The Burden of Treatment and the Burden of Symptoms: the problem of workload and institutional boundaries in chronic disease

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Abstract

The discourse of self-care, so prevalent across the advanced economies, is formed around neo-liberal ideas about the changing nature of patient-hood. Self-government and self-sufficiency are crucial to this. But underpinning this reconfiguration of patient-hood are deeper structural shifts about the distribution, intensification and reorganization of work. Applying my work on Normalization Process Theory to the experiences of patients and their families, this paper explores the problem of work and workload in patient-hood, and examines the ways that as the boundaries between formal healthcare institutions and the informal sphere of the home and family become more permeable, the nature of patient-hood itself is thrown into doubt, and the patient and family find themselves increasingly constituted as casual workers in a fragmented healthcare economy.

Introduction *

In this paper, I am going to do three things. (a) I'm going to briefly recapitulate the policy problem of longstanding illnesses and explore some of their structural implications; (b) I'm going to introduce a theoretical model through which we can explore those implications; and finally (c), I am going to consider how that theoretical model leads us to take a slightly different tack in the way that we might think about some elements of patient-hood. All of this will involve some rhetorical conceits. It means that I am going to have to speak about patients as if they are homogeneous; illnesses as if they are undifferentiated; professions as if they are generalizable; and that I must pretend that services themselves are all the same. So, I am going to be speaking about very concrete things, in quite an abstract way. The paper is a conference plenary paper, and it is intended to review the course of my personal programme of research and publication over a period of years, and describe how my work has interacted with others.

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The policy problem: epidemiological and demographic transition, corporate transitions, and their consequences

Across the developed world health services are subject to political demands for policies and practices of modernization and reform in the face of growing problems of costs and coverage (Moran, 1999). Following from these problems of political economy are important shifts in the political epidemiology of problem populations, increasingly rapid socio-technical change in healthcare organization and delivery, and profound changes in the experiences of patients and their significant others. These changes have important implications for the ways in which patient-hood is, itself, constituted in the healthcare systems of the advanced economies.

Underpinning contemporary debates about the identity and expectations of patients is the sense that healthcare is at a cross-roads, and that this cross-roads defines more than the problems of demography and costs that policy makers—on both sides of the Atlantic—sometimes seek to make the focus our attention. Indeed, the current healthcare crisis can be characterized as the price that the advanced economies must pay for successfully overwhelming the mass of infectious and acute disease that winnowed their populations until the mid-twentieth century. Nevertheless, in those same advanced economies these successes are infrequently celebrated by policy-makers, who see in place of those winnowed generations an ever-growing cohort of older people with multiple chronic co-morbidities, and who require care over lifetime illness careers in place of cure for episodes of acute disease

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and who frequently experience multiple co-morbidities and socio-economic disadvantages (May, 2010a). The policy problem is therefore composed of a set of anxieties about the management of increasingly scarce healthcare resources, in the face of ever growing demands from increasingly complex patients (Holman, 2006). In fact, the epidemiological and demographic transition to longstanding complex illnesses brings in its wake a set of new kinds of problems not simply for policy-makers—but also for patients, their families, and the clinicians who work with them. I want to signal some of these new kinds of problems, and examine the impulses that have driven them.

Let us start with some things that are happening within healthcare systems. I want to point to structural changes that are derived from two main sources. First, the reconfiguration of professional-patient relationships as individual professional autonomy has diminished in the face of changes in the structure of healthcare organizations, knowledge, and practice over time. These are reflected in important changes in the character of personal relations between providers and consumers of healthcare services, which are increasingly regulated and governed by the corporate impulses of healthcare systems (May, 2007). Second, the industrialization of healthcare systems and the increasing convergence of their forms and functions with other kinds of organizational structures and processes. In this context, organizations work to minimize both costs and risks by the application of standardized human processes (clinical protocols, for example) and standardized decisions and choices (decision-making tools, for example), which rely on mediating technologies.

In other words, health care work is increasingly experienced and organized through economic and organizational systems that make health services rather like other kinds of services, and healthcare work rather like other kinds of work. In turn, these structural changes have led to important shifts in the ways that healthcare work is experienced.

> a. The *intensification* of activity within healthcare as providers seek to do more work, with fewer people, in less time, at lower costs. This leads to stricter patterns of corporate controls on practice for professionals and patients (May, 2007).
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> b. The *substitution* of algorithms for expertise, of protocols for autonomous practice, and of more qualified for less qualified staff. This leads to more highly regulated patterns of healthcare work (May, 2005).
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> c. The *penetration* of the domestic sphere by health technologies that do more than deliver treatment but that also monitor and timetable practices of self-care (May, 2010a).

This leads to more permeable boundaries between

> d. The *transfer of work* and the *delegation of responsibility* from formal divisions of labor within healthcare organizations, to patients and their social network—notably through the application of policy and practice around expert patients, and supported and unsupported self-care (May et al., 2009b).

This is a good deal more than rationalization within healthcare organizations, and a good deal more than cost shifting between different sectors of healthcare activity. Current political ideas about patient choices, shared decisions, distributed expertise, and citizen consumers do not necessarily configure well with these impulses—which focus on episodes of care for patient management at an individual level, and the management of throughput at a population level.

Talking about the ways that healthcare systems are changing—and they are changing rapidly—may seem to take us a little distance from the topic of this talk, which is about patient-hood. But we ignore these structural shifts at our peril, because they are every bit as important as the symptoms of disease in framing experiences of patient-hood. In fact, we can see in them the beginnings of a wholesale re-arrangement of the work of being sick and the beginnings of a reworking of the social contract between sick people and the professionals and organizations that care for them. Of course, I don't want to push the 'everything is changing' argument too far. Healthcare is quite a conservative business, and also quite a moral one. Intelligent people become health professionals because they want to help people in different ways, and not because they are case studies in behavioral economics and expected utility theory. Patterns of behavior in professional-patient interactions are historically and culturally very stable. Amongst patients, neither expectations of clinicians, nor the trust and esteem that they attribute to them, seem to have changed greatly over the past twenty years.

So far, I have set out some trends in the organization and delivery of health care. These are structural changes and they are important because they change the experience of sickness by changing the ways that patients, their carers, and wider social networks experience and act upon expectations and demands that re made on them by healthcare systems.

Experience is important too. Central concerns in the social and clinical sciences over the past four decades has been how people experience clinical signs and subjective symptoms, their understandings and beliefs about illness and disability; their psychosocial responses, adjustment and coping behaviors; the ways that they negotiate interpersonal interactions and asymmetries of knowledge and power with health professionals; and the individual factors that promote or inhibit adherence to treatment.

In this context, our understanding of lifetime sickness careers is currently dominated by studies of the relationships between the patient and the burdens of their illness. Some of these burdens are physical or are iatrogenic, others interpretive and psychological, others interactional and social, and still more are economic and political. There are multiple burdens of sickness that we have tended to understand in relational terms in which a person's interaction with the illness itself is at the centre of analysis. From the 'burden of symptoms' perspective social and clinical scientists have sought to understand the relational qualities of people's interactions with their symptoms (Tran et al., 2012, Eton et al., 2012).

The corollary of burden of symptoms might be the burden of treatment (May et al., 2009b, Shippee et al., 2012). Once we put these programs of work into changes in the wider structural contexts of healthcare that I have discussed earlier, then it begins to make sense to see patients not simply as 'patients', or even 'partners' in clinical encounters. Perhaps they are also 'co-workers' or even 'subordinates' to whom work is assigned that is often technically and organizationally demanding, and which may require not only a compliant patient, but also a co-operative social network. I now want to turn to the problem of patient work, and explore the ways that applying a theory of implementation, embedding, and integration of socio-technical practices might help us to illuminate the nature of this work.

Normalization Process Theory

At first sight, a theory of implementation does not look like an auspicious model to apply to patients' experiences of care. Normalization Process Theory (NPT) came about originally because I and others wanted to explain why some health technologies and complex healthcare interventions seemed to be easily incorporated in routine clinical practice and others did not. So, over a period of ten years, we developed an explanatory model of the social processes that are implicated in the work of implementation, embedding and integration. Over time, this grew from a local explanatory model of complex interventions to a middle range generic theory of the embedding of social practices (Schatzki, 1996) in their everyday contexts (May and Finch, 2009, May et al., 2009a, May, 2006, May, 2013).

This is not the place to give a detailed account of NPT, but put simply, it invites us to see the business of patient-hood not as a life project that involves engaging with complex work. Here, patient-hood is about the things that people do, as well as what they interpret, believe and experience.

Normalization Process Theory can help us to identify the domains of work that make possible the routine incorporation of patient work into everyday life (May, 2010b, May, 2010a). In this context, we can see the work of the patient—or indeed the doctor and nurse—in terms of four generative mechanisms and their necessary investments. It focuses attention on four areas of patient activity (Gallacher et al., 2011, Finch et al., 2007, Blakeman et al., 2012).

a. Processes of individual and collective sense-making in which sick people and members of their social networks seek to define and plan their work, and to internalize its requirements.

b. Processes of participation where sick people and members of their social networks act to initiate, legitimize and sustain different elements of their work, and to enrol others into it.

c. Processes of action in which sick people and members of their social networks allocate and execute specific tasks, negotiate accountability for their outcomes, and organize and realize the mobilization of resources that make their work possible.

d. Processes of individual and collective monitoring where sick people and members of their social networks engage in the systematic collection of information about signs and symptoms and about the views of significant others (for example professionals), undertake its individual and collective appraisal, and apply it to the reconfiguration of their work.

Sense-making, Participation, Action, and Monitoring define factors that can be empirically demonstrated to matter, as patients seek to engage with their treatments and which tell us something about the complexity of behavior change and self-care. Since, in chronic and longstanding conditions we really are talking about lifetime illness careers.

Using NPT changes the focus of interest then by asking us to look at the factors that promote or inhibit the routine incorporation of the delegated work that patients are asked to do in supported self-care, and the co-production of care related activities within hospital and other services. It also means that we can start to look at the effects of this work in a new way. *Action* (which is what the work of being a patient *is)*; requires actors (the individuals and groups that encounter each other to *do* the work); who in turn employ *objects* (the techniques, artifacts, and devices); and who do so in *contexts* (the physical, organizational, institutional, and legislative structures that enable and constrain, and resource and realize, people and procedures). Thus, when we talk about being a patient, we are often actually specifying *an active worker who possesses significant agency.* Talk about the *management of conditions specifies the management of persons.*

Work, workload, and burdens

Why does it matter if they (and their significant others) are really unpaid co-workers in the healthcare system whose job is to manage increasingly complex treatment modalities and technologies?

With my colleagues Frances Mair and Victor Montori, I have argued that we need to worry about work because work-load and work-content may be an important factor that *inhibits* self-care in chronic illness and co-morbidity, and co-operation and engagement with healthcare services in relation to episodes of acute illness (May et al., 2009b). We have called this problem *Structurally Induced Non-Compliance,* or SINC. This is a policy problem for clinicians, and it surfaces a fundamental problem for people who are ill.

Non-adherence to treatment regimens is frequently construed as an individual failure to follow reasonable instructions from the physician. Montori, Mair and I argue that a proportion of such patients present problems of SINC which do not represent patients' culpability in not following physicians' instructions, but rather their susceptibility to the iatrogenic effects of the burden of increasingly numerous, complex, and demanding treatment regimens and management technologies as they pass from the healthcare system to the home. We have demonstrated this is in studies of people with heart failure (Mair et al., 2012, Jani et al., 2013).

In this context, the compliance or otherwise of the *individual* patient is no longer the sole issue. Responsiveness to treatment and management may also require the involvement of family, significant others, and members of extended social networks on a spectrum between a minimum level of co-operation (for example in sharing dietary regimens with a person with diabetes) and a maximum level of active participation (for example, in managing multiple co-morbid conditions and interactions with healthcare providers and health insurance for a person who is severely cognitively impaired).

Understanding treatment burden, then, is not simply a matter of understanding the workload assigned to individual patients. It includes understanding the voluntary and sometimes involuntary participation of members of social networks, and the distribution of knowledge, practice and resources amongst them. Factors that dispose individual patients to be compliant with medical or nursing instructions are complicated by the effects of these wider social networks and—as Tim Rapley's brilliant analysis (2008) reminds us—by decision-making that is distributed in time as well as space.

a. Collective action: Increasingly requires both symptom management and service coordination work to make care workable and integrated. Workload increases as treatments multiply.

b. Cognitive participation: Work multiplies against a background of diminishing cognitive capacity and demands for increased support. Social networks are under strain as work is dispersed.

c. Sense-making: The work of understanding treatment and communicating needs multiplies in the face of uncoordinated care from multiple clinicians. Sick people have to mediate between powerful professionals.

d. Reflexive Monitoring: Evaluating symptoms and outcomes is complicated by fragmented information and incomplete knowledge. The healthcare system is indifferent to the patient's story.

The response to this problem ought to be something called minimally disruptive healthcare—a mode of thinking about patients (and families) that emphasizes co-ordination of both treatments offered and system level expectations of patients. Taking what the patient has to do, and their capacity to do it, into account in designing their care seems like a no-brainer. Indeed, we might say that it is the proper business of primary care to co-ordinate care and assess its impact. These are areas that we might wish to take an interest in, since patient behavior is framed by the structural constraints and professional expectations. A perspective on patient behavior that takes into account capacity to routinely incorporate practices of self-care and engagement with services reveals much about the interdependence of individual and collective contributions to successful patient outcomes, and also much about the ways that some patients heroically negotiate different kinds of socio-economic disadvantage.

Burden of Treatment Theory

Having focused on the problem of workload, we must now turn to the problem of the capacity needed to meet the demands of delegated clinical work. We can characterize this in several ways. In an important intervention, (Shippee et al., 2012) set this out in an arithmetical way, showing how the accumulation of complex experiences of care and self-care over time and the demands that these make on patients' capacity to meet their requirements leads first to poor adherence to treatment regimens and other forms of healthcare utilization, and then inevitably to poor health outcomes. In other words, increasing workload without a concomitant increase in capacity does not make sick people better, but instead reduces the chances of good outcomes.

Following from this, a formal theory of Treatment Burden was developed. This is a valuable addition to the conceptual armory of healthcare researchers because it specifies a set of important mechanisms that *support* sick people, and that add to their resilience. With colleagues (May et al., 2014), I argued that

a. Interventions that interventions that build and strengthen relational networks around sick people, and that equip them to more effectively navigate system controls and opportunities, are therefore likely to improve effective healthcare utilization.

b. Interventions that facilitate work to secure co-operation and social capital and so compensate for deficiencies in functional performance and improve structural resilience are therefore likely to increase capacity to take on delegated healthcare tasks.

c. Interventions that facilitate controls on the load of cognitive and practical tasks delegated to patients and their relational networks, and that monitor their effects, are therefore likely to improve capability to perform delegated healthcare tasks.

d. Interventions that maximize collective competence in enacting practical tasks, distributing help and exploiting local resources, and effect increased confidence in healthcare processes and outcomes, are therefore likely to reduce inappropriate demands on healthcare services.

Evidence in support of this comes from multiple sources, but two particular sets of studies appear to be of particular value. The first is a set of studies of long-term life-limiting conditions undertaken by Frances Mair's group in Glasgow (Jani et al., 2013, Gallacher et al., 2013a, Gallacher et al., 2013b, Mair et al., 2012), and that have culminated in a study of 1.5 million Scots' experiences of polypharmacy (Gallacher et al., 2014). The second is a systematic review of interventions intended to reduce hospital readmissions undertaken by Victor Montori's group at the Mayo Clinic (Leppin et al., 2014) and a set of developmental studies towards a measure of burden of treatment by David Eton, also at the Mayo (Ridgeway et al., 2014, Eton et al., 2012). Further empirical support for this perspective comes in a set of studies by Andrew Sav and colleagues in Brisbane (Sav et al., 2013b, Sav et al., 2013a).

Conclusion

The programme of work described here has contributed to our understanding of the experience and management of long-term and life-limiting conditions by presenting structural models that can help us identify, characterize, and explain important aspects of experiences and trajectories of illness. The most important of these is to begin to interrogate the hard work of being sick, and to explore this work in terms of the complex interactions that take place between patients and members of their social networks and healthcare providers. Understanding the dynamics of these complex and emergent relations is important because it will help us develop interventions that reduce demands on patients and their social networks and increase their personal and psychological capacity to endure adversity. So, in this talk I have tried to work together several rather complex problems and show the links between them.

Throughout the paper, I hope I have made the case for seeing health behaviors of all kinds as the products of organization through directed and disciplined agency. I have talked about how healthcare work is becoming steadily more demanding and complex, and that this is happening in parallel with a demographic and epidemiological transition that leads to sick people becoming sick for longer, as they grow older, and suffering a steady accumulation of co-morbidities. I have also talked about the importance of seeing people who are being patients as also doing work, not just for themselves, but for healthcare providers. That work may include the operation of self-monitoring or managing technologies as more conventional treatment modalities. Patients may be experiencing this as a gradual withdrawal of previously taken-or-granted services, but may not have yet got into the way of seeing it as work. I have then put these two contextual changes in the organization of healthcare into the frame of a theory that helps us to understand how social practices (of healthcare or of other forms of activity) are implemented, embedded, and integrated in everyday life. This led me to discuss the kinds of work that people do, and how these practices could be conceptualized.

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