

To cite: Dunn, M. (2019) 'Review of *Ethics and Chronic Illness* by T. Walker, *Ethics and Social Welfare*, 13(3): 311-314.

This is a book that sheds light on a notable, but rarely acknowledged, blind spot in the field of health care ethics. It poses a critical question: how ought good care be conceived for, and provided to, patients living with chronic illness? After all, chronic conditions present few of the immediate, big-ticket, life or death decisions facing health professionals who are tasked with acute health problems. Alluring thought experiments do not pair well with the realities of managing the continually fluctuating pain associated with rheumatoid arthritis or the daily grind of managing glucose levels by a patient with Type 2 diabetes. But, as Tom Walker articulates in this ground-breaking, important contribution, there are rich, sophisticated ethical dimensions to the care of people with chronic illness that deserve careful and explicit consideration.

In one of the first ever contributions to what remains a relatively small literature on the ethics of chronic illness, published in 1988, Jennings, Callahan and Caplan poignantly claimed that “[c]hronic care is a tedious, grinding labor of Sisyphus... and the special characteristics of chronic illness make it an ideal domain in which to explore some new ethical and philosophical approaches”. Jennings and colleagues’ work marked a significant initial signposting about what the special ethical issues in the care of people of chronic illness might consist in: a modified relationship between patient and practitioner as a focus on health management replaces one fixated on treatment and cure, the varying moral obligations that fall on both patient and practitioner in light of sharing responsibility for managing long-term conditions, and the role of the family, community and non-professional care providers in meeting a patient’s broader personal and social welfare needs.

In recent years, these ethical issues have been increasingly acknowledged as health policy and service delivery has increasingly shifted its attention onto managing chronicity, but there has been little systematic, analytic progress in addressing such issues. Walker wades into this space and offers genuinely new insights, reformulating long-held ethical values and recasting ethically mandated practices to shape a clear and practicable account of how good care in chronic illness ought to be interpreted.

Walker opens his analysis by motivating the problem as he interprets it. He carefully argues for why the reader should recognise chronic illness as different from other forms of illness, and, on p. 3, outlines three necessary conditions of chronicity: i) the illness is currently incurable, ii) the illness is not immediately life threatening when appropriate treatment is given, and iii) the illness is long-lasting. For Walker, the defining feature is that chronic illnesses become part of a patient’s life – something that s/he comes to live with.

Understandably, then, the aims of interventions provided by health care providers is to assist and best support patients to best live with the conditions that they have. From this initial claim about the specialness of chronic illness, Walker reveals why the management of chronic illness ought to focus our attention away from definable points of decision-making that patients authorise through well-established consent requirements, to temporally

extended, and far more oblique, moments of choosing, acting, supporting, advising and preventing. Persuasively, Walker proposes that the ethics of chronic illness is best understood as being comprised through a patchwork of these continually evolving moments. Within this patchwork, there is no definitely right or wrong decisions to be made by practitioners at any pre-determined point in time, but rather better or worse strategies that can be invoked to enable patients to live well with their illnesses.

Having sketched out this initial picture of how ethics manifests itself in the care of patients with chronic illness, Walker turns his attention to questions of choice-making in Chapters 2, 3 and 4. In Chapter 2, the challenges of determining which interventions will benefit patients with chronic illness are considered in light of a typically understood requirement that gives patients the central role to make their own choices, by being provided with information, about which intervention will most benefit them. Walker problematises this argument in situations of chronic illness where patients are often treating themselves, and settles on a more moderate position in which he hedges his bets somewhat: in different situations there will be different methods that need to be employed to determine which interventions are likely to be best for patients, all things considered. One of the important implications of this moderate position is that it immediately displaces the role that ought to be accorded to informed consent as the central ethical requirement in enacting a treatment decision-making process.

In seeking to flesh out this moderate position further, Chapter 3 sees Walker taking up the question about whether a patient's choice will provide good evidence that the option chosen is the best option for that patient. Again, the complexity of managing chronic illness leads to no definitely position being adopted. Walker claims that, in some situations, the patient's choice will provide definitive evidence about what is best for that patient (and the patient's choice should be shown 'compliance respect' and followed to shape the particular intervention that s/he receives. In other situations, by contrast, the patient's choice should be taken into account (shown 'consideration respect' only by the practitioner) but will not be definitive in determining the best course of intervention.

In Chapter 4, the act of choosing, and the associated ethical requirements of making choices concerning the management of chronic illness, is viewed not from the standpoint of the requirement to benefit the patient, but from the principle of respecting the patient's autonomy. By dissecting numerous conceptual accounts of autonomy, Walker draws the sensible conclusion that respect for the patient's autonomy does not equate with a requirement for the patient to be in charge of determining which course of treatment (if any) s/he receives and that is provided necessarily by other autonomous agents. Instead, the intuition that patients ought to choose what treatment they receive is defended by recourse to the symbolic value of choice, as defended by Scanlon (1998) in his contractarian account of our moral obligations to each other. On this view, competent adults patients are wronged if they are not allowed to choose the treatment for their chronic illness because to be denied such a choice demeans that person, reflecting a judgement that the person does not have the standing that is normally accorded to an adult member of a society.

Having sketched out the moral terrain of choice-making in the management of chronic illness, Walker turns his attention to actions taken on the basis of choices made in Chapter

5. Given that when a practitioner needs to act, doing so will sometimes be wrong unless the patient permits that action, turns the focus of this chapter onto the process of consent in the management of chronic illness. As Walker makes clear, consent practices in this context are clearly broader and more wide-ranging than they are in acute health care or medical research contexts, covering such actions as conducting tests, carrying out everyday tasks, entering into patients' private spaces, and sharing information with others. Once again, the complexity of acting in complex ways to support a patient managing chronic illness rightfully prevents Walker from drawing any overarching conclusions for how consent ought to be sought from patients in this health care setting.

In the rest of the book, Walker shifts his attention away from the choices and actions made by health practitioners towards those governed by patients themselves, or by family members or other non-professionals involved in supporting them. In Chapter 6, Walker's focus is on the management of actions undertaken by patients who are involved in self-managing their health conditions. First, Walker explores the resources that patients need to successfully self-manage their illnesses and here draws attention to an overarching requirement to enable patients to act autonomously, rather than seeing respect for autonomy as being limited to the authorisation of a treatment pathway in the first instance. Second, Walker examines issues round patient non-adherence, and he explores the reasons that might lie behind this phenomenon, much of which have little to do with what the patient aims to achieve but rather to limitations in the context of patients' lives that make adherence a challenge.

Chapter 7 turns its attention to the role of non-professional caregivers and the role of non-health professionals in supporting patients with chronic illnesses. Walker explains how this expansion of the treatment and support circle can give rise to two distinctive ethical challenges, which he goes on to analyse in depth: i) the need to ascertain another person's willingness and ability to be involved (and thereby sharing information about the patient's illness with them), as well as the ethically justifiable parameters for such involvement, and ii) the fact that once another person agrees to join those health professionals who are supporting the patient, they might not fulfil the requirements that they agree to take on.

The final chapter of the book returns to one of the defining features of chronicity: its temporally extended nature, and therefore the requirement for treatment, support and management to be instigated over long periods of time. As Walker eloquently describes, one of the main issues with the need for support over time, is the uncertainty and change that often results as available resources, willing participants, and specific needs evolve and are often limited. Perhaps the most important lesson that Walker puts forward here is that holding onto overarching principles – such as seeking to benefit patients or respecting the patient's autonomy – can prevent ethically defensible pathways of support being identified as the patient's needs and circumstances change over often long periods of time. This is partly because of a desire to assert ideal normative requirements in non-ideal circumstances. Whilst Walker does not expand on his proposed strategy for managing this challenge in detail, it is clear that he is looking to a much more particularist specification of moral obligations in the context of the care of people with chronic illness – determined by the moral contours of each patient's unique journey through illness.

There is much to admire in Walker's careful, analytically rigorous treatment of the ethical considerations that arise in the care of patients with chronic illness. Readers of *Ethics and Social Welfare* will, I think, recognise how the defining features of chronic illness in the health context here connect very closely with the ethical challenges that can arise in providing social care, services and support to people with long-term and enduring conditions – those with dementia, mental illnesses, and intellectual disabilities, amongst others. Indeed, one criticism that might be put forward concerns the 'health care' focus that Walker largely remains committed to throughout his treatment of the issues. Much of the care and support he considers takes place outside of health settings, and many of the needs that people with chronic illness have include personal and social support needs, rather than nursing or medical interventions alone. As such, Walker's book looks to straddle the health and social care divide, yet those working in social care or social services feature briefly and only in so far as they might become involved in providing assistance as non-health care professionals.

The absence of any strong interest in chronic *mental* illness rather than chronic *physical* illness is also notable, and something that Walker himself reflects on briefly. This is an important omission to me, as whilst mental illness will often meet the criteria for chronic illness that Walker outlines, and raise very similar ethical challenges to those considered at length in the book, some of the strategies adopted to do justice to, for example, choice-making or agency did not come across so persuasively if extended to the psychiatric setting. Those readers who have a strong interest in practice might also be craving more extensive, richer cases to which the analysis is applied, with the reality of living with chronic illness most typically appearing as a series of examples used to illustrate the theoretical points being made.

Ethics and Chronic Illness is a dense, though rewarding, piece of analytic applied ethics, that lays out novel ethical thinking on an inexplicably under-represented area of health care ethics. It will be of particular interest to those who work in the care of people with chronic illnesses and long-term conditions, and who have a particularly keen philosophical concern with the ethical underpinnings of their practice. I would expect that the arguments developed across the book will gain traction, and I would like to see them being extended to other areas of care practice, including social care and social work, as well as functioning to highlight some problematic assumptions that remain prevalent in mainstream health care ethics itself.