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Imagined futures in living with multiple conditions: Positivity, relationality and hopelessness

Lindsay-Ann Coyle, Sarah Atkinson*

Durham University, Department of Geography and the Centre for Medical Humanities, Lower Mountjoy, DH1 3LE, United Kingdom

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ABSTRACT

Hope serves as an overarching concept for a range of engagements that demonstrate the benefits of a positive outlook for coping with chronic conditions of ill-health and disability. A dominant engagement through medicine has positioned hope as a desirable attribute and its opposite, hopelessness, as pathological. In this engagement hope is individual, internally located and largely cognitive and able to be learned. Attaining hope reflects a process of coming to terms with the losses associated with long-term conditions and of imagining new meanings and purposes for the future ahead. This process is characterised by a set of linear temporal stages, from loss and denial to acceptance and reappraising the life-course, by an emphasis on the morally desirable exercise of self-care and by a desired outcome that, in the absence of cure, is hope. Through interviews, we aim to unsettle the privileged status given to a positive outlook through examining the expressions, contexts and negotiations of hopelessness of people living with multiple conditions of ill-health and/or disability. These narratives of hopelessness disclose the ways in which realistic imagined possibilities for the future are constrained by external structures of time and function that demand complex negotiations with places, bodies and other people. As a situated and relational narrative, hopelessness draws our attention to the need to rebalance the exclusive attention to individual, internal resources with a renewed attention to contexts and settings. Moreover, hopelessness can be generative for those living with multiple conditions in shaping alternatively framed priorities with respect to their temporal and interpersonal relations.

1. Introduction

It has become a truism that a positive outlook contributes to getting on in life and to managing adversity, including ill-health. The support for this comes from the strong and consistent association of positivity with various forms of coping and related self-reported psychological evaluations, such as self-esteem, self-worth and self-confidence. These relationships have been documented across a range of long-term conditions including those related to cancer, cardiovascular disease, respiratory failure, spinal cord injuries and ageing (Avenuti et al., 2016; Livneh and Martz, 2014; Martz and Livneh, 2016). Whilst the corollary also holds that a lack of positivity is associated with poor coping, passivity and depression, research on the pathways underpinning these associations has largely privileged positivity operationalised through concepts such as optimism or hope. We have, by contrast, little insight into the emergence of hopelessness and its impacts, nor any consideration as to whether it is always undesirable or may ever constitute a resource for living with chronic conditions.

The paper aims to unsettle the privileged status given to a positive

outlook through examining the expressions, contexts and negotiations of hopelessness of people living with multiple conditions of ill-health and/or disabilities (hereafter referred to as multiple conditions). The empirical data come from a larger qualitative study of the experiences of living with multiple conditions in which hopelessness emerged as a significant theme. We argue that medicine operates within a dominant cultural script comprising individualised temporal and linear stages of coming to terms with illness and disability and of imagining hopeful futures. The empirical data enable an interrogation of these narratives of time and hope through accounts by people living with multiple conditions about how they imagine their financial, health and relational futures.

Existing research on chronic ill-health or disability has predominantly related to cases of single, diagnosed conditions; there is, to date, only limited research in relation to living with multiple conditions. Research has also tended to be undertaken within medical settings rather than in the context of everyday lives (Ironside et al., 2003). Attending to the experiences of those living with multiple conditions is timely since their number is increasing rapidly. In the United Kingdom,

* Corresponding author.

E-mail address: s.j.atkinson@durham.ac.uk (S. Atkinson).

this number will have increased by a million in just one decade, from 1.9 m in 2008 to a predicted 2.9 m in 2018 (Department of Health, 2012). Multiple conditions are recognised to present challenges to current medical practice and which recently have been addressed in the United Kingdom through new clinical guidance addressing issues such as the interactions of multiple drug prescriptions and the time demands of multiple symptoms on consultation scheduling (NICE (National Institute for Health and Care Excellence), 2016; Farmer et al., 2016).

2. Hope

Hope may be constructed in various ways: as a noun, inhering to objective circumstance or subjective resource, or as a verb, foregrounding the agency of the hoper and the act of hoping (Elliott and Olver, 2007). Hope is underpinned by diverse assumptions about where hope is located and how it may come to be: an entity or a psychosocial resource to acquire through having and maintaining hope (see Duggleby et al., 2012); an affective flow in being and becoming hopeful (see Anderson, 2006); a given disposition of personality through the binary of optimists and pessimists (see Carver et al., 2010); a moral virtue within traditional and contemporary expressions of spirituality and Christianity (see Crapanzano, 2003).

This diversity of engagements notwithstanding, the last thirty to forty years have witnessed the emergence within medicine of what is recognised as the current dominant understanding of hope in both scientific and popular thinking (see Elliott, 2005; who documents this). The development of 'Hope Theory' began in the 1980s, growing in close association with the expansion in psychology of the field of cognition and the turn to positive psychology. In this dominant understanding, hope is always good and desirable; it is located as an individual, internal and, mostly, cognitive perceived capability for identifying routes to desires and for motivating action to follow such routes. In this, hope may motivate the pursuit of both positive goals and the avoidance of negative outcomes (Snyder, 2002). Hope is one of a family of measurable constructs related to positivity that includes optimism, self-esteem, wellbeing and happiness (Alarcon et al., 2013; Elliott, 2005; Martz and Livneh, 2016; Snyder, 2002). The closest of these, optimism and hope, have been subtly differentiated as measurable constructs (Snyder, 2002) and as popular concepts have subtly different opposites (pessimism and hopelessness). Nonetheless, these nuances notwithstanding, hope and optimism also share a number of important attributes. First, they both concern positive thinking or imagination in relation to potential futures, and both treat such positivity as a good and desirable state. This is supported since both optimism and hope as constructs within positive psychology demonstrate consistency in direct and buffering effects on adapting well to chronic ill-health or disability, which is, in turn, associated with higher levels of positive self-worth, life satisfaction, quality of life and so forth (Martz and Livneh, 2016). Secondly, they are both positioned as internal to the individual and, perhaps most importantly, as states that can be learned, such that individuals can do something themselves or be helped to do something about their internal levels of hope or optimism (Seligman, 1991; Snyder, 2002). As such, both suggest that acquiring either hope or optimism become the responsibility of the individual, with the corollary that the fault for a lack of hope or optimism be similarly placed with the self. However, whilst these two concepts are closely connected, the term 'optimism' has become particularly associated with the positive psychology of Martin Seligman (1991) and, in part to countenance understandings beyond the dominant framing, we have favoured the less partisan language of hope and hopelessness as our overarching concepts.

Coming to terms with a chronic condition is often framed in terms of stages: as a staged grieving process (Dorsett, 2010) characterised by the expression of chronic sorrow (Ahlström, 2007) or stages of defiance and acceptance (Soundy et al., 2012). Defiance may be expressed both as initial denial but also as hope for stability in symptoms and retention of

functions; acceptance may be expressed both through passivity and potential despair but also through reappraisal and finding alternative meanings and purposes for living (Soundy et al., 2012). In this framing, hope in relation to chronic ill-health or disability may always reflect a certain paradox in that finding hope, as an individualised, internal and desired goal, is closely connected to adjusting to the consequent losses in chronic ill-health or disability to bodily functions, relationships, an autonomous life, an expected life, roles, activities and identity (Ahlström, 2007; Soundy et al., 2012). Philosophers have offered an alternative framing in which understanding the processes of developing hopeful futures emphasises the role of the imagination within a multi-dimensional theory of emotions and interpersonal encounters (Simpson, 2004). Simpson draws on William Lynch's argument that hope, by definition, expresses an imaginative ability for identifying different future possibilities. While not all possible imaginings will be realistic or even necessarily positive, sharing one's hopes with others and the role of emotions as an interpretative framework serve to foreground those imaginings that have potential traction (Simpson, 2004). There are, of course, risks in imagining possibilities; the imagination can conjure negative, hopeless, as well as positive, hopeful, futures and thus the relationship between imagination and hope is not deterministic. Moreover, the dominant medical discourse of cure and progress may itself constrain the capacity to imagine beyond pre-defined 'successful outcomes' (Wendell, 1996).

The experiences of chronic illness and disability may undermine medicine's central 'dominant cultural script' (Dias, 2013: 31) in which the imagined future involves progress through treatment, remission and cure. However, positivity affords a way of repackaging this cultural script for those conditions with no cure and only likely deterioration. Combining stages to acceptance with imagining hopeful possibilities for the future effectively constitutes a parallel dominant script for medical approaches to chronic ill-health and disability: building psychosocial health as progress; acceptance as a variant on remission; hopeful imagined futures as an alternative desired outcome to cure. In a society that associates 'getting well' or 'overcoming disability' with progress, it is unpopular to think negatively about the already negative emotions associated with illness and disability such as pain, unhappiness and loss (see Atkinson and Rubinelli, 2012; Ehrenreich, 2009 in relation to cancer). This imperative to be hopeful is also associated with neoliberal economics, in which the promise of hope is similar to the promise of happiness and in which both are bought and sold (Davies, 2015; Good et al., 1990). Advancing the idea that everyone is entitled to happiness gains academic validation through the rise of positive psychology (Miller, 2008) and supports a marketplace for products through which this may be realised, such as self-help guides, material possessions and antidepressants (Schoch, 2006). But this narrative of hopefulness is not an automatic given, it is neither natural nor universal but is always intimately tied to particular notions of progress, morality and political ideology.

There are other less dominant elaborations of the notion of hope in circulation that also challenge some of the core tenets of the dominant biomedical construction. A primary assumption of positivity in general and hope in particular is that this is an unequivocally desirable state. The possibility of a profound challenge to the assumption of the desirability of hope is evident from historical studies of the very different social context of ancient Greece. Hope, for the Greeks and their adherence to an immutable destiny, was a highly ambivalent quality, more an evil than a virtue, and associated with illusion, confusion and folly (see Elliott, 2005). In contemporary engagements, biomedicine does appreciate that hope can sometimes have negative consequences if hope is misleading and prevents the individual facing difficult realities, particularly in relation to a poor prognosis in ill-health. This has mostly been framed as a bioethical question and related to the advocacy of full transparency in providing medical information to patients (Simpson, 2004), although Snyder (2002) also argues that the problem is overstated. However, ability to imagine and hope for what may seem

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