

Family experiences of living with an eating disorder: A narrative analysis

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Abstract

Families are considered important in the management and treatment of eating disorders. Yet, rarely has research focused on family experiences of living with an eating disorder. Addressing this gap, this study explores the experiences of an elite 21 year-old triathlete with an eating disorder in conjunction with the experiences of her parents. Family members attended interviews individually on 3 separate occasions over the course of a year. In line with the narrative approach adopted, whereby stories are considered the primary means to construct experience, interviews encouraged storytelling through an open-ended, participant-led structure. Narrative analysis involved repeated readings of the transcripts, sensitizing towards issues of narrative content (key themes) and structure (overarching plot). Family difficulties arose when personal experiences strayed from culturally dominant narrative forms and when family members held contrasting narrative preferences. Suggestions are forwarded as to how an appreciation of eating disorder illness narratives might inform treatment and support.

Keywords

Eating disorders, parents, illness, narrative psychology, athlete, sport.

Pressures to be thin permeate sporting environments and can encourage an unhealthy preoccupation with weight in athletes. Athletes have reported that weight based pressures can emanate from coaches, teammates, specific sport demands and revealing attire (Reel, SooHoo, Petrie, Greenleaf, and Carter, 2010). As a result of these pressures, participation in competitive sport is considered a risk factor for the development of disordered eating and clinical eating disorders such as anorexia nervosa and bulimia nervosa (Thompson and Sherman, 2010). Although male athletes do experience eating disorders (see Petrie, Galli, Greenleaf, Reel and Carter, in press), the consensus is that female, elite level athletes competing in sports with a lean or aesthetic focus are at greatest risk. There is now wide acceptance that eating disorders in sport are a problem of great concern to the broader eating disorders field.

To date, studies on athletes with eating disorders have predominately focused on factors specific to the immediate sporting environment. Consequently, inward-looking perspectives that prioritise personal pathologies of the mind dominate the literature (Papathomas & Lavalley, 2012). An athlete's life outside sport, such as interpersonal relationships within the immediate family, is rarely considered. Parental voices are completely absent from the literature, which is something of an anomaly given that parents are often greatly involved in a child's sporting experiences (Wylleman and Lavalley, 2004). When athletes have reflected on wider family issues, the findings suggest that parents play a large role in an athlete's experience of an eating disorder. For example, athletes in qualitative investigations have described both positive (Papathomas and Lavalley, 2010) and negative (Papathomas and Lavalley, in press) parental influences on their eating disorder experience.

Within the general psychology eating disorders literature, the wider family context is more overtly emphasised. Through a collection of qualitative studies, parents

have associated the eating disorder experience with relationship deterioration with their child (Gilbert, Shaw, and Notar, 2000), an impaired relationship with their partner (Espina, de Alda, and Ortego, 2003), great emotional distress (Highet, Thompson and King, 2005), and an inability to cope successfully (Hillegge, Beal, and McMaster, 2006). Parents have also described feelings of frustration, disempowerment and uncertainty regarding recovery progress (Tierney, 2005). These qualitative perspectives provide a welcome counter-narrative to the dominant medicalised approach to eating disorders family research, which has tended to obsess over cause-effect relationships (Botha, 2010) and has been accused of naive parental blaming (Vandereycken, 2005). Specifically, it is argued that parents' perspectives can illuminate the broader impact of an eating disorder and provide insights into the illness experience within the family environment (Hillegge et al., 2006).

On the other hand, addressing parents in isolation gives few insights into the eating disorder experience across the whole family unit. Further, the majority of these studies offer descriptive accounts of the illness experience through the thematic analyses of interview data. Although content-driven approaches can tell us much regarding the conceptual issues that characterise life dealing with an eating disorder, they offer scant regard for the social construction of the eating disorder illness experience. Specifically, how personal interpretations of illness are shaped through social and cultural narrative auspices is rarely addressed. This is a significant oversight given the prominent role narrative studies of illness have within health psychology.

Narrative and Illness

As an approach to understanding illness, the role of narrative has consistently grown in popularity since the 1980s when a number of influential works identified its importance in the illness experience (e.g., Bury, 1982; Kleinman 1988). Broadly

speaking, it is asserted that narratives not only reflect the nature of the chronic illness experience but can also be constitutive of it (Kleinman, 1988). For example, chronic illness has been described as a form of biographical disruption (Bury, 1982), as it ruptures life's "perceived normal trajectory" to damaging effect (p. 17). Essentially, when illness breaks our anticipated life-paths our narratives lose coherence and with it meaning and identity is also lost. Crossley (2000) draws from these fundamental ideas when she argues that the "narrative incoherence" associated with serious illness and trauma is devastating because so much of life is implicit, routine and taken for granted. She adds that adapting to such trauma is a process of narrative reconstruction, whereby new stories are sought and created to provide new coherences that give meaning to illness. In tune with this, Hyden (1997) makes the distinction between narrative as illness and illness as narrative. The former is when "an insufficient narrative generates illness" (p. 55) such as Crossley's (2000) described devastation at narrative incoherence. In turn, the latter is when a narrative can "integrate the symptoms and the consequences of illness into a new whole...a new world of illness" (p. 54) such as Crossley's (2000) identified process of adaptation through narrative reconstruction. Returning to Kleinman (1988), both categories illustrate how the experience of illness can be shaped through narrative or a lack of it.

A further contribution to the role of narrative in shaping chronic illness experiences is provided by the seminal work of Arthur Frank in his 1995 book "The Wounded Storyteller". Frank identifies 3 broad narrative types that underpin personal stories of illness, namely restitution, chaos and quest. The restitution narrative is the most dominant form and asserts the basic plotline "yesterday I was healthy, today I'm sick, tomorrow I'll be healthy again" (p. 77). The chaos narrative is considered the opposite of restitution as it "imagines life never getting better" (p. 97). The chaos

narrative is rooted in an absence of narrative coherence as a means to explain illness. The quest narrative sees illness as the “occasion of a journey that becomes a quest” with the ill person holding a belief that something is to be gained from the experience (p. 115). The type of narrative told is also consequential for the listener, as well as the teller, of an illness story. Specifically, Frank suggests individuals, particularly in Western cultures, prefer restitution stories and their promise of health restoration in contrast to chaos stories that make for uneasy listening. These narratives shape experience as a person living to a restitution plot would likely pursue, be hopeful of and even expect recovery. Likewise, a person deep in chaos is expected to encounter a psychologically troubled future. Finally, Frank asserts that although one narrative is usually foregrounded at any given time all three narrative types are told in an illness story, alternately and repeatedly.

The work of Frank (1995) has become ubiquitous in the study of chronic illness and has been used to interpret experiences of cancer (Simpson, Heath & Wall, 2014), stroke (France, Hunt, Dow, & Wyke, 2013), spinal cord injury (Smith & Sparkes, 2005) and HIV (Ezzy, 2000), amongst numerous other bodily conditions. This narrative approach has also been successfully applied to the study of mental illness (see Carless, 2008; Gold, 2007), although not the study of eating disorders. As well as patients’ stories of physical and mental illness there has been an emerging recognition that Frank’s narrative types may be equally important in shaping the experiences of an ill person’s family. For example, parents of children with cancer have told stories characterised by restitution, chaos and quest (Bally et al. in press). Further, individuals caring for family members with severe psychosis drew from restitution narratives as a way out of chaos (Stern, Doolan, Staples, Szmukler & Eisler, 1999). These narrative studies of illness traditionally offer only singular perspective accounts which underplay

the notion of narratives as interactional accomplishments (Reissman, 2008). Given that there is “a dialectical interplay between the storyteller and his or her world” (Murray, 2000, p. 343), there is much to be gained from an exploration of how illness might be co-constructed across multiple members of the same family unit.

In sum, the impact of the athlete eating disorder experience outside of the immediate sporting context is rarely considered and the families of athletes with eating disorders are a noted absence from the existing literature. Although family members feature in the wider eating disorder literature, they do so in isolation. Addressing these gaps in the literature, this study adopts a unique research design that explores, for the first time, the perceptions of life with an eating disorder for a single family unit; a mother, father, and their daughter *in parallel*. If families construct shared as well as individual meanings of experience (see Daly, 1992), studying more than one member of the same family is critical to interpreting this joint meaning-making process. Continuing the innovative approach, interviews occurred on several occasions during the course of a year. This longitudinal element to data collection facilitates interpretations of how the family eating disorder experience is constructed over time. The overarching aim of this study is to theorise the role of narrative in shaping a family’s experience of life with an eating disorder. The following research questions were posed: What dominant illness narratives do family members draw from to make sense of an eating disorder? To what extent are narratives co-constructed within the family unit? What is the impact of an adopted narrative type of on each participant’s day-to day illness experience? How do narrative constructions of an eating disorder evolve over time?

Methodology

Participant recruitment

With University ethical approval granted, and in line with narrative “case-centred research” (Riessman, 2008, p. 11), a family was recruited through purposive sampling. Purposive sampling involves selecting participants according to their relevant experiences of a phenomenon of interest. All participants signed informed consent forms prior to the study commencing.

Kelly. Kelly, who was 21-years-old at the time of the study, is an undergraduate still competing in elite triathlon, a sport she first engaged in at the age of 16. Kelly lived with her parents before moving away from the family home to study for her degree. Eating disorders onset occurred at University, within a highly competitive sporting culture. She described her current eating disorder as having evolved from an original diagnosis of bulimia nervosa towards current behaviours that also incorporate symptoms associated with anorexia nervosa such as severely restricted eating. Although Kelly has engaged in various one-off sessions with psychologists, she has not embarked on a sustained programme of therapy and did not receive any treatment during the time period of this project. Kelly stated that she continued to binge and purge regularly.

Mum. Mum is in her fifties and works for a large company in a job she has held for several years. She remembers Kelly as an energetic, popular and talented child with a variety of interests. Mum described the huge commitment required to support Kelly’s sporting pursuits but that she did not regret this given Kelly’s obvious talent and the joy she and her husband received from watching Kelly achieve.

Dad. Dad is also in his fifties and is self-employed, owning a very profitable company. He reflected on Kelly as an outgoing, friendly, and cheerful child, with a passion for sports. He suggested that his role in a range of extra-curricular activities was that of a taxi driver and a supporter. Dad is a qualified sports coach, although he has

never formally coached Kelly. A former sportsman himself, he regularly discussed the feelings of pride and joy he feels when Kelly succeeds in sport.

Interviews

I (first author) interviewed each family member on 3 separate occasions over the course of a year. As a researcher with an eating disorders focus, I was initially perceived by the participants to be an “expert”. As is the norm in much narrative research, it was duly emphasised in each interview that the participants *themselves* were the experts of *their* own experiences. It was also important to emphasise that I was not a therapist. These strategies helped dispel perceptions that I might somehow be able to provide a form of family-therapy or even offer treatment for Kelly’s eating disorder. Clarifying such issues, minimising possible power discrepancies and striving to build trust and rapport constitute part of a raft of procedural ethical considerations that it was important to be diligent of throughout the data collection process.

Interviews ranged between 80 and 140 minutes in duration and yielded a total of 15 hours of data. An effort was made to interview family members within a few days of each other. This strategy ensured a degree of commonality of experience, enabling some comparison between participants’ perspectives on pertinent issues of the time. Although I always interviewed family members individually, I informed them that discussed issues might be made known to the other family members over the course of the study.

Narrative interviewing should generate detailed, extended accounts on an issue and seek to relinquish researcher control towards “following participants down their trails” (Riessman, 2008: 24). Interviews were therefore largely unstructured with family members encouraged to discuss issues *they* thought relevant. The first series of interviews began with the suitably broad question: *Can you tell me something about your recent experiences of dealing with an eating disorder?* Subsequent interviews

opened with the more informal: *How have things been recently?* This non-specific approach did not assume that experiences had been dominated by the eating disorder and its symptomatology. It encouraged participants to speak naturally about day-to-day issues and concerns. From these start points, I explored particular areas of interest through the use of open-ended probes (e.g., Can you tell me more about that? What does that mean to you?). I transcribed all interviews verbatim and forwarded transcripts to the relevant interviewee for comment. No issues were raised.

Narrative analysis

Generated data was subjected to what Riessman (2008) terms a structural analysis of narrative. In terms of how this analysis was done, first the transcripts were read through several times in order to become immersed in the stories and gain an impression of how the stories were structured. Next, conceptual comments were made on the transcripts in terms of what narrative plots framed personal accounts. The development of the plot was then identified by noting how events were connected, how the story told connected the past, present, and future, and asking questions such as: *What narrative resources shape how the story is being told?* Frank's (1995) narrative typology acted as a general guide in this process. Finally, the type(s) of narrative drawn on and used was named. Analytical attention was also paid to specific content within the narratives told. Orienting to thematic elements of the data illuminated the idiosyncratic circumstances within the generic narrative type. This ensured the particularity of experience was preserved amidst the generality of a guiding narrative type.

With participants fully aware of the family focus to the study, it was expected that each family member would lead the interview dialogue towards family issues and events that were dominating family life at that time (e.g. by offering a story about a recent argument or a relapse in Kelly's eating behaviours). Given the purpose of the

study, this awareness provided a useful but non-prescribed structure across interviews at each of the three interview time points. Further, when such an issue of shared concern became apparent during interviews, it was possible to probe for similarities and discrepancies in perspective across family members. The presence of three different accounts on a central family issue allowed analytical inferences to be made as to how each participant's narrative might be impacting the narratives of others. In turn, the identification of shared family concerns served as a useful loose guide to the selection of quotes used. Quotes were also selected based on perceived richness, conceptual relevance (eating disorders and/or narrative), narrator emphasis, and the role in the broader story told (Sparkes & Smith, 2014).

Results and Interpretations

Throughout this section interpretive insights are offered as to how an eating disorder experience is narratively constructed from the multiple, interacting vantage points within a family. Interpretations, grounded chiefly in narrative theory and the eating disorders literature, seek to construct an account of what living with an eating disorder is like for Kelly and her parents. Participant stories are discussed in temporal order to give a sense of living through pertinent issues as the family encountered them.

First set of interviews

I (first author) interviewed Kelly first of all in my University office, with Mum and then Dad interviewed the next day, separately, at their family home.

Family wreckage - 'it's a bombshell'. We coin the term "family wreckage" to reflect the collective breakdown to family life that occurred when family member's initially tried to make sense of the eating disorder. It depicts the shocks of illness that overwhelms experience and family relationships. Dad described the impact of first discovering that his daughter was suffering with an eating disorder over 3 years earlier:

“it’s a bombshell...our lives have changed completely. Our family has changed completely”. Narrating from the perspective of her husband, Mum expressed a similar sentiment:

from his (Dad) point of view to a certain degree everything in the garden was rosy. She was at university where she wanted to be. She enjoyed it. She was with her friends. She was doing triathlon. She was going to be moving into a house of her own. She had no money worries. She had a car that was all fully paid for...it was a case of never come across anybody like that, who did anything like that, and the fact that everything was being provided for...

Firstly, Dad’s “*bombshell*” metaphor corresponds with descriptions of narrative disruption (Bury, 1982) and wreckage (Frank, 1995) and the associated feelings of identity loss, fear and uncertainty that characterise patients’ experiences of chronic or serious illness. Unlike these previous works however, Dad speaks from the standpoint of a carer as opposed to a direct sufferer. He asserts that it is his life and the lives of each member of his family that have “*changed completely*” as a consequence of Kelly’s illness. Mum elucidates one of the processes by which narrative wreckage occurs for her husband. Specifically, interpreting that “*everything in the garden was rosy*” in terms of education, friendships, sport and financial support, the next logical step in the story is for Kelly to achieve success and happiness in these domains, for example graduation or major sporting accomplishments. When it becomes evident that these expected eventualities might not materialise, the narrative line is effectively wrecked. Crossley (2000) warns that we often live life subconsciously projecting to the future in this way, routinely assuming certain narrative coherences, which, in the event of illness or trauma, can be shocked into disarray. The narrative coherence assumed by Mum and Dad is that given “*everything is being provided for*” Kelly will go on to lead a happy and unproblematic existence. In effect, the emergence of an eating disorder interrupts

the anticipated life path held for Kelly and their personal life paths, as parents, are also interrupted. Thus, narrative wreckage may not be the sole preserve of the ill person but can also occur in their significant others. In this particular case, the narrative breakdown associated with Kelly's eating disorder extends to a form of *family wreckage*.

On the other hand, Kelly, although troubled by the impact of her illness on others, gave little hint of narrative wreckage as a result of her eating disorder. It may be that as eating disorders emerge unknowingly on to the 'patient' and often go unacknowledged in the early stages, the sudden shock to a narrative project that is associated with the onset of other illnesses, for example cancer, does not occur. Further, many individuals, even those eager to recover, can conceive that there are benefits to an eating disorder (Shohet, 2010). This is particularly the case with athletes who often perceive low weight as crudely synonymous with improved performance (Papathomas & Lavalley, in press). An illness that brings with it perceived advantages is unlikely to rupture one's biographical trajectory but rather, for better or worse, be integrated into it. That is not to say people with eating disorders do not experience wreckage, but that it might be experienced at a different stage to other illnesses.

Restitution - 'back on to that mainline'. It was apparent that each of the participants, having encountered narrative wreckage directly or indirectly, now lived by a new story. Crossley (2000) states that when the routine order that once characterised life is broken, "we attempt to rebuild it through the use of stories and narrative" (p. 541). As noted, these stories do not come from inside us, but rather circulate in culture as resources to draw on. Kelly and her parents drew on the restitution narrative. The ensuing words from Kelly bear the hallmark of classic restitution:

I actually wrote to the hospital here because they have a specialist clinic and they got back to me and said no they don't do that maybe look at somewhere else. I'm

being shuffled from areas and areas...I don't give up...say I have a binge I don't go "you know what this is it. I'm just going to keep like this". Every day I battle it and that's where I battle myself and my head. The harder part is the recovery but I'm far more willing...I've gone through life pushing myself, challenging myself, nothing's easy. I'm willing to challenge it, to work towards it because I've always been a hard worker in everything I do so why not this? I don't like to be seen as someone who gives up or doesn't try or...I don't like the word quit so I'm not going to quit on that (eating disorder) and I'm not going to quit on myself

The fundamental assumptions of the restitution narrative are that for every illness there is a cure and that "returning the sick person to the status quo ante" (Frank, 1995: 83) is the expected outcome. The restitution narrative, as a resource to understand and construct personal stories, is drawn on by Kelly and artfully spun in relation to her eating disorders as: "yesterday I was a healthy athlete, today I have an eating disorder, tomorrow I'll be a healthy athlete again". Kelly's allegiance to telling a restitution story is hugely consequential for how she interprets and experiences her eating disorder. That is to say, the restitution narrative acts on her, conducting her to do certain things over others. For example, her motivation to seek medical expertise through a specialist clinic is underpinned by the anticipation that there is a cure for her eating disorder. Even when this is unforthcoming, faith in restitution is unwavering and Kelly refuses to "*give up*". This determination to recover depicts a strong sense of concrete hope that is typical in restitution stories (Smith and Sparkes, 2005).

Given its status as the dominant illness story in Western cultures, and that it is a story that will often get under the skin of most parents whose son or daughter is ill, it is unsurprising that Mum and Dad also subscribe to a restitution narrative. During our first meeting Dad constructed the following understanding of his daughter's eating disorder:

She started off her sport at an elite level...she represented Great Britain and she's been at the very top, so that's the mainline that she went down, but there was, not so much a fork, but there was a branch line that went off when she thought obviously that she could improve her lot by losing weight... If she lost weight then she would become even better and that would be, not a branch off of the mainline, but that would be a shortcut across to the very top. But of course, as you start going down that branch line you realise it's a branch line to nowhere and that's where she ended up. Now what we're doing is trying to map a way, any way, to get back on to that mainline.

Dad's journey metaphor is very much couched in restitution, with Kelly depicted as beginning healthily, taking a wrong turn towards illness, to some day, with the appropriate support, be set back along the "*mainline*" of health. This restitution-based understanding prompts both parents to actively support this coveted resolution and "*map a way*" for Kelly to be restored to her former healthy and athletically successful self. This is in line with Honey and Halse (2006) who state that how parents construct an understanding of a daughter's eating disorder affects how they deal with the issue.

The following quote from Kelly is one of many to illustrate that she is appreciative of her parents' efforts: "*I know that I've got enough back up and belief from my parents, which is great, to financially, emotionally, whatever, keep me going and for that I am really grateful*". The manner in which parental support is so well received is indicative of the potential benefits associated with a mutual affinity for a restitution narrative. The family members essentially work together towards the shared goal of Kelly's recovery. In contrast, the notion of a shared goal is complicated by important distinctions in how restitution is conceived across the family. Dad constructs the eating disorder as a sporting obstacle to be overcome, much like an athletic injury whereby practical steps can be mapped towards full fitness. Kelly's language is

considerably less pragmatic and more emotive. For her, pursuing restitution represents an ongoing and emotionally draining battle with no obvious routes to fulfilment.

Essentially, both Kelly and Dad draw on restitution as a preferred narrative, but each stories it differently. As illustrated in the subsequent section, these subtle idiosyncrasies in how a restitution narrative is spun proved troublesome.

Problematizing restitution - ‘don’t make me have to remind you’. What impact does restitution have on experience when the anticipated recovery does not occur? Although Kelly and her parents predominantly found the restitution narrative useful, as these initial interviews progressed it became apparent that, as a story to live by, it was not without complications. Mum voices some of these complications:

I think the hardest part has been not being able to come really and truly across somebody that genuinely, genuinely, knows how to deal with the situation and what to do. The one thing that I would say though is that I don’t think Kelly has given them a 100% of herself...that’s my belief and I’ve said that to Kelly “you know in order for people to help you, you do have to help them. You have to give it a 100%”...it’s a difficult place to be in at the moment because, well mainly because it’s frustrating, you know it’s just frustrating. You can’t just take it away.

Mum experiences immense frustration as Kelly’s restitution proves continually elusive. The efficacy of eating disorder treatments is notoriously inconsistent (Bulik, Berkman, Brownley, Sedway, and Lohr, 2007) and both parents (Tierney, 2005) and sufferers (Halvorsen and Heyerdahl, 2007) have previously articulated dissatisfaction at the treatment process. Given Frank (1995) suggests restitution is first and foremost a story about the expertise of others and the heroism of the medical world, it makes sense that Mum should berate health professionals when what is culturally promised is undelivered. Responsibility is however also allocated to Kelly who Mum believes has not fully dedicated herself to the recovery process. The view that Kelly can be

instrumental in her own recovery partially contradicts Frank's (1995) assertion that the ill person is at best a "passive hero", merely getting through their days as a patient subordinate to the all-conquering "active heroism" of modern medicine (p. 93). The roots of this discrepancy can perhaps be traced to the fact that Frank's (1995) theory was primarily framed around bodily impairment rather than mental illness. It is a popular assumption that unlike the biologically diseased who once attacked by some viral agent is totally at the mercy of the physician's cure; the psychologically ill are to some degree accountable for their illness and therefore should hold some capacity to "snap out of it" (Kendell, 2001). Consequently, returning to Frank (1995), Kelly may well have the opportunity to be more "actively heroic" in her recovery. It is, however, an opportunity that comes with great pressure to *get herself better* and the risk of liability should she fail.

Desperate for his daughter's suffering to end, Dad also encapsulates the expectancy for Kelly to bring about her own restitution:

Kelly seemed to be getting on better and there seemed to be a bit of a relapse and then we've had sort of big chats again and maybe I changed tact, rather than trying to be totally supportive and trying to protect her and cajole her and encourage her maybe I would turn round and say maybe we've gone far enough maybe I'm totally pissed off now maybe I'm throwing money at things and you're playing at what you're doing you're not making serious efforts to actually get better with your illness, as they call it

Angry and frustrated by the absence of restitution, Dad threatens to withdraw the support he has offered to facilitate it. Even more forthrightly than Mum, he places the onus of recovery with Kelly and questions the sincerity of her desire to get well. He takes this further by calling into doubt the legitimacy of Kelly's eating disorder as an illness. The assertion that mental illness is somehow less "real" than physical disorders

due to the absence of a tangible local pathology is a damaging but popular opinion, which leaves the patient feeling dismissed and distrusted (Kendell, 2001). The above accounts of both Mum and Dad show restitution in a different light to the hopeful and positive story it sometimes is. Frank (1995) specifies that problems arise when someone who can only tell restitution stories encounters another whose health will not be restored. The family's desire for restitution crowds out other forms of storytelling, blocking new ways of dealing with the eating disorder. The impact of Dad's comments and the pressure to not be ill impacts Kelly significantly:

dad says "did you keep things down today?" and at the same time it annoys me because I think don't make me have to remind you or lie because I have to lie sometimes because I feel it protects them. Because I don't want them to feel like I'm not getting better or I'm not doing things. That was what a big part of that argument the other weekend was with my dad...he says "you know I think that sometimes you don't want to help yourself and you don't want to get better" as if to say "I think you enjoy what you do and you don't want any respite or to get better" and that really hurt me

Frank (1995) suggests that most people have a preference for hearing restitution stories and find other stories about illness uncomfortable to listen to. Kelly seems aware that her parents fall into this bracket. Consequently, when probed as to the status of her health by her father, she feels obligated to lie in order to protect him from the reality of unfulfilled restitution and the distress this will cause him. Kelly is therefore silenced and, as Sparkes and Smith (2002) argue, such silencing denies the opportunity to articulate the emotionality of experience and blocks new ways of storying a life. The implicit message is that stories that betray restitution are unwelcome ones.

Second set of interviews

Communication issues - ‘I wonder if she’s been alright this week?’ Just over 3 months had lapsed before I recommenced narrative interviews with the family. On resuming interviews, it became apparent that a lack of communication between Kelly and her parents had developed into a major issue. With Mum and Dad eager for positive health updates and Kelly reluctant to disappoint their hopes of restitution, exchanges between them were scarce. Dad seemed to suffer particularly in this regard:

I’m a little bit frustrated at this moment because I’m sending her emails and I’m texting and so on and I’m having to wait for some time and often prompted by Jill before I get a reply from Kelly...I get a little bit frustrated especially when I talk to Jill and Jill says “oh yeah I text her earlier” or “Kelly text me earlier” and I say “how come she’ll communicate with you but she won’t reply to me?”

It is not uncommon for fathers to experience feelings of rejection when a daughter is suffering with an eating disorder (Gilbert, Shaw, and Notar, 2000). From Kelly’s perspective, this is not a personal slight, nor is it, as Dad would later suggest, indicative of a “*closer relationship*” with her Mum, but rather it reflects what Kelly constructs as a greater need to protect Dad from her issues: “*that’s where I try not to tell him so much, because I know I don’t want to mentally disturb him and upset him*”. This effortful management of the feelings of others is defined as “emotion work”, a sometimes psychologically distressing process of caring for and protecting others (Exley and Letherby, 2001). The focus of Kelly’s emotion work towards Dad more than Mum is telling. If Dad holds a greater preference for restitution stories, as Frank (1995) tells us certain people do, then Kelly’s stories of suffering are likely to be harder for him to hear. Given masculine values and male sporting cultures often suppress the telling of sensitive stories (Smith and Sparkes, 2002), this may extend to hearing such stories also. From Kelly’s perspective, by communicating less on issues of health, she saves her Dad, and to a degree herself, from what is the painful truth; she is not yet healthy

and she is not yet back to her athletic best. For Mum, Kelly's emotion work can present negative consequences:

I know it upsets him really because it literally just takes a minute to bang out an email or a text...if he hasn't heard from her he'll say things to me that I think "ooh, he's a bit touchy". A bit touchy because he hasn't heard from her and maybe I will then send her a text just to say "how's things? Did you get your dad's text?"

The above quote illustrates how Dad's annoyance at Kelly's lack of communication places a strain on his relationship with Mum. Although Mum's sensitivity to Dad's frustrations enabled her to address the issue without conflict, such instances present potential for relationship deterioration (e.g., Espina, de Alda, and Ortego, 2003).

In contrast to Kelly's described intentions, the lack of communication with her parents actually served to accentuate rather than alleviate their worry. With very little information available regarding Kelly's eating disorder, both Mum and Dad engage in on-going speculation. Dad describes a process of "*reading between the lines*":

I don't know how Kelly is progressing from a food point of view...we haven't spoken about it...but when she says that she's down or feeling low or had a bad week, to me, reading between the lines, that means that she's reverted back

In the absence of concrete facts, Dad perceives Kelly's low moods as indicative of underlying eating disorder issues. For Mum, even Kelly's positive moods can be interpreted negatively:

When I've spoken to her she's seemed fine. Sometimes I just hope that she's not saying what she thinks I want to hear because I'd much rather hear it from the roots really... I think she does sometimes so that she doesn't think that we're worrying

Both parents partake in guesswork – what we might call narrative speculation - as to the status of Kelly's eating disorder and invariably fear the worst. Gaining knowledge as to the specifics of a daughter's eating disorder behaviours is an identified coping strategy

that helps guide the course of supportive action a parent takes (Honey and Halse, 2006). Unable to gain this knowledge, Kelly's parents are uncertain as to what support they can offer, a troubling circumstance given their commitment to a restitution narrative. Mum discusses why asking Kelly about her health directly is rarely a viable option:

I would never dream of asking on an absolutely regular, not even on a regular once a week basis because I don't think that helps her. It's almost as though "oh you don't really believe what I'm saying" or "you don't trust me" and you have to have that element of trust you see. Although sometimes you can't help but think to yourself "oh I wonder if she's been alright this week?"

The tension between a concern not to appear distrusting and a desire to know specific details is managed through concerted efforts not to quiz Kelly on eating disorder issues during interactions with her. From Kelly's perspective, not being asked questions about her illness translates as an indication that they are no longer worrying:

I think because they know I'm ok they almost don't feel that they need to be ringing me up all the time or checking on me and stuff which is a good thing and I don't mind that and I guess if I want to talk to them I can pick up the phone but I'm happy not doing that.

Kelly's reference to "they know I'm ok" is at odds with the concerns expressed by Mum and Dad and underlines the deep-rooted communications problems that characterise the eating disorder experience.

Restitution ambivalence - ‘I can do this off of an eating disorder’. Despite pressures from cultural, medical and familial sources to adhere to a restitution narrative, Kelly begins to articulate an element of ambivalence towards the notion of eradicating her eating issues. Whereas in the first interview Kelly primarily drew from restitution, during our second meeting this was much less so:

at the end of the day I would still rather, I think that’s again as a sacrifice, I’d still rather almost suffer a little bit with you know not getting fully recovered if it means I can still be strong enough, fit enough, happy enough to go on with my sport I think. You know it’s not ideal and I’d rather have my sport illness free but at the end of the day I would still rather put sport ahead of quitting it...

Kelly reasons that so long as she is able to perform successfully in her sport then recovery is not a priority for her but rather a sacrifice worth making. She contends that although she would ideally compete in sport illness free, she is unwilling to terminate her involvement to pursue recovery. The subtext here suggests that recovery cannot occur within a sporting context, which implicates sport as a contributing factor in her on-going eating disorder experience. Further, describing her continued suffering as a “*sacrifice*”, Kelly’s understanding of her experience is in line with what is termed the sport ethic (Hughes and Coakley, 1991) whereby athletes take the notion of sporting commitment too far, often to dangerous or deviant extremes. In Kelly’s case, persistent issues with food at times represent a necessary evil, akin to her gruelling bike rides and early morning swims; the experience is not enjoyed or desired but she is willing to endure it in the name of sporting glory. In taking such a stance the urgency she has previously expressed in relation to recovery, and which her parents continue to express, is somewhat absent. Kelly elaborated further on her ambivalence towards restitution:

I still know that no Olympic medallist or top athlete has eating disorders. They might have had one but you know the top athletes are usually free of things like

that so I know that I still have to be absolutely rid of it before I can get the absolute best out of me but yeah I have got that knowledge that yeah I've done alright but I know I'm not fully recovered and in another way I think I can do this off of an eating disorder but it's nowhere near the extent that it was that's why...it's still an eating disorder however way you look at it but I don't see it too much as a struggle. I don't feel I'm particularly struggling. Maybe that's why I haven't rung the therapist back because I don't think it's making me think 'God, you know what? This is really bringing me down, really impacting me'. Because I don't feel down and I don't feel rundown by it

In the first instance Kelly again builds the case for restitution, citing her belief that no successful Olympian has an eating disorder. Kelly then goes on to construct an alternative, conflicting understanding with the critical statement "*in another way I think I can do this off of an eating disorder*". This contradictory understanding implies that Kelly can achieve the success she desires with, perhaps even because of, the continued presence of her illness. With restitution ceasing to be a prerequisite for sporting success, or indeed for a functional existence, its necessity is diminished and Kelly neglects to contact a therapist. Compounding this turn away from restitution is the fear that without an eating disorder athletic performance could actually worsen: "*say if I was rid of it and I still wasn't successful, would I think hmmm maybe this isn't the key to it? Maybe I was better slightly with the eating disorder*".

Kelly's conflicting narrative constructions of her illness echo the findings of Rich (2006) who described how anorexic schoolgirls contradictorily understood their eating disorder as both destructive and empowering, the former leading to compliance with treatment and recovery efforts and the latter associated with non-compliance. For Kelly, a negative view of her eating disorder is much less prominent when she is performing well in sport and in life. In these times, it is easy for the nagging belief that

she might be better off with it to prevail. In this respect, the eating disorder is managed and controlled but not overcome completely. Shohet (2007) also identifies ambivalence as an instrumental feature in the persistence of eating disorders. She coins a “struggling to recover” narrative type that is characterised by the envisioning of self-starvation as both good and bad (p. 375). This is hugely problematic for Kelly’s parents who cling, albeit increasingly desperately, to the promise of restitution.

Third set of interviews

Approaching restitution? - ‘90% of a good news story’. The interviews took place while Kelly was on a forced break from all training, the consequence of a severe sporting accident. Despite this obvious setback, there was agreement among all participants that Kelly’s physical and mental health had improved considerably since the previous interviews. Interpretations of this improvement differed between the family members. Having described Kelly’s recovery to date as “90% of a good news story”, Dad suggested the worst of the experience was over:

those dark days hopefully have gone forever and I believe they have, I really do believe they have. The despondency, the helplessness, the fear that we experienced and the tears that we shed in private as a family, they’re behind us now. We were frightened. We really were frightened. Which way would it go? You know it could have gone either way and thank God that it hasn’t and all of the things that are around her pulled her through but mostly of course she pulled herself through because you can only have support and assistance around you, there’s only one person who can actually make that happen and that’s, it had to come from within herself. The recognition and the knowledge that she had to do it and the determination to go out and do it and she’s still got a way to go I would say, she’s probably still got a couple of years of recovery and then look out world.

Although Dad eventually acknowledges that Kelly is not quite fully recovered, he largely pays testament to what he considers to be Kelly's fulfilment of restitution. The most troublesome illness experiences, referred to as "*those dark days*", are placed firmly in the past and Kelly is credited for instigating her own return to health. Viewing Kelly's self-determination as the primary factor in recovery corresponds with Dad's previously highlighted accusation that her lack of recovery was the result of a lack of effort. This consistent understanding underlines his construction of mental illness as something that can be overcome through personal endeavour. The danger of such thinking is that although, for now, Kelly is the hero of the story, should she relapse, she may once again be considered responsible.

Mum also perceived that Kelly's health had improved. For much of the interview she speculated as to the reasons for the improvement:

I certainly do see an improvement and I think it's a culmination of all that we've talked about. It's the leaving university, leaving the academic world, it's getting out and getting in to different areas where she's doing slightly different things, meeting different people, it's having the boyfriend around, there's a lot of stuff and it is being reflected in what she's doing and how she's approaching things.

Mum sees Kelly's recovery as a consequence of a range of changing social and environmental factors rather than the result of Kelly's personal resolve. Diversifying her interests and widening her social network outside of sport were considered by Mum to be likely influences on Kelly's improved health. Research has shown that such a broadening of identity can help athletes alleviate disordered eating symptoms (Papathomas and Lavalley, 2010).

Completing the consensus, Kelly also acknowledged that her psychological well-being had changed for the better over recent months:

it's how I deal with it and accept it to a point and not let it get me down. I've got to think right Ok I've had a bit of a slip, if I dwell on it I'm just going to slip further and further down again and it will be harder to get back up to where I've been. The fact is I've got to almost have a bit of amnesia with it. I've got to accept that I've done it and then block it out as if I haven't done it or else I will dwell on it

Kelly does not understand her recovery as a reduction of eating disorder symptoms but rather in terms of management and acceptance. Instead of suffering the debilitating guilt commonly associated with a binge-purge episode (Broussard, 2005), Kelly is able to “*block it out*”. Rather than punishing herself and slipping “*further down*” in her mood she is able to move on. Learning to accept relapses such as these is considered a key feature in some models of recovery. As she expands on her views, acceptance is constructed as a strategy to manage living with an eating disorder long-term:

I've kind of just accepted a lot of things. I've accepted that Ok I don't think for the rest of my life I'm going to be fully clean slate with having disordered views or behaviours so I've got to change that and think, don't get depressed about it almost accept it and think ok how can I make this as easy as I can?

Kelly suggests she accepts that a full recovery, in terms of completely eliminating disordered views and behaviours, might never happen for her but she does have the capacity to make the experience an easier one. It is a view that suggests recovery has come to mean something different for Kelly, which echoes a prominent debate within the field of mental health. Specifically, Kelly's stance closely allies social or “survivor” models of recovery that emphasise lifelong management of mental illness allowing the fulfilment of a meaningful life, in contrast to psychiatric models that rigidly emphasise the amelioration of symptoms and a return to ‘normal’ functioning as barometers of recovery (Davidson, O'Connell, Tondora, Lawless and Evans, 2005). The restitution narrative, with its focus on restoring the ill person to their former self, affiliates strongly

with the latter, clinical conception that Kelly rebuts. This presents scope for future family conflict given Kelly's redefinition of recovery diverges from the restitution perspective that Mum and Dad have, to date, drawn so heavily from. On the contrary, both parents expressed their own re-conceptualisations of what recovery might mean for Kelly. For example, Dad stated, "*I suspect Kelly will always have to be wary*" and Mum commented, "*it will be a case of her managing it. I don't think she'll ever be over it now entirely*". Equally then, the potential for a convergence of perspectives exists.

A turn to quest - 'I'm just trying to make the most of it'. Throughout her final interview Kelly performed a narrative that resonated with many of the essential features of a quest narrative. Quest stories "meet suffering head on; they accept illness and seek to use it...the quest is defined by the ill person's belief that something is to be gained through the experience" (Frank, 1995: 115). The following account from Kelly is illustrative of an ill person living through quest:

As much as on the flip side I really do wish I never had it, because I wouldn't wish it on anyone, I don't regret not having it because it's really made me open up a lot of things in my life in terms of opportunities...small little things like doing your interviews. It's giving you an insight that you can use for a study as well as other people. I think it's made me appreciate a lot more about who I am as a person...it means a lot to me about who your real friends are and the true meaning of love and support...obviously my family have been through it a lot, probably a lot more than they'll ever let me know but at the end of the day it's been so unconditional. We've had our arguments, we've had our upsets, they've certainly had their upsets but at the end of the day we've all come out of it and we're coming out of it together and I don't think you could ask any more out of a family and that's where it really meant a lot to me in terms of they will always support me...yeah I don't have regrets, I'm quite pleased to say that I don't regret anything so far in my life. That

makes me a little bit more content, I think if I had a lot of regret I'd probably be a lot sadder and a lot worse off than I am with my eating disorder. I don't think I would improve. I'm always learning. I'm learning a lot about what's going on in my life, what suits me, what doesn't suit me, who my friends are. The minute you stop learning is when life gets a bit boring...I'm just trying to make the most of it

Exploring the intricacies of Kelly's narrative provides further evidence of its quest orientation. She begins by emphasising that she does not regret her eating disorder due to various positive outcomes. This is consistent with Frank (1995) who states that in almost every quest story "losses continue to be mourned but the emphasis is on gains" (p. 128). Further, Kelly describes a process of continued learning about "*what's going on in my life, what suits me, what doesn't suit me, who my friends are*". She depicts a journey, but the journey is not dominated by the goal of recovery of her former healthy self as in restitution, it is rather a journey of personal discovery and growth and the emergence of a new self. As Frank (1995) specifies, the quest narrative tells self-consciously of being transformed.

The essential themes of a quest narrative did not surface during the final interviews with Mum and Dad. This was telling as it typified the resounding belief in restitution that was a principal feature of all their interviews. Their hopes for their daughter were centred on restoration not transformation. The previous, illness-free version of their daughter was still the preference to the new person who had integrated an eating disorder into her sense of self. The desire for one's child to fully overcome an illness is a 'logical' one but it may not be a productive one long-term. Eating disorders are notoriously difficult to treat and are invariably chronic conditions. Interpreting the illness through a quest narrative may be a more effective way of successfully managing the eating disorder family experience over time.

Discussion and Conclusion

In this study we have extended knowledge of athlete eating disorders by identifying the wider impact of the illness beyond the sporting environment. We show that an eating disorder penetrates all facets of life and is a psychologically challenging experience for not just the athlete, but the whole family. Moreover, troubled interpersonal relationships within the family unit can be mentally burdensome in their own right. We have also added to the narrative illness literature by demonstrating that an athlete with an eating disorder and her parents draw on dominant illness narratives – as identified by Frank (1995) – to interpret their experience and guide their behaviours. We have also shown that although the type of narrative adopted by an athlete with an eating disorder can evolve over the course of the illness; parental understandings may be less malleable and can remain couched in restitution. When family members construct illness differently to each other in this way, the conflicting narratives can lead to frustration, anger and poor communication within the family setting. We assert that the personal illness experience is influenced by the power of broad cultural narratives that dictate to us how life is supposed to be.

Interviewing members of the same family in parallel produced unique insights into family life dealing with an eating disorder. This study suggests that the experience of an eating disorder is very much a shared, family experience whereby each family member's narrative understandings impact on one another. For instance, Dad's focus on restitution was particularly influential on how Kelly and the family as a whole interpreted the eating disorder and how they lived with it. The instrumental role of Dad is intriguing given that fathers represent a neglected voice in eating disorders research (Hillege et al., 2006). Perhaps when the illness incorporates sport, a typically masculine domain, a father may be more ready to be involved. Future research should further explore the largely unknown role of the father in the eating disorder experience.

Those working within psychology and eating disorders should be aware of the ways dominant culture impacts on individual behaviour. For example, initially, the restitution narrative provided hope and a passage out of family narrative wreckage. It unified the family as they worked towards a shared goal of recovery. As the illness persisted and recovery proved elusive, living by a restitution narrative became a source of frustration and disappointment for all participants. This mismatch between actual experience and preferred experience placed great strain on all family relationships. Communication between Kelly and her parents deteriorated as she feared quashing their hopes of restitution. Once Kelly constructed her illness as a quest, focussing on acceptance and personal growth, the eating disorder became manageable. This improved her well-being, which in turn appeased her parents.

From an applied perspective, this study holds numerous possible implications for the narrative treatment of eating disorders. By naming the narratives that guide the lives of those dealing with an eating disorder, we provide a valuable ‘listening device’ (Frank, 1995) to help therapists hear what story is shaping a person’s life. With this information at hand, therapists can then work to develop more appropriate treatment strategies based partly on what the story does to and on the ill person and how dangerous it might be to continue living by it. As an example, an individual with a strong commitment to restitution might anticipate a quick eating disorder recovery and become easily frustrated with what is typically a gradual process. The therapist who is appreciative of this potential eventuality can look to manage expectations accordingly, ensuring such an individual does not become dispirited by treatment setbacks. By the same rationale, an appreciation of the narratives held by significant others may help enhance the appropriateness of family-based therapies. For example, therapists could be sensitive to situations where family members hold disagreeing narrative constructions

of illness and be better placed to deal with the intra-family conflict that can ensue.

Ultimately, stories matter and tending to them should prove fruitful for a therapist.

On a cautionary note, various moral issues must be considered on the basis of the stories told in this research. Both restitution and quest narratives can provide great benefits to understanding illness but neither can be seen as a panacea. The suitability of each is subject to individual preference, context, and timing. Particularly, as we have described, the hope of restitution can soon give way to disappointment and frustration. Restitution is the master narrative of the Western world; it presents a default way of thinking that might fuel well-meaning individuals to thrust it on the ill as means of showing encouragement – “you *can* get better”. Yet those who advocate restitution cannot ignore the trauma that can materialise when recovery is not forthcoming. This study warns of the limits of restitution.

It is important to be cognizant of the primary limitation associated with this study. As family members were interviewed separately to each other, the joint meaning-making process described in the analysis can only be viewed as an inferred interpretation – albeit inferences based on extensive longitudinal data. There were advantages to this approach – participants may have been more inclined to articulate thoughts and feelings they might not reveal in front of a family member. Nevertheless, it may still be argued that to properly document narrative co-construction, the family should have participated in a group interview. Although future research has much to gain from such an approach, it too comes with methodological concerns. Primarily, narrative constructions are always transient, context-dependent and performative endeavours. As such, the narrative co-constructed at interview may differ enormously to the narrative co-constructed at home.

To conclude, eating disorders can be chronic illnesses that lead to challenging and troublesome experiences for athletes and their families. The everyday interactions that usually typify family life dictate that the eating disorder experience is, to a degree, socially constructed within the family unit. The meaning making that occurs within a family is guided by culturally dominant illness narratives as defined by Frank (1995). This research supports the Academy for Eating Disorders (AED) position paper statement that “families should be involved routinely in the treatment of most young people with an eating disorder” (Le Grange, Lock, Loeb, and Nicholls, 2010: 4). We proffer that such family-based treatments would benefit from an awareness of the illness narratives the familial eating disorder experience.

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