

Title Page

Short title

"IF SHE HAD BROKEN HER LEG SHE WOULD NOT HAVE WAITED IN AGONY FOR NINE MONTHS." - CAREGIVER'S EXPERIENCES OF EATING DISORDER TREATMENT.

Short running title (40 characters): currently 53

CARER EXPERIENCE OF EATING DISORDER TREATMENT

Full names of authors:

Isa Robinson, Division of Medicine, University College London, London, UK
Hannah Stoyel, Life Sciences, University College London, London, UK
Paul Robinson, Division of Medicine, University College London, London, UK

The author's institutional affiliations where the work was conducted, with a footnote for the author's present address if different from where the work was conducted;

All 3 – University College London (UCL)

The corresponding author's contact email address and telephone number:

isa@isarobinsonnutrition.co.uk
07834988092

Acknowledgements?

Beat, the UK's leading eating disorder charity.

Data Availability statement?

Data is unavailable as held by a third party

Conflict of Interest statement (for all authors)

None

Names and grant numbers of any sources of funding or support in the form of grants, equipment, drugs etc.

None

"IF SHE HAD BROKEN HER LEG SHE WOULD NOT HAVE WAITED IN AGONY FOR NINE MONTHS."- CAREGIVER'S EXPERIENCES OF EATING DISORDER TREATMENT.

Abstract

This study aims to explore caregivers' experiences of eating disorder services and subsequent impacts on the caregiving burden and patient outcomes. Thematic analysis was employed to investigate qualitative data from a caregiver-targeted online survey run by BEAT, the UK's largest Eating Disorder charity. Six hundred and sixteen caregivers completed the survey. Participants' experiences of eating disorder treatment were predominantly negative, characterised by three main themes: (a) *Barriers to care*: enduring obstacles caregivers face in accessing support for their loved ones, (b) *Experiences of services*: high levels of unmet needs for caregivers and patients alike, (c) *Affected domains*: the pervasive impact of caregiving, influenced by experiences of services. This study is the largest of its kind to explore caregivers' experiences of eating disorder treatment services and aims to give voice to this overlooked group within research. Notably, little has been done to address broader systemic challenges faced by caregivers in accessing support for loved ones. Results indicate these challenges may play a substantial role in shaping the caregiving burden, carer coping styles, and subsequent patient outcomes. Findings denote wider systemic issues and a lack of specificities of information and practical skills that could help prevent caregivers from experiencing the caregiving burden and subsequent consequences on eating disorder patient outcomes.

Keywords: Eating disorders, caring, caregivers

Highlights:

- Caregivers of individuals with eating disorders experience significant ongoing barriers to accessing treatment for their loved ones, high levels of unmet needs and significant ramifications in multiple domains of everyday life.
- Whilst some initiatives are underway to attend to certain unmet needs, little is being done to address broader systemic challenges faced by caregivers in accessing support for their loved ones.
- Findings indicate these challenges may impact the caregiving burden with potential subsequent consequences on eating disorder patient outcomes.
- Siblings and partners have largely been overlooked in research investigating caregivers' experiences of eating disorders.
- Addressing barriers to care and unmet needs for both caregivers and sufferers remains a crucial area for intervention.

Introduction

Eating Disorders (EDs) are serious mental illnesses with substantial direct and indirect costs (Keski-Rahkonen & Mustelin, 2016). The role of caregivers in EDs has been overlooked in research, with studies suggesting a significant burden (Coomber & King, 2013).

The caregiving burden encompasses the objective and subjective consequences of care (Schene, 1990). The objective burden denotes actual disruptions and demands of caring, including disruptions to employment with financial ramifications, consequences to family routines, and disruptions to socio-familial relationships which negatively impact the lives of caregivers (Hillege, Beale & McMaster, 2006; Whitney & Eisler, 2005). The subjective

burden represents caregivers' psychological distress and perceived quality of life in relation to the objective burden (Raenker *et al.*, 2012). Numerous studies have identified sentiments of guilt, shame, and helplessness associated with caring for a loved one with an ED along with increased rate of anxiety and depression (Fox, Dean & Whittlesea, 2015; Kyriacou, Treasure & Schmidt, 2008; Stefanini *et al.*, 2018). Research exploring the caregiving burden has mainly focussed on parents with siblings and partners' experiences remaining grossly under-investigated (Fox *et al.*, 2015).

Whilst research has highlighted the significant negative impacts of the caregiving burden, contradictions exist (Fox *et al.*, 2015). Certain caregivers express how EDs may bring families closer together and express sentiments of positive personal development (Anastasiadou, Medina-Pradas, Sepulveda & Treasure, 2014). Thus, research supports that positive aspects can coexist with negative consequences. The caregiving burden may be influenced by numerous factors, the most commonly researched include coping mechanisms, interactions, and support from services and resources (Coomber & King, 2013; Fox *et al.*, 2015).

Coping mechanisms

Coping mechanisms include reducing maladaptive mechanisms, particularly expressed emotion (EE) and accommodation (Fox *et al.*, 2015). EE encompasses the negative attitudes that relatives may express towards affected individuals, including criticism and emotional overinvolvement. Accommodation refers to carer responses to ED behaviours that collude with the ED, subsequently maintaining the illness (Fox & Whittlesea, 2016; Whitney & Eisler, 2005). Eisler's (2005) theoretical framework explains how families 'reorganize' around ED symptoms with consequent impacts. Within the interpersonal model, the aforementioned objective and subjective burdens provoke significant distress in caregivers whose natural responses to problematic symptoms and behaviours may be emotionally charged, characterised by EE (Treasure & Schmidt, 2013).

ED caregivers express high levels of EE, which predict negative caregiving experiences, including increased psychological distress, as well as impacting treatment engagements from patients and outcomes (Anastasiadou *et al.*, 2014; Schmidt, Tetzlaff & Hilbert, 2015; Treasure & Nazar, 2016; Zabala, Macdonald & Treasure, 2009). For instance, family-Based Treatment (FBT) is the first-line intervention for adolescents and children with AN and BN (NICE, 2017). During FBT, parents manage the ED symptoms at home. Subsequently, families must adopt the skills and responsibility of clinicians in managing their loved ones' ED which can cause significant stress and strain (Zabala *et al.*, 2009). FBT is less effective for families with higher EE (Eisler *et al.*, 2007). High levels of EE are directly linked to aforementioned accommodating behaviours including buying expensive foodstuffs and turning a blind eye on ED behaviours (Anastasiadou *et al.*, 2014; Fox & Whittlesea, 2016). Accommodation is further correlated with increased carer burden, psychological distress and further EE, as well as poorer outcomes for the sufferer highlighting this area as key for intervention (Fox & Whittlesea, 2016; Zabala *et al.*, 2009).

Interactions and support from services

Caregivers' confidence in services influences treatment outcomes and may influence the caregiving burden (Le Grange, Lock, Loeb & Nicholls, 2009; McCardle, 2017). A qualitative study of parents' experiences of services for EDs, which is also echoed in wider research, identified 'treatment hurdles' as one of the main impacts, including poor initial interactions with GPs, BMI blocking referral, waiting times, poor follow-up post-discharge, and poor transitions between adult mental health services (AMHS) and child and adolescent mental health services (CAMHS), (McArdle, 2017; McCormack & McCann, 2015; Mitrofan *et al.*, 2019). These negative experiences augment the caregiving burden (Hight, Thompson & King, 2005; Honey *et al.*, 2007; McArdle, 2017; McCormack & McCann, 2015).

Studies indicate that carers perceive health care professionals (HCPs), especially GPs, as lacking in knowledge and expertise in EDs (Fox *et al.*, 2015; McArdle, 2017). Positive encounters with services are limited, with evidence showing only occasional circumstances when caregivers have reported compassionate and competent HCPs (McMaster, Beale, Hillege & Nagy, 2004; Mitrofan *et al.*, 2019).

Unmet needs

Carers' unmet needs are frequently cited as increasing caregiving distress (Coomber & King, 2013; Fox *et al.*, 2015) Whitney, Haigh, Weinman & Treasure (2007) found that lack of information regarding EDs and treatment was highly predictive of negative experiences. Similar results have been shown in numerous studies, with carers stating the need for more information before and during treatment to help understand and manage the ED (Highet *et al.*, 2005; Honey *et al.*, 2007; McArdle, 2017; McCormack & McCann, 2015; Rhind *et al.*, 2016).

The aim of the current study aims to give voice to this overlooked group within ED research, with the intention of addressing caregivers' experiences of ED services and subsequent impacts on the caregiving burden using a larger sample size and a diverse range of caregivers over a broad spectrum of EDs.

Methods

Data was provided from an online survey specifically aimed at carers and conducted by BEAT, the UK's largest ED charity between 25 September and 5 October 2017 (appendix 1). The purpose of the survey was to investigate experiences and impacts on people caring for someone with an ED with the aim of advising clinicians and governments on how to address needs. It was promoted via e-mail database, Facebook, and Twitter. Demographic data

collected is presented in Table 1 and included gender and ethnicity of caregiver, relationship to affected individual, type of eating disorder, number of years spent caring and age when their loved one became ill. One thousand seven hundred and four subjects completed with survey, of which 616 subjects answered the last optional qualitative question used for this study: *If you'd like to tell us more about your experiences as a carer, please do so in the box below (Optional)*.

[INSERT TABLE 1 HERE]

Caregiver responses varied in length and all responses were included in the analysis. To maintain anonymity BEAT supplied the qualitative data separately to the participant demographics collected. Therefore, no personal data from which respondents could be identified was provided in line with GDPR. Consequently, it was not possible to know which qualitative data relates to which specific caregiver e.g. mother of daughter with anorexia unless the caregiver stated this in their response. Names and contact details were also excluded. Named hospitals and geographical locations have been replaced by 'XXX'.

A qualitative design was used to explore the complexity of individuals' experiences of caring for a loved one with an ED, suited to understanding users' experiences of services (Maher & Dertadian, 2017; Sibeoni *et al.*, 2017). Braun and Clarke's (2006) six phases of thematic analysis were employed (appendix 2). Data was analysed using inductive thematic analysis to identify themes without a specific research question in mind. Initially, the complete dataset (all participants' full responses) was coded by one author manually. This was intended to capture a rich description of the entire dataset, although it is important to acknowledge the author's active role in the research process due to pre-existing knowledge and bias (Charmaz, 2006; Braun & Clarke, 2006). After familiarisation with the data through several repeated reads of the data, data codes were collated to generate initial themes (patterns within the dataset). Themes were based on topics most commonly endorsed by participants

and contradictions to main themes were also acknowledged by the author and are included in the results and analysis. Themes and thematic maps were revised and re-examined by the authors collaboratively to check validity in relation to the entire dataset. Narratives were written to capture each theme which helped authors collectively agree on wording of themes and quotations used to support themes.

3. Results

Three main interrelated themes and ten subthemes emerged from thematic analysis. Main themes included: Barriers to care, Unmet needs, and Affected domains. Themes and subthemes illustrate experiences most commonly reported by caregivers in relation to carers' experiences of ED treatment (Figure 1).

Barriers to care encompass the enduring obstacles caregivers face in accessing support and treatment for their loved ones. Experiences of services comprise the unmet needs of both patients and caregivers alike. Affected domains indicate the pervasive impacts of caregiving and how these are mediated by experiences of services. In the following sections, caregivers' quotes are used to illustrate each theme.

[INSERT FIGURE 1 HERE]

3.1 Barriers to care

Carers expressed frustration at barriers encountered during every stage of the treatment process from primary to tertiary care (GP, CAMHS, IP), as well as issues transitioning back into the community. These challenges added to both the subjective and objective caregiving burden increasing caregiving distress and despair.

3.1.1. The GP

The GP was usually the caregivers' first contact with services. Most carers perceived their GP to be dismissive when raising concerns. Often this led carers to visit more than one GP to receive the appropriate support for their loved one. Carers were extremely frustrated that

lack of GP awareness frequently resulted in delayed diagnosis or blocked referral. Carers perceived GPs to lack knowledge and expertise on EDs, describing them as *'hopeless'*, *'useless'* and *'dangerous'*, for missing vital signs and making triggering comments. This had serious implications with regard to delayed diagnosis or treatment, preventing opportunity for early intervention, adding to carer frustration and potential treatment outcomes as affected individuals were left untreated, or triggered by the experience.

There was common consensus regarding the need for better education and training.

Although, in some instances, a GP facilitated an immediate referral, a number of carers also referred to treatment barriers outside the GPs' control, including BMI and hurdles at every stage of the treatment process, reflecting ongoing barriers.

'Well you LOOK fine' he said, dismissing her weight loss as not dangerous until she has dropped further. She came out of the surgery feeling that she should now drop another stone simply to demonstrate that she was actually ill.

The GP was sympathetic but my daughter wasn't considered bad enough to not have to wait a year for an appointment to see someone for assessment, despite vomiting all her meals up and hiding it from us in carrier bags in the bin.

3.1.2. The wait and weight

Carers cited BMI as a frequent barrier to treatment. The common rhetoric of *'not thin enough'* or *'not sick enough'* meant sufferers and their families were left without professional help or support, adding to their desperation. Numerous carers reflected on the challenges of this, which meant their loved one had to starve themselves further to be considered ill enough for help. Carers expressed the agony in having to watch their loved one deteriorate

whilst waiting for support. Numerous carers reflected on how their loved one was 'near death' or 'could have died' due to lack of appropriate treatment earlier on blocked by weight and waiting times. This added to the carer despair both due to the physical and emotional change in their loved ones, as well as feelings of helplessness regarding where to turn to in order to access treatment.

Caregivers often perceived treatment (OP and IP) as being too weight orientated, which neglected the psychiatric and behavioural support necessary for their loved ones' recovery. Some carers cited how once their child was out of physical danger, support disappeared, leaving carers feeling abandoned and helpless, significantly adding to the caregiving burden. Several carers cited the differences in access to routine care between mental and physical conditions, expressing frustration that they would not have had to wait if their loved one had a physical condition.

Distressing to see someone who so desperately wants help to be refused twice because she isn't 'thin enough'. Very dangerous carrot to dangle in my opinion

The waiting heightens the emotional turmoil and is affecting my daughter's mental health even more. Whilst waiting she is getting worse. You have to be at death's door to get a bed.

If she had a broken leg she would not have waited in agony for nine months!!

3.1.3. Fighting for treatment

Many participants expressed exhaustion at having to fight or beg for adequate support, which significantly added to caregivers' distress. Participants were frustrated at having to fight professionals from whom they were supposed to be receiving help, leaving caregivers feeling helpless and internalising failure and self-blame. Fighting was associated with

ongoing barriers whereby caregivers fought and then refought the system dependent on whether treatment was offered or presumed to be ineffective or withdrawn.

It has been an uphill battle all the way, not simply fighting the disease, which is hard enough, but fighting the healthcare system.

After pleading and begging my son was eventually referred to a specialist unit and I completely broke down feeling I had failed as a mother which still affects me today.

Continually fighting for professional help, angry that this stops when she is WR but still strong AN thoughts and behaviours. Not ill enough, constant relapse cycles. Life is on hold

3.2. Experiences of services

This theme comprises poor interpersonal interactions with services, as well as unmet needs of both caregivers and sufferers, which augment the caregiving burden.

3.2.1. Carers feeling mistreated and excluded

Participants reported hostile interpersonal exchanges with HCPs who frequently made unhelpful comments. Caregivers felt that many HCPs lacked understanding and awareness about EDs and the impact they inflicted upon themselves and their families. Carers frequently felt misunderstood, ridiculed, and overlooked, which left them feeling increasingly frustrated at their situation.

Carers reported the difficulties in being excluded from their loved ones' treatment once they reached eighteen years of age. This left caregivers of 'adult children' in an 'impossible

position-caring without information'. Carers indicated their loved ones were not of *'sound mind'* and therefore not capable of asking for support or making informed decision.

Respondents perceived this to be a major shortcoming of the system which frequently resulted in clinical deterioration.

Several carers also reported poor transitions between CAMHS and AMHS, described as *'disruptive'* and a fertile ground for relapse. In addition to being excluded from treatment once the sufferer reached eighteen, many caregivers felt this was a particularly stressful period. Carers frequently called for different approaches including a *'continuum between child and adult services'* including a CAMHS services extending up to twenty-five or a *'teenage and young adult approach to EDs'* as carers felt that *'18 yr olds with EDs are not remotely able to act or behave like adults'*. In one extenuating circumstance this had a positive outcome.

I don't think the trauma of those years will ever leave her or me. Our trauma was increased by ill trained 'professionals'.

Eating disorders are so difficult to understand, and it's hard to provide support when the sufferer does not want help. But what makes it all so much worse is that often you feel you are blamed, not listened to, not communicated with, not considered to be of use.

My daughter has just turned 18. She was promised a 'seamless transition' to adult services. She was assessed and told she would go onto the 'priority waiting list.' Then we were informed that this would be 7 months long. I have felt suicidal.

We were exceptionally lucky that our daughter continued to be managed by CAMH team even when she was 18 and not moved to adult services. I fully believe that this continued family therapy enabled us to change our behaviour as a family and was responsible for ensuring that our daughter is now almost fully recovered.

3.2.2. Patient needs

Caregivers indicated a 'loss of hope in the services offered by the NHS' referred to as a 'post-code lottery', 'underfunded', 'stretched' and 'thread-bare'. Many participants perceived CAMHS to be 'not enough', 'haphazard' and 'spasmodic'. HCPs again were perceived to lack adequate training, often making mistakes which frustrated caregivers, adding to their stress. One participant expressed how records were mixed with another patient's without an 'apology or rectifying the mistake'. Participants therefore deemed CAMHS as 'negligent' and 'ill-equipped' to deal with EDs. Perceived inadequacies in services often led to disengagement from either caregivers or patients. There were occasional exceptions wherein carers expressed more positive experiences of NHS care. However, positive aspects of treatment most frequently existed alongside less favourable accounts.

Daughter has had a disorder since she was 13 months. GP never took it seriously. Eventually school referred her to CAMHS. We were offered family therapy 3 years ago, we are still waiting for this. She now refuses to attend such a session as communication is at an all-time low at home.

The inpatient care was fabulous but my daughter was discharged too early due to NHS funding. The gap between inpatient care and community is far too big.

3.2.3. Unmet carer needs

Many carers cited a lack of information and practical and emotional support made available to them. Some carers felt there was a distinct lack of information from HCPs, leaving them

'*in the dark*' and dependent on '*Dr Google*'. Many carers wanted broader information on EDs, including illness duration, outcomes and specificities of their loved one's condition throughout treatment.

While a few participants indicated that parent groups provided was perceived to be '*an enormous help*' the vast majority of participants indicated frustration at the lack of practical support with the main therapy provided, FBT. Carers felt that many HCPs lacked awareness of the challenges of undertaking FBT at home and wanted more practical guidance.

Lack of emotional support from services was also frequently cited by carers. Participants expressed the practical and psychological difficulties caring had inflicted, and the lack of recognition of this by services and insufficient support offered left them feeling '*abandoned*', '*ignored*' and '*unimportant*,' adding to their distress.

We found FBT very stressful and felt a lack of guidance – ‘you know as parents how to feed your child’. When they are swearing, screaming, throwing food, and at times violent it’s not easy!

It’s horrible watching your precious baby daughter die slowly every day. Receiving almost no help ever. Just take her home and feed her. Thanks...Tips ?????

3.3. Affected Domains

Negative experience of ED treatment had significant implications in almost all domains of carers' lives referred to as a '*LIVING NIGHTMARE*'. This theme had four corresponding subthemes.

3.3.1. Financial

Caregivers' expressed numerous financial impacts presented in Table 2, which augmented the caregiving burden, frequently resulting in further negative ramifications. The nature of FBT meant carers frequently had to reduce work hours or give up work, which often resulted in financial consequences. Whilst some caregivers referred to giving up work as a choice, others used language of being forced or having to give up work alluding to the lack of support available which meant they had to take on the burden. In extreme cases, carers were dismissed from work, augmenting financial pressures and leading to reduced self-esteem and helplessness.

'Postcode lotteries' meant many carers were faced with additional costs *'too great'* or *'difficult to calculate'*; for accommodation and travel to visit their loved ones in IP units. Barriers to NHS care meant carers frequently resorted to private treatment for their loved ones illustrating how systemic shortcomings of the system increased the carer burden. Those with the means or health insurance benefits to pay for private care expressed their *'luck'* and thankfulness, acknowledging their privilege. However, in certain cases associated financial costs resulted in severe life-changing circumstances for carers, including delayed or early retirement, debt, or having to sell or re-mortgage the family home. This burden was exacerbated for single-parent carers. Lack of emotional support for carers often meant they were paying for their own private therapy or counselling *'just to stay sane'* or alleviate the stress, increasing the financial costs of caring. This was considered *'another expense'*, reflecting the magnitude of financial costs associated with care, although such treatment was often considered *'invaluable'* in helping to improve carers' skills and coping.

[INSERT TABLE 2 HERE]

3.3.2. Socio-familial

Socio-familial impacts were frequently cited by caregivers, presented in Table 3. The overwhelming and relentless burden of care, especially FBT was frequently described as a '24/7 job' at the expense of the normality of previous daily life, with *'family, work and friendships all monopolised by the illness'*. Carers stressed the *'whole family suffers, not just the patient'*. Other respondents reflected on the changes to *'normal'* family functioning, including holidays, meal times, and leisure activities that they could previously just do *'without thinking'*.

Family conflict was overwhelmingly cited with one carer saying the *'illness rips families apart'*. Tensions were often created between carers and the sufferer, as well as amongst different family members. EDs were frequently cited as the source of marital or relationship breakdown. Although in the minority, there were some exceptions wherein carers felt the experience, however difficult, brought the family *'closer together'*. This was mainly cited by carers whose loved one was progressing in recovery or remitted, where families perceived strength in overcoming hardships, or by carers who were partners.

[INSERT TABLE 3 HERE]

3.3.3. Health

Numerous caregivers cited knock on mental and physical health impacts due to the level of stress associated with their experience of treatment and implications. Mental health implications included disturbed sleep, anxiety, depression, PTSD, and suicidal idealisation. In many instances, carers had been prescribed medications (sleeping pills, anti-anxiety, and antidepressants) without supplementary counselling, and many cited subsequently developing addictions.

Carers also cited impacts on physical health further associated with stress. In pre-existing medical conditions, the ED was described as the *'nail in the coffin'*, contributing to death in the most extreme cases. Siblings were also thought to be particularly vulnerable to health consequences, including exercise addiction, anxiety, low moods, social withdrawal and developing EDs themselves. The severe and enduring nature of EDs was also reflected in caregivers expressing how even once their loved one is improving in their recovery, the anxiety and stress remains high, illustrating how just like the illness itself, the impacts on caregivers may be chronic. Findings are summarised in table 4.

[INSERT TABLE 4 HERE]

3.3.4. Accommodation

Carers frequently exhibited a *'would do anything'* mentality with regards to supporting their loved one, reflecting their selflessness. However, this commonly resulted in accommodating behaviours described by carers, including spending extra money to buy any food in the hope to try to get the sufferer to eat, reassurance, and treading on *'eggshells'* around ED symptoms and behaviours. There was also evidence of EE. Although carers did not actively cite accommodation, they recognised certain responses or behaviours were not conducive to ameliorating the ED symptoms or behaviours. Carers frequently referred to *'falling into traps'*, *'compromising'*, being *'indulgent'* and making *'mistakes'* regarding desperate attempts to manage the illness. Many respondents felt better *'schooling in EDs'* would help avoid accommodating behaviours, emphasising their desire for more support which would improve their caregiving experience and, potentially, patient outcomes.

We made a lot of mistakes, reacted inconsistently, my husband and I reacted differently and got into conflict, which aggravated the situation, and got incredibly stressed and distressed.

I have been manipulated by my daughter without realising it and now believe I have made things so much worse. I was not hard enough on her and have always fallen into the trap of spending hours of talking about it and food for far too long with her. I'm always compromising which I know I shouldn't. I could write a book on my mistakes. I am desperate for support, but it isn't there.

3.3.5. Needs expressed by caregivers

Numerous caregivers' expressed specific needs to be addressed with regard to support specifically for caregivers and their loved ones presented in table 5. Needs predominantly centred on needs pertaining to challenges encountered by caregivers in the treatment that in turn increased the overall burden including weight blocking access to treatment, the need for more GP training, the need for day and better adult services and more seamless transitions to adult services from CAMHS. These may in turn have made caregiver's felt more supported by ensuring their concerns were initially acknowledged by the GP and that they were being helped by services in place. Better adult services and more seamless transitions may have prevented relapse and additional caregiver and patient distress at this time. Day services may have allowed loved one's to remain at home and reduce the knock on financial costs of travel and accommodation.

Caregivers also expressed the need for more information, practical skills and their own emotional support. Caregivers often cited charities, books or groups that had been an immense help, but that they found these too late needed signposting. Needs for siblings and partners were also cited such as groups specific to their own need reflecting how caregivers will have differing needs which must not be overlooked.

[INSERT TABLE 5 HERE]

4. Discussion

This study is the largest of its kind to explore caregivers' experiences of ED services and subsequent impacts on the caregiving burden. Results indicate caregivers' experiences of these services are predominantly negative and are characterised by the three main themes and ten subthemes : (a) Barriers to care: GP, fighting for treatment, the wait and weight, (b) Experiences of services: patient needs, unmet carer needs, carers feeling mistreated and excluded, (c) Affected domains: health, social / familial, financial, accommodation.

Consistent with wider research, caregivers noted barriers encountered at numerous stages of the treatment process and high levels of unmet needs for themselves and their loved ones which compounded their distress (McArdle, 2017; Mitrofan *et al.*, 2019). Caregivers expressed frustration at having to fight the healthcare systems, which were supposed to be supporting them, leaving them feeling isolated and helpless (Fox & Whittlesea, 2016). Research has shown barriers and persistent fighting can augment caregivers' psychological distress, indicating the valuable impact reduced barriers may play in alleviating the caregiving burden (Honey *et al.*, 2007; Treasure *et al.*, 2001). Results are compatible with Eisler's (2005) proposed theoretical framework which explains how families 'reorganize' around ED symptoms with subsequent impacts on socio-familial domains including marital breakdown and family meals.

In accordance with Treasure and Schmidt's (2013) cognitive-interpersonal model for AN, findings indicate evidence of accommodation and EE. Consistent with previous studies, results also show caregivers' awareness of these counterproductive strategies are commonly referred to as 'mistakes' but that they have a lack of information or skills to appropriately respond (Fox & Whittlesea, 2016; Sepulveda *et al.*, 2009).

Findings from this study and how these results fit into the landscape of previous research can be found in Figure 2, based on Treasure and Schmidt's (2013) cognitive-interpersonal model for AN. Figure 2 is a conceptual model designed to show how poor experiences of services including barriers to care and unmet needs of both patients and caregivers may play a key role in mediating the caregiving burden. This, in turn, may provoke the poor carer coping strategies mentioned above, which subsequently impact outcomes including illness severity, duration and treatment resistance (Fox & Whittlesea, 2016; Kyriacou *et al.*, 2008; Schmidt *et al.*, 2015; Treasure & Nazar, 2016). Research has demonstrated that illness severity and parental psychological functioning can predict EE and that higher levels of EE can increase illness severity and duration, creating a vicious cycle (Duclos *et al.*, 2014; Stillar *et al.*, 2016).

[INSERT FIGURE 2 HERE]

These systemic shortcomings of treatment for EDs have been overlooked in how they may indirectly impact carers as well as sufferers, augmenting the caregiving burden and provoking poorer coping strategies and negative outcomes. The difficulties in accessing appropriate information, practical skills and care for their loved ones was heavily cited by caregivers, which resulted in significant effects on socio-familial, financial, and health consequences, ultimately resulting in helplessness and despair. The ego-syntonic nature of EDs further leaves caregivers feeling isolated and helpless, and they often feel they are left fighting the system as well as their loved one, who may be ambivalent to change (Gregertsen, Mandy & Serpell, 2017). Conversely, in favourable accounts characterised by swift referral and expert HCPs, caregivers reported hope and empowerment (McCormack & McCann, 2015). Acknowledging these positive encounters is important because they signify that measures to improve caregivers' experiences may alleviate the overall burden, reduce

negative coping styles, and improve patient outcomes. Results indicated caregivers feel lucky and thankful for favourable experiences of services. This highlights their perceptions and acknowledgement of widespread difficulties that the majority will face in accessing ED support.

Results are noteworthy because caregivers still express the same challenges and unmet needs described in the literature over ten years ago (de la Rie, Noordenbos & van Furth, 2005; Hight *et al.*, 2005; Hillege *et al.*, 2006; Honey *et al.*, 2007). GPs remain a pertinent issue for caregivers, often considered dismissive and uninformed regarding treatment options and delaying intervention (Fox & Whittlesea, 2016; McArdle, 2017; McMaster *et al.*, 2004; McCormack & McCann 2015; Mitrofan *et al.*, 2019). GPs are often the first interaction most families will have with HCPs, so caregivers express that they must be better trained to recognise the signs and symptoms and refer quickly. Treatment is currently often perceived by caregivers as being too weight orientated, overlooking the psychological and behavioural components key for sustainable recovery.

Analysis illustrates the unique additional challenges of accessing treatment once patients reach eighteen. The Beat (2017) reports adults waiting 176 weeks (3.5 years) on average between ED onset and treatment; this is over the crucial three-year threshold, after which symptoms become more entrenched and resistant to treatment (Treasure & Russel, 2011). As well as resulting in poorer outcomes for sufferers, results indicate that waiting times are particularly agonising for caregivers, increasing psychological distress and subsequently exacerbating the caregiving burden. This may potentially impact carer coping styles and subsequent outcomes (Anastasiadou *et al.*, 2014; Beat, 2017; Mitrofan *et al.*, 2019). Children are protected by the access and waiting times legislation, passed in 2015, that ensures those under eighteen are seen and treated within four weeks; however, this does not apply to adults equally in need of professional support (Beat, 2017). Accessing similar funding to support early intervention for adults with EDs remains crucial.

Consistent with previous studies, exclusion from treatment was identified as a major mediator of carer distress (Highet *et al.*, 2005; Kyriacou *et al.*, 2008; McMaster *et al.*, 2004). Whilst previous studies have expressed the negative impacts of exclusion on caregivers, results from the current study indicate this is an especially pertinent issue for caregivers of 'young adults'. Research indicates that EDs may impact normal maturation, which means adults sufferers of EDs may present with more childlike qualities and may be more dependent on caregivers both emotionally and financially (Buhl, 2002; Robinson, Kukucska, Guidetti & Leavey, 2015). The fixed threshold of eighteen years for adulthood may not be appropriate for sufferers whose impeded development may benefit from the continued inclusion of caregivers. Transitions from CAMHS to AMHS were cited as particularly difficult for carers and a significant factor in relapse, increasing their distress and augmenting the caregiving burden, consistent with findings by Mitrofan *et al* (2019), who concluded transitions frequently trigger clinical deterioration. Findings from this study indicate carers perceive transfers between care facilities to often fail their loved ones due to the nature of the illness, which may not allow affected individuals to advocate for themselves or accept help. When caregivers are excluded, the ED may lead patients to lie and deceive HCPs, resulting in relapse (Treasure & Schmidt, 2013). Findings from this current study also indicate caregivers' desire for a continuum of care. Extending CAMHS services up to 25 years and including caregivers in treatment during this time may be a positive benefit for sufferers and families alike.

Caregivers also expressed the need for more community-based treatment, including intensive day care, due to the gap between IP and OP services and the drawbacks of having their loved one living far from home. The large well-conducted trial by Herpertz-Dahlmann *et al* (2014) showed cost and patient outcome benefits, particularly mental well-being and psychosocial adjustment, of stepped care with DP treatment after an initial short (three-week) inpatient period. Stepped care may support more sustainable recovery by giving more

focus to the psychological and behavioural needs of the patient, as indicated by caregivers, and alleviate some of the burden by sharing the responsibility of care between HCPs and carers, additionally allowing caregivers to retain some sense of 'normal' everyday life including employment and socio-familial routines. More local day services would reduce the financial and time costs in travel and accommodation to distant units.

Strengths and limitations of this study

A particular strength of this study is the large number of participants included. The rich qualitative data presented was intentionally included to give a voice to this overlooked group. Online surveys have the advantage of providing anonymity, offering a private and non-judgemental medium for participants to express honest views on sensitive topics, reducing social desirability bias. However, online respondents are more likely to be 'viewpoint orientated', with participants expressing extreme views which may have impacted results (Mann & Stewart, 2005). Coupled with most caregivers being mothers, this may have skewed perspectives towards more negative experiences and evoked more active opinions. Nevertheless, these findings do echo wider literature, building on existing evidence that suggests widespread need for improved service provisions and support for caregivers.

As BEAT provided data pertaining to participant demographics separately to qualitative responses to maintain anonymity in line with GDPR, a significant limitation of the study is not being able to give the quotes more context. In addition, it was not possible to look for patterns in responses with regard to the different relationships to the affected individuals this relationship was identified by the participant within the quote.

Self-selection bias is a common limitation of online surveys as there is a tendency for some individuals to respond to surveys, whilst others ignore them, resulting in systematic bias (Wright, 2006). The survey design itself, may have further skewed data negatively. Not one

question asks if there was anything positive, valuable or appreciated about carer's experience of services or treatment. The qualitative question was also preceded by drop-down multi-response questions asking about experiences of and what might be done to improve ED treatment, which may have led the responses to be influenced negatively. Although coding and themes were reviewed multiple times by authors, initial coding was conducted manually by one researcher, increasing potential for bias.

Conclusion

This qualitative study sought to explore caregivers' experiences of ED services and how these may impact the caregiving burden. Results indicate that the majority of surveyed caregivers felt unsatisfied with such services, facing numerous barriers in attempting to access them, and finding they fell short of their own needs, and the needs of their loved ones. Findings suggest the key role services may play in mitigating the pervasive impacts on caregivers' lives and addressing underlying systemic shortcomings in mental health provision, including more funding and overhauls in current clinical pathways to include more local community-based treatment and address specific issues related to care for young adults.

Future Research

Future studies are needed to test the conceptual model presented in Figure 2 and pilot initiatives suggested by caregivers in Table 5. These may inform changes to improve caregivers' experiences of services and help caregivers best care for sufferers. These may help to alleviate the caregiving burden, equipping caregivers with the tools and emotional support necessary to increase their self-efficacy to best support their loved ones in recovery. The current research validates previous findings and proposes areas of further investigation. However, addressing caregivers' experiences of ED treatment through a range of avenues remains a crucial target for intervention.

References

- Anastasiadou, D., Medina-Pradas, C., Sepulveda, A., & Treasure, J. (2014). A systematic review of family caregiving in eating disorders. *Eating Behaviors, 15*(3), 464-477. doi: 10.1016/j.eatbeh.2014.06.001
- Beat. (2017). *Delaying for years, denied for months..* Retrieved from <https://www.beateatingdisorders.org.uk/uploads/documents/2017/11/delaying-for-years-denied-for-months.pdf>
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research In Psychology, 3*(2), 77-101. doi: 10.1191/1478088706qp063oa
- Buhl, C. (2002). Eating disorders as manifestations of developmental disorders: language and the capacity for abstract thinking in psychotherapy of eating disorders. *European Eating Disorders Review, 10*(2), 138-145. doi: 10.1002/erv.440
- Charmaz, K. (2006). *Constructing grounded theory*. London: Sage.
- Coomber, K., & King, R. (2013). Perceptions of Carer Burden: Differences Between Individuals With an Eating Disorder and Their Carer. *Eating Disorders, 21*(1), 26-36. doi: 10.1080/10640266.2013.741966
- de la Rie, S., Noordenbos, G., & van Furth, E. (2005). Quality of life and eating disorders. *Quality of Life Research, 14*(6), 1511-1521. doi: 10.1007/s11136-005-0585-0
- Duclos, J., Dorard, G., Berthoz, S., Curt, F., Faucher, S., Falissard, B., & Godart, N. (2014). Expressed emotion in anorexia nervosa: What is inside the "black box"? *Comprehensive Psychiatry, 55*(1), 71-79. doi: 10.1016/j.comppsy.2013.10.002
- Eisler, I. (2005). The empirical and theoretical base of family therapy and multiple family day therapy for adolescent anorexia nervosa. *Journal of Family Therapy, 27*(2), 104-131. doi: 10.1111/j.1467-6427.2005.00303.x
- Fox, J., & Whittlesea, A. (2016). Accommodation of Symptoms in Anorexia Nervosa: A Qualitative Study. *Clinical Psychology & Psychotherapy, 24*(2), 488-500. doi: 10.1002/cpp.2020
- Fox, J., Dean, M., & Whittlesea, A. (2015). The Experience of Caring For or Living with an Individual with an Eating Disorder: A Meta-Synthesis of Qualitative Studies. *Clinical Psychology & Psychotherapy, 24*(1), 103-125. doi: 10.1002/cpp.1984
- Gregertsen, E., Mandy, W., & Serpell, L. (2017). The Egocentric Nature of Anorexia: An Impediment to Recovery in Anorexia Nervosa Treatment. *Frontiers In Psychology, 8*. doi: 10.3389/fpsyg.2017.02273
- Herpertz-Dahlmann, B., Schwarte, R., Krei, M., Egberts, K., Warnke, A., & Wewetzer, C. et al. (2014). Day-patient treatment after short inpatient care versus continued inpatient treatment in adolescents with anorexia nervosa (ANDI): a multicentre, randomised, open-label, non-inferiority trial. *The Lancet, 383*(9924), 1222-1229. doi: 10.1016/s0140-6736(13)62411-3
- Hight, N., Thompson, M., & King, R. (2005). The Experience of Living with a Person with an Eating Disorder: The Impact on the Carers. *Eating Disorders, 13*(4), 327-344. doi: 10.1080/10640260591005227
- Hillege, S., Beale, B., & McMaster, R. (2006). Impact of eating disorders on family life: individual parents' stories. *Journal Of Clinical Nursing, 15*(8), 1016-1022. doi: 10.1111/j.1365-2702.2006.01367.x
- Honey, A., Boughtwood, D., Clarke, S., Halse, C., Kohn, M., & Madden, S. (2007). Support for Parents of Children with Anorexia: What Parents Want. *Eating Disorders, 16*(1), 40-51. doi: 10.1080/10640260701773447
- Keski-Rahkonen, A., & Mustelin, L. (2016). Epidemiology of eating disorders in Europe. *Current Opinion In Psychiatry, 29*(6), 340-345. doi: 10.1097/ycp.0000000000000278
- Kyriacou, O., Treasure, J., & Schmidt, U. (2008). Understanding how parents cope with living with someone with anorexia nervosa: Modelling the factors that are associated with carer distress. *International Journal Of Eating Disorders, 41*(3), 233-242. doi: 10.1002/eat.20488

- Le Grange, D., Lock, J., Loeb, K., & Nicholls, D. (2009). Academy for eating disorders position paper: The role of the family in eating disorders. *International Journal Of Eating Disorders*, NA-NA. doi: 10.1002/eat.20751
- Maher, L., & Dertadian, G. (2017). Qualitative research. *Addiction*, 113(1), 167-172. doi: 10.1111/add.13931
- Mann, C., & Stewart, F. (2005). *Internet communication and qualitative research*. London: Sage Publications.
- McArdle, S. (2017). Parents' experiences of health services for the treatment of eating disorders: a qualitative study. *Journal Of Mental Health*, 28(4), 404-409. doi: 10.1080/09638237.2017.1417558
- McCormack, C., & McCann, E. (2015). Caring for an Adolescent with Anorexia Nervosa: Parent's Views and Experiences. *Archives Of Psychiatric Nursing*, 29(3), 143-147. doi: 10.1016/j.apnu.2015.01.003
- McMaster, R., Beale, B., Hillege, S., & Nagy, S. (2004). The parent experience of eating disorders: Interactions with health professionals. *International Journal Of Mental Health Nursing*, 13(1), 67-73. doi: 10.1111/j.1447-0349.2004.00310.x
- Mitrofan, O., Petkova, H., Janssens, A., Kelly, J., Edwards, E., & Nicholls, D. et al. (2019). Care experiences of young people with eating disorders and their parents: qualitative study. *Bjpsych Open*, 5(1). doi: 10.1192/bjo.2018.78
- NICE. (2017). Overview | Eating disorders: recognition and treatment | Guidance | NICE. Retrieved 21 March 2020, from <https://www.nice.org.uk/guidance/NG69>
- Raenker, S., Hibbs, R., Goddard, E., Naumann, U., Arcelus, J., & Ayton, A. et al. (2012). Caregiving and coping in carers of people with anorexia nervosa admitted for intensive hospital care. *International Journal Of Eating Disorders*, 46(4), 346-354. doi: 10.1002/eat.22068
- Robinson, P., Kukucska, R., Guidetti, G., & Leavey, G. (2015). Severe and Enduring Anorexia Nervosa (SEED-AN): A Qualitative Study of Patients with 20+ Years of Anorexia Nervosa. *European Eating Disorders Review*, 23(4), 318-326. doi: 10.1002/erv.2367
- Schene, A. (1990). Objective and subjective dimensions of family burden. *Social Psychiatry And Psychiatric Epidemiology*, 25(6), 289-297. doi: 10.1007/bf00782883
- Schmidt, R., Tetzlaff, A., & Hilbert, A. (2015). Perceived Expressed Emotion in Adolescents with Binge-Eating Disorder. *Journal Of Abnormal Child Psychology*, 43(7), 1369-1377. doi: 10.1007/s10802-015-0015-x
- Sibeoni, J., Orri, M., Valentin, M., Podlipiski, M., Colin, S., Pradere, J., & Revah-Levy, A. (2017). Metasynthesis of the Views about Treatment of Anorexia Nervosa in Adolescents: Perspectives of Adolescents, Parents, and Professionals. *PLOS ONE*, 12(1), e0169493. doi: 10.1371/journal.pone.0169493
- Stefanini, M., Troiani, M., Caselli, M., Dirindelli, P., Lucarelli, S., Caini, S., & Martinetti, M. (2018). Living with someone with an eating disorder: factors affecting the caregivers' burden. *Eating And Weight Disorders - Studies On Anorexia, Bulimia And Obesity*, 24(6), 1209-1214. doi: 10.1007/s40519-018-0480-7
- Stillar, A., Strahan, E., Nash, P., Files, N., Scarborough, J., & Mayman, S. et al. (2016). The influence of carer fear and self-blame when supporting a loved one with an eating disorder. *Eating Disorders*, 24(2), 173-185. doi: 10.1080/10640266.2015.1133210
- Treasure, J., Murphy, T., Szmukler, T., Todd, G., Gavan, K., & Joyce, J. (2001). The experience of caregiving for severe mental illness: a comparison between anorexia nervosa and psychosis. *Social Psychiatry And Psychiatric Epidemiology*, 36(7), 343-347. doi: 10.1007/s001270170039
- Treasure, J., & Nazar, B. (2016). Interventions for the Carers of Patients With Eating Disorders. *Current Psychiatry Reports*, 18(2). doi: 10.1007/s11920-015-0652-3
- Treasure, J., & Russell, G. (2011). The case for early intervention in anorexia nervosa: theoretical exploration of maintaining factors. *British Journal Of Psychiatry*, 199(1), 5-7. doi: 10.1192/bjp.bp.110.087585
- Treasure, J., & Schmidt, U. (2013). The cognitive-interpersonal maintenance model of anorexia nervosa revisited: a summary of the evidence for cognitive, socio-emotional and

- interpersonal predisposing and perpetuating factors. *Journal Of Eating Disorders*, 1(1). doi: 10.1186/2050-2974-1-13
- Whitney, J., & Eisler, I. (2005). Theoretical and empirical models around caring for someone with an eating disorder: The reorganization of family life and inter-personal maintenance factors. *Journal Of Mental Health*, 14(6), 575-585. doi: 10.1080/09638230500347889
- Whitney, J., & Eisler, I. (2005). Theoretical and empirical models around caring for someone with an eating disorder: The reorganization of family life and inter-personal maintenance factors. *Journal Of Mental Health*, 14(6), 575-585. doi: 10.1080/09638230500347889
- Whitney, J., Haigh, R., Weinman, J., & Treasure, J. (2007). Caring for people with eating disorders: Factors associated with psychological distress and negative caregiving appraisals in carers of people with eating disorders. *British Journal Of Clinical Psychology*, 46(4), 413-428. doi: 10.1348/014466507x173781
- Winn, S., Perkins, S., Walwyn, R., Schmidt, U., Eisler, I., & Treasure, J. et al. (2007). Predictors of mental health problems and negative caregiving experiences in carers of adolescents with bulimia nervosa. *International Journal Of Eating Disorders*, 40(2), 171-178. doi: 10.1002/eat.20347
- Wright, K. (2006). Researching Internet-Based Populations: Advantages and Disadvantages of Online Survey Research, Online Questionnaire Authoring Software Packages, and Web Survey Services. *Journal Of Computer-Mediated Communication*, 10(3), 00-00. doi: 10.1111/j.1083-6101.2005.tb00259.x
- Zabala, M., Macdonald, P., & Treasure, J. (2009). Appraisal of caregiving burden, expressed emotion and psychological distress in families of people with eating disorders: A systematic review. *European Eating Disorders Review*, 17(5), 338-349. doi: 10.1002/erv.925

Figure Legends

Figure 1: Graphical Illustration of Themes and Sub-Themes

Figure 2: A conceptual model representing impacts of negative experiences of services

Tables

Table 1: Characteristic of Study Participants

| CHARACTERISTIC | PREVALENCE (N%) |
|--|-----------------|
| GENDER OF CARER | |
| MALE | 57 (9.25%) |
| FEMALE | 557 (90.4%) |
| NONBINARY | 2 (0.32%) |
| RELATIONSHIP TO AFFECTED INDIVIDUAL | |
| MOTHER | 505 (82%) |
| FATHER | 40 (6.5%) |
| SISTER | 18 (2.9%) |
| BROTHER | 0 (0%) |
| GRANDMOTHER | 4 (0.7%) |
| GRANDFATHER | 0 (0%) |
| AUNT | 1 (0.2%) |
| UNCLE | 0 (0%) |
| HUSBAND | 2 (0.3%) |
| WIFE | 0 (0%) |
| PARTNER | 21 (3.4%) |
| SON | 0 (0%) |
| DAUGHTER | 2 (0.3%) |
| FRIEND | 16 (2.5%) |
| COLLEAGUE | 2 (0.3%) |
| OTHER | 5 (0.8%) |
| ED DIAGNOSIS | |
| AN | 552 (89.6%) |
| BN | 134 (21.75%) |
| BED | 100 (16.2%) |
| ARFID | 63 (10.2%) |
| OTHER | 40 (6.5%) |
| AGE OF AFFECTED INDIVIDUAL AT TIME OF INITIAL ONSET (YEARS) | |
| <10 | 1 (0.16%) |
| 11-17 | 200 (32.47%) |
| 18-25 | 277 (44.97%) |
| 26-30 | 65 (10.6%) |
| 31-40 | 51 (8.28%) |
| >40 | 19 (3.08%) |
| GENDER OF AFFECTED INDIVIDUAL | |
| MALE | 38 (6.17%) |
| FEMALE | 576 (93.5%) |
| GENDER NEUTRAL | 2 (0.32%) |

n=616

Values displayed as (n%)

Participants were included in all the diagnoses and services identified by caregivers.

ANOREXIA NERVOSA (AN)

BULIMIA NERVOSA (BN)

BINGE EATING DISORDER (BED)

AVOIDANT/ RESTRICTIVE FOOD INTAKE DISORDER (ARFID)

ATYPICAL EATING DISORDER (EDNOS OR OSFED ETC)

CHILD AND ADOLESCENT MENTAL HEALTH SERVICES (CAMHS)

ADULT MENTAL HEALTH SERVICES (AMHS)

Table 2. Quotes illustrating financial impacts on caregivers

| FINACIAL IMPACTS | QUOTE(S) |
|---|--|
| <p>REDUCED WORK HOURS / GIVING UP WORK</p> | <p><i>The illness is so demanding and care so intensive (meal supervision 3 meals and 2 snacks a day) it's very hard to work and one of us gave up work for 10 months – we are both self-employed, so no compassionate leave or sick leave for stress. The impact financially was hard.</i></p> <p><i>My daughters illness has yet to be treated because her BMI is deemed to be within normal limits and so she doesn't qualify for help. Her untrained Care Co ordinator gives her support and we pay for a dietician privately. The stress of coping with this was partially responsible for me deciding to leave my job.</i></p> |
| <p>POSTCODE LOTTERIES RESULTING IN ADDITIONAL COSTS FOR TRAVEL AND ACCOMMODATION</p> | <p><i>Difficult to quantify costs as my daughter is currently in an inpatient unit. We live in XXX, and she was in XXX for 6 months, recently transferred to XXX, which is much closer to home. Still having to travel 2-4 times per week with hotel costs once a week.</i></p> <p><i>The cost is too great to calculate. She has had 2 inpatient admissions in XXX and XXX, and we live in XXX in XXX. We travelled every weekend to see her so we had petrol and overnight accommodation to find, and this was for 14 months approx.</i></p> |
| <p>PRIVATE THERAPY / COUNSELLING FOR CAREGIVERS.</p> | <p><i>I went to therapy myself, which I found invaluable in learning how to cope. From this I discovered how to bear the stress and help my daughter indirectly.</i></p> <p><i>there is almost no support aimed specifically at carers. most carers I know have turned to privately funded therapy - another expense - to help them manage their emotions and be able to put one foot in front of another.</i></p> |
| <p>PRIVATE TREATMENT FOR LOVED ONES</p> | <p><i>The burden of paying for private care at more than £1000 per month knowing there is no other option.</i></p> <p><i>We couldn't get any help unless her BMI dropped less than 15 otherwise we had to wait for NHS psychologist but they said waiting list was long . We ended up referring ourselves to a private centre in XXX and ended up paying privately for approx 6 months but then discharged our daughter from their care and did it all ourselves at home which proved more stressful for myself but helped our daughter to improve significantly</i></p> |
| <p>LIFE CHANGING FINANCIAL IMPACTS</p> | <p><i>So, so little help under the NHS resulted in sending daughter to eating disorder clinic in States for 6 months, which was amazing but cost me half a house.</i></p> <p><i>I had to give up my job (I worked full time). I am badly in debt and at risk of losing my home. I am now under the care of a mental health team. There is little if no support for carers.</i></p> |

Table 3. Quotes illustrating socio-familial impacts on caregivers

| SOCIO-FAMILIAL IMPACTS | QUOTE(S) |
|--|--|
| CHANGES TO 'NORMAL' FAMILY FUNCTIONING | <p><i>The joy is lost from the daily simplicity of sitting as a family chatting and enjoying food together. You feel powerless terrified and trapped by the disorder.</i></p> <p><i>It has always been a constant worry and caused problems whenever there has been a family gathering (e.g. wedding, Christmas etc.) and at any event where food forms part of the occasion. As a family, we have become accustomed to her strange eating habits but it prevents her from being socially accepted outside. It is a HUGE blight on her life and it is very upsetting.</i></p> |
| FAMILY CONFLICT | <p><i>Mealtimes were a massive stress, just one little wrong word said or food not ready for a certain time could cause massive stress and trauma.</i></p> <p><i>This illness rips families apart. They lie and steal and the whole family feel like their walking on eggshells as the sufferer is very volatile and snappy.</i></p> |
| MARITAL / RELATIONSHIP BREAKDOWN | <p><i>It has affected my marriage as my husband struggled to accept the illness and adopted what I refer to as an ostrich approach. He isolated himself from us as he found it so hard to deal with. This left me feeling angry and frustrated as I felt I had been left to cope with everything alone.</i></p> <p><i>Her father said it was her who left the house or him. He left and we are now divorced.</i></p> |
| LACK OF UNDERSTANDING | <p><i>Also the lack of general understanding of this issue means people say things like 'tell her to pull herself together - it's just attention seeking - it's just a fad - it's so selfish'. Which makes you feel more on your own.</i></p> <p><i>It can often feel very lonely and an uphill battle, most people are still of the opinion that it is something that can be solved with 'a good meal and I am constantly battling against others. There is also a lot of blame, particularly from the older relatives who feel it is somehow my fault (but not my husbands!) And it does lead to constantly questioning of parenting skills.</i></p> |
| POSITIVE IMPACTS ON FAMILY (USUALLY PARTNERS) | <p><i>We are both exhausted by this, but I see a little more of the person I fell in love with every day. Just need to see her more!</i></p> <p><i>It has been very challenging and upsetting but in a strange way brought my wife and myself closer at some deeper level.</i></p> |

Table 4. Quotes illustrating health impacts on caregivers

| HEALTH | QUOTE(S) |
|------------------------------------|---|
| MENTAL HEALTH IMPACTS | <p><i>The level of stress for such an extended period of time takes its toll on the mental health of carers – I myself have had suicidal thoughts, not knowing how to get out of bed and do the same thing all over again with no end in sight. Depression, unable to function in public, social anxiety.</i></p> <p><i>I feel helpless. When I am asked by my daughters doctors whether I am receiving any help - the answer is yes, and no. My husband, my son and myself have all been prescribed anti-depressants and anti-anxiety tablets.</i></p> <p><i>Developed an addiction to sleeping medication due to the trauma of daughter being sent so far away from home for treatment.</i></p> |
| PHYSICAL HEALTH IMPACTS | <p><i>I have been admitted to hospital three times by 999 call due to cardiac symptoms brought on by the distress and fear of my daughter's deterioration. My mental health and sleep pattern have been badly affected as all the systems of her body are shutting down.</i></p> <p><i>This illness is cruel, relentless, devastating and destroys families. It wore my husband out and was a contributory factor to his premature death earlier this year. I am now left to cope with a very ill daughter and this beast of an illness on my own. I despair for her and for myself.</i></p> |
| IMPACTS ON SIBLINGS | <p><i>My other daughter developed an ED herself and I am certain that this was because of the fallout from her older sister's eating disorder. Both my daughters, my husband, and I now take antidepressants.</i></p> <p><i>My son is addicted to exercise I am sure through my daughters illness.</i></p> |
| SEVERE AND ENDURING IMPACTS | <p><i>Although our daughter has been well now for about three years I know that she is still frightened of how this got a hold of her and that it is always "there" no matter what.</i></p> <p><i>Our daughter is fingers crossed recovering, but we are still constantly on edge & worrying about food, and feel unable to plan family gatherings etc in case our slaughtered 'slips back' She's just left for uni, so the worry has ramped up.</i></p> |

Table 5. Quotes illustrating caregiver's wishes with regard to treatment provision

| WHAT CARERS WANTED | QUOTE(S) |
|--|--|
| BETTER GP AWARENESS/TRAINING | <p><i>I think it is about time GPs were given proper training on eating disorders and mental health issues so they can understand and support the patients and carers properly.</i></p> <p><i>There needs to be a lot more support at the beginning of the journey i.e. educating parent/carers in the illness and how it affects the patient.</i></p> |
| BETTER EDUCATION AND INFORMATION | <p><i>Patients and their carers should be given the information of what help there is locally, through the NHS and charitable organisations once the doctor observes that there is a mental health issue, especially if it is an eating disorder-related condition.</i></p> <p><i>What we really needed at the outset was someone to sit us down and talk to us about the likely pattern of the illness.</i></p> |
| EARLY INTERVENTION | <p><i>Real early intervention needs to be effective, readily available and encompass the family to avoid eating disorders destroying lives.</i></p> <p><i>There needs to be more resourcing available for the early treatment of eating disorders.</i></p> |
| BETTER PRACTICAL ADVICE AND GUIDANCE ON CARING AT HOME (FBT) | <p><i>Had to find my own information. Never really knew how to support her. Do I sit with her to encourage her to eat? This took a huge amount of time and never really worked. Should we just leave her to eat if and when she wants? What if she never ate? We need more information about how to support our sufferers.</i></p> <p><i>NHS support for parents in our area (CAMHS) is almost non-existent. We were told that we were going to do FBT, recommended a book, and basically left to find out how to apply it in practice ourselves, with no guidance on weight recovery, target weights, historic growth curves, etc; I had to find that out all by myself and set the target weight myself.</i></p> |
| LESS FOCUS ON WEIGHT IN TREATMENT BUT A MORE HOLISTIC / FLEXIBLE / INDIVIDUALISED APPROACH. | <p><i>There needs to be a more holistic approach to eating disorders, working on the reasons why and not just gaining weight.</i></p> <p><i>I have been frustrated by the 'only one way of working' in services, my daughter needed a flexible/individualised approach that only happened once she became an inpatient.</i></p> |
| BETTER ADULT SERVICES | <p><i>As my daughter was over the age of 18 and considered an adult, it made it very difficult to get her to access the care we felt she needed.</i></p> <p><i>It is recognised that teenage and young adults need specialist services in cancer, it seems ridiculous that this is not recognised in mental health.</i></p> |
| BETTER TRANSITION BETWEEN CAMHS AND AMHS | <p><i>A continuum between child and adult services is needed.</i></p> <p><i>There needs to be a far more integrated and seamless approach for sufferers transitioning from adolescence to adulthood.</i></p> |
| INCLUSION IN TREATMENT (ESPECIALLY WHEN SUFFERER REACHES EIGHTEEN) | <p><i>Parents need to be included to help support their children at that transitional time of their life when they may be classed as adults but are still very fragile at a very vulnerable stage.</i></p> <p><i>I find that experts are very secretive with carers and whilst I appreciate the need for Confidentiality and Data protection, I feel that parents should be included more when it comes to the experts because I firmly believe that whatever age someone with an eating disorder is, they</i></p> |

are extremely vulnerable and therefore from the offset approval of the patient should be given to the experts to include the parents or relatives in decisions and they should not be excluded or made to feel they are overstepping the mark when asking for more.

**DAY PROGRAMMES AND
BETTER COMMUNITY
SERVICES / BETTER
TRANSITIONS FROM IP
BACK INTO THE
COMMUNITY**

We needed a lot more support in the community when she was discharged from inpatient care as we couldn't manage the transitions ourselves so she relapsed repeatedly. I would like the model to be local day care settings where meals are handled but coming home at night.

The inpatient care was fabulous but my daughter was discharged too early due to NHS funding. The gap between inpatient care and community is far too big.

**SUPPORT FOR
CAREGIVERS
(EMOTIONAL, FINANCIAL,
GROUPS)**

Families need to be offered more support as the impact on families is massive and there is very little support offered for the carers and families of a child suffering with an eating disorder.

There needs to be support for carers through counselling as we won't ask for it until we're at breaking point.

**SUPPORT FOR SIBLINGS
(INFORMATION, SUPPORT
GROUPS, COUNSELLING,
EDUCATION)**

I think it is crucial that siblings should be given their own support, maybe a group for them at the centre.

There is support for parents of children with eating disorders, but nobody thinks of their siblings. I have never received any kind of support and I think I would have benefitted from it.

Figures

Figure 1. Graphical Illustration of Themes and Sub-Themes

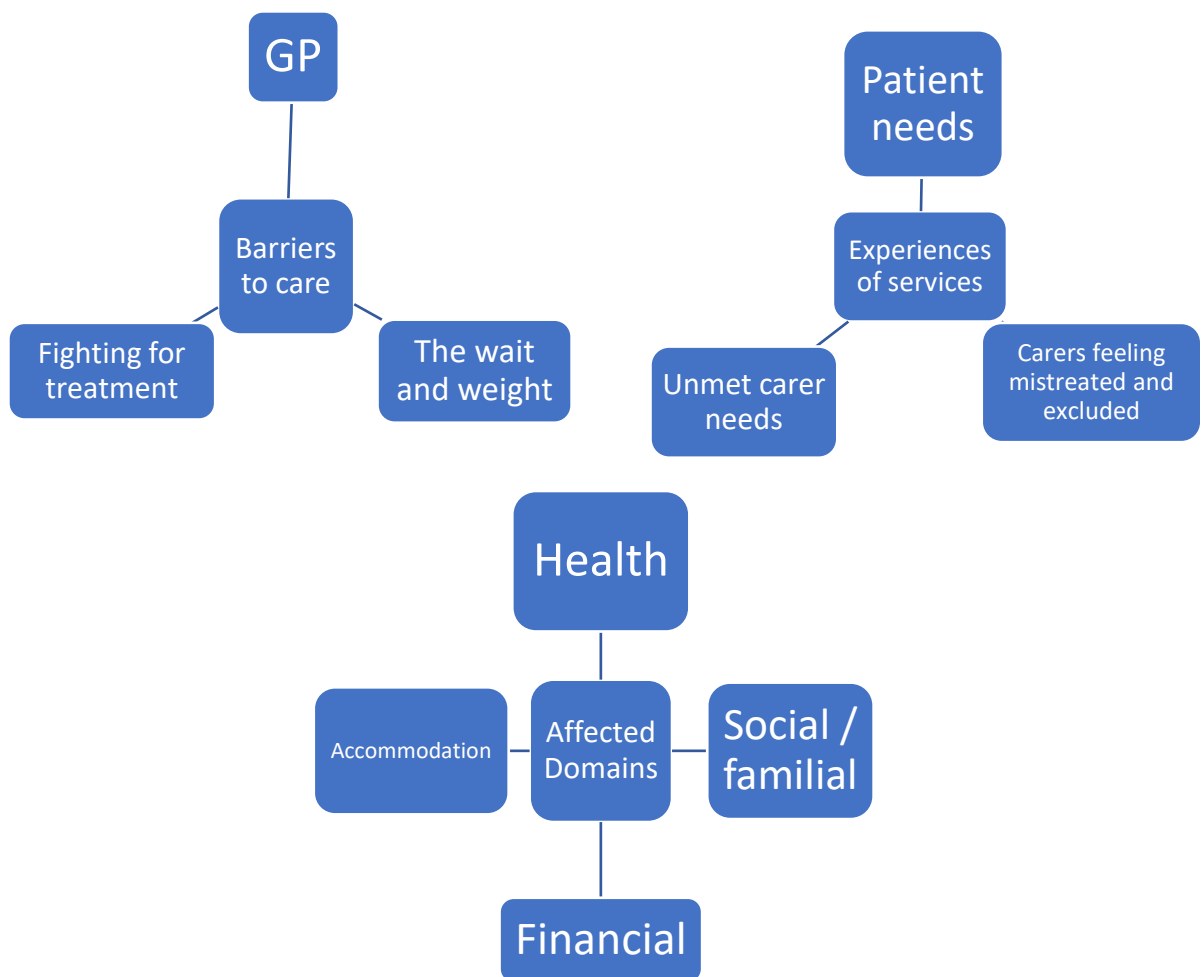
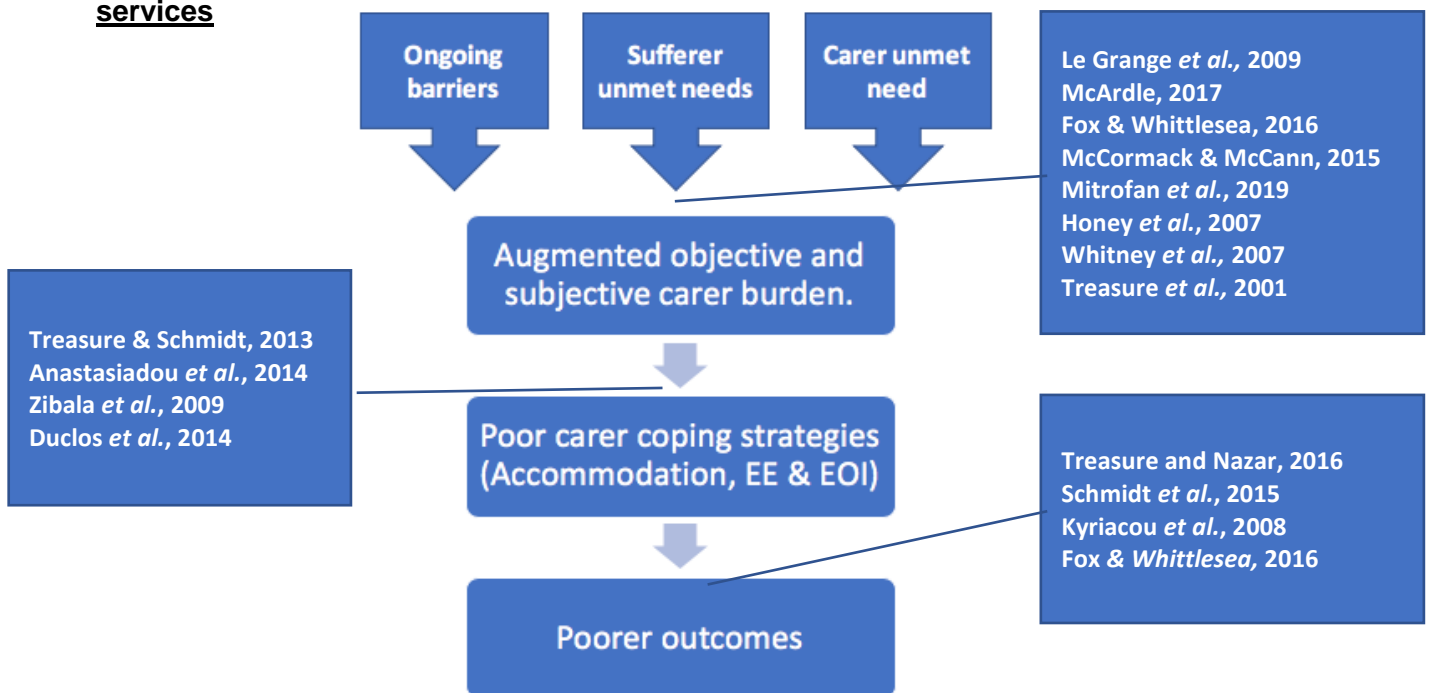


Figure 2: A conceptual model representing impacts of negative experiences of services



Conceptual model based on Treasure and Schmidt's (2013) Interpersonal Model of AN and wider studies indicating how poor experiences of services play a role in the caregiving burden and may subsequently impact patient outcomes.

