or psychotherapeutic treatment is adopted during the patients' follow-up, because it is not part of the formal clinical protocol. Ethical procedures were adopted following the institutional protocol, and using an Informed Consent Form.

Data collection

Demographical and clinical data was collected using a general questionnaire with simple closed questions.

Two face-to-face interviews, lasting between 45 to 60 minutes, were performed with each patient. Each interview's last 10 to 15 minutes, were used to apply the general questionnaire, to assess demographic and clinical data. This protocol was designed to provide the patients with a trust setting, in order to facilitate their narratives about their subjective experiences of becoming amputee. The process of selecting patients was performed in partnership with the physician who coordinates the medical follow-up for amputees. A total of 65 patients were invited and 42 accepted and fulfilled all inclusion criteria.

Semi-structured interviews were conducted using open-ended questions that were created in order to be bias free and to allow any kind of narrative about each theme, as well as to facilitate the fluency of the participants' narratives about their experiences (see appendix1). These questions were elaborated to address three core areas: the emotional impact of becoming an amputee; the adjustment to amputation; and relation with external resources – social support and rehabilitation. Nonetheless, the interview was conducted without any predetermined sequence and respecting the patient's generated themes and questions. All interviews were conducted and recorded by the same researcher (HS) who had no previous relationship with the participants. Although this researcher is experienced in clinical interviews, he was supervised during the whole study by another researcher (RAO).

The interviews continued being conducted even after researchers felt saturation had been reached, in order to get the maximum variation of sample's characteristics. A total of 85 interviews were conducted for all 42 participants (n=42). As can be seen in table 1, the mean participants' age was 61 (SD= 13.5) and 35 were men. Most of them (61.9%) were transtibial amputations performed after the age of 40 (59.5%). The main aetiology of the amputations was vascular disease (83%). In terms of the state of rehabilitation, the same portion of patients (50%) was in an ongoing rehabilitation process, and the remaining had already concluded it.

Table 1 Characterization of the sample

VARIABLE	**VARIABLE GROUPS**	**N**	**Valid %**
Age (M=61 / SD=13.5 / Min:22; Max=82)	22-45 years	4	9.5%
	46-64 years	18	42.9%
	≥65 years	20	47.6%
Gender	Male	35	83.3%
	Female	7	16.7%
Marital Status	Married	23	54.7%
	Single	4	9.5%
	Divorced	8	19%
	Widower	7	16.8%
Education Level	Up to 9 years	31	73.8%
	> 9 years	11	26.2%
Age at amputation (M=57.4 / SD=14.2 / Min:18; Max=81)	18 to 39	4	9.5%
	40 to 64	25	59.5%
	≥ 65	13	31%
Type of Lower Limb Amputation	Above Knee (Transfemoral=100%)	16	38.1%
	Below Knee (Transtibial=84.6%; Foot=15.4%)	26	61.9%
Main Aetiologies of Lower Limb Amputation	Vascular Disease	35	83%
	Oncologic Disease	4	9.5%
	Trauma	3	7.1%
Time between amputation and interviews (years) (M=2.3 / SD=3.3 / Min:0.3;Max:17)	Up to 1 year	25	59.5%
	>1 to 5 years	14	33.3%
	> 5 years	3	7.1%
State of Rehabilitation	In progress	21	50%
	Concluded	21	50%
Prosthesis Wear	Not wearing yet	24	57.1%
	Wearing	18	42.9%

Data Analysis

After the interviews were recorded, they were transcribed verbatim. Then, they were analysed using the Thematic and Categorical Analysis proposed by Bardin (33). In this method we adopted an inductive analysis modality, using an open coding technique (34,35), because we did not have any previous ideas or conceptualizations about subjects. The content analysis was conducted, and the following steps were ensued: transcriptions were read at least twice, line by line to infer their global and specific meanings, and structure; each narrative’s specific meanings, that generated open codes (semantic criteria), were identified and labelled; codes sharing common themes were gathered; themes were reanalysed and reviewed in order to be labelled and regrouped in thematic categories; thematic categories were validated by returning to the data through the patients’ direct quotations. This procedure was performed by two researchers (HS, RAO), who made an exhaustive discussion and reflexion on each meaning, and defined criteria for each theme’s categorization, during all the steps of the analysis. There was a high consensus between researchers, and disagreements were solved by returning to the transcripts.

RESULTS

Eight themes emerged from the interviews’ three core categories. The category “Emotional impact of amputation” generated two themes: Reactions and feelings about becoming amputee; and Changes in own life. The category “Adjustment to amputation” generated the following four themes: Self-perceptions in terms of relation with the impairment; Relation with the prosthesis; Aims related to the rehabilitation and future plans; and Problems in well-being. The category "Relation with the external resources generated two themes: Perceived rehabilitation; Perceived social support.

Reactions and feelings about becoming amputee

Patients' verbalizations about the diagnosis and becoming amputee reported different kinds of meanings. Most of them (n=20) verbalized reactions and feelings such as: sadness; shock; insurgence; surprise; non-acceptation of the situation; anger; and suicidal thoughts.

- *At the beginning I was very revolted with the guy that caused the accident! I felt very angry... I stopped making love to my wife... I became more isolated from my colleagues and friends, and more dependent on my family... I was feeling very sad depressed... it was a shock to me! Until I started using the prosthesis, I was more dependent on others... However I still need a lot of help... (P39).*

Some patients (n=5) also verbalized pain relief, as a consequence of the amputation. In these cases the limb loss seems to have a less negative resonance and to be associated with pain cessation.

- *It was a relief, because the pain was very strong and unbearable!! I couldn't sleep! I couldn't live with that pain, and now I feel better! (P2).*

There were also patients that avoided theme (n=3), or rationalized it (n=5) and did not verbalize any feelings related to the diagnosis or the amputation.

- *I always reacted well, and placed all my trust in doctors! It had to be done, because my leg was very ill and I could die!! I didn't feel traumatized nor had any complex with it! I faced it well and said "let's go on with it"! (P10)*

Changes in Own Life

Regarding this theme, most patients (n=38) reported feelings and ideas about a life before and after the limb loss. Patients reported changes caused by the amputation both in their inner and relational life, such as: difficulties with basic skills and daily activities – loss of independence; inferiority feelings; problems regarding well-being; negative changes in the professional life and achievements; identity changes; changes in the affective or sexual life; and feeling abandoned by others.

- *After the amputation I stopped working and doing many things I love... I had to cope with this! I was a very dynamic person; I worked a lot and had a good income! Today I can't do many things, I became more dependent on others, with less autonomy and I changed myself! Today I'm a more nervous and explosive person... I liked reading and today I don't... many things changed for me. (P39)*

Self-Perceptions in terms of the relation with the amputation

Fifteen (n=15) patients recognized and identified themselves as impaired. These patients: accepted and used assistive devices, including prosthesis; adapted their lives to the new condition; talked about themselves as amputees; and did not tend to be isolated from others.

- *Today I'm a new person! I returned to school and to work! I bodyboard! My life is not the same but it (amputation and prosthesis) is already a part of me! I* *adjusted my life to it, but I haven't stopped doing my favourite hobbies or meeting my friends. It was worse at the beginning, when I became an amputee, but now it's different! (P24).*

The majority of patients (n=27) continue to resist to assistive devices and/or not accepting their new situation at all. They already began to cope with their loss and using some assistive devices, but the impairment is not a part of them, yet. These patients are in the transition from perceiving themselves as "not amputee" to "amputee".

- *Rehabilitation has helped me, but it's very hard for me, and I don't know if I'll be able to walk alone! The prosthesis is painful... I can't accept this situation because it's revolting being like this... without driving, walking, working... it's very sad depending on others... I was a very dynamic man before this happened... (P9).*

Relation with the Prosthesis

Both for patients who were wearing the prosthesis and for those who were still learning how to use it, the prosthesis was a stressed theme. While some patients (n=14) expressed negative attributions, such as a source of pain, others (n= 28) associated it with improvements in autonomy, in daily life activities, in basic skills, or as being a part of themselves (n=2).

- *It is precious to me! Without it I was another person. I couldn't walk alone, bath alone, drive, or meet my friends! It is a part of me. (P2)*

Aims related to the rehabilitation and future plans

Most of patients (n=38) verbalized personal aims related to the rehabilitation and general recovery, such as: to improve basic skills and daily life activities; to be able to wear the prosthesis; The majority of patients just verbalize future plans for recovery in terms of becoming more independent and improving some daily living skills. Only two patients referred returning to work, even another work and lifestyle, as a main future goal after the rehabilitation is finished.

- *Rehabilitation is important because it is helping me to return to do my daily life and most importantly to walk again! I have hope in the prosthesis! It will help me become a different person and leave the wheelchair. (P14)*

Problems in Well-Being

The majority of patients (n=29) report physical or emotional complaints often associated with their medical condition: pain; sadness; depressive humour; sleep disorders; anxiety; and irritability. Regarding pain, most of them (n= 28) did not report stump pain, nor phantom limb pain (n=29). Those who reported stump pain associated it with the decrease in their quality of life and to a poor adjustment to the new situation.

- *Lately I have been having trouble sleeping! In fact, I'm a little depressed, my wife knows... I get easily annoyed! I've been feeling this since the amputation!" (P7).*

Perceived Rehabilitation

Most patients (n=39) reported positive feelings and their satisfaction regarding the rehabilitation program and staff. They stressed the new skills learned, the program, the environment, and the possibility to use prosthesis. The remaining three patients appraised the rehabilitation as an inadequate or an insufficient resource.

- *Rehabilitation has been very helpful for me... I am able to walk alone again! The staff has been lovely and I'm feeling like another person! (P27).*
- *It's very hard for me! Probably for other patients it's easier, but for me... Exercises won't give me my leg back! It's very sad being like this! (P9).*

Perceived Social Support

Some patients (n=27) verbalized their satisfaction with their family and friends' support, considering it a valuable resource to improve their adjustment. The others (n=15) reported a bad or inadequate social support.

- *My family is the main reason for my recovery! They have been giving me a lot of support, helped me to walk again and to cope with this situation. (P4).*
- *I am alone! Nobody cared about me... My sons left me alone... they have their lives... I miss my wife! She died last year... (P38).*

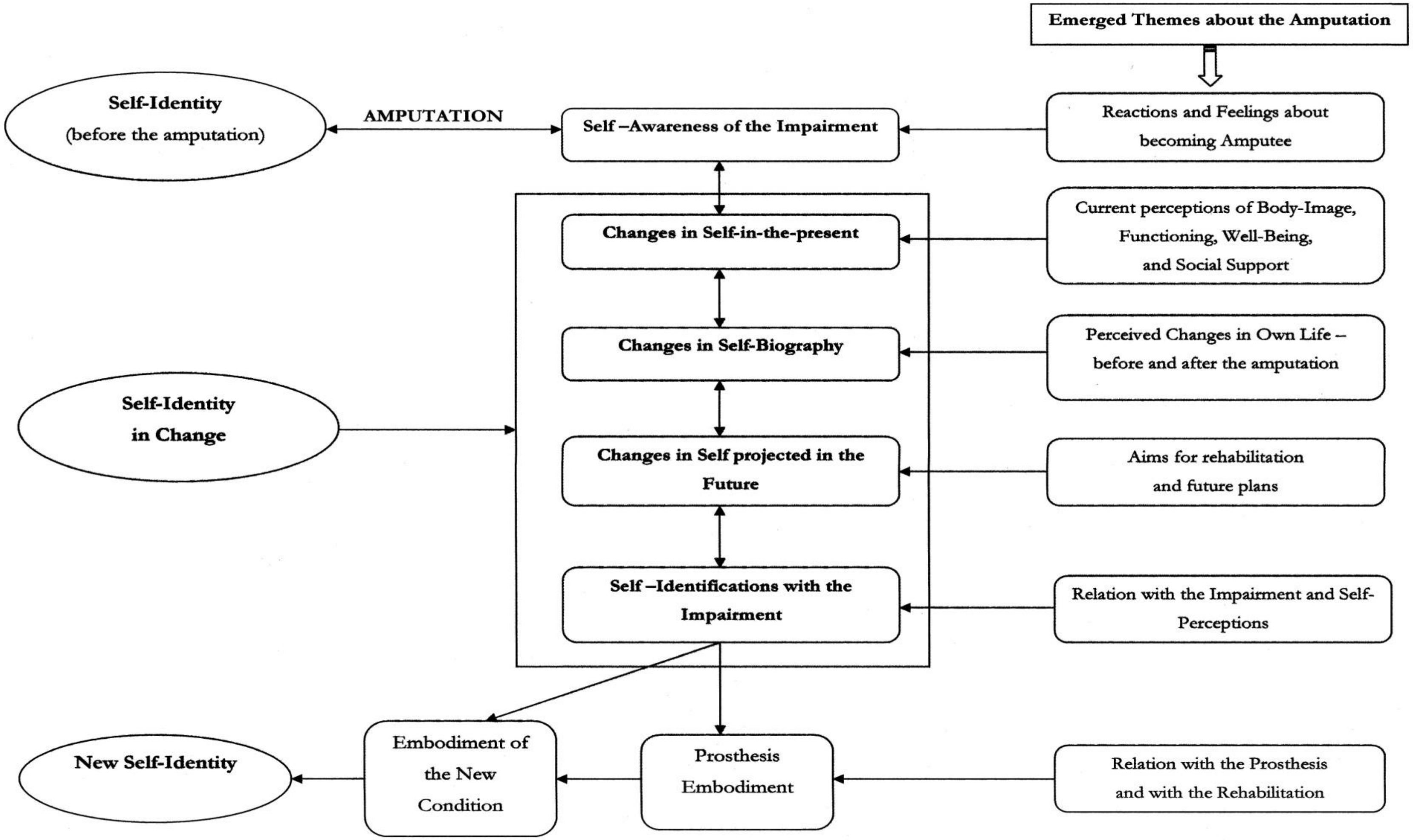
Rehabilitation and the Experience of Limb Loss

The frequencies of each theme that emerged associated with the experience of limb loss, for patients going through rehabilitation and for those who have already completed it, are presented in table 2.

Table 2 Frequency of emerged themes in two stages of rehabilitation

Experience of Lower Limb Loss		**Rehabilitation**	
		In progress (n=21)	Finished (n=21)
Verbalized Reactions and Feelings	Verbalized	14 (67%)	15 (71%)
	Not verbalized	7 (33%)	6 (29%)
Verbalized Changes in Own Life	Verbalized	20 (95%)	20 (95%)
	Not verbalized	1 (5%)	1 (5%)
Relation with Prosthesis	Positive attributions	13 (62%)	17 (81%)
	Negative attributions	5 (24%)	4 (19%)
Relation with the impairment and Self-Perceptions	As in transition	18 (86%)	9 (43%)
	As amputated	3 (14%)	12 (57%)
Perceived Problems in Well-Being	Reported	17 (81%)	12 (57%)
	Not Reported	4 (19%)	9 (43%)
Stump Pain	Reported	5 (24%)	9 (43%)
	Not Reported	16 (76%)	12 (57%)
Phantom Limb Pain	Reported	6 (29%)	7 (33%)
	Not Reported	15 (71%)	14 (67%)
Perceived Social Support	As a good resource	12 (57%)	17 (81%)
	As inadequate	9 (43%)	4 (19%)

Figure 1 Model for Self-Identity Changes related to the Lower Limb Amputation



DISCUSSION

The main purpose of current study was to the explore adults' experience of lower limb amputation and its implications for their self-identity. Due to the fact that our patients' interviews were not marked out by any structured questionnaire or quantitative instrument, the experience of amputation was explored in depth and through true life stories. The qualitative data showed several aspects of this experience, including different self-identity changes arising from the situation of becoming an amputee.

Our qualitative data supports a dynamic model of the patients' self-identity changes composed by three core phases (figure 1): the first individual's contact with the amputation and his/her self-awareness of the impairment; change in the individual's self-identity, in several domains of the Self; and the final embodiment of a new self-identity in consequence of becoming amputee. Unlike other previous studies, the identity changes were not only addressed in terms of body image (10,16-18) and prosthesis embodiment (7,9,26), but also in other dimensions of the Self.

Regarding the first phase of the self-identity changes, our study retrieved two major kinds of verbalizations that surround the emotional impact of amputation: patients who presented an emotional response to the situation of becoming amputee, addressing their feelings and reactions and that, therefore, appeared to be more aware of their impairment; and patients who did not exhibit any emotional resonance to amputation and its implications and that, therefore, appeared to be less aware of their situation. Thus, the self-awareness of the impairment arises as the first trigger to self-identity changes after the amputation. Without self-awareness of the impairment, patients could not experience losses in several life domains and consequently, feelings and reactions such as sadness, revolt, shock, or catastrophizing. These feelings and reactions were also retrieved by other qualitative studies (3,5,10,25). However, the self-awareness of the impairment was not a theme addressed by these studies, except in the Saradjian's qualitative study (25). Nevertheless, there are two main differences between this study and ours: first, it addressed the self-awareness more focused on the body-image changes and its restoration after the prosthesis' wearing, while ours looks on the self-identity changes beyond the body image and including other dimensions of the individual's self; second, its sample was composed by upper limb amputees, while ours is on lower limb amputees.

The second phase of the self-identity changes after the amputation, has to do with a set of domains of the Self in which the personal and relational losses and transformations operated. In the present, the patient becomes aware of his/her new physical appearance, functioning limitations and quality of well-being and social support. This is the domain which most of previous studies have approached (3,13,16). In agreement with these studies, our results also point the body image anxiety and the patients' looking for the prosthesis as two common reactions at the beginning of the adjustment process.

Beyond the body image, patients also addressed other important areas of the individual's Self. The results showed that, in terms of self-biography, most of patients addressed their amputation as a potential break with the past and with what they were waiting for the future. This break was not only regarding body-image, but also in patients' very identity, personality, functioning, sexual life, and relationships.

In terms of future projection of the Self, most of patients only referred their desire of returning to the same skills and activities (to walk alone, or to drive). This fact appears to be explained by two main reasons: a great portion of patients is able to return to the same activities without great alterations; most of them are elderly at non working-age and, therefore, they do not need to ponder a work change, with its inherent adaptations and restrictions.

Concerning the self-identification with the impairment, it has to do with two embodiment processes: prosthesis; and the new condition of being amputated. These embodiment processes are inwardly dependent on the changes in patient's self (present; biography and future), and which internal and external resources he/she has to deal with the impairment. In the same way, several studies (9,25,30,36) have stressed the prosthesis' wearing as an important milestone for the patients' self-worth and body image restoration, autonomy recovery, and well-being improvement.

In terms of embodiment of a new self-identity, our results showed that most of patients are in transition between being identified with the impairment and, therefore, renegotiating their new identity. This is a well supported finding by Hamil's study (31), where the process of transition to a new identity was also found in a group of amputees.

The final phase of this process, to reach a new self-identity, is completely dependent on how the patient performed his/her self-identity changes in the other domains. Therefore, there is no specific sequence or pre-determined course for the self-identity changes. They are inter-related and dynamic, because they operated in several parts of the same Self.

Despite the fact that our model has a high correspondence with our patients' narratives of limb loss, we also found other patients who reported a different experience. These patients appraised the amputation positively, and reported less losses and changes in their self-identity domains. Even though they did not represent the larger portion of patients who had an amputation, they arise as a different group of patients who tend to report less pain, more social functioning and fewer health concerns, as the literature has stressed (32).

Our results suggested that rehabilitation may have a positive effect on patients' relation with the prosthesis and therefore to increase their well-being satisfaction and functioning. Nonetheless, a considerable portion of them continues to report problems in well-being, even after the rehabilitation has finished. This finding appears to be explained by the absence of a systematized psychological or psychotherapeutic work providing to our patients, during the rehabilitation period. This psychotherapeutic work has been proven to be an indispensable support along the whole adjustment process to limb loss (37,38).

Some limitations of this study need to be acknowledged. First, even though our sample's size is big enough for a qualitative study, it is a relatively selected sample mainly composed by subjects who were amputated in consequence of a vascular disease. Therefore further research including more patients with other type of aetiologies such as trauma or cancer is needed.

Second, the interviews were only semi-structured. Even though the interviews were conducted with the concern of being bias free, three core areas were pre-defined to be addressed. Thus, interviews tended to be steered to these areas and, therefore, they could have biased the results.

Third, due to the fact that our study is a cross-sectional study, instead of a longitudinal study, the evolution of the patients' adjustment to limb loss overtime was not assessed. It would be interesting to perform this assessment in future studies.

Finally, although our findings bring into light a new model for the changes in patients' identity related to becoming an amputee, it cannot be generalized to other samples, and only reveals the experiences of our patients. Thus, it only provides relevant clues to be taken into account in clinical practise and future research.

Our study raises some important new findings on an understudied aspect of the experience of limb loss: the self-identity changes. Even though some of the referred patients' themes have been also addressed by previous studies, they have never been explored and approached as being integrated, and as being part of the whole Self. The resulting theoretical model offers a great picture of these self-identity changes, points to some clues concerning the adjustment process, and identifies which areas of the patients' functioning might be more affected by the impairment. These findings are particularly important to understand the patients' course of adjustment and to plan some psychotherapeutic targets, during these patients' clinical follow-up.

CLINICAL MESSAGES:

- The self-identity changes were reported beyond the body-image, affecting the patients' awareness of the impairment, biographical Self and its future projections.
- An assessment and intervention work directed to these dimensions of the patient's Self might be a good practice, especially for psychologists, during the rehabilitation and follow-up periods.

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Appendix 1 – Core Questions for Patients' Interviews

1. Beginning of the Interview:
    a. I would like to know more about you, your history, what has happened to you, your feelings, how did you come here...?
2. Psychological Impact
    a. What has happened to you? How did you know that you were having problems with your leg?
    b. Do you remember the day you were talking with your doctor about it? How did you feel? How did you deal with it?
    c. Do you consider there is a life before the amputation and after the amputation? Is there one person before, and another after the amputation? What else has changed?
3. Adjustment to limb loss
    a. What do you think about the prosthesis? How was your adaptation to the prosthesis? Has it being useful?
    b. What personal goals do you have regarding the rehabilitation? Do you have any plans for the future?
    c. How did/is your rehabilitation go/going? Was it/has it been helpful?
    d. How do you feel now? Are you having any particular problems?
4. Relation with the external resources
    a. How did your family and friends react to your situation?
    b. Have you had significant support from your family, friends, or others?

PAPER 4

TITLE: How Depressive Levels are related to the Experience of Lower Limb Amputation: a mixed methods study

ABSTRACT

Background: Recently, self-awareness of impairment and self-identifications with the impairment were stressed as two important intrapersonal variables for the adjustment to limb loss. However there is no knowledge on how these variables might be related to depressive levels.

Aim: Our study wants to know how self-awareness of impairment and self-identifications with the impairment might be related to depressive levels in lower limb amputees. The main hypothesis is that these intrapersonal variables are linked to depressive levels.

Methods: A cross-sectional study, using both qualitative and quantitative instruments was adopted. Our sample was composed by a selected group of 42 adults (mean age of 61; SD=13.5) with a lower limb amputation performed after the age of 18, and being followed-up in a Physical Medicine and Rehabilitation Department. The experience of limb loss was collected through semi-structured interviews retrieved from another previous study developed by us. Depressive levels were assessed using CES-D.

Results: 31% of patients meet CES-D criteria for depression. Higher depressive levels ($p<.05$) were found in those who showed: greater self-awareness of impairment; lower identification with the impairment; and worse appraisals of the prosthesis, social support and well-being.

Conclusions: An increase in depressive levels arose related to intrapersonal variables involved in the adjustment process to amputation, especially the changes in self-identity. Therefore, depressive levels are more likely to be part of the adjustment process, instead of being just a sign of poor outcomes or negative coping.

Key words: Self-identity; Limb Loss; Depression; Adjustment.

INTRODUCTION

The lower limb amputation results from a surgical procedure often due to a serious medical condition. The most frequent aetiology is vascular disease, often associated with diabetes mellitus (1), and affecting mostly adults and elderly (1). Due to its potential functional and psychological implications, a lower limb amputation has been associated with problems in well-being (2), decreasing the quality of life (3,4), and causing emotional distress (5,6).

According to several studies (5-8) mood disorders such as depression and anxiety arise as common reactions after amputation. Even though some authors have argued an absence of evidence for emotional distress after a lower limb amputation (9,10), most studies are at odds with this idea. A range of 13% to 30% of lower limb amputees has depression according to previous studies using different measures (5,7,11-13).

While some literature has pointed out the higher levels of depression during the first two years after the amputation (8), other authors have found a significant drop in its incidence by the time of discharge from a rehabilitation setting (11,12). Studies from Singh and colleagues (11,12) have found a rapid resolution of depression and anxiety after the patients have completed their rehabilitation. The possible reasons pointed by authors for this drop were the positive effect of rehabilitation in terms of independence restoration, and the changes in amputation appraisals and future outlooks. However, as in the majority of studies (8), Singh’s research proved that depression rises again during the second or third year after the limb loss and tends to persist for long time.

Mood disorders after an amputation have been linked to: negative coping (13-15); catastrophizing (13,16); having other comorbidities (11,17); and having a poor social support (18,19). On the other hand, positive appraisals of amputation might be associated with a better psychosocial adjustment to amputation in terms of depressive levels (20). Nevertheless, the little is known yet about the reasons for why depression happens and remains overtime in these patients. Furthermore, almost nothing is known about the relation between the experience of limb loss and depressive levels.

A previous study from us (21) stressed the importance that changes in self-identity, beyond the body image, have for the adjustment process to limb loss. In the same research, the self-awareness of impairment and the self-identifications with the impairment arose as the two main variables involved in the changes in self-identity after amputation.

In the same way, a study from Malec and colleagues (22,23) with patients with other physical disabilities, found a strong association between patients' self-awareness of impairment and early, as well as late, depression after physical impairment.

As far as our knowledge goes, there is no research on how self-awareness of impairment and the self-identifications might be linked to depressive levels in lower limb amputees.

The main aim of our study is to know if the individual's self-awareness of impairment and self-identifications with the impairment are associated, or not, with the depressive levels. Our study's hypothesis is that there is a connection between these intrapersonal variables and depressive levels. With the current study we do not intend to find any causal relations or predictions for depressive levels, but rather to explore possible connections which might offer useful cues for a deeper understanding in further research.

METHOD

The current research was performed adopting a cross sectional design, using qualitative and quantitative methods. Our sample and qualitative data on the patients' self-awareness of impairment and self-identifications with the impairment were retrieved from a previous study developed by us (21). Other intrapersonal variables that emerged in this research were also considered for the current study, due their potential influence on depressive levels: the perceived well-being; and the perceived social support.

The sample was composed by adult patients recruited from a Physical Medicine and Rehabilitation Department from a public general hospital. A total of 65 patients were invited and 42 accepted and fulfilled all inclusion criteria (n=42).The mean age of our sample was 61 years. Most of them (61.9%) had transtibial amputations, performed after the age of 40 (59.5%). The main cause for the amputations was vascular disease (83%). Half the patients (n=21) were ongoing rehabilitation (see Senra and colleagues (in press) for more detailed sample information).

The inclusion criteria were: minimum age of 20 at the time of interview; amputation performed after 18 years of age; the amputation had to be of a lower limb; and the patients had to be followed-up by the rehabilitation medicine department. Patients who did not fulfil the inclusion criteria or that had any confirmed cognitive, neurological or other serious medical condition were excluded as it could interfere with the patients' outcomes.

Patients in two different stages were considered: ongoing rehabilitation; and after discharge, at the follow-up stage to monitor their health condition and functional progressions.

This rehabilitation setting included an overall program of functional recovery, focused on enhancing patients' daily life skills and on restoring their independence. During rehabilitation, patients were followed-up by a specialised physician, a physical therapist, and an occupational therapist. Both during the rehabilitation period and after discharge, no systematic psychological or psychotherapeutic treatment was provided for these patients, because it was not part of the clinical formal protocol.

Ethical procedures were adopted following the institutional protocol, and using an Informed Consent Form.

Data Collection

Data was collected using an assessment protocol composed by two interviews per patient, lasting between 45 and 60 minutes. The last 30 minutes of the second interview were used to collect the patient's biographical and clinical data and to assess depressive levels. The main aim of this protocol was to provide a confidential and reassuring setting, in order to facilitate their narratives about the subjective experience of becoming amputee. All interviews were conducted by a psychologist experienced in interviewing physically impaired patients (HS).

The experience of lower limb loss was assessed using semi-structured interviews (see Senra et al. (in press) for more details).

Demographical and clinical data were collected using a general questionnaire with simple closed questions.

Depressive levels were assessed using the Centre Epidemiologic Studies Depression Scale (CES-D) (24). CES-D is a self-rating scale, whose final score ranges from 0 to 60. A cut score of 23 was defined for CES-D as the instrument's authors suggested.

Qualitative Data Analysis

Qualitative data analysis was based on the Thematic and Categorical Analysis proposed by Bardin (25). All of the coding procedures were performed by two independent researchers through an exhaustive content analysis. The consensus was high, and disagreements were solved by returning to the transcripts.

The process of assessing and coding the selected intrapersonal variables from our previous study is summarized below.

The patients' self awareness of impairment was based on patients' two themes: their reactions and feelings in response to limb loss; and the reported changes in relational and inner world caused by the amputation. Thirteen patients showed a lower awareness of impairment (n=13), while twenty nine (n=29) patients exhibited a greater self-awareness of impairment.

Concerning the self-identifications, this variable was assessed through the analysis of three themes: self-perception and relation with the impairment; relation with prosthesis; and relation with rehabilitation. Twenty seven patients (n=27) were self-identified as being in transition between not being impaired and being an amputee, and fifteen patients (n=15) showed a greater self-identification with the impairment.

Both the patients' perceived social support and well-being were based on their appraisals of these themes.

Statistical Data Analysis

Considering the normal distribution with homogeneity of the variances of our dependent variable (depressive levels) between the analysed groups, parametric tests were adopted with a 95% confidence interval. Qualitative variables were dichotomized in order to enable the statistical analysis.

Pearson’s correlation test was adopted to correlate depressive levels with the elapsed time between limb loss and first interview correlations. The T-Student Test was chosen to compare mean scores of CES-D for each independent variable: type of amputation; state of rehabilitation; self-awareness of their impairment; self-identification with the impairment; prosthesis’ appraisals; the perceived well-being; and perceived social support.

Where statistically significant results were found, Cohen’s *d* was used to measure the effect size (26). According to Cohen’s criteria: a *d* value of approximately 0.2 is considered to be a small effect; a *d* value of approximately 0.5 is considered to be a medium-sized effect; and a *d* value of 0.8, or higher, is considered to be a large effect.

RESULTS

31% (n=13) of patients scored 23 or above on the CES-D, and met its criteria for clinical depression.

No significant correlation was found between depressive levels and the elapsed time since amputation (.84; p=.595).

The t-Student tests (table 1) showed significant higher depressive levels in patients who: had a greater self-awareness of their impairment ($p \leq .05$); were identified as being in transition ($p \leq .05$); reported an inadequate well-being ($p \leq .01$); and reported an inadequate social support ($p \leq .01$). The other variables did not show significant differences for depressive levels.

Pearson’s correlation test results showed (n=42) no significant correlation (.084; *P*=.595) between the time since the amputation and the depressive levels (CES-D).

Table 1 *Depressive levels between each variable group*

VARIABLE	**CES-D – M(SD)**	***p* (TST)**	***d***
Type of Amputation		**.955**	---------------
Transfemoral (n=16)	18.9 (11.2)		
Transtibial (n=26)	18.7 (11.6)		
State of Rehabilitation		**.406**	---------------
Ongoing (n=21)	20.3 (10)		
Finished (n=21)	17.3 (12.5)		
Elapsed time between amputation and first interview (years)		**.614**	---------------
0 to 2 (n=29)	18.1 (10.9)		
> 2 (n=13)	20.2 (12.5)		
Prosthesis Wear		**.225**	-------------
Wearing (n=18)	16.3 (11.8)		
Not Wearing (n=24)	20.6 (10.8)		
Self-awareness of Impairment		**.036***	**.701**
Greater Awareness (n=29)	21.2 (10.5)		
Lower Awareness (n=13)	13.4 (11.7)		
Self-Identification with the Impairment		**.014***	**.850**
As being in transition (n=27)	22 (10.9)		
As amputee (n=15)	13.1 (10)		
Perceived Well-Being		**.003****	**1.18**
As inadequate (n=29)	22.2 (11.6)		
Not report problems (n=13)	11.2 (6.1)		
Perceived Social Support		**.009****	**.856**
As inadequate (n=29)	15.8 (9.2)		
As good (n=13)	25.5 (13.1)		

* Significant differences between groups for p (2-tailed) ≤.05; **Significant differences between groups for p (2-tailed) ≤.01; p= probability; d= Cohen’s effect size; CES-D= Centre Epidemiologic Studies Depression Scale; TST= T-Student Test; M=mean; SD= State Deviation.

DISCUSSION

Our previous study (21) demonstrated the importance of self-identity changes beyond the body image for the adjustment process to lower limb loss. In these changes, self-awareness of impairment and self-identifications with the impairment arose as being two core intrapersonal variables concerning the experience of amputation. Results from the current study support the fact that these intrapersonal variables might be strongly associated with depressive levels, and therefore, our hypothesis is confirmed.

Even with different types of samples and different outcome measures, three previous studies are consistent with these findings. Two studies from Malec and colleagues (22,23), with patients with Orthopaedic and Neurological impairments stressed depressive levels as being strongly associated with self-awareness and self-assessment of impairment. In a qualitative study from Hayeems and colleagues (27), with patients with Retinitis Pigmentosa, the self-identifications with the impairment arose associated with better outcomes in terms of independence levels. Both studies supported the idea that these two intrapersonal variables can be associated with outcomes in physically impaired patients.

In terms of the frequency of depression, our study found a similar percentage (31% of patients with CES-D≥23) when compared with previous studies with similar populations (5,11,28).

The overall results strengthen the idea that the intrapersonal variables, related to the experience of becoming an amputee, can be linked to depressive levels. In addition, the effect sizes for these variables were medium to high, which strengths the suggestion the existence of these connections. All cases where depressive levels were significant higher, the CES-D scores were around the cut score for depression criteria. This means that these patients tend to be emotionally distressed. Therefore, these findings are supported by previous studies where poor outcomes, especially in terms of depression, were associated with worst social support (18,19) and problems in well-being (29).

Regarding the self-awareness of impairment, our previous study stressed this variable as being related to the first confrontation of the Self with the impairment (21). Thus, greater depressive levels in those who are more aware of their impairment appear as having a logical sense. Depressive levels rise when the patient becomes aware of his/her situation of serious loss, with its inherent effective limitations and changes. On the other hand, lower depressive levels might also be explained by a lower self-awareness of the impairment, and not only as a sign of better outcomes, as previous studies have stressed (19,30). Therefore, the self-awareness of impairment might be a helpful variable to ascertain the extent to which a patient is presenting a better outcome, or just being in denial of his/her impairment.

In our previous study (21), the self-identification with the impairment arose as being associated with patients' embodiment of their impairment, and therefore it is a variable that reveals the process of an emerging a new self-identity. Lower depressive levels in patients who are more identified with the impairment, as our study found, strengthen the previous fact, considering this variable as a core milestone of the adjustment process (21,27). The final embodiment process of the impairment clearly represents the possibility of more toleration and acceptance of the loss. Furthermore, it represents the patient's efforts to reformulate his/her life, and integrate a new condition of self-identity. Therefore, patients less identified with their impairment are more suitable to have problems in accepting the loss and to be more depressed.

Previous research (11,12,31) has stressed the positive effect that rehabilitation can have for the adjustment to limb loss. According to these studies it can promote the patients' self-worth, self-confidence, functional skills, daily life activities, especially preparing patients to wear prosthesis. Our results did not find any significant differences in depressive levels between patients at different stages of rehabilitation (ongoing and finished). At least two reasons can explain this fact: our patients did not have any psychological follow-up since the surgery; our study's design is cross-sectional and therefore less sensitive to the rehabilitation state's effect.

Both Pearson's correlation test and T-Student test suggested no connections between the time post-amputation and depressive levels. However, for this variable, our results may be limited in exploring its effects as it would be expected in a cross-sectional study. Interestingly, most of literature found a tendency for depression to become a chronic problem in the second or third year after the amputation, even after the rehabilitation is concluded (8,11).. The previous suggestions from Singh (11) pointed to two explanations: the provisory and artificial reassurance offered at wards ends after discharge; and the fact that many patients do not have any psychotherapeutic and/or psychiatric support during the follow-up after discharge.

Even though our study cannot explain why depression can persist overtime, some hypotheses can be raised. Based on our findings we can hypothesise that, during the rehabilitation, patients improve their self-identifications towards the impairment, but probably never reach a complete embodiment of the impairment. This fact has to do with the difficulties that patients experience in overcoming such a great change in their lives, as amputation (21). Therefore, patients can look at the prosthesis as an attempt to return to their previous body image and as a solution for a complete functioning restoration. Overtime, after discharge from the rehabilitation ward, patients begin to be confronted with the lack of that setting's reassurance and with the inherent limitations of being amputee. At that time, patients can become more aware of their real limitations and in consequence, more emotionally distressed. For these reasons, the psychotherapeutic and psychiatric support should be part not only of the rehabilitation protocol, but also of these patients' follow-up after discharge, as some authors have suggested (32-34).

Although the current study has raised some relevant findings, some limitations have to be acknowledged. First, due the fact that our study is cross-sectional instead of longitudinal, its findings do not allow any causal relation or prediction for depressive levels. Therefore, we just have explored some potential links between intrapersonal variables and depressive levels in order to point out some relevant cues and further research. Moreover these findings reveal only the experiences of a selected group of patients in a specific setting, and we cannot generalize them to other populations.

Second, even if our effect sizes were acceptable, our sample size was relatively small for a mixed method study and therefore does not allow for powerful conclusions.

Finally, although our sample was composed by patients at different phases of their rehabilitation, those who had not started it yet were not assessed by our study. It would be interesting for further studies to include this group and/or compare it with the other groups, in terms of adjustment variables and depressive levels.

Most of the literature on lower limb amputation has stressed depression as a sign of poor adaptation and outcomes (8,19,30). Our study suggests that the rising of depressive levels can also occur as an adaptive phenomenon in response to limb loss and, therefore, being part of the adjustment process. The intrinsic psychological variables that appeared potentially associated with this rising were: the patients' awareness of the impairment and its implications; and the patients' self-identifications with the impairment, or the impairment's embodiment.

Therefore, more research is needed, especially using longitudinal studies, on the relations between these intrapersonal variables and depressive levels. Knowing better these connections, the depressive phenomenon might be understood in depth and new targets for psychological intervention might be reached.

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OVERALL DISCUSSION

DISCUSSION

Study's Purpose and Hypotheses

The papers presented in the current dissertation successfully addressed the two main purposes of our research: to study the experience of becoming physically impaired (visually, or lower limb amputated), exploring possible changes in self-identity caused by the impairment; and to explore, preliminary, the relation between the experience of becoming impaired and the depressive levels. As was presented in our papers' results, most of our hypotheses were confirmed. Changes in self-identity in terms of self-awareness of impairment and self-identifications with the impairment were found in both patients' experiences of vision loss and of lower limb amputation. In addition, different meanings and attributions on vision loss were found in comparison with elderly patients. Although our results come from preliminary studies, we can also partially confirm the other two hypotheses, there might be a relation between the experience of impairment and depressive levels. The exception is for the relation between self-identifications with the impairment and depressive levels in patients with vision loss. Further we will discuss and analyse these differences.

The Experience of becoming Physically Impaired

Both papers, with a qualitative exploration of the experience of becoming visually impaired and a lower limb amputee, found many patients' reports of changes in self-identity caused by the impairment. Furthermore, themes like perceived social support, perceived well-being, relation with prosthesis/cane, and relation with the rehabilitation, appeared as personal core areas in the relation with impairment and the adjustment process, in agreement with the previous literature (1-4). The great novelty of the current research lies in the patients’ reports of changes in their identity, throughout the adjustment process to vision / limb loss. In this process two core variables were raised: the self-awareness of impairment and the self-identifications with the impairment. As discussed and analysed previously in the discussion of each paper, these variables arose as two crucial milestones of the overall process of transformation in the individual’s self.

In the case of patients who lost their vision, different meanings and attributions concerning vision loss were found, in comparison with elderly patients. According to studies by Boerner and colleagues (5,6), and Popivker and colleagues (7), vision loss in adulthood can be experienced in a more negative and disruptive way, when compared with the elderly. These conclusions were retrieved from the patients’ reports on life-goals and changes in several life domains. Our findings are consistent with those from Boerner et al. (5), but also add other important conclusions to this topic. Beyond the differences between the two groups, vision loss arose, in our sample, particularly related to the construction of a new meaning for own life. In this way, there are not only differences in terms of the type of life goals or changes, but especially in terms of what the vision loss can represent for the individual’s self-conception. Therefore, we presented a new approach for the experience of vision loss and its adjustment process.

In amputees, although our sample was mostly composed by older adults, similar findings arose, in comparison with the sample from the study on vision loss which was composed by adults in working age. The experiences of our sample of amputees revealed a set of changes in self-identity, from the self-awareness of impairment to the self-identification process with the impairment. As we had previously hypothesised, the individual identity changes arose beyond the changes in body image, also affecting other aspects of the Self, as another study had already argued (8).

Both qualitative studies on the experiences of becoming impaired justified a new theoretical approach on the experience of vision/limb loss and its adjustment process. Both models emphasize the role of the individual’s self-awareness of impairment and self-identifications with the impairment. The core point is that both experiences appear to entail a reorganization of the individual’s Self in its several domains.

As can be seen in both papers (the experiences of vision loss and lower limb loss), our findings supported two comprehensive approaches, where the Self-awareness of impairment arises as the first domain of the Self, during the adjustment process. In patients with vision loss it is the awareness of losing the vision, or of having lost it, and especially the awareness that it is a permanent condition for their lives. Unfortunately, most patients never recover their vision, because the most frequent causes for vision loss are ophthalmological diseases that tend to be chronic (9). Furthermore, this condition implies a set of new limitations that turns this awareness even more difficult to overcome. In patients with lower limb amputation, this awareness has to do with the new body image and its implications, both in terms of self-consciousness and functional limitations. Nevertheless, due to the prosthesis effect on the body-image restoration, there might be a regression in patients’ confrontation with the own impairment. A good prosthesis’ adaptation can lead to a great impairment disguise, as some authors have stressed (10,11).

After patients have become more aware of their new condition, another great challenge arises: to identify themselves with the impairment. It will allow them to achieve better levels of functioning and take advantage of the assistive devices. Most of the literature has described the rehabilitation outcomes and the functional recovering as being associated with specific coping strategies (12,13), or cognitive appraisals (14,15). Nonetheless, little is known about which mental processes underlie these strategies, appraisals and behaviours. Our patients' narratives gave some cues for that question. Besides the patients' acceptance behaviours, their toleration towards the impairment and their capacity to integrate it as being part of their new identity arose. Thus, until patients integrate their impairment and recognize themselves as having a new condition, the assistive devices can be refused, and the outcomes tend to be poorer. That was clear in visually impaired patients when they resisted using the white cane or in amputees when they reported systematic pain complaints. Therefore, we confirmed Murray's (16) previous idea, based on Merleau Ponti's (17), that there might be a common denominator between the prosthesis and the cane's embodiment. In our study both arose deeply related to the process of self-identification with the impairment. This means that both processed embodiments can be strongly linked to another important process: the embodiment of the impairment/new condition for the Self. In this way, both "tools" can be conceived as being great representatives of the overall embodiment process of the impairment. Nevertheless, further research is needed on this topic.

Although the theoretical approach that we propose for the adjustment process to vision/limb loss contains several innovative issues, it also strengthens some previous ideas developed by other authors. Works by Oliveira (18-20) have stressed the grieving and transformation process entailed by an acquired physical impairment. In this approach, the author emphasizes that the experience of physical/functional impairment goes beyond the functional losses. It often includes other relevant personal losses in terms of the individual's relation with himself and with the external world, which will be handled according to the individual's mental functioning and inner resources. On the other hand the author (18-20) also stressed the potential disruptive effect of the impairment for the self-identity, its oneness, and, therefore, implicates a hard process of transformation of the Self. According to this approach, the impairment demands a set of transformations in which the subject has to introject, in the sense used by Klein (21), the underlying new elements that are part of the new condition of being amputee or visually impaired. The inherent difficulties of this process make it a usually hard and unfinished transformation process of the Self, as it was suggested by Wilson (22).

From a developmental perspective, our findings can also raise several questions. Our adjustment model is consistent with the idea that the physical/functional losses can affect not only the current integrity of the individual, but also his/her biographical Self as well as the future projections of his/her Self. In this sense, our findings are consistent with the Damasio's approach of the Self (23,24). Applying his concepts of the Self to our adjustment model many questions can be raised. In the sense of what is currently happening, the individual's *Core Self* can give the information that now he/she is not seeing, or that he/she does not have a part of his/her body. This information is provided repeatedly to the subject's brain until being part of his/her *Auto-Biographical Self.* At this stage, the information that the subject is impaired can trigger two main parts of the Self: the subject's self-concept based on his/her previous experiences and biography, through the past *Core Self*; and the future projections of Self – how the subject projected him/herself in the future, before being impaired. The vision/limb loss has proved to be a potential disruptive event for a person, because it can compromise the subject's overall previous expectations for his/her life. Furthermore, these impairments limit the individual's relation with his/her own and the external reality. In the case of visual impairment, the patients lost their main way of keeping in touch with the reality (inner and relational), which is their vision. Amputees do not have the same problem because they can still see, hear, and feel. However, their body changed and, therefore, their public and private self-consciousness can be affected. Consequently, their relation with their own body and with others can also change, as previous authors have stressed (25,26).

In conclusion, the experience of being physically/functionally impaired implies a condition where great transformations in self-identity can operate. These changes appear to be phased from the self-awareness of impairment to the final embodiment of the new condition which needs a successful process of self-identification with the impairment.

The Connection between Depressive Levels and the Experience of becoming Physically Impaired

Although we cannot make any predictions, or discuss causal effects between the studied intrapersonal variables and depressive levels, the connections that we found deserve a brief discussion.

The idea of studying the relation between depressive levels and self-awareness of impairment came from two previous studies: Tabrett's paper (27) where the depression is considered as being part of the adjustment process and not only a sign of maladjustment; and studies by Malec and colleagues (28,29) where depression was linked to the self-awareness and self-assessment of impairment.

In both our studies (vision loss and lower limb amputation) results suggested that depressive levels could be higher in patients with greater self-awareness of impairment. This finding is supported by Malec studies (28,29) and raises the idea that depressive levels can rise in response to a first contact between the Self and the impairment with its disruptive effect. In this way, we can hypothesise that the higher depressive levels are, in a first period of the adjustment, an adaptive response to the impairment.

Regarding the self-identifications with the impairment, some differences were found between patients with vision loss and amputees. While amputees who were more identified with the impairment showed lower depressive levels, the group of patients with vision loss did not show any difference for the same variable. According to the literature (30-33) the prosthesis embodiment process has been related to less emotional distress, social discomfort and body-image anxiety. After a patient has worn a prosthesis, body image can be partially restored, and functioning can be significantly improved. Therefore, patients can be, at least temporarily, less depressed.

In the case of patients with vision loss, it is different. The cane can improve their autonomy and functioning, but cannot be perceived as restorative for the patients' connection with the external reality; they continue to be deprived of seeing. Therefore, the process of self-identification with the impairment appears to be harder, and consequently the patient can be depressive for longer.

In or to confirm/refute the hypothesis risen by our findings, on depressive levels in amputees and visually impaired patients, more research is needed. Therefore, it would be interesting to perform longitudinal studies on this area, in order to conclude more about the real causal relation between these variables and depressive levels.

Main Research Limitations

The main limitations of our research were also acknowledged in each paper presented in the current dissertation.

Although our research raises innovative approaches to address the experience of becoming physically impaired, our findings reflected only the experiences of our samples. Moreover they were samples studied in a cross-sectional design that offered many advantages but it is also more restrictive in terms of extrapolation and generalization.

On the other hand, even though our interviews were designed to be bias free, there is always a tendency to there is always a tendency to address issues that we know to be potentially related to the experience of being impaired.

In terms of the variable "rehabilitation", although it was controlled in the study with amputees, it was not controlled for the patients with vision loss. Therefore, we cannot have a broad sense of these experiences, considering the period pre and post rehabilitation.

Finally, as we already referred, the connections between intrapersonal variables and depressive levels were weak due to the cross sectional design of our study, and therefore we cannot argue a real causal relation. However we can raise some relevant cues for further research in a poorly studied topic.

Implications for Research

Considering that most of our findings raise innovative aspects of the experience of vision/limb loss, further research will be needed to develop this topic, and to confirm, or refute, our findings. Due to the fact of self-awareness of impairment and self-identifications with the impairment are two variables that were almost not studied before our research, it would be interesting to perform new studies where these variables were considered. In this way, our findings suggest further research on the following topics:

- The experience of vision loss, in terms of changes in self-identity throughout the pre, peri and post rehabilitation periods, using a longitudinal design;
- The changes in self-identity in other clinical samples such as: traumatic brain injury; stroke; spinal cord injury; chronic pain, etc.;
- The changes in self-identity in younger patients (children and teenagers) with acquired physical impairment, and its implications for families;
- A comparative and longitudinal study of depressive and the anxiety levels between patients more aware of their impairment/health condition;
- A comparative and longitudinal study of depressive and the anxiety levels between patients more identified with their impairment/health condition;

Implications for Clinical Practise

In terms of clinical practise, two great areas can benefit directly from our findings: the psychological/medical assessment; the psychological/psychotherapeutic intervention. These two areas must be considered for the entire adjustment period this is, from the moment of diagnosis, to the follow-up period. Even after discharge from rehabilitation. Nevertheless, our findings might, indirectly, help all practitioners who are involved in the whole healthcare and social support of these patients (from primary care to medical follow-up, and including the rehabilitation program).

In this way, it would be interesting to consider the assessment and monitoring of patients' self-awareness of impairment in an early period of the adjustment process. The aim would not be to promote patients' awareness of impairment, but to monitor it in order to watch over the patients' emotional state and prepare them for the rehabilitation process. Previous studies (31,34) have stressed the importance of an early intervention and rehabilitation to prevent serious problems in the adjustment process, especially the tendency for depression to become chronic. Moreover, during the rehabilitation process it would be interesting to differentiate whether the patients are well adapted to their condition or whether they simply are little/not aware of their impairment and of its implications for their future life.

Concerning the depressive levels, our study found a great portion of depressed patients. Previous literature (30,35,36) has also found a great tendency for depression to become chronic in these patients. Therefore, it would be a good practise to promote psychotherapeutic interventions, since the diagnosis.

Other important cue for clinical practise is to assess the patients' self-identifications with the impairment. This can be useful both before and during the rehabilitation program. To understand how much the patients are identified with their impairment it can be helpful to link their attitudes, feelings, behaviours, and outcomes to their identity changes caused by vision/limb loss. Moreover, it can help clinicians to adjust rehabilitation tasks and goals to the patient's real needs, because the targets cannot be the same for patients who are less identified with the impairment, and those who are already more identified with the impairment.

Regarding the psychotherapeutic work with these patients, we should consider the impairment's implications beyond the functional limitations, and address the emotional suffering related to the changes in self-identity. As we referred previously, an acquired physical impairment is a situation of involuntary change in one's own body and its functions that can irreversibly compromise the subject's relationship with his/her reality. Therefore, there is much more than a functional compromise.

As Oliveira stressed (20), a psychotherapeutic work with this population should be focused on important individual inner features such as: mental functioning, mental defence mechanisms; inner conflicts; and other unconscious features of the subjects' relationship with the own internal and external world. In this way, the focus should be beyond the rehabilitation outcomes, because there is a hard transformation process that is at stake. This transformation process, operated in the psychological dimension, is often extremely hard to perform by the subject. It is a process that might question the spatial, temporal and social links of the individual's Self, in the sense used by Grinberg (37). Therefore, while these dimensions of the Self were not acknowledged in the psychotherapeutic work, the rehabilitation work is incomplete.

Based on this Freudian's approach, Thomas (38) hypothesised that the acquired physical impairment, like a limb loss, could be conceptualised as an object loss, which implications could require coordination between the specific rehabilitation efforts (the functional rehabilitation) and a period of *working through* (mourning work). The point is to be a prime initial focus on *working through*, however integrated in the rehabilitation and functional efforts.

The ultimate aim is to offer the patients the opportunity to think, and mentalize, in the sense used by O'Gorman (39) and Fonagy,(40) about their new condition in a more tolerable way, in order to promote a less painful transformation process of the self-identity. It is that psychotherapeutic transformation that can increase the patients' integration of the new impairment-related elements into the Self, and, consequently, promote their willingness to accept themselves as being in new individual condition. The functional and rehabilitation outcomes will arise as result of that patient's achievements.

Our findings support these previous ideas about the psychotherapeutic work with the physically impaired patients. Patients' narratives about their impairment suggested that helping the patients to overcome the awareness of their losses, to verbalize feelings and ideas about themselves and the impairment, and to acquire new meanings for being impaired; the impairment might become more easily faced and accepted. In addition, a psychotherapeutic intervention addressing the patients' self-identifications with the impairment might facilitate their embodiment process, both for the prosthesis and for the cane. Therefore, the patients' times of adjustment, in terms of awareness and identification with the impairment should be respected and not forced. The patients' outcomes should be defined in terms of what they can achieve and not in agreement with functional goals previously defined by the rehabilitation staff.

Finally, the psychotherapeutic work with these patients can benefit from the idea that it should allow patients to be free to feel and to have thoughts about themselves weather impaired or not impaired.

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APPENDICES

APPENDIX A

Table 1 Summary of papers on the adjustment to Vision loss

Table 1 Summary of papers on the adjustment to Vision loss

Author(s)	Country	Year	Population	Publication	N	Mean Age	Methodology	Design	Measures	Main Findings
Dodds & Ferguson	U.K.	1994	Adults with Acquired Visual impairment	Journal Article	469	21 to 48	Quasi-experimental; Quantitative	Cross-sectional	GHQ; RSEQ; ABQ; RLCQ; LADQ; SSQ; ASQ.	Authors explored the Nottingham Adjustment Scale and present a theoretical model of the self in terms of two latent factors--internal self-worth and self as agent-and discuss the relationship between the two and the implications for intervention with cognitive therapy.
Davis & Lovie-Kitchin	USA	1995	Adults with Acquired Visual impairment	Journal Article	30	81	Mixed methods (quantitative and qualitative)	Cross-Sectional	Structured Interview; LSI-W; SSS; RFIS; HS; SCAS	A poor adjustment to vision loss appeared associated with less life satisfaction, worse social support and higher levels of stress.
Jackson & Lawson	USA	1995	Adults with Acquired Visual impairment	Journal Article	76	18-94	Quantitative Correlational	Cross-sectional	FES; GSI	Cohesion was negatively correlated with distress, and conflict and control were positively correlated with distress, in patients with vision loss.
Reis	Canada	1996	Adults with Acquired Visual impairment	Journal Article	8	52	Case study	---------	Semi-structured interviews	Emotions, thoughts, relationships, meanings, existential state, coping process, changes and losses, and sense of self appeared as significant factors for the experience of retinitis pigmentosa.
Benn	USA	1997	Adults with Acquired Visual	Journal	150	79	Qualitative;	Cross-	Semi-structured	Escape-avoidance and neuroticism were associated with reduced adaptation to vision loss, whereas

			impairment	Article			Grounded Theory	Sectional	interviews	positive reappraisal, optimism and distancing were related to greater adjustment to the impairment.
Upton et al.	USA	1998	Adults with Acquired Visual impairment	Journal Article	80	58	Quasi-experimental Quantitative	Cross-sectional	IMIQ; WCCL; HSCL; IADLS	Diabetes with a recent onset of sight loss, coping by escape, blaming oneself and absence of planful problem solving, were associated with problems in: daily living activities; well-being; and depression.
Lindo et al.	Sweden	1999	Adults with Acquired Visual impairment	Journal Article	515	G1:42 G2:81 G3:51	Comparative; Quantitative	Cross-sectional	MAQ; PAQ; ADLS	Neurological group have levels of adjustment similar to low vision group. However, elderly group showed the worst level of adjustment and more well- being problems than others.
Wahl et al.	Germany	1999	Adults with Acquired Visual impairment	Journal Article	168	78	Comparative; Quantitative	Longitudinal	ADLS/ IADLS scale.	Visually impaired group demonstrated lower IADL competence than mobility impaired group. The long-term adjustment of the visually impaired remained relatively stable in the behavioural domain. Emotional adaptation tends to be decreased over the 5-year longitudinal interval in the group of patients with vision loss.
Kleinschimdt et al.	USA	1999	Adults with Acquired Visual impairment	Journal Article	12	79	Qualitative; Grounded Theory	Cross-Sectional	GDS; STAI	From interviews, the following themes emerged: prior life experiences; internal resources; and external resources. Internal resources were: positive attitude; sense of humour; problem solving perspectives; and religious beliefs.
Brennan et al.	USA	2001	Adults with	Journal	593	80	Qualitative;	Cross-	Semi-structured	In patients' narratives, several themes on coping with

			Acquired Visual impairment	Article			Grounded Theory	sectional	interviews.	sight loss emerged, such as difficulty in balancing norms of independence with the functional losses resulting from eye disease, and the importance of the informal social network.
Heyl et al.	USA	2001	Adults with Acquired Visual impairment	Journal Article	84	81	Quasi-experimental Quantitative	Longitudinal	PGCMS; ADLS; IADLS scale	Findings disclose the importance of the earliest possible intervention and rehabilitation to prevent psychosocial harm to elderly people who experience severe vision loss.
Reinhardt	USA	2001	Adults with Acquired Visual impairment	Journal Article	570	80	Quantitative Quasi-experimental	Cross-Sectional	OARS; CES-D; ASSIS; LSIW	Visually impaired elders who receive more affective support showed less depressive levels. Greater life satisfaction appears associated with better adaptation to vision loss.
Van Huijgevoort et al.	USA	2002	Adults with Acquired Visual impairment	Journal Article	2	---	Case study	-----	Semi-structured interviews	Authors analyse two case studies in order to develop self-confrontation method in patients with vision loss and its value to help patients to cope with their vision loss.
Burmedi et al.	Germany	2002	Adults with Acquired Visual	Journal Article	------	-----------	Literature Review	-------------------	-------------------	Vision loss appeared associated with depression, problems in well-being and emotional functioning.

			impairment							Social adjustment to vision loss is construed to involve difficulties in social functioning, changes in social support and loneliness.
Coyne et al.	UK	2004	Adults with Acquired Visual impairment	Journal Article	15	54	Qualitative; Grounded Theory	Cross-Sectional	Semi-structured interviews	Patients described several difficulties in daily living activities. Loss of independence and mobility and the fear of accidents were the main reported concerns.
Horowitz	USA	2004	Adults with Acquired Visual impairment	Journal Article	adults	-----	Literature review.	-----------------	-------------------	Author explores the prevalence of depression in VI patients and its importance to reduce well-being and as a barrier for rehabilitation.
Wong et al.	USA	2004	Adults with Acquired Visual impairment	Journal Article	15	77	Qualitative; Grounded Theory	Cross-sectional	Semi-structured interviews	Study underscores the importance of understanding patients' experience, coping and psychosocial well-being to promote their adaptation and rehabilitation.
Gresset et al.	Canada	2005	Adults with Acquired Visual impairment	Journal Article	20	79	Qualitative; Grounded Theory	Cross-Sectional	Semi-structured interviews	Elderly patients reported experiences of emotional distress, isolation, depression and loss of autonomy associated with the experience of vision loss. Patients revealed the following meanings related to vision loss: death; fear; the end of life as patients know it.
Hayeems et al.	Canada	2005	Adults with Acquired Visual impairment	Journal Article	43	51	Qualitative; Grounded Theory	Cross-sectional	Semi-structured interviews	Study emphasizes the importance of patients' self identification with impairment for rehabilitation outcomes. It's proposed a new conceptual model to understand patient's adjustment to vision loss.

Teitelman et al.	USA	2005	Adults with Acquired Visual impairment	Journal Article	15	78	Qualitative; Grounded Theory	Cross-sectional	Semi-structured interviews	Adjustment to low vision was explored and three themes related to psychosocial experience emerged: Emotional Challenges; Negative Emotional Outcomes; and Indicators of Emotional Adaptation.
Tolman et al.	USA	2005	Adults with Acquired Visual impairment	Journal Article	144	77	Quantitative Quasi-experimental	Cross-Sectional	AVLS; SPMSQ; GDS	Three main factors for adaptation to vision loss were found: acceptance of vision loss; negative impact on relationships; and attitudes toward compensation. First and third were associated with depressive effect. Rehabilitation appeared having a positive effect on adaptation and emotional status.
Boerner et al.	USA	2006	Adults with Acquired Visual impairment	Journal Article	155	77	Quantitative Quasi-experimental	Longitudinal	ECRC; FVSQ; MFAQ	Instrumental coping proved to be the best coping to promote the adjustment process and to enhance rehabilitation outcomes.
Boerner et. al.	USA	2006	Adults with Acquired Visual impairment	Journal Article	53	53	Mixed methods (quantitative and qualitative)	Cross-sectional	Interview; CES-D; SWLS	Life changes in midlife adults were reported in 4 life domains: goals/priorities; self-views; world views; and relationships. More negative than positive changes were reported. The most referred changes were “in between”. Authors stressed the need to explore these changes in rehabilitation settings.
Cimarolli et al.	USA	2006	Adults with Acquired Visual impairment	Journal Article	114	47	Quantitative; Quasi-experimental	Cross-sectional	CES-D; FVSQ; NHIS; ARS; OPSA; BAI.	Strong and positive correlation between depression and anxiety levels and perceived overprotection. Perceived overprotection in social support appears associated with more emotional distress and poor adjustment to vision loss.

Cimarolli, Reinhardt & Horowhitz	USA	2006	Adults with Acquired Visual impairment	Journal Article	584	80	Quantitative Quasi-experimental	Cross-sectional	OARS; OPSA; AVL	Perceived overprotection were associated with less optimal adjustment to vision loss; Higher levels of functional disability and instrumental support received were associated with higher levels of perceived overprotection.
Horowitz	USA	2006	Adults with Acquired Visual impairment	Journal Article	438	71	Correlational; qualitative	Longitudinal	Semi-structured interviews	Optical, but not adaptive, device use was significantly associated with declines in functional disability and depressive symptoms over time.
Lee et al.	USA	2006	Adults with Acquired Visual impairment	Journal Article	507	78	Qualitative; Grounded Theory	Cross-sectional	Structured Interviews.	The analysis of stress constellation yielded five Groups: stoics (n = 83), complainers (n =42), taciturns (n =304), sentimentalists (n = 67),and articulates (n =11). The analysis of coping style codes yielded five cluster solutions: mavericks (n = 12), autonomous (n= 76), pragmatists (n = 44), hermits (n = 41), and nonchalants (n = 334).
Fourie	Ireland	2007	Adults with Acquired Visual impairment	Journal Article	1	NA (Adult)	Self-study	----------	Narrative – self-study	Author's self study explores the emotional and the personal experience of diagnosis and has received a white cane. Themes emerged are consistent with some previous conclusions from the Hayeems' study.
McKinzie et al.	USA	2007	Adults with	Dissertation	549	72	Qualitative /	Cross-	Semi-structured	Self-reported adaptation to vision loss was the unique

			vision loss: African American and Caucasians.	abstracts			Comparative	Sectional	interviews	domain where variations between races were found.
Smith	USA	2008	Adults with Acquired Visual impairment	Journal Article	1	65	Case study	------	Semi-structured interview	Author discusses through a case study report the importance of patient's variables for the adjustment to sight loss: attitudes of acceptance and independence; social support; and using other senses.
Wang & Boerner	USA	2008	Adults with Acquired Visual impairment	Journal Article	58	51 and 84	Qualitative; Grounded Theory	Cross-Sectional	Semi-structured interviews	Social re-establishing relationships following vision loss appeared as a complex process in which patients have several challenges and using specific strategies to deal with it. Most of them reported problems in re-establishing relationships after loss their vision.
Yampolsky	USA	2008	Adults with Acquired Visual impairment	Journal Article	85	23 to 97	Quasi-experimental Quantitative	Cross-sectional	MCSDS; SWBS	Findings proved that religious well-being is a good predictor for adaptive coping behaviours.
Bambara	USA	2009	Adults with Acquired Visual impairment	Journal Article	-----	----	Systematic literature review	------	---------------	Review found that most literature has focused on the unique role that the family plays in providing both instrumental and motional support to adults with low vision. The impact of low vision on the psychosocial adjustment of the family has been largely understudied.

Reinhardt et al.	USA	2009	Adults with Acquired Visual impairment	Journal Article	313	79	Quantitative Quasi-experimental	Longitudinal	FVLS; OARS; ASSIS; AVL; CES-D	Greater use of acceptance coping, less use of wishfulness coping, lower endorsement of chance locus of control, and higher family support were associated with better baseline adaptation.
Standford	U.K.	2009	Adults with Acquired Visual impairment	Journal Article	226	81	Qualitative; Grounded Theory	Longitudinal	Patients' Diaries	Findings generated 7 themes from patients' diaries about their experience of vision loss: safety; loss of independence, isolation, support mechanisms, mood, effects of the media and psychosocial adjustment.
Chong-Wen & Chan	China	2009	Adults with Acquired Visual impairment	Journal Article	167	76	Mixed methods (quantitative and qualitative)	Cross-Sectional	NEI-VFQ-25; AVL; Structured Questionnaire.	Psychosocial adaptation appears associated with vision loss health related quality of life in several domains such as: mental health symptoms caused by vision loss; and dependency on others caused by vision loss.
Boerner et al.	USA	2010	Adults with Acquired Visual impairment	Journal Article	44; 107	55;82	Mixed methods; comparative	Cross-sectional	Interview; CES-D; SWLS	Midlife adults reported more negative and significant changes than the older adults. In adulthood the vision loss seems to be more disruptive than in elderly.
Dale	UK	2010	Adults with Acquired Visual impairment	Journal Article	NA	(adults) NA	Qualitative	Cross-sectional	Patient's narratives in counselling.	Patients' narratives suggested that negative changes caused by vision loss can be related to their confrontation with a society whose appraisals to vision loss tend to be negative. Addressing that negative impact and facilitating their emotional verbalizations appear to be a good practice to promote the adjustment to the impairment.

Garnefsky	Netherlands	2010	Adults with Acquired Visual impairment	Journal Article	67	51	Quasi-experimental	Cross-sectional	Semi-structured interviews; Depression scale; cognitive coping strategies scale.	Ruminative coping in responding to visual impairments was related to more depression and refocusing attention by seeking and re-engaging in alternative, was related to less depressive symptoms.
Green & Capella	USA	2010	Adults with vision loss: African American and European American	Dissertation abstracts	NA	>50	Quantitative Quasi-experimental	Cross-Sectional	AVL 12	No statistic differences between groups in terms of adaptation to vision loss.
Popivker et al	USA	2010	Adults with Acquired Visual impairment	Journal Article	216	55	Mixed methods (quantitative and qualitative)	Cross-Sectional	Interviews; FVLS.	Findings stressed that vision loss in adulthood can be a barrier for individual's life goals, causing a great change in patients' life. Addressing the specific life goals in middle age patients can be a good practise in rehabilitation programmes.
Thurston et al.	UK	2010	Adults with Acquired Visual	Journal Article	18	64	Mixed methods (quantitative and	Cross-Sectional	NEIVF; Semi-structured	Patients showed common emotional issues about their experience of transition from sighted to blind: the diagnosis experience; coping with deteriorating of

			impairment				qualitative)		Interview	sight; experiencing loss; experiencing changed perceptions of self in relation to society; experiencing others differently; and experiencing rehabilitation.
Thurston	UK	2010	Adults with Acquired Visual impairment	Journal Article	18	64	Mixed methods (quantitative and qualitative)	Cross-Sectional	NEIVF; Semi-structured Interview	Author explore a new conceptual model for adjustment to vision loss based on patients' transition process form sight to blindness.
Weber et al.	USA	2010	Adults with Acquired Visual impairment	Journal Article	30	65-95	Qualitative; Grounded Theory	Cross-Sectional	AVL; Interviews	A correct balance of support, confidence and acceptance improve the ability to optimize function with vision loss in adult patients.

ADL: Activities of Daily Living; IADL: Instrumental Activities of Daily Living; NA: Not Available.
ABQ: Attitudes to Blindness Questionnaire; ADLS: Daily Living Activities Scale; ARS: Activity restriction Scale; ASQ: Attributional Style Questionnaire; ASSIS: Arizona Social Support Interview Schedule; AVLS: Adaptation to Vision Loss Scale; BAI: Beck Anxiety Inventory; BDI: Beck Depression Inventory; CES-D: Center for Epidemiological Studies of Depression Scale; CHART-SF: Craig Handicap Reporting Technique - Short Form; EBS: Emotional Bondedness Scale; ECRC: Elderly Care Research Center; FES: Moos Family Environment Scale; FVLS: Functional Vision Loss Scale; FVSQ: Functional Vision Screening Questionnaire; GDS: Geriatric Depression Scale (short form); HS: Hassles scale; HSCL: Hopkins Symptom Checklist; IADLS: Instrumental Daily Living Activities Scale; IMIQ: Implicit Models Illness Questionnaire; LADQ: The Linkowsky Acceptance Disability Questionnaire; LSIW: Life Satisfaction Index Well-Being; MACL: Mood Adjective Checklist; MCSDS: The Marlowe-Crowne Social Desirability Scale; NEI-VFQ: National Eye Institute Visual Function Questionnaire; NHIS: National Health Interview Survey; OARS: Multidimensional Functional Assessment Questionnaire; OPSA: Overprotection Scale for Adults; PAQ: Person's Adaptation Questionnaire; PGCMS: Philadelphia Geriatric Center Morale Scale; RFIS: Revised Feelings of Inadequacy Scale; RLCQ: Recovery Locus of Control Questionnaire; RSEQ: Rosenberg Self-Esteem Questionnaire; SCAS: Self-care Assessment Schedule; SPMSQ: Short Portable Mental Status Questionnaire;SSQ: Sheers' Self-Efficacy Questionnaire; SSS: Social Support Scale; STAI: Spielberg State Trait Anxiety Inventory; SWBS: Spirituality well-being scale; SWLS: 5-item Satisfaction with Life Scale; WCCL: Ways of Coping Checklist.