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Claire Kehoe

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**University of Limerick  
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## **The sociology of chronic illness: an experiential account of the benefits of a sociological perspective to students of medicine**

*Claire Kehoe*<sup>1</sup>

BM BS Graduate Medical Programme

*This paper presents an experiential account of the benefits of a sociological perspective to students of medicine. The University of Limerick Graduate Medical curriculum requires its students to follow a chronically ill patient from the community for 2 years. Informal meetings are set-up to allow the student to understand the impact of illness on the person's daily life. The sociology of chronic illness helps the student to understand the patient's interactions with their environment. The literature provides illuminating sociological concepts such as, the reconstruction of self, resilience and compliance, isolation, religion and an understanding of the importance of patient narratives. The impact of a long list of illnesses on patients is analysed by sociology. Progressing further, external factors are also taken into consideration: the importance of family, the views of the medical profession. Through the sociology of chronic illness, medical students can get a much better understanding of the overall experience of the patient. This knowledge goes beyond the medical aspects and is extended to the place of a chronically ill person in society.*

### **Introduction**

The Limerick Graduate Medical School is a newly founded programme for mature graduate students. The shorter curriculum emphasizes students' autonomy with most of the learning being self-directed. The ambitious aim of the course is to create modern Irish doctors following the path of other medical universities in the world. Emphasis is placed on the patient, with communication, law and ethics, public health and sociology being important parts of the curriculum. In the students' first year, a patient community project

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<sup>1</sup> I would like to acknowledge Dermot Bowens' contribution to the original essay, which this paper has evolved from.

is set up to allow students to follow patients for the next two years. Monthly informal meetings are organised between a pair of students and a particular patient. These meetings aim to raise the student's awareness of patients' everyday experience of chronic illness. The focus is centered on how the patient overcomes, or struggles with, the illness throughout his daily life. As the project does not focus primarily on the medical side of the illness, it is argued that the sociology of chronic illness is able to shed some useful light on the position of the chronic patient in society. This sociological paper presents a reflexive account of the manner in which a sociological understanding of chronic illness provided a medical student with insights into the experiences of the community project patient.

The paper is composed of two sections. The first section introduces the reader to the literature relevant to the sociological experience of chronic illness. The main points considered are the current state of the sociology of chronic illness, the more recent focus on the ill person's narratives, the subjectivity of these narratives and the ill persons' coping strategies. The second section presents an account of the manner in which sociological theories were usefully applied to the more hands-on aspects of the community patient work.

### **Sociological Literature and Chronic Illness**

The literature shows a progression in sociological approaches to chronic illnesses (Pierret 2003). Initial research was centered on the notions of stigma and shame felt by the ill person. The central notion is society, the patient coming second. The patient's exclusion from society is one of the main points of study (Scambler and Hopkins 1986).

As sociological studies went on, the ill person themselves became of central interest. The patient's stories became prime sociological material. The ill person

was listened to and was valued while telling his lived experience of the illness. Illness narratives show how the ill person's life is changed, 'disrupted' by the illness (Bury 1982; Bury 2001). A long list of chronic illnesses became the focus of the sociology of illness: rheumatoid arthritis (Bury 1982), HIV infection of homosexuals and hemophiliacs (Carricabaru and Pierret 1995), chronic muscular pain (Werner et al 2004), epilepsy (Scambler and Hopkins 1986), Alzheimer's disease (MacRae 1999), and Thalassaemia Major (Atkin and Ahmad 2000). Bury (1982) also focused on the medical system describing it as an ambivalent entity for the patients, providing rationalisation but also controlling the meaning of the illnesses. He then studied the effect of the illness on family coherence, employment situations and patients' identity and value of self.

A recent focus of the sociology of illness is the subjectivity of the illness. Illnesses impact on the maintenance of a functioning identity that fits the person's social role and maintains the integrity of the person's self. The patient's identities are disrupted by the illness experience but hopefully can be rebuilt fully or partially. The process of 'reconstruction' described by Williams involves recreating a functioning self 'using present, past, own beliefs' related to the illness progression and triggers (Williams 1984). The social class, gender and age of the ill person are important factors impacting on the success of the reconstruction of self (Charmaz 1983; Bury 1982). Older people seem to be able to reconstruct their identities better than younger people. Another success factor in the reconstruction of self can be linked to the degree of conjuncture between the identity associated with the illness and the person's previous identity: people with hemophilia who contract HIV seem to experience a lot more difficulty in rebuilding their sense of self than gay men who become HIV positive (Carricabaru and Pierret 1995).

As the narratives show, an ill person must develop coping strategies that impact on simple things in their everyday life or change their entire existence (Charmaz 1983). The uncertainty of everyday life is also influenced by the uncertainty of the medical world because the patient expects a “scientific” and definite diagnosis. The ill person might cope with the illness by trying to influence or “bargain” over the diagnosis (Scambler and Hopkins 1986). Most chronic illnesses seem to prevent ‘normal’ life. The ill person often lives a very limited life “living a restricted life in social isolation and becoming a burden” (Charmaz 1983). The isolation is more painfully felt when the ill person lives alone and social isolation is further added to the existing physical loneliness. Family members may adopt varying attitudes to chronic sickness (MacRae 1999). Some family members completely deny the illness and even condemn medical professionals for the occurrence of the disease. At the same time, heroic female family members, generally a wife or a mother, often bear the full weight of primary care, looking relentlessly after the ill relative (MacRae 1999). Other chronically ill persons cope with a chronic illness by joining support groups. While medical professionals are sometimes seen as helpers or a hindrance; support groups appear more neutral (Bury 1982). Coping with chronic illness involves using existing support resources or creating new ones, such as the powerful HIV positive political groups (Carricaburu and Pierret 1995).

The last approach to chronic illness introduced in this section is the macro level perspective. In society, illnesses are also shaped by health policies and system of care. Several studies have been done on the inequalities of health that affect illnesses (Bury 2005). In addition, the stigmatisation of long-term illness, which mainly appears to be motivated by fear and ignorance of the illness, can be addressed by societal efforts to educate the ‘stigmatisers’ (MacRae 1999). The medical professionals and the media have a very important role to play. The media play a very biased role in the stigmatisation process. They have an all-

mighty power in promoting models of health and beauty that don't take illness into account.

### **The Chronically Ill Community Patient**

This section of the paper focuses on the author's experience of the utility of a sociological perspective in community patient work. The aim of the community patient project is to raise medical students' awareness of chronic illness. The main focus of the project is on developing an understanding of the impact of chronic illness on the ill person's daily life, and not the medical aspect of the illness. This section demonstrates the manner in which the sociology of chronic illness illuminates the meaning of the experiences and events which were related to us through the interviews held with our community patient every month. C.S. is pseudonym of the community patient we met once a month. The gentleman is in his sixties, but appears older. He has been diagnosed with various autoimmune diseases since childhood. These progressing diseases have lead to the culmination of the illness into a life-threatening cardio-pulmonary condition, necessitating a heart operation.

Many aspects of the patient's narratives can be illuminated by the Sociology of Chronic Illnesses as introduced in the first section. The various chronic illnesses affecting the patient must have caused him to revisit his sense of self continuously since childhood. Speaking with reference to a group of patients who had hemophilia, Carriburu and Pierret argue, "we cannot talk about biographical disruption because these men had organized their biographies around their illness trajectory" (Carriburu and Pierret 1995). Likewise, C.S. has most likely been rebuilding his sense of self again and again over time. Some of his illnesses came and went, some stayed. One illness in particular, is affecting the patient on a long-term basis. The patient has digestive problems and must be follow a severe diet. The impact on his life is fairly important and disruptive as

described by Charmaz (1983). The patient must be careful all the time about his food, be it in a family setting or in public setting. This creates a sense of difference and isolation. . As he recalls ‘my brother told me to take some normal bread, I took a slice of brown bread and had a few mouthful. I was sick straight away’.

Throughout his illness, his most important support is a family that nonetheless seems to have an ambivalent role (MacRae 1999). His parents and siblings are very close and very supportive but sometimes seem to deny his illnesses. He tells us in one narrative how one of his brothers said ‘How come you are the one who gets all these illnesses in the family’. The patient understood this statement as a denial of the diseases. This is interesting given that another family member died of similar illnesses some years ago. According to Power and Dell Orto (2004), family members show different attitudes toward disease. Ambivalent reactions from family members can however be generated by insufficient knowledge of the illnesses.

Our community patient suffered from various lengthy chronic illnesses but he was also hit by a relatively rapid heart failure that left him bed-ridden for a lengthy period of time. This recent episode appears to be the most important in all his narratives. He provides extensive details of the decline of his health, of his isolation from his friends and family, of the forced abandon of his beloved hobbies. His last acute illness seemed to have provoked the most painful reconstruction of self. Charmaz’s (1983) “...consuming thoughts of illnesses” completely took C.S. over before the resulting surgery. Following the chronological progression of C.S.’s illnesses, Power and Dell Orto’s (2004) arguments about coping strategies can be applied. The coping strategies of the ill person and his family have to be progressively adapted to his state of illness. Other sociological understandings also apply, emerging from the development

of the acute phase. Medical professionals have a paramount importance for C.S.; adherence and compliance are absolute fundamentals of his narrated self. As mentioned previously, the relationship with medical professionals and particularly his GP are of utmost importance (Charmaz 1983). Werner also mentioned the importance of caring and supportive doctors for patients' self-esteem (Werner et al 2004). Our community patient relates that his GP prepared him physically and mentally for weeks for his surgery. A striking contrast exists between the all-positive self-image promoted by his General Practitioner and his family and the restricted life he led at the time.

Although he is a very happy and outgoing person, C.S. has experienced significant loss. Within a few years, he lost three close family members. A young relative also became permanently disabled by an accident. Nevertheless his religious faith is profound. Atkin and Ahmad (2000) indicate that faith is a very important coping resource enabling ill persons to make sense of the illnesses.

Although C.S. was mentally and physically ready for the surgery, he had to wait past the appointed time of his operation. The life-saving surgery was postponed for several weeks while his quality of his life was further deteriorating. As a public patient, he had to wait for the operation while his GP continuously campaigned for funding. Bury (2005) describe the inequalities of the health system that patients have to face and how society unequally relates to disease. Although this paper focuses on the impact of chronic illness on patients' lives, rather than macro-level health inequalities, this incident is worth mentioning as the waiting and uncertainty of the health care process added greatly to the profound disruption of self that C.S felt at the time.

## Conclusions

The sociology of chronic illness sheds important light on our understanding of patients' illnesses. Although the initial sociological literature focused on the shame and stigma felt by ill persons in society, more recent studies emphasize the patient's experiences as prime sociological material. The literature dealing with the ill person's sense of self, the influence of illness on relatives and the importance of the patient's social and medical environment is extremely relevant to understanding the experiences of our community patient. Each meeting allows us to gain a more meaningful view of the person's illness trajectory. Resilience, compliance and religiosity are also strong components of the patient's narratives elucidated in the sociological literature. Our own perception of our patient is greatly enhanced, evidencing the merit of several important conclusions of the sociology of chronic illness such as the importance of narratives, the disruption and reconstruction of self, and the role of the medical environment. Subsequent meetings with the patient acquire a deeper meaning as the patient's interviews are strongly illuminated by sociological research and literature.

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