Preface

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Biographical Disruption

During the 1960s and 1970s mainstream sociology had little interest in health and medicine, at least in Britain and other European countries. The few sociologists who were interested in these subjects worked in academic departments of public health, primary care and psychiatry. Research funding tended to reflect the preoccupations of these medical specialties. Two main features of a changing health (and health care) landscape were evident. The first was a marked 'epidemiologic transition' from a period of morbidity and mortality dominated by the infections to one characterised by chronic disabling conditions. Although HIV/AIDS later reminded everyone of the power of infections to alter the social fabric as well as people's lives, even here the passage of time turned the disorder into a chronic one to be managed, rather than biomedical problem demanding a cure.

Second, a steady and irreversible 'demographic transition' was underway, as fertility rates fell year by year and average life expectancy rose. This process was accompanied by greater survival among older populations, as mortality rates in later life also improved. The result was not just an ageing population, but one where the 'oldest old' grew more rapidly than any other section of the population. Although this was most evident in developed societies, it was an emerging theme in developing ones as well. Assumptions about health, medicine and society were being reconsidered, not only in medical practice but in the social sciences that were feeding into research, and, in cities such as London, into medical education.

Another crucial factor contributed to the development of sociological interest in (chronic) health disorders during this period. Much descriptive epidemiology and official statistics were meeting the challenge of documenting changing patterns of illness and disability. In the latter case, where trauma and the effects of war injury had been the preoccupation of rehabilitative medicine, now disability among the elderly was the main priority. However, despite the value of official statistics and sensitive measures of physical and cognitive function, the social context and day to day realities of living with chronic illness were all but absent from the research agenda.

During in the 1970s, first in the U.S. (in the research of Anselm Strauss and his colleagues) and then in Britain, a number of themes emerged from closely observed sociological studies of everyday life among those living with chronic illness. In my own case, interviews with those living with rheumatoid arthritis, in their own homes in the North West of England and at the clinic where they were treated threw into relief the disruptive nature of the illness and emerging disability. The interview data showed that almost invariably life was seen in terms of a ‘before and after’ bifurcation. The ‘assumptive world’ of the individual and of those to whom the person related was seriously compromised. But it was also clear that the patients I met did not simply react; they actively responded. New strategies were formed, successfully or otherwise, in attempts to mitigate the intrusiveness of symptoms as far as possible.

One of the main aims of this work was to indicate to health care providers that managing chronic illness was not simply a matter of devising appropriate drug regimens or other forms of treatment, however important these were. Indeed, in turning to professional help many patients sought an authorative warrant for the altered state of their everyday lives. Whilst help with physical functioning was of utmost important, so, too, was the need for understanding in the work of building or rebuilding a different form of life. The implications of this research showed that medical management needed to go with the grain of everyday activities that patients undertook in order to overcome ‘biographical disruption’. It also indicated to mainstream sociology that disruptive events such as chronic illness were important windows on the social fabric and on social interaction.

Since the publication of these early papers and books a range of studies appeared in the 1980s and nineties. For those interested in this literature a useful website can be found at: http://bit.ly/90fRn8. Some of this literature has extended the range of disabling illnesses to include studies of stroke, diabetes, Parkinson’s disease and other major conditions. This has provided a more nuanced and detailed picture of daily life of with chronic illness. The impact on family and significant others has also emerged more clearly. Whilst medicine has tended to treat individual patients as discrete entities, life with chronic illness invariably involves social dynamics – how and when to communicate information about the illness, how far to expect or ask for help, the limits of tolerance of others and the like. The strategies and tactics employed by those living with long term illness require constant attention. The ‘unending work and care’ in such circumstances, has a poignancy that simply talking of ‘managing illness’ fails to convey.

Several lines of debate have developed as the literature has built up. Perhaps the sharpest has concerned the relationship between disability and chronic illness. Some writers in a ‘disability activist’ vein have objected to what is a seen as a medical bias in sociological research. This, it is sometimes alleged, cuts across the need for a politics of disability where rights and political action are needed, not medical intrusion. For some this may well be true, but much disability is caused by the kind of diseases mention above, and their medical dimensions remain a reality for many. In recent years the boldly drawn line between medical sociology and disability activism has faded somewhat, as the complexities of chronic disorders, especially among older people have become more evident.

This brings us to a second point. Research since the 1980s has extended the age range of some of the original studies, such as that of my own on arthritis.

Although some of my original respondents were elderly, several were middle aged. This has led some to argue that 'biographical disruption' is more evident among younger rather than older people, especially those from poorer backgrounds. Among such latter individuals it is argued, the onset of illness (for example, having a stroke) is one more problem in a generally problematic social setting. From this viewpoint, age and social circumstances are important dimensions in shaping illness experience. Indeed, it has been alleged that insufficient attention has been played to the material circumstances in studies of chronic illness. In my original paper, and in subsequent writing on the topic, I did emphasise the nature of available resources in attempts to fashion appropriate responses, but it is arguable that much of the research in the earlier period was concerned with interactional difficulties and attendant social strains in living with chronic illness.

Finally, critiques of the notion of biographical disruption have argued that continuity is more evident among those with chronic illness that I allowed – this is sometimes referred to as 'biographical reconstruction' or 'biographical flow'. Studies of illness narratives have argued that various discursive tropes are frequently employed by those living with illness, in order to help maintain a sense of normality, or even achieve a different form of identity. Of course, the accounts that people give of their experience in illness narratives are essentially 'speech acts', and stand in a complex relationship to the realities of experience. But such analyses provides an important vantage point (as ever, in need of careful interpretation) in furthering our understanding of chronic illness and its ramifications.

I hope these brief remarks we help as a preface to the articles that follow. The debates about biographical disruption underscore, it seems to me, the continuing importance of chronic disorders and ageing in understanding our fast changing societies.