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Families facing a loved one’s illness

Couple psychotherapy in the shadow of illness

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Summary

The paper argues from a psychoanalytic perspective that loss is at the centre of both the individual and couple experience of serious illness. Despite the plethora of related research about the impact of illness on the individual, there is a dearth of psychoanalytic literature about its impact on the couple relationship. I examine the impact of loss related to illness in individual patients from the perspective of the research of Frank (2009) and Toombs (1987) and attempt to apply these findings to couple relationships noting how it is the competing narratives, often encompassing significant denial which are helpful to address in therapy with couples facing such issues.

Keywords: illness, couples, couple psychotherapy, narrative research, phenomenology.

Résumé. *La psychothérapie de couple à l’ombre de la maladie*

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Cet article soutient, d'un point de vue psychanalytique, que la perte est au centre de l'expérience de la maladie grave, tant pour l'individu que pour le couple. Malgré la pléthore de recherches sur l'impact de la maladie sur l'individu, il y a une pénurie de littérature psychanalytique sur l'impact de la maladie sur la relation de couple. J'examine l'impact de la perte liée à la maladie chez les patients individuels du point de vue de la recherche de Frank (2009) et Toombs (1987) et tente d'appliquer ces résultats aux relations de couple en notant comment ce sont les récits concurrents, englobant souvent un déni important, qui sont utiles à aborder dans la thérapie avec les couples confrontés à de tels problèmes.

Mots-clés: maladie, couples, psychothérapie de couple, recherche narrative, phénoménologie.

Resumen. *Psicoterapia de pareja a la sombra de la enfermedad*

En este artículo se argumenta, desde una perspectiva psicoanalítica, que la pérdida es fundamental en la experiencia de una enfermedad grave, tanto para el individuo como para la pareja. A pesar de la plétora de investigaciones sobre el impacto de la enfermedad en el individuo, hay una escasez de literatura psicoanalítica sobre el impacto de la enfermedad en la relación de pareja. Examino el impacto de la pérdida relacionada con la enfermedad en pacientes individuales desde la perspectiva de la investigación de Frank (2009) y Toombs (1987) e intento aplicar estos hallazgos a las relaciones de pareja señalando cómo son las narrativas contrapuestas, que a menudo abarcan una negación significativa, las que son útiles para abordar en la terapia con parejas que se enfrentan a estos problemas.

Palabras clave: enfermedad, parejas, psicoterapia de pareja, investigación narrativa, fenomenología.

Introduction

Illness comes in a variety of different forms and at all stages of life. It may be as innocuous as a brief cold, over and done within a few days, only disrupting normal activities to a minimal degree. However, more serious illness can have a disruptive effect on normal life, creating high degrees of stress on family and couple relationships. In these circumstances, some couples seek out couple psychotherapy where one or both partners are currently ill, facing the therapists who work with them particular challenges which are partly to do with understanding the phenomena before them but, also, in meeting the emotional challenges that this type of work presents. In this paper I will offer a way of understanding illness as it is experienced from, first, the standpoint of patient and, second, from that of the couple. I will discuss some of the emotional challenges which therapists will confront in this area of practice and illustrate my main points by reference to two couples who sought therapy from me. I have disguised the material heavily but the dynamic issues are preserved.

The interface between illness and couple functioning, on the one hand, and couple psychotherapy practice on the other, is not well represented in the U.K. literature. Important books have been written by Evans and Garner (2004) and Davenhill (2007) but the major contributor has been Andrew Balfour, whose recent book (2025) brings together his clinical and research work developed over many years. His approach considers illness in the context of ageing and brings a Kleinian perspective to his analysis. My interest has longstanding personal and professional roots. In my professional role, I began, in 2007, to develop a qualitative research study in a U.K. health service out-patient clinic, caring for couples and families contending with a range of different dementias, including those of old age, but also involving early onset dementias. This study ended when, as a consequence of the 2008 financial crisis, the service I was working with was shut down and I was forced to switch my research focus to couples living with Huntingtons disease (HD), having established a good working connection with the charity supporting the HD-affected community. Two important consequences flowed from this change. The first followed from the fact that HD can manifest itself at any age. While the most common age range for the illness to run its course is between the mid-thirties and mid-fifties, symptoms can also appear in childhood and many patients live into old age and die from other illnesses. These features of the condition meant that my interest in disease and illness was not restricted to old age. The second consequence was that my research interests took me outside my familiar psychoanalytic clinical framework as I began to explore different qualitative research methodologies and, in parallel, undertook a literature search into how the experience of illness and its impact on couples had been written about.

I learnt that most of the qualitative research looking at how illness is experienced concentrates on the reports of individual patients and, in this sense, follows the dominant medical disease paradigm of seeing disease as an individual's bodily dysfunction. Less attention has been paid to the impact of illness on couple relationships nor how the impact of illness can be understood within a psycho-dynamic framework. This is a gap that needs to be filled because there is considerable evidence to show that, overall, the strains placed on couple relationships are great. For example, a study in the U.K. (Golics, et al, 2013), looking at the impact of chronic disease on family life across twenty-six medical specialties, found that, of the one hundred and thirty-three family members interviewed, 92% were adversely affected emotionally by the patients' illnesses, mentioning worry, frustration, anger and guilt. Of the total sample, 56% were spouses and, in relation to them, the authors observed that «Partners and spouses found the role change to carer challenging, many reported a negative effect on their sex life. Others reported a decline in their sexual relationship due to the patient's physical condition» (*ibid.*, p 792). Moreover, there is widely reported research finding that the quality of life of partners across a range of different health conditions is worse than that of the patient. Rees (2001), for example, confirms this finding in a helpful summary of studies of patients with prostate cancer. The same general finding has been found in the fields of dementia care (Ablitt, 2009) and HD (Kaptein, 2007; O'Connor, 2008). Under these stressful circumstances, and those reported by other researchers, we can understand that the resilience of many couples will be tested, individual and shared defences will be mobilised and couple therapy explored.

Characterisations of the body as object: the patient's perspective

When well, Sartre said that our bodies are "transparent" by which he meant that we take for granted the embodied aspects to our lived experience. «The body tries to stay out of the way so that we can get on with our task; it tends to efface itself on its way to its intentional goal» (Sartre quoted in Gallaher and Zahavi, 2008, p. 163). All of this changes when the body malfunctions and the unity of self and body can no longer be taken for granted. If the illness is serious the failing body can become a pre-occupying presence or object whereby, in its new troublesome guise, it can feel alien or 'other' while at the same time belonging to 'me'. This sense of a disconnection between self and body may be reinforced by intensive medical treatment and was vividly described by the author, Hanif Kurieshi, who became paralysed following a fall and spent a year in hospital before returning home. He reported that, while in hospital, «you realise quite quickly that your body doesn't belong to you anymore, that you are changed, washed, poked and prodded by nurses and doctors» (Clinton, 2023).

Making sense of the failing and alien body is a major challenge which extends beyond an understanding of the medical diagnosis and treatment options, important as this is. This task has been helped by those researchers and clinicians who have conceptualised the complex and idiosyncratic experience of being ill.

Illness narratives

The sociologist, Arthur Frank, (2009) made a seminal contribution to understanding how the body is experienced and talked about under a variety of different ill health conditions. He identified three common narratives that the ill person might adopt. These are the restitution narrative, the chaos narrative and the quest narrative. He makes the point that these different ways of relating to illness and the sick body are not specific to any one disease or groups of disease and, it is possible that any one ill person might use all three narratives when traversing the course of managing an illness, even referring to elements of all of them in one conversation.

When illnesses are transient and curable, Frank talks about the patient and close family adopting a restitution narrative. He says that this narrative has the basic storyline: «Yesterday I was healthy, today I am sick, but tomorrow I'll be healthy again» (*ibid.*, p. 77). Within this narrative, the body is largely viewed in mechanistic terms; it is something to be fixed, often by the assistance of medical interventions, the passage of time and a healthy mindset of wanting to get better. It is a body that can be cured, anxiety about the illness can be contained and there is a conviction that the sufferer will return to the pre-morbid state. There are, of course, exceptions to the smooth unfolding of this story – the course of treatment may not run smoothly – but it is one that most people want for themselves unless secondary gains are obtained from perpetuating a sick role (Parsons, 1978).

Frank suggests that the chaos narrative and the quest narrative emerge in the context of serious illness. The chaos narrative is, in fact, an anti-narrative because there is no narrative order and, sometimes, a limited verbal narrative, as meaning is conveyed through repetitive and agitated behaviour. Acute anxiety impels the individual to stay paralysed in one position as if unable to make sense of events and move forward. Such stories typically belong to the early stages of learning that a serious illness is diagnosed or when the illness produces acute crises. Charlotte Raven (2021), a distinguished journalist, wrote about her experience of living with HD and her compulsion to obsessively look for things as a defence against mourning the losses that her illness produced:

«When I lose things, I always look in the places they are likely to be first. If my mobile phone isn't in the basket with the cat food, the box file in my study or my knicker drawer, it might be on the sideboard, where it is meant to be... If I tried the sideboard first, I would see that it wasn't there and panic. Then there would be no point in looking in out-of-the-way places, so I might as well spend the rest of the morning in tears on the phone to the mobile company, asking for a replacement. This strategy protects me from the trauma of loss» (p. 49).

One can sense from this account the internal emotional chaos that Raven experienced when coming to terms with the losses that her illness was bringing about. Frank puts it well: «The challenge of encountering the chaos narrative is...to hear. Hearing is difficult because chaos stories are told on the edge of a wound, they are also told on the edges of speech» (*ibid.*, p. 101).

If it is possible to think of the restitution narrative as involving the ill person having a dialogue with the body, albeit one thought about in mechanistic terms, the state of chaos, in the terms Charlotte Raven was describing, has no bodily object because it cannot be symbolised, or only partially so; the significant body is the agitated body of the storyteller.

The third of Frank's narratives, the quest narrative, arises when the ill person meets suffering head on and is required to find meaning in a life upended by a condition that might not be cured and needs to be managed. Of the three types of narratives, the quest narrative affords the narrator the most distinctive voice because he or she is free of the overwhelming anxiety typical of the chaos narrative and, as compared with the restitution narrative, the roles of the medical profession and medical interventions, although likely to be present, are less prominent.

The psychological challenge revealed in the quest narrative is to strike a balance between mourning what has been lost and making the most of life's opportunities in circumstances which will be limiting and uncertain. Whitemore and Dixon (2008) describe this balance as between 'Living the Illness' and 'Living a Life' while Paterson (2001) writes about the difficult balance of having illness or wellness in the foreground of life. There are parallel ideas from within the psychoanalytic literature. Jaque's paper "Death and The Mid-life Crisis" (1965) suggests that the apprehension of personal mortality in mid-life (something accelerated by serious ill health) requires a reckoning with one's past so that achievements can be valued and losses mourned. The dual theory of mourning (Stroebe & Schut, 1999) also addresses this process by suggesting that, when seriously ill, living well in the present requires mourning what has been lost. This model proposes that there are two types of stressors, loss-oriented and restoration-oriented, and, in the process of coming to terms with both, the individual oscillates between mourning what has been lost and making the most of what life has to offer. For chronic illnesses this is likely to be a continuous process throughout life.

Phenomenological perspective on illness

One helpful way to understand the existential dimensions of the losses which patients must mourn comes from the writings of Toombs (1987) who adopted a phenomenological approach in her research. She proposes that there are five general areas of experience with which the patient is confronted, all of which involve losses and all of which overlap with one another. These are the loss of body wholeness, the loss of certainty, the loss of control, the loss of freedom to act and the loss of the familiar world.

By the loss of body wholeness, Toombs is referring to the perception of body impairment and the fact that the body can no longer be taken for granted; it is no longer 'transparent' as Sartre observed. As a consequence, self-image and confidence are often threatened resulting in a narcissistic wound. The loss of certainty follows on from an awareness of a body now impaired; it won't do what it did before. «Illness is experienced as a 'capricious interruption': an unexpected mishap in an otherwise carefully crafted life» (Carel, 2016, p. 42) and there are many examples of ill people attributing agency to the capricious and failing body. For example, Frank quotes Friedrich Nietzsche who suffered chronic pain and wrote about it, «I have given a name to my pain, and call it "dog"… I can scold it and vent my bad mood on it, as others do with their dogs, servants and wives» (*ibid.*, p. 116) and Churchill was known to refer to his depression as the "black dog".

The lack of certainty overlaps with the loss of control over the body and mind ("Will the latest steroids reduce the pain in my leg? Will the drugs control the spread of my cancer?").

Dartington, in a jointly written account of her own experience of early onset dementia (Dartington & Pratt, 2007) describes in vivid terms how she lost control of her mind and how it could no longer be trusted.

«Can I tell you about the day my brain left me? My unfaithful brain left me slowly [...] I know I didn't lose my brain, but my brain lost me... these moments came up on me like the fox, very, very quietly» (p. 287).

The loss of bodily control often results in the loss of the freedom to act. This loss affects many areas of life but it was striking in my HD study how the loss of the ability to drive a car surfaced regularly as a resented limitation on the freedom to act independently, placing those affected reliant on others to provide a taxi service.

Rachael, one of the participants in the HD study (Vincent, 2017), talked animatedly about the arguments she had with her husband, Sam, whose driving licence had been revoked because of his symptoms, yet, continued to insist he could continue to drive. In the face of Sam's obstinacy, Rachael had to limit his freedom.

"But when he had his licence revoked, he thought he's fine to drive…(the problem is) his physical jerkiness I would say, slightly, I think that is the main reason, what will happen if somebody pulled out in front of him, he wouldn't be able to respond…we have got a great big dent in the front of his car which he did…he said, oh it was just like it was dark and the car was all misted up. But his spatial awareness, he knew I was going to go mad because I hid the car in the garage...So it has been over a year now unable to drive and... (he) still doesn't accept it, still fighting to get his licence back."

A consequence of being unable to drive was that Sam lost contact with his familiar world, Toomb's fifth loss, and this closing in of personal horizons is a common experience for couples living with serious illness. The isolation which follows is often the consequence of financial problems when the paid employment of one or both partners is no longer possible. The U.K study mentioned earlier described how family members, in their role as carers, talked about how their own medical conditions worsened resulting in them becoming 'hidden patients' and unable to contribute to family income. The authors called this a 'ripple effect' whereby the presence of one patient being seriously unwell in the family has the potential to create several more. This dynamic may have been present in the interaction between George and Jane, a couple of pensionable age in the HD study who both had on-going chronic health problems. Jane had HD while George had a recent stroke and a perforated stomach ulcer which meant that, in Jane's words:

"We are a bit like a pair of old bookends holding one another up... you see... it would be just nice, sometimes, to be husband and wife and not carer and cared for. That's because the boot's on either foot at the moment, you know,"

The background to their precariousness and socially isolated situation was explained by George:

"We are both only children, so Jane lost her father many, many years ago…I lost my parents in the 90s and the 00s…So we had no one else to share that burden other than each other."

Characterisations of the body as object: the couple's perspective

With the exception of my last reference to George and Jane supporting one another, I have, so far, described responses to illness as reported by or attributed to individual patients. This perspective needs development in two ways in order to reflect the impact of serious illness on couple relationships. The first is to acknowledge that all family members affected by illness will construct their own narratives which may or may not broadly agree with one another. The second development is to acknowledge that the narratives each family member adopts may be defensive in nature, warding off significant anxiety about the impacts of illness on their lives.

I will describe two couples managing illness in different ways but for both couples coming to terms with the meaning of the losses, and the readjustments illness were forcing them to make, were very difficult. The first couple, Alan and Anna, held different and conflicting narratives about their understandings of illness and these differences produced polarised positions which could not be reconciled. In the second example both David and Sylvia held broadly similar narratives about illness but, in spite of similar approaches found themselves conflicted as their shared defence made it difficult to manage loss and changes to their lives.

Conflicting couple illness narratives

Alan, was a sixty-two-year-old man who very reluctantly agreed to attend a series of joint couple sessions with his wife, Anna, who was twelve years his junior. Alan had been diagnosed with Parkinson's disease ten years before and his symptoms, which included a propensity to fall and a difficulty in concentrating, had obliged him to step down as the successful head of a major engineering firm during the previous year. It was through work that he and Anna met, and Alan's somewhat dour personality and technical brilliance was matched by Anna's exuberant personality and great skills in selling the company's products. They thought this mix created the 'perfect couple' albeit one in which Alan thought of himself as the 'boss'. His ill health destroyed this 'couple fit' and it was clear that Alan hated his dependence on Anna and others, including professionals like me.

At the point I first saw them, their sexual relationship had ended seven months earlier and, being stuck at home without work, Alan had become severely depressed. Anna presented as both anxious and very angry with Alan and wanted therapy to help them think about a physical separation. She complained that Alan did not accept his illness, believing that he could function in the way he lived before illness struck. She was angry that, at home, he did no housework while she continued to work in their company and was concerned for their teenage daughter whom, she said, Alan lent on to pick him up when he fell over or needed help around the house. She went on to say that Alan did not take sufficient heed of medical advice and was not attending 'physio' regularly. Alan's take on this was that he thought his medication was helping him and that he was confident of returning to sufficient strength to obtain a senior position in a new company; he referred to a business colleague who had him in mind as the CEO of a start-up venture.

Alan's behaviour and narrative were predominately imbued with restitution-like themes particularly in his belief that he would return to work and in his wish that he and Anna might have a sexual relationship again. If Frank's restitution narrative has the structure "Yesterday I was healthy, today I am sick, but tomorrow I'll be healthy again", Alan's belief was "Yesterday I was healthy, today I am sick and, while I won't be well tomorrow, I can function as if I were". This approach, imbued with elements of denial and omnipotence, was from Anna's point of view, unhelpful and disconnected from the reality of his illness. Her narrative was dominated by her encouragement for them both to confront the illness. She accepted that her wish to separate was extreme but only because Alan had refused in the recent past to face up to the limitations and possibilities that his illness presented them so that she could see that she might come across as emphasizing the negatives in what the future offered.

Alan withdrew from joint therapy after three sessions. Had therapy continued it may have been possible to have found some middle ground between the couple; Alan might have been better able to accept limitations imposed by the illness and the realistic possibilities that then followed, and Anna might have become less rejecting and able to value what the relationship offered, albeit radically changed by Alan's ill health. For this to happen both would have had to mourn the passing of a 'perfect couple' relationship and come to terms with the reverberations this would have on their inner worlds.

Alan had been the favoured son in his family and had excelled at school; to be anything other than 'on top' was difficult for him. By contrast, Anna grew up never believing that, however hard she worked and achieved, she was good enough. There was an obvious sense in which their 'perfect' couple fit allowed each to project disowned parts of themselves into the other, an inter-personal chemistry which was upended when Alan became ill. When their joint therapy ended at Alan's insistence, it was apparent that Anna was beginning to be more comfortable in being angry. While much of her anger was directed towards Alan, she was beginning to see that her problems in being angry rather than compliant had roots which went back to her childhood. This growing insight made her resolved to seek help with her own therapy.

Congruent couple illness narratives

David and Sylvia were both in their late fifties when they approached me for couple therapy with the encouragement of the daughter. There were two precipitating events for them seeking help. In the previous year, David had taken early retirement which had left him unsure what to do with his spare time and he had had surgery for a melanoma on his neck. This was the latest in a succession of skin cancers which he had been told were a consequence of earlier ultra-violet therapy he had received as a young man for his psoriasis. In addition, he told me about a long-standing arthritic condition for which he received monthly injections at a local hospital and self- administered weekly injections. The injections left him feeling nauseous for several days but without them he knew he would be unable to walk and in a lot of pain.

At our first meeting, David joked about his illnesses and their current problems which made me feel uncomfortable because it was so at odds with the story being told. He put himself down when he talked about the possibility of becoming a 'cripple' and he was disparaging when saying that Sylvia had a 'butterfly mind'. Neither I nor Sylvia could see the funny side of these descriptions. He went on to say that he and Sylvia speak "different languages", he being the rational thinker while Sylvia's mind was, he thought, driven by her emotions. After a reticent start, Sylvia bridled at the suggestion she had a butterfly mind and, as she gained confidence, began to express her anger and frustration with David. She conveyed a clear sense of being frustrated by David's jokey manner which pushed her away and prevented them being intimate with each other. They had not had sex for fifteen years which was just one aspect of them feeling isolated and alone in their marriage. Sylvia felt strongly that one consequence of being emotionally distant from one another was that they both felt unappreciated and that the lack of mutual gratitude fuelled resentment and anger. They insisted that family, friends and acquaintances would not know about their problems because they were both adept at hiding them; they said that they put on a good "double act". As Sylvia described their inability to be close, David looked very uncomfortable but did not disagree.

Sylvia went on to explain that over many years they had grown apart and developed separate interests. David had been heavily invested in his career while she had worked at local stables and, through this connection, had developed a passion for horse-riding and grooming the horses in the yard's care. However, a recent fall from one of the horses had damaged her spine and she remained unsure whether she would ever be able to ride again. She said that she would not bother to ask David for sympathy because she knew he wouldn't give it-he would pretend he hadn't heard it, he might be absorbed in something of his own or, if he did hear what she said, would make light of it. So, in her own way, Sylvia put on a "good act" for David and herself, for by maintaining an upbeat mood most of the time she protected herself from being rejected or disappointed.

At our first meeting I learned something of their histories. David talked about growing up in a small village community where patriarchal values were generally accepted. This included the discouragement of showing affection and he gave as an example his father telling his brother not to hug his grandfather: "We don't do that sort of thing" were his father's words. Sylvia grew up in the same village and within her family she was made to feel special by her adoring father but the authority of the men over women, as far as major decisions were concerned, was not to be questioned and the discouragement of showing open affection was repeated.

These values carried over into David and Sylvia's marriage which became dysfunctional when their second child, a son died at three months as a cot death. Their reaction to this loss was very different. David did not want another child but

Sylvia, in the face of his opposition became obsessed with wanting another child and was pregnant again within a year. This child is now a young woman and is in on-going court battles with her former husband over the custody of their daughter. As her grandmother, Sylvia had been very involved in her day care and she talked at length about her concern that the bitter relationship between the parents might rob her and her granddaughter of a mutually loving relationship.

When I thought about our first meeting I was struck by their similar defensive narratives which were to deny the vulnerability and pain caused by their current ill health. As I thought about them, the title of the Monty Python song “Always Look on the Bright Side of Life” came to mind. The title is deeply ironic advice when the lyrics describe being in the dumps of depression.

I was aware that this shared narrative, thought of as a defence, was breaking down at times causing great distress to them both. One of the recurring arguments came about when David attended the hospital for his monthly injections. He needed to be driven there and collected after his treatment but, on several occasions, arrangements with Sylvia broke down and taxis were needed. Hearing this was enormously painful because it captured the problem between them in stark terms. Could they rely on each other when they were needy? Were they destined to feel abandoned when they were most in need? In thinking about the significance of these ruptures in care, I had in mind both the glimpse I was given into the ways they had reacted to the loss of their second child and also the anxious relationship Sylvia had with her granddaughter. I felt fairly sure that her work with the horses at the stable produced loving relationships which were more dependable than those she had at home.

I worked with David and Sylvia for two years and they made good progress in developing a more straightforward emotional relationship with each other. They found it very difficult to accept that the earlier cot death had a bearing of the possibility of losing contact with their granddaughter, yet they were able to accept that they were unable to be vulnerable and needy with each other and that it was safer to talk about their children and granddaughter’s needs rather than their own. It was apparent that the joint discussions helped them be more communicative at home across a whole range of day-to-day concerns and they felt happier as a result. When we finished working together, sex had resumed when they were on holiday and David felt more confident and in control.

Discussion

In this paper I have tried to show there is benefit to be gained by sensitizing ourselves as therapists to the experience of being ill and that we are helped to do this by drawing on the works of researchers outside the psychoanalytic field who have explored these matters. There are also other sources we call on, including our personal experiences of illness and the prolific literature written by individuals who have gone through illness or have helped others to do the same. The work of Couser (1997) and Hawkins (1999) provide excellent scholarly analyses of this literary genre.

From all these sources we learn that a central challenge that illness presents is coming to terms with loss and, I think this explains why working in this field is challenging for therapists and this is particularly so if losses are cumulative, as they can be when illnesses are incurable and lead to premature death. Set against a need to acknowledge losses is a need to acknowledge and reinforce progress in managing inevitable limitations. This is as difficult a balance to strike for therapists as it is for clients as holding to either position can, at times, be a defence against confronting the other.

I have tried to show that the experience of illness is helped by the drawing on work outside the couple therapy field, but I hope the cases I have described demonstrate that a couple psychoanalytic framework deepens our understanding in two ways. First, it is necessary to think beyond the individual patient's experience to include that of the couple. This is particularly important when the medical disease paradigm focuses mostly on the individual patient. Secondly, it is necessary to think about what people report in dynamic terms because anxiety associated with serious illness can generate conflicting couple defences, or a breakdown in them, which require a couple psychoanalytic intervention.

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