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“The ED Has Cost Us Our Savings, Home, Career—But Recovery Is Worth It”: Support Needs of Adult Caregivers of People With a Diagnosed or Suspected Eating Disorder in New Zealand—A Mixed Methods Study

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ABSTRACT

As most individuals diagnosed with an eating disorder are between 12 and 25 years old, parents or guardians frequently assume a caregiver role. Although caregiving can be rewarding, it is often associated with a high level of burden and requires a correspondingly high level of support. We aimed to examine the support needs of caregivers of people with a diagnosed or suspected eating disorder in New Zealand. Using an anonymous online survey, we asked caregivers about their role, the supports they accessed, and their experiences of these supports. Supports most accessed were support groups, mental health therapists, and self-help materials. The greatest benefits from the supports were emotional and psychological support, gaining eating disorder-specific knowledge, and building eating disorder management skills. The main barriers to accessing support were financial, lack of availability, and the individual with the eating disorder being ineligible for support. These findings reflect multiple shortcomings in New Zealand's health system regarding support available for caregivers. The development of an information hub, use of a standardized screening questionnaire, eating disorder training for healthcare providers, and funding for eating disorder-related support may help to meet some of the needs highlighted in this study.

Clinical implications

- Service providers or relevant government departments could develop and maintain an online information hub, providing information, availability, and options for support.
- Health care practitioners should be supported to proactively explore the support needs of caregivers.
- There is an acute need for more, and more accessible, support to be available to caregivers.
- Service providers could further utilize the demonstrated benefits of lived experience in the support they offer.

1 | Introduction

Eating disorder (ED) onset commonly begins in adolescence [1] and those presenting with symptoms are often under the care of a guardian, usually a parent. Due to increased mortality among individuals with EDs [2], difficulty accessing timely treatment [3–5], and the intensive nature of treatment, parents (and sometimes other family members) often adopt a caregiver role to support their loved one.

Adopting the caregiving role can significantly impact wellbeing with many experiencing caregiver burden [3, 4, 6, 7]. Caregivers

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must frequently take time off work to support nutritional, behavioral, and psychological rehabilitation of the person with the ED. The cumulative effect of stressors can negatively impact the caregiver's physical and psychological health, reducing their quality of life through a deterioration of mood, increased stress, and social isolation [7–10]. Furthermore, caregiver life satisfaction decreases as barriers to formal support, services offered by trained healthcare providers (HCPs), are more frequently encountered [11, 12].

The amount of support caregivers receive directly influences their experience of caregiving. Support can be categorized as either direct or indirect. Direct support, such as psychotherapy, focuses on improving the caregiver's quality of life by directly addressing the caregiver's needs [13, 14]. Indirect support focuses on improving the condition of the individual with the ED, thereby reducing the caregiver's burden [13, 15–17].

However, caregivers also encounter various obstacles when seeking support [3, 4]. Financial costs, limited geographical availability of services, and lengthy waitlist times are barriers reducing accessibility to New Zealand (NZ) mental health services [5, 18]. This lack of support availability and access to support impacts the burden experienced by caregivers as they take on these responsibilities.

To our knowledge, no NZ study has explored the availability or benefit of support to caregivers of persons with ED. This research is particularly important to better understand how supports can be further developed and improved. Furthermore, this research is timely given the recent announcement of the refreshment of the NZ ED strategy [19] and the role of caregivers within this strategy. As such, we aim to document what supports are accessed by people caring for someone with an ED in NZ and how these supports could be improved.

2 | Method

An online anonymous survey containing both open and closed questions was used to gain insight into caregivers' support needs and experiences. The use of a mixed methods approach was based on similar approaches documented in existing NZ ED literature [4, 6, 20]. The survey was developed in conjunction with Eating Disorders Carer Support NZ stakeholders (EDCS; S.R. and K.M.). The base survey consisted of 129 closed questions and 14 open questions exploring the psychological impacts of caregiving, supports accessed, and unmet support needs. The survey length varied depending on the answers provided by participants, with a median completion time of approximately 28 min (range = 5 min to 66 h, with the upper end reflecting participants who paused and returned to the survey across multiple sessions). An analysis of the psychological impacts of caregiving experienced by this sample is reported elsewhere [10, 21].

2.1 | Participants

Eligible participants were, or are, caregivers of an individual with a diagnosed or suspected ED, residing in NZ, over 18 years of age, proficient in English, and with access to an internet connection to complete the survey. We did not limit the study to a timeframe for caregiving, as many caregivers described ongoing caregiving duties even when their loved one was considered to be “in

remission from ED” by healthcare professionals. There were no exclusion criteria.

2.2 | Recruitment

Ethical approval was received on the 26th of March 2024 from the Auckland University of Technology Ethics Committee (24/50). Recruitment commenced on the 27th of March 2024 and closed on the 30th of June 2024. Recruitment strategies included the dissemination of a flyer via email to key ED providers throughout NZ, as identified through an internet search, including specialist public services (e.g., Tupu Ora, the Central Region Eating Disorder Service, the South Island Eating Disorder Service, and regional Te Whatu Ora child and youth mental health services); national NGOs, such as the Eating Disorders Association New Zealand (EDANZ), Eating Disorders Carer Support (EDCS), and the Eating Difficulties Education Network (EDEN); and a range of private psychology, counseling, and dietetic practices. Unpaid social media advertising through Facebook and LinkedIn was also undertaken by the researchers through their personal and professional networks. The email and the social media advertising contained a hyperlink that directed participants to a Qualtrics-hosted participant information sheet and then to the questionnaire. Participants confirmed consent by beginning the questionnaire. No compensation was provided for participating in this study.

2.3 | Data Collected

Participants provided key demographic information about themselves, as well as the person they provided care for, including age, age of onset, gender, relationship with the caregiver, ED type, co-occurring mental health conditions, and treatments accessed or declined. Participants were asked about their role as a caregiver, including the recency of caregiving and whether the role was shared. Questions about caregiver support needs explored what support was received, how support was accessed, the caregiver's experiences of that support, its benefits, and how it could be improved. When support was inaccessible, participants were asked what made the support inaccessible, why they wanted to access that support, and what would have improved accessibility. To reduce respondent burden, participants were not required to answer every question.

2.4 | Data Analysis

2.4.1 | Statistical Analysis

Statistical analyses were conducted using IBM SPSS Statistics Version 29. Participants who had completed less than 5% of the study (10 items) were excluded, ensuring that, at a minimum, demographic statistics were completed to provide an overview of caregivers in NZ. Based on kurtosis and skewness values, all variables were suitable for parametric statistics. Descriptive analyses were used to summarize demographics, the use, accessibility, and helpfulness of the supports.

2.4.2 | Content Analysis (CA)

The qualitative data were analyzed using CA. CA is a systematic technique by which large quantities of text are compressed into categories to describe the underlying meaning of the phenomena

studied [22, 23]. There are three phases to CA: preparation, organizing, and reporting [23].

For the preparation phase, a manifest CA approach was chosen. This focus on describing and summarizing the sample's voice enabled the researchers to analyze the participants' responses qualitatively whilst capturing the frequencies of identified codes [22, 24]. This process also enabled each caregiver's views to be fully expressed whilst also capturing the proportion who held a particular view.

The organizing phase was conducted in two stages. In the first stage, each participant's responses ('meaning units') were selectively reduced into codes based on commonalities [22]. Frequencies for each code were calculated. Codes were then further synthesized into categories capturing higher-order themes. RS and LD collaboratively synthesized codes into categories to confirm coding frame accuracy. Code and category frequencies were counted (N_c) for reporting. As the number of caregivers responding to each question varied, N_r represented the total number of responses to each question, while n_c and n_r represented respective sample frequencies. The final phase involved interpreting the results with the research team. Categories and codes were used to formulate descriptions relevant to each research question [24].

3 | Results

3.1 | Demographics

A total of 273 caregivers began the survey. Of these, 153 were retained in the final sample due to meeting the minimum requirements for inclusion. Caregivers were predominantly female (94.12%, $n_r = 144$), of European descent (97.39%, $n_r = 149$), between 40 and 64 years old (84.97%, $n_r = 130$), had a university qualification (81.04%, $n_r = 124$), and were in a relationship at the time of caregiving (83.66%, $n_r = 128$). Some caregivers did not disclose their relationship to the individual with the ED, but at least 73.20% ($n_r = 112$) of the caregivers were a parent and 48.37% ($n_r = 74$) of the respondents shared the caregiving role to some extent. Further demographics and caregiving role characteristics are provided in Appendices A and B.

Individuals with the ED were predominantly young ($M = 19.1$ years, $SD = 6.1$ years) and female (89.06%, $n_r = 114$; see Appendix C) with diagnosed or suspected anorexia nervosa (70.59%, $n_r = 108$). Co-occurring mental health disorders were common, with 56.86% ($n_r = 87$) experiencing anxiety and 30.07% ($n_r = 46$) experiencing depression. Treatment was accessed predominantly through the public health service (see Table 1).

3.2 | Support Accessed by Caregivers

Caregivers more frequently accessed generalist supports than ED-specialized ones (see Table 2). This result was reflected in the comments that highlighted the challenges faced by many caregivers in terms of being able to access supports with ED-specific training or knowledge. On average, caregivers accessed three generalist supports and two ED-specialized supports for their loved one; both before being offered treatment and throughout the recovery process. The range of support sought reflected their purpose with few, if any, services meeting all caregiver needs.

Caregivers frequently sought indirect support to access additional support for the person with the ED. Support was commonly sought while waiting for public health services to treat their loved one or for the loved one to become unwell enough to meet service admission criteria. Caregivers also noted being excluded from appointments or treatment planning once their loved one turned 18 years old.

"In the early years (ages 16 and 17) treatment was FBT based and so we were included with the counselling sessions. But as soon as my daughter became an "adult", i.e. overnight on her 18th birthday, we were excluded by the health practitioners and continue to be so. It is very very frustrating since I am at the coalface (so to speak) of dealing with the symptoms of the disease every single day, yet I feel unwelcome in any treatment assessment or planning."

A lack of direct support for the caregiver, who was often seen as a treating team member, was apparent. Many caregivers indicated a desire for more support to enable them to better care for their loved one and their own wellbeing, particularly as caregivers delivered the bulk of many interventions at home. Caregivers would have received supervision and collegial support from the wider treating team if employed as a team member. Instead, the support caregivers received was often for the person with the ED, rather than for themselves:

"The support was always related to my daughter's treatment and I was related to as mum rather than as a person with distinct needs. It was helpful for education but not the emotional impact of what I went through as a caregiver."

"I felt like I was doing it on my own really never told what to do at home. I only felt supported once she went into [Regional Service] as an Inpatient."

3.3 | Reasons for Accessing Supports

Caregivers primarily sought emotional or psychological support to manage their mental health and ED-specific knowledge to help facilitate ED recovery of their loved one (see Table 3). Those seeking ED-specific knowledge typically sought guidance on ED management, such as practical tools to support refeeding.

The benefits caregivers reported obtaining from support broadly mapped onto the types of support they had set out to seek; that is, those who sought emotional or psychological support tended to report receiving emotional or psychological benefit, and those who sought ED-specific knowledge or management skills tended to report gaining those (see Table 3). Caregivers also benefited from seeking support from others caring for someone with an ED. Such support was frequently received through services such as EDCS and EDANZ. Caregivers felt peers could offer hope, guidance about what had worked for them, validation of the difficulties of caregiving and the emotional impact, and a reduction in the sense of isolation experienced. The sharing of lived experience was perceived as invaluable:

"All the support I got came through me seeking options and talking with a friend who also had a daughter with AN. None

TABLE 1 | Treatment accessed by individuals with the eating disorder.

Treatment received	<i>n_r</i> (%)
Public system in NZ	
Outpatient	66 (51.97)
Inpatient	62 (48.82)
Day patient	16 (12.60)
Waitlist	9 (7.09)
Private treatment provider in NZ	
Outpatient/individual therapy	53 (41.73)
Inpatient	5 (3.94)
Day patient	5 (3.94)
Waitlist	6 (4.72)
Overseas	10 (7.87)
Did not receive treatment	13 (10.24)
Declined	11 (8.66)
Others	21 (16.54)

Note: *N_r* = 127. *n_r* indicates the number of times this option was endorsed. As participants could access more than one option, percentages do not add to 100%.

of the professionals we saw offered support or spoke about the toll being a caregiver would take.”

“Many parents have had lived experience of the ‘system’ which was nice to find others who had been there and knew how tough it is dealing with the situation your loved one was in.”

3.4 | Accessibility and Sufficiency of Caregiver Support

In this study, accessibility refers to whether a caregiver was able to reach or obtain a support when needed (e.g., whether it was geographically available, affordable, and offered within a reasonable timeframe), whereas sufficiency refers to whether the support, once accessed, was enough in quantity, intensity, or scope to meet the caregiver’s needs. Accordingly, a support could be perceived as accessible but insufficient (e.g., a single brief appointment that was easy to obtain but did not meet ongoing needs through lack of information or support) or perceived as

sufficient when received but rarely accessible (e.g., specialist input that was only intermittently available).

Few caregivers described support as always accessible (i.e., able to be reached; *n_c* = 15) or sufficient (i.e., enough to meet the caregivers’ needs; *n_c* = 7; Figure 1). Of the inaccessible supports mentioned (*n_c* = 57), caregivers were primarily unable to access ED-specialized support (35.09%; *n_c* = 20) and functional support (14.04%; *n_c* = 8), such as meal support (see Appendix D). Other barriers encountered were financial (35.48%; *n_c* = 22), lack of support availability (35.48%; *n_c* = 22), and treatment ineligibility of the individual with the ED (9.68%; *n_c* = 6). These barriers are not easily navigated as the contributing factors are often outside the caregiver’s control. Similarly, many caregivers described issues with accessibility due to not knowing what was available to them or insufficiency due to a lack of clear detail or plan that would allow them to better support the care of their loved one.

“I have been told so many times that I need support and asked ‘what support can we give you?’. But I don’t know what support there is. I haven’t been provided with an assortment of options or services to select from. It’s felt very much that’s it’s my job on top of everything else to go and arrange that for myself and find it.”

“Once discharged from hospital no one could ever give us a definitive plan for how to help our daughter - felt very much like we had to figure out what worked on our own.”

Difficulty accessing ED-specific knowledge was frequently highlighted as an issue. Even within specialty services, challenges were faced where the person living with the ED had other co-occurring difficulties such as self-harm, diabetes mellitus, or autism spectrum disorder. Thus, the management of co-occurring disorders frequently required support from additional services or were not considered in the delivery of treatment, likely impacting their effectiveness.

“Never received any ED outpatient treatment as they would not take her due to Autism (high functioning). Has been under MHA multiple times in psychiatric wards for severe suicidality and self-harm, and has had 3 inpatient stays in a ED ward,

TABLE 2 | Supports accessed by caregivers.

Support type	<i>n_r</i> (%)	
	Generalist ^a	Eating disorder-specialized ^b
Support groups	83 (72.80)	68 (66.67)
Mental health therapist	81 (71.05)	37 (26.27)
Self-help materials	73 (64.04)	52 (50.98)
General practitioner (GP)	47 (41.23)	7 (6.86)
Police	19 (16.67)	0 (0.00)
Others	19 (16.67)	17 (16.67)
Workshops	18 (15.79)	15 (14.71)
Other therapy	8 (7.02)	1 (0.98)

^aNumber of respondents = 114.

^bNumber of respondents = 102.

TABLE 3 | Summary of caregiver impact and support findings.

Caregiver findings	<i>n_r</i>	%
Most common supports sought ^a		
Emotional or psychological support	42	44.21
Eating disorder-specific knowledge	31	32.63
Support for the individual with the ED	9	9.47
Medication	9	9.47
Most common supports received by caregivers ^b		
Informational	260	32.10
Emotional or psychological	199	24.57
Peer support	95	11.73
Greatest support benefits ^c		
Receiving emotional or psychological support	216	48.32
Gaining eating disorder-specific knowledge	126	28.19
Building eating disorder management skills	62	13.87

^a*N_r* = 95.^b*N_r* = 810.^c*N_r* = 447.

however they have now discharged, said she is severe, and is no longer allowed back. She is dying in front of my eyes.”

“Treatment was declined for the eating disorder by the public system because she is also a diabetic but her self-harm made her too risky for any private clinic. The public system also won’t treat her because her weight is too high.”

3.5 | Financial Support

Financial support encompasses government funding in the form of additional funding to support treatments or to support caregiving (e.g., a disability allowance) as well as other forms of financial assistance such as insurance payments. Government funding tends to consist of the Child Disability Allowance (a nonmeans-tested payment of approximately NZD\$62.43 per week for the main carer of a child

under 18 with a serious disability) and the disability allowance (up to approximately NZD\$77 per week, income-tested, to cover ongoing disability-related costs). Full-time carers of someone needing hospital-level care may also qualify for the supported living payment, which is income-tested and paid at standard benefit rates of roughly NZD\$360–\$450 per week.

Of the 108 responses from caregivers about accessing financial support, 61.11% (*n_c* = 66) noted not receiving any financial support and 11.11% (*n_c* = 12) reported that additional financial support was caregiver-sourced. Caregivers’ sources of funding included private sponsorship, private insurance, church trusts, withdrawing superannuation funds, and fundraising:

“I raised money by shaving my head.”

“The ED has cost us our savings, home, career - but recovery is worth it.”

Where people were able to access government funding, the two main funding sources were the Child Disability Allowance (12.96%, *n_c* = 14) and the work and income New Zealand Carer Support Subsidy (7.41%, *n_c* = 8). Thus, only approximately 25.00% (*n_c* = 27) of caregivers received government funding to enable them to care for their loved one with an ED.

3.6 | Support Improvements

Caregivers were asked to recommend improvements for each support type. The answers (*N_c* = 319) reflected the challenges experienced and supports available in NZ. Predominantly, caregivers desired a centralized system containing information and resources that would support them during recovery (24.14%, *n_c* = 77). Greater ED-related training for nonspecialist healthcare professionals (18.18%, *n_c* = 58) and increased availability of ED-specialized supports (15.36%, *n_c* = 49) were also desired. Increasing funding availability (9.40%, *n_c* = 30) and availability of direct support specifically for caregivers (8.60%, *n_c* = 27) were also commonly mentioned.

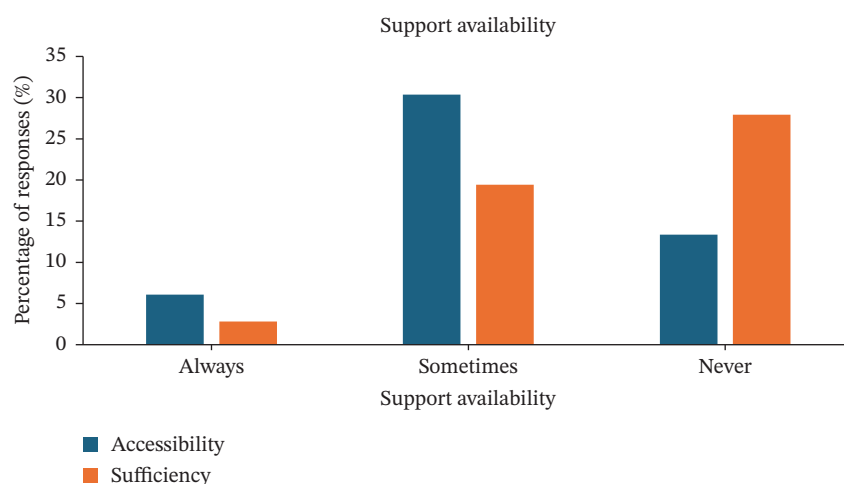


FIGURE 1 | Support accessibility and sufficiency. Note: accessibility refers to whether a caregiver was able to reach or obtain a support when needed (e.g., geographical availability, affordability, and timeframe), whereas sufficiency refers to whether the support, once accessed, was enough in quantity, intensity, or scope to meet the caregiver’s needs.

4 | Discussion

4.1 | The Support Needs of Caregivers

This is the first study to explore the support needs of caregivers of those affected by an ED in NZ. Findings largely reflect a lack of perceived support available to caregivers across both public and private providers, with caregivers frequently describing themselves as carrying significant treatment-adjacent responsibilities without corresponding access to information, services, or financial assistance for themselves. Issues regarding the accessibility and sufficiency of support available to caregivers were evident across both sectors.

Caregivers identified a broad range of needs focused on emotional, informational, functional and financial support. The supports most frequently accessed by caregivers were support groups and self-help materials, likely due to their ease of access and low cost. Consistent with current literature, support groups provided peer support that helped caregivers feel understood and reduced their sense of isolation, offering the desired emotional and social support, and provided valued tips and strategies [4, 7, 25, 26]. However, the strong theme of lack of support, irrespective of accessing support groups, indicates that these groups cannot replace formal direct support but instead play a crucial supplementary role.

ED-specialized and functional supports were the most inaccessible support options. ED-specialized and functional supports are likely challenging to access due to the limited number of professionals trained to work with individuals affected by an ED [5, 27]. Furthermore, as ED specialists are often considered the best support for EDs, many seek their services, resulting in lengthy waitlists [5, 28]. This is exacerbated by the high turnover of staff across the NZ mental health sector [29, 30] resulting in the loss of skills and knowledge required to provide specialized and functional support [27, 31].

Finances and lack of support availability were the main barriers to support. As caregivers focus their resources on ensuring the recovery of the individual with the ED, their ability to afford support for themselves is compromised. This financial strain is exacerbated by many caregivers having to reduce work hours. Financial support directly available to caregivers remains limited [32] despite the NZ government investing approximately NZD\$15.5 million into regional ED services annually [27]. Increasing accessibility to financial support would increase access to formal support, such as mental health therapists, through which the range of support needs of caregivers could be addressed. This, in turn, may mitigate the burden of caregiving and improve ED outcomes [31, 33].

The support afforded to the individual with the ED directly impacted caregiver burden. Several caregivers shared that their child fell through the cracks as their condition was too severe to receive private treatment, but not acute enough to receive public treatment. This situation is also common in the UK and Australia, with few private specialists taking on clients with acute needs due to their inability to provide 24/7 support with the associated management of medical risk [3, 34]. Furthermore, a systematic review noted that those with lower BMIs were prioritized for specialist care, hindering those with EDs not characterized by low BMI from receiving treatment [35, 36].

Delaying admissions raises the risk of morbidity and mortality and places greater pressure on caregivers to provide comprehensive day-to-day support themselves. When the person with the ED eventually does receive treatment, their condition is typically more entrenched and resource-intensive, requiring longer admissions and more intensive clinician input. The associated indirect costs to families such as reduced work hours, travel to specialist services, and out-of-pocket expenses for ancillary supports not covered by the public system accumulate over this extended trajectory, reducing the financial capacity of caregivers to purchase support (such as their own therapy) for themselves.

Even though a lack of support was evident, caregivers described multiple benefits of support they accessed. Caregivers particularly valued receiving emotional and psychological support likely because it bolstered their mental health and facilitated the development of coping strategies. Consistent with existing literature, gaining ED-specific knowledge was also a key benefit as it enabled caregivers to be more effective support providers, thereby reducing some distress [37, 38]. Previous research has further shown that psychoeducation about the causes, symptoms, and potential implications of the ED can support caregivers in “separating” their loved one from the ED, which can reduce the likelihood that caregivers inadvertently accommodate or reinforce ED-driven behaviors (for example, by acquiescing to safety behaviors, avoiding mealtime conflict, or modifying family routines around the ED) [39–41]. Caregivers also valued acquiring ED management skills, such as how to facilitate refeeding [40]. This is unsurprising as restoring eating behaviors and extinguishing ED behaviors are central to FBT [42].

4.2 | Practical Recommendations

4.2.1 | Developing and Maintaining an Information Hub

Identifying available services can be challenging for caregivers. A website containing up-to-date details of reliable resources and recommended support services should be established such as those seen in Australia [43, 44]. This central database for ED support would be searchable, enabling easier identification of available evidence-based resources, thereby increasing information and support accessibility and reducing the time required to find adequate supports.

4.2.2 | Increasing Support Availability for Caregivers

Established caregiver ED support organizations in NZ, such as EDANZ or EDCS, already offer services such as virtual support groups and telephone helplines [45, 46]. These services fill gaps in the current support available and align with the government’s interest in establishing a peer support workforce [47, 48]. However, as these services are run by a small number of volunteers, to improve support availability and accessibility, we recommend funding peer support staff to cover peak service times. Likewise, better support for the peer workforce such as access to training and supervision would likely improve the longevity and wellbeing of this important workforce.

4.2.3 | Increasing Funding Availability for Caregivers

In NZ, the two main publicly funded entitlements available to family caregivers are the Child Disability Allowance, a fortnightly payment for the parent or guardian of a child with a serious disability or chronic health condition, and the Carer Support Subsidy, which contributes towards the cost of short-term relief care to provide respite for caregivers [32]. Neither the Child Disability Allowance nor the Carer Support Subsidy enabled caregivers to access formal support services other than relief care [32]. However, finding time for respite can be difficult, particularly when undertaking FBT or maintaining feeding routines [49, 50]. Therefore, we recommend amending the Carer Support Subsidy purchasing rules so caregivers can use the funding for formal support services or ED-related support in a manner that works for them. This could increase accessibility to ED-specific information and emotional support for the caregiver, subsequently improving the emotional, psychological, informational, and financial support received.

4.2.4 | HCPs Proactively Assess Support Needs

We are conscious of the pressure HCPs currently experience in NZ. Nonetheless, HCPs should be further supported to be more proactive in engaging with caregivers about their current well-being and support needs. This includes providing information about services available and checking in with caregivers regularly to assess changes in support needs and ensure they are receiving adequate support. Multiple prior studies noted a lack of ED-related information available from HCPs [3, 6, 7, 50], suggesting that this need is unmet internationally. HCPs providing reliable and sufficient information could assist in reducing a caregiver's burden of responsibility and psychological stress by meeting their need for ED-specific knowledge [6, 51].

4.2.5 | Increasing ED-Related Training for HCPs

As EDs can require high levels of support and often specialized knowledge [52], HCPs require an appropriate level of training. Multiple caregivers commented on HCPs' lack of foundational ED understanding, aligning with the Ministry of Health review (2008). Based on the findings of this study and the recommendations from a recent Australian review on navigating similar HCP training issues, primary care clinicians, mental health workers, and dietitians would benefit from such training [53]. To augment the HCP training offered by Whāraurau (a government-funded workforce development hub) [27, 54] that is freely available to HCPs working in relevant publicly funded services, a foundational ED training block course could be incorporated into their respective training curricula. This would reduce harm caused inadvertently through ill-advised responses, such as normalizing dieting behavior. Training more nonspecialized HCPs to provide ED-specific support would also increase capacity to implement early detection and intervention [53, 54].

4.2.6 | Targeted ED-Specialized Support

We recommend implementing tools to support HCPs, such as the development/utilization and dissemination of a reliable and valid ED triage questionnaire to streamline the assessment process.

Utilizing a reliable and validated ED triage questionnaire, alongside upskilling nonspecialized HCPs, would enable better detection of EDs and assessment of needs [55, 56]. In turn, early detection and intervention will likely mean that the number of individuals requiring specialized care will likely reduce [57]. We recognize that increased screening may lead to increased detection in an already overburdened NZ health system [5, 19, 48]. However, early detection would be advantageous, while inadequate triaging can result in a rapid decline in the health of those with acute needs due to insufficient or a lack of timely care.

4.3 | Limitations

Of the 153 eligible participants, 38.56% ($n = 59$) did not complete the survey. These incomplete responses may be due to the survey's length (up to 190 questions if participants endorsed all types of support). As participants experienced a significant caregiver burden, having to commit their time and energy to their dependent with an ED, a high level of motivation was required to complete the survey. However, many participants did not complete the basic demographic information. Such participants may have been interested in learning about the survey but were less motivated to complete it. This indicates that it is likely various factors contributed to the high noncompletion rate. It is unclear how this would impact the results.

The recruitment methods here (primarily through ED networks) increased the likelihood of participants being aware of or enrolled in a support service. Thus, our results are likely biased towards the views of caregivers already recognizing the need for support. They may be less reflective of the views of caregivers new to the role without the same connections or those experiencing less caregiver burden and thus have not sought support. As such, broader recruitment methods, such as a prospective design, should be adopted in future research.

4.4 | Future Research

The perceived availability and sufficiency of supports across ED types should be studied as the objective hardship experienced by caregivers can differ by ED- and treatment-related factors [58–60]. We anticipate that greater support will be available for individuals with EDs widely recognized within NZ, such as anorexia nervosa and bulimia nervosa. A lack of research on lesser-known EDs within NZ [61], such as rumination disorder, may result in individuals with EDs encountering more treatment barriers, such as ineligibility for financial support.

5 | Conclusion

This study demonstrates that caregivers of people with a diagnosed or suspected ED in NZ experience substantial and largely unmet support needs, with treatment barriers for their loved one and a lack of direct support for caregivers themselves emerging as the most consistent challenge across our quantitative and qualitative findings. These gaps were reflected in the high use of self-help materials, online support groups, and GPs as default sources of support. Our findings highlight the need for HCP training and funding to establish or augment caregiver

support services to reduce the caregiver burden and the morbidity and mortality associated with ED.

Author Contributions

Rebecca Sinclair is a counseling psychologist intern who has observed the impact of EDs on two of her friends and their caregivers. Previously, Rebecca Sinclair was a police officer for the NZ Police. As part of this role, she worked with multiple individuals experiencing mental distress. Jason Landon is an academic psychologist who has undertaken research to understand the needs of caregivers and document the impacts associated with caregiving for family members experiencing various conditions. Sarah Rowland is a dedicated advocate and ambassador for EDs and multisector system reform, driven by her personal lived experience and caregiving journey in NZ and Australia. Her work emphasizes essential carer and family inclusion, and she is a co-founder of EDCS. Kahlia McDougall (Ngāti Porou) is a lived experience caregiver. Having navigated the complexities of supporting a loved one with an ED 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. Liesje Donkin is a health and clinical psychologist who has worked with EDs in private practice, at a tertiary specialty service, and in secondary mental health services. For the past 2 years, she has also been a caregiver to a child with deteriorating health.

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Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability Statement

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

References

1. A. P. Association, "Feeding and Eating Disorders," in *DSM Library. Diagnostic and Statistical Manual of Mental Disorders* (American Psychiatric Association, 2022).
2. M. M. Fichter and N. Quadflieg, "Mortality in Eating Disorders-Results of a Large Prospective Clinical Longitudinal Study," *International Journal of Eating Disorders* 49, no. 4 (2016): 391–401, <https://doi.org/10.1002/eat.22501>.
3. I. Robinson, H. Stoyel, and P. Robinson, "'If She Had Broken Her Leg She Would Not Have Waited in Agony for 9 Months': Caregivers' Experiences of Eating Disorder Treatment," *European Eating Disorders Review* 28, no. 6 (2020): 750–765, <https://doi.org/10.1002/erv.2780>.
4. L. J. Surgenor, S. Dhakal, R. Watterson, et al., "Psychosocial and Financial Impacts for Carers of Those With Eating Disorders in New Zealand," *Journal of Eating Disorders* 10, no. 1 (2022): 37, <https://doi.org/10.1186/s40337-022-00565-2>.
5. R. Lawson, R. Watterson, M. A. Kennedy, C. M. Bulik, and J. Jordan, "Time Taken to Reach Treatment for Eating Disorders in New Zealand," *Australasian Psychiatry* 33, no. 3 (2025): 525–529, <https://doi.org/10.1177/10398562241298082>.
6. L. Fletcher, H. Trip, R. Lawson, N. Wilson, and J. Jordan, "Life is Different Now-Impacts of Eating Disorders on Carers in New Zealand: A Qualitative Study," *Journal of Eating Disorders* 9 (2021): 91, <https://doi.org/10.1186/s40337-021-00447-z>.
7. J. R. Fox, M. Dean, and A. Whittlesea, "The Experience of Caring for or Living With an Individual With an Eating Disorder: A Meta-Synthesis of Qualitative Studies," *Clinical Psychology & Psychotherapy* 24, no. 1 (2017): 103–125, <https://doi.org/10.1002/cpp.1984>.
8. E. Berglund, P. Lytsy, and R. Westerling, "Health and Wellbeing in Informal Caregivers and Non-Caregivers: A Comparative Cross-Sectional Study of the Swedish General Population," *Health and Quality of Life Outcomes* 13 (2015): 109, <https://doi.org/10.1186/s12955-015-0309-2>.
9. L. Calvó-Perxas, J. Vilalta-Franch, H. Litwin, O. Turró-Garriga, P. Mira, and J. Garre-Olmo, "What Seems to Matter in Public Policy and the Health of Informal Caregivers? A Cross-Sectional Study in 12 European Countries," *PLoS One* 13, no. 3 (2018): e0194232, <https://doi.org/10.1371/journal.pone.0194232>.
10. L. Donkin, R. Sinclair, S. Rowland, K. McDougall, and J. Landon, "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," *Journal of Eating Disorders* (2025).
11. M. L. Contreras, E. Mioshi, and N. Kishita, "Factors Related to the Quality of Life in Family Carers of People With Dementia: A Meta-Analysis," *Journal of Geriatric Psychiatry and Neurology* 34, no. 5 (2021): 482–500, <https://doi.org/10.1177/0891988720924713>.
12. M. D. Guerra-Martín, M. D. R. Casado-Espinosa, Y. Gavira-López, C. Holgado-Castro, I. López-Latorre, and Á. Borrallío-Riego, "Quality of Life in Caregivers of Cancer Patients: A Literature Review," *International Journal of Environmental Research and Public Health* 20, no. 2 (2023): 1570, <https://doi.org/10.3390/ijerph20021570>.
13. L. Hannah, M. Cross, H. Baily, K. Grimwade, T. Clarke, and S. M. Allan, "A Systematic Review of the Impact of Carer Interventions on Outcomes for Patients With Eating Disorders," *Eating and Weight Disorders-Studies on Anorexia, Bulimia and Obesity* 27, no. 6 (2022): 1953–1962, <https://doi.org/10.1007/s40519-021-01338-7>.
14. A. Padierna, J. Martín, U. Aguirre, N. González, P. Muñoz, and J. M. Quintana, "Burden of Caregiving Amongst Family Caregivers of Patients with Eating Disorders," *Social Psychiatry and Psychiatric Epidemiology* 48, no. 1 (2013): 151–161, <https://doi.org/10.1007/s00127-012-0525-6>.
15. Eating Disorder Association New Zealand (EDANZ), *Getting Help: Eating Disorder Services in New Zealand* (2024).
16. Eating Disorders Victoria, *Find Eating Disorder Support*, <https://www.eatingdisorders.org.au/find-support/>.
17. The Eating Disorders Association of Ireland, *Bodywhys-Support Services* (2024).
18. V. Kulshrestha and S. M. Shahid, "Barriers and Drivers in Mental Health Services in New Zealand: Current Status and Future Direction," *Global Health Promotion* 29, no. 4 (2022): 83–86, <https://doi.org/10.1177/17579759221099312>.
19. H. Ministry of, *New Zealand Eating Issues and Eating Disorders Strategy* (Wellington, New Zealand: Ministry of Health, 2025).
20. M. T. R. Clark, J. Manuel, C. Lacey, S. Pitama, R. Cunningham, and J. Jordan, "Reimagining Eating Disorder Spaces: A Qualitative Study Exploring Māori Experiences of Accessing Treatment for Eating Disorders in Aotearoa New Zealand," *Journal of Eating Disorders* 11, no. 1 (2023): 22, <https://doi.org/10.1186/s40337-023-00748-5>.
21. R. Sinclair, J. Landon, S. Rowland, K. McDougall, and L. Donkin, "'The ED Has Cost Us Our Savings, Home, Career-But Recovery is Worth It': Support Needs of Adult Caregivers of People With a Diagnosed or Suspected Eating Disorder in New Zealand. A Mixed Methods Study" (2025).
22. C. Erlingsson and P. Brysiewicz, "A Hands-On Guide to Doing Content Analysis," *Afr J Emerg Med* 7, no. 3 (2017): 93–99, <https://doi.org/10.1016/j.afjem.2017.08.001>.

23. S. Elo and H. Kyngäs, "The Qualitative Content Analysis Process," *Journal of Advanced Nursing* 62, no. 1 (2008): 107–115, <https://doi.org/10.1111/j.1365-2648.2007.04569.x>.
24. M. Vaismoradi, H. Turunen, and T. Bondas, "Content Analysis and Thematic Analysis: Implications for Conducting a Qualitative Descriptive Study," *Nursing and Health Sciences* 15, no. 3 (2013): 398–405, <https://doi.org/10.1111/nhs.12048>.
25. M. Grover, U. Naumann, L. Mohammad-Dar, et al., "A Randomized Controlled Trial of an Internet-Based Cognitive-Behavioural Skills Package for Carers of People With Anorexia Nervosa," *Psychological Medicine* 41, no. 12 (2011): 2581–2591, <https://doi.org/10.1017/S0033291711000766>.
26. J. H. Joo, L. Bone, J. Forte, E. Kirley, T. Lynch, and H. Aboumatar, "The Benefits and Challenges of Established Peer Support Programmes for Patients, Informal Caregivers, and Healthcare Providers," *Family Practice* 39, no. 5 (2022): 903–912, <https://doi.org/10.1093/fampra/cmz004>.
27. Manatū Hauora and Ministry of Health, *Briefing: Eating Disorders (H2024036864)* (Wellington: Ministry of Health, 2024).
28. G. Johns, B. Taylor, A. John, and J. Tan, "Current Eating Disorder Healthcare Services—The Perspectives and Experiences of Individuals with Eating Disorders, Their Families and Health Professionals: Systematic Review and Thematic Synthesis," *BJPsych Open* 5, no. 4 (2019): e59, <https://doi.org/10.1192/bjo.2019.48>.
29. Te Pou, *2024 Health New Zealand Te Whatu Ora Adult Workforce Estimates* (2025).
30. J. A. Foulds, B. Beaglehole, and R. T. Mulder, "Time for Action Not Words: The Urgent Rebuilding of New Zealand's Mental Health Workforce," *New Zealand Medical Journal* 136, no. 1576 (2023): 8–10, <https://doi.org/10.26635/6965.e1576>.
31. R. Patterson, M. Durie, B. Disley, and S. Tiatia-Seath, *He Ara Oranga: Report of the Government Inquiry into Mental Health and Addiction* (2018).
32. Ministry of Social Development, *Financial Assistance for Caregivers—Budget 2021 Factsheet* (Wellington: Ministry of Social Development, 2021).
33. A. M. Monteleone, G. Cascino, L. Salerno, et al., "A Network Analysis in Adolescent Anorexia Nervosa Exploring the Connection Between Both Patient and Carer Reactions and Outcome," *European Eating Disorders Review* 31, no. 1 (2023): 65–75, <https://doi.org/10.1002/erv.2933>.
34. *Royal Commission into Victoria's Mental Health System* (Melbourne: Final Report. Melbourne: State of Victoria, 2021).
35. A. K. Garber, "Moving Beyond "Skinniness": Presentation Weight is Not Sufficient to Assess Malnutrition in Patients With Restrictive Eating Disorders Across a Range of Body Weights," *Journal of Adolescent Health* 63, no. 6 (2018): 669–670, <https://doi.org/10.1016/j.jadohealth.2018.09.010>.
36. A. F. Ralph, L. Brennan, S. Byrne, et al., "Management of Eating Disorders for People With Higher Weight: Clinical Practice Guideline," *Journal of Eating Disorders* 10, no. 1 (2022): 121, <https://doi.org/10.1186/s40337-022-00622-w>.
37. G. Pépin and R. King, "Collaborative Care Skills Training Workshops: Helping Carers Cope With Eating Disorders From the UK to Australia," *Social Psychiatry and Psychiatric Epidemiology* 48, no. 5 (2013): 805–812, <https://doi.org/10.1007/s00127-012-0578-6>.
38. R. Hibbs, C. Rhind, J. Leppanen, and J. Treasure, "Interventions for Caregivers of Someone With an Eating Disorder: A Meta-Analysis," *International Journal of Eating Disorders* 48, no. 4 (2015): 349–361, <https://doi.org/10.1002/eat.22298>.
39. T. Uehara, Y. Kawashima, M. Goto, S. Tasaki, and T. Someya, "Psychoeducation for the Families of Patients With Eating Disorders and Changes in Expressed Emotion: A Preliminary Study," *Comprehensive Psychiatry* 42, no. 2 (2001): 132–138, <https://doi.org/10.1053/comp.2001.21215>.
40. K. Kurnik Mesarič, Ž. Damjanac, T. Debeljak, and J. Kodrič, "Effectiveness of Psychoeducation for Children, Adolescents and Caregivers in the Treatment of Eating Disorders: A Systematic Review," *European Eating Disorders Review* 32, no. 1 (2024): 99–115, <https://doi.org/10.1002/erv.3028>.
41. L. M. Anderson, K. E. Smith, M. C. Nuñez, and N. R. Farrell, "Family Accommodation in Eating Disorders: A Preliminary Examination of Correlates With Familial Burden and Cognitive-Behavioral Treatment Outcome," *Eating Disorders* 29, no. 4 (2021): 327–343, <https://doi.org/10.1080/10640266.2019.1652473>.
42. J. Lock and D. Le Grange, *Treatment Manual for Anorexia Nervosa: A Family-Based Approach*, 2nd ed. (Guilford Press, 2012).
43. I. Institute, *InsideOut Institute-Australia's National Eating Disorder Research and Clinical Excellence Institute*, <https://insideoutinstitute.org.au>.
44. National Eating Disorders Collaboration (NEDC), *NEDC-Portal for Eating Disorders Information and Service Navigation*, <https://nedc.com.au>.
45. Eating Disorders Association of New Zealand (EDANZ), *EDANZ – Eating Disorders Association of New Zealand*, <https://www.ed.org.nz>.
46. Eating Disorders Association of New Zealand (EDANZ), "Eating Disorder Services-Getting Help in New Zealand," <https://www.ed.org.nz/getting-help/eating-disorder-services/>.
47. Ministry of Social Development, *Carers' Strategy Action Plan 2019–2023* (Wellington: Ministry of Social Development, 2019).
48. Manatū Hauora and Ministry of Health, *Mental Health Portfolio Priorities (Cabinet Paper CAB-24-MIN-0191)* (Wellington: Ministry of Health, 2024).
49. S. Forsberg, J. Lock, and D. Le Grange, *Family-Based Treatment for Restrictive Eating Disorders: A Guide for Supervision and Advanced Clinical Practice* (New York, NY: Routledge, 2018).
50. T. Allen, A. Kercher, and L. Donkin, "Surviving the Storm: A Qualitative Study Caregivers' Challenges in Family-Based Treatment for Adolescent Anorexia Nervosa," *International Journal of Eating Disorders*, In Press.
51. C. Rhind, L. Salerno, R. Hibbs, et al., "The Objective and Subjective Caregiving Burden and Caregiving Behaviours of Parents of Adolescents With Anorexia Nervosa," *European Eating Disorders Review* 24, no. 4 (2016): 310–319, <https://doi.org/10.1002/erv.2442>.
52. A. M. Monteleone, F. Pellegrino, G. Croatto, et al., "Treatment of Eating Disorders: A Systematic Meta-Review of Meta-Analyses and Network Meta-Analyses," *Neuroscience & Biobehavioral Reviews* 142 (2022): 104857, <https://doi.org/10.1016/j.neubiorev.2022.104857>.
53. D. Maloney, S. H. Ong, J. Miskovic-Wheatley, et al., "The Essentials: Upskilling a National Health Workforce in the Identification and Treatment of Eating Disorders," *International Journal of Eating Disorders* 57, no. 12 (2024): 2427–2437, <https://doi.org/10.1002/eat.24297>.
54. R. Lawson and B. Dunnachie, "Workforce Development in the Child and Adolescent Mental Health Sector: The Challenge of Rolling out a Specialist Eating Disorders Treatment in New Zealand," in *Child and Adolescent Mental Health*, ed. R. Lawson and B. Dunnachie (IGI Global, 2016), 234–252.
55. S. Maguen, C. Hebenstreit, Y. Li, et al., "Screen for Disordered Eating: Improving the Accuracy of Eating Disorder Screening in Primary Care," *General Hospital Psychiatry* 50 (2018): 20–25, <https://doi.org/10.1016/j.genhosppsych.2017.09.004>.
56. M. A. Cotton, C. Ball, and P. Robinson, "Four Simple Questions Can Help Screen for Eating Disorders," *Journal of General Internal Medicine* 18, no. 1 (2003): 53–56, <https://doi.org/10.1046/j.1525-1497.2003.20374.x>.
57. P. Hay, D. Chinn, D. Forbes, et al., "Royal Australian and New Zealand College of Psychiatrists Clinical Practice Guidelines for the

Treatment of Eating Disorders,” *Australian and New Zealand Journal of Psychiatry* 48, no. 11 (2014): 977–1008, <https://doi.org/10.1177/0004867414555814>.

58. J. Martín, A. Padierna, U. Aguirre, N. González, P. Muñoz, and J. M. Quintana, “Predictors of Quality of Life and Caregiver Burden Among Maternal and Paternal Caregivers of Patients With Eating Disorders,” *Psychiatry Research* 210, no. 3 (2013): 1107–1115, <https://doi.org/10.1016/j.psychres.2013.07.039>.

59. C. Ohara, G. Komaki, Z. Yamagata, M. Hotta, T. Kamo, and T. Ando, “Factors Associated With Caregiving Burden and Mental Health Conditions in Caregivers of Patients With Anorexia Nervosa in Japan,” *BioPsychoSocial Medicine* 10, no. 1 (2016): 21, <https://doi.org/10.1186/s13030-016-0073-5>.

60. M. J. Pehlivan, B. Rodgers, J. Schlage, S. Maguire, and J. Miskovic-Wheatley, “Characteristics, Correlates of Burden and Support Service Use of a Help-Seeking Carers of Loved Ones With an Eating Disorder,” *European Eating Disorders Review* 32, no. 3 (2024): 458–475, <https://doi.org/10.1002/erv.3059>.

61. L. Cleland, H. L. Kennedy, M. A. Pettie, M. A. Kennedy, C. M. Bulik, and J. Jordan, “Eating Disorders, Disordered Eating, and Body Image Research in New Zealand: A Scoping Review,” *Journal of Eating Disorders* 11, no. 1 (2023): 7, <https://doi.org/10.1186/s40337-022-00728-1>.

Supporting Information

Additional supporting information can be found online in the Supporting Information section. **Supporting Information.** Appendix A: caregiver demographic statistics. Appendix B: caregiver role characteristics. Appendix C: demographic statistics of individuals living with the eating disorder. Appendix D: summary of findings—inaccessible supports.