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How does mental—physical multimorbidity express itself in lived time and space? A phenomenological analysis of encounters with depression and chronic physical illness



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ABSTRACT

Mental-physical multimorbidity (the co-existence of mental and physical ill health) is highly prevalent and associated with significant impairments and high healthcare costs. While the sociology of chronic illness has developed a mature discourse on coping with long term physical illness the impact of mental and physical health have remained analytically separated, highlighting the need for a better understanding of the day-to-day complexities encountered by people living with mental-physical multimorbidity. We used the phenomenological paradigm of the lived body to elucidate how the experience of mental-physical multimorbidity shapes people's lifeworlds. Nineteen people with chronic obstructive pulmonary disease (COPD) and depression (defined as a score >8 on depression scale of Hospital Anxiety and Depression Scale) were recruited from secondary NHS care and interviewed at their homes. Data were analysed phenomenologically using van Manen's lifeworld existential framework of the lived body, lived time, lived space, lived relations. Additionally, we re-analysed data (using the same framework) collected from 13 people recruited from secondary NHS care with either COPD, rheumatoid arthritis, heart disease, or type 1 or type 2 diabetes and depression. The phenomenology of mental-physical multimorbidity was articulated through embodied and emotional encounters with day-to-day life in four ways: [a] participants' perception of lived time and lived space contracted; [b] time and [c] space were experienced as liminal categories, enforcing negative mood and temporal and spatial contraction; and [d] time and space could also be customised to reinstate agency and self-determination. Mental-physical multimorbidity negatively impacts on individuals' perceptions of lived time and lived space, leading to a loss of agency, heightened uncertainty, and poor well-being. Harnessing people's capacity to modify their experience of time and space may be a novel way to support people with mental-physical multimorbidity to live well with illness.

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1. Introduction

1.1. Temporality and the lived body in the sociology of health and illness

Rapid social, cultural, political, and technological change of the late twentieth and early twenty-first century has propagated a rich

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strand of contemporary sociological research in which the body is located as a space in which a struggle between the symbolic self and the biological self is played out (Waskul and Vannini, 2006). The most mature expression of this embodied brand of sociology is found in the sociology of health and illness, especially in relation to accounts about the consequences of living with chronic illness for self and self-identity (Conrad and Barker, 2010).

Critical contributions stem from the phenomenologically inspired work of Strauss (Strauss et al., 1984) in which the concept of self-identity and the imputation of identity through interaction with others is rooted in the bodily basis of chronic illness in time and place (Kelly and Field, 1996). These themes run through, to a greater or lesser extent, biographical accounts of chronic illness

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which elaborated on how the onset of illness can disrupt and dismantle people's sense of ontological security, leading to uncertainty and impaired self-identity (Bury, 1982). Here, illness, by imposing new limits on the practical and social aspects of daily life, is perceived as restrictive (Williams, 1993), and much day-to-day activity is linked to dramaturgical displays to preserve self-identity and make sense of illness in the face of newly acquired bodily and social disadvantage (Charmaz, 1995).

For Charmaz the experience of chronic illness not only threatens the meta-narrative of one's life but is a challenge to the organisation and presentation of self over time (Charmaz, 1991). Her concept of temporal incongruence hints at the notion that illness can distort people's sense of lived time, leading to negative consequences for self and others. However the stock in trade of Charmaz's analysis tends towards explicating the logistical and cross-sectional use of time to strategically preserve self-identity in the face of illness as disruption. In this sense, while Charmaz took up the long ignored call to mainstream Meadian concepts of temporality in sociology (Flaherty and Fine, 2001), her interactionist accounts of the minutiae of daily life stop short of fully explaining how the embodied experience of illness can change the character of lived time and lived space (Toombs, 1988).

Biographical accounts lend themselves to understanding illness in narrative form – the storying of people's responses to illness often articulates a sense of a future life lost, and is often told as a story about restitution of the self by reconciling the past with the present (Carel, 2013a; Frank, 2013). More nuanced renderings of biographical and narrative accounts of chronic illness have since lent sociologists the conceptual tools to conceive of alternative illness narratives in which the future as well as the past and present can also figure (Sanders and Rogers, 2011). Rather than always being disruptive illness can be also construed by people as part of an unfolding biography; flow and continuity as well as a sense of repeated and anticipated discontinuity are thus also realisable in the presence of chronic illness (Faircloth et al., 2004; Larsson and Grassman, 2012). However, while on-going modifications to Buryian notions of biography underscore that the experience of chronic illness is not invariant in time and space the biographical mode of inquiry is presupposed on an overly reflexive model of self that privileges mind over body, thereby overlooking the embodied and emotional work invested in living with illness (Reeve et al., 2010).

Moreover, by maintaining mind-body dualism, biographical and narrative accounts of illness obscure the multi-faceted nature of space, time, and the body as it is 'suspended in webs of significance' (Geertz, 1973). While the thick description of Geertz offered anthropology scope to unpick these webs to reveal how people of all cultures become 'enselved' through bodily interaction in time and space, the sociology of time and space was, until relatively recently, under-developed and heavily influenced by structural perspectives (Urry, 2002). As such, much theorising in sociology of time and space has focused on explicating how the emergence of post-modern and post-industrial societies has led to varying forms of time-space shrinkage owing to the effects of advances in telecommunications, the availability of mass air travel, and the development of more rapid modes of production and consumption (Giddens, 1984; Harvey, 1989). While this tranche of work has contributed to unveiling the temporal and spatial character of human activity it has drawn criticism for not conceptualising time (or space) as a resource (Urry, 2002). Additionally, such a macro perspective is unable to untangle how the dialectical relationship between the embodied subject and the external world of people and objects can result in a changed sense of lived time and space.

The sociology of Michael Flaherty is a notable exception here (Flaherty, 1999). Drawing on the social psychology of Mead (Flaherty and Fine, 2001), his phenomenology of time consciousness offers a mediational framework to understand the linkage between subjective (i.e. individual) time consciousness and inter-subjective (i.e. social) temporal rhythms. Flaherty's analysis is told through the narratives of people exposed to illness. suffering, and emotional upheaval, with a view to understanding how the perception of time varies when moving from one social realm to another. In this way Flaherty has offered an analytical template to understand temporal paradoxes such as how time can seem to be protracted during periods of high as well as low activity, and how, through retrospective formulations about the passage of time, temporal experience can become compressed. He has since gone onto conceptualise ways in which 'time work' can be deployed as a resource (Flaherty, 2003), making his work highly relevant for the sociology of health and illness, not least in terms of understanding how the experience of living with long term conditions can change perceptions of time (and space), and how such temporal transformations can impact on people's capacity to live well with illness. As McCoy (2009) has since gone onto elaborate in her study of medication adherence among people living with HIV time work is part and parcel of the doing of self-management and adjusting to chronic illness, but how this concept is manifest and articulated in the presence of multimorbidity is however largely unknown.

1.2. Multimorbidity and the limits of self-management

Epidemiological shifts in the prevalence of chronic illness have led to major changes in the distribution and experience of illness and ill-health. In high income countries, and increasingly also in low to middle income countries, ageing populations are living longer with the effects of chronic illness and this has very real implications for organising and delivering care for people affected by chronic illness. Multimorbidity — the co-occurrence of more than one illness in the same person (Valderas et al., 2009) — is common, and the prevalence of mental health disorders in an individual increases with the number of physical disorders that they have, especially in younger adults from socioeconomically disadvantaged areas (Barnett et al., 2012). When combined with a chronic physical disease depression is associated with greater decrements in health than other disease combinations (Moussavi et al., 2007).

The dominant policy response in high income countries to this epidemiological shift is underscored by health economic imperatives to reduce the cost of care associated with chronic disease by promoting self-management of illness. This health economic and self-management narrative is founded on the notion that people are rational actors that can be equipped with the skills, knowledge, and confidence to self-care, thereby limiting further disease progression and reducing healthcare utilisation. Here, the capacity and indeed moral responsibility to self-care is believed to rest with the individual patient, leading to psychological interventions to change behaviour by increasing self-efficacy (i.e. confidence to produce a desired outcome) (Bandura, 1997).

Such health psychological models are enshrined in the chronic disease self-management programme (CDSMP) that underpins educational and organisational interventions in the USA and UK to enhance patient self-management. However, while interventions premised on the CDSMP can increase self-efficacy, they have little or no impact on self rated health, and do not lead to reductions in health service use (Griffiths et al., 2007). Even whole system approaches that involve training health professionals as well as patients in self-management have so far failed to improve health

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