What does positive participation in leisure occupations mean to people with complex neurological disabilities?

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Chronic illness and disability restrict people's access to work and leisure occupations, so that they experience a loss of valued roles, self-identity and self-esteem (Reynolds, 1997). Swanson and Chenitz (1993) found that people with a chronic condition commonly describe themselves as having to redefine their sense of self, roles and goals, re-framing their place in the world ... and learning to live with a "new me" Jenson and Allen (1994).

This paper sets out to review the literature and demonstrate that positive participation in a leisure occupation, which is meaningful and challenging, will combat boredom and will enable the person to maintain a social identity that may have been lost when work roles are no longer an option.

Leisure

Leisure time is free time or time with out the constraints of duty during which people have discretion to choose which occupations they undertake. Leisure time is therefore when someone is not "working" or performing self-maintenance tasks (Baxter et al 1995). Because the individual is not obliged to participate in the activity, they are motivated either intrinsically e.g. by enjoyment or extrinsically i.e. with an end goal/ score or to create a product (Baxter et al 1995).

Participation

Participation in Leisure occupations allows people to form friendships, develop skills, express creativity, and develop a social identity (Kinney & Coyle, 1992; Lyons, 1993). Satisfaction with leisure occupations is an important predictor of life satisfaction among adults (Kinney & Coyle, 1992) and is associated with adjustment and well-being (Brown & Gordon, 1987).

Participation is a complex issue, with many factors influencing the occupations that people do every day. (King, Cathers,

Polgar, MacKinnon, & Havens, 2000 and Webre & Zeller, 1990) The most important factors, which influence participation for people with complex neurological disabilities, include environmental factors (accessibility and attitudes of society), family factors (interests in recreation), and personal factors (functional ability, behaviour, cognition, communication or social competence).

This insight is vital because patterns of social restriction and isolation begin very early, after a significant disruption in occupation, supporting the need for early intervention (Brown & Gordon, 1987). Conaster, et al (2000) and Reid et al (2001) reinforced the observation that the level of disability has a significant impact on carer attitudes. This goes on to impact on whether the leisure occupation is sufficiently adapted to allow the person to participate as fully as possible.

Boredom may then be the inevitable accompaniment of the absence of meaningful social or leisure occupations, or even serious uncertainty about the stability, and reliability, of values, purposes, meanings and commitment (Healy, 1984, Farnworth 1998). Many occupational scientists have written about the human right to meaningful occupation (Clark, 1997; do Rozario, 1994; Farnworth, 1995; Toulmin, 1995) and thus avoiding boredom.

Passmore (1998) found that there are three types of leisure occupations that contribute to personal growth and the enhancement of mental health and well-being:

1. ***Achievement leisure*** - provides challenges, is demanding and requires commitment, such as found in sports and music performances;
2. ***Social leisure*** - is more obvious where engaging in leisure is primarily about being with others, such as dinner with friends;
3. ***Time-out leisure*** - for relaxation includes TV watching, lying on one's bed and reflecting or listening to music – occupations which tended to be more socially isolating, less demanding and frequently passive.

Identity through occupation

Laliberte-Rudman (2002) suggests that limitations in occupation could limit the

ways in which people perceive themselves and maintain a satisfactory social identity, whereas engagement in leisure occupations could lead to opportunities for growth and life satisfaction (Drummond and Walker, 1996). Social identity comes about because life is not usually a solitary experience. It usually involves interweaving our lives around the lives of others (Larson & Zemke, 2003).

Gender, age, educational level, ethnicity and socio-economic status all affect leisure and work patterns according to Allen Dickie (2003) and McKay (1986). Some leisure occupations facilitate social engagement and/or provide participants with challenges to overcome (Csikszentmihalyi, 1975; Passmore, 1998), whereas others involve rules, rituals, customs, and traditions that are important for the meaning that they give to the participant (Klapp, 1986., & Farnworth, 1998)

Leisure as a substitute for employment

It is important to consider the emotional aspect as well as the practical aspect of any occupation. Employment status is a source of developing and maintaining our identity, feelings of competence, sense of belonging as well as playing a major role in structuring society and the people position within it (Pettifer 1993). Csikszentmihalyi and LeFevre (1989) found that people experienced their most satisfying and engaging experiences more often at work, but were more likely to report increased motivation and relaxation when engaged in leisure occupations.

Some unemployed people and people with complex neurological disabilities may not anticipate working in the future. This has brought about a traumatised and divided society characterised by boredom, intolerance, desperation and resentment. Pettifer (1993) felt that the vision of a future 'leisure age' is unlikely to be a real substitute for purposeful work.

Csikszentmihaly, 1975) noted that pleasure and enjoyment are strongly associated with a perception of choice, which is missing in the free time of the unemployed with its associated financial and lifestyle stresses, loss of structure

and sense of purpose. It is not surprising therefore that unemployed people experience stress, depression, low self-esteem, diminishing sense of personal control and feelings of disengagement. (Pettifer, 1993).

Occupation to combat boredom

In the Csikszentmihalyi and Csikszentmihalyi (1988) model, boredom is a state where the person perceives the challenges of the occupation engaged in to be less than the skills they bring to the situation, leading to under arousal. Berlyne (1966) assumed that a fundamental human motive is curiosity, and that the nervous system was designed to be active, rather than merely a passive recipient of stimulation, (which is why time out leisure was found to have a negative impact on mental health outcomes) (Passmore 1998).

Meyer (1977) hypothesised that peoples daily occupations have two major dimensions: performance and personal meaning/ interest.

Klapp (1986) and Farnworth (1998) believed that meaning and variety, include qualities such as adaptation, learning and discovery, and are very important in combating boredom. While Baxter et al (1995) felt that leisure occupations could relieve boredom by providing "diversion from everyday routine."

Leisure and Neurodisability

Doble, Haig, Anderson, & Katz, (2003) indicate that people with complex neurological disabilities engage in a significant degree of social interaction. However, Moos and Schaefer (1984) argued that chronically ill people face four common adaptive tasks, namely;

- To preserve a satisfactory self-image and sense of achievement or competence
- To retain a psychological equilibrium (maintaining hope and humour; controlling anxiety, anger and other negative feelings)
- To maintain positive relationships with family and friends
- To prepare for an uncertain future.

The achievement and maintenance of an acceptable social identity is a key factor in adapting to life events and achieving well-being (Laliberte-Rudman 2002). Also there is documentary evidence that leisure participation decreases after a neurodisability (Sjogren, 1982; Feibel and Springer, 1982; Drummond, 1990), and that a significant number of patients are depressed after neurodisability (Collin et al., 1987; Wade et al., 1987). Feibel and Springer (1982) suggest that such depression may be part of the loss of social occupations experienced by people and thus having a more limited social identity.

Behavioural difficulties such as aggression, non-compliance, self-injury, impulsiveness, and disinhibition are common manifestations of neurological disabilities (Willis & LaVigna, 2003) which prove a great challenge to integrating into social activities (Willis & LaVigna, 2003; Ylvisaker, Jacobs, & Feeney, 2003).

It may take more than 6 months after discharge for the side effects of a reduction in hobbies and interests to become apparent.(Drummond and Walker 1996). However, creative leisure occupations allow people to 'make their mark' on the world, empowering them, promoting feelings of self-worth and enhancing the sense of control, particularly if the body is experienced as 'out of control'/ choice (Szepanski, 1988). Conversely, therefore, people who participate in a variety of leisure occupations may be able to diminish their depression or better still avoid its onset.

Finkelstein and French (1993) defined Disability as "the loss or limitation of opportunities that prevents people who have impairments from taking part in the normal life of the community on an equal basis with others due to physical and social barriers'.

Summary

Leisure occupations are important to the self image of participants! some recent writers say that disabled people engage in them to a significant degree (Doble, Haig, Anderson, & Katz, 2003), but the level of depression following neurological disability would suggest that this is still not enough (Collin et al.,

1987; Wade et al., 1987) and that people with complex neuro disabilities are at risk therefore of occupational deprivation. People who are stuck in front of a TV all day or who are passive recipients of leisure activities will become socially isolated (Passmore, 1998), with all the impacts on mental health that this brings.

Achievement leisure occupations are important (Passmore, 1998), and will require everyone's sense of ingenuity to adapt them in order to make them accessible for people who are dependent on ventilators, wheelchairs or who have limited dexterity, cognition or social skills. Above all society needs to acknowledge the right of all human beings to engage in meaningful occupations to maintain their identity as people and avoid boredom (Laliberte-Rudman, 2002).

Facilitating an engagement in leisure activities should begin as soon as the person is medically stable, alongside other therapies such as Speech and Language Therapy, Physiotherapy and Occupational Therapy. This will allow them to begin to define the sense of self, roles and goals (Jenson and Allen, 1994) and stave off the negative psychological impacts of such major life events as acquiring a complex neurological disability.

After all as J F Kennedy is supposed to have said, there is no point in adding years to a life, if you don't add life to those years.

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