The Impact of Stigma on the Detection, Treatment and Management of Eating Disorders in Ireland

Final Research Grant Report

Prof. Fiona McNicholas (PI)
Dr. Niamh McNamara (CI)
Dr. Lesley O’Hara
Dr. Cliodhna O’Connor

Funded by Saint John of God Research Grants Scheme

Principal Investigator

Prof. Fiona McNicholas
Consultant Child and Adolescent Psychiatrist
Lucena Clinic
Rathgar
Tel: 01 4923596
Email: fiona.mcnicholas@sjog.ie

Copies of this report are available from Saint John of God Library Services.

Enquires about the research can be addressed to Prof. Fiona McNicholas (fiona.mcnicholas@sjog.ie) or Dr. Niamh McNamara (Niamh.McNamara@beds.ac.uk).

This report was initially submitted in November 2014 and revised in March 2015.

ACKNOWLEDGEMENTS

This research was made possible through a generous grant from the Saint John of God Research Grants Scheme. We are extremely grateful for the financial and administrative support provided by the Saint John of God Research Department.

We would like to acknowledge the support of the expert committee who advised the project: Dr Barbara Dooley (UCD), Dr Dasha Nichols (Great Ormond Street Hospital), Prof Walter Cullen (UL), Ms Jacinta Hastings (Bodywhys).

We would like to thank MidWest Radio, Siobhan Parker, Liz Barrett, Triona Byrne and Jacinta Hastings for helping to publicise the research and recruit participants.

Laura Currin and William Rhys Jones generously shared their research materials with us.

Two anonymous reviewers provided valuable comments on an initial version of this report.

Finally, we extend sincere thanks to all those who participated in the research, and to the schools and health professionals who helped us access potential participants.

TABLE OF CONTENTS

1. EXECUTIVE SUMMARY

Eating disorders (EDs) pose a considerable threat to the health and well-being of children and adults in Ireland. However, there is strong evidence that ED services are underutilised and that many young people struggling with disordered eating are not receiving appropriate professional support (Fursland & Watson, 2014). To reduce ED morbidity and mortality, there is an urgent need to identify the barriers that prevent people from engaging with ED services and develop appropriately targeted interventions. The stigma associated with mental illness in general, and EDs in particular, has been posited as a key barrier to effective help-seeking. However, our knowledge of the magnitude of this problem and how to de-stigmatise EDs through health promotion activities and professional education is limited. In Ireland, there are no available data illuminating how people experience living with or receiving treatment for an ED. Nor do we have reliable data on public and professional attitudes to EDs, and how these might influence an individual's willingness and ability to seek out effective support and treatment. There is an urgent need to address these gaps in knowledge, to facilitate the development of evidence-based strategies to increase self-presentation at primary care.

The over-arching aims of this mixed-methods research project were to (i) generate knowledge in relation to service provision, engagement and outcome for individuals with EDs in Ireland: (ii) assess the quality of health professionals' knowledge of ED treatment and diagnosis; and (iii) explore social attitudes to EDs and discern the extent to which stigma acts as a barrier to service provision and use. These objectives guided the development of three original studies: a multi-perspective qualitative analysis of the experiences of young people with EDs, their parents and health professionals; a nationwide survey of health professionals involved in primary and secondary care; and a nationwide survey of secondary school students. The results offer valuable insight into the quality of ED service provision in Ireland and the social factors that influence people with EDs' general wellbeing and willingness or ability to secure effective treatment.

1.1. KEY IMPLICATIONS OF RESULTS FOR DECISION MAKERS

This research project suggested three main issues that impact on the care of young people with EDs. Firstly, although a comprehensive care pathway for EDs was outlined in the 2006 publication of *A Vision for Change* (Department of Health & Children, 2006), this has not yet been fully implemented in practice. Secondly, the research identified important gaps in professional training. Thirdly, EDs are highly stigmatised conditions in Ireland, and these processes of stigmatisation and stereotyping can inhibit disclosure and help-seeking. The following section presents a number of recommendations for service development, professional training, and health promotion activities based on the results of the STEDI project.

1.1.1. Service development

a) Service provision for young people with EDs remains poor. We recommend the investment of the necessary supports, resources and training in order to implement the care pathway outlined in *A Vision for Change*.

b) A comprehensive protocol for diagnosing and treating EDs should be prepared and disseminated to clinicians across disciplines.

c) GPs require comprehensive training in mental healthcare and need reliable access to appropriate professional supports if the ED care pathway proposed in *A Vision for Change* is to be properly implemented.

d) Increased collaboration between statutory and voluntary services would prove fruitful, particularly in assisting with support needs of young people and parents.

e) Additional support services are needed for both young people and parents/families affected by EDs. For young people, a safe way to interact with others going through the same experience may be particularly helpful. Online platforms offer a viable means of securing such support, although research should be conducted to assess the effectiveness of such interventions.

f) EDs affect not only the individual, but also have a significant impact on their family. We recommend that this be acknowledged in ED care pathways (as it is in NICE guidelines) and that professionals make a concerted effort to include parents and siblings in the treatment plan and ensure that their support needs are also being met.

1.1.2. Professional training

a) We recommend that professional education programmes across disciplines include specific training on ED detection and treatment. This should include all ED subtypes.

b) Training programmes for professionals should not just focus on knowledge but also attitudes. Clinicians need to be aware of the stigmatising beliefs that impact on service quality, in addition to the detrimental effect stigma consciousness can have on service engagement.

1.1.3. Health promotion

a) *A Vision for Change* recommended the instigation of health campaigns promoting awareness of health eating and body image. While it is clear that the adolescents in our sample did exhibit body dissatisfaction, we remain unconvinced that campaigns that focus on healthy eating and body image will resolve the issue. In our interviews with young people currently in recovery, they reported that their eating problems were a reaction to life stressors rather than resulting from poor body image in itself or inadequate knowledge of healthy eating. We recommend that educational interventions focus on developing self-efficacy and positive coping strategies in young people.

b) A public awareness campaign, targeted at both young people and parents, is needed to increase levels of ED literacy. Such campaigns should also include information about how and where to seek help for eating concerns.

c) Public information campaigns should be developed with the aim of dispelling ED stereotypes in order to encourage disclosure and help-seeking on the part of those affected. Our data from Stages I, II and III suggest that the specific misconceptions that need to be addressed include the misperceptions that EDs are ‘female’ disorders, that EDs are self-inflicted and that the individual has a high level of control over their behaviour, that full recovery is unlikely, and that EDs are fundamentally about eating choices rather than underlying psychological, social and biological factors.

d) Some parents in Stage I reflected on difficulties encountered in discussing their child’s illness with schools. It may be helpful to provide schools nationwide with information on recognising the signs of EDs and how to support young people in their schools that have been diagnosed with an ED.

1.2. SUMMARY OF KEY RESULTS

Three studies were undertaken as part of this project: a multi-perspective qualitative analysis of the experiences of young people with EDs, their parents and health professionals; a nationwide survey of health professionals involved in primary and secondary care; and a nationwide survey of secondary school students. What follows summarises the key findings that emerged from each of these studies.

1.2.1. Stage I: Multi-perspective study of experiences with eating disorders

Interviews with eight young people living with an ED revealed that they viewed their ED as providing a solution to, or way of coping with, life stressors. They conceptualised their disorders as being caused by a combination of events, although they often focused on to a single pivotal causal event (which was typically social in nature). While disordered eating behaviours were reinforced in the short term by positive comments from others on their appearance, deeper psychological benefits (e.g. a sense of calm, feelings of order, stability and control) functioned to maintain the eating disorder over time. Living with an ED involved the implementation of a strict behavioural ‘code’ in relation to eating, which helped maintain a sense of order and control. Engaging with treatment involved dispensing with this structure and some participants felt they were left without ways of coping with life stressors. Young people tended to view EDs as chronic and were not optimistic about a full recovery. The disorder was characterised as something that would have to be managed throughout their life.

Parents reported a difficult transition in adapting to their new role as the carer of someone with an ED. Overwhelmingly, parents felt isolated and helpless in this role. Many reported both support and informational needs that they felt were unmet by services. Parents described EDs as exerting a significant impact on the wider family, and were concerned about siblings as well as the child directly affected by an ED. However, such issues were often perceived to be neglected in care pathways or treatment.

Both parents and health professionals were critical of the services available to young people. Parents felt that services were inadequate with unacceptable waiting times and insufficient levels of intervention. Clinicians criticised the lack of referral options available to them and reported that time constraints limited the amount of support they could offer to those under their care.

1.2.2. Stage II: Health professionals' survey

A nationwide survey of 171 health professionals revealed that on the whole, levels of knowledge of ED were moderately good, with clinicians correctly answering an average of 4.2 of 6 questions about the diagnosis and treatment of EDs. However, the survey revealed some specific gaps in knowledge: for example, less than half of participants knew the BMI parameters that would indicate the presence of Anorexia Nervosa (AN). In responding to a range of vignettes describing the symptoms of an illness, participants were significantly less likely to recognise the symptoms of EDs than depression and seemed vague in their knowledge of potential causes of EDs. The research also revealed a number of differences between the professional categories included in the survey. Statistical analysis showed that psychiatrists had significantly greater levels of knowledge about and professional confidence in the diagnosis and treatment of EDs.

There were some indications that health professionals stigmatise EDs to a greater extent than depression or T1 diabetes. The findings suggested that professionals would prefer working with those with depression over individuals with EDs. EDs were viewed as primarily affecting females, and as chronic disorders that were both controllable and curable. Psychiatrists were the professional group that held the most pessimistic views on the long-term prospects of individuals with EDs and reported highest belief in the controllability of the disorder.

Professionals were almost unanimous in their call for a standardised protocol for the treatment of EDs. They were highly critical of the quality of services in this area and of the difficulties associated with accessing them. While many seemed aware of support organisations (80%), the percentage of participants who reported referring patients to these services was considerably lower (63%).

1.2.3. Stage III: Young people's survey

A nationwide survey of 290 secondary school students found that rates of body satisfaction among the young people sampled were extremely low, with just 5% rating themselves as 'very satisfied'. Although boys reported higher levels of body satisfaction than girls in our sample, both genders placed equivalent importance on their appearance. Approximately one-third of the sample reported that they were concerned about their eating habits, but half of these young people had not disclosed their concerns to anyone, often due to stigma-related concerns. Young people did not have a good understanding of how to access support for eating problems. While most reported that they would prefer seeking help from a family member or friend if they developed eating concerns, many also reported that they would not know how to help a friend who approached them with their own concerns. Additionally, young people's ED literacy appeared to be quite low. Respondents were able to correctly identify the symptoms of depression more frequently than any of the EDs presented. This indicates that young people may have difficulties in detecting risk factors for EDs in themselves or the people around them.

The results confirm previous international findings that in the general population, EDs are stigmatised to a greater extent than other mental or physical health conditions. This is not necessarily something of which young people are consciously aware: when directly asked whether people with EDs face social marginalisation or disparaging attitudes, the sample responded equivocally. However, on a more implicit level our data revealed the presence of unfavourable attitudes to people with EDs. In conceptualising the causes of illnesses, Anorexia Nervosa (AN), Bulimia Nervosa (BN) and Binge Eating Disorder (BED) incurred more individual blame than either depression or T1 diabetes. While depression and T1 diabetes were largely seen as conditions beyond an individual's control, participants were more likely to see EDs as caused by factors internal to the individual, such as their personality or behavioural choices. Additionally, people with EDs were ascribed more negative and less positive personality traits than people suffering from depression and T1 diabetes. The data revealed a particularly unfavourable view of the personal character of people affected by BED. Participants' responses suggested that BED was conceptualised as a failure of self-discipline rather than a medical condition.

The remainder of this report outlines the background to this research project, details the three studies in full, and discusses their implications for our understanding of ED literacy, attitudes and services in Ireland. It provides a much-needed evidence-base to inform the design of targeted interventions to improve the psychological, social and physical welfare of the 200,000 people in Ireland living with EDs.

2. INTRODUCTION

Eating disorders (EDs) pose a considerable threat to the health and well-being of children and adults in Ireland. It is estimated that up to 200,000 people in Ireland are affected by eating disorders, with 400 new cases emerging each year (Department of Health & Children, 2006). EDs account for a particularly significant portion of the mental health morbidity of children and adolescents, accounting for approximately 12% of all admissions of people aged 18 and under to Irish psychiatric units (Health Research Board, 2013). However, there is strong evidence that ED services are underutilised and that many young people struggling with disordered eating are not receiving appropriate professional support (Fursland & Watson, 2014). To reduce ED morbidity and mortality, there is an urgent need to identify the barriers that prevent people from engaging with ED services and develop appropriately targeted interventions.

The stigma associated with mental illness in general, and EDs in particular, has been posited as a key barrier to effective help-seeking. However, our knowledge of the magnitude of this problem and how to de-stigmatise EDs through health promotion activities and professional education is limited. In Ireland, there are no available data illuminating how people experience living with or receiving treatment for an ED. Nor do we have reliable data on public and professional attitudes to EDs, and how these might influence an individual's willingness and ability to seek out effective support and treatment. There is an urgent need to address these gaps in knowledge, to facilitate the development of evidence-based strategies to increase self-presentation at primary care.

The over-arching aims of this mixed-methods research project were to (i) generate knowledge in relation to service provision, engagement and outcome for individuals with EDs in Ireland: (ii) assess the quality of health professionals' knowledge of ED treatment and diagnosis; and (iii) explore social attitudes to EDs and discern the extent to which stigma acts as a barrier to service provision and use. These objectives guided the development of three original studies: a multi-perspective qualitative analysis of the experiences of young people with EDs, their parents and health professionals; a nationwide survey of health professionals involved in primary and secondary care; and a nationwide survey of secondary school students. The results offer valuable insight into the quality of ED service provision in Ireland and the social factors that influence people with EDs' general wellbeing and willingness or ability to secure effective treatment.

2.1. ED SERVICE PROVISION IN IRELAND

The most recent expert review of ED service provision in Ireland was contained in the 2006 review of national mental health policy, *A Vision for Change* (Department of Health & Children, 2006). *A Vision for Change* characterised ED services in Ireland as "very poorly developed" (p. 76). The report identified a number of specific weaknesses, including:

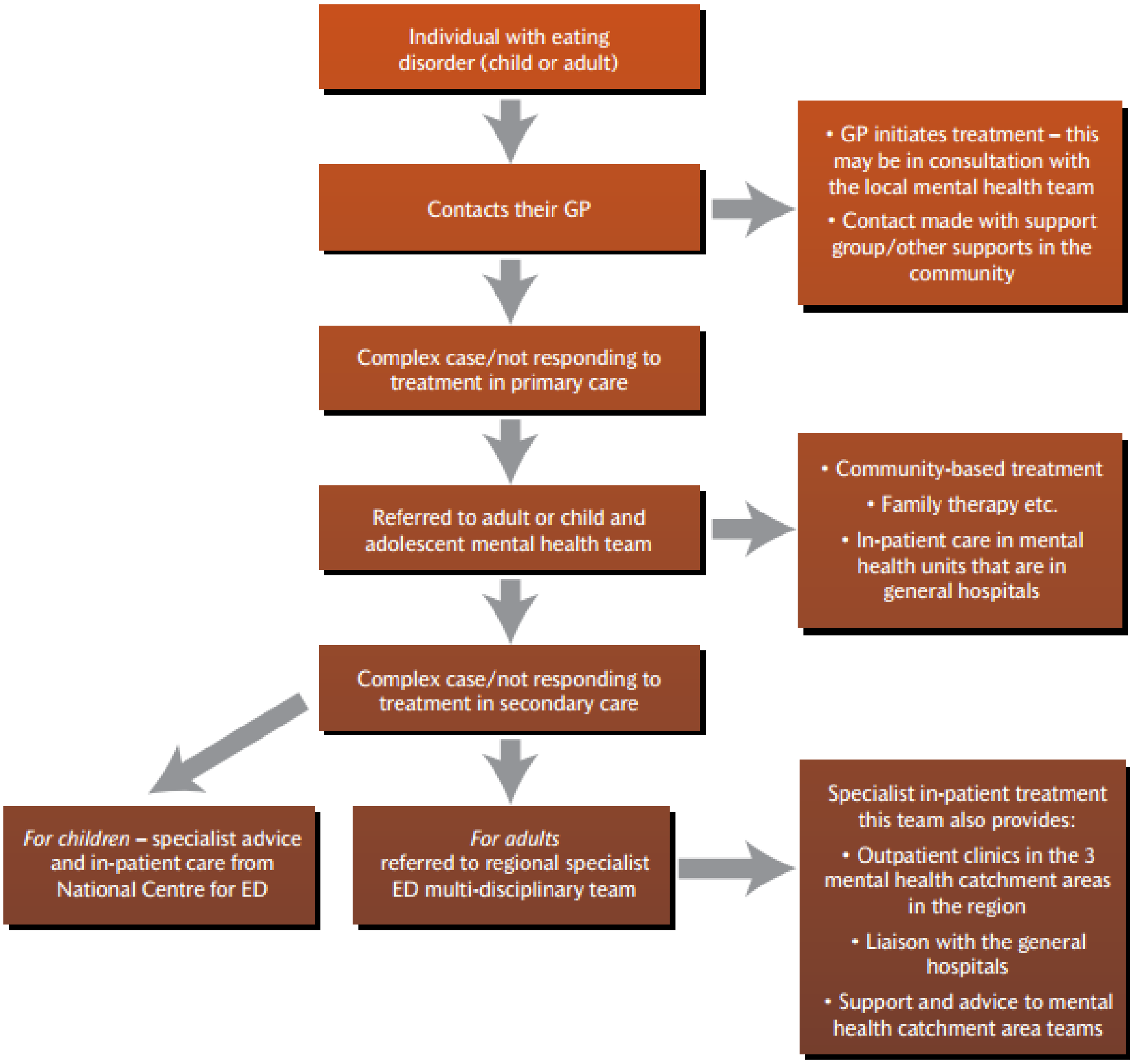
- An inadequate national stock of in-patient beds (3 in the public mental health system and 16 in the private sector);
- Little cohesion between child and adolescent mental health services and adult mental health services in relation to service provision, early identification and continuity of care;
- A need for greater public awareness of eating disorders at community and family level;
- Insufficient attention to EDs in medical education, leaving general practitioners and other health professionals ill-equipped to detect or treat the symptoms of EDs.

The Expert Group made a number of recommendations to improve ED service provision, including:

- For adults with EDs, the establishment of one specialist multidisciplinary CMHT per HSE region (a total of four nationally) and the availability of six beds in the regional acute in-patient unit;
- For children and adolescents, the management of most EDs within primary care and child and adolescent CMHTs, and the establishment of a national tertiary referral centre with a full multidisciplinary team for more complex cases;
- The prevention of the development of eating problems through health campaigns promoting awareness of healthy eating and body image;
- Support for the activities of voluntary agencies in promoting awareness and responses to eating disorders;
- The provision of specialist training in EDs in medical education programmes.

Figure 1 displays the care pathway that *A Vision for Change* envisioned for children and adults with EDs.

Figure 1. Envisioned care pathway for children and adults with EDs (Department of Health & Children, 2006, p. 153)



A Vision for Change was launched with a planned implementation period of 7-10 years, such that the recommendations it proposed should be actualised by 2013-2016. Unfortunately, the College of Psychiatry of Ireland's subsequent progress reports suggest that mental health service provision appears to be moving further away from, rather than closer to, compliance with the report's recommendations (College of Psychiatry of Ireland, 2010). For example, no progress has been achieved towards establishing a national tertiary referral centre or attaining the recommended 6-8 publically-available beds (College of Psychiatry of Ireland, 2012). Additionally, the clinical landscape has shifted considerably since *A Vision for Change*, particularly in relation to the establishment of a new ED diagnostic category. Binge Eating Disorder (BED) was officially included as a distinct category of ED in the 2013 publication of the DSM-V; previous to this it was subsumed into the category of Eating Disorder Not Otherwise Specified (EDNOS). As *A Vision for Change* looked solely at services available for Anorexia Nervosa (AN) and Bulimia Nervosa (BN), how BED is managed in contemporary mental health services remains unknown.

Data on how national ED policy translates into day-to-day clinical practice are sparse. The research described in this report provides insight into the actual implementation and delivery of ED services, from the perspective of both patients and professionals (Studies I and II).

2.2. SERVICE UNDERUTILISATION

In addition to the deficiencies of existing ED services, there is strong evidence that the services that are available are underutilised. Research indicates that substantial proportions - possibly even the majority - of people who meet the criteria for ED are not receiving any professional support (Fursland & Watson, 2014). Data collected by Bodywhys suggest that 50% of callers to its telephone helpline and 65% of users of its online support forum are not engaged in active treatment, despite suffering symptoms as severe as those seen in clinical populations (Bodywhys, 2013; Darcy & Dooley, 2007). These figures are likely an overly optimistic indication of the full extent of undertreatment of EDs in Ireland, since those who engage with Bodywhys' services represent only a minority of the population of people with disordered eating.

For EDs as for all mental illnesses, early intervention is critical to prevent disordered eating from becoming a chronic condition with serious personal, social and economic consequences. It is therefore essential to identify the barriers that prevent people from accessing services, so that they can be tackled with tailored interventions. Such barriers can stem from two places: the attitudes and practices that operate within the health services themselves, and the attitudes and beliefs that populate the wider communities in which potential service-users live.

2.2.1. Attitudes and awareness in the health services

As *A Vision for Change* acknowledges, early detection for EDs is challenging, because those affected often deny their illness or resist seeking treatment. As a result, first presentations often occur when people present with other medical conditions to GPs or Accident & Emergency units. This means that primary care practitioners have a crucial role in detecting cases of ED and initiating appropriate care pathways. However, *A Vision for Change* identified "strong evidence" that GPs and other health professionals are insufficiently equipped to do so effectively, due to a lack of education in the field of EDs (Department of Health & Children, 2006, p. 151).

Unfortunately, *A Vision for Change* did not specify the nature of the evidence that prompted their conclusion that general health professionals' knowledge of ED diagnosis and treatment is deficient. Currently, there are no available data indicating how informed Irish healthcare professionals are about the aetiology, symptoms and recommended treatment of EDs. Also absent is any evidence about healthcare professionals' attitudes to people with EDs, which may influence their clinical and interpersonal interactions with ED patients, and hence patients' engagement with health services. Acquiring this information is critical for evaluating the quality of ED support services in Ireland and developing targeted education/awareness initiatives for health professionals. This report presents the first evidence of this kind, acquired through a nationwide survey of healthcare professionals (Study II).

2.2.2.Attitudes and awareness in the community

Most mental health conditions involve some element of social stigma, and this stigma can be a critical barrier to seeking out and maintaining engagement with professional support (Booth et al., 2004; Byrne, 2000). The internalisation of stigma by those suffering from a mental illness fosters a sense of shame and reluctance to disclose one's condition, which impedes access to both clinical and social supports (Byrne, 2000). This issue is particularly pertinent to EDs, because research suggests that EDs are stigmatised to a greater extent than other mental or physical disorders. Relative to other mental and physical disorders, EDs are more likely to be seen as self-inflicted or as a manifestation of attention-seeking (Crisafulli, Van Holle, & Bulik, 2008; Crisp, 2005; Ebneter & Latner, 2013; Roehrig & McLean, 2010; Stewart, Keel, & Schiavo, 2006). Despite this, however, EDs have been relatively neglected in debates about mental illness stigma, which have tended to focus on depression and schizophrenia (Zwickert & Rieger, 2013).

Although several studies of ED stigma have been conducted internationally, as yet there are no data available in Ireland that illuminate the general population's attitudes to EDs or their knowledge about how to access support for disordered eating. Additionally, even internationally there has been very little research that has focused on the attitudes held by adolescents. This is a critical gap in the literature because, due to the early age of onset of most EDs, this cohort represents the most immediate source of social support or stigmatisation for young people struggling with disordered eating. Additionally, both nationally and internationally there is a striking dearth of evidence on how ED stigma is experienced by people with EDs themselves. Such evidence is crucial for tracing the processes by which cultural attitudes might compound the distress of those affected by EDs or inhibit them from pursuing effective treatment.

The attitudes to EDs that circulate in the general population, and their effects on the lives of people affected by EDs, are illuminated in this report through a nationwide survey of secondary school students (Study III) and a multi-perspective qualitative study of the experiences of young people with EDs, their parents and their healthcare professionals (Study I).

The remainder of this report will describe each study undertaken for this project in turn. The results of each study will be prefaced by an introduction that reviews previous relevant research, and superseded by a discussion of the study's implications for our understanding of services and public attitudes. The report will conclude with a general discussion of its key findings and recommendations for service development and future research.

3. STUDY I: MULTI-PERSPECTIVE STUDY OF EXPERIENCES OF EDS

3.1. INTRODUCTION

This research was set against the backdrop of the 2006 report *A Vision for Change,* which advocated that research should "involve people with experience of mental health difficulties at every stage of the research process" in order to deliver "ethical, progressive mental health research that will impact through policy, service and societal change on the lived experience of service users, carers, and the public" (Department of Health & Children, 2006, p. 213). Despite a growing prevalence of ED diagnoses, and a particular vulnerability to onset during adolescence (Hudson, Hiripi, Pope, & Kessler, 2007), very little is known about the lived experience of adolescents with EDs in Ireland. We sought to address this gap by recruiting a qualitative approach that would allow those affected by EDs (adolescents, their parents/carers, along with members of the healthcare team) to share the experiences relevant to them, along with their perspectives on service provision and the experience of ED-related stigma.

A review of the qualitative literature involving adolescents with EDs highlights a dearth of literature informed by young people who are currently experiencing EDs. For the most part, the existing qualitative literature involving young people as participants is compartmentalised by ED category (with a focus on AN), and/or by a specific ED-related theme (e.g. 'treatment' and 'recovery'). For example, in the field of law and psychiatry, issues around personal identity, autonomy and control have been examined in the context of 13-21 year old women with AN (Tan, Hope & Stewart, 2003; Hope, Tan, Stewart & McMillan, 2013; Tan, Hope, Stewart & Fitzpatrick, 2003). In each of these cases, the authors considered the findings from a legal perspective in terms of the ethical delievery of care and issues around capacity and consent.

In their review of the qualitative literature into AN, Bezance and Holliday (2013) identified a total of eleven relevant studies, all of which fall under the themes of treatment and recovery. For the most part, qualitative research into adolescents with EDs is conducted from the perspective of care-givers. Svensson, Nilsson, Levi and Carbelleira (2013) highlight the hardship and strain endured by parents of children with EDs while also pointing to the need for increased information and support. Informed by parents of children with AN, Thompson, Marriott, Telford, Law, McLaughlin and Sayal (2012) explored parents' experience of recognising that their child had an eating-disorder and how they set about seeking help. Their findings illuminate parents' attempts to normalise the early signs of AN, resulting in delayed help-seeking, and their ultimate efforts to obtain professional help for their child. Consistent with Svensson et al. (2013), the Thompson et al. (2012) research highlights parents' need for information and support.

The stress endured by mothers of children with AN was further highlighted by Bezance and Holliday (2014) in their investigation of a home treatment programme, while King and Turner (2000) have examined the experience of caring for adolescent females with AN from the perspective of nurses, highlighting the need for greater education and on-going support to ensure that these young people receive understanding care.

Research into the *holistic* experience of those living with EDs is notably absent from the literature. The research which does offer a more holistic account (i.e. not compartmentalised by themes of ‘treatment’, ‘recovery’ etc.) is informed by a life-history approach (Patching & Lawler, 2008) in which accounts of living with an eating disorder are obtained from those now recovered. While these retrospective accounts do provide valuable insight into these people’s experience, it could be argued that personal recollections may have altered over time. What is obtained by these accounts may be considered a reflection on experience rather than an active and ‘real-time’ representation of living with an eating disorder.

In summary, the existing qualitative literature into adolescents with EDs is concentrated in the area of AN, and is for the most part, concerned by issues relating to treatment and recovery. The existing literature highlights the strain experienced by parents and carers and the support needs of this group. What the literature fails to do is give any insight into the lived experiences of adolescents affected by EDs. With this in mind, the aim of this stage of the project was to describe the lived experiences of dealing with an eating disorder, as informed by young people with EDs, their parents/carers and members of their healthcare team. The interviews furnish a revealing insight into how these people experience encounters with services, connections with other similar individuals, family relationships and experiences of stigma.

3.2. METHOD

3.2.1.Design

This stage of the research utilised a case-study approach. The purpose of the case study method is to build an in-depth understanding of a particular phenomenon and its context. This method relies on multiple sources of evidence. Specifically, this study drew data from clinical case notes and interviews with service users, their carers, and the professionals involved in their care. Initially, we proposed to conduct both within-case and cross-case analyses. However, due to recruitment challenges (discussed further below) we did not gather complete cases for all participants, with interviews with healthcare professionals particularly infrequent. As such, our analytic approach had to be adapted accordingly. Rather than conducting within-case analysis, we offer a cross-case analysis with a focus on the accounts of young people with EDs and their families.

3.2.2.Participants

3.2.2.1. Recruitment

Our original recruitment strategy was to approach GPs in each HSE area and ask them to identify any patient aged between 15 and 25 attending for ED treatment, and invite them to participate in the study. Ten GPs in each HSE area were randomly selected and contacted via telephone. GPs who were willing to take part received documentation relating to the study, including an information sheet and consent forms (one for young person and one for their parent/carer), which they were asked to provide to suitable patients. Young people interested in participating were asked to contact the researcher directly. While many GPs agreed to take part, the response from patients remained low. There are a number of possible reasons for this, including that GPs forgot to pass on the information, that the GP could not identify eligible young people, or lack of interest amongst young people themselves. Although we broadened our sample of GPs, contacting 144 in total, response rates remained poor.

To address these challenges, we adapted our recruitment strategy by (i) also approaching psychiatrists, psychologists and counsellors and (ii) publically advertising the research via press releases, radio interviews and eating disorder support websites. This successfully increased response rates and, as demonstrated in Appendix A, most of the recruitment to the study resulted from these efforts.

3.2.2.2. Demographic composition

Participants' demographic details are displayed in Appendix A, along with details about participants' clinical histories, which were gleaned from a review of the case notes that could be accessed.

In total, eight young people were recruited to the study. Six were female and two male. Their diagnoses included AN and BN. One participant had originally been diagnosed with and received inpatient treatment for AN, but was subsequently diagnosed with BN. BED was not represented in our sample. At the time of interviews, participants had held their diagnosis for an average of was 9.87 months (range 3-14 months). It should be noted, however, that duration of diagnosis is not synonymous with duration of illness: all of our participants reported engaging in ED behaviours and having ED thoughts for a prolonged period of time (ranging from 1 to 6 years before diagnosis). The majority of participants (*n*=5) received treatment via CAMHS. One participant received only private treatment, while two had experiences of both private treatment and CAMHS.

Parents of seven of the participants also participated (five mothers alone; one father alone; and both parents of one participant). Three health professionals took part: the GP and psychologist of a 16 year-old boy with AN, and the GP of 16 year-old girl with AN.

A synopsis of each young person's case is included in Appendix A.

3.2.3. Interview procedure

Data were collected via one-to-one semi-structured interviews with the young person; their parent/carer; and their health professional (where applicable). This approach to data collection was selected because it allows the research to go 'beneath the surface of ordinary conversation' (Charmaz, 2006, p. 26) and draw-out topics which otherwise remain silenced. We designed the interviews to provide participants with the opportunity to discuss their 'ED-story'. In keeping with the principles of Grounded Theory, we kept the interview questions broad and open-ended. We allowed participant's accounts to direct the flow of the interviews. However, in order to ensure the interview produced 'in-depth' data, the research often 'probed' particular statements by asking 'can you tell me more about that?' or 'how did you feel about that', in order to "encourage reflection and introspection about particular issues, events, and experiences" (Oliffe & Mróz, 2005).

Participants were given the opportunity to view the interview schedule prior to the interview. At the beginning of the interview, participants were reminded that they were free to decline to answer anything they wished. As we were interested in their lived experience of ED, participants were given the opportunity to talk about what was relevant to them, even if this did not come under the remit of the interview schedule. Following the interview, audio files were transcribed verbatim and irrevocably anonymised.

3.2.4. Analysis

Interview data were analysed using a Grounded Theory (GT) approach. GT was originally developed by sociologists Glaser and Strauss (1967) as a method of building theory from data in their studies of dying patients in hospitals. Charmaz's (1990, 2006) version of GT, used here, is informed by a social constructionist approach. Her use of the term "social constructionist" relates to a focus on: "(1) Ill people's creation of taken-for-granted interactions, emotions, definitions, ideas, and knowledge about illness and about self and (2) Researchers' sociological instructions which they develop, in turn, by studying chronically ill people's constructions" (Charmaz, 1990, p. 1161). This use of GT ultimately functions to "provide physicians with alternative understandings of patients' beliefs and actions than those readily available in clinical settings" (Charmaz, 1990, p. 1161).

Our goal for this stage of the research was to offer a holistic account of living with an eating disorder, as informed by adolescents with EDs, their parents/carers and members of their healthcare team. As such, we wanted the research to be led by the participants rather than by a predetermined hypothesis based on previous findings in the literature. The GT methodology facilitates the pursuit of such participant-led research (Charmaz, 2006). It recommends that one starts with a broad and general research question which gradually narrows around the findings of the analysis. It further recommends that the researcher delays the literature review in order to limit the interference of findings from previous research in the area. The closeness to the data, achieved by the coding procedures of the GT method, means that the resultant analysis is firmly grounded in the participants' accounts, and our researcher's interpretation of these accounts.

Analysis of the data began with coding. Coding can be viewed as a means of decomposing the data into analytic 'chunks'. The subsequent grouping of similar codes into categories is the first step in piecing the analytic story together. In practice, the researcher coded the data *line-by-line;* assigning codes to each line or incident in the data. By coding the entire interview-transcripts in this way, we accumulated a list of codes which represented the threads by which an unstructured account of living with an eating disorder could be pulled together. We set about examining the similarities and differences between codes, and grouped codes together based on their likeness (clustering). As clusters were developed, we examined their properties and the relationship between their codes before proceeding to group similar clusters together to make concepts, which were ultimately grouped together to produce the categories constructed through this iterative process.

3.3. RESULTS

The results presented here follow a GT analysis of the data. Firstly, we present the findings of our exploration of the *lived experience* of those dealing with EDs, namely young people and their parents. We then proceed by discussing the perspectives of young people and their parents with regards to their experience of mental health services and access to treatment. We then move on to consider the perspectives of the health professionals who participated in this study, before considering the issue of stigma and how it is manifested in our data. Finally, we offer an overview of the services available to a selection of our participants, as detailed in their CAMHS case notes.

3.3.1.Lived experience of young people

Analysis of interviews conducted with young people allows for an understanding of the lived experience of adolescents affected by EDs. Key to this understanding is the young person's construction of an 'acceptable self' and the central role of 'moral code' in the process of eating disorder entrenchment and recovery. Three categories were constructed following analysis of the data: *The disordered solution*; *Entrenching morality;* and *Realigning morality*.

3.3.1.1. The disordered solution

Participants in the study consistently referred to their initial engagement in eating disordered behaviour as a solution to a life stressor. While all participants commented that a combination of events may have contributed to the causation of their ED, many were inclined to pinpoint a pivotal event which initiated ED behaviours. Such events included remarks about their physical appearance, or a growing awareness that they were bigger in size when compared to their friends.

> *Well because when I, two years ago I was very big for my age so I was and one day at school one of the children called me fat so they did and I took, I took that to heart so I did.* (P3 'Daniel')

For others, comparisons with peers served to fuel a negative perception of oneself as being insignificant.

> *I felt like I was really getting any attention or I didn't know, like who I was, I didn't really, I was kind of like acting differently and I was like trying to like stand out because I didn't think I was very good at much. And I thought that maybe if like, if I lost weight then people would notice me and that.* (P1 – 'Clara')

Engagement in ED behaviours was perceived as a solution to weight-related teasing, and to a personal appraisal of being insignificant. As we will see in the next section, engagement in these initial ED behaviours yielded positive results for the young person. As a result these behaviours quickly became reinforced and contributed to the development of an 'acceptable self'.

3.3.1.2. Entrenching morality

Issues of identity and morality are key to understanding a young person's experience of life with an eating disorder and their construction of an acceptable self. In this section we will see that what begins with engagement in ED behaviours progresses through to the entrenchment of a moral identity (being 'good' at ED) by consistent reinforcement of ED behaviours.

Reinforcing ED behaviour. The efficacy of ED behaviours as a solution to life's stressors is represented in, and positively reinforced by, physical weight loss and psychological gain. When participants received positive comments about their weight loss from friends and family, the success of their ED behaviour became increasingly apparent to them. Weight loss was framed by others as a positive achievement and their congratulatory remarks served to promote further engagement in ED behaviours.

> *At twelve people like started saying things and like "oh my God you're so thin, you look so great" because I was like overweight as a child anyway like even in photos and stuff so it was kind of, that was like good in my head that turned to like a plus* (P6 – 'Brian')

For others, weight loss resulting from their ED behaviours served to 'get them noticed'. Their engagement in these behaviours, and the resulting weight-loss, removed them from a position of perceived invisibility.

> *I think she [mother] was saying like once oh you know you have to start eating more and I was like, I think I was kind of like oh yeah, yeah I will and then next day would just be the same. And like when she said it, like kind of made me feel like good because I thought oh good people are noticing. And then I kind of even like really wanted to cut out more then, because I thought oh people notice now, they might notice if I cut out less, more food.* (P4 – 'Kelly')

While positive comments regarding weight-loss, and the attention garnered by this weight-loss, reinforced ED behaviours during the period of initial onset, it was the psychological benefits of ED which served to reinforce and sustain engagement in ED behaviours over time.

> *for me I think it wasn't just coping, like it was coping, but it was also something that gave me confidence, and something that like a drug like it just gives you many different things that keep you up all day, and you know give you your pep or give you your like confidence. And like especially with anxiety like it would have calmed my anxiety. And like it made me feel at ease when I wanted to be relaxed, and also made me feel like really high and really energetic when I want to, and have confidence when I want to. And it's like, you know, like a lot of people say, like doctors and stuff like "oh you know it ruins you on the inside" and all this thing, and it does, but it also like the truth for me anyway was, it made me, or it helped me go out and do things with my friends, and it helped me wear the clothes I wanted to wear, and you know have energy when I needed it* (P6 – 'Brian')

Our participants referred to the sense of calm and feelings of control their ED gave them over their lives. For some, this sense of control was especially relevant if their family circumstances were unstable (i.e. following breakdown of parents' marriage). In these cases, their ED allowed them a sense of stability and control in what was otherwise a volatile environment.

As engagement in ED behaviours become reinforced, participants began to express a sense of agency and reviewed the results of the behaviours they have engaged in as a personal success.

> *Like just say if I'm annoyed about something, I'd say ok I'm not eating this or I'm not going to eat my dinner tonight or I'm not going to eat this snack or something. Then after that and I don't eat it and then I feel like ok good, I did something, like I achieved something.* (P1 – 'Clara')

It is this sense of agency and personal achievement which leads to a progression from engaging in ED behaviours to *being* 'someone with an ED'. These behaviours are no longer occurring in isolation. Rather, they are becoming a part of the young person's standard behavioural repertoire because of their intrinsic personal reward.

Building a moral identity and abiding by a moral code. Borne out of the sense of agency our participants express, is a growing *moral* identity. Participants identify themselves as being 'good' at ED behaviours. They have become experts at living a life with ED. Accompanying and informing this identity is the formation of a 'moral code' by which the ED life should be lived. This code determines what food choices are 'good' and which are 'bad'. Eating outside of these strict guidelines was described by our participants in terms of 'slip-ups' or 'failings'. As such, participants made moral judgments about their behaviour in relation to the moral code of ED. When ‘slip-ups’ happened, the young person felt obliged to make amends by engaging in compensatory behaviour.

> *like if you felt like you’d eaten a meal that was unhealthy or big or anything in it that you didn’t feel comfortable eating, you’d kind of be like ok tomorrow I’m not going to eat this or I’m not going to eat this because of what you’ve just eaten then. And then the next day you’d need to stick to what you said. I can remember one day I ate something and after I got really angry and I was like ok tomorrow I’m not going to eat a lunch and I’m not going to eat a snack after dinner and all this. And the next day at lunch time came around and I was starving and my mum was like you have to have lunch now and I was like oh no I’m not hungry and she was like, I was saying I’m not hungry but like I was hungry, I was just saying that because I told myself the day before like you need to stick to it. You can’t like change a plan and say oh its fine, I’ll eat today, you need to do what you said or else you’ll just feel really bad and guilty.* (P5 – ‘Michelle’)

As the moral code of ED becomes more entrenched in the young person’s identity, their individual agency and ability to control their own behaviour wanes. Instead, they become governed by their ED code and compelled to comply with ED practice.

> *I don’t know, it’s like you just can’t eat, you can’t bring yourself to eat because it doesn’t feel right, it’s, it feels like you don’t deserve the food and then you do eat, I don’t know if you’ve heard this before but you get like all the voices and they’re kind of like shouting at you for eating and it’s, it’s really horrible…. the voices are just shouting ‘why did you eat it, don’t eat it, you don’t need food’ just over and over again to the point of like I would feel physically sick when sitting down to eat something because I just couldn’t bring myself to do it.* (P7 – ‘Edel’)

Here we see a lack of agency and power over their eating disorder. They have gone from a position of feeling ‘in control’ to feeling ‘under control’ of their ED.

Up to this point, the progression of the eating disorder had been marked by feelings of personal control. The realisation that this control had been taken away and an awareness that their engagement in ED behaviour is compelled rather than voluntary was, for many of our participants, the indicator of a greater problem.

> *I realised that like I couldn’t make myself eat more and like I was losing a lot of weight and then I realised then that there was a problem.* (P8 – ‘Debbie’)

3.3.1.3. Realigning morality

It is the intertwining of the moral ED code with personal identity which poses the greatest challenge to the treatment of EDs. Cessation of engagement in ED behaviours does not equate to the abandonment of the ED moral code. Rather, as our participants entered treatment for their ED they commented that they were required to turn their back on the order they have lived by and adopt a new approach.

> *I've learnt to kinda deal with food. Like even though I'd want to be sick after eating something I've kinda learnt to just go okay like it's not gonna do you any good, just gonna make things worse and you're not going to put on weight straight away especially if you eat something healthy like it's just…like it's okay like you have to eat. So that's helped me deal with things because it's been a few times when I've gone – ah I want to get sick. But I've managed to stop myself, not all the time* (P2 – 'Laura)

However, rather than experience a lifestyle free of restriction, for many of our participants treatment imposes its own routine which requires 'strict care' over oneself (as described below). The focus of treatment, as described by our participants, is to break the link between ED thoughts and ED behaviour.

> *You know have, keep strict care on yourself because any sort of, if you get a chance, any chances at all, you take it in this condition that I'm in, because I've been through it on the road to recovery. Like only the smallest chance I got I was straight upstairs and then I had a relapse.*
>
> *Q Yeah.*
>
> *A The smallest little chance, that's all it takes*
>
> *(lines omitted)*
>
> *They (parents) can only help so much but they can't really help the thoughts that go through your head, the feelings and everything, it's just, it's such strong feelings, such strong urges to do these things. To me it feels like someone gets a feeling to eat, I get a feeling to get sick.*
>
> *Q Yeah.*
>
> *A It's about the same.*
>
> *Q So what's natural for me to eat, being sick is what's natural for you.*
>
> *A Yeah.*
>
> *Q Yeah.*
>
> *A And it's been very hard to try and resist but within time it does turn around, it does go your way.* (P3 –'Daniel')

Treatment requires that the moral code of ED be ignored and a new and healthy concept of what is 'good' and 'bad' be developed. In our participants' accounts this new conceptualisation of what is healthy is observed in a shift in the moral language they use. When considering recovery, ‘a slip-up’ refers to one-off engagement in an ED behaviour (for example, purging). In this case, the ED behaviour is positioned as ‘bad’. While presenting their accounts of being entrenched in their ED, ‘slip-ups’, ‘mishaps’ and ‘mistakes’ were aligned to eating and as such ‘healthy’ (in the normative sense) was labelled as ‘bad’.

Despite this new moral code, recovery from an eating disorder did not sit easily with young people who have experienced so many intrinsic benefits as a result of their ED. Without the ability to engage in ED behaviours, these young people no longer had the tools to deal with life’s stressors. For some, life without ED made more apparent the challenges that the ED was helping them ignore.

> *I feel like I’ve taken off, this is like the simple man’s explanation, but I think this will make sense – like I’ve taken off a plaster, a band aid, and the eating disorder, or my eating disorder was the band aid, but now all of the stuff, the cuts or the wounds, bruises, underneath it, are still there.* (P6 – ‘Brian’)

Indeed, it may be the case that confronting the underlying issues that ED has helped to cover up, may deter some young people from engaging in treatment. This will be discussed later in relation to young people’s perspectives of treatment and services.

In terms of recovery, one would expect that healing these ‘cuts’ and ‘wounds’ is the goal of treatment. However, our participants described a state of ‘recovery’ as being free of a preoccupation with food and the fear of engaging in ED behaviour. All bar one of our participants described recovery as something situated in the future, as something they are striving towards but could not give any certainty that they will reach. Many conceded that they feel they will live with the remnants of the ED code for the rest of their lives. While they may be in recovery at some point, there is always the possibility that they will relapse.

> *But then again I still think that even though I’m recovered, later down the line I reckon sometimes I’ll still get them thoughts and still them same feelings but I have the experience, I can get through it.* (P3 – ‘Daniel’)

One participant presented a more active notion of recovery. This participant (who experienced extensive therapeutic intervention at a private ED clinic before moving to CAMHS where he meets with a psychologist on a fortnightly basis) described being actively in recovery each day. His account points to his engagement in his own recovery. He expressed personal agency and pride at this success in recovery. He is forgiving of himself and does not allow a ‘mishap’ to determine where he is on his journey.

> *I do try to remind myself like maybe once a day, or when I'm having my food, or when I wake up "every day I'm in recovery – today I'm in recovery". Like no matter what happens today, whether things go brilliantly and I'm on a high all day, or whether things go really badly and something happened, I'm in recovery, so those things like don't affect recovery today*
>
> *Q Ok. And what does recovery mean?*
>
> *Ahm, getting better, improving, ahm, making a lot of mistakes, ahm, throwing perfection out the window! Just like almost the opposite of being sick during an eating disorder. Like everything changes, like everything gets a lot brighter, and like just having like feelings, which sounds so strange, but like when you're, like when I was suffering really badly with my eating disorder, and when I was very depressed, and had a lot of anxiety, I didn't even know like what I was feeling, but I just wasn't really feeling anything* (P6 – 'Brian')

We would suggest that the personal agency expressed in this account of recovery serves to foster a new acceptable sense of self, in which feelings of accomplishment and worthiness are borne out of his engagement in 'recovery' as opposed to his abidance to an ED moral code.

3.3.2.Lived experience of parents

Our analysis of the lived experience of parents of young people with EDs depicts their journey from the build-up to the initial diagnosis and through the treatment process. We highlight how many parents progress from an initial phase of attempted normalisation (in which they explain their child's behaviours as typical of their age), to their role of carer. The acceptance of their role as carer is expedited by an event which illuminates the severity of their child's condition to them. All parents then proceed with haste to seek out the best possible treatment for him/her. It is at this point the treatment process and path to recovery can begin, and the parent must adapt to their new role as carer for a child with an eating disorder.

3.3.2.1. Normalising

Consistently, parents spoke about the gradual build-up to their child's diagnosis as they attempted to normalise the indicators of EDs and reduce their significance.

> *So, em, she lost weight and at first I thought, you know, kind of, this is, well, this is kind of, going from a child to a woman. She wants to train her body, then she went running and well, she wants to shape, you know. And then em, it was loss of weight over time, more and more but first not really noticeable. She got slimmer, yes, you know, a lot of people do.* (P8 'Debbie's' Dad)

As demonstrated in the extract from one father (above), the initial tendency of parents is to rationalise weight loss as a natural development in their child's life. For this father, weight loss comes with maturation, as does a desire to discipline one's body. His daughter gradually becoming slimmer was not something to raise alarm bells as 'a lot of people do' and so there was no reason to look upon this weight loss as problematic.

For others, their child's behaviour regarding food fitted into their concept of a 'healthy home'. When compared with their own eating habits and the health-related behaviours of their other children, they felt there was nothing to worry.

> *So I've been like that so I just thought yeah she's like me, she's fine, you don't really worry as your kids get older because you think, you know they're growing into teenagers and they naturally change and my son was going through a big fitness thing with the gym and protein and all this with the lads now. So it was kind of a healthy house.* (P1 'Clara's' Mum)

Here, the mother's own identification with her daughter's eating habits serves to temporarily alleviate any concern she may have about her daughter's weight loss. She considers the likeness between herself and her daughter, and the fact that she herself is healthy allows her to dismiss any concern. Again, natural growth and the progression from childhood to adolescence serve to explain changing physical shape while suggesting that these changing behaviours are a temporary ('going through') rather than permanent feature of her child's life. The familial focus on what is 'healthy' allows for these behaviours to 'fit' and pass without problematization.

3.3.2.2. Becoming a carer

The progression from normalising their child's changing condition to accepting the presence of an ED happened in one of two ways for the parents in this study. For some, it was the visual reality of their child's dramatically changing body shape:

> *You know, the first time I saw her looking like that was, she was upstairs in the bathroom and she was trying on a bikini and she came out and I was like oh my god, because you don't see them.*
>
> *Q Of course.*
>
> *And everyday she's in her uniform and its like a bulky big thing and you just see bones everywhere and hair growing on the back and hip bones and all this kind of stuff, you know it just was like oh my god.* (P5 'Michelle's Mum)

For mothers in this situation, being faced with the visual representation of an eating disorder came as a shock. Their efforts to normalise their child's behaviour served to buffer parents from the reality of their child's condition. 'Seeing is believing', and when confronted with this reality parents were quick to accept the 'abnormality' of the situation and puruse medical intervention with haste.

For other parents, having been made aware by their child of their issues around food they originally adopted a ‘softer’ approach to treatment, in the hopes that the issue may be quickly resolved without any intervention or simply by some counselling sessions. This could be likened to the buffer effect of normalising: parents resist the potential seriousness of the situation and in so doing protect themselves from the reality of their child’s condition.

> *And at that time I thought okay she’s told me, I spoke to her, em…everything will be fine, that’s what I thought. And every now and again I'd say to her are you okay? And then I didn’t know whether to talk about it, not talk about it, mention it to her, bring it up. So I left it then, so to me she was fine. She was cured. And about six months later, about six months later it was em…she said mam I'm after been sick again. And my whole world fell apart* (P2 ‘Laura’s’ Mum)

Here, her daugher’s disclosure that she had been purging but was going to stop, served to bring her illness to her mother’s attention whilst also lessening the seriousness of the situation for ther mother. Indeed, her reassuring words served to help her mother believe that ‘everything was fine’. While other parents strove to *normalise* their child’s behaviour in the build-up to diagnosis, it could be argued that this mother clung to her daughter’s reassuring words in order to protect the normality of their lives. Learning that her daughter was still engaging in ED behaviours shattered this perception of their normal life and her ‘whole world fell apart’.

Irrespective of how parents became aware of their child’s eating disorder, once the seriousness of the illness became apparent to them an immediate pursuit of care was initiated.

> *it was one particular session with the counsellor, she (the counsellor) rang me after the session and she said to me em, she’s slipping away, we have to catch her quick. And this was for me an alarm call, you know and em, first of all I contacted my GP to make, you know, blood samples. And I contacted my em, therapy friend again to get another contact quick, something good* (P8 ‘Debbie’s’ Dad)

In the extract above, a father of a 16 year old girl with AN describes how he learned of the seriousness of his child’s condition. His daughter had spoken with him about her issues concerning food and her desire for counselling. He organised for her to see a counsellor privately in the hopes that this would fix the problem. However, her condition continued to deteriorate and a phonecall from the counsellor *(she’s slipping away, we have to catch her quick’)* began an urgent journey for intervention *(‘something quick’)*. At this point, the father pursues multiple options of help including GP and recommended therapists.

As is discussed later in relation to parents' perspectives on services and treatment, once intervention begins, the parent is required to orchestrate care and feels solely responsible for the provision of care outside of the clinic. However, they often express feeling unqualified to take on this role and unsupported in their efforts.

3.3.3.Perspectives on services and treatment

Of the young people who participated in this study, five received CAMHS intervention only. One participant received private treatment only (in the form of inpatient care) and at the time of interview, reported being unaware that there was publically available treatment for people with EDs in Ireland. The remaining two participants had experience of both CAMHS and private care. Of these two, one boy with AN sought private care until it became financially impossible to sustain and his GP referred him to CAMHS. The family of the other young person who had experienced both services were unhappy with the length of time it took to be seen in CAMHS, and with the old and unwelcoming appearance of the CAMHS clinic. They chose to pursue private treatment even though travel to the private clinic required a six-hour roundtrip and placed a significant demand on the limited resources this family had.

3.3.3.1. Young people's perspectives on treatment and services

Generally, young people who received CAMHS care were happy with the services they received. However, some did express feeling passive recipients of care. They reported that their clinician's assumed that they wanted to get better without asking for their thoughts on recovery:

> *What about when you meet CAMHS, do they ever talk to you about if it's something that you want to recover from?*
>
> *Not really, they just take it as like I want to get better, they don't really ask me. So when they say like oh you've lost weight this week or you've gained weight this week, they don't really say like, you know they don't like ask me like do you actually want this.* (P1 – 'Clara')

This participant goes on to highlight the implications for the efficacy of treatment when recovery is not necessarily her goal.

> *It would work if like, it's not really CAMHS or it's not the doctors that are making this not work, it's me, so. You know sometimes she [Mum] like wants to blame like, the services or there's no help out there for them like, there is help and help will work if you actually use the help. So sometimes I'm like, maybe I'm just wasting it all like, going here and maybe I should just get proper help when I think I will use the help.* (P1 – 'Clara')

This raises issues around the ethics of treating someone who does not want to be treated. We would suggest that this links with our earlier discussion of the acceptable identity afforded to the young person by their ED. In this case, recovery from ED poses a significant threat to her sense of self and also threatens to take away ‘the one thing’ she feels she is good at. It is important that clinicians attend to what recovery represents to these young people and provide therapeutic intervention that will work towards fostering a valued identity in the young person.

In terms of improvement to services, every young person who took part in the study advised that the services would be improved by the provision of support groups.

> *Ok and if you could change something or if you could recommend that they would improve it in any way, what recommendation would you make?*
>
> *A Support groups.*
>
> *Q Really, yeah.*
>
> *A That’s the main one.*
>
> *Q Yeah every young person I chat to says the same thing, yeah, why would you like a support group?*
>
> *A Well because it’s someone who I can talk to who is going through what I’m going through, they understand. Like the doctors that I talk to, they know, they’ve studied it but they don’t really know what I’m going through, they only have an idea.*
>
> *Q Yeah.*
>
> *A But if I talk to someone who is going through what I’m going through it would help me a lot.*
>
> *Q Yeah.*
>
> *A Or if I talked to someone who has recovered from this, will help so much, you know because then I know that these people know exactly what I’m going through and they have ways to help me.* (P3 – ‘Daniel’)

As is the case with both mental and physical illness, the presence of a condition which sets one apart from their peers can result in feelings of isolation and loss. It is unsurprising, then, that the young people in this study expressed a desire to be part of a support group along with other young people with EDs, or with people who have recovered from ED. Participation in such a group would allow them to feel ‘understood’ and to participate in a supportive discussion with others who have a genuine understanding of their situation. Such discussion can also offer some encouragement in terms of recovery. By speaking with people who have recovered from an ED, recovery may be transformed from a lofty concept to something which is realistically attainable.

3.3.3.2. Parents' perspectives on treatment and services

While young people who participated in the study were generally happy with the services available to them, their parents were not. Overwhelmingly, parents describe feeling alone and unsupported in their role of carer to their child. Their accounts depict feelings of hopelessness and frustration as they struggle to give their child the care they require, while at the same time caring for their rest of their family.

> *I mean it affects everybody in so far as that, like I would have gotten more stressed, kind of over, especially the first few months it was very stressful (upset), like it was really stressful, you know to see her like just going to sleep with hunger, do you know like she'd be, like lying in the bed and she was just tiny and its just like, just feels so like nobody will help her, really do, you know. And when its just you, just you know and then, so you'd be very upset for a while and then, I suppose the other kids you just don't have as much time* (P1 'Clara's' Mum)

All of the parents spoke about feeling stressed and under pressure to care for the child with ED while at the same time trying maintaining a 'normal' household for the rest of their family. For many parents, their own well-being suffered and their attempts to find the help and support they needed were unsuccessful.

> *So since he was discharged (following 6 weeks of inpatient treatment) how has the care been since then?*
>
> *It's not, there is no care, there's no outlet or outreach that we could go, like I tried myself to try and get somewhere, there is nowhere. I asked my GP can you put me, because I really thought I was losing my mind, I wasn't sleeping, because I was watching him the whole time. I said can you put me in some kind of a counselling session or, he sent me to a stress management clinic, I said I don't want to go to, I don't need a stress management clinic, I need someone to talk to that understands EDs which my son has got. And I said it has affected all of us. But there is nowhere, there is no help.* (P3'Daniel's' Mum)

We would suggest that parents feel forced into a position they are unqualified for. They require reassurance from health professionals that they are 'doing it right'. In order to be able to maintain a healthy family life, which meets the treatment demands of their child with ED and is inclusive of the rest of their family, parents must be supported and their needs must be assessed and provided for.

3.3.3.3. Health Professionals' perspectives on treatment and services

While only a small number of health professionals took part in the study, their insights allow for some important recommendations in terms of treatment and service delivery.

GPs spoke about a lack of referral options available to them, and the length of time it took for their referrals to be followed up by CAMHS:

> *I would prefer if I had better and more, better resource to referral options. Eh and better structures, shall we say, for the different age tiers that we encounter. 'Cos in reality they, they're not there, eh, and what services we have there are stressed. So some respects they're on paper only, where you might look for prompt intervention, what you might achieve is someone going on a waiting list. Which is, less than ideal, you know, it's, it's a resource issue, you know. But resource and perhaps, also a sufficiency of expertise in the field, you know. For us as GP's, I wouldn't regard myself as any, having any particular expertise in eating disorder, other than to recognise it. And perhaps offer some form of support, that's something I would refer very early on in the cycle, as a GP.* (P8 'Debbie's' GP)

Both parents and GPs alike spoke with frustration of the length of time taken for a referral to CAMHS to lead to an initial appointment. Some parents explained that their child's condition deteriorated so much during this time that their GP referred them for hospital intervention as emergency cases. Others advised that their GP had recommended they seek private care if they could afford it.

One GP suggested a referral process whereby eating disorder cases could be prioritised by need.

> *I suppose from our point of view like the more Service, you know, the quicker access to Service the better. I don't know is there any way of streamlining it, that you know if we pick up, even if you say like in the U.K. they have some kind of a system, where you can rate the severity of an individual, and then based on that be able to submit that and say "of the ten points, my patient meets nine of them at the moment" that that could be taken into account. I suppose they probably get millions of referrals about EDs, so it is just trying to, if we could calibrate where our patient is on the list, so if there was something like that available, or that could be drawn up, that would be helpful for us, and then we could submit that, and then you know they would be able to fast-track that person if needs be.* (P6 'Brian's' GP)

For the one CAMHS representative who participated (a psychologist), resourses were identified as the greatest obstacle to treating and caring for young people with EDs. She explained:

> *We would seek to ensure they are seen as quickly as possible, but we can never guarantee they'll be seen within two weeks, because for example last year we were two registrars down, we only had a consultant, so we had no registrars, no senior, and then no psychologist for three months so obviously our service was compromised.* (P6 'Brian's' Psychologist)

3.3.4.Perspectives on stigma

Discussions of stigma did not come up organically in our interviews, and rather were purposefully raised by the researcher. Young people expressed an awareness of stigma relating to mental health and EDs, but they did not express personal feelings of stigmatization. This may be due to increasing societal awareness of mental illness:

> *I think like an eating disorder is just the same as like cancer, you know whatever, any type of physical illness, but there is also like a stigma with it. Like I think recently like people have gotten so much better like understanding mental illness and stuff, but like when I was like ten and like trying to purge for the first time, that wasn't there, like it's with a lot of things like, like society now, I think like people are starting to change and understand* (P6 - 'Brian')

While discussion of stigma related to EDs did not come up explicitly in young people's elements of their accounts are consistent with efforts to *manage stigma* (Goffman, 1963) and thereby protect oneself form the threat of a stigmatizing identity. Specifically, young people's concern about disclosing their diagnosis to their friends, and indeed their efforts to keep their diagnosis hidden, are consistent with what Goffman (1963) refers to as 'passing' and 'covering'.

> *I'm always afraid that if someone finds out that they'll think I'm looking for attention.* (P5 – 'Michelle')

Here, fear of disclosing about her diagnosis of bulimia is due to a concern of being labelled an 'attention-seeker'. By viewing EDs as a means to get attention, an ED is reduced in severity to an elective condition – one which you may choose as a means of getting attention. This perception not only serves to limit the severity of the condition, it also discredits the young person with the eating disorder.

For others, the seriousness of an initial disclosure was reduced by 'covering', which Goffman (1963) refers to as an attempt to 'keep the stigma from looming large' (p.125).

> *Q. And so you were fourteen, when did somebody notice? Or when did you start to have to look for help?*
>
> *A: I told my mam a few months, and then because I think I was just afraid and I knew it wasn't right what I was doing. But I was just afraid and I told her, I said like I'm fine I'm going to be okay I'll stop now and she was like right, I said no I'm fine I'll stop but she was like okay she put it to the back of her mind. And then a few months later, maybe a few weeks I started again and then another few months passed, like I got sick again but I was fine, like I've stopped now, kind of put it to the back of my mind again. She kicks herself over doing it now.* (P2 – 'Laura')

Here an initial disclosure to her mother is 'covered' by the reassurance that 'I'm fine, I'm going to be okay, I'll stop now'. Indeed such a reassurance was welcomed by her mother who clung to her daughter's reassurance that these ED behaviours were temporary and did not represent a significant problem. This effort to conceal the perceived stigma of an eating disorder, had the effect of delaying help-seeking.

The implications of perceived stigma in terms of help-seeking were also considered in the unique account of one female participant with BN, who had previously received private in-patient treatment for AN.

> *You know I was very ashamed because I thought like, you know I went into hospital like with such control, I was so afraid of people seeing me again like, you know with this no control.*
>
> *(lines omitted)*
>
> *Q. Have you ever encountered stigma because of it or negative response from anyone?*
>
> *A Not really, like I think it's, it's probably more of what I think myself, like I kind of always, I suppose you know it was said to me at one stage like did I want to do another period in hospital or like did I want to do some day care and I kind of said no because if I go back and people see me now, like you know I think once, yeah I suppose there is a lot of stigma around like, you know when I was in hospital and somebody came in, who wasn't like emaciated or whatever, like I remember like other girls would say like oh she must be bulimic. And that was kind of a big like you know I always kind of associated then heavier people with having bulimia if they came in, so yeah.*
>
> *Q Yeah.*
>
> *A So there was a big stigma of like weight attached to certain disorders when it isn't true really, whatsoever like.*
>
> *Q. Yeah but that's an insider stigma in a way, something rather than experiencing it from somebody who doesn't have an eating disorder, its.*
>
> *A Yeah, no it is, yeah I don't, like I don't think anybody, somebody who doesn't have an eating disorder wouldn't, probably wouldn't see that but that probably is an insider's kind of a thing.* (P4 – 'Kelly')

In this case, feelings of shame and a stigmatized identity are situated within the world of EDs. This participant judges herself against the ED hierarchy which confirms superiority on AN (due to its qualities of control and will-power) while BN is lacking in these valued qualities and thus represents a more shameful ED (and therefore a more shameful identity). The implication in terms of help-seeking is that this young woman, who currently engages in episodes of binging and purging, will not seek help due as she is fearful of positioning herself in an ED arena where she will be judged upon her decline in ED status.

3.4. INTERIM DISCUSSION

In this section we have presented the findings of our qualitative exploration into the lived experience of adolescents with EDs, along with the experiences and perspectives of their parents and members of their healthcare teams.

Concerning the experience of adolescents with EDs, our analysis highlights the process by which adolescents construct an acceptable self through engagement with eating disordered behaviour. Initial engagement in ED behaviours poses a solution to a life stressor and the success of these behaviours in alleviating such stressors serves to quickly reinfoce the behaviour. Feelings of achievement, agency, and personal success emanating from ED behaviours contribute to the development of a moral identity as being either 'good' or 'bad' at ED. The self-worth of our young participants became bound to their success at ED behaviours. A moral code of ED (against which young people assess their worth) becomes entrenched in the young person's psychological repetoire and dictates their behaviour. At this point, personal agency is lost. The task of treatment is to realign this morality and these beliefs of what is 'good' and what is 'bad'. The challenge is that their very identity and sense of self is so strongly informed by their moral code that treatment poses a threat to their sense of who they are.

For parents of adolescents with EDs, our analysis points to a parent's progression to the role of carer. Parents progress from periods of 'normalisation', in which they try to explain their child's condition as 'typical' of their age. By normalising, parents termporarily protect themselves and their famillies from the 'abnormality' of an eating disorder. When the seriousness of the eating disorder is eventually accepted, an immediate call to action is initiated and the parent is propelled into position of carer as they hurriedly strive to have their child's health needs met. Rather than adjusting to this role, parents are forced into it and often feel ill-equipped and unsupported in dealing with the complex needs of their child.

Overwhelmingly, discussions of treatment and services, point to the need for support. This is consistent for young people, parents, and health care professionals. Young people need to feel understood and believe that this could be facilitated through support groups with others who live with EDs or with those who have recovered from EDs. Parents expressed feeling alone, unsupported, and unqualified to meet the needs of their child. Parents need support, through workshops, positive/constructive feedback from clinicians, and through reassurance that they are taking the right steps to assist their child to recovery. Healthcare providers also require support. GPs and CAMHS clinicians battle with a system crippled by limited resources. GPs face a situation where they feel they lack the expertise to provide anything more than referral and support to an ED patient. They need increased referral options, a new system of referral, and improved training.

Finally, discussions around stigma did not come up organically during the interviews with young people. When asked directly about stigma, young people showed an awareness of how people with eating disorders may be stigmatized or discriminated against, however they did not share any personal experience of such stigma. The lack of naturally occurring discussion around stigma may suggest that it was not of particular concern to young people, or at least not of as great a concern as the many other issues borne out of their eating disorder (e.g. loss of control). Nonetheless, references to stigma were *implicitly* present in the accounts of young people. Concerns about potential prejudice and discrimination were evidenced and young people engaged in strategies to help protect themselves from a stigmatized identity. By 'passing' and 'covering' through a reluctance or refusal to disclose their ED diagnosis to others, these young people kept a stigmatized part of themselves private. This has very serious implications in terms of help-seeking, as many of our participants were reluctant to talk their parents about their problem. Some participants secretly engaged in ED behaviours for between one to six years before help was sought or a diagnosis obtained.

3.4.1. Study strengths & limitations

Sampling for this study proved challenging and the ultimate sample size was lower than would be desired. It is difficult to assess the extent to which the findings are specific to the lives of these eight young people, rather than representative of the broader experience of EDs. However, generalisation is typically not the aim of a qualitative approach, which tends to prioritise analytic depth over breadth. In the academic literature on EDs, there is a dearth of research exploring how EDs are understood and experienced from the perspective of those directly affected by them. Filling this gap is an empirical and ethical imperative, in order to ensure that the delivery of ED services is sensitive to the everyday realities of the individuals at which they are directed. The limited number of people who partook in this research allowed the analysis to delve deep into the nuances of their social, emotional and behavioural repertoires. This produced a rich and contextualised account of living with an ED, which can inform and complement future quantitative research.

4. STUDY II: HEALTH PROFESSIONALS' SURVEY

4.1. INTRODUCTION

A Vision for Change, the expert review of national mental health policy commissioned by the Department of Health & Children in 2006, characterised service provision for people with eating disorders as very poorly developed. With only three specialist beds available for the treatment of eating disorders on the public health system, the skills of staff in GP surgeries, accident and emergency units and community mental health teams are a critical resource in identifying and treating EDs. However, the Expert Group strongly suggested that GPs and other health professionals are insufficiently equipped to manage cases of ED (Department of Health & Children, 2006). Problems with professional knowledge and beliefs regarding EDs are potentially significant barriers to effective service provision and engagement for individuals with these disorders (Currin, Waller & Schmidt, 2009).

As yet, no data are available indicating how informed Irish healthcare professionals are about the aetiology, symptoms and recommended treatment of EDs. However, a number of studies in other jurisdictions confirm that internationally, levels of professional knowledge about EDs are highly variable. Linville, Brown and O'Neil's (2012) study of medical providers in the US (including general practitioners, nurse practitioners and paediatricians) found that 59% felt that they were not adequately skilled to treat EDs. Similarly, a study of British psychiatrists reported that only 25% were satisfied with the level of training they had received in EDs (Jones, Saeidi & Morgan, 2012). Jones et al. (2012) identified several notable gaps in psychiatrists' clinical knowledge: for example, less than half of respondents recognised amenorrhoea as a diagnostic criterion for AN, while 35% falsely believed that NICE guidelines recommended SSRIs for the treatment of AN. A survey of 3,783 British GPs found that the majority did not use the recommended BMI criterion to guide referral decisions, while only one-quarter ensured that every patient presenting with an ED was provided with information about their illness (Currin et al., 2006). Further, evidence suggests that health professionals and services are more oriented to AN than BN or BED, even though the latter conditions are 2-4 times more prevalent (Royal College of Psychiatrists, 2012).

These shortcomings in clinical knowledge may have undesirable effects on clinicians' likelihood of detecting cases of ED or selecting appropriate treatment paths. For instance, Currin et al. (2009) found that clinicians with lower ED knowledge were less likely to offer patients with ED symptoms follow-up appointments. Ascertaining the quality of Irish health professionals' knowledge about EDs is therefore critical to ensure effective service provision and engagement.

Clinical knowledge is not the only important variable in determining the quality of ED service provision; also significant are health professionals' attitudes and beliefs about individuals with EDs. There is evidence that ED services are underutilised in Ireland (Darcy & Dooley, 2007), and a major barrier to help-seeking is the social stigma that surrounds EDs (Booth et al., 2004; Hackler, Vogel, & Wade, 2010). Studies conducted in the US and the UK suggest that people with EDs are viewed negatively by the public (Crisp, 2005; Stewart, Schiavo, Herzog, & Franko, 2008). In particular, relative to other mental and physical illnesses, EDs are more often seen as self-inflicted or as a manifestation of attention-seeking (Crisafulli et al., 2008; Crisp, 2005; Ebneter & Latner, 2013; Roehrig & McLean, 2010; Stewart et al., 2006). This results in people distancing themselves from individuals with EDs (Crisp, 2005; Stewart et al., 2008; Zwickert & Rieger, 2013), which can foster a sense of isolation among those affected and a reluctance to disclose their illness.

While most stigma research has focused on attitudes held by community samples, health professionals are not immune to these negative cultural representations of mental illness. Indeed, some data suggest that medical professionals may hold *more* negative views about mental illness than the general population: a study by Jorm et al. (1999) found that Australian clinicians were more pessimistic about the prospects of recovery from mental illness than the lay public. A small amount of research has focused specifically on medical professionals' attitudes towards ED patients, and has shown that the prejudice evident among the general public also occurs within professional groups (Thompson-Brenner, Satir, Franko, & Herzog, 2012). For instance, Byrne (2000) found that health professionals viewed individuals with AN as less likeable than other patient groups. A perception that ED patients have personal control over their disorder, which is linked to a sense of blame, is also evident within clinician populations (Currin et al., 2009). Moreover, some medical experts may attribute EDs to defects of personality or character, such as vanity (Crisafulli et al., 2008). Such beliefs can have tangible consequences for treatment decisions. For example, Currin et al. (2009) found that clinicians who were pessimistic about the prospects of recovery from BN were more likely to refer a patient onwards. Additionally, qualitative research with patient groups indicates that individuals with ED are acutely sensitive to disparaging attitudes, which can either be internalised or construed as a deterrent to service engagement (Easter, 2012). Stigmatising attitudes held by healthcare providers may therefore undermine the experience, extent and quality of the care available to individuals with EDs.

Health professionals' beliefs about EDs may also have implications for collaboration and communication within health services. Different professional categories undergo different training programmes and operate under different professional goals and conditions, which may cultivate discipline-specific beliefs about the nature and cause of EDs. Such discrepancies between clinical professions might pose difficulties for effective multidisciplinary initatives (Dryer et al., 2013). Some evidence suggests that psychiatrists hold less stigmatising attitudes than professionals who do not specialise in mental health, and that psychiatrists' beliefs become less stigmatising with greater clinical experience (Jones et al., 2012). However, Dryer et al.'s (2013) survey of a range of professional groups in Australia (GPs, psychiatrists, social workers, psychologists, mental health nurses, dieticians) found few differences in their beliefs about the causality of BN. Given these conflicting findings from other jurisdictions, and the lack of evidence from within Ireland, it remains unclear whether Irish health professionals hold systematically different representations of EDs, or the potential implications of this for clinical practice.

With these issues in mind, we undertook a national survey of health professionals in Ireland with a view to gaining an understanding of their attitudes towards individuals with EDs, and their level of ED knowledge. The study sought to identify elements of health professionals' attitudes and beliefs that might serve as barriers to the effective detection, treatment or management of EDs in Ireland.

4.2. METHOD

4.2.1. Design

A survey was constructed and uploaded to an online survey platform (SurveyMonkey).

4.2.2. Participants

4.2.2.1. Recruitment

The contact details of a purposive sample of 1,916 health professionals were obtained through national representative bodies (Irish Medical Directory; consultant lists for CAMHS and AMHS; Heads of Psychology Services Ireland; Irish Association for Counselling and Psychotherapy; and the Irish Nutrition & Dietetic Institute). Details about the survey were circulated to all of these professionals. Follow-up emails were sent to those who had not responded within several weeks. In total, 171 health professionals accessed the online version of the survey, representing a response rate of 9%.

4.2.2.2. Demographic characteristics

171 health professionals participated in the study. Of those who stated their gender, 72% (*n*=109) were female. Participants ranged in age from 28 to 73, with a mean age of 48.5 (*SD*=9.4). Respondents were recruited from across the country, with 60% (*n*=74) based in Leinster, 24% (*n*=29) in Munster, 11% (*n*=13) in Connacht and 1% (*n*=2) in Ulster. In a free-response item querying the respondent's race/ethnicity, 95% (*n*=141) described themselves as either 'white' or 'Irish'.

4.2.2.3. Professional characteristics

Counsellors/therapists were the professional group most prominently represented in the sample (40%, *n*=60), followed by psychiatrists (20%, *n*=30), GPs (15%, *n*=23) and psychologists (14%, *n*=21). 16 respondents did not fall into any of these categories (e.g., dieticians, social workers) and were classified as 'other'. The full breakdown of professional groups is displayed in Figure 2.

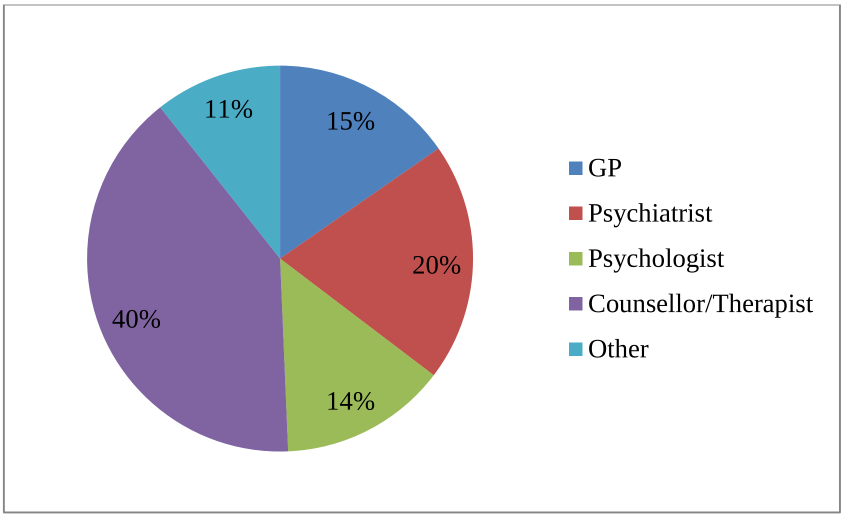


Figure 2. Professional groups represented in sample

Participants had an average of 15.8 years of clinical experience (*SD* = 9.2). 37% (*n*=56) worked in the public sector, 29% (*n*=43) in the private sector, and 34% (*n*=51) in both. 27% (*n*=40) focused exclusively on children and adolescents in their clinical practice.

4.2.3.Survey design

The survey is presented in Appendix D. After viewing an information page and indicating consent, participants were asked a number of questions about their demographic and professional characteristics.

In accordance with previous research (Mond & Hay, 2008; Roehrig & McClean, 2010; Stewart et al., 2006, 2008), participants were randomly assigned to view one of five vignettes depicting a young person ('Morgan') who had presented to their GP with symptoms consistent with the presence of: Anorexia Nervosa (AN), Bulimia Nervosa (BN), Binge Eating Disorder (BED), Depression or Type 1 Diabetes. The subsequent questions assessed participants' responses to the vignette on a number of measures:

- In line with previous research (e.g. Mond & Hay, 2008), respondents were first presented with free-response boxes and asked to indicate what they believed Morgan's 'main problem' was and 'the steps they would typically take in order to diagnose Morgan's problem'.
- Participants were then administered an adapted 12-item version of the Illness Perceptions Questionnaire (Moss-Morris, Weinman, Petrie, Horne, Cameron & Buick, 2002). This instrument comprised three 4-item subscales assessing beliefs about (i) the likely timeline of an illness, (ii) the amount of personal control the individual has over the illness, and (iii) the efficacy of treatment for the illness.
- Participants were asked to describe in their own words what they believed had caused Morgan's problem.
- Participants were asked to provide a projection of Morgan's long-term life outcomes on 8 dimensions (e.g. mental health, relationships, employment). On each dimension, they indicated

whether if Morgan received appropriate help, he/she would fare equivalent to, better than or worse than other people in the community.

- Respondents were asked to rate their agreement with three statements exploring health professionals' feelings about interacting with a patient like Morgan.

After indicating their responses to the vignette, all participants were administered a 6-item measure of their knowledge about ED diagnosis and treatment. They were then asked a number of questions about their professional experience with EDs, their confidence in treating and diagnosing EDs, their personal experience with EDs, and their perceptions of existing services and voluntary organisations.

4.2.4.Analysis

All data were imported into SPSS for statistical analysis. On continuous variables, analyses of variance with post hoc pairwise comparisons were used to identify differences related to vignettes and professional categories. Normality was assessed with normal Q-Q plots and homogeneity of variance was evaluated using Levene's tests. When these assumptions were violated, Kruskal-Wallis H tests were used instead of ANOVAs. On categorical variables, chi square tests were used. Open-ended responses were analysed using content analysis. In the statistical analyses reported below, all missing cases were excluded pairwise, and all proportion figures were derived from the subset of the sample who responded to that item.

4.3. RESULTS

Means and standard deviations for all variables are presented in Appendix C.

4.3.1.Experience with EDs

4.3.1.1. Professional experience of EDs

Though only 29% (*n*=26) of respondents worked within a service that provided specialist treatment for people with EDs, the vast majority (94%, *n*=85) of respondents reported that they had previously treated an individual with an ED. Figure 3 details the mean number of 15-18 year olds with EDs that participants reported having treated in the previous 12 months, broken down by professional category. Overall, in the previous year participants had assessed or treated an average of 3.65 15-18 year olds presenting with an ED.

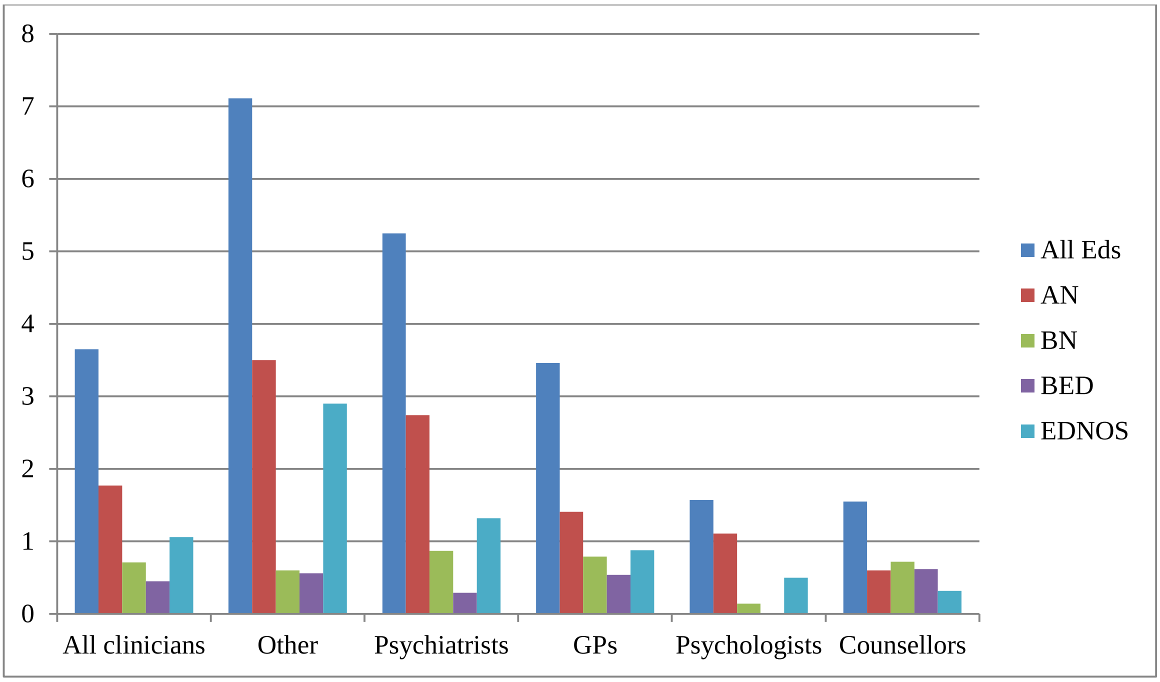


Figure 3. Mean number of 15-18 year old patients with EDs in previous 12 months

Respondents reported that they had an average of 2.36 (*SD*=4.1) 15-18 year olds with EDs currently in active treatment, of whom 86% were female.

4.3.1.2. Personal experience of EDs

88% (*n*=79) of participants reported that they knew someone with an ED. This person was usually described as an acquaintance (47%, *n*=42), a work colleague (26%, *n*=23) or a close friend (23%, *n*=21). 19% (*n*=17) of those who responded to this question reported that a member of their extended family had been affected, and 17% (*n*=15) had an immediate family member who had been affected by an ED. No participant reported that they themselves had been diagnosed with an ED.

4.3.2.Knowledge & clinical practice

4.3.2.1. Diagnosis of problem in vignette

After reading the vignette, participants were asked to specify what they believed Morgan's main problem to be. Figure 4 displays the percentage of responses that correctly categorised the symptoms described in the relevant vignette. Statistical analysis showed that the different vignettes produced significantly different rates of correct classifications, χ^2 (4, *N*=127) = 20.17, *p*<.001, *V*=.4. Using the conventional standardised residual of >2 as the criterion of significance, depression was significantly more likely to be correctly diagnosed, relative to the other conditions. AN and BED vignettes showed significantly lower rates of accurate diagnosis. There were no significant differences between the various professional disciplines' likelihood of offering a correct classification for the three ED vignettes, χ^2 (4, *N*=72) = 8.59, *p*=.07, *V*=.35. It should be noted that when respondents failed to specify the correct illness label in their free responses, this did not necessarily indicate an incorrect diagnosis;

often, their responses simply expressed a reluctance to make any diagnosis on the basis of the limited information available.

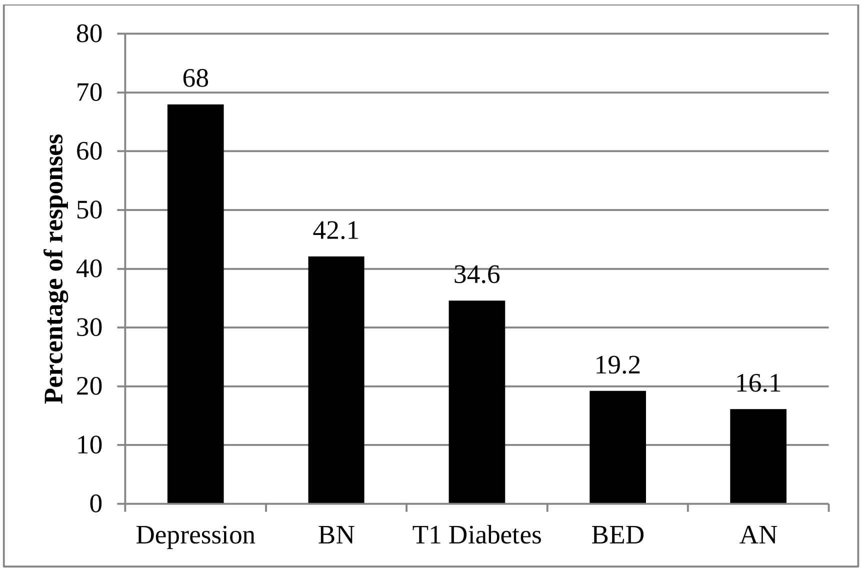


Figure 4. Percentage of respondents who correctly diagnosed each vignette

Looking solely at responses to the three ED vignettes, statistical analysis did not detect any significant differences in the various professional categories' likelihood of offering a correct diagnosis.

4.3.2.2. Steps to diagnose problem in vignette

After viewing the vignettes, respondents were asked to give details of the steps they would take to diagnose Morgan's problem. Figure 5 codifies the responses to this question, presenting the proportion of responses that proposed (i) a mental health assessment, (ii) a physiological assessment, (iii) onward referral and (iv) consideration of collateral reports.

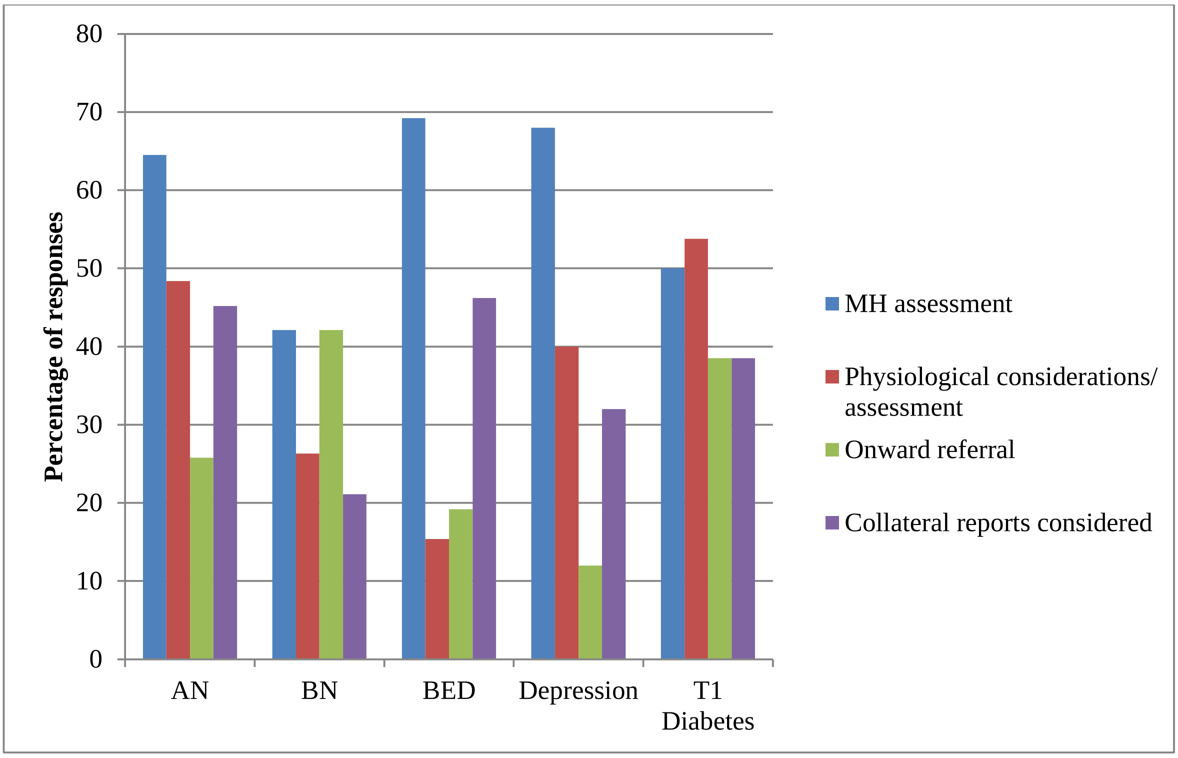


Figure 5. Steps to diagnose problem

Looking solely at the data from the three ED vignettes, statistical analysis showed that the various professional categories differed in their likelihood of initiating the different diagnostic steps. GPs and ‘other’ health professionals were more likely to refer the patient onward than the other professional groups (χ^2 [4, *N*=72] = 18.75, *p*=.001, *V*=.51). Counsellors were less likely than psychiatrists to mention physiological assessments (χ^2 [4, *N*=72] = 32.17, *p*<.001, *V*=.67). Psychiatrists were most likely to recommend collateral reports (χ^2 [4, *N*=72] = 21.67, *p*<.001, *V*=.55). GPs were less likely to undertake a mental health assessment than psychiatrists or psychologists (χ^2 [4, *N*=72] = 10.05, *p* =.004, *V*=.37).

4.3.2.3. Cause of problem in vignette

After indicating how they would handle the diagnosis of Morgan’s problem, respondents were also invited to offer their thoughts on what had caused that problem. Figure 6 demonstrates the prevalence of the various causal factors that were mentioned in this free response question. Though the data do not meet the criteria for nonparametric analysis, descriptive results show that environmental causes were the most frequent explanations offered for all ED vignettes, with genetic explanations rare. The data show that the cases of AN and BED elicited different patterns of causal attribution: while AN was associated with issues regarding body image or sexual development, BED was conceptualised as arising from emotional factors such as anxiety, depression, self-esteem or difficulty with emotional regulation. The data also indicate a particularly high level of expressed uncertainty about the cause of BN.

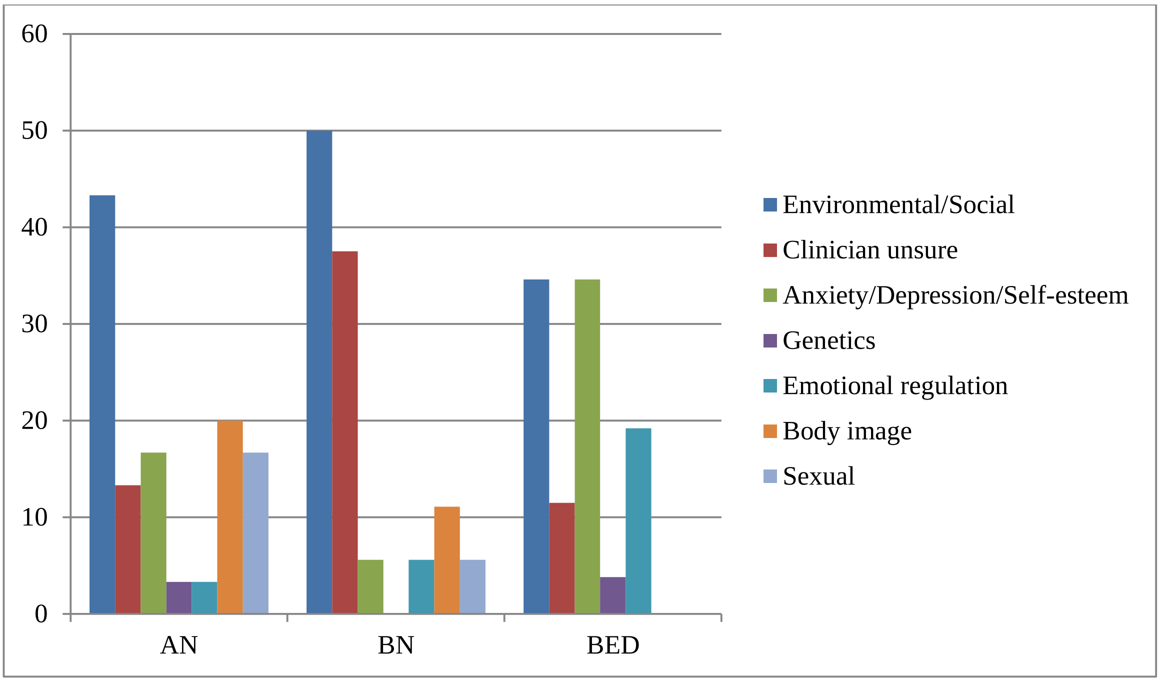


Figure 6. Perceived causality of the ED vignette problems

4.3.2.4. ED knowledge

Respondents were administered six multiple choice questions assessing their knowledge about the detection and treatment of EDs. Figure 7 displays the mean number of correct responses achieved by participants from the various professional categories. A one-way ANOVA showed that total levels of knowledge varied significantly across professional groups, *F* (4,82) = 9.18, *p*<.001, $\eta^2 = .31$. Post hoc pairwise comparisons revealed that psychiatrists recorded significantly higher levels of knowledge than all the other professional groups. The knowledge scores of the other professional groups did not significantly differ from each other.

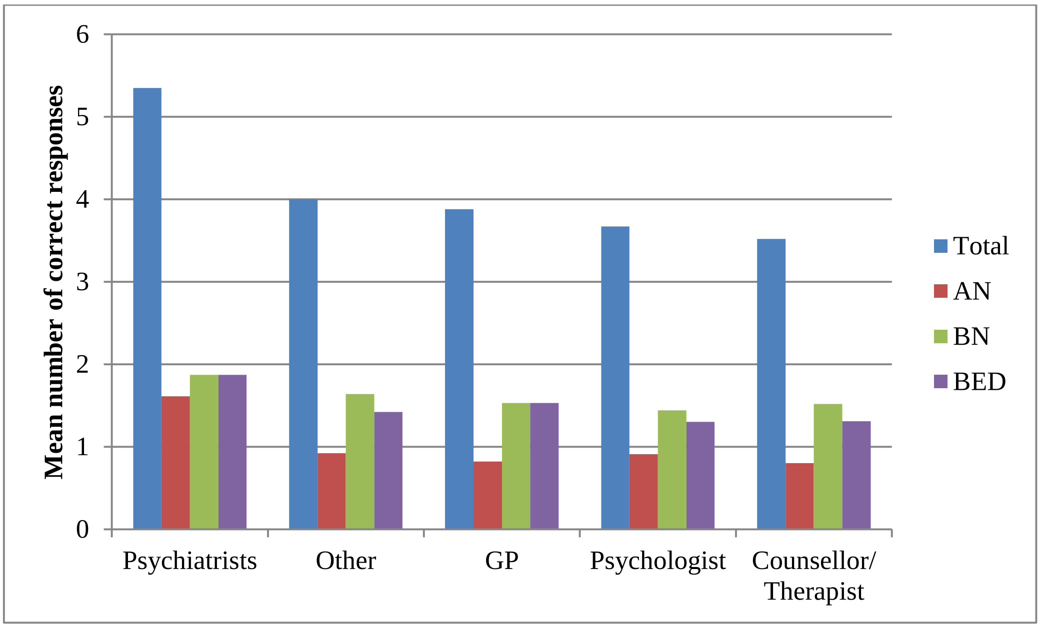


Figure 7. Levels of knowledge about detection and treatment of EDs

The less accurate responses to the AN questions relative to the BN and BED items may be due to the very specific nature of the AN diagnosis question, which asked respondents to choose from three figures the BMI parameters that would indicate the presence of AN. This question produced a much lower level of correct responses (48.4%) than the questions regarding the diagnostic criteria for BN (68.5%) and BED (76.8%).

4.3.2.5. Confidence in ED diagnosis and treatment

Consistent with psychiatrists' greater knowledge scores, psychiatrists also reported greatest confidence in diagnosing and treating EDs, $F(4,85) = 8.99$, $p<.001$, $\eta^2 =.3$. Post hoc pairwise comparisons showed that psychiatrists' mean confidence levels (*M*=4.02, *SD*=0.7) were significantly greater than those of GPs (*M*=3.03, *SD*=0.8), counsellors (*M*=3.33, *SD*=0.88) and 'other' professions (*M*=2.46, *SD*=0.81), but were not significantly different from those of psychologists (*M*=3.6, *SD*=0.74).

4.3.3.Attitudes and stigma

4.3.3.1. Illness perceptions questionnaire

Respondents were asked to indicate their attitudes towards the illness described in the vignette using an adapted 12-item version of the IPQ. This instrument comprised three subscales assessing beliefs about the likely timeline of an illness, the amount of personal control an individual has over the illness, and the efficacy of treatment for the illness. One 'timeline' and one 'treatment' item were removed because they undermined the reliability of the scales. The final Cronbach's alpha scores were .581 for the timeline scale, .616 for personal control and .614 for treatment.

Figure 8 illustrates the average scores recorded on the three subscales for each of the five vignettes. These variables were scored on a range of 1-5, with higher scores indicating (i) greater belief that the problem will last a long time, (ii) greater belief that the individual can control the problem, and (iii) greater belief that treatment can improve the problem.

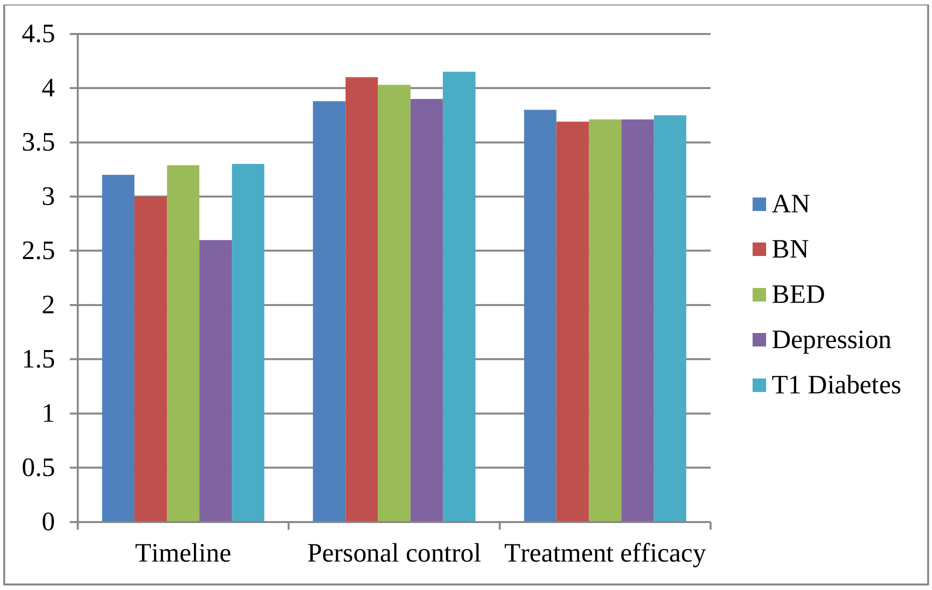


Figure 8. Means on IPQ subscales for each vignette

One-way ANOVAs revealed no significant differences between the five vignettes on perceptions of personal control (*F* [4,103] = 1.01, *p*=.4, η^2=.04) or treatment efficacy (*F* [4,101] = .14, *p*=.97, η^2=.01). A statistically significant difference was detected in the timelines ascribed to the various conditions (*F* [4,103] = 4.68, *p*=.002, η^2=.15). Post hoc pairwise comparisons indicated that clinicians believed that the depressive symptoms would last a significantly shorter duration (*M*=2.6, *SD*=.62) than the symptoms described in the AN (*M*=3.17, *SD*=.64), BED (*M*=3.29, *SD*=.47) or T1 diabetes (*M*=3.3, *SD*=.71) vignettes. The timelines ascribed to the BN (*M*=3, *SD*=.59), AN and BED vignettes did not significantly differ from each other.

One-way ANOVAs were conducted to determine if there was an effect of professional category on illness perceptions. For these analyses, since the three cases of ED did not significantly differ on any of the three subscales, their data was merged into one overarching ED category in order to ensure adequate sample sizes. The different professional categories did not significantly differ in their perceptions of the treatment (*F* [4,59] = .96, *p*=.44, η^2=.06) or timeline (*F* [4,62] = 1.85, *p*=.13, η^2=.11) of EDs. On personal control, there was a statistically significant main effect of professional group (*F* [4,61] = 2.78, *p*=.035, η^2=.15), with psychiatrists scoring highest (*M*=4.31, *SD*=0.36) and GPs lowest (*M*=3.67, *SD*=0.63).

4.3.3.2. Long-term outcome assessment

After viewing the vignettes, participants also completed a measure investigating their projections of Morgan's long-term life outcomes, relative to other people in the community. Figure 9 displays the mean scores recorded on this variable for each vignette. A significant Levene's test indicated that the assumption of homogeneity of variance was violated for this data. A Kruskal-Wallis H test was therefore performed to assess whether the target characters in the various vignettes were judged to have different prospects. This test was not statistically significant (χ^2 [4, N=104] = 5.77, p = .217, η^2=.06).

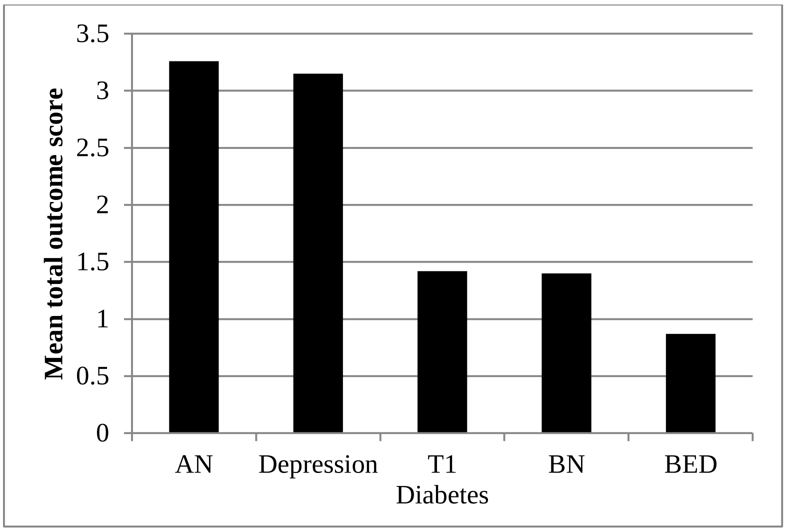


Figure 9. Mean outcome appraisals for each vignette

A Kruskal-Wallis H test on the collapsed ED data revealed a significant difference between the professional groups' outcome assessments for the ED vignettes (χ^2 [4, N=65] = 15.84, p = .003, η^2=.25). Psychiatrists were most pessimistic about ED patients' outcomes, and post hoc pairwise comparisons showed that psychiatrists projected significantly poorer outcomes than counsellors/therapists. There were no other significant differences between the professional groups.

4.3.3.3. Professionals' feelings about interaction

Respondents completed a 3-item scale assessing their perception of health professionals' feelings about interacting with the patient in the vignette. Figure 10 presents the means for each vignette. The various vignettes produced significantly different responses to this variable, F (4,101) = 5.11, p=.001, η^2=.17. Post hoc pairwise comparisons showed that respondents believed that health professionals liked working with individuals with depression or Type 1 diabetes significantly more than with AN patients. There were no other significant differences between the vignettes. Furthermore, there was no main effect of professional category on feelings about interacting with the ED targets, F (4,62) = .54, p=.7, η^2=.03.

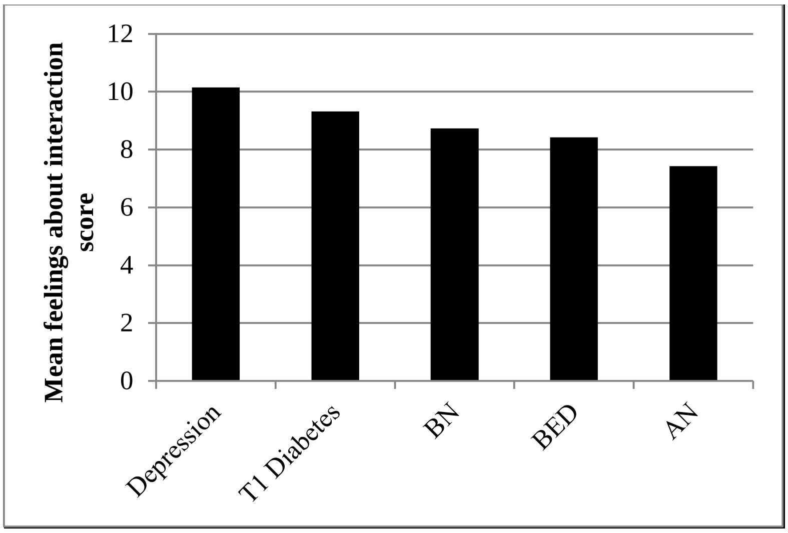


Figure 10. Feelings about working with individuals in vignettes

4.3.3.4. Perceived gender of vignette character

Respondents were asked to indicate their assumptions about the gender of the character they had encountered in the vignette (‘Morgan’). Figure 11 demonstrates the proportion of respondents for each vignette who imagined Morgan to be male or female. The vignettes differed significantly in their tendency to be interpreted as describing a male or female, χ^2 (4, N=96) = 16.6, p=.002, V=.42. Inspection of the standardised residuals (using >2 as the significance criterion) showed that participants were significantly more likely to assume the target character in the depression vignette was male and the AN vignette female. In explaining their inference, many respondents indicated that they believed that Morgan was a more common name for men than women, which likely accounts for the male-oriented interpretations of the depression and Type 1 Diabetes vignettes. However, when reading about the behaviour patterns typical of EDs (particularly AN), clinicians became more likely to assume that Morgan was female.

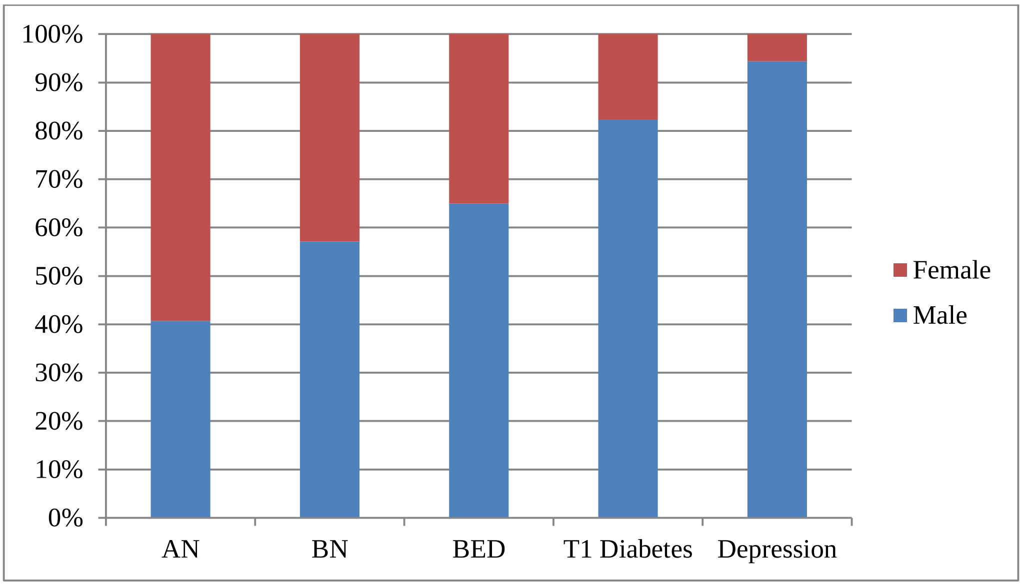


Figure 11. Inferred gender of vignette character

4.3.4. Experience of services

4.3.4.1. Change in profile of ED patients

When asked whether they had observed any changes in the profile of people attending their care with EDs, 33% (*n*=60) of participants responded in the affirmative. As Figure 12 shows, the most common changes noted were younger ages of onset and an increase in the number of male presentations. There was a significant difference between the various professional categories' likelihood of reporting a change (χ^2 [4] = 20.94, *p*<.001, *n*=118): psychiatrists showed a disproportionately high tendency to report a change, and counsellors a disproportionately low rate of observing change.

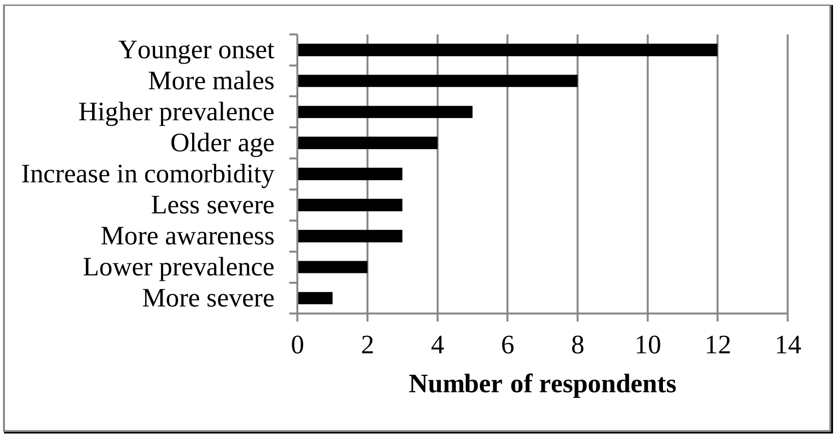


Figure 12. Changes observed in profile of ED cases

4.3.4.2. Desire for standardised protocol

90% of respondents indicated that they would benefit from the publication of a standardised protocol for treatment of EDs.

4.3.4.3. Voluntary organisations

The majority (80%) of respondents stated that they were aware of voluntary organisations that specialise in EDs, with just 18 indicating no knowledge of voluntary organisations. When asked to name voluntary organisations of which they were aware, Bodywhys was offered as the most common example, named by 57 participants. Eight people suggested Overeaters Anonymous, which is not a service for EDs per se, and three named non-voluntary organisations (Lois Bridges and St John of God).

Only 63% of respondents (*n*=55) stated that they had previously referred a patient to a voluntary organisation. Figure 13 demonstrates respondents' views of the role that voluntary organisations play in the treatment of people with ED. Voluntary organisations were predominantly seen as a source of support/advice and education/information. Relatively few participants assigned them a role in advocacy or research.

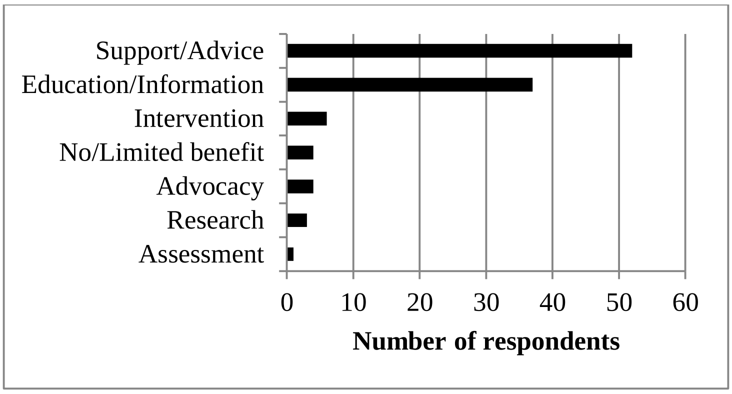


Figure 13. Perceived role of voluntary organisations

4.3.4.4. Appraisal of services

In a final free-response question, participants were invited to contribute information about their experience of the services available to people with EDs. 79 participants provided comments. Most of these were critical in nature, as detailed in Figure 14. Echoing the views of the health professionals who participated in the previous qualitative study (Stage I), particular foci of criticism were the limited geographic distribution of services, inadequate provision of specialist services and difficulties in securing access to services (particularly for older adolescents).

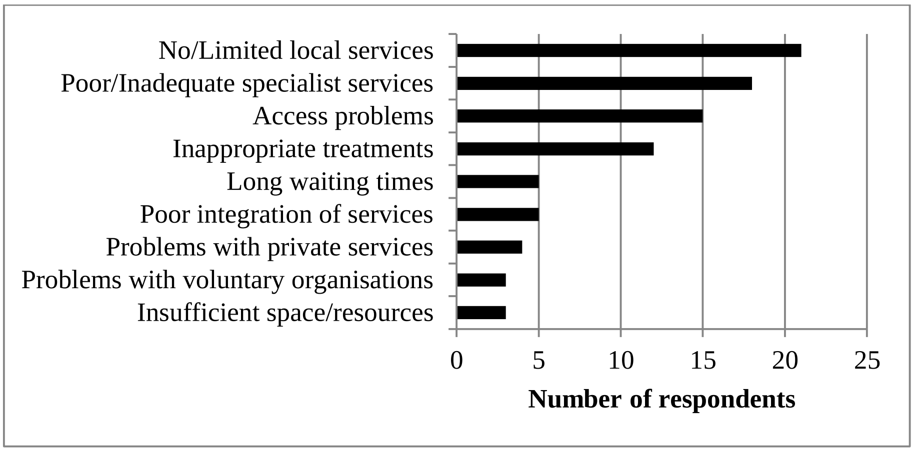


Figure 14. Negative comments about existing services

Sixteen participants offered positive comments about existing services. Eleven respondents praised the quality of the services they had experienced, five specifically commented on the high quality of private services, and five stated that they had experienced easy access to necessary services.

4.4. INTERIM DISCUSSION

The objectives of Stage II were to: (1) establish health professionals' knowledge in relation to EDs in order to identify any gaps that might exist; (2) explore attitudes of professionals towards individuals with eating disorders; and (3) assess organisational links and the extent of interagency collaboration.

4.4.1. Health professionals' ED Knowledge

In relation to the first objective, across all participants levels of knowledge of EDs were moderately good, with clinicians correctly answering an average of 4.2 of the 6 questions. However, respondents fared poorly on the question regarding the BMI parameters that would indicate the presence of AN, which was correctly answered by less than half of participants. A very similar finding previously emerged in a study of British clinicians (Currin et al., 2006), suggesting that this gap in knowledge may have international relevance. However, this pattern should be understood in light of recent debates about BMI thresholds for AN: clinical guidelines place increasing emphasis on proportional weight loss rather than absolute BMI figures, and the recently revised DSM-V criteria recommend BMI as a guide for determining the severity of an ED rather than its presence per se. Additionally, in children and adolescence, BMI centiles charts are more meaningful than absolute BMI values. Given the reduced centrality of BMI in ED diagnosis for young people, the poor response to this question may not have particularly critical clinical repercussions.

Although participants performed relatively well overall on the factual questions about EDs, the current study raises doubt about whether this knowledge is implemented into clinical practice. When confronted with a hypothetical clinical case, participants struggled to distinguish the various categories of EDs, and were much more likely to recognise symptoms of depression. Fewer than half of respondents who saw the BN vignette and less than one-fifth of those exposed to the BED and AN vignettes correctly classified these disorders. It should be noted that additional participants did recognise the problems presented as indicating some type of 'eating disorder' but did not specify which type. If these responses are included, the rates of identifying the presence of an ED rise to 58% for BN, 55% for AN, and 38% for BED. Nevertheless, this still indicates a substantial rate of non-recognition of the presence of an ED. While these data may partly reflect clinically-prudent misgivings about making a diagnosis on the basis of limited information, such reluctance did not deter people from assigning a diagnosis to the depression vignette. This suggests some lack of certainty surrounding typical clinical presentations of EDs.

4.4.2. Health professionals' ED attitudes

Secondly, we were interested in exploring the attitudes held by professionals towards individuals with eating disorders. Consistent with previous research highlighting the presence of prejudice towards individuals with EDs among health professionals (Thompson-Brenner et al., 2012), our data revealed some indications that health professionals stigmatise EDs to a greater extent than other mental or physical illnesses. Our data demonstrated a belief that clinicians prefer working with patients with depression than with EDs. This aligns with previous work suggesting that health professionals view patients with AN as less likeable than other patient groups (Byrne, 2000).

Professionals generally viewed EDs as chronic disorders. Specifically, AN and BED were seen as significantly more chronic conditions than depression. However, alongside this, professionals held optimistic beliefs regarding controllability and treatment efficacy. This pattern of beliefs is discrepant with Weinman, Petrie, Moss-Morris, and Horne's (1996) proposition that belief in the controllability and curability of an illness should be associated with shorter perceived illness duration. In addition, the beliefs held by this professional sample are at odds with those held by people affected by AN, who tend to view their disorder as characterised by low controllability and curability (Holliday, Wall, Treasure & Weinman, 2005). Discrepancies in the illness beliefs held by patients and people around them are associated with psychological distress on the part of the patient (Quiles Marcos, Weinman, Terol Cantero, & Belendez Vazquez, 2009). Undoubtedly, these patient-professional discrepancies could contribute to difficult clinical interactions, particularly if the patient perceives a stigmatizing attitude on the part of the health professional (Easter, 2012; Stevenson, McNamara & Muldoon, 2014). Such tensions could potentially underlie our finding that participants believed health professionals disliked working with those with EDs more than other patient groups.

Further illuminating professionals' potentially biased preconceptions of individuals with EDs, the data indicated the gendered nature of clinical representations of EDs. On encountering the depression and T1 diabetes vignettes, the vast majority of participants assumed that the patient was male. In explaining their answer, many commented that in their experience 'Morgan' is more typically a male name. Participants' elaborations suggested that these associations with the name 'Morgan' continued to influence interpretations of the ED vignettes, which considerable numbers of people continued to judge as male. However, the masculine connotations of this particular name became significantly less important when the vignette described disordered eating patterns, which swayed more participants towards a female judgement. This likely reflects an implicit association between females and eating problems, particularly in the case of the dietary restriction typical of AN. The association between EDs and women does have a basis in epidemiological reality. However, the widespread feminisation of representations of EDs compounds the difficulties experienced by men with EDs, who feel that their masculinity is brought into question (Griffiths et al., 2014a, 2014b). Future research should investigate whether the gendered interpretation of ED symptoms has implications for clinicians' diagnosis of or attitudes towards male patients who present with EDs (Strother, Lemberg, Stanford, & Turberville, 2012). Future research on the gender judgements that vignettes elicit may also benefit from including a response category of 'other' or 'unknown': the dichotomous male/female options used in the current study may have unduly restricted responses.

As noted above, we were interested in exploring the relationship between knowledge, attitudes and service provision. Apart from the small collection of participants categorised as 'other', psychiatrists had the highest levels of professional contact with ED patients. Consistent with this, psychiatrists had the greatest levels of knowledge about and professional confidence in the diagnosis and treatment of

EDs. These differences in psychiatrists' clinical competence were paralleled by certain differences in their attitudes and beliefs about EDs. Of all the professional groups, psychiatrists ascribed ED patients the most personal control over their illness. However, psychiatrists also expressed the most pessimistic views regarding ED patients' long-term life prospects. The finding that those with the most expertise in EDs are most negative about ED patients' outcomes is concerning, given the centrality of these professionals in the clinical care available to people with EDs. Outcome perceptions were not statistically related to participants' level of experience with ED patients, which suggests psychiatrists' pessimism about ED patients' prospects is due to factors other than greater exposure to the progression of ED pathology. It is possible that psychiatrists see a disproportionate amount of people with severe and enduring EDs, with milder cases presenting in primary care. However, even if psychiatrists' pessimism is grounded in a greater awareness of the high mortality and morbidity associated with EDs, it could nevertheless have a detrimental effect on clinical outcomes if their pessimistic outlook is unconsciously transmitted to patients.

The research also has implications for the recommendation made in *A Vision for Change* that EDs be initially treated at primary care level (Department of Health & Children, 2006). Our data vindicate *A Vision for Change*'s contention that GPs are ill-equipped to treat EDs. The GPs in this sample had a relatively limited level of ED knowledge and reported a lack of confidence in diagnosing and treating EDs. This reiterates the issue of inadequate mental health training for GPs (Copty & Whitford, 2005). However, it is worth noting that GPs ascribed patients the least personal control over their illness, which is consistent with the illness belief model held by those with AN themselves (Holliday et al., 2005). This could promote a successful initial clinical consultation.

4.4.3. Health professionals' perspectives on ED services

This study afforded original data regarding clinicians' perspectives on national service provision for EDs, and their experience of accessing and delivering support for people affected by EDs. It is clear that in the eight years since the publication of *A Vision for Change* (Department of Children, 2006), service provision for individuals with EDs has remained substandard. The fact that 90% of respondents expressed a wish for a standardised protocol for treatment of EDs indicates a need for clearer, more structured guidance for health professionals who encounter cases of ED. Additionally, the finding that the steps taken to diagnose an ED differ by professional category suggests that individuals are likely to encounter different treatments, depending on the health discipline they first consult. This implies that more resources need to be dedicated to improving awareness and implementation of the standardised care pathway proposed in *A Vision for Change* (see Figure 1, p. 13).

The survey showed that clinicians recognised the need for greater support of patients and families, but felt unable to provide this due to resource constraints. Voluntary organisations are ideally placed to supplement strained clinical resources, as acknowledged in both *A Vision for Change* and the National

Clinical Programme for Mental Health. For example, problems relating to the limited geographic distribution services could be partly addressed through online support groups and other VSO-initiated activities. However, although most health professionals who responded to the survey were aware of voluntary organisations that specialise in EDs, only a minority of clinicians reported referring to these groups, and there was confusion regarding which service-providers were based in the voluntary sector. There is clearly room for increased collaboration between clinical and voluntary services. However, the development of a defined role for voluntary services in ED prevention and treatment programmes is contingent on the tangible support promised to voluntary services in *A Vision for Change.*

Finally, the research provides much-needed data on the prevalence of EDs in Irish health professionals' caseloads. In the year prior to the survey, participants reported that they had treated an average of four young people affected by an ED. Consistent with previous data from Ireland (Flahavan, 2006) and the UK (Royal College of Psychiatrists, 2012), AN was the ED most frequently encountered in clinical practice. However, epidemiological data shows that BN and BED are considerably more prevalent than AN in the general population. The discrepancy in prevalence rates in community and clinical settings is consistent with evidence that health services are disproportionately oriented towards AN (Royal College of Psychiatrists, 2012) and indicates a particular problem with underdetection of BN and BED. Efforts should be made to heighten awareness of these disorders among clinical professionals and the general population.

4.4.4.Study strengths & limitations

This study represents the first attempt to assess both professional knowledge of EDs and professional attitudes towards individuals with EDs in Ireland. *A Vision for Change* noted that health professionals were insufficiently equipped to deal with EDs, but offered no insight into the precise nature of the posited deficiencies. This study has identified specific gaps in knowledge and illness belief models that conflict with those held by ED-affected individuals themselves, which may have negative implications for professional-client interactions.

However, it is important to acknowledge the study's limitations, most notably the relatively low response rate. Despite extensive efforts to disseminate the survey, and numerous communications from clinicians acknowledging the need for this research, only 9% of the 1,916 health professionals contacted participated. This type of response rate is not unusual in surveys of health professionals (e.g. Aitken, Power, & Dwyer, 2008; Kim et al., 2000), which typically deliver lower responses than general household surveys (Asch, Jedrziewski, & Christakis, 1997). It likely reflects the pressurised workloads of health professionals in Ireland: numerous practitioners responded that they would like to contribute to the research but simply did not have the time. The low response rate may have introduced a source of bias into the research, which should be borne in mind when interpreting its results. However, it is difficult to assess the full implications of the high non-response rate for multiple reasons. Firstly, as all survey invitations were sent via email, it is impossible to tell how many invitations were delivered to active email accounts or read by the intended recipient. The ‘true’ rate of response (i.e. the number of participants relative to the number who actually read the email) is therefore unclear, but is likely higher than 9%. Secondly, because there is no available information about the characteristics of non-responders, it is not possible to determine whether those who did respond were demographically or professionally distinctive in some way. However, other studies have found that low response rates in surveys of health professionals only minimally increase the risk of response bias (Cull, O’Connor, Sharp, Tang, 2005). Additionally, our results show external validity by corresponding with findings from other jurisdictions relating to both knowledge (e.g. Currin et al., 2006) and attitudes (e.g. Byrne, 2000; Thompson-Brenner et al., 2012).

Despite the low response rate, in absolute terms the sample size is considerably higher than the only previous Irish study on this topic (Flahavan, 2006). However, due to the five-way comparison involved in the vignette design, many analyses had low statistical power. Post hoc power analysis (performed using the G*Power programme) indicated that, given the conservative Bonferroni-corrected significance criterion, the maximum power achieved for the analyses performed was .21. This is much lower than typically recommended (Cohen, 1988). Future research with a larger sample size may identify more subtle effects that this analysis was unable to detect.

A further limitation relates to the vignette-based design. Although vignettes are recognised as powerful means of accessing valid, naturalistic responses (Chambers, Murphy & Keeley, in press), it is sometimes difficult to determine the extent to which data reflects the specific features of the vignettes provided, rather than more generalizable illness representations. For instance, although the name ‘Morgan’ was selected to represent a gender-neutral character, participants’ responses indicated that it was more strongly associated with men, which influenced their inferences about the vignette target. This illustrates how rather superficial details of vignette content can shape the data collected. These issues do not negate the value of vignette designs, but rather highlight the need for external validation of results through different vignette texts and through alternate, non-vignette-based methodologies. This should be a priority for future research.

Key recommendations derived from our results are presented in the Discussion section.

5. STAGE III: YOUNG PEOPLE'S SURVEY

5.1. INTRODUCTION

EDs are particularly prevalent among young people, and 86% of EDs commence before the age of 20 (National Association of Anorexia Nervosa and Associated Disorder, 2000). Previous research shows that body image concerns are pertinent to Irish adolescents. A 2011 survey of over 2,000 young people found that 77% of Irish adolescents ranked body image as personally important, while 43% expressed some dissatisfaction with their body (Department of Children and Youth Affairs, 2012). Another survey of 3,031 Irish adolescents found that 71.4% felt adversely affected by media portrayal of body weight and shape, with over a quarter (25.6%) characterising it as 'far too thin' (McNicholas et al., 2009). These body image concerns have detrimental implications for this cohort's levels of self-esteem and general well-being (Kostanski & Gullone, 2003), and in a minority of cases risk developing into full-blown EDs.

As for all mental illnesses, early intervention is critical to prevent disordered eating from becoming a chronic condition with serious personal, social and economic consequences. However, there is strong evidence that ED services in Ireland are underutilised. Data collected by Bodywhys suggest that 50% of callers to its telephone helpline and 65% of users of its online support forum are not engaged in active treatment, despite suffering symptoms as severe as those seen in clinical populations (Bodywhys, 2013; Darcy & Dooley, 2007). These figures are likely an overly optimistic indication of the full extent of undertreatment of EDs in Ireland, since those who engage with Bodywhys services represent only a minority of the population of people with disordered eating. Thus, many young people who meet the clinical criteria for an ED diagnosis may not be identified or offered appropriate professional support (Fursland & Watson, 2014).

Research indicates that the stigma that surrounds EDs is a critical barrier to seeking out and maintaining appropriate support (Darcy & Dooley, 2007). Qualitative studies with young people show that they can be reluctant to seek help for mental health concerns due to a fear of being judged (Booth et al., 2004). International research suggests that EDs are stigmatised to a greater extent than other mental or physical disorders. Roehrig and McLean (2010) compared responses to vignettes describing individuals with AN, BN and depression, and found that the AN and BN targets were perceived as more culpable, attention-seeking and fragile than the person with depression. A similar vignette-based design by Stewart et al. (2006) found that participants were more likely to blame the AN target for their illness, and to believe that they could simply 'pull themselves together'. Another study by Stewart et al. (2008) found that relative to targets suffering from depression or infectious disease, people attributed less positive characteristics to and anticipated greater discomfort interacting with an individual affected by AN. These findings were corroborated by Crisp's (2005) analysis of nationally representative survey data, which found that approximately one-third of the British public saw people with EDs as hard to talk to or empathise with, while a similar proportion viewed EDs as self-inflicted. Such attitudes can contribute to a desire for social distance from people with EDs (Zwickert & Rieger, 2013), which compounds ED sufferers' sense of isolation and motivation or ability to seek help. Recent research by Griffiths, Mond, Murray & Touyz (in press) reports that greater experience of stigmatisation is associated with higher levels of eating disorder psychopathology, a longer duration of disorder, lower self-esteem, and more negative attitudes to seeking psychological help.

However, despite this strong evidence of the prevalence and negative effects of ED stigma, EDs have been relatively neglected in debates about mental illness stigma, which have tended to focus on depression and schizophrenia (Zwickert & Rieger, 2013). Additionally, very little research on public attitudes has concentrated on young people. This is a serious oversight, as this is the cohort most at risk of developing EDs. Additionally, because young people compose such a large proportion of the population with acute EDs, the attitudes held by their peers are likely to be pivotal in their experience of social stigmatisation or support. A small amount of research has examined young people's ED literacy, generally finding that it is poor. For instance, a survey of 942 French adolescents detected relatively low recognition the behavioural and physiological signs of AN and BN (Rousseau, Callahan, & Chabrol, 2012), while research with Australian schoolgirls shows them to considerably overestimate the prevalence of BN (Mond & Marks, 2007). However, minimal research has investigated the prevalence of stigmatising attitudes among young people. Some research has focused on university populations, within which vignette-based designs reproduce previous findings that EDs are more stigmatised than other disorders (Griffiths, Mond, Murray & Touyz, 2014). Stigma research with adolescents is lacking.

Attitudes to EDs are complicated by their highly gendered nature. As in other developed countries, in Ireland disordered eating is more prevalent among girls than boys (McNicholas et al., 2012). However, there is growing evidence that body image concerns are increasingly pertinent to boys (Grogan & Richards, 2002). These pressures are often more subtle in male peer-groups, within which openly discussing body image can be stigmatised as reflecting feminine or homosexual tendencies (Hargreaves & Tiggemann, 2006). EDs are commonly stereotyped as 'female' disorders (Griffiths et al., 2014), and males with EDs frequently report feeling that they are 'less of a man' (Griffiths et al., in press). Thus, boys may face particularly severe social or emotional barriers to divulging eating concerns. Although girls also perceive EDs as disabling and shameful, evidence suggests that for many women, this can be tempered by a belief that it 'might not be too bad' to have an ED, due to its signification of discipline and the attainment of the thin ideal (Mond & Hay, 2008; Mond et al., 2004). Roehrig and McLean (2010) suggest that this element of envy or admiration of people with EDs may be unique among mental illnesses. Mond and Marks' (2007) study of Australian schoolgirls suggests that the perception of EDs as desirable begins in adolescence. Thus, it is crucial to consider the gender dynamics that influence young people's responses to EDs, because girls' ambivalent attitudes to disordered eating and boys' inhibitions about body concerns may both be risk factors for the development of mental health problems.

In considering attitudes to EDs, a further dynamic that requires attention relates to the specific ED in question. Clinical guidelines stipulate four main categories of ED: AN, BN, BED and EDNOS. Each has a unique complex of psychological, behavioural and physiological symptoms, which may provoke different social responses. AN may particularly resonate with the aforementioned tendency for EDs to elicit a level of admiration, due to its congruence with the cultural values of self-control and self-discipline (Joffe & Staerklé, 2007). However, the skeletal bodies that are prominent in media representations of AN may induce a disgust response, as might the purging patterns that are central to a BN diagnosis. Public attitudes to cases of BED are particularly interesting, due to the relatively recent establishment of this diagnostic category. Levels of public (and indeed clinical) awareness of BED are low (Mond & Hay, 2008). As such, the disorder might not be afforded the same legitimacy as more established disease categories. Additionally, because individuals with BED are often overweight, they face the double stigma of obesity and mental illness (Mond & Hay, 2008). Furthermore, BED affects more men than AN or BN (Smith et al., 1998), which means that the gender dynamics at play in attitudes to BED are likely to be distinctive.

To understand the barriers to young people's engagement with ED services and develop targeted interventions, we need concrete information about how EDs are viewed by Ireland's youth. Currently, there are no data available in Ireland that illuminate young people's knowledge of or attitudes towards EDs and ED support services. The current research delivers the first evidence of this kind, obtained through a nationwide survey of 15-19 year old secondary school students. The study sought to (1) assess the level of body satisfaction and eating concerns in Irish adolescents, (2) identify their help-seeking behaviours in relation to these concerns and (3) explore young people's eating disorder literacy and their attitudes towards individuals with eating disorders.

5.2. METHOD

5.2.1.Design

A survey was constructed and made available in both paper and electronic (using the online survey platform SurveyMonkey) form.

5.2.2.Participants

5.2.2.1. Recruitment

260 schools from across Ireland were randomly selected from Department of Education lists and invited to participate in the research. Schools were contacted by telephone in the first instance, followed by emails if no response was forthcoming. In total, 63 schools agreed to recruit students to the survey.

After confirming a school's willingness to participate over the telephone, schools were sent information sheets, parental consent forms and student assent forms. Schools were asked to circulate these to students, who would pass them to their parents for consent. The school then collected all completed student and parental consent forms and returned them to the researchers, along with email addresses for the students who had agreed to participate. After the necessary consent forms had been received, students were emailed individualised links to the survey website. Survey submissions whose unique link did not match completed parental and student consent forms were removed from the dataset. Students who had not completed the survey after several weeks were sent one reminder email. In total, 350 students returned consent forms and were issued electronic invitations.

A small number of schools chose to administer paper versions of the survey. The completed surveys and consent forms were returned to the researchers and manually entered into the dataset.

In total, 319 responses to the survey were collected (263 online and 56 on paper). After removal of responses that could not be matched with signed consent forms, the dataset contained a usable sample of 290 respondents.

5.2.2.2. Demographic characteristics

Of those participants who indicated their gender, 51.1% (*n*=145) were male and 48.9% (*n*=139) female. Their mean age was 16.76 (*SD*=.891). At the time the survey was completed, 24.6% (*n*=70) were in transition year, 44.9% (*n*=128) in 5th year and 30.5% (*n*=87) in 6th year. Just under half (46.3%, *n*=132) of participants were enrolled in all-girls schools, with 20.7% (*n*=59) in all-boys schools and 33% (*n*=94) in mixed-gender schools. 25.5% (*n*=74) attended fee-paying schools.

5.2.3. Survey design

The survey is presented in Appendix D. After viewing an information page and indicating consent, participants were first asked a number of questions about their demographic and educational characteristics.

In accordance with previous research (Mond & Hay, 2008; Roehrig & McClean, 2010; Stewart et al., 2006, 2008), participants were then randomly assigned to view one of five vignettes depicting a young person ('Alex') who had presented to their GP with symptoms consistent with the presence of: AN, BN, BED, Depression or Type 1 Diabetes. The subsequent questions assessed participants' responses to the vignette on a number of measures:

- In line with previous research (e.g. Mond & Hay, 2008), respondents were first presented with a free-response box and asked to indicate what they believed Alex's 'main problem' was.

- Participants were given a list of 10 people (e.g. GP, counsellor, family member) and 10 treatments (e.g. counselling, admission to hospital, diet and exercise programme) and asked to select one from each list that would be most helpful for Alex.
- Participants were administered an adapted 12-item version of the Illness Perceptions Questionnaire (Moss-Morris et al., 2002). This instrument comprised three 4-item subscales assessing beliefs about (i) the likely timeline of an illness, (ii) the amount of personal control the individual has over the illness, and (iii) the efficacy of treatment for the illness.
- Participants were asked to rate their agreement with a list of 11 potential causes of Alex's problem (5-point scales from 'strongly disagree' to 'strongly agree').
- Participants were asked to rate the likelihood that they would experience a list of 10 emotions if they interacted with Alex (5-point scales from 'strongly disagree' to 'strongly agree').
- Participants were asked to characterise their impressions of Alex on a range of 10 personality traits (5-point scales from 'strongly disagree' to 'strongly agree').
- Participants were asked to indicate whether they believed Alex was male or female and give a reason for that belief.

After completing these items assessing their responses to the vignette, participants provided information about their level of body satisfaction and the perceived importance of their appearance (5-point scales). They completed four items querying the frequency with which they engaged in efforts to regulate their body weight or size. They then were asked a range of questions relating to their personal experience of EDs.

To assess participants' beliefs about the social stigma surrounding EDs, they completed five questions regarding the extent of social marginalisation experienced by people with EDs, and five items querying the prevalence of various stigmatising beliefs about people with EDs.

Finally, participants rated their own understanding of how to seek help about eating concerns and their likelihood of requesting help from a range of people/organisations if they developed concern about their eating habits.

5.2.4. Analysis

All data were imported into SPSS for statistical analysis. The effects of the vignettes viewed, demographic characteristics and participants' experience with EDs were explored using analysis of variance, correlation and chi-square tests.

5.3. RESULTS

Means and standard deviations for all variables are presented in Appendix C.

5.3.1.Experience of EDs

5.3.1.1. Personal and vicarious experience of EDs

Two participants reported that they had been previously diagnosed with an ED (both BN). Neither was currently in active treatment.

Many respondents (35.9%; *n*=104) failed to answer a question about whether they knew someone affected by an ED. However, of the 186 who did answer, the majority (62.4%; *n*=116) responded in the affirmative. When asked to specify who this person was, 6 indicated that it was themselves, 14 a member of their immediate family, 53 a close friend, 9 a member of their extended family, and 36 an acquaintance.

This information was used to create a scale indicating personal experience with EDs, ranging from 1 (no contact) to 6 (affected oneself). Boys' mean score on this variable (*M*=2.35, *SD*=1.43) was significantly lower than girls' (*M*=2.94, *SD*=1.667), *t*(186) = 2.595, *p*=.01.

5.3.1.2. Body satisfaction

Participants were asked to indicate their satisfaction with their body on a 5-point scale. As a whole, levels of body satisfaction were not high (*M*=2.94, *SD*=1.51). Only 4.6% of participants rated themselves as 'very satisfied' and 38.5% as 'satisfied' with their body.

A two-way ANOVA was conducted to evaluate the influence of gender and school type on body satisfaction. The analysis revealed a significant main effect of gender (*F*[1,252]=22.72, *p*<.001), with boys rating themselves more satisfied (*M*=3.36, *SD*=1.05) than girls (*M*=2.54, *SD*=1.1). There was no significant main effect of school gender composition (*F*[1,252]=.04, *p*=.847). Neither was there a significant interaction between school gender composition and participant's gender (*F*[1,252]=.38, *p*=.54), although descriptive results did show that the males with the highest body satisfaction were those attending single-sex schools, while female body satisfaction was highest among those in mixed-sex schools.

Higher levels of personal experience with ED were associated with lower levels of body satisfaction (*r*=-.229, *n*=185, *p*<.005).

Participants were also asked to rate the importance of their appearance on a five point scale. As a whole, the sample rated their appearance as moderately important (*M*=3.91, *SD*= .918). Only 8.4% of participants stated that their appearance was either 'unimportant' or 'very unimportant'. The perceived importance of appearance did not differ according to gender, age or school type.

5.3.1.3. Weight-regulation concern

On 6-point scales, participants were asked to indicate the frequency with which they engaged in four activities to regulate their body weight/size. The mean scores decomposed by gender are displayed in Figure 15. Girls reported greater engagement in all activities except for exercising to increase muscle size.

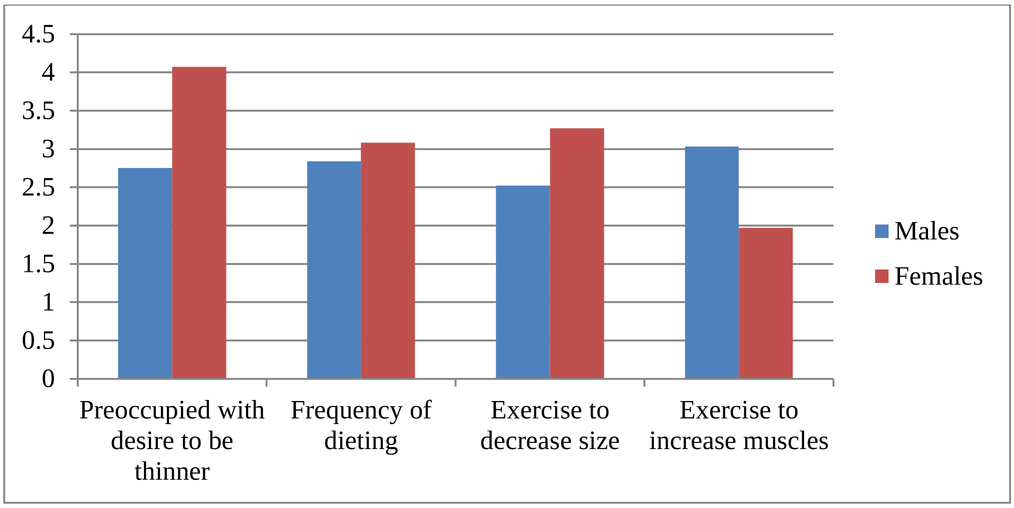


Figure 15. Engagement in weight-regulation activities

5.3.1.4. Eating concerns and their disclosure

When asked if they were concerned about their own eating habits, 34.1% of the sample (*n*=99; 60 female, 27 male, 2 unspecified) responded that they were and 56.2% (*n*=163) denied concern (9.7% of participants declined to answer this question). Approximately half of the subset who professed concern (*n*=51; 25 female, 24 male, 2 unspecified) had discussed these concerns with someone else. This person was usually a family member (*n*=30) or friend (*n*=17). Only three had consulted a health professional and one a support organisation.

Of those who chose between a range of possible reasons for not discussing eating concerns with someone else, 19 participants responded that a fear of being judged would deter them from communicating their concerns, while 10 indicated that they would not know who to tell. Of those who elected to respond to this question in a free-form manner, the most prominent reason (accounting for 16 of the 28 responses offered) was that their concerns were not sufficiently serious.

5.3.1.5. Help-seeking preferences and understanding

Participants were asked to rate on a 4-point scale their likelihood of seeking help from a range of sources, in the event that they developed a concern about their eating. A principal components analysis with Varimax rotation was performed on this data, and a scree plot indicated that a three-factor solution was appropriate. The three factors accounted for 60.68% of the total variance. Four items referring to expert help (health professional, email/online counselling, telephone counselling, Bodywhys) loaded onto the first factor (21.27% variance), four items relating to personal contacts (parent, friend, family friend, relative) loaded onto the second factor (20.19% variance), and three items relating to impersonal information-providers (book/magazine, internet website, social network site) loaded onto the final factor (19.22% variance). The items corresponding to each factor were summed to create three composite variables labelled ‘Expert’ (Cronbach’s α=.73), ‘Personal’ (Cronbach’s α=.68) and ‘Media’ (Cronbach’s α=.69).

A repeated measures ANOVA detected a statistically significant difference between the likelihood of seeking help from the three sources (*F*[2,492]=25.38, *p*<.001). Post-hoc pairwise comparisons with Bonferroni corrections showed that personal advice (*M*=2.51, *SD*=.63) was significantly preferred to both media (*M*=2.23, *SD*=.73) and expert (*M*=2.15, *SD*=.65) advice. There was no significant difference between participants’ likelihood of seeking help from media and expert sources.

Four items assessed participants’ self-rated understanding of how to seek help for eating problems, on a five-point scale from ‘not good at all’ to ‘excellent’. Table 1 shows that the mean for all four items was below the mid-point of the scale (3=‘good’). Participants’ confidence that they would know how to obtain access to a health professional was particularly low. The four items showed a Cronbach’s alpha score of .825 and were combined to create a composite scale of understanding of help-seeking. Scores on this variable did not differ according to gender, age, school type, personal experience with EDs or body satisfaction.

Table 1. Mean scores for understanding of help-seeking

	M	*SD*
Who to talk to if you were worried about your eating habits?	2.97	1.17
Where else to look for information on eating problems?	2.93	1.19
How to help a friend who is worried about their eating habits?	2.85	1.25
How to access a health professional?	2.68	1.29

5.3.2. Responses to vignette

All participants were randomly assigned to read one of five vignettes. 16.3% (*n*=46) read a vignette describing the symptoms of T1 diabetes, 25.1% (*n*=71) depression, 19.1% (*n*=54) AN, 17% (*n*=48) BN and 22.6% (*n*=64) BED.

5.3.2.1. Characterisation of problem

After reading the vignette, participants were asked to specify what they believed Alex’s main problem to be. Figure 16 displays the percentage of responses to each vignette that correctly categorised the illness described. Statistical analysis showed that the different vignettes produced significantly different rates of correct categorisations, χ^2 (4) = 36.125, *p*<.001, *n*=283. The symptoms of depression were recognised almost twice as frequently as any of the other disorders. No respondent mentioned the clinical category of BED.

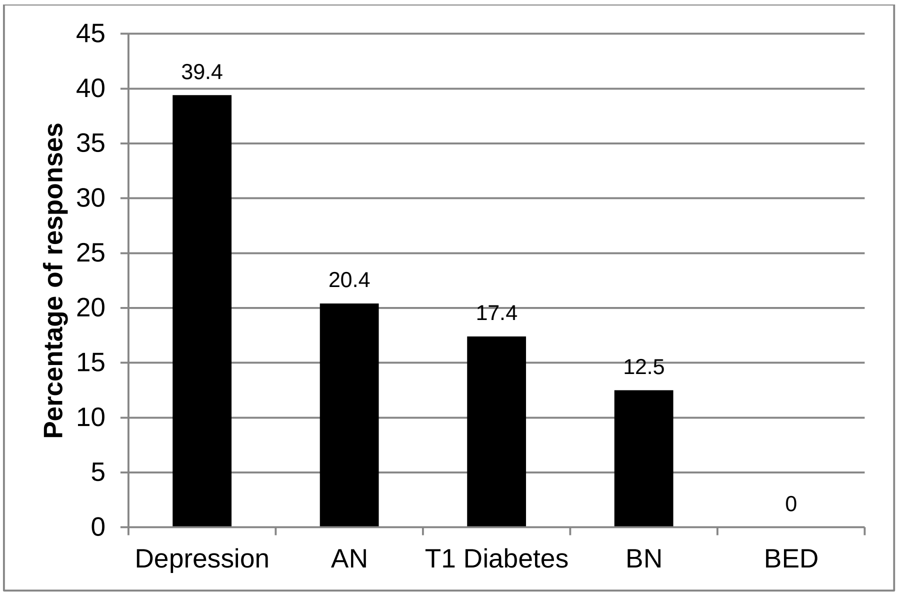


Figure 16. Percentage who correctly categorised illness in vignette

The majority of responses to the ED vignettes did not contain a diagnostic label, instead revolving around characterising Alex' psychological, behavioural or social problems. A content analysis was performed to capture these responses. Participants' characterisations of the vignette problem could be classified in terms of 12 categories. Figure 17 illustrates the percentage of participants in the various vignette conditions who referred to each of these explanations. The AN and BN vignettes were mainly described as problems of self-esteem or unhealthy eating habits. AN was distinctive in its frequent characterisation in terms of anxiety, obsession or phobia, and also in its attribution to deficits of knowledge or education regarding nutrition. Interestingly, the BED vignette elicited consistently different interpretations from the other ED vignettes, most obviously in the major focus on deficits of self-control or self-discipline. The behavioural patterns described in the BED vignette were also often understood as resulting from maladaptive cognitive or emotional patterns, or difficulties with social relationships. In contrast, the depression and T1 diabetes vignettes were more frequently framed as reflecting the effects of nutritional deficiency, stress or exhaustion, or a physiological disorder.

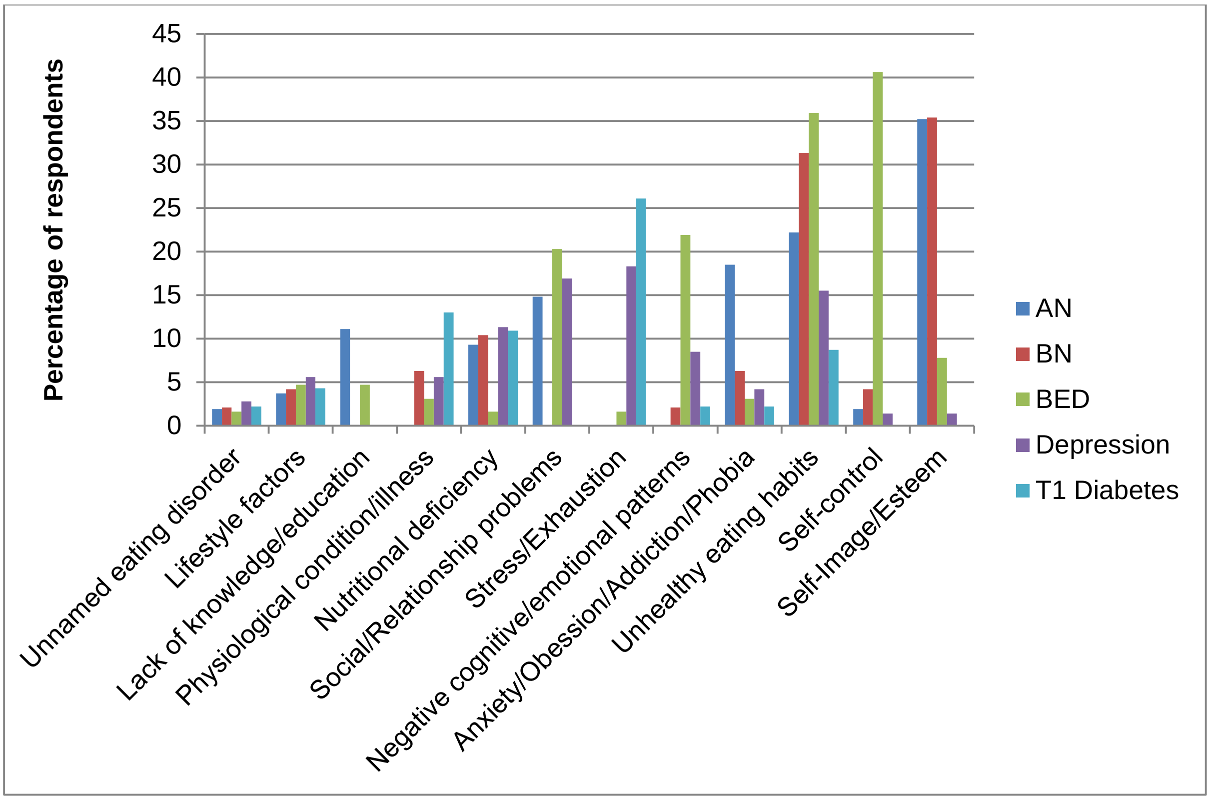


Figure 17. Percentage of respondents who referred to the various categories

5.3.2.2. Recommended help for Alex

Figure 18 displays the percentage of participants in each vignette condition who recommended that Alex seek help from a range of sources. While the T1 diabetes case was seen as requiring help from a GP and depression a family member, participants typically advised that the three ED cases would benefit from consultation with a dietician/nutritionist or psychiatrist/psychologist. No participant in any vignette recommended consultation with an alternative therapist.

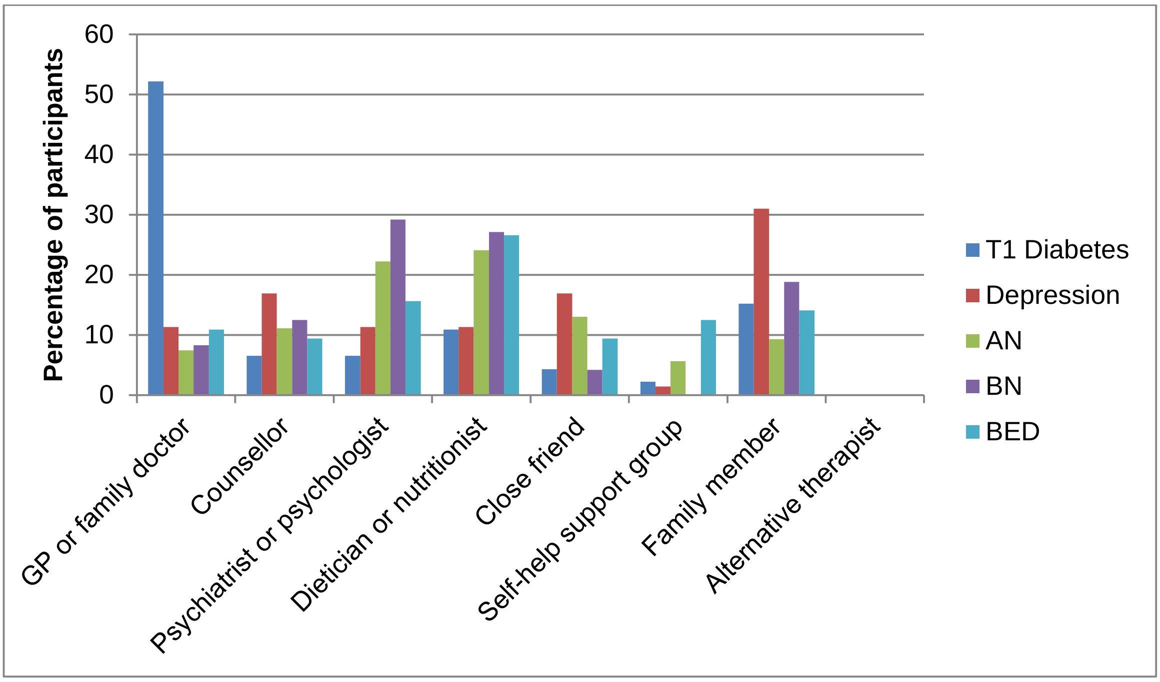


Figure 18. Most helpful person

Participants were also asked to indicate the type of treatment that they believed would be most helpful for Alex. Figure 19 illustrates the responses to this question. Counselling, 'just talking' about the problem and acquiring information about the problem were seen as viable options for all vignettes. Medication or hospital admission were rarely recommended for the ED vignettes. Relative to the other ED cases, BED was seen as manageable by more non-clinical means, such as 'getting out and about more' or a diet and exercise programme.

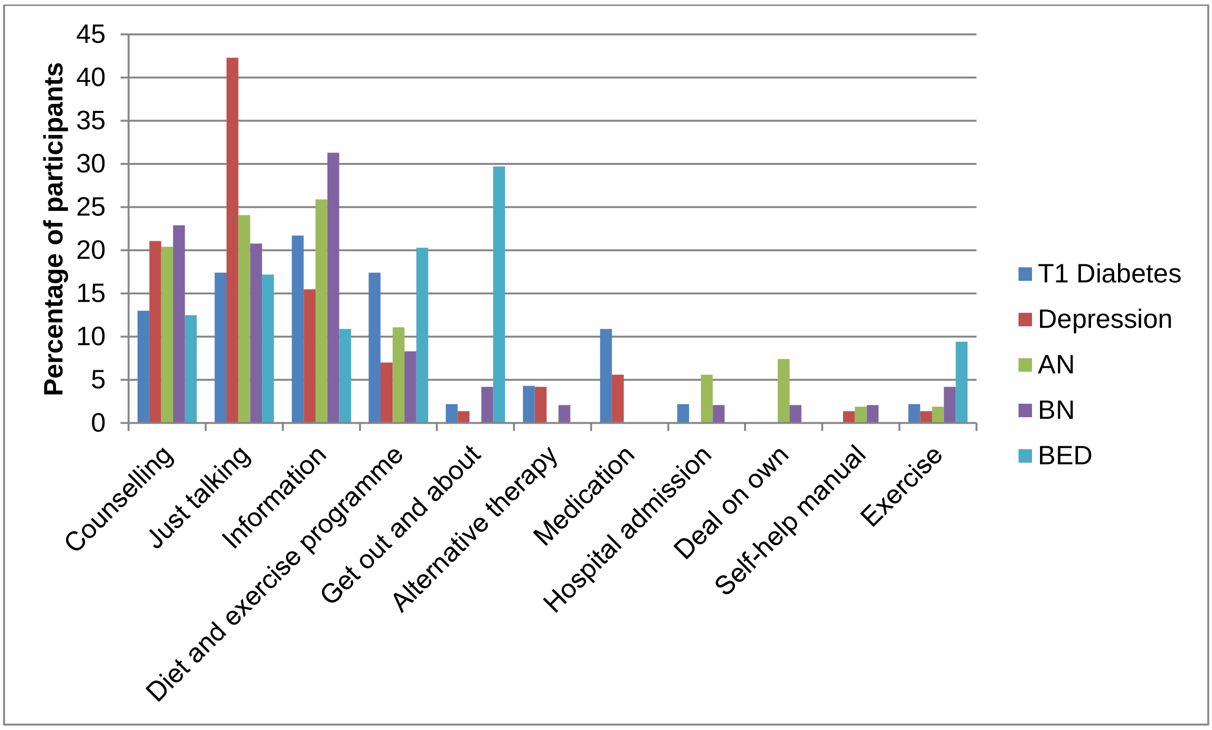


Figure 19. Most helpful treatment

5.3.2.3. Cause of problem

Participants were presented with a list of 11 potential causes of Alex' problem and asked to rate their importance on a 5-point scale. A principal components analysis with varimax rotation was performed on this data, and a scree plot indicated that three factors should be extracted. Four items relating to stress or emotion (stress/worry, family problems, overwork, emotional state) loaded onto the first factor, four items relating to Alex' behaviour or personal traits (Alex' diet/eating habits, own behaviour, mental attitude, personality) loaded onto the second factor, and three items relating to factors beyond Alex' control (hereditary, chance/bad luck, poor medical care) loaded onto the final factor. The items corresponding to each factor were summed to create three composite variables labelled 'life stress causes' (Cronbach's α =.686), 'individual causes' (Cronbach's α =.573) and 'external causes' (Cronbach's α =.431). Figure 20 shows the mean scores recorded on these variables in each vignette condition.

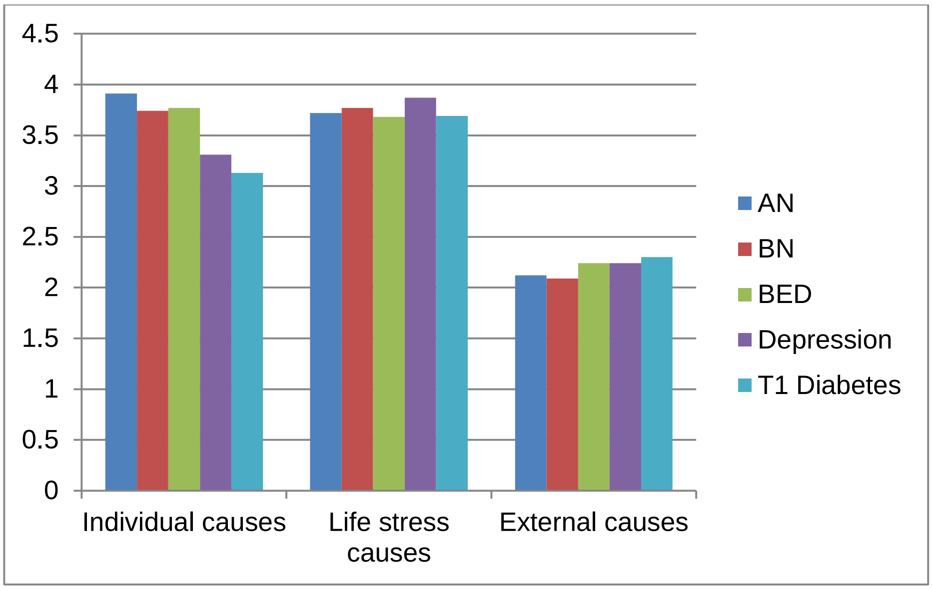


Figure 20. Perceived causality of the various conditions

One-way ANOVAs detected significant differences between the vignettes in individual causes (*F* [4,269] = 18.526, *p*<.001). Post hoc tests showed that all three EDs were rated as significantly more individually-caused than either depression or diabetes. The three ED vignettes did not differ from each other on individual causation. There were no significant differences between any vignettes on endorsements of life stress or external causes.

Within the BN vignette, gender had a significant effect on endorsement of both individual causes (*t*[44] = -2.756, *p*<.01) and life stress causes (*t*[44] = 2.453, *p*<.05). Male students (*M*=3.943, *SD*=.408) rated the BN vignette higher on individual causation than females (*M*=3.531, *SD*=.582) and lower (*M*=3.58, *SD*=.542) on life stress causes than females (*M*=3.99, *SD*=.587). In the BED condition, females (*M*=3.833, *SD*=.519) endorsed life stress causes significantly more than males (*M*=3.55, *SD*=.484), *t(*55) = 2.132, *p*<.05. Additionally, participants with lower levels of body satisfaction tended to implicate more life stress causes for BED, *r*=-.268, *n*=56, p<.05. School type, age, and personal experience with EDs did not influence causal attributions.

5.3.2.4. Illness perceptions

Respondents were asked to indicate their attitudes towards the illness described in the vignette using an adapted 12-item version of the Illness Perceptions Questionnaire. This instrument comprised three four-item subscales assessing beliefs about the likely timeline of an illness, the amount of personal control an individual has over the illness, and the efficacy of treatment for the illness. The Cronbach's alpha scores were .684 for the timeline scale, .638 for personal control and .504 for treatment. The mean scores recorded in each vignette condition are displayed in Figure 21.

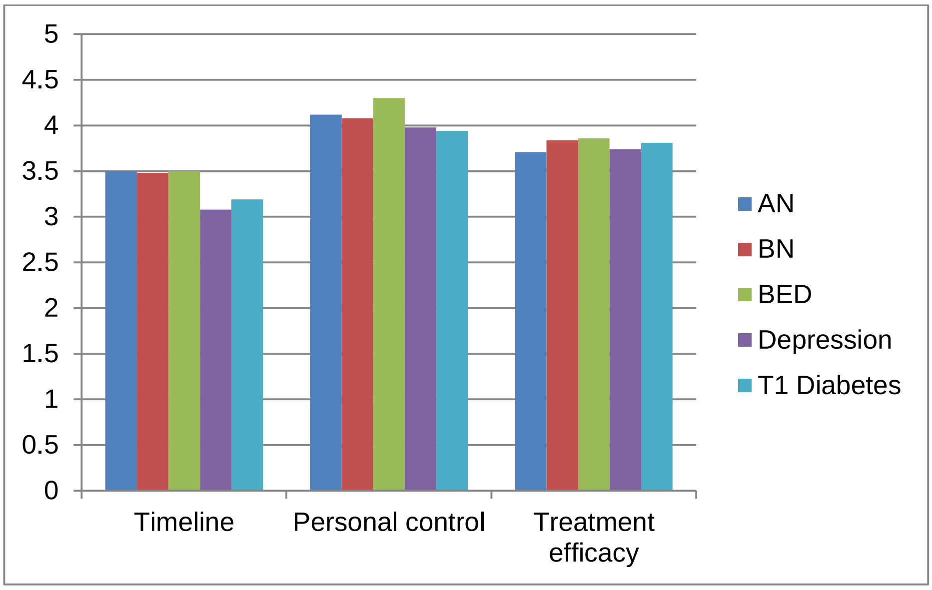


Figure 21. Mean scores on IPQ subscales

One-way ANOVAs detected significant differences between the vignettes in relation to timeline (*F* [4,267] = 6.208, *p*<.001) and personal control (*F* [4,264] = 3.555, *p*<.01). Post hoc tests showed that for timeline, depression was rated significantly shorter than all three EDs. The BED individual was rated as having significantly more personal control than the characters in either the depression or T1 diabetes vignettes.

A number of demographic differences emerged within the AN condition. Here, gender showed a significant effect on perceptions of personal control (*t*[51] = -2.363, *p*<.05), with males ascribing more personal control (*M*=4.32, *SD*=.773) than females (*M*=3.938, *SD*=.69). Also within the AN condition, there was a significant negative correlation between age and perceptions of control, *r*=-.327, *n*=52, *p*<.05. Participants with greater levels of body satisfaction saw AN as shorter (*r*=-.297, *n*=50, *p*<.05) and more personally controllable (*r*=.382, *n*=51, *p*<.01). Participants with greater personal experience with EDs saw AN as lasting significantly longer (*r*=.398, *n*=52, *p*<.05).

Few significant demographic differences emerged in the BN or BED conditions, apart from the finding that people with greater personal experience with EDs saw BN as more resistant to treatment (r=-.41, n=33, p<.05).

5.3.2.5. Feelings about interacting with Alex

Respondents were asked to rate the likelihood that interacting with Alex would produce a range of 10 feelings, of which 5 were negative and 5 positive. The negative and positive items were combined to create two scales. One item (empathic) was removed from the positive scale in order to increase the Cronbach's α score to .704. The five negative items showed a Cronbach's α of .685.

The vignettes did not differ in their likelihood of eliciting negative emotions (F [4,382] = 1.43, p=.23). However, a one-way ANOVA detected a significant differences between the vignettes' likelihood of eliciting positive emotions (F [4,261] = 2.954, p<.05). Post hoc tests indicated that significantly greater positive emotion was anticipated for BED (M=3.538, SD=.609) than depression (M=3.182, SD=.731). The depression vignette also elicited significantly less positive emotion than T1 diabetes (M=3.573, SD=.692).

Analysis detected no significant effect of gender, age, school type or personal experience with EDs. Within the BN condition, greater negative emotion was anticipated by those with lower levels of body satisfaction (r=-.352, n=44, p<.05).

5.3.2.6. Alex' characteristics

Respondents were asked to rate their impression of Alex on a number of characteristics, of which five were positive and five negative. The negative and positive items were combined to create two scales. Cronbach's α for the positive scale was .552 and for the negative .439.

A one-way ANOVA detected a significant difference between the ascription of positive characteristics to the various vignettes (F [4,255] = 12.906, p>.001). Post hoc tests on the positive variable showed that all three ED targets were rated significantly less positively than the T1 diabetes target (M=3.145, SD=.471). Additionally, the BED target was ascribed significantly less positive traits (M=2.567, SD=.393) than either the depression (M=3, SD=.473) or AN (M=2.847, SD=.413) targets.

For the variable of negative characteristics, a significant Levene's test indicated that the assumption of homogeneity of variance was violated. A Kruskal-Wallis H test was therefore performed to assess whether the target characters in the various vignettes were judged to have different prospects. This test revealed a significant difference between the vignettes (χ^2 [4, N=104] = 44.581, p >.001). Post hoc pairwise comparisons with Bonferroni corrections showed that the BN, BED and AN targets were all rated significantly more negatively than the depression and T1 diabetes targets.

Within the BN condition, gender had a significant effect on the positive scale (*t*[41] = 3.312, *p*<.005), with females (*M*=2.971,*SD*=.365) giving more positive ratings than males (*M*=2.555,*SD*=.453). Also within the BN condition, there was a significant positive correlation between age and the ascription of negative characteristics, *r*=.332, *n*=45, *p*<.05. Otherwise, participants' impressions of Alex did not differ according to school type, personal experience with EDs or body satisfaction.

5.3.2.7. Perceived gender of vignette character

Respondents were asked to indicate their assumptions about the gender of the character they had encountered in the vignette. Figure 22 demonstrates the proportion of respondents for each vignette who imagined Alex to be male or female. The vignettes differed significantly in their tendency to be interpreted as describing a male or female, χ^2 (4) = 16.055, *p*<.005, *n*=262. The T1 diabetes vignette was about equally likely to be interpreted as describing a male or female character. However, the behavioural patterns described in the BN and AN vignettes were more likely to encourage an inference that the individual was female, while the depression and BED vignettes were construed in more masculine terms.

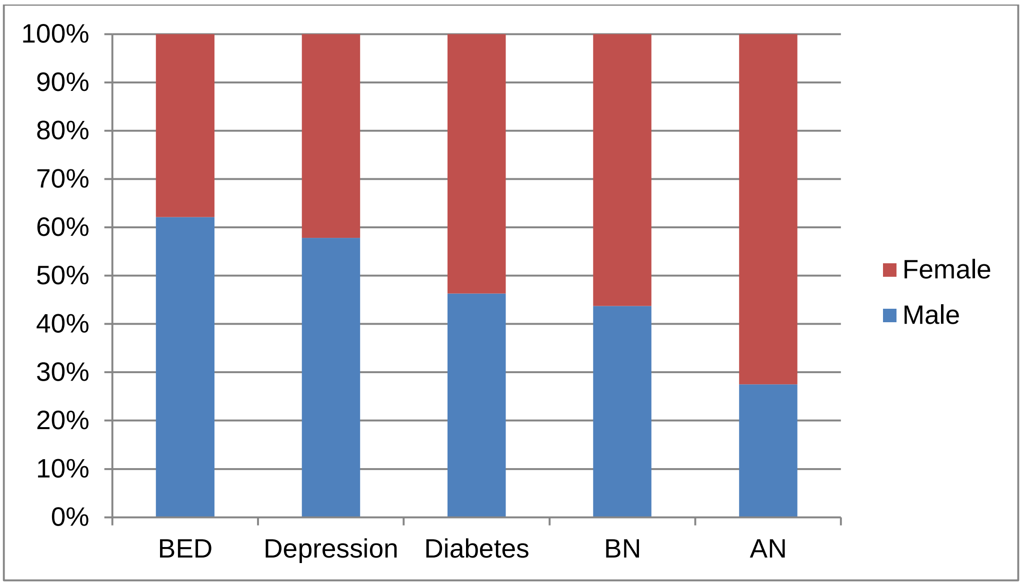


Figure 22. Inferred gender of vignette character

Participants were asked to explain the reasons for their inference about Alex' gender. A content analysis was performed to codify these responses. Figure 23 shows the results of this content analysis. Most commonly, participants derived Alex' gender through matching the vignette to gender-typed behavioural scripts (for example, the notion that women are more concerned about their appearance, or that men don't talk about their feelings). The AN and BN vignettes also often prompted a statement that EDs were more prevalent among females.

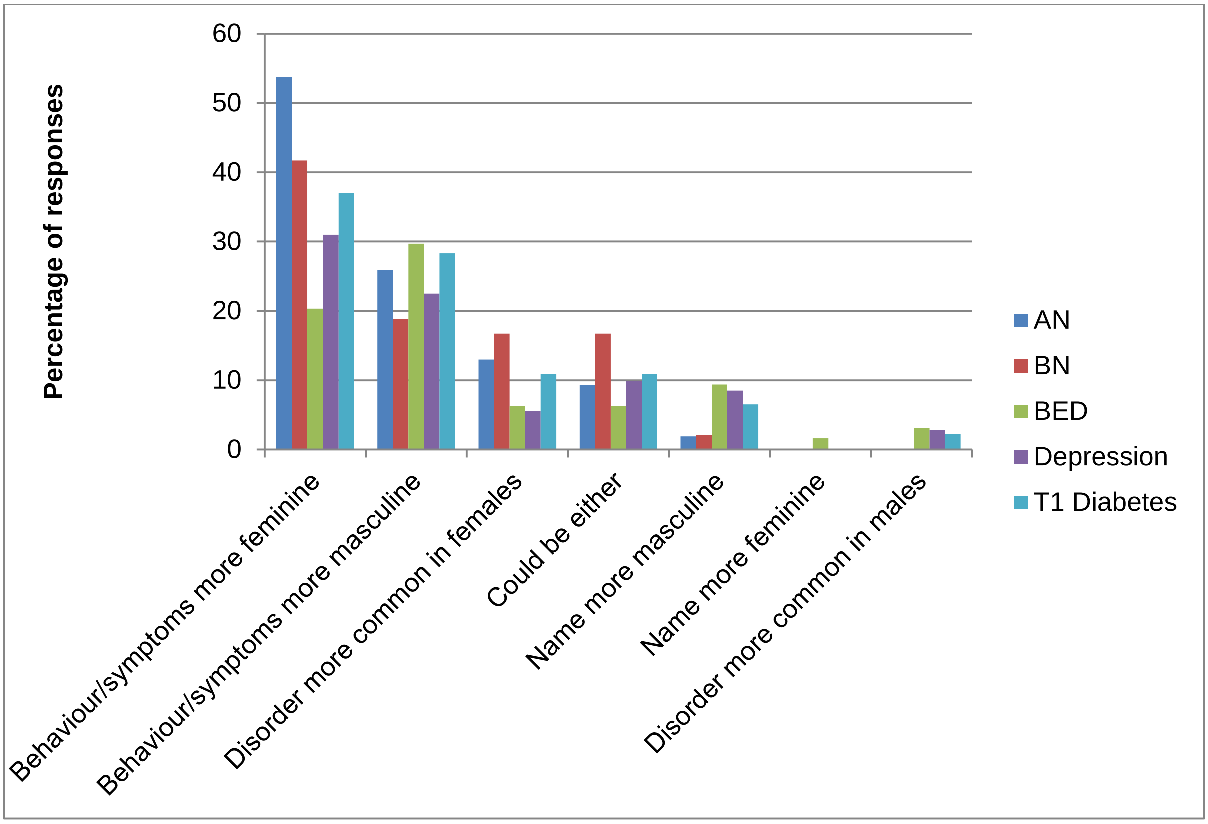


Figure 23. Reasons for gender attribution

5.3.3.Stigma in society

5.3.3.1. Social distance

Participants were presented with a list of five instances of social marginalisation experienced by people with EDs and asked to rate how often they believe these occur (5-point scale from ‘never’ to ‘always’). Figure 24 shows that mean scores on all items clustered around the midpoint of the scale (‘sometimes’). As a whole, this sample was rather equivocal about the extent of social marginalisation that people with EDs encounter.

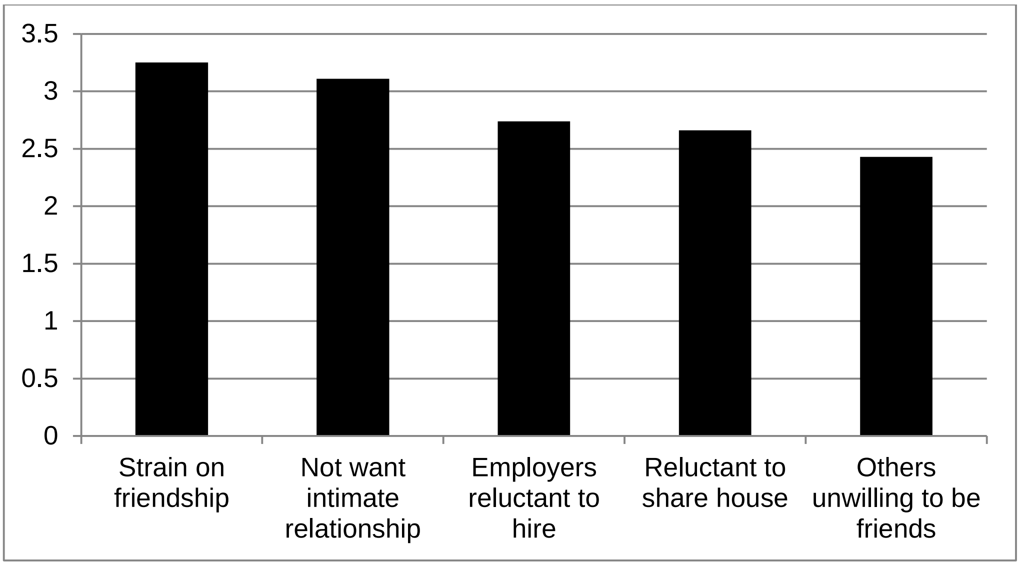


Figure 24. Mean scores on social distance items

The five items showed a kappa value of .776 and were summed to create a composite variable. Analysis did not detect any significant effect of demographic characteristics, body satisfaction or ED experience on this variable.

5.3.3.2. Stigmatising beliefs

Participants were also asked to rate their agreement with five statements asserting that many people hold various stigmatising beliefs about EDs (5-point scale from 'strongly disagree' to 'strongly agree'). Figure 25 shows the mean responses for these items. As a whole, participants were largely neutral on the question of whether people with EDs faced stigmatising attitudes.

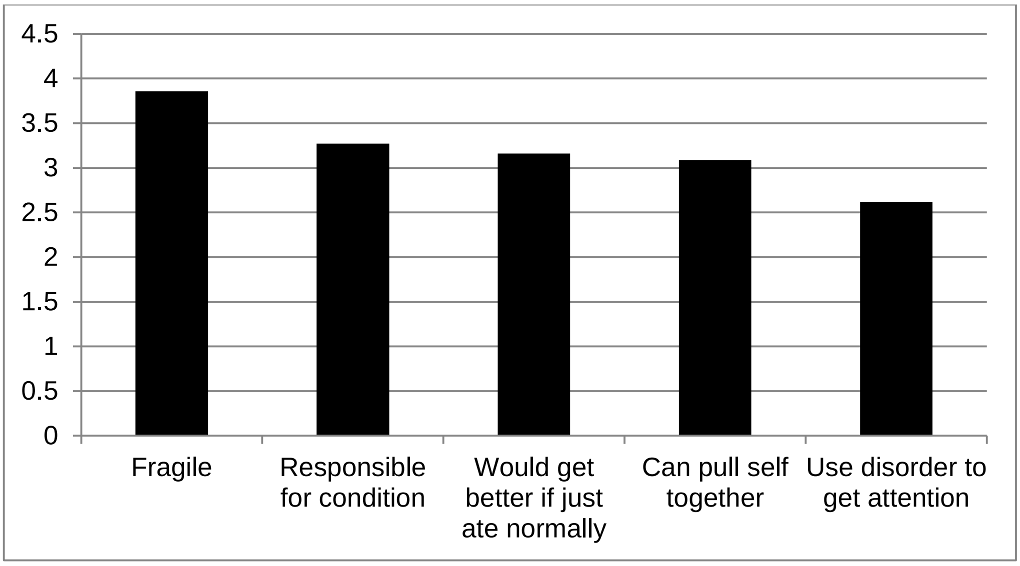


Figure 25. Mean scores on stigmatising beliefs items

The five items showed a kappa value of .751 and were summed to create a composite variable. Analysis did not detect any significant effect of demographic characteristics, body satisfaction or ED experience on this variable.

5.4. INTERIM DISCUSSION

The aims of this study were to: (1) assess the level of body satisfaction and eating concerns in Irish adolescents, (2) identify their help-seeking behaviours in relation to these concerns and (3) explore young people's eating disorder literacy and their attitudes towards individuals with eating disorders. There is a clear need to collect this data in order to inform the development of targeted health promotion initiatives and encourage early disclosure of disordered eating habits.

Previous research has identified that Irish adolescents experience significant challenges related to body image (Department of Children and Youth Affairs, 2012; McNicholas et al., 2009). The results of the current study echo these findings. 78% of our respondents described their appearance as important, yet only a minority expressed satisfaction with their body (with just 5% rating themselves as 'very satisfied'). It is important to note that although boys did report higher levels of body satisfaction than girls in our sample, appearance appeared equally important to both. This corroborates previous findings regarding the growing importance of appearance to young men (Grogan & Richards, 2002). Over one-third of participants indicated that they were concerned about their eating habits, but half of these had not divulged these concerns to someone else. The reasons most commonly cited for non-disclosure implicated stigma concerns, namely a fear of being negatively judged and not being taken seriously (Booth et al., 2004; Darcy & Dooley, 2007). The presence of stigma consciousness in young people reiterates the importance of reassuring adolescents that they will not be negatively judged if they disclose any eating-related concerns.

In general, young people did not feel that they had a good understanding of how to access support for eating problems. Their particularly low confidence that they would know how to obtain professional help for eating concerns indicates a need for greater dissemination of information about routes of access to mental health services. Participants' preferred pathways of help-seeking for eating concerns revolved mainly around personal contacts, such as family and friends. Mental health campaigns may benefit from harnessing these authentic social networks to effectively deliver information and support to Irish young people. However, before such measures are implemented, it is important first to ensure that lay members of the public (both adults and young people) feel confident that they can help a young person who expresses eating concerns. Many of our participants reported that they would not know how to help a friend with an eating problem. Additionally, the low rates of identification of the EDs described in the vignettes indicate that young people may have difficulty identifying behavioural patterns as clinically problematic. Future research should continue to explore young people's knowledge and cognitions associated with EDs, which can provide vital insight into both mental health literacy (Jorm, Korten, Jacomb, Christensen, Rodgers & Pollitt, 1997) and people's likelihood of defining an issue as necessitating professional intervention (Jorm, 2000).

The results confirm previous international findings that in the general population, EDs are stigmatised to a greater extent than other mental or physical health conditions (Roehrig & McLean, 2010; Stewart et al., 2006, 2008; Crisp, 2005; Griffiths et al., 2014). This is not necessarily something of which young people are consciously aware: when directly asked whether people with EDs face social marginalisation or disparaging attitudes, the sample responded equivocally. However, the differential responses to the various vignettes show that unfavourable attitudes were present in our sample. Irish adolescents see people with EDs in a negative light relative to other mental and physical illnesses. Specifically, and consistent with previous research in other jurisdictions (Roehrig & McLean, 2010; Stewart et al., 2006, 2008; Crisp, 2005), the adolescents in our sample tended to hold individuals with EDs personally responsible for their illness and ascribe fewer positive characteristics to them compared to those with depression and T1 diabetes. This result was detected despite relatively high levels of reported personal acquaintance with people affected by EDs, contradicting previous findings that personal experience with EDs (whether direct or indirect) reduces the tendency to stigmatise (Crisp, 2005).

The results also show that in considering ED stigma, it is critical to attend to the unique illness representations of the different categories of ED. In particular, responses to the BED vignette were distinctive on a number of dimensions. Firstly, the absence of any mention of BED in respondents' characterisations of 'Alex's main problem' reflects a very low awareness of this diagnostic category. Participants' responses intimated that the behavioural patterns described in the BED vignette were not seen as a medical condition, but rather as a failure of self-discipline. The BED target was ascribed significantly more personal control over their condition than the targets with other illnesses. Consistent with the framing of BED as a matter of poor behavioural choices, relative to the other disorders BED was seen as manageable by more non-clinical means, such as 'getting out and about more' or implementing dietary or exercise regimes. The data revealed an unfavourable view of the personal character of the BED target, who was ascribed significantly fewer positive traits than the depression or AN vignettes incurred. Despite this, however, participants anticipated most positive emotion interacting with the BED target. This result is puzzling, but may reflect the greater perceived 'normality' of the BED behavioural patterns, or the relatively non-threatening nature of an overweight person who is unable to control their food intake.

The distinctive emotional and attitudinal responses elicited by the BED vignette may also be linked to the different gender assumptions that it prompted. The individual in the BED vignette was the most likely of all illnesses to be judged male, whereas the other ED vignettes were mostly interpreted as describing females. This is consistent with research by Griffiths et al. (2014) which found that AN was perceived as a 'female' disorder while muscle dysmorphia was represented as 'male'. In the explanations participants offered for their gender assumptions, people mobilised a wide range of prevailing gender stereotypes regarding men and women's differential values, communication patterns, activity preferences, and relationships with food and bodies. Representations of men as incommunicative and emotionally inhibited, and women as appearance-obsessed and emotionally volatile, were both reflected in and reinforced by people's readings of cases of ED. Gender differences also manifested in the young people's relationships with their bodies: girls recorded significantly lower levels of body satisfaction than boys and reported greater levels of personal acquaintance with people with ED. In the responses to the vignettes, boys tended to locate responsibility for EDs within the individual, while girls conceptualised them as a response to emotional stress. These findings illustrate that attitudes to EDs in Ireland cannot be abstracted from their embeddedness in a highly gendered society.

5.4.1.Study strengths & limitations

A key strength of this research is its uniqueness. There are very few published studies, either in the Irish or international context, which explore young people's knowledge or attitudes regarding EDs. Previous research exploring the lay beliefs and stigma associated with eating disorders has tended to recruit adult community or university samples rather than adolescents, despite the fact that most EDs commence during this stage of life. This study has addressed this gap in the literature by specifically targeting adolescents in the 15-19 year age group, a cohort who are at particularly high risk of the development of EDs.

The research will be of particular value in informing the design of future psycho-educational initiatives. Our findings have highlighted gaps in adolescents' knowledge of EDs that health promotion initiatives should address, particularly in relation to BED. One positive pattern that emerged from our data is young people's high levels of literacy concerning depression. This is perhaps testament to the effectiveness of recent national campaigns on behalf of the HSE, which have highlighted the symptoms of depression and urged young people in particular to confide mental health concerns to other people. We argue that a similar campaign dealing with EDs could help to increase the general population's ED literacy, both in terms of recognising and defining maladaptive behavioural patterns as problematic, and highlighting how to seek help. In line with our findings, however, we note that encouraging someone to talk to friends or family about their problems will only be effective if those friends and family have a satisfactory level of awareness of EDs and ED support services. We also suggest that public information campaigns should not restrict themselves to raising awareness, but must also tackle stereotypes in order to encourage disclosure and help-seeking on the part of those affected. In particular, our data indicates that the myth that EDs are self-inflicted is widely endorsed by Irish young people. This should be dispelled by promoting awareness of the complex biological, social and psychological factors that contribute to the development of disordered eating patterns.

It is important to also acknowledge limitations of the study. Most notably, the response rate is lower than would be expected relative to previous similar research. The rather drawn-out process of obtaining school, student and parental approval may have contributed to this: the many different steps involved in the recruitment processes may have increased rates of attrition. The reliance of the data collection strategy on a web-based survey, while helping to promote anonymity and honest responding, also introduced some confusions in the dataset. Although each student was issued a unique identifying number in their email invitation, in a small amount of cases the same identifying number appeared more than once. It is possible that students may have forwarded the email onto others or completed the survey with friends using the same link. The data corresponding to any duplicated numbers were deleted because consent could not be verified, which led to a further constriction of the dataset. Future similar research may benefit from the researcher directly travelling to the schools and personally overseeing data collection.

On a positive note, the relatively low size of our sample is partly mitigated by its demographic balance. The sampling strategy obtained good representation of students of different ages, genders and school-types. This provides confidence that the research is not biased or unrepresentative.

Key recommendations derived from our results are presented in the Discussion section.

6. DISCUSSION & RECOMMENDATIONS

Dealing with eating concerns is a challenge confronting many young people and their parents in Ireland. There is clear evidence that services are under-developed and healthcare professionals are insufficiently prepared to provide comprehensive care (Department of Health & Children, 2006). Coping with the stigma associated with eating disorders is an additional burden to bear. During the consultation process for the compilation of *A Vision for Change*, the problem of stigma was identified as a key concern for individuals recovering from mental illness (Department of Health & Children, 2006). While understanding the stigma associated with mental illness has been the focus of significant research effort, eating disorders have tended to receive less attention compared to disorders such as depression or schizophrenia (Mond, Robertson-Smith & Vetere, 2006; Zwickert & Rieger, 2013). Consequently, there is a limited evidence base which can inform stigma-reduction interventions and wider public health initiatives. Addressing this gap is of vital importance given that educational actions form a cornerstone of the mental health promotion policy recommendations outlined in *A Vision for Change* (Department of Health & Children 2006). Furthermore, improving service infrastructure will have little tangible impact if social barriers to service use are not also addressed.

Internationally, the research that is available confirms that EDs are stigmatised conditions. Studies have revealed both public and professional endorsement of beliefs that EDs are self-inflicted disorders, which are a manifestation of attention-seeking and are under a high degree of individual control (Byrne, 2000; Crisafulli et al., 2008; Crisp, 2005; Currin et al., 2009; Roehrig & McLean, 2010). Individuals living with EDs report awareness of these stereotypes and often expect to be negatively treated if they reveal their stigmatised status to others (Easter, 2012; McNamara, 2014). This stigma consciousness (Pinel, 2002) acts as a significant barrier to accessing appropriate support and treatment (McNamara, 2014). Furthermore, it can reduce the effectiveness of the support that is already provided. Poor knowledge of EDs and their causes can lead to family members, friends and sometimes health professionals offering advice and support that is based on misconceptions of the nature of EDs and the recovery process (Linville, Brown, Sturm & McDougal, 2012; McNamara, 2014). Such support is judged to be inappropriate by recipients and may hinder rather than facilitate recovery (Linville et al., 2012), in addition to acting as a source of tension between individuals and their support network (McNamara, 2014).

However, almost all the research conducted in this area has involved adult samples. Very little published data is available on the experiences of young people who are living with an eating disorder from their own perspective. Furthermore, we have virtually no information on younger generations' levels of ED literacy or their attitudes towards individuals with EDs. This is especially true in the Irish context. Thus, while the international literature suggests (primarily from an adult perspective) that stigma is a problem for those struggling with eating concerns, we do not have knowledge of the magnitude of this problem for young people in Ireland.

The STEDI project was designed to address this significant knowledge gap. Our over-arching research aims were to: (i) generate knowledge in relation to service provision and outcomes for individuals with eating disorders and (ii) identify the extent to which stigma acts as a barrier to service provision and use. In order to achieve these aims we set out to: (a) describe service provision, engagement and outcome for young people with EDs in Ireland, (b) identify any gaps in service provision and education of health professionals, and (c) understand the impact of stigmatisation on help-seeking behaviour and outcome. A significant part of this research was establishing the levels of ED literacy in health professionals and young people in addition to exploring the attitudes both groups hold towards individuals with eating disorders. It is these beliefs and attitudes that form the social context within which service provision and service use are embedded (Stevenson et al., 2014). In order to make specific recommendations for education or public health initiatives, it is important to establish current knowledge and attitudes.

The following presents an overview of the key findings to emerge from this three-stage, multi-method project.

6.1. SUMMARY OF KEY FINDINGS

6.1.1.Stage I: Multi-perspective study of experiences with eating disorders

- Interviews with young people revealed that they viewed their eating disorder as providing a solution to, or way of coping with, life stressors. They conceptualised their disorders as being caused by a combination of events, although they often pointed to a single pivotal causal event (which was typically social in nature).
- While disordered eating behaviours were reinforced in the short term by positive comments from others on their appearance, deeper psychological benefits (a sense of calm, feelings of order, stability and control) were reported to maintain the eating disorder over time.
- Living as someone with an ED involved a strict behaviour code in relation to eating, which helped maintain a sense of order and control. Engaging with treatment involved dispensing with this ‘code’ and some participants felt they were left without ways of coping with life stressors.
- Young people tended to view EDs as chronic and were not optimistic about a full recovery. The disorder was characterised as something that would have to be managed throughout their life.
- Parents reported a difficult transition in adapting to their new role as the carer of someone with an eating disorder. Overwhelmingly, parents felt isolated and helpless in this role. Many unreported both support and informational needs that were unmet by services.

- Parents reported that EDs have a significant impact on the wider family. Such issues are often perceived not to be addressed in care pathways/treatment.
- Both parents and health professionals were critical of the services available to young people. Parents felt services were inadequate with unacceptable wait times and levels of intervention. Clinicians criticised the lack of referral options available to them and reported that time constraints limited the amount of support they could offer to those under their care.

6.1.2.Stage II: Health professionals' survey

- Levels of professional knowledge regarding EDs were moderately good. However, there was some uncertainty detected. Professionals tended to recognise symptoms of EDs less frequently than those of depression and seemed vague in their knowledge of potential causes of EDs. Psychiatrists reported greatest levels of knowledge of EDs and confidence in treating individuals who present with EDs.
- There were some indications that health professionals stigmatise EDs to a greater extent than depression or T1 diabetes. The findings indicated that professionals would prefer working with those with depression over individuals with EDs.
- EDs were viewed as primarily affecting females in addition to being chronic disorders that were both controllable and curable. Psychiatrists were the professional group that held the most pessimistic views on the long-term prospects of individuals with EDs and reported highest ratings on the controllability of the disorder.
- Professionals were almost unanimous in their call for a standardised protocol for the treatment of EDs. They were highly critical of the quality of services in this area and of the difficulties associated with accessing them. While many seemed aware of support organisations (80%), this was not reflected in the percentage of reported referrals (63%).

6.1.3.Stage III: Young people's survey

- Approximately one third of the young people in our sample were concerned about their eating habits. Half of these young people had not disclosed their concerns to anyone, often due to stigma-related concerns.
- Young people did not have a good understanding of how to access support for eating problems. While most reported that they would prefer seeking help from a family member or friend if they developed eating concerns, many also reported that they would not know how to help a friend who approached them with their own concerns.
- Young people's ED literacy appeared to be quite low. Respondents were able to correctly identify depression more frequently than any of the EDs presented. There was particularly low awareness of BED.

- Young people perceived individuals with EDs relatively negatively compared to those with depression and T1 diabetes. EDs were seen as self-inflicted disorders primarily affecting females (with the exception of BED, which was seen as a ‘male’ disorder). Targets with EDs tended to be ascribed fewer positive characteristics. The data revealed a particularly unfavourable view of the BED target.

In the following section, we integrate the findings from all three project stages in order to address our overall research aims. We caution that our interpretation of the findings is constrained by the limitations previously highlighted in the discussion section of each project stage.

6.2. IMPLICATIONS FOR RESEARCH OBJECTIVES

6.2.1. Service provision and outcome for individuals with eating disorders

A Vision for Change (Department of Health & Children, 2006) highlighted a number of shortcomings in ED service provision. In order to address this, the Expert Group offered recommendations and provided a tailored ED care pathway for both young people and adults who are diagnosed with an ED. In keeping with the policy’s recovery ethos, the Expert Group recommended that EDs be managed by GPs at primary care level with the assistance of CMHTs and appropriate voluntary support services. Secondary and tertiary services would be involved only in complex cases that did not respond to earlier treatment. Thus, primary care practitioners have a crucial role in detecting cases of EDs and initiating appropriate care pathways. The success of this recommended pathway depends on appropriate investment in service infrastructure as well as professional knowledge of and confidence in treating EDs. Our data provided an insight into levels of professional knowledge across a range of disciplines, as well as the implementation and delivery of ED services from the perspective of young people, their carers, and health professionals. Findings from Stages I and II suggest that care is not being delivered as outlined in the pathway recommended by the expert group.

Service provision generally remains a problem for individuals with EDs. Our clinician survey highlighted difficulties accessing ED services. This was corroborated by both the GPs and parents interviewed in Stage I. The two GPs interviewed indicated a significant problem with access to secondary mental health services, particularly in relation to long waiting lists. There was the suggestion that families would deal with these access delays by pursuing private treatment; however this option is clearly not available to all. Parents also criticised delays accessing treatment and reported pursuing private treatment (typically with counselling services) until this option became financially unsustainable.

A second issue highlighted by parents was their unmet informational and emotional needs and their dissatisfaction with the level of intervention provided. They indicated that although EDs impacted on the entire family, this was often not addressed in treatment. This was in some cases due to parents’ wishes to ‘protect’ siblings from the knowledge that their brother/sister was attending a psychiatric service. However the fact that family treatment and support did not appear to be provided to young people and their families suggests a gap in the care pathway proposed by the Expert Group (Department of Health & Children, 2006). In contrast, the UK’s NICE guidelines relating to care across all EDs recommends that family members (including siblings) be included in treatment through the use of interventions that include “the sharing of information, advice on behavioural management, and facilitating communication” (NICE, 2004, p.4). It is clear from our interviews with parents that providing such interventions as a matter of course could combat a sense of isolation and help increase parents’ sense of confidence and efficacy in supporting their child in their recovery. Thus we would suggest that this should be included in the ED care pathway.

Our data also suggest that the role ascribed to VSOs in existing mental health policy be formally implemented in practice. Although the Expert Group’s proposed pathway recommends involving community supports, only 63% of clinicians reported referring to these groups. Both parents and young people felt that they needed greater levels of social support, however clinicians felt that they were not in a position to provide such support due to time and resource constraints. Voluntary organisations are in a prime position to fill this gap. In particular, problems relating to limited local services could be partly addressed through online support groups and other VSO-initiated activities. However, this is contingent on the tangible support promised in *A Vision for Change.* Future research is needed to investigate the effectiveness of VSO services in addition to parents’ and young peoples’ willingness and ability to engage with them.

Finally, Stage II findings revealed that professionals tended to recognise EDs less frequently than depression. While this suggests gaps in training across all disciplines, we believe our data have particular implications for the Expert Group’s recommendation that EDs be treated at primary care level. Currently our data would suggest that GPs remain under-confident and ill-equipped to treat EDs. The GPs in our sample had a relatively low level of knowledge relating to the detection and treatment of EDs and reported a lack of confidence in diagnosing and treating EDs. Furthermore, when outlining how they would deal with the ED presented in the vignette, GPs were unlikely to undertake a mental health assessment and were more likely to indicate that they would make an onward referral. The lack of knowledge and confidence reported by GPs, eight years on from the publication of *A Vision for Change*, reiterates the issue of inadequate mental health training for GPs (Copty & Whitford, 2005). Our survey findings would suggest that those seeking treatment for EDs are not receiving the care outlined in the recommended pathway described above (Figure 1, p. 13). These findings would seem to be supported by our Stage II interview data. Both GPs interviewed indicated that they would typically refer young people presenting with EDs to CAMHS services and would not play a significant role in the treatment of the young person thereafter. Whilst it may be appropriate to refer young children with ED early to CAMHS, the GPs still play a pivotal role in early detection and treatment in mild cases, and have a very important role after CAMHS intervention by way of ongoing support and relapse prevention.

In summary, our data suggest that services for individuals with EDs remain under-developed and that ED care pathways recommended by policy makers are not being followed in clinical practice. Furthermore, there are gaps in professional training, particularly for GPs that impact their confidence in dealing with this client group.

6.2.2.Stigma as a barrier to service provision, access and use

Investing in service infrastructure and professional training for EDs will have limited success in encouraging service engagement, if issues relating to ED literacy and stigmatising beliefs and attitudes are not concurrently addressed.

Regarding ED literacy, we have previously noted the importance of early intervention in EDs, but also highlighted that this rarely happens in practice (Department of Health & Children, 2006). Increasing early intervention rates will come as a result of not only increasing professional knowledge, but also public awareness of the signs of EDs. Our Stage I data suggest that parents were unsure of the signs that their child was at risk for ED development, which led to a delay in contacting health services as parents 'normalised' the behaviours. In addition, our findings from Stage III revealed that young people were poor at recognising when a target was suffering from an ED. This implies that both young people and parents need to be provided with knowledge that alerts them to possible signs of eating problems.

Young people in Stage III appeared highly literate concerning the signs of depression. This is unsurprising given recent national campaigns on behalf of the HSE, which have highlighted symptoms of depression and urged young people in particular to talk to someone about their concerns. A similar campaign dealing with EDs could both increase ED literacy in terms of recognising and defining concerns as clinically problematic and highlighting how to access support. This latter issue is crucial, as increasing awareness of the signs of EDs is likely to be limited in its usefulness unless it is accompanied by a recommendation on how and where to seek help. Again our data suggested that this is a need that is not currently being met, with both parents in Stage I and adolescents in Stage III reporting a lack of knowledge in how to access support for eating problems. Furthermore, our Stage III survey findings indicate that adolescents are most likely to turn to a parent or friend for support with their eating problems. This underlines the need to increase public ED literacy.

However, it is clear that a lack of knowledge is not the only barrier to early intervention and service engagement. Stigma too emerged as a potential barrier to service access, use and provision. Regarding accessing services, half of our young people in Stage III who reported having eating concerns had not disclosed these concerns to anyone, often due to stigma concerns. In particular, respondents reported a fear of being judged and not having their concerns taken seriously. Examining both clinician and adolescents’ beliefs around EDs in Stages II and III suggests that this is not an irrational fear. Both professionals and young people tended to view individuals with EDs in a negative light. This stigma consciousness was evident in Stage I with many interviewees reporting that they were selective in disclosing their ED, that they hid it from siblings, and some feeling ashamed or embarrassed. It was also clear from our Stage I data that young people were acutely aware of the stereotypes associated with EDs. They often spoke of a general lack of understanding among others, even close friends and family who tried to support them. Limited or inaccurate knowledge of EDs and the nature of recovery can lead to a mismatch between support offered and the recipients’ actual support needs (Linville et al., 2012). This was illustrated in one interview with a young person who isolated herself from her friends because “*they’d either mention I’d lost weight or they’d make me go somewhere where I’d have to eat, or they’d do something mean like that*.” Consistent with previous research (Linville et al., 2012; McNamara, 2014), well-intentioned support can often be met with a negative response, leading to tensions between the young person and their immediate support network.

This latter point regarding the need to provide appropriate, acceptable support and be sensitive to inaccurate beliefs around EDs is as important for health professionals as it is for the young person’s immediate social network. As indicated in our data, clinicians hold beliefs about EDs (i.e. that they are controllable and curable) that are at odds with the illness beliefs reported to be held by those living with an ED (Holliday et al., 2005). As mentioned, young people are aware of these stereotypes and individuals with EDs tend to be sensitive to such attitudes (Easter, 2012). Even if a clinician does not overtly display negative attitudes, young people might approach the interaction expecting to be negatively judged, and interpret the subsequent encounter through that lens. In turn, the clinicians’ perceptions will also be used as a basis to interpret the young person’s responses and behaviours. Thus, the responses of each party in the interaction form the context for the interpretation and counter-response of the other (Reicher, 1996; Stevenson et al., 2014). Ambiguous situations, off-the-cuff comments from support providers, or perceived resistance from the young person, have the potential to be interpreted in a negative way, leading to a breakdown in communication and a suboptimal support experience – a process termed the ‘social curse’ (Stevenson et al., 2014).

Inaccurate beliefs on the part of clinicians regarding EDs can impact treatment decisions and potentially who gets diagnosed with an ED in the first place. As our data illustrated, clinicians were uncertain regarding the causes of EDs but tended towards individual-level explanations. This could in turn affect treatment provided, for example leading to a focus on self-esteem or emotional regulation. While this is a necessary part of treatment, individual-level psychological issues are located within a wider familial and social context, which should be recognised and addressed by the treatment package. Our data suggests that this does not currently happen, given the lack of involvement of parents/siblings in treatment reported in Stage I.

Finally in terms of detection and service access, our data illustrate that EDs remain primarily associated with females. Both clinicians and young people tended to associate EDs with females and depression/diabetes with males. This could potentially discourage or delay boys and young men disclosing their concerns to others and it might inhibit early detection in primary care. However, a notable exception was BED in the adolescent sample, which tended to be seen as a ‘male’ behavioural pattern.

The beliefs and attitudes held by professionals, young people and the wider general public form the social context within which service provision and use are embedded (Stevenson et al., 2014). Our data suggests that there is a clear need to raise ED literacy and tackle prevailing ED stereotypes both in clinicians and young people in order to improve the quality of services and encourage disclosure of eating concerns.

6.3. RECOMMENDATIONS

This research project suggested three main issues that impact on the care of young people with EDs. First, the care pathway outlined in *A Vision for Change* has not yet been fully implemented. Second, there are gaps in professional training. Third, EDs are stigmatised conditions and the awareness of ED stereotypes can inhibit disclosure. The following presents a number of recommendations for service development, professional training, and health promotion activities based on the results of the STEDI project.

6.3.1. Service development

g) Service provision for young people with EDs remains poor. We recommend the investment of the necessary supports, resources and training in order to implement the care pathway outlined in *A Vision for Change*.

h) A comprehensive protocol for diagnosing and treating EDs should be prepared and disseminated to clinicians across disciplines.

i) GPs require comprehensive training in mental health and need reliable access to appropriate professional supports if the *A Vision for Change* ED care pathway is to be properly implemented.

j) Increased collaboration between statutory and voluntary services would prove fruitful, particularly in assisting with support needs of young people and parents.

k) Additional support services are needed for both young people and parents/families affected by EDs. For young people, a safe way to interact with others going through same experience was suggested as potentially helpful. Online platforms offer a viable means of securing such support, although research should be conducted to assess the effectiveness of such interventions.

l) EDs affect not only the individual young person but also have a significant impact on their family. We recommend that this be acknowledged in ED care pathways (as it is in NICE guidelines) and that professionals make a concerted effort to include parents and siblings in the treatment plan and ensure that their support needs are also being met.

6.3.2. Professional training

c) We recommend that professional education programmes across disciplines include specific training on ED detection and treatment. This should include all ED subtypes.

d) Training programmes for professionals should not just focus on knowledge but also attitudes. Clinicians need to be aware of the stigmatising beliefs that impact on service quality, in addition to the detrimental effect stigma consciousness can have on service engagement.

6.3.3. Health promotion

e) *A Vision for Change* recommends the instigation of health campaigns promoting awareness of health eating and body image. While it is clear that the adolescents in our sample did exhibit body dissatisfaction, we remain unconvinced that campaigns that focus on healthy eating and body image will resolve the issue. . In our interviews with young people currently in recovery, they reported that their eating problems were a reaction to life stressors rather than resulting from poor body image in itself or inadequate knowledge of healthy eating. We recommend that educational interventions focus on developing self-efficacy and positive coping strategies in young people.

f) A public awareness campaign, targeted at both young people and parents, is needed to increase levels of ED literacy. Such campaigns should also include information about how and where to seek help for eating concerns.

g) Public information campaigns should be developed with the aim of dispelling ED stereotypes in order to encourage disclosure and help-seeking on the part of those affected. Our data from Stages I, II and III suggest that the specific misconceptions that need to be addressed include the misperception that EDs are ‘female’ disorders, that EDs are self-inflicted and the individual has a high level of control over their behaviours, that full recovery is unlikely, and that EDs are fundamentally about eating patterns rather than underlying psychological, social and biological factors.

h) Some parents in Stage I reflected on difficulties encountered in discussing their child’s illness with schools. It could be helpful to provide schools nationwide with information on recognising the signs of EDs and how to support young people in their schools that have been diagnosed with an ED.

6.4. FUTURE RESEARCH

The STEDI project provides a valuable glimpse into the actual implementation and delivery of ED services in Ireland, from the perspective of young people, their parents, and health professionals. It also identified the social barriers that can hinder disclosure and service engagement, namely, the attitudes and practices that operate within health services themselves and the beliefs and attitudes that exist within the wider community. Our study is unique in that we collected data indicating levels of ED knowledge and attitudes towards individuals with EDs across a range of health professionals in Ireland. In addition, we established levels of ED literacy and ED attitudes in an adolescent sample. This addressed a gap in the international as well as the national literature. Finally, we undertook to conduct research with adolescents currently living with an ED themselves, rather than relying on caregivers or retrospective accounts of the illness and recovery experience. Our data offer an insight into the active and lived experience of young people dealing with EDs and that of their parents. While there were some methodological limitations, most notably with participant recruitment, we believe that we have successfully achieved our research aims and objectives. On the basis of the current findings, we are also in a position to suggest a number of avenues for future research:

i. We would suggest adapting the survey used in Stage III and distributing this to a younger sample. While the age group used in STEDI are thought to be at high risk for development of eating concerns and are the most common age at which an ED develops, there is evidence to suggest that ED development is occurring at an earlier age. The UK's Health and Social Care Information Centre (2013) suggested that there is a rise in the number of pre-teen children being treated by NHS hospitals for eating disorders.

ii. While we successfully gathered data on assessing illness beliefs and perceptions regarding ED controllability, treatment efficacy, and chronicity in health professionals and 'lay' adolescents, it would be fruitful to also measure these beliefs in an adolescent sample who had received an ED diagnosis to determine any similarities or differences in the patterns found. This would provide additional insight into how best to manage interactions between young people and health professionals. It could also provide a basis on which to develop interventions for young people with EDs who may have internalised stigmatising beliefs.

iii. Further research is needed on the actual interactions themselves between clinicians and young people in order to identify the social psychological factors that contribute to a positive or a negative service interaction. Such data would provide valuable insight into future service development.

iv. Research is urgently needed on how to address the social support needs of young people and parents in an effective and safe environment. Given the financial constraints faced by voluntary support organisations, many have turned to providing support online. It would be useful to determine the effectiveness of these services for young people and parents, alongside understanding the psychological mechanisms through which social support from similar others has a positive impact on well-being.

REFERENCES

Aitken, C., Power, R., Dwyer, R. (2008). A very low response rate in an on-line survey of medical practitioners. *Australian and New Zealand Journal of Public Health,* 32, 288–289.

Asch, D.A., Jedrziewski, M.K., Christakis, N.A. (1997). Response rates to mail surveys published in medical journals. *Journal of Clinical Epidemiology* 50, 1129-1136.

Bezance, J., & Holliday, J. (2013). Adolescents with Anorexia Nervosa have their say: A review of qualitative studies on treatment and recovery from Anorexia Nervosa. *European Eating Disorders Review, 21,* 352-360.

Bezance, J., & Holliday, J. (2014). Mothers' experiences of home treatment for adolescents with Anorexia Nervosa: An Interpretative Phenomenological Analysis. *Eating Disorders: The Journal of Treatment and Prevention*, *22,* 386-404.

Bodywhys (2013). *Annual Report.* Retrieved 20 November 2014, from http://www.bodywhys.ie/m/uploads/BWAR2013Final.pdf

Booth, M.L., Bernard, D., Quine, S., Kang, M.S., Usherwood, T., Alperstein, G., & Bennett, D.L. (2004). Access to health care among Australian adolescents: Young people's perspectives and their socio-demographic distribution. *Journal of Adolescent Health*, *34*, 97-103.

Byrne, P. (2000). Stigma of mental illness and ways of diminishing it. *Advances in Psychiatric Treatment, 6,* 65-72.

Chambers, D., Murphy, F., Keeley, H.S. (in press). All of us? An exploration of the concept of mental health literacy based on young people's responses to fictional mental health vignettes. *Irish Journal of Psychological Medicine.* Online early publication, doi:10.1017/ipm.2014.82

Charmaz, K. (1990). 'Discovering' chronic illness using grounded theory. *Social Science and Medicine, 30,* 1161-1172.

Charmaz, K. (2006). *Constructing Grounded Theory. A Practical Guide Through Qualitative Analysis.* London: Sage Publications

College of Psychiatry of Ireland (2010). *The College of Psychiatry of Ireland submission to the 2nd A Vision for Change Monitoring Group.* Retrieved 20 November 2014, from http://www.irishpsychiatry.ie/Libraries/External_Events_Documents/College_report_to_the_2nd_Indep_monitoring_group_on_AVFC_progress_Nov_2010.sflb.ashx

College of Psychiatry of Ireland (2012). *Submission to the Independent Monitoring Group on progress of A Vision for Change in 2011*. Retrieved 20 November 2014, from http://www.irishpsychiatry.ie/Libraries/External_Events_Documents/CPsychI_report_to_IMG_re_vision_in_2011_Final_3_February_2012_1.sflb.ashx

Cohen, J. (1988). *Statistical power analysis for the behavioural sciences (2nd ed.)*. Hove: Lawrence Erlbaum Associates.

Copty, M., & Whitford, D. L. (2005). Mental health in general practice: Assessment of current state and future needs. *Irish Journal of Psychological Medicine, 22*, 83-86.

Crisafulli, M.A., Van Holle, A., & Bulik, C.M. (2008). Attitudes towards Anorexia Nervosa: The impact of framing on blame and stigma. *International Journal of Eating Disorders, 41*, 333-339.

Crisp, A. (2005). Stigmatisation of and discrimination against people with eating disorders including a report of two nationwide surveys. *European Eating Disorders Review*, *13*, 147-152.

Cull, W. L., O'Connor, K. G., Sharp, S., & Tang, S. F. S. (2005). Response rates and response bias for 50 surveys of pediatricians. *Health Services Research*, *40*, 213-226.

Currin, L., Schmidt, U., Treasure, J. et al. (2006). *Entry into specialist services for the eating disorders: Audit of clinical pathways through primary and secondary care.* Report from the Specialist Clinical Audit Programme for South London, Kent, Surrey and Sussex. NHS Specialist Clinical Audit Office.

Currin, L., Waller, G., & Schmidt, U. (2009). Primary care physicians’ knowledge of and attitudes towards the eating disorders: Do they affect clinical actions? *International Journal of Eating Disorders*, *42*, 453-458.

Darcy, A. M., & Dooley, B. (2007). A clinical profile of participants in an online support group. *European Eating Disorders Review, 15*, 185–195.

Department of Children and Youth Affairs (2012). *How We See It: Report of a Survey on Young People's Body Image.* Retrieved 20 November 2014, from http://www.dcya.gov.ie/documents/childyouthparticipation/BodyImage/DCYABodyImageReport.pdf

Department of Health & Children (2006). *A Vision for Change: Report of the Expert Group on Mental Health Policy.* Dublin: Government Publications Office.

Dryer, R., Tyson, G. A., & Kiernan, M. J. (2013). Bulimia nervosa: Professional and lay people's beliefs about the causes. *Australian Psychologist*, *48*, 338-344.

Easter, M. M. (2012). “Not all my fault”: Genetics, stigma, and personal responsibility for women with eating disorders. *Social Science & Medicine*, *75*, 1408-1416.

Ebneter, D. S., & Latner, J. D. (2013). Stigmatizing attitudes differ across mental health disorders: A comparison of stigma across eating disorders, obesity, and major depressive disorder. *Journal of Nervous and Mental Disorders, 201*, 281-285.

Flahavan, C. (2006). Detection, assessment and management of eating disorders; how involved are GPs?. *Irish Journal of Psychological Medicine*, *23,* 96-99.

Fursland, A. W., & Watson, H. J. (2014) Eating disorders: A hidden phenomenon in outpatient mental health? *International Journal of Eating Disorders*, *47*, 422-425.

Glaser, B., & Strauss, A. (1967) *The discovery of grounded theory*. Chicago: Aldine.

Goffman, E. (1963). *Stigma: Notes on the management of a spoiled identity*. New York: Prentice-Hall.

Griffiths, S., Mond, J. M., Murray, S. B., & Touyz, S. (2014), Young people's stigmatizing attitudes and beliefs about anorexia nervosa and muscle dysmorphia. *International Journal of Eating Disorders, 47*, 189–195.

Griffiths, S., Mond, J. M., Murray, S. B., Touyz, S. (in press). The prevalence and adverse associations of stigmatization in people with eating disorders. *International Journal of Eating Disorders*. Early online publication. doi: 10.1002/eat.22353

Grogan, S., & Richards, H. (2002) Body Image: Focus groups with boys and men. *Men and Masculinities, 4*, 219-232.

Hackler, A. H., Vogel, D. L., & Wade, N. G. (2010). Attitudes toward seeking professional help for an eating disorder: The role of stigma and anticipated outcomes. *Journal of Counseling & Development*, *88,* 424-431.

Hargreaves, D.A., & Tiggemann, M. (2006) “Body Image is for Girls”: A qualitative study of boys’ body image. *Journal of Health Psychology*, *11*, 567-76.

Health Research Board (2014). *HRB Statistics Series 25: Activities of Irish Psychiatric Units and Hospitals 2013.* Dublin: Health Research Board. Retrieved 20 November 2014, from http://www.hrb.ie/uploads/tx_hrbpublications/HRB025_Statistics_Series_25_Activities_of_Irish_Psychiatric_Units_and_Hospitals_2013_online.pdf

Holliday, J., Wall, E., Treasure, J., & Weinman, J. (2005). Perceptions of illness in individuals with Anorexia Nervosa: A comparison with lay men and women. *International Journal of Eating Disorders, 37*, 50-56.

Hope, T., Tan, J., Stewart, A., & McMillan, J. (2013). Agency, ambivalence and authenticity: the many ways in which anorexia nervosa can affect autonomy. *International Journal of Law in Context, 9,* 20-36.

Hudson, J. I., Hiripi, E., Pope, H. G., & Kessler, R. C. (2007). The prevalence and correlates of eating disorders in the National Comorbidity Survey Replication. *Biological Psychiatry, 61*, 348-358.

Joffe, H., & Staerklé, C. (2007). The centrality of the self-control ethos in Western aspersions regarding outgroups: A social representational approach to stereotype content. *Culture & Psychology, 13,* 395-418.

Jones, W.R., Saeidi, S., & Morgan, J.F. (2012). Knowledge and attitudes of psychiatrists towards eating disorders. *European Eating Disorders Review, 21*, 84-88.

Jorm, A. F. (2000). Mental health literacy: Public knowledge and beliefs about mental disorders. *British Journal of Psychiatry*, *177,* 396-401.

Jorm, A. F., Korten, A. E., Jacomb, P. A., Christensen, H., Rodgers, B., & Pollitt, P. (1997). Mental health literacy: A survey of the public's ability to recognise mental disorders and their beliefs about the effectiveness of treatment. *Medical Journal of Australia, 166,* 182-186.

Jorm, A. F., Korten, A. E., Jacomb, P. A., Christensen, H., & Henderson, S. (1999) Attitudes towards people with a mental disorder: a survey of the Australian public and health professionals. *Australian and New Zealand Journal of Psychiatry, 33*, 77–83.

King, S., & Turner, D.S. (2000). Caring for adolescent females with anorexia nervosa: Registered nurses' perspective. *Journal of Advanced Nursing, 32,* 139-147.

Kostanski, M., & Gullone, E. (1998). Adolescent body image dissatisfaction: relationships with self-esteem, anxiety, and depression controlling for body mass. *Journal of Child Psychology and Psychiatry, 39*, 255–262.

Linville, D., Brown, T., & O'Neil, M. (2012). Medical providers' self-perceived knowledge and skills for working with eating disorders: a national survey. *Eating Disorders, 20,* 1–13.

Linville, D., Brown, T., Sturm, K., & McDougal, T. (2012). Eating disorders and social support: Perspectives of recovered individuals. *Eating Disorders*, *20*, 216-231.

McNamara, N. (2014). *Living with an eating disorder: The impact of stigma on help-seeking and support experiences*. Dublin: Bodywhys The Eating Disorders Association of Ireland.

McNicholas, F., Dooley, B., McNamara, N., & Lennon, R. (2012). The impact of self-reported pubertal status and pubertal timing on disordered eating in Irish adolescents. *European Eating Disorders Review, 20*, 355–362.

McNicholas, F., Lydon, A., Lennon, R., & Dooley, B. (2009). Eating concerns and media influences in an Irish adolescent context. *European Eating Disorders Review, 17*, 208–213.

Mond, J. M., & Hay, P. J. (2008). Public perceptions of binge eating and its treatment. *International Journal of Eating Disorders*, *41*, 419-426.

Mond, J. M., Hay, P. J., Rodgers, B., Owen, C., & Beumont, P. J. V. (2004). Beliefs of women concerning the severity and prevalence of bulimia nervosa. *Social Psychiatry and Psychiatric Epidemiology*, *39*, 299-304.

Mond, J. M., Robertson-Smith, G., & Vetere, A. (2006). Stigma and eating disorders: Is there evidence of negative attitudes towards anorexia nervosa among women in the community? *Journal of Mental Health, 15,* 519-532.

Mond, J., & Marks, P. (2007). Beliefs of adolescent girls concerning the severity and prevalence of bulimia nervosa. *Australian Journal of Psychology,59,* 87-93.

Moss-Morris, R., Weinman, J., Petrie, K., Horne, R., Cameron, L., & Buick, D. (2002). The revised illness perception questionnaire (IPQ-R). *Psychology and Health*, *17,* 1-16.

National Association of Anorexia Nervosa and Associated Disorder (2000). *ANAD Ten Year Study.* Retrieved 20 November 2014, from http://www.anad.org

NICE (2004). *Core interventions in the treatment and management of anorexia nervosa, bulimia nervosa and related eating disorders*. London: National Institute for Health and Care Excellence

Oliffe, J., & Mróz, L. (2005). Men interviewing men about health and illness: Ten lessons learned. *The Journal of Men's Health & Gender, 2,* 257-260.

Patching, J., & Lawler, J. (2008). Understanding women’s experiences of developing an eating disorder and recovering: A life history approach. *Nursing Inquiry, 16,* 10-21.

Pinel, E. C. (2002). Stigma consciousness in intergroup contexts: The power of conviction. *Journal of Experimental Social Psychology*, *38*, 178-185.

Quiles Marcos, Y., Weinman, J., Terol Cantero, M.C., & Belendez Vazquez, M. (2009). The dissimilarity between patients' and relatives' perception of eating disorders and its relation to patient adjustment. *Journal of Health Psychology, 14,* 306-312.

Reicher, S. D. (1996). 'The Battle of Westminster': Developing the social identity model of crowd behaviour in order to explain the initiation and development of collective conflict. *European Journal of Social Psychology*, *26*, 115-134.

Roehrig, J.P. & McLean, C.P. (2010). A comparison of stigma towards eating disorders versus depression. *International Journal of Eating Disorders*, *43*, 671-674.

Rousseau, A., Callahan, S., & Chabrol, H. (2012). Representations and beliefs about eating disorders in a sample of French adolescents. *International Journal of Eating Disorders, 45*, 247–251.

Royal College of Psychiatrists (2012). *Eating disorders in the UK: Service distribution, service development and training. Report from the Royal College of Psychiatrists Section of Eating Disorders.* London: Royal College of Psychiatrists.

Smith, D. E., Marcus, M. D., Lewis, C. E., Fitzgibbon, M., & Schreiner, P. (1998). Prevalence of binge eating disorder, obesity, and depression in a biracial cohort of young adults. *Annals of Behavioral Medicine*, *20*, 227-232.

Stevenson, C., McNamara, N., & Muldoon, O. (2014). Stigmatised identity and service usage in disadvantaged communities: Residents', community workers' and service providers' perspectives. *Journal of Community & Applied Social Psychology*, *24*, 453-466.

Stewart, M.-C., Keel, P. K., & Schiavo, R. S. (2006). Stigmatization of Anorexia Nervosa. *International Journal of Eating Disorders, 39*, 320–325.

Stewart, M.C., Schiavo, R.S., Herzog, D.B., & Franko, D.L. (2008). Stereotypes, prejudice, and discrimination of women with Anorexia Nervosa. *European Eating Disorders Review, 16,* 311-318.

Strother, E., Lemberg, R., Stanford, S.C., & Turberville, D. (2012). Eating disorders in men: Underdiagnosed, undertreated and misunderstood. *Eating Disorders, 20*, 346-355.

Svensson, E., Nilsson, K., Levi, R., & Carbelleira, N. (2013). Parents' Experiences of Having and Caring for a Child With an Eating Disorder. *Eating Disorders, 21,* 395-407.

Tan, J., Hope, T., & Stewart, A. (2003). Anorexia nervosa and personal identity: The accounts of patients and their parents. *International Journal of Law and Psychiatry, 26*, 533-548.

Tan, J., Hope, T., Stewart, A., & Fizpatrick, R. (2003). Control and compolsury treatment in anorexia nervosa: The views of patients and parents. *International Journal of Law and Psychiatry, 26*, 627-645.

Thompson, S., Marriott, M, Telford, K., Law, H., McLaughlin, J., & Sayal, K. (2012). Adolescents with a diagnosis of anorexia nervosa: Parent's experience of recognition and deciding to seek help. *Clinical Child Psychology and Psychiatry*, 19, 43-57.

Thompson-Brenner, H., Satir, D. A., Franko, D. L., & Herzog, D. B. (2012). Clinician reactions to patients with eating disorders: A review of the literature. *Psychiatric Services*, *63*, 73-78.

Weinman, J., Petrie, K.J., Moss-Morris, R., & Horne, R. (1996). The illness perception questionnaire: A new method for assessing the cognitive representation of illness. *Psychology & Health*, *11*(3), 431-445.

Zwickert, K., & Rieger, E. (2013). Stigmatizing attitudes towards individuals with anorexia nervosa: an investigation of attribution theory. *Journal of Eating Disorders, 1*:5. doi:10.1186/2050-2974-1-5

APPENDIX A: STAGE I PARTICIPANT DETAILS, CASE NOTE DETAILS, AND CASE SYNOPSES

ID	GENDER	AGE	RECRUITMENT	DIAGNOSIS	DIAGNOSIS DURATION	TREATMENT	INPATIENT?
P1	Female	15	Bodywhys website	Anorexia Nervosa	12 months	CAMHS	N (has since been referred for inpatient care)
P2	Female	15	Clinician	Bulimia Nervosa	12 months	CAMHS	N
P3	Male	15	Press release	Bulimia Nervosa	10 months	CAMHS	Y
P4	Female	19	Press release	AN but has since dx BN	11 months	Private inpatient and private counsellor	Y
P5	Female	16	Press release	Anorexia Nervosa	12 months	CAMHS	Y
P6	Male	16	Clinician	ED unspecified: AN with BN symptom	14 months	Private treatment initially but moved to CAMHS for financial reasons.	N
P7	Female	15	Bodywhys website	Anorexia Nervosa	5 months	CAMHS	Y
P8	Female	15	Bodywhys website	Anorexia Nervosa	3 months	Private treatment. Had 1 appointment with CAMHS but unhappy with service.	N

CASE NOTE REVIEW

	ID	Referred By	Reasons for referral	No. of weeks between referral & assessment
REFERRAL	P1	GP (following hospital admission)	Socially withdrawn; unable to eat; poor concentration	2.5 weeks
	P6	GP	Eating disorder	10 weeks

	ID	Assessed by	Initial diagnosis	Previous contact with CAMHS
ASSESSMENT	P1	Social Worker & Senior Registrar	Anorexia Nervosa	No
	P6	Consultant Psychiatrist	Eating disorder unspecified (AN and BN symptoms). Emotional disorder of childhood with anxiety, panic, perfectionism, low self-esteem and body image issues.	No

	ID	Interventions delivered	Frequency of appointments	CAMHS professional who delivered face-to-face work	Consultation and/or liaison with other agencies
INTERVENTION	P1	• Medication: Sertaline • Family therapy • Individual therapy • Parenting support	Weekly	• Mental health nurse • Psychiatrist • Social Worker	Referral to inpatient service
	P6	• Reflective Family therapy • Individual therapy • Parenting support	Fortnightly	• Clinical psychologist • Psychiatrist • Dietician	N/A

APPENDIX B: STAGE I INTERVIEW SCHEDULES & OVERVIEW OF ANALYTIC CATEGORY CONSTRUCTION

INTERVIEW WITH ADOLESCENT

The interview shall be very informal and it is hoped that the participant shall have the opportunity to discuss any topics that are of particular interest to him/her. As such, the following interview schedule is only a guide to the possible areas that will be covered.

Before diagnosis/Lead-up to help-seeking

- Can you start by telling me a little about what life was like before your illness came about? Prompts: school, friends, family.
- Tell me about when things started to change, when you started to notice a difference in the way you thought about food.
- Did you talk to anybody else about these changes? Why
- Do you think anybody else noticed these changes? Did they speak to you about it? Expand.
- So you had been feeling this way for X length of time, tell me about getting help. Prompts: when did you/your carer decide to? What happened that made you/your carer decide that the time was right to seek help?
- How did you feel about getting help?

The diagnosis

- Tell me about when you were first told you had ED. Prompts: how did you feel?
- Tell me what you had known about ED before you were told you had one.
- Did you tell your friends when you were diagnoses? If no, why not? If yes, tell me about their reaction. How did their reaction make you feel?
- Tell me about your family's reaction. How did this reaction make you feel?

Living with an ED

- Looking back to what we spoke about at the beginning of our conversation, how has your life changed since then?
- On a daily basis, how does having an ED affect your life?
- How does it make you feel? Do you talk about your feelings? How do you deal with your feelings?
- What about your family – how do you think it affects them? How do they feel?
- How do other people react to you? Friends. Strangers. How does this make you feel?

Experience of services

- So you were diagnosed X long ago. Can you tell me about the treatment you have received since then.
- What is the best part of the treatment? What part of the treatment do you least like? Why to both.
- Is there anything you would like to change about the treatment you receive?
- If you were speaking to someone who had just been diagnosed with an eating disorder, what treatment would you recommend to them?

Recovery

- Talk to me about what you think ‘recovery’ means. What does it mean to you?

Ending questions

- Having lived with an eating disorder for X time, tell me about the strengths you have discovered.
- Is there anything that you might not have thought about before that occurred to you during this interview?
- Is there anything else you think I should know or anything I should understand better?
- Is there anything you would like to ask me?

INTERVIEW WITH HEALTH PROFESSIONAL

The interview shall be very informal and it is hoped that the participant shall have the opportunity to discuss any topics that are of particular interest to him/her. As such, the following interview schedule is only a guide to the possible areas that will be covered.

Questions specific to adolescent's case

- Can you start by telling me about when you first encountered Morgan? What was the initial consultation like?
- Can you tell me about how you interpreted Morgan's symptoms? Was it clear to you that Morgan had an eating disorder?
- What steps did you take to reach your opinion of Morgan's diagnosis?
- Once you identified that Morgan may have an eating disorder, what was the next step? Did you know where to refer? How easy or difficult was it to get specialised help?
- Can you tell me about how you felt about treating Morgan?
- How would you describe your role in Morgan's treatment?

General questions about the treatment of people with EDs

- When a patient like Morgan presents to you, how equipped do you feel to give that patient the treatment they require? Do you feel that you have the level of knowledge of EDs necessary?
- Can you tell me about your experience of treating people with eating disorders?
- Have you ever felt personally affected by treating someone with an eating disorder? You may decline to answer if you wish.
- Based on your experience of treating people with EDs, what do you feel causes these disorders?
- As a patient, how do people with eating disorders compare to other patients you see? Are they open to your advice? Expand.
- Can you tell me about logistics of treatment provision/treatment pathway? Where do you fit in? What is the next step for you once you have identified a possible ED case? How straight-forward or complicated is the system?
- If you could, what changes would you make to service provision?

Recovery

- As a clinician, what do you think constitutes 'recovery'? How can it be measured? How can it be achieved?
- What do you think 'recovery' means to somebody with an eating disorder?

Ending questions

- How would you describe service provision in Ireland for the treatment of young people with eating disorders?
- Is there anything else you think I should know or anything I should understand better?
- Is there anything you would like to ask me?

INTERVIEW WITH CARER

The interview shall be very informal and it is hoped that the participant shall have the opportunity to discuss any topics that are of particular interest to him/her. As such, the following interview schedule is only a guide to the possible areas that will be covered.

Before diagnosis/Lead-up to help-seeking

- Can you start by telling me a little about what ‘Morgan’ was like before the illness came about? Prompts: school, friends, family.
- Tell me about when things started to change, when did you start to notice that something was wrong?
- What did you do?
- At what point did you start to suspect that ‘Morgan’ may have an eating disorder? Tell me more about this.
- How did you feel?
- Tell me about seeking help. What were the circumstances that led up to it? How long between when your concerns were first raised to when you sought help? Why this length of time?
- Can you tell me about how you went about getting help? Did you know where to go etc.? How did you get information about where to go?
- How did you feel about getting help?

The diagnosis

- Tell me about when ‘Morgan’ received the diagnosis of eating disorder. Prompts: how did you feel?
- Did you share your feelings with anyone? How did that come about? What was their reaction? (If no, why not? Was support available to you?)
- Can you tell me about what your interaction with ‘Morgan’ was like at that time? How did you talk to ‘Morgan’ about this new diagnosis?
- Do you ever wonder what caused Morgan’s eating disorder? Expand.
- What you had known about eating disorders before this?
- What had your opinion been of somebody with an eating disorder?

Living with an ED

- How has your life changed since Morgan’s diagnosis?
- On a daily basis, how does living with somebody who is affected by an ED affect your life?
- How does it make you feel? Do you talk about your feelings? How do you deal with your feelings? Do you think Morgan is aware of how you feel?
- What about your family – how do you think it affects them? How do they feel?

- How do other people react to you? Friends. Strangers. How does this make you feel?

Experience of services and treatment

- Going back to talk about help-seeking and treatment, can you tell me about the treatment Morgan has received since diagnosis?
- How easy or difficult has it been to access this treatment?
- What has your role been in Morgan's treatment?
- Is there anything you would like to change about the treatment Morgan receives?
- Have your needs, as someone who cares for a person with ED, been catered for by these services? Expand.
- What changes would you like to make to the way adolescents with eating disorders and their families are treated?
- If you were speaking to the family of someone who had just been diagnosed with an eating disorder, how would you describe the treatment services to them? (i.e. useful, accessible etc.)

Recovery

- Talk to me about what you think 'recovery' means. What does it mean to you?
- How can 'recovery' be achieved?

Ending question

- Can you tell me about how your views about eating disorders today compare with your views prior to Morgan's illness.
- Having cared for somebody with an eating disorder for X time, tell me about the strengths you have discovered.
- Is there anything that you might not have thought about before that occurred to you during this interview?
- Is there anything else you think I should know or anything I should understand better?
- Is there anything you would like to ask me?

OVERVIEW OF ANALYTIC CATEGORY CONSTRUCTION

Line-by-line coding of the transcripts from interviews with the 8 young people resulted in a list of 1,004 codes. Similar codes were grouped together to create clusters which in turn were grouped together to make concepts. Similar concepts were combined and the three main analytic categories of ‘The Disordered Solution’, ‘Entrenching Morality’, and Realigning Moral Identity’ were formed. The table below details a selection of some of the codes which contributed to the formation of each category, along with supporting quotes.

Category 1:	**The Disordered Solution**
Codes:	Trying to find an identity Weight loss as means to becoming somebody. Finding a purpose weight loss as a solution Getting noticed Feeling different Feeling bigger Finding the solution – linking not eating with weight loss = solution to perceived ugliness Losing weight as a solution to the teasing BN as means of improving athletic ability
Quotes:	*Well because when I, two years ago I was very big for my age so I was and one day at school one of the children called me fat so they did and I took, I took that to heart so I did.* (P3 ‘Daniel’) *I felt like I was really getting any attention or I didn’t know, like who I was, I didn’t really, I was kind of like acting differently and I was like trying to like stand out because I didn’t think I was very good at much. And I thought that maybe if like, if I lost weight then people would notice me and that.* (P1 – ‘Clara’)
Category 2i):	**Entrenching Morality:** **Sub-category: *Reinforcing ED Behaviour***
Codes:	Finally being noticed Reinforcing comments about weight loss Compliments Conceptualising ED: more than a coping mechanism; a drug; confidence; pep; gets him through the day; calming; relaxing; euphoric; energizing feeling in control feeling special doing something right anorexia as a linchpin pride and sense of success due to weight loss
Quotes:	*At twelve people like started saying things and like “oh my God you’re so thin, you look so great” because I was like overweight as a child anyway like even in photos and stuff so it was kind of, that was like good in my head that turned to like a plus* (P6 – ‘Brian’) *I think she [mother] was saying like once oh you know you have to start eating more and I was like, I think I was kind of like oh yeah, yeah I will and then next day would just be the same. And like when she said it, like kind of made me feel like good because I thought oh good people are noticing. And then I kind of even like really wanted to cut out more then, because I thought oh people notice now, they might notice if I cut out less, more food.* (P4 – ‘Kelly’) *for me I think it wasn’t just coping, like it was coping, but it was also something that gave me confidence, and something that like a drug like it just gives you many different things that keep you up all day, and you know give you your pep or give you your like confidence.*

	And like especially with anxiety like it would have calmed my anxiety. And like it made me feel at ease when I wanted to be relaxed, and also made me feel like really high and really energetic when I want to, and have confidence when I want to. And it's like, you know, like a lot of people say, like doctors and stuff like "oh you know it ruins you on the inside" and all this thing, and it does, but it also like the truth for me anyway was, it made me, or it helped me go out and do things with my friends, and it helped me wear the clothes I wanted to wear, and you know have energy when I needed it (P6 – 'Brian') *Like just say if I'm annoyed about something, I'd say ok I'm not eating this or I'm not going to eat my dinner tonight or I'm not going to eat this snack or something. Then after that and I don't eat it and then I feel like ok good, I did something, like I achieved something.* (P1 – 'Clara')
Category 2ii):	**Entrenching Morality:** **Sub-category:** ***Building a moral identity and abiding by a moral code***
Codes:	Seeing restrictive eating as success – being successful 'doing so well' 'I can keep' – agency, personal achievement Moral identification; 'slip-up' self-punishment judgement perception of what is not acceptable/bad realising a lack of power and control (nothing I could do)
Quotes:	*like if you felt like you'd eaten a meal that was unhealthy or big or anything in it that you didn't feel comfortable eating, you'd kind of be like ok tomorrow I'm not going to eat this or I'm not going to eat this because of what you've just eaten then. And then the next day you'd need to stick to what you said. I can remember one day I ate something and after I got really angry and I was like ok tomorrow I'm not going to eat a lunch and I'm not going to eat a snack after dinner and all this. And the next day at lunch time came around and I was starving and my mum was like you have to have lunch now and I was like oh no I'm not hungry and she was like, I was saying I'm not hungry but like I was hungry, I was just saying that because I told myself the day before like you need to stick to it. You can't like change a plan and say oh its fine, I'll eat today, you need to do what you said or else you'll just feel really bad and guilty.* (P5 – 'Michelle') *I don't know, it's like you just can't eat, you can't bring yourself to eat because it doesn't feel right, it's, it feels like you don't deserve the food and then you do eat, I don't know if you've heard this before but you get like all the voices and they're kind of like shouting at you for eating and it's, it's really horrible…. the voices are just shouting 'why did you eat it, don't eat it, you don't need food' just over and over again to the point of like I would feel physically sick when sitting down to eat something because I just couldn't bring myself to do it.* (P7 – 'Edel') *I realised that like I couldn't make myself eat more and like I was losing a lot of weight and then I realised then that there was a problem.* (P8 – 'Debbie')
Category 3):	**Realigning Moral Identity**
Codes:	Who is really in control? thoughts gradually losing their grip slip up' – turning it on its head: When talking about recovering a 'slip-up' refers to engaging in ED behaviour whereas before, it referred to eating. Stop trying to undo the sin Acceptance Being an agent in his own recovery Recovery is not perfect Seeing the good even when feeling bad
Quotes:	*I've learnt to kinda deal with food. Like even though I'd want to be sick after eating something I've kinda learnt to just go okay like it's not gonna do you any good, just gonna make things worse and you're not going to put on weight straight away especially if you eat something healthy like it's just…like it's okay like you have to eat. So that's helped me deal*

	with things because it’s been a few times when I’ve gone – ah I want to get sick. But I’ve managed to stop myself, not all the time (P2 – ‘Laura) *You know have, keep strict care on yourself because any sort of, if you get a chance, any chances at all, you take it in this condition that I’m in, because I’ve been through it on the road to recovery. Like only the smallest chance I got I was straight upstairs and then I had a relapse.* *Q Yeah.* *A The smallest little chance, that’s all it takes* *(lines omitted)* *They (parents) can only help so much but they can’t really help the thoughts that go through your head, the feelings and everything, it’s just, it’s such strong feelings, such strong urges to do these things. To me it feels like someone gets a feeling to eat, I get a feeling to get sick.* *Q Yeah.* *A It’s about the same.* *Q So what's natural for me to eat, being sick is what's natural for you.* *A Yeah.* *Q Yeah.* *A And it’s been very hard to try and resist but within time it does turn around, it does go your way.* (P3 –‘Daniel’) *I feel like I’ve taken off, this is like the simple man’s explanation, but I think this will make sense – like I’ve taken off a plaster, a band aid, and the eating disorder, or my eating disorder was the band aid, but now all of the stuff, the cuts or the wounds, bruises, underneath it, are still there.* (P6 – ‘Brian’) *I do try to remind myself like maybe once a day, or when I’m having my food, or when I wake up “every day I’m in recovery – today I’m in recovery”. Like no matter what happens today, whether things go brilliantly and I’m on a high all day, or whether things go really badly and something happened, I’m in recovery, so those things like don’t affect recovery today* *Q Ok. And what does recovery mean?* *Ahm, getting better, improving, ahm, making a lot of mistakes, ahm, throwing perfection out the window! Just like almost the opposite of being sick during an eating disorder. Like everything changes, like everything gets a lot brighter, and like just having like feelings, which sounds so strange, but like when you’re, like when I was suffering really badly with my eating disorder, and when I was very depressed, and had a lot of anxiety, I didn’t even know like what I was feeling, but I just wasn’t really feeling anything* (P6 – ‘Brian’)

APPENDIX C: DESCRIPTIVE STATISTICS FOR STAGE II & III

STAGE II: HEALTH PROFESSIONALS' SURVEY

Measure	Vignette condition	*N*	Mean	Standard deviation
IPQ-Treatment	AN	27	3.80	.56
	BN	15	3.69	.62
	BED	22	3.71	.42
	Depression	21	3.71	.58
	T1 Diabetes	21	3.75	.66
IPQ-Timeline	AN	28	3.17	.64
	BN	15	3.00	.59
	BED	24	3.29	.47
	Depression	20	2.60	.62
	T1 Diabetes	21	3.30	.71
IPQ-Control	AN	28	3.88	.69
	BN	15	4.10	.44
	BED	23	4.03	.51
	Depression	21	3.90	.50
	T1 Diabetes	21	4.15	.58
Long-term outcome	AN	27	3.26	3.81
	BN	15	1.40	3.94
	BED	23	.87	4.91
	Depression	20	3.15	3.53
	T1 Diabetes	19	1.42	2.80
Feeling about interaction	AN	28	7.43	2.35
	BN	15	8.73	1.39
	BED	24	8.42	1.86
	Depression	20	10.15	2.37
	T1 Diabetes	19	9.32	2.52
ED knowledge		87	4.15	1.33
Confidence treating EDs		91	3.36	.93
Personal experience with EDs		89	3.49	1.79

STAGE III: YOUNG PEOPLE'S SURVEY

Measure	Vignette condition	*N*	Mean	Standard deviation
IPQ-Treatment	AN	51	3.71	.57
	BN	46	3.84	.41
	BED	61	3.86	.48
	Depression	66	3.74	.54
	T1 Diabetes	46	3.81	.53
IPQ-Timeline	AN	52	3.50	.65
	BN	47	3.48	.63
	BED	62	3.50	.52
	Depression	66	3.08	.65
	T1 Diabetes	45	3.19	.65
IPQ-Control	AN	53	4.12	.61
	BN	48	4.08	.46
	BED	61	4.30	.53
	Depression	62	3.98	.59
	T1 Diabetes	45	3.94	.59
Life stress causes	AN	54	3.72	.51
	BN	47	3.77	.61
	BED	58	3.68	.51

	Depression	67	3.87	.68
	T1 Diabetes	45	3.69	.68
Individual causes	AN	53	3.91	.57
	BN	47	3.74	.54
	BED	62	3.77	.51
	Depression	66	3.31	.52
	T1 Diabetes	46	3.13	.66
External causes	AN	54	2.12	.58
	BN	48	2.09	.64
	BED	61	2.24	.62
	Depression	66	2.24	.64
	T1 Diabetes	44	2.30	.71
Positive feeling about interaction	AN	53	3.36	.75
	BN	47	3.38	.64
	BED	59	3.54	.61
	Depression	66	3.18	.73
	T1 Diabetes	41	3.57	.69
Negative feeling about interaction	AN	53	2.54	.61
	BN	46	2.62	.66
	BED	60	2.40	.68
	Depression	67	3.00	.38
	T1 Diabetes	42	2.45	.72
Positive impression	AN	51	2.85	.41
	BN	44	2.77	.46
	BED	60	2.57	.39
	Depression	65	3.00	.47
	T1 Diabetes	40	3.15	.47
Negative impression	AN	51	3.33	.44
	BN	45	3.32	.29
	BED	61	3.30	.31
	Depression	67	3.00	.38
	T1 Diabetes	41	2.87	.62
Personal experience with EDs		188	2.60	1.56
Body Satisfaction		260	2.94	1.15
Importance of appearance		261	3.91	.92
Frequency of dieting		261	4.03	1.42
Preoccupied with desire to be thinner		261	3.57	1.64
Change exercise levels to decrease body size		261	4.10	1.49
Change exercise levels to increase muscles		261	4.52	1.45
Concern own eating habits		262	1.62	.49
Social distance		258	2.84	.71
Stigmatising attitudes		258	3.21	.83

APPENDIX D: STAGE II & III SURVEY MATERIALS

Health Service Provision for Adolescents in Ireland

You are invited to participate in a research study conducted by Prof. Fiona McNicholas, Dr. Niamh McNamara and Dr. Lesley O'Hara of the Lucena Clinic, Rathgar, and University College Dublin. If you have any questions about this study you can contact Dr. Lesley O'Hara at lesley.ohara@sjog.ie.

What is this research about?
This study looks at adolescents' experience of the health service in Ireland. We are also interested in determining the educational/training requirements of clinicians in primary care and in the mental health services.

Why are you doing this research?
We hope that by finding out the factors that affect adolescents' access to and engagement with services that we will be able to greatly improve services for all young people.

How will the data be used?
The results of this study will be written in a report for St John of God Hospitaller Services and be submitted for publication in academic journals or presented at relevant conferences. However, all information will be treated in a confidential manner, and no personal details will be included in any reports and you will never be identifiable in any way.

What will happen if I decide to take part in the research study?
If you decide to take part, you will be asked to complete an online survey which takes approximately 20 minutes to complete. Prior to completing the survey you will be asked to read and complete the online consent form.

How will you protect my privacy?
All the information you provide will be anonymous. The research team will not collect any information that can identify you. To protect your confidentiality, the information you provide will not be shared with anyone. All data will be stored in line with the Data Protection Acts 2001/2003. Electronic data will be stored on a password protected computer. After a designated period of time (10 years) all data will be destroyed.

Can I change my mind at any stage and withdraw from the study?
Participation in the study is completely voluntary. You do not have to take part if you choose and you can leave the study at any time without any consequence. As the information collected is anonymous, it is not possible to remove your data from the dataset at a later date.

Thank you very much for your help with this research!

Health Service Provision for Adolescents in Ireland

1. Thank you for taking part in the research. Before beginning the survey, please read and complete the participant consent form.

Participant consent:

By clicking on the 'Yes' box below and proceeding to the rest of the survey, you are indicating that you have read and agree with the following:

- **I have read the information sheet and have had time to consider whether to take part in this study**
- **I also confirm that I have had the opportunity to ask questions about the study**
- **I have been given information with the researcher's name and a contact number and address if I require further information**
- **I understand that if I take part in this study that I will be asked to complete an online survey**
- **I understand that all the information I provide will remain confidential and no information that identifies me will be made publically available**
- **I realise that I may withdraw from the study at any time without giving a reason**
- **I understand that the results of this study may be published in a report, book or article but that any personal information I provide will not be identifiable and I will not be recognised.**
- **I understand that all the data I provide will be stored in a secured place and destroyed 10 years post publication in line with the Data Protection Acts 2001/2003.**

○ Yes ○ No

2. Are you male or female?

○ Male

○ Female

3. What is your age?

☐

4. Please describe your race/ethnicity.

☐

5. What is your profession?

○ GP

○ Nurse

○ Counsellor/Therapist

○ Adult Psychiatrist

○ Child and Adolescent Psychiatrist

○ Psychologist

○ Dietician/Nutritionist

○ Paediatrician

○ Gastroenterologist

○ Other

Other (please specify)

6. Please provide the age-range of the patients you see.

7. Is your service regulated by a national regulatory body (for example HSE; Mental Health Commission)?

○ Yes

○ No

If 'yes', please give the name of the regulatory body:

8. Please specify which sector you work in:

○ Private

○ Public

○ Both

9. How many years have you worked in clinical practice?

10. What county do you work in?

In this section you will be presented with a vignette depicting a patient called 'Morgan'. Please read the vignette and answer the questions which follow.

Morgan is 15 years old and has attended your surgery because of parental concern regarding Morgan’s eating habits and recent weight loss. Morgan’s parents are also concerned that Morgan should be taller for their age. Morgan expresses a dislike of the bodily changes that have occurred since puberty and a fear of becoming fat. As a result of these feelings, Morgan has started to exercise regularly and is following a ‘diet’, joined a fitness programme and is running daily. As part of their diet, Morgan avoids all fatty foods, does not eat between meals, and eats set portions of ‘healthy foods’ each day. On some days, Morgan does not eat at all. Morgan thinks their parents’ concern is unnecessary. Morgan is not prepared to make any effort to put weight back on.

Respondents: 20%

Morgan is 15 years old. Morgan’s parents have attended your clinic with Morgan as they are concerned about their child’s eating habits and recent weight loss. Whilst Morgan was slightly overweight when younger, Morgan’s size now appears to be smaller than most of Morgan’s peer-group. However, Morgan is dissatisfied with current weight. Morgan recently joined the athletics club at school and runs regularly. Morgan avoids all fatty foods and eating between meals. Morgan tries to eat set portions of ‘healthy foods’, mainly fruit and vegetables and bread or rice each day. However, Morgan has found it difficult to maintain the weight loss and for the past 6 months Morgan’s weight has been continually fluctuating, sometimes by as much as 5 kilograms within a few weeks. While able to restrict during the day, at night Morgan describes being out of control and unable to stop eating, bingeing on, for example, a loaf of bread and a tub of ice cream. To counteract the effects of this bingeing, Morgan vomits post bingeing and takes laxatives. On other occasions, Morgan vomits after overeating.

Respondents: 20%

Morgan is 15 years old and has been overweight since adolescence but in recent years this has increased to the point of severe obesity. Morgan has tried a number of diets however, has never stayed with the recommendations for very long. Morgan does not have many friends at school and often feels lonely; to counteract these feelings Morgan likes to have treats such as chocolate and cheesecake. Morgan’s diet is generally regular, with three meals a day, and it contains a wide variety of foods. After school, Morgan goes to the fridge for a small snack; however, Morgan finds that after eating the snack, it is difficult to stop eating and continues to eat a large amount of food, for example, an apple, a slice of cheesecake, five biscuits, a jam sandwich and three glasses of milk. Morgan feels guilt and sadness after eating like this and worries about loss of control. Morgan has never told anyone about these feelings. Morgan has often thought about different weight control methods (e.g., exercise or laxatives) but has never done them.

Respondents: 20%

Morgan is 15 years old and has attended your surgery complaining of feeling unusually low and very tired for the last few weeks. Day-to-day tasks seem over-whelming and Morgan puts off making any decisions. Morgan is finding it hard to concentrate in school and has failed to keep on top of homework. Morgan has been a member of the school choral society for the last year and enjoyed socialising with others in the society. However recently Morgan has stopped attending weekly practices and has decided not to take part in the annual concert. Despite being tired all the time, Morgan finds it difficult to sleep and often wakes a number of times during the night. Morgan has also lost weight and enjoyment of eating in this period. Morgan is spending less and less time with friends, who are becoming very concerned.

Respondents: 20%

Morgan is 15 years old and has recently been feeling very tired and lethargic. Morgan has also lost weight in recent weeks, despite having an increased appetite. Morgan’s parents are concerned about this weight loss and find it difficult to explain given that Morgan appears to be eating as much as ever, if not more. Morgan also complains of being incredibly thirsty and is going to the toilet more frequently than normal. Additionally, Morgan has a spot of eczema which has worsened recently and is causing considerable discomfort. Morgan was a member of the athletics club at school but as a result of feeling so tired, has stopped attending training. Up until recently, Morgan would spend weekends at athletics events and socialising with friends, but now does not have the energy to do these things.

Respondents: 20%

11. What would you say is Morgan's main problem?

12. Please give details of the steps you would typically take in order to diagnose Morgan's problem.

13. How much do you agree or disagree with the following statements?

	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
Morgan's problem will last a short time	○	○	○	○	○
Morgan has the power to influence the problem	○	○	○	○	○
The negative effects of Morgan's problem can be prevented (avoided) by treatment	○	○	○	○	○
Morgan's problem is likely to be permanent rather than temporary	○	○	○	○	○
What Morgan does can determine whether the problem gets better or worse	○	○	○	○	○
Treatment will be effective in resolving Morgan’s problem	○	○	○	○	○
Morgan’s problem will last for a long time	○	○	○	○	○
The course of the problem depends on Morgan	○	○	○	○	○
Treatment can control Morgan’s problem	○	○	○	○	○
Morgan’s problem will pass quickly	○	○	○	○	○
Nothing Morgan does will affect the problem	○	○	○	○	○
There is very little that can be done to improve Morgan’s problem.	○	○	○	○	○

14. What do you think caused Morgan’s problem?

15. Suppose that Morgan had the sort of help that you think is most important for their health problems. How do you think Morgan would be in the long term compared to other people in the community?

	More likely	Just as likely	Less likely
Be a productive worker	○	○	○
Drink too much	○	○	○
Take illegal drugs	○	○	○
Be a caring parent	○	○	○
Have poor friendships	○	○	○
Have a good marriage	○	○	○
Attempt suicide	○	○	○
Understand other's feelings	○	○	○

16. Please indicate how much you agree with the following statements

	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
Compared to other patients, I think health professionals generally enjoy working with patients like Morgan.	○	○	○	○	○
I think health professionals generally find patients like Morgan difficult to deal with.	○	○	○	○	○
I think health professionals would prefer not to have to deal with patients like Morgan.	○	○	○	○	○

17. Do you think Morgan is

○ Male

○ Female

Please give reasons for your answer:

This section assesses health professionals' knowledge of the diagnostic criteria and recommended treatment of eating disorders.

18. With reference to recommended diagnostic criteria, which of the following would suggest the presence of Anorexia Nervosa in an adolescent? Please select only one.

○ BMI < 16

○ BMI < 17

○ Failure to maintain growth (BMI) trajectories

19. With reference to recommended treatment guidelines, which of the following is the recommended treatment of an adolescent with Anorexia Nervosa? Please select only one.

○ Cognitive behaviour therapy adapted for adolescent.

○ Family-based treatment

○ Psychodynamic Therapy

20. Which of the following may indicate the presence of Bulimia Nervosa in an adolescent? Please select only one.

○ Cold peripheries

○ Parotid swelling

○ Yellow skin discoloration

21. With reference to recommended treatment guidelines, which of the following is the recommended treatment of an adolescent with Bulimia Nervosa? Please select only one.

○ Cognitive behaviour therapy adapted for adolescent.

○ Fluoxetine 20 mg.

○ Eye movement desensitization and reprocessing (EMDR)

22. With reference to recommended diagnostic criteria, which of the following is one of the elements which must accompany episodes of excessive eating, if a diagnosis of Binge Eating Disorder (BED) in an adolescent is to be reached? Please select only one.

○ Obesity

○ A sense of lack of control during eating

○ Vomiting post bingeing

23. With reference to recommended treatment guidelines, which of the following is the recommended treatment of an adolescent with Binge Eating Disorder (BED)? Please select only one.

○ Psychodynamic Individual Therapy

○ Systemic Family Therapy

○ Cognitive behaviour therapy adapted for adolescent

This section asks about the prevalance of eating disorders amongst your patients.

24. Please give the number of 15 to 18 year olds who presented to you for assessment/treatment for each of the following types of eating disorders, in the last 12 months.

Anorexia Nervosa

Bulimia Nervosa

Eating Disorder Not Otherwise Specified (EDNOS)

Binge Eating Disorder

25. Approximately how many 15 to 18 year olds with eating disorders are in active treatment with you?

Insert number of girls

Insert number of boys

26. Have you observed a change in the profile of people attending your care with an eating disorder?

○ Yes

○ No

If yes, please give details.

This section asks how confident you feel about treating patients with eating disorders.

27. Please indicate how much you agree or disagree with the following statements.

	Disagree Strongly	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
I am confident in my ability to diagnose cases of eating disorders.	○	○	○	○	○
I am confident in my ability to treat patients with eating disorders.	○	○	○	○	○

28. Would the publication of a standardized protocol for the treatment of eating disorders benefit you in your clinical work?

○ Yes

○ No

29. Does your service provide specialist treatment for people with eating disorders?

○ Yes

○ No

30. Have you ever treated an individual with an eating disorder?

○ Yes

○ No

This section asks about the impact of working with patients who have eating disorders. You are free to skip any question that you do not want to answer.

31. Has your own view of food changed since working with eating disordered patients?

○ Yes

○ No

If yes, please give details.

32. Have your eating habits been affected by working with patients with eating disorders?

○ Yes

○ No

If yes, please give details about how your eating habits have been affected.

This section asks about your eating habits. You can skip any question that you do not want to answer.

33. On reflection, have you ever been concerned about your own eating habits?

○ Yes

○ No

34. If yes, who have you told about your concerns?

☐ Family member

☐ Friend

☐ GP

☐ Support Organisation

☐ Health Professional

☐ Colleague

☐ Nobody

35. If no, what is the main reason you have for not telling anyone about your eating concerns?

36. Do you know anyone who has been affected by an eating disorder?

○ Yes

○ No

37. Is this person (tick all that apply)

☐ You

☐ A member of your immediate family

☐ A close friend

☐ A member of your extended family

☐ An acquaintance

☐ A work colleague

38. Have you ever been diagnosed with an eating disorder?

○ Yes

○ No

39. If yes, please specify the nature of the eating disorder.

○ Anorexia Nervosa

○ Bulimia Nervosa

○ Binge Eating Disorder

○ EDNOS

○ Other

Other (please specify)

40. What stage of treatment are you currently at? (tick all that apply)

☐ I have not sought any treatment

☐ I have contacted my GP about my eating problems

☐ I was in treatment but not anymore

☐ I am receiving treatment

☐ I have relapsed

☐ I have relapsed and am receiving further treatment

41. Are you aware of voluntary organizations in Ireland which specialize in eating disorders?

○ Yes

○ No

If yes, please give name of organisation(s)

42. In your opinion, what role do such organisations have in the treatment of people with eating disorders?

43. Have you ever referred a patient to such an organisation?

○ Yes

○ No

44. We are interested in hearing about your experience of services for the treatment of eating disorders in Ireland. In the box below, please tell us about the services that are available in your area, and your experience of referring patients with eating disorders.

Thank you for your participation in this study!

The purpose of this study is to explore adolescents' experience of the health service in Ireland and determine the educational and training requirements of clinicians in primary care and in the mental health services. In particular, this study looks at both therapeutic and support service provision for people living with eating disorders. We hope that by finding out the factors that affect the access to and engagement with services, we will be able to greatly improve services for all young people living with an eating disorder

Once again, we would like to thank you for participating in this study. If you have any further queries regarding this study, please contact Dr. Lesley O'Hara at lesley.ohara@sjog.ie or at the contact details below.

Dr. Lesley O'Hara
Lucena Clinic
59 Orwell Road
Rathgar
Dublin 6
01-4999349.

STEDI School Survey

You are invited to participate in a research study conducted by Prof. Fiona McNicholas, Dr. Niamh McNamara and Dr. Lesley O'Hara of the Lucena Clinic, Rathgar, and University College Dublin. If you have any questions about this study you can contact Dr. Lesley O'Hara at lesley.ohara@sjog.ie.

Why are you doing this research?
We hope that by finding out how well informed young adults are about eating disorders compared to other health issues that we will be able to make recommendations for future support and health service development to encourage those who are worried about their eating habits to talk to health professionals.

How will the data be used?
The results of this study will be written in a report for St John of God Hospitaller Services and be submitted for publication in academic journals or presented at relevant conferences. However, all information will be treated in a confidential manner, and no personal details will be included in any reports and you will never be identifiable in any way.

What will happen if I decide to take part in the research study?
If you decide to take part, you will be asked to complete an online survey which takes approximately 20 minutes to complete. Prior to completing the survey you will be asked to read and complete the online consent form.

How will you protect my privacy?
All the information you provide will be anonymous. The research team will not collect any information that can identify you. To protect your confidentiality, the information you provide will not be shared with anyone. All data will be stored in line with the Data Protection Acts 2001/2003. Electronic data will be stored on a password protected computer. After a designated period of time (10 years) all data will be destroyed.

Can I change my mind at any stage and withdraw from the study?
Participation in the study is completely voluntary. You do not have to take part if you choose and you can leave the study at any time without any consequence. You can skip any question that you do not wish to answer. As the information collected is anonymous, it is not possible to remove your data from the dataset at a later date.

Thank you very much for your help with this research!

STEDI School Survey

***1. Thank you for taking part in the research. Before beginning the survey, please read and complete the participant consent form.**

Participant consent:

By clicking on the 'Yes' box below and proceeding to the rest of the survey, you are indicating that you have read and agree with the following:

- **I have read the information sheet and have had time to consider whether to take part in this study**
- **I also confirm that I have had the opportunity to ask questions about the study**
- **I have been given information with the researcher's name and a contact number and address if I require further information**
- **I understand that if I take part in this study that I will be asked to complete an online survey**
- **I understand that all the information I provide will remain confidential and no information that identifies me will be made publically available**
- **I realise that I may withdraw from the study at any time without giving a reason**
- **I understand that the results of this study may be published in a report, book or article but that any personal information I provide will not be identifiable and I will not be recognised.**
- **I understand that all the data I provide will be stored in a secured place and destroyed 10 years post publication in line with the Data Protection Acts 2001/2003.**

○ Yes ○ No

2. Are you:

○ Male

○ Female

3. What age are you?

☐

4. What year are you in?

○ Transition Year

○ 5th Year

○ Leaving Certificate (6th Year)

5. What kind of school do you attend?

○ Mixed school

○ All-girls school

○ All-boys school

6. Is your school:

○ Fee-paying

○ Non fee-paying

In this section you will be presented with a vignette depicting a person called 'Alex'. Please read the vignette and answer the questions which follow.

Alex is 15 years old. Recently, Alex has been very conscious of the changes that have occurred since the onset of puberty, which happened later than others in the class. As a result of these feelings, Alex joined a fitness programme at the gym and started running daily. Through this effort, Alex gradually began to lose weight. At the same time Alex started to 'diet', avoiding all fatty foods, not eating between meals, and trying to eat set portions of 'healthy foods' each day. On some days Alex doesn't eat anything at all. Through this combination of dieting and exercise, Alex has been able to lose more weight. People have started to express concern at Alex's weight, but Alex thinks their concern is unnecessary. Alex is terrified of becoming 'fat' and refuses to make any effort to put weight back on.
Respondents: 20%
Alex is 15 years old. Although slightly overweight when younger, Alex's current weight is below average for Alex's age and height. However, Alex feels overweight. Recently, Alex joined a fitness programme at the gym and also started running regularly. Through this effort Alex gradually began to lose weight. Alex then started to 'diet', avoiding all fatty foods, not eating between meals and trying to eat set portions of 'healthy foods', mainly fruit and vegetables and bread or rice each day. Alex also continued with the exercise programme, losing several more kilograms. However, Alex has found it difficult to maintain the weight loss and for the past 18 months Alex's weight has been fluctuating, sometimes by as much as 5 kilograms within a few weeks. While able to restrict during the day, at night Alex is often unable to stop eating, bingeing on, for example, a loaf of bread and several pieces of fruit. To counteract the effects of this bingeing, Alex takes laxative tablets. On other occasions, Alex vomits after overeating.
Respondents: 20%
Alex is 15 years old. Alex has been overweight since childhood but in recent years this has increased to the point where Alex has severe obesity. Over the years Alex has tried a number of diet and health eating plans; however, Alex has never stayed with the recommendations for very long. Alex often feels lonely; to counteract these feelings Alex likes to have treats such as chocolate and cheesecake. Alex's diet is generally regular, with three meals a day, and it contains a wide variety of foods. After class, Alex goes to the fridge for a small snack; however, Alex finds that after eating the snack it is difficult to stop eating and continues to eat a large amount of food, for example, an apple, a slice of cheesecake, five biscuits, a jam sandwich and three glasses of milk. Later in the evening Alex will eat dinner and sometimes Alex loses control with this also and eats the extra helping that Alex was planning to save for the next day. Alex feels guilt and sadness after eating like this. Alex has never told anyone about these feelings. Alex has often thought about different weight control methods (e.g. exercise or laxatives) but has never done them.
Respondents: 20%
Alex is 15 years old. Alex has been feeling unusually low and very tired for the last few weeks. Day to day tasks seem overwhelming and Alex puts off making any decisions. Alex has always done well academically but recently that has changed. Alex is finding it hard to concentrate in school and is falling behind on homework. Alex has been a member of the local choral society for the last year and enjoyed socialising with others in the society. However recently Alex stopped attending weekly practices and has decided not to take part in the annual concert. Even though Alex is tired all the time, Alex finds it difficult to sleep and often wakes a number of times during the night. Alex has also lost weight and enjoyment of eating in this period. Alex is spending less and less time with friends, who are becoming very concerned.
Respondents: 20%
Alex is 15 years old. Recently, Alex has been feeling very tired and lethargic. Alex has also lost weight in recent weeks, despite having an increased appetite. Alex's friends are concerned about this weight loss and find it difficult to explain given that Alex appears to be eating as much as ever, if not more. Alex also complains of being incredibly thirsty and is going to the toilet more frequently than normal. Additionally, Alex has a spot of eczema which has worsened recently and is causing considerable discomfort. Alex was a member of the local athletics club but as a result of feeling so tired, has stopped attending training. Up until recently, Alex would spend weekends at athletics events and socialising with friends, but now does not have the energy to do these things.
Respondents: 20%

7. What would you say is Alex's main problem?

8. Which of the following people do you think would be the most helpful for Alex? Choose 1 person only

○ GP or family doctor

○ Counsellor

○ Psychiatrist or psychologist

○ Family member

○ Close friend

○ Dietician or nutritionist

○ Naturopath or other alternative therapist

○ Self-help support group

○ Other

○ Do not know

9. Which of the following treatments would be the most helpful for Alex? Choose 1 treatment only.

○ Just talking about the problem with someone close to them

○ Counselling

○ Alternative or relaxation therapy, e.g. naturotherapy, homeopathy, etc.

○ Admission to hospital

○ Try to deal with the problem on their own

○ Self-help treatment manual

○ Getting really fit/increasing time spent on exercise

○ Getting out and about more/finding some new hobbies

○ Getting information about the problem and available services

○ Diet and exercise programme

○ Medication

○ Other

○ Do not know

10. How much do you agree or disagree with the following statements?

	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
Alex's problem will last a short time	○	○	○	○	○
Alex has the power to influence the problem	○	○	○	○	○
The negative effects of Alex's problem can be prevented (avoided) by treatment	○	○	○	○	○
Alex's problem is likely to be permanent rather than temporary	○	○	○	○	○
What Alex does can determine whether the problem gets better or worse	○	○	○	○	○
Treatment will be effective in resolving Alex’s problem	○	○	○	○	○
Alex’s problem will last for a long time	○	○	○	○	○
The course of the problem depends on Alex	○	○	○	○	○
Treatment can control Alex’s problem	○	○	○	○	○
Alex’s problem will pass quickly	○	○	○	○	○
Nothing Alex does will affect the problem	○	○	○	○	○
There is very little that can be done to improve Alex’s problem	○	○	○	○	○

11. Below is a list of possible causes of Alex's problem. How much do you agree or disagree that they are causes of Alex's problem.

	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
Stress or worry	○	○	○	○	○
Hereditary - it runs in Alex's family	○	○	○	○	○
Diet or eating habits	○	○	○	○	○
Chance or bad luck	○	○	○	○	○
Poor medical care in Alex's past	○	○	○	○	○
Alex's own behaviour	○	○	○	○	○
Alex's mental attitude, e.g. thinking about life negatively	○	○	○	○	○
Family problems	○	○	○	○	○
Overwork	○	○	○	○	○
Alex's emotional state, e.g. feeling down, lonely, anxious, empty	○	○	○	○	○
Alex's personality	○	○	○	○	○

12. If you were to interact with Alex, indicate how you would feel.

	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
Optimistic	○	○	○	○	○
Anxious	○	○	○	○	○
Supportive	○	○	○	○	○
Fearful	○	○	○	○	○
Empathic	○	○	○	○	○
Disgusted	○	○	○	○	○
Comfortable	○	○	○	○	○
Irritable	○	○	○	○	○
Relaxed	○	○	○	○	○
Nervous	○	○	○	○	○

13. Based on your impressions, rate Alex on the following characteristics

	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
Strong	○	○	○	○	○
Insensitive	○	○	○	○	○
Sociable	○	○	○	○	○
Emotional	○	○	○	○	○
Kind	○	○	○	○	○
Awkward	○	○	○	○	○
Intelligent	○	○	○	○	○
Insecure	○	○	○	○	○
Open	○	○	○	○	○
Cold	○	○	○	○	○

14. Do you think Alex is

○ Male

○ Female

15. Give a reason for your choice

This section asks about your personal information and eating habits. You can skip any question that you do not want to answer.

16. What is your height (metres and centimetres)?
(Note: 1 foot = 0.3048 Metre)

Metres

Centimetres

17. What is your weight (kilograms and grams)?
(Note: 1 stone = 6.35029 kg)

Kilograms

Grams

18. How satisfied are you with your body?

○ Very dissatisfied ○ Dissatisfied ○ Neither ○ Satisfied ○ Very satisfied

19. Please rate the importance of your appearance

○ Very unimportant ○ Unimportant ○ Neither ○ Important ○ Very important

20. I engage in dieting behaviour

○ Always ○ Usually ○ Often ○ Sometimes ○ Rarely ○ Never

21. I am preoccupied with a desire to be thinner

○ Always ○ Usually ○ Often ○ Sometimes ○ Rarely ○ Never

22. How often do you change your level of exercise to decrease your body size?

○ Always ○ Usually ○ Often ○ Sometimes ○ Rarely ○ Never

23. How often do you change your level of exercise to increase the size of your muscles?

○ Always ○ Usually ○ Often ○ Sometimes ○ Rarely ○ Never

24. Are you concerned about your eating habits?

○ Yes

○ No

25. Do you know anyone who has been affected by an eating disorder?

○ Yes

○ No

26. If yes, is this person

○ Yourself now recovered

○ A member of your immediate family

○ A close friend

○ A member of your extended family

○ An acquaintance

27. Have you told anyone about your concerns?

○ Yes

○ No

28. If yes, who have you told?

○ Family member

○ Friend

○ GP

○ Support Organisation

○ Health Professional

29. What is the main reason for not telling anyone about your eating concerns?

○ Don't know who to tell

○ Fear

○ Afraid of what recovery means

○ Afraid of being judged

○ Other (please specify)

30. Have you been diagnosed with an eating disorder?

○ Yes

○ No

31. If yes, please specify

○ Anorexia Nervosa

○ Bulimia Nervosa

○ Binge Eating Disorder

○ Eating Disorder Not Otherwise Specified (EDNOS)

32. What stage of treatment are you currently at? (tick all that apply)

☐ I have not sought any treatment

☐ I have contacted my GP about my eating problems

☐ I was in treatment but not anymore

☐ I am receiving treatment

☐ I have relapsed

☐ I have relapsed and am receiving further treatment

33. Please specify treatment type you have received or are receiving

34. How often do you think the following happens to someone who people know or suspect has an eating disorder?

	Never	Rarely	Sometimes	Often	Always
Others are unwilling to be friends with them	○	○	○	○	○
The disorder puts a strain on their friendships	○	○	○	○	○
People would be reluctant to share a house/flat with them	○	○	○	○	○
People would not want to get involved in an intimate relationship with them	○	○	○	○	○
Employers would be reluctant to hire them	○	○	○	○	○

35. How much do you agree or disagree with the following:

Many people believe that people with eating disorders...

	Strongly disagree	Disagree	Neither Agree or Disagree	Agree	Strongly Agree
... are responsible for their condition	○	○	○	○	○
...are able to pull themselves together	○	○	○	○	○
...use their disorder to get attention	○	○	○	○	○
...are fragile	○	○	○	○	○
...would get better if they just ate normally	○	○	○	○	○

36. How would you rate your understanding of

	Not good at all	OK	Good	Very good	Excellent
Who to talk to if you were worried about your eating habits?	○	○	○	○	○
How to access a health professional?	○	○	○	○	○
How to help a friend who is worried about their eating habits?	○	○	○	○	○
Where else to look for information on eating problems?	○	○	○	○	○

37. How likely would you be to seek help from the following if you were ever concerned about your eating habits?

	Very unlikely	Unlikely	Likely	Very likely
Friend	○	○	○	○
Parent	○	○	○	○
Family friend	○	○	○	○
Relative	○	○	○	○
Health professional	○	○	○	○
Telephone counselling	○	○	○	○
Email/online counselling	○	○	○	○
Bodywhys	○	○	○	○
Internet website	○	○	○	○
Book/magazine	○	○	○	○
Social network site	○	○	○	○

Thank you for your participation in this study!

The purpose of this study is to explore adolescents’ experience of the health service in Ireland and determine the educational and training requirements of clinicians in primary care and in the mental health services. In particular, this study looks at both therapeutic and support service provision for people living with eating disorders. We hope that by finding out the factors that affect the access to and engagement with services, we will be able to greatly improve services for all young people living with an eating disorder

Once again, we would like to thank you for participating in this study. If you have any further queries regarding this study, please contact Dr. Lesley O’Hara at lesley.ohara@sjog.ie or at the contact details below.

Dr. Lesley O’Hara
Lucena Clinic
59 Orwell Road
Rathgar
Dublin 6
01-4999739.