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Youth with Fetal Alcohol Spectrum Disorder: Suggestions for Theory-Based Career Practice

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Yesterday Eric learned how to tabulate and record the number of items sold at the local craft store where he was employed. Yet today Eric clearly can not remember the steps involved in completing the task. When his employer gave him notice, Eric seemed unable to understand the consequences of not fulfilling his agreed upon duties.

The scenario offered above gives insight into the impact of alcohol use during pregnancy and its complex effect on behavioural and cognitive functioning of affected individuals. The continuum of disabilities that are experienced as a result of brain damage caused by prenatal exposure to alcohol is referred to by the umbrella term, Fetal Alcohol Spectrum Disorder (FASD). FASD is a life-long disability that affects an estimated 9.1 per 1000 live births in the United States (Chudley et al., 2005). Currently no national statistics are available on the rates of FASD in Canada. The effects of alcohol exposure vary by individual depending on amount, timing, and frequency of exposure (Chudley et al., 2005). FASD is a largely invisible disability, characterized by cognitive, neurological, social, and/or emotional challenges (Streissguth, 1997). The effects of prenatal alcohol exposure carry heavy costs for the individual, their family, and society (Premji, Serret, Benzies & Hayden 2004). Youth with FASD and their caregivers require appropriate career counselling services and career interventions. However, there is a clear lack of attention to advancing career theory and practice to persons with disabilities (Cummings, Maddux, & Casey, 2000), particularly those with neurological impairments.

In this article we apply concepts from Social Cognitive Career Theory (SCCT; Lent & Brown, 1996; Lent, Brown, & Hackett, 2000) to potential career counselling interventions for youth with FASD who are making the transition to adulthood. The recent literature that has sought to understand the connections between individuals with neurological disabilities and career options has tended to focus on the barriers that negatively influence their career development (Cummings et al., 2000; Ettinger, 1996; Levinson, 1998). For example, some challenges include low self-esteem, difficulties in establishing routines, challenges related to information processing, and a tendency toward passive learning styles. Other contributions have sought to expand our understanding by emphasizing strengths and resources (Malbin, 2002). Following the idea of building on the strengths of young people with FASD, we use SCCT (Lent & Brown, 1996; Lent et al., 2000) to provide a conceptual framework for understanding how personal attributes, the environment, and overt behaviours can be harnessed to awaken the potential and strengths that are within the reach of this population. As such, the goal of the present article is to encourage practitioners to use SCCT as a means to develop appropriate transition planning and career interventions for young people with FASD.

FASD: An Invisible Disability

The leading cause of developmental disability among Canadian children is Fetal Alcohol Syndrome (FAS) (Public Health Agency of Canada, 2005). The umbrella term, Fetal Alcohol Spectrum Disorder (FASD), is used to depict a range of disabilities as well as the diagnoses related to prenatal exposure to alcohol including Fetal Alcohol Syndrome (FAS), partial FAS (pFAS), Alcohol-Related Neuro-developmental Disorder (ARND), and Alcohol-Related Birth Defects (ARBD).

The effect of prenatal alcohol exposure varies greatly among individuals, but the specific neurological impairments all impact abilities related to adapting to daily living as adolescents and adults (Streissguth, 1997). ... affected people exhibit a wide range of expression, from severe growth restriction, intellectual disability, birth defect and characteristic dysmorphic facial features to normal growth, facial features and intellectual abilities but with lifelong deficits in several domains of brain function (Chudley et al., 2005, S1).

Alcohol-related central nervous system dysfunction includes memory impairment, attention deficits, specific learning difficulties (e.g., mathematics or verbal reasoning), difficulty in abstracting, and difficulty with impulse control, all of which have implications for education and career planning. Difficulty in tasks that involve planning and following through with goal-directed action is a particularly common issue (Olson, Feldman, & Streissguth, 1992).

A considerable range of intellectual dysfunction is found among individuals with FASD. While organic brain damage does create particular cognitive and behavioural issues for individuals with FASD, individuals may have normal IQ scores (Streissguth, 1997). The effect of the brain damage is such that individuals' ability to access and utilize their intelligence is impaired. Unfortunately, standardized test scores in the normal range may mean that those individuals do not qualify for special educational and vocational services that use mental retardation as their qualifying criterion (Streissguth, 1997).

Impairments that develop or become evident over the course of the individuals' lifespan are referred to as secondary disabilities. These secondary disabilities associated with FASD may be more debilitating for the individual than the primary disability (Fast & Conry, 2004; Streissguth, 1997). Mental health issues, drug and alcohol addiction, trouble with the law, and difficulty with employment and life management are commonly cited (Famy, Streissguth, & Unis, 1998; Streissguth, Barr, Kogan, & Bookstein, 1997). Early diagnosis of FASD is in itself a protective factor, as this allows the individual to receive appropriate services and support from a young age (Streissguth et al., 1997). However, many young adults living with the disorder may have no formal diagnosis because they do not meet the out-dated criteria for a formal diagnosis or are unable to access limited diagnostic services (Premji et al., 2004). Those individuals with less severe symptoms are often at higher risk for secondary disabilities due to lack of understanding of the source of their behavioural problems (Streissguth, 1997). In addition, the most common secondary disability – mental health issues – may further complicate the presenting situation for these individuals. Comorbid conditions including depression, anxiety, and substance use highlight the need for practitioners to be sensitive to this combination of disability and mental health problems. These clients are neither solely organically brain-damaged nor solely emotionally disturbed (Streissguth & O'Malley, 1997).

Given the gaps and limitations of the current FASD career literature; there is a clear need for theory-based career development interventions that will address the unique needs of alcohol-affected individuals. In addition to the challenges that these young adults face, they also have strengths and abilities upon which to build. These strengths include good visual memory and verbal skills, persistence, commitment, success in low-stress, structured situations, a strong sense of fairness, and success in learning with hands-on tasks (Malbin, 2002). By recognizing and building on these strengths, suitable systemic transition planning can be engaged in for young people with FASD.

Transition to Adulthood

During the period from ages 18 to 25, referred to as emerging adulthood (Arnett, 2001), young people face a multitude of new opportunities and responsibilities that require the addition of new information, knowledge, and skills (Arnett, 2001; Mortimer, Zimmer-Gembeck, Holmes, & Shanahan, 2002). Successful transitions to adulthood appear to rest on a number of “readiness” factors and include objective and psychological aspects (Phillips, Blustein, Jobin-Davis, & White, 2002; Solberg, Howard, Blustein, & Close, 2002). Readiness is acquired objectively by engaging in work-based learning and exploration and through the instrumental and emotional support of adults who can orient youth to the world of work. Additionally, readiness is acquired through internal psychological contexts, for example, facilitative attitudes of curiosity and sustained attention, confidence about one’s future plans, and flexibility in responding to challenges and obstacles (Blustein & Flum, 1999; Phillips et al., 2002).

FASD is a condition that children do not outgrow. Biological, adoptive, and foster parents have noted that raising children with FASD to adulthood is full of uncertainty for a number of reasons. Individuals with FASD lag behind developmentally when compared to other youth their age. Therefore, the readiness skills needed for successful transitions to adulthood may be delayed by several years and these youth will require more support between the ages of 18 and 25 years compared to their counterparts (Malbin, 2002). Additionally, adolescents with FASD are likely to display poor judgement, difficulty in perceiving social cues, and failure to understand the consequences of one’s actions (LaDue, Schacht, Tanner-Halverson, & McGowan, 1999). In the transition to adulthood, lack of social skills may affect the ability of those with FASD to gain positive work-based learning experiences. However, emotional and instrumental support may be provided by caregivers and professionals. Although the majority of children diagnosed with FASD are being cared for in foster or adoptive homes (Hess & Kenner, 1998), foster and adoptive caregivers tend to be highly committed to maintaining long-term, stable, and nurturing environments for their children (Streissguth et al., 1997).

Social Cognitive Career Theory and FASD

Traditional career models imply that individuals have the ability to choose a preferred career based on values, interests, and abilities, and to plan and implement their choice. For individuals with FASD, this is not the case. However, little is known about how these individuals can successfully navigate life-career pathways. In essence,

“the people who are in greatest need of assistance with career development are the ones about whom the least is known” (Harmon as cited in Chartrand & Rose, 1996).

Effective support of alcohol-affected youth requires that practitioners appreciate the impact of social environment, as well as the effects of the brain damage (Streissguth & O’Malley, 1997). The appropriate career development model must therefore take into account the individual’s abilities and disabilities as well as family, school, and other socio-cultural factors or contextual affordances that have influenced the individual’s development up to this point, and may continue to influence the success of any intervention. A life-span approach is also called for, as individuals with FASD will need strategies and support to manage their disability throughout their lives.

Social Cognitive Career Theory (SCCT), an evolving model of life-career development, provides a conceptual framework for understanding how individuals develop interests in educational and career areas, make choices, and implement these choices with varying levels of success. SCCT incorporates Bandura’s triadic reciprocal model of causality which assumes individual characteristics, environmental/contextual factors, and behaviour interact and influence each other throughout this process. Self-efficacy beliefs, outcome expectations, and personal goals are highlighted within this model of reciprocity and can be conceptualized as a developmental-contextual model made up of environmental layers, where the individual (with her/his personal characteristics) is embedded within their immediate family system, and within consecutively larger layers of context (Lent et al., 2000). Developmental-contextualism emphasizes the dynamic interaction that occurs between individuals and their environments (for example: community, sociocultural context, educational environment, and family situation). In this model, neither contextual factors nor individual characteristics (e.g., ability) are sole determinants in the life-career development process. Rather, individuals are able to exercise agency within the dynamic relationships that exist (Patton & McMahon, 1999). An individual filters and interprets information from the environment, which in turn affects self-perception and perceptions of the environment.

Personal resilience factors identified in the literature on disabilities include attainment of clear goals, ability to reframe the disability to recognize strengths, and the development of strategies and techniques to enhance performance (Dolyniuk et al., 2002; Garber, 2001). Environmental factors which foster positive interactions include supportive social environments, mentors who teach and guide performance, and the goodness of fit between the individual and their job or career (Garber, 2001; Hurlbutt & Chalmers, 2004).

Status variables such as disability affect individuals, not through the meaning or fact of the disability itself, but through the intrinsic effect of responses from the sociocultural environment with regards to the disability (Fabian, 2000). Attitudes based on myths, stereotypes, or on a lack of knowledge are likely to create substantial barriers including physical barriers, policy and procedural barriers, and attitudinal barriers. If, on the other hand, an individual’s disability is not recognized, as is often the case, responses to behaviour cannot be interpreted through that lens of understanding. Individuals with alcohol-related effects as a result of maternal alcohol exposure are likely to experience frustration and low self-esteem, contributing to secondary disabilities. The relationship between an individual and his/her environment is seen as directly influencing life-career decision-making, which has important implications in planning career development programs.

The emphasis on the individual-contextual relationship is a departure from traditional models, which tend to place greater emphasis on values and aptitudes. In SCCT, values and aptitudes are seen as only one aspect of an individual. Individual characteristics influence career choices and behaviour through self-efficacy beliefs, outcome expectations, and personal goals. Self-efficacy beliefs are a dynamic combination of beliefs about oneself, linked with performance experiences (Lent & Brown, 1996). Outcome expectations are beliefs about projected results of behaviours. A type of outcome expectation that is particularly relevant to this discussion are those in relation to one's view of the environment – specifically, barriers to employment (Lent et al., 2000). Contextual affordance, or how environments may promote or obstruct one's ability to translate personal strengths into life-career possibilities (Patton & McMahon, 1999), is an important area to address in career counselling, as unaddressed barriers will hamper any progress that is made on the individual level, negatively affecting self-efficacy beliefs.

For individuals with FASD, self-efficacy beliefs, outcome expectations, and contextual barriers to employment may have an especially strong influence on personal goals. Self-efficacy beliefs are formed through “(a) personal performance accomplishments, (b) vicarious learning, (c) social persuasion, and (d) physiological states and reactions” (Lent & Brown, 1996, p. 311). Given that alcohol-affected individuals may be operating on experiences of failure, are easily influenced by others, and have difficulty in managing difficult emotions, self-efficacy beliefs may be particularly low for these individuals. Improving self-efficacy beliefs is a key step in career development, as negative self-beliefs may lead to avoidance behaviour (Lent, Hackett, & Brown, 1999). The importance of realistic self-appraisals must also be stressed as unduly negative or unrealistically optimistic self-appraisals will have detrimental effects on progress in forging life-career pathways.

In terms of occupational choice, SCCT proposes a linear progression in which self-efficacy and outcome beliefs influence life-career interests, which in turn are translated into career choice goals, and result in motivation and action towards the goals (Lent & Brown, 1996). While the first part of this process – the influence of self-efficacy and outcome beliefs on interests and goals – is likely to hold true for individuals with FASD, translating goals into action will likely require support and advocacy on the part of the counsellor. Novick and Streissguth (1996) found that although clients often spoke about their situation as though resolution of problems would be easy to accomplish, “in reality they are often unable to follow through in obtaining services on their own behalf” (p. 21) and “memory problems, attentional problems, and poor organizational skills make these patients dependent on a strong infrastructure” (p. 21). Premji and colleagues (2004) highlight the need for structure and consistency in all areas of life for individuals diagnosed with FASD, particularly in regards to transitions, which should be gradually structured so as to ease anxiety and behavioural problems.

Counselling Strategies and Implications

The following recommendations represent a combined understanding of the spectrum of FASD, drawing on existing practical applications for career counselling with individuals diagnosed with other neurobehavioural disorders (e.g., Cummings et al., 2000; Hutchinson, 1995; Reekie, 1993; Schmucker, 1997) and from the personal

experience of the first author in working with this population. Additionally an extensive review of peer-reviewed and grey literature databases by Premji and colleagues (2004) further inform the ideas presented in this paper. A broad understanding of career development is taken and includes psychological, social, educational, and physical factors that shape the career of an individual over their life-span (Herr & Cramer, 1996).). Suggestions include strategies for relationship building and assessment, identifying and building on individuals' strengths, and creating structure and support. It is essential that these suggestions be instituted in accordance with a prior multidisciplinary assessment of the individual's executive functioning, neuromotor or motor and sensory impairments, emotional functioning, medical treatment including diagnosis, and speech/language function usually undertaken by a team of health professionals.

relationship building and assessment. General strategies for working with youth with FASD involve observing patterns of behaviour which reflect developmental stages in different life arenas; eliciting clients' understanding of what it is like to live with FASD; reframing their behaviour as a neuro-developmental disorder; establishing concrete routines in the counselling sessions to avoid client frustration and to increase retention; preparing clients for transitions by posting activities to engage in during the session with time allotments; modeling positive interpersonal behaviours and providing feedback on body language and facial expressions; using visual aids; providing simple instructions using concrete examples from a multi-sensory approach; and making certain that the physical environment is organized, low in sensory stimuli, quiet and comfortable; and providing templates and examples of written components such as resumes (Malbin, 2002; Reekie, 1993; Stade, Clark, & D'Agostino, 2004).

An individualized approach is mandatory, as individuals with FASD will have varying abilities and disabilities (Burgess & Streissguth, 1992; Olson, 1994). Rather than expecting the client to fit the intervention, the intervention should be designed to be flexible and adaptable to meet the unique and changing needs of the affected youth (Burgess, 1994; Olson, 1994). If a client does not identify as having a diagnosis of FASD, and the counsellor suspects that this could be an issue, the possibility of diagnostic testing should be discussed (Premji et al., 2004). Although testing can be expensive and difficult to access, for individuals with more severe symptoms on the spectrum, obtaining an accurate diagnosis may help individuals to access available services. Particularly helpful would be an individual support worker who can help to co-ordinate the various supports that the individual may need, for example, ongoing therapy, housing, job coaching, transportation, and financial assistance (Novick & Streissguth, 1996). Although an individual's IQ may fall within the average range, other features associated with alcohol-related birth disorders may affect the individual's ability to function at that level (Burgess, 1994; Premji et al, 2004.). While superficially youth with FASD may present as more competent than they actually are, when expectations are too high, they may show signs of disintegration (Coe, Sidders, Riley, Waltermire, & Hagerman, 2001; Dyer, Alberts, & Niemann, 1997). Positive correlations were found between IQ and symptoms of moodiness, depression, aggression, inattentiveness, and hyperactivity of alcohol-affected individuals and high IQ (Coe et al., 2001), suggesting greater susceptibility among this group. In any case, a comprehensive evaluation "which identifies areas of strength and need, is critical to

develop realistic expectations, secure appropriate supports, and develop effective interventions” (Premji et al., 2004, p. xii).

Involving an individual’s family in the career counselling process is an asset as sustaining progress in behaviour change is heavily dependent on the individual’s receiving adequate understanding and support from their family (Novick & Streissguth, 1996; Premji et al., 2004). Most foster or adoptive parents of a youth with FASD want information in order to understand the physical, intellectual, and behavioural concomitants of their diagnosis (Brown & Bednar, 2004) and to use this information to develop reasonable expectations and to assist in the planning process. Biological parents, on the other hand, may first need support in working through possible feelings of guilt and shame before they will be able to provide support to their youth (Chudley et al., 2005). In family sessions, clients can receive comments on FASD traits that affect their performance, for example, how rigid and inflexible thinking gets in the way of learning new skills. Family members can be involved in counselling sessions, either as supportive observers, or actively, in eliciting strengths and resources, in teaching functional skills, and in interviewing or self-advocacy skills role-plays.

sources of self-efficacy and outcome expectations. From a strengths-based perspective it is important to include an appreciation of strengths in our work with these youth. Rather than an exclusive focus on the challenges faced by alcohol- affected youth in the transition to adulthood, solutions may be found in the unique experiences, strengths, resources and skills of the youth, their caregivers, the family, and even the community in which they live (Premji et al., 2004). Such strengths-based information provides indications of the solution that is likely to best fit the youth’s unique circumstances. This is particularly true in working with youth who have experienced a history of school failure and early drop-out, social isolation, and behavioural problems (Reekie, 1993). The shift from exploring the nature of problems and how they affect clients to exploring how clients have responded and coped with these problems in the past can be empowering in that it assumes an active coping response on the part of the client (Wade, 1997). Efforts to teach new skills must build on areas of strength, as memory impairments and other issues impact the ability of individuals with FASD to maintain new learning.

Many alcohol-affected youth are tactile and visual learners. They benefit from “hands-on” activities and enjoy moving while they are learning. Their visual learning style encourages the use of “to-do” lists and day planners that also provide them with the structure and routine that is so critical to their well-being. Amundson (2003) suggests the use of chart paper to map out activities in the counselling session, for example, in goal setting. Concrete representations might be particularly useful in helping to retain new knowledge by accessing visual memory. Audio/visual playback is another technique suggested by Amundson, where audio or video is used to record parts of sessions, which may then be reviewed as a memory aid. This might be useful for rehearsing behaviours, and also in tracking client progress to provide concrete proof of progress.

Structure and consistency provided by caregivers or professionals is known to positively impact the performance of youth with alcohol-related disabilities. Timler and Olswang (2001) suggest applying Vygotsky’s theory of the zone of proximal development to youth with FASD. According to this theory, the adult gradually moves the youth to more complex levels of performance while structured support is provided

and then faded out. Scaffolding, the term used to describe the manner in which an adult adjusts or modifies the support to the youth, could be used by career counsellors to best facilitate career-related behaviours, for example, conducting a follow-up call by telephone.

Novick and Streissguth (1996) indicate that cognitive-behavioural approaches are most effective for individuals with FASD, as these interventions may be designed so as to take into account the executive functioning challenges faced by many of these youth including storage and retrieval of information, interpretation of information, and utilization of information (Premji et al., 2004). As individuals may be unable to generalize skills learned in counselling sessions to other settings, it may be more effective to teach the consistent use of rules of behaviour that can guide and structure behaviour across multiple situations (Novik & Streissguth, 1996). Premji et al. (2004) also emphasize the need to focus on developing an individual's functional skills through concrete learning experiences and cognitive rehabilitation approaches. One successful cognitive career-related education program for individuals with learning disabilities (Hutchinson, 1995) focused on increasing participant's awareness of self and of career areas through the use of an interactive computer program. Employability skills that address the vocational, social, and emotional skills necessary to enter a training program included listening, problem exploration, goal setting, and decision making. Interpersonal skills including cognitive rehearsal, imagery, and stress testing experiences were also taught. Programs for individuals with FASD could build on such a model, modifying it to include more behavioural strategies, modelling, and practice in implementing basic life skills in real life situations, for example, filling out a job application, keeping a job, interacting socially, managing time, and decision-making.

promoting supportive and structured environments. The relationship between self-efficacy beliefs and success proposed by the SCCT model illustrates the need for training and work experience situations in order to provide individuals with opportunities to improve life-work skills and enhance feelings of self-efficacy through positive experiences. Volunteering, 'take your child to work' initiatives, job shadowing, and structured, supervised work situations where outcome measures are adjusted to a realistic and attainable success level, are some practical work experience suggestions (Mader, 2004). In order to assist alcohol-affected youth to make successful transitions to adult roles, community leaders can redesign jobs to accommodate the capabilities and limitations for persons with FASD. Youth with alcohol-related disabilities need job duties, responsibilities, expectations, and rules clearly described ahead of time (Stade et al., 2004). Receiving positive feedback during such experiences enhances feelings of self-efficacy, which will in turn influence success. Group counselling settings are recommended for youth with learning disabilities (Hutchinson, 1995). This may also be beneficial for youth with FASD. Job clubs, for example, may provide opportunities for positive social experiences and skill development which will enhance self-efficacy beliefs as alcohol-affected youth require learning in multiple settings to increase transferability (Premji et al., 2004).

As the disabilities are not going to change or go away, modifications to the environment to accommodate disabilities are essential (Schmucker, 1997). The provision of a personal tutor, mentor, or job coach may be necessary to help them learn skills and to maintain the job. Potential employers or mentors may need to be educated about FASD, and education, training, or work situations may need to be modified to

accommodate the individual's particular strengths and limitations. For example, neuromotor impairments may manifest as sensory sensitivities which may necessitate changes to workplace temperature, lighting, and noise levels (Premji et al., 2004) or modifications to productivity demands based on client's capacity for speed and efficiency may need to be made. Advocacy may form an important component of the counselling relationship. Counsellors may need to exert pressure on community agencies and to orchestrate a variety of people, resources, and services to meet the needs of their clients and caregivers.

Conclusion

Youth with FASD encounter specific obstacles in their career development that are often due to a lack of awareness and sensitivity on the part of educational institutions, employers, and the public. Providing effective career development interventions requires practitioners to possess the requisite knowledge, skills, and awareness for addressing the career needs of alcohol-affected youth. The overarching recommendation for career counsellors is to keep in mind that each client with FASD has a unique combination of strengths and disabilities, which must be understood within that individual's life context. A thorough neurobehavioural assessment can highlight assets and challenges in executive functioning, neuromotor and sensory areas, and speech/language. SCCT provides one possible framework for identifying barriers and building on strengths of youth with prenatal alcohol effects. However, there is an acute need for research and theory to inform career counselling practice that accounts for the individual's special needs as related to the specific experience of FASD, and the complex contextual factors which influence the life-work success of these individuals.

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The Role of Career Development in the Process of Psychosocial Adaptation to Cancer: Re-visiting the Task Model Approach

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The word cancer still evokes fear. For a large segment of the population, cancer is synonymous with suffering, grief, and death (Cunningham, 2002). These perceptions are comprehensible since cancer continues to be one of the leading causes of premature death in our society. In Canada, the overall prevalence of cancer is increasing, impacting a major segment of the population. Canadian cancer statistics indicate that an estimated 139,900 new cancer cases will occur in Canada in 2003 (Canadian Cancer Society, 2002-03).

In recent years, however, improved detection and screening have resulted in increased survival among individuals diagnosed with cancer. Moreover, improved medical practices have notably extended the length of survival for many patients and improved their quality of life. Statistical information from the Canadian Cancer Society for the year 2003 suggests that the prognosis for long-term cancer survivorship is good. The survival rate (i.e., proportion of people diagnosed with cancer who are still alive five years after the onset of the disease) for all ages and cancers combined is at present 51% (Canadian Cancer Society, 2002-03).

However, the survival rate for different categories of cancer can fluctuate significantly. According to the Canadian Cancer Society, the most frequently occurring cancers continue to be breast, colorectal, and lung for women, and lung, prostate, and colorectal for men. Data suggests that lung cancer remains the primary cause of cancer death for both men and women in 2003. Lung cancer accounts for approximately one-third of the cancer deaths in men, and an estimated one-quarter of the cancer deaths in women (Canadian Cancer Society, 2002-03).

Conversely, the prognosis for other types of cancer is excellent. This is particularly true of breast and prostate cancer. The Canadian Cancer Society reports that death rates amongst women diagnosed with breast cancer and men diagnosed with prostate cancer have dropped by nineteen and ten percent respectively. In summary, while some cancers are responsible for a higher proportion of deaths, other types of cancer are successfully treated (Canadian Cancer Society, 2002-03).

Medical advances and improved treatments have not only necessitated a rethinking of the traditional view of cancer as a life-threatening illness, but also represent inducements to individuals striving to adapt in order to prolong their life. While some cancer patients struggle with the disease, others manage to cope, adapt, survive, recover, and lead meaningful and productive lives (Hounshell, Tomori, Newlin, Knox, Rundhaugen, Tallman, M., et al., 2001; Muzzin, Anderson, Figueredo, & Gudelis, 1994; van der Wouden, Greaves-Otte, Greaves, Kruyt, & van Leeuwen, 2001).

Consequently, it has become crucial that researchers gain a better understanding of the process of adaptation to the experience of cancer, given that increased

survivorship has become a familiar consequence in the lives of patients. While much of the literature reviewed to date identifies some potentially useful coping strategies for those who have been diagnosed, there is little discussion on theoretical approaches that may be useful in gaining a better understanding of the overall process of adaptation to chronic illness. One theoretical approach that can help us to better understand the process of adaptation to chronic illness is the task model. (Cohen & Lazarus, 1979; Corr, 1991-92; Doka, 1995-96; Moos & Tsu, 1977).

The task model has been revised numerous times in the thirty years since its introduction. Moos and Tsu (1977) and Cohen and Lazarus (1979) posited models which comprise an array of tasks. Their representation of tasks, however, is too fragmented and ambiguously demarcated. It is Corr (1991-92) who presents the most systematic and comprehensive account of task adaptation. His model is divided into four distinct areas of coping; these are as follows: (a) Physical; (B) Psychological; (c) Social; (d) and Spiritual.

As previously noted, none of the previously mentioned authors include the role of work and career development in their models. Given the fact that cancer patients are living longer and leading relatively normal lives, a serious diagnosis is not inevitably predictive of major disruptions in the work life and career development of chronically ill persons. In other words, despite their illness, individuals may continue to be engaged in their careers and feel that they can keep working. Consequently, we believe that the vocational task should be considered within the domain of the task model. The final section will consider the limitations of the current research and suggest potential questions for further study in this subject (Brown & Tai-Seale, 1992; Samson & Zerter, 2003).

Task Model Approach: Phenomenological & Holistic Aspects

The task model posits a dynamic model which introduces a phenomenological perspective. The model recognizes individual differences, and underlines each person's unique capacity for adapting to the demands and pressures of the chronic illness. Central to this theme is the notion that individuals' subjective perceptions of their disease allow them to construct their own reality. Chronic illness, therefore, does not affect individuals in a uniform way because the experience of illness is a function of each individual's perceptions, interpretations, and understanding of what is happening to him/her (Cohen & Lazarus, 1979).

The task model also represents a holistic system that focuses on the process of reconstruction of a person's existence. The model does not prescribe a specific path towards reconstruction; rather it offers a framework that portrays the fundamental aspects of human existence, which are referred to as "tasks." The tasks central to this model are physical, psychological, social, spiritual, and vocational. The completion of the tasks is usually hindered by a diagnosis of cancer, but it is foundational in regard to the process of reconstruction. Through such a process, individuals may make lifestyle changes, seek out social support, or search for meaning and purpose in his/her experience and life.

The process of adaptation, therefore, means that a person rebuilds his/her life. It is an ongoing phenomenon, characterized by constant and sometimes difficult changes. Individuals may confront these changes in gradual increments or simultaneously.

Frequently, the completion of one task establishes a solid foundation from which other tasks are realized. As well, tasks are continuously prioritized and re-evaluated by individuals as a means of developing a manageable hierarchy. This process contributes to the chronically ill patient's ability to cope with the non-stop changes successfully (Corr 1991-92; Doka, 1995-96).

Trajectory of the Illness and Subjective Perception

As previously mentioned, the task model places emphasis on the individual's subjective perceptions of an event (i.e., phenomenology). In other words, the patient's subjective perceptions of an event not only determine the trajectory of the illness, but also provide the impetus for the adaptation process. In other words, the patient's experience is shaped by his/her unique insight. Implicit in this view is the notion that there are many ways to construe a situation, and each viewpoint is likely to produce consequences that may facilitate or impede the process of adaptation (Cherny, Coyle, & Foley, 1994; Cohen & Lazarus, 1979).

The process, as described in the preceding paragraph, results in different ways of conceptualizing and dealing with the impacts of the chronic illness. For example, those who are not overwhelmed by their fears may worry less about the effects of the disease on their lives. Paradoxically, for others, the experience of cancer is a great stressor that causes profound fear and distress. The intensity and variations of these emotional expressions is determined by the process of cognitive appraisal or subjective perceptions. These processes, can, generally speaking, elicit a crisis reaction in which the implications of a serious illness like cancer are seen as potentially dangerous and deadly. This phenomenon is fully articulated in what is commonly referred to as the *initial crisis* (Cherny et al., 1994; Lazarus & Folkman, 1984; Samson & Zerber, 2003).

the initial crisis. As stated above, the news of a serious diagnosis often provokes what is commonly referred to as the *initial crisis*. The essential idea that is conveyed by this concept is that under the impact of traumatic events, individuals understandably develop a crisis reaction because their circumstances are considered overwhelming or insurmountable. For example, persons may wonder whether or not they have adequate resources to deal with their new and painful reality. Consequently, numerous individuals feel very shocked by the diagnosis.

Thus, it is not uncommon, when the news of a diagnosis is first received, for individuals to feel sullen, vulnerable, and helpless. Other reactions could include fear of dying, anguish, despair, anger, and denial. In terms of career development, many who were looking forward to fulfilling some of their dreams, career ambitions or plans, instead view these as lost ambitions or opportunities. To some extent, one's hopes and ambitions are subject to the unpredictable nature of the outcome of the life-threatening illness, which can lead individuals to wonder and worry about the future (Muzzin et al., 1994; Samson & Zerber, 2003; Thomas, 1995).

Gradually, even if one is confronted with the possibility of death, the diagnosis usually loses its menacing countenance, and the confusion, uncertainty, and paralysis initially felt slowly lose their hold on the affected individual. As patients gain more insight into their illness, they begin to interpret its consequences as less imposing (Cohen & Lazarus, 1979).

In accordance with this awareness, a more differentiated view of the illness emerges. As pointed out earlier, the degree to which the patient is able to adapt or adjust to the various demands and processes surrounding his/her illness is determined by the patient's cognitive appraisal and subjective perceptions of his/her circumstances. Over a period of time, the individual's cognitive appraisal or subjective perceptions of what is happening to him/her slowly change, and the emotional reactions, natural after the initial disclosure of a life-threatening illness, appear somewhat less severe (Kangas, Henry, & Bryant, 2002; Turnquist, Harvey, & Andersen, 1988).

Therefore, the disease is progressively perceived as less menacing or dangerous, and its consequences alternatively re-conceptualized as challenging rather than as threatening. Accordingly, the illness is gradually assimilated into the life and identity of the chronically ill patient. In this situation, individuals slowly get over the crisis period and begin to see themselves as more able to cope with the anticipated hurdles. In short, this phenomenon represents not only a turning point in the way patients conceptualize their illness, but also a critical variable in aiding the process of adapting to the new situation.

With the passing of time, then, persons come to terms with the diagnosis. They begin to diminish its impact and seek constructive ways to deal with the difficulties, restrictions, and demands the illness imposes on their lives (Taylor, 1983). The emphasis in this process, therefore, is on carrying on with life and relinquishing the past. This provides perspective and gives individuals an opportunity to rebuild their lives, alter their self-image, strengthen old relationships, and establish new social networks (Schlossberg, Waters, & Goodman, 1995).

Description of Adaptive Tasks

A diagnosis of cancer is a life-changing experience, and its influence on the lives of individuals is often profound and lasting. Such an event represents a period during which individuals begin to question their dreams, aspirations, goals, relationships, and even their existence.

While nearly everyone exposed to a life-threatening illness will experience some sort of initial crisis, not all will continue to be negatively impacted by their situation. With time, the shock of the diagnosis is absorbed; its impact is gradually accepted and integrated into the life of the affected individual. Accordingly, individuals slowly begin to reconstruct their lives (Kurtz, Wyatt, & Kurtz, 1995).

The task model helps us to better understand how individuals reconstruct their lives in spite of their illness. The process of adaptation in Corr's task model is divided into four major tasks. These are as follows: (a) Physical; (B) Psychological; (c) Social; (d) Spiritual. The authors suggest the addition of the Vocational task to the current task model. Let us now consider each of these tasks.

the physical task: supervision of health. One of the first important steps in task adaptation is coping with the physical impacts of the illness. This process calls for individuals to take whatever means are necessary to increase their chances of survival. The manner in which this will progress will depend largely on the individuals and his/her circumstances (Cohen & Lazarus, 1979; Corr 1991-92; Moos & Tsu, 1977).

Cancer often results in the appearance of symptoms such as severe pain, lack of appetite, lack of energy, headaches, gastrointestinal distress, sleep disturbance,

dizziness, vomiting, weight loss, weight gain, and others (Canadian Cancer Society, 2002-03; Cherny et al., 1994).

The most common modalities of treatment for cancer include radiation, chemotherapy, surgery, and pharmacology. At times it is difficult to decide whether the benefits of the treatment are being obscured by its side effects. Some of the physiological symptoms that are common to many cancer patients receiving chemotherapy include loss of hair, nausea, and fatigue. As well, the use of drugs can have numerous unwelcome side-effects. Medications such as busserelin, which is used to treat cancer of the prostate gland, can cause a decrease in sexual desire, impotence, and sudden hot flashes as side effects (Canadian Cancer Society, 2002-03).

Understandably, the symptoms of the disease and the side-effects of available treatment interventions can cause enormous distress in patients. Exposure to this may evoke concerns about one's own efficacy in life. Individuals may feel, for example, that their ability to perform everyday tasks is severely diminished. This can influence the degree to which one feels in control over his/her destiny. As well, aggressive treatments such as surgery and chemotherapy may result in frequent side-effects which sometimes can make the patient feel sicker than before. These factors, taken together, may negatively influence the task adaptation process, making it difficult for the cancer patient to enhance the quality of his/her daily existence and move towards a healthier and happier life (Cunningham, 2002).

How can patients, then, adapt to the physical aspects of their illness and reconstruct their lives? According to research, the patient's pro-active supervision of his/her health becomes critical in generating an outcome that is more likely to be positive and progressive. Patients, in other words, have to become actively involved in the maintenance of their health. The way in which this process takes shape will depend on each individual's situation, and grouping and severity of symptoms.

This "taking charge" approach usually entails going to regular medical appointments, collaborating and co-operating with physicians, and complying with physicians' therapeutic interventions. It is also usually helpful for patients to deepen their knowledge base of their illness and possible treatments via information gathering. This awareness may allow patients to better assess their situation and to generate more realistic and effective coping strategies (Cohen & Lazarus, 1979; Doka, 1995-96; Moos & Tsu, 1977).

Most significantly is the fact that as patients become more actively involved in their medical treatment, they begin to develop a sense of control over their life and illness. In summary, the patient's efforts are combined with treatment recommendations from physicians, pharmacological, and other therapeutic interventions. Thus, both the patient and physician are involved in assessing what is going on and deciding what to do. This relational dimension not only provides a means by which the negative symptomatology may become less prevalent, but also plays a constructive role in aiding the recovery process.

Furthermore, recurrence of the disease remains a continuous possibility. Such a possibility can provoke feelings of uncertainty and helplessness. A readjustment of lifestyle, therefore, is preferable. A recognition and discontinuance of lifestyle risk factors or cancer-causing habits, for example, may become a preferred coping strategy. This may involve dietary modification, the addition of regular exercise, monitoring sleep habits, and the avoidance of stressors. Injurious behaviours, such as smoking and

taking illegal drugs that are not amenable to continued good health may eventually be discarded (Canadian Cancer Society, 2002-03).

These lifestyle changes are repeatedly tested, re-evaluated, and prioritized as a means of developing the necessary coping mechanisms for dealing with the day-to-day problems characteristically associated with chronic illness, and, as well, as a means of reducing the threat of recurrence. Most significantly, perhaps, is the fact that developing and adopting new behaviours gives patients a sense that they still have some measure of control over their lives (Samson & Zerter, 2003).

the psychological task: the maintenance of emotional equilibrium. The diagnosis of a chronic illness often affects the emotional equilibrium of the affected individual for many reasons. Firstly, an illness like cancer is characterized by pathologies that are potentially deadly and often difficult to treat. The diagnosed individual is confronted with the possibilities of a shortened life span and the eventual degradation of his/her health.

Secondly, the threat of recurrence remains a frightening prospect. With the passing of time, the patient may find himself/herself facing more malignant and virulent forms of the disease. Such a possibility threatens one's sense of safety and security. Patients may feel helpless and extremely distressed. Eventually, these emotions may grow stronger and shift the individual's attention to a repetitive anguish about the possibility of the disease rearing its ugly head once again. In short, then, the deterioration of a patient's condition after recovery is an ever-present possibility, which can generate much worry and stress-it almost always has a deep and lasting effect on the chronically ill individual (Kornblith, 1998; Samson & Zerter, 2003).

Thirdly, a disease like cancer can negatively influence or alter a person's self-image. It is difficult to come to terms with the realization that a once strong and vital person has been weakened and incapacitated by a serious illness. This reality is disconcerting and painful for the patient who perceives his/her physical disintegration as an attack against his/her self-image. The individual may begin to feel different, undesirable, or inferior. Perhaps more damaging to the individual's psychological health is the fact that he/she perceives that others feel the same way. This emotional turmoil takes its toll on the patient. The patient recognizes that he/she has changed, but not for the better. The effects of such a narcissistic wound on the individual are often exacerbated by others who view him/her in a negative manner (Cohen & Lazarus, 1979; Corr, 1991-92; Moos & Tsu, 1977; Taylor, 1983).

Individuals who perceive themselves as passive victims of their disease may feel powerless and despairing about the future. This sort of thinking may ultimately undermine the individual's capacity for action in the face of the challenge. Conversely, a proactive stance in which the individual perceives himself/herself as capable of exerting some control over his/her situation represents one of the most efficacious ways of sustaining emotional health (Cella, Mahon, & Donovan, 1990; Kornblith, 1998). For example, for those diagnosed with cancer, confronting the uncertainties of the disease and the possibility of recurrence can be more of an impending threat to psychological health than the initial diagnosis. In these instances, therefore, it is important to see oneself as having power and control over the situation. Taylor (1983) places a lot of emphasis on cognitive skills in this process. Indeed, she demonstrates that via causal attribution, a person is likely to comprehend and predict what will happen to him/her.

Additionally, the implementation of new lifestyle practices may be beneficial to maintaining psychological well-being. This may involve dietary modification and the addition of regular exercise, for example. Equally important is the fact that incorporating such strategies into daily routines can give an individual a sense that he/she still has some measure of control over his/her illness (Samson & Zerter, 2003).

the social task: the importance of adequate social support. Chronic illness often imposes a certain form of marginalization. This is because the affected individual is eventually cut off from his/her regular social support system. In effect, the experience of a life-threatening illness often results in the discontinuance of a life that is conducive to the development of social relationships. The individual may not be able to go to work or go out for a period of time. He/she may engage in fewer professional, cultural or leisure activities; often patients abandon these altogether. In short, the patient experiences a loss of social attachments as a result of his/her illness (Cohen & Lazarus, 1979; Corr, 1991-92; Moos & Tsu, 1977; Muzzin et al., 1994).

Generally speaking, the affected individual is treated by others as a sick person, and as such, is considered as an unfit member of society. This tendency highlights the stigma commonly associated with illnesses like cancer. The impact of stigma often makes it difficult for cancer patients to rely upon the usual avenues of support to work through the recovery process (Cohen & Lazarus, 1979; Corr, 1991-92; Moos & Tsu, 1977). Eventually, they may begin to feel like they are no longer part of society. Moreover, instead of feeling like contributing members of society, cancer patients often feel like they have become a burden to it.

Thus, persons with cancer can be affected by society's response to the disease. The particular type of cancer can carry with it a form of social stigmatism which further isolates the chronically ill individual (Shaw, Segal, Polatajko, & Harburn, 2002). Persons diagnosed with lung cancer, for example, are vulnerable to the negative reactions of society. There is a tendency in our society to characterize the lung cancer patient under the general stereotype of smoker. There are noticeable prejudices and negative judgments prevalent in our current society about people who smoke, which are difficult, if not impossible, to change. This negative conditioning can produce feelings of shame, unworthiness, and guilt in the affected individual. These feelings, in turn, can prompt him/her to withdraw from others, which eventually contribute to social isolation (Kunkel, Bakker, Myers, Oyesanmi, & Gomella, 2000).

Finally, serious illness creates profound fear in the minds of many people. The awareness of a life-threatening condition is sufficient enough to evoke fears of dying and suffering amongst those who are healthy. The mere presence of a seriously ill person and the acknowledgement that he/she may die can remind those who are well that they too may one day have to accept the same reality. While the person who is seriously ill may adapt to the reality that he/she may not survive, others may be unwilling to accept the fact of death. This potential confrontation with death and suffering may prove to be too strong for those who represent the closest supports to the sick individual. Accordingly, the person with cancer may feel isolated and open to fears of being rejected.

As we have just seen, the experience of a life-threatening illness can lead to social isolation. It is crucial for the patient to seek comfort and support from people who are willing to be with her/him and to listen intently and respectfully, and who are sensitive to the emotional and physical stresses associated with their condition. Whether

or not this is found amongst friends, family, or clergy, patients need people with whom they can openly discuss their experiences and express their feelings. Finding the needed support may be difficult, but it is essential. According to research, individuals with strong supportive social networks deal much more successfully with a serious diagnosis and its aftermath than those without support (Muzzin et al., 1994).

Similar to the physical task, the patient's proactive participation plays a crucial role in the process. It is incumbent on the patient, then, to find the required supports as necessary within his/her community. Research indicates that belonging to a support group comprising of peers constitutes an excellent social support system. Another way individuals can benefit from social support is through volunteerism. In short, the patient needs to take active steps in finding a social support system which can provide nurturance, acceptance, and kindness. The task of achieving this can be relatively effortless, but it can also be very difficult for some as it implies increased dependency on others (Muzzin et al., 1994).

the spiritual task: the vital breath. The diagnosis of life-threatening illness can promote in a person a desire to find new meaning and purpose in his/her experience and life. Finding meaning and purpose in life are tasks often associated with the domain of spirituality. Yalom (1980) has long emphasized the importance of spirituality in the lives of those affected by cancer. According to him, those who come face-to-face with their own mortality are more likely to ascribe a new meaning to the value of life. This in itself represents a major milestone for those who are affected. Priorities are re-organized. The quest for material wealth seems less attractive and interpersonal relationships, living for the moment and the simple things in life are placed at the pinnacle of the priorities' list.

But what does spirituality mean? It is necessary to start with looking at the etymology of the noun itself. The roots and meaning of the word are derived from the Greek word *pneuma*. For the ancient Greeks, *pneuma* represented the invisible but vital breath that nourished human existence by providing sense of meaning and purpose. In that manner, all persons are imbued with spirituality and capable of drawing from it as a means of influencing their destiny (Ingersoll, 1994). This mysterious and intangible reality has been ignored by many researchers who believe that things that cannot be measured do not exist. Conversely, other researchers have shown that spirituality is central to the existence of the individual (Pargament, 1997).

For cancer patients, spiritual involvement seems to play a vital role. In effect, spirituality can become an important element of a person's life context within which more adaptive strategies can be developed. It has often been associated with improved psychological functioning and an increased capacity for coping with one's stressful life circumstances. For example, spirituality can be particularly helpful in alleviating anguish and facilitating well-being and coping with pain (Georgeson & Duncan, 1996; Jenkins & Pargament, 1995).

As well, spirituality can provide sources of meaning and significance to life. By making sense of what has happened, individuals can reinterpret their situation in a more positive light. Those who are unable to find meaning in their experience may find themselves struggling with coming to terms with their reality (Corr 1991-92; Samson & Zerter, 2003).

Spirituality can also furnish patients with new sources of meaning and purpose in life through relationships beyond the self to others (e.g., a counsellor) and/or to a

supernatural power. These types of relationships can provide energy, motivation, and hope, and remind individuals that they are not alone and that they are capable of regenerating themselves and rebuilding their lives (Rohr, 2001; Yalom, 2003). Most significantly perhaps is the fact that only spirituality can make sense of what is essentially absurd, that is, suffering and death (Samson & Zerter, 2003).

vocational task: the development of the career. It is easy to justify the addition of work and career development to the current task model since work life in general and the concept of career represent a central focal point in human experience. Firstly, work plays an important part in the lives of individuals. Secondly, a career helps define individual aspects of identity or personality, ensures a certain measure of autonomy and financial independence, and provides a mechanism for social interaction (Hoffman, 1997).

According to Riverin-Simard (2002), individual identity was in the past fashioned by his/her culture; however, that is no longer the case. She maintains that it is the career which provides the individual with his *raison d'être*, his/her identity or personality, and an opportunity for social interaction. Of course, this process is interspersed with periods of preparation, re-integration, and constant adaptation.

Often, the diagnosis of a chronic illness has a major impact on a person's work life. For example, employers may question whether or not the individual is capable of maintaining his/her previous work performance level. Also, the individual may be considered to be less of an asset and more of a burden to the employer. In short, the medical consequences related to the chronic illness can prevent an individual from applying himself/herself fully and effectively to day-to-day work activities and tasks. Under these circumstances, individuals must often undergo a continuous process of career re-orientation and re-adaptation (Hoffman, 1997; Roessler & Rumrill, 1998).

A meta-analysis conducted by Brown and Ming Tai-Seale (1992) indicates that cancer survivors often confront numerous obstacles when they return to work. The dominant theme that surfaces from their research is certainly that of discrimination. The stigma often related to potentially deadly diseases like cancer can inhibit efforts to secure new employment, extinguish one's hopes of promotion or vocational training, or quite simply lead to lay-off. However, individuals with little education and from lower socioeconomic strata are often more affected by discrimination in the workplace than those who are highly educated and privileged.

Despite these obstacles, the career can help individuals to maintain their emotional equilibrium and important interpersonal relationships, to improve their self-image, and to rebuild their existence (Roessler & Rumrill, 1998). Often, chronic illness adds a new dimension to life by giving those afflicted a new set of values; the career can become the conduit for the expression of these values. Individuals tend to appreciate more important things in life as opposed to material wealth, financial success, and accomplishments. Accordingly, they demonstrate their concern for others in vulnerable circumstances as never before through volunteer work. In this setting, the career can become a way for individuals to re-charge their energy and come alive again.

The preceding comments point to the important role of the career in the process of rebuilding the lives of chronically-ill individuals. While much of the literature reviewed to date identifies some of the challenges commonly associated with chronic illness, there is often little or no discussion on the role of career development in the

adjustment process. Further research is needed in order to develop a better understanding of this.

Nevertheless, our review of the literature has allowed us to discover the importance of career development in leading chronically ill persons to move ahead in their lives. As pointed out earlier, the vocational task provides the individual with a means to express his/her *raison d'être*, his/her identity or personality, and an opportunity for social interaction.

Conclusion

In this paper, we have posited a theoretical model which helps us to better understand the process of psychosocial adaptation to chronic illness.

As noted earlier, the task model represents a holistic system that is derived from the major dimensions of life. The model recognizes the interaction of psychological, physical, psychosocial, spiritual, and vocational factors in the lives of individuals. As well, the task model acknowledges the centrality and primary importance of subjective perceptions in the adaptation process. Moreover, the addition of the vocational task to the current model allows us to consider and appreciate the relationship between the individual's career development and work environment and his/her ability to adapt more effectively.

As previously mentioned, the completion of one task establishes a solid foundation from which other tasks are accomplished. For example, our research indicates that an adequate social support system and the proactive maintenance of health can promote positive cognitive adaptation and emotional equilibrium. The task model, in other words, affirms the principle that viewing the situation as a whole instead of dividing each task into a separate compartment is an essential component of an individual's psychological performance.

Finally, the present research also underscores the need for researchers to further study the importance of the vocational task in the process of adaptation in individuals diagnosed with chronic illness. Greater knowledge in this area may lead to better interventions that will foster optimal adaptation in individuals.

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