

NEW DIGS

FoCUS

Financing and Reimbursement
of Cures in the US

RESEARCH BRIEF

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The resource navigation challenges for patients and caregivers. While the problem of finding system-wide, implementable precision financing models for curative and durable therapies involves all stakeholders, patients and caregivers are directly affected by many different elements of financial burden. Generally, patient and caregiver financial challenges related to their disease and treatment are bracketed by categories that relate to money: outlays, such as co-pays and deductibles, and lost income. Our research revealed more nuanced, wider-reaching challenges, including several under the theme of resource navigation.

WHAT MAKES UP THE PATIENT AND CAREGIVER EXPERIENCE?

A previous research brief summarized the [systematic literature review and thematic analysis](#) of patient and caregiver financing challenges.

The analysis identified 27 themes from 423 published articles; themes spanned patient-specific and caregiver-specific challenges, finance-specific challenges and health, economic, and social challenges, including age and race (see Fig 1 and Fig 2).

“Resource Navigation” was the fourth-most common theme established (after payments, socio-economic challenges, and medical care reduction) and the second-most co-occurring set of themes out of the six groups (after payments and financing).

WHAT IS RESOURCE NAVIGATION?

Resource navigation refers to a fragmented landscape of support in the US – formally of monies, direct and indirect, but also institutional support from payers and providers; informally, resources also can exist within the family and community.

A patient’s or caregiver’s ability to locate resources to meet medical expenses decreases the pressure on

Key takeaways

Patients and caregivers identified a ‘resource navigation’ barrier – the challenges in finding and using financial and other resources.

Resource navigation challenges are heterogeneous in part because patients and their diseases are heterogeneous.

Many groups might provide resource navigator services.

But **none are the clear navigator** in the current fragmented healthcare system.

A **resource navigation tool** developed collaboratively could address this unmet need.

their household finances, and for this reason plays a central role in the patient and caregiver financial experience.

WHAT ARE RESOURCE NAVIGATION CHALLENGES?

We found that patients and caregivers experience two points of frustration finding formal resources to support care: (i) navigating the fragmented landscape of potential monies available, and (ii)

locating people who could help them with this task.

We read varying examples of patients and caregivers who reported high levels of financial burden but who were either not aware of, or did not draw upon, resources available to them:

- Not knowing about public insurance resources such as the Children’s Health Insurance Program (CHIP) or public prescription drug programs like Medicare Part D.
- Not knowing about Private sources, like developer coupon programs or provider sponsored co-pay assistance programs.

Many studies concluded that there is a need for a more active intervention by providers, public payers, or government agencies to raise awareness among targeted demographics – a mixture of a need for more resources themselves but also a financing analogue of a “travel agent” for patients and caregivers.

While these do exist at both the payer and provider level, they are also fragmented, looping recursively into the same challenges for patients and caregivers who also reported administrative barriers to navigating the institutions providing them, both public and private.

OTHER STAKEHOLDERS

Patient and caregiver relationships seem to drive how other stakeholders can be inveigled into these challenges. Providers, in particular, arose as having the highest expectations because (i) they are an authoritative figure with whom patients and caregivers interact directly, and (ii) they administer the therapy and hence are connected to its payment.

We found a debate in the literature among physicians and nurses about whether or not they should assume this role – and whether

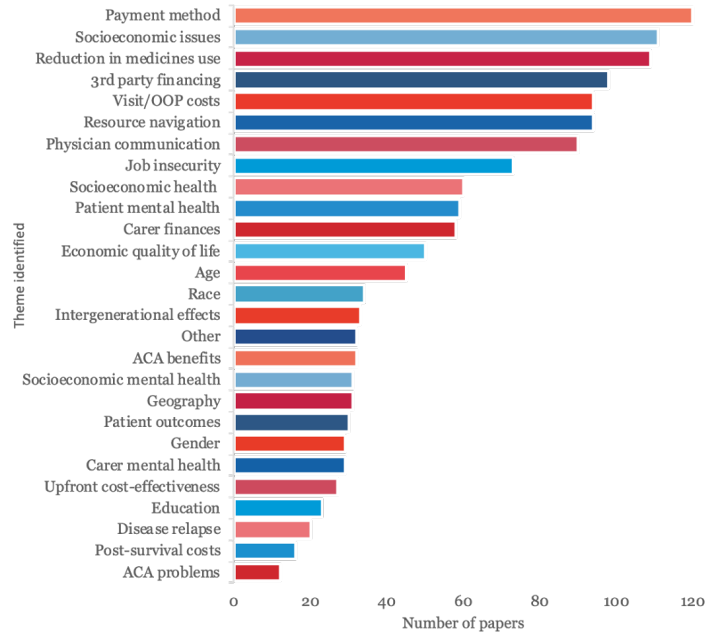
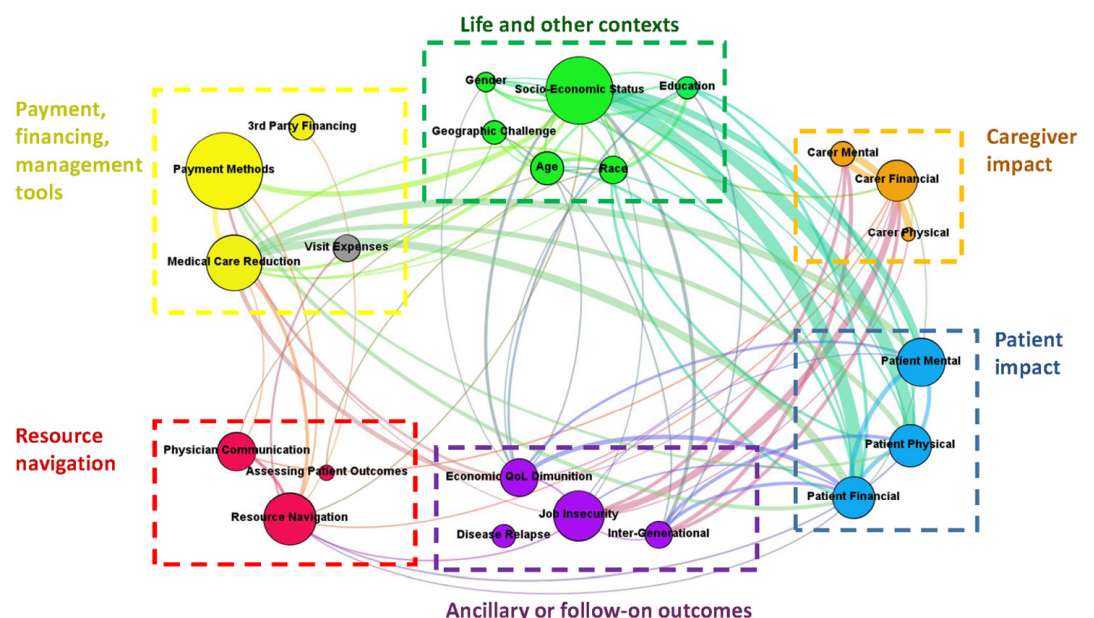


Figure 1. Themes from literature review and textual analysis

or not they were qualified for it. So much so that ‘Physician Communication’ is one of our 27 key themes (Figure 1).

Pharmacists also emerged as potential ‘resource navigators’, though they appeared to be under-used. Pharmacists reported being willing to take on more of this responsibility in part because they understand themselves to be more socially and geographically accessible to patients than, e.g., clinicians. Developers were rarely mentioned as sources of help among patients and caregivers.

Figure 2. Theme, Category, and Cooccurrence Relationships



PATIENT AND CAREGIVER EDUCATION

Age, education, gender, geographical location, race, and socio-economic status all emerged as issues across multiple themes.

We found a strong relationship between levels of formal education and success accessing government assistance programs, while the intersection of gender and race is highly correlated to patients' and caregivers' comfort in asking for resource navigation assistance from physicians.

Patient and caregiver education arose in our results when it came to being trained and supported in the healthcare system on available resources, financial literacy, and navigational skills.

POLICY IMPLICATIONS

In a hierarchy of policy, process, and procedure, the resource navigation challenges can be considered not as a failure in terms of policy: between our research and the MIT Design Labs run by the MIT NEWDIGS FoCUS consortium, all stakeholders express a commitment, and often action, in trying to ensure that patients, particularly seeking cell and gene therapies, have access to the financial and material resources they need.

We found instead, in our work, what appear to be failures at process and procedure levels. The US healthcare system is itself very fragmented, and even navigating care per se presents a challenge for patients and caregivers.

Financing and financial support is similarly but also differently fragmented, adding an additional layer to the challenge.

Patients and caregivers are not properly equipped to navigate this themselves; much like they require provider support in determining adequate care, so do they likewise need help with financial support. At the patient and caregiver level, the shortcomings are heterogeneous, including:

- Formal education
- Financial literacy specifically and prior financial education surrounding the treatment
- Socio-economic status, age, and other factors determining forwardness in seeking support at all
- Where each person is in their disease, treatment, or other situations (e.g., housing, rurality, other factors) and how these circumstances can affect their capability.

TOWARDS A COLLABORATIVE RESOURCE NAVIGATION TOOL

Procedurally, there are system-wide changes that can be made. One that arose from our research was a type of diagnostic tool that could, up-front, assess the financial literacy and preparedness of patients and caregivers, and which could be used periodically to check in on them.

This tool would have a wider impact than finances alone; it could be as expansive as family and community available resources, and stability in employment, housing, and more – all aspects of a person's life that create resource needs but also resource navigation barriers and obstacles.

Given the fragmented nature of the US healthcare system and financing, this tool would have to be collaboratively multi-stakeholder in development, deployment, and use, and connected to resources or case management.

Collaboratively constructing a resource navigation tool that engages many stakeholders could leverage the knowledge, skills and resources of all and reduce the burden on any one entity to address this healthcare system-wide challenge. Such an open approach over time would also attract more organizations with resources to offer and enable self-sustaining operations for the tool itself and the community.

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 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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