

Chronic illness: epidemiological or social explosion?

As befitting a new journal devoted to chronic illness, Carl May's essay addresses the wide-ranging implications for patients and their carers of this form of illness. It is the 'epidemiological explosion in chronic illness', he argues, that has disturbed traditional forms of clinical practice and brought about new opportunities for involvement by patients in managing their own problems. This epidemiological explosion, it is claimed, has had widespread social effects — substantive enough to merit extensive research and a stream of reports, many of which will now flow to this new journal. There is, however, one important flaw in this otherwise plausible thesis: the evidence for the 'epidemiological explosion in chronic illness' is very weak.

It is certainly true that the extensive literature on the (increasing) prevalence of chronic illness has only appeared over the last half-century. Indeed, chronic illness was only recognized as a classification term by *Index Medicus* in about 1950. But the relative recentness of this recognition does not mean that chronic illness did not exist prior to 1950 or that it significantly increased in extent following this date. So, what is the evidence for an 'epidemiological explosion' in chronic illness in the latter half of the twentieth century? Clearly, using the growing literature on the problem is entirely circular. As noted, a major expansion in the literature on chronic illness does not equate to an epidemiological increase.

Another way of asking the question is to enquire whether, compared with the past, there are more of those chronic pathological processes that make up today's category of 'chronic illness'. But even this question is difficult to answer. Since the mid-nineteenth century, there have been good mortality data for the population, with, it appears, increasing accuracy of recorded cause of

death, but of course chronic illness is assumed not to be a major cause of death, so these data are unhelpful. Ideally, surveys of morbidity could be examined to plot the changing profile of illnesses in the community over time: but surveys of morbidity belong to the chronic-illness era of the late twentieth century. Given these serious limitations of the data sources, there would not appear to be any supportive evidence for an 'epidemiological explosion' in chronic illness. Absence of evidence is not evidence of absence, but it takes a brave leap of faith to suggest that periods in the past (such as the Victorian) were not characterized by large numbers of people with chronic illnesses and disabilities.

Although the claim for an epidemiological explosion in chronic illness might not be proven (or testable), there clearly is evidence for an explosion of interest in the phenomenon. In other words, there certainly was an explosion in terms of rhetoric and debate (and classification change). From the early 1950s, a group of illnesses were thrust into the forefront of public consciousness; they were studied and reported upon, more illnesses were identified as 'belonging' to the group, and soon there appeared to be an 'explosion' in their prevalence.

What might explain this fundamental shift in perception? Ironically, May provides many of the answers in the way he describes the effects of chronic illness. He identifies a number of consequences of the increase in chronic illness, among which he lists a new attention to patients' experiences and personal agency, surveillance and monitoring of illness, and more regulation of professional work. But instead of labelling these as the effects of the appearance of chronic illness, they can be reconfigured as the drivers that made chronic illness such a socially salient problem. Indeed, these supposed

consequences can be re-read as the social processes that enabled chronic illness to be constructed as a major medical problem for our times.

Over the last few decades, there has been a sea-change in the place of patients in medical interaction, involving them becoming more active and experiential participants. There were early signs of this change well before the problem of chronic illness reared its head. Moreover, consumerism and autonomy have associations both with other types of illness and outside of medicine. Ethical concerns with patient autonomy, for example, emerged at about the same time as chronic illness. So did chronic illness 'appear', and bring about a new concern with autonomy and the new discipline of medical ethics? Or could it be that both chronic illness and ethics have their basis in the new social importance of autonomy?

And there is ample evidence that modern society is broadly characterized by audit and surveillance. Is that too to be placed at the fecund door of chronic illness? Or is chronic illness the ideal construct on which these forms of social management can be practised? Equally, the increasing regulation of professional work surely extends too far beyond medicine to support the contention that chronic illness was seriously implicated in its spread.

In short, the supposed consequences of the 'new' appearance of chronic illness often appeared many years before chronic illness itself, and the supposed consequences also manifested themselves in other areas of social life well beyond even the indirect influence of chronic illness. This must lend support to the likelihood that the appearance of chronic illness owes more to social rhetoric than pathological shifts, and that its appearance provided yet another point on which these various social imperatives could be articulated.

At more fundamental level, the appearance of chronic illness did not emerge in a conceptual vacuum. A key characteristic of chronic illness is that it exists over time. But a concern with time in clinical practice was

of increasing interest in the post-war years in the form of temporal problems and phenomena — from the new appointment systems in general practice (in the UK at least), through a concern with the use of time in the consultation, to the notions of continuity embedded in the extended consultation, personal doctoring and the promotion of effective patient records.

None of the above arguments is conclusive — the historical record does not work in such clear ways. Either there was an explosion in chronic illness that went beyond previous experiences of illness, and at the least propelled some nascent developments into major phenomena, while, quite independently, other temporal issues appeared; or chronic illness was a part of a post-war reconfiguration of medicine, a productive period in which the form, nature and target of clinical work were refashioned. Without evidence for an epidemiological explosion, the latter explanation seems more credible.

Does this matter, especially for a new journal such as *Chronic Illness*? Most studies reported in the journal's pages are likely to address the agenda that Carl May has clearly laid out — the relationship between chronic illness and patients' subjectivities and new forms of clinical practice. But a constructionist approach as described above opens up an additional line of enquiry that attempts to situate chronic illness in its proper social context. Thus, the publication of a new journal affirms once again that an important socio-medical problem appeared across medicine in the last half-century. But it also could celebrate a more nuanced view of chronic illness as both determined by and determining clinical practice. I therefore welcome the new journal, but invite readers to remember that, despite appearances, chronic illness is a product of socio-cultural forces that lie outside of medicine.

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