RESEARCH ARTICLE

Setting the Eating Disorder Aside: An Alternative Model of Care

Kim D. Williams[1]*, Tracey Dobney[2] & Josie Geller[1,3]

[1]St. Paul's Hospital, Vancouver, British Columbia, Canada

[2]Vancouver Coastal Health, Vancouver, British Columbia, Canada

[3]University of British Columbia, Vancouver, British Columbia, Canada

Abstract

Eating disorder treatment typically involves psychotherapy, structured programmes to normalize eating behaviours, and weight restoration. Unfortunately some individuals who receive these treatments do not recover. The Community Outreach Partnership Program (COPP) was developed to address the needs of these individuals. Using a team approach which combines both community and hospital services, COPP assists clients increase their quality of life by fostering independence, increasing hope and enhancing social skills in the context of the client's economic, social and physical living environment. Preliminary outcome research reveals significant improvement in eating disorder and psychiatric symptoms in individuals who complete four or more months of COPP.

Keywords

eating disorders; chronic; motivational interviewing; harm reduction; quality of life

***Correspondence**

Kim D. Williams, Eating Disorder Program, St. Paul's Hospital, 1081 Burrard St., Vancouver, British Columbia, V6Z1Y6, Canada.

Tel: 604-682-2344 (62260). Fax: 604-806-8631.

Email: kwilliams@providencehealth.bc.ca

Published online 22 January 2010 in Wiley InterScience (www.interscience.wiley.com) DOI: 10.1002/erv.989

Introduction

Eating disorder treatment has as its goal the reduction of eating disorder thoughts and behaviours. Although many individuals with eating disorders benefit from programmes that focus on symptom reduction, some individuals refuse intensive treatment, drop out from treatment, or relapse soon after discharge. As a result, eating disorder symptoms such as low body weight, dietary restriction, episodes of bingeing and purging or maladaptive thoughts about shape and weight persist for years or even decades. Long-term eating disorder outcome studies indicate that 30% of patients are non-responsive to treatment and that 30–42% of individuals who become weight-restored following treatment go on to relapse (e.g. Ratnasuriya, Eisler, Szmukler, & Russell, 1991; Strober, Freeman, & Morrel, 1997; Pike, 1998).

The following is an example of an individual who has made several treatment attempts, with little or no long lasting symptom relief:

> *Lauren was diagnosed with anorexia nervosa, restrictive subtype at the age of 16 following an acute childhood illness during which she lost weight. Lauren was an extremely shy child and experienced difficulties fitting in with her peers. Following her illness, she said she no longer felt hungry and refused to eat, despite her parents' coaxing at meal times. She remained underweight and began a rigorous running program. Between the ages of 16 and 21, Lauren was*

hospitalized several times for medical complications due to extreme weight loss. Her admissions frequently occurred in response to her parents' or physicians' concerns, and rarely in response to her own expressed wishes. Lauren complained that her parents over-reacted to her low body weight and that she was 'fine'. Although she did not want to gain weight, upon persuasion of her parents and caregivers, she completed two courses of intensive residential eating disorder treatment in which she achieved a healthy body weight. Within a year of completing each program however, she returned to her previous low weight, or lower. At the age of 22, Lauren continued to exercise compulsively and her weight reached an all time low. Although her parents encouraged her to remain in treatment, she frequently missed appointments, and argued with care providers when they suggested that she needed to be admitted to hospital for weight gain.

An alternative to recovery focused treatment

In situations like Lauren's, it is common for care providers to continue offering treatment focusing on symptom reduction despite this approach's failure to produce long-term improvements to health or well-being. In an attempt to better address the needs of patients like Lauren, an initiative was taken to develop a new model of care for this group. As a first step, clients with longstanding eating disorders were invited to attend a weekly support group to discuss their treatment experiences and to explore treatment approaches they thought would be beneficial. Key points identified by the group included:

- Improving quality of life while living with an eating disorder.
- Decreasing anxiety and depression symptoms.
- Increasing autonomy.
- Increasing hope for the future.

Based upon these recommendations, The Community Outreach Partnership Program (COPP) was launched. The programme was designed to offer an alternative to recovery-focused treatment for patients who have not benefited from traditional approaches. COPP was designed to assist individuals like Lauren form more productive connections with care providers by ensuring that treatment goals are matched to participants' wishes and providing treatment that focuses on improving quality of life and increasing independence. In other words, a shift *away* from focusing on the eating disorder and *towards* increasing quality of life, reducing distress and increasing hope for the future. A comparison of the approach used in COPP with recovery-based treatment is provided in Table 1.

The Community Outreach Partnership Program

The COPP is an outpatient service that is jointly operated by staff of a hospital-based eating disorder programme and a community-based mental health rehabilitation team. Therefore, COPP is able to provide specialized medical, nutritional and psychiatric services in a community setting. The programme provides patients with access to a multidisciplinary team, including a psychiatrist, medical internist, outreach counsellor, case manager, dietitian, programme coordinator, family therapist and eating disorder programme nurse.

The role of the outreach counsellor is central to the COPP programme. Unlike typical eating disorder interventions, the goal of treatment is not necessarily to reduce or eliminate eating disorder behaviours. Instead, a harm reduction approach is used, in which client and outreach counsellor work together to reduce

Table 1 Comparison of recovery focused treatment with the Community Outreach Partnership Program

	Recovery focused treatment	COPP
Goal of Treatment	• Recovery	• Increase quality of life • Harm reduction
Who sets goals?	• Treatment team	• Client
Therapy focus	• Symptom Reduction and/or abstinence • Education about risks of symptoms	• Symptom management to reduce harm; skill development • Understanding benefits and risks of symptoms
Pace of treatment	• Determined by programme	• Determined by client
Treatment milieu	• Therapist's office	• Client's community

harms resulting from eating disorder behaviours and increase client quality of life. Examples of treatment goals include reducing the client's dependency upon hospitalizations, slowing down weight loss or stabilizing a low weight, bingeing on foods that are less harmful (e.g. not bingeing on raw meat, pet food or food from the rubbish bin), and containing time spent on eating disorder behaviours in order to reduce their impact on daily living. The outreach counsellors meet clients in the community, typically once a week. Outreach counsellors come from a variety of educational backgrounds including counselling psychology, nursing and social work. A full-time outreach counsellor sees up to 20 clients in 1 week, resulting in efficient use of treatment resources.

Other staff members are available (i.e. family therapist, internist, nurse, psychiatrist, dietitian) on a consultative basis. For example, the dietitian in COPP sees clients who have expressed an interest in reducing eating disorder symptoms. This work is also done in the community, for instance in the client's home, a restaurant or at a community agency. It may involve food/nutrition related skill building, teaching and/or discussion regarding strategies to reduce eating disorder behaviours. Outreach counsellors support nutritional goals on a practical level by providing assistance with grocery shopping, meal support, menu planning, meal preparation, problem solving and supportive counselling.

In COPP, team members work to develop and maintain a strong working alliance by incorporating a motivational interviewing stance (Geller, Williams, & Srikameswaran, 2001) such that treatment is tailored to the client's stage of change (Miller & Rollnick, 2002). Motivational interviewing is intended to foster a relationship that increases client self-awareness and self-acceptance, and place responsibility for change in the hands of the client. Central to this stance is the care provider conveying their belief that the eating disorder exists for a reason and recognizing the extent to which the eating disorder symptoms fulfil a valued function in the life of the individual. By using a curious, non-judgmental approach, this stance promotes a deeper understanding of how the eating disorder has helped the client, which can, in turn, help validate and clarify the client's ambivalence towards change. Within the context of such a relationship, clients have an opportunity to consider alternate views of themselves and their experiences, which in turn promotes greater understanding, acceptance and the desire to improve their lives.

Amy had severe bulimia nervosa for over 20 years. At the time of her referral to COPP, she was bingeing and purging several times per day. She expressed intense shame and guilt for these behaviours and isolated herself from family and friends. With her COPP dietitian, Amy was encouraged to examine her behaviours and discover how the eating disorder uniquely functioned in her life. For instance, she learned that her eating disorder behaviours helped her cope with overwhelming unpleasant emotions. In her discussions she became more accepting of herself and appreciated that change would take time. This decreased her sense of paralysis and allowed her to experiment with new ways of managing her difficult feelings.

In addition to its reliance upon harm reduction and motivational principles, COPP also incorporates principles from psychosocial rehabilitation. That is, COPP recognizes the importance of environmental factors, meaningful work or activity, and skill development (Zahniser, 2005). According to this model, the focus is on healthy functioning, and on building strengths and abilities. Psychosocial models advocate providing treatment in the community, enabling staff to understand the client's life context and to provide appropriate treatment suggestions, goals and or skill development exercises. Community is defined by the client and examples can include church, friends, family, school, work, and/or a community centre. The philosophy of COPP is to build a support system that is less dependent upon hospitalizations and health care providers and increase environmental or community supports and resources. COPP also focuses on skill building and problem solving as ways to increase client independence. By actually doing meaningful and productive activities while using effective life management skills, positive self-esteem and client autonomy is fostered.

Jane wanted to have more fun in her life. Her outreach counselor helped her identify things she liked to do, and to explore what had prevented her from engaging in these activities. In the course of these discussions, Jane decided to take an art class. However, she was afraid to go by herself. Initially, her counselor accompanied her to a drop-in drawing class, and over time, Jane was

able to go on her own. She discovered that once she overcame her anxiety of trying something new, she appreciated the opportunity to develop a new skill. She decided to take a more intensive, weekly, three-hour art class, but encountered a new barrier; her poor nutritional status was impacting her ability to stay focused throughout the session. At that point, Jane decided to increase her caloric intake in order to improve her experience of her art class.

This is an example of how a client may work on a personally meaningful goal (attending art class), while at the same time, decreasing eating disorder symptoms. Examples of other COPP activities are included in Table 2.

In order to balance these harm reduction treatment goals with the need to ensure client's safety, COPP makes use of treatment non-negotiables, or mandatory treatment components. These non-negotiables are established on a case-by-case basis according to the client's needs, and are mutually agreed upon prior to the client enrolling in the programme. COPP workers ensure that non-negotiables have a sound rationale that is explained to the client, are implemented consistently, and maximize client autonomy (Geller & Srikameswaran, 2006). For example, clients are required to attend medical or psychiatric appointments as recommended by their physicians, in order to ensure client safety while working in the community (e.g. medication monitoring, electrolyte repletion, hospitalization). If clients do not follow through with attending such appointments, the outreach counsellor may as a first step, accompany the client to the appointment. If the client continues to refuse to attend the appointment, he/she would be 'stepped out' of COPP until seeing the appropriate medical professional. In implementing treatment non-negotiables, client autonomy is maximized by providing a menu of options. For instance, for individuals who are medically unstable, a number of choices, including brief hospitalizations to reduce imminent danger from symptoms, outpatient nasogastric refeeding or meal support in the client's home, may be offered. COPP does not provide palliative care.

Julie had anorexia nervosa, binge-purge subtype for 16 years. She had been hospitalized involuntarily several times for weight restoration and electrolyte repletion. In her initial meetings with COPP workers, Julie described having been traumatized by the forced weight gain, and said that the repeated hospital admissions perpetuated an ongoing cycle of anger, depression and rapid weight loss upon discharge. Furthermore, she found herself isolated and unwilling to engage in social activities. She felt that her ongoing battles regarding boundaries with care providers prevented her from understanding her

Table 2 Examples of COPP activities

General life skills	• Finding appropriate housing • Career/school exploration • Time management • Incorporating leisure activities into daily routine • Self care • Budgeting • Parenting
Social functioning	• Assertiveness training • Conflict resolution • Boundary setting • Improving interpersonal relationships
Emotion regulation	• Relaxation • Mindfulness • Grounding
Nutritional management	• Keeping food records • Use of distraction to delay purging • Normalizing eating • Meal planning and preparation • Grocery shopping
Psychiatric symptom management	• Managing anxiety and depression • Techniques to reduce self-harm • Sleep hygiene

Table 3 Description of questionnaire measures used in the evaluation of COPP

Domain	Measure	Description
Psychiatric symptoms	Brief Symptom Inventory (BSI: Derogatis & Spencer, 1982)	Provides a global severity index score in relation to outpatient psychiatric norms
	Beck Hopelessness Scale (BHS: Beck, Weissman, Lester, & Trexler, 1974)	Assesses hopelessness about the future, expectations and loss of motivation
Eating disorder symptoms	Shape and Weight Based Self-Esteem Inventory (SAWBS; Geller, Johnston, & Madsen, 1997)	Assesses the influence of shape and weight on feelings of self-worth
	Health Inventory Questionnaire (HIQ; Geller et al., 1997)	Assesses the presence and severity of disordered eating
Quality of life	Quality of Life Inventory (QOLI: Frisch, Cornell, Villanueva, & Retzlaff, 1992)	Assesses life satisfaction from the patient's perspective

difficulties and being able to work on goals that were meaningful for her.

In COPP, Julie agreed to maintain her weight at a low, but safer level, while being regularly monitored by her physician. It was initially decided that recovery would not be a goal. In order to maintain her predetermined low weight, Julie either increased her oral intake or used outpatient or in-patient naso-gastric tube feeding. As a result of the more conservative goals around weight, power struggles diminished, and a more positive rapport was built between Julie and her care providers. Most importantly, once Julie was free from the anxiety of involuntary hospitalizations, she had time to think about other areas in her life. She began considering a career change and recognized that in order to do so, she would need to increase her weight.

Julie has been able to maintain regular contact with the COPP team and to follow up with medical appointments. When asked to describe what was most helpful about the treatment she received, Julie wrote the following:

'The key factor in motivating me to change my negative outlook and increase my propensity to challenge anxious and depressive traits has been the relinquished agenda of forced treatment in exchange for a non-threatening and comprehensive, interactive treatment plan…The recognition of my limitations and boundaries, and the understanding that threatening them and attempting to remove them is not only of no personal benefit or advantage, but extremely detrimental. An agenda that seeks nothing more than to provide support, one that meets me where I'm at psychologically, recognizes my boundaries, and enables me to work to my best possible advantage within these boundaries not only endows me with a richer life, it allows me life itself'.

Outcome evaluation

Outcome research assessment began at the inception of COPP in 1995. The areas assessed were based on the initial goals of the programme; to decrease distress, increase hope, and increase quality of life. Eating disorder symptoms were also evaluated. The outcome measures are described in Table 3 and were completed upon admission (baseline), annually, and at the time of discharge. Thirty-one COPP clients completed the measures at least twice. For 18 individuals, discharge assessments were used. Time in programme for this group ranged from 4 to 53 months, with a mean of 25.64 months. Thirteen participants were still in programme at the time of this analysis, and their most recent annual assessment was used. Time in programme for these clients ranged from 12 to 96 months, with a mean of 33.69 months. Table 4 describes COPP participants.

Table 4 Description of COPP participants

Diagnosis	
Anorexia nervosa (AN)	15 (48%)
Bulimia nervosa (BN)	3 (10%)
Eating disorder not otherwise Specified (EDNOS)	13 (42%)
Body mass index (BMI)	16.17 kg/m^2 (3.16)
Age	31.07 years (8.63)
Age of onset	15.76 years (5.45)
Duration of eating disorder	15.23 years (8.15)

Table 5 Baseline and post scores for psychiatric symptoms, eating disorder symptoms and quality of life

Domain	Baseline (*SD*)	Post† (*SD*)	*t* score
Psychiatric symptoms			
BSI global severity index	59.28 (9.86)	53.34 (11.22)	3.20**
Beck hopelessness scale	13.07 (4.98)	10.93 (5.82)	2.31***
Eating disorder symptoms			
SAWBS weight and shape	157.44 (82.14)	95.19 (59.38)	2.63*
SAWBS intimate relationships	28.88 (43.02)	69.25 (60.23)	−2.91*
Body mass index	16.15 (3.21)	17.39 (4.27)	−2.61*
Health inventory questionnaire	43.12 (15.82)	32.36 (15.39)	2.72**
Quality of life			
Quality of life inventory	23.00 (14.71)	25.93 (14.96)	−0.97

Note: BSI = Brief Symptom Inventory, SAWBS = Shape and Weight Based Self-Esteem.
† Refers to discharge or annual score. * $p < .05$; ** $p < .01$; *** $p < .001$.

Results

As shown in Table 5, COPP clients reported high levels of global distress, hopelessness and eating disorder symptom severity at baseline. At the second evaluation, there were significant improvements in global distress scores, hopelessness, BMI and eating disorder symptoms. COPP participants also reported increased importance of relationships, and decreased importance of shape and weight, as determinants of self-esteem. Interestingly, there were no significant differences on the QOLI, which was surprising given the programme's focus on enhancing quality of life. This may be due to the time period being too short to detect change, the QOLI not being sensitive to change in this population or to clients' quality of life standards improving over the course of treatment (thus making improvements more difficult to detect). Future outcome evaluation addressing these issues is warranted.

While further research is needed, these preliminary outcome results are promising, and suggest that programmes using this alternative model of care may be of benefit to these individuals.

Conclusion

The COPP is an innovative outpatient eating disorder treatment programme developed to work with individuals who have not benefited from traditional intensive treatment. Instead of focusing on reducing eating disorder behaviours, the programme uses principles from psychosocial rehabilitation, motivational interviewing and harm reduction to improve the client's quality of life *while* living with an eating disorder. Using a team-approach which combines both community and hospital eating disorder programme services, COPP assists clients identify and work towards goals that are meaningful to them. Preliminary outcome results indicate that individuals in COPP experience significant eating disorder symptom improvement, shifts in cognitive/affective domains, increased value on relationships, and decreased hopelessness and distress.

Acknowledgements

This research was supported by a grant from the Canadian Institute of Health Research IMPART Training Fellowship awarded to the first author and by a grant from the Michael Smith Foundation for Health Research awarded to the third author.

Portions of this manuscript were presented at the 2008 National Conference on Collaborative Mental Health Care in Victoria, British Columbia.

References

Beck, A. T., Weissman, A., Lester, D., & Trexler, L. (1974). The measurement of pessimism: The hopelessness scale. *Journal of Consulting and Clinical Psychology*, *42*, 861–865.

Derogatis, L. R., & Spencer, P. M. (1982). The brief symptom inventory (BSI): Administration, scoring, and procedures manual. Towson, MD: *Clinical Psychometric Research*.

Frisch, M. B., Cornell, J., Villanueva, M., & Retzlaff, P. J. (1992). Clinical validation of the quality of life inventory.

A measure of life satisfaction for use in treatment planning and outcome assessment. *Psychological Assessment*, *4*, 92–101.

Geller, J., Johnston, C., & Madsen, K. (1997). The role of shape and weight in self-concept: The shape and weight based self-esteem inventory. *Cognitive Therapy and Research*, *21*, 5–24.

Geller, J., & Srikameswaran, S. (2006). Treatment non-negotiables in the eating disorders: Why we need them and how to make them work. *European Eating Disorders Review*, *14*, 212–217.

Geller, J., Williams, K. D., & Srikameswaran, S. (2001). Clinician stance in the treatment of chronic eating disorders. *European Eating Disorders Review 9*, 365–373.

Miller, W. R., & Rollnick, S. (2002). *Motivational interviewing. Preparing people for change*. New York: Guildford Press.

Pike, K. M. (1998). Long-term course of anorexia nervosa: response, relapse, remission, and recovery. *Clinical Psychology Review*, *18*, 447–475.

Ratnasuriya, R. H., Eisler, I., Szmukler, G. I., & Russell, G. F. (1991). Anorexia nervosa: Outcome and prognostic factors after 20 years. *British Journal of Psychiatry*, *158*, 495–502.

Strober, M., Freeman, R., & Morrel, W. (1997). The long-term course of severe anorexia nervosa in adolescence: Survival analysis of recovery, relapse, and outcome predictors over 10–15 years in a prospective study. *International Journal of Eating Disorders*, *22*, 339–360.

Zahniser, J. H. (2005). Psychosocial rehabilitation. In C. Stout, & R. Hayes (Eds.), *The evidence-based practice: Methods, models and tools for mental health professionals*. (pp. 109–152.) Hoboken, NJ: John Wiley & Sons.