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Psychological issues in prosthetic and orthotic practice: a 25 year review of psychology in *Prosthetics and Orthotics International*

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Abstract

In the inaugural edition of *Prosthetics and Orthotics International*, Fishman identified the psychological sciences as one of six indispensable areas of skill and knowledge in professional prosthetic-orthotic practice. Given the journal's significant role in reporting and developing pertinent research and practice, this review assesses the profile of psychology in prosthetic and orthotic research, as evidenced by the content of *Prosthetics and Orthotics International* since its inception. A MEDLINE search of the journal's abstracts over a twenty-five year period was conducted using the search terms: 'psychology', 'psychosocial', 'quality of life', 'developmental' and 'coping'. Results of this search are summarised under the following headings: (a) body image; (b) coping and adjustment; (c) developmental issues; (d) psychosocial well-being; (e) quality of life; and (f) psychological factors leading to amputation. On the basis of this review, the authors conclude by highlighting a number of key areas where the psychological aspects of prosthetics and orthotics warrant further investigation and dissemination.

Introduction

The area of prosthetics and orthotics continues to make significant technological gains and innovations on the materials and methods used by practitioners. For instance, high-tech

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prostheses now offer patients the possibility of regaining much of the function traditionally lost through limb amputation (Engstrom and van de Ven, 1999). While such technology is welcome and exciting because of its rehabilitative potential, it is important that attention is also focused on psychosocial issues that may affect physical rehabilitation (Williamson *et al.*, 1994). In fact, the authors suggest that the realisation of the potential of technological innovations in this field may only fully be achieved through a comprehensive understanding of the psychological complexities pertaining to the therapeutic context (MacLachlan and Gallagher, *in press*).

Prosthetics and Orthotics International plays a significant role not only in reporting pertinent research and practice, but also in developing it, and may thus be seen, to some extent, as 'constructing' and 'guiding' expectations about psychosocial issues in the field of prosthetics and orthotics. Indeed, in the journal's inaugural edition, Fishman (1977) emphasising the fact that often "successful fitting of a prosthesis lies in the psychology of the wearer rather than in any physical problem" and cites the psychological sciences as one of six indispensable areas of skill and knowledge in professional prosthetic-orthotic practice.

A decade ago Grise *et al.* (1993) argued that numerous studies concentrate primarily on physical factors while affording little consideration to psychosocial, demographic and disability related factors. Similarly, in a recent ten-year review of the prosthetics rehabilitation literature, Geertzen *et al.* (2001) concluded "no good articles were found which considered socio-economic, vocational or psychological

aspects in relation to amputees". In light of these assertions, the objective of this review is to assess the profile of psychology in prosthetic and orthotic research, as evidenced by an analysis of the content of *Prosthetics and Orthotics International*.

Thematic analysis

A MEDLINE search of the journal's abstracts published between its inception in 1977 and August 2001, using the search terms; 'psychology' (and its derivatives), 'psychosocial'. 'quality of life', 'developmental' and 'coping', was further validated by a detailed reading of the journal itself, and an extension of the search to December 2001. This process revealed that twenty-one articles with some psychological content were published in *Prosthetics and Orthotics International* over this twenty-five year period; however, it is important to acknowledge that the depth of consideration of psychological issues varies greatly from a single line in some instances, to entire articles in other cases.

This thematic analysis of the psychology of prosthetics and orthotics identified six broad categories with evidence of some overlap between categories and considerable disparity in the level of attention received by each: (a) body image and cosmesis; (b) coping, adjustment and acceptance; (c) developmental issues; (d) psychosocial well-being; (e) quality of life; (f) psychological factors leading to amputation.

Body image and cosmesis

The experience of amputation encompasses the disturbance of body image, which must be reconceptualised to incorporate both the loss of the limb as well as the probable phantom sensation of the limb. The psychological impact of dramatically changed body image is briefly referred to by Narang and Jape (1982), who suggest that in the case of traumatic amputation "the sudden and dramatic physical loss of limbs is unsettling in the extreme". Further, they propose that the greater number of clinics visits by lower limb amputees is driven by the fact that lower limb prostheses are both functionally and psychologically more satisfying than upper limb prostheses, and hence receive more use (Narang and Jape, 1982). The lasting impact of losing cosmesis is alluded to by Chadderton (1983) who reported that World War II trans-radial

amputees, who had never worn a prosthesis, had still not become used to the loss of cosmesis involved in the empty sleeve. Similarly, Burger and Marincek (1994) acknowledge that a "large number of amputees are very sensitive about their cosmetic appearance", and suggest that reactions of society at large toward the individual amputee are closely tied to the cosmetic appearance of their prosthesis. The importance of the cosmetic appearance of the prosthesis as a factor in acceptance or rejection of prosthetic use is acknowledged by Millstein *et al.* (1986), and, in investigating this relationship, van Lunteran *et al.* (1983) concluded that for most wearers of arm prostheses the cosmetic function of the prosthesis was a highly important and valued attribute.

Coping, adjustment and acceptance

The category 'coping, adjustment and acceptance' receives the lengthiest coverage when reported in the journal, although significant coverage of the topic is confined to a small number of papers. Furst and Humphrey's (1983) "Coping with the loss of a leg", is primarily concerned with the psychological aspects of coping, and covers a wide range of topics including self-consciousness, the amputee's and others' attitudes to handicap, grief reactions and acceptance of a prosthesis. Similarly, van Lunteran *et al.* (1983) report a post-clinical investigation of coping with amputation and the role the prosthesis plays in the amputee's life; Gallagher and MacLachlan (2000*) investigate factors which promote positive adjustment following amputation. The complexity of the psychological factors involved in the amputee's acceptance of the prosthesis is acknowledged by Millstein *et al.* (1986), while acceptance by the amputee's non-disabled social milieu is briefly referred to by Burger and Marincek (1994) and Furst and Humphrey (1983). Grief reactions are referred to, again only briefly by Chadderton (1978) who suggests, that "psychological" effects are "perhaps an area which we tend to ignore".

Developmental issues

Reference to the implications of psychological developmental stages and issues in prosthetic/orthotic practice is poorly represented in the journal, despite its potential importance.

To date, *Prosthetics and Orthotics International* has not included an article explicitly addressing psychological aspects of paediatric development specific to the needs of families where a child requires orthotic and/or prosthetic intervention. A recent article by Kuyper *et al.* (2001) focusing on the prosthetic management of children with upper limb deficiencies highlights the importance of age at first fitting as a factor in rejection/acceptance of prostheses. Four articles published over a fifteen-year period afford very brief reference to developmental issues: Paul (1977); Narang and Jape (1982); Setoguchi (1991); and Lord and Foulston (1991). Parents' reactions to their child's disability, and the importance of counselling parents to develop realistic goals with regard to their child's future development form the basis of a paper by Setoguchi (1991), and are also briefly addressed by Narang and Jape (1982) and Boonstra *et al.* (2000). On a related topic a short article by Bruce (1991) discussed the function and operation of a parent support organisation.

Psychosocial well-being

Reference to psychosocial well-being post-amputation is made in a number of papers published in the journal (Chadderton 1978; Hunter, 1985), however, detailed (i.e. more than one paragraph) consideration of the topic is found in only four papers: Hunter and Middleton (1984); De Fretes *et al.* (1994); Grieve and Lankhorst (1996), and Gallagher and MacLachlan (2000^a). The vast majority of research on the psychosocial sequelae of amputation has focussed exclusively on the negative effect the event has on psychosocial well-being, for example, increased social dependence, grief and depression (Rybarczyk *et al.*, 1995; Schubert *et al.*, 1992; Frierson and Lippmann, 1987). In contrast Gallagher and MacLachlan's (2000^a) "positive meaning in amputation and thoughts about the amputated limb", focusses on the potential for something positive to emerge from the amputation experience.

Quality of life

A MEDLINE search of the journal using the search term 'quality of life' yields ten publications between 1983 and August 2001, however, when cross-referenced with those yielded using the term 'psychology' only three

papers remain: Gallagher and MacLachlan (2000^a) De Fretes *et al.* (1994) and van Lunteran *et al.* (1983); however, the psychosocial dimension of quality of life are not the exclusive focus of any of these articles. More recently, Hagberg and Branemark (2001) in a survey of the quality of life of non-vascular trans-femoral amputees, advocate increased effort to improve psychological well-being of this group.

Psychological factors leading to amputation

Four papers (Hunter, 1985 and 1992; Wood *et al.*, 1987; Hunter and Middleton 1984) published between 1984 and 1992 consider the potential for psychological factors to lead to amputation in adults. Hunter (1992) provides a fourfold classification of these factors: chronic pain syndrome, artefactualists (individuals whose amputations result from secondary complications associated with self-injurious behaviour), self-mutilation, and attempted murder (where severe physical injury leads to amputation in survivors of murder attempts).

An earlier paper by the same author (Hunter, 1985) focusses exclusively on "limb amputation and re-amputation in association with chronic pain syndrome", termed "mania operativa", that is, an "obsession with pain and disability and the seeking of relief from this pain by repeated surgical procedures" (Hunter and Kennard, 1982). Further reference to this topic is provided by Wood *et al.* (1987) who advocate rigorous psychological assessment of patients prior to surgery. Similarly, the fourth paper by Hunter and Middleton (1984), suggests that cold injury amputations, i.e. amputations resulting from exposure to extreme environmental conditions, are predominantly associated with psychological disorders, including alcoholism, and personality disorders, and hence, the success of rehabilitation these patients is strongly influenced by psychological factors rather than the physical disability itself.

Discussion

Despite Fishman's (1977) paper in the inaugural edition of *Prosthetics and Orthotics International* indentifying the psychological sciences as one of six areas of importance for prosthetics and orthotics, psychological issues have largely been overshadowed by physical aspects of the subject. It is important to emphasise that this is not necessarily any

reflection of editorial policy, rather it most likely reflects the scarcity of psychological research, and indeed psychological practice, in the area. How then should psychological aspects of prosthetics and orthotics be developed and what might key concerns be? By drawing on the literature cited above and supplementing this with other salient publications, the authors now address this question.

Psychological assessment

Geertzen *et al.* (2001) propose that more research is needed "regarding the development of questionnaires which concentrate on handicap and quality of life issues of amputees". The development of a pre-amputation protocol to adequately prepare the patient for surgery, and the evaluation of the effectiveness of psychotherapeutic interventions both clearly require some form of specialised assessment. Indeed, there is also a case for undertaking routine psychometric assessment of the salient experiences of amputees particularly given the increasingly evidence-based context in which we operate. However, while acknowledging that considerable scope for development remains in the assessment domain the authors wish to highlight the existence of a multidimensional assessment specifically developed for the amputee population: the Trinity Amputation and Prosthetic Experience Scales (TAPES) (Gallagher and MacLachlan, 2000^b). The TAPES is a self-report questionnaire, comprising 54 items including 3 psychosocial scales, 3 activity restriction scales, 3 satisfaction subscales, and a section on the experience of phantom limb pain and stump pain as well as other medical conditions not related to amputation. The TAPES is distinguished from other instruments by its ability to predict stump pain, phantom limb pain and the extent of prosthetic use, all of which are clinically relevant indices of rehabilitative success.

Psychological intervention – promoting positive coping and adjustment

Evidence suggests that appropriate preparation for surgery, through education and support, alleviates stress and eases the patient's rehabilitation; including the length of time they remain in-patients, and the amount of medication they require (Butler *et al.*, 1992; Sherman, 1997). Counselling with regard to

development of realistic rehabilitation expectations and methods of coping with personal concerns or social difficulties, should form an integral part of this preparation. While some researchers have reported significant levels of clinical depression, anxiety, grief and social isolation (e.g. Williamson *et al.*, 1994; Schubert *et al.*, 1992; Frierson and Lippman, 1987; Thompson and Haren, 1983), others have questioned the assumption that amputation is necessarily associated with such outcomes (e.g. Dunn, 1996; Fisher and Hanspal, 1998^a; Gallagher and MacLachlan 2000^b). However, for those who do experience negative reactions, structured therapeutic interventions operating through individual, couple, family or group therapies, for problems such as depression, anxiety, sexual difficulties, maladaptive coping behaviours (e.g. smoking, drug/alcohol consumption) and pain may sometimes be necessary (Williamson and Walters, 1996).

Post-traumatic stress disorder (PTSD), an anxiety disorder evidenced after exposure to trauma, is characterised by three primary symptoms: 1) re-experiencing trauma, 2) avoidance of trauma reminders, and 3) hyperarousal (American Psychiatric Association, 1994). Although results are inconclusive, some researchers have reported (Ehlers *et al.*, 1998; Mollica *et al.* 1998) that the extent of physical injury caused by the traumatic event may predict PTSD (Maes, 2000). Furthermore, diagnosis and treatment of a life-threatening condition can meet the stressor criteria for PTSD (Androwski *et al.*, 1998). Therefore it is reasonable to suggest that patients undergoing treatment for life-threatening conditions (for which amputation may be a treatment), particularly as a result of traumatic injury, may be at increased risk for developing post-traumatic stress disorder (PTSD). As trauma exposure is associated with over-utilisation of medical services and increased rates of health complaints and physical disorders (Boscarino, 1997; Wolfe *et al.*, 1994), it is crucial that early rehabilitation efforts include interventions specifically designed to address the implications of PTSD.

Implications of developmental stage and age

Given the paucity of reported research in the developmental context of amputation and its implications for psychosocial adjustment and

prosthetic use, there is a clear and urgent need for further research in this domain. Congenital limb deficiency, acquired limb deficiency and traumatic loss of limbs with each represent distinctive developmental challenges both for the child and their relationship to siblings, parents, clinicians, teachers and others (Desmond and MacLachlan, 2002). Some developmental stages are likely to be more significant than others in terms of the individual's potential vulnerability to issues associated with disturbance of body image and low self-esteem precipitated by amputation (Rybarczyk *et al.*, 1997).

Despite considerable research on phantom sensation in adult amputees, there is relatively little research on child and adolescent amputees (Wilkins *et al.*, 1998). Melzack *et al.* (1997) recently reported that 33% of individuals born with a congenital limb deficiency or undergoing limb amputation before the age of five, develop phantom sensation of the limb. These results contradict the prevalent belief that people with congenital limb deficiency do not experience phantom sensations and that phantom sensations rarely appear after amputation at an early age. As it has now been established that child and adolescent amputees do in fact experience phantom sensations and phantom pain (Wilkins *et al.*, 1998; Melzack *et al.*, 1997; Krane and Heller, 1995), further investigation of the implications of these experiences for the developing child are warranted.

Indeed among adults the age at which one receives an amputation is also an important factor (Gallagher and MacLachlan, 2001). For a young traumatic amputee, limb loss and the accompanying loss of function may represent the loss of life opportunities, while for an elderly person with peripheral vascular disorder, amputation may offer relief of pain, increased mobility and/or an easing of physical distress (Williamson *et al.*, 1994). With regard to ensuing body image disturbance, Fisher and Hanspal (1998^b) suggest that individuals suffering traumatic limb loss at any age are likely to suffer subsequent difficulties with their body image, but that these relationships are more striking in the younger age groups who have experienced traumatic injury. Similarly, Rybarczyk *et al.* (1997) propose that the older adults may not experience as extreme a reaction as younger adults because the amputation and

resulting changes in the body image while undesirable are perceived as relatively "on time".

Body image and one's sense of self

The image of one's body is a critical element of the individual's formulation of the 'sense of self' (Klapheke *et al.*, 2000). Experiences of one's own body are the basis for all other life experiences (Novotny, 1991), hence the disruption of body image engendered by amputation can have significant and long-lasting impact (positive and/or negative) on the individual's sense of self and consequently on relationships and interactions with others.

The way in which the amputee experiences him- or herself, and how they construct meaning out of their experience will also be influential in their attitude toward the wearing of a prosthesis. A given prosthesis may embody ability for one individual, because they feel it *enables* them to perform certain physical functions and social roles, whereas the same prosthesis may embody disability for someone else because they view it as *prohibiting* those same functions and roles. In this regard health professionals should be aware of the potential importance of an amputee's 'relationship' to their prosthesis as a psychically invested aspect or extension of self, and its potential to symbolise how they relate to the world. Given that changes in bodily functioning and appearance are a feature of health as well as illness and/or disability, and are often considered 'normal' consequences of ageing, this relationship may change and fluctuate throughout the lifespan.

Conclusion

In the light of the influential position of *Prosthetics and Orthotics International* in guiding expectations about the role of psychology in prosthetic and orthotic practice, the authors suggest that the last twenty-five years has witnessed relatively few substantive psychological contributions to the Journal. Indeed those papers published have relied heavily on quantitative methodology, thereby largely ignoring the perspective of the individual amputee, indicating a clear need for research using a qualitative approach to provide opportunity for amputees to voice their opinions. While it is unrealistic to expect that prosthetic/orthotic practitioners can

comprehensively address the psychological dimension of care for their patients, it is important that practitioners develop an understanding of the complexities pertaining to the therapeutic context in order to fully realise the potential of technological developments in the field, and appreciate their constraints.

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