

The Experiences and Needs of Carers and Families Living with an Eating Disorder



Research conducted by the Project Management Group
in a partnership between
beyondblue: the national depression initiative
and The Network for CARERS of People with a Mental Illness

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Eating Disorders Include:

- Anorexia Nervosa
- Bulimia Nervosa
- Binge Eating Disorder
- EDNOS (Eating Disorders Not Otherwise Specified)

Prevalence

Eating Disorders have the third highest mortality rate for adolescents and are the most lethal of all psychiatric illnesses.¹ After obesity and asthma, anorexia is the most common disease in females aged 15-24.² It is generally estimated that in Australia 2-3% of adolescent and adult females satisfy the DSM IV diagnostic criteria for anorexia and bulimia nervosa.³ The incidence of bulimia nervosa in the general Australian population is 5 in 100.⁴ The prevalence of Binge Eating Disorder in the general population is estimated to be 4%.⁵ Onset of anorexia is generally in adolescence, with bulimia and binge eating more likely to first occur in late adolescence or early adulthood. The long-term nature of these disorders means that many people carry these conditions well into their adulthood. Bulimia and Binge Eating disorders are by nature, secretive. It is common for people with bulimia to keep their disorder hidden for 8-10 years, at great cost to their physical and psychological health.⁶ It is estimated that only one in ten cases of bulimia nervosa are detected.⁷ Average duration of anorexia is 5 years.⁸ 20% of 18-22 year old Australian women have symptoms of Binge Eating Disorder.⁹ The incidence of Binge Eating Disorder in males and females is almost equal.¹⁰ Of those experiencing an eating disorder, one in ten are male.¹¹

Common Comorbid Conditions

Psychological conditions associated with eating disorders include: depression, anxiety disorders (commonly obsessive compulsive disorder), borderline personality disorders, substance and alcohol abuse.

The physical complications caused by prolonged mal-nourishment, vomiting, use of laxatives and emetics are numerous: reduced bone density and osteoporosis, infertility, kidney dysfunction, low blood pressure, anaemia, hair loss, cardiac irregularities, low body temperature, erosion of tooth enamel, oesophagitis, heartburn, enlarged salivary glands, electrolyte imbalance resulting in cardiac arrhythmia, muscle fatigue and cramps, bowel problems, chronic constipation or diarrhoea.

¹ The overall mortality rate for anorexia is 5 times that of the same aged population in general (depression = 1.4), with death from natural causes being 4 times greater (eg cardiac arrhythmia, infection) and deaths from unnatural causes 11 times greater (depression = 7). Risk of successful suicide is particularly high being 32 times that expected (depression = 20). ¹ Mortality rates for anorexia nervosa after 20 years are between 15-20%. Beaumont, P. Cited in *The encultured body* p 80 School of Nursing Queensland University of Technology 2000

² Beaumont, P. Cited in *The encultured body* p 80 School of Nursing Queensland University of Technology 2000

³ Cited in *The encultured body* p 6 School of Nursing Queensland University of Technology 2000

⁴ (Women's Health Queensland Wide Fact Sheet, 2.021 1997 in Sanders et al, *Body Image, Sex Role Stereotyping and Disordered Eating Behaviours*, University of Queensland, 1995)

⁵ Wilfley, D., Agras, W., Telch, C., Rossiter, E., Schneider, J., Cole, A., Sifford, L., & Raeburn, S. (1993) cited in Howell, P (1999) *Information on Eating Disorders for Health Practitioners*. EDFV, Victoria)

⁶ *Understanding Eating Disorders*, Women's Health Queensland Wide Inc and The Eating Disorders Association Inc Resource Centre, 1997)

⁷ *Through the Looking Glass*. Newsletter of the Eating Disorders Association of Queensland, Vol 3, Issue 11)

⁸ Beaumont, P. Cited in *The encultured body* p 81 School of Nursing Queensland University of Technology 2000

⁹ (*The Australian Longitudinal Study on Women's Health* conducted by Universities of Newcastle and Queensland. Commenced 1996)

¹⁰ (Paxton, S. (1998) *Do men get eating disorders?* in *Everybody*. Newsletter of Body Image and Health Inc. Vol 2, August 1998)

¹¹ Paxton, Susan (1998) "Do Men Get Eating Disorders?" in *Everybody* – Newsletter of Body Image and Health Inc. Vol 2 August 1998, pg 41

Carer Definition

The term 'carer' in this document is used to refer to those people, directly affected by or having a significant role in the life of a person with an eating disorder because of kinship, or regular and significant informal contact.

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We would also like to thank Dr Ross King, Senior lecture, Department of Psychology, Deakin University for his contribution to the literature review and forthcoming academic publication.

The Project Management Group are also grateful to those carers who so willingly came forward and shared their deeply personal stories. Their invaluable contribution has enabled us to gain an understanding and great appreciation of carers' experiences when living with, and caring for, a person with an eating disorder.

The contribution of these carers has enabled us to contribute to and extend upon the existing body of knowledge surrounding issues that carers face when living with and caring for a person with a mental illness.

Partners' Perspectives

The Network for Carers of People with a Mental Illness

As Chair of the Network for Carers of People with a Mental Illness (the Network), I am delighted to write a foreword for this preliminary report.

The Network is the peak carer body in Victoria within the Mental Health Community and has within its membership organisations and groups that provide day to day support to carers and their families. We also have family carers as active members who bring a practical, hands on experience to our decision making process.

The Network and *beyondblue: the national depression initiative* have joined together in partnership in order to explore the impact of living with High Prevalence Disorders (i.e. eating disorders, anxiety disorders and depressive disorders) on primary carers and families. It is reasonable to say there has been very little attention paid to carers of family members with these disorders until now. It is our expectation that the findings, and the potential outcomes relating to policy and service changes could have a significant influence across the broad service delivery area.

I wish to refer you to the foreword written by Ms Karen Elford from the Eating Disorders Foundation of Victoria, an active Member of the Network, who will articulate a practical and realistic perspective on this important project.

I wish to take this opportunity to express the appreciation of the Network to *beyondblue* for their support in both financial and human resources, and particularly Dr Nicole Highet and Ms Marie Thompson for their commitment and professionalism. Also a big thank you to the Project Management Group, who in true volunteer style have contributed many hours and lots of energy to achieve the pleasing outcome of this project.

In commending the report to you I trust that it will not be the *end*, but in fact the *beginning* of new innovative policies and practices that will provide *real* support and assistance for the carers of people experiencing High Prevalence Disorders.

John McGrath
Chair of the Network for CARERS of People with a Mental Illness

Eating Disorders Foundation of Victoria

Encompassing a spectrum of behaviours and symptoms, eating disorders are high prevalence conditions with the highest mortality rates of all psychiatric disorders, yet research into their impact on individuals and effective treatment is in its infancy. The experiences and needs of family members, friends and other carers are similarly under-researched; less than a handful of studies worldwide document the consequences of these debilitating illnesses on those who are at the frontline of caring – namely the families and friends of those affected.

Eating disorders pose particular issues for carers. Myths and misunderstandings abound and there is great stigma and secrecy associated with the conditions. Eating disorders often go misdiagnosed or undetected for long periods, exacerbating the problems associated with accessing treatment and care. The nature of the conditions also means sufferers are often unable to play an active role in the initial stages of their recovery. A universally successful model of treatment is yet to be developed and current health resources disallow a comprehensive spectrum of treatment provision. Eating disorders are complex conditions with both psychological and physical consequences; treatment and support needs to occur across several domains with medical, nutritional, psychological and social support all critical factors in resilience building and recovery. Accordingly, carers often find themselves undertaking multiple roles – mother, father, partner, sibling, friend, educator, researcher, case manager, support person, to name a few.

This study aims to describe and document the lived experiences and needs of people who care for others affected by eating disorders. The information from the project will be disseminated as widely as possible to increase understanding amongst the general community, health providers and policymakers about the important role this group of people plays and the lack of resources and supports available to them. Ultimately the goal is that the findings and recommendations from this study are translated into policy developments and a commitment to resources that will result in addressing the unmet support needs of both carers and the family members and friends they care for.

Karen Elford
Executive Officer
Eating Disorders Foundation of Victoria

beyondblue; the national depression initiative

beyondblue is proud to fund and work in partnership with the Network on this important research project. This project is fundamental to the work of *beyondblue* in a number of respects. First it contributes to our broader goal pertaining to *consumer and carer issues* as it examines the impact disorders related to depression (such as eating disorders) and the significant impact that these illnesses have on not only the consumer, but also the carer and their family. Second, the project contributes to the great need for ongoing *research* into the lived experience of these disorders, adding to the growing body of research that *beyondblue* has undertaken to date in this area and across a number of disorders. Third, research such as this has important implications for *healthcare reform* in Australia and *beyondblue* as with other key organisations and departments, is strongly committed to advocating for improved mental health services in Australia. Finally, and very importantly, the project is indicative of *beyondblue's* strong commitment to working in partnership with other key organisations such as the Network whose consistent dedication and enthusiasm for this project has resulted in a comprehensive report encompassing a range of important perspectives.

The invaluable contribution of the carers who came forward and shared their stories has enabled us to derive what we believe to be, a unique and comprehensive understanding of the needs and experiences of carers who live with persons with eating disorders. Following the initial phase of the research *beyondblue* together with the Network will continue to ensure that these findings are taken forward: to ensure that the voices of carers living with eating disorders are heard and to work collectively with The Network and other key groups in order to improve their experiences, quality of life and wellbeing.

Leonie Young
Chief Executive Officer
Beyondblue: the national depression initiative

Executive Summary

beyondblue and the Network for CARERS of People with a Mental Illness recognise that mental health disorders have a significant impact upon those experiencing them. This impact has led to the generation of clinical and academic attention in the area. However, when considering the experiences and needs of families and friends *living with* and *caring for* these persons, this experience continues to be unrecognised, underestimated and largely ignored. This is highlighted by the minimal Australian and international literature that currently exists pertaining to the needs and/or experiences of carers of people with high prevalence disorders.

In response to this, *beyondblue* and the Network aim to collaboratively explore the experience of carers living with persons with high prevalence disorders, namely eating disorders, anxiety disorders and depression. Across the spectrum of these illnesses, the project seeks to identify the needs of carers particularly, address the issues which are increasing their burden of care, and suggest ways in which this burden may be alleviated.

This document constitutes the first in this series and specifically explores the issue of caring for a person with an *eating disorder*. By gaining insight into the experience of caring for a person with an eating disorder, this research not only highlights the impact of the disorder on the carer and other family members, but importantly provides strategic direction for both clinical practice and healthcare policy reform.

From a research perspective, as highlighted in the literature review, the present study makes a unique contribution to the existing body of research. In particular, the methodology, or research approach has enabled us to explore the *process* of the illness from the carers' perspective, over time. This has provided a unique level of insight into the carers' experience across the *stages of illness*. This has led to the production of three extensive papers, each of which explores the experience of carers, from the initial stages of detection and recognition of an eating disorder, through to accessing treatment services.

Paper one, *The Detection and Identification of Eating Disorders: "How did it get to this stage?"* reveals *how* early signs and symptoms of a disorder are often unrecognised by families and health professionals, allowing the disorder to progress over time and in severity. In addition, the carers' experience when coming to realise the presence of an eating disorder in a family member is explored and discussed. This paper has important implications with respect to highlighting the need for *increased community and professional awareness and understanding* about eating disorders, and how this is vital to the areas of *prevention and early intervention*.

Paper two, *The Experience of Living with an Eating Disorder: The Carer's Perspective*. "*Walking on eggshells*" provides an in-depth analysis of how the symptoms and associated behaviours of the illness can have a profound impact upon the carer and other members of the family. This paper reveals how this disorder affects relationships and family life, and how accessing treatment places significant demands on the carer and other family members. In addition to highlighting the significant personal, social and economic burden that an eating disorder can have, this paper highlights how an absence of support further compounds this experience. Again this has important implications for *community awareness* and the provision of *education* and *social support* networks and services. These are vital to establishing a more socially aware and responsive community and to reducing carers' and families' isolation, confusion and distress, which would significantly alleviate the burden that carers currently experience.

Paper three *Accessing Treatment and Support for a Person with an Eating Disorder and their Family: The Carer's Experience* focuses specifically upon the carers' experience of accessing treatment services. The paper highlights the numerous barriers to accessing services, and exposes inadequacies of primary care and specialist mental health services. Ultimately these deficiencies of the healthcare system compound the duration and severity of illness, increasing the burden of care for the family even further. This paper has important implications for *health service* and *policy reform*, as the paper highlights a critical need to ensure the provision of more effective and efficient services not only for the consumer, but also for the carers who are ultimately left to shoulder the burden.

This project represents the formation of an important and unique partnership between *beyondblue: the national depression initiative* and the Network for Carers of People with a Mental Illness. It is through the combined efforts and dedication of the Project Management Group that we have been able to derive a unique and comprehensive understanding of the needs and experiences of carers who live with persons with eating disorders. The Project Management Team would like to thank those carers who came forward and allowed us to explore and gain insight into the carers' experience.

In particular, the Project Management Group identifies the following specific conclusions and implications for reform:

- Detection of an eating disorder in a family member was impeded by the secrecy associated with the illness and misattribution of symptoms by families and health professionals which allows the disorder to progress without recognition over time and in severity. Early symptoms were commonly only recognised in hindsight.
- Increased community awareness about signs and symptoms of eating disorders would facilitate detection, early intervention and the supportive capacity of the community. Ultimately this could reduce the isolation and increase the level of support for carers, thus reducing their burden of care.
- On recognition of an eating disorder in their family member carers experienced a range of responses including shock and disbelief at the presence of the disorder, coupled with guilt and blame as they question their own possible contribution to the development and progression of the illness. On recognising the profound potential impact of the illness on the individual and the family, carers also expressed grief and fear for the future. It is crucial that these experiences and needs of carers are recognised and addressed during this stage by the provision of information and referral for support.
- Eating disorders had a profound impact upon all areas of life. Living with a person with this illness impacted upon relationships as it altered family dynamics, reduced the level of intimacy, led to social and emotional distancing, and restricted social relationships for families and other carers. Furthermore, there were significant financial costs related to not only accessing treatment, but also to the demands of specific aspects of the illness (e.g. binge eating).
- Additional costs incurred by the carer and family include the carers' commitment, time and effort required to access effective treatment, which was not only a frustrating and disheartening experience for carers, but also led to significant time away from the family and ability to continue in employment.
- As eating disorders have physiological and psychological implications, the person who is unwell may become increasingly frail and vulnerable, which can be highly distressing for the carer as

they witness a deterioration of their family member while simultaneously feeling helpless and powerless to prevent it. Meanwhile carers feel largely unsupported by other family members, friends and often health professionals, placing their own mental and emotional well-being at risk.

- The carers' experience is compounded by difficulties encountered when accessing effective treatment for their family member. A number of barriers exist including: lack of knowledge and awareness of eating disorders, limited availability of information, inadequate awareness and skills among health professionals, the absence of early intervention or effective crisis management, waiting lists, lack of appropriate services and costs associated with treatment and exclusion of carers from the treatment process.
- Carers' and families' need for support, information and guidance during all stages of the disorder must be recognised, so that support services and networks for carers in metropolitan and rural areas can be adequately funded, available and accessible.
- Health professionals should aim to educate themselves about carers' needs and concerns, and adopt a more inclusive approach to treatment and management. Specialists should aim to educate carers about the disorder and its management, provide information about appropriate carer and family services and eligibility for assistance including mutual support groups and financial entitlements.
- There is an obvious need for greater community awareness and understanding about the nature of eating disorders and the significant impact on the lives of those who live with them. This is likely to not only reduce the stigma for the person with the disorder and their family, but is also likely to increase the level of empathy and support provided to carers.

Following this initial phase of the research the partnership between beyondblue and the Network will continue to ensure that these findings are taken forward, and that the voices of those who live with, and care for persons with eating disorders in Australia are heard, their needs are addressed, and the lived experiences of carers are significantly improved.

Methodology

Six focus groups (three groups, each consisting of two sessions) were conducted with primary carers of people with an eating disorder (both anorexia nervosa and bulimia nervosa) in rural and metropolitan Victoria, Australia. Between six and eight people were initially recruited to attend the focus groups (each of two hour duration) with a total of twenty people participating. As most of the focus group participants consisted of parents of adolescent girls with an eating disorder, four additional depth interviews were conducted to provide a more representative population sample. These depth interviews included friends or a partner of adults with an eating disorder. Additionally, one participant from a focus group submitted a written expression of their experiences.

The final sample (N=24) were recruited by advertisements in related newsletters, through support groups, local newspapers and radio, together with liaison with local mental health professionals.

Five open-ended questions were asked consistently across the groups and interviews:

- 1) What were the first signs of something being wrong that you noticed?
- 2) What effect has the disorder had on you emotionally, physically, socially, financially?
- 3) What effect has the disorder had on your family life and family relationships?
- 4) What were the difficulties and barriers in obtaining help?
- 5) What do you need from health and mental health professionals and services that would help you in your caring role?

All focus groups and depth interviews were recorded with permission given by the participants, and transcriptions were made to enable thematic analysis. Two researchers conducted thematic analysis independently in order to ensure reliability and results were analysed using the qualitative NUDIST thematic analysis program.

Paper One

**The Detection and Identification of Eating Disorders:
“How did it get to this stage?”**

The Detection and Identification of Eating Disorders: “How did it get to this stage?”

Introduction

The present paper serves to outline the experience of carers when suspecting, identifying and acknowledging an eating disorder in a family member or close friend. There has been limited research examining the process of identification, particularly from the carer's perspective. In response to this, the current research aims to explore the carers' experience as they begin to recognise and accept the presence of an eating disorder in a friend, partner or family member.

Results

The first signs that something was not quite right

When asking carers to reflect on the initial process around identifying signs of an eating disorder in a family member or partner, a range of physical, psychological and behavioural indicators were identified and described. While the number and nature of these symptoms may vary in magnitude and/or order of presentation, carers were rarely able to recognise these signs within the context of an eating disorder at the time: their significance was only recognised in hindsight.

In turn, this lack of recognition often resulted in the condition becoming quite progressed before any intervention was sought. In addition, those living with the person with an eating disorder experienced considerable difficulties, confusion and frustration, which over time had a profound impact on the relationships within and outside of the family unit.

Through detailed qualitative exploration of the process and experience of carers with respect to ***detecting the presence of an eating disorder*** in a family member, this paper aims to highlight:

- i) the process surrounding the identification of an eating disorder,
- ii) the factors which inhibited early identification of an eating disorder,
- iii) the impact of these processes on the carer and other family members.

Behavioural Signs

Many carers were able to identify a number of specific *behaviours*, which alerted them to the fact that something was unusual, and possibly a cause for concern. For some carers the behavioural signs were markedly apparent, with the sufferer engaging in extreme eating behaviours and/or exercise regimes. For others, however, this was only recognised in hindsight.

(i) Preoccupation with food

One of the earlier warning signs noted by some carers in hindsight was that the person with the eating disorder became *fascinated* by food. Often this was demonstrated by the *constant reading of recipe books*, and/or continually wanting to *cook for others* or being *involved in* or *taking control of the cooking process*. At the time however, this was only likely to be perceived as a new interest, being helpful, and nothing out of the ordinary.

“She is a fantastic cook and she would cook fantastic food ... but it was always for us.”

“They are very obsessive about food, yet don’t want to eat it themselves – so having to prepare it for other people.”

“She wanted to cook more food, I’m not huge on cooking and she would say ‘can I do that for you?’. So I didn’t have a problem with that. She had always been really helpful at home ... I didn’t even take any notice of it. I just thought she was giving me an extra hand.”

It was only in hindsight that carers recognised this preoccupation with food. In many instances this preoccupation was camouflaged by the person with the disorder focusing the attention around eating on others in the family, hence diverting attention from themselves.

“What really drew my attention was the fact that she was trying to feed everyone else. I’d question my other daughter why she wasn’t eating and she’d say ‘Kate has been feeding me ever since we came home from school.’”*

As the disorder progressed, this fascination was often seen to become more obsessional. Carers reported that the person with the disorder would be *fussy or rigid* about *what foods* were purchased, the *ingredients* they contained and *how they were prepared* and *when food is eaten*.

“With everything you buy, they check the labels ... they read all the packets, read all the contents.”

“My daughter wanted to watch what I was doing, to make sure I wasn’t putting any oil in.”

“My daughter used to come shopping with me just to see what I would buy, but I don’t know whether the vegetarian thing was an excuse to read all the packets ‘oh this has got animal something or other in it.’”

This need for control over food and/or the cooking process would often cause considerable friction as the family complied, catered and conformed to the dysfunctional requirements of the eating disorder. Over time these obsessional behaviours sometimes caused frustration and friction between family members.

“She would cook her own food, and I would just for peace sake, let her.”

“We went to the supermarket once, he (my son) wanted to buy half a dozen iced donuts – he’s a growing lad, she wanted to buy ten packs of jelly because she was living on them. She wasn’t getting them, she wouldn’t buy him those donuts, but she bought some jelly ... my son seems to be intolerant, he didn’t get angry, because he doesn’t get angry so much, but he says she’s such a sook – she cries over everything – she cries over jelly – WHO CRIES OVER JELLY?!”

(ii) Food and eating related behaviours

Catering for these obsessional thoughts, in order to satisfy the need to control food and eating, resulted in a number of specific behaviours. In the case of anorexia, this included *refusing to eat* what had been served, *hiding food*, being *selective about the types of food* that they would eat, *insisting that they cook their own food*, *avoiding meals* with family or friends, and/or having *minimal food intake*.

"Then I realised she is not eating – I hadn't noticed that before ... I did notice that she wasn't not eating what we were eating."

"For the first few weeks she'd say 'I don't want potatoes with dinner' and then it would get 'don't give me so many peas' or 'that's too much chicken'. Just very gradually she was doing that sort of thing."

"She had been on a trip, and three days into the trip they rang me up said that she had not been eating at all."

"We'd go to visit her and notice yoghurts in the fridge and that's about all – or leftover food in cupboards. Lots and lots of leftover food where she would take a bite out of something and leave it somewhere else – nothing was totally finished."

As a result this led to the first stages of social withdrawal from the family as the person with the disorder avoids eating situations which otherwise may have been an important time for social cohesion and interaction.

"She would not eat with us as a family. She used to be in her room all the time - it wasn't a real situation."

"The withdrawal from having dinner with us and being very selective about what she was eating."

The need to isolate oneself from the family was often disguised by conveying a need to engage in other activities, hence allowing the person to avoid mealtimes while drawing minimal attention to their absence.

"But she wouldn't sit with us as a family – she would come out and eat hers later. She'd be in her room saying – 'oh, I'm doing my homework' or 'I'm doing something.'"

Despite the withdrawal or rigid behaviour around eating, carers were often only able to recognise these signs in hindsight, as such behaviours would be attributed to other factors. For example, refusing to eat certain types of foods was attributed to *being fit and/or healthy* and/or trying to obtain a *more healthy/ideal weight or becoming vegetarian*. At the time, these were likely to be considered as a trend or a phase, usually within adolescence and hence no cause for significant concern or alarm.

"She just decided that she was going to start eating healthily and I didn't think there was anything wrong with that."

"You think she's eating fruit, she wants to be healthy. You don't think that there's actually anything going on."

"I foolishly thought it was because she was doing netball – I thought she wanted to be fitter – you don't think of those things. And then I thought she was getting healthy, eating an apple instead of potato chips – 'oh good!'"

"I thought she was just being very selective, she had become vegetarian and not having bread or rice or carbohydrates, and just eating really small amounts."

"I never really noticed her problem with fats or anything, it was more so because 'I want to be a vegetarian'. I don't know if that was an excuse because she is not one now (a vegetarian)."

Similarly, in the case of those suffering from bulimia, this would also involve *refusing to eat* with the family, *irregular eating patterns* as well as other behaviours such as *gorging food*, and going to the *bathroom* immediately following a meal. Often even these more extreme behaviours were disguised, hidden or denied by the person with the disorder, preventing detection of a disorder by the carer.

“So we went through a stage when she wouldn’t eat, you’d have your food, she’d come out later and eat hers - scoff it down – she ate everything with bread. She’d come and she would gormandise her food, and I mean gormandise it. And then later on she would disappear and be sick.”

“My daughter would go to the bathroom at the same time every night, turn up the music loud so that you couldn’t hear anything. That was when she was sicking, being sick all the time. In the shower or in the basin in the bathroom.”

“I had no idea what could be wrong with her. Eventually at my sisters wedding, one of my other sisters came out and said to me – ‘Ruth is in the toilet, it sounds like she is being sick.’ I went in there and said ‘what’s wrong?’ She said ‘that vegetarian thing was just horrible. I just threw up because it was so horrible.’ We would never have thought about it after that.”*

In turn this behaviour perpetuated isolation and social withdrawal from family members.

“She would go out at night ... she would come home at one or two o’clock in the morning and gorge then – she would just eat at night (when we were in bed). There was no pattern at all to her eating so she would never eat in public. It just affects everybody in the family.”

(iii) Exercise behaviours

Another common behaviour noted by many carers of people with eating disorders was that of *excessive physical exercise*. Again initially a number of factors prevented this behaviour being viewed in the context of a disorder. In particular, the sufferer would *hide* or be *secretive* about it, and/or *minimise the extent* and/or *intensity* so as not to attract attention or alert the carer to any obsessional thoughts and/or the presence of a disorder.

“One night in the summertime I had the air-conditioning going and I could just hear something and of course she couldn’t hear me going up to her room ... I switched the light on and she was in bed, late, doing sit-ups in bed!”

“She was also leaving the house during the night...she was running at night, so she was sneaking out and if you caught her, she was wet, saturated, and just said that she couldn’t sleep.”

“I’d go in there, open the door and say your tea is ready. She is on the floor, a lather of sweat and her stomach would be red raw just from pushing herself to the limit of exercising.”

“She used to go to her room, shut the door and say that she was doing homework, and she would be exercising ... she used to go to the toilet and shut the door and we would hear jumping.”

In the early stages, such behaviour was likely to have been attributed to health and fitness, which allowed such behaviours to be viewed within a normal context and prevented identification of any disorder.

"It's also very hard with exercise ...she has always loved her sport, so she had always played sport, so I didn't think her wanting to go the gym was anything unusual. They all do that – go through that phase so I didn't have a problem with that. But then I realised she was just getting in (the gym) and pounding herself so we had to stop that."

Physical Signs

(i) Significant weight loss

For others, these behaviours were so well hidden that the carer did not realise the presence of an eating disorder until it had manifested physically. In the case of anorexia, this was notably significant *weight loss*, which in some cases was rapid, but for others was a more gradual process.

"She lost the weight very fast, before I knew anything was happening, but we think for weeks she was not wanting to eat."

"It was a very slow, gradual weight loss, so I hadn't noticed it. And she's very tall, she's always been about a size 12. She didn't look sick or anything, she just looked quite comfortable."

The inability of those living with the person to see these initial signs was considered by participants to be due to the fact that when living with the person, and thus seeing them everyday, it was more difficult to notice any change. In some instances, when the weight loss was gradual, it was only apparent to the carer when external people and/or someone who may not have seen the person for some time, noticed a change.

"It's hard to remember what the first signs were ... I think it was probably about four or five months of very slow weight loss and the not eating and becoming more anorexic, but me not ever, ever knowing anything about it, and never knowing what to look for, what to expect, until three or four people on the same day phoned me and said Mary's lost a lot of weight."*

"She started a little bit of exercise, and I must say, that it was a gradual thing, and it probably wasn't until a family outing and my sister-in-law who hadn't seen her in while said 'I didn't recognise her- she's lost so much weight!'"

Despite these physical and hence visible signs, the person with the disorder would effectively hide their weight loss, in many cases by wearing *oversized, baggy clothing*. This ultimately enabled the disorder to become more progressed and remain unrecognised.

"She wore baggy clothes ... so we didn't realise."

"She always covered the body up, so with her natural round face she didn't always look so anorexic until she was on death's door."

"She's got tracksuit pants on, a big jumper on and probably two or three other items on under her jumper - and those are her summer clothes!"

"I would not have picked it, I could tell she was thin but she was really good at covering it - the extra jacket and thicker pants."

“There’s a lot of effort that goes into wearing bigger clothing, and it’s only when you give them a cuddle that you feel how tiny they are.”

Once again, this loss in weight was often attributed to factors associated with life stages and adolescence. For example, the physical change in body size may have been perceived as part of *maturation and normal physical development*, and hence not unusual.

“Early in year eight she had a bit of puppy fat, but we just thought it was puppy fat. ... Probably at Christmas our friend said ‘Oh, Jane’s looking good!’ but I still just thought she’s just lost her puppy fat.”*

Moreover, it was largely considered normal for girls to become more self-conscious about their bodies, particularly at a time when their bodies were changing with physical development.

“We first noticed a marked change in weight. It was fairly rapid, but at that age we thought it was just girls being teenagers.”

The detection process was considered to be further complicated when the person with an eating disorder was male, since such an illness is traditionally regarded as being more prevalent among females.

“I suspected what was wrong, not that I knew much about it because it’s a girlie disease, not thinking that it would affect a boy.”

Furthermore, often the person with the disorder living away from home served to prolong the detection process.

“But we didn’t know all this was happening until she came out and visited ... I could see all the shoulder bones and blades sticking out and when I hugged her to kiss her, I just thought, ‘Oh God, this has gone way too far’. – I could feel it!”

It was also noted that this move from home was sometimes deliberate, giving the person the freedom to continue engaging in specific behaviours related to their eating disorder, without the close scrutiny of family.

“She couldn’t adequately explain why she had to go, but I’m fairly sure that it had to do with her food regime. I think looking back, she couldn’t get any purchase on the food control, like she might have been hankering for.”

(ii) Physical distancing

In addition to social withdrawal, carers discussed signs of physical distancing, as the person with the disorder avoided *physical contact*. This distancing could be related to the reduced capacity of the person to express, or respond to, emotions and relationships in a constructive way due to the effects of the eating disorder and any underlying problems, and also potentially to avoid others noting any weight loss. In turn this impacted on the level of intimacy and affection, which could be shared between family members.

“Initially she was a very cuddly girl, and now she is very standoffish and withdrawn...she will hug us but we can’t come to her- it has to be on her terms, but she used to be a very affectionate, touchy, feely child.”

Again this distancing was often attributed to a life stage, in which adolescents may be perceived to be more moody, private and less likely to engage in public displays of affection, particularly with parents.

(iii) Lethargy and concentration difficulties

The lack of food and energy intake, sleep disturbance, changes in body chemistry caused by vomiting and over exercising often led to other physical indicators for both anorexia and bulimia, namely *tiredness, difficulties with concentration and poor information retention*. These in turn impacted upon performance at school, university and at work.

“I noticed how she was getting tired, that’s really the first thing ... just coming home from school and lying on the couch and not being able to do anything ... then I noticed she’s not eating – I hadn’t noticed that before.”

“During year twelve I would try and help my daughter a bit with some of her work, and the next morning, she couldn’t remember. It was affecting her ability to concentrate and remember. Again a sign that you wouldn’t have known, only in hindsight do you recognize.”

“A couple of her work associates rang and said that she wasn’t coping at work and that she didn’t eat any lunch.”

Over time, not only would this inability to concentrate or function impact on the ability to continue school, work or university, but also may have prevented the person from successfully concealing evidence of their disorder. Hence this enabled some family members to become acutely aware of the presence of an eating disorder.

“I found ice-cream containers full of vomit in the garden and in the bedroom. If she was really thinking rationally she would have thrown it away.”

Other observed physical signs mentioned included abdominal pains, poor circulation and over the progression of the disorder, changes in menstrual cycle were apparent, but naturally difficult for carers to detect.

Psychological Signs

In addition to the above behavioural and physical signs of an eating disorder developing, there were also a number of psychological indicators that the person was in distress. In some cases these psychological signs were the first evidence of an eating disorder.

“We didn’t really notice a big difference until we saw mood swings and depression and anxiety – she had the whole lot.”

(i) Depression

Depression was commonly identified as a sign by many of the carers in our sample. The existence of depression was considered to have resulted in further withdrawal from others, and for many was an early warning sign that something was not right.

"I noticed that she started to withdraw from her friends at school. As it went on a bit, she really didn't want to be there. It was the friends thing I tended to notice at the time, but then again, I didn't know at the time that that was part of the illness – I had no idea!"

In addition to withdrawing to conceal evidence of a disorder, in many cases this social distancing and isolation may have increased the likelihood of developing depression, compounding depression and/or progressed the eating disorders.

"For us it wasn't (a sign) at first, but it became a sign. Our daughter was also extremely popular, always had kids around, but during year twelve, she started to push her friends away, and in fact now doesn't have any friends from our home town. She had so many friends. These kids knew something was happening, but they didn't know what it was. No one knew what was going on, but she was behaving in such a way, that in the end, they just withdrew from her, and she wanted that because that allowed her that freedom."

Hence the nature of eating disorders was reported to not only alienate the sufferer from the family, but also friends and social networks.

"It's a very lonely disease."

Other reported signs suggestive of depression included *low mood, cognitive distortions, low self-esteem and deliberate self-harm*. In some cases these signs were observed in the context of depression, while in many cases they were not recognised at all.

"She said herself that she was depressed. Her depression predated the anorexia, but I didn't notice that she was depressed."

"They can turn from the minute you speak to the words they hear – they have turned it right around in a different way...they put a negative slant on everything, self loathing, and the wish of death."

"It wasn't picked up that she had depression, and yet, of course as a parent you don't sort of realise what depression is. We talked often and it appeared to me...to be just teenage girl problems – thinking she wasn't attractive and thinking she was fat and that nobody liked her, and yet she looked as if she was popular. She gave the appearance that she was full of confidence."

In some cases mood swings and/or low mood was likely to be attributed to hormonal changes as part of adolescence or PMT, as opposed to a psychological problem.

"We didn't even know the mood swings were there...and they're at an age when they're changing anyway."

Becoming aware of these psychological aspects of the disorder was distressing for the carer. Carers expressed the great sadness they felt at observing a person they care for obviously suffering.

"And that's where it's so frustrating again because you've got a beautiful, intelligent, funny, great person and yet she is just so down on herself and can't see all of those things that everyone else can see."

(ii) Anxiety and the obsessive compulsive nature of eating disorders.

Carers also commonly reported signs of anxiety in the person, which may or may not have been viewed within the context of an eating disorder. Often anxiety and obsessive thoughts would be observed in

relation to everyday situations or events (e.g. being a perfectionist or high achiever). It is when these symptoms of anxiety occurred and impacted on other behavioural and physical aspects of the disorder, that the signs of an eating disorder per se seemed to become more apparent. Over time the anxiety would often escalate to the point where the person could no longer retain control over their compulsions, preventing behavioral signs from being contained or hidden.

It was at this point that carers often became aware of the behavioural signs of an eating disorder. In particular, obsessions pertained to and impacted upon behaviour related to exercise and food.

“She got these two chicken breast fillets out, chopped every bit of fat off it, chopped it up into small pieces, cooked it in a fry pan and then put it in the colander and put it under the hot tap, and kept washing it, and washing it and washing it, making sure she would get the last bit of fat out.”

“One hour walking, and if she's got to study, you'll find her walking down the road with her notes in her hand studying, because she still does so well. High distinctions. And an hour of something else and then it will be back to the hour of exercising...My daughter would do one hour slots and my sister said to me, ‘what's this one hour this, one hour that, it's so annoying.’”

“I remember one day we were walking down the street, she used to do circles around the post, people used to think that she was really trying to draw attention to herself - the obsessive compulsive.”

Often this anxiety not only impacted directly on the person with the eating disorder, but was also seen to have more far reaching consequences on other family members.

“When my daughter started to control me, I thought and I still think that anxiety controls her and then it controls us. Because she's so panic driven you get sucked into that. Things that you wouldn't normally get involved in... My life was revolving around her phone calls. But I knew I saw her as trying to control me as the anxiety was controlling her, her way of coping.”

(iii) Personality traits.

Many carers frequently reported personality traits in their family member, which in hindsight they considered to be possible indicators that something that was not quite right. These traits related to their family member being an extreme *perfectionist* and/or a *high achiever*. At the time such factors were seen only as facets of character and not a cause for concern; thus hindering the detection process.

“She was a sensitive child, a high achiever, a perfectionist.”

“It's interesting to hear how many others that are suffering are high achievers. ... I just thought it was part of who she was, didn't think anything of it.”

“Her need to be perfect is so great.”

Recognising the Signs in the Context of an Eating Disorder

It was only when the disorder progressed and the signs became more *prominent in number* and/or *severity*, that some carers started to consider the possibility that there may be an eating disorder. However, by this time, the eating disorder would usually have become quite progressed and established.

In some cases this led the carer to then seek other forms of evidence to confirm or refute their suspicions, either through directly asking the person or trying to observe behaviours. This process often created feelings of distrust and resentment, as the carer was desperate to try and understand the problem and make sense of unusual behaviours.

"I used to follow her to the toilet and I used to think I'd better take my shoes off so that she wouldn't hear me creep up. It's amazing the antics you put yourself through to protect your child."

"There was an outside loo, and I used to run out, I felt so silly for doing this. I used to run out of the front door. I was spying on my own daughter! How does it feel when you are spying on your own daughter? ... And then it was the laxatives, I used to run around to the toilet, I'd get down there and she'd go 'I know you're out there mum.'"

"I knew something was wrong when I found her diary. It's not good for a mum or dad to look in their daughter's diary, but when you know that your daughter is doing 'something' and there is something triggering it off, and the fact that she came home very depressed from school."

"You look, you check, you're watching all the time. I used to watch her all the time – and she knew, and she hated it. She'd say 'stop watching!', 'you've been listening – haven't you?' and I would say 'Yes I have been, and I know what you are doing.' And, I would check her bags, but I was probably more confrontational with her."

In response to this, some carers attempted to confront the situation directly by asking about the unusual behaviours. This was seen to often result in feelings of animosity and distrust, ultimately creating conflict within the family unit.

"I tried to talk to her about it...and she gave me a blast. She was furious at me."

"I'd say to her 'you've been sick' and I'd confront her, and she used to hate that, that I would know and I suppose she thought that I was watching all the time."

In other cases, despite warning signs, it was not until others pointed out signs of the disorder that carers actually considered the possibility that an eating disorder may exist. Even in such instances the carer would sometimes deny the notion that an eating disorder may be present.

"It was actually my other daughter that kept saying to me – there's something wrong with her. She even used the words 'she's anorexic mum, she's anorexic!' And I really couldn't see that."

"You turn off. I turned off because I didn't want to believe there was a problem."

Thus, the recognition process is probably best understood in terms of the carer, over time, putting together the pieces of a puzzle and finally being able to see the bigger picture.

"The change in weight, the obsession with food...the obsession with running and keeping fit ... and when you put it all together, you think, hang on, that's all fitting a pattern."

"Why was this going on, and then it all fitted in to a pattern all the time ... it all seemed to come together."

“Oh my God, that’s what it is!”

“...you wouldn’t have known, only in hindsight do you recognise.”

Recognising an Eating Disorder – The Emotional Impact on the Carer.

Once the signs were recognised in the context of an eating disorder, often an intense and complex psychological reaction would ensue. For some, there was an initial sense of *relief* when the physical, behavioural and psychological signs had finally been accurately contextualised.

“I felt relief, relief that there was a name to this weird behaviour.”

When reflecting on the process, many carers described *disbelief* that they did not detect that something was wrong much earlier.

“It’s all very well in hindsight to look back and see signs – but I didn’t think anything of it at the time.”

“I felt negligent that we’d missed it, and it had happened right under our eyes...why didn’t we pick this up earlier – how did it get to this stage?”

Despite the presence of several signs pointing to the presence of a disorder, actual realisation still evoked a *shock* response in many carers.

“When I found out about my daughter, I just felt as though I had been hit by a truck. I did the crying thing...I was devastated. I used to be a teacher and I used to teach about this sort of stuff with kids, but when it’s your own daughter, I just wasn’t ready for it.”

Another initial psychological response experienced was that of *anger*. At this stage carers for the most part were relatively uneducated about the disorder and some mistakenly believed the disorder to be a choice on the part of the sufferer.

“I cried. I was so distressed. I was angry with her. Why is she doing this to us? And then I started to blame myself, what have I done. It was guilt. Why can’t I do something?”

Feelings of *guilt* and *blame* often followed. This response was twofold. Firstly carers often blamed themselves for the emergence of the disorder.

“We all go through that, ‘what have I done, what have I done? Am I a failure or a bad mother?’ I haven’t listened, I didn’t see it, I didn’t know it was happening or whatever.”

“When something like this happens you think ‘what have I done wrong?’, ‘where did I go wrong?’... Could we have done something?”

“I kind of wonder if I pushed her there.”

Secondly, carers often reported feelings of guilt and blame because they had not been able to detect the disorder.

“I should have clicked.”

“And I didn’t click. Too involved in my own thing to realise that my kid is actually screaming for help.”

Carers in our sample also reported feelings of anxiety, apprehension and fear for the future. There were a number of aspects to this. Firstly carers expressed fear for the person, and the suffering that was likely to ensue for them in the future. Secondly, in some instances, the fear related to the carers themselves, namely concern that the disorder would take over to the detriment of family relationships.

“I felt really frightened, really really frightened for her future...but I was also frightened for me because I knew she was going to turn on me...I didn’t sleep for some nights because I was so frightened for her future because I knew it wasn’t looking good and I was frightened because I knew where I was going to have to fit.”

A sense of apprehension and grief were common among some carers in response to the possibility that the person they knew prior to the onset of the disorder may not return.

“My biggest emotion is the fear of Hannah never returning back as the Hannah* she was.”*

Discussion

As revealed in the above analysis, while there may be a range of possible indicators that an eating disorder may be present, there are also a number of factors that are likely to disguise its presence, hence making the task of detection difficult for carers. For example, changes in food intake and exercise were likely to be interpreted as healthy living while physiological changes (eg. weight loss) and psychological changes (eg. mood state) were frequently attributed to adolescence or other events. Furthermore, the behaviours which perpetuate the eating disorder make the task of detection even more difficult for carers, and ultimately impede the opportunity for early intervention.

Prior to detection of an eating disorder, before they have any knowledge or understanding of the illness, carers experience significant distress as they strive to recognise, understand and accept the impact that the eating disorder has on them and the family unit. In particular carers report experiencing anger and frustration in response to the early manifestations of the disorder, feelings which at the time may be considered appropriate as the behaviours are not known to be symptoms of a disorder. Rather, in the absence of information and support about the disorders, carers are likely to view the symptoms in the context of annoying and/or unreasonable behaviours/personality traits that others must live with, and in many instances accommodate, on a daily basis.

At the point of realising that a disorder may be present, carers describe experiencing shock and disbelief. These feelings are often further compounded by feelings of guilt and blame as carers contemplate their own possible contribution to the development and progression of an eating disorder.

As the disorder progresses, over time and in severity, carers realise the possible/likely implications of the illness. Carers express fear for the future and grief as they come to realise the profound effect that the eating disorder is having not only on the person with the illness, but also on the carer and the family. (For further information on the impact of the disorder on others, see paper two).

In conclusion, the current analysis of the detection process, barriers to recognition and the impact of this process on carers and families provides a deeper and more comprehensive understanding of carers' experiences and issues than reported in the existing literature. The level of detail derived from the qualitative data highlights a number of specific implications surrounding the issues of detection. Firstly, there is a need for greater awareness within the community about the incidence, and potential signs and symptoms of eating disorders, how they may present, and factors that may inhibit detection. In turn this may serve to enable more prompt detection of the disorder by people close to the sufferer and early intervention being sought.

It would be expected that this factual information and raised awareness would assist families to detect early signs of the disorder which would provide opportunities for early intervention, and possibly prevention of the disorders. This would also help to dispel misinformation about family or parental involvement in the aetiology of the disorder, and unhelpful notions that imply defectiveness in the family and/or person with the eating disorder. Reducing these stigmatising attitudes and ideas may help families to deal with the onset of the disorder more openly, and alleviate some of the negative feelings and conflict experienced by carers and family members as they come to terms with the disorder.

Secondly, the needs of carers themselves should be addressed during this early phase. As they may experience a range of possible responses (including shock, disbelief, guilt, blame, fear and/or anticipatory grief), carers need to be supported as they come to recognise and accept the presence of an eating disorder, and the potential effects it is likely to have on the person, the carer and the family. Peer support (such as support groups, help lines and support networks) and professional support (such as counselling and educational programs) are critical in these early stages of the illness and need to be

addressed through the provision of specific, specialised services and programs. Access to both quality information and support would ensure that carers are not left to struggle alone with the impact of an emerging eating disorder on themselves and their family, and would provide carers with a greater sense of control and direction as the disorder develops and takes hold.

Paper Two

**The experience of living with an eating disorder:
the carer's perspective.
“Walking on eggshells”**

The experience of living with an eating disorder: the carer's perspective. "Walking on eggshells"

Introduction

Living with a person with an eating disorder can impact upon the carer in many dimensions. We note in our previous paper how the process of detection of an eating disorder is distinct and hindered due to the behaviours which perpetuate the eating disorder. Carers reported a complex psychological reaction as they became aware of the disorder's presence.

This paper will identify the ways in which an eating disorder may impact on carers and other family members, and examines the experience from a carer's perspective of living with a person with an eating disorder over time.

Results

Carers reported that the experience of caring for a person with an eating disorder had a significant impact on many areas of life. These are outlined and detailed below.

The Impact on Relationships

(i) Family relationships

Following detection of an eating disorder, many carers described a significant impact upon family dynamics. Carers noted that while the carer is attending to the needs of the family member with an eating disorder, the needs of other members of the family were often relegated, as the eating disorder often became the primary focus, to the extent that their relationships with other family members suffered.

"When I think of my family, if I had a picture, it would be myself and my daughter standing out the front, and the others perhaps in the background."

"We were so consumed in Rachel and the illness, it was like Sam* was out there on her own. And I can see it now but at the time we were locked in. It was a very difficult time for Sam* in the sense that she was going through early adolescence herself and going through this hell on earth."*

"She's (sibling of child with eating disorder) also quite willing to believe we don't love her. She'll say 'oh, you don't care about me.' ...It will affect her for years to come unfortunately."

"But I do know that for me to be able to deal with Sarah, I do have to change the way I interact with my partner and my younger daughter ... I certainly can't give them as much time and I'm not as relaxed with them. If I can see that Sarah* is really trying and needs help, then I will give her help, time, space, and in doing that sometimes I isolate my partner and other daughter."*

"My wife gave up a lot of things because of it, and my family ... they lost me, because I was spending a lot of time with him (my friend with the eating disorder), it looked like I was prioritising the wrong way."

"It has impacted on my relationship (with my partner), ... it's the despair that he feels at seeing what happens when Ruth lives under our roof, which is why she never will again. And at what happens to not only my relationship with him but my relationship with my younger daughter, because my life is dominated by Ruth*."*

"We actually separated for a period."

Parents indicated that it was often hard to know where to put the boundaries around acceptable and unacceptable behaviour, given the distinct needs of a person with an eating disorder. Not only was this often confusing for the parent, but it also caused resentment among other siblings.

"Last year we had such horrible fights most nights ... and it's really hard to know how strong to be with your child because the behaviour you'd expect of the others, and then they see you as being lenient because you don't want these big arguments that you're never going to win. ... It's just awful."

In some instances, the illness progressed to such a stage that relationships with siblings became strained. At times the presence of the eating disorder caused feelings of jealousy and powerlessness in siblings, leading to irrational behaviours, disaffection and estrangement between siblings.

"One day I saw all this sugar at the bottom of this glass. Sarah would get Sue's* drink and put all this sugar in the bottom of a glass of lemonade, she was trying to feed Sue* up, and that hurt."*

"Emma has a flat stomach as most thirteen year olds do. She used to touch her and say I wish I had your stomach or I wish I had your hair. And she's always touching her and Emma* used to say 'I wish she wouldn't touch me'. She can't wait for Rachel* to go to uni because she'll feel free."*

Furthermore, carers reported a range of other reactions and feelings from siblings, which included anger, sadness and worry, social and emotional withdrawal, and in some instances, led to leaving home.

"Her brother cried and he'd say 'why is she doing it?' and he was really upset all the time."

"My son just didn't want to know about it. We'd talk and he'd just walk off."

"My other daughter was initially a bit angry I suppose, and ... thought 'well why didn't we stop it?' Angry that her sister had let herself get to this stage. Frustration's probably more the thing."

"(Her sister) found it very hard to deal with. She moved away from home and had a really hard time dealing with it all. And I don't think she could have come back to live at home, I think the house would have just exploded. Because you know, they don't understand what's it all about, 'why can't she just snap out of it?'"

For some carers the presence of an eating disorder was seen to hinder the development of a close sibling relationship, and prevented siblings from experiencing normal activities and interactions.

"They have lost their friendship, they lost it last year because her sister was no fun anymore. ... It was like having a total stranger in the house."

"There is sometimes a real sadness that she hasn't got a real sister; she's only got a sometimes sister."

In other instances where the person with an eating disorder was a partner/spouse, similarly the disorder had a profound effect. In particular, partners commented that there was a considerable change in the behaviour and personality of the person as a result of the illness. This served to significantly alter the relationship they had with their partner, leading some to question their position and desire to continue in the present relationship.

“It’s slightly different from caring for a child, this is someone I’ve chosen to be with ... so it’s hard, really hard ... and when we separated, in some ways it was a relief for me ... now I can concentrate on what I need to be doing.”

“I’ve gone through the whole thing of jees, maybe I’m just better walking away, but then I think well this is an illness that she has. ‘Would I do this if she had cancer or if she broke her leg?’ and the answer is of course no. ... I just want to see her as normal as can be ... whether I’m still married to her or not I don’t know. I’d love to be but if it doesn’t happen it doesn’t happen.”

In contrast, others suggested that the disorder actually strengthened the relationship they have with their partner, perceiving the disorder as an obstacle, which could be conquered together.

“Never once has there been a day where I’ve thought that we don’t want to be together or that this is too hard, what are we going to do, this always happens to us, or this is too hard or this isn’t fair. Ok, this is another little obstacle, we’ll get through it and keep going.”

(ii) Distancing

Carers also reported that the person with the eating disorder created distance between themselves and others around them, both physically and emotionally. This distancing appeared to be related to the reduced capacity of the person to express, or respond to, emotions and relationships in a constructive way due to the effects of the eating disorder and any underlying problems. Distancing aimed to either prevent others from recognising physiological impact of the illness and/or enable the person to engage in specific behaviours related to the disorder, without the scrutiny of others. In turn these efforts to create and/or maintain this distance significantly impacted upon relationships.

“When we actually started living together again, the picking of fights led to eventual separation so that she could be by herself and control what she was doing and be able to do exactly what she wanted to do.”

“She will hug us but we can’t come to her, it has to be on her terms. But she used to be such a very affectionate, touchy feely child.”

In turn, carers described experiencing a great sense of sadness as they were no longer able to be as affectionate with the person who has the disorder.

“We used to have a really close relationship and now all of a sudden I can’t have that relationship with her, and that really hurts. I find that very sad.”

“When she was really thin I couldn’t cuddle her. It hurt too much.”

(iii) Intimacy

Another way in which carers reported that relationships were adversely affected by the presence of an eating disorder pertains to the issue of intimacy. In instances where the carer is a partner for example,

relationship strain was reported to be further intensified as the person with the illness avoided and/or expressed dislike of, physical affection.

“During her sickest times she doesn’t want to be touched, she doesn’t want to be hugged. She feels so uncomfortable about herself so you start to doubt your relationship, does she still care about me because she doesn’t want me to give her a kiss, she doesn’t want me to give her a cuddle. Our sex life has completely stopped.”

This created feelings of rejection for the carer/partner and at times signified to them that they were no longer loved or cherished by the person with the illness. This has the potential to cause damage to the relationship, particularly when the reasons behind such behaviour are not fully understood.

“All of those issues come and for a little while that really did affect the relationship because maybe it’s me, maybe she’s falling out of love with me because she feels so bad about herself, it’s something that I’m doing, why can’t I do more to make it better. ... Those sort of issues are not something that I think are probably spoken about much, but then I realised as we started to work through it together it did make us closer. And now the more understanding and the more knowledge I’ve got about the disease, the easier those sorts of things are now.”

(iv) Social relationships

Carers often reported the detrimental effect that living with a person with an eating disorder can have on the family’s social life. Social relationships were hindered as friends of the family did not feel comfortable visiting the family, and invitations were frequently turned down as the family tried to cater for the needs of the person with the disorder.

“Because so much of adult interaction involves food, most of the events we go to involve food in one shape or form. ... I’ve said on a number of occasions to our friends that do know (about the eating disorder) if it involves food we can’t do it. Or I go to things by myself sometimes as well.”

“People don’t pop in unannounced ... she prefers to know when people are going to be there in case she’s bingeing at the time ... she’s just really embarrassed about her behaviour.”

The idea of leaving the person with the disorder alone while the carer pursued his or her own leisure or social pursuits was often too difficult. This resulted in a restricted social circle for carers and families as they became trapped by their caring role and unable to live a life apart from it.

“Unless Jane comes with us, we don’t go at all. My husband and I probably wouldn’t go away for a weekend or anything like that. Not unless I’m prepared to go and say right, Jane’s* not going to eat for the weekend. So in that respect it’s hard.”*

The Impact of the Behaviours Associated with an Eating Disorder

(i) Living with the symptoms of the illness

Carers often felt they had little choice but to accommodate the symptoms associated with the disorder. The dominating influence of these symptomatic behaviours often led to a sense of chaos and feelings

of frustration permeating the family. The need for the person with the disorder to have greater control over the selection and preparation of food, rigidity around mealtimes and engaging in excessive exercise were just some examples of specific behaviours which were highly frustrating and disruptive to family members.

“She had to eat at six o’clock, and sometimes that just didn’t suit us.”

“In my moments of nastiness I thought if this (antidepressant medication) was a suppository, I would happily shove it up your backside.”

Carers’ perceptions of the sensitivity and vulnerability of the person with the illness often led carers and other family members to feel in a constant state of emotional tension. Hence carers often expressed in various ways the notion that the experience of living with someone with an eating disorder was like ‘walking on eggshells’.

“With the boys, the type of thing they say, little things that mightn’t worry us, but you’re watching everything you say ... and now the boys don’t say anything, they don’t say anything at all.”

“To be able to speak to your child without the negative mind, trying to work out if it’s the child or the negative mind that’s acting out, it’s tricky, it’s really scary, having to think twice before we speak.”

Further to this, when the person with the illness also engaged in drug and alcohol abuse, carers’ anticipatory stress and trepidation intensified.

“It so overwhelms you ... when you have more than one thing at play (alcohol abuse), if it can ever be more overwhelming, it is ... there are other elements of unpredictability. ... And it’s like your whole life is perpetual eggshells. You don’t get a second of relief, and you find you are so bound up in it all ...you cannot get away from it. ... It’s far more complex.”

In response to living with these symptoms on a daily basis, some carers indicated that they externalised and/or separated the illness from the person. This strategy was adopted to assist the carer to direct their frustrations at the illness as opposed to the person with the illness, and ultimately minimise potential damage to relationships.

“You could get very angry and get cross and all those sorts of emotions, but I had to sort of separate the disease and him. I knew how he was behaving and talking - that was the disease, it wasn’t him. It’s the only way I could deal with it.”

“We call it (the eating disorder) Rex.”

(ii) Binge eating

Carers reported binge eating to be highly protected behaviour, often occurring in secrecy. Not only was this secretive behaviour unsettling for the family, but it usually had financial implications also. In many instances, bingeing resulted in a marked reduction in the family’s food supply. Again while this fuelled feelings of frustration, anger and resentment, simultaneously carers felt constrained from venting or expressing these feelings. Rather carers often felt they had no choice but to accept this behaviour and accommodate resultant financial consequences of bingeing as yet another burden of the illness.

"My husband is a strong man but his words were 'I don't need this shit, she's costing us money that we haven't got.' And she was. Every time I'd go to the fridge to get food, it was gone. It's ridiculous, I was doubling up on everything...money was going down the drain, literally."

"It seems like a trivial thing, but after a while, it's just so much food."

Friction resulted when behaviours associated with eating disorders placed unreasonable demands on the spouse in order to accommodate the bingeing associated with the illness. This was highly frustrating for the carer, and led to further underlying resentment in the relationship.

"I have to call her when I'm leaving work and let her know roughly how long I'm going to be as well, and there's been a few occasions when 'can you ride the long way home?' It's 7.30; I've been here for twelve hours I really just would like to come home if that's all right. And when I get home half the house is blocked off. That's our relationship at this stage."

(iii) Anger and Aggression

Some carers also described high levels of aggression and anger by the person with the disorder which could be highly distressing for carers and family members. This violence and the subsequent impact on family members could be exacerbated by drug and alcohol abuse.

"If she knew I was here tonight I guarantee she would come at me with a knife."

"When it happened it was like, ok, use me as a punch bag, I don't care. If this helps you just go for it. What else can you do? But I felt sad."

"When they are high on drugs and alcohol... they become this monster, this physical monster and it is really hard. I'm strong but it's really hard to control them. ... You've only got to turn your back for ten seconds and you just don't know what's going to happen. So I feared for my safety and I feared for my younger daughter's safety."

(iv) Suicidal ideation

Carers expressed concerns about the strong feelings of self-worthlessness that were apparent in their family member with an eating disorder and fears that this could increase the risk of suicide and self-harm. Where there was a dual diagnosis of drug and alcohol abuse, carers expressed a heightened concern that this risk may be further increased. Fears of suicide and self-harm were extremely distressing to family members. Carers were concerned about knowing the right thing to do if they had to deal with suicidal behaviour and were emotionally distressed by anticipating the associated grief and loss. Where a suicide attempt or self-harm had already occurred, these fears were constant and intrusive.

"I hid everything, every single solitary Panadol, even tea tree oil, everything, I hid it all because I was scared she was going to down it all."

"My daughter overdosed one night and I called an ambulance and they took her and I followed in the car...I was sitting in the hospital at four in the morning by the bed watching the thing on the beeper thing."

One carer came to some level of acceptance that their family member may indeed succeed in their endeavour to take their own life at some time in the future. Accepting this possibility was also associated with emotional devastation and immense sadness.

"I know that when she's particularly unwell it wouldn't take her much to get her over the edge. Sometimes I wish she would for her own peace. I'm resigned to the fact that she's not going to have a long life. ... It makes me terribly sad."

The impact of treatment.

Commonly, carers reported that after the eating disorder was identified, professional intervention was sought. Treatment programs were described as intense and appointments with professionals were said to be numerous, costly, and prolonged. Carers identified a range of demands and costs that treatment imposed on the family, not only financially but also in terms of its impact upon family dynamics, and daily routine.

(i) Financial impact of treatment

Carers described specialised treatment to be costly and overwhelming. Carers attributed this to the limited availability of public specialist services (inpatient and outpatient), forcing many to seek help through the more expensive, private treatment programs. The significant costs involved were exemplified by the fact that many carers indicated that they needed to borrow funds and/or consider remortgaging their house to pay for treatment. As a consequence, often other family members were forced to make sacrifices in order to meet the financial demands of professional intervention.

"We've had financial assistance from my mother."

"The first time her parents paid, or helped pay ... that was seven grand a week, so it was pretty hefty. We've got medical insurance now."

Carers indicated that financial difficulties were not only limited to the actual cost of treatment per se, but that there were also additional associated costs such as having to take time off work in order to attend appointments, and the cost of getting to treatment. This latter cost was particularly pertinent to those living in rural and remote areas. Carers expressed particular frustration at the need to allocate an entire day and significant travel costs in order to attend an appointment.

"You get up at six or five o'clock in the morning, race down and catch a train because I don't drive in Melbourne. So we're on a train for four hours. A taxi out there, and you get there and oh, I'm running late, I've got to be such and such at such and such a time, and you might be with him half an hour, 3/4 hour. Then you spend the rest of the afternoon wandering around Melbourne then we catch a train for four hours again."

"I couldn't go back and forwards three times a week and maintain my job so I took three months leave of absence."

Caring for someone with an eating disorder can be a full time occupation and in some cases carers reported having given up work in order to attend to the needs of their family member.

"I had to give up work to care for my daughter."

(ii) Family dynamics and routines

Carers reported grieving for the absence of their family member during the long periods of in-patient care that were required to treat their eating disorder. These extended periods of separation from their family member, due to lengthy hospital stays, were commonly experienced by carers when the eating disorder was in an acute or severe stage, due to the physical impact of the disorder and the need for both medical and psychiatric care. Carers noted that in such circumstances relationships suffered under the strain of separation and grief.

"We missed each other... We've been together so long that when she's not in the bed next to me I can't sleep, so it's very difficult. It was ... very depressing, very hard."

In a family situation, often the primary carer needed to be with their child for long periods of time during in patient care, which often left the other family members without a parent or spouse/partner. This caused significant disruption to family life as other family members were forced to adapt and accommodate for the absence of the primary caregiver. This was found to be particularly unsettling for siblings, who felt the loss of that parent, albeit temporarily.

"My other daughter had a lot of problems...when her sister wasn't around and her mother wasn't around."

"It's a heavy toll on the whole family."

Carers indicated that this experience was further intensified in the cases of those families in rural and remote areas where being with the person in hospital entailed travel time and thus the parent being absent from the family for days or weeks at a time.

"It dominated our life; half our family is here (in the country) and the other half is down there (in Melbourne)."

The effects of this disruption often continued even on the return of the primary caregiver, as they would feel exhausted and hence less available to other family members when they were home.

"I just felt so full and tight and ready to explode. I think I coped with crying, or by going to bed. By going to bed I didn't have to deal with all the other demands of being a wife and mother as well as with the demands of illness."

Further to this, the return from an inpatient stay in hospital required readjustment within relationships and the family unit as a whole, which were often described as being uncomfortable and unsettling.

"It was the visits and the homecoming I dreaded the most; the adjustments took up too much energy and the anxiety was always just beneath my skin...I hated the coming home. We all tried to act normal...but we couldn't get our old life back again. The house was tense and we all watched Sophie, wondering what was going on inside her head."*

The impact of caring for someone with a visible physiological / psychological illness

Eating disorders, in particular anorexia nervosa, are distinct from most other mental illnesses in that there are visible physical indicators that a disorder exists. This physiological component of the illness compounded the experience of caring for, or living with someone with this mental illness, particularly in relation to stigma. For example some carers reported extreme embarrassment when seen in public with

the person who is unwell. Furthermore, when the person with the illness is a child, some parents described experiencing blame directed at them from the community, as they were perceived to be in some way responsible for their child's disorder.

"I would be embarrassed to walk down the street with her. That's probably what I felt more than anything, embarrassment because she used to wear these tight clothes and her bones sticking out and she just looked pale...People think you're doing it or 'why don't you stop it?'"

Carers also described the devastating consequences of facing the physiological dimension of the disorder, particularly in the situation when the disorder had reached an acute stage. Carers experienced great distress as they were forced to witness what was potentially a shocking reality of the disorder on their family member.

"You walk in that first time and you see this skeleton sitting on a white bed, and it breaks your heart. They just look so frail."

"I saw my daughter...and I found it really stressful. She looked pathetic, she looks absolutely woeful. These tiny pathetic bones with this head that looks too big for her."

This is further intensified by the fact that the carer felt powerless and unable to improve the situation.

"She was just a skeleton. She couldn't walk and couldn't do anything. So when I carried her in the hospital I realised, you know there's nothing, all the advice, and all the things that I was trying to do, there's nothing that you can do other than just be there and love her and look after her and give her hugs and listen to what she's got to say...That was crushing ... (I was) crushed, absolutely crushed. I was devastated."

The experience of watching a loved one be so near to death was described as terrifying for the carer. This fear and emotional devastation was compounded by an inability to help the person, or indeed an inability of professionals, to help the person. Feelings of dread, numbness, grief and despair were commonly described amongst carers and consequently, extreme responses occurred.

"On admission I thought she was going to die. Had I known better... I would have done more than watch the tube slide down my daughter's nose and throat, immobilised by horror and fear; I would have reacted with anger and indignation."

"All her levels were down so low she was heading for a major heart attack, her heart was missing beats, she was gaga, she was like a walking dead person. She looked terrible, she looked so gaunt. ...I just said to her I'm not coming back to visit you. This is something you've got to get yourself out of. I'm not going to deal with this anymore. ... And I just said if you can't get yourself out of this you'll die alone, I can't see you die anymore, it's killing me. ... I took her to the morgue... and showed her what they did to people when they died, how they treat them. I took her out to the cemetery she wanted to be buried in and I asked her where she wants to be buried, and said I'll get a plot for her... It's the hardest thing I ever did...I cried all the way home."

Grief and Loss

As the disorder progressed, many carers indicated that they would gradually come to terms with the implications of the illness and its potential impact on reducing the person's quality of life. This was often expressed through carers' grief and disappointment that their family member was no longer the person they once were, and may never achieve their goals or aspirations nor achieve their full potential. Thus

this led to a great sense of loss with respect to what was, is, and could be, for the person with the disorder.

"I held Emily in my arms but she lay there stiffly. Where had she gone?"*

"I just find it so sad that a nineteen year old girl, she's not like a nineteen year old girl, she's like a little girl...her sister has grown up and kept going whereas Sheila just seems to have stopped."*

"My biggest emotion is the fear of Ruth never returning back as the Ruth* she was."*

Carers indicated that they were forced to confront the severe physiological complications and alarming appearance associated with a severe eating disorder, leading to the realisation that the person was so unwell, and may die. This was a frightening and distressing time for the carer, and feelings of anticipatory grief and loss were commonly expressed.

"I was so afraid of the hideous illness that was taking my daughter's life away."

"I was in tears and saying 'I can't watch you do this, you can't kill yourself.'"

"You're watching your child commit suicide."

"It's a slow suicide."

Shouldering care responsibilities alone

For some carers, the burden of care came down to one individual, be it a partner in a relationship, a close friend or a parent. Due to an apparent lack of awareness and understanding, this burden was frequently experienced alone, without any support from others as the primary carer felt they carry most of the responsibility.

"My husband just can't accept the issue, it upsets him. He thinks she just needs strong discipline."

"My husband stood back, he didn't know what to do. It was like, 'you do it'. ... He'd get angry. He just didn't know what to do or what to say. He left it to me."

This experience was further intensified when friends and family withdrew from the carer. This appeared to be a common eventuality amongst our sample, leading carers to perceive that people were unwilling to get involved.

"Everybody in the family was really shocked... but nobody ever... provided me with anything, any understanding."

With time, as carers became more acutely aware of the disorder and the needs of the person experiencing it, they in turn, became more understanding and empathic, however this also served to create a level of dependence. Over time this was draining for the lone carer as they were continually relied upon to absorb and respond to the underlying needs and/or insecurities of the person with the illness.

"I could be peeling potatoes or cleaning the toilet or I don't know, anything, scrubbing the floor or whatever, and she'll just sit exactly where I am and talk and talk and talk ...and she just off loads. ... And just to tell her that well, I'm here and nobody can take you away because I'm not going to let them."

To be there all the time, ... now she will always come to me, so if she's worried about something or frightened about something or doesn't know, the thing that I learned to do was to be completely non-judgemental. Not always completely honest, but to listen and to look her in the face and just: 'I know. I can feel it; I can see it, and one day it won't be there'. Because she will always say 'just take it away mum, take it away, I want it to go away. It's not me, there's something there.'

"You just sort of get to the stage where he'd ring up and say 'come on up' and I'd think, oh no, I don't have to go again. But you'd go and you'd talk about things for a while and he'd seem to be all right. But it did get a bit harrowing."

Often carers felt ill-equipped to deal with the complexities of the disorder, which generated feelings of inadequacy and frustration on the part of the carer.

"When my daughter would say 'look how fat I am', I needed to learn how to answer those questions... It was like I was the one who was on trial. ... And she puts me on the spot and I've got to know how to answer that question. ... And I tell you what, it's not easy, it's definitely not easy."

The overwhelming and unrelenting impact of the caring role.

As indicated, eating disorders impinged upon all areas of life, making the role of carer all encompassing and often overwhelming. As a result it became difficult for the carer to perceive their existence apart from the disorder.

"It flows into everything in the family, everything you do, every attitude.

"They take over your everyday thinking."

"We tailor our life around her."

"You can't see the light at the end of the tunnel."

"It just gets to you and you can't keep it up. I'm too old and tired."

"Her illness had taken control of my waking hours as much as it had taken control of her mind and body."

For many this experience was so overwhelming that carers described feeling that they themselves were also controlled by the illness, as they and other family members became enmeshed into the demands of the illness and felt compelled to accommodate the needs of the person who has the illness.

"It's a constant battle ... she's a very intelligent rational person but this eating disorder has taken control."

"The anorexia controls her and she controls us."

"Your whole life gets controlled by this damn person who is controlling their own life and everything they do, and it's like you can never do anything. ... so it doesn't make for comfortable living. But at the same

time it's your flesh and blood, what are you going to do? ... Everybody sort of put up with it and almost pandered to her behaviour."

Carers reported that the reality of living with a person with an eating disorder included a lengthy treatment process, with recovery potentially taking years as opposed to weeks or months. Carers spoke of losing hope as time progressed. While initially believing that the problem may have been tackled with their parental input, with time carers began to realise that the problem was complex, and likely to require long-term professional intervention. Realisation of this fact rendered the carer feeling hopeless and powerless.

"When she first had an eating disorder, yes, I felt powerless. But these days I feel useless, ... It's a worse feeling than when she just had an eating disorder. It's like she is beyond any help I can ever give her other than just to be here...and if I can't be there for her, then why be?... The opportunities to do anything become less and less as time goes on. And that's sad, I would have hoped it would be the other way round, that we would have more of an opportunity to enjoy a life, bits of life together. But no, that will never happen."

While people living with an eating disorder may well recover, the impact of the illness on the carer does not always stop there, as even after recovery, carers were fearful of the illness' potential to return.

"It still stays with you. ... If anything negative happens you think 'oh God, I hope she doesn't go backwards'. And my husband and I talk about it, 'do you think she's still doing it?' and I said 'well I don't think she is'. And that's how you talk, and this has been since she was fifteen."

"But then I worry that if she recovers from this, what's the next thing that's going to take its place ... it concerns me a little bit that maybe that's just the type of person she is and there's always going to be something else."

The neglected needs of the carer

As demonstrated in this paper, the experience of caring for a person with an eating disorder can be traumatic, overwhelming and highly demanding. The impact on the carer was often intensified as their own physical, emotional and psychological needs are ignored and/or neglected.

"At the time I didn't know it but I was angry and depressed. My distress confused everything, even my ability to know what I was feeling."

In the face of additional stressful life events, the carer's grief was further confounded by behaviour exhibited by the person living with a dual diagnosis of an eating disorder and substance abuse.

"My partner died and I was at the hospital and Kate walked in absolutely drunk and abused me. It took me ages to forgive her for that but I know that that was just her way of coping ... I just felt as though...she was dragging me down. I was actually suicidal at one stage ... I couldn't deal with life without my partner, let alone deal with this daughter who was a noose around my neck with a blinking tonne of bricks at the end of it."*

A carer who had experienced an eating disorder themselves indicated that the experience may be further complicated. While such carers may be able to demonstrate an understanding and empathy beyond that of other carers, the overwhelming strain that living with a person with an eating disorder can present potentially increased the likelihood of relapse for the carer.

"I do find myself being very susceptible because some of her behaviours are identical to the ones I had. If I'm feeling terribly over-tired or over-wrought, then yes I could see that I could easily slip back into it. Of course the worst thing is to be in the house where there is more than one person with disordered eating because you spur each other on. So in a way I have had to learn to control myself even more."

While it is apparent that living with a person with an eating disorder and being a primary support does impact considerably upon the carer, some did not actually recognise their caring role as such or identify with the term "carer". Essentially they were doing what families do - care for those in need.

"I never really saw myself in that role, I was only helping out. There was no defining of who was a carer, that's your words today, I've never really thought of myself as a carer ... Somebody forgot to pay me!"

Valued Peer Support

In coping with these many demands and stresses, carers expressed the vital importance of support groups, which reinforced to them that they were not alone, and provided useful insights and strategies for living with and accessing effective treatment for their family member.

"I needed another parent to tell me 'you will be alright' because I just felt I couldn't survive."

"I went to some of the support groups which were fantastic because I didn't know enough about it and I'd be going 'she does this and she does this' and they'd be going 'yeah, yeah they do that as well', so they were like imperative to getting through the whole situation, knowing that everyone else was the same. And for Claire, her going to a couple of those, it was the first time she realised 'I'm not alone, I'm not the only one, I'm not completely mad'. There's other people feeling exactly the same way. So it really made a difference to her as well."*

Discussion

The current research clearly demonstrates the significant impact that eating disorders have on primary carers, as well as on others who are living with the person with the illness. As highlighted, an eating disorder ultimately has a profound impact on relationships, as it can alter family dynamics, reduce the level of intimacy, lead to social and emotional distancing, and restrict social relationships for families and other carers.

Further to existing research, this research identifies that the disorder can also be seen to control other family members. While the person with the disorder may be controlled by the symptoms of the illness, others are often forced to accommodate the symptoms of the disorder also, in an attempt to minimise distress caused to individuals and disruption to the family unit. Such accommodation of the symptoms is often to the extent that family members function “on eggshells”.

When considering the impacts of treatment on the family, this study identified considerable costs. First, there are significant financial costs, the most apparent of these being directly associated with accessing and receiving specialist treatments. For some carers this additionally entails loss of income from time off work for treatments or ongoing care. In addition, financial costs are also associated with binge eating. Further to financial costs this research (unlike other studies) has unveiled additional costs incurred by the carer and/or family. These include the impact upon the carer of the commitment, time and effort required to access effective treatment which for many carers was a frustrating and disheartening experience. This led to significant time away from the rest of the family and hindered the ability to continue in employment, thus potentially threatening their identity outside the caring role. Further to this, accessing and attending treatments impact heavily upon routines, relationship dynamics and family life, as the primary caregiver is often needed to be with the person with the eating disorder and to provide active support during various phases of treatment and recovery.

With eating disorders having physiological implications as well as psychological, progression of the disorder (particularly in the case of anorexia nervosa) can lead the person with the illness to become increasingly frail and vulnerable. This paper contributes to the current literature by noting that this can be highly distressing for the carer as they witness the deterioration of their family member, while simultaneously feeling helpless and powerless to prevent it. The severity of these potentially life threatening consequences of the illness can evoke feelings of grief and loss for the carer. These feelings are also evoked and intensified by fears that their family member with the disorder may never reach their full potential.

Carers clearly expressed the often overwhelming experience of caring for someone with an eating disorder. This is exacerbated when the primary carer feels unsupported by other family members and friends, as they find themselves shouldering most of the responsibility and strain alone. In many instances the carer’s own mental and emotional wellbeing can be at risk. Furthermore, these stresses are compounded by a lack of understanding and support about the disorders and their impact on other family members from the wider community.

This research clearly identifies the factors that contribute to, or exacerbate the negative experiences of the disorder on the carers’ part, as well as highlighting the importance of forms of support, which may serve to alleviate the burden of care.

Firstly, as part of their commitment to the health and wellbeing of the family, health professionals should also aim to educate the carer and other family members about the disorder and its management, so as to enhance their understanding and sense of control over their lives. Information

about the availability of appropriate services and the carers' eligibility for various forms of assistance is also necessary, in particular about mutual support and carer services that can link to other resources. Furthermore, health professionals should aim to educate themselves about carers' needs and issues in order to discuss, acknowledge and address carers' concerns and the need for psychological and practical support for carers. The need for counselling and peer based programs that deal with the many relationship changes and complex emotional responses of different family members would appear to be particularly needed.

Secondly, the value of peer support and positive contacts with specific organisations which support and assist people and families living with eating disorders (for example, support groups or a carer advisor) highlights the need for strengthening and extending these services throughout Victoria. This indicates the importance of further development and expansion of these organisations and support services, and the provision of specific funding to enable them to develop close partnerships with primary and secondary health professionals, and public and private treatment services. Such development and expansion would ensure the dissemination of information about the disorder, its management, available supports and entitlements, and would provide linkages with other relevant services.

Finally this study highlighted the need for greater education and understanding. As identified with respect to other forms of mental illness, there is an obvious need for greater community awareness and understanding about the nature of eating disorders and the significant impact on the lives of those who live with them. This is likely to not only reduce the stigma for the person with the disorder and their family, but is also likely to increase the level of empathy and support provided to carers.

Paper Three

**Accessing treatment and support for a person with an eating disorder and their family:
The carer's experience.**

Accessing treatment and support for a person with an eating disorder and their family: The carer's experience.

Introduction

We note in a previous paper (paper one) how the process of detection of an eating disorder is distinct and hindered due to the behaviours that perpetuate the eating disorder and the lack of information and understanding about eating disorders in the general community. The second paper (paper two) identifies how an eating disorder severely impacts on the carer and other family members. Strains on family relationships, carers' employment, social participation, financial situation and adverse effects on carer health and wellbeing were typical.

The current paper focuses largely on the issues of *accessing care* and *receiving treatment* for a family member with an eating disorder. In particular the research sought to assess processes and services that were perceived by carers to be helpful, as well as to identify potential barriers to receiving effective intervention. The current paper will also explore the ways in which the process of seeking and accessing treatment impacted upon the carer and other family members, and the supports that they themselves found to be helpful in meeting their own needs.

Results

Despite the need for early and effective intervention, our study demonstrated that there were many barriers to accessing help. In particular, carers reported that lack of clear pathways, poor referral processes, waiting lists and staff attitudes created barriers to seeking effective intervention.

Barriers to accessing effective treatment

(i) Lack of information

Following identification of an eating disorder, most carers attempted to access information about the disorder and available treatments to educate themselves and find professional intervention for their family member. Attending support groups and obtaining information through specialist agencies were cited as being successful strategies to access information, however, the route to these sources of assistance were generally not direct and straightforward. Many carers described their experiences of seeking information to be frustrating, time-consuming and confusing. They indicated that accessing specific and relevant information would have been easier if it was readily available in places such as primary care settings.

"It's knowing which avenue to go through, or putting you in a direction where you can contact someone. I didn't know anything; you have to learn for yourself."

"You start chasing round the country. Where do you go, who do you need to see; do you need to see a dietician, do you need to see a psychologist? ... We need to be guided as to which road to go down."

"You feel frustrated and angry at the system because every which way you turn you're shoved another bunch of pamphlets. I just couldn't connect up with anybody."

(ii) Lack of awareness and skills among health care professionals

Many carers reported on the lack of awareness and understanding about eating disorders not only in the wider community, but also among many healthcare professionals. In particular carers reported that some professionals appeared relatively unaware of the potential signs, symptoms and manifestations of eating disorders, leading to difficulties surrounding their detection.

"Miranda went to the doctors' when she was 16, she didn't get her period so she was going to the doctors. And they were coming up with all these things as to why she wasn't getting it, and 'oh she must have this, she must have this problem or she must have this problem', and the answer was that she was underweight and clearly anorexic. ... It was staring them in the face."*

Difficulties with detection appeared to be compounded by misattribution of symptoms. For example, carers described professionals in both primary and specialist care settings attributing symptoms to physical problems, a life phase, or a personality trait.

"I was taking her to the doctor who was looking at thyroid, and anything but anorexia. I think it's a problem in the system."

"We couldn't find any doctor or even psychiatrist that knew anything about eating disorders. They just had the mentality of 'eat your dinner', and of course that made it worse. ... She'd be talking to a psychiatrist, telling her inner most feelings and the psychiatrist, quite an accomplished psychiatrist, just wasn't picking up on what she was saying, didn't realise it was an eating disorder."

For many carers, this lack of awareness and understanding impeded early detection and intervention, and allowed for further entrenchment and progression of the disorder. Not only did this leave the carer feeling unheard, misunderstood and frustrated, but also forced them to have to continue in their quest for treatment of an undetected disorder.

"I feel that perhaps at the time if our GP had been able to pick up on it a bit quicker so that we could have started getting help earlier in the piece, I'm not saying we wouldn't have had the problem, but maybe, just maybe there's that chance it might not have got this bad."

"It was so frustrating and yet my family doctor seemed to know what she was doing and I had a lot of faith in her."

Furthermore, carers described a lack of sound understanding of the complex and multifaceted nature of eating disorders among health professionals they encountered. This often resulted in a reluctance by primary health professionals to refer to psychiatric or psychological services and/or inappropriate attitudes about the disorder by professionals, often reflective of stigma which exists in the wider community. This ignorance often led carers to experience significant distress and frustration when attempting to access appropriate intervention for their family member.

"They are treated quite often as though they are being a petulant child."

“...They feel ‘you’re wasting my time, you’re not really worth it, you choose not to eat’... so what they do is they compound the message you chose this, you don’t want to get well, you are the problem, and so in fact they make the person sicker. ... But why would you choose this?”

(iii) Absence of early intervention / crisis management

Carers expressed significant frustration and distress regarding the issue of eligibility criteria for access to services (often due to limited service provider resources). Carers in our sample reported that many services are unable to provide treatment to people with an eating disorder until their Body Mass Index (BMI) decreased to a certain point. This was highly distressing for the carer as they see their family member in need of immediate care. Inability of services to intervene until the person reaches an acute or life-threatening stage of the illness leads to the carer feeling helpless and discouraged and resigned to what they referred to as ‘the waiting game’.

“We had the problem that the doctor said she can’t go into an eating disorder clinic until she is below a certain BMI. I literally had to watch her losing weight and exercising. I mean she would walk around the block for seven hours during the school holidays and just around and around, and she wouldn’t drink water, she wouldn’t do anything. ... And so I literally had to watch her starve herself until she was thin enough to be admitted to hospital.”

“She became a totally different person. ... Within a few months there was a dramatic personality change from a very kind gentle individual to a very aggressive person. She used to beat me up, she used to pull knives on me, she cut herself, she broke things in the house... But we were waiting on that number before she could get into the program.”

“And they (the health professionals) said we don’t do much from now, we’ve got to wait until she gets to a certain weight. She got to that certain weight and then she got lower and they still didn’t do anything. I thought this is ridiculous ... and he just let her keep going.”

(iv) Delays in accessing treatment

Many carers reported that the demand for services for people with eating disorders, coupled with limited funding, resulted in people with the illness being subjected to frustrating waiting lists, particularly within the public system, before they can have access to treatment. As time and the illness progressed, carers described their increasing concern at being denied intervention for their family member.

“She had to wait for two months and I know she said ... ‘that’s stupid, how come I can’t ring up, I want the help now and I need the help now, why can’t I have the help now?’. Well sorry; you’ve just got to wait for six weeks or whatever. And so she did, she just had to wait.”

"I couldn't get any help anywhere, for years and years, I would ring every hospital, every person I could think of down there and they just said we can't do anything, there's a long waiting list and if you've got to force her to come in, she's still driving a car so she's competent, she's not little enough yet, and this went on for ages. So yes, I got no help from anyone. And I rang every lead I could, everything that came to my attention I would ring or write letters to and I was just going round and round. I found it virtually impossible to get help."

"I could have carried her there in my arms...and there'd be a waiting list of six months, or there'd always be something."

This exacerbated the situation for the carer who, in the interim had to assume sole responsibility for the mental and physical health of their family member. This was often a daunting experience leaving many carers feeling out of their depth.

"...what are they meant to do in the meantime? They need help when they need help, and 'not when you want me to come in because I might be having a good day that day. My desperation is such at the moment that yeah, I'm happy to go and I know I've got to get help and I feel strong enough that I can do it. But don't ask me tomorrow because my strength will be gone'. And always always, always, the onus of care comes down to the carer... 'Your problem till then, you must be partly to blame for this, why didn't you keep an eye on her?'"

(v) Costs associated with treatment

Carers in our sample often perceived there to be a poor quality and limited choice of treatment available within the public health system. However, the high financial costs of private health care, left most carers with no option but to remain in the public system. For some carers the apparent lack of access to effective services in the public system led to such desperation that they and their families made considerable sacrifices in order to pay for private treatment services. For the families caught in the public system and unable to meet such financial demands, the pressure and distress was exacerbated by long waiting lists, which allowed the disorder to become more progressed, and could potentially make the eventual treatment process more protracted and difficult.

"If we can get her into a private hospital they treat her as an individual. But that costs five hundred bucks a day!"

"I took my daughter to somewhere in Wangaratta ... and they said to be in the public scheme you're going to have to go on a waiting list, this is what the doctor said. You're in a critical state you can't wait. You've got to go into somewhere private, it's going to cost you one hundred dollars every time."

"I wondered how much this hour plus consultation was costing, and wondered how a person's life could be a thing to earn money from. There was a financial value put on my daughter's life."

"Knowing it was costing me so much money, I couldn't relax in there."

“You come out (of the treatment session) and think, gee, I don’t think I got my money’s worth.”

“At \$180 a session, I watched all our savings go to nothing.”

As alluded to in a previous paper, the financial implications of treatment were found to be significant. A number of other costs were also identified, such as the need to take time off work to attend appointments with their family member. Carers indicated that these costs were even greater for those living in rural communities who needed to allow for greater periods of time, accommodation and/or travel expenses in order to receive treatment in metropolitan areas where specialist services were considered to be more likely to be available.

“Her psychiatrist would like to see her once a week. There is no way. That is such a big day, I mean you take a day off work, it costs \$150 just for the transport. I mean I would sell the farm if it meant she would get better but the reality is you’ve got to live from week to week. So it would probably cost me \$250 for one day to see a doctor for one hour. One hour. And then you come away thinking ‘well was it worth it?’ That’s the reality.”

(vi) Treatment not available at all

It was not uncommon for carers living in rural areas to report on the lack of appropriate services which existed locally. This led these carers to believe that they and their relative were being denied better treatment options which were likely to be available in metropolitan areas.

“You’re so far away in terms of services. There are doctors who know, dieticians who know, psychiatrists who know... We want it here.”

“Wouldn’t it be easier if one or two or three people came here to save us going there.”

As a result, these barriers to accessing appropriate clinical intervention increased the duration of the untreated illness and further deterioration of the individual, which was highly frustrating and concerning for the carer.

“It’s taken us sixteen months to get her into a program where there’s a lot of caring and a lot of support.”

“All this takes time, and too much time slips away.”

“There’s a huge gap in time from when it started to getting treatment... It’s been very frustrating.”

The Quality of Care

Carers described the continual effort and energy required to assist their family member to access services. Most carers in our sample found it difficult to access thorough and effective treatment, and finding a treatment provider who is inclusive of the role of the carer was found to be even more difficult. Insufficient and inappropriate services served only to complicate and intensify the experience of caring for a person with an eating disorder which was highly frustrating for carers. They were able to easily identify gaps in service provision and expressed frustration and concern that services were failing to provide adequate treatment services which would meet the needs of the person with the disorder and indeed the carer and the family.

(i) Exclusion from the treatment process

Another major criticism of services expressed by carers in our sample was the fact that services neglected to keep carers informed. They described feeling on the outside and uninformed about treatment options and progress, their opinions or input was not acknowledged, and that their role as the primary carer was undervalued.

“I’m curious as to why they don’t communicate (with the carer) a bit more. I don’t think it helps her by keeping us out the loop.”

“I felt so left out of treatment. I wished that the therapist would stop and talk to me and acknowledge me and my pain somehow. I wished that there was some practical matter I could talk about just so I could make some contact with her... there must be a better way, one that does not alienate the carer so much from the treatment. I struggled so much with the triangle; the therapist, Jane, myself. The trouble was, only I saw it as a triangle. To Jane and the therapist it was a line with two points, not three.”*

Carers reported that healthcare professionals justified this exclusion from the treatment process by indicating that they cannot take part in the treatment process, due to issues of patient confidentiality. Once again this left the carer feeling frustrated and powerless.

“I found it so frustrating because I wasn’t allowed to know. I was so frightened so many times, but we’re not allowed to know...they hide behind patient confidentiality. They don’t realise it’s a family disorder.”

“I found that I wasn’t getting any information. If I asked what was going on I’d be told ‘oh because of privacy you can’t be told that.’ And I found that very difficult...no one explains it to you.”

For parents in particular, this exclusion left them with a sense that they are perceived by health professionals to have contributed to the development or maintenance of the eating disorder.

“I believe there is a pervasive distrust of mothers and their instincts, or at least no room for them, in the treatment of anorexia.”

For carers who were not family members, inclusion in treatment was found to be even more difficult, eliminating a potentially vital avenue of constructive support for the person with the disorder.

“I went down once to see the psychologist with him (my friend), the psychologist asked me to go down. I met her, that was it. It would have been good to know a little bit more to make sure I was doing the right thing. Just a bit of guidance.”

(ii) Lack of collaboration across multi disciplinary teams.

The most effective treatment of eating disorders was considered by carers in our sample to be that offered by multidisciplinary teams. However, carers reported a significant lack of collaboration between such teams, at times resulted in the need for the carer to assume the role of case manager to ensure instigation of team meetings and ultimately that their family member was being treated appropriately. This pressure compounded the carer's experience.

"There's a team working with our whole family ranging from dietician to nutritionist to psychiatrist to family therapist ... but not from the one place. We've sort of taken from here and there. I feel I have a reasonably good case manager ... who's co-ordinating all these people. And I take a fairly active part in that as well. And we have regular team meetings and family meetings."

"Nothing gets done unless I make the phone calls ... and I don't need this added pressure."

Carers in our sample reported that responsibility for treatment was often the cause of further conflict amongst professionals as they debate whether to treat the person in a medical or psychiatric capacity. Many carers expressed frustration and anger at the inability of services to treat eating disorders as an illness in its own right, and that no provision is made for the multifaceted basis of the illness.

"She got down to a BMI that was, she was teetering between life and death. They didn't want to give her a medical bed because she was psychiatrically so unsound. She was committed by a psychiatrist but the psych ward wouldn't have her because she had a nasal gastric tube in. So they literally fought about her. So they pulled the nasal gastric tube out and sent her to the psych ward in which she actually collapsed, her blood pressure wasn't showing at all."

As a result, carers reported that the lack of communication and continuity of care (due to length of time taken for recovery and thus staff turnover and ineffective information sharing) often made it necessary for the carers themselves to assume the role of case manager, in an attempt to maximise the effectiveness of intervention from the different health professionals on a team.

"She's tired of telling her story again. If you get referred to another psychiatrist she has to tell the whole story again and after a while they give up, it's just too frustrating. I don't even think it's got to do with confidentiality or anything."

"The number of times the CAT team had been called because she was suicidal, she overdosed and she cut herself. She'd be taken to the local hospital and she'd be sitting there and would see a different psychiatrist every time. Her file was so thick, she'd have to give her history every time."

For many carers the overwhelming need to take control of the treatment process was fuelled by a sense of desperation, particularly when the person with the illness was acutely unwell and the consequences of insufficient or inappropriate intervention could be fatal. In response to this carers commonly described the importance of an effective case manager to not only ensure responsive treatment for the person with the illness, but also to relieve carers of this responsibility.

"The week leading up to the admission however, was one of the worst in my life. I felt so very alone and insecure about what I was doing. I had to rely on my own resources. ...I had to do the negotiating with

the clinic staff myself. I can't remember the conversations I had or what barriers I had to overcome. I do remember thinking though, that I shouldn't have been the person making the phone calls, negotiating a bed, explaining how sick Abi was. At that point she was either screaming in her bed, or staring blankly as if in a coma. She was refusing to eat or drink. I felt let down by the people who were caring for Abi* as I believed it should have been they, not me, making the phone calls and getting her admitted to the clinic."*

(iii) Lack of individualisation of treatment.

Some carers found that the individual needs of their family member were not sufficiently catered for in treatment programs due to a generalised approach which emphasised the needs of adolescent females, and did not adequately take into account the needs of males and/or adults with eating disorders.

"The clinic was a debacle, their program is terrible, absolutely shocking. It crushed her. When she was in there it made her so much worse because she went in as a 26 year old doctor, an independent woman, and they just made her feel like a small child and treated everyone the same and didn't individualise the treatment and took all her self esteem away. It was horrible, useless."

"There were faults in that program as well and again, dormitory style rooms and it's not too bad because most of the girls were young in there but Eleanor was thirty now, sharing a room with a group of sixteen or fifteen year olds, it's just not something that's easy. You're independent at that stage."*

(iv) Negative attitudes exhibited by health professionals towards carers

Carers reported experiencing a sense of blame apportioned to them by professionals that they and/or their family were in some way responsible for the eating disorder in their family member. This was particularly apparent for parents, who frequently reported feeling that professionals blamed them for the onset of the disorder in their daughter, leading to feelings of guilt and responsibility in the carer.

"The hospitals blame the mother...it's the mother's fault, the mother has made the child like this, therefore we'll stop visitations, the mother can't come and visit."

"They blamed her mother, put her in isolation and blamed me. ... 'Oh no, she's in isolation you can't see her."

(v) Equity in access to crisis intervention services

Carers reported finding crisis situations extremely frightening and frustrating, due to difficulties in accessing psychiatric emergency services. Difficulties included finding the appropriate psychiatric emergency service for their area, and discovering that there were some conditions or restrictions that would prevent the service from assisting.

"I called the CAT team and they said no, you're not in our area,- they gave me another number, I called them, they said you're in another area. - I called them back you're in this area. And then they say 'no, your daughter's too young; we only come out for adults'. So with the CAT team we had major battlings,

and this was the time my daughter was seriously cutting herself and trying to cut me too. I ended up having to call the police, so the police take her."

(vi) Support for carers

Carers reported that there were significant consequences on their own mental, emotional and physical well being due to the unrelenting demands of the eating disorder, coupled with the ongoing efforts to access services. This led to a great need for carers to access support from others, though for many carers this was difficult to obtain from family, friends or the wider community due to a lack of understanding about the illness and its diverse impacts on the carer and family.

As mentioned in the previous paper a number of carers described the importance of support groups comprising other carers who have similar experiences. Carers expressed the vital role that these groups played through the provision of useful and important information about the illness, available services, and strategies for caring as well as the empathy hope and understanding they found from connecting with others in a safe and non-judgemental environment. As these critical features of support were reported to be unable to be derived from treatment services, carers emphasised the importance of the existing support organisations.

"I needed another parent to tell me 'you will be alright' because I just felt I couldn't survive."

"I went to some of the support groups which were fantastic because I didn't know enough about it and I'd be going 'she does this and she does this' and they'd be going 'yeah, yeah they do that as well', so they were like imperative to getting through the whole situation, knowing that everyone else was the same. And for Claire, her going to a couple of those, it was the first time she realised 'I'm not alone, I'm not the only one, I'm not completely mad'. There's other people feeling exactly the same way. So it really made a difference to her as well."*

"You need sometimes to have a bitch. To say 'this happened', or 'she got so shitty'... and then you have a laugh about it."

"How different I think it would have been if I had had the chance to fully express my fears and feelings, and to know they had been heard and taken seriously."

As detailed in the former paper, during acute phases of the illness carers were often faced with very distressing situations. Despite the fact that this significantly impacted on the carer's own mental and physical health and functioning, overall these needs were perceived to be neglected by healthcare professionals and carers expressed feeling unsupported in their role.

"I'm not leaving this place until somebody gives me some sort of indication. I am not going to go home. ... I just felt so much as though something was not right. ... I went up to the nurse's station ... and I said 'I can't go home. I am not in a fit state; I am just going to do my block here. Somebody has to help me cope with whatever the hell's going on before I go home to the rest of my family'. So one of the nurses put me in front of a video...about anxiety, panic attacks and depression. It wasn't anything different to what I'd seen."

While there may be other services available for carers (eg. counselling, education programs, respite, and financial assistance), these were noted only by their absence, as carers in our sample did not indicate knowledge or use of these services. Rather, the focus of participating carers was the family member with the disorder, and as such carers perceived their own individual needs as secondary. This may be considered indicative of the fact that when asking respondents to identify their needs, or consider what would assist them in their role as carers, generally the responses reflected the direct needs of the person with the illness. For example, carers specified a need for more education about the illness and/or how to access effective treatments for the person with the disorder, as opposed to their own individual needs (e.g. respite).

“I think that it’s not important to look after myself because I want Sarah to get better.”*

“I never really saw myself in that role, I was only helping out. There was no defining of who was a carer, that’s your words today, I’ve never really thought of myself as a carer but after you say so you probably are. Somebody forgot to pay me!”

However, carers clearly stated their need for help, support and information.

“(There needs to be) support for the family. Because the road to getting help for this person and the road to recovery is a long road and the only way you’re ever going to get on that path or go down that road is if the family are intact or if the family are coping.”

Discussion

Caring for a person with an eating disorder has been seen to impact significantly on the family (papers one and two). This experience is compounded by the difficulties experienced by the carer when accessing treatment and care for their family member.

Firstly, these difficulties largely relate to the numerous barriers that prevent the carer accessing effective treatment for their family member. These barriers include a lack of knowledge and awareness in the community about the disorder, limited availability of information, lack of awareness and skills amongst health professionals, the absence of early intervention and/or crisis management, waiting lists and unavailability of appropriate services (particularly for those in rural areas) and costs associated with accessing or receiving treatment.

In many cases public treatment services are perceived to be inaccessible and inadequate, yet private treatment is so costly that carers are forced to incur significant debt in order to access effective intervention. Carers are further frustrated when treatment offered by the private system also appears inadequate. The exclusion of psychological treatment from Medicare also compounds the financial strain entailed in accessing effective treatment.

Interestingly, despite the possible availability of financial entitlements or assistance (such as rural transport subsidy or Centrelink carer benefits), many carers in this sample appeared unaware of such entitlements or their eligibility requirements. Carers within the private sector especially may be uninformed of and poorly linked to public benefits. Furthermore, despite revised guidelines carers in the private sector are unable to access the state Mental Health Carer Support Program brokerage fund. Service providers and government policy makers should acknowledge and address these financial issues. The financial strain on carers is exacerbated when the family income is reduced, often as a result of the impact of the eating disorder on the person themselves, or due to the overwhelming impact of caring for a person with an eating disorder, to the extent that the carer and/or the person with the disorder becomes unable to maintain employment.

This experience of seeking intervention, yet being unable to access appropriate help is frustrating and frightening for the carer who in the meantime must assume responsibility for the carer of their family member. In keeping with findings from other research relating to accessing intervention for mental illness, this can render the carer feeling out of their depth and emotionally distressed.

Secondly, once assistance for an eating disorder has been accessed, there are further problems that arise for the carer, particularly surrounding the quality of care. Carers confront issues surrounding medical versus psychiatric responsibility of care, lack of continuity of care, lack of individualisation of treatment, discrimination exhibited by health professionals, and equity in accessing crisis intervention. Not only are these inadequacies highly frustrating and potentially distressing for the carer, but they are further compounded by their exclusion from the treatment process, which carers find frustrating and frightening.

The current research points to a number of recommendations surrounding service provision for eating disorders. First there is a need for health professionals and services to have a greater depth of understanding about eating disorders, in particular issues around detection, management and treatment. A key element of the Third National Mental Health Plan is improving the attitudes, skills and training of the mental health workforce (Outcome 32), a strategy that must include education about eating disorders and their impact on families. Secondly, sensitivity needs to be directed towards the needs of the carer by way of regular reviews. Consideration should be given to their potential role in the treatment process, their need for information relating to the progress of their family member, and levels of support they may require.

Thirdly, our study indicated that there is little concept of prevention and early intervention, with people having to be acutely unwell before receiving appropriate specialist treatment. Given the complex physical as well as psychological nature of eating disorders, this is highly distressing for carers as they are faced with what could be a potentially fatal situation. It must be recognised that by the time the physical symptoms are obvious, the psychological state of the person with an eating disorder is undoubtedly worse. Services, treatment providers and funding bodies should respond to this lack of prevention and early intervention by providing more adequate training of health professionals in order that they fully understand the complex multifaceted basis to the illness, greater education of the wider community and by provision of services to deal with the demands upon its resources. In particular, the Third National Mental Health Plan calls for strategies that will improve access to early intervention services including practice incentives for public, private and non-government sectors, and training for carers/families in understanding signs of illness. Other directions linked to improving access to private psychiatrists and to general practitioners are also important steps in addressing the barriers carers reported to accessing appropriate treatment. Similarly, implementation of directions for enhancing care pathways such as pathways that reflect the complexity of needs and eligibility criteria, need to be responsive to issues raised in this paper.

Fourthly, carers in this research alluded to the stigma that currently exists, not only in the general community, but also among health professionals who were perceived at times to hold carers responsible for the illness. Again, by providing greater education about the illness, together with important information about the experience of both consumers and carers, this may serve to increase health professionals' awareness, sensitivity, and ultimately improve their attitudes, when working in this area. While such issues are addressed in the Third National Mental Health Plan, 2003, specific attention must be given to these issues relating to stigma with regard to eating disorders. The Third National Mental Health Plan addresses mental illness in general, and in doing so, such directives may not be implemented amongst the wider community, health professionals and eating disorder-specific policy.

These treatment inadequacies clearly place even greater strain and demands on carers as they struggle to seek prompt and effective treatment for their family member, and continue to live with demands and impacts of the disorder in the meantime. Despite this, carers are often unsupported in their role. Support groups alleviate some of the burden, and many carers report that they are a vital means of support. However despite the significant emotional and practical impacts on carers and other family members, when asked to identify other desirable options for support, carers rarely focused on needs specific to themselves, rather they were more fixated on the needs of the person with the illness. They perceived that their own needs would be alleviated if their family member was receiving effective care. This primary focus on the needs of the person with the illness and not on their own needs may reflect a number of factors. For example a lack of information about available assistance for

carers/families; a lack of identity with the term carer (and hence associated supports); a lack of referral to agencies such as those providing family counselling, sibling support groups, respite, carer education, financial assistance; and the lower policy focus on carer/family needs in the private sector compared to public services.

The current paper highlights how all aspects of the disease and its treatment affect the whole family, and in doing so has significant implications for health professionals and services, who may need to be aware of, and more responsive to, not only the needs of the person with the disorder (which would alleviate carer burden) but also the needs of the carers, who may be unlikely to request direct support. Further, the research highlights that health professionals have a role to play in offering consumers the option of including their carer in the treatment process, informing and educating carers about the disorder, as well as services and entitlements that may exist to address the otherwise neglected needs of carers.

Literature review

The experience of caring for a person with mental illness has been well documented as being potentially traumatic, burdensome, distressing, demanding and detrimental to the carer's physical, emotional and mental well-being. The role has also been recognised as having potentially rewarding and uplifting outcomes. These positive aspects have been variously referred to as caregiver esteem or satisfaction, caregiver gain and finding or making meaning through caregiving, while the negative aspects have been conceptualised as caregiver burden or the burden of care, caregiver strain, stress, or distress (Hunt, 2003; Schene, 1990, Szmukler, 1996).

Such factors contributing to the experience of burden, which have been highlighted in the literature relate to difficult behaviours (such as unpredictability or moodiness), stigma, problems with services, impact on the family, the need to provide support, dependency, loss, impact on work and leisure, and the financial impact of the caring role. (Pai & Kapur, 1981; Fadden, Bebbington & Kuipers, 1987; Szmukler, Burgess, Herrman, Benson, Colusa & Bloch, 1996; Baronet, 1999.) Furthermore, caring for a person with a mental illness is frequently associated with both physical and psychological distress (Baronet, 1999; Perring, Twigg, & Atkin, 1990).

Despite the surge of literature around the experience of caring for a person with a mental illness, little attention has been given to the distinct experience of caring for a person with an eating disorder. Yet, published personal accounts of parents (e.g., Crisp, 1995; MacDonald, 2000; Meyer, 1984) attest to the significant burden involved in caring for someone with an eating disorder, and account for the many books written specifically for family and friends of those with an eating disorder (e.g., Ball & Ball, 1995; Bryant-Waugh & Lask, 1999; Byrne, 1987; Dawson, 2001; Siegel, Brisman, & Weinshel, 1997) and the large number of support groups and eating disorder organizations which assist families, partners and friends.

Much of the existing literature relating to living with an eating disorder pertains to the demands on society, or to the experience of the person with the disorder, with the needs of the carer being somewhat overlooked.

From a societal perspective, eating disorders rate 15 in the top 20 causes of disability in females in terms of years of living with disability (Vos et al., 2001). In Australia, a principal diagnosis of an eating disorder accounts for the third highest number of same day admissions (9.3%) for females receiving specialised psychiatric care and 1.8% of overnight admissions (Australian Institute of Health & Welfare, 2003). Furthermore, a US study of health insurance claims found that the economic burden for treating eating disorders is comparable to that of other disorders such as schizophrenia and obsessive-compulsive disorder (Striegel-Moore, Leslie, Petrill, Garvin, & Rosenheck, 2000).

From a personal perspective, the eating disorders impose considerable burdens and debilitating outcomes. The mortality rate for anorexia is higher than that of any other psychiatric disorder, at approximately 5.6% per decade (Sullivan, 2002) while the suicide rate is over 30 times higher than expected, a figure exceeding even that of depression (Beumont, 2000). Anorexia is also associated with significant morbidity, impacting upon most physical systems of the body, including the cardiovascular, gastrointestinal, endocrine, orthopedic, and neurological (Carney & Andersen, 1996; Pomeroy & Mitchell, 2002). In addition, anorexia is associated with significant comorbid psychiatric conditions such as major depression, anxiety disorders, substance abuse and personality disorders (Godart, et al., 2002; O'Brien & Vincent, 2003). While mortality in bulimia appears significantly less frequently (Nielsen et al., 1998; Sullivan, 2002) and is associated with less physical morbidity, serious complications such as cardiac dysfunction due to electrolyte abnormalities and gastrointestinal

conditions such as ruptures, Mallory-Weiss tears, and colon dysfunction as a result of laxative abuse can occur (Pomeroy & Mitchell, 2002). Furthermore, Flament, Godart, Fermanian, and Jeammet (2001) found that 86% of people with anorexia nervosa and 65% of people with bulimia nervosa experienced disability with respect to performing social roles, and that similar numbers were disabled with respect to fulfilling employment roles.

When considering the experience of *caring* for a person with an eating disorder, there is very little empirical literature in existence. That which has been conducted indicates that this burden is considerable.

Treasure, Gavan, Todd, and Schmidt (2003) found that the disorder may engender emotional responses in carers, ranging from guilt and self-blame for possibly contributing to the condition to anger and disgust because of the perceived use of the disorder to punish family members. Furthermore, carers may be consumed with fear regarding the dangers to physical health the disorders pose and may be concerned about the impact it may place upon their own health as a result of the strain involved in caring for their family member. This role as carer may also restrict or deprive them of the opportunity to fully participate in other occupational or social roles.

Gilbert, Shaw, and Notar (2000) suggest that everyone in the family is affected by the presence of an eating disorder. Santonastaso, Saccon, and Favaro (1997) found that the relatives of individuals with eating disorders reported both objective burden (the extent of disruptions or changes to the carer's life, e.g., difficulty in inviting friends, neglect of other family members) and subjective burden (the emotional costs and the carer's attitude towards care giving, e.g., feeling of not being able to stand the situation any longer) associated with their role as carer. The subjective burden was perceived to be higher than the objective burden for both anorexia and bulimia though this discrepancy was greater for anorexia, demonstrating that carers rated the emotional impact of caring as greater than the actual disruptions which result from the role.

Treasure et al. (2001) compared carers of those with eating disorders and schizophrenia on the Experience of Caregiving Inventory. This tool was developed by Szmukler et al. (1996) as a self report measure of the experience for caring for a person with a mental illness, such as psychoses or schizophrenia. Treasure et al. (2001) adopted this scale in their study and found that those caring for people with eating disorders reported higher levels of distress and difficulties in most areas of caregiving than those caring for people with schizophrenia. These areas of difficulty related to difficult symptom related behaviour, negative symptoms, stigma, problems with services, effects on the family, loss, dependency, and the sufferer's need for support. Haigh and Treasure (2003) also surveyed carers of people with anorexia using the Experience of Caregiving Inventory and found carers reported moderate to high levels of distress associated with the sufferer's disorder. Fear of long term dependency upon them as a carer was most distressing, as was a sense of grief for the sufferer having lost opportunities and life experiences, in addition to the impact of the disorder on the family and its members. Problematic behaviours related to moodiness, negative symptoms such as withdrawal, and difficulties accessing services were rated as moderately distressing. However, as in other studies of the caring relationship, the carers also reported some positive outcomes such as a sense of being useful to the sufferer and having developed personal qualities such as an understanding of others with problems.

Living with a person with an eating disorder impacts heavily on the family, affecting numerous areas of life as the intrinsic and complex relationship between sufferer and food is, in time, projected upon the family (Kinoy, 1984). Intimate relationships are a major area where the burden of care is felt. Where the sufferer is a spouse, levels of marital intimacy, openness, and satisfaction are significantly less than those of non-distressed couples (Van den Broucke, Vandereycken, & Norré, 1997). While causal relationships cannot be determined from these studies, Espina et al. (2003) argue that the burden

associated with care may have a reciprocal impact on both the marital relationship as well as the course of the sufferer's disorder. Parents of eating disorder sufferers also report not just a poorer relationship with the sufferer (Gilbert et al., 2000) but also poorer marital adjustment and satisfaction (Espina, de Alda, & Ortego, 2003; Humphrey, 1988, Vandereycken, 1994), although Kinoy (1984) reports that sometimes under the stress, the parents find a new strength together.

Research has shown that relationships with siblings can also be affected by the eating disorder. For example, an antagonistic, rivalrous, and jealous relationship can exist between the anorexic sufferer and her well sister (Murphy, Troop, & Treasure, 2000; Williams & King, 2001) and a rivalrous relationship can occur between people experiencing bulimia and their well sisters (Sights & Richards, 1984). This negative sibling relationship may lead to the well sister de-identifying or withdrawing from her sister in an attempt to reduce this tension (Roberto, 1988; Schacter & Stone, 1987). Kinoy (1984) has shown that siblings respond by distancing themselves from the situation, denying the problem, trying to cope and understand, and by rebelling later in life. Parents often feel undermined by the eating disorder as previous ways of handling situations are deemed to be ineffective and outside intervention must be sought (Kinoy 1984). Despite this burden to the family, spouses, parents, and siblings typically remain involved in the situation, despite their ambivalence or resentment (Colahan & Senior, 1995).

Carers living with a person with bulimia, report on the financial impact of bulimic behaviour. While studies (Rosen, Leitenberg, Fisher, & Khazam, 1986; Rossiter & Agras, 1990) indicate that the number of calories consumed during binges varies greatly, a quarter of such episodes exceed that consumed by normal individuals in a 24 hour period. Furthermore, since the amount of food consumed by the sufferer may result in other family members going without, feelings of anger, frustration and tension result. (Kinoy,1984).

The issue of accessing intervention for people with mental illness appears frequently in the literature and evidence suggests that carers are generally dissatisfied with mental health services (Fadden et al., 1987). Several studies have shown that problems with accessing and working collaboratively with treatment services contributes to the burden of caring for a person with a mental illness. (Baronet, 1999; Fadden et al., 1987; Pai & Kapur, 1981; Szmukler et al., 1996). These types of problems may begin with general practitioners who are typically the first health professionals involved. Two British studies relating to eating disorder services specifically (King, 1989; Whitehouse, Cooper, Vize, Hill, & Vogel, 1992) indicated that general practitioners were not aware of the presence of an eating disorder in a patient in 50% of cases. More recently, Boulé and McSherry (2002) found that the majority of Canadian family physicians felt their training with respect to eating disorders was poor and were especially concerned regarding their capacity to manage such patients. However, brief intensive and interactive workshops and other professional development activities may be effective means to increase knowledge and skills, thus improving both detection and effective intervention (Boulé & McSherry, 2002; Gurney & Halmi, 2001).

Due to the severe physiological and psychological symptoms, which can occur with further progression of the disorder, effective and early intervention is of paramount importance. However, carers frequently complain of difficulty accessing treatment services and other resources (Gilbert et al., 2000). Despite feeling least equipped to deal with mental illness, families often find themselves as the main source of support to a severely ill family member due to the difficulties in accessing care (Rose, Mallinson, & Walton-Moss, 2002). As a result the role can include managing treatment, for example, administering medication and organising their family member to attend appointments.

Furthermore, when treatment is accessed, the needs of carers are frequently overlooked. The respondents in Haigh & Treasure's (2003) study reported a need for information regarding treatment

options, prognosis, and future treatment plans as well as information on coping strategies. Haigh and Treasure identify that carers' most prominent need is for practical and emotional help in dealing with the eating disorder. Two-thirds felt their family doctor was not meeting their support needs while 50 percent felt the same with respect to the treating health professionals.

Involving the family in the treatment of eating disorders is considered to be commonplace and beneficial (Eisler et al., 1997; Gowers et al., 2000), and considerable attention has been given to how families respond to symptoms of the disorder. However, Surgenor, Rau, Snell, and Fear (2000) found that while both patients and their relatives and friends express a high interest in education regarding eating disorders and their management, clinical staff consistently underestimate the degree to which this is valued. Treasure et al. (2001) indicate that lack of information relating to how to respond to and accommodate a person with an eating disorder may result in high levels of expressed emotion in the family, which can lead to subsequent maintenance of the disorder. Furthermore, Gilbert et al. (2000) state that despite models of treatment aimed at involving the family, many families continue to report that they are not included in the treatment process, and that this lack of inclusion can contribute further to the negative emotions that carers are already experiencing. These findings indicate a lack of knowledge of, or compliance with, the specific recommendations in clinical practice guidelines (e.g. American Psychiatric Association, 2000; Australian and New Zealand College of Psychiatry, 2003; Australian Health Minister's National Mental Health Working Group, 2003; Department of Human Services, Melbourne, 1996) that the burden on the family be assessed and support and education of family form part of the overall treatment.

The general lack of commitment by service providers and health professionals to these guidelines suggests a lack of understanding, awareness and appreciation of the complexities of eating disorders and the benefits of including carers and families in treatment. Further research should aim to explore systemic, training and attitudinal issues in the health and mental health sectors that negatively impact upon the treatment and care needs of people with eating disorders and their families.

There is little literature examining the distinct experience of suspecting the presence of an eating disorder within a family member, and the measures that are taken to reaffirm or refute suspicions, or relating to the impact this can have on the carer. The literature which does exist states that carers are usually the first people to detect and recognise an eating disorder, and that this process can lead to conflict and distress (Treasure et al. 2003). This is particularly the case where the sufferer has anorexia nervosa and is ambivalent or resistant about the need for intervention (Vitousek, Watson, & Wilson, 1998). Gilbert et al. (2000) note the importance of parental knowledge about symptoms of eating disorders, given that it is often the parent who notices changes in their child's behaviour and begins to seek help for the child. Shame, stigma, guilt, denial, anger, anxiety, fear and blame are cited as reactions of carers to the realisation that anorexia nervosa is present in their family member, and disgust and shame are cited as reactions to identifying symptoms of bulimia nervosa (Gilbert et al., 2000; Treasure et al., 2003).

The perception that carers have little information relating to the nature of the disorder provides direction for further research to specifically determine the aspects of service provision which will benefit carers, and ultimately the person with the disorder. Future research should aim to identify and address the specific needs of carers of people with an eating disorder, and should aim to influence services and organisations to move towards providing support and information and to increase carer involvement and inclusion in treatment planning and delivery.

Further research should aim to explore systemic, training and attitudinal issues in the mental health sector that negatively impact upon the treatment and care needs of people with eating disorders and their families. This is likely to alleviate the burden experienced by carers.

The literature considered in this review does go some way towards addressing the impact of caring for a person with an eating disorder and the impact of diagnosis and the initial detection process on the family. However, the distinct experience of picking up initial signs of a disorder, conceptualising these signs as indicative of an illness, and the response to the realisation that an eating disorder is present has not been fully explored in terms of the impact on the carer, and has not been explored at all outside the UK. This highlights the importance of research to reveal the potential barriers to earlier identification of the disorder by families and health and educational services. Results of such research should be used to implement systemic change in the health and mental health sectors, in carer support services, and in community awareness promotion campaigns generally. This would facilitate accessibility to information relating to the signs and symptoms of eating disorders, common misattributions of these symptoms, and the pathways to accessing intervention for the family member or friend with the disorder.

Recent developments in the literature have begun to identify certain issues compounding the experience of caring for a person with an eating disorder. Despite these developments, there remains a void in the current focus of the literature in that there is no literature thoroughly exploring this experience in its entirety. The literature would benefit from greater exploration of all aspects of the experience of caring for a person with an eating disorder. This would include research assessing the impact upon the carer and family members at all stages of the progression of and/or recovery from the illness and should address issues relating to the costs incurred by the family as a result of the presence of an eating disorder. Research should also aim to identify the extent to which carers feel supported by the wider community and/or specific services.

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