The Wiley Handbook of Healthcare Treatment Engagement
Theory, Research, and Clinical Practice

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and
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WILEY Blackwell
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A chasm separates what we know from sound scientific research to be potentially beneficial for healthcare and what we achieve for people with health disorders. This is a very complicated problem, with many known and unknown contributors. Arguably, the most important general contributor is a lack of acceptance by people of the prescriptions of practitioners, especially for treatments that are to be self-administered, such as medicines, exercise, and diet. We have a considerable knowledge now that can be applied, but we also need new thinking and new knowledge to bridge the chasm. The contributors to this book combine expertise and evidence to advance this mission, especially in relation to patient engagement in recommendations for their healthcare, and also for engaging practitioners in this process.

People not following medical advice for self-administered healthcare treatments has no doubt been happening since the beginning of human existence – and this shows no sign of abating. Initially, it is fair to say that this trait provides some protection against prescribed treatments that are worthless or cause more harm than good. There are many such prescriptions and treatments to this day, but current times are different in at least one important way. Clinicians now deal with many health conditions for which efficacious treatments have been validated, and this list grows daily. What was once justifiable self-defense against quackery, and is still justifiable for many healthcare treatments, has now also become a major tragedy of our times.

Simple algebra illustrates the problem. A 25% relative risk reduction in patient-important health outcomes is a moderately large effect for the efficacy of a new treatment compared with other treatments, or “usual care,” but typically no more than 50% of practitioners will prescribe new treatments within a generation of their validation and no more than 50% of people who could benefit will adhere to the intervention if prescribed. Thus, a net benefit is achieved of no more than \((0.25 \times 0.5 \times 0.5 =) 6\%\) at best. For example, for many people with atrial fibrillation oral anticoagulants can reduce the risk of stroke by over 50%, but surveys show that clinicians prescribe anticoagulants for only about 50% of eligible patients, and of patients for whom anticoagulants are prescribed only about 40% take them as intended, whittling a 50% relative benefit down to about 10%. About 5% of middle-aged people have atrial fibrillation and 3% of these will suffer a stroke over a 15-year period as a result of the atrial fibrillation. Anticoagulation, fully applied, would reduce the attributable stroke rate to 1.5% or less, but at current uptake rates only to 2.7%. Extrapolated worldwide, annually, this is the difference of over 86,000 strokes averted per year versus over 17,000 strokes averted per year.
Overcoming this problem is inherently complex, as it requires simultaneous solutions for both practitioner and patient actions to gain traction. For instance, increasing appropriate prescribing from 50% to 75%, without increasing patient adherence, would increase the benefit to only 15%, whereas increasing both prescribing and adherence to 75% would increase the net benefit to 28%. To make matters worse, increasing either practitioner or patient acceptance for unvalidated or discredited interventions would have adverse effects without benefits. At present, efficiently, consistently, and affordably resolving this problem is beyond our understanding and reach.

The knowledge–practice gap exists for virtually all health interventions. The loss that it causes for return on investment in research is staggering and assuredly leads to more deaths and suffering than any natural disaster in human history.

I first became familiar with “patient compliance” (as it was referred to at the time) when I was a graduate student working with Professor David Sackett at McMaster University in 1971. At that time, hypertension was one of the first chronic medical conditions for which efficacious treatments had been discovered and the problem of patient compliance had been documented as a barrier to blood pressure control through a growing number of observational studies. The more I looked into the topic, the more fascinated, mystified, and horrified I became. What was the point of doing healthcare research if so few practitioners and patients “bought in”? What validated remedies for the problem existed? What approaches were promising but inadequately tested? At the time “patient education” based on education theory and “cues and rewards” based on behavioral psychology were in fashion, but there were no randomized trials of any intervention showing effects on patient-important outcomes. Today, thousands of studies later, including hundreds of trials, we have documented the lack of efficacy of many interventions (including most forms of patient education), and the efficacy of a few interventions, but none with a substantive effect on patient-important outcomes or the simplicity that would allow widespread implementation (Nieuwlaat et al. 2014).

Clearly, we need new thinking and insights into this pervasive problem! The editors, Andrew Hadler, Stephen Sutton, and Lars Osterberg, have assembled an impressive, transdisciplinary team of experts from around the world, working under the theme of a fresh perspective, “patient engagement.” The authors comprehensively review what we know, what we can apply now, what is promising, but needs further testing, or refining for practical application, and where the frontier is for creating new knowledge. All clinicians and as many scientists as possible are needed for traveling this last mile for getting healthcare knowledge into practice.

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Reference

This volume is devoted to the topic of patient engagement in healthcare treatment. This is a realm which has been overlooked in the great majority of medical texts, and in clinical practice it is all too often taken for granted. Following the assumptions implicit in the “sick role,” the medical model, and what is widely understood as the “traditional medical interaction,” it is expected that a person who is unwell, or is concerned by their health, will rationally follow the advice and treatment recommendations as agreed with their professional health provider. In fact, the observed reality of human behavior in relation to treatment adherence and health behavior change commonly runs contrary to expectations, limiting the effectiveness of treatment in the majority of healthcare settings. Such conventional medical wisdom also typically overlooks how health and wellbeing varies across different groups and is shaped by social factors, such as poverty. This book is intended to support healthcare practitioners and service planners in the immensely varied field of healthcare practice, improving care by working with patients, helping them achieve the positive changes that they wish to make in order to improve their health and quality of life.

The origins of this book began with a conference organized by one of the editors in 2010. Following that meeting, a discussion took place between the contributors, who realized that it appeared that a book did not exist which would bring together and explore the material and themes which had been discussed. During early development, it became clear to the editorial panel that the scope of such a volume would be considerable. In order to offer the reader a robust understanding applicable to the needs of a variety of patients accessing care, it would be necessary to describe methods which could enhance communication and patient engagement in treatment across different clinical specialties, and also provide an introduction to fields such as the ethical and legal aspects of the subject. Resources dedicated to service design and delivery would be required. Benefitting from the support of the commissioning editors at Wiley, the co-editors collaborated to bring the vision closer to completion. After many hundreds of discussions, decisions, and dilemmas accompanying the contribution of the chapter authors, the current volume has become a reality.

The editors are a psychiatrist with experience of practice in physical medicine, a physician with an interest in health behavior and medical education, and a professor of behavioral medicine with experience of researching health behavior and designing population health interventions. We share a passionate interest in the topic of patient
engagement in treatment and have experience in putting into practice the methods described in this volume. We have repeatedly witnessed situations in which the behavior of healthcare service users has differed from the expectations of those delivering care and have observed the increased demand on health services that has arisen as a result of poorly managed chronic health conditions. Our intention has been to create the volume which practitioners would seek to use in order to enhance their current clinical practice, as well as informing the development of health-care services.

We have made no assumptions of prior expertise in the various topics on the part of the reader. We have thought of the reader as any healthcare practitioner, trainee, or student, from any discipline or field of practice in health care, who can expect to speak to patients or their caregivers regarding health, wellbeing, healthcare treatment or health behavior, as well as any person involved in delivering, planning or setting direction in health services or systems. The volume has been prepared with a worldwide audience in mind.

The contents of the volume reflect that few healthcare practitioners will practice alone and are likely to work in multidisciplinary clinical teams within complex health systems, anticipating the support which may be required on an organizational level to support service delivery attuned to the theories, clinical methods, and service developments which are described. Likewise, recipients of care do not exist in isolation; the significant role of relationships with caregivers is acknowledged, as well as the influence of social factors upon access to care and health outcomes. Treatment itself is recognized in the context of potentially complex needs and co-morbidities, often taking the form of a package of care to address these needs. We intend that the approach offered by this volume will leave the reader well placed to respond to all such eventualities.

An exploration of the term patient engagement in healthcare treatment, chosen as the subject for this volume, is included in the introduction. In brief, we found widespread reference to the concept of patient engagement in treatment in various fields and considered the term better suited to promote consideration of the complex interplay of factors which may impact on health outcomes in individual clinical cases than suggested by terms such as “adherence” alone.

We have sought to bring together in a single volume the considerable body of literature which provides eloquent, evidence-based explanations of human behavior in relation to health and treatment as well as the beliefs, assumptions, emotional processes, social factors, and qualities of treatment itself which may underlie and determine this behavior. In spite of the immense significance of this field, this knowledge is not yet consistently in the hands of either those delivering care or those planning services. We have adopted an interdisciplinary approach to deliver a comprehensive resource, which will support the task of delivering the most effective clinical interventions, in a manner with which patients are more likely to meaningfully engage. In addition to providing a resource of factual knowledge, we have encouraged a critical and reflective stance in the reader, supporting those who seek to change the way they see and understand this field of practice.

The material is presented in a user-friendly format. The reader will find a logical progression of the topics through the overall structure of the volume, divided into five parts; a more detailed introduction to the structure of the book is offered in the introduction. Each chapter offers “key points,” an introduction, and conclusion, as well as, where appropriate, clinical vignettes to place the material in context. The
chapter authors have been chosen by virtue of their expertise and have focused on principles and factors with relevance across a variety of settings, rather than on specific behaviors, treatments, or health conditions. A commentary is offered between chapters to draw connections and distinctions between the contents across the volume.

There are compelling reasons to study this fascinating topic and for far greater attention to be devoted to it than is the case at the present time. Bringing into existence a new book has not been without its challenges; this first edition embodies our best efforts to present the volume that would represent this field and be of most use to the reader. We recognize that there will be continuing developments in this field during the life of this edition as well as other limitations, for example those arising from our perspective and experience of the topic as well as the experience of the authors. We recognize that it will be in healthcare practice that the volume will be put to the test and that, in this way, the volume will be improved for future editions; we will be pleased to hear from our readers of their experiences of bringing the material into the real world of practice.
Andrew Hadler is a Consultant Forensic Psychiatrist, working with people living with mental health problems who commonly have complex patterns of engagement in treatment. He is appointed as Honorary Lecturer at Brighton and Sussex Medical School, teaching on the topic of patient engagement in healthcare treatment, and has conducted research exploring the experiences of engagement in treatment amongst people living with mental health problems. He has received a national award for innovation from the NHS Institute for Innovation and Improvement, is a member of the Royal College of Psychiatrists and is an Editorial Board member of the journal, the BJPsych Bulletin.

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Acknowledgments

This book began life in 2010, in the shape of a proposal for a volume with more limited scope, and the editorial committee for that book, including Simon Draycott and David Reiss, were instrumental in the creation of the current handbook. The contribution of Amrit Sachar was invaluable. Alex Lord and Jean Ledger have remained consistent friends of the project, from conception until completion, with contributions including valued guidance and proofreading drafts of the introduction and afterword. Without the encouragement of Mary McMurrnan and Darren Reed at Wiley this book may not have developed into its current form. Our editors at Wiley, and Monica Rogers in particular, have maintained their encouragement, faith, and patience in this project over a prolonged period and for this we are immensely grateful.

We must recognize the support of our librarians, who are always at risk of remaining among the unsung heroes of healthcare. These have included Pauline Bishop, Amy Dunn, and Helen Ewell, who have gone above the call of duty by assisting in the numerous literature searches which have informed our approach, as well as providing some of the volumes we have consulted.

The lively correspondence we have enjoyed with many of the chapter authors has remained among the most rewarding aspects of our immersion in the topic; we are pleased that this continues past the completion of the chapters and look forward to future collaborations. Not only have we been welcomed into a greater understanding of their work, but have been inspired by the continued commitment made by the authors through major life events and unexpected challenges in the world of clinical practice. We have followed our authors through their own experiences of ill-health and medical treatment including emergency surgery and chemotherapy, as well as for conditions as varied as pneumonia, fracture and, happily, a new birth.

We thank our friends, who have provided sustenance through their good humor and warmth as we have worked toward completion, as well as those who have offered valued comments and opinions. We have greatly enjoyed working with Mathilde Le Coutour, who has brought a creative flair by means of her art work for the volume. Finally, we must acknowledge the love and support of our families and partners, whose faith and encouragement we have been able to depend on during the years we have been wedded to this project.
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Key Points

• The literature refers to individuals who have sought help to improve their health, but struggle to initiate and maintain commitment to health behavior change.
• The literature on the topic of adherence to treatment with medication demonstrates low rates of adherence.
• In order to understand the behavior of patients who seek to engage in healthcare treatment, it may be necessary to look beyond the rational assumptions implicit in the “medical model.”
• The global burden of disease is increasingly shifting toward chronic health conditions and co-morbidities, for which management commonly requires changes in health behavior such as lifestyle modification.
• The concept of patient engagement in healthcare treatment reflects a broader definition of health behavior and healthcare treatment than adherence to medications alone, supporting more holistic approaches to healthcare delivery.
• Interventions to enhance patient engagement in treatment may include innovations in the manner in which healthcare services are delivered and types of treatment offered, as well as measures to address structural barriers preventing patients accessing those treatments.

Since the dawn of the practice of medicine, healthcare providers have struggled to engage patients in treatment. In fact, Hippocrates recognized that patients might appear to deceive their physicians when asked about their medication-taking, as described in The Decorum:

Keep watch also on the faults of the patients, which often makes them lie about the taking of things prescribed. (Jones 1923)

Reading the above comment through the lens of the major themes of this volume suggests that here Hippocrates is failing to appreciate his patient’s role as an autonomous
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actor in the process of treatment and, instead of seeking to understand their behavior, maintains an expectation that the patient will act according to the advice offered by the physician.

**Introduction: What Is This Book About?**

This book is being published at an exciting time. Life expectancy is rising, the causes of mortality and morbidity are increasingly understood, and a range of highly effective treatments are available to an increasing proportion of the global population. However, health systems across the globe face rising costs and ill health predominantly due to chronic health conditions which often include in their etiology a significant contribution from lifestyle factors (OECD 2017).

However, simply because a treatment which has the potential to save a person’s life is readily available, it cannot be assumed that such treatment will be implemented effectively. As described by Oshotse et al. in Chapter 1 of this volume, approximately half of patients with chronic diseases fail to adhere to prescribed medications and thus do not gain benefit from treatment. Contrary to the expectations of the majority of practitioners, non-adherence to prescribed treatment may even be regarded as the norm rather than the exception. It has been postulated that, because the results could be applied so broadly, effective ways to help people follow medical treatments could have far larger effects on health than any treatment itself (Haynes et al. 2002; Sabaté 2003).

This volume seeks to inform the reader of the extent, causes, and impact of suboptimal engagement in healthcare treatment, to explore issues such as the legal and ethical implications of practice in this field, and to describe a range of interventions applicable to the care of individual patients as well as the configuration of healthcare services and the health of populations, which may promote patient engagement in healthcare treatment. A holistic stance is adopted throughout regarding wellbeing and healthcare treatment, respecting as healthcare treatments a variety of approaches that go beyond pharmacological and surgical interventions. Other approaches increasingly constitute contemporary healthcare treatment, including lifestyle modification and social prescribing, the practice of referral to non-clinical services in order to improve health (Pescheny et al. 2018).

The literature on the topic of medication adherence finds that no single approach is likely to prove successful in improving treatment outcomes by improving treatment adherence (National Institute for Health and Care Excellence [NICE] 2009; Nieuwlaat et al. 2014) and that interventions tailored to the needs of individual patients will be required (Sabaté 2003). To address these needs, an interdisciplinary approach is adopted throughout the volume, drawing together theories from a range of clinical and academic specialties, all of which stand to enhance our understanding of the factors governing the motivations and behavior of patients, clinicians, and organizations. Eloquent explanations are offered of behaviors which run counter to expectations underlying the “medical model” and evidence-based practice, such as that users of healthcare services will follow the rational expectations of healthcare providers. This is an evolving and exciting field.

The concept of patient engagement in treatment fits with and complements contemporary developments and approaches which seek to increase patient choice and