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QUALITY OF LIFE ASSOCIATED WITH ADULT DAY CENTRES (ADC)

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Abstract

150 words focusing on findings and conclusions

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The purposes of this study were to: describe the quality of life (QOL) of current users of adult day centres (ADC) and caregivers to identify aspects of ADC that clients and caregivers believe would enhance their QOL. Semi-structured interviews were held with 10 clients of ADC and 10 caregivers. Data analysis

QUALITY OF LIFE ASSOCIATED WITH ADULT DAY CENTRES (ADC)

Quality of life (QOL) of older adults is particularly important in our aging societies. It is widely accepted that it is better to have QOL than a long life of low quality (Gems, 2003). While there has been some research on QOL of older adults (Bryant, Raphael, & Brown, et al., 2002; Garrido et al., 2003; Hwang, Liang, Chui & Lin, 2003; Souza, Galante & Figueiredo, 2003), it is not always clear what factors influence QOL and how various programs and interventions affect QOL of this population.

Adult day centres (ADC) are accepted and integrated components of a community-based system of services for older persons. However, there has been little recent research pertaining to ADC. Earlier studies may be less relevant because the population of older adults has changed considerably and there is a need to evaluate the current models of ADC in light of the shift in the client base to higher levels of acuity and a greater prevalence of dementia.

Purpose and Research Questions

The overall purposes of this study were to: describe the quality of life (QOL) of current users of ADC and their caregivers, and to identify aspects of ADC that clients and caregivers believe would enhance their QOL. The ultimate goal of the research was to identify best practices to enhance QOL of this population.

The research questions for the study are:

1. How do older adults participating in ADC in Greater Victoria describe their QOL?
2. How do caregivers of older adults in ADC in Greater Victoria describe their QOL?
3. What aspects of ADC programs/activities do older adults and their caregivers consider to be most important for their QOL?

Summary of Literature

Quality of Life of Older Adults

QOL is a concept that has been defined and measured in many different ways. The question of what constitutes QOL has been a focus of exploration and investigation since the days of the early philosophers (Adler, 1970; 1978). The introduction of the concept to health care research came at a time when the predominance of traditional medical outcomes such as mortality and morbidity was criticized because they did not adequately represent a wide range of other potential outcomes.

Measurement of QOL is a challenge because of the range of definitions and conceptualizations of the concept. The creation, adaptation and testing of measures of QOL has increased exponentially over the last 20 years in Europe and North America; several guides have been developed for the selection and use of these measures (e.g., Bowling, 1997, 2001, ProQOLID, 2005). Some of these measures reflect similar concepts such as life satisfaction, happiness, and subjective well-being, while other measures reflect related but different concepts such as depression, anxiety, health status, functional status, independence, and self-esteem.

While there is a large volume of literature pertaining to QOL of older adults, much of it pertains to definition and conceptualization of the concept (Farquhar, 1995; Xavier, Ferraz, Marc et al., 2003). Variables that have been found to contribute to QOL of older adults include health and functional status, social support, and environment; these findings are briefly summarized below.

Health and functional status are two variables that are often found to explain QOL of older adults. In a review of the nursing research literature on perceived health of older adults and QOL, Moore, Newsome, Payne and Tiansawad (1993) reported that for 11 of 17 studies, there

was a strong positive relationship between these two variables. Raphael et al. (1997) also reported a positive relationship between QOL and health status of older adults.

Social support and variables pertaining to social networks are also important factors related to QOL of older adults. In a meta-analysis of 286 empirical studies on the association of social position, social network, and competence with subjective well being, all three variables were positively associated with well-being (Pinquart & Sorensen, 2000). Similarly, Sparks, Zehr and Painter (2004) found that social interaction was the only significant factor explaining life satisfaction, when health and social position were held constant. In contrast, McCamish et al. (1999) examined the relationship between social support (of family and friends) and life satisfaction with cohorts of 80 and 83 year olds and found that support was not related to life satisfaction in either group; satisfaction with sibling contact was related to life satisfaction in the eighty-three year old cohort only.

Living in desirable surroundings (Farquhar, 1995) has been positively associated with QOL. Also, living in an environment with few barriers to being active has been significantly and positively linked with QOL (Stuifbergen, Seraphine & Greg, 2000). Bowling et al. (2002) report similar findings in relation to the quality and safety of the surrounding physical environment.

Relatively little research has been conducted examining QOL of older adults participating in adult day programs. Since these programs have the potential to improve QOL of older adults through the provision of social support/networks and through a stimulating environment, it is important to further explore how older adults engaged in day programs perceive their QOL and what aspects of the program contribute to their QOL.

There has been considerable research regarding caregiver burden, but less research relating specifically to QOL of caregivers. It is known that spouse caregivers of people with

Alzheimer's disease experience burden, anger and resentment toward the patient, as well as limitations in social life and personal time (Croog, Burleson, Sudilovsky & Baum, 2006). Some interventions have been studied to enhance the QOL of families who use adult day services, but QOL is not usually measured (Gillin, Reeve, Dennis, Mathie, Hauk, 2006; Kuzu, Beser, Zencir, et al, 2005). There has also been some research examining the relationships between QOL and caregiver burden. For instance, Ekwall, Sivberg and Hallberg (2004) conducted a survey of caregivers over the age of 75 and found that low QOL was predicted by adapting activities to be prepared if anything happens and keeping in touch at least once per week. Fewer economic resources and requiring help with practical tasks such as cleaning or cooking were also predictors of low mental and physical domains of QOL in this study. Further research to understand the experience of caregivers of older adults receiving care in adult day programs would enhance our knowledge about how best to meet their needs.

Adult Day Programs

Community-based models of care are favored to support independence and individuality of elderly people. In a study of 60 ADC in the United States (US), Weissert (1977, 1978) and Weissert et al. (1989) described various models of day programs. Similarly, Gutman, Milstein, Killam, Lewis and Hollander (1993 a & b) examined models of service, client characteristics, and reasons for referral to ADC in British Columbia (BC). The main model was the freestanding day program offering a variety of comprehensive services. The key difference between the BC and US programs was that the US programs were fully funded under the Veterans Administration while client fees were required to financially support the BC programs.

In some early studies, it was concluded that ADC have little or no effect on the health status of clients (Cummings, Kerner, Arones & Steinbock, 1985; Eagle et al., 1991; Hedrick,

Rothman, Chapako, Thomas et al., 1993a & b), but these earlier programs had little focus on social programming, and the expectations for improvement may have been unrealistic for frail older adults, many of whom had multiple chronic conditions (Ross-Kerr, Warren, Schalm, Smith & Godkin, 2003). A richer understanding of the current experience in ADC in the context of increasing acuity is needed.

One of the goals of ADC is to provide respite to primary caregivers. Zarit, Stephens, Townsend and Greene (1998) found that overload and depression decreased in the ADC group, whereas the control group had an increase in overload and exhaustion. Similarly, Gaugler, Jarrott, Stephens, Townsend and Greene (2003) found that caregivers reported spending less time redirecting their relative and in assisting with activities of daily living and a decrease in role overload. Schacke and Zank (2006) interviewed 77 caregivers of people with dementia and found that in the ADC group, there was a reduction in care-related stressors and an increase the caregiver's ability to tolerate stress. In a comparative longitudinal study, Leitsch, Zarit, Townsend and Greene (2001) explored outcomes of medically and socially based programs on 261 caregivers over a three month period. Few differences in stressors were found even though the programs were different; the researchers speculated that the ADC programs were modified to meet clients' needs. Warren, Kerr, Smith and Godkin (2003), in a study of 140 pairs of clients of ADC and caregivers in Alberta found no changes in burden, QOL, health status, and opinions about ADC over six months. However, Schacke and Zank (2006) theorize that no change may actually be positive since the expected outcome is a decline in coping strategies.

In summary, there is a need for further research involving ADC. Programming is often targeted to improve QOL and reduce caregiver burden, but further research is necessary to

understand, from the perspectives of both the client and the caregiver, what aspects of the program are important to how they might contribute to QOL.

Methods

Given that little is known about QOL of older adults participating in adult day programs, it was appropriate that a qualitative descriptive study be conducted to obtain a richer deeper understanding of the experience of older adults and caregivers in ADC through individual interviews.

Sample and Setting

The sample consisted of ten older adults who were clients in ADC and ten lay caregivers who were considered by program staff to be good informants and who have had at least three months experience with the ADC. All informants were interviewed in English and were able to articulate their opinions verbally. Currently, there are nine adult day programs in this region, and attempts were made to obtain participants from a number of different day programs, because the focus of the study was on QOL associated with day programs in general, rather than experience with any particular program.

Data Collection Procedure

An information sheet about the study was distributed to eligible clients and caregivers, inviting them to call the research team if they were willing to be interviewed. When potential participants called, the research assistant obtained verbal consent, and arranged a time and convenient location for the interview. Before the interview, a formal consent form was signed.

Participants were interviewed about their QOL. Interviews were semi-structured and started with a broad question such as “Can you tell me about the quality of your life at the present time?” Questions gradually became more focused and addressed aspects of life that were

most important and least important to the person. Participants were asked what factors maintained or improved their QOL and how the day program affected their QOL. Each interview was approximately one hour in duration, and was conducted in client homes. The interviews were audio-recorded and transcribed.

Data analysis was inductive and a constant comparative approach was used.

Informed consent was obtained from all participants. Because many clients of adult day programs had mild to moderate cognitive impairment, their caregivers were also asked to sign the consent for client participation. Approval was obtained from an institutional ethics review board before commencing the study.

Findings

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