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Title: Establishing the True Costs of Anorexia Nervosa: Asking Those Affected

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Introduction:

Anorexia nervosa (AN) is a serious illness with significant physical and psychological effects that impact on relationships and finances. It is defined by an intense fear of weight gain and a disturbed body image, leading to a restriction of food and severely low bodyweight. Research abroad has indicated direct and indirect costs (eg. treatment, disrupted education/employment) are substantial and long-lasting. Data from New Zealand is needed to establish the costs for those locally affected.

Aim:

To identify and measure the costs experienced by a national sample of those with a lifetime history and carers of someone with AN.

Impact:

To our knowledge, this is the first study to gather a range of costs associated with AN in New Zealand. Our findings have potential for informing healthcare services about experiences of those affected and will contribute to a larger project examining costs of eating disorders in New Zealand.

Method:

To recruit those with a lifetime history (over age 16) and carers of someone with AN, an online questionnaire was publicised through EDANZ (the Eating Disorders Association of New Zealand) and via social media channels (Twitter, Facebook). The survey, based on studies in Australia and the United Kingdom (Butterfly Foundation report, 2012; Beat report, 2015), asked about symptom duration, treatment pathway and quality and impacts on work and study, family and relationships. Carers completed a parallel version.

Results:

Of 58 healthcare consumers, the average age was 22 and over 90% were Caucasian female. Symptom onset was typically at age 14. It took 6 – 12 months for 35% of consumers to seek help but 30% took 12 months or more. Half the specialist referrals were wait-listed but most were seen within six weeks. Inpatient admissions lasted 2 – 4 months, outpatient 1 – 2 years, on average. Relapse occurred for 37%, and 15% relapsed multiple times. The average duration of AN was 7 years.

Most participants rated the quality of treatment as average or better, but a sizeable minority were not happy with treatment received. Feedback for improvements included wanting a choice of therapist and therapy type, more specialist services and trained staff and a focus on more than weight-restoration.

An average of 4 – 5 associated health problems were reported, including high rates of anxiety (84%) and depression (71%), digestive (36.5%), dental (21%), and cardiac issues (21%), further increasing health costs.

Participants reported median out-of-pocket expenses per year of \$3500 for private treatment and \$500 for travel-to-treatment. Relocation or overseas travel to treatment centres costed thousands or considerably more.

Very significant impacts were felt in areas of well-being and quality of life for almost all consumers and carers, as well as in their relationship with each other. Partners, family, and social life were also significantly affected for the majority.

Work and/or study suffered 50% loss of productivity, with consumers needing 4 – 6 months off and carers taking two months off, on average. Longer absences meant having to drop out to focus on recovery, thereby delaying or losing opportunities to gain qualifications, income and social connections.

Conclusion:

Participants in this study resemble other treatment seeking samples in New Zealand and elsewhere in terms of early teen onset, predominance of females and symptom duration. Relative to the United Kingdom (Beat report, 2015), the time to seek help, wait-list duration and relapse rate are less in New Zealand. Though feedback about treatment quality is comparable, productivity loss and absenteeism are higher in New Zealand than in Australia (Butterfly Foundation report, 2012). Challenges in accessing treatment, like travel to major centres, may mean related health issues arise adding complexity and cost to that of AN.

The current practice of briefer admissions or outpatient treatment and lack of choice of therapy modality are seen as problems by a number of participants (consumers and carers). Some felt the need to seek other treatment, evidenced by the high costs of private treatment. Limitations of this preliminary study is that it is small and publicly-funded treatment costs for AN in New Zealand are excluded from these current analyses. As well, the study uses an online methodology with self-selected participants, many of whom described significant costs but found it difficult to quantify these financially. Rather than use retrospective recall, prospective collection of costs data would give better accuracy.

In conclusion, participants reported major effects on study, work, family and personal lives. Changing priorities to cope with the illness adds pressure on relationships and loss of earning potential for carers, but especially for those with AN, is likely to be substantial and long-lasting given the duration of illness. Improving early recognition of symptoms, continuing to improve the treatment pathways and acceptability of treatment for those affected are key to minimising longer term impacts.