

HealED Together: EVALUATING THE EAST KOOTENAY PEDIATRIC EATING DISORDER PROGRAM

EVALUATION SUMMARY REPORT

A. PROJECT BACKGROUND AND PURPOSE

The East Kootenay Pediatric Eating Disorder Program has been in operation for approximately five years. A product of the East Kootenay CYMHSU Collaborative, it was developed to provide local treatment for youth with significant, health compromising, eating disorders. The intention of the program is to enhance access to high quality team-based care and to improve communication between youth, caregivers, and health care providers. The program ensures that treatment is provided in one location at a single appointment.

While anecdotally the program appears to be successful, it has never been evaluated and there may exist opportunity to expand optimum processes. Shared Care, in conjunction with the EK Division of Family Practice, was asked to support an evaluation of the East Kootenay Pediatric Eating Disorder (ED) Program. Results of this evaluation will provide a deeper understanding into the experiences of youth, caregivers, and health care providers associated with the EK Eating Disorder Program, and will inform the development and implementation of effective quality improvement processes.

B. EVALUATION METHODOLOGY

During phase one of this project, logic models of the eating disorder program were developed and used to inform the project evaluation tools, namely, a series of interview questions for youth, caregivers, and health care providers connected to the ED program. An online survey was also designed to assess East Kootenay General Practitioner eating disorder and program knowledge.

We are now in phase two of the project where the interviews and surveys have been conducted, summarized, and are being shared. More specific methodology is presented in each of the Interview Summary Reports by Respondent Groups appended below.

C. EVALUATION FINDINGS

STRENGTHS OF THE EATING DISORDER PROGRAM

DEDICATED PEOPLE PROVIDING HIGH QUALITY CARE...

- Service providers are dedicated and caring
- The program provides high quality, evidenced-based, specialized, eating disorder care
- The program serves as a “Model of Care” for other communities and has drawn interest across British Columbia
- Intervention happens early, quickly, and with a high level of intensity
- Service providers stay current and are active in ongoing education initiatives despite a lack of support for this
- East Kootenay General Practitioners are 100% willing to refer to the program and value its work
- The service providers themselves developed the program idea, process, and put it into practice; they are proud of the service they provide

LOCAL CARE

- Youth and caregivers have access to local specialized care
- Community eating disorder awareness is growing

IMPROVED LOCAL HOSPITALIZATIONS

- Local hospitalizations are coordinated and quality of care is improving once admitted

DECREASED TERTIARY CARE REFERRALS

- Introduction of the program reduced tertiary care center referrals from 100% to 10%

CLEAR CARE PATHWAYS

- One appointment, every two weeks. Youth and caregivers are not responsible to navigate an unfamiliar and cumbersome system for months at a time during a very difficult and stressful time in their lives
- No need for caregivers to co-ordinate care amongst health care providers

TEAM BASED CARE:

- Communication and Collaboration:
 - One voice. All team members, including the youth and caregivers, hear the same message at the same time
 - Effective case collaboration amongst ED team members
- Support:
 - Team members are supported by each other while treating a challenging, demanding, and often long term, illness
 - Many youth and caregivers expressed feeling supported by the ED team
 - ED team members learn from one another
- Work Satisfaction:
 - Providers reported they enjoyed being part of a supportive team’
- Workload:

- Overall, the program process tends to decrease service provider workload demands

GAPS/CHALLENGES ASSOCIATED WITH THE EATING DISORDER PROGRAM

YOUTH AND CAREGIVER SUPPORT

- Expressed Needs Not Part of Current Program
 - Support group options for the youth, caregivers, and family members
 - In home support
- Role Clarity
 - It is unclear who's role it is to provide family systems support and how to coordinate this care: the ED Team versus CYMH Team?
 - CYMH clinicians unsure of their role in support for youth engaged with the ED clinic
- Distance is a barrier to service for youth and caregivers who live in outlying communities

PROGRAM AWARENESS AND UNDERSTANDING

- Youth and caregivers experienced high levels of anxiety prior to their first clinic visit
- Youth found the first visit particularly intimidating and scary
- Youth and caregivers arrived to their first appointment with little understanding of the program and its demands
- Despite it being short, the wait time between being referred and the first appointment is a particularly stressful time for youth and caregivers
- Youth and caregivers suggested that having more information about what to expect would ease fears
- Referrals to the program often lack important information

EATING DISORDER TREATMENT MODEL

- The ED Clinic uses a family-based treatment approach. This is known to be best practice, and is well supported by the users and providers of the ED Program. In order to be accepted into the eating disorder program the child/youth must be accompanied by a caregiver who is able and willing to provide support at home
 - Not everyone fits this model
 - It is our most vulnerable youth who do not fit
 - Not all youth can identify a caregiver capable of support
- Children and youth who do not fit this model are currently managed in collaboration by their general practitioner, a CYMH clinician, +/- a dietician.
 - Eating disorder knowledge of East Kootenay general practitioners is low to moderate
 - General practitioners also expressed low to moderate comfort, and confidence, levels in the treatment of eating disorders
 - The ED service providers and collaborative team members wonder if this is best practice and if not, is there another way to support these youth?

THE PHILOSOPHY OF CARE

- Youth are confused about their rights in regard to their treatment planning
- CYMH Clinicians identified struggling in how to support a youth/caregiver in a program that does not necessarily feel voluntary
- Some youth and caregivers expressed the experience of:
 - feeling judged and not believed
 - feeling like team members were aligning against them
- Some youth and caregivers felt that needs went unmet due to:
 - a perceived lack of what felt to be an individualized treatment approach or,
 - a lack of flexibility in treatment approach
- CYMH Clinicians identified struggling in how to support a youth/caregiver in a program that does not necessarily feel voluntary

COMMUNICATION PATHWAYS

- Few opportunities exist for case collaboration and information sharing amongst the ED team and other service providers
- CYMH clinicians are unsure of the communication pathway, and boundaries, with the ED team
- Inconsistent/conflicting information sharing among pediatricians with youth and caregivers

OTHER NOTABLE POINTS:

- There are no patient reported experience measures (PREMs) in place
- There is currently no advisory committee to the Eating Disorder Program

D. FACTORS THAT IMPACT CHALLENGES:

Service providers highlighted:

- Funding and resource limitations

Youth and caregivers highlighted:

- Communication/relationship issues with service providers

E. OTHER IMPORTANT FINDINGS

INDIGENOUS YOUTH PARTICIPATION

During this evaluation process, service providers noted that there is very little Indigenous youth engagement with the EK Pediatric Eating Disorder Program. The questions being asked by service providers included:

- Is the prevalence and severity of eating disorders in local indigenous youth the same as non-indigenous youth?
- Why are Indigenous youth not being referred to the clinic?

- Is there a barrier to eating disorder care experienced by Indigenous youth?
- Do local Indigenous youth experience eating disorders the same way non-Indigenous youth do?

As part of this project, a number of partners in care were approached for insight into this observation . The following are their responses:

1. Outreach and Education Coordinator at NEDIC (National Eating Disorder Information Centre):
 “As with many things, our Indigenous communities are underserved when it comes to eating disorders and we haven’t come across any statistics on the prevalence of the condition among Indigenous youth despite our trying.”
2. BC Provincial Eating Disorders Network: (includes representatives from Kelty Mental Health, BC Children’s Hospital, Looking Glass)
 They note the same experience across BC: (all information is anecdotal)
 1. Prevalence is lower in terms of Indigenous youth that access or are referred to ED clinics compared to non-Indigenous youth
 2. This finding is mirrored in the acute/tertiary care settings
 3. The feeling is the numbers are not reflective of the population incidence however, due to acute admissions being lower it is likely the prevalence of ED’s is lower in Indigenous youth populations.
3. Wellness Team Leader, Ktunaxa Kinbasket Child and Family Services in Cranbrook:
 - i. ED services have not been accessed (other than the odd referral) because there has not been the need
4. Nurse Practitioners, Interior Health/Ktunaxa Nation
 - i. After conducting four years of health screening with ?Aq’am youth where they measured height and weight they did not find very many ‘underweight’ youth
 - ii. A number of complex barriers to care exist for Indigenous populations for accessing any kind of health care service

*Further exploration into this topic is needed.

(* Addendum June 19th: since these questions were asked and the responses provided, a number of further conversations and meetings have happened to explore this further)

E. QUALITY IMPROVEMENT IDEAS AND PROCESSES

East Kootenay Pediatric Eating Disorder Program quality improvement ideas and processes will be summarized following the Eating Disorder brainstorming meeting scheduled for April 14th. Ideas will be shared back with meeting attendees as well as project stakeholders.

F. PROGRAM SUSTAINABILITY

As part of this project, an information sharing session has been conducted to increase program awareness and build stronger relationships between pediatricians and family doctors in the region.

Funding capacity remains an issue for physicians who are not salaried.