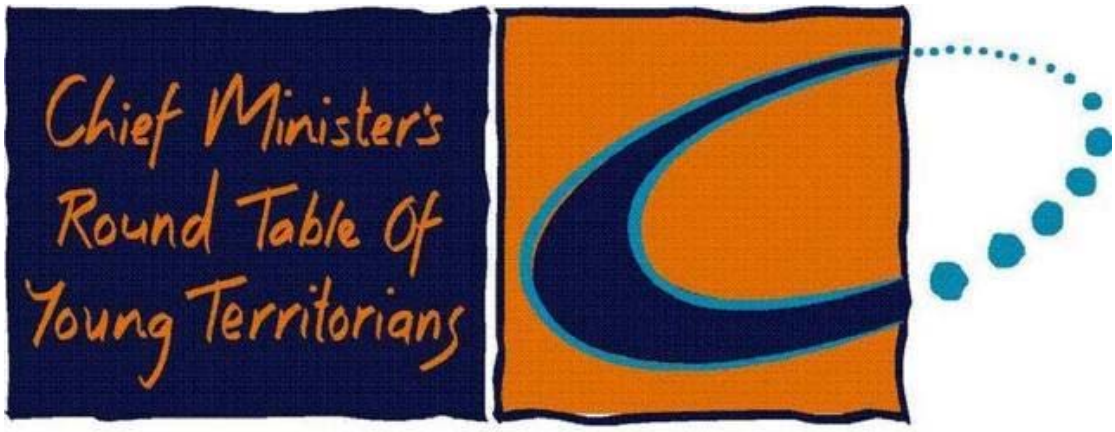

Eating Disorder Specialty Bed at Royal Darwin Hospital

Venaska Carmoni Cheliah

2015

Disclaimer:

Please note: *The Chief Minister's Round Table of Young Territorians is an independent advisory body. The views expressed in this report are those of the authors and are not necessarily reflective of those of the Office of Youth Affairs or the Northern Territory Government.*

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Abbreviations

- DoH: Department of Health
- NT: Northern Territory
- OYA: Office of Youth Affairs
- GP: General Practitioner
- RDH: Royal Darwin Hospital

Abstract and recommendations

A lack of specialty eating disorder beds in Northern Territory hospitals is putting the lives of gravely ill sufferers in jeopardy. Around two million Australians will develop an eating disorder in their lifetime with most of them likely to die from the illness. Unfortunately there is a dire lack of treatment services in the public health system as a whole but especially in the Northern

Territory. An analysis of the current literature, survey and a focus group has been undertaken in order to put forward a recommendation to the Northern Territory Government, aiming to provide more support and services for suffers seeking help. These recommendations are:

1. Establish an eating disorder specialty bed at Royal Darwin Hospital
2. Review the admission process for eating disorder patients in the Northern Territory.

Aim

This report aims to underline the importance of securing a bed specifically for eating disorder patients in the Northern Territory by illustrating the results of a survey focused on young and linking it to current literature and research.

Method

For this research report, a number of approaches were undertaken to strengthen the development of the recommendation. These included:

1. An online survey gathering information on the prevalence of eating disorders and body image dissatisfaction in the Northern Territory.
2. Liaising with a range of community members with experiences with these issues.
3. A focus group with five members of the community, diagnosed with an eating disorder and their recovery experience.
4. An analysis of current research.

Introduction to eating disorders

Eating disorders are a type of mental illness that has a significant and underestimated impact on Australian society. They affect around 9% of the

Australian population and can metastasize by various different characteristics and causes (NEDC 2012). In general, an eating disorder is characterized when eating, exercise and body weight/shape becomes an unhealthy preoccupation of someone's life. It can lead to long term physical, psychological, social, cognitive and functional impairments and the impact may include psychiatric effects, medical complications, social isolation, disability, behavioural effects and an increased mortality rate (Eating Disorders Victoria 2015).

According to the latest Diagnostic and Statistical Manual of Mental Disorders (DSM-5), there are currently 8 different types of feeding and eating disorders; Anorexia Nervosa, Bulimia Nervosa, Binge Eating Disorder, Pica, Rumination Disorder, Avoidant/Restrictive Food Intake Disorder (ARFID), Other Specified Feeding or Eating Disorder (OSFED) and Unspecified Feeding or Eating Disorder (UFED). A short explanation of the most prevalent types in the Territory according to the DSM-5 criteria is as listed in Appendix 1(American Psychiatric Association 2013).

It is important to note that an eating disorder is not a lifestyle choice, a diet gone wrong or a "just a fad". There are very strong links to low self-esteem, ideas of perfectionism and an attempt to deal with underlying psychological issues through practicing an unhealthy relationship with food (Diss 2014). Furthermore, the impact of an eating disorder is not only felt by the individual, but often by that person's entire family or circle of support (Neumark-Sztainer et al. 2008). This impact can translate to caregiver stress, loss of family income, disruption to family relationships and a high suicide risk, all of which can be a burden on our health system (Eating Disorders Victoria 2015).

Eating disorders, disordered eating and body image issues can occur in people as young as 7 or as old as 70. According to the results of the annual Mission Australia Survey of Young Australians, body image was in the top three personal concerns of young people in, with the statistics increasing over the past couple of years (Mission Australia 2014).

Eating disorders and body image issues are normally classified as a “female disorder” through general belief (ANAD 2015). However, rates of body dissatisfaction in males are rapidly increasing, leading to more prevalence of males with eating disorders. In Australia, one in four minors and one in ten adults with anorexia nervosa is male (Eating Disorders Victoria 2015). Furthermore, in a 2009 study, the Butterfly Foundation discovered that one in three male year 9 students uses fasting, skipping meals, diet pills, vomiting, laxatives and smoking cigarettes as weight loss methods.

While there is a slow but gradual increase in programs and counseling services that specialize in eating disorders, there is still a gap in the accessibility of these services. Nationwide there is a deficit of public hospital beds for eating disorders. There are only 25 public hospital beds across Australia, 5 in New South Wales, 6 in South Australia, 9 in Queensland, 14 in Victoria and none in Tasmania, the Northern Territory or Western Australia (Hall 2012) (Milligan 2015). Public hospital beds allow eating disorder patients to access hospital services without needing to be psychiatrically very ill. Additionally, it will allow the care to be eating disorder focused rather than a general psychiatric care. This is concerning considering that The Butterfly Foundation recommends every major Australian hospital provide four to six dedicated beds for eating disorder sufferers and that the rise in the prevalence of eating disorders would lead to an increase in the loss of lives due to this illness (Butterfly Foundation 2014).

RISK FACTORS OF EATING DISORDERS

The risk factors associated with eating disorders are commonly seen habits in society today. Eating disorders are a multifaceted illness comprising of genetic, cultural, social, physical and personality factors. However, some common personality traits have been observed amongst those diagnosed with an eating disorder. These include perfectionism, obsessive-compulsiveness and neuroticism (Shisslak et al. 2001). Individuals with Bulimia Nervosa tend to be impulsive and exhibit sensation seeking behaviour while those with anorexia nervosa tend to exhibit constraint and persistence (Butterfly Foundation 2012). Commonly seen risk factors include disordered eating,

dieting, and body dissatisfaction (Eating Disorders Victoria 2015). According to the NEDC (2012), Australian adolescent females who diet at a severe level are 18 times more likely to develop an eating disorder within six months.

MORTALITY RATES

- Eating disorders are the 3rd most common chronic illness in young females.
- The risk of premature death is 6-12 times higher than the general population.
- Anorexia Nervosa has the highest mortality rate than any other psychiatric disorder.
- 1 in 5 premature deaths of individuals with Anorexia Nervosa are caused by suicide.
- The debilitating effects are comparable to psychosis and schizophrenia (Eating Disorders Victoria 2015) (The Butterfly Foundation 2012).

FINANCIAL COSTS

According to a report conducted by the Butterfly Foundation, the individual and their families endure 60% of the health system costs that arise from eating disorders. Many families have spiraled into financial difficulties as a result (Milligan 2014) (Virtue 2015). The article further noted that in 2012, the total social and economic costs of eating disorders was around $69.7 billion with the Burden of Disease (BoD) cost being $52.5 billion, higher than the BoD cost for anxiety and depression.

Body image and eating disorders in the NT – the current picture

In 2010, the Skin Deep Team conducted a survey of young Territorians which provided information of their views on the topics of eating disorders and body image. 257 young Territorians participated in the survey with an almost even split between genders (52% identified as female, 44% identified as male and 4% were unspecified). 60% of the participants thought that body image and self-esteem were big issues for young Territorians. 40% indicated that they, or somebody that they knew, had experienced an eating or body image disorder and out of that, 66% of respondents answered that the individual or themselves had not sought help (Moss and Woerle 2011).

In addition the results of the 2014 Mission Australia's Survey of Young Australians indicated that body image was a major concern of 34% of the Northern Territory respondents with 13 % being extremely concerned (Mission Australia 2014).

Official statistics on eating disorders in the NT have been difficult to obtain as individuals admitted to the hospital with an eating disorder are admitted into the Psychiatric "Cowdy" Ward with other inpatients experiencing a range of mental illness (Moss & Woerle 2011). Furthermore, a Consultant Psychiatrist at RDH informed that most eating disorder cases are outpatient and are managed by private psychiatrists, local psychologists and General Practitioners. This is a concerning situation as it is easy for an eating disorder patient to be "lost" in the system when placed in an environment with patients experiencing a very different kind of mental illness (Moss and Woerle 2011). Hence, it is vital to ensure that there is more support in the hospital for patients with eating disorders to ensure that they are receiving the most appropriate treatment. Additionally, if hospitalization was required, most of the cases were handled by Darwin Private Hospital at the individual's cost.

Survey overview

Most of the research for this project was undertaken in the format of a survey. The survey consisted of 10 questions (the last one allowing the participant to add any additional comments) and comprised of 43 participants. Participants were primarily sourced through social media and caution was taken in designing the questions to prevent participants from being grieved by the issues that arose. Additionally, contact details for Lifeline were included in the survey to offer support if needed.

The questions in the survey were specifically designed for the purpose of this study, to generate some statistics regarding eating disorders in the Northern Territory and to stress the importance of setting aside a bed in the hospital for patients with eating disorders. The questions took into consideration the sensitive nature of the research and the literacy levels of the target groups.

PROFILE OF PARTICIPANTS

Out of the 43 participants the majority were aged 18 - 25 years (67%) and were female (83%). 4 participants identified as Aboriginal. Tables 1,2 and 3 below illustrate the breakdown of the participants.

Table 1: Age of participants

Age of Participant/s (Years)	Number of Participants
12-18	2
18-25	29
25 +	12
Total	43

Table 2: Gender of participants

Gender	Number of Participants
Male	7
Female	36

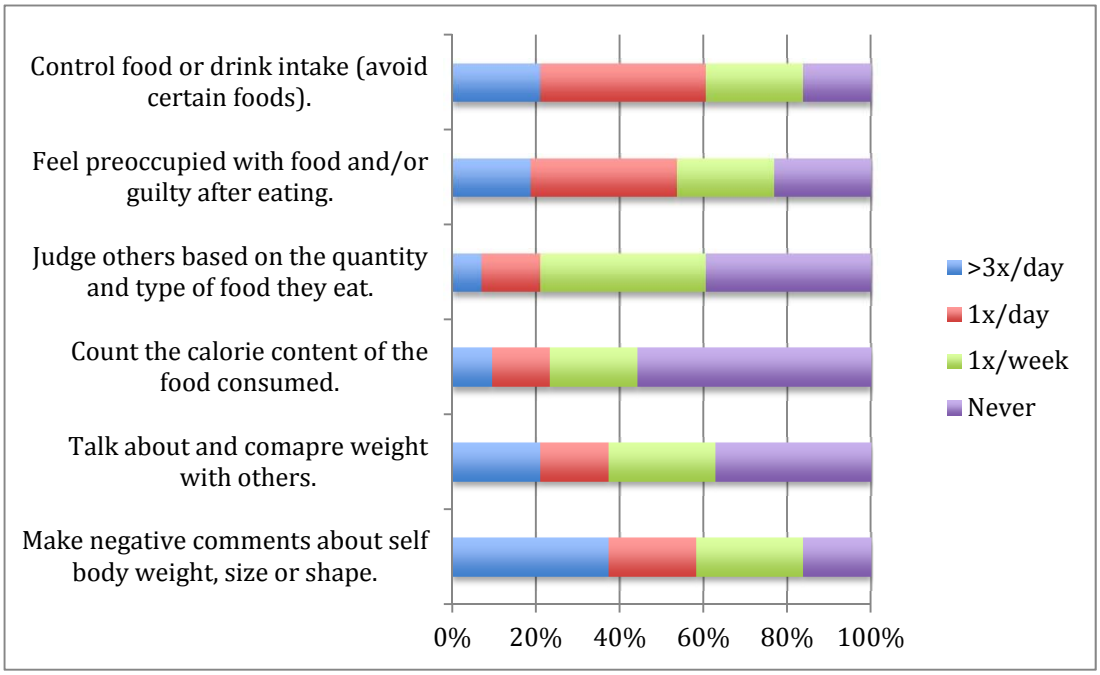
Table 3: Cultural Identification of participants

Aboriginal	4
Torres Strait Islander	0
Neither	39

SURVEY RESULTS – See Appendix 2.

The results from the survey indicated that although 76% of participants believe that body image is very important to general health and well being, more than 50% of the participants make negative comments about their own body weight, size or shape at least once per day. Furthermore, more than half the participants admitted to feeling preoccupied with food and/or guilty after eating and controlling their food and drink intake. However, participants less frequently counted calories, talked about and compare their weight with others and judged others based on the quantity or the quality of food they were consuming.

While 86% of respondents specified that they or someone they know has suffered/is suffering from an eating disorder, 55% illustrated that they were unaware of the services available in the Darwin and rural areas for people with eating disorders. This is most concerning as eating disorder sufferers most commonly present with other mental illnesses such as depression and anxiety, and can be very detrimental to their health and wellbeing.



This further reinforces the prevalence and seriousness of these mental illnesses, whose debilitating effects are comparable to psychosis and schizophrenia.

The suffering faced by individuals with an eating disorder and their families are significantly increased by the difficulty in accessing timely and appropriate treatment. The impediment in access to care not only prolongs and exacerbates the medical condition but also costs the community and the affected individuals dearly leading to a tragic waste of personal and economic potential (The Butterfly Foundation 2015).

The lack of awareness of the services available for patients with eating disorders shows that in severe instances, patients are more likely to turn to easily accessible services (i.e. Royal Darwin Hospital), which further raises the significance of a public bed.

The personal experience

A focus group was conducted with five members of the community currently or previously diagnosed with an eating disorder and have been previously been admitted for their illness. A majority of the group reported that the aspect of their journey that they struggle with the most is the difficulty accessing treatment once they had found an effective provider. A number of patients in the Territory have reported moving interstate or even overseas to undertake treatment at enormous expense. Paying for treatment was also difficult and many patients complained about recent changes to Medicare which have almost halved its psychiatric support.

The economic and social costs on sufferers and their families are devastating and the down stream effects that can result include deaths (including suicide), marriage breakups and heart attacks from stress. The recovery process has a long duration with a pattern of recurrence sometimes after a number of years or recovery and the absence of support systems in the public system leave the sufferer vulnerable to relapse. Non personalised and/or standalone medical or psychological treatment can make the condition worse and extend the course of the illness while integrated treatment approach, isolated from the triggers and stressors, over a short time frame (e.g. two weeks in the hospital), can reduce the burden of this illness and increase prognosis. It is also vital to acknowledge the importance and longevity of post recovery support to avoid relapse; one comment focussed on this topic “I still see a psychiatrist every 2-3 months even though I have recovered from bulimia”.

Case Study #1 - The story of Miss A.

Miss A. is a 29 year old female who has lived in Darwin for most of her life. This is the story of her battle with an eating disorder.

I have been suffering from an eating disorder for the past 15 years and at the age of 16 I was referred to a psychologist, who unfortunately had little experience dealing with eating disorders. This experience led to me avoiding any kind of treatment for the next few years. During this time, my bulimia had gotten completely out of control but my blood results and body mass index were always normal. There was nothing to physically indicate the struggle I was privately dealing with.

When I was 25, I finally sought out help again, my motivation being that I was in a new relationship. I was again referred to a psychologist and a psychiatrist from Sydney, as there were no public psychiatrists in Darwin who specialise in eating disorders. I felt like I had no support and because of the distance I found it difficult to keep in contact with my psychiatrist. Furthermore, 6 months after I started therapy, my psychologist moved interstate and once again I was left without any support. Because of my age, it was difficult for me to seek help from places like Headspace and Tamarind Centre.

One year later, my bulimia got worse and I was not able to function anymore. I was spending close to $300 in food per week and was putting in overtime to help pay the bills. My weight dropped to the lowest it had ever been and I started physically harming myself to help relieve all the stress I was under. My relationship was on the brink of a breakdown and suicidal thoughts started creeping in. I went to see my general practitioner who put me on some anti-depressants and sent me home. Two weeks later, I was pretty much binging and purging from the moment I woke up to the moment I went to bed and after a fainting episode due to low potassium levels, I was admitted to the hospital. While I was sufficiently treated for my low potassium levels, I was not encouraged to stay in the hospital because my condition was “not serious enough”. Even though I had expressed my desire to seek help and that I felt I

was out of control, they said that they did not have a bed dedicated to eating disorder patients and I would have to be treated as an outpatient.

That was the hardest thing to be told and there were numerous times when ending it all crossed my mind because I was just so tired of fighting this battle. Two days after being discharged from the hospital, I came close to ending my life. I tried to drive my car into a tree and was again admitted into hospital. This time though, I was admitted into the psychiatric unit and finally I felt like I was being heard. As there was no dedicated area in the Royal Darwin Hospital for eating disorder treatment, a consultant psychiatrist arranged a six week admission at the Statewide Eating Disorder Service in Adelaide for inpatient treatment. This was the best thing to ever happen to me. The tailored treatment program I received, tackling the illness from all aspects, with support from a multi-disciplinary team helped me get back on my feet and with life.

Three years on, I am healthier, stable and happy. The help I received helped me save my relationship, allowed me to be more financially stable and allowed me to get on with my life and achieve my dreams. I have two wonderful children, which would not have happened if I did not get the help I needed three years ago. I am telling my story of fighting to get treatment because I hope that it will contribute to bringing treatment changes for people with any kind of eating disorder, and to encourage investment into a treating centre at the Royal Darwin Hospital.

Case study #2 – The story of Mrs B.

Mrs B. is the mother of a 21 year old female currently recovering from an eating disorder. This is the story of the impact eating disorders can have on a family.

I have a daughter who has suffered with anorexia and bulimia for the past 7 years. Her battle with the illness started when she was in Year 10. Initially, when I expressed my concern to the people around me, I was told that it was a phase and after a while she will come out of it. I was told it was common amongst girls her age and I was told I had nothing to worry about. As she continued to lose weight, I thought if I could just force her to eat, she would get better, not realising that she started purging after eating her meals in front of me. Looking back now, it did not take me very long to realise that I was dealing with something that I could not fix myself, something that I could not control and that my child was very ill.

Four years ago, I sought out help from my family general practitioner who referred me to a psychologist and one of the three private psychiatrists in Darwin. Treatment was expensive and lengthy. Each visit to the psychiatrist and psychologist was costing between $300 and $500 out of pocket and my daughter initially required a three visits a month to the psychologist and one visit a month to the psychiatrist. Then there were visits to the dietician, which was around $80 per visit. The financial commitment that families have to make for treatment is incredibly taxing and it is a huge burden.

At one time, early on in her illness, my daughter had to be hospitalised. This was by far the most difficult challenge we faced in accessing treatment. As there was no dedicated unit here in the territory to eating disorders, we had to arrange inpatient treatment in the Flinders Medical Centre, Paediatric Unit. As I could not take anymore time off from work, my husband followed my daughter to Adelaide. They were away for six weeks and this increased the financial and emotional burden on the family. However, the time my daughter spent in the inpatient unit was incredibly valuable to her recovery process. It

helped her focus solely on recovering without any of her stresses and triggers, leaving her less vulnerable to relapses.

After years of regular treatments and several episodes of hospitalisation, my daughter is finally fully motivated to recover. Although it will still be a few more years before she can be fully well again, the hospitalisations and inpatient treatments in Adelaide helped her to maintain the recovery path that she is on. I am fully supportive of an eating disorder bed in the Royal Darwin Hospital as I am of firm belief that if it weren't for the inpatient treatment she had received, my daughter would not be alive, here with me today.

Quotes from the Darwin community

"I have been in hospital twice for mental health issues and both times I was put in a room with just a couch to spend the whole night. I'm not too fussed because there are people with physical injuries that actually need a bed, but I have a friend who was admitted into ED while having a psychotic schizophrenic episode and he escaped twice, completely naked screaming that the world was going to end. I guess where I am getting at is often people with mental health issues in the hospital are clumped together and not necessarily getting the attention and long term support they need."

- *Pritika Desai, ShoutOut Youth NT*

'If there are beds in other hospitals in Australia, why not Darwin?
RDH is the largest public hospital in the NT. Having a bed would encourage people with this illness/issue to seek treatment.
The only place in public system for mental health admission is "Cowdy" ward or JRU (isolation ward). Not many people get admitted for eating disorders. You tend to get support for other mental illnesses, which is surprising considering eating disorders have one of the highest mortality rates. RDH needs more beds as a whole."

- *Bernadette Dezylva, Year 3 Medical student, Northern Territory Medical Program*

Everyone should have access to support . It is NOT FAIR that many, many people cannot access this type of care due to cost.

- 16 year old Male, living in Palmerston, Suffering from anorexia.

Conclusion

The importance of establishing an Eating Disorder Specialty bed in the Northern Territory, more specifically Royal Darwin Hospital, cannot be understated. Sufferers experience many stresses and difficulties in seeking help and this is compounded by the most accessible health services not having the resources to help these Territorians. The illness is relatively treatable and can have good prognosis if hospitals could increase their services provided to eating disorder patients and therefore reduce the high morbidity rate.

Evaluation

I joined the Chief Ministers Round Table of Young Territorians (Round Table) because of my own personal experience with an eating disorder and the difficulties I faced seeking treatment. The time I have spent on the Round Table was more inspiring that I could ever have expected it to be. It was wonderful to meet so many young people so passionate about their community. There is no doubt in my mind that the future of our community will be in great hands. I would like to thank OYA and the Round Table for giving me platform to help me push the importance of this issue that is close to my heart.

I would also like to thank the young Territorians who shared their stories, experiences and opinions that contributed to the development of this project.

Regardless of what happens with my recommendations to the Northern Territory Government, I know that my passion surrounding this issue will not diminish and through this project and my future career as a doctor, I hope to keep fighting towards and healthy and happy future, free of eating disorders and body image issues.

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Appendix 1 – DSM-5 Criteria for eating disorders

(American Psychiatric Association 2013)

Anorexia Nervosa

Anorexia Nervosa involves persistent restriction of energy intake leading to significantly low body weight (in context of what is minimally expected for age, sex, developmental trajectory, and physical health), an intense fear of gaining weight and a disturbance in the way one's body weight or shape is experienced.

Bulimia Nervosa

Bulimia Nervosa involves recurrent episodes of binge eating, which is defined as eating, in a discrete period of time, an amount of food that is definitely larger than most people would eat during a similar period of time and under similar circumstances and/or a sense of lack of control over eating during the episode with inappropriate compensatory behaviour in order to prevent weight gain.

Binge Eating Disorder (BED)

BED is classified as recurrent episodes of binge eating episodes that are associated with three or more of the following: eating much more rapidly than normal, eating until feeling uncomfortably full, eating large amounts of food when not feeling physically hungry, eating alone because of feeling embarrassed by how much one is eating and feeling disgusted with oneself, depressed or very guilty afterward. Additionally, marked distress regarding binge eating is present.

Pica

Persistent eating of non-nutritive substances for a period of at least one month makes a diagnosis of Pica. The eating behaviour is usually inappropriate to the developmental level of the individual and is not part of a culturally supported or socially normative practice.

Rumination Disorder

A Diagnosis of Rumination Disorder requires repeated regurgitation of food for a period of at least one month that is not due to a medical condition. Patients with the condition usually repeatedly and unintentionally regurgitate undigested food from the stomach, rechew it, and then either reswallow the food or spit it out. It is a reflex, not a conscious decision.

Avoidant/Restrictive Food Intake Disorder (ARFID)

ARFID is an eating or feeding disturbance manifested by persistent failure to meet appropriate nutritional and/or energy needs associated with significant loss of weight.

Other Specified Feeding or Eating Disorder (OSFED)

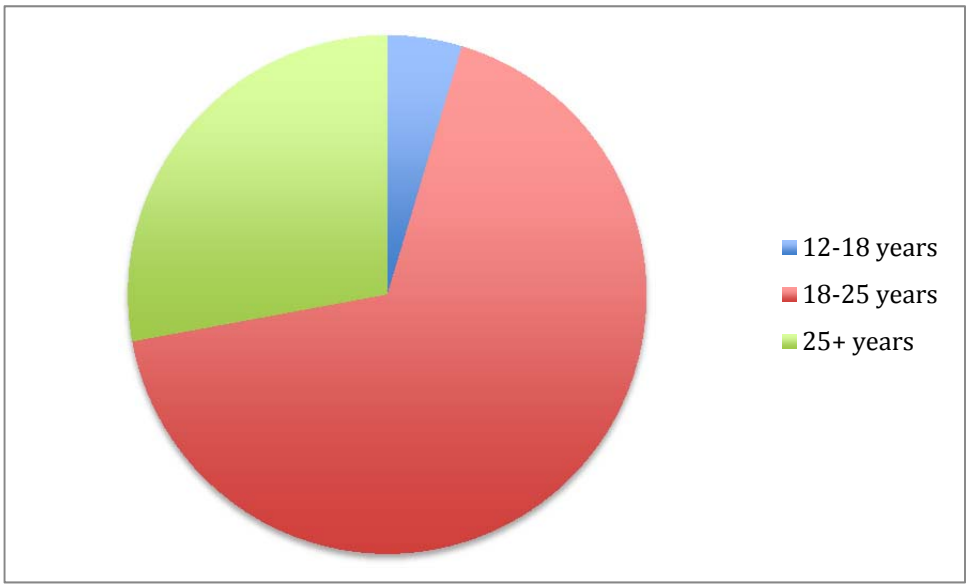
OSFED involves feeding or eating behaviours that cause clinically significant distress and impairment in areas of functioning, but do not meet the full criteria for any of the other feeding and eating disorders. Examples include atypical Anorexia Nervosa and atypical Bulimia Nervosa. These disorders fulfill some of the features of Anorexia Nervosa and Bulimia Nervosa but the overall clinical picture does not justify that diagnosis. For instance, one of the key symptoms, may be absent.

Unspecified Feeding or Eating Disorder (UFED)

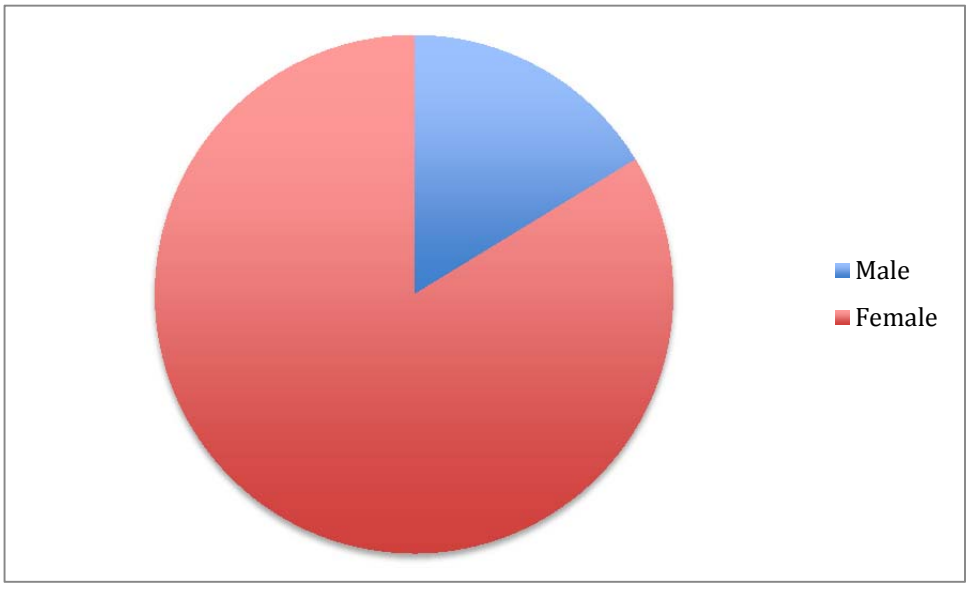
The UFED condition is a unique one in which the eating behaviors cause clinically significant distress/impairment of functioning, but do not meet the full criteria of any of the feeding or eating disorder criteria.

Appendix 2 - Survey Results

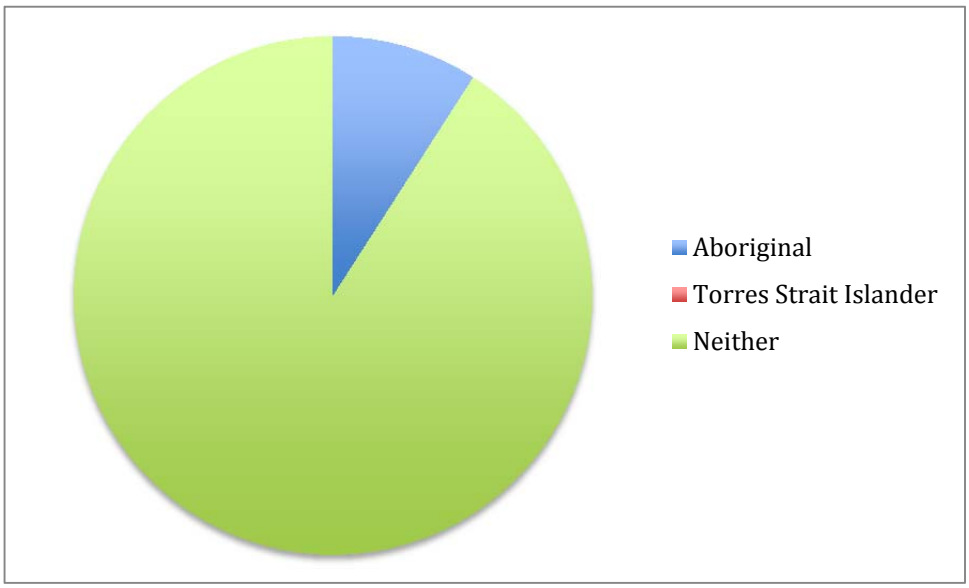
1. What is your age?



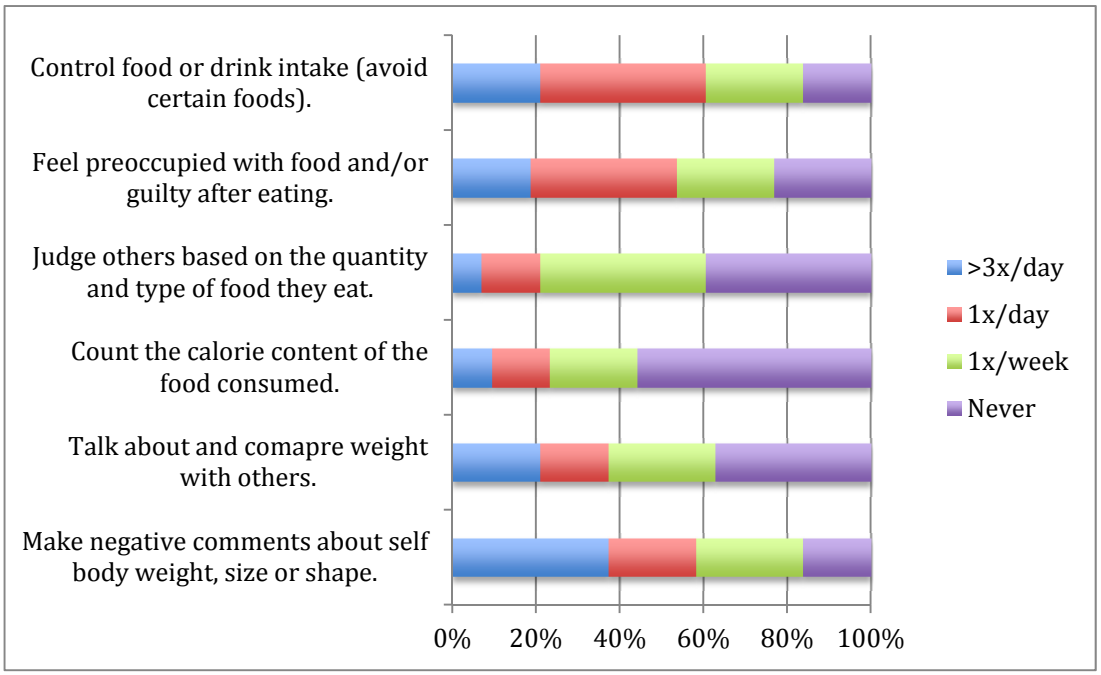
2. What is your gender identity?



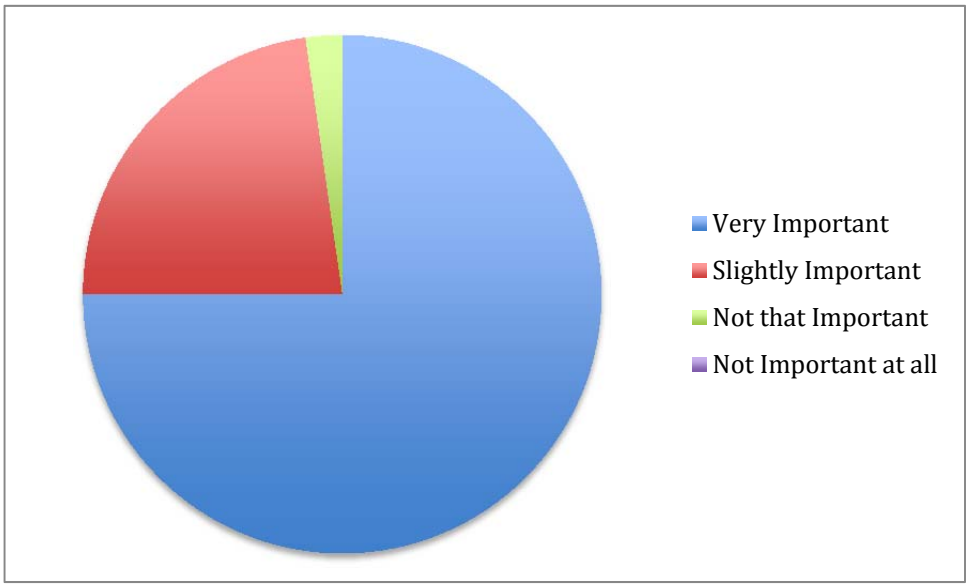
3. What do you identify as?



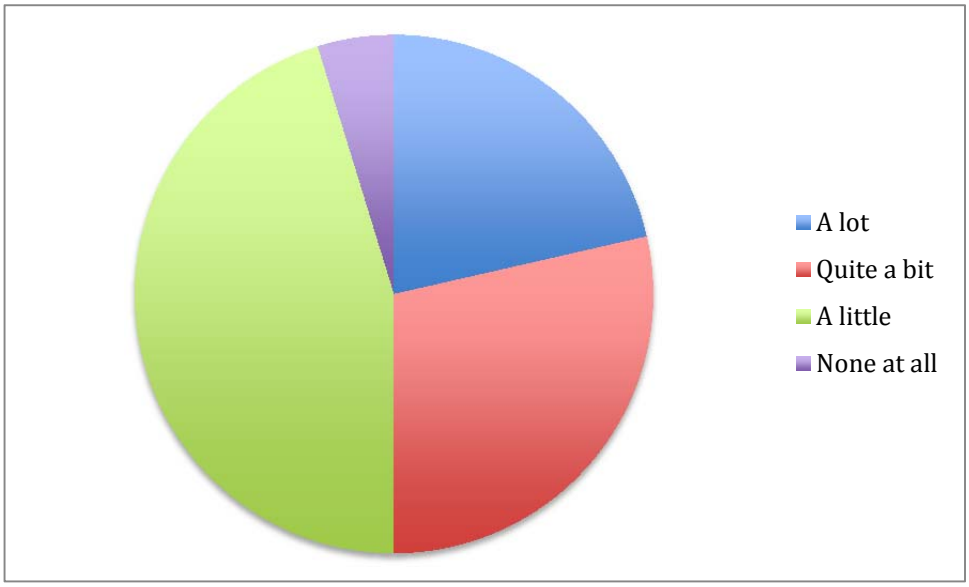
4) How often do you:



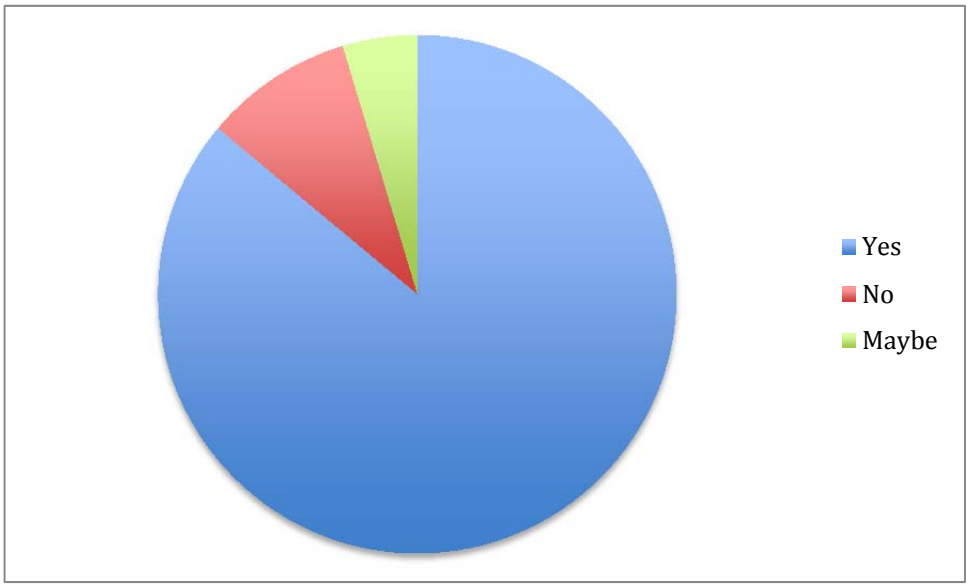
5) How important do you think positive body image is to general health and wellbeing?



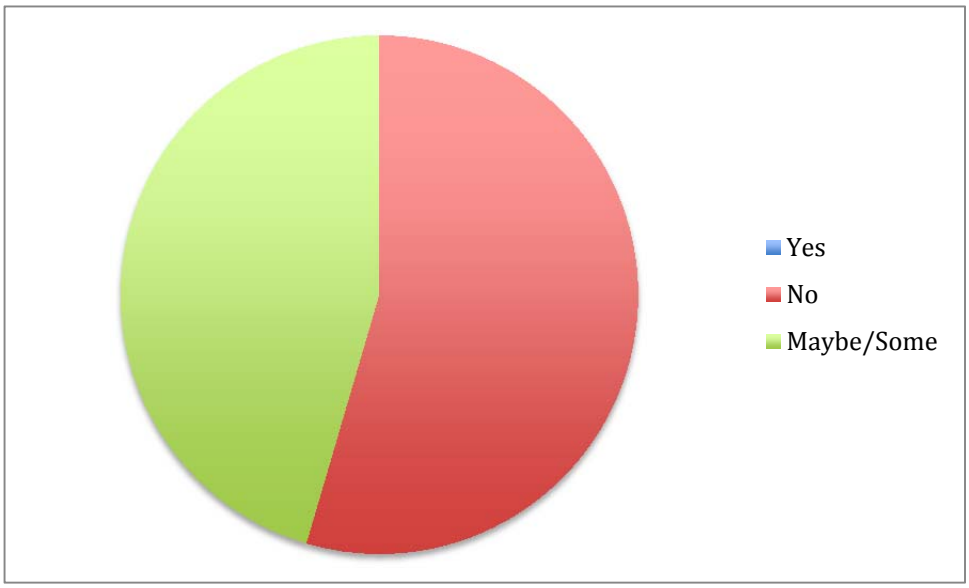
6) How much do you know about eating disorders?



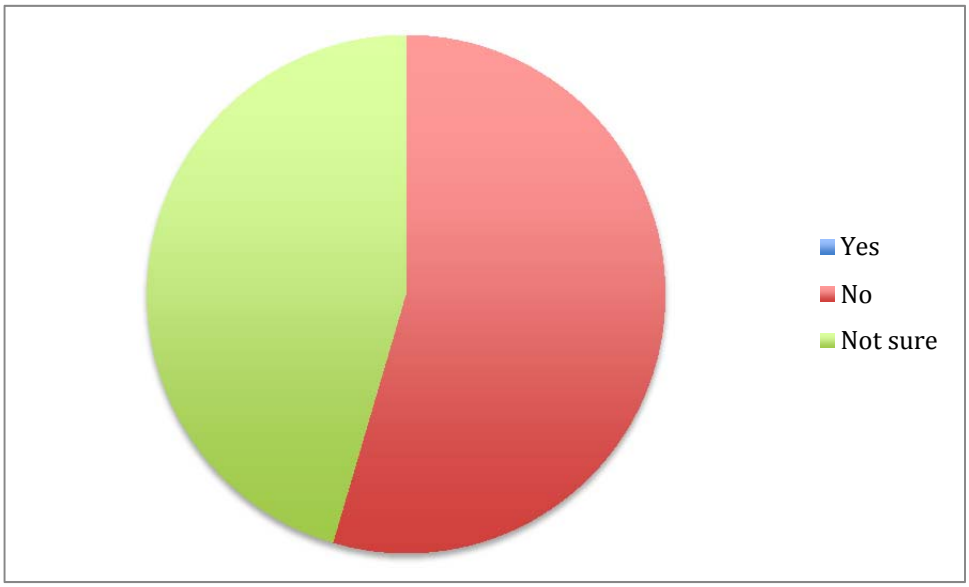
7) Have you, or do you know anyone who has ever suffered/is suffering from an eating disorder?



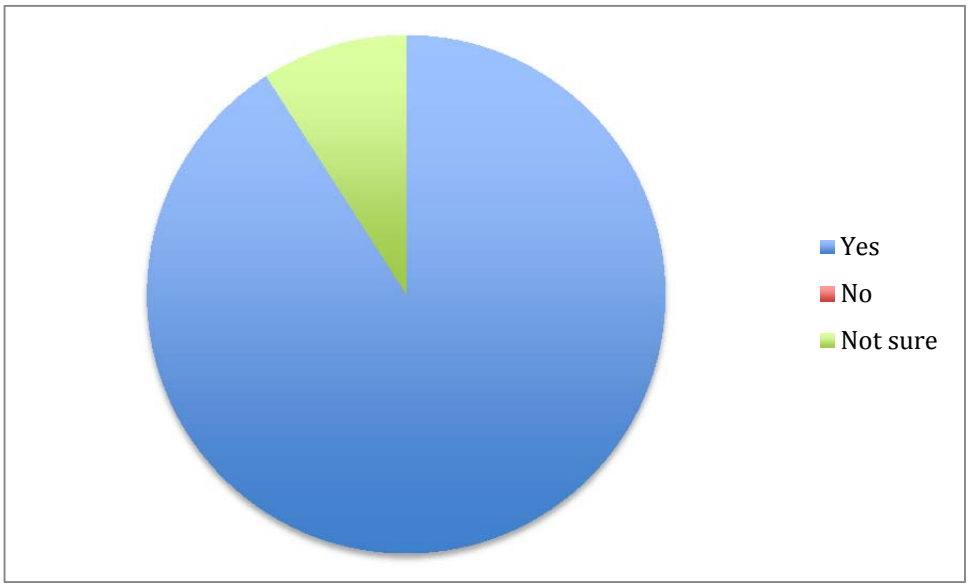
8) Are you aware of the services available in the Darwin and rural areas for people with eating disorders?



9) Do you believe that there are enough accessible services and resources that deal with body image and eating disorders in the Northern Territory?



10) Currently there is no bed allocated to patients with eating disorders in RDH (with only 25 public beds in the whole of Australia). Do you believe that it is important to have a bed that is accessible for patients with eating disorders?



Appendix 3 – Focus Group Questions

A focus group was conducted with five young Territorians aged 16 – 23 who were currently in the recovery process for an eating disorder. Due to the sensitivity and nature of the illness and the questions, it was decided that the participants remain anonymous to encourage full disclosure.

Q: What was your motivation to seek treatment in the first place?

- Prevented me from achieving my dreams.
- I was spiraling out of control and did not know what else to do.
- My family forced me into getting help.
- I wanted to be a better person for myself, for the people around me because I deserve more than this illness.

Q: Who (health professional) did you first seek out when you tried to get help?

- General practitioners.
- The main theme that came out of this discussion was the lack of services. Most of the general practitioners referred the patients to psychologist.

Q: Have you ever been admitted to RDH for your eating disorder? Describe some of your experiences.

- Most of the participants were admitted to Royal Darwin Hospital primarily because of their suicidal tendencies, which is very common in people with eating disorders. Many patients suffer from other underlying mental illness such as depression and anxiety and eating disorders can exacerbate the condition.
- The main themes that came out from this discussion;
    - I did not feel safe in “Cowdy” ward due to the nature of the illness of other patients.

- Despite the best efforts of my parents and them begging the doctors to keep me in hospital, I was discharged after one week because I was no longer “suicidal”.
- Surprisingly I managed to lose 4kgs during my stay in the psychiatric ward in RDH. My food intake was not monitored and it was easy for me to avoid eating all together.

Q: What were the main difficulties you faced when getting help?

- The cost of treatment was a lot.
- Private psychiatrists were expensive and private insurance did not fully cover my stay in a clinic down south.
- The lack of resources in the territory was very evident. Psychiatrists and psychologists trained in eating disorders were hard to come by and often fully booked due to the high prevalence of the illness.

All of the participants fully supported the idea of an Eating Disorder Specialty bed in Royal Darwin Hospital and mentioned that it would have been beneficial for them during their own recovery journey.