



The Quality of Life in Eating Disorders Project (EDQLS)

The EDQLS project is a study to develop, field test and validate a Quality of Life (QoL) measure for adolescents and young adults with eating disorders. We are pleased to share our first newsletter of 2004 with you. Enjoy.

USING THE INTERNET IN INSTRUMENT DEVELOPMENT

Article in preparation

In our study we are using many sources of data to inform the ultimate content of our instrument. These have included the scientific literature, and interviews with health professionals and patients. We have also, for the first time, in this project – used stories about ED that have been posted on the internet. The Internet material turned out to be so useful that we have drafted an article about the process for submission to the Journal of Quality of Life Research.

The article describes the methods, we used to collect 31 narratives of individuals who reported suffering from anorexia or bulimia. Authors of the

stories reported on present or past experiences of the illness and/or the recovery process. The stories were very rich with relevant information because the anonymity of the internet allowed expression of thoughts and feelings without feelings of judgment or shame. Due to uncertainty about the veracity and representativeness of the internet stories we don't recommend using them as the *sole source* of information for instrument development. But they were useful in supporting the development of our patient interview schedules and supplemented the other sources of qualitative material.

We plan to publish the abstract of this article in a future newsletter.

Introducing ... Dr. Sandra Ziolkowski, EDQLS Co-Investigator

Dr. Sandra Ziolkowski, PhD is the coordinator of the Industrial Internship Program in the Department of Psychology at the University of Alberta. Sandra earned her doctorate degree in Psychology from the University of Alberta in 1997. Her career focus has been in the field of child and adolescent mental health research and evaluation. Over the past several years she has coordinated various research and program evaluation activities related to clinical practice and policy.



In her previous role as the Lead for Children's Mental Health Research and Evaluation for the Alberta Mental Health Board, she was involved in developing evaluation processes for the Provincial Eating Disorder Service, and was one of a group of key stakeholders to identify the need for a Quality of Life measure for ED services. Sandra believes that the development of a quality of life tool for persons with eating disorders will be useful in the evaluation and improvement of treatment services from the patient perspective.

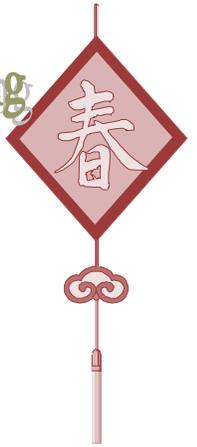
We would like to thank our funders: the Alberta Children's Hospital Foundation, the Calgary Health Region's Mental Health Research Fund, and the Alberta Heritage Foundation for Medical Research.

OUR CURRENT ACTIVITIES



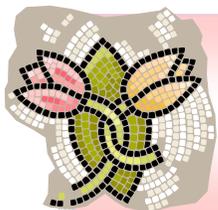
With the holiday season, no-shows, rescheduling, and hectic schedules, we encountered some recruitment challenges for obtaining our goal of 20 participant interviews. Because we have multiple sources of material, and similar issues were being raised repeatedly in the patient interviews to that point, we were able to safely cap these initial interviews at 12 participants (7<18yrs; 5>18yrs). We are currently reviewing transcripts, and compiling themes for discussion and exploration at the next stage – which will be small group discussions (i.e. focus groups) for validation of the themes identified so far. We will hold two focus groups of seven: one for each age group. The groups will be held at the Calgary Eating Disorder Program and include some of the participants from previous interviews and some new participants.

Spring



Upon completion of the review of existing generic Quality of Life instruments we are now assessing the burden associated with completing the battery in a pretest. These five instruments: SF-12 (1995), 16-D Health related QL (1996), Quality of Life Inventory (1994) will be used in the national field test to validate our new instrument in addition to the Eating Disorder Inventory (1991) and Beck Depression Inventory II (1996). Our goal in selecting these instruments was to balance health related questions with questions that also address the broader components of quality of life (e.g. friends, school) and to validate the items/domains in our new instrument that are developmentally specific to adolescents.

Next Steps... We're beginning to prepare ethics forms for the respective programs from across Canada that will take part in Phase III—the testing and validation of the Eating Disorder Quality of Life Scale (EDQLS). We'll be in touch with those individuals who have confirmed interest in participating and will be organizing a teleconference as soon as all programs are confirmed and initial steps for ethics review have been taken.



While collecting program information from various ED services across Canada, many clinicians and researchers have expressed interest in connecting with others across the country. Preliminary discussions have suggested developing a National clinical and research network for Eating Disorders. One possibility would be to come together for a one-day symposium on the topic to identify the interest and need for such a Network. *Let us know what you think.*



Please forward any questions or comments you have to the Principal Investigators:

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