Journal of Eating Disorders

RESEARCH

Open Access

"It's never ending and overwhelmingly difficult": a mixed-methods survey of the impact of caregiving for a loved one with an eating disorder in New Zealand

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Abstract

Background Caregivers of people with eating disorders (EDs) often support refeeding, behavioural monitoring, and co-ordinate therapeutic and medical appointments. Available support is often focused on the person with the ED and rarely on the caregiver. This study examined the impact of caregiving in New Zealand (NZ).

Methods Current and previous caregivers completed an online, anonymous survey exploring their experience of caregiving and its psychological impact using the Depression, Anxiety, and Stress Scale (DASS-21), the Eating Disorders Symptom Impact Scale (EDSIS), and questions about the long-term impact of caregiving on caregivers' mental health. A comparison was made with data on Australian caregivers.

Results Current caregivers reported higher levels of depression and stress than those not currently caregiving, as well as higher levels of depressive symptoms than Australian caregivers. The impact of ED symptoms were also generally higher in NZ participants compared with Australian caregivers.The perceived impact of the ED was associated with the psychological distress experienced by caregivers with greater impact being linked to more distress. Of those whose loved ones were in recovery, more than 25% experienced ongoing post-traumatic symptoms related to their caregiving experience.

Conclusion NZ caregivers reported ongoing effects related to caregiving even when the person with the ED had recovered. NZ caregivers experience a high level of distress and burden that can persist once recovery is achieved. Comprehensive ED support should include interventions to improve caregivers' wellbeing.

Plain English summary

Caring for someone with an eating disorder (ED) can impact all aspects of daily life. We surveyed 153 New Zealand adults who are, or have been, the main caregiver for a loved one with an ED to learn how this role affects them. Most were parents, and about 70% cared for someone with anorexia nervosa.
The toughest part was emotional: more than 60% of caregivers described relentless fear, anxiety, and isolation as their biggest challenges.

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Common mental health tests showed current caregivers had moderate depression and stress and mild anxiety—higher than scores in both the general public and Australian ED caregivers. Roughly one third also reported nightmares, flashbacks, or strong physical reactions when reminded of the caregiving period, pointing to trauma-like stress.

Overall, the findings show that ED services need to recognise and actively support caregiver wellbeing during treatment and long after recovery, not just focus on the person with the ED.

Keywords Caregiver burden, Feeding and eating disorders, Mental health, Depression, Anxiety, Eating disorders

Background

Eating disorders (EDs) are serious mental health conditions that affect millions globally, with lifetime prevalence estimates ranging from 0.6 to 17.9% [1]. Adolescents, particularly those who are biologically female, are disproportionately affected [2]. EDs are associated with high medical and psychiatric morbidity and, given the early onset and potentially chronic or life-limiting trajectory of these disorders, effective treatment often involves a high level of caregiver engagement. For adolescents, caregivers are frequently parents or guardians; for young adults and adults, partners, siblings, or adult children often assume responsibility. Often, caregiving also requires adaptation for developmental stage; adolescents may require direct parental involvement in meals, while adults benefit from a more collaborative, autonomy-supportive approach.

Various physical and emotional impacts can arise from caring for someone with an eating disorder (ED) [3–8]. Caregivers can experience high levels of anxiety, depression, and perceived burden [9–11]. Guilt for their loved one's condition may occur, along with worry about their loved one's wellbeing [12] and grief when witnessing the declining health of the individual with the ED [13]. When stressed and tired, irritability, anger, and frustration occur more readily [14]. Even following ED recovery, caregivers can continue to be impacted by heightened vigilance and worry [5]. These potential emotional impacts can be exacerbated by experiencing stigma around the ED, role strain, financial strain from the cost of treatment and support seeking, and the lack of information and support available [15–17].

Positive aspects associated with caregiving do occur and can buffer the negative impacts [18, 19]. Across healthcare populations, positive caregiving experiences have been found to mediate the relationship between caregiver burden and life satisfaction [20–22]. If the caregiver finds their role enjoyable, meaningful, or rewarding, caregiving can enhance self-esteem, increase life satisfaction, and alleviate the impact of caregiver burden through a greater sense of resilience and purpose [5].

Social support can considerably influence a caregiver's capacity to cope with caregiving stressors. Caregivers receiving social support display more adaptive coping strategies than those without social support [23]. However, accommodating the perceived needs of the individual with the ED can substantially impact a caregiver's capacity to engage in life, health, and social activities [24]. For example, caregivers may avoid eating at restaurants to facilitate the observation of rigid mealtimes [15] or due to feeling that they need to be constantly available to the person with the ED. Social engagement reduces even more when caring for an individual with high needs, such as those with anorexia nervosa [13]. As such, caregivers frequently sacrifice occupational, social, and leisure activities [15], which can lead to feelings of social isolation [8, 25] and worsening psychological and physical health [7, 10, 25–27].

Exploration of the impact of caring for a loved one with an ED in New Zealand (NZ) is only in its infancy. Surgernor et al. [8] found that 93.2% of caregivers felt all aspects of family life had been significantly impacted by the ED, while 89% of caregivers noted a reduced quality of life, thus reflecting the burden of care experienced. These impacts were reflected in a qualitative study by Fletcher et al. [5], which found an overarching theme that "life is different now" for caregivers. Even following recovery, caregivers continued to be impacted by heightened vigilance and worry [7]. Beyond these studies, little literature has explored the impact on caregivers of caring for a loved onewith an ED in NZ.

It is possible that experiences of caregiving drawn from overseas could aid in understanding the impact of caring for someone with an ED in NZ. NZ and Australia share comparable publicly-funded healthcare systems and sociocultural profiles, making Australia a logical benchmark for NZ [28]. Additionally, it is estimated that several hundred people travel to Australia from NZ each year to access specialised ED treatment programmes—likely driven by perceived greater service availability and structured pathways that are not available in NZ.

Despite the growing recognition of EDs within NZ, empirical research investigating the impact of caregiving remains limited. Recent government initiatives, including the Ministry of Health's Eating Disorders Strategy [29] and the Mental Health and Addiction Services Report [30], have highlighted the urgent need for local data to inform service development, workforce training, and family-inclusive models of care. While international evidence—particularly from Australia—provides useful comparisons given the similarities across healthcare

systems, these insights cannot substitute for data responsive to NZ's cultural context, service structure and availability, and resource constraints. Establishing NZ-specific evidence on the psychological impact of caregiving is essential to facilitate the translation of government policy commitments into services that adequately meet the needs of both individuals with EDs and their families and caregivers, who are critical partners in recovery. Therefore, we aimed to explore the psychological impact of caregiving for an individual with an ED in NZ and how this compared to data on caregivers in Australia.

Methods

This study utilised an anonymous online survey which included psychometrics and open-text questions to explore caregiver experiences across the caregiving timespan (i.e., caregivers with a loved one who is yet to receive treatment, is in treatment, or who is in recovery). This approach follows a similar method to prior NZ ED literature [5, 8, 13] and was developed in conjunction with Eating Disorders Carer Support NZ (EDCS) lived experience stakeholders (SR and KM).

Four hypotheses were generated to be tested in this study:

1. Caregiving would have an overall negative effect on caregiver self-reported wellbeing (H_1).
2. Caregivers who reported greater impacts of the ED would report poorer psychological wellbeing (H_2).
3. Caregivers would report less psychological distress when caregiving for someone in recovery from their ED compared to caregivers of individuals awaiting or undergoing treatment (H_3).
4. There would be a difference between the NZ and Australian caregivers, with NZ caregivers reporting higher levels of distress (H_4).

The base survey comprised 129 closed questions and 14 open-ended questions, covering a range of aspects of caregiving experiences and associated support needs. A publication describing findings relating to the support needs and supports accessed by caregivers is available elsewhere [31].

Participants

Eligible participants were current or former adult caregivers of an individual with a diagnosed or suspected ED in NZ. To participate, caregivers needed to be proficient in English and have access to an internet connection. There were no exclusion criteria; this meant that more than one caregiver from the same family could participate, given that caregiving responsibilities may fall to multiple family members.

Recruitment

Recruitment took place over 13 weeks between March 27, 2024 and June 30, 2024. Convenience and snowball sampling were used by emailing the study invitation to ED stakeholders, who were identified through an internet search using google.co.nz and a combination of "eating disorder" OR "disordered eating" and "support" OR "treatment" OR "help" keywords. This resulted in a list of five ED support services, 18 private clinics or services, and 11 publicly-funded services. Unpaid social media advertising was also undertaken by the researchers, and through stakeholders sharing the study invitation through their networks. Study invitations and social media advertising contained a link to the Qualtrics online survey platform (www.Qualtrics.com) where the study was hosted. Study information was provided at the start of the survey, with consent being implied through participation. Ethical approval was received from the Auckland University of Technology Ethics Committee (24/050).

Measures

Demographic and caregiving information

Participants provided basic demographic information and information about the individual living with the ED, including age of onset, relationship, ED type, co-occurring mental health difficulties, and supports accessed/declined. Caregiving behaviour questions included the recency of caregiving, sharing of caregiving responsibilities, the impact of being a caregiver, and the long-term effects of caregiving.

Psychological impact

Mood was assessed using the 21-item Depression, Anxiety, and Stress Scale (DASS-21; [32]). The DASS-21 consists of three subscales: Depression, Anxiety, and Stress. Subscale scores are calculated by summing the scores of the seven corresponding items for each scale. To compare scores to the original DASS-42 scale, subscale scores can be multiplied by two. Total scores range from 0 to 126 with higher scores indicating a higher level of symptoms. The DASS-21 has sound psychometric properties, with very strong internal consistency across subscales (Depression: $\alpha = 0.91$; Anxiety: $\alpha = 0.84$; Stress: $\alpha = 0.90$; [32]) and the total scale ($\alpha = 0.93$ [33]). The DASS-21 has been widely used internationally [34], including with caregivers of people living with an ED [27].

Impact of eating disorder symptoms

The Eating Disorders Symptom Impact Scale (EDSIS; [35]) was used to measure caregiver burden and the impact the ED has on family life, as experienced by current caregivers. The EDSIS comprises 24 5-point Likert scale questions with responses ranging from "never" (0) to "nearly always" (4). The EDSIS contains four subscales:

Nutrition, Guilt, Social Isolation, and Dysregulated Behaviour. Subscale scores are calculated by summing the scores of the respective scale items. The EDSIS composite score is the sum of the subscale scores, with a possible range of 0 to 96. Higher scores indicate a more negative appraisal of the measured caregiving aspect(s). The EDSIS was only completed by current caregivers.

Reliability of the EDSIS is acceptable (α = 0.69–0.90) [35, 36], with strong internal consistency across the individual subscales (Nutrition: α = 0.89; Guilt: α = 0.84; Dysregulated Behaviour: α = 0.82; Social Isolation: α = 0.86; [35]). The EDSIS has been moderately correlated with the negative burden subscale of the Experiences of Caregiving Inventory ($0.42 \leq r \leq 0.60$) [35] and the General Health Questionnaire-12 [36].

Ongoing traumatic impact of caregiving

Four fixed-answer questions were administered to assess traumatic-stress symptoms associated with past caregiving experiences, thereby capturing the ongoing psychological impact of caregiving. These specific questions were: "How much are you bothered by repeated, disturbing and unwanted memories or dreams of your time as a caregiver?", "How much are you bothered by suddenly feeling or acting as if stressful experiences whilst caregiving were happening again?", "How much are you bothered by feeling very upset when something reminded you of the stressful aspects of being a caregiver?", and "How much are you bothered by having strong physical reactions when something reminded you of the stressful aspects of being a caregiver?". Each item was rated on a 5-point Likert scale ranging from "not at all" to "extremely". As these questions were assessing ongoing impacts, they were only asked of caregivers whose loved one was in recovery.

Open-text questions

Twelve open-text questions were included, allowing participants the opportunity to provide further detail about their experiences of caregiving and its impact on their wellbeing. Examples of open-text questions include "What is/was the most difficult part of caregiving for you?", "How has caregiving impacted you?", and "How has caregiving impacted you long term?". Two more open-text boxes allowed participants to add further information if they desired.

Power calculation

A power calculation was undertaken using G*Power to conservatively estimate a sample size for the study. Using an independent samples two-tailed *t*-test to compare the two groups, and a small-medium effect size ($d = 0.3$), 80% power, and an α of 0.05, the estimated sample size was 176 participants. This was higher than a similar previous NZ study that obtained a sample size of 121 participants [8]. This indicated that recruitment of 176 participants may be obtainable and was therefore considered to be an appropriate sample size for adequate powering of our study.

Data analysis

Statistical analyses were conducted using IBM SPSS Statistics version 29. A sample of 153 people was included in the analysis based on meeting the minimum requirement of completing at least 5% of the survey, which captured baseline demographic information to provide an overview of ED caregivers in NZ. Missing data were managed by using the mean of related subscale items for that participant; participants missing more than one item per subscale were excluded. Measures were checked for kurtosis and skewness, which indicated that the data were approximately normal, so parametric statistics were used for the analysis.

To determine the impact of caregiving on psychological wellbeing, scores on the DASS-21 were calculated and compared to population norms (H_1). As no norms for NZ were available at the time of writing, an Australian community sample was used [37] in a two-tailed one-sample *t*-test. To assess the impact of the ED and caregiver behaviours on wellbeing (H_2) for current caregivers, the impacts of the ED (EDSIS) were correlated with psychological wellbeing outcomes (DASS-21). A two-tailed independent samples *t*-test was used to explore if psychological wellbeing changed throughout the caregiver journey by comparing DASS-21 scores between current caregivers and caregivers with a loved one in recovery (H_3). Finally, to determine if there was a difference in the experience of caregiving between caregivers in NZ and Australia (H_4), two-tailed, one-sample *t*-tests were used to compare psychological wellbeing (DASS-21), and eating disorder impact (EDSIS) scores, where the mean, standard deviation, and sample sizes from the Australian studies were entered for comparison. Where appropriate, Hedge's *g* effect sizes were calculated and reported given the unequal sample sizes and comparisons across studies.

The Australian comparison studies were selected based on: (a) being an examination of the Australian eating disorder caregiving population; (b) being most similar to the present study's population, based on demographic characteristics and temporality; (c) utilising the DASS-21 or EDSIS; (d) reporting descriptive statistics in the paper that would allow a comparison of psychometrics; and (e) being the most recent publications available that met these criteria.

Analysis of open-text questions

Qualitative data from open-text questions were analysed using content analysis, a structured method for

interpreting text-based data [38]. This approach enables researchers to draw credible and repeatable inferences about the context and meaning taken from the data [39]. Specifically, content analysis involves systematically reducing extensive qualitative data into meaningful categories that capture key aspects of the phenomenon under investigation. The steps relating to the content analysis used in this study are described in Sinclair et al. (under review), which also includes further findings [31]. In brief, the process used three key stages: preparation of data, the development of an organised coding framework, and the clear presentation of findings. For this study, RS prepared the data with support from LD. RS completed the initial coding to develop a coding framework with the process overseen by LD, while LD coded a portion of the answers to allow comparison and a review of the coding framework. Once the codes were completed, RS and LD reviewed the initial codes and collapsed these into appropriate categories for the final analysis. The data was then presented as frequencies (*n*) of the total number of sub-codes for the primary code. During the preparation phase, it was observed that participants frequently provided information about the psychological impact of caregiving in "non impact-specific" questions (e.g., "What support did [service type] provide?"). Given this, all answers were coded with an openness to where they may best fit. Final codes were discussed with the wider research team to check interpretation.

While content analysis is considered less interpretative than other qualitative approaches such as reflexive thematic analysis, trustworthiness was enhanced through researcher triangulation, the review of coding decisions, and the involvement of a diverse range of perspectives in the research team [40], including lived experience researchers and a clinical psychologist who works with people with eating disorders.

Table 1 Caregiver and person living with the ED demographics (*N* = 153)

Sociodemographic factors	Caregivers *n* (%)	Person living with ED *n* (%)
Gender		
Woman	144 (94.1)	114 (89.1)
Man	7 (4.6)	11 (8.6)
Transgender male	1 (0.7)	
Non-binary	0 (0.0)	3 (2.3)
Did not answer	1 (0.7)	
Age		
Mean	50.1 (10.6)	19.4 (7.2)
Range	18–79	9–89
Relationship status		
Single	12 (7.8)	
Dating	4 (2.6)	
Partnered/married	124 (81.1)	
Separated/divorced/widowed	11 (7.2)	
Did not answer	2 (1.3)	
Ethnicity		
NZ European/European	149 (97.4)	
Māori	10 (6.5)	
Pacific Peoples	2 (1.3)	
Asian	1 (0.7)	
Other	3 (2.0)	
Education level		
High school (NCEA Level 1, 2, or 3)	22 (14.4)	
University certificate or diploma	38 (24.8)	
Bachelor's degree	43 (28.1)	
Postgraduate	43 (28.1)	
Overseas secondary school qualification	1 (0.7)	
No qualification	2 (1.3)	
Did not answer	4 (2.6)	
Household income (NZD)		
≤ $40,000	10 (6.5)	
$40,000–$59,999	10 (6.5)	
$60,000–$79,999	8 (5.2)	
$80,000–$99,999	9 (5.9)	
$100,000–$149,999	38 (24.8)	
$150,000–$199,999	17 (11.1)	

Results

Caregiver demographics

Caregiver demographics are presented in Table 1. Approximately 87% (*n* = 111) of participants were parents of the individual with the ED, 5.9% (*n* = 8) were other family members, and 2.0% (*n* = 4) were partners. Of the current caregivers (*n* = 92, 60.1%), most lived with the person who had the ED (*n* = 83, 90.2%) and provided around-the-clock care. Based on the review of the data, it appeared that only one caregiver per individual with the ED completed the survey.

In terms of the clinical presentation of the individuals with EDs, the average age of onset for ED symptoms was 13.9 years (*SD* = 2.8). The most common ED presentation was anorexia nervosa (*n* = 109, 71.2%), followed by avoidant restrictive food intake disorder (*n* = 28, 18.3%), then bulimia nervosa (*n* = 22, 14.4%). In terms of treatment, 24.2% (*n* = 53) reported that the person with the ED had been hospitalised due to their ED, and 3% (*n* = 7) had sought treatment overseas.

Co-occurring mental health issues were common. Approximately 57% (*n* = 87) of the people with EDs also experienced anxiety, 31% (*n* = 47) experienced depression, 20% (*n* = 31) were people with autism, 15% (*n* = 23) had post-traumatic stress disorder (PTSD), and approximately 14% (*n* = 21) had attention deficit hyperactivity disorder. For those with co-occurring mental health conditions, 36% of individuals had been experiencing these mental health difficulties before the onset of the ED.

Psychological wellbeing of caregivers

Psychometric scores for all scales are presented in Table 2. The mean score for current caregivers fell in the moderate range for depression and stress and the mild range for anxiety.

Compared to the Australian general population, current NZ caregivers experienced significantly higher levels of depression ($t(61) = 10.26$, $p < 0.001$, Hedge's $g = 1.29$, 95% CI [0.95, 1.62]), anxiety ($t(61) = 6.54$, $p < 0.001$, Hedge's $g = 0.82$, 95% CI [0.53, 1.10]), stress ($t(61) = 12.74$, $p < 0.001$, Hedge's $g = 1.60$, 95% CI [1.22, 1.97]), and total distress ($t(61) = 11.30$, $p < 0.001$, Hedge's $g = 1.42$, 95% CI [1.06, 1.77]).

Table 2 Comparison of caregiver DASS-21 and EDSIS scores with comparable Australian studies

Sample	Current study (*N* = 128)		Comparison studies	
			Crawford, Cayley [38] (*N* = 497)	Lefkovits, Pepin [25] (*N* = 104)
	NZ current caregivers	NZ caregivers whose loved one is in recovery	Australian community	Australian current caregivers
Female gender	93.5%	92.2%	46%	93.9%
Age *M* (*SD*)	49.22 (10.62)	50.41 (10.09)	42.14 (17.93)	51.61 (7.48)
Partnered relationship	81.5%	83.4%	NR	80.0%
Parent of individual with ED	88.9%	85.0%		93.9%
DASS-21	M (SD)	M (SD)	M (SD)	M (SD)
Total	42.87 (24.09)	28.55 (23.26)*[a]	8.30 (9.83)*[b]	NR
Depression	15.48 (9.91)	8.95 (9.79)*[a]	2.57 (3.86)*[b]	12.67 (9.77)*[b]
Anxiety	8.39 (8.01)	6.65 (7.00)[a]	1.74 (2.78)*[b]	8.78 (7.79)
Stress	19.00 (9.28)	12.95 (9.33)*[a]	3.99 (4.24)*[b]	17.17 (8.31)
EDSIS[c]				
Total	48.34 (15.7)			42.62 (14.05)*[b]
Nutrition	19.92 (5.8)			20.03 (5.71)[b]
Guilt	11.77 (4.5)			10.13 (4.89)*[b]
Dysregulated behaviour	9.38 (5.8)			4.85 (3.95)*[b]
Social isolation	8.6 (3.7)			7.62 (3.91)[b]

DASS-21 Depression, Anxiety and Stress Scale 21; *EDSIS* Eating Disorders Symptoms Impact Scale; *NR* not reported

*Indicates significance of 0.05 or less using a two-tailed test; [a] indicates a comparison between current caregivers and caregivers whose loved one is in recovery; [b] indicates a comparison between New Zealand and Australian caregivers; [c] no comparison was made between current caregivers and caregivers of people who were in recovery due to the questionnaires assessing current impact and behaviours related to the ED

Impact of recovery on caregiver psychological wellbeing

When comparing participants who were current caregivers with those whose loved one was in recovery, participants currently caring for an individual with an ED had significantly higher levels of depression ($t(100) = 3.27$, $p = 0.001$, Hedge's $g = 0.66$, 95% CI [0.25, 1.06]), stress ($t(100) = 3.21$, $p = 0.002$ Hedge's $g = 0.65$, 95% CI [0.24, 1.05]), and total distress ($t(100) = 2.97$, $p = 0.004$, Hedge's $g = 0.60$, 95% CI [0.19, 1.00]). Anxiety symptoms were not significantly different between current caregivers and caregivers whose loved one was in recovery ($t(100) = 1.12$, $p = 0.26$, Hedge's $g = 0.23$, 95% CI [0.17, 0.62]).

More than 30% of caregivers whose loved one was in recovery reported being moderately or extremely bothered by disturbing memories of their time being a caregiver, approximately 38% were moderately to extremely distressed from feeling as though they were reliving their caregiving experience, approximately 31% were moderately or severely distressed when reminded about their caregiving experience, and approximately 25% had moderate to severe physical reactions to reminders of caregiving (refer to Fig. 1).

Impact of the ED and caregiver behaviours on caregiver psychological wellbeing

Pearson correlation coefficients were computed to examine the relationship between current caregiver psychological wellbeing and the impact and accommodation of the ED. For current caregivers, greater ED symptom impact (EDSIS) was significantly associated with higher psychological distress as measured by the DASS-21 total distress score ($r(50) = 0.60$, $p < 0.001$).

Comparison of NZ caregivers and Australian caregivers

Compared to Australian caregivers in Lefkovits et al. [25], NZ caregivers experienced significantly higher levels of depression ($t(61) = 2.24$, $p = 0.029$, Hedge's $g = 0.28$, 95% CI [0.03, 0.53]) but anxiety ($t(61) = 0.70$, $p = 0.350$, Hedge's $g = 0.05$, 95% CI [0.20, 0.29]) and stress ($t(61) = 1.55$, $p = 0.126$, Hedge's $g = 0.20$, 95% CI [0.05, 0.44]) were not significantly different.

The impact of ED symptoms on family life and the level of caregiver burden experienced—as measured by the EDSIS total score—was higher in NZ caregivers than in Australian caregivers [25] ($t(47) = 2.64$, $p = 0.011$, Hedge's $g = 0.37$, 95% CI [0.084, 061]). Specifically, the family lives of our participants were found to be more impacted by guilt ($t(47) = 2.62$, $p = 0.012$, Hedge's $g = 0.37$, 95% CI [0.08, 0.66]) and dysregulated behaviour ($t(47) = 5.15$, $p < 0.001$, Hedge's $g = 0.07$, 95% CI [0.41, 1.04]) than Australian caregivers. There was no difference in the nutrition subscale ($t(47) = 0.414$, $p = 0.68$, Hedge's $g = -0.06$, 95% CI [-0.03, 0.22]) and the socially isolating impact of

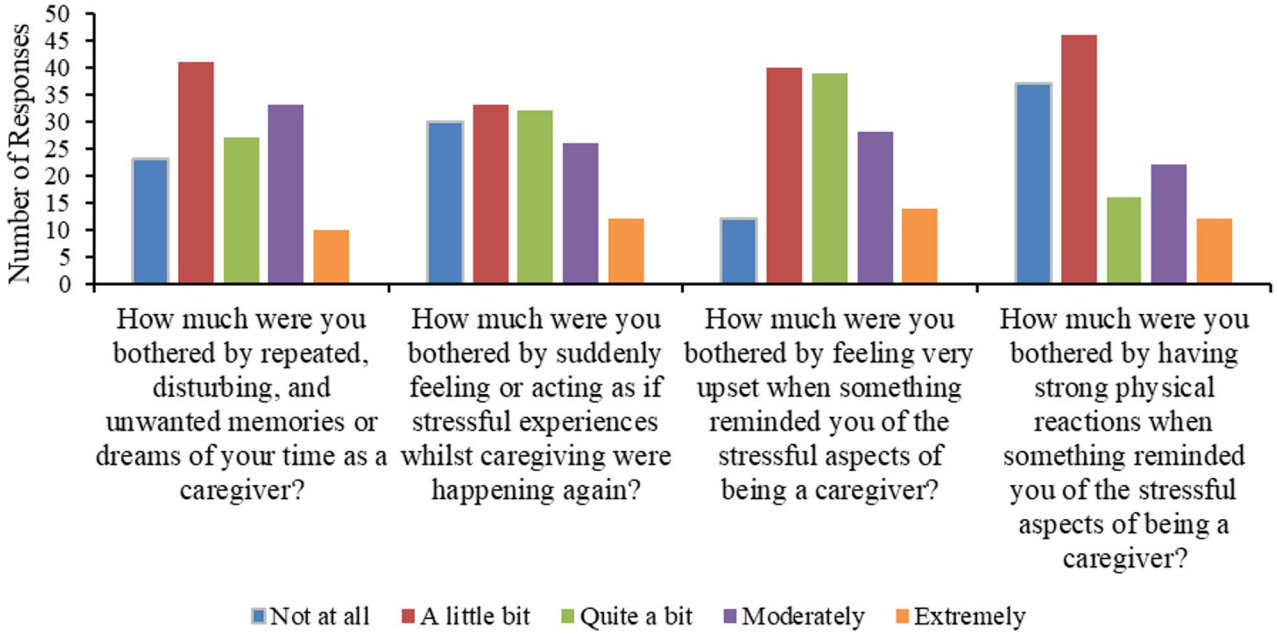

Fig. 1 Proportions of participant responses to closed questions about ongoing impact

the ED ($t(49) = 1.68$, $p = 0.099$, Hedge's $g = 0.23$, 95% CI [-0.04, 0.51]).

Content analysis results

Caregivers reported a range of psychological impacts from caregiving for someone with an ED. It was observed that the majority of codes generated related to the negative emotional ($n = 507$, 72.0%) and psychosocial impact ($n = 87$, 12.4%) of caregiving, with few participants reporting the positive aspects ($n = 24$, 5.4%).

> *"[the hardest part of caregiving was] Everything. The stress of trying to get them to eat, the mental anguish they have, self-harm, suicidal thoughts and will they act on that? Trying to be there for your other loved ones as they need their mum and wife also. The financial toll, having to give up work and to get specialist help means you pretty much have to go private. And the help that is given is to the person with the eating disorder, which is the most important, but you feel left out in the cold trying to make your child eat and navigate all that entails."*—Participant 150
>
> *"The stress, exhaustion, effects on my mental and physical health and finances."*—Participant 147

The high frequency of codes related to negative impact was believed to reflect the high level of caregiver burden. The main emotional impacts experienced by caregivers were feelings of anxiety ($n = 106$, 23.8%), depression ($n = 53$, 11.9%), and a sense of isolation ($n = 48$, 10.8%).

> *"Managing own emotions (fear, despair, sadness) in order to help my daughter manage her strong emotions."* – Participant 164
>
> *"Fear that she'll never recover, terror that in the morning I'll wake up and find her dead."*—Participant 171
>
> *"Constant worry about relapse into full-blown refusal to eat. The stress is all day, every day."*—Participant 161
>
> *"It feels very lonely as it is not something people really understand unless they have been there. People think that you can just tell the child to eat more, and it will all be sorted. They don't understand that the mental battle going on means the child can't eat normally. It is the hardest and most isolating experience I have ever been through."*—Participant 71

For those who were no longer actively engaged in caregiving because their loved one was in recovery, additional challenges existed. Specifically, long-term challenges included ongoing anxiety and fear ($n = 4$, 22.8%), intrusive memories about caregiving and hypervigilance for signs of relapse ($n = 33$, 18.3%), a continued sense of disconnection and isolation from peers ($n = 19$, 10.6%), chronic exhaustion ($n = 15$, 8.3%), ongoing restlessness ($n = 10$, 5.6%), and depression ($n = 9$, 5.0%). A further 29.4% ($n = 53$) reported ongoing unspecified symptoms that indicated a worsening of mental and physical health compared to before becoming a caregiver.

> *"Our [child] struggled with an eating disorder for approximately 12 months. It was a very difficult and*

stressful period which brings back painful memories. While [they] have made a good recovery you never assume that will always be the case, so I guess there is a degree of anxiety around the future for [them] at times."—Participant 180

"I can no longer care for her. I have PTSD [post-traumatic stress disorder] and get panic attacks. She's living with [parent] who has stepped up for the first time in over two years. Before she went to her [other parent's], I wasn't sleeping, it was affecting my work. My kids are as burnt out from anorexia as I am. I said to [regional specialist service], I'm collateral damage and you don't give a f##&" —Participant 2

"My therapist has suggested that through caring for my [loved one], I developed a difficulty to detach from conflict and am often unable to temper my response. I jump to worst case scenario and catastrophize things in my head. [Therapist] thought that this may have been because when my [loved one] was sick it was a 'help/react or she dies' situations a lot of the time."—Participant 13

Positive aspects related to caregiver for a loved one with an ED included perceived personal growth as a result of the experience ($n = 12$, 2.7%), learning new effective coping strategies ($n = 6$, 1.4%), improved relationships with family members ($n = 4$, 0.9%), gratitude and appreciation for support networks ($n = 1$, 0.2%), and hope for future without an ED ($n = 1$, 0.2%).

"A lonely process, but worth every tear, every ounce of pain to get my [child] well."—Participant 27

"The long-term impact is positive. Personal growth and deep connection with sufferer." —Participant 48

Discussion

This study explored caregiver burden associated with caring for a loved one with an ED in NZ, how this burden differed when the loved one was in recovery, and a comparison of these findings with data from Australia. High levels of anxiety, depression, and stress were found in NZ caregivers that exceeded those reported in general, non-caregiving populations [37]. Qualitative comments contextualised these findings through an emphasis on the overwhelming sense of responsibility for being the person keeping their loved one alive, and the pervasiveness and relentlessness of the role.

These findings align with existing local and international research which has found that the emotional burden and constant vigilance experienced by caregivers of individuals with EDs has a significant and ongoing psychological impact on the caregivers' lives, including disruption to relationships and poorer wellbeing. These findings also resonate with broader caregiving research where similar themes of psychological distress and fatigue are evident for caregivers of individuals experiencing psychological disorders [41–43] and chronic medical conditions [44–46]. However, we would argue that, unlike caregiving for physical illness or age-related decline, caregiving for someone with an ED involves unique challenges that may increase caregiver burden: for example, intensive behavioural monitoring which may lead to interpersonal conflict, increased vigilance due to behavioural secrecy, and providing support while the person with the ED denies their disorder. This can result in high distress and conflict and can negatively impact the relationship between the caregiver and the individual with the ED [10, 12] in addition to impacting caregiver wellbeing. Moreover, as EDs often occur in young people, parents face the increased emotional burden of enforcing treatment adherence while trying to raise their child and often meet the needs of their other children [10, 47].

Strong associations were found between the level of psychological distress experienced during caregiving and the level of ED impact experienced by caregivers. Specifically, greater levels of distress were associated with greater impact of the ED. Although this was only examined using correlational analysis, this finding is consistent with studies that have shown that the perceived impact of an ED is associated with caregiver distress and burden [48, 49]. Further supporting this, interventional studies targeting ED impact [50, 51] and caregiver burden [50] improved caregiver wellbeing, thus demonstrating the relationship between impact and burden.

Levels of caregiver distress decreased following recovery; however, many caregivers reported traumatic stress symptoms from their caregiving experiences, hypervigilance for signs that their loved one was relapsing, and ongoing disconnection and isolation from their peers. This is consistent with findings both locally [5] and internationally [10]. Positive enduring aspects of caregiving were occasionally noted, but these were outweighed by the negative impacts; the profound and ongoing impact of caregiving may persist even when the loved one is in recovery. These experiences are likely worsened by an expectation that "everything is better" when the person with the ED is in recovery and the subsequent withdrawal of treatment, which may leave the caregiver feeling more isolated and distressed [52, 53].

Consistent with our findings that caregiver burden decreased between being a current and previous caregiver, research has shown that ED symptom impact decreases over the course of treatment through to recovery [48]. This may be because the emerging signs of recovery build hope and reinforce the beneficial impact of caregiving, thus buffering the emotional burden. However, this may also mean that, for caregivers of people

with long-lasting or multi-problematic presentations where initial treatments have been ineffective, hopelessness and a sense of pervasiveness may lead to worsening mental health.

Finally, the endorsement of traumatic stress symptoms is consistent with other studies [54–57], albeit at a lesser level than previous findings [56]. Given that traumatic stress symptoms have been associated with greater mood [56] and coping challenges during caregiving [58, 59], our findings further reinforce the need to provide timely intervention and support for caregivers to reduce the long-term burden experienced. Similarly, self-blame—often evidenced by feelings of guilt—is associated with PTSD [55], therefore highlighting the importance of practitioners providing early psychoeducation to parents about the multifactorial aetiological factors of EDs and clearly communicating that the development of an ED is not due to one person's behaviour [58, 59].

Participants in our study showed elevated levels of psychological distress compared to their Australian counterparts. The increasing rates of EDs in NZ [60, 61] along with a shortage of specialist clinicians and often long waits for treatment [61], means that caregivers are increasingly required to support their loved one with an ED whilst waiting for care [5, 8, 61]—more so than ever before. In NZ, treatment access challenges are further exacerbated by a lack of formal support for caregivers, rural–urban disparities in specialist service availability, and an outdated ED strategy that primarily focuses on treatment without prevention, has poor national coordination and accessibility, is underfunded, and lacks an evidence-based policy [30]. Our data suggests that tailored support for caregivers and further investment in making ED treatment more accessible are needed; otherwise, these disparities in caregiver burden are likely to persist. Disparities are likely to be even greater for demographics for whom a lack of research and appropriate resources are available, such as older people with EDs (individuals aged over 25), Māori (the Indigenous people), neurodiverse populations, and rural families. Therefore, until more resources are available for ED treatment and caregiver support, it is likely that positive outcomes for people with EDs in NZ will come at a considerable cost to caregivers.

Limitations

The non-completion rate for the study was high; whilst this could be due to the length of the study, many participants stopped before completing basic demographic information, unaware of the survey's length. It is possible that these individuals were initially curious about the study but less motivated to complete the whole survey. Additionally, the significant burden of caregiving, as highlighted in this study, may have made it difficult for caregivers to complete or engage with the survey. Thus, there are several unknowns about the reasons for non-completion. It is unclear how non-completion may have impacted the results; perhaps only caregivers who were highly motivated to share their experiences (which we could assume were those who experienced higher levels of distress) completed the survey. Given this, results should be interpreted with a degree of caution.

Recruitment occurred through caregiver networks such as the EDCS network, suggesting that the participants surveyed were likely already engaging in some level of support seeking. It is possible that being engaged with a support network indicates a recognition of the need for support, and that a willingness to seek support may be protective. Conversely, it could be that caregivers who are not engaged in support are experiencing less caregiving burden and thus have not sought support. Given this, future research should use broader recruitment methods, ideally using a prospective design to better capture caregiver burden over time.

The discussion of traumatic stress symptoms is limited by a lack of validated measures to assess these symptoms. Whilst the study could have used a validated measure for PTSD, we were aware this would have added more items to an already long survey. Thus, we can only suggest that participants have indications of traumatic stress symptoms, but not PTSD. These diagnostic indications are further complicated by ongoing debates in the literature about what constitutes a traumatic event in the criteria for PTSD, and if caregiving for an acutely unwell loved one meets these criteria.

Also noted was a lack of diversity in the study sample, which could impact the generalisability of these results to other populations. Specifically, the sample was highly skewed towards NZ European women in relationships. This may be particularly relevant when exploring the impact of gender on distress and caregiver behaviour, as previous research has noted that mothers and fathers differ in psychological distress levels and in their behaviours in response to the ED [62–64]. It is possible that the study sample is not reflective of the populations of caregivers supporting people with EDs and thus results should be considered with caution.

We observed that our sample contained only a small number of Māori participants, which meant that a subgroup analysis was not completed. Given the paucity of information and under-recognition of the experience of EDs by whānau Māori (Māori families) [28, 65], it is critical that future research explores this through purposeful recruitment. Furthermore, both psychometric questionnaires used in this study lack validation in populations with different cultural backgrounds from those on whom the questionnaires were developed; this would likely limit

the utility of these questionnaires for Māori and other diverse populations.

Finally, the direct comparison with data from pre-existing Australian studies does introduce a bias that would not be present should this study have concurrently recruited Australian caregivers as part of our sample. Specifically, socio-economic contexts, the impact of temporal stressors (e.g., the COVID-19 pandemic and other world events), and methodological differences such as the recruited disordered eating populations all potentially add variables that limit the reliability of this comparison.

Future research

The impacts of caring for a child with an ED may differ from those of caring for an adult child, partner, or sibling with an ED, as indicated by some of the qualitative data. The eligibility for children's healthcare services often ends at age 18 in NZ, and transitioning to adult services means that the person with the ED has more autonomy and can choose to exclude caregivers, which likely brings additional stressors. Future research could explore caregivers' experiences of this transition, including longitudinal follow-up of caregivers to assess the impact of excluding caregivers from treatment on caregiver wellbeing and treatment outcomes. Similarly, an in-depth qualitative study could further explore the nuances and challenges of caring for a loved one who is a child compared to loved ones who are adults, to understand the unique challenges experienced when supporting individuals with EDs in these age groups.

Whilst this research has emphasised the negative impact of caring for people with EDs, it would be useful to consider a strengths-based approach and examine the factors that are protective in maintaining wellbeing during caregiving. Ideally, such a study would be prospective in nature and would follow people through treatment, offering greater insight into which caregivers can best buffer the effects of their role and why. This could include an analysis of clinical indicators, factors related to individuals with EDs, caregiver factors, and treatment factors to explore the contribution of each to wellbeing, as well as which factors have the greatest impact at different stages of the treatment process.

Research has shown that interventions for caregivers are moderately effective at reducing caregiver distress [50] and may improve recovery outcomes for the individual with the ED [18]. However, it is unclear how beneficial these interventions are for caregivers who may be from minority groups, including Indigenous populations and those who are neurodiverse. Future research could explore how to integrate caregiver support programmes into standard care, how to adapt these programmes for caregivers who might be poorly served by standard care, and how such programmes impact outcomes for both caregivers and individuals with EDs.

Conclusion

Given the high burden of caregiving, more research and better support for caregivers is needed to support caregiver wellbeing [8], both during treatment and after recovery is achieved. The anxiety and distress experienced when caregiving for someone with an ED can continue in the form of ongoing traumatic stress symptoms, even when the loved one is in recovery. This highlights that the impact of caregiving persists well beyond the active treatment phase. While international literature and sector guidance can be usefully referenced, New Zealand's distinctive challenges—including fragmented service availability, long waiting lists, and significant rural–urban and ethnic equity gaps—demand targeted practice and policy solutions. This study indicates that the current fragmented and under-resourced system likely exacerbates the distress that caregivers experience, and further resources to support caregivers and reduce distress across the caregiving timespan are urgently needed.

Practice implications

- Caregivers of people with eating disorders report a high level of distress that can persist after the individual with the ED is in recovery.
- Approximately one third of caregivers experience traumatic stress symptoms related to their caregiving experience.
- Caregivers should receive support and intervention throughout the recovery process to reduce caregiver distress, while a proportion of caregivers may need ongoing support once their loved one has recovered.
- There is an urgent need in NZ for dedicated support pathways for caregivers, particularly during long waiting periods for specialist treatment and after services discharge the individual with the ED.

Abbreviations

DASS-21	Depression, Anxiety and Stress Scale-21
ED	Eating disorder
EDCS	Eating Disorder Carer Support Network
EDs	Eating disorders
EDSIS	Eating Disorders Symptom Impact Scale
NZ	New Zealand
PTSD	Post-traumatic stress disorder

Acknowledgements

Thank-you to the participants for sharing their experiences with the research team.

Author contributions

LD co-designed the study, supervised RS, oversaw and completed analysis, and wrote the manuscript. RS co-designed the study, oversaw the data collection, completed preliminary analysis and the content analysis, and

reviewed the manuscript. SR and KM co-designed the study, contributed to the content analysis, and reviewed the manuscript. JL supervised RS, oversaw the analysis, and contributed to the writing of the manuscript.

Funding
No funding was obtained for this research.

Data availability
The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

Declarations

Ethics approval and consent to participate
Ethical approval was received from the Auckland University of Technology Ethics Committee (24/050). Participants provided consent by completing the survey after reading the participant information sheet.

Consent for publication
Consent for participating included consenting for answers to be included in publication in a de-identified format.

Competing interests
SR is the co-founder and co-chair of Eating Disorder Carer Support NZ (EDCS).

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Received: 20 May 2025 / Accepted: 17 November 2025
Published online: 29 November 2025

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Publisher's note

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Rebecca Sinclair is a counselling psychologist intern who has observed the impact of EDs on two of her friends and their caregivers. Previously, RS was a police officer for the NZ Police. As part of this role, she worked with multiple individuals experiencing mental distress.

Sarah Rowland is a dedicated advocate and ambassador for eating disorders and multi-sector system reform, driven by her personal lived experience and caregiving journey in New Zealand and Australia. Her work emphasises essential carer and family inclusion, and she is a co-founder and Chairperson of Eating Disorders Carer Support NZ (EDCS).

Kahlia McDougall (Ngāti Porou) is a lived experience caregiver. Having navigated the complexities of supporting a loved one with an eating disorder in both NZ and Australia, she now advocates for positive sector change, increased peer support, and greater inclusion of caregivers and whānau in their vital role supporting recovery. This advocacy is amplified through the lived experience voice.

Jason Landon is an academic psychologist who has undertaken research understanding the needs of caregivers and documenting the impacts associated with caregiving for family members experiencing various conditions.