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Title- Rescripting – A grounded theory study of the contribution that fathers' make to Family Based Treatment when a young person has anorexia nervosa.

Short Title- Fathers and Family Based Treatment for Anorexia Nervosa

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Acknowledgements- Thank you to all the fathers who participated in this study and to Dr Stoddart and Dr Harris for their ongoing support and encouragement.

Conflict of interests-No conflict of interest is declared.

Funding- There was no funding attached to this study.

This is the peer reviewed version of the following article: McMahon, K., Stoddart, K., & Harris, F. (2022). Rescripting—A grounded theory study of the contribution that fathers make to Family-Based Treatment when a young person has anorexia nervosa. *Journal of Clinical Nursing*, 31, 1598-1611, which has been published in final form at <https://doi.org/10.1111/jocn.16013>. This article may be used for non-commercial purposes in accordance with Wiley Terms and Conditions for Use of Self-Archived Versions. This article may not be enhanced, enriched or otherwise transformed into a derivative work, without express permission from Wiley or by statutory rights under applicable legislation. Copyright notices must not be removed, obscured or modified. The article must be linked to Wiley's version of record on Wiley Online Library and any embedding, framing or otherwise making available the article or pages thereof by third parties from platforms, services and websites other than Wiley Online Library must be prohibited.

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ARTICLE SUBMISSION Journal of Clinical Nursing

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Abstract

Aim: To present a grounded theory of the contribution that fathers make to family based treatment when a young person has anorexia nervosa.

Background: Research indicates a potential to improve outcomes by involving both parents in the treatment of anorexia nervosa. However, fathers are underrepresented both within treatment and research. Family Based Treatment requiring the involvement of both parents presents an opportunity to better understand the role of the father in treatment.

Design: Classic grounded theory.

Methods: Individual interviews conducted with fifteen fathers involved in Family Based Treatment. The COREQ checklist was followed.

Results: Fathers valued being involved in Family Based Treatment and felt they had an important contribution to make. The analysis captures the overall contribution that fathers make and the impact of their involvement. Four categories; Being on the Outside, Finding a Way In, Finding a Way to Be and Finding a Way to Let Go and one core category Repositioning were generated from the data. A substantive theory of Rescripting, generated from categories and the core category, describes the way that participating in Family Based Treatment changes fathers and their role.

Conclusions: Fathers make an important and significant contribution to Family Based Treatment when a young person has anorexia nervosa. The findings inform clinicians about the importance of including fathers in the treatment of young people with anorexia nervosa. They highlight the importance of incorporating support mechanisms into Family Based Treatment to harness and maximise the paternal contribution.

Relevance: Paternal contribution to Family Based Treatment can be maximised to improve outcomes for young people with anorexia nervosa.

Keywords: Fathers, Family Based Treatment, Anorexia Nervosa, Grounded Theory.

What does this paper contribute to the wider global community?

- The study is one of the first to examine the contribution of fathers to family based anorexia nervosa treatment.
- Highlights a barrier to the involvement of fathers in supporting young people with anorexia nervosa is a sense of being on the outside.
- Clinicians who adopt approaches that support fathers in the process of 'rescripting', enable them to collaborate in the treatment and care of their daughters and sons.

1 | Introduction

Globally the rising incidence of eating disorders represents a public health concern (Rodgers et al., 2020). Anorexia Nervosa (AN) is an eating disorder that significantly impairs physical health and psychosocial functioning (Lask and Bryant-Waugh.,2007, Lock and Le Grange.,2012).AN has the potential to become chronic, conferring lifelong detrimental effects and has proven to be challenging to treat (Fairburn and Harrison, 2003, Le Grange et al.,1992, Zipfel.,2015). A longer duration of illness is strongly associated with poorer outcomes and increased risk of death by medical complications or suicide (Cass et al.,2020, Cliffe et al., 2020). Early intervention increases the likelihood of a positive outcome and improves the chances of a full recovery (Ebenreuter, 2015, Espie and Eisler,2015, Olivo et al.,2018, Jones et al.,2012, Treasure and Russell,2011).

AN most commonly develops during adolescence, between 15 and 19 years of age (Gowers et al., 2007, Gowers et al.,2010, Lock and Le Grange., 2012) when parents are potentially well positioned to intervene early in the life cycle of the problem to promote full recovery. Parental involvement in treatment is promoted as the first line treatment intervention for an adolescent with Anorexia Nervosa (AN) (Matrix, 2015, NICE,2017). Research undertaken to date has focused predominantly on treatment efficacy from a clinical perspective rather than on parental experience or contribution. A small number of qualitative studies have addressed parental perceptions with a focus on the maternal rather than the paternal experience (LaMarre et al 2015, Bezance and Holliday, 2014). The study reported here was undertaken to address this knowledge gap by exploring the contribution that fathers make to a family based intervention when a young person has AN. It highlights the facilitators and barriers that influence the paternal contribution and demonstrates that fathers have an important part to play in early intervention and treatment for adolescent AN.

2|Background

Anorexia Nervosa (AN) is increasingly recognised as developing from a complex interplay of genetic, biological, psychological and socio-cultural factors (Hooper and Williams,2011, Lask and Bryant-Waugh, 2007, Nicholls et al., 2010, Price-Evans and Treasure, 2011, Strober and Johnson 2012). It is characterised by pathological thoughts and behaviours regarding food and weight leading to a refusal to maintain a healthy body weight (Lock et al.,2001).

In the adolescent age range family interventions for AN are increasingly accepted and advocated for and Family Based Treatment (FBT) is an approach that requires

the involvement of all family members in the treatment process. In clinical practice FBT can be delivered to different family combinations often involving extended family members. However, fathers are often absent from or only partially involved in treatment for adolescent mental health difficulties in general and AN in particular (Kyriacou et al., 2011, Tully, Hawes and Dadds, 2021).

A family therapy approach that directly addresses eating disorder behaviours is recommended for the treatment of young people diagnosed with AN (NICE, 2017). FBT in manualised form (Lock and Le Grange, 2012) is currently the most extensively researched and best supported intervention for use with the adolescent age range (Couturier et al. 2015; Downs and Blow, 2013; Lock, 2018; Lock and Le Grange 2018). It is an outpatient treatment delivered in three phases over approximately 20 sessions or one year that centrally involves parents in supporting the young person, particularly in relation to eating and refeeding (Lock and Le Grange, 2012). The treatment approach is focused on directly tackling eating disordered behaviour rather than searching for causation (Lock and LeGrange,2012).

FBT as a distinct form of family intervention has been studied since the publication of the first edition of the treatment manual in 2001(Lock et al., 2001). Globally there have been six randomised controlled trials (RCTs) focusing specifically on FBT in adolescent AN (Agras et al., 2014, Le Grange et al., 2016, Lock et al., 2005, Lock et al., 2010, Lock et al., 2015, Madden et al., 2015a). The small number of published studies reflects the challenges inherent in conducting RCTs within the eating disorder field (Strober, 2014).

Implementation studies of FBT across the Americas (Couturier et al., 2010, Loeb et al., 2007, Turkiewicz et al., 2010, Wallis et al., 2007) have taken a quantitative approach to assessing effectiveness and acceptability. Treatment studies addressing the factors that potentially influence outcome within FBT are clinician rather than parent focused. Family engagement with treatment was examined by Lock et al. (2006a). Some attention has been paid to the relationship between components of FBT and treatment outcome (Ellison et al., 2012, Le Grange et al., 2012, Lock et al., 2006b). The influence of early weight gain on response to treatment has been considered (Doyle et al., 2010, Madden et al., 2015b). The influence of the therapist/parent alliance has been examined (Couturier and Isserlin, 2010, Forsberg et al., 2013, Murray et al., 2012a, Zaitsoff et al., 2015). Only two studies have addressed the perceived helpfulness and acceptability of FBT to patients and families (Krautter and Lock 2004 and Singh 2017).

Most treatment studies have looked at the delivery of FBT (Agras et al., 2014, Le Grange et al., 2016, Lock et al., 2005, Lock et al., 2010, Lock et al., 2015, Madden et al., 2015b), the response to treatment in terms of weight gain and the components that are influential. The parental contribution to promoting early weight gain during treatment has been explored (Doyle et al., 2010, Madden et al., 2015b); however, the day to day challenges faced by parents supporting an adolescent, with AN, to eat have received less attention (Conti et al., 2017, Wufong et al., 2019). The paternal contribution has been least considered. This qualitative Grounded Theory (GT) study addressed a significant gap in the literature regarding the role and contribution of fathers to FBT, when an adolescent has AN. In the study, the underrepresented views of fathers regarding the support and treatment of young people with AN were explored, leading to the development of a substantive theory.

3 Aim

The aim of this study was to develop an understanding of the experience of fathers and the contribution that they make to FBT when a young person has AN. The research questions were

- What is it like for fathers encountering services when their child or adolescent is receiving treatment for AN?
- What are the factors that promote or hinder fathers ongoing involvement in FBT for AN?
- What is the experience of FBT like for fathers?

4 Method

4.1 Design

This research employed a classic Grounded Theory (GT) methodology (Glaser, 1978, 1992, 1998, 1999, 2001). Grounded Theory encompasses approaches focused on the generation of substantive theory by examining and understanding basic social processes (Glaser and Strauss, 1967). The three main schools of GT are classic (Glaserian), Straussian and Constructivist. These approaches share many common features including theoretical sampling, concurrent data collection and analysis, theoretical coding and memoing and theoretical sensitivity. However, they diverge in relation to how the researcher is positioned and in the approach to data analysis. Within Classic GT the researcher remains objective, as far as possible, and approaches the data with an open mind, sets aside preconceptions, explores what is happening within the data and allows this to shape theory development by utilising a process of constant comparative analysis. Within

Straussian GT prescriptive coding procedures are applied to data analysis and Constructivist GT is interpretivist, viewing theory as co-created by the researcher and participant rather than generated solely from the data.

Classic GT approach was chosen because little is known about the contribution that fathers make to FBT. As new territory it required to be approached without preconceived opinions in order to develop a theory rooted in and informed by the data. Data collection and analysis were undertaken concurrently, utilising the process of constant comparative analysis, to identify and compare categories leading to the generation of the substantive codes that informed the discovery of a substantive grounded theory. The Consolidated criteria for reporting qualitative research (COREQ) guidelines were followed (Tong, Sainsbury and Craig, 2007) (see File 1).

4.2 Recruitment

Participants were recruited from eight Child and Adolescent Mental Health Services (CAMHS) across Scotland between December 2015 and April 2017. At the outset of the study only two health board areas in Scotland were delivering FBT. One of these areas could not be recruited from, as the researcher had clinical involvement with all cases, and in the other area recruitment proved slow. As more services started to deliver FBT the recruitment protocol was extended to include eight research sites across Scotland. The recruitment process was revised to begin in Phase 2 of FBT rather than Phase 3 to allow clinicians more time to discuss participation prior to discharge from CAMHS. A convenience sampling strategy was utilised to identify clinical areas as potential research sites and to identify potential participants.

Information packs were provided to clinicians/ case managers (delivering FBT to young people with AN) who acted as gatekeepers. This pack contained a covering letter explaining the study, an information sheet, a contact sheet, and a stamped addressed envelope. Fathers and young people were provided with the pack and returned the completed contact sheet directly to the researcher if they wished to participate in the study. Only fathers and young people who returned a completed contact sheet were contacted and there was no previous involvement with them prior to participation in the study. Participation was voluntary, and fathers could choose to withdraw at any time.

Fifteen fathers chose to participate, and this proved to be sufficient to reach theoretical saturation. No new categories were emergent in the data after interview thirteen. Interviews fourteen and fifteen were used to verify the categories and core category and to confirm that saturation had been reached.

Insert-Table 1- Participants Demographics (Pseudonyms have been used)

4.3 Data Collection

Individual interviews were chosen as the mode of data collection to answer the research questions as the aim was to collect detailed accounts of participants' lived experiences, and this was most achievable using one to one interviews. Qualitative interviews are particularly useful when considering social processes and facilitate the gathering of rich and meaningful data (King et al., 2018). Individual interviews are suitable where the topic is emotive or difficult to talk about (Dempsey et al., 2016, Elmir et al., 2011, Sydor 2013). It was anticipated that fathers might be reluctant to discuss their experiences in a group setting and that speaking with them on a one to one basis would be more comfortable for them. Within the study, fathers welcomed being seen

individually and having the opportunity to discuss their experience. Most fathers stated that in this setting they were able to discuss their thoughts and feelings about FBT openly for the first time, and they were surprised by the level of detail they were able to recall once involved in the research interview.

Following review of the literature several key areas were identified as important to explore. These included the constitution of the family, who attended FBT, the referral process in to Child and Adolescent Mental Health Services (CAMHS), meeting up with CAMHS clinicians and FBT therapists, information seeking, attendance at treatment sessions, the different phases of treatment and transitioning between them, the family meal, balancing competing demands, involvement in day to day care, particularly eating, ending treatment and beyond. A flexible interview schedule (Table 2) was developed to act as an aide memoire (Charmaz,2014). Theoretical sampling guided revision of the schedule as the study progressed and areas of emerging interest were followed up in subsequent interviews.

Insert here Table 2 Initial Interview Schedule

Fourteen interviews took place in person within the fathers local CAMHS clinic and one was conducted by telephone. The interviews were all 55- 65 minutes in duration and were audio recorded and transcribed. Most of the audio recordings were transcribed by the researcher (n=10) and five were transcribed by an NHS secretary bound by confidentiality.

Memos and field notes were completed after each individual interview and throughout the analysis. These separate but inter-related documents record the way that data is thought about and analysed over the course of a Grounded Theory study (Montgomery and Bailey, 2007). Early thoughts about concepts were written down as they occurred

during data collection and were returned to repeatedly, as patterns in the data emerged. Transcripts and field notes, produced during the study, formed the foundation from which theoretical memos developed.

4.4 Data Analysis

In line with classic grounded theory the constant comparative analysis method was employed with iterative data collection and analysis, which facilitated the collection of rich data and allowed exploration of similarities and differences between participants. By comparing data with data, the recurrence of concepts and codes from different data segments started to build up a picture regarding shared concerns and preoccupations across participants. Open coding was used to break the data down and to facilitate the discovery of initial categories and properties (Glaser, 1992). This process is illustrated in Table 3.

Insert here Table 3 Open Coding

Open codes were grouped together prior to selective coding commencing (Holton and Walsh, 2016, Urquhart, 2012). Selective coding was undertaken utilising Computer Assisted Qualitative Data Analysis System (CAQDAS) Nvivo11 (Hutchison,2010). Thus, a clearer picture of substantive codes and categories and the connections between them was established. The process of immersion in the data was facilitated by dealing with the data in this way and it supported the development of the analysis.

Theoretical saturation (Glaser and Strauss, 1967, Urquhart, 2012) was reached by the thirteenth interview, with no new codes emerging thereafter and repeated incidents of already identified codes apparent in the new data.

Patterns or recurring incidences identified in the data informed the development of thirteen substantive codes and four categories. Connections between the categories led to the emergence of one core category of Repositioning. This encapsulated the main concern that fathers were struggling with within FBT and led to the development of a substantive theory of Rescripting.

4.5 Ethics

Ethical approval was granted by the University of Stirling and West of Scotland Research Ethics Service. Informed consent was established verbally and in writing prior to individual interviews being undertaken (Creswell, 2009; Denscombe, 2010; Holloway and Galvin, 2017). Participants were made aware that all data collected would be anonymised and securely stored and that findings would be discussed in a doctoral thesis and articles for publication. Participants were provided with the contact details for Support in Mind Scotland and advised to seek support from their case manager if necessary.

Several steps were taken to increase the credibility of this study. When conducting interviews, 'member checking' was employed (Lincoln and Guba, 1985) by paraphrasing and summarising fathers responses to ensure that what participants' were communicating had been understood. As such, any misunderstandings could be corrected at the time and this commentary was recorded and could be utilised to deepen understanding and increase sensitivity.

Rigour was enhanced within the study by sharing anonymised interview transcripts and analysis with research supervisors. In so doing, the coding process was made transparent and inter-rater reliability was established. Feedback informed coding and increased conceptual analysis. Thick description was used to present participants'

narratives and recording my thoughts and feelings in field notes as the study progressed, this promoted reflection and reflexivity. Peer review of emergent themes was undertaken by two specialist FBT clinicians.

5 Findings

In total fifteen fathers from eight different NHS Trusts across Scotland contributed to the study. All fathers had a daughter or son diagnosed with AN and had been involved in FBT within CAMHS services. Thirteen substantive codes emergent from the data informed the development of four categories. These are represented in Table 4

Insert here Table 4 Development of Categories from Substantive Codes

5.1 Being on the outside

Initially fathers felt on the outside of a problem that they did not see coming. An important concern for fathers was that they had 'failed' to recognise the signs of AN as it was emerging.

*"Now I have always been athletic and taking exercise...
She started to look after her diet particularly and going to
the gym more frequently which we thought yeah keeping
healthy fantastic... a positive step, keeping healthy."
(Arran)*

The first signs of the eating disorder coincided with the young person becoming or being an adolescent. Adolescence is recognised by parents as a time of change in relation to physical appearance, emotional development, and psychological growth. It is a developmental stage during which young people begin to individuate from their

parents by seeking independence and increasingly asserting their right to make choices and decisions for themselves. Changes, in the amount of time young people choose to spend with their parents and the way that daily routines are organised and managed, are not unusual, and, as such, are anticipated by parents and seen as part of a normal developmental process. Differentiating normal adolescent development from the onset of AN proved problematic. Changes in diet, activity levels and behaviour were attributed to normal adolescent development.

“We came on to it as a family a little bit late, and I came on to it later still, because Natalie doesn’t live with me. She spent time with me maybe two days a week ... I had seen signs that, in hindsight, we should both have been concerned about, but we passed over for various reasons, assuming it was normal teenage behaviour. Very faddy eating, extreme health consciousness and excessive exercising ... strange behavioural patterns over the summer period.” (Harry)

As the situation escalated, characterised by marked weight loss and associated physical health concerns, many fathers found it difficult to accept the changes they were observing in their son or daughter.

“I mean, never in a million years could you foresee what was coming with Adam. Especially the type of character, the type of boy he was: he was so bubbly, so sociable and to see that change happening was really hard to take in, but you still believe as a parent that you can control it, that

you could turn it round, that it was just a phase ... for so long you are probably kind of in denial. Thinking: there is no way it can be this serious, there is no way that it can be this that is going on in his head. I know my son better than anybody, so you don't accept that for a long time."

(Anthony)

Not recognising the initial signs of AN or denying what was happening to the young person, placed some fathers on the outside of the help seeking process.

"I didn't go to the initial GP appointment, no. Because, I mean, I knew there was something, but you always think, this ain't happening to me. This is not happening to me; she could not possibly do this ... I mean, naively, I thought that the doctor would tell her the downsides of what she was doing and that she would mend her ways and that there would be no problem ... phew was that a mistake."

(Kevin)

At the point of seeking an initial health assessment for the young person, most fathers remained fully immersed in the world of work, while the young person's mother took responsibility for arranging and attending the initial appointment.

"No, it was all very sudden. It just spiralled out of control between a visit to the doctors one day; I got a phone call in the afternoon. Eh my daughter came up here for a check-up (CAMHS Department) and I was phoned at work, my wife was with her- she is not getting out of

hospital she is going straight to Edinburgh. It was sudden as that.” (Michael)

It was only following referral to CAMHS, for assessment and treatment, that most fathers started to fully appreciate the seriousness of the situation they were facing.

In CAMHS, FBT was presented as the only treatment choice and all fathers described deferring to and accepting professional advice that this was the best way to proceed. As they prepared to enter treatment fathers described feeling overwhelmed, confused, and powerless. By making a decision to engage with FBT they were faced with reassessing their commitment to work in order to make space for a treatment process that demanded their presence at both clinic appointments and in the family home providing direct support to the young person.

“So, I just hope that the path we are taking is the right one...Well really just accepting that this is the path that has been chosen to be taken. Really, because well, you have no other knowledge to know anything else would work.” (James)

FBT requires fathers to take on an active role from the outset of treatment and to be involved, fathers had to find a way in; that is to move from a peripheral to the difficulties their young person was experiencing, to a central position in order to manage, support and help.

5.2 Finding a Way In

To ‘find a way in’ fathers had to accept that AN was an illness that required to be dealt with and that the whole family needed to be involved. They were brought face

to face with their own lack of knowledge and had to cope with and try to overcome feelings of being overwhelmed and inadequacy. In relation to lack of knowledge, fathers embarked on a journey to try to make sense of this disorder that had taken hold of their daughter or son.

At the outset of FBT, fathers utilised information seeking as both a psychological and emotional strategy in order to counteract feelings of overwhelm. Trying to acquire knowledge and develop some understanding of AN decreased feelings of powerlessness and gave fathers some sense of control over the situation. However, good quality information was not always provided by FBT clinicians and this left fathers trying to negotiate an information maze on their own.

“I mean perhaps we weren’t looking in the right place; the information for parents is not always necessarily easy to come by. So, you kind of feel a bit in a vacuum.”

(Graham)

The provision of good quality information early in treatment made a significant impact on fathers overall experience of FBT.

“The thing I would say is to give them that information sheet. I would say that is probably one of the most important things because half the families probably don’t even know what is involved...if you don’t have that then you haven’t a clue what’s happening... if you can give it out early... it would make a big difference.”

(Curtis)

A fundamental task parents are charged with within FBT is to halt weight loss and promote weight restoration by supporting the young person to eat an adequate dietary intake (Le Grange and Lock,2015).Fathers said it was made clear to them from the outset that this was a parental responsibility but that they had no idea how to make it happen in practice. Initially fathers had little or no idea how all-consuming the process of refeeding, gradually returning the young person to a healthy eating pattern including regular meals and snacks, would become.

In relation to finding a way to support eating most fathers did not experience the family meal session as particularly useful. The artificiality of the situation, feeling observed and potentially scrutinised or judged by professionals often made it difficult for fathers to fully engage with the process. When therapists were active in providing direct coaching to fathers in relation to eating strategies, learning was more likely to be transferred from the clinic to the home environment.

“...you know sitting holding his hand trying to encourage him to eat this yoghurt it was just horrible. ...I think because of that happening sitting down at the family meal I totally understood why that had to happen... I do remember being very sceptical... thinking how is this going to help and then sitting in it very emotional and felt drained coming out of it but I totally got why it had to happen.” (Anthony)

Less active therapists left fathers questioning the purpose of the session and no link was established between the family meal and challenges being faced in the home environment.

“So there wasn’t much interjection by the therapists, they just took notes, and they never said a lot to us...and we thought we would maybe get a bit more feedback at the next appointment and I honestly can’t remember if we did or not. I mean the family meal as far as I am concerned was just an event that was kind of non-descript.” (Kevin)

Experienced therapists who approached the family meal and FBT overall, in an informed and collaborative way helped fathers to begin to take an active role in treatment and enhanced confidence in themselves and the approach.

“... and that actually worked reasonably well, because she realised that we weren’t playing by that stage, and like, we were telling her, ‘Natalie, you are going to eat that, and we are staying here till you eat.’ ... the meal itself was excruciating, but I think the training we got there was really helpful...” (Harry)

5.3 Finding A Way to Be

As FBT progressed and fathers became increasingly involved in supporting the young person, the role they adopted became all-consuming on both an emotional and practical level. They had to manage their own emotional reaction and reconsider relationships both within and out with the family.

At this stage fathers reassessed their priorities and work moved into a secondary position in their lives. Prior to the onset of AN all fathers identified as being professionally successful and being moved in to a new and different position by FBT,

challenged and altered their worldview. Involvement in FBT changed the way that fathers viewed themselves and their relationships with others, in and beyond the family.

Although fathers often reduced the time they were physically spending at work in order to be at home to support the young person, on an emotional level they highly valued the attitude of their employer to supporting flexible working arrangements or a leave of absence. A sound attachment to the world of work provided a base from which fathers felt able to rebalance and reassess their priorities for a period in the knowledge that they would return to it in the future.

“Yeah, but things fell off the cliff in early August, you know, when we came back again, and that’s when things got really ... then I contacted my employer, and the director, and said I couldn’t come back to work ... I took a whole term off, took a whole term off ... she had become physical and my wife couldn’t ... and this wee thing you know that you would; the loveliest, most gentle girl in the world you know became something else.”

(Martin)

They expressed concern for fathers who were not able to secure time away from work and wondered how they would cope with the demands of the illness and the treatment for it.

In relation to the task of supporting the young person at home, the demands of managing AN had the potential to both unite and undermine the marital relationship.

“...it [AN] definitely drove a bit of a wedge between us”

(Gordon)

Regardless of the impact that managing the disorder had on the marital relationship, all fathers identified that finding ways to work together as a parental unit was crucially important.

“...my experience is that as a disease it exploits any chink in the armour and if you haven’t got a united front it’s no good it’s not going to work.” (Graham).

Separated fathers particularly valued the opportunity to become more involved in the life of the young person for a period of time and appreciated the inclusivity of FBT in this regard.

“...in some ways being kind of separated from the family I think I had been kept at arm’s length for a while and it actually helped me greatly to actually be pushed right in...” (Harry)

However, it was described as difficult for fathers to talk openly in family sessions about their own emotional reaction to the adolescent’s struggle, the challenges they were facing in managing AN and their fears for the future.

“You are kind of watching your words because you don’t want to upset your daughter who is sitting there every time, we went to the sessions ... I was a wee bit iffy whether to say things or not.” (Curtis)

“No, no it is just the usual, finding it sometimes tough to open up, but I think that is probably a male thing. You know, when they said it is family based and we all have to go, I was like oh no it is like my worst nightmare.” (John)

As part of the treatment process fathers were challenged to find ways to deal with and manage their emotional reaction to the situation.

“So, there were times she would just refuse to eat, leave the room and storm away that kind of thing... So okay don’t lose your temper, no point in losing your temper... It was trying to split it into that not to lose your temper...” (James)

As they coped with the challenges that AN presented feelings of blame and stigma impacted on how able fathers felt to access external support. Blame, felt at the outset, persisted across the duration of treatment and was resistant to therapist reassurance.

“You know, if it was cancer, I think the reaction would be different, you know, it is the stigma around mental health that gets in the way. But, you know, I think the reaction would be different for cancer patients.”

(Andrew)

“Looking for someone to blame, aye, somebody to blame, something to blame. At the end of the day it is your fault...” (Michael)

Fathers frequently felt isolated without a natural peer group to confide in and relied on their own personal qualities to keep going rather than on the support of others. Perseverance, meal by meal, and hopefulness over the course of treatment were personal attributes that all fathers identified as important.

“It’s not easy. It’s not easy. And when you are hitting the brick wall ... Just go away sit up the stairs for 10 minutes, have a cup of tea and then come back... You can’t give up...And even the next months and years to come I don’t know what is going to happen. So hopefully she will be fine.” (Michael)

The understanding that fathers developed of AN and their relationship with the young person were important influences on the contribution that they felt able to make across the course of FBT.

Where weight gain was secured early in treatment fathers grew in confidence and felt increasingly engaged within treatment. The converse was also true, lack of weight gain or weight loss led to loss of self-belief, feelings of inadequacy and distance in the therapeutic relationship. In these circumstances fathers felt they had to rely on themselves and felt less in receipt of support.

“...that was really in relation to all the family based therapy. It seemed to be pushing all the onus on correction and enforcement on to my wife and I, and nothing coming from the clinicians, no support for us in our battle, and it was a battle with the illness.” (Gordon)

Throughout FBT all fathers sought to hold on to and build on their pre-existing relationship with the ‘well’ young person, at the same time as developing a new and different relationship with the ‘ill’ young person, in order to try to release them from the grip of AN.

5.4 Finding a Way to Let Go

During individual interviews fathers focused much less on the final stage of FBT (Phase 3). Although FBT had drawn to a close, fathers remained unconvinced that their encounter with AN was over.

“It will always be there. I cannot see a time in my life when I am not going to be thinking ... I do have a fear about it. I don’t think it will be as large a fear as when we first found out, if it comes back. Which I don’t know, but it may, and, we will, do our, go through it all again if we have to.” (John)

Despite these fears, fathers overall were optimistic about the future and felt that at the end of treatment their young people were in a stronger position.

“She has goals and objectives and I can’t see Clare failing on any of them. But to do that she has got to keep eating and that’s what I am happy about. I will be on the side-lines, watching, cheering her on hopefully.”
(Michael).

5.5 Rescripting

The core category of repositioning emerged in relation to the challenge fathers face in holding on to who their young person is at the same time as coping with the effects of AN upon them. During treatment fathers “find a way to be” by holding their young person in mind at the same time as taking action to deal with the effects of AN upon them. To achieve this, the father must first move into a close enough position in relation to AN to appreciate that they have a contribution to make.

It is important to note that the presence of AN alone did not change or challenge the established work position of fathers. Lack of recognition of AN and denial, contributed to fathers largely remaining on the outside. Initially for fathers, life carried on as normal and they remained centrally involved in and positioned within their established work identity. It is significant that only once involved in FBT did fathers become repositioned in relation to work and family. Having been repositioned by therapy, the increased knowledge and close involvement in supporting the young person and challenging AN facilitated fathers in rescripting their role within the family.

Joining treatment moved fathers beyond denial and lack of understanding. Treatment changed the way that they related to and connected with family members practically, emotionally, and psychologically. These changes occurred as fathers tried to find a way to be part of the treatment process. Demands placed upon them, within FBT, led them to develop a new and different role. Their main concern, during FBT, was to find a way to adapt to and manage the responsibilities of the new role in which they found themselves. Having been Repositioned by choosing to participate in FBT, fathers then actively Rescripted their role within the family, in order to make a valuable contribution to supporting the young person. The process of Rescripting is represented in Diagram 1.

Insert here Diagram 1

6 Discussion

The limited scholarship highlighting fathers experiences of supporting a young person with AN and their perceived lack of engagement with clinic based treatment approaches informed the development of key research questions. The findings of this

study demonstrate that fathers are willing to and can meaningfully contribute to a family focused intervention for adolescent AN. It is the process of engaging with treatment that facilitates fathers overcoming denial and lack of knowledge/understanding and to get alongside the young person within treatment sessions and in the home environment. The development of AN disrupts family life and challenges paternal views of competence and ability to help and support the young person. However, AN is responsive to early intervention and galvanising the timely contribution of fathers has the potential to improve outcomes for young people.

All fathers shared that engaging with services moved them from a position of being on the outside, not knowing or understanding what was happening to accessing information, skills and knowledge, that led them to feel more prepared to face and deal with the challenges presented by AN. Faced with AN, in a daughter or son, the process of Rescripting represents an attempt by fathers to make sense of and manage the experience. Initially, AN pushes fathers out; leaving them on the outside, confused and bewildered, and then FBT pulls them in. By requiring fathers to play an active part in the provision of practical, emotional, and psychological support, FBT disrupts and recreates the paternal role. To meet the demands of this new and different role, fathers rescript their involvement in family life, they develop a new biographical narrative that is entirely driven and shaped by the demands of coping with AN in the family. Proximity to the adolescent's struggle, places fathers in a position to see beyond the physical and behavioural manifestations of the illness, to the emotional and psychological impact it is having on their son or daughter. Being informed about the disorder and its effects significantly influences paternal commitment to and confidence in the role of supporting recovery from adolescent AN.

The actual components or mechanisms that bring about change within FBT remain uncertain and unclear (Darcy et al., 2013, Dimitropoulos et al., 2016). While an association has been made between the sustained involvement of fathers in FBT and improved outcomes for young people, fathers have been found to disengage early in the treatment process (Hughes et al., 2017). In this present study all fathers remained involved across a full course of FBT, providing previously undocumented insights. Three key aspects of treatment that promote fathers involvement were discovered to be inclusion in treatment, provision of good quality information and feeling supported.

Being invited to participate in a Family Based Treatment approach was the primary catalyst that moved fathers from a peripheral position characterised by denial to taking action and becoming directly involved in supporting the young person.

Regardless of the efficacy of treatment thereafter the relationship of the father to the young person and their proactive involvement in dealing with anorexia was shaped by being included in treatment from the outset.

A combination of good quality information, sufficient advice, guidance, and feedback has been demonstrated to influence parental efficacy when supporting young people with eating disorders (Coomber and King, 2012). FBT sessions alone do not meet the informational and support needs of fathers. Many fathers felt that they had to access information on their own, find their own direction and navigate a way forward with insufficient guidance from involved professionals.

As treatment progresses within family based treatment sessions, there are insufficient opportunities for fathers to talk openly about the situation, the challenges they are facing and the stress they are experiencing. This can present a barrier to ongoing involvement in treatment, given that males have been found to be reluctant to seek

psychological support for personal problems (Berger et al., 2013, Corrigan, 2004, Corrigan et al., 2009, Corrigan and Rao, 2012, Levant et al., 2013 and Corrigan et al., 2014) and as such may avoid seeking support for the role they are undertaking. A need to be strong, independent and to avoid exploration of emotions has been shown to impact on how willing men are to engage with psychological support and therapy for themselves (Galdas et al., 2005). Feeling overwhelmed and confused about how to deal with the eating disorder, leads to feelings of inadequacy that precludes fathers from openly sharing their thoughts, feelings, and fears in front of the young person. Within a treatment designed to be collaborative, they feel alone and unsupported. Fathers said that individual meetings where they could talk openly with the clinician, about the challenges they are facing would improve the treatment experience and enhance the support they are able to provide. In conjoint treatment (all family members present), individual space for young people is considered, but this is not recommended for parents or fathers. It is significant that fathers discussed these issues openly for the first within individual research interviews. This indicates that where individual space is integrated into the therapeutic approach it will be utilised by fathers. If fathers are in a position where they might withhold emotional communication, therapists could form an inaccurate picture of how they are managing and coping, rendering treatment less effective.

This GT study demonstrates that AN is experienced as a disruptive event, altering a father's previously held view of himself as a competent and successful individual (informed by previous personal and professional achievement) and introducing a new narrative of failure and blame. For this narrative to be transformed again into coping and taking action, inclusion, knowledge and support in the treatment process are essential. Biographical disruption (Bury, 1982) considers how identity is

disrupted and reshaped by significant health challenges and has been applied to men living with prostate cancer (Cayless et al., 2010), managing chronic illness as 'work' at home (Corbin and Strauss, 1985) and mothers living with HIV (Wilson, 2007). Some limited attention has been paid to the impact of young people experiencing long-term physical health issues or mental health problems and the way that this impacts on the family biography (Bray et al., 2014, Harden, 2005). This is the first study of its kind to specifically focus on the paternal experience of and contribution to treatment when a young person has AN.

Fathers interviewed for this study felt strongly that FBT by virtue of its nature and design required their involvement and they welcomed being included. This involvement in AN and the treatment for it, were experienced as life changing and having participated, they identified factors that hinder involvement and those that maximise and harness their contribution. These factors require to be considered by clinicians to ensure that paternal involvement is central to early intervention for adolescent AN and provide a platform for future research.

7 Strengths and Limitations

A strength of this study is that it contributes to the limited knowledge base regarding the paternal experience of involvement with CAMHS services. Within CAMHS fathers are often considered to be the most challenging parent to involve in treatment, and, as such, they continue to be underrepresented both within clinical services and in research studies (Phares et al., 2010). The findings have applicability to all clinicians working within CAMHS who have a role in engaging fathers into the assessment and treatment process.

A key strength is that this study addresses a gap in the current knowledge base regarding paternal involvement in FBT for adolescent AN. Globally, there are no other studies focused specifically on fathers experience of and contribution to FBT. Significant challenges were overcome to successfully recruit 15 fathers with direct experience of participating in FBT. By using a classic Grounded Theory approach, the substantive theory, constructed from substantive codes and categories, is fully emergent from and grounded in the data collected. In this way fathers have centrally informed and shaped the development of theoretical knowledge of an experience that only they truly know and understand.

A limitation of this study is that only fathers who engaged with FBT were involved. Future research should focus on including the perspectives of fathers who do not engage with or who disengage from FBT. Another limitation is that due to difficulty in recruiting fathers, there was not time to focus on recruiting a small group of young people into the research. Their inclusion could have brought another perspective to the study. However, data collected from fathers engaged in treatment does provide a rich account of the paternal experience and makes a useful contribution to the literature and informs clinical practice. The small sample size recruited from one country makes it difficult to ascertain how generalisable the study findings are and future research should focus on developing understanding of the contribution that fathers make.

8 Conclusion

Early intervention and involving all family members in treatment is associated with improved outcomes for young people with AN. Fathers included in this study welcomed being invited to participate in FBT and prioritised involvement over other

aspects of their lives. Future research should also include fathers who choose not to participate in FBT or who disengage from it. The way that clinicians are supported to engage with and involve fathers is central to capitalising on and galvanising the paternal contribution. Policy developers and strategy makers should consider developing and integrating strategies to engage fathers and should take cognisance of the emotional impact of participation, on the health and wellbeing of fathers.

9 Relevance/ Recommendations for Clinical Practice

This study demonstrates that fathers can make a significant contribution to FBT and that this contribution can be maximised by support from informed and collaborative clinicians.

- Fathers need to be provided with good quality information as early as possible.
- To maximise their contribution fathers need support and should be offered opportunities to meet with therapists individually.
- Treatment must be flexible and responsive to the needs of fathers, families and young people.
- To support fathers to move from a position of being on the outside to being actively involved treatment must be collaborative and supportive.
- Paternal involvement is a priority for all young people with eating disorders and should be considered for all clinical presentations within CAMHS.

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Tables

| Pseudonyms | Marital Status | YP with AN | Other Children | Age of YP at start of FBT |
|-------------------|-----------------------|-------------------|-----------------------|----------------------------------|
| Michael | Married | Daughter | Sibling | 14 |
| James | Married | Daughter | Sibling | 16 |
| Anthony | Married | Son | Sibling | 12 |
| Graham | Married | Daughter | Sibling | 14 |
| Curtis | Married | Daughter | Sibling | 14 |
| Kevin | Married | Daughter | Sibling | 14 |
| Mark | Divorced | Daughter | Sibling | 11 |
| Andrew | Married | Daughter | Siblings | 15 |
| David | Married | Daughter | No sibling | 13 |

| | | | | |
|--------|----------|----------|------------|----|
| Martin | Married | Daughter | Sibling | 15 |
| Arran | Married | Daughter | No sibling | 17 |
| Harry | Divorced | Daughter | Sibling | 16 |
| Gordon | Married | Daughter | Siblings | 17 |
| John | Married | Son | Sibling | 12 |
| Robert | Married | Daughter | Sibling | 17 |

Table 1- Participants Demographics Page 9

Table 2 Interview Guide Page 10

1. Can you tell me a bit about the make-up of your family?
2. What age were your daughter/son when they developed an eating disorder?
3. How were they referred to CAMHS?
4. As a father were you involved in seeking this referral?
5. When you were seeking information about ED's where did you look?
6. Did you go to the first CAMHS appointment?
7. When did you first hear about FBT?
8. When you were going through FBT what was a typical day like? Can you talk me through it?
9. As a dad how did you find the beginning stage of treatment? And the Family Meal?
10. From your point of view as a father what was it like moving on to Phase 2 &3 of treatment?
11. As a dad were there things that felt particularly helpful or unhelpful about FBT?
12. When your young person was referred for help did you expect to be asked to take an active part in treatment?
13. What was ending FBT like?
14. What contribution do you think you made to FBT?
15. Were there challenges in taking part?
16. Anything else you would like me to know?

Table 3 Open Coding Page 11

| Interview Transcript | Coding |
|---|---|
| <p>Did you find anywhere where you could do that as parents? Erm, yes but at times it was difficult to access that, it wasn't always easy to get that information and to find that space to talk to staff about concerns we had, or how best to approach things. I think we both found that quite hard, the lack of, I mean it's not a complete lack of support it's just whether the support is always there in the way that you need it. Because the sessions are very much focussed on our daughter and it there was a time for her to discuss things independently of us but not the other way around. I think that would have been helpful at times.</p> <p>What places did you find to do that? Erm, relatively, I think we did have some discussions on the telephone, more than anything else, because it wasn't easy to always find time to actually have face to face sessions but I think that was about all we had.</p> <p>So, you had telephone support with the clinician?</p> <p>Yes, that was more or less and that was quite limited. And we weren't quite sure how best to kind of approach that may have been that we could have been a bit more proactive on that, but it wasn't obvious how it fitted within the overall kind of treatment.</p> | <p>Separate time for young person but not for parents.</p> <p>Having to create space for yourself and not knowing best how to do this or if this is okay.</p> <p>Support available but not always the kind of support you need at the time.</p> <p>Speaking with clinicians by telephone.</p> <p>Lack of separate face to face clinical time.</p> <p>Uncertainty about boundaries in clinician/ family/ parent relationships.</p> <p>Unclear if separate parental support fitted with overall treatment approach.</p> <p>Unsure if it was acceptable to seek/ ask for this.</p> |

Table 4 Development of Categories from Substantive Codes Page 13

| Substantive Codes | Categories |
|---|-------------------------|
| Not knowing Denying Feeling overwhelmed | Being on the outside |
| Information seeking Starting to find a way in Being offered a direction | Finding a way in |
| Connections Feelings Personal Attributes & Qualities Lenses Balancing | Finding a way to be |
| Hoping for the best Preparing for the worst | Finding a way to let go |

Figures

Diagram 1 Page 25

