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Subjective well-being and severe motor impairments: the Tetrafigap survey on the long-term outcome of tetraplegic spinal cord injured persons

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Abstract

The purpose of the research described in this article is to study the effects of severe motor impairments on a person's well-being, by attempting to throw light upon the inconsistencies found in the previous literature, which are due to problems of a conceptual and methodological nature. The data were gathered during the Tetrafigap survey on the long-term outcome of tetraplegic persons in France. This survey involved 1668 tetraplegic spinal cord injured people. We examine the relationships between the overall assessment of well-being as expressed by the people interviewed, and a range of clinical, social and psycho-social factors. A progressive approach, along with the use of adjustments via linear regressions, has allowed us to identify certain confounding factors, and to analyse the respective effects of the different types of variables studied. Thus current age, the age at which the impairment occurred and having or not having a professional activity do not have any direct links with the assessment of well-being, whereas the existence of pain and the subjective assessment of one's own independence and of the severity of one's disability are predictive factors. The functional independence indicators are only linked to well-being when they relate to situations in which the dependence creates embarrassment due to socio-cultural taboos. The loss of autonomy only affects well-being in as much as it imposes limits to social activity, whether they be relational or occupational. Living as a couple is a negative predictive factor if the couple were together prior to the impairment occurring. The overall results demonstrate the importance of moving beyond any conception of the impact of the impairments on well-being that is too exclusively focused on the individual, and of integrating the socio-cultural meanings of handicap situations and the dynamics of the interactions which take place therein. © 2001 Elsevier Science Ltd. All rights reserved.

Keywords: Well-being; Spinal cord injury; Tetraplegia; Disability; Motor impairment

Introduction

Self-assessment of well-being is often considered to be an appropriate outcome measure, indicating the way in which people perceive and react to their health and to other non-medical aspects of their lives (Gill & Feinstein, 1994; Triemstra, Van Der Ploegg, Smit, Briët, Adér & Rosendaal, 1998). The effect of acquiring motor impairments on subjective well-being has given rise to a number of studies which, more often than not, take place within the fields of physical medicine and rehabilitation. Such research traditionally looks at the impact of the clinical factors linked to the

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impairments — such as the severity of the impairments, the level of incapacity and of functional independence, pain, and the age of onset of the disability. These analyses usually also take into account standard socio-demographic variables — age, family and professional situation, level of education, and financial resources. From a more psychological perspective, some authors also examine the subjective perception of the severity of the impairments, and the level of social support available to the individual (Gignac & Cott, 1998; Triemstra et al., 1998).

This literature reveals a great number of inconsistencies, particularly in terms of the influence of clinical factors. For example, with regard to the relationship between perceived well-being and the severity of the impairments, some studies highlight a negative correlation between perceived quality of life and the severity of the impairments. Whilst this is a weak relationship in the study reported by Decker and Schulz (1985), it is far more pronounced in the work carried out by Clayton and Chubon (1994). A meta-analysis based on 32 publications, which were compiled by cross-referencing the keywords “quality of life” and “spinal cord injury”, led Evans, Hendricks, Connis, Haselkorn, Ries and Mennet (1994) to observe that perceived quality of life diminishes as the severity of the impairments increases. This result must nevertheless be qualified, due to the limited rigor of research design and to the poor validity of measurements in the studies included in the meta-analysis, as stressed by the authors themselves. Finally, Mehnert, Krause, Nadler and Boyd (1990) also show that satisfaction with life decreases in line with the severity of the incapacities. However, results from other studies would appear to contradict this assertion of a negative relationship between severity of impairment and perceived quality of life. For example, Siosteen, Lundqvist, Blomstrand, Sullivan and Sullivan (1990) report no difference between the assessments of quality of life made by persons who are tetraplegic, paraplegic and in wheelchairs, and paraplegics who can walk. Similarly, Dunnum (1990) and Fuhrer, Rintala, Hart, Clearman and Young (1992) show that satisfaction with life is independent of both the severity of the impairments and of the level of independence, and is instead linked to three dimensions of handicap defined by ICIDH (WHO, 1980), social integration, occupation and mobility, with greater life satisfaction being associated to lesser handicap (Fuhrer et al., 1992).

It should be pointed out that most quality of life scales are more often than not saturated with items relating to functional independence, with the negative relationships that are observed partly reflecting the assumptions — prior to the creation of the assessment tools — of the existence of a direct link between well-being and functional independence. Whilst such a link is frequently stated by disabled informants, it does not necessarily

mean that this link is direct. It may result from the consequences of the functional status, in other words, from the limitations to social activity rather than from the functional status itself. It is nevertheless legitimate to question whether it is dependence or the inability to do certain activities which really affects assessments of quality of life and well-being.

Inconsistent results also appear when we look at age and at the age at onset of the disability. Mehnert et al. (1990) show that younger people, and people who acquired their impairments at an early age, are more satisfied with life. Similarly, Decker and Schulz (1985) show a negative correlation — weak, but nevertheless significant — between self-perceptions of quality of life and these two variables; however, these correlations are not confirmed by other studies (Crisp, 1992; Fuhrer et al., 1992). Stensman (1994) finds that quality of life is less well perceived when impairments occur after the age of 35. Finally, it appears that perceived quality of life, which is low soon after the accident, tends to increase up until the age of 50 (on average) and then decrease slightly thereafter (Whiteneck et al., 1993).

With regard to socio-demographic variables, their impact on assessments of well-being and quality and satisfaction of life tend to show a greater level of agreement. Self-reported quality of life, life satisfaction and well-being increase with increased quality and richness of social contacts — number of friends, the frequency at which the disabled persons see them (Schulz & Decker, 1985; Crisp, 1992; Clayton & Chubon, 1994) — as well as with indicators of social status such as income and level of education (Decker & Schulz, 1985; Mehnert et al., 1990; Clayton & Chubon, 1994) and the general level of occupation (Siosteen et al., 1990).

By contrast, studies that examine the impact of social support are by no means unanimous in their conclusions. Thus, whilst some of them highlight a positive link between support and well-being (Fuhrer, 1994; Decker & Schulz, 1985), Triemstra et al. found that “social support could not be fitted as a mediator between disability and well-being, so the role of this construct remains somewhat unclear” (1998, p. 591), whilst Revenson, Schiaffino, Majerovitz and Gibofsky (1991) show that “problematic supports” exist, and that non-supportive interactions with close social members may have detrimental effects on psychological well-being.

There are several possible reasons for these contradictions. The first is related to the diversity of the tools and methods used, thus making it dangerous to compare one study with another (Beaufils, 1996). This diversity goes hand in hand with a conceptual ambiguity whereby terms such as satisfaction with life, well-being and quality of life are sometimes used interchangeably, without being clearly defined. In addition to this lack of conceptual reflection and consistency, there is a

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