

# Pediatric Nonadherence

A Solutions Based Approach

Victor Fornari  
Ida Dancyger  
Peter Silver



Springer

# Pediatric Nonadherence

Victor Fornari • Ida Dancyger • Peter Silver  
Editors

# Pediatric Nonadherence

A Solutions Based Approach

 Springer

*Editors*

Victor Fornari  
Psychiatry and Pediatrics  
Northwell Health  
Glen Oaks, NY, USA

Ida Dancyger  
Psychiatry, Northwell Health  
Hofstra University  
Hempstead, NY, USA

Peter Silver  
Pediatrics  
Hofstra University  
New York, USA

ISBN 978-3-031-58140-3      ISBN 978-3-031-58141-0 (eBook)  
<https://doi.org/10.1007/978-3-031-58141-0>

© The Editor(s) (if applicable) and The Author(s), under exclusive license to Springer Nature Switzerland AG 2024

This work is subject to copyright. All rights are solely and exclusively licensed by the Publisher, whether the whole or part of the material is concerned, specifically the rights of translation, reprinting, reuse of illustrations, recitation, broadcasting, reproduction on microfilms or in any other physical way, and transmission or information storage and retrieval, electronic adaptation, computer software, or by similar or dissimilar methodology now known or hereafter developed.

The use of general descriptive names, registered names, trademarks, service marks, etc. in this publication does not imply, even in the absence of a specific statement, that such names are exempt from the relevant protective laws and regulations and therefore free for general use.

The publisher, the authors and the editors are safe to assume that the advice and information in this book are believed to be true and accurate at the date of publication. Neither the publisher nor the authors or the editors give a warranty, expressed or implied, with respect to the material contained herein or for any errors or omissions that may have been made. The publisher remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.

This Springer imprint is published by the registered company Springer Nature Switzerland AG  
The registered company address is: Gewerbestrasse 11, 6330 Cham, Switzerland

If disposing of this product, please recycle the paper.

# Foreword

Chocolate chip cookies, baked with the right ingredients, at the right temperature, and for the right time, may provide enjoyment with the desired and satisfying outcome. Once a basic cookie recipe, originating in the late 1930s, the concoction has been modified to a multitude of variations to accommodate food allergies and sensitivities, baking environments, and differences in bakers. Run into trouble or have doubts as a first timer, a young baker needs more direction, or one is unsure of nuanced instructions, substitutions, or the tools needed? There are now in-home, online, or other resources to call on to guide the baker through the experience—and to a great outcome.

Why are we talking about cookies?

Children and cookies go hand in hand. As the parent of a child with severe food allergies who also loves to bake, we have navigated the baking journey.

We are also navigating the health care journey. We continue to work to understand her allergies, pursue innovative and experimental therapies, and hone the ongoing management of the risks and challenges presented by her condition in the context of our lives—from her diagnosis as an infant through her (present) teen years.

Like cookies, if any of the prescribed “ingredients” or environmental “conditions” are off, her health outcomes are off. The ingredients are prescribed by her clinical team and the conditions are her, our family, her school and social environments, and the world at large where understanding and appreciation of her situation is variable—at best.

In the 85 years since chocolate chip cookies were created, pediatric research has yielded amazing discoveries to improve the prevention, diagnosis, and treatment of many pediatric illnesses and adult diseases that originate in childhood. We are on the cusp of many more.

In the chapters of *Pediatric Nonadherence: A Solutions-Based Approach*, the authors pause and ask critical questions about addressing patient, family, or their environmental conditions and the resulting nonadherence on the efficacy of the prescribed therapies and guidance. Like many who will learn from, be inspired by, and leverage the solutions and tools that are masterfully researched, distilled, and shared, I also have a professional perspective on the significance of this content.

As the President of the Children’s Hospital Association, I have the privilege of seeing the impact of collaboration among teams of physicians, nurses, and other providers—and increasingly families and communities—both within an organization and together with others across the country to improve health and health care outcomes for children. Importantly, their work has resulted in novel insights, new practices, and demonstrated care bundles that have changed the trajectory of patients’ illnesses, conditions, and/or quality of life. What were once life-threatening issues we believed to be unavoidable now have therapeutic or process solutions—resulting in more positive clinical outcomes for the patient and family.

The same pediatricians, pediatric subspecialists, and the pediatric clinical teams have also been pioneers in patient and family-centered care. The family is part of care team and decision-making. But what does this really mean? Is being part of the conversation enough? Once the patient and family are discharged from an inpatient stay, subspecialty outpatient visit or other emergent or ambulatory health care experience, are they equipped partners in managing their condition at home and in school? Is there a deeper level of engagement and understanding with the patient and/or family needed to achieve better health outcomes? And how do these interactions and needs change over the course of childhood?

Peter Silver, Victor Fornari, and Ida Dancyger are relentless innovators in improving care for children, adolescents, and families; and with the contributing authors, they have taken on these tough questions. Their collaborative work brings together the physical and mental health of the child and the family, inviting a new level of exploration and understanding. In the discerning chapters that follow, they engage nationally and internationally recognized pediatric experts to delve into medical nonadherence across a host of pediatric disease states and public health issues and to consider the social and economic realities of care, recommending solutions that are practical, grounded in science, and driven by their clinical experience. Building on Drs. Fornari and Dancyger’s *Psychiatric Nonadherence* (2019) in which they explored the impact of nonadherence on the management and treatment of psychiatric illness across the lifespan, *Pediatric Nonadherence: A Solutions-Based Approach* captures crucial insights and solutions to address nonadherence in the realm of pediatric disease—organic and inorganic.

The work is timely, and it would be short-sighted to not reflect on three critical themes woven throughout the chapters—the role of the social determinants of health, the challenges of achieving health equity, the importance of effective communication and the unintended costs associated with nonadherence. Disparities in care and outcomes are identified and demonstrable realities, and while every root cause may not be able to be addressed by a single practice or care team, awareness and the mitigation strategies outlined are valuable steps to supporting the patient and family toward a collective journey to more comprehensive solutions. Likewise, effective communication that is age, culturally, and educationally appropriate; conveys empathy and respect; and ensures understanding is central to medical adherence.

If you provide care to children, you will benefit from applying the learnings, and importantly, the tools to engage families and get to the root of nonadherence for a patient or populations of patients. In aligning clinical therapies and expected behaviors with individual, family, and socio-economic conditions, outcomes will only continue to improve.

*Act so as to treat humanity, whether in your own person or in that of another, at all times also as an end, and not only as a means.* Kant, Groundwork of the Metaphysics of Morals

Children's Hospital Association  
Washington, DC, USA

Amy Wimpey Knight

# Preface

Acceptance of a pediatric diagnosis and its subsequent treatment, as well as adherence to the therapeutic recommendations, presents significant clinical challenges. The path to recovery is often in strong opposition to the patient's and/or the parents' desires and beliefs. We will discuss various approaches to engage the patient and the parents in this book. This volume was inspired by our (VF & ID) previous book on psychiatric nonadherence. The recognition of nonadherence to medical care across all specialties prompted the development of this edition.

The first part of the book is entitled Framing the Issue. Silver and Schleien review Health Economics: The Hidden Cost of Childhood Illness. Bernstein and Kilinsky present Public Health Policy, Children and Their Families, and the Changing Socio-Political Climate. Kainth and Rubin offer Lessons Learned from COVID-19 Mitigation Strategies for Youth.

In the second part, entitled How Nonadherence Impacts Children and Adolescents, we offer a series of six chapters reflecting the range of specific pediatric conditions and nonadherence. Schimmel and Reingold describe nonadherence in the care of At-Risk Infants. Salvatore-Farkas and colleagues review nonadherence in the care of youth with Avoidant Restrictive Food Intake Disorder. Koumbourlis and Santiago focus on the treatment of Asthma across the childhood continuum. Fornari and colleagues report on Pediatric Nonadherence in the Emergency Department. Fornari and colleagues illustrate Pediatric Nonadherence in Orthopedic Surgery. Sathya and colleagues reflect on the Gun Safety.

In the third part, entitled Solving the Dilemma, seven chapters offer opportunities to enhance adherence to pediatric care. Barone and colleagues offer Communication Skills to Enhance Adherence. Dicker and Hodge elaborate on strategies for Enhancing the Therapeutic Alliance. Huang and Mema inspire with their chapter on Humanism. Adragna and Sengupta illuminate the Use of Technology to Enhance Treatment Adherence. Rathus and DeRosa propose the Dialectic Behavior Strategies for Children and Adolescents. The final chapter by Becker and colleagues conclude with There is No Health Without Mental Health.



Finally, we propose the development a pediatric nonadherence checklist to close the gap and offer future directions to enhance the care of children, adolescents, and their families.

We are honored that so many leading experts in the field of pediatrics graciously and generously contributed to this volume. There continues to be progress in the field with the goal of increasing the strength of the evidence to provide for clinical practice. There have been developments across the range of treatment modalities, and the authors have reviewed and incorporated the latest research and information into their chapters.

We are enormously grateful to the over 40 contributing authors for their unwavering commitment to excellence, their enthusiasm, as well as the time and effort each has given to the work of creating the chapters for this book. In addition, we wish to express our deep appreciation to our families for their continued support throughout the preparation of this manuscript.

Glen Oaks, NY, USA

Hempstead, NY, USA

Hempstead, NY, USA

Victor Fornari

Ida Dancyger

Peter Silver

# Contents

## Part I Framing the Issue

<b>Health Economics: The Hidden Cost of Childhood Illness and Nonadherence</b> . . . . .	3
Alexandra Cummings, Charles Schleien, and Peter Silver	
<b>Vaccine Hesitancy: The Problem at Hand and Solutions to Address It</b> . . .	17
Alexandra Kilinsky, Alix Rosenberg, and Henry H. Bernstein	
<b>Lessons Learned from COVID-19 Mitigation Strategies for Youth</b> . . . . .	39
Mundeep K. Kainth and Lorry G. Rubin	
<b>Special Topic: Potential Harms of Excessive Social Media and Smartphone Use on Youth Mental Health</b> . . . . .	59
Bora Colak	

## Part II How Nonadherence Impacts Children and Adolescents

<b>Medical Compliance and Adherence Post-Discharge from the Neonatal Intensive Care Unit</b> . . . . .	73
Michael S. Schimmel and Stephen M. Reingold	
<b>Enhancing Adherence with Children and Families in the Treatment of Avoidant/Restrictive Food Intake Disorder</b> . . . . .	83
Lauren Salvatore Farkas, Marianna Ashurova, Ayelet Hochman, Sona Dave, and Yaara Shimshoni	
<b>Nonadherence in Pediatric Asthma</b> . . . . .	95
Maria Teresa Santiago and Anastassios C. Koumbourlis	
<b>Non-Adherence in the Pediatric Emergency Department</b> . . . . .	107
Marci J. Fornari and Christina R. Rojas	

**Nonadherence in Pediatric Orthopedics: A Solutions Based Approach** ..... 121  
 Catherine Mackey, David H. Ge, Peter O. Newton, and Eric D. Fornari

**Pediatric Healthcare Providers are the Cornerstone of Firearm Injury Prevention** ..... 137  
 Bailey Roberts, Colleen Nofi, Emma Cornell, and Chethan Sathya

**Part III Solving the Dilemma**

**Communication Education for Trainees to Enhance Adherence in their Patients** ..... 157  
 Stephen Barone, Stacy McGeechan, and Roya Samuels

**The Influence of the Therapeutic Alliance on Treatment Adherence.** . . . . 167  
 Robert Dicker and Brian Hodge

**Humanism as a Foundation for Understanding and Addressing Non-adherence.** ..... 183  
 Briseida Mema and Lennox Huang

**DBT Enhances Treatment Engagement, Motivation, and Adherence in Multi-Problem, High-Risk Adolescents.** ..... 193  
 Jill H. Rathus and Ruth R. DeRosa

**Diversity, Equity and Inclusion, and Its Impact on Enhancing Pediatric Treatment Adherence** ..... 203  
 Pascale Chrisphonte, Priyank Algu, and Julio Miguel

**The Use of Technology to Enhance Treatment Adherence** ..... 215  
 Michael S. Adragna and Sourav Sengupta

**There is No Health Without Mental Health** ..... 225  
 Sarah H. Becker, Vera Feuer, Ida Dancyger, Sara Bezalely, and Victor Fornari

**Closing the Gap: Where Do We Go from Here?** ..... 239  
 Victor Fornari and Ida Dancyger

**Index.** ..... 243

**Part I**  
**Framing the Issue**

# Health Economics: The Hidden Cost of Childhood Illness and Nonadherence



Alexandra Cummings, Charles Schleien, and Peter Silver

## 1 Introduction

The concept of compliance and the implications when one is not is a topic frequently discussed in healthcare, particularly as it relates to health outcomes. Equally as important, though, are the economic implications of noncompliance, the long-term consequences of which may be compounded when it affects our pediatric population. When positive health behaviors are not established early on when they have their biggest impact, it may lead to nonadherence in adolescence, which predicts nonadherence in adulthood [1].

Compliance is commonly defined as “the extent to which the patient’s behavior matches the prescriber’s recommendations” [2]. Failing to comply with professional direction assumes some level of intentionality which implies the patient assumes sole responsibility for a failed treatment plan. The concept disregards patient autonomy and other contributing external factors to noncompliance, like a child’s limited decision making capacity or other socioeconomic barriers [2]. In an effort to properly emphasize the patient’s role in this therapeutic alliance, adherence has been used as an alternative term to compliance, where adherence represents “the extent to which the patient’s behavior matches agreed recommendations from the prescriber” [2]. It appropriately emphasizes active patient involvement in a mutually agreed upon care plan, thereby creating a shared responsibility model between patient and

---

A. Cummings · C. Schleien

Department of Pediatrics, Cohen Children’s Medical Center of NY, Hempstead, NY, USA

Donald and Barbara Zucker School of Medicine, Hempstead, NY, USA

e-mail: [acummingsdel@northwell.edu](mailto:acummingsdel@northwell.edu); [cschleien@northwell.edu](mailto:cschleien@northwell.edu)

P. Silver (✉)

Pediatrics, Hofstra University, Hempstead, NY, USA

e-mail: [psilver@northwell.edu](mailto:psilver@northwell.edu)

provider [2]. Of course, there are times when a patient may be either intentionally or unintentionally nonadherent, the former often occurring when the treatment plan does not align with the patient’s personal views or preferences. However, when the prescribed regimen is a product of collaboration and agreement, it is considered to be concordant with the patient’s informed choice and therefore the optimal course. Ultimately, the preferred terminology may be patient- or even disease-specific, but regardless of word choice, the consequences of being noncompliant, nonadherent, or discordant are far-reaching and have significant economic impact.

## 2 Specific Pediatric Reasons for Nonadherence

The reasons a patient may be nonadherent are extensive and may be patient related, provider related, or disease or health systems related (see Fig. 1) [3]. Some patient-related factors include those surrounding health literacy, predetermined health beliefs, and more broadly, one’s socioeconomic status as it influences health care access and affordability. Some examples include, but are not limited to, race or ethnicity, primary language proficiency, disagreement with the treatment choice, fear of adverse effects, mistrust, education, vocational restrictions, and insurance coverage. Provider-related causes are largely rooted in miscommunication or inadequate communication, but also include one’s implicit bias as well as the ability to recognize and circumvent risk factors for nonadherence. As the ability to recognize and circumvent risk factors for nonadherence [3]. Disease or health systems-related factors are heavily influenced by an overburdened healthcare workforce with insufficient time and resources to allow for comprehensive provider-patient encounters [3], but also encompass disease chronicity and comorbidities, treatment complexity, frequency or duration of the treatment, and cost. In fact, the inability to afford medications is consistently cited as one of the most common reasons for nonadherence among all age groups [4]. In 2021, 8.2% of adults reported not taking their medication as prescribed due to cost which is, not unexpectedly, more commonly seen in those who live at or below the federal poverty level or who are uninsured

<b>Patient Related</b>	<b>Provider Related</b>	<b>Disease/Health Systems Related</b>
Health literacy	Communication	Disease chronicity
Education	Implicit bias	Comorbidities
Fear/mistrust	Recognition of non-adherent behavior	Treatment complexity
Cultural & health beliefs		Treatment frequency and duration
Race/ethnicity		Adequate time for comprehensive provider-patient encounters
Primary language proficiency		Cost
Vocation		
Access to healthcare		
Ability to pay/insurance coverage		

**Fig. 1** *Factors Influencing Adherence*: This table summarizes three major categories (patient, provider, and disease/health systems-related) of potential sources for nonadherence

[5]. This phenomenon is three times more likely to occur if that individual has a disability, and three times more likely to occur if that individual is already in poorer health [5].

General adherence rates in children and adolescents are largely variable, but average approximately 58% in developed countries, where adolescents are often found to be less adherent than younger children [6]. Children and adolescents make up a special population in which compliance is at least partially, if not completely, dependent on a reliable caretaker. As a result, children and adolescents are more vulnerable to situations of neglect or abuse. Intentional parental noncompliance, perhaps encountered more commonly than incidents like non-accidental trauma, may also qualify as neglect or abuse in extreme cases. These situations are typically a result of conflicting perceptions between the parent and provider regarding the best interest of the child [7]. They often reflect a level of misunderstanding of the clinical situation, mistrust of the provider, or inability to cope with the stresses surrounding the recommended treatment [7]. Providers must maintain a heightened level of awareness for parental noncompliance in order to anticipate and prevent it from occurring, as well as recognize defensiveness to help achieve cooperation instead [7].

Besides neglect or abuse, the pediatric population has a unique susceptibility to nonadherence for many other reasons, some of which stem from their reliance on governmental programs. Delayed referrals to or evaluations by programs like Early Intervention, along with delays in determining eligibility, serve as a salient example of unintentional nonadherence. Contributing further to this problem, parents often experience confusion or extreme difficulties simply navigating state and school services, particularly during the transition out of Early Intervention programs and into school-based programs. Unfortunately, the success of a child's development is also heavily influenced by the limited government resources, both state and federal, available to provide appropriate rehabilitative and educational services to meet each child's needs.

Pediatric adherence is also subject to developmental or behavioral limitations, or a child's inability or refusal to cooperate with therapies or medications. As adolescents, their decisions are increasingly influenced by the fear of social isolation due to medical therapies. Transitions of care to adult providers may also serve as a point where adherence can decrease, as for many, this represents a shift in responsibility of their health maintenance from parent to patient. Furthermore, studies have supported that simply being a child with a limiting health condition is a risk factor in itself for noncompliance, as those families are more likely to delay or fail to fill a necessary prescription, which is compounded further if that family has more than one child with a limiting health condition [8]. Each one of these factors represents important and largely pediatric-specific barriers that one must take into consideration when trying to elucidate reasons for pediatric noncompliance.

Additionally, the COVID-19 pandemic or other global or local emergencies that preclude an individual's ability to access care at all, let alone in a timely fashion, is a barrier, regardless of age or demographic, that has significant health and economic repercussions. The health debt created by the COVID-19 pandemic, for example,

represents the accumulated impact of changed behaviors that will have a long term negative effect on health [9]. This includes issues such as missed preventative care visits or screenings, delayed or missed vaccinations, delays in seeking care and thus, delayed treatments, forgone chronic disease management, virtual education, postponed or canceled therapy sessions, reduced physical activity, or increased mental health disorders related to social isolation [9]. It is evident that children were not immune to these complications and unfortunately, their debt will continue well into the future. Those already living with chronic health conditions may feel the impact most directly, however, the debt will unfortunately be paid by those who can afford it the least; for example, those who are uninsured or who already have limited access to healthcare resources [9]. The impact of the COVID-19 pandemic is expansive, and the discussion of how it negatively affected adherence only scratches the surface.

### 3 Economic Implications of Nonadherence

It is important to understand the self-propagating cycle that occurs once noncompliance is established. Noncompliance of course leads to poor health outcomes, but with that comes increased health care utilization and therefore increased cost. An important consequence is that increased cost is then passed to the patient by the payer in the form of increased cost sharing [10]. Cost sharing refers to the portion of costs covered by insurance that an individual pays out of pocket for, such as deductibles, copayments, and premiums [11], but may also take the form of higher cost to the employer to maintain coverage [10].

To better understand how cost sharing impacts compliance, we can look at it in the context of prescription drugs. In 2021, 378 billion dollars were dedicated towards spending on pharmaceuticals [12]. Although accounting for only 9% of the nation's health expenditure [12], this represents a doubling of the pharmaceutical spend since 2000, a rise reflective of novel therapeutic advances and overall greater medication use relating to the increasing burden of chronic disease [13]. Currently, nearly half of the US population has taken at least one prescription drug in the last month, and one-fifth are patients under the age of 18 [14]. In an effort to curb drug utilization, and therefore spending, payers commonly employ the strategy of increased cost sharing, which would theoretically compel more thoughtful and selective health care choices [15]. However, this approach has only proven to be detrimental, as increased cost sharing is consistently associated with decreased medication adherence [13], therefore enabling patients to perpetuate the cycle of nonadherence. It does not decrease overall healthcare costs as intended, but paradoxically is associated with higher overall costs. This results from patients waiving essential healthcare due to their inability to pay, leading to worse health and greater inpatient and lower outpatient utilization [15].

Additionally, other unintended consequences of nonadherence are a worsening of the underlying disease state and the development of other comorbidities. The inevitable medical and psychosocial complications of disease ultimately reduce



quality of life and waste healthcare resources [6], often leading to loss of vocation or absenteeism, loss of employer-sponsored insurance, lost economic productivity, and greater use of disability services. These factors ultimately lead to a strain on societal resources and contribute even further to noncompliance [10]. Although children may not necessarily be contributing economically to our workforce, they of course suffer a similar, and perhaps more impactful, consequence of missed developmental milestones and educational opportunities leading to impaired future ability to pursue an occupation and contribute economically. Childhood illness also results in increased absenteeism in the adult workforce due to childcare needs.

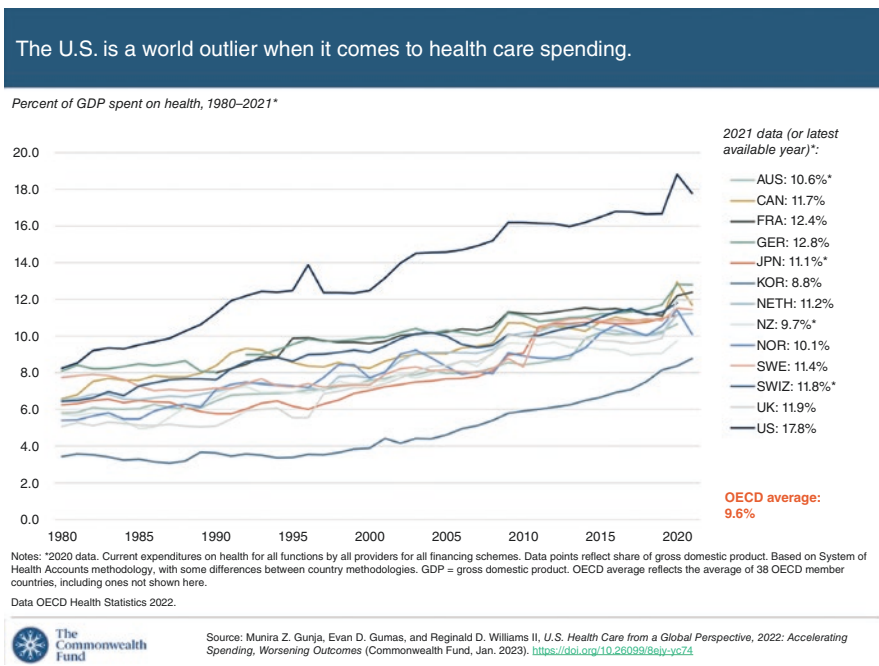
## 4 The Magnitude of the Problem

Because compliance is an inherently comprehensive term that, when used in the context of medicine, refers to adherence to all facets of healthcare, not just to a prescribed medication regimen, it is difficult to accurately quantify rates of adherence in the general sense. Rather, one can quantify adherence on a more situationally specific basis, for example to antihypertensive regimens, or to recommended life-style changes. Additionally, adherence is a behavior with many dependent variables, and therefore hard to measure beyond the limited self-reporting techniques in which patients of all ages tend to exaggerate their adherence [6]. For the same reasons, it is also challenging to simply quantify the cost of nonadherence, as it is a complicated, multifactorial assessment with both economic and medical consequences that are appreciated on multiple levels. For example, noncompliance to the treatment of infectious diseases with antimicrobials leads to treatment failure and, particularly with incomplete antibiotic courses, the development of antimicrobial resistance. This not only has the direct added cost of preventable morbidity and mortality with the associated increase in health care spending in the form of longer, more complicated hospitalizations, but it also has the indirect added cost of increased investment in research to develop cost-effective, alternative therapies [6]. Noncompliance in this sense has both local and global health implications with opportunity for public health emergencies due to epidemics of resistant organisms. Despite its complexity, though, one must still try to put into perspective even the projected impact that noncompliance has on healthcare spending so that meaningful change can occur within public health policy.

In 2021, the Center for Medicare and Medicaid Services (CMS) reported that the United States' National Health Expenditure (NHE) grew 2.7% from the year prior to 4.3 trillion dollars, or \$12,914 per capita, accounting for 18.3% of the nation's 23.3 trillion-dollar Gross Domestic Product (GDP) [16]. Growth in NHE in the US has been steady since 1960, albeit notably smaller than the 10.3% increase seen in 2020 in response to the COVID-19 pandemic, which at the time accounted for 19.7% of the GDP [12]. Going forward, both the NHE and the GDP are expected to continue to grow by 5.1% annually, and therefore, the projected. NHE share of the GDP in 2030 is expected to reach the level seen in 2020 of 19.6% [16].

Currently, 17% of the NHE, or 734 billion dollars, is dedicated towards Medicaid spending, with 22 billion of that totals dedicated to the Children’s Health Insurance Program (CHIP) [16], accounting for just 0.5% of the total NHE. CHIP is a program funded jointly by both federal and state governments and intended to provide insurance to eligible children whose families earn too much to qualify for Medicaid, but too little to afford private insurance. There are approximately 74 million children under the age of 18 in the US, accounting for about 22% of the US population [17]. Combined, both Medicaid and CHIP now insure more than half of the nation’s children [18], reflecting a steady increase in enrollment over time. After the implementation of the Affordable Care Act (ACA), the number of uninsured children in America dropped significantly, however has now steadily remained at 5% since 2016 [18]. Reducing the number of uninsured individuals and families was hugely beneficial, enabling patients to more readily afford their medications, thereby reducing the prevalence of cost-related medication nonadherence [19].

Importantly, the US continues to be one of the highest spenders on healthcare (see Fig. 2) [20], however this is not a result of having a sicker population with higher healthcare utilization, but rather a product of the existing healthcare infrastructure that incurs a higher overall fee for equivalent healthcare services offered by other similar nations within the Organization for Economic Co-operation and



**Fig. 2** This table depicts the continued rise in healthcare spending as a proportion of the overall economy amongst all OECD countries since the 1980s. In 2021, the US spent nearly twice as much as the average OECD country on healthcare. *OECD* Organization for Economic Co-operation and Development [20]. (Reprinted with permission from the Commonwealth Fund)

Development (OECD) [21]. The OECD is a group of 38 countries of similar income, democratic principles, and market economy that can be more usefully compared amongst each other than to other developing or underdeveloped countries [21]. Major factors that contribute to greater healthcare spending in the US are higher overall salaries for physicians, higher administrative costs, and greater pharmaceutical spending per capita as a result of drug pricing that is not federally regulated [21].

To bring this into perspective, experts estimate that approximately 25% of our NHE is wasteful in the form of failure of care delivery, failure of care coordination, over-treatment or low-value care, pricing failure, fraud and abuse, and administrative complexity [22]. Furthermore, a report by the IMS Institute for Healthcare Informatics estimated that avoidable healthcare costs from improper or unnecessary use of medicines reached 213 billion dollars in 2012, accounting for approximately 8% of the NHE that year [23]. Medication nonadherence was responsible for nearly 50% of these avoidable costs, accounting for 105 billion dollars and roughly 3% of total healthcare costs, 72 billion of which was inevitably spent in a hospital setting [23]. It is important to note that of the nation's 4.3 trillion dollar NHE, approximately 31% is attributable to hospital care [24], representing the largest component of healthcare expenditure and therefore the greatest opportunity for lowering costs. A study in 2017 estimated that approximately 8% of pediatric hospitalizations, 61% of which were due to chronic diseases like asthma or diabetes, are potentially preventable [25]. This highlights the direct impact that chronic disease has on healthcare spending and reveals the financial impact of noncompliance in these settings.

## 5 The Impact of Chronic Disease on Adherence

Data published by the WHO in 2003 estimated that, in the general population, adherence to long term therapies in patients with a chronic disease in developed countries approached only 50%, and was presumably less in developing countries given the paucity of resources and inequities to healthcare [6]. Even more staggering is that approximately 50% of children and 65–90% of adolescents living with chronic diseases are nonadherent [26]. With an aging population, the number of individuals living with a chronic disease requiring increasingly complex management has and will continue to increase, as will their vulnerability to nonadherence [27]. Current data shows nearly 60% of US adults living with a chronic disease, and 42% living with two or more [9, 28, 29]. Similarly, the number of children diagnosed with chronic medical conditions has also continued to rise [1], most of whom will inevitably graduate into adulthood and magnify the problem further.

According to the CDC, more than 40% of school-aged children and adolescents have at least one chronic health condition such as asthma, diabetes, epilepsy, obesity, food allergies, and disorders related to oral health [30, 31]. Of course, chronic disease is not limited to these few diagnoses, but rather is defined as a health condition that lasts  $\geq 12$  months [32]. This encompasses a large spectrum of disease states that also include disorders of mental health, development, and behavior, and

frequently require ongoing management into and throughout adulthood. This increasing burden of chronic disease is a multifactorial phenomenon driven in part by increased disease prevalence (for example, asthma and obesity), as well as increased survival owing to scientific and medical advancements [1, 33]. Sickle cell disease, leukemia, Down Syndrome, neonatal HIV, cystic fibrosis, solid organ transplants, and disorders related to prematurity are only a few examples amongst an exhaustive list of disease states where management has benefited greatly from this scientific progress, leading to many remarkable outcomes that were previously unattainable. The consequence of improved survival, though, is increased prevalence of complex chronic disease, and as this continues to rise, estimates of adherence will continue to fall.

The unintended consequences of improved worldwide rates of survival in extremely preterm infants (<28 weeks gestational age) serves as an important illustration of this complex issue, where developing countries like China have demonstrated improved survival with its associated morbidities over the last decade [34]. This ultimately contributes to greater healthcare costs both in the immediate sense, with extended and more complicated NICU courses, as well as chronically, with managing the expected long-term sequelae of prematurity such as bronchopulmonary dysplasia, intraventricular hemorrhage, periventricular leukomalacia, necrotizing enterocolitis, sepsis, or retinopathy of prematurity. Each of these disease entities requires careful medication management, frequent office visits with various subspecialists, potentially additional surgical procedures, and the possibility of frequent emergency department visits and hospitalizations due to exacerbations or complications. It is evident that, although the increased survival for these extremely preterm infants is a remarkable achievement, it does not come without great individual and societal costs.

Another chronic disease of increasing prevalence is childhood obesity. Various social determinants of health such as personal, financial, and poorer food choices in the US have a progressively greater influence on an individual's adherence, and therefore, success in management. Importantly, 20% of children today are obese, a number that has more than tripled since the 1970s [35]. Unsurprisingly, the isolation associated with the COVID-19 pandemic further exacerbated this preexisting epidemic, resulting in children gaining weight faster with a rate of BMI change that was 2.5 times higher than prior to the pandemic [35]. Adherence to lifestyle changes and establishing healthy routines to combat and prevent obesity was already difficult beforehand, and the COVID-19 pandemic only complicated this further, creating new barriers to healthcare that did not exist previously while simultaneously reinforcing antecedent ones.

With increased availability of complex medical therapies comes more opportunity for noncompliance with multiple therapies. Patients who are noncompliant with one aspect of their medical regimen (for example, taking medication) are more likely to be noncompliant with other aspects of their care (for example, attending regularly scheduled office visits) [1]. Importantly, adherence is a primary determinant of treatment effectiveness, and ineffective treatment inevitably leads to worsening disease burden, an independent risk factor for poor adherence [6]. To put this

into perspective, 90% of the US 4.1 trillion dollars in annual healthcare expenditures are for people with chronic and mental health conditions [36]. More chronic medical conditions is correlated with a greater consumption of resources [29] and a higher risk of nonadherence.

## 6 The Importance of Mental Health and Associated Healthcare Disparities

Mental health disorders in children and adolescents, particularly anxiety and depression, have continued to rise over time [37]. The 2022 National Healthcare Quality and Disparities Report cites a prevalence of nearly 20% for mental, emotional, developmental, or behavioral disorders in children aged 3–17 years, with an alarming 40% increase in suicidal behaviors observed in high school teenagers over the last decade [38]. Evidence supports that the presence of any chronic disease, especially diabetes, is associated with a higher likelihood of concurrent mental illness and is predictive of greater health care expenditures [39, 40]. Children of parents with severe mental health disorders are also more likely to develop a mental health disorder [41], as are children in low-income households or who were discriminated against based on race or ethnicity [42, 43].

By some accounts, mental health disorders are the most costly conditions in the United States, the leading cause of disability, and the single largest source of disease-related economic burden worldwide, costing the United States 201 billion dollars in 2016 [44, 45]. Children with mental illness have associated annual direct medical costs that are nearly triple that of children without mental illness [46]. In the long term, these individuals tend to miss important educational time, thereby limiting their ability to work and generate income as adults [47]. The economic burden imposed on families caring for children with mental health disorders is substantial, as these families are more likely to cut back on work hours or stop working altogether compared to those families caring for children with other special needs [48]. This more heavily affects privately insured families than publicly insured, which is likely related to the less generous mental health coverage offered by private payors resulting in greater out-of-pocket responsibility for those families [48]. As discussed earlier in this chapter, it has been well-established that increased cost sharing inevitably leads to worse adherence. However, despite the apparent impact on privately insured families, low-income children are still less likely to receive treatment for depression, anxiety, or behavioral or conduct disorders [49]. In addition, children and adolescents with more severe illness and greater comorbidity burden are also less likely to adhere to treatment regimens [50]. Although there are no estimates of the economic impact of nonadherence to mental health treatments in children and adolescents, it is known that noncompliance, particularly due to cost, places an even greater, disproportionate burden on people of color and low-income families, who are already more vulnerable to developing mental illness [51, 52].

## 7 Economic Benefits of Adherence

It is well-understood that adherence is associated with improved health outcomes and decreased disease-related complications. As a result, this leads to both direct and indirect economic benefits. Directly, there is reduced healthcare spending on sophisticated and expensive services related to disease progression or exacerbation, complication, or relapse [6]. This cost savings occurs in a variety of ways, from reduced hospitalizations, transportation, medications, procedures, equipment and technology, imaging, and subspecialty and other follow-up appointments. Indirectly, the preservation of life allows an individual to remain working for longer periods of time, providing a greater contribution to the overall economy [6]. In fact, health-related productivity loss costs 2.3 times more than direct healthcare costs [53], suggesting that strategies used to promote adherence may offer an even greater economic benefit than is generally appreciated. It is well accepted that investments in strategies to improve adherence are fully repaid with savings in healthcare utilization, and fully justifiable by their improved health outcomes [6]. For the child or adolescent, fewer hospitalizations and emergency room visits means less time away from school and extracurricular activities, therefore preserving normal childhood development and fostering a stronger educational experience also leading to improved longer term productivity.

## 8 Focusing on Intervention Efforts

Adolescence represents a critical transitional developmental period where both positive and negative health behaviors are established, thus representing a period of great opportunity for altering disease trajectory [54]. It is within the adolescent group that intervention efforts should be focused, as nonadherent behavior in this age group serves as a modifiable predictor of health care use and cost into adulthood [1].

As mentioned previously, the success of a child's health maintenance is largely dependent on a reliable caregiver, whose adherence may be further limited due to restrictive access to health resources or other barriers outlined earlier on in this chapter. As children grow, they develop the cognitive ability to carry out treatment tasks, although still requiring a certain level of parental supervision [6]. As the child develops into adolescence and young adulthood and assumes more responsibility with their own health care, one can expect adherence to suffer, as nonadherence is routinely observed when self-administration of therapy is required, regardless of the type of disease, disease severity, or accessibility to resources [6]. Additionally, the adolescent becomes increasingly influenced by their peers or social environment, shifting their time away from home and away from the parental supervision that they still rely on [6]. Unfortunately, adolescents who assume earlier responsibility of their treatment regimens are often found to be less adherent resulting in less

disease control over time [6]. Strategies that emphasize a shared family responsibility model and reinforcement of other behavioral techniques like goal setting, cueing, or rewards have been found to be beneficial in improving adherence in the school-aged population [6]. Finally, in addition to prevention, efforts must also be focused on reversing nonadherent behavior, as patients who were previously nonadherent and become adherent may have health care costs that are similar to those who were always adherent from the beginning [55].

## 9 Conclusion

This chapter has highlighted the extraordinary expense of healthcare in the US and the added cost associated with nonadherence in the pediatric population. Adherence in this age group deserves special focus, as nonadherent behavior in children serves as a modifiable predictor of health care use and cost into adulthood [1]. Careful attention should therefore be paid towards mitigating risks of noncompliance in this population through improved healthcare access, patient and family education, and shared responsibility in healthcare decision making. Improved understanding and greater recognition by pediatric providers of barriers to adherence, along with thoughtful interventions to both improve and reverse nonadherent behavior, will result in better health outcomes at a decreased expense.

## References

1. Medication adherence and health care utilization in pediatric chronic illness: a systematic review. <https://doi.org/10.1542/peds.2013-1451>.
2. Chakrabarti S. What's in a name? Compliance, adherence and concordance in chronic psychiatric disorders. *World J Psychiatry*. 2014;4(2):30–6. <https://doi.org/10.5498/wjp.v4.i2.30>.
3. Brown MT, Bussell JK. Medication adherence: WHO cares? *Mayo Clin Proc*. 2011;86(4):304–14. <https://doi.org/10.4065/mcp.2010.0575>.
4. Shaw CR. Reducing the burden of medication costs to improve medication adherence. *Nurse Pract*. 2014;39(7):43–7. <https://doi.org/10.1097/01.NPR.0000450739.27061.e2>.
5. Mykyta L, Cohen RA. Characteristics of adults aged 18–64 who did not take medication as prescribed to reduce costs: United States, 2021. Hyattsville: NCHS Data Brief; 2023. <https://www.cdc.gov/nchs/data/databriefs/db470.pdf>.
6. World Health Organization, Sabaté E. Adherence to long-term therapies: evidence for action, vol. xv. Geneva: World Health Organization; 2003. p. 198.
7. Menahem S, Halasz G. Parental noncompliance—a paediatric dilemma. A medical and psychodynamic perspective. *Child Care Health Dev*. 2000;26(1):61–72. <https://doi.org/10.1046/j.1365-2214.2000.00115.x>.
8. Stoddard-Dare P, DeRigne L, Mallett C, Quinn LM. Unintentional prescription drug noncompliance for financial reasons in families with a child with a limiting health condition. *Soc Work Health Care*. 2015;54(2):101–17. <https://doi.org/10.1080/00981389.2014.975315>.
9. Hoffman D. Commentary on chronic disease prevention in 2022, vol. 5. Decatur, GA: National Association of Chronic Disease Directors; 2022.



10. Iuga AO, McGuire MJ. Adherence and health care costs. *Risk Manag Healthc Policy*. 2014;7:35–44. <https://doi.org/10.2147/RMHP.S19801>.
11. Cost Sharing. <https://www.healthcare.gov/glossary/cost-sharing/>. Accessed May 2023.
12. National Health Expenditures 2022 Highlights 4. 2022.
13. Eaddy MT, Cook CL, O'Day K, Burch SP, Cantrell CR. How patient cost-sharing trends affect adherence and outcomes: a literature review. *P T*. 2012;37(1):45–55.
14. National Center for Health Statistics. Health US. Table [039]. Table 39. Prescription drug use in the past 30 days, by sex, race and Hispanic origin, and age: United States, selected years 1988–1994 through 2015–2018. In: National Health and nutrition examination survey (NHANES), appendix I. Hyattsville, MD: cdc.gov; 2019.
15. Fusco N, Sils B, Graff JS, Kistler K, Ruiz K. Cost-sharing and adherence, clinical outcomes, health care utilization, and costs: a systematic literature review. *J Manag Care Spec Pharm*. 2023;29(1):4–16. <https://doi.org/10.18553/jmcp.2022.21270>.
16. Services USCfMM. National Health Expenditure Data, NHE Fact Sheet. [https://www.cms.gov/data-research/statistics-trends-and-reports/national-health-expenditure-data/nhe-fact-sheet#:~:text=NHE%20grew%202.7%25%20to%20%244.3,Gross%20Domestic%20Product%20\(GDP\)](https://www.cms.gov/data-research/statistics-trends-and-reports/national-health-expenditure-data/nhe-fact-sheet#:~:text=NHE%20grew%202.7%25%20to%20%244.3,Gross%20Domestic%20Product%20(GDP)). Accessed May 2023.
17. Statistics FIFoCaF. In: AsCaa G, editor. America's children: key national indicators of well-being. Washington, DC: U.S. Government Printing Office: childstats.gov; 2023.
18. Children's health coverage trends: gains in 2020–2022 reverse previous coverage losses. 2023.
19. Kennedy J, Wood EG. Medication costs and adherence of treatment before and after the affordable care act: 1999-2015. *Am J Public Health*. 2016;106(10):1804–7. <https://doi.org/10.2105/AJPH.2016.303269>.
20. Gunja MZ, Gumas ED, RDI W. U.S. Health Care from a global perspective, 2022: accelerating spending, worsening outcomes. New York, NY: Commonwealth Fund; 2023. <https://doi.org/10.26099/8ejy-yc74>.
21. Vankar P. Health expenditure as a percentage of gross domestic product (GDP) in selected countries in 2022. Hamburg: Statista; 2023.
22. Shrank WH, Rogstad TL, Parekh N. Waste in the US health care system: estimated costs and potential for savings. *JAMA*. 2019;322(15):1501–9. <https://doi.org/10.1001/jama.2019.13978>.
23. Avoidable Costs in U.S. Healthcare: The \$200 Billion Opportunity from Using Medicines More Responsibly 57. 2013.
24. National Center for Health Statistics. Health US, [edition 2020–2021]: Table [HExpType]. National health expenditures, average annual percent change, and percent distribution, by type of expenditure: United States, selected years 1960–2019. Centers for Medicare & Medicaid Services, Office of the Actuary, National Health Statistics Group, National Health Expenditure Accounts, National health expenditures. Hyattsville, MD: cdc.gov. 2020
25. McDermott KWPD, Jiang JHPD. Characteristics and costs of potentially preventable inpatient stays. In: HCUP Statistical Brief #259. Rockville, MD: Agency for Healthcare Research and Quality; 2020. <https://hcup-us.ahrq.gov/reports/statbriefs/sb259-Potentially-Preventable-Hospitalizations-2017.jsp>.
26. Carmody JK, Gutierrez-Colina AM, Hommel KA. Fact sheet: adherence to pediatric medical regimens for chronic disease. New Orleans: Society of Pediatric Psychology; 2023. [https://pedpsych.org/fact\\_sheets/medical\\_regimens/](https://pedpsych.org/fact_sheets/medical_regimens/). Accessed May 2023.
27. Raghupathi W, Raghupathi V. An empirical study of chronic diseases in the United States: a visual analytics approach. *Int J Environ Res Public Health*. 2018;15(3):431. <https://doi.org/10.3390/ijerph15030431>.
28. (NCCDPHP) C-NCfCDPaHP. About Chronic Diseases. <https://www.cdc.gov/chronicdisease/about/index.htm>. Accessed May 2023.
29. Buttorff C, Ruder T, Bauman M. Multiple chronic conditions in the United States. Santa Monica: RAND Corporation; 2017.
30. (NCCDPHP) C-NCfCDPaHP. Promoting Health for Children and Adolescents. <https://www.cdc.gov/chronicdisease/resources/publications/factsheets/children-health.htm>. Accessed May 2023.