

## NEW DIGS

# FoCUS

Financing and Reimbursement  
of Cures in the US

## RESEARCH BRIEF

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**Themes in patient and caregiver financial challenges.** Patients and caregivers are key stakeholders in the development of system-wide, implementable precision financing models for durable and curative therapies. Patient and caregiver challenges are generally assumed to be primarily financial, including co-pays, deductibles, and lost income. We undertook a systematic literature review to investigate current understanding of the patient and caregiver experience, including both financial and other related issues.



### What makes up the patient and caregiver experience?

In published literature on patients and caregivers, the majority of studies focus on the patient share of direct medical costs (co-pays and deductibles). These studies generally use claims databases as their source. This emphasis ignores the complex and multi-faceted experiences of patients and caregivers, which also includes many other challenges relating to their disease and their interactions with components of the healthcare system. This study examined a broader set of papers that drew data directly from patient and caregiver voices.

A systematic literature search was conducted using PubMed, with search facets for: economic or financial burden, stress, or distress; patients, caregivers, or family. Studies had to be

published in English, based in the US, and from 2010 onwards. The year 2010 was selected as it slightly preceded costly durable treatments for cancer. The US was used as a filter because of the specificity of patient and caregiver experiences sought.

### KEY TAKEAWAYS

Patients and caregivers face many interconnected challenges in navigating their disease and treatment.

Some of these challenges are linked to costs and lost income/job insecurity.

Others relate to non-finance-specific issues such as provider communication, resource navigation within the healthcare system, unevenness of adequate medical care geographically, and managing mental health and stress.

Future primary research is needed to hear from patients and caregivers directly in order to both test and refine the themes that arose from our systematic review as well as ascertain if patients and caregivers are able to productively use existing financing tools.

**RESULTS**

Our search results (see Figure 1 below) affirmed part of the premise for the research: from an overall set of slightly more than 8,000 published studies, 6,842 were excluded at a title review on the basis of being studies only of treatment costs – claims database reviews, cost-effectiveness analyses, etc. Many were also evident from their titles to be papers on adherence.

From the 1,226 studies retained for abstract review, a majority were excluded, mostly due to being non-US studies or covering unrelated topics – again, these tended to be studies only enumerating treatment costs, looking at adherence, or reporting payers’ budget impacts.

400 papers were retained. They were reviewed independently by two reviewers.

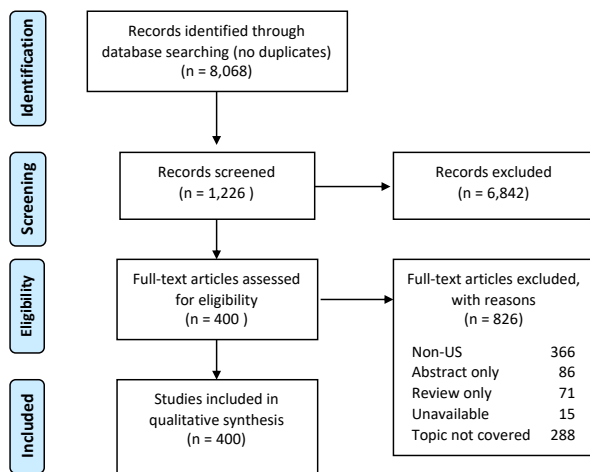


Figure 1. Study PRISMA diagram

Figure 2 lists the themes identified in the published literature. There were 27 themes in total, corresponding to a range of concepts spanning finances, mental health, demographics and socioeconomics, and a range of challenges that relate specifically to how patients and caregivers actually navigate the healthcare system to access treatment.

The themes were categorized into five core groups of issues relating to:

1. The healthcare system
2. Patient or caregiver health
3. Treatment financing
4. Treatment payment
5. The context of treatment and financial challenges.

Groups #3 and #4 exist separately because payment for treatment is not the same as financing that payment. However, many of the themes and their larger categories overlap. In the full set, only a handful of themes and categories were standalone, and all of the categories themselves overlapped.

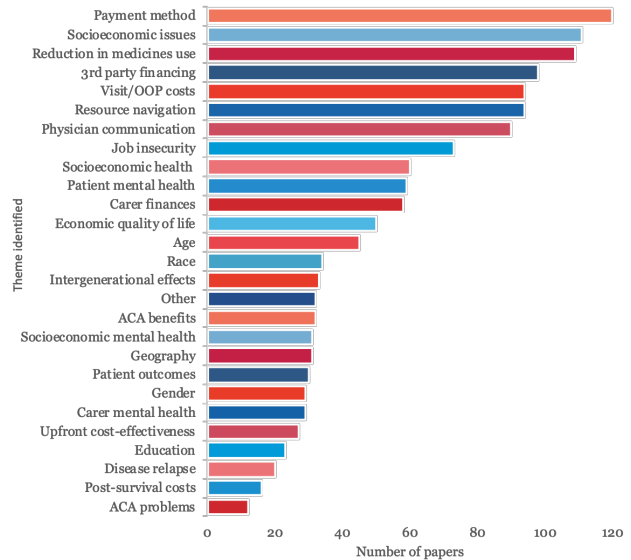


Figure 2. Themes from systematic review of patient and caregiver perspective

In order to capture the challenges faced by patients and caregivers in a broad narrative, themes were assessed for their co-occurrence, i.e., the degree to which given themes generally would be seen together.

Third-party financing was positively correlated with every other theme, which reflects the degree to which a person’s health insurance will affect every other aspect of their care and resource navigation, as well as employment, mental stress, etc., and how it can be affected by demographics and socioeconomics.

In the studies we extracted there was a very small number of patients and caregivers using financial tools such as bankruptcy, asset liquidation, or credit maximization to meet their medical expenses. Instead, patients and caregivers appear to take on more physical, emotional, mental, and/or social stress. This calculus brings together a number of themes like reduction in medicines use, socioeconomic health, economic quality of life, disease relapse, and mental health issues.

A strong narrative arose centering the issue of resource navigation and physician communication. Resource navigation and physician communication are not the highest listed in Figure 2 but presented the most cohesive story: patients and caregivers feel anxiety as a result of what they considered to be a lack of adequate guidance when it came to managing their financial burden, as well as frustration with the fragmented nature of financial resources available to them to meet their growing medical bills. This connected with physician communication, including both patient/caregiver and physician perspectives on the role of physicians in this regard.

Other themes emerged around resource navigation tied to education: the need for financial planning and improved financial literacy; the need for simpler administrative burden, particularly on caregivers; and the need for an ‘agent’ to help patients and caregivers.

### CONCLUSIONS AND IMPLICATIONS FOR PRECISION FINANCING SOLUTIONS

Our systematic review of the literature pertaining to patient perspectives in the US since 2010 illustrates how heterogeneous the patient and caregiver experience is, and how many factors intersect to influence that experience.

To develop financing tools that meet the needs of patients and caregivers, it is critical to have a clear understanding of what their challenges are.

Published literature can be taken as a first step in exploring this story, but primary research that elicits patient and caregiver voices directly should be considered as a necessary step in the further testing and refining of these themes.

### ABOUT FOCUS

The MIT NEWDIGS consortium FoCUS Project (Financing and Reimbursement of Cures in the US) seeks to collaboratively address the need for new, innovative financing and reimbursement models for durable and potentially curable therapies that ensure patient access and sustainability for all stakeholders. Our mission is to deliver an understanding of financial challenges created by these therapies leading to system-wide, implementable precision financing models. This multi-stakeholder effort gathers developers, providers, regulators, patient advocacy groups, payers from all segments of the US healthcare system, and academics working in healthcare policy, financing, and reimbursement in this endeavor.

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#### *Please cite using*

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