

Issue 1
May 2003



QUALITY OF LIFE IN EATING DISORDERS PROJECT

Newsletter

The Quality of Life in Eating Disorders Project (EDQLS)

We are pleased to present our first newsletter for the Quality of Life in Eating Disorders Project to our community partners. We hope to share our progress with you and with each issue we will introduce you to each of our investigators and collaborators. The purpose of the newsletter is to keep interested individuals including policy makers, managers, clinicians and clients and families 'in the loop' about developments and progress. If you do not wish to receive further issues of our newsletter or if you know of others who might like to receive it in the future please contact Gisèle Marcoux (403) 210-8552.

The EDQLS project began in January 2003. A team of health service researchers and mental health professionals are working on a study to develop, field test and validate a Quality of Life (QoL) Measure for Adolescents and Young Adults with Eating Disorders.

For many years health care providers relied on change in symptoms alone to demonstrate improved health after treatment. Today we know that better health is much more than symptom improvement - and that the person's own perspective on how their health condition affects all parts of their lives (such as functioning at work and in relationships) is very important. Quality of life (QoL) questionnaires have been developed for many different conditions in the past 20 years to measure this broader impact of treatment. For ED there is currently no QoL instrument that examines how the broader aspects of a person's life are specifically affected by the illness and how they might improve with successful treatment.

Key staff and clinicians who provide services to clients with eating disorders in Alberta identified the need for this measure.

A three-phase project is proposed. We applied to and received funding from the Alberta Children's Hospital Foundation and the Calgary Health Region's Mental Health Research Fund for Phase 1: Development (systematic literature review, item generation and pre-testing), and Phase 2: Pilot Validation (local recruitment of 60 subjects) of this project. Ethics approval has also been received for phases 1 and 2.

We've also submitted funding proposals to the Alberta Heritage Foundation For Medical Research (AHFMR) for Phase 3: Field testing in which the Eating Disorders Quality of Life Scale (EDQLS) will be validated and tested for responsiveness using a time series design in a multi-site sample across several provinces.

Introducing ... The Investigative Team

The EDQLS project is headed up by co-principal investigators Dr. Marlene Reimer, University of Calgary and Dr. Carol Adair, University of Calgary and Alberta Mental Health Board (AMHB). The co-investigators are Carol Ewashen, University of Calgary; Dr. Brian Cram of the Calgary Eating Disorders Program, Calgary Health Region; and Dr. Sandra Ziolkowski.

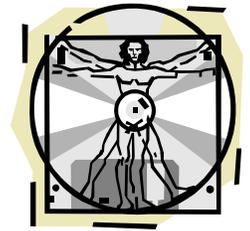


Left to Right: Gisèle Marcoux, Janet Chafe, Carol Ewashen, Dr. Marlene Reimer, Dr. Carol Adair, Dr. Brian Cram (absent: Dr. Sandra Ziolkowski).

The project coordinator is Gisèle Marcoux.

The current or past project collaborators include Dr. Phil Eaton, Calgary Health Region; Sandra Harrison, Darlene Harris and Fee Forbes from AMHB; and Janet Chafe of the Calgary Eating Disorder Program, Calgary Health Region.

OUR CURRENT ACTIVITIES



And just how are we getting started?

Our first step is Item Generation which consists of a systematic literature review and interviews with health professionals who have extensive experience working with the eating disorders population.

Our literature search is complete, 248 abstracts have been rated for relevancy on the topic of Eating Disorders and Quality of Life. We are currently ordering these articles and will be extracting 'themes' or attributes of quality of life from them to inform item development for the draft instrument.

Eleven health professionals were identified by Janet Chafe and Dr. Brian Cram, they are multi-disciplinary in nature and work at various eating disorder programs from across Canada. It is our hope that they will offer valuable insight, experience and perspective of the impact that disordered eating has on the quality of life of those affected. Interviews with these clinical experts will be transcribed and analyzed for themes which will also inform item development.

Our next steps include semi-structured interviews and focus groups with approximately 20 participants selected across a range of ethnic groups ages (14 and 25 years) with anorexia nervosa, bulimia nervosa, or EDNOS (Eating Disorder Not Otherwise Specified). This process will enable us to further refine and identify any additional domains and items.

“ You start the work of getting better, then things get better. Not a lot changes very quickly after that.”

Annie maintains that recovery is a slow process, but most people expect you to be completely well once your disorder is acknowledged, and you've decided to get well. It just doesn't work that way. Everything doesn't just get better when the person starts eating again; a lot more has to change.

After having serious health problems ...with my heart and kidneys, I faced the ultimatum, was I going to listen to my body or my eating disorder. ~Michelle

Now I'm living at home, going to college, and I'm still having all of the same thoughts pertaining to food and exercise. At least my mood is better and I love being social now. ~ Alison



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

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The Co-Investigators include clinicians and researchers from the University of Calgary, the University of Alberta, and the Calgary Eating Disorder Program: Dr. Carol Ewashen, Dr. Brian Cram, Dr. Sandra Ziolkowski, and Janet Chafe.

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