Opinion

Motor neurone disease (MND) is a rapidly progressive neurological disease of unknown cause, which results in relentless loss of function and, conversely, high levels of disability. There has been a significant increase in quality of life (QoL) literature in recent years and the philosophy of the occupational therapy process may be considered consistent with the QoL construct. However, little is documented in occupational therapy literature that promotes consideration of the QoL construct in practice. This may be explained by the profession’s adherence to the medical model of health care intervention.

Expectations and desires continually shift for people with MND and individual-perceived QoL is determined by a continuous process of adjustment to increasing disability. In order to promote wellbeing, occupational therapists must identify what people with MND consider important in their lives.

Introduction

For all its utility, the medical model always bears a hidden negative assumption that what is important about a person is his or her injury, disease, deficiency, problem, need, empty half. The able, gifted, skilled, capable, and full part of a person is not the focus of the medical model (McKnight 1994, p25).

Motor neurone disease (MND), also known as amyotrophic lateral sclerosis (ALS), is described as a progressive and fatal neurodegenerative disorder of unknown aetiology. It is characterised by a progressive loss of limb, bulbar and respiratory muscle function due to the selective degeneration of upper and lower motor neurones in the central nervous system (World Federation of Neurology Research Group 1994). The average life expectancy is 2 years for a person presenting with bulbar symptoms and 4 years for someone with limb-onset disease. The incidence of the disease is one per 100 and it predominantly affects middle-aged and elderly people, with a mean age of 55 years, although younger people are occasionally affected. Despite a modest effect of recent licensed medical treatment for MND, to date pharmaceutical agents promise no expected survival advantage. Medical treatment remains symptomatic and optimal health care appears to depend on a well coordinated and multidisciplinary team approach (Corr et al 1998, Han et al 2003).

Quality of Life (QoL) remains a uniquely subjective and multidimensional phenomenon (O’Boyle et al 1992, Bowling 1995, Hickey et al 1996). Bowling (1995, p25) defined QoL as ‘optimum levels of mental, physical, role (e.g. work, parent, carer, etc) and social functioning, including relationships, and perceptions of health, fitness, life satisfaction and wellbeing’. Bowling (1995) stated that QoL should also include some assessment of a person’s level of satisfaction with treatment outcome, health status and future prospects. The World Health Organisation Quality of Life Group (1995) defined QoL as:

… individuals’ perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept, incorporating in a complex way individuals’ physical health, psychological state, level of independence, social relationships, personal beliefs and their relationships to salient features of their environment (p1405).

Quality of Life for People with Motor Neurone Disease: a Consideration for Occupational Therapists

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QoL and MND: a concern for occupational therapists

QoL for people with MND is an area of growing concern for many health professionals, where the emotional impact may be greater than that of any other diagnosis (Stead and Jenkins 1996). There is an increasing desire from the social sciences to understand better what QoL might mean for a population group who experience a rapid physical and...
functional decline, from a condition for which there is no cure. Lifespan remains astonishingly short and many view MND as palliative from the time of diagnosis (Oliver 1996).

Despite the fact that the recent decade has seen a significant increase in QoL literature within the social sciences, this increase is not necessarily paralleled in occupational therapy literature (Gill et al 1984, McKenna 1993, Mayers 1995, Radomsks 1995, Lau et al 1998, Liddle and McKenna 2000). Indeed, no QoL literature was found in relation to occupational therapy with people with MND. This seems somewhat contradictory.

The occupational therapy philosophy is founded in the belief that engagement in client-desired and client-valued activity contributes to client-perceived wellbeing (Christiansen 1999). The QoL construct similarly considers the importance and subjectivity of person-identified life domains that promote meaningful existence, contributing to the socially useful, intellectually full and interpersonally rich lives of individuals. In this context, the QoL construct is congruent with the philosophical basis and process of occupational therapy. The occupational therapy literature strongly advocates its use in practice (McKenna 1993, Radomsks 1995). However, do occupational therapists actually adhere to and consider the basic premise of the QoL construct in their therapeutic intervention with clients and, if they do not, why is this?

Lack of use of the QoL construct

Scientific vs phenomenological approaches

As stated above, apart from occupational therapists who are renowned for their growing expertise in this area (Liddle and McKenna 2000), published literature that wishes to add to sound evidence-based practice for the profession has not necessarily made explicit reference to the QoL construct. This is, perhaps, explained by the pressure placed on the profession to adhere to a reductionist orientation, illustrated by the importance placed on diagnosis and by the associated mechanistic reasoning strategies of the medical model. Indeed, there is increasing pressure on health care services to use outcome measures based on fixed external value systems to quantify the effect of illness and the outcomes of health care intervention. Such measures used by occupational therapists include various functional rating scales and activities of daily living scales. The argument is whether this approach in clinical research is in conflict with a notion that is founded in the humanistic philosophy of the profession, that is, should belief in client choice and autonomy demand phenomenological approaches to clinical reasoning (Mattingly 1991a)?

The model of scientific reasoning has, to date, guided most research on clinical reasoning in health care. It assumes that professional reasoning is a comparatively straightforward application of knowledge and theory. Given the current power of theory in occupational therapy practice, occupational therapists must ask if frames of reference, therapeutic techniques and rating scales are sufficient to guide best practice for people with MND. Clinical reasoning, when treated as an applied natural science, is directed only to the practical problems of prediction and control (Mattingly 1991b). This is in conflict with the basic premise of occupational therapy. Clinical reasoning should be ‘a largely tacit, highly imaginative and deeply phenomenological mode of thinking’ (Mattingly 1991b, p979). Indeed, occupational therapy was founded on humanistic values, where individual life experiences are considered and given due weight (Yerxa 1994).

A shift in the determinants of QoL

The literature suggests that individual-perceived QoL for people with terminal illness does not follow a linear course and that psychological adaptation to terminal illness may involve a shift in focus on the determinants of QoL. (Waldron et al 1999). Nordenson et al (1998) suggested that people with progressive neurological illness may adapt by lowering their expectations regarding their physical disabilities and by focusing on life areas that are independent of physical capabilities. In the initial stages of a terminal illness people may focus on physical functioning but, as physical disability increases, the importance of such issues may be replaced by a focus on the psychological and spiritual domains.

Bromberg and Forshew (2002) found noticeable response shifts by people with MND during the course of their illness. Response shifts represent changes or recalibrations of the terms or internal standards of reference used by a person to judge QoL. Until recently, this process was poorly understood (Sacks 1982), but more recent literature has applied this process to the self-reported and positive life quality of people with MND (Young and McNicoll 1998).

The self-perceived QoL literature in terminal illness appears not only not to follow a linear course but also to be multidimensional, that is dependent on coping mechanisms and psychosocial and existential issues (O’Boyle and Waldron 1997, Robins et al 2001). Clarke et al (2001) used the SEIQoL (O’Boyle et al 1992), which allows individuals to nominate and weight individual-perceived QoL domains, to measure QoL in MND; they found that the individual nature of QoL was evident in the variety of cues nominated by participants and in the different weights or importance attached to them. Indeed, many studies have identified little correlation between perceived QoL and illness severity. Clarke et al (2001) found no direct relationship between MND duration and a global QoL index of their sample, derived from using the SEIQoL. Ganzini et al (1999) found the correlates of poor QoL to be poor social support and increasing hopelessness as opposed to increasing disability. Robins et al (2001) and Lou et al (2003) found that QoL in MND was independent of physical function and concluded that consideration of spiritual, religious and psychological factors was necessary rather than consideration of physical function alone.
Promoting QoL for people with MND

The multidimensional aspect to QoL and the continuous process of adaptation to increasing disability emphasise the need for occupational therapists to consider people with MND beyond their physical disability and in the context of their individual desires and expectations. Bolmsjo (2001) identified that some participants expressed concern about not being regarded by health professionals as people in their own right, independent of MND. In the light of this finding, true appreciation of a person’s own experiences regarding his or her welfare, wishes, values and interests may well promote QoL for people with MND (Bolmsjo 2001).

Occupational therapists’ use of standardised outcome measures remains problematic. First, individual factors appear to be related to individually perceived QoL for people with MND, such as psychological, spiritual, existential and social support. Secondly, the life of a person with MND appears to be one of constant readjustment to a changing level of ability, where each day if not hour brings new losses. Thirdly, domains deemed important by individuals with MND vary substantially between individuals with MND. The diversity of such domains and the variance between their importance are not necessarily considered by the outcome measures used in occupational therapy intervention.

Although people diagnosed with MND pose great emotional challenges for occupational therapists, empathy with and understanding of what is important to them may prove pivotal in addressing client-centred care for people with MND.

References


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