

Butterfly

# MAYDAYS

*#PushingPastPostcodes*

MAYDAYS 2020  
SURVEY REPORT  
**BARRIERS TO ACCESSING  
EATING DISORDER  
HEALTHCARE & SUPPORT**

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# Pushing Past Postcodes

## Summary

The purpose of this research was to better understand how seeking help and getting treatment for carers and individuals with eating disorders is impacted by where they live.

An anonymous online survey was sent out through Butterfly Foundation's networks in April 2020. 563 respondents completed the survey.

The findings demonstrated that location plays a role in experience and access to help for eating disorders. Many of the barriers experienced by people living in Urban, Metropolitan and Suburban areas were acutely compounded for those living in Rural, Remote and Very Remote areas. Barriers included a paucity of specialised treatment and professionals who were trained specifically to deal with and understand eating disorders. Long waiting lists and a lack of inpatient services were also highlighted. Participants living in metro areas had more positive service experiences. The cost of accessing treatment was a burden for all of the respondents. Public patients and those from 'disadvantaged' suburbs appeared to be particularly disadvantaged when it came to receiving optimal care. Travel and associated costs were most difficult for respondents living in RRR areas. Many respondents had experienced stigma and discrimination with comments from participants suggesting that weight and age discrimination was a major form of discrimination encountered by the respondents. People also spoke about stigma due to their ethnicity, sex, parental status, and gender.

The vast majority of people who responded to this survey identified as female and were aged between 18 and 30. In order to obtain a more diverse sample, it would be valuable to also send the survey out through organisations that focus specifically on servicing people who identify as male as well as people who identify as gender diverse.

# Introduction and background

This report outlines the findings from a survey undertaken in April 2020 in Australia on the experiences of accessing healthcare and other support for people living with an eating disorder and those who care for them. The main aim of the survey was to understand if where individuals reside, impacts on their access and experience of seeking help so that Butterfly can better understand and advocate for the needs of these individuals. The survey focused on carers, individuals currently experiencing an eating disorder and individuals who had previously experienced an eating disorder. Both findings from the forced-choice questions and the findings from the open-ended questions are outlined in the findings below.

## Methodology

An anonymous online survey comprised of both open-ended and forced choice questions was sent out through the Butterfly Foundation's social media and organisational networks (see appendix A for a copy of the survey). The survey contained 59 questions and was analysed through statistical software package SPSS. The survey was kept open over two weeks in April.

## The sample

The overall sample was comprised of 563 respondents. The samples were divided into three cohorts:

1. Individuals currently experiencing an eating disorder
2. Individuals who had previously experienced an eating disorder
3. Carers of people with eating disorders

The vast majority of the individuals currently experiencing an eating disorder were female and aged between 18 and 30 residing in Metro areas. The vast majority of the individuals who had previously experienced an eating disorder were female and aged between 18 and 30 residing in Metro areas. The majority of carers who responded to the survey were aged between 46 and 60 and all of them were female. A detailed breakdown of the three cohorts is provided in the profile section of the statistical analysis in the findings.

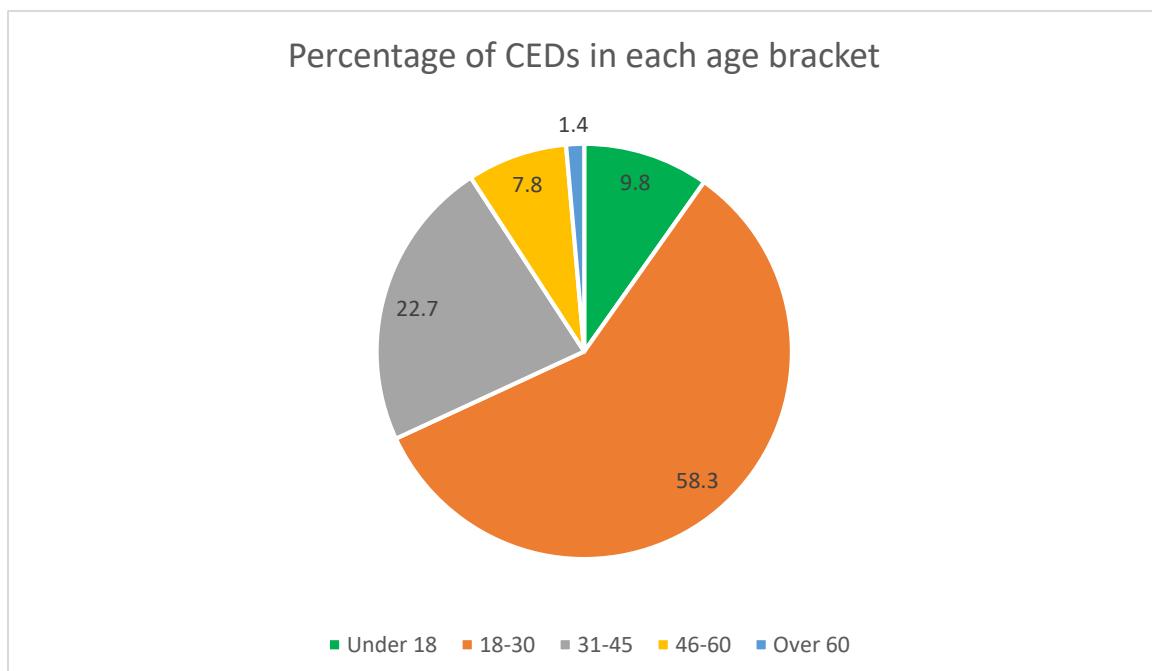
# Quantitative Findings

## Sample characteristics

There were three discrete groups of people who completed the 2020 Maydays survey: those who were currently experiencing an eating disorder (61.8%; n=348), those who had previously experienced an eating disorder (20.4%, n=115) and carers (who have never personally experienced an eating disorder; 17.8%, n=100).

### 1. Currently experiencing an eating disorder (CED)

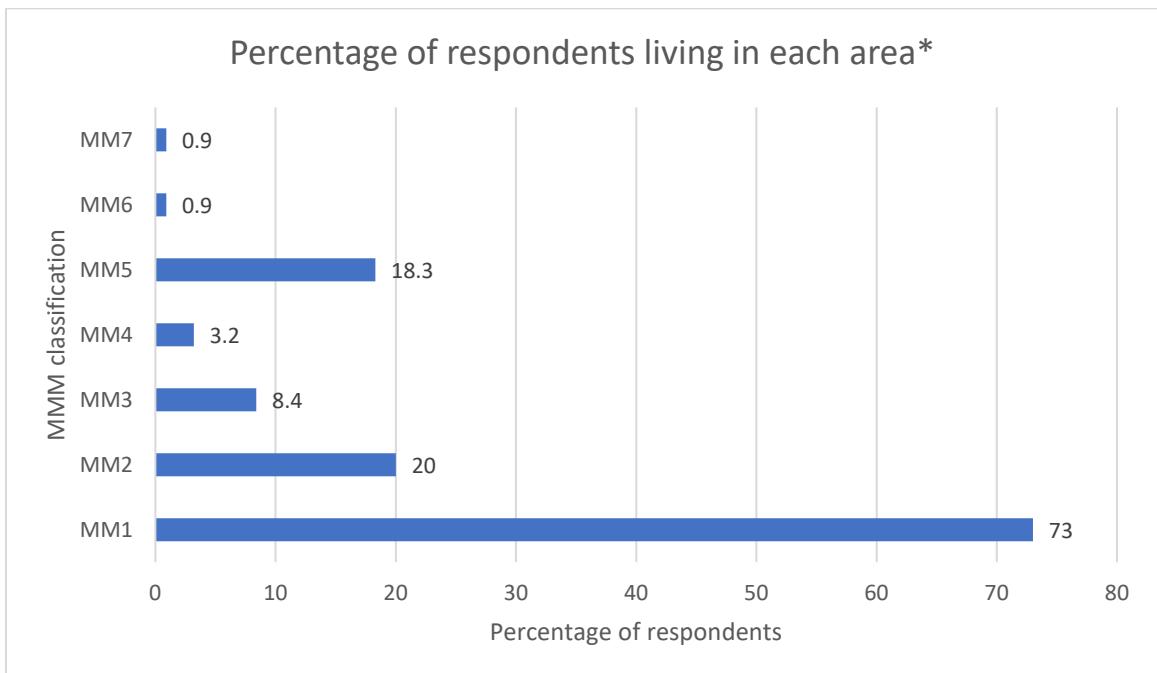
The vast majority of CEDs were female (94.8%, n=330) and aged between 18-30 years of age (58.3%, n=203) (see **Figure 1**).



**Figure 1:** Percentage of CEDs in each age bracket

The minority gender identities included male (n=7; 2.0%); non-binary (n=8; 2.3%) and demigirl (n=1). Three people chose 'different identity' and opted not to provide specifying information. Just over two-thirds (67.5%; n=235) self-identified as living in urban or suburban areas (metro) and 14% (n=50) as living in either regional remote or very remote areas (RRR). Six people were unsure about whether the area they lived in classified as RRR or metro. Fifty-four CEDs did not complete this question.

In Australia, to decrease the barriers to people being able to receive health care, the Australian Government Department of Health allows people who live in regional, remote and very remote areas to receive a Medicare rebate for telehealth consultations. Medicare items for telehealth were first introduced in 2011. Just prior to the introduction of the new temporary COVID-19 related telehealth item numbers, in order to receive this rebate, the patient/ client had to live in a rural, remote or very remote area and be located more than 15 kilometres by road from the providing practitioner. The Modified Monash Model (MMM; Australian Government Department of Health, 2020b) was used as a system for classification. The Monash Model uses MM codes for this classification, where MM1 is a major city and MM7 is very remote. People who live in MMM classifications from 2-7 are classed as living in rural or remote areas, where it can be harder to find medical help. According to this model, for people living in these areas, accessing doctors can take longer and cost more. A Medicare rebate however, is only available if the patient/client lives in an area classed between MM4-7.

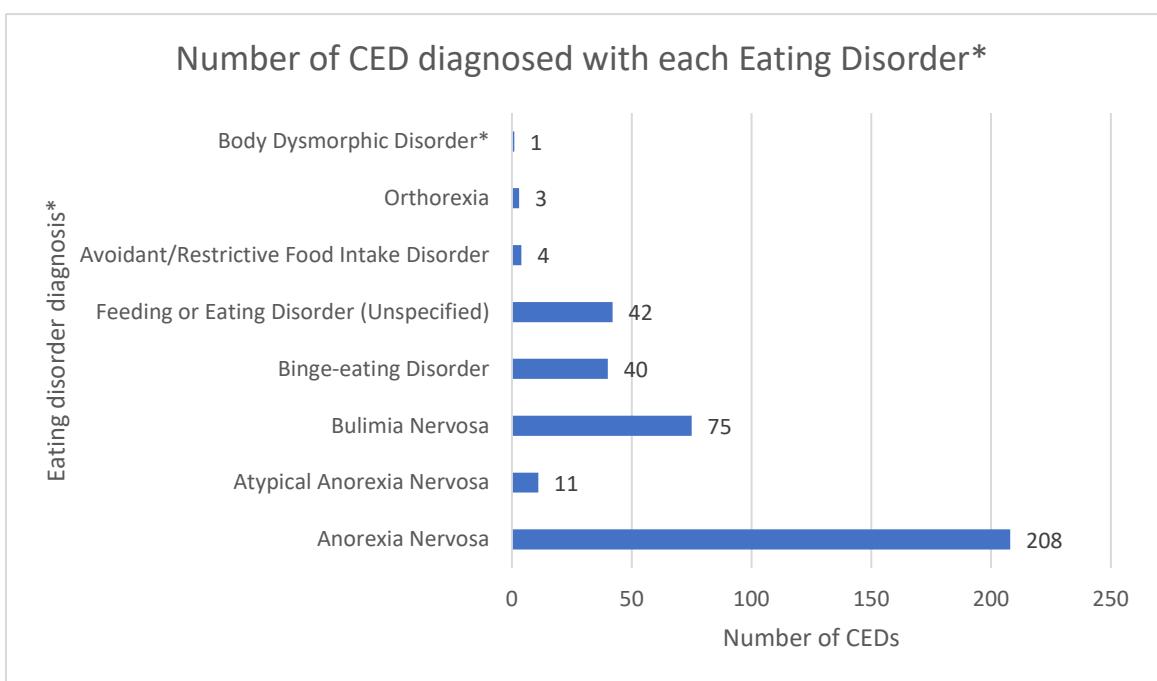


**Figure 2:** The percentage of CEDs who live in the different MMM classifications.

\* The total percentage adds to greater than one hundred, as some postcodes had more than one MMM classification. This occurs where a postcode may be shared by multiple locations.

From **Figure 2** it is clear that the majority of people reside in MM1 areas, which are major cities (73%, n=252), where there is easier access to health care. However, 27% of the samples live in areas where there is a lower level of accessibility. As postcodes can have more than one MMM code, it is difficult to ascertain the exact number of participants who would be eligible to a Medicare rebate for telehealth, but it is possible to estimate between 7.5% and 35.7% of the sample of CEDs.

The vast majority of CED reported having officially been diagnosed by a health professional with an eating disorder (88.5%; n=308). Respondents were asked for the most recent diagnoses they had been given; see **Figure 3**. Nearly two-thirds of the sample had received a recent diagnosis of Anorexia Nervosa (59.8%; n=208) and a further 3.2% (n=11) with Atypical Anorexia Nervosa. Bulimia Nervosa was reported by 21.6% (n=75), and approximately 10% reported either Binge-Eating Disorder (11.5%, n=40) or Feeding and Eating Disorder (unspecified) (12.1%; n=42). Four people (1%) were diagnosed with Avoidant/Restrictive Food Intake Disorder and three people with Orthorexia. One person was not given the name of the diagnosis, as the professionals believed this would be unhelpful given their obsession with diagnoses. One person was given a diagnosis of Body Dysmorphic Disorder, which in DSM-V is classified as an Obsessive–Compulsive and Related Disorder, rather than an eating disorder (American Psychiatric Association, 2013).



**Figure 3:** Number of people who are currently suffering from an eating disorder (CED) who have been diagnosed with the different eating disorders. Noting: It is possible for a person to have been given more than one diagnosis.

\*Body Dysmorphic Disorder is not classified as an eating disorder, but rather an Obsessive–Compulsive and Related Disorder (American Psychiatric Association, 2013)

## 2. Previously experiencing an Eating Disorder (PED)

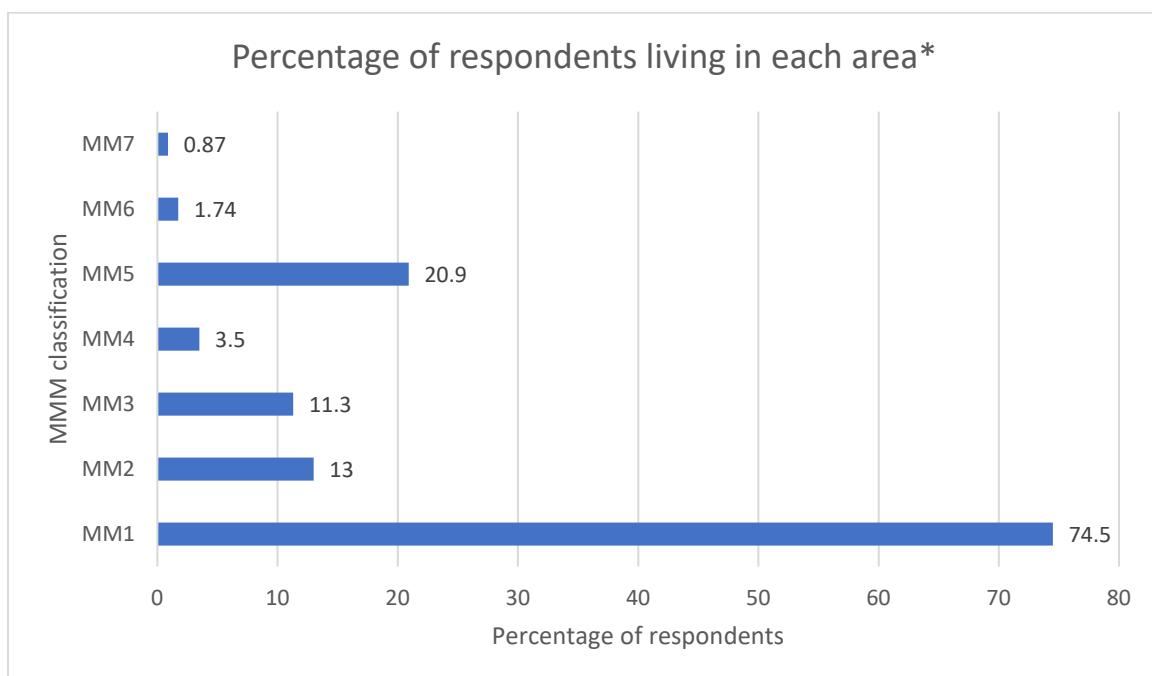
The vast majority of PEDs who completed this survey were female (93.9%; n=108) and aged between 18-30 years of age (51.3%; n=59). The age and gender breakdown of PEDs can be seen in **Table 1**.

Age bracket	Gender Identity		
	Male	Female	Non-binary
Under 18	0	6	0
18-30	0	56	3
31-45	1	28	1
46-60	2	17	0
Over 60	0	1	0
<b>TOTAL (% of total PEDs)</b>	<b>3 (2.6%)</b>	<b>108 (93.9%)</b>	<b>4 (3.5%)</b>

**Table 1:** The number of respondents who identified with the different gender identities by age group.

The majority of PEDs reported living (at the time of completing the survey) in urban/suburban (metro) areas (63.5%; n=73). Just over one-in-seven respondents (14.8%; n=17) reported living in regional, remote or very remote (RRR) areas. Whilst four people were unsure about the classification of where they lived, twenty-five people did not complete this question.

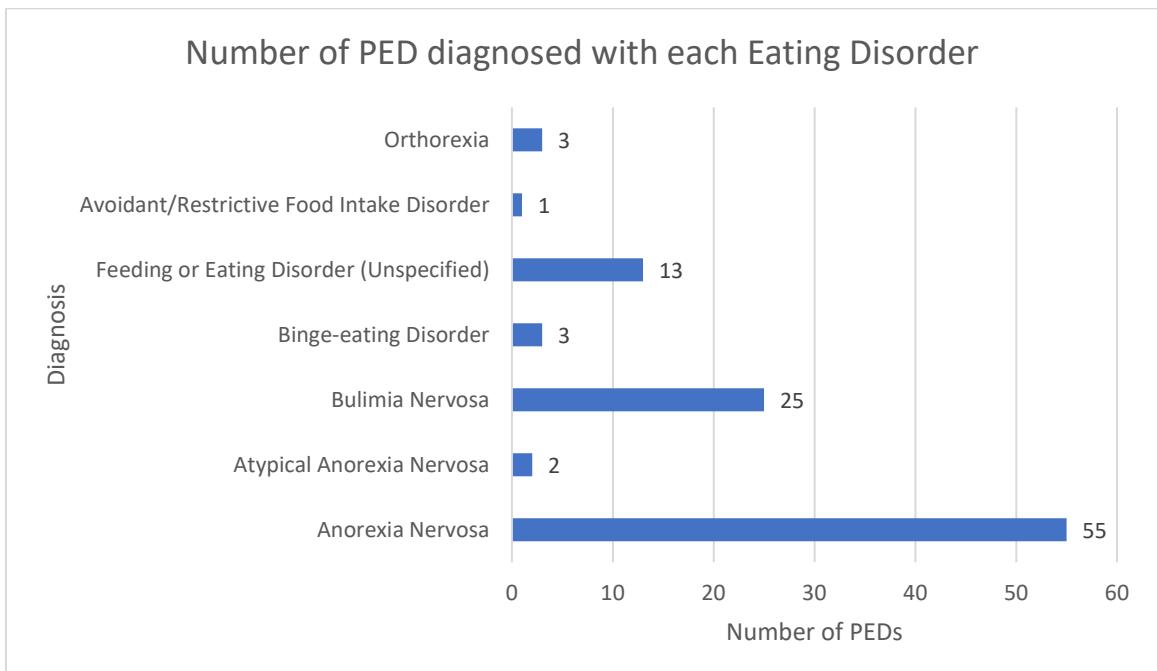
Based on the MMM classification (see **Figure 4**) the majority of respondents lived in areas classified as major cities (n=86; 74.8%). As postcodes can have more than one MMM code, it is difficult to ascertain the exact number of participants who would have been eligible for a Medicare rebate for telehealth, but it is possible to estimate between 7.0% and 27.0% of the sample of PEDs.



**Figure 4:** The percentage of PEDs who live in different MMM classifications.

\* The total percentage adds to greater than one hundred as some postcodes had more than one MMM classification. This occurs where a postcode may be shared by multiple locations.

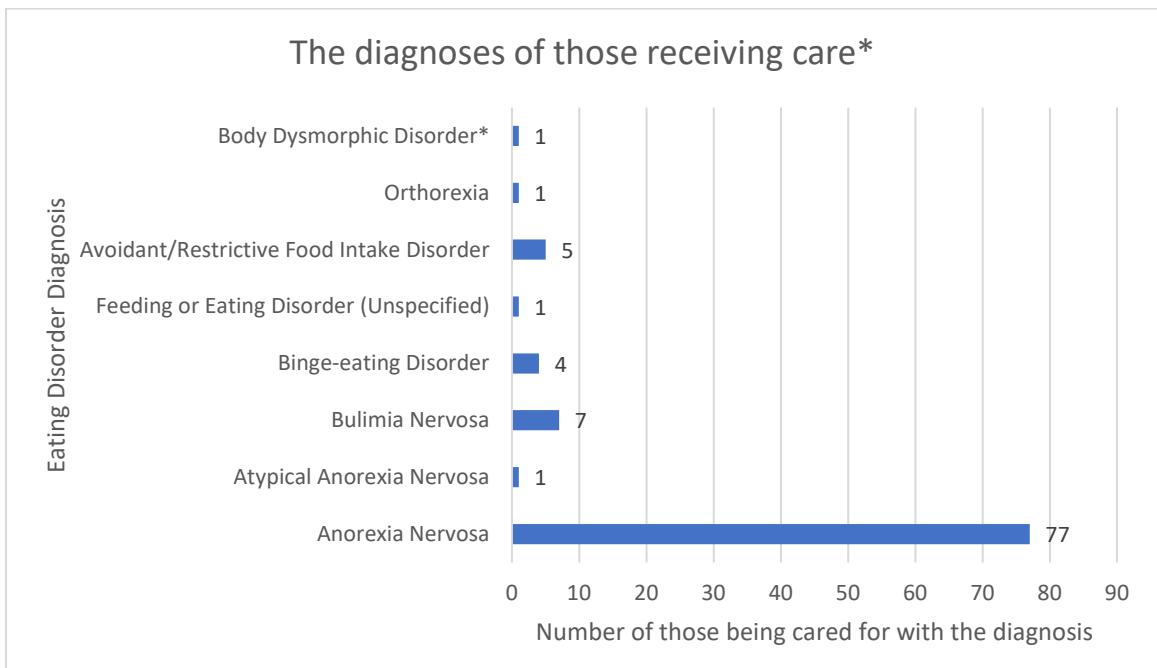
The vast majority of PEDs (73%, n=84) reported having been 'officially' diagnosed by a health professional. As seen in **Figure 5**, the most common diagnosis was Anorexia Nervosa (47.8%; n=55), followed by Bulimia Nervosa (21.7%; n=25) and Feeding and Eating Disorder (Unspecified) (11.3%; n=13).



**Figure 5:** Number of PEDs who have been diagnosed with the different eating disorders. Noting: It is possible for a person to have been given more than one diagnosis.

### 3. Carers

The majority of carers were between the ages of 46-60 years old (55%, n=55) when they completed this survey and were all female (n=100). The vast majority were currently caring for a person experiencing an eating disorder (77%, n=77). The majority of those they care for, had been officially diagnosed by a health professional with an eating disorder (90%, n=9). Only one carer was uncertain whether the person they cared for had ever received an official diagnosis. The greatest proportion was caring for a person diagnosed with Anorexia Nervosa (77%, n=77) as can be seen in **Figure 6**.



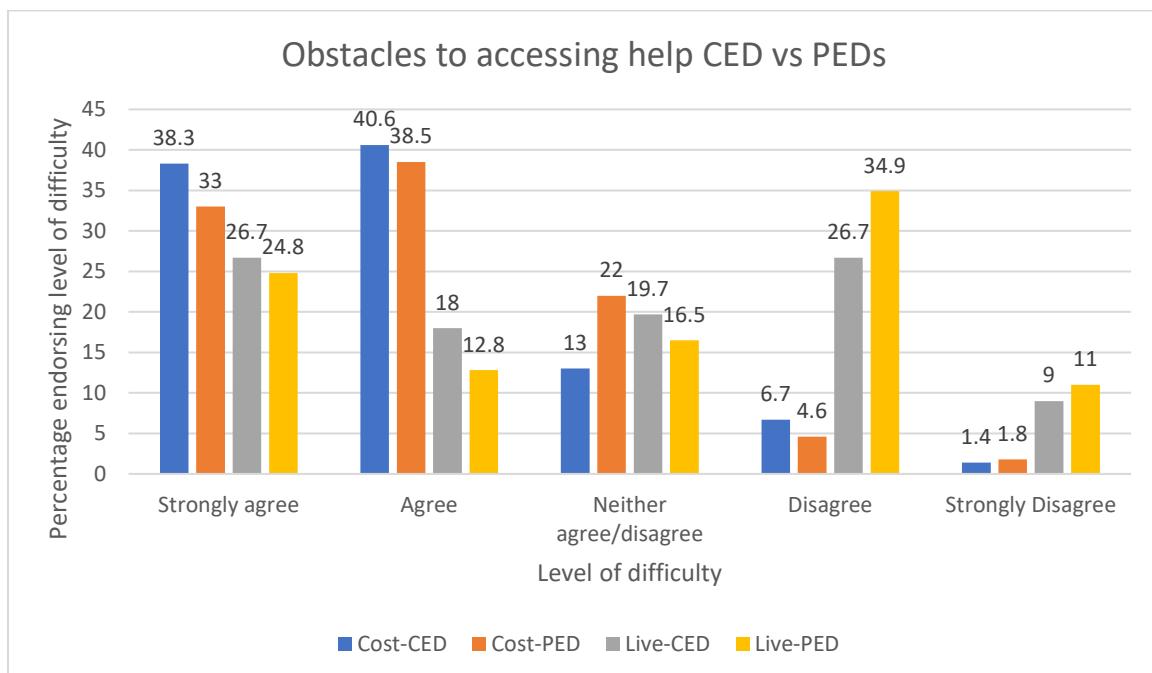
**Figure 6:** The number of people being cared for who have been diagnosed with each of the different eating disorders. Noting: It is possible for a person to have been given more than one diagnosis.

\*Body Dysmorphic Disorder is not classified as an eating disorder, but rather an Obsessive –Compulsive and Related Disorder (American Psychiatric Association, 2013)

## Perceived obstacles of accessing help

Respondents currently experiencing an eating disorder were asked to rate how difficult it was to access treatment and support services for eating disorders due to the **cost** of these services from 'strongly agree' (1) to 'strongly disagree' (5).

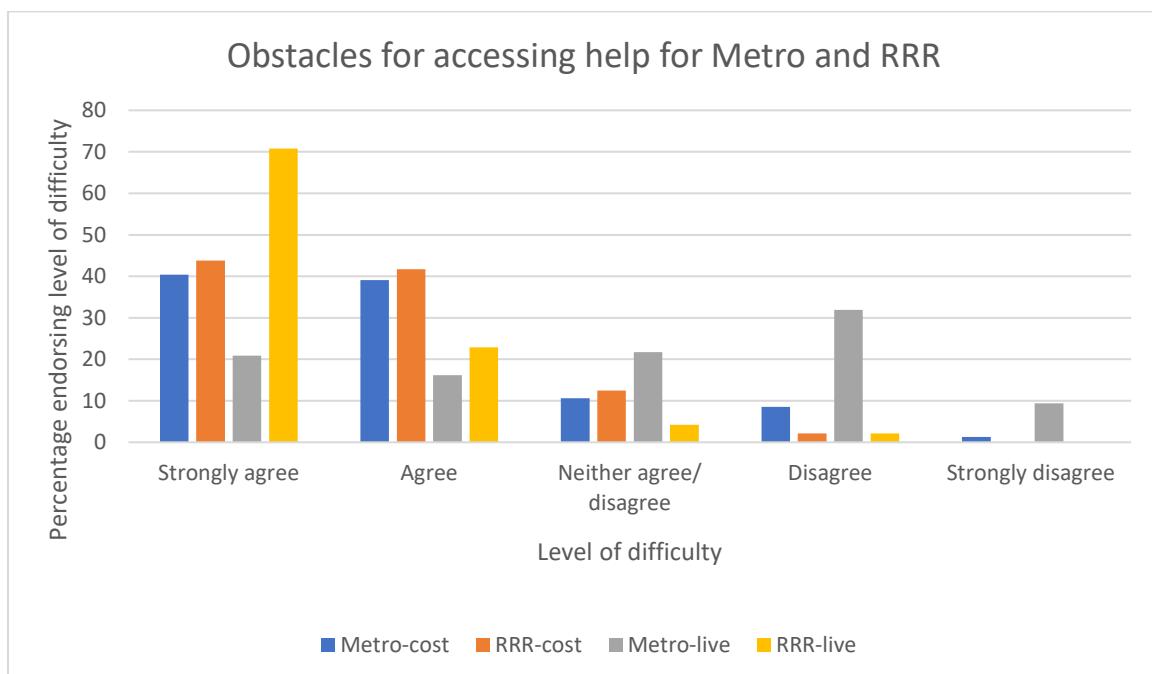
The vast majority of CEDs (78.9%, n=272) agreed that the cost of services was an obstacle to accessing help and 44% (n=154) agreed that where they lived is an obstacle to accessing help (see **Figure 7**). This was compared with the perception of PESs to determine if such obstacles have changed over time (see **Figure 7**).



**Figure 7:** The perception of CEDs and PEDs for how cost and location impeded their ability to access help.

There was no significant difference in perception between CEDs and PEDs in terms of how cost ( $t(452)=1.071$ ,  $p=0.29$ ) and where they live ( $t(452)=1.42$ ,  $p=0.16$ ) impeded their ability to access help.

The perception of CEDs who reported living in RRR compared to Metro was also compared (see **Figure 8**).



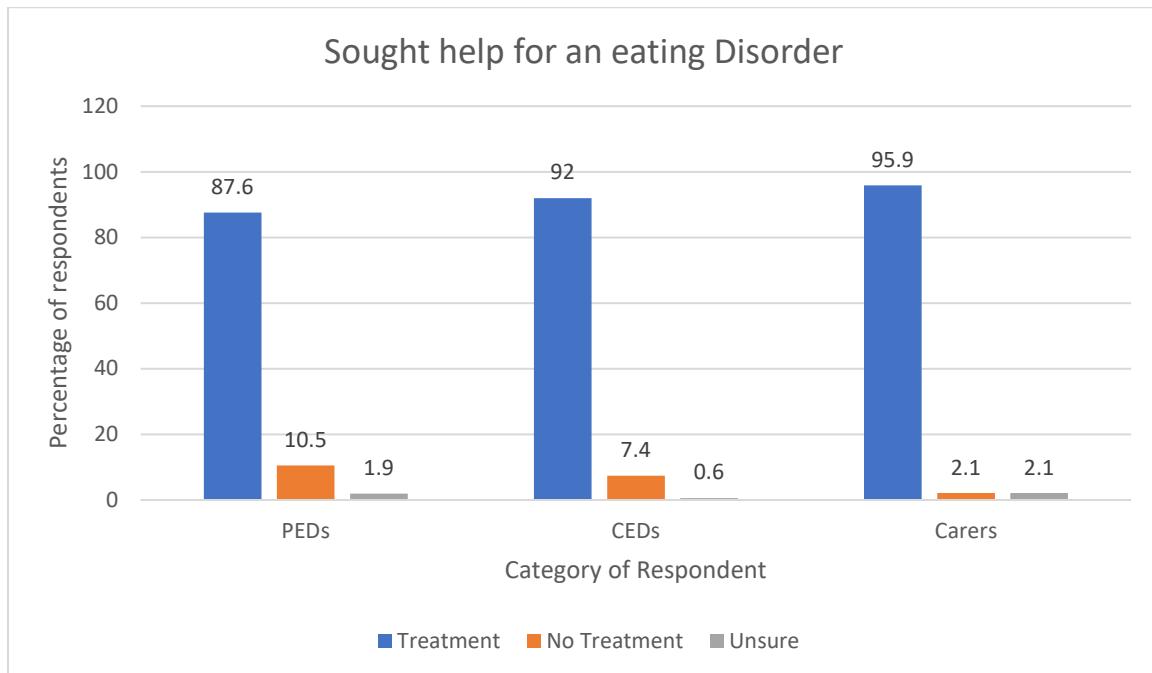
**Figure 8:** The perception of Metro and RRR for how cost and location impeded their ability to access help.

Whilst CEDs in RRR and Metro areas did not perceive the cost significantly differently ( $t(281)= 1.21$ ,  $p=0.23$ ), there was a significant difference in terms of 'where they live' being a perceived impediment to accessing help ( $t(281)= 8.05$ ,  $p<0.001$ ). The CEDs in RRR were significantly more likely to agree that where they live was an obstacle compared with those CEDs who live in Metro areas.

## Health care experience

### 1. Help seeking numbers

Respondents were asked to indicate if they (or the person they care for) had ever sought help from a health care professional for an eating disorder - **Figure 9**. For both CEDs (92%, n=311) and PEDs (87.9%, n=92) the vast majority reported having treatment for an eating disorder. The vast majority of carers (95.9%, n=93) also reported that the person they were caring for had received treatment for an eating disorder. In the overall sample 91.9% (n=540) had sought treatment.



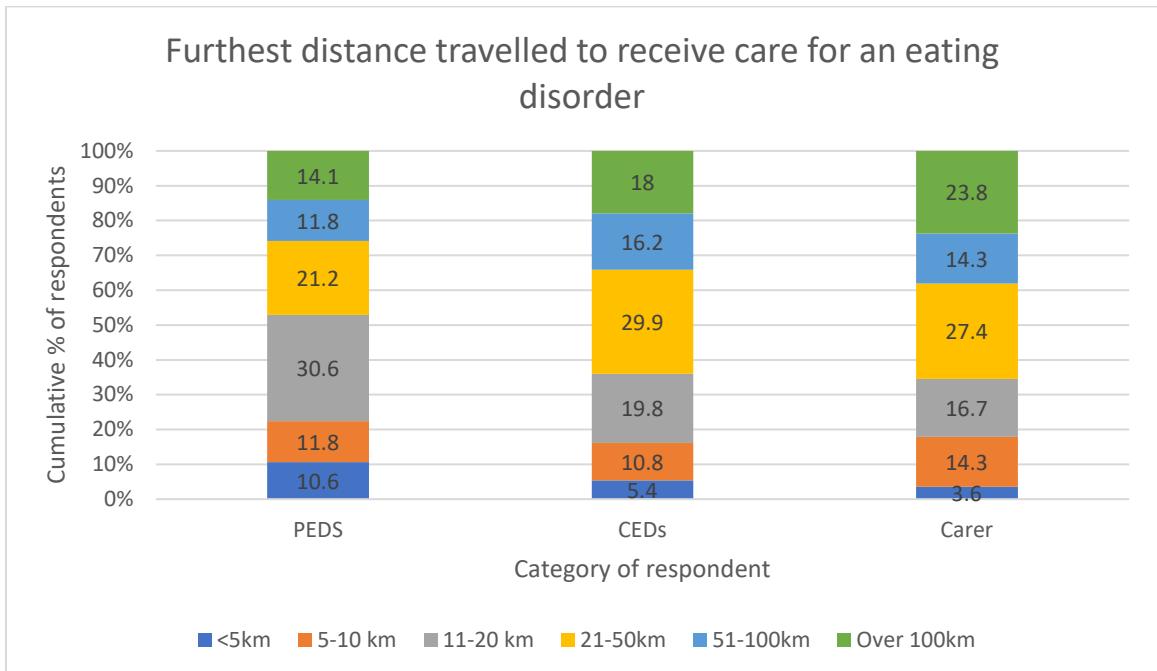
**Figure 9.** The percentage of people receiving treatment for an eating disorder: CED, PED and Carers

### 2. Obstacles to care: Logistics and cost

The actual distance and costs associated with this treatment were examined.

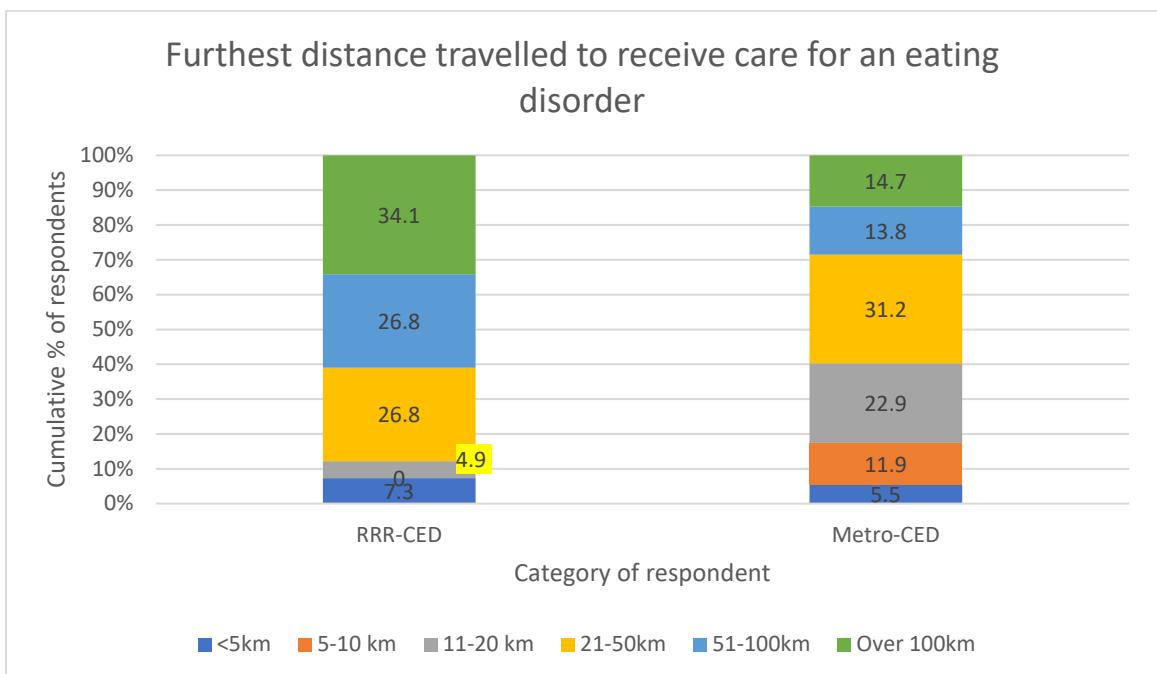
**Furthest distance travelled to receive care for an ED:** Respondents were asked what the furthest distance either they (or the person they care for) had to travel to receive treatment for an eating disorder. The median response for the entire sample was between 21-50 kilometres for treatment. The median response varied between PEDs (11-20km), CEDs (21-50 km) and Carers (21-50km; i.e. the furthest distance travelled by the person being cared for). See **Figure 10**.

For the overall analysis of differences between the groups, the distance categories were categorised with 1='less than 5 kilometres', 2='5-10 kilometres' and 6='Over one hundred kilometres' etc. Overall there was a significant difference between the groups in terms of the furthest distance travelled ( $F(2,445)=3.34$ ,  $p=0.036$ ), with CEDs (Mean=3.94) travelling significantly further than PEDs (Mean=3.54) ( $t(445)=-.23$ ,  $p=0.02$ ). There were no other significant differences between the individual groups.



**Figure 10:** The cumulative percentage of respondents who travelled the different distance as the ‘furthest distance they had to travel to receive care’ for PEDs, CEDs and for those treated by carers.

The furthest distance travelled was also compared for the CEDs who lived in RRR and metro areas. Overall, there was a significant difference between CEDs who lived in RRR and those in Metro areas ( $F(2,257)=8.23, p<0.001$ ). With CED-RRR (Mean=4.68) reporting having travelled the furthest distance compared with the CED-Metro (Mean 3.80). This can be seen in **Figure 11**.



**Figure 11:** The cumulative percentage of RRR-CEDs and Metro-CEDs who travelled the different distance as the ‘furthest distance they had to travel to receive care’.

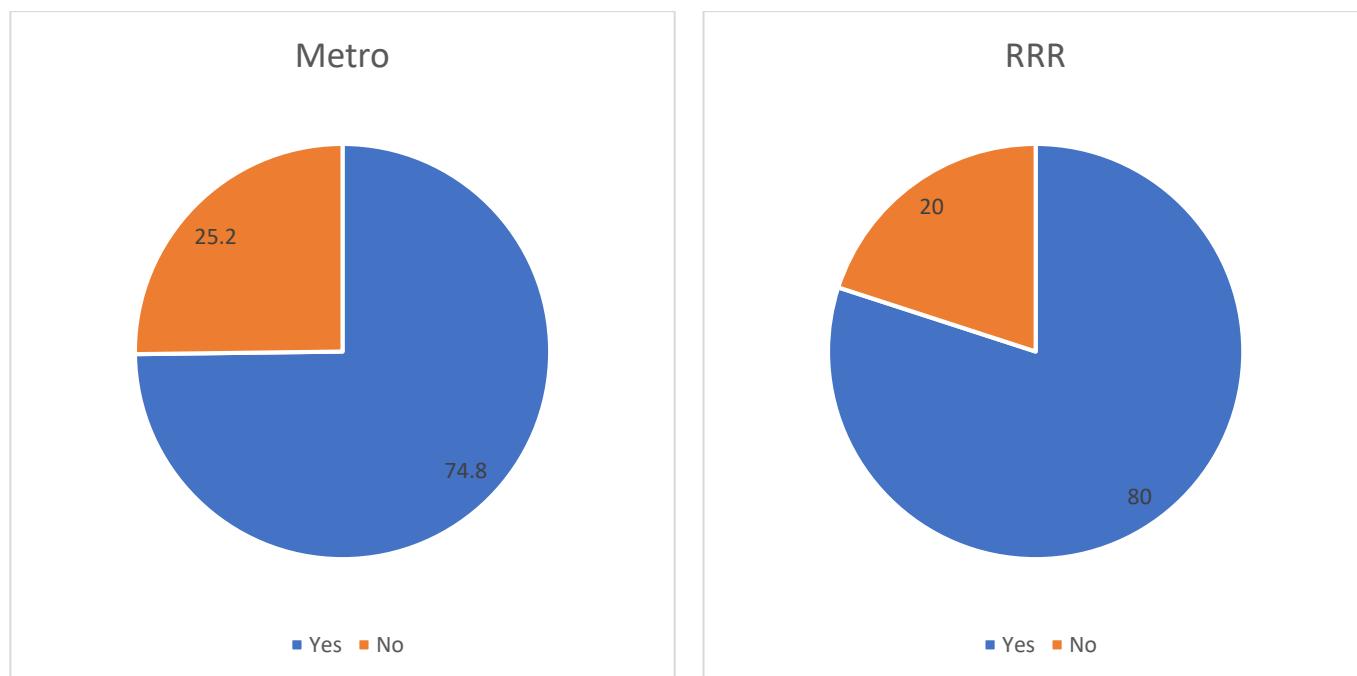
**Interstate travel of an ED:** Approximately 10% of PEDs (10.6%, n=9), CEDs (10.8%, n=30) and those being cared for (10.7%, n=9; i.e., carer group) reported having to travel interstate to receive treatment for an eating disorder. The difference between groups was not significant ( $F(2,445)=0.03, p=0.71$ ).

In terms of the difference between those who live in RRR and Metro areas (independent of group – CED, PED, Carer) there was no significant difference in travel interstate for treatment, with 10.3% of people in Metro areas (n=36) and 14.7% in RRR (n=11) reported having ever had to travel interstate to receive treatment for an eating disorder.

**Financial costs for receiving treatment:** Respondents were asked if they had incurred significant financial costs to receive treatment for an eating disorder. The majority of CEDs (70.1%, n=190), PEDs (61.0%, n=50) and those being cared for (80.7%, n=76; i.e., carer group) reported encountering significant financial costs to receive treatment for the eating disorder. The difference between these groups also reached significance ( $F(2,404)=3.07, p=0.047$ ), with carers

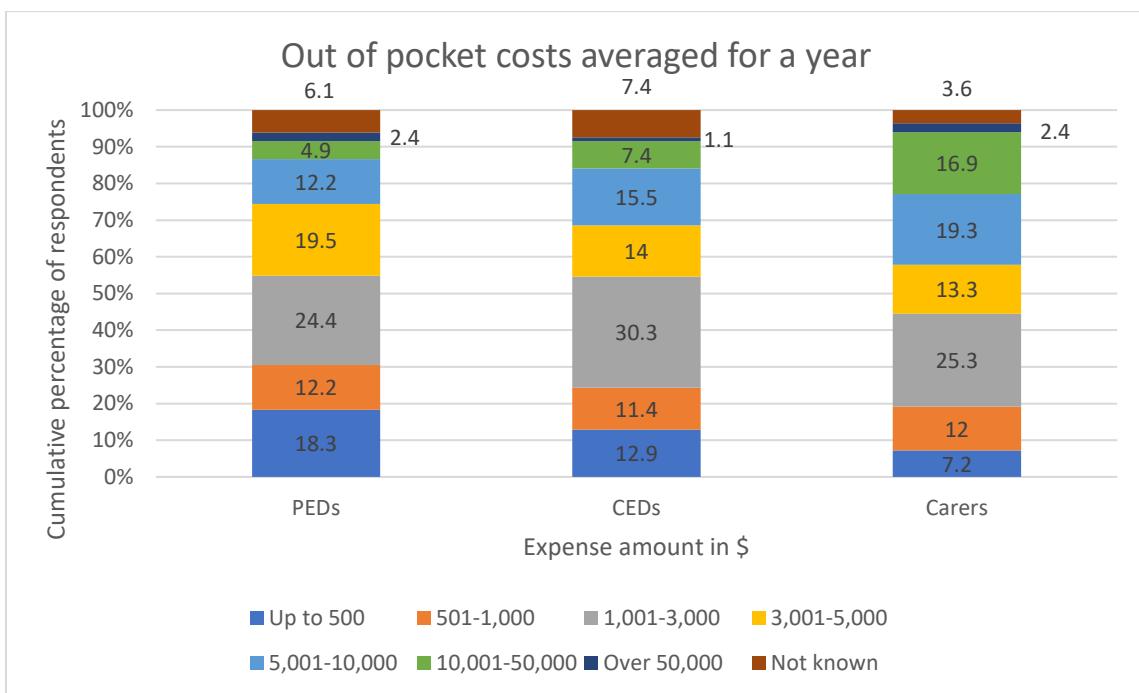
being more likely to report significant financial costs than CEDs and PEDs combined ( $t(155.9)=2.47$ ,  $p=0.015$ ). The difference between CEDs and PEDs was not significant ( $t(112.9)=1.427$ ,  $p=0.156$ ). This may reflect that it is the 'carer' having responsibility for the payment of treatment costs and being either more aware of the costs, or the one who is more likely to have the burden of payment.

When comparing the overall sample who live in Metro compared with RRR areas, there was no significant difference in reports of experiencing significant financial costs to receive treatment for an eating disorder ( $F(1,397)=0.86$ ;  $p=0.356$ ), largely because the majority of respondents in both RRR (80%,  $n=56$ ) and Metro (74.8%,  $n=246$ ) reported having incurred significant financial costs (**Figure 12**).



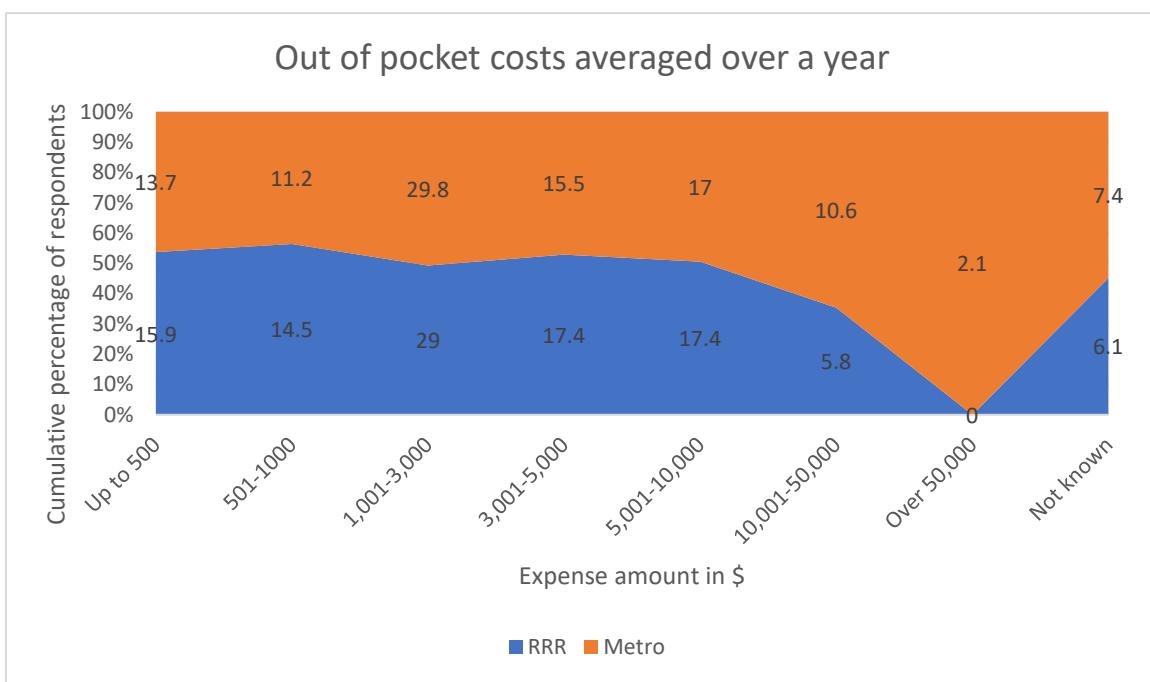
**Figure 12** The percentage of people in RRR and Metro areas who reported experiencing significant financial costs to receive treatment for an eating disorder.

**Out-of-pocket costs averaged over a year:** Respondents were asked the average out-of-pocket expense for the treatment of an eating disorder. From **Figure 13** it can be seen that over 80% of PEDs and CEDs are paying \$10,000 or less in out-of-pocket expenses, but less than 80% of carers fall within this category or lower (i.e., 22.9% are paying \$10,001 or over). This difference is significant in terms of overall out-of-pocket expenses, with carers reporting significantly higher costs than the CEDs and PEDs combined ( $F(4.5)=2.995$ ,  $p=0.003$ ), but no real difference between the CEDs and PEDs ( $t(405)=-0.809$ ,  $p=0.419$ ).



**Figure 13:** The estimated out-of-pockets costs averaged over a year of treatment for the eating disorder for PEDs, CEDs and the person being cared for (Carer)

Respondents in RRR and Metro also did not report a significant difference in out-of-pockets expenses averaged over a year ( $F(1,396) = 1.833$ ,  $p=0.177$ ). The number of participants with substantial costs for both groups is high (See **Figure 14**), with 29.7% of Metro ( $n=98$ ) and 23.2% of RRR ( $n=16$ ) paying more than \$5001 out-of-pocket expenses in an average year.



**Figure 14** Out-of-pocket expenses averaged over a year for RRR and Metro for the treatment of an eating Disorder.

### 3. The quality of care

CEDs, PEDs and carers, were asked to rate the quality of care they were provided for the treatment of the eating disorder. They made a rating on 5 different aspects of the care on a 5-point rating scale indicating how strongly they agreed or disagreed with the statement about their care. These statements included:

1. Contact with the health care professional for the eating disorder was a **positive experience**
2. The experience could have been improved if the health professional had **greater knowledge of the eating disorder**
3. The experience could have been improved if the health professional had **greater empathy for an eating disorder**
4. This experience could have improved if the health professional had the **ability to refer me (or the person I care for) to an appropriate service provider**
5. This experience could have been improved if the health professional had been **able to spend more time** with me (or the person I care for) in the consultation for the eating disorder.

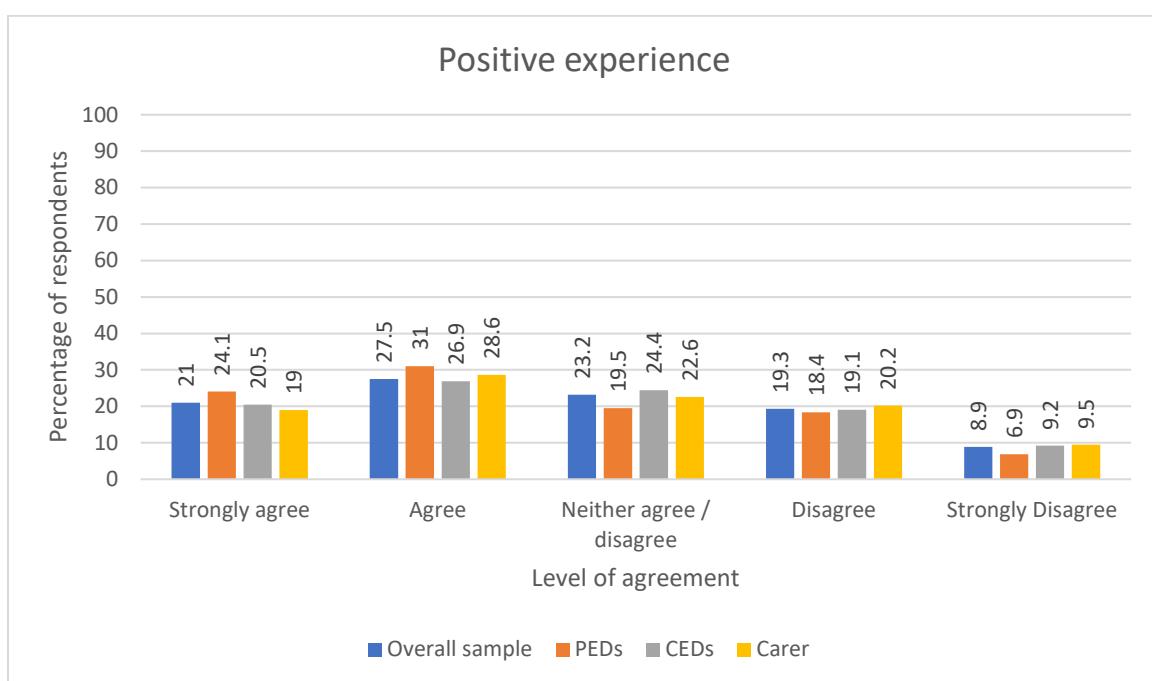
The scores on these statements were then summed together to provide an 'overall quality of care' score which ranged from 5-25, with a higher score indicating a higher level of care. Items that needed to be reversed to ensure a higher score indicated better care, were recoded to reflect this. The mean score for ALL respondents was 12.87 (SD: 5.15) and the scores ranged from 5 – 25.

**CED, PED and Carer ratings of overall quality of care:** In terms of the three different groups of respondents (CEDs, PEDs and Carers) there was no significant difference in their ratings on the overall quality of care provided ( $F(2,451)=0.578$ ,  $p=0.56$ ).

**RRR and Metro:** Respondents who lived in metro areas (Mean: 13.73, SD: 5.21) reported a significantly higher overall quality of health care than those on RRR areas (Mean: 11.45, SD: 4.68) ( $F(1,424)=7.85$ ,  $p=0.005$ ).

These overall scores were then explored in terms of the individual questions.

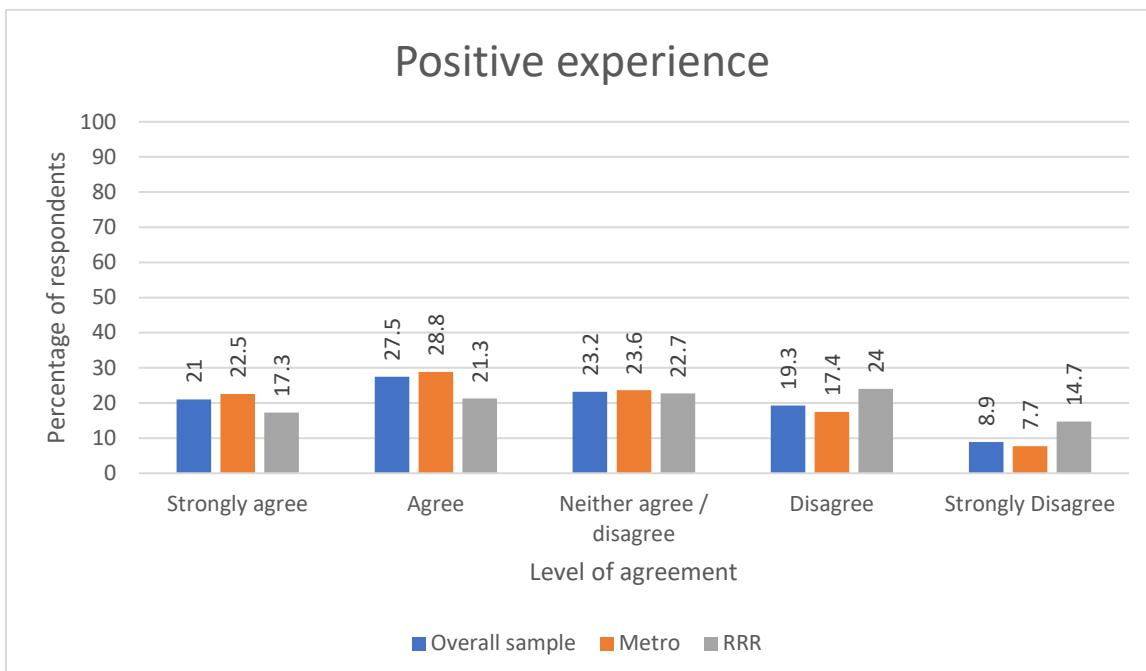
**Positive experience:** Overall the *CEDs* ( $M= 2.70$ ,  $SD=1.25$ ), *PEDs* ( $M= 2.53$ ,  $SD=1.24$ ) and *Carers* ( $M=2.73$ ,  $SD=1.25$ ) did not differ significantly in how positive they believed the contact was with the health professional for the eating disorder ( $F(2,451)=0.705$ ,  $p=0.495$ ). In the overall sample, nearly half of the respondents 'agreed' or 'strongly agreed' the contact with the health care provider was positive (48.5%,  $n=224$ ). Nearly 30% of respondents ( $n=130$ ) 'disagreed' or 'strongly disagreed' that it was a positive experience (See **Figure 15**).



**Figure 15:** The percentage of respondents in the different groups (overall sample, PEDs, CEDs and carers) level of agreement with the statement: 'contact with the health care professional for the eating disorder was a positive experience'.

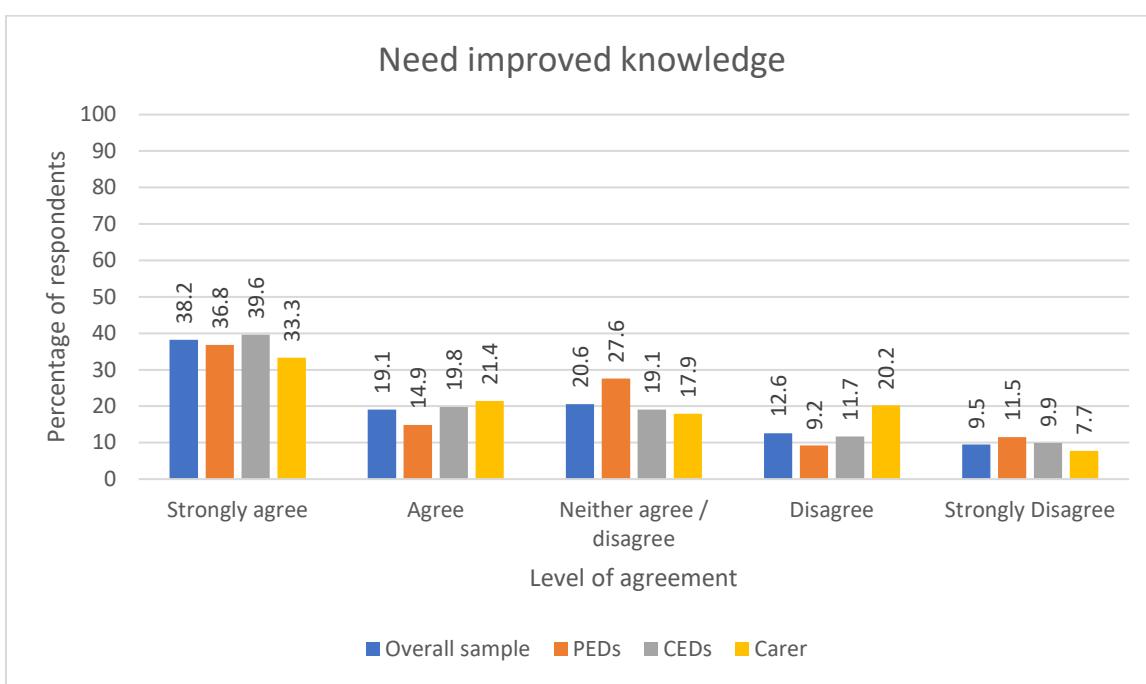
There was a significant difference between *RRR and Metro* in terms of how positive the experience had been for them when they had contact with a health care provider ( $F(1, 424)=5.869$ ,  $p=0.016$ ). Respondents who lived in Metro areas (Mean=2.59, SD=1.23) rated the experience to be significantly more positive than those in RRR areas (Mean=2.97,

$SD=1.33$ ); noting a lower score on this variable is associated with a more favourable impression. It can be seen in **Figure 16** that 38.6% of people residing in RRR areas ( $n=29$ ) ‘agreed’ or ‘strongly agreed’ the contact with the health care professional was a positive experience, compared to 51.3% ( $n=180$ ) in Metro areas. Likewise, 38.7% ( $n=29$ ) in RRR areas ‘disagreed’ or ‘strongly disagreed’ with the statement that contact had been a positive experience. This compared to 25.1% ( $n=88$ ) in Metro areas.



**Figure 16:** The percentage of respondents living in RRR compared to Metro (and overall sample) level of agreement with the statement: ‘contact with the health care professional for the eating disorder was a positive experience’.

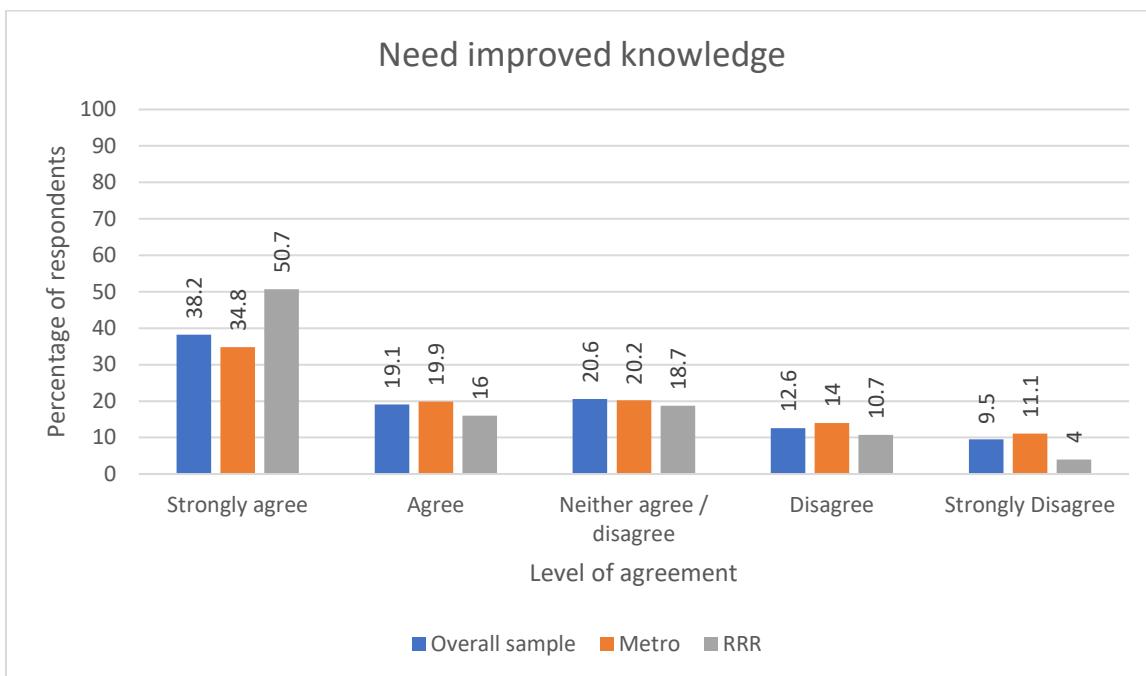
**Knowledge of eating disorders:** The *CEDs*, *PEDs* and *Carers* did not differ significantly in terms of their satisfaction with the health professionals’ level of knowledge about eating disorders ( $F(2,451)=0.464$ ,  $p=0.63$ ). In the overall sample, over half of the respondents ‘agreed’ or ‘strongly agreed’ the experience would have improved if the health care provider had a greater knowledge of eating disorders (57.3%,  $n=264$ ). Just over one in five (22.1%,  $n=102$ ) ‘disagreed’ or ‘strongly disagreed’ with this statement (See **Figure 17**).



**Figure 17:** The percentage of respondents in the different groups (overall sample, PEDs, CEDs and carers) level of agreement with the statement: ‘this experience could have improved if the health professional had a greater knowledge of eating disorders’.

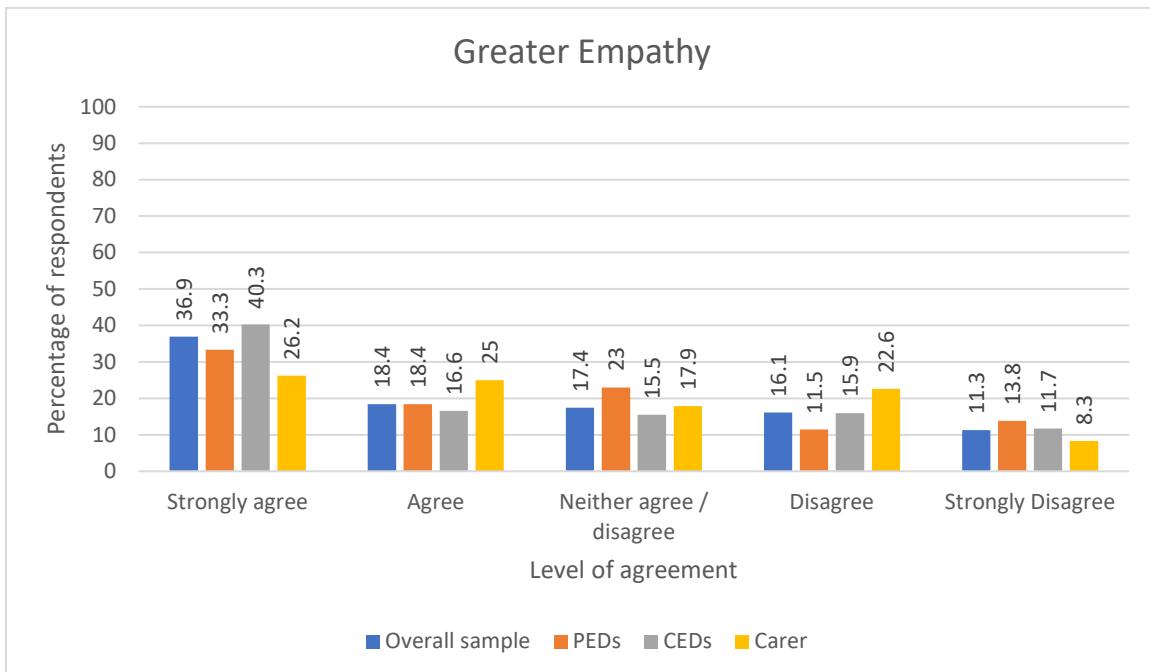
There was a significant difference between *RRR* and *Metro* in terms of their satisfaction with the health professional’s level of knowledge about eating disorders ( $t(117.50)=2.848$ ,  $p=0.005$ ). Respondents who lived in *Metro* areas ( $Mean=2.47$ ,  $SD=0.38$ ) had a significantly higher level of satisfaction with the knowledge of health care providers than those in *RRR* areas ( $Mean=2.01$ ,  $SD=1.22$ ). It can be seen in **Figure 18** that half the people residing in *RRR* areas (50.7%,  $n=38$ ) ‘strongly agreed’ that a greater level of knowledge was required, compared to 34.8% ( $n=122$ ) in *Metro*

areas. Likewise, only 4% (n=3) in RRR areas 'strongly disagreed' that extra knowledge was required compared with 11.1% (n=39) in Metro areas.



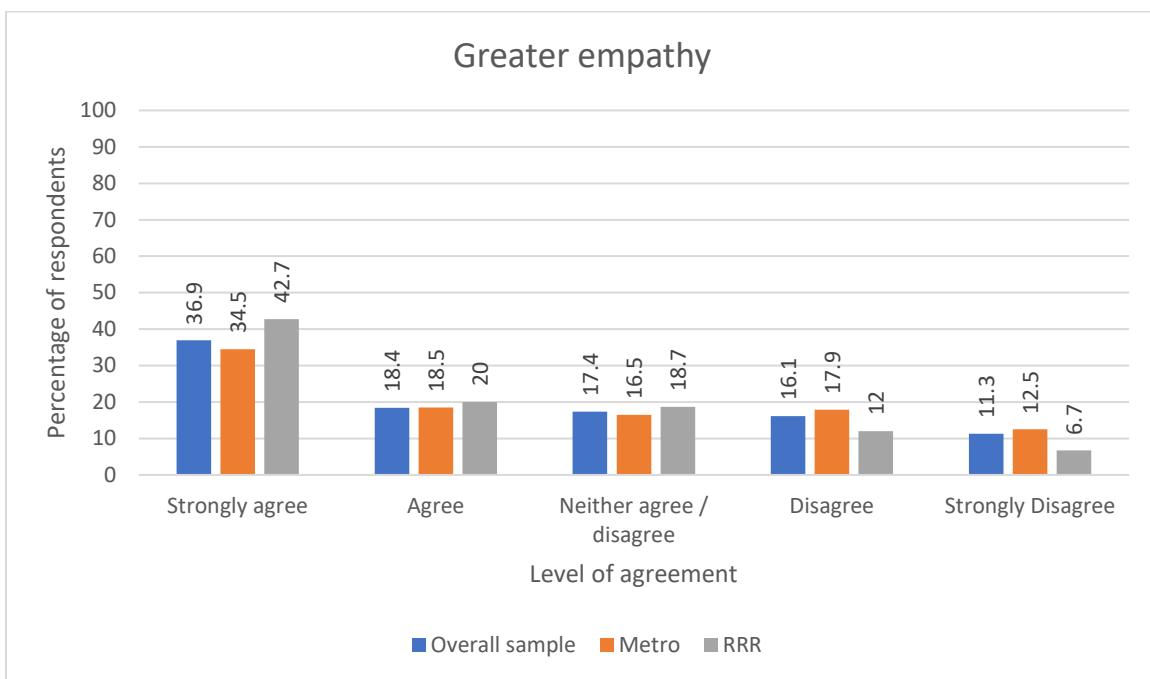
**Figure 18:** The percentage of respondents living in RRR compared to Metros (and overall sample) level of agreement with the statement: 'this experience could have improved if the health professional had a greater knowledge of eating disorders'.

**Greater empathy for eating disorders:** The CEDs, PEDs and Carers did not differ significantly in terms of their satisfaction with the health professional's level of empathy for eating disorders ( $F(2,451)=0.737$ ,  $p=0.479$ ). In the overall sample, over half of the respondents 'agreed' or 'strongly agreed' the experience would have improved if the health care provider had a greater level of empathy for eating disorders (55.3%,  $n=255$ ). Just over one quarter of respondents (27.4%,  $n=126$ ) 'disagreed' or 'strongly disagreed' with this statement (See **Figure 19**).



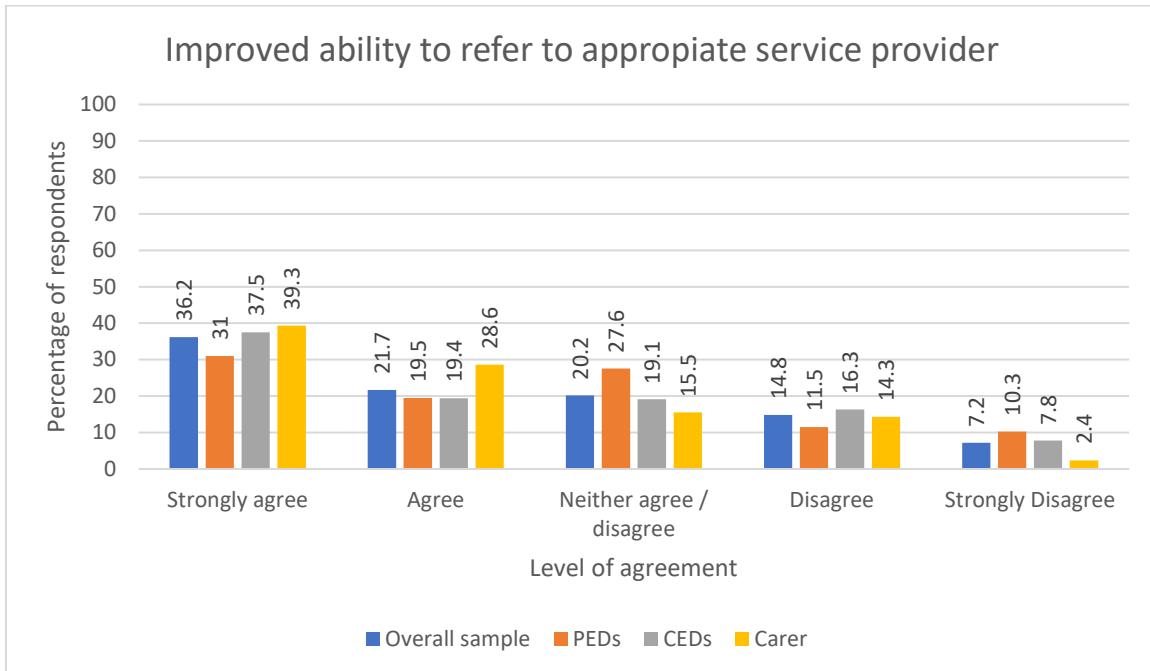
**Figure 19:** The percentage of respondents in the different groups (overall sample, PEDs, CEDs and carers) level of agreement with the statement: 'this experience could have been improved if the health professional had greater empathy for eating disorders'.

There was a significant difference between RRR and Metro in terms of their satisfaction with the health professional's level of empathy for eating disorders ( $t(116.14)=2.118$ ,  $p=0.036$ ). Respondents who lived in Metro areas (Mean=2.56,  $SD=1.43$ ) had a significantly higher level of satisfaction with the empathy of the health care providers than those in RRR areas (Mean=2.20,  $SD=1.29$ ). It can be seen in **Figure 20** that 43% of people residing in RRR areas ( $n=32$ ) 'strongly agreed' that a greater level of empathy was required, compared to 34.5% ( $n=121$ ) in Metro areas. Likewise, only 6.7% ( $n=5$ ) in RRR areas 'strongly disagreed' that extra empathy was required compared with 12.5% ( $n=44$ ) in Metro areas.



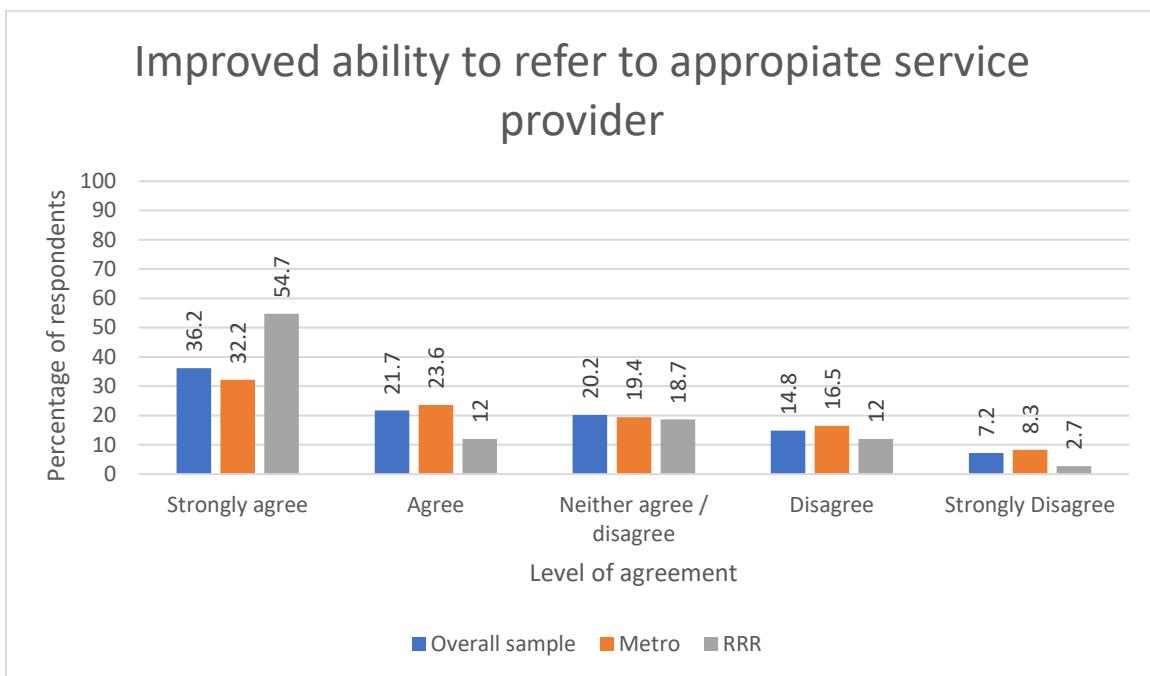
**Figure 20:** The percentage of respondents living in RRR compared to Metros (and overall sample) level of agreement with the statement: 'this experience could have been improved if the health professional had greater empathy for eating disorders'.

**Ability to refer to appropriate service provider:** The *CEDs*, *PEDs* and *Carers* did not differ significantly in terms of their satisfaction with the health professional's capacity to refer them to an appropriate service provider ( $F(2,451)=1.998$ ,  $p=0.137$ ). In the overall sample, almost three in every five of the respondents 'agreed' or 'strongly agreed' the experience would have improved if the health care provider had the ability to refer to an appropriate service provider (57.9%,  $n=267$ ). Just over 20% of respondents ( $n=101$ ) 'disagreed' or 'strongly disagreed' with this statement (See **Figure 21**).



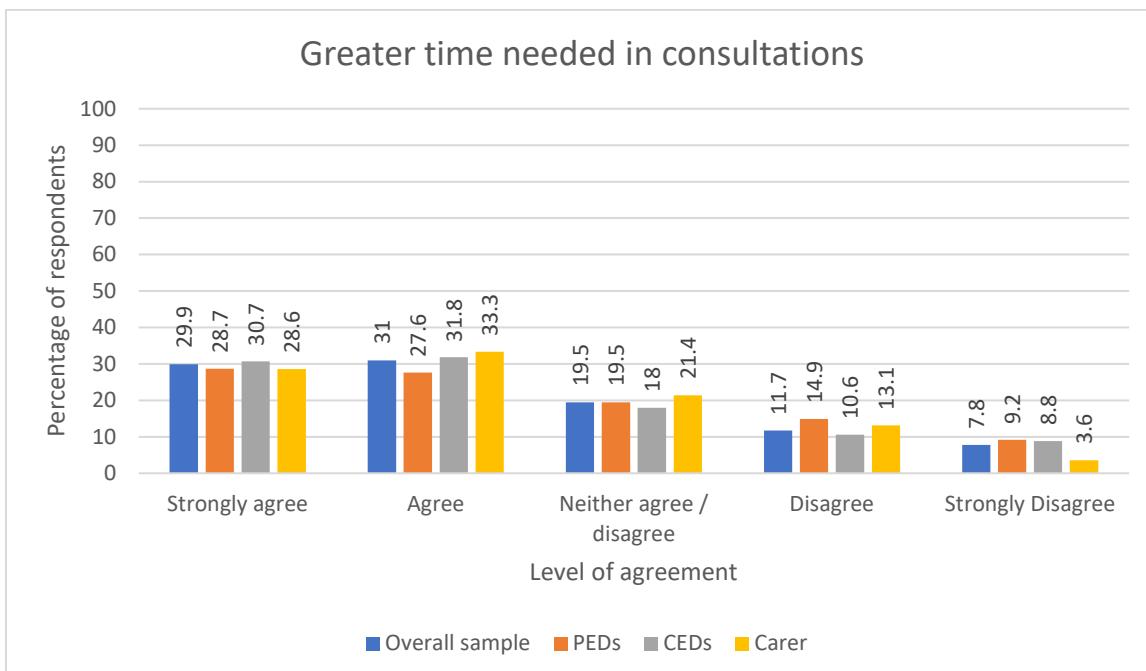
**Figure 21:** The percentage of respondents in the different groups (overall sample, PEDs, CEDs and carers) level of agreement with the statement: 'this experience could have been improved if the health professional had the ability to refer me (or the person I care for) to an appropriate service provider'.

There was a significant difference between *RRR* and *Metro* in terms of their satisfaction with the health professional's ability to refer to an appropriate service provider ( $F(1,424)=8.844$ ,  $p=0.003$ ). Respondents who lived in *Metro* areas (Mean=2.45, SD=1.31) had a significantly higher level of satisfaction than those in *RRR* areas (Mean=1.96, SD=1.21). It can be seen in **Figure 22** that 54.7% of people residing in *RRR* areas ( $n=41$ ) 'strongly agreed' that the capacity to refer to an appropriate service provider needed to be improved, compared to 32.2% ( $n=113$ ) in *Metro* areas. Likewise, only 2.7% ( $n=2$ ) in *RRR* areas 'strongly disagreed' with the need for a greater capacity to refer to appropriate service providers, compared with 8.3% ( $n=29$ ) in *Metro* areas.



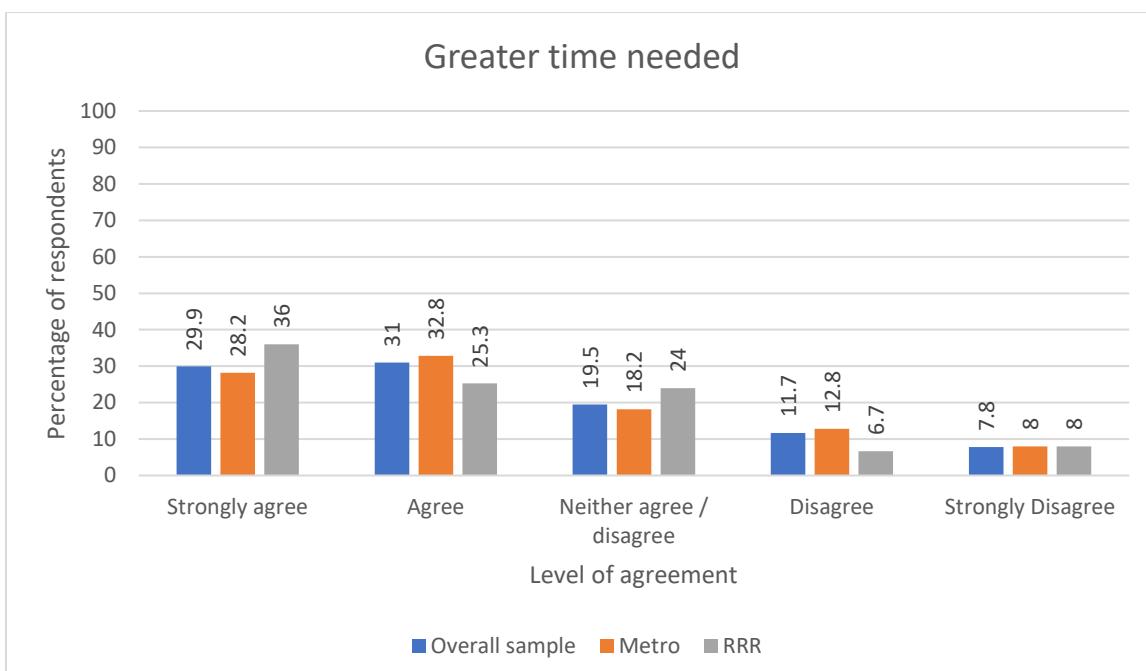
**Figure 22:** The percentage of respondents living in *RRR* compared to *Metros* (and overall sample) level of agreement with the statement: 'this experience could have been improved if the health professional had the ability to refer me (or the person I care for) to an appropriate service provider'.

**Greater time spent in consultations for EDs:** The CEDs, PEDs and Carers did not differ significantly in terms of their satisfaction with the time the health professional spent with them in consultations for the eating disorder ( $F(2,451)=0.533$ ,  $p=0.587$ ). In the overall sample, over 60% of respondents 'agreed' or 'strongly agreed' the experience would have improved if the health care provider had spent a greater amount of time in the consultation (60.9%, n=281). Nearly 20% of respondents (19.5%, n=90) 'disagreed' or 'strongly disagreed' with this statement (See **Figure 23**).



**Figure 23:** The percentage of respondents in the different groups (overall sample, PEDs, CEDs and carers) level of agreement with the statement: 'this experience could have been improved if the health professional had been able to spend more time with me (or the person I care for) in the consultation about the eating disorder'.

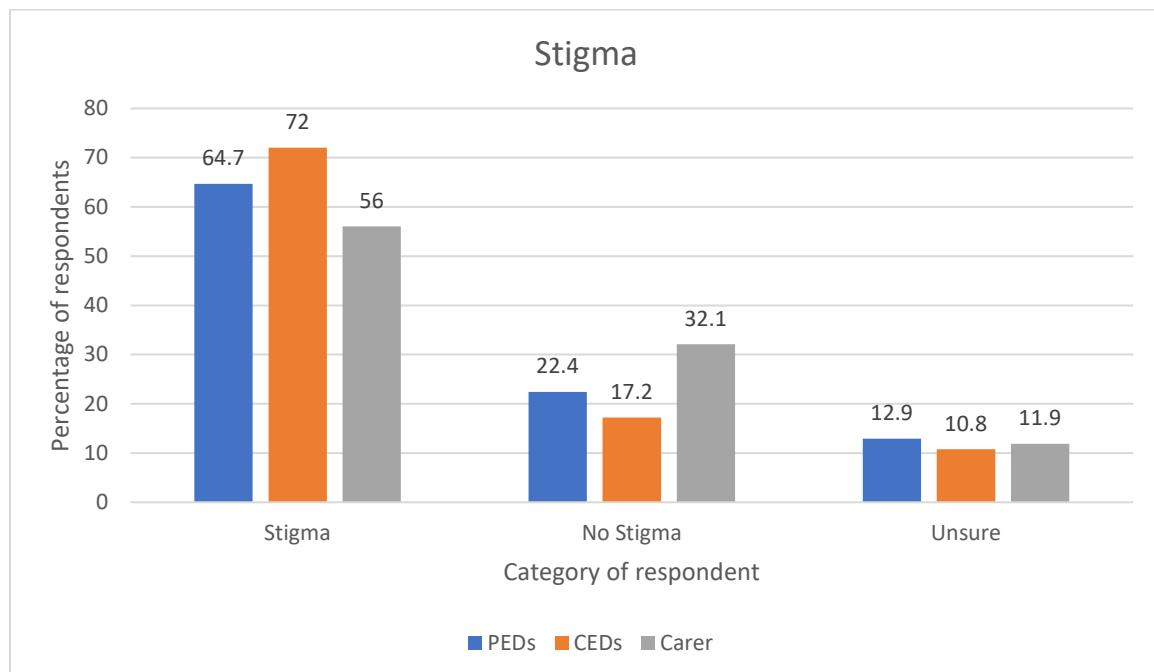
In addition, there was no significant difference between respondents in RRR (Mean=2.253, SD=1.24) and Metro (Mean=2.396, SD=1.24) level of dissatisfaction with the amount of time the health care professional spent in the consultation about the eating disorder ( $F(1,424)=0.815$ ,  $p=0.367$ ; see **Figure 24**). In Metro areas, 61% of respondents (n=214) either 'strongly agreed' or 'agreed' the experience could be improved if more time was given in a consultation. An equal percentage of RRR respondents shared this view (61.3%, n=46).



**Figure 24:** The percentage of respondents living in RRR compared to Metros (and overall sample) level of agreement with the statement: 'this experience could have been improved if the health professional had been able to spend more time with me (or the person I care for) in the consultation about the eating disorder'.

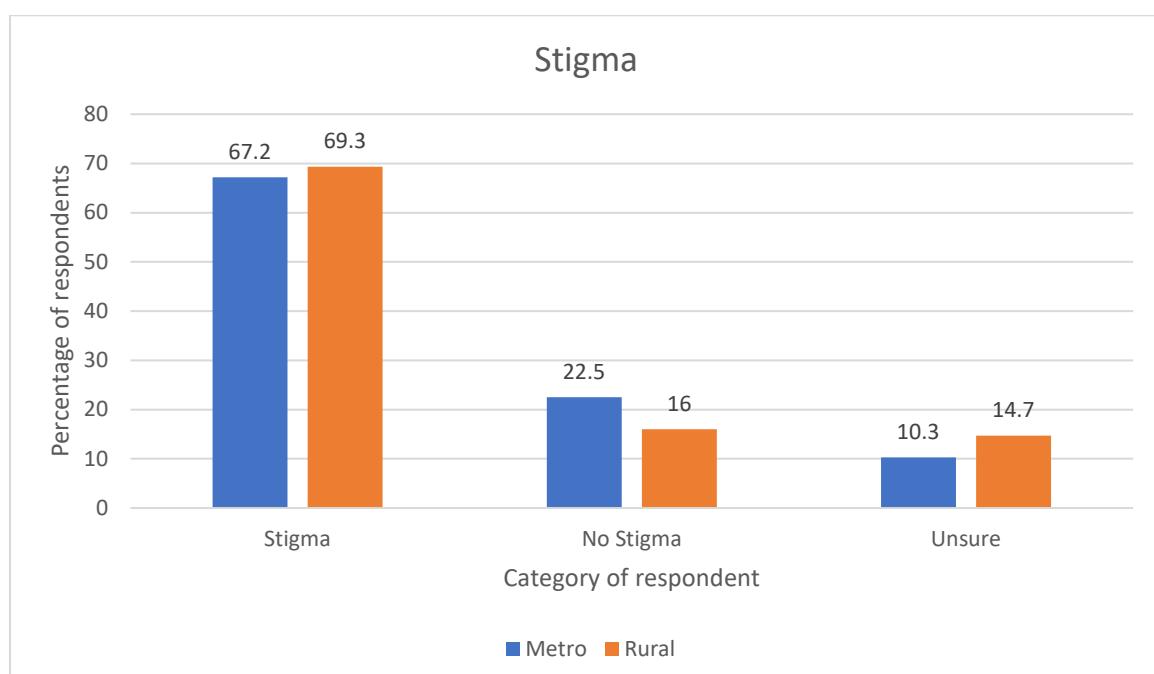
## 4. Stigma

Respondents were asked if they had ever faced stigma from those in the healthcare system as a result of the eating disorder. Of those who had sought help (n=455) from a healthcare provider, 67.9% (n=309) reported having faced stigma, 11.2% (n=51) were unsure and 20.9% (n=95) reported having not experienced any stigma. There was no significant difference in reports of having faced stigma from those in the health system for PEDs, CEDs and Carers (for the person they care for) ( $F(2,445)=2.256$ ,  $p=1.06$ ). From **Figure 25** it can be seen that for all groups over 50% of respondents had faced stigma, with 72% of CEDs reporting having faced stigma from those in the healthcare system as a result of an eating disorder.



**Figure 25:** The percentage of respondents reporting having ever faced stigma from those in the health care system, broken down by group (PEDs, CEDs, Carer).

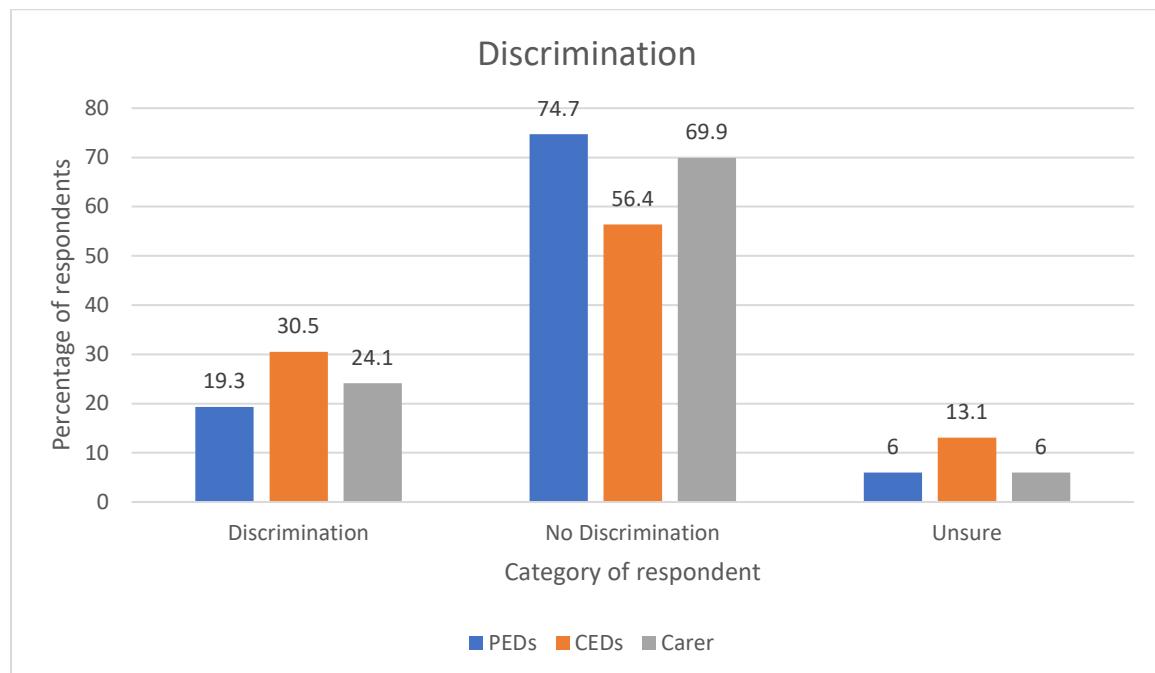
Likewise, there was no significant difference in the number of respondents who reported having ever faced stigma from those in the health care system as a result of an eating disorder ( $F(1,424)=0.071$ ,  $p=0.791$ ). As can be seen from **Figure 26** the vast majority of respondents in both Metro (67.2%, n=236) and RRR (69.3%, n=52) areas had faced stigma.



**Figure 26:** The percentage of respondents in Metro and RRR areas reporting having ever faced stigma from those in the health care system.

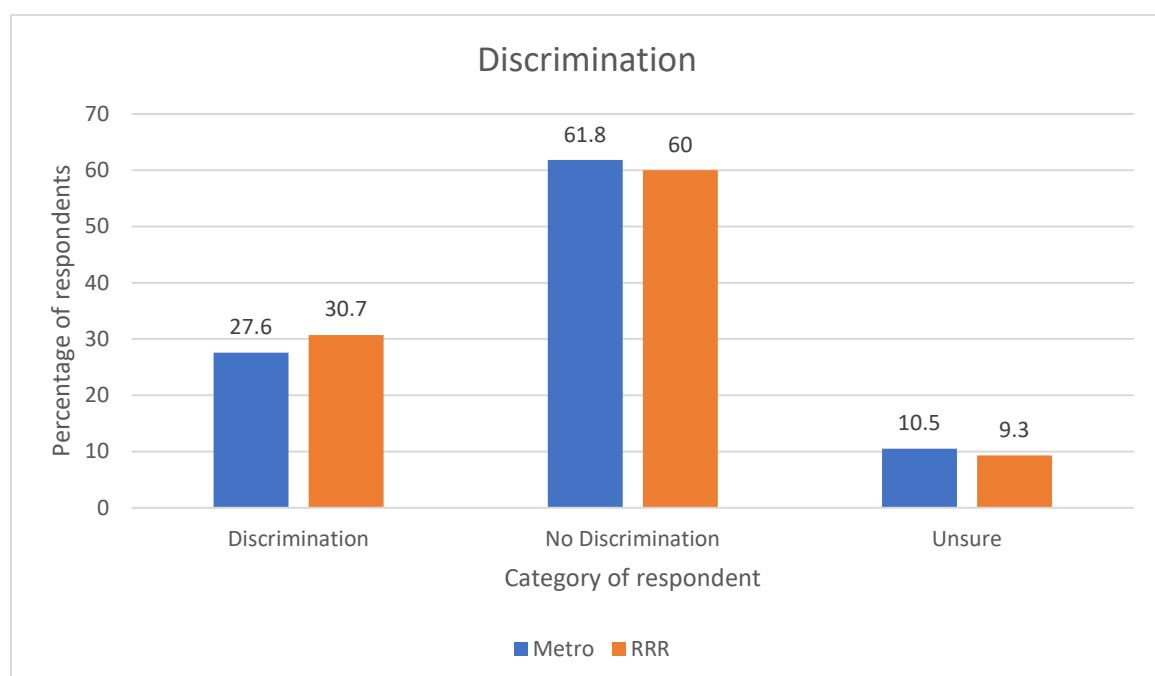
## 5. Discrimination

Respondents were asked if they had ever been discriminated against when receiving eating disorder treatment: for example, on the basis of gender ('men don't get anorexia') or age ('you're too old to have an eating disorder'). Of those who had sought help (n=448), 27.2% (n=122) reported they had experienced discrimination, 62.1% (n=278) had not experienced discrimination and 10.7% (n=48) were unsure. There was no significant difference in reports of having faced discrimination from those in the health system for PEDs, CEDs and Carers (for the person they care for) ( $F(2,438)=0.185$ ,  $p=0.831$ ). From **Figure 27** it can be seen that 19.3% (n=16) of PEDs, 30.5% of CEDs (n=84) and 24.1% (n=20) of carers reported discrimination.



**Figure 27:** The percentage of respondents reporting having ever faced discrimination from those in the health care system, broken down by group (PEDs, CEDs, Carer).

There was also no significant difference between those who live in Metro or RRR areas in terms of the number of respondents who had experienced discrimination ( $F(1,424)=0.313$ ,  $p=0.576$ ). It can be seen in **Figure 28** that the majority of people in both Metro (61.8%, n=217) and RRR (60.0%, n=45) did not report having experienced discrimination.

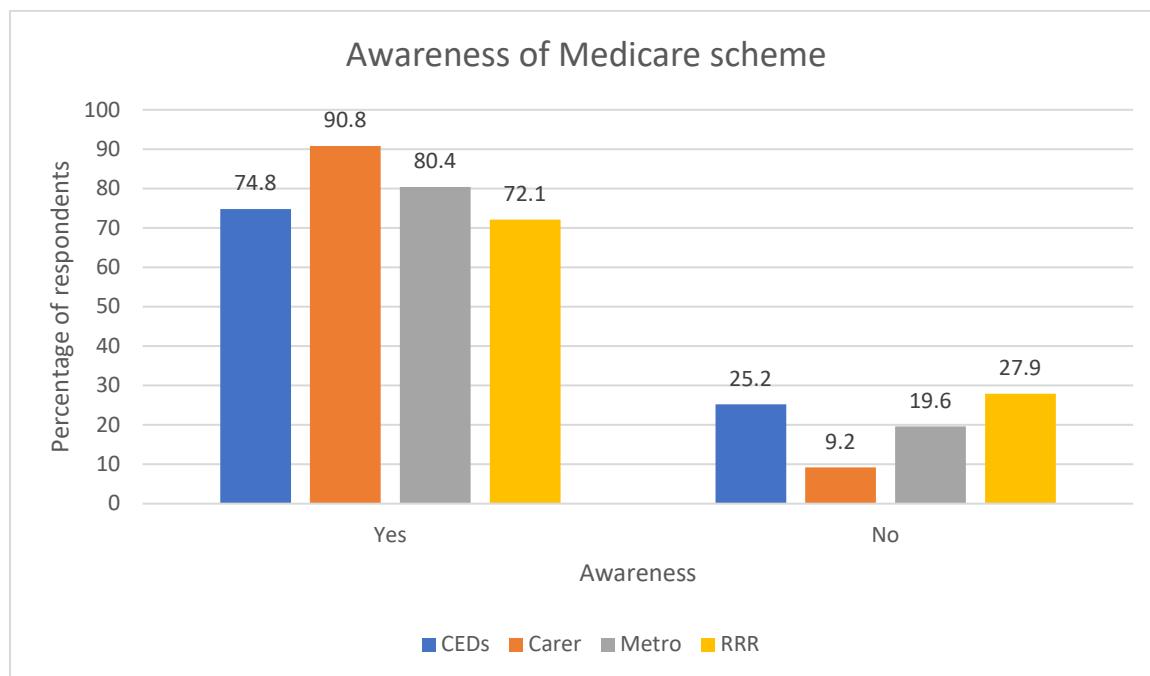


**Figure 28:** The percentage of respondents in Metro and RRR areas reporting having ever faced discrimination from those in the health care system.

## Medicare Item numbers for people with eating disorders

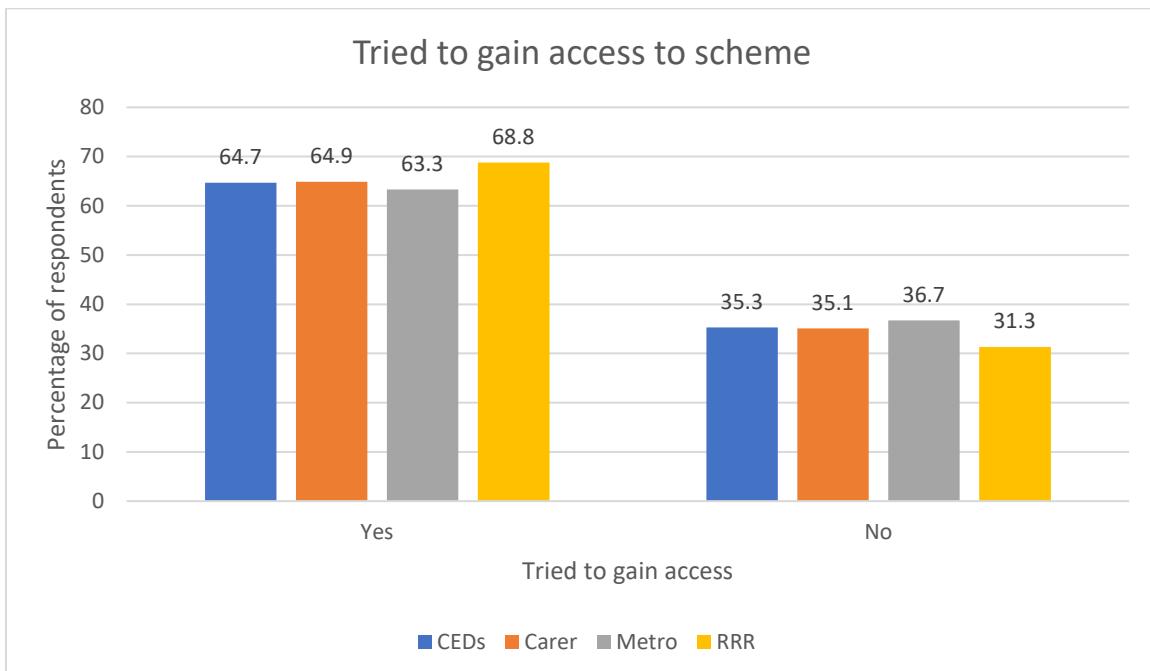
On 1 November 2019, the Australian government introduced 64 new special items under the Medicare Benefits Scheme (MBS) for people living with eating disorders, allowing up to 40 sessions with a mental health practitioner and up to 20 dietetic sessions of treatment from a certified dietician over the span of a 12-month period (Butterfly: Foundation for Eating Disorder, 2018). Given this scheme was only introduced in November 2019, PEDs were not included in the analysis as the scheme was not available.

In terms of respondents' awareness of this new scheme, 78.5% (n=302) of the respondents who completed this question were aware of the scheme, and 21.6% (n=83) were unaware of the scheme. There was a significant small association between the awareness of this new scheme and respondent's status (carer vs. CEDs) ( $\chi^2(1) = 10.16$ ,  $p=0.001$ ). A higher percentage of carers were aware of the scheme in comparison with CEDs, while CEDs were less aware than carers. There was no significant difference in the level of awareness in Metro and RRR areas ( $\chi^2(1)= 2.31$ ,  $p=0.128$ ). These relationships can be seen in **Figure 29**.



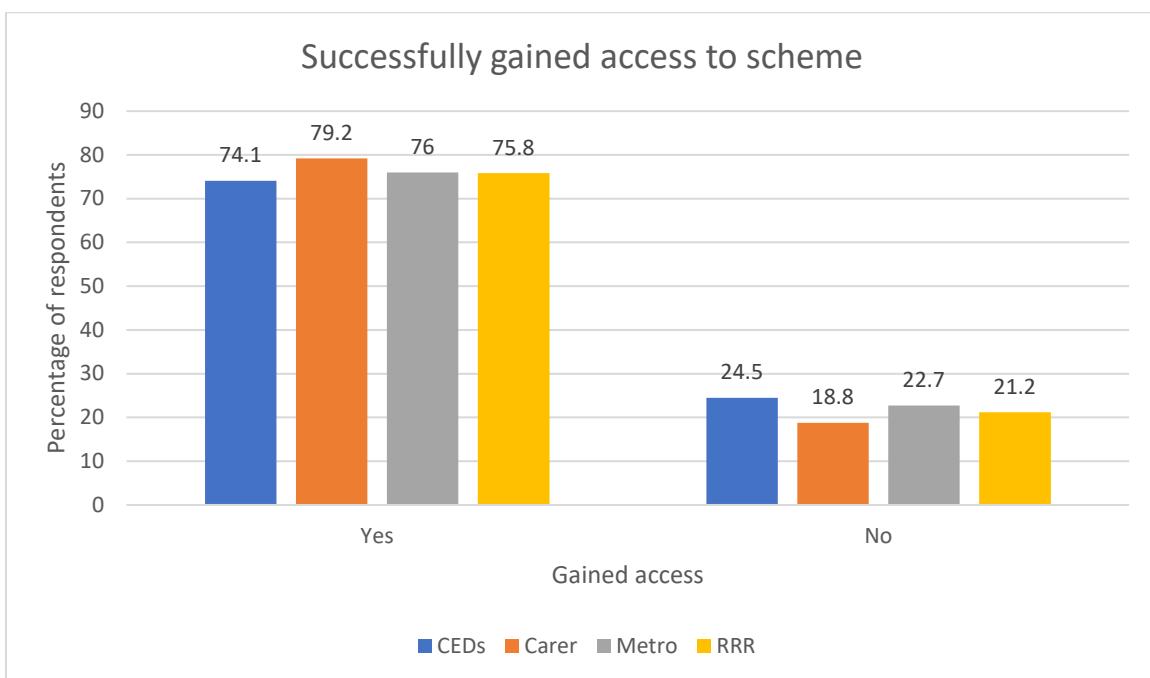
**Figure 29** Awareness of the new Medicare Eating Disorder Scheme by respondent status (CEDs or carer).

Of those who were aware of the scheme (n=302), nearly two-thirds (63.2%, n=191) had tried to gain access to the extra provisions/sessions. Over 60% of CEDs and Carers had tried to gain access to the scheme. Likewise, similar proportions of those in Metro (63.3%, n=150) and RRR (68.8%, n=33) areas had tried to gain access. As is evident, there were no associations between trying to gain access and the status of the respondent (CEDs and carers) ( $\chi^2(1) = 0.001$ ,  $p=0.980$ ) or the place where they lived (Metro and RRR) ( $\chi^2(1) = 0.52$ ,  $p=0.47$ ).



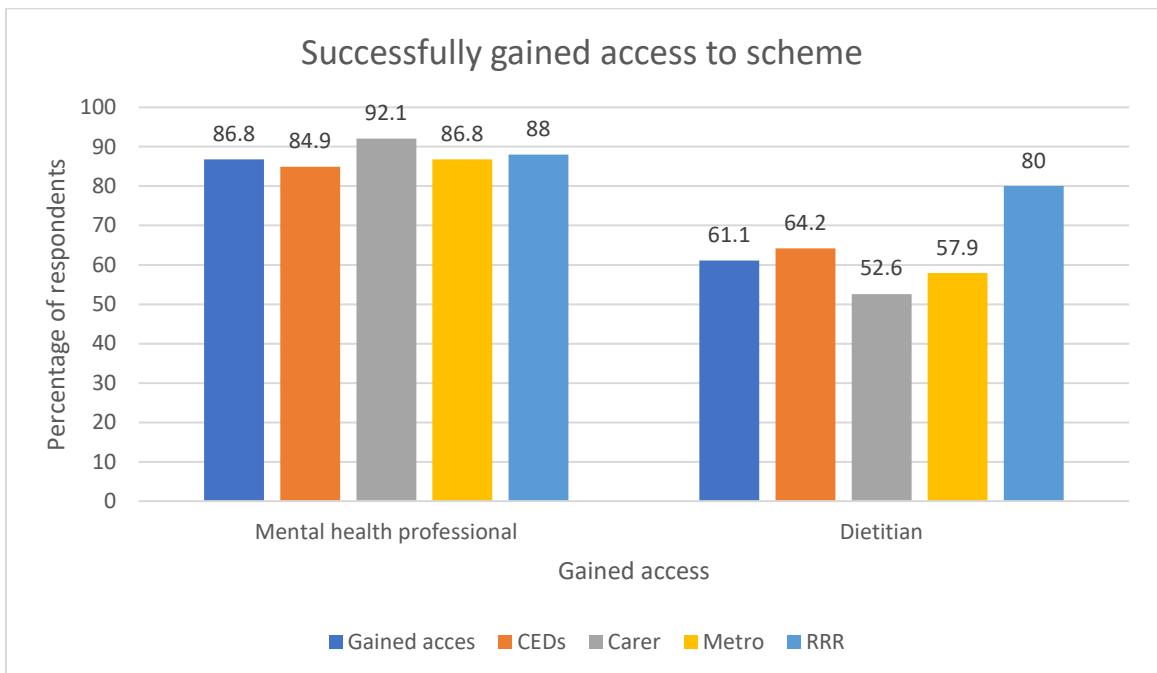
**Figure 30:** The breakdown of those who tried/did not try to gain access to extra provisions by respondent status (carer, CED) or place where the person with the ED resides (Metro, RRR).

Of those had tried to gain access to the scheme, 75.4% (n=144) were successful, 23% were unsuccessful (n=44) and 3 respondents (n=3) were unsure. It is observable in **Figure 31** that there is not a significant relationship between a person's ability to access the scheme and their respondent status ( $\chi^2(2) = 0.740$ ,  $p=0.691$ ), or where the person with the eating disorder resides (for CED and carers) ( $\chi^2(2) = 0.501$ ,  $p=0.778$ ).



**Figure 31:** The relationship between the success of gaining access to the scheme and respondent status (carer, CED) or place where the person with the ED resides (Metro, RRR).

Those who had gained access to the scheme (n=144) were asked if they had seen a mental health professional or dietitian under this scheme. In terms of the receipt of care, 86.8% (n=125) had seen a mental health professional and 61.1% (n=88) had seen a dietitian (see Figure 32). There was no relationship between respondent status (CED versus carer; ( $\chi^2(2) = 0.224$ ,  $p=0.894$ )) and having seen a mental health care professional under this scheme. Nor was there a relationship between areas of residence of the person with the eating disorder and having seen a mental health care professional under this scheme ( $\chi^2(2) = 1.401$ ,  $p=0.496$ ). There was also no relationship for having seen a dietitian with the status of the respondent ( $\chi^2(2) = 2.103$ ,  $p=0.349$ ) or area of residence of the person with the eating disorder ( $\chi^2(2) = 4.308$ ,  $p=0.116$ ).

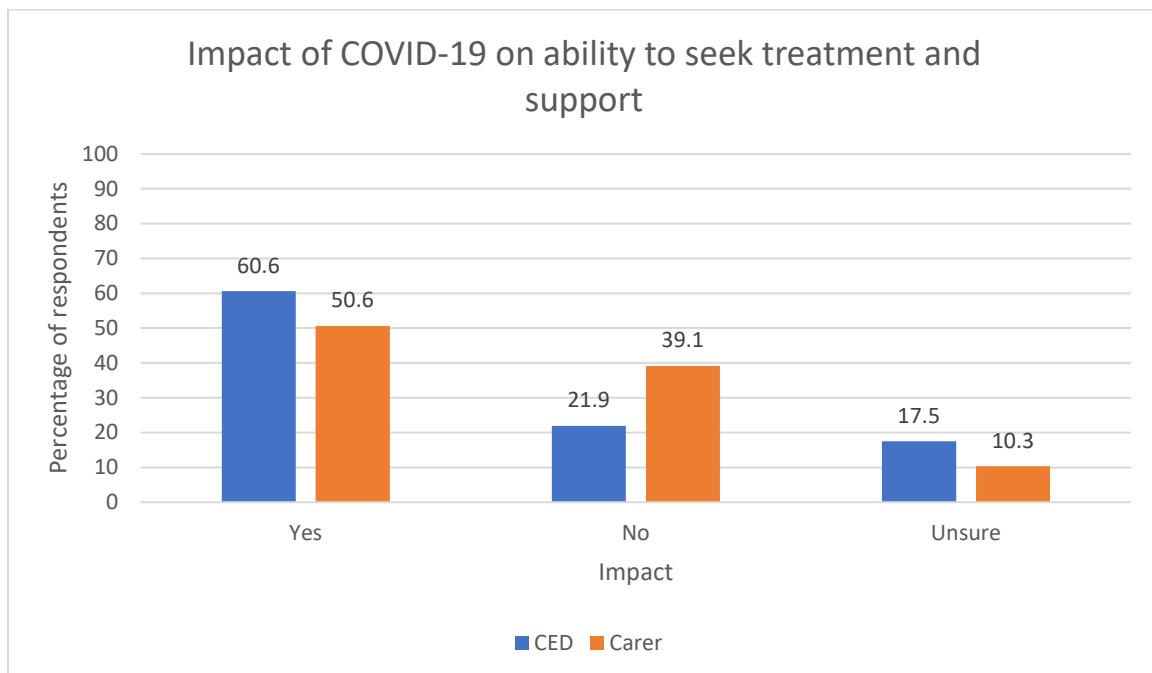


**Figure 32:** The percentage of respondents who had received treatment from a mental health professional or dietician by respondent status (carer, CED), location of residence of the person with the ED (Metro, RRR) and overall sample who gained access.

## The impact of COVID-19

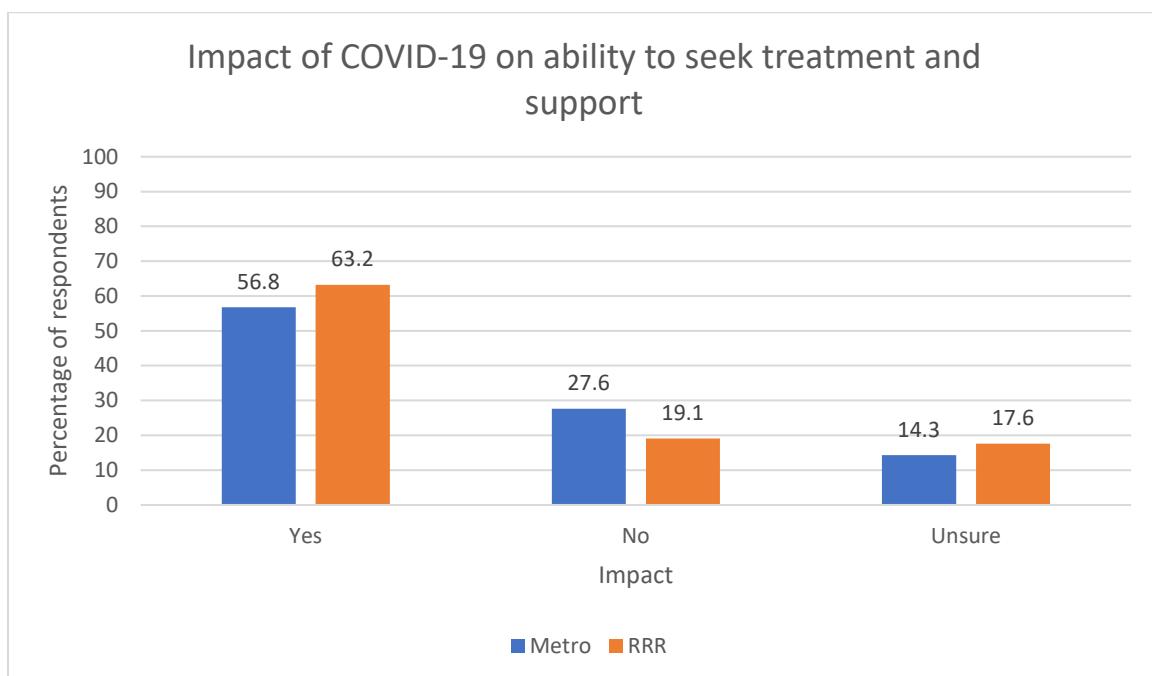
Due to the outbreak of COVID-19, the world is currently facing a global health crisis. In the case of Australia, the virus has had a monumental impact on people's everyday lives in unprecedented economic and social ways (Australian Government Department of Health, 2020a). This survey explored how COVID-19 impacted the respondents' mental health and wellbeing and the impact on respondents' access to health services. Given COVID-19 is a current issue; PEDs have been excluded from all analyses.

Figure 33 shows the percentage of CEDs and carers who reported that COVID-19 either had or had not impacted their ability to seek treatment or support. Of the eighty-five percent of CEDs (n=297) who responded to this question, 60.6% (n=180) reported that COVID-19 has affected their ability to seek treatment and support, and 21.9% (n=65) reported that there had been no impact. Eighty-seven percent of carers completed this question, with, 50.8% (n=44) similarly reporting the pandemic had affected the ability to seek treatment and support for the person for whom they care. Nearly forty percent (39.1%, n=34) reported no impact. There was a significant association between the reported impact of COVID-19 and whether the person was a carer or CED ( $\chi^2(1) = 8.100$ ,  $p=0.004$ ). Current sufferers were more likely to report an impact than carers (who were reporting about the impact on the person for whom they care).



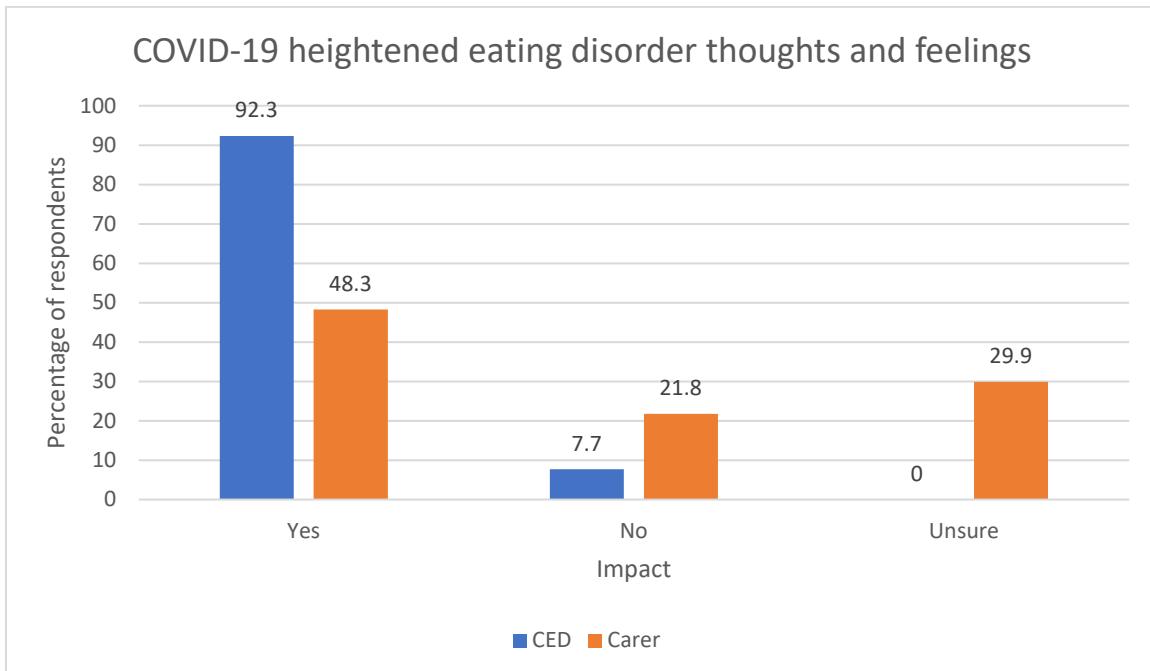
**Figure 33:** The percentage of CEDs and carers who reported that COVID-19 either had or had not impacted their ability to seek treatment or support, and those who were unsure of the impact.

Of the 301 respondents from Metro areas who responded to this question, 56.8% (n=171) reported that COVID-19 had impacted their ability to seek treatment or support. As can be seen from **Figure 34**, this was comparable to those in RRR areas, where 63.2% (n=43) reported an impact. There was no association between place of residence and the impact of COVID-19 on the ability to seek treatment and support ( $\chi^2(1)=1.92$ ,  $p=0.17$ ).



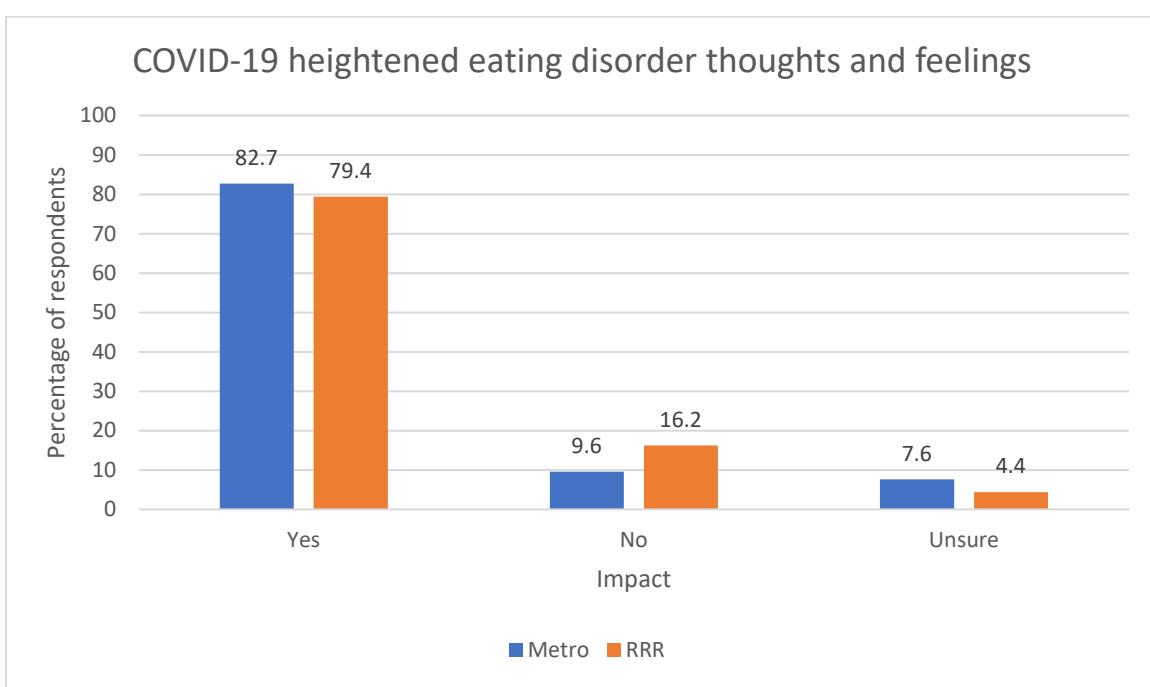
**Figure 34:** The percentage of CEDs and carers who reside in Metro compared with RRR areas who reported that COVID-19 either had or had not impacted their ability to seek treatment of support, and those who were unsure of the impact.

Moreover, respondents were asked whether the pandemic heightened thoughts or feelings related to eating disorders. The majority of the sample (82.3%) reported heightened eating disorder thoughts for themselves (or the person they care for). Figure 35 shows this figure broken down for CEDs and Carers. The vast majority of CEDs reported a heightening of eating disorder thoughts and feelings, whereas half of carers reported that the person they cared for had reported such heightened feelings. When carers who were ‘unsure’ of the impact were excluded from the analysis, there was a small to moderate significant association between the impact and whether the person was a CED or carer ( $\chi^2(1) = 26.77$ ,  $p<0.001$ ). That is, CEDs were significantly more likely than Carers to report that COVID-19 had heightened eating disorder thoughts and feelings, and less likely to say there had been no impact.



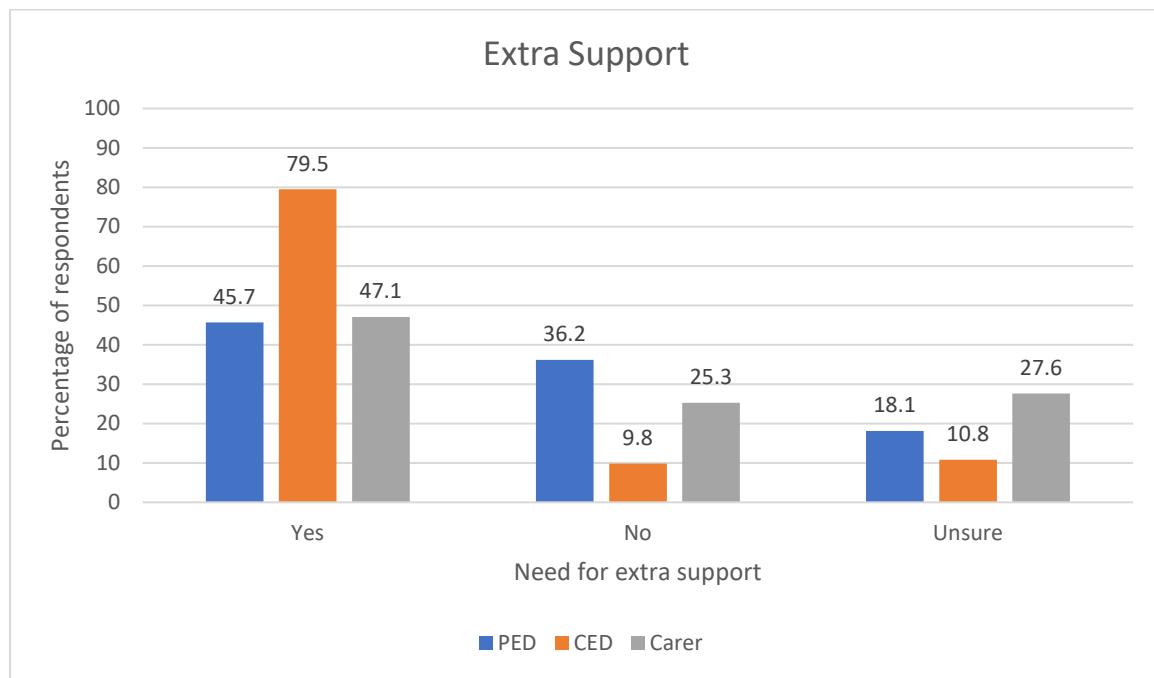
**Figure 35:** The number of respondents (CEDs or Carers) who reported COVID-19 had heightened their eating disorder thoughts or feelings.

As can be seen from **Figure 36**, the majority of respondents in both Metro (82.7%, n=249) and RRR (79.4%, n=54) areas reported a heightening of eating disorder thoughts and feelings as a result of COVID-19. There was, however, no significant association between the areas of residence and the impact on eating disorder thoughts and feelings ( $\chi^2(1) = 2.16$ ,  $p=0.142$ ).



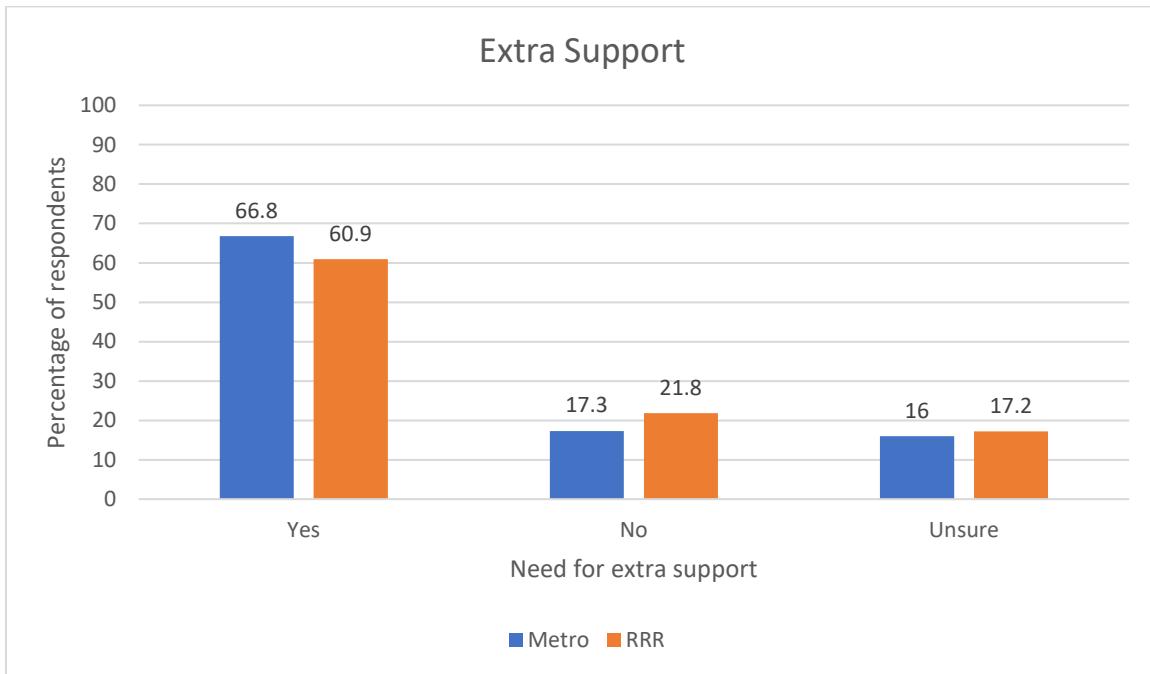
**Figure 36:** The number of respondents (CEDs or Carers) who reported COVID-19 had heightened their eating disorder thoughts or feelings in Metro compared with RRR areas.

PEDs, CEDs and Carers were ALL asked, in general, if they needed extra support as a result of the outbreak of COVID-19. The question did not directly relate to support for the eating disorder. Given PEDs may need some support, irrespective of eating disorder status, this question was broken into all three categories of respondent (PED, CED and Carer). As can be seen in **Figure 37**, the percentage of respondents endorsing the need for extra support was greatest among the CEDs (79.5%, n=236) compared with the PEDs (45.7%, n=43) and Carers (47.1%, n=41). This difference was significant ( $\chi^2(4)=62.71$ ,  $p <0.001$ ). Given some respondents were ‘unsure’ if they needed greater support, they were excluded from further analysis. This exclusion can be justified as the survey was conducted at the beginning of the outbreak of COVID-19, where carers may have been unsure of the need for extra support, as the person they care for may not have yet told them. By contrast, a CED or PED would be more likely to be able to answer this question more definitively at the time. When all those who were ‘unsure’ were removed from the analysis, the association between the status of the respondent and the need for extra help remained ( $\chi^2(2)=48.42$ ,  $p <0.001$ ). CEDs were far more likely than PEDs and Carers to report the need for extra support, whilst PEDs and Carers were far more likely than CEDs to report they did not need the extra support.



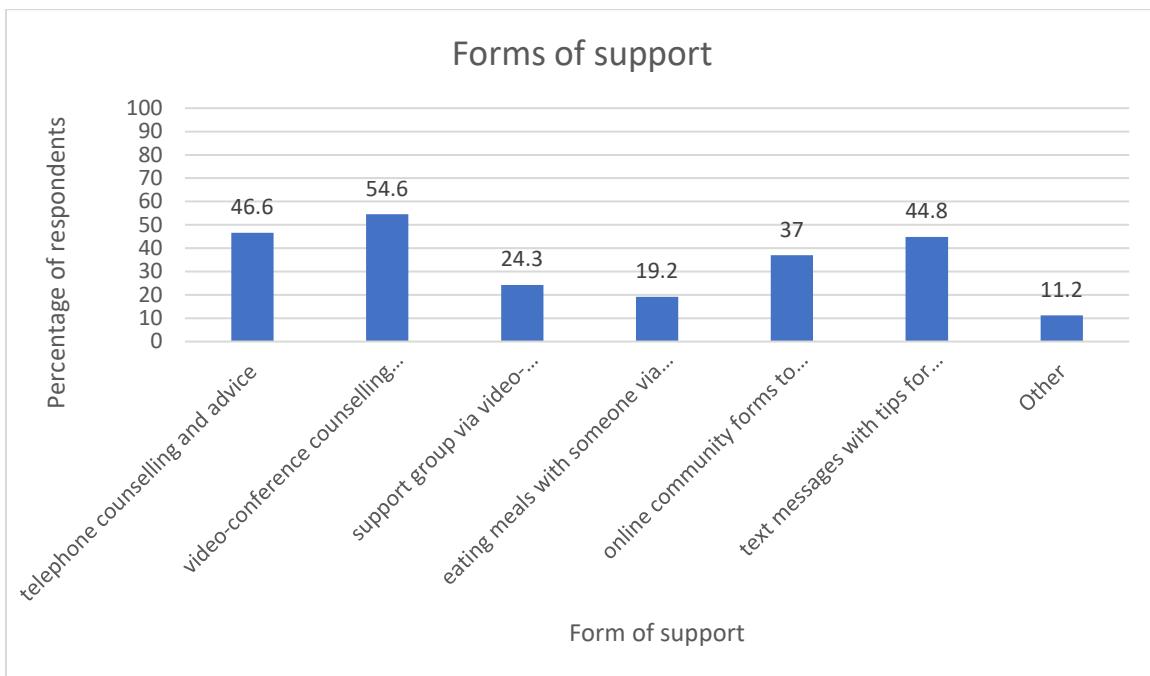
**Figure 37:** The number of respondents (PEDs, CEDs or Carers) who reported needing extra support as a result of the outbreak of COVID-19.

From **Figure 38** it can be seen that over 60% of Metro (66.8%, n=255) and RRR (60.9%, n=53) respondents reported needing extra support as a result of the outbreak of COVID-19. There was no association between the location where the respondent lived and their need for extra support.



**Figure 38:** The number of Metro and RRR respondents who reported needing extra support as a result of the outbreak of COVID-19.

Due to these uncertain times, the 489 respondents were asked what extra support they thought would be most helpful in these circumstances. They were asked to nominate up to three sources of help they thought would be most useful and given the following options: telephone counselling and advice, video-conference counselling and advice, support group via video-conferencing, eating meals with someone via video-conferencing, online community forms to connect with peers, text messages with tips for recovery and self-care, or could specify other methods. As can be seen in **Figure 39**, the three most commonly nominated types of support were telephone counselling and advice (46.6%, n=228), videoconference Counselling and advice (54.6%, n=267) and text messages with tips for recover and self-care (44.8%, n=219).

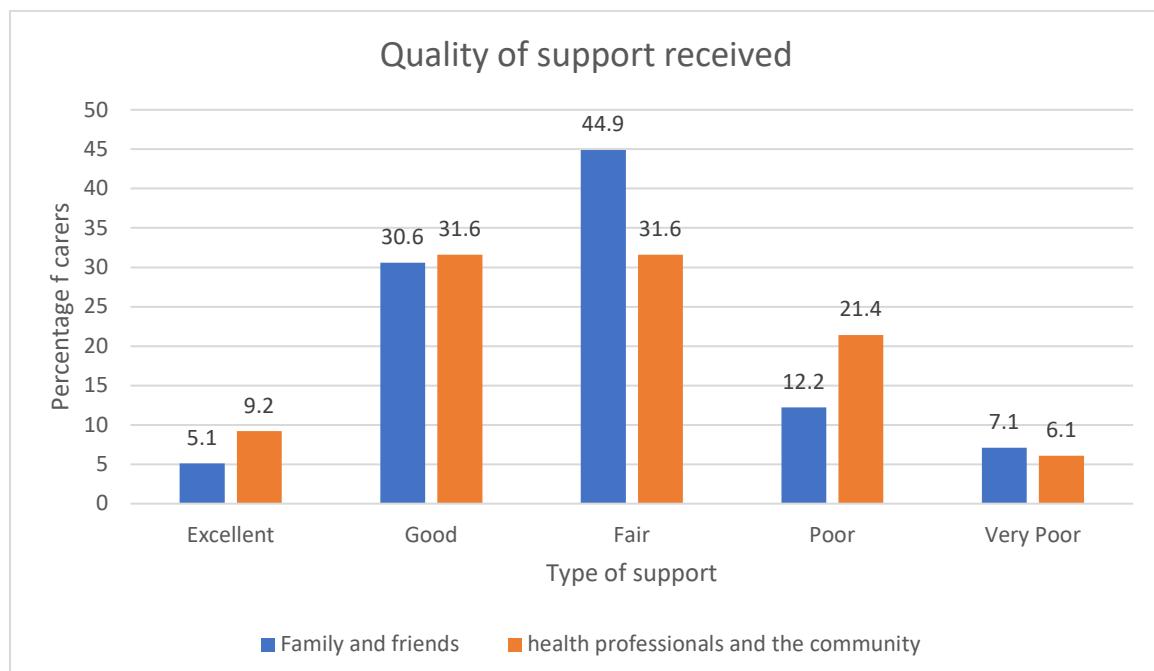


**Figure 39:** Form/s of support, which respondents believed would be beneficial during the outbreak of COVID-19.

## The carer experience

### 1. Quality of support received by the carer

On average, the carers reported that the support they received from 'family/friends' (Mean: 2.86) or 'health professionals or other services' was 'fair' to 'good' (Mean: 2.83). Carers did not report a significant difference in the quality of support from these two different arenas ( $t(97)=0.18$ ;  $p=0.86$ ). The percentage of carers who endorsed the different ratings for the quality of care can be seen in Figure 40.



**Figure 40:** The percentage of carers who endorsed how 'good' they believed the support was from either family/friends or health professionals or other community services.

### 2. Perceived support of carers by location

In terms of the Modified Monash Model, 84% (n=84) carers resided in MM1-MM3 areas, the remaining 16% (n=16) in MM4-MM7 areas; the areas to be deemed remote under the Medicare telehealth eligibility. The level of care provided by 'health professionals and other community services' was not perceived to be of a significantly different quality for carers in MM1\_MM3 (Mean=2.87) and MM4\_MM7 (Mean=2.69) areas ( $t(96)=-0.61$ ,  $p=0.54$ ). Neither was the care they received from 'family/friends' considered to be significantly different to those living in MM1-3 (mean=2.78) and MM4-7 (mean=3.25) areas ( $t(96)=-1.3$ ,  $p=0.07$ ).

## The Rural, remote and very remote experience

Of the 563 respondents who completed this survey, 50 CEDs (14.4% of CEDs), 20 carers (20% of carers), and 17 PEDs (14.8% of PEDs) said they/the person they care for live in RRR areas, which was defined as: country areas, town or villages which have low population densities and large areas of undeveloped land. Of utmost importance for this section were respondents' access to treatment and support in RRR communities and their experiences engaging with healthcare workers in their respective locations. For CEDs and current carers, many claimed the biggest barrier to accessing treatment and support services was the lack of resources in those areas, as well as little to no specialised services addressing eating disorders.

The majority of this RRR subsample (92.2%, n=83) reported that healthcare workers in RRR areas need more training/education on eating disorder treatment; 2 respondents did not believe it was necessary and 4 were unsure. There was no association between the respondent type (CED, PED Carer) and the belief that healthcare workers in RRR areas needed more training and education ( $\chi^2(4) =2.725$ ,  $p=0.605$ ). For these respondents, the issue in these communities

was the lack of empathy as well as specialised knowledge from medical professionals regarding eating disorders, with many being disregarded for their condition.

In RRR areas, 60% of respondents (n=54) said they have travelled to a capital city or regional city in order to receive appropriate eating disorder treatment: 56.0% of CEDs (n=28), 83.3% of carers (n=15) and 62.5% of PEDs (n=10). There was no significant association between respondent type and travel to a capital or regional city for treatment ( $\chi^2(4) = 8.98$ ,  $p=0.062$ ).

There was an almost unanimous belief that there needed to be more awareness around what services were available in RRR places for people with EDs (98.9%, n=86), with one respondent being ‘unsure’ and the remaining three not providing a response to this question. The belief there needed to be greater awareness was unanimous with CEDs (100%) and Carers (100%). One PED reported being ‘unsure’. The relationship between the type of respondent and this belief was non-significant ( $\chi^2(2) = 3.69$ ,  $p=0.186$ ).

Whilst the majority of respondents did not believe there was any benefits (72.2%, n=65), nearly one-quarter did believe there was some benefit (24.4%, n=22). In terms of the respondent status, 31.3% of PEDs (n=5), 24.0% of CEDs (n=12) and 22.2% of Carers (n=4) believed there was a benefit if the person resided in a RRR area when they were suffering from an ED. There was no significant association between carer status and belief in any benefits associated with residing in an RRR area when suffering from an ED ( $\chi^2(2) = 0.420$ ,  $p=0.811$ ).

# Open ended Findings

## Service Access

*Just want to clarify that I have only been able to access care through a general mental health clinician. I have never been able to access specialised care. I cannot emphasise enough how much cost is a barrier. Living regionally, if I want to access specific care I would need to pay provider cost, travel cost, childcare, time off work to travel and attend appointments... it is so hard. I'm crying writing this.*

The responses from people who participated in this survey indicate that where people lived influenced their experiences as carers and as individuals experiencing eating disorders. Postcodes influenced people's access to treatment and to their subjective experiences of their eating disorders.

Respondents who lived in rural, remote and regional (RRR) areas also answered a specific set of additional questions that focused on living in RRR areas. Open-ended responses from this segment of the survey have been integrated throughout this section of the report.

## Services on a national level

Two participants suggested that eating disorder treatment was not adequate within Australia.

*In Australia there are very, very limited options for ED treatment. I have had two admissions to a private psychiatrist hospital and one to a public medical hospital. None of my admissions have been able to really help me in the long term. The private facility was very understaffed and I received minimal support whilst dealing with the stress of refeeding. My admission to a public hospital was much more supportive however very quick and so my risk of relapse was very high. There are not enough eating disorder specialised in-patient programs in the country with only 17 public beds in NSW between Westmead and RPA. This is unacceptable when 1 in 10 Australian women suffer from an eating disorder and for some the medical health risks as well as the mental strain are very great. My family have been looking with desperation at sending me overseas to receive treatment because there is such a lack of options in Australia.*

*We accessed treatment in the USA for my ED affected daughter. These options were not and are still not available in Australia*

## Services on a state level

Comments from respondents suggest that in certain states in Australia, it is more difficult to access eating disorder treatment than in other states.

*Live in Canberra. Very limited support options (no Butterfly foundation services?)*

*There's nothing here in the NT to support us. Absolutely nothing*

*Well if Western Australia actually had more treatment options then I would be able to access more help. The private program rejects people daily, the state system just forms us all and puts us on CTO's. If we had more options like the eastern states then maybe we could get some decent help, especially since outpatient treatment is so expensive*

*Again, we have absolutely no dedicated inpatient or outpatient treatment for Eating Disorders in the whole state of Tasmania, Australia*

*Access to facilities available in Perth for over eighteens governed by locations. Two designated beds only in Western Australia.*

*SA has severely lacking facilities for ED especially inpatient. We should not have to travel interstate for treatment*

*Western Australia has no state beds, and very little support for eating disorders.*

*I live on the west coast of Australia. I feel our resources are not as great as those in other areas of Australia.*

*Minimal resources available in WA, if not underweight, lucky to have found an ED psych through a private clinic- and also lucky enough to be able to afford it*

*Significant, moved from Tas to QLD to support our adult daughter*

*When I was 16 with severe anorexia nervosa, I couldn't access appropriate treatment. In Tasmania, we do not have an inpatient facility for eating disorders, so I had to spend 6 months in a general paediatric ward where I didn't receive good treatment... Once discharged, there was no real support in the community, even though I lived in the city (Launceston).*

*In Tasmania we have no dedicated services inpatient or outpatient for adults with eating disorder*

## Catchment area and zoning

Respondents in both urban and rural areas spoke about falling outside particular zones, which made it difficult for them to receive treatment.

*I live about 50metres over the NSW/ACT border but work, shop and access all of my healthcare in the ACT. Because I have a NSW postcode, I am not eligible for the eating disorder program at The Canberra Hospital. This is even despite being referred to the program by a diabetic educator and nutritionist in the same hospital. There is nothing else available in the area, and I live 400 kms from Sydney, which is where they suggested I seek treatment.*

*I live in the border of NSW and ACT in a small town which means I can't access services in Canberra even though it's only 5 minutes away.*

*It is hard to go to hospitals that can treat me for my disorder because of catchment areas*

*It's difficult because I attended Alfred CYMHS until I was 18 which was working really well, then I got kicked out of their service because I didn't live in the right zone and was told to go 40 mins away to Dandenong. Extremely unfair especially when people living further away than I am can access Alfred CYMHS until they're 25. Obviously access to better mental health support is beneficial when you live in rich areas*

*We are out of the inner city and live in outer suburbs; we are around 30kms to the nearest catchment hospital for eating disorders ward and clinics. We have been denied services because of our postcode. Access to the "best" services is restricted because of the huge*

*demand on them so we were referred back to a hospital which has one bed allocated for ED and little understanding/ expertise. That is not OK*

*As I went through the public system for treatment, where I lived determined the catchment area I fell into and consequently which hospital I was eligible to receive services from. And while I think Monash provided a great treatment program, it would have been nice to choose which hospital and treatment program to attend*

*Hospitals are split into zones and you can't move to one out of your zone no matter what.*

*I live on the border of NSW and Victoria. Previously I had to use a friend's address (who lives in Victoria) in order to get access to a psychologist who specialised in EDs. I live in NSW and she was unable to see me unless I was living in Victoria, even though it was just 10minutes from my home in NSW.*

## **Paucity of specialised services in urban areas**

Despite living in an urban area, an overwhelming number of urban/metropolitan respondents felt there was a lack of specialised services and professionals trained to deal with eating disorders. Being a public patient appeared to make specialist services even less accessible.

*There is no inpatient treatment that is available to public patients. There are no day programs that are available to public patients.*

*Limited number of psychologists who specialise in eating disorders are available for outpatient treatment. Have to travel a long way to access care.*

*Central Coast of NSW does not have adequate services to support & prevent eating disorders. The loss of the day program on the Coast and at Royal Prince Alfred Hospital is totally unacceptable.*

*There are resources around however I think in Australia as a general rule; there is a lack of treatment centres for eating disorders. They are such a complicated thing to treat and there are not enough inpatient and outpatient services available. Because of the limited number, it also makes it harder to get into a program for treatment.*

*At the time I needed the help there were very limited services locally on the central coast and the ones that were available were under resourced and costly*

*There's very limited services and those that are available through the public health system do more damage than good. We've had better help from services like Centacare PACE*

*Lack of health services that specialise in eating disorders*

However, some respondents indicated that they were fortunate to live in a metropolitan/urban area.

*Being in an urban area in Melbourne I was extremely fortunate to have accessible services, however I am aware that it is not the same in more remote areas. Also, having suffered my eating disorder in Melbourne, and visiting back home in the U.K. a couple times, I have noticed that the services in Melbourne and Australia for sufferers of eating disorders are more widely available and accessible than the U.K. with a greater support system.*

*The Butterfly Foundation is located very close to my residential address and very easy to access by car. Had it been further or more difficult to access then I feel this may have impacted my attendance.*

*Living in the city has given us the opportunity to have inpatient and outpatient services readily accessible to assist our daughter and us in this difficult journey.*

*As we live in an affluent area, sadly I believe there is a high incidence of diagnosis of eating disorders. As a result, both our local GP and our daughter's school are familiar with and exposed to many girls that are impacted by eating disorders, however their exposure to this illness has meant that they are very experienced with these issues and they have both been extremely supportive and also provided excellent guidance and support.*

*We have excellent services near us- so lucky! Her psychologist is 200m away and the private eating disorders hospital that her psychiatrist has access to is less than 2km away so fortunate!*

*The age of diagnosis and living in a capital city meant that support in the public system was available*

## Paucity of services and resources in regional, rural and remote areas

This paucity of services is compounded in RRR areas. Like many urban respondents, lack of specialised services, support groups, inpatient, and outpatient services were felt acutely by respondents in RRR areas. However, some RRR respondents had limited access even to general healthcare while another respondent had limited access to food. RRR respondents also reported the high turnover of healthcare workers in their area.

### Limited resources and general healthcare services

*Access to food they can eat in supermarkets if they need to be on a special diet, for example I am following a FODMAP diet as I get very bad bloating daily.*

*I live in a remote country town with not great access to medical services*

*Not as many services as a city like Sydney*

*Resource deficit, lack of training and knowledge for professionals*

*No expert care, general mental health care only*

*Now her father has passed away from a brain tumour her eating disorder has tenfold & for her to be hospitalized she would have to be over 6 hour round trip drive to the nearest hospital for treatment which is not practical when I'm now a widow with 5 young children. Our large local hospital about 40 minutes away should be able to accommodate this. It would be nice to have a local support group in our area... we just don't have the resources for this*

### Limited access to specialised services and in-patient services

*Far West NSW, closest clinic is 500-600km away*

*I live in a regional area where there are NO specific services for eating disorders and access to mental health professionals in general is still exceptionally challenging*

*I live on the central coast of NSW. Whilst I have a psychologist and dietitian - my psychiatrist is in Sydney. Also access to inpatient care and outpatient support groups and programs are based in Sydney*

*Regional - makes it hard to know where to go, who to go to and what is available/ what is the best treatment.*

*Rural areas have less services available and often cover a wide area*

*Rural mental health is hard to access and is spread very thinly*

*There's nothing at all*

*We are 3 hours from a capital city where all the treatment centres are. There are NO specialised regional centres and finding local GP's, dieticians and therapists who have experience in treating eating disorders.*

*We live in a small coastal town I would love to go to a support group for carers but nothing in our area*

### Limited access to support groups

*Just not enough support groups or courses you can do in person. We need more places that have accommodation available for more intensive care when things get bad*

*There are no support groups nearby*

*GPs not great at recognising eating disorders, extremely hard to access psychologist until diagnosed, reliant on videoconferencing to talk to other parents in same situation to get advice and support*

## High turnover of healthcare workers

*I live in country SA in a small town. Never the same GP in a medical centre let alone anyone else*

*Growing up [in rural Tasmania] we never had a regular psychologist available and there was never support services in place for people that needed it*

*Living in the country, not being provided with many healthcare professionals who are qualified or knowledgeable to know the best ways of support and treatment for eating disorders*

*There are no specialist services in my town or even region... I do not even have a regular GP, as there are only locum doctors*

## Distance and travel

The distance of healthcare services also impacted the healthcare experience of many respondents. Many urban and rural respondents were forced to travel to receive treatment.

### Travel for RRR respondents

*7 hour drive for specified psychology*

*I have not been able to find any specialised psychologists or GPs near my home. I travel 93kms every week for treatment*

*Always have had to travel for services. We live in a rural area, and have been trying to get our daughter well for many years.*

*I live in the semi-rural outskirts of a large city, so I think there are slightly less options near me, hence why I drive around 45km to access helpful treatment.*

*I am over 300 km each way and no one who follows up and too complex for local*

*In order to access psychological support I have to travel 1 hour. I tried a couple closer to home but due to my diagnosis there were no psychologists who were able to assist me*

*Places where treatment is available are hours away from where I live and will take up a whole day to drive there, have an appointment, and drive back again. Very exhausting*

*It's a 6 hour round trip to get to eating disorder clinic*

*When the bridge floods cannot get access to help*

### Travel for urban respondents

*I live in a well-connected suburban area close to a major city. Yet there are no eating disorder specialist dietitians and psychiatrists, and only 1 psychologist, within an hour radius from me.*

*I live in Adelaide's northern suburbs and most, if not all, of the ED specialised treatments and therapists are in the city or the southern suburbs. I also have fibromyalgia so driving an hour to then sit in an appointment for an hour, then drive home again, is something I can't do.*

*Butterfly Foundation is our greatest support provider, but in-person access. Due to living distance means our engagement is reduced. Having a branch closer would be fantastic. This would reduce resistance from loved one to seek and follow up on treatment and keep her more consistently engaged and allow for independence to self-guided treatment.*

*Just not many eating disorder professionals work near my area for example I was at butterfly house since Oct 2019 and I had to travel an hour to get here*

## Inability to drive

For some respondents in both urban and RRR areas, being unable to drive impacted on their ability to access services.

*As someone without a car, who lives by myself, I am still unable to travel to health services, despite being in a close locality to them*

*It's difficult to get on public transport - the locations of some of the clinics. I am too anxious to drive and park. Most places are closed to the city, which is close to me, but my anxiety is high about getting to these places & thus I am reluctant.*

*Many hospitals are far away and I do not have the right means of transport to access them regularly... as I'm under 18 I can't drive alone and all the nearest treatment facilities that have been recommended are too far for public transport*

*There aren't enough mental health services in my area, let alone ones that specialise in eating disorders. Therefore I can't access certain treatments and support because I am unable to regularly travel out of my local area - I can't drive and I struggle to use public transport so I would have to organise for someone to take me there which isn't always a viable option. I may also have to be apart from my parents for a while which is not ideal as they are my main support network*

## Social, emotional and financial burden of travel

Urban and RRR respondents spoke of the disruption to their lives due to travelling long distances for treatment.

*Having to travel to Orange for treatment, 110 kilometres away, made life so difficult when my 1 extremely ill anorexic, daughter objected so strongly to our every appointment. It became like a war every time we had to get into the car. (This was 15 years ago and thinking about it has made me cry!)*

*I have to travel or I can't stay in inpatient hospital treatment long enough because I'm a single mum with no one to care for my son while I'm in hospital*

*I was in a ten-week eating disorder program through flinders. As I was living in Whyalla and had to travel to Adelaide each week in order to attend I ended up giving up after 3 weeks into the program despite finding it extremely effective as it was too hard to travel 4 hours there and back. Particularly during my binging and purging phase as I was completely run down physically.*

*It is a 2.5-hour or more round trip. Very costly in tolls and causes child to miss lots of school*

*The travel time alone to see my dietitian, GP, and my psychiatrist for my weekly appointment with each is over an hour. That is \$20 of fuel for each appointment if they are on different days on top of the cost of seeing professionals in the private sector. Even with a Medicare rebate that is a significant amount of the money I have going to treatment weekly due to travel.*

*There is no treatment available here. You have to travel 6 hours to Sydney to get support that costs a lot of money*

*Long-distance travel to programs, professionals and hospitals means high cost in fuel and tolls and lost income from leaving work early*

*I live in Adelaide's northern suburbs and most, if not all, of the ED specialised treatments and therapists are in the city or the southern suburbs. I also have fibromyalgia so driving an hour to then sit in an appointment for an hour, then drive home again, is something I can't do.*

Some participants had to move, or were even considering relocating, to access treatment.

*I actually moved from where I was living in the suburbs to the city area in order to access better treatment options. There was nothing out where I used to live*

*I have only lived in Sydney for 10months. I was born & grew up in a rural area & had to travel to Sydney every week for therapy &/or inpatient treatment. I moved to Sydney to have better access to outpatient treatment, but now don't have family support & the outpatient facility have had to decrease their hrs.*

*There are no inpatient services in my state - so if my son requires admission it will mean moving interstate. This would be very challenging in terms of the family structure, my work etc. etc.*

## Financial burden of healthcare treatment

Financial costs of travel time are compounded by healthcare costs.

*The travel time alone to see my dietitian, GP, and my psychiatrist for my weekly appointment with each is over an hour. That is \$20 of fuel for each appointment if they are on different days on top of the cost of seeing professionals in the private sector. Even with a Medicare rebate that is a significant amount of the money I have going to treatment weekly due to travel.*

*I have spent over \$500,000-1,000,000 on eating disorder treatment (inpatient, day patient, hospitalisations, therapy, medication, Dietician appointment, psych appointment, GP appointment, ECG and bloods)*

*You have to go private which I simply cannot afford, not being covered by Medicare*

*Gap payments mean the cost of treatment is still out of my reach. One hour with a psychiatrist is a fortnight's income for me.*

*Cost. If I had the money, psychologists will listen to us. But we're stuck with the public health system who don't look hard enough.*

*There needs to be more accessible services, more knowledge and education in area mental health services. There needs to be more consideration for the financial burden placed on individuals and families due to travelling and seeking private treatment due to the lack of services in the public system.*

## Ineligibility for Medicare covered Telehealth

A number of respondents were not eligible for Medicare rebates for telehealth sessions despite living far away from onsite health services.

*Because of the MMM classifications my locality is not considered remote enough to cover telehealth for psychology or dietitian. There are no local practitioners who specialise or have the skills to provide appropriate treatment. I am located 450km from Perth so this means that I have to pay out of pocket for my treatment other than when I am an inpatient (privately), which takes me away from my work and family.*

*There are no services for eating disorder treatment in the Northern Territory. Darwin is not considered remote enough by Medicare so I cannot get a rebate for my telehealth sessions.*

*Increased access to services and supports for people outside metro areas; access to telehealth*

*In this day and age of technology, there is so much more we could be doing and Medicare should embrace and recognise this. There are so many places in Australia that cannot access the appropriate care, and rebates should be available for telehealth etc. in these areas. Also national organisations such as Butterfly and the leading eating disorder organisations could be providing online support groups to those outside the areas (noting the different time zones)*

*Access to rebates for eating disorder professionals for all telehealth appointments.*

*It's Skype only. I was in Melbourne until 2018 so I just changed my psychologist to Skype... if I Skype with them, it's not covered.*

*Psychological support & those who I have found elsewhere who Skype/FaceTime etc. don't accept care plans to assist financially.*

## Postcode Differences

Although there is an urban/rural divide, it is important to note that within urban areas and within rural areas there is diversity. Postcodes influenced individuals' experiences of eating disorders beyond just whether they lived in RRR areas or urban areas.

## **Suburb differences**

Some respondents felt it was harder to access treatment with treatment being located in more affluent suburbs.

*I lived in Brisbane, QLD and there were plenty of community outreach organisations that I was aware of. This does not seem to be the case in Sydney - everything seems to be privatised and not a lot of in-person support which is a shame*

*The clinics are expensive in my area. I live in government housing in a high socioeconomic area. The rates for therapy and dietetic services around me are high. I do not have a car and physically travelling is tough so I need to stay close. There is also very few bulk billing GPs in the North Shore*

*Low socioeconomic area. The specialised treatment facilities in Melbourne are ALL in the affluent leafy Eastern suburbs. Double whammy financially when you're travelling distances*

Several respondents living in particular suburbs felt an increased pressure to have a thinner body.

*There is an expectation that because the area is more affluent people should dress a certain way and wear certain brands. And these certain brands require a certain body shape*

*Near the beach, a lot of fit skinny people*

*I live in a very "fit" neighbourhood, always seeing people running or going to the gym is very triggering. Learning how to manage this would be really helpful.*

However, one respondent felt that living in a metropolitan area helped combat their ED.

*The eating disorder started in a remote town. It is definitely easier to stay healthy living in the metro*

## **Rural towns**

Anonymity was a big issue in rural towns and sometimes prevented people from seeking support and treatment.

*Stigma. Worry about people finding out because everyone knows*

*The problem of small town gossip*

*Previously lived rural and did not pursue support due to small community and working as a health professional. Living in the city has resolved this issue.*

*In regional towns, people are more connected and the added fear of people knowing may hinder people accessing help.*

Only a small percentage thought that there were benefits living in RRR areas.

*Less people judge them and comment on their appearance – once they were diagnosed they got excellent treatment. That it is home for people and less hectic.*

# Healthcare Issues

*I have suffered from EDs for over 30 years and there is only minor improvement in understanding of EDs in the health system during this time. Going through the medical system re-traumatises me each time and I continue to avoid it where possible*

When asked about their experience with healthcare workers/services, urban and RRR respondents cited multiple problems.

## Lack of ED knowledge among HC workers

Most respondents reported that healthcare workers know very little about EDs.

### Urban respondents

*I have found that the staff are not very experienced in dealing with eating disorders and the communication between the doctor and nurses is very poor. The rules and expectations seem to change on each shift change, which is really challenging.*

*My psychiatrist says she feels helpless to help me... and my premature discharge from inpatient care reinforced this. She has since been unavailable for our twice-weekly psychotherapy that had been underway for 3 years*

*Psychological services or support say that they work with people experiencing eating disorders - however treatment does not tailor to this - is just generic short term psychological interventions or solution focused therapy. No plan or medium or longer-term plan offered by health professionals. No treatment or support offered.*

*The main message was you have to eat but we never got to the root cause of the disorder*

*The majority of interactions I've had over the past 10 years of treatment have been from ignorant and/or burnt out people. I only started receiving the proper care from one amazing psychiatrist 8 years into treatment.*

*They didn't appear to have any education about eating disorders, didn't know how to help me*

### Rural respondents

*It means good treatment is hard to come by. Yes there may be help available in my area but the experience of those who attempt to help is often very limited (Rural)*

*Living in rural Tasmania there is no awareness about eating disorders and professionals are uneducated often about eating disorders and diagnosing them (Rural)*

*There are no ED trained professionals within 4 hours of me... GPs in my city do not understand EDs (Rural)*

*There are NO specialised regional centres and finding local GP's, dieticians and therapists who have experience in treating eating disorders*

*They had such poor knowledge of EDs and said things that were literally congratulating my plan to lose weight!*

*They were not able to handle intense thoughts*

*I was told basic information about my diet and how to do better*

*Unfortunately whilst my Psychologist was very lovely and understanding he didn't really seem to have a grasp of the ED. He thought it was a food-based issue. I educated him with the honesty of my deepest thoughts in the hope he could learn what an ED was really like, and pass that on to the others in his care. The dietitian was a no go and I just shut down completely around her, and tried to see her as little as possible.*

## Treatment that is not holistic or patient-centred

### Punitive treatment

*Unrealistic standards on adolescents such as being threatened with an ambulance despite being weight restored (hospitals enforcement policy) if one did not eat the entire meal given; utter mortification being at school made to eat lunch in front of the school therapist/receptionists (care takers would be called if one didn't show up). Overall traumatic experience with ridiculous expectations of young teenagers (Rural)*

*Being belittled and punished for my illness Being forced to sit in front of my own vomit at a meal table Being kept isolated from a group Refusal to treat me because my symptoms were unusual and difficult to 'fit' to hospital systems (Urban)*

### One-size fits all approach

*Felt they had one technique and no tool box when that didn't work (Urban)*

*Something that impacted my recovery journey significantly is that you cannot do an Eating Disorders Program as a vegan. I refused to give up my values, so I was not able to be admitted to an inpatient or outpatient program in Australia. I was a general inpatient, but was not allowed to partake in the EDP (Urban)*

*Take an approach that works with the client rather than just doing the same method of recovery (Urban)*

*The one size fits all program does not work. Care needs to be individualised. Northside has done so much damage to me. I am still traumatised by Northside years later, and now relapsing and have nowhere to go to get treatment (Urban)*

*Clients want their care personalised. Everyone's experience is different (Urban)*

*Don't put me in a box. My experience of ED is individual. Don't take my control away & treat me like a child...There is a human, a whole person with a name & feelings inside this body - not just an "illness" (Urban)*

### Division of physical and mental health

This division of physical and mental health was particularly pronounced in rural areas where mental health treatment was not available.

*My daughter lives in Lismore. She can get help for the physical side but not the mental side (Rural)*

*Focused on physically restoring health rather than any help mentally (Rural)*

*I felt that the health care professional only cared about the physical effects of the eating disorder and once those were reconciled, failed to give me access to help for the mental effects. I also felt judged and felt as though the doctor thought I was being over dramatic for suggesting that this condition was more than just a number on a scale (Urban)*

*My experience wasn't good, as they never addressed my feelings or why I stopped eating, they just forced down food to make me gain. I developed other mental health problems after this experience (Urban)*

*Focus on weight restoring, no psychological help so my body heals but my brain didn't and therefore couldn't cope with the weight gain in a short amount of time was discharged then quickly relapsed (Urban)*

### Comorbidities

*I probably needed to have treatment focused intensely on my eating disorder. I found that the treatment was more based on dealing with anxiety, which is also important however; I think I just needed something more intense to really confront my disorder (Urban)*

*Treatment never seems to be holistic. For 15 years I have cared for a loved one with anorexia who as a result of her illness has drug/alcohol issues, as well as heart/liver issues. These are all always treated separately, in different wards or hospitals, with no link to the cause of the problem which is anorexia. As her anorexia was brought on by sexual assault experienced as a child, this is also treated as a separate issue. Many health professionals have a very limited knowledge of the disease (Urban)*

*I feel like a lot of therapists don't understand how my autism and depression impact my disorder and only see me as anorexic not a whole person. My current therapist is good as she sees the whole picture and tries to understand my whole life story and how it led to my disorder (Rural)*

## Under resourced GPs with limited ED knowledge

An overwhelming number of urban and RRR participants believed GPs needed much better ED training as they are (1) an individual's first point of contact and (2) most often the referral point between an individual and specialised ED services.

*GPs should try to refer patients to places that specialise in ED treatment instead of generic mental health places like headspace (Urban)*

*GPs need to be provided with more training and information about eating disorders so that they can spot the symptoms, monitor patient's condition more closely and refer patients to appropriate services within a reasonable timeframe (Urban)*

*I believe GPs need greater knowledge about eating disorders as I was initially referred to inappropriate psychology services which could not cater to the treatment of anorexia. I also believe that GP's need improved and clear guidelines on how to look after someone with an eating disorder (Urban)*

*GPs need further education on how to identify and treat eating disorders. Many of them are old school and just have no clue (Urban)*

*Greater training available for GPs on eating disorder diagnosis, or if not the ability and knowledge of GP who specialise or express strong interest in eating disorders to refer patients to. (Urban)*

*More support for GP's. It would be awesome to have adult physicians who specialise in eating disorders as there is in paediatrics as their health needs are often way too complex for a GP to manage (Urban)*

*GPs need way better training - they have no idea who to refer to and just guess hoping that they will be the right person. Whole system was a joke (Rural)*

*GP was unable to provide any specialised treatment options (Rural)*

## Poor access to information

Many urban and RRR respondents had to search for information on their own, without the help of HC workers.

*I still feel there is a lack of transparency on how to get the help and where to reach out to if you need it for yourself or a loved one locally. It's not talked about here enough (Rural)*

*Much more information about the process of entry (Urban)*

*Once suspicion of ED a supply of information and a list of support groups would be great. A physical file of info and phone numbers etc. because the home situation is so desperate that carers don't have capacity to search for information (Rural)*

*We need to know where to go for help from the start. I do not work in the medical area and was not aware of services to address EDs (GP should have referred us to ED clinics when I first expressed my concerns - not me doing the research (Urban)*

*In general, I think it would prove beneficial to provide a list of ALL health care services an individual can access in their local area, as it has been incredibly frustrating to receive bits and pieces over time which would have been more helpful had I known about it from the start (Rural)*

*It would be really helpful to have a register that's accessible to the public that provides first point of contact professionals. E.g. which doctor to go to get a mental health care plan and appropriate referral (Rural)*

*Being aware of funding options available to ensure continuity and best follow up care (Rural)*

## Arduous search for the right HC workers

*Took us a while to get good support. Wasted a lot of time at revives who did not support us (Urban)*

*The majority of interactions I've had over the past 10 years of treatment have been from ignorant and/or burnt out people. I only started receiving the proper care from one amazing psychiatrist 8 years into treatment (Urban)*

*We had a poor experience from the beginning. Most doctors had no understanding of the causes of an eating disorder although they thought they did. We finally found a doctor who admitted she knew little but wanted to learn. We helped educate her about our understanding and she has been fantastic. The Oak House were amazing and helped us to learn and so it was disgraceful when they had to close due to no funding from the government (Urban)*

*Before having the support I have now I had to try many different health care providers (GP, psychologists and psychiatrists)... I believe I would have had a much greater chance at recovering if I had received specific eating disorder treatment years ago from people who have knowledge in the area. It has been incredibly difficult to find people who know how to work with a patient who has an eating disorder and even when I did find people they only became more knowledgeable after I had shared my own insight into my illness and them going out of their way to learn (Rural)*

## Have to be seriously ill to get help

Some respondents were only treated if they were seriously ill.

*There aren't any services available unless you are severely underweight and actively dying (Urban)*

*Where I live I have to be doing quite well, or extremely badly for the available treatment to be helpful. This causes a 'revolving door' issue of inpatient treatment. We don't have access to an eating disorder day programme here which makes life extremely difficult (Urban)*

*Minimal resources available in WA, if not underweight (Urban)*

*I have personally strived to be sicker before to be able to get treatment because there seems no other way. It is wrong and corrupt in every way! Makes me mad that people who have a high death potential are turned away because there are 8 others who weigh slightly less (Urban)*

## Long waitlists

Long waitlists for ED services are a major issue for respondents, irrespective of location

*For private inpatient treatment I have to travel to Sydney and be away from my family, and the waitlists are always long.*

*Living near the Sydney CBD means I'm fortunate enough to be able to access a number of services, however there are still barriers - i.e. long waitlists - so I can only imagine how bad it would be living rurally with an ED*

*When we lived on the far South Coast the fact that my daughter had to wait sooooo long to see someone in CAMHs impacted on the 'early intervention' component. Daughter went downhill so quickly that she was admitted to local hospital and transferred to Children's hospital Westmead before her FIRST appointment with the local CAMHs team*

*Anywhere you live there is great waits for treatment*

*Waiting list for government-funded eating disorders program is very long in ACT. We had to wait 9 months.*

*All treatment centres... that are close are at full capacity with 6 months + waiting lists*

*...the wait lists to get appointments are ridiculous.*

*It means months and months on lists, not being taken seriously and for someone battling this on their own with no support network extremely difficult as a single parent*

*Really long waiting times for treatment, not too sure about recent times but when I was receiving treatment, it took roughly 6 months to finally have access to therapists who specialise in eating disorders.*

## Poor service integration and continuity of care

Respondents in urban and RRR areas believed that services were fragmented and felt overwhelmed navigating through the healthcare system - particularly the public system.

*Public system is overwhelmed and in disarray. Poor patchy treatment led to multiple hospitalisations. Private care ultimately sought.*

*The professionals themselves have generally been lovely, but the system is not. The threats, the hospital restraints, the unclear communication, and the lack of overall help from the professionals was disheartening. It's like everyone has given up on me because this has gone on for so long... no one knows what to do with me. GP's in particular have been unhelpful- they put every physical health problem I have down to my eating disorder without even running tests. The hospital system sucks and is super traumatic.*

*I felt like I was not being heard. I am a private patient but when I struggle with the acute stages of my eating disorder I am put in the public system. In the public system I am not allowed to see my private Psychiatrist and have to start my story over again with a new team. This is extremely traumatic. I do not feel safe in a public mental health ward and this only makes the disorder worse... the communication between the Dr. and nurses is very poor. The rules and expectations seem to change on each shift change, which is really challenging. I also found that the staff were not interested in what was causing the disorder, they just wanted to get you physically well and kick you out and expect that you would not come back*

## Poor recovery support

*I felt like recovery was hurried/rushed, so that they could free up your spot for someone else (I understand this). I suppose what I'm trying to say is that more long-term support would've been great.*

*The psychologist appointments ended once I reached the 'goal weight', which I think was not helpful. Just because I was better physically did not mean I was fully recovered mentally. Psychologist sessions should have been ongoing.*

*There was a lack of professional support once outpatient.*

## Good therapeutic relationship

Of the respondents who reported having positive healthcare experiences, almost all cited having a good therapeutic relationship with their healthcare professional.

*... I moved to another [psychologist] and she changed my life. I am still in contact with her, even though I would say I'm 95% recovered. She even came to my year 12-graduation ceremony. She saved me (Urban)*

*Being able to finally open up to a therapist about my past ED meant I was able to fully recover finally... and she is amazing! She challenges me and also supports me, so I've achieved some amazing growth. (Urban)*

They valued healthcare professionals who (1) actively listened to them, (2) acknowledged their feelings, (3) saw them as a whole person and treated them like an equal, (4) believed in them and their ability to recover and (5) were kind and empathetic.

*XXX, the psychiatrist has such incredible insight into ED's and makes you feel really cared for, understood and supported. The nurses go above and beyond to care for you and show so much empathy and compassion. I never expected them to fully understand my ED but they were willing to sit with me, problem solve and help me come to the answers (Urban)*

*She was very kind and empathetic (Rural)*

*I am lucky to have a GP who takes time to listen and validate, is sensitive and has the right balance of accepting where I am at whilst gently challenging me. I now have a dietitian specifically trained in eating disorders who doesn't focus on the number on the scales as the only metric of improvement (Urban)*

*Dr. XXX - she's the most understanding, kind, empathetic and compassionate psychologist (Urban)*

*They are very friendly, approachable and very accommodating to my needs, very supportive and understanding (Rural)*

*Listens without judgment, was made to feel safe (Rural)*

*I didn't particularly warm to him but that didn't matter as our daughter did. He never gave up on her and showed he actually cared. We will forever be grateful for his care and that he was willing to try new treatments (Urban)*

## Stigma and Discrimination

*I work as an RN in healthcare. I have heard colleagues say extremely insensitive things and make jokes. I am very, very private and do not disclose my ED with anyone for this reason.*

An overwhelming amount of negative healthcare experiences was due to stigma and discrimination. According to most respondents, the stigmatisation of eating disorders is entrenched in mainstream Australian healthcare culture.

### 'Eating disorders aren't a real illness'

Many respondents felt that healthcare workers minimised the seriousness of EDs. Some healthcare workers did not believe that EDs were real illnesses. A number of respondents were told they were wasting hospital beds and that they should simply 'eat more' or 'eat less'.

*I have been hospitalised approx. 5 times. The general feeling is that an eating disorder is "not a real illness". The last time I was hospitalised, I had a nurse tell me that I wasn't really sick and all I needed to do was eat. She told me I was wasting a bed for more serious mental illnesses. It was awful. In addition, I was quite unwell 2 years ago over the Christmas break and could not be prioritised for a bed as an eating disorder was deemed "not critical" (Urban)*

*A nurse once told me to go to McDonalds and get a burger, it couldn't be so hard. (Urban)*

*Medical wards tell me they have people really ill to deal with who do want to live, when my organs were shutting down from anorexia. (Urban)*

*GP did not take me seriously when I was worried about my eldest girl with anorexia. I was told my younger daughter (with ARFID) was just a 'picky eater' & would grow out of it when I was concerned about her initially. (Urban)*

*As an ED patient my daughter heard staff on the ward talking about how frustrating it was to have to spend so much time with "those girls" when they could be spending time caring for "patients who really needed care". Many times nurses told me to "just go home and be strict (Urban)*

*I spent 2 weeks in a psych ward where the nurses all guilt tripped me because I wouldn't eat - telling me there were people who would kill for the food I had in front of me and that I should feel blessed and it's all in my head (Urban)*

*Admitted to emergency in SVT. I was reviewed for a short stay and was turned down based on my eating disorder. The face and tone of the doctor indicated I was there because of my own actions and did not deserve a bed (Rural)*

*They tell you to stop eating when I can't stop eating (Rural)*

*As I was admitted to a public hospital my eating disorder seemed to be treated as if it was minor and insignificant in comparison and that my admission was seeming voluntary which it was not (Rural)*

## 'Eating disorders are a choice'

Some healthcare workers believed that EDs were a lifestyle choice.

*I was treated as if I was stupid, not paying attention and choosing the disorder not dealing with a mental illness (Rural)*

*I'm choosing my ED (Urban)*

*That I 'did it to myself' (Urban)*

*Also I was told at a hospital that they would not treat her, as it is her choice to have an eating disorder. (Urban)*

*I once saw an endocrinologist who left me in tears because he was so judgmental about my anorexia. He was basically saying that it was my choice to be anorexic and that my health issues were my fault because I made this choice (Urban)*

*I would say 80% of professionals I have dealt with treat you like you are choosing to have an illness (Urban)*

*First GP response - 'all teenage girls go on a diet'*

This dismissal of disordered eating as a choice is even more heightened in weight gain EDs like binge eating disorder.

*I feel my eating disorder, intense binge eating, isn't seen as an actual issue or disorder. The way I am left feeling, the sickness, the bloating, my emotional state, is no less important or scary than those that under eat. I am just seen as an overweight woman who needs better self-control. They don't understand the addiction... (Rural)*

*I've had medical professionals not take me seriously because binge eating wasn't seen as a real disorder. Also, I felt like some of these professionals treated me reaching out for help as an excuse for my obesity, rather than helping me get the right support I needed.*

*Never taken seriously - dismissed. My other mental health issues focused on instead. My distress has been ignored and I have been told 'not to focus on it too much', to be nicer to myself and to just accept and love myself... Just told to write a food diary. Leaves me feeling invalidated and helpless. Binge eating disorder is not recognised as a real issue (Urban)*

*Not being taken seriously for having binge eating disorder just seen as an overeater (Rural)*

*There is a huge amount of stigma around binge eating disorder - that it's not an eating disorder at all, it's just a "lack of willpower" (Urban)*

*As I said, I'm one of the lucky ones. I know so many other people especially those in larger bodies who can't access the treatment they need or who are told that the behaviours we use are bad for me but good for them (Rural)*

*Lack of importance of the necessity to treat binge eating disorders*

## 'People with eating disorders are doing it for attention'

Many respondents reported that either they or their loved one with an ED was labelled as 'attention-seeking' by healthcare workers.

*In their eyes it was a tool to gain attention/make a bigger deal of it than it is (Rural)*

*Nurses, doctors - thinking an eating disorder is attention seeking. (Rural)*

*...The nurses on the ward though, were completely insensitive, and would talk about us outside our rooms, saying things like why would they do this to themselves, that we were attention seeking, and they're getting paid to make us do normal human things like eat. (Urban)*

*Assumptions made about my eating disorder and whether it is even real or just attention-seeking (Urban)*

*Being told I was attention seeking and just losing weight to be in hospital as I also have BPD (Urban)*

*Being told that I was doing this for attention, that took a massive blow to my recovery (Urban)*

*He told me that I was just doing it for attention. Even though I had a diagnosis from my doctor (Urban)*

*... I also felt judged and felt as though the doctor thought I was being over dramatic for suggesting that this condition was more than just a number on a scale (Urban)*

## 'Parents of a child with an ED are neurotic and controlling'

Parents were also stigmatised because of their child's disorder.

*That initial consultation... I was completely dismissed as being an 'overreacting' mother and yet, within weeks we were told our daughter's organs were in shutdown (Urban)*

*GP blamed us as parents for our XXX being a picky eater (Urban)*

*Parents are made to feel neurotic or overly anxious. GPs collude with the eating disorder by dismissing a parent's genuine concern & not listening or not recognising the urgency of the situation (Urban)*

*I have been told by a health professional that it is my fault my daughter has an eating disorder and was going to report me to DHHS (Urban)*

*I was made to feel like I was to blame for my daughter's eating disorder. It was the MDT team versus us as parents rather than putting our ideas together to help our daughter (Urban)*

*'You need to stop controlling your daughter's eating and let her start making her own choices about what she eats and when she eats' (Urban)*

*Three highly regarded eating disorder professionals refused to provide treatment, and ostracized our family. Because they did not know what to do, they blamed us as parents (Urban)*

## Weight Stigma and Discrimination

Weight stigma and discrimination was a major finding from this report. Many healthcare workers had preconceived ideas about ED symptoms and misguidedly assumed that individuals only suffered from EDs if they were severely underweight. Consequently, many respondents - particularly those in larger size bodies - were dismissed and/or ridiculed for attempting to access ED treatment and support.

*As a 6 foot three inch 180kg female being told you can't have an eating disorder. Blood work showed malnutrition. Told I was making it up (Rural)*

*I have had a lot of rude comments from those who don't understand in the healthcare system, like nurses telling me I'm eating too much for someone with an eating disorder and a psychologist telling me I was too fat for anorexia - they were all assuming I was supposed to be thinner (Urban)*

*At 65 kilos told too big for an eating disorder (Rural)*

*I was told I did not look 'thin enough' to have an eating disorder. Very disheartening and a huge setback in my recovery (Urban)*

*Weight based discrimination 90 kgs you wouldn't be that weight if it was an eating disorder (Rural)*

*Criteria for treatment CANNOT be based on BMI only (Urban)*

*I went to headspace and they told me I didn't 'look like' I had an eating disorder, followed by "no offence, but you don't LOOK underweight" (Urban)*

*Being told BMI was too high (Rural)*

*Due to having atypical anorexia I was told by a GP and psychologist I was not thin enough to have an ED (Rural)*

*I wasn't taken seriously when I was at a healthy weight and I wasn't able to access services based on my BMI. I ended up becoming very unwell and very underweight before professionals decided it was time to provide treatment based on my eating disorder. I've had professionals say "you're not that unwell because your BMI isn't that low so you don't need to have eating disorder treatment" despite being underweight and engaging in what is considered severe behaviours (plus the awful mental state I was in) (Rural)*

*My daughter normal weight but very sick – was dismissed really (Rural)*

*Sometimes because she looks well they assume she is well (Rural)*

A number of respondents were even fat-shamed by healthcare workers who encouraged them to lose weight.

*Being told I don't have anorexia because I am not thin enough and denied treatment (multiple times), being told to go on various restrictive diets to lose weight, being told my health problems are because I need to lose weight (Urban).*

*They just think I eat bad food and I get scorned at for being so fat (Rural)*

*'Fat people can't have anorexia.' Repeated unsolicited referrals to bariatric surgeons and being labelled non-compliant when I refused them. Being called a liar - that if I was in Auschwitz I would not be fat. Being encouraged to skip my only meal a day if I wasn't hungry because it would help me get thin and healthy. Being refused diagnosis and care for other conditions because I was fat so that HAD to be my real problem. Being encouraged to develop habits like bouncing my legs under the table when I sit to burn more calories while sitting down (endocrinologist gave that one). Being told by 3 separate doctors that I should keep smoking because quitting would sabotage my weight loss. Being told that if I just ate cucumber my body would eat itself and the fat would go away, then I could get any remaining issues taken care of if they didn't go away with the weight loss (Urban)*

Some healthcare workers also believe that an eating disorder ends when an individual attains a 'healthy' weight.

*I've been told I don't look sick by nurses as I had been weight restored (Urban)*

*Because I'm a healthy weight I'm better (Urban)*

*GP didn't seem to know what to do, also commented 'you look fine to me', brushed me off when I asked if I might be eligible for a mental health plan (Urban)*

*I also felt that once I gained enough weight to be considered healthy, my eating disorder was dismissed and I was told very bluntly that I didn't have a problem (Urban)*

*"Oh your weight restored so you all better now" (Urban)*

*Even though I am weight restored my head is still not recovered (Urban)*

*The misconception that an eating disorder is something "you grow out of". After a period in which I was weight restored I no longer felt able to access more intensive care unless I specifically asked for it (not an easy thing for someone with an active ED to do)*

*In recovery for anorexia and weight restored - 'oh you don't need treatment anymore'*

## Age Discrimination

Many health professionals believed eating disorders only afflicted teenagers. Consequently, a number of respondents were perceived to be 'too young' or 'too old' to have eating disorders.

*Daughter was 11 and GP felt she was too young to have anorexia, which slowed down diagnosis and allowed further weight loss*

*I am now 60 years old, and feel judged by healthcare professionals that are much younger than me. It feels like a massive failure on my part, that they are almost disbelieving that it is possible for an eating disorder to come back (Urban)*

*She was told by the initial diagnosing psychiatrist that at 22 she was 'unusual' as it was perplexing that she had developed an Eating Disorder at that age and not as a teen*

*I felt like no one believed me as I was a 40 y/o male (Urban)*

*Because she was only 12 she was too young to have eating disorder so found this extremely hard to get her the help she needed to begin with*

*Since I am a middle-aged woman my GP simply does not believe me that I have a genuine eating disorder (Urban)*

*For me it's age. I'm 38, married with two kids. I should 'know better' or should just 'grow up' and snap out of it. 'Don't be so self-absorbed'*

Some adult respondents also reported that healthcare workers treated them like children due to their eating disorder.

*Even on an eating disorders ward there were professionals who treated us like babies who were stupid and couldn't be involved with decision making (Urban).*

*Hospital nurses treated me like I'm a teenager or stupid (Urban)*

*'You're an intelligent girl, haven't you figured this out yet?' 'Just go eat an ice-cream' 'you are an anxious overachiever? Surprise, surprise - you have an eating disorder' (Urban)*

*My age, denture issues, menopausal - treated as an adolescent, very condescending*

*My daughter was not treated as an individual; felt she was treated as a naughty child Urban)*

*I was told that I was being a 'silly little disobedient girl' (Urban)*

## Minority Discrimination

Several respondents also described being marginalised due to their class, disability, race, sex and gender.

### Racial discrimination and cultural incompetence

*I was told that my ethnic background doesn't get EDs and that I would grow out of it (Urban)*

*Racial discrimination. Parents ESL so difficulty communicating with healthcare workers.*

*I found it difficult to talk about my emotions and my eating disorder through a cultural lens, as there didn't seem to be an understanding of cultural barriers - so more knowledge and insight into intersectionality would have been good (although I didn't know about intersectionality when I first received support) (Urban)*

### Class discrimination

*'I am not rich enough [to get an ED]'*

*In the private system the head psychiatrist refused to deal with me because I didn't have the finances to be able to afford a dietitian and psychologist every week. Being someone who gets DSP means that even health insurance is a struggle for me to manage.*

### Transphobia, sex and gender discrimination

*Transphobia, and clinicians having no idea how to treat me.*

*LGBTIQA+ inclusive care. Having to see one professional for an ED and another for gender and sexuality is ridiculous (Urban)*

*Understanding of disordered eating in the trans/non binary community (Urban)*

*Being trans/non-binary it's all in my head. And I'm too old for an eating disorder (Urban)*

*Being called the wrong name and pronouns consistently. Accessing some of the healthcare systems made me worse instead of better (Urban)*

*Men don't get bulimia or anorexia etc. is a standard phrase I hear<sup>1</sup> (Urban)*

*He's too young to have an eating disorder. Really, only girls have eating disorders.*

## Ableism

*Knew a decent amount about ARFID, knew nothing about autism and behaved in an extremely ableist manner.*

*Disability access time providers is impossible. The psychiatrist I saw weekly is up several flights of stairs. When I ended up in a wheelchair I could not get treatment. When my needs increase I get less care (Urban)*

*My daughter's eating disorder is directly linked to her autism and sensory issues... [It has to] be acknowledged or the therapist was wasting everybody's time... The ward in hospitals need to have reduced sensory rooms for patients that are autistic, ward life bright lights, movement multiple people, sounds etc means shut down for people on the spectrum and make it impossible to work on better eating (Urban)*

*People assumed that the only reason I didn't want certain foods is because I wanted to starve myself not just because I struggle with sensory issues (Rural)*

## COVID-19

For some respondents, COVID-19 has negatively impacted upon their treatment.

*The virus makes getting food impossible so it's a time bomb isn't it?*

*As she is a young adult with BPD, accepting she has an issue is half the battle. I feel I need strategies on how to manage her, particularly while living together in lockdown.*

*I have had issues finding my 'favoured/safe' foods when grocery shopping due to stock shortages*

*Due to Covid-19 all facilities who treat wasting disorders have been shut down. My sister is going to be going home from the hospital in 2 weeks - she is scared to go home as she needs treatment and she cannot get it. I do not find it acceptable that during a pandemic that Best and Less is still open but these mental health facilities are not (Urban)*

*During Covid -19 we can't leave the house let alone go to Melbourne god treatment (Urban)*

*I was discharged from a general mental health facility treating me for my eating disorder, MDD and PTSD due to concerns about my potential immune compromise while I was very unwell and deteriorating from hospital (Urban)*

In terms of the other types of help respondents suggested during the pandemic was having direct face-to-face access to health professionals (psychologist, psychotherapist, GP), crisis support, chat lines, daily food delivery for those who struggle from binge eating, provision of specific brand foods for those with ARFID, exercise therapy, support with school/university work and support from people who have recovered from an ED.

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<sup>1</sup> Within eating disorder spaces, men are also minorities.

# Discussion

The findings from this survey demonstrate that location plays a large role in how carers and individuals with eating disorders experience those eating disorders. Many of the barriers experienced by people living in Urban, Metropolitan and Suburban areas were acutely compounded for those living in Rural, Remote and very Remote areas. Individuals experiencing eating disorders living in RRR areas were significantly more likely to view where they were living as an obstacle to receiving help for their eating disorder. While this report focuses on carers and individuals experiencing eating disorders – it is important to acknowledge that being a healthcare professional working in an RRR area would exacerbate many of the difficulties experienced by healthcare professionals in carrying out their roles to an optimal level. Comments from respondents highlighted a high turnover of staff in RRR areas.

Access to services, particularly specialised treatment, was compounded for people living in RRR areas. Respondents who lived in metro areas reported a significantly higher overall quality of health care than those in RRR areas. There was a significant difference between people living in *RRR areas and those in Metro areas* in terms of satisfaction with health professional's level of knowledge about eating disorders. People living in RRR areas perceived it to be much more difficult for healthcare workers to refer them on to an appropriate service provider. The majority of respondents believed that healthcare workers in regional, remote or very remote communities needed more training and education in the treatment of eating disorders. Respondents living in Metro areas also had significantly higher levels of satisfaction with the knowledge of health care providers than those in RRR areas. Comments provided by participants suggest that there was also a paucity of inpatient services.

Participants living in RRR areas provided numerous comments that emphasised the multiple problems they experienced with accessing health professionals that had specialised knowledge in eating disorders with many GP's having no understanding of eating disorders. In addition to services with professionals who lacked knowledge about eating disorders, many services were under-resourced and had long waiting lists.

Cost was a significant burden for many of the respondents in this survey, particularly carers.

Those living in RRR areas reported having to travel the furthest distance to access help than those living in Metro areas. Having to travel distances to access treatment added to the financial burden that individuals were already experiencing due to the costs of treatment.

The research indicates that access to treatment for public patients was even more difficult with socio-economic status being an important factor in an individuals' access to quality and specialised treatment. The findings suggest that quality care was more difficult for people to access if they were from disadvantaged backgrounds.

Respondents also commented on a lack of access to information about eating disorders, particularly in RRR areas. No respondents believed awareness around available health services for people with eating disorders in RRR communities was satisfactory.

Participants living in rural areas commented on a high turnover of health professionals making it difficult to build up therapeutic relationships. A lack of integration of services and continuity of care also created barriers for individuals and their carers. Respondents mentioned poor recovery support. Some individuals had initial experiences of not finding the right health professionals but then finally managed to get a highly effective team of professionals around them to treat their eating disorders. Approaches to treatment were seen by some to be punitive and not client centred. Respondents also commented on how stereotyped ideas of who could get an eating disorder and what constituted an eating disorder acted as a barrier to receiving the care that they needed. This resulted in delayed diagnosis for some of the respondents in this survey.

Only a small minority of the respondents qualified for the additional Medicare items introduced in November 2019 with the success of those located in metropolitan regions being significantly higher than those located in RRR areas. It was difficult to ascertain the exact number of participants who would be eligible to a Medicare rebate for telehealth, but it is possible to estimate between 7.5% and 35.7% of the sample of individuals currently experiencing eating disorders. Comments provided by respondents suggested that people were falling between the gaps because of not fitting into particular catchment areas/zoning and also not being able to access Medicare funded telehealth.

While there was a rural/urban divide in treatment and experience of eating disorders, comments made by participants suggests that there was also a divide within in urban areas. Postcodes appeared to influence individuals' experiences of their eating disorders.

Treatment centres appeared to be located in more affluent neighbourhoods with those who were in less affluent neighbourhood having the extra burden of the travel costs to access treatment. Several respondents also commented that they lived in neighbourhoods that were particularly fitness or fashion focused which they perceived as exacerbating their need to look a certain way.

There were also state differences in access and experiences of treatment.

There was a significant difference between *RRR* and *Metro* respondents in terms of their satisfaction with the health professional's level of empathy for eating disorders. Respondents who lived in Metro areas had a significantly higher level of satisfaction with the empathy of the health care providers than those in RRR areas.

Of those who had sought help from a healthcare provider, 67.9% of the overall sample reported having faced stigma. Respondents in both metro and RRR areas also commented on experiences of discrimination. These included healthcare workers minimising the seriousness of ED's and perceiving them to be lifestyle choices. Carers were stigmatised as being controlling and neurotic. One of the major findings from this report was that many healthcare workers had preconceived ideas about ED's and perceived only severely underweight individuals as having eating disorders. Individuals were perceived to be either too young or too old to have eating disorders with some healthcare workers telling older people experiencing eating disorders that they should 'snap out of it'. Some respondents were told that they were too smart to have an eating disorder or should know better because of their educational status. Several respondents also described being stigmatised due to their class, disability, ethnicity, sex and gender.

COVID-19 had impacted negatively on the experiences of individuals and carers due to closed health facilities, stock shortages and for carers managing in isolation with those they cared for. **During the pandemic both carers and** people experiencing eating disorders called for extra support. Telephone counselling, videoconference counselling, and text messages were perceived to be most helpful during the pandemic.

These findings highlight the structural and social barriers, particularly in RRR areas, for carers and individuals experiencing eating disorders. The findings demonstrate that a person's postcode has a critical influence on their access to and experience of eating disorders.

## Limitations

The vast majority of people who responded to this survey identified as female and were aged between 18 & 30. There was very little diversity in terms sex and gender identification. Also, of the all carers identified as female. We know from other Butterfly Foundation research that there are a high proportion of people who identify as trans and gender diverse that experience eating disorders, in addition to individuals who identify as male. For future surveys, it would be valuable to also send the survey out through organisations that focus specifically on servicing these cohorts.

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