

Personal illness narratives: rheumatoid arthritis (ra)



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Introduction

This essay employs excerpts from the narrative of a 38 year old woman named Francesca, a lady who has been given a diagnosis of rheumatoid arthritis (RA), to illustrate key concepts from the sociological, and psychological literature. This approach will illustrate the writer's ability to critically appraise the literature, its relevance to the narrative in question, and using narrative, places these concepts within a real life clinical situation. This in turn provides insight into the value of narrative as a methodological approach in the 21st Century and how it intertwines with the rich tapestry of sociological theories and concepts that are available to the researcher studying the current sociological evidence base. For the purpose of this assignment, peer reviewed articles and textbooks were searched within the past 10 years.

The work introduces RA as a clinical entity (pivotal to understanding the comments of Francesca) and goes on to outline the use of narrative, particularly its utility in the study of chronic disease. The essay then goes on to cover some key important issues, namely:

- The biomedical versus the sociological approach of illness management
- The Study of Personal Illness Narratives
- Sociological perspectives on depression
- Chronic Illness and Disability
- Social construction of medical knowledge and the Politics of Disability
- Labelling
- Stigma.

For each of the above, concepts are presented and mapped against selected statements from the narrative of Francesca (written in italics for clarity).

These statements illustrate real world data gleaned from Francesca; valuable comments that are grounded in the experiences of a person living with a chronic disease. The work also contains an appendix comprising a reflective postscript which outlines the way that the work evolved from earliest outline, to the finished product.

Rheumatoid arthritis (RA) is a chronic inflammatory disorder that affects not only the synovial joints but multiple body systems (Goodacre 2008). The exact cause of RA remains unknown; it is a disease that affects more women than men, often of a young or middle age demographic unlike osteoarthritis which affects predominately older people. RA follows a somewhat unpredictable course of exacerbations and remissions. RA carries huge psychological problems in view of its unknown aetiology, uncertain prognosis, and loss of function. Additional symptoms include early morning stiffness, pain, limitation of activities of daily living, and socio-economic problems inasmuch as it may have a severe impact upon a person's ability to work and function in society (Kojima et al 2009). The discussion now begins with a section on models of illness.

Biomedical and biopsychosocial models of disease

The biomedical model of health takes the reductionist view that people are "biological entities" (Lewis 2009 p745). In the clinical management of RA there is some merit in this biomedical approach, for example the monitoring of inflammatory mediators in the blood as a marker of disease activity or responses to drug intervention is well established in the literature (Lee & Kim

2009). This biomedical approach is reinforced by the GP comments from the narrative, i. e. That there was “ no cure” and that “ the tablets” were the key to preserving normal function. This approach may contribute to Francesca’s frustration, as it ignores the wider psychological and sociological ramifications of living with a chronic debilitating disease such as RA. It is unclear from the narrative whether the GP tempered his comments by adding that there are means by which the signs and symptoms of RA can be successfully managed.

Critical appraisal of the literature reveals that biopsychosocial models advocate a more holistic view of illness, for example according to Smith (2002) the biopsychosocial model seeks to address not only the client and his or her illness but also their capacity to deal with being ill. The value of adopting the narrative approach as part of the biomedical model is effectively illustrated at the point where Francesca states

“ I just burst into tears”

At the perceived effect that this illness will have upon her loss of function in the future.

So whereas the biomedical model will operationalise function using objective outcome measures, here the use of narrative permits a biopsychosocial approach that provides rich client centred data on how it feels to be diagnosed with chronic and currently incurable disease. This in turn can help to inform our understanding of Rheumatoid arthritis as a disease thereby influencing the social construction of medical knowledge by giving voice to service users (Balen et al 2009).

The Study of Personal Illness Narratives.

Illness narratives concern a person's views and beliefs about their illnesses and the effect on their lives (Hydén 2007). There is increasing acceptance and recognition of the valuable role that such grounded narratives play in understanding the journeys that people with chronic diseases such as RA have to embark upon if they are to manage their illness on a day to day basis. For example Haidet et al (2006) found in a narrative study of people with diabetes that people narrated four illness-management strategies whose story elements were in dynamic interplay, each with unique variations for each individual revealing a level of complexity that had not been previously described.

As a method, narrative provides rich data (Furman & Cavers 2005; Poindexter 2002) and in this case gives a voice to Francesca that would otherwise remain unheard (Grills 1998). Much can be gleaned from studying Francesca's narrative, for example Francesca begins to paint a picture of her hopes and fears upon being given a diagnosis of RA combined with an insight into her past and thoughts about the future.

Francesca's narrative provides us valuable insight into her views of the self- a key component of narrative (Voilmer 2005), her relationships to others, and how these relationships have changed or may change in the future. In her narrative Francesca gives us some insight into the pain of living with rheumatoid arthritis, in her comments we can detect also a stark dichotomy in that she notes how healthy she had been in the past then uses the term "Excruciating" to describe her current pain, thus Francesca's narrative hints

at the loss of self in that she will no longer be a dancer or even a valid spouse as exemplified by the narrative quote.

“ I won't be the woman he fell in love with”

Here she literally describes herself as becoming another person. Here Francesca is able to provide the reader or researcher with valuable information on the loss of the self, which resonates with other narrative research (Roe & Davidson 2005; Doba et al 2007). Francesca goes further and also hints at the change in her illness self concept (ISC) that is to say the extent to which a person is defined or consumed by their disease or disability (Morea et al 2008). Francesca also hints at the concept of disease as a biographical disruption, described by Bury, this is said to occur when a person's planned future cannot unfold as planned. (Bury 1982);

will he even want to marry me? I'm too young to have this.

What makes Francesca's narrative particularly interesting is the fact that she is a twin; this may emphasise any change in self since she has in essence an unchanging control (her twin sibling) to against which to compare herself as her disease, her self identity (and possibly disability) progresses. The next section outlines sociological perspectives on depression.

Sociological perspectives on depression.

Francesca's depression is likely to be multifactorial; for example there is evidence that the disease RA itself causes depression (Kojima et al 2009) as will living with pain. From a sociological perspective Francesca's strained

personal relationships may contribute to depression, for example her fear of being rejected as a potential spouse (Waite & Gallagher 2001), see below.

will he even want to marry me?

This feeds in to the earlier section on biomedical versus biopsychosocial models of health and illness and the different paradigms or world views in which they are situated. A biomedical explanation of depression is likely to focus on the biochemical aspects of the person whilst a more sociological approach would acknowledge the impact of socio economics, personal relationships and so on (Covic et al 2003). Caution is needed however here since the short excerpt of narrative that we have provides no direct evidence that Francesca is in fact depressed, indeed a review of the literature suggests that there is a tendency to over diagnose depression (Parker 2007).

Chronic Illness and Disability.

A chronic incurable disease such as RA would require Francesca to make significant adjustments to her life over time. The sociological literature now provides increasingly refined conceptualisations of these adjustments, acknowledging that the experience of chronic disease necessitates adaptations in multiple domains of the person's life. This adjustment is often referred to as a trajectory (Stanton et al. 2007). This concept, introduced by the sociologist Strauss in an attempt to capture experiences and behaviours occurring in response to chronic illness (Strauss & Corbin 1998), goes beyond depicting the physiologic unfolding of disease and encompasses the total organisation of work done over the course of the illness (Strauss et al 1984). Francesca's narrative hints at this changing trajectory tracing the

commencement of her life changes to a time six months ago when she was much more active and defined herself as a dancer. Furthermore Francesca looks to her future and wonders about her ability to fulfil the stereotype of a perfect spouse.

It is important to engage with how Francesca and her fiancé will make sense of the illness. The term “illness cognition” has been defined as “a patient’s own implicit common sense beliefs about their illness” (Leventhal and Nerernz 1985, p. 517). When people experience symptoms, they embark upon a cognitive search which enables them to interpret and make sense of the symptoms they are experiencing. Typically a critical review of the literature distils out into five categories:

1. Identity, including the description of symptoms experienced and their meaning (e. g. pain, fatigue). In the narrative Francesca describes her pain as “Excruciating” for example.
2. Belief about causes (e. g. accident, genetics or stress). People like to have a label for their symptoms for legitimisation although, once given, people are likely to interpret diverse symptoms as evidence of the label. Francesca has problems with causality and is likely to do so for the foreseeable future since there is no established medical cause for RA.
3. Timeline (beliefs about duration and time for recovery), namely is it acute or chronic? These beliefs will be re-evaluated as time progresses.
4. Consequences (e. g. loss of lifestyle, goals in life). These representations may only develop into more realistic beliefs over time.

Francesca uses the narrative to discuss the change in her life from active dancer to unappealing spouse within the space of six months.

5. Beliefs about controllability. (Furnham, 1989; Landrine and Klonoff 1992, 1994)

These categories are pivotal to understanding how people make sense of, and decisions about managing a changeable chronic disease such as RA. Evidence of Francesca attempting to make sense of her symptoms by embarking upon a cognitive search may be seen in the example below:

I couldn't understand it - I'm the healthiest person I know. I've never had problems with my health - never had a day off sick in my life. I never go to the doctor, no matter what, I've always been fit as a flea.

From the narrative provided we also have limited information concerning Francesca's partner's views, for example (although not from Dave himself)

Dave wore me down, telling me I've got to see a doctor

This may be interpreted in various ways, not least that Dave was keen for Francesca to obtain a diagnosis and thereby a label to legitimise the illness, whether such labelling is disabling or enabling is not fully resolved in literature (Huibers & Wessley 2006). Francesca's comment does however open up the interesting issue of how partners cope with chronic disease, in RA in particular there is evidence that a strong marital relationship correlates with the couple's psychological adjustment to the illness (Mann & Zautra 1990). These authors go on to claim that in RA, partners are most affected by their perceived vulnerability to disease and coping ability, whereas the

wives who have RA were more affected by pain itself and how they will cope with the effects of the disease- reflected in Francesca's comments below;

I started having excruciating pains in my feet when I woke in the morning

To further corroborate the findings of Manne & Zautra (1990) concerning male worries about coping at a more abstract level see the example below:

Dave has been great but he has his own worries - he's just been laid off from his job and he's worrying about paying for the wedding

Mann & Dieppe (2006) have also more recently acknowledged coping differences between males and females in RA, (n = eight women with RA ages 31-60 years and their partners, and 4 men with RA ages 43-75 years) although methodologically their sampling may be flawed in that those couples currently experiencing severe marital problems are unlikely to submit to the type of phenomenological interviews that they undertook.

The social construction of medical knowledge and politics of disability

It is not possible in an essay of this length to provide a full account of the politics of disability, primarily since the topic is multi-factorial, fluid and indeed is covered to an extent in the other sub sections of this work, furthermore we have insufficient data from the narrative to comment in depth. Kitchen and Wilton (2003) comment that our views of disability as a medical entity viewed in paternalistic terms have changed in favour of equality and empowerment. However Francesca can expect to experience a host of politically related issues, for example social exclusion and poverty (Foley & Chowdhury 2007).

Francesca has already stated in her narrative;

I've got to work- we need the money.

In terms of medicine's social construction, as far back as 1982, Wright & Treacher (1982) claimed that medical knowledge inevitably contains a social component incorporating moral values and prejudices, and that diagnosis ascribes a certain meaning. We still see this thirty years later where the GP abruptly (allegedly) advocates of drugs to preserve normal function. This reinforces the paternalistic medical approach. RA in its early stages does not present with any obvious physical deformity and affects the young demographic, it is conceivable that she may experience disbelief from her peers; this may in turn make her life difficult in an era of financial unease, Government budgetary cuts and political uncertainty.

Labelling.

Labelling theory (social reaction theory) has its roots in the work of sociologist Howard Becker (Becker 1997). It centres on peoples tendency to negatively label those who are different from ourselves. As a person with chronic arthritis Francesca will not be immune to this labelling, for example being labelled as " disabled" or " arthritic" are all real possibilities. Arthritis organisations and acts such as the Disability Discrimination Act (DDA) are at great pains to encourage activity and maintenance of full function and contribution to society, however all this may be negated by her GPs comments that there is;

no cure and I had to take tablets everyday to be able to function normally.

Labels can however be positive, Francesca describing herself as “glamorous” for example on two occasions in the narrative, and her previous label of salsa dance teacher is something that defines her in a positive way.

Yes, I’m a salsa dance teacher

Stigma

Stigma has recently been defined by Scambler (2009) as “ a social process, experienced or anticipated by exclusion, rejection, blame or devaluation that results from experience, perception or reasonable anticipation of an adverse social judgement about a person or group”(p441)

Francesca may feel stigmatised by all of the factors previously discussed, attitude of her GP, loss of self, worry about the future, inability to act out the role of spouse. Factors such as depression, the lack of a cause for her RA and her inability to teach salsa dancing may amplify her feelings of being stigmatised, it is also important from the wider perspective to acknowledge that stigma may affect Francesca’s partner. Struening et al (2001) for example reported that 43-92% of caregivers (to people with mental health problems) reported feeling stigmatised, again this suggests that living with this disease does not only affect Francesca but also her partner.

Conclusion

This essay has employed extracts from the narrative of a 38 year old lady with Rheumatoid arthritis, to illustrate some key sociological concepts. The essay has provided a valuable opportunity to map some key concepts from the literature onto a narrative excerpt. Whilst the essay has not been able to enter the field in great depth; It is a testament to the thick description

provided by patient narratives that such a wealth of information can be generated from a relatively short piece of description.

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Appendix Reflective postscript

This is written in the first person since it is a reflective piece of writing

This was a challenging yet fascinating project to complete. I was unsure how to approach the topic and how much weight to attach to the various theories available and the comments of Francesca , once it became clear that I was actually trying to explain what was going on with Francesca by using

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academic theory to illustrate her comments the task became rather enjoyable. Tight word count restrictions as always meant that I had to do some brutal editing, but the positive side to this is that it makes one more selective in ones writing. For example my earliest version was heavy on sociological theory and light on mapping this theory to the comments of Francesca, whereas the final version makes more explicit links between what Francesca says and the theory behind why she says it.

The fact that I had some real comments to sink my academic teeth into made the process of literature searching interesting and relevant since I was able to think about Francesca's comments and her personal situation for each search that I undertook.

The areas that gave me most difficulty were the political aspects of disability since they seemed so wide ranging and actually intertwined with everything that I was writing about. All in all I have learned a great deal about the usefulness of narrative form this project.