

# Image management for women, with invisible chronic illness, in the various aspects of life.

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## Abstract

Image management for the chronically ill woman in her various roles in life is, at best complicated and at worst can be a nightmare. This is particularly the case for those with unseen chronic illnesses. The "unseen" aspect of illnesses such as multiple sclerosis, crohn's disease, arthritis and chronic fatigue syndrome (to name just a few) mean that individuals devote considerable energy to the process of managing the way they are seen and perceived in the various facets of their lives. Concepts such as 'passing' and 'covering' are important aspects in the management of a chronic illness. The manner in which individuals employ these "tools" to manage their image in the different aspects of their lives is impacted significantly by the social reactions of family, friends and colleagues to their illness. This paper examines a narrative of a woman whose chronic illness flared for a period of months and how she approached the management of this sudden and unprecedented flare at work, at home and with friends. Discussion will address the theories relating to illness, specifically chronic unseen illness and the sick role and why it doesn't explain well the process of an invisible chronic illness. This paper explores the reality of unseen chronic illness and its impact on the roles of women at home, at work and with friends.

## Introduction

Women in today's society take on many roles, often as family member, colleague and friend, among others. When a "deviant" sick role is added to this, the opinions, reactions and observations of colleagues, family and friends can substantially influence the ability of the individual to manage her many roles and perhaps more importantly manage her image.

This paper will use a narrative approach to draw together the experiences of the author, who after suffering a severe bout of Crohn's disease paused to reflect on the impact this invisible chronic illness had on the relationship with individuals closest to her. Notions such as passing, covering, the sick role and the deviant sick role are discussed in relation to the events surrounding this event. This paper looks at a cross section of a woman's life and discusses tensions that illness places on the various roles she undertakes.

Other authors have limited their discussion to one particular aspect, such as illness in relation to work or family life. This paper attempts to focus on the whole woman and the impact that chronic illness, specifically, invisible chronic illness has on each aspect of her life.

## Methodology

Chronic illness has a profound influence on every aspect of an individual's life. Using a narrative approach provides a greater understanding of these influences and the interconnectivity between each of them. "Narratives are constellations of relationships (connected parts) embedded in time and space, constituted by causal emplotment [the pulling together of selected events]" (Somers & Gibson, 1993). The use of narrative gives information which is better situated as it is framed within its context. "Narrative demands that we discern the meaning of any single event only in temporal and spatial relationship to other events" (Somers & Gibson, 1993).

"Narrative is the fundamental scheme for linking individual human actions and events into interrelated aspects of an understandable composite" (Polkinghorne, 1988). The opportunity to learn from events and the relationships between events is enabled through the use of narratives. This is particularly useful when looking at illness as the impact it has on the life of the individual is influenced by the various life situations and the reactions of others in those circumstances. Polkinghorne (1988) comments that "[n]arratives exhibit an explanation instead of demonstrating it".

## What is invisible chronic illness?

Bury's (1991) definition is used as a starting point for this paper: "chronic illness is...a long-term, and perhaps permanent event in a person's life". The addition of the invisible component to this definition seems quite simple as if it wouldn't require a great deal of adjustment to the definition. However the implications of an invisible chronic illness require that this definition be broader and provide a greater scope to ensure that the reader obtains a better understanding

of the implications of these insidious and often misunderstood illnesses.

Vickers (1997) states that “invisible chronic illness might be described as an ongoing medical condition, which impacts on the physical, emotional, judgemental or cognitive attributes of the individual”. This definition begins to extract the essence of the far reaching nature of a chronic illness as it highlights the impact such an illness has on the various aspects of life.

It would be nice to assume that the difficulties of illness are limited to those particular vagaries of that illness, but in fact the physical characteristics are only one nebulous layer in the trifle<sup>1</sup> the makes up the constantly changing life of an individual with invisible chronic illness. The individual quickly learns that managing the illness and managing your image as one with illness, are two concepts which are inextricably intertwined (a lot like trifle). The process of learning this after the diagnosis can provide a painful and yet necessary learning curve. Sadly, necessary only because of the society in which we live. Bury (in Anderson and Bury, 1988) comments that there are a “...host of possible social and emotional uncertainties for the individual, in addition to physical disability. Suffering the onset of symptoms involves changes in the body and in social relationships which are already likely to be complex”.

“Society is inclined to see an illness, not just as being the responsibility of the individual concerned, but also as a failure on the individual’s part to adhere to exercise or hygiene regimens, or appropriate diets” (Turner, 1995). Turner (1995) then goes on to say that illness is often understood, by society, “in individualistic terms rather than in terms of environmental and social causes. Illness is seen to be the personal problem of the worker often resulting from his or her moral failing”. Contrary to this, is the view that many people with chronic illness see themselves as being basically healthy (Bury in Anderson and Bury, 1988). This highlights one of the many disconnects endured by those with invisible chronic illness.

### **To disclose or not to disclose...**

A difference between invisible chronic illnesses and other more readily seen chronic illnesses, is that the person with an unseen illness generally has a choice regarding whether to disclose this illness to her family, friends or colleagues. However, individuals “may find that a recent exacerbation of their condition may necessitate frequent visits to specialists, hospitals or rehabilitation centres for treatment. Frequent workplace absences require explanation and may

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<sup>1</sup> Trifle is a dessert made up with layers of fruit, diced cake, jelly or jello, custard and cream.

precipitate a frank admission to an employer” (Vickers, 1997). These circumstances may necessitate “coming out” or revealing the illness, hopefully, in a way that suits the image of the individual.

One of the main influencing factors in the decision to disclose her illness to others is the stigma which she fears she might encounter. “Fears of stigma and discrimination derive not so much from the disability as from the significance accorded to the condition by others” (Bury in Anderson and Bury, 1988). Myers (2004) noted that “coming out [or disclosing] as a person with illness... was far more complex and intricate process than [she] had imagined”. Some of the factors that Vickers (1997) cited for disclosure include “an aid to self esteem, empowerment and coping; for the edification of colleagues; or, a blunt refusal to accept the mantle of stigmatisation”.

Choosing to disclose as a step in refusing to accept stigmatization is far from the norm and many more individuals choose not to disclose their illness until they have considered their options while others will not disclose their illness until they no longer have the choice to hide their symptoms (Vickers, 1997). The majority of individuals faced with these circumstances react in comparable ways, this is supported by Goffman (1968) who states that “persons with different stigmas are in an appreciably similar situation and respond in an appreciably similar manner”. Continuing to pass or cover in order to conceal illness can be important to individual’s with invisible chronic illness for any number of reasons, including being unwilling to accept a sick role or deviant sick role in order to more easily manage their image for as long as they are able.

### **The sick role**

“Being chronically ill presents problems for anyone trying to work. Chronic illness does not follow the predictable route of warning signs, illness, recuperation and full recovery” (Vickers, 1997). This creates difficulties, when after disclosure of the illness has occurred, family, friends or colleagues tend to like to apply a sick role to the individual. However the sick role, as defined by Parsons (1951) “is framed by both rights and responsibilities for the one labeled sick and for society in general. The two rights are as follows:

1. The sick person is exempt from the performance of normal social role obligations
2. The sick person is exempt from being held responsible for being sick.

The two responsibilities imposed on a sick person are as follows:

1. The sick person should be motivated to get well quickly.
2. The sick person should seek technically competent help and then cooperate with those experts” (Parsons, 1951 as cited in Myers and Grasmick, 1990).

According to Parsons (1951) these rights and responsibilities make up what is known as 'the sick role'.

It is widely accepted that the sick role is limited in terms of its applicability to chronic illness. However in the absence of a socially acceptable sick role for those with chronic illness many people are confused and unsure of how to treat an individual with unseen chronic illness. Parsons in Turner (1995) "argues that permanent incumbency of the sick role should be regarded as a form of social deviance" viz resulting in a deviant sick role (Turner 1995). As unflattering as the term deviant sick role seems it still does not fit the role of an individual with unseen chronic illness. Where a woman has choice about revealing her illness there is initially no type of sick role as she is considered to be 'passing' (Vickers 1997, Myers, 2004, Goffman, 1963) as normal and when her illness flares there might still be an option for her to 'cover' (Vickers 1997, Myers, 2004, Goffman, 1963) her illness in order to appear well. It is only once she has disclosed her illness and her illness flares or relapses that it becomes obvious that she doesn't fit society's expectations of being ill, receiving some kind of health care and ultimately recovering.

### **The experiences of the author...**

I have been diagnosed with Crohn's disease for more than 15 years. The situation examined in this narrative involves a flare of the disease which occurred in the later half of 2006. I became ill quite suddenly, and found that despite my best efforts I had very little energy and lost quite a bit of weight in a short space of time. Throughout the worst three months of my illness, I didn't ever think it would take longer than a month to get better, however it did.

Following is the author's own reflective narrative on her experience of invisible chronic illness.

#### **Image management at work**

"One may expect a certain amount of callousness in modern organisations" (Vickers, 1997). This combined with an uncertainty of how colleagues would react when they understood the full extent of my illness has resulted in my employing a policy of gradual disclosure and to certain degree, desensitization. Through this process I had developed an awareness with my colleagues and my boss that I already had some health issues when I had a sudden and unprecedented flare of Crohn's disease.

I was extremely fortunate to have an understanding boss, a job which I could largely do from home, and supportive colleagues. Initially I approached my boss and asked for some time off, thinking at the time that I was quite ill with a flare but should be right in a few weeks. 1 month later I again spoke to my boss and

made some additional arrangements about work because it was becoming obvious that I was indeed suffering significantly and probably wouldn't be able to work at work for about a month (or so I thought). I negotiated my work for the remainder of the semester. We discussed what sick leave I would need to take, how I would manage my work and what I would endeavour to do in terms of going in to work for meetings. During my illness I went to my place of work from time to time, during these visits I attempted to 'cover' my illness, even though the environment there was very supportive in an attempt to manage my image. For the individual with an invisible chronic illness who is passing or covering even the deviant sick role doesn't fit. I feel that this is in part because I didn't want it to fit any kind of sick role.

There is no doubt that my stress levels during this time were mitigated by the lack of stigma I was exposed to (Myers, 2004, Goffman, 1968) and the support I received from my supervisor and colleagues. Unfortunately both the literature on this topic and the narratives of others, who have endured unseen chronic illness in its myriad forms, show that this is far from normal. Myers (2004) felt compelled in her circumstance to prove her "normalcy and productivity", showing that despite the fact that she decided to disclose her illness she still was making a significant effort to manage her image. Possibly her strategy was one of risk minimization in case she experienced a flare of her disease whilst attending an important residential school.

Stigma can take the form of a perception of malingering (Vickers, 2001). One aspect that is unique to unseen chronic illness is that because it is invisible to onlookers there may be a tendency of colleagues to look for other explanations for the behaviour of the individual. Malingering or delusions of illness may be the result of "the appearance of wellness in the bearer" (Vickers, 2001). This was not an issue that arose during my illness however, I was concerned that I might appear to be malingering and had my recovery taken any longer I had planned some informal ways of managing my performance so that I could be seen to be accountable resulting in yet another way of managing my image. I found that managing my illness in the workplace turned out to be an easier task than expected, however the image management I undertook with my friends was less straightforward.

#### **Image management with friends**

The lack of formalised structure in social circles makes image management among friends more complicated. I found that during this flare of my illness, the most difficult thing was to ask for help from my friends, I believe this was for two reasons. The first is that I didn't know what to ask for and I didn't want to look like a "whinger". My close friends are all aware of my

illness and are accustomed to my “dipping” out of society for short periods of time while recovering from flares of the disease (Bury, 1991). So when word got around that I was ill, my friends seemed to presume that it was nothing unusual. And in usual fashion gave me space, no pressure to do things, but neither did they call to make sure I was alright, as I believe there was an expectation that after a couple of weeks I would resurface and join in with life again. After the first month passed and the worst of my flare was over, friends started to notice how much weight I’d lost and how little I was able to function normally.

To give the impression that no-one helped out is probably somewhat erroneous as one friend helped out by picking the kids up from school when I was unable to drive. Another made us a meal which was really fabulous while another friend would visit from time to time to make sure we were managing. And these things were important in their value as encouragement and validation (Millen, Petersen & Woodward, 1998) of the fact that I was ill.

I felt that I had lost my “voice” (Vickers & Parris, 2005) my family was in a situation where life was quite difficult for a number of months and I didn’t know how to change it. On reflection I believe that had I been well enough to formulate a strategy we would have been better able to manage my illness and the impact it had on our family and friends. Bury (1991) uses the term strategy to “refer to the actions taken to mobilize resources and maximize favourable outcomes”. The irony is that I wasn’t well enough to think through the issues sufficiently well enough to develop a coping strategy.

The image management I employed in this environment was limited to withdrawing from our social circles and not inviting friends to our house during my recovery. The strategy, if you could call it that, was basic and built around “getting by” rather than managing the illness process. But even with the limited social contact we had with friends, I rarely admitted how ill I was feeling and so ‘covered’ as much as I was able. I’m not sure if this was because I feared some degree of stigmatization or lack of understanding. This resulted in another situation where the deviant sick role (Turner, 1995) didn’t fit the role I had undertaken in order to image manage my illness with my friends.

### **Image management at home**

This part of the paper has been the most difficult for me to construct, particularly with reference to theory. Although sorting out the pertinent issues from our home life has been difficult to do, this part of the narrative is more circumspect. Initially I felt that I needed to fit in with the current thinking on the topic but then discovered I didn’t really care. This is my

own story, as fractured (Vicker, 2005) as it might seem from the outside.

Subsequently I re-read Vicker’s (2005) article which uses ante-narratives to explore the illness of women. She defines an antenarrative as something which is “never final, never complete, but gives attention to what is going on” (Boje, 2001 in Vickers, 2005). This, I thought, this is me, the way my family and I cope is as unique as our own family identity. We use humour as a way of coping and we don’t get hung up on things that don’t get done. If the house is a mess, and anyone dropped in, it was simply too bad. So here is the story from the perspective of my family...

My rapid precipitation into this flare of Crohn’s disease took all of the family by surprise. We initially adjusted the roles in our family from Mum and Dad sharing the load at home to Dad doing everything that needed to be done and anything that wasn’t of immediate importance was left undone. Bury (1991) notes that “... the severity and nature of symptoms, as well as the values held by the individual and the responses of others, help determine what it is that people must cope with”. My immediate family were very supportive, although my 5 year old son was less than happy with the changes to the household – possibly this had more to do with missing out on his favourite dinners than anything else. My parents made a weekly trip from their home (2 hours away) to help with cooking, cleaning and ironing, their support was invaluable.

Millen, Peterson and Woodward (1998) state that sufferers of Chronic Fatigue Syndrome (CFS) often have difficulty in “gaining initial and continuing full acceptance and support from even close kin, spouses, parents and siblings about their ‘mystery illness’”. While the diagnosis of my illness was clear. The form that this flare took was very unusual and there was no indication from my past experiences with Crohn’s disease how long this would take to pass. The unconditional support of my family enabled me to continue an adjusted form of work and also to continue with a limited form of socialisation with my friends. There was no passing in this situation and only minimal but necessary covering was instituted to help alleviate the children’s fears and concerns about Mum being ill.

“Sufferers [of CFS] have persistent fears of being called ‘malingerer’ as it serves as a milder negative sanction within the family... such a negative (deviant) label can erode a sufferer’s personal status and reduce self esteem very quickly (Millen, Peterson & Woodward, 1998). This is not something I had to contend with because of the support of my family, there was no need to manage my image within the family. This gave me the confidence and self efficacy to continue with my work despite the severity of my

illness. Millen, Peterson & Woodward (1998) go on to say that "...the family... are crucial for the essential care and emotional equilibrium of CFS sufferers in order to build and maintain positive esteem...".

The end result was, we did get by, however it seemed quite obvious to me that everyone in the family, were very glad when Mummy started cooking again, probably all for different reasons!

### Conclusions

I feel that in many ways I have skimmed across the surface of many issues. The type of sick role I enjoyed with my family was not a typical sick role or even a deviant sick role. I was given the freedom to be ill and allowed to heal as I was able without pressure to conform to the preconceived ideas of others, of what it is to be sick and how quickly to recovery should take place. The only pressure I received was from myself to recover and be able to fulfill my chosen roles of mother, wife, friend and colleague.

My aim in writing about my experiences with invisible chronic illness has been to extend the thinking on the topic past any one scenario, particularly in relation to work. These issues are multifaceted and impact on all aspects of a woman's life. Vickers (1997) notes that "the 'journey' associated with living and working with an 'invisible' chronic illness (ICI) is traumatic and poignant". This has certainly been my experience, despite all of the support from colleagues and family, just dealing with the image management issues was exhausting, without the added weight of the illness itself. Essential elements of this type of image management are passing and covering and they are critical for the image management of the individual with invisible chronic illness.

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