People Over Profits

A Values-Based Movement for Declining Health

NPHI
National Partnership
for Healthcare and
Hospice Innovation

Partners and Acknowledgements

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Letter from the CEO & President

For more than 50 years, nonprofit providers who serve patients and families in declining health have built a reputation for delivering elite care in often chaotic circumstances. Across the continuum from illness to aging to end of life, the individuals who do this work every day are nothing short of heroic. Together, they represent the vanguard of a movement to transform healthcare in the United States.

This transformation has never been more urgent and necessary. As this blueprint details, healthcare costs—and profits—keep rising, while outcomes for patients and families grappling with declining health keep getting worse. This is particularly true in the most vulnerable communities, who face greater risks and have less access to treatment. By reimagining care to better address the needs of the most vulnerable, we can improve care for everyone. Community-based, values-driven organizations, like the 100+ members of NPHI, have known this all along.

What unites these organizations is something much deeper than nonprofit tax status—it's about values, vision, and expertise. Only by raising our collective voice and asserting ourselves as the trusted authority on quality care for those in declining health can we fight back against the cynical profit-seeking that threatens our industry. As you will see in the data we have collected, widespread public distrust of the healthcare system is linked to the financial motives that dictate how that system works.

This is only the first step. In the coming months and years, we will advance a shared story that speaks to the concerns of patients, families, healthcare providers, payers, and policymakers. This is our moment, and we will rise to the occasion—together.

Sincerely,

Tom Koutsoumpas

Chief Executive Officer, National Partnership for Healthcare and Hospice Innovation
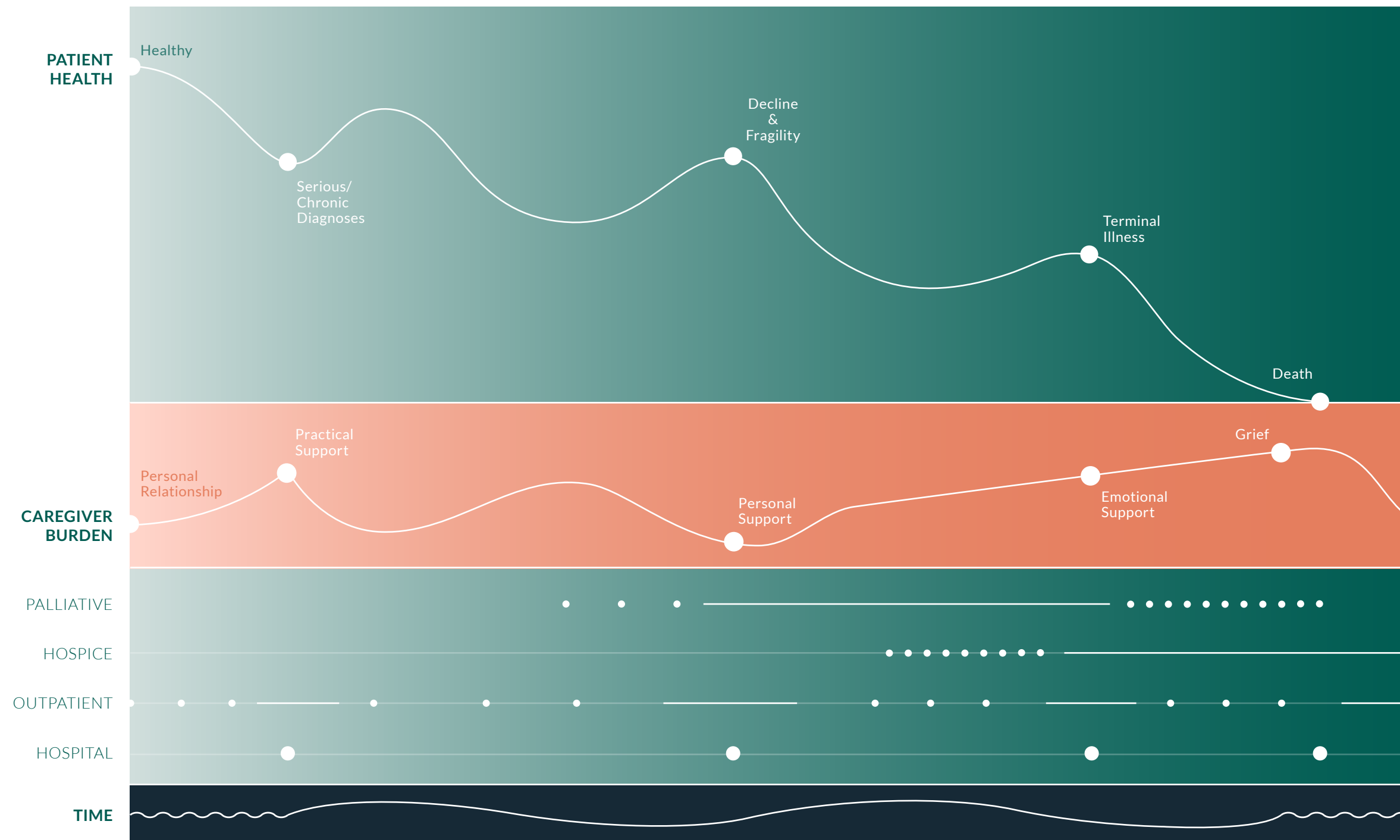
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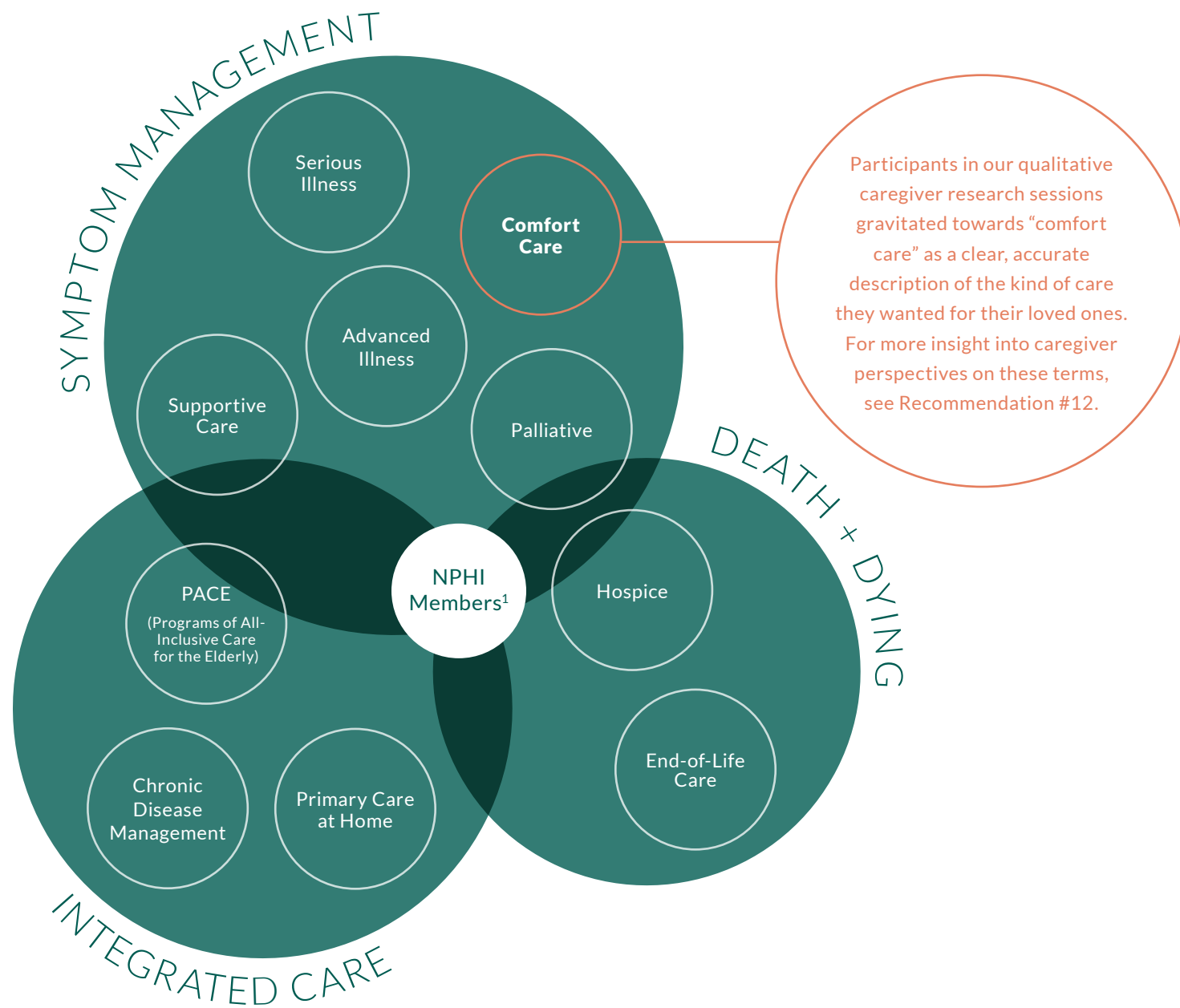
Executive Summary

Good times, bad times

The United States healthcare system is facing a reckoning. A set of interconnected social, demographic, medical, and economic forces are radically reshaping how healthcare works—and doesn't work—in our society. Despite America's reputation as a world-leader in research, innovation, and treatment, health outcomes at the population level are getting worse even as costs soar. The reason for this is not necessarily that people are getting "sicker" or that they are getting "sick" in new ways. Many of the factors that drive high costs and poor outcomes could be managed effectively and efficiently. Instead, our fractured healthcare system often stands in the way of coordinated, comprehensive, human-centered care. Resolving these tensions will require grappling with the experiences and attitudes of the American public—as well as the systemic factors that shape their perceptions. Based on that understanding, community-based, mission-driven organizations can offer a new narrative of what healthcare can and should be.

PATIENT HEALTH

Healthy

Serious/ Chronic Diagnoses

Decline & Fragility

Terminal Illness

Death

CAREGIVER BURDEN

Personal Relationship

Practical Support

Personal Support

Emotional Support

Grief

PALLIATIVE

HOSPICE

OUTPATIENT

HOSPITAL

**TIME**

Slipping through the cracks

Unsurprisingly, the impact of this flawed system is felt most acutely by those in declining health. Declining health can be understood as an umbrella term that encompasses serious, advanced, terminal, and chronic illnesses, as well as the natural effects of aging. After centuries of progress in medicine, nutrition, and physical safety, it is now the combination of illness and aging that leads to the vast majority of deaths in the US. Accordingly, a variety of models have emerged to address different facets of the aging process and the continuum of illness. This complex landscape produces myriad logistical and bureaucratic challenges and prevents many individuals from getting the kind of care they want and deserve when and where they need it.

SYMPTOM MANAGEMENT

Serious Illness

Comfort Care

Advanced Illness

Supportive Care

Palliative

PACE (Programs of All-Inclusive Care for the Elderly)

NPHI Members[1]

Hospice

DEATH + DYING

Chronic Disease Management

Primary Care at Home

End-of-Life Care

INTEGRATED CARE

Participants in our qualitative caregiver research sessions gravitated towards "comfort care" as a clear, accurate description of the kind of care they wanted for their loved ones. For more insight into caregiver perspectives on these terms, see Recommendation #12.

The gaps in care become even more stark when we consider the experiences of the most vulnerable communities. From higher infant mortality rates to decreased life expectancy, health disparities between white and non-white communities have persisted for decades, but only recently have these issues begun receiving the public attention they deserve. A wealth of evidence demonstrates that non-white patients experience significantly worse outcomes than white Americans with the same health conditions. For example, African Americans are 30% more likely[3] than whites to die prematurely from heart disease, and African American men are twice as likely as white men to die prematurely from stroke.

On top of a long legacy of institutional racism and bias in healthcare, a significant factor in these disparate outcomes is the role of social determinants of health. Issues like access to housing, nutritional foods, and clean air and drinking water are increasingly understood to be drivers of morbidity and mortality that disproportionately affect vulnerable communities. Studies show that social determinants may account for more than 50% of health outcomes,[4] while clinical care accounts for as little as 16%.[5]

Effects on Health Outcomes

	Social Determinants (50%)
	Clinical Care (16%)
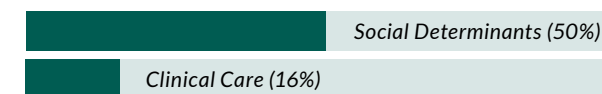
There is growing consensus that social supports have a positive effect on health and well-being and must be integrated with the healthcare system to not only eliminate health disparities, but improve care for the entire population. While there are models and organizations practicing this type of integrated care across the country, our public policy and medical institutions have not fully embraced this evolution in thinking. The US currently spends[6] only 90 cents on social support for every dollar spent on healthcare, while other industrialized nations spend twice as much on social support as they do on healthcare.

Follow the money

Despite these sobering realities, for companies in the healthcare sector, business is booming. Profits for the healthcare industry are expected to approach $700 billion by 2025,[7] with no signs of slowing down.[7a] What should we make of the immense profitability of the industry and its shortcomings in achieving quality outcomes for those in declining health? A recent survey of the American public found that only 18%[2] of Americans trust the US healthcare system to put their well-being ahead of profits.

ONLY 18%

of Americans trust the US healthcare system to put their well-being ahead of profits.

The growth and profitability of the healthcare industry didn't happen overnight. Spending and profits exploded in the post-World War II era,[8] due to factors like the introduction of Medicare and Medicaid; the growth of the hospital industry; and advances in medical technology, procedures, and pharmaceuticals. Alongside these shifts—and perhaps because of them—the physician workforce has become increasingly specialized, prompting dire warnings about the coming shortage of primary care physicians, especially in rural areas. Without access to a consistent primary care physician, it will become ever more challenging for individuals in declining health—particularly those from vulnerable populations—to find the kind of coordinated, multidisciplinary care they need. Despite a pandemic that had an outsized impact on these populations and a mountain of research detailing the problem, there has been little progress on the kind of systemwide transformation the moment demands.

Past is prologue

Meanwhile, a very different story has unfolded in parallel. Starting in the 1960s, the pioneering work of figures like Dame Cicely Saunders, Elisabeth Kubler-Ross, and Florence Wald gave birth to a new model of healthcare, focused on relieving pain and improving quality of life for the seriously ill and dying. As hospice organizations began to emerge across the US throughout the 1970s and 1980s, almost all were community-based nonprofits. Many of those organizations continue their work today, often with a significantly expanded set of services to meet the needs of a more diverse population and changing clinical realities.
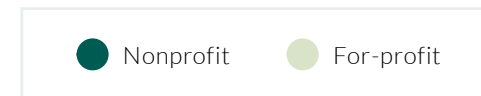
One critical facet of the hospice model with significant implications for the current healthcare environment is an emphasis on providing care in the patient's home. Home-based care aligns with hospice's prioritization of comfort and quality of life, but it also offers care teams crucial insight into social and environmental health risks. Patient preference for home-based care has increased in recent years, accelerated by the COVID-19 pandemic. A recent survey[9] found that some 70% of Americans over 50 would prefer to receive care in the home, and by some estimates[10] up to 25% of all Medicare fee-for-service and Medicare Advantage spending could shift to home-based care by 2025. With decades of experience delivering quality, home-based care for patients and families with complex needs, nonprofit hospice organizations should be viewed as leaders in this transformation. Yet for all their expertise, compassion, and courage, nonprofits are now facing an existential threat.

Since the passage of the Medicare hospice benefit in 1982, a growing number of new, for-profit companies have entered the space. Some 40 years later, hospice has become the single most profitable sector[11] of healthcare in the US. Private equity firms have taken an interest in the space, and the number of for-profit hospices has exploded from 30% of all providers in 2000 to 73% in 2020. While more patients are using hospice services than ever before, the quality and variety of care delivered by for-profits, as well as the
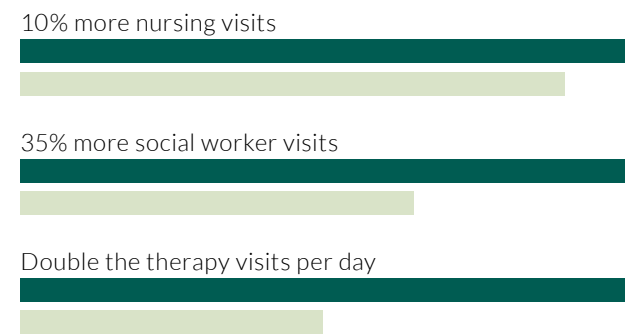
types of patients they serve, differs sharply from nonprofit providers.

The NPHI-sponsored 2019 study,[12] *Hospice Medicare Margins: Analysis of Patient and Hospice Characteristics, Utilization, and Cost* outlined these differences:
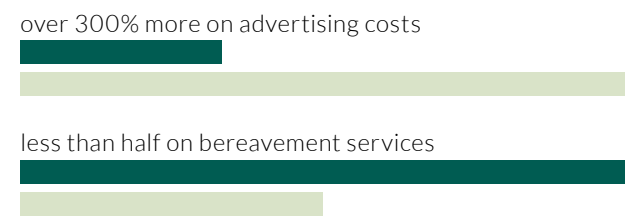
Nonprofit vs. For-Profit

● Nonprofit   ● For-profit

Non-profits provide:

10% more nursing visits

35% more social worker visits

Double the therapy visits per day

Meanwhile for-profit hospices report spending:

over 300% more on advertising costs

less than half on bereavement services

Margins

3.0% vs. 19.9%

These findings were validated by a 2023 review[13] of more than 650,000 patient and family surveys about experiences with hospice care, conducted by the RAND Corporation. On average, families reported having worse care experiences with for-profit hospices and were less likely to recommend for-profits to their peers. Significantly more for-profits were rated in the low-performing category across all eight measures the researchers studied.

In addition to these important distinctions, the rapid growth of the for-profit industry has coincided with even more alarming trends like outright fraud and abuse targeting both the Medicare hospice benefit and patients. A 2022 *ProPublica* investigation,[14] published in the *New Yorker*, revealed a widespread pattern of potential criminal misconduct that lined the pockets of shareholders and executives at the expense of patients, families, and taxpayers. While these bad actors represent a minority of providers, they reflect a broader trend in healthcare of prioritizing profit over patient well-being.

Urgent need, immense opportunity

American attitudes about healthcare, illness, aging, and death are complex and occasionally contradictory. Yet, across the board, there is a clear pattern of distrust in the healthcare system, a significant amount of which appears to be driven by the financial aspects of care—high costs, profiteering, and lack of transparency. Decision-making around care for those in declining health will never be "easy" and it may be impossible to truly say what the "right" decision is in a particular situation. But in the absence of a trusted authority to help guide those decisions, people are left with no choice but to rely on the same healthcare system they overwhelmingly do not trust, with predictably unsatisfying—and, at worst, catastrophic—results.

This blueprint aims to equip community-based, mission-driven providers across the country with the tools to assert themselves as the trusted authority on delivering home-based care for patients and families navigating declining health, advanced illness, and bereavement. It draws on extensive quantitative and qualitative research into the American public's perceptions and experiences of illness, aging, and the healthcare system at large, with guidance from some of the country's leading subject matter experts. By elevating the legacy, expertise, and innovative approach of these organizations and individuals, we can offer an alternative to the financially motivated, fractured model of care that we experience today. In its place, we will advance a coordinated, nationwide movement that relieves the burdens of declining health for patients, families, communities, and providers who seek to put patients over profits.

I trust the healthcare system to...[2]

27% Care about the conditions of your daily life

18% Put your well-being ahead of profits

17% Prepare you for cost of care

29% Educate you about all of your options for end-of-life care

44% Protect your privacy

27% Help you live on your own terms as you get older and near the end-of-life

33% Collaborate with you to get the care you need

30% Care for you as you age

37% Respect your religious or spiritual concerns

37% Treat you equitably

35% Help you live as long as possible

33% Help prevent avoidable pain and distress

38% Accurately diagnose problems and prescribe treatments

37% Help you stay healthy

33% Understand and respect your culture

40% Treat you with respect & empathy
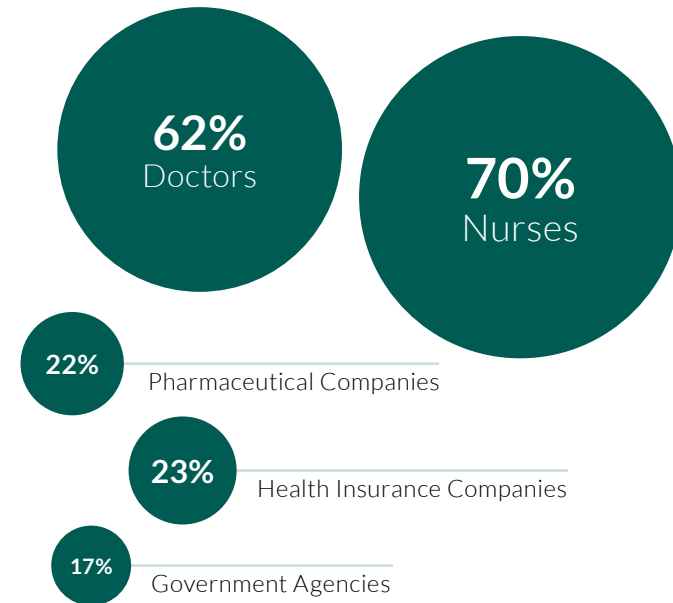
27% Understand your unique needs

01

Healthcare for the (Mostly) Healthy

Peer pressure

Individual attitudes about healthcare in the context of declining health are not formed at the precise moment of diagnosis. They are shaped by a lifetime of experiences—from routine check-ups to treatment for acute needs. On top of those direct lived experiences are external factors, like a friend's anecdote or a news story. In recent years, there has been a great deal of bad press about various aspects of healthcare. Price gouging "pharma bro" Martin Shkreli became one of the most hated people in America overnight, drawing new attention to profiteering in the pharmaceutical industry. In parallel, more than two-thirds[15] of all bankruptcies in the US are now the result of medical debt. COVID-19 did not create the deep structural flaws of American healthcare, but it did exacerbate them and drive a surge in media attention.

NPHI survey data offers a deeper perspective on the general attitudes of the American public regarding the healthcare system. The word "system" is critical here—opinions about care providers, like doctors and nurses, remain generally favorable, in sharp contrast to the way the public views institutions.

How much do you trust the following?[2]

62% Doctors

70% Nurses

22% Pharmaceutical Companies

23% Health Insurance Companies

17% Government Agencies

These jarring statistics present a significant opportunity for community-based "safety net" providers to assert themselves as trustworthy institutions that stand in sharp contrast to the perceived shortcomings of both the public and private sectors. Every time a new story is published about price hikes in the pharmaceutical industry or an insurance provider denying coverage for a lifesaving treatment, the public's faith is further eroded. By contrast, providers who care for all patients, regardless of their ability to pay, have a compelling story to tell about their role as "safety net" providers, delivering the best care to those who need it most.

All Bankruptcies in the US

>66% Medical Debt
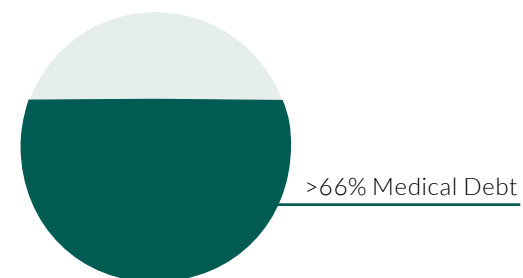
Out of the mouths of babes

Given that younger, healthier individuals have less firsthand experience interacting with healthcare, external influences like media coverage may play an outsized role in shaping how they view the healthcare system at large. Politically, younger people tend to be more critical of institutions than older generations on issues ranging from climate change to criminal justice reform to universal healthcare. It is no surprise, then, that even in the context of generally negative opinions about healthcare, younger generations stand out. NPHI survey data found stark differences in opinion between the oldest and youngest respondents.

This may be explained by a general resistance to the idea of "American exceptionalism" among younger respondents, as well as a greater awareness of injustice and inequality across American society.

While community-based providers in the declining health space tend to have older patient populations, the philosophy and mission that drives these organizations may be appealing to younger members of the community.

How do you rate the US healthcare system overall?[2]

People born before 1945

Millennials

38%

15%

3%

19%

Poor

Very good
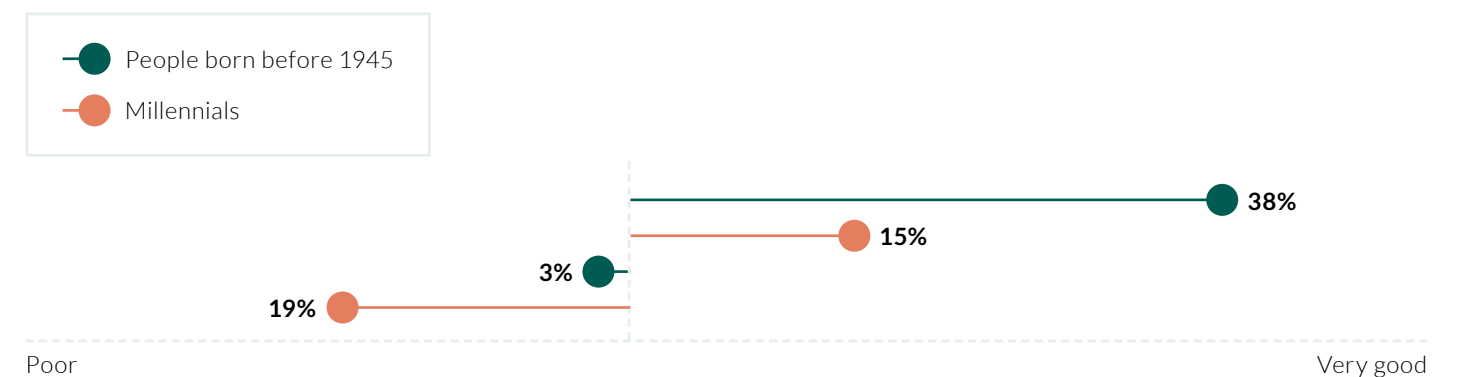
Real Stories:
Shanu

Shanu was born in India and raised in the US, and now cares for both her parents and her husband's parents, along with her own children. All three generations of the family live together and share responsibility for care of the elderly family members.

For Shanu, the biggest burden comes not from providing care but from the paperwork and bureaucracy associated with insurance and healthcare. Even after living in the US for many years, she is still disturbed by how complex the healthcare system is and how transactional her interactions with it can feel. She sees many of these issues as symptomatic of a broader self-centeredness in American culture, and is quick to contrast this mentality with the more communal, tight-knit culture of families in India. When she's unable to pick up a prescription or drive one of her parents to the doctor, someone else in the family is always ready to pitch in, exemplifying this spirit of shared responsibility.

Balancing her work, family, and caregiving duties is taxing, but Shanu sees it as a privilege to care for her parents just as they cared for her when she was young. Similarly, she knows that her own children are internalizing this philosophy and will care for her in old age, continuing the circle of life.

"Just like it takes a village to raise a child, it takes a village to make the elderly comfortable…but this culture is not a village. Our village in America sucks, it's been burned down.

United we stand, divided we fall

Pinpointing the primary source of the public's skepticism of the healthcare system is not challenging—it's about money. A 2022 NPHI survey probed on trust of the healthcare system in general, but also looked at how much the public trusts that system across a variety of more specific areas, from privacy to quality of care to respecting an individual's culture. The two lowest-rated categories both relate to financial aspects of care.

How much do you trust the US Healthcare System to...[2]

18% Put your well-being ahead of profits

17% Prepare you for cost of care

These dismal numbers only tell part of the story. When examining the views of uninsured populations, the results are even more striking. Nearly 80% say they don't trust the healthcare system to accurately diagnose and treat conditions or prevent avoidable pain and distress. One could argue that accurately diagnosing and treating conditions, as well as preventing avoidable pain and distress, are among the most fundamental tasks of healthcare. If the system can't be trusted to perform these functions, something is deeply broken.

As noted in the Executive Summary, many of the factors driving poor health outcomes stem not from healthcare itself, but from social determinants of health. Data has shown that housing instability[16] and food insecurity[17] affect 10-15% of the population, and those factors are independently associated[18] with health outcomes like postponing medications or medical care, emergency department visits, and hospitalizations. To truly address issues of trust in healthcare, it will be essential to account for related social and economic factors.

Support for resources like housing, food, and transportation is often accessible only through a patchwork of means-tested programs, which often involve onerous, bureaucratic processes. As in the case of healthcare, there are thousands of local service providers in communities around the country working to fill the gaps against immense odds. Similarly, mission-driven organizations that care for those in declining health, following the original hospice model, place great emphasis on social, behavioral, and emotional considerations. This is a significant point of differentiation from the narrower medical model pursued elsewhere in the healthcare system, and lays the groundwork for natural alliances among values-aligned health and social service providers in communities around the country.

02

Navigating Chronic, Serious, and Advanced Illness

An 85 year-old living with dementia. A 65 year-old managing cardiovascular disease. A 45 year-old diagnosed with advanced cancer. A child born with a congenital heart defect. Being diagnosed with a serious or chronic illness is a profoundly disorienting experience at any age. Despite the distinct pathology of different conditions, reckoning with a drastic shift in health status causes a break in one's sense of self. We all have an internal narrative, a story we are constantly writing about who we are as human beings, and with a change in physical or mental circumstances, that narrative can collapse—this is not what was "supposed" to happen. For both the patient and their loved ones, real support is about something bigger than treatment. It's about conceptualizing what a new story can look like, and having the courage to write it.

"I cannot make you understand. I cannot make anyone understand what is happening inside me. I cannot even explain it to myself."

Kafka, *The Metamorphosis*

"As people become more aware of the finitude of their life, they do not ask for much... They ask only to be permitted, insofar as possible, to keep shaping the story of their life in the world—to make choices and sustain connections to others according to their own priorities."

Gawande, *Being Mortal*

In the context of serious illness, the idea of "care" is often synonymous with "treatment." Disease is a problem to be solved, not a state of being to be understood, processed, and managed. As physician specialization has accelerated over the past 50 years, the healthcare system has gotten better at treating the illness, perhaps to the detriment of caring for the patient. The exception to this is the field of palliative medicine, which offers a more holistic view that focuses on the human being with an illness, rather than just the illness. There is broad recognition in the medical community of the value that palliative medicine can have. In 2008, the American Board of Medical Specialties (ABMS) began offering board certifications[19] in hospice and palliative medicine across 10 different subspecialties—"the first time 10 ABMS member boards have collaborated to offer certification in one area."

Such broad recognition of the value of palliative medicine has had mixed results. One analysis[20] found that acceptance of palliative medicine has increased to the point where 85% of medium to large hospitals now have palliative medicine teams present. Yet, the same paper used survey data of current palliative medicine practitioners to warn of a looming shortage of palliative specialists, with "19% [of providers] expressing a 50% or higher chance of leaving the field in 5 years, 47% intending to leave in 10 years, and 66% leaving in 15 years." Low reimbursement rates for palliative medicine result in less competitive salaries, which drives more new medical school graduates towards other specialties. Against the backdrop of an aging population with ever more patients managing multiple chronic, complex, serious health conditions, this projected shortfall should be cause for alarm.

Real Stories:
Corrina

Corrina is a young Black woman who cares for her aging mother, now in the final stages of lung cancer. On top of being a caregiver, she's balancing school, work, and motherhood, leaving her with very little time for herself.

When Corrina's mother was initially diagnosed with cancer, she refused treatment and didn't tell anyone in her family about it. Only when her condition worsened and she became visibly frail did Corrina and her brother learn of their mother's illness. As a Black woman, Corrina's mother deeply distrusts the healthcare system, which influenced her decision to forego aggressive treatment for her cancer. She was adamant about not wanting to be in a hospital, but her home was not wheelchair accessible and as her condition worsened, Corrina had no choice but to admit her anyway.

The guilt over this decision haunts Corrina, and she's highly vigilant about the quality of care her mother gets and the compassion of the hospital staff. She's able to find inspiration in her young son and talks about the importance of celebrating life and accepting death, but also knows from past experience that the grief may stay with her long into the future.

> I learned from my mom that being African American and female, automatically we don't feel like we're getting the top treatment.

Hope for the best, plan for the worst

As disorienting as a diagnosis of serious illness can be, it's something the majority of Americans have given at least some thought to.

The challenge, of course, is that it is impossible to truly think through what it will be like to have a serious illness until it happens. Further complicating matters is the well-documented difficulty of providing an accurate prognosis. The groundbreaking research of Nicholas Christakis has highlighted the tendency of physicians to be overly optimistic in their predictions of life expectancy, in particular among oncologists. Aside from the clinical difficulty of accurately determining prognosis, there is a deeply human factor at play here. No one wants to be the bearer of bad news, yet looking at actual patient preference is instructive.

While it is unsurprising that, given the choice, the majority of Americans would prefer both honesty and hope, it's striking just how few seem to prioritize hope over honesty. Concluding that physicians need to be more forthright with patients navigating declining health is easier said than done.

How much have you thought of the following...[2]

● A great deal   ● Some   ● Not very much   ● Not at all

How you would pay the costs of medical care and other services you or another family member might need as they age

| 32 | 43 | 18 | 7 |

Your own wishes for medical treatment if you were to become seriously ill

| 31 | 47 | 18 | 6 |

Who would help care for you or another family member if someone became seriously ill or needed special support

| 32 | 46 | 17 | 7 |

56%
Both

36%
For their doctors to be completely honest when there is little chance of recovery

When a patient is seriously ill, which of the following do you think is more important?

3%
Not sure

3%
For their doctors to emphasize hope

1%
Neither

Worse outcomes, less trust

Vulnerable populations face both greater risk of developing certain serious and chronic illnesses, as well as worse outcomes from those conditions. The factors driving these disparities are complex—from a lack of preventative care to the influence of social determinants—and earlier, more sustained engagement of palliative medicine would have distinct benefits in these populations. It is impossible to talk about the future of healthcare in the US without centering the experiences of vulnerable populations. "By the year 2044, [minorities] will account for more than half of the total U.S. population, and by 2060, nearly one in five of the nation's total population will be foreign born."[3] Alarmingly, insofar as certain disparities have decreased in recent years, the cause is often a decline in the health of majority groups, rather than improvements in minority health. By reimagining healthcare to be responsive to communities with the greatest health needs, we can elevate the quality and accessibility of care for all.

"Racial and ethnic disparities are arguably the most obstinate inequities in health over time."

Communities in Action[3]

Along racial and ethnic lines, the interplay between trust in the healthcare system, proactive health management, and development of chronic disease is a major driver of disparate outcomes. NPHI's survey data[2] showed that about 1 in 5 Americans actively avoid healthcare unless it is absolutely necessary. Among Black respondents who avoid healthcare, some 76% say it is because the healthcare system does not treat their racial or ethnic group well (compared with only 23% of white respondents). This finding aligns with studies showing that Black and hispanic patients receive fewer primary care visits and preventive health measures, like cancer screenings and flu vaccines.

Lower rates of primary care utilization in these communities, along with environmental factors like access to nutritious food, contribute to higher incidence of chronic diseases. This is particularly noteworthy with respect to conditions related to obesity, such as diabetes and heart disease.

- 47%[21] of Black adults have been diagnosed with cardiovascular disease, compared with 36% of white adults.

- Black adults are 30% more likely[3] than whites to die prematurely from heart disease.

- Black men are twice as likely as white men to die prematurely from stroke.

- Hispanic women are more than twice as likely as white women to have diabetes.

- American Indians are three times more likely than whites to have diabetes.

Black Americans also face higher risk and mortality for certain types of cancer. The death of actor Chadwick Boseman at age 43 highlighted the elevated risk for colon cancer in the Black community, prompting discussion about the importance of earlier screenings for at-risk groups. It is noteworthy that overall incidence of colon cancer among younger people is also on the rise. Focusing on improving screening practices and treatment for the highest-risk communities is about more than justice—it's about improving outcomes for the entire population.

As it pertains to palliative medicine, one well-documented form of health inequity is treatment for pain. A 2016 study[22] found that black patients were half as likely to receive pain medication as white patients reporting the same symptoms. There are similar disparities in pain treatment related to gender. Women may be perceived as less tolerant of pain and more likely to exaggerate it, resulting in undertreatment. For example, pelvic pain, a common cause of pain among women, goes untreated in one-third of all cases.

Compounding these trends is a lack of awareness of palliative medicine among non-white communities. One study of adults in California found that three-quarters of black and hispanic patients had never heard of palliative care, compared with only half of white patients. Access to and utilization of palliative consultations varies widely by institution, but lack of awareness, unequal treatment of pain, and higher incidence of serious illness all suggest that non-white communities would benefit from better integration of palliative approaches. A recent mixed-methods study[23] found that "[Minority] patient and family caregivers revealed positive experiences with palliative care but demonstrated experiences of discrimination in health care before referral to palliative care."

In addition to racial and ethnic disparities, rural populations are also vulnerable to unequal access to care. One study[3] highlighted a disconcerting trend: "...after a period of steady decline over decades, rural counties are experiencing an increase in the number of premature deaths." The same study found that, compared with urban residents, "...rural communities have higher rates of preventable conditions (such as obesity, diabetes, cancer, and injury), and higher rates of related high-risk health behaviors (such as smoking, physical inactivity, poor diet, and limited use of seatbelts)."

As in the context of racial disparities, awareness and comprehension of what palliative medicine is and can offer are significant factors in underutilization of these services in rural communities. Conflation of palliative and hospice—among physicians and patients—fuels the perception that introducing palliative medicine means that the physician has "given up" and death is near. That association has also contributed to the proliferation of terms used to describe palliative programs: serious/advanced illness care, symptom management, supportive care, etc. Improved education of the general public and healthcare providers are essential to bringing the benefits of palliative medicine to more patients across the continuum of care.

The barriers to wider access to palliative medicine extend far beyond individual attitudes and perceptions, however, particularly in the rural context. In one qualitative study[24] of rural palliative practitioners in Indiana, participants cited poor compensation, lack of outpatient resources, and logistical challenges of following up with patients who live in remote areas. Thus communities with some of the highest need for palliative services may be least able to access those services.

Pediatrics: a unique challenge

In the pediatric context, many of the same barriers to wider utilization of palliative care hold true, but there are also a number of factors that make this population distinct.

In response to these diverse needs, significant strides have been made in recent years to increase the availability of specialized pediatric palliative care programs in both inpatient and outpatient settings. A review[25] focusing on implementation of palliative care in the pediatric oncology setting found that children who received specialized palliative care "...had improved symptom burden, pain control, and quality of life with decreased intensive procedures, increased completion of advance care planning and resuscitation status documentation, and fewer end-of-life intensive care stays with higher likelihood of dying at home. Family impact included satisfaction with SPPC and perception of improved communication."

Of particular importance for policymakers and payers are the potential financial savings associated with more proactive use of palliative care. A pilot[26] program in California reported the following results:

Pediatric palliative care pilot program found...

● before enrolement	● in program

Nearly 50% reduction in the average number of inpatient days per month

4.2 days
2.3 days

61% reduction in average length of stay per hospitalization

16.7 days
6.5 days

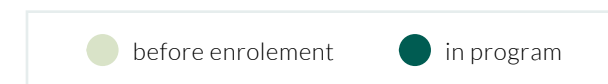PER ENROLEE PER MONTH HEALTH CARE COSTS DECREASED BY

$3331

INPATIENT COSTS WERE REDUCED BY

$4897

Despite these massive individual and systemic benefits, palliative medicine remains a comparatively poorly-compensated specialization, limiting the number of trained providers. Current reimbursement mechanisms have also hindered the uptake of such programs, particularly in the outpatient or home-based setting. Community-based organizations that serve the needs of declining health are well-positioned to advocate and provide more consistent, comprehensive, and high quality care for pediatric patients with serious illness. Part of that mission requires educating payers and policymakers about the medical, personal, and financial benefits of palliative medicine.
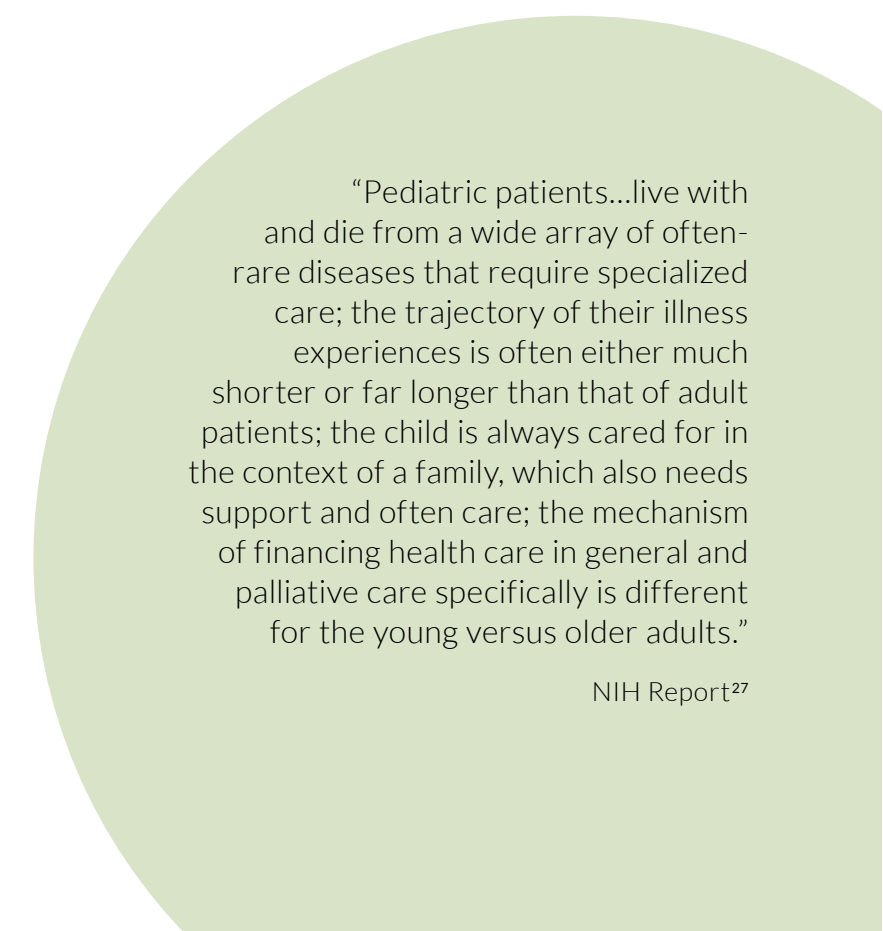
"Pediatric patients...live with and die from a wide array of often-rare diseases that require specialized care; the trajectory of their illness experiences is often either much shorter or far longer than that of adult patients; the child is always cared for in the context of a family, which also needs support and often care; the mechanism of financing health care in general and palliative care specifically is different for the young versus older adults."

NIH Report[27]

> Why her? What did she do? ...You can't plan these things. There's no rhythm, no rhyme, no method... Sometimes our responsibilities choose us.

Real Stories:
Delilah

Delilah is a writer and event planner from Mississippi, who lost her daughter after a difficult series of health issues that began when her daughter was a child. Just as her daughter was nearing the end of her life, Delilah's husband was diagnosed with Parkinson's, so her caregiver journey continues.

When her daughter was only 8 years old, she developed brain tumors, which were treated but then reappeared every few years until she died. While struggling with the intensive treatment the tumors required, she also developed severe obesity and diabetes, which further complicated her prognosis. A self-described "hardass," Delilah was outraged when nursing homes refused to admit her daughter because of her age and size. Finally, after both her daughter and her husband had a series of falls at home, she knew she couldn't care for them both on her own. She was able to get her daughter into a nursing home, and then reluctantly contacted a local hospice agency when it was clear that she was declining. Immediately, she was blown away by the understanding and comfort provided by the hospice team, and she regrets not contacting them sooner.
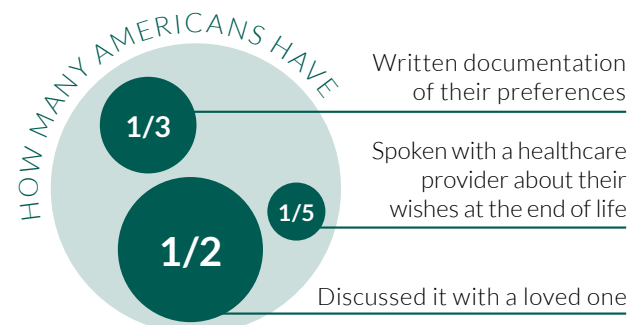
Now, as she contemplates her husband's declining health, she says she's learned to be more patient and accepting of what she can't control. As painful as the loss of her young daughter was, it taught her to be more present and to focus on the time she and her husband have together.

03
Aging

You're only as old as you feel

Like illness, the experience of aging can be profoundly disorienting, and is unique to every individual. Aphorisms like "40 is the new 30" or "70 is the new 50" illustrate the subjectivity of what it means to age or "become old." In fact, research[28] has demonstrated that as we get older, our perception of our age tends to lag behind our actual age. It's no surprise, then, that decisions about the changing conditions of a person's life—such as moving into a retirement community or assisted living facility—are inherently fraught. In American society, the absence of robust community-based social and personal support for people who are aging, coupled with the increasing precarity of housing for much of the population, have left healthcare institutions "holding the bag" for care of the elderly. It's hard enough to admit we need help with activities that were once second-nature. When the only option for support involves the healthcare system, with all of its baggage and public distrust, it's no wonder so many Americans resist making plans and taking action to prepare for aging and declining health. According to NPHI survey data[2]:

HOW MANY AMERICANS HAVE

1/3 — Written documentation of their preferences

1/5 — Spoken with a healthcare provider about their wishes at the end of life
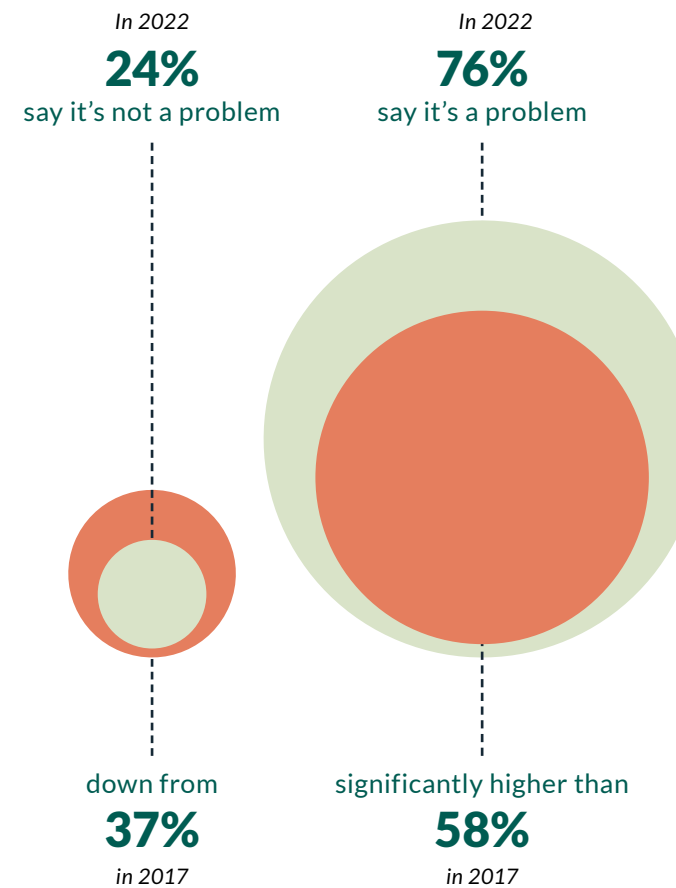
1/2 — Discussed it with a loved one

Yet, perhaps paradoxically, the same survey showed that a majority have given at least "some thought" to key questions about care they might need as they age.
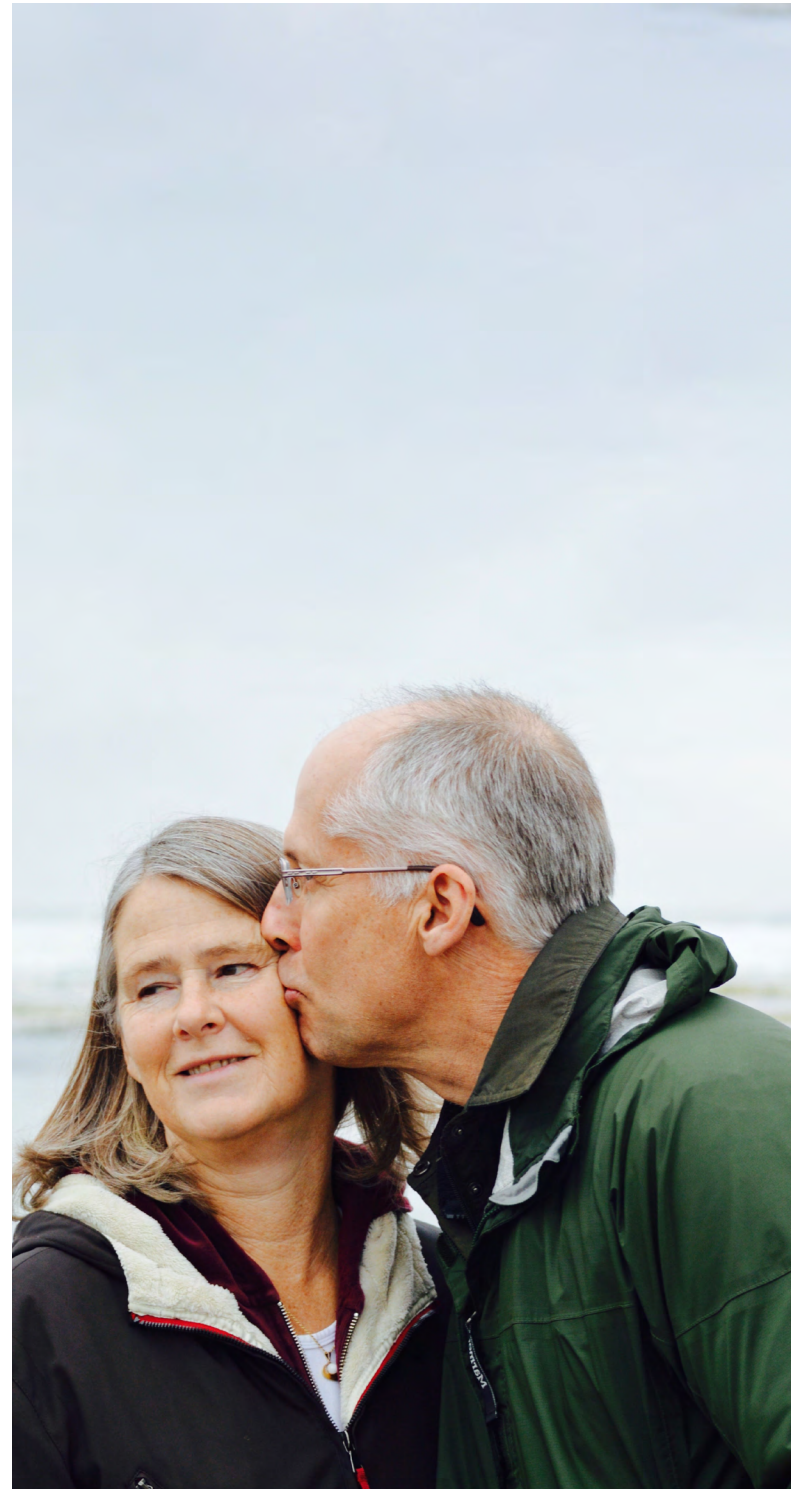
Similarly, the survey findings demonstrate that beyond an individual awareness of their own aging, most respondents are broadly aware that the US population at large is aging—and they're concerned. What's more, data suggest that the population is becoming ever more concerned about the age wave. Comparing the recent NPHI survey with the 2017 Kaiser Family Foundation study that was used as a model, we see a noteworthy trend.

How much of a problem, if at all, is the growing number of older people in the US?

In 2022
24%
say it's not a problem

In 2022
76%
say it's a problem

down from
37%
in 2017

significantly higher than
58%
in 2017

In summary, we can see that Americans are aware of the realities and challenges of aging, both as individuals and as a society. But translating that awareness to consideration and action remains one of the signature challenges facing healthcare providers who serve aging populations. A key factor, yet again, is trust. Only 30% of NPHI survey respondents trust the healthcare system to care for them as they age, and the number drops to 10% for uninsured respondents.
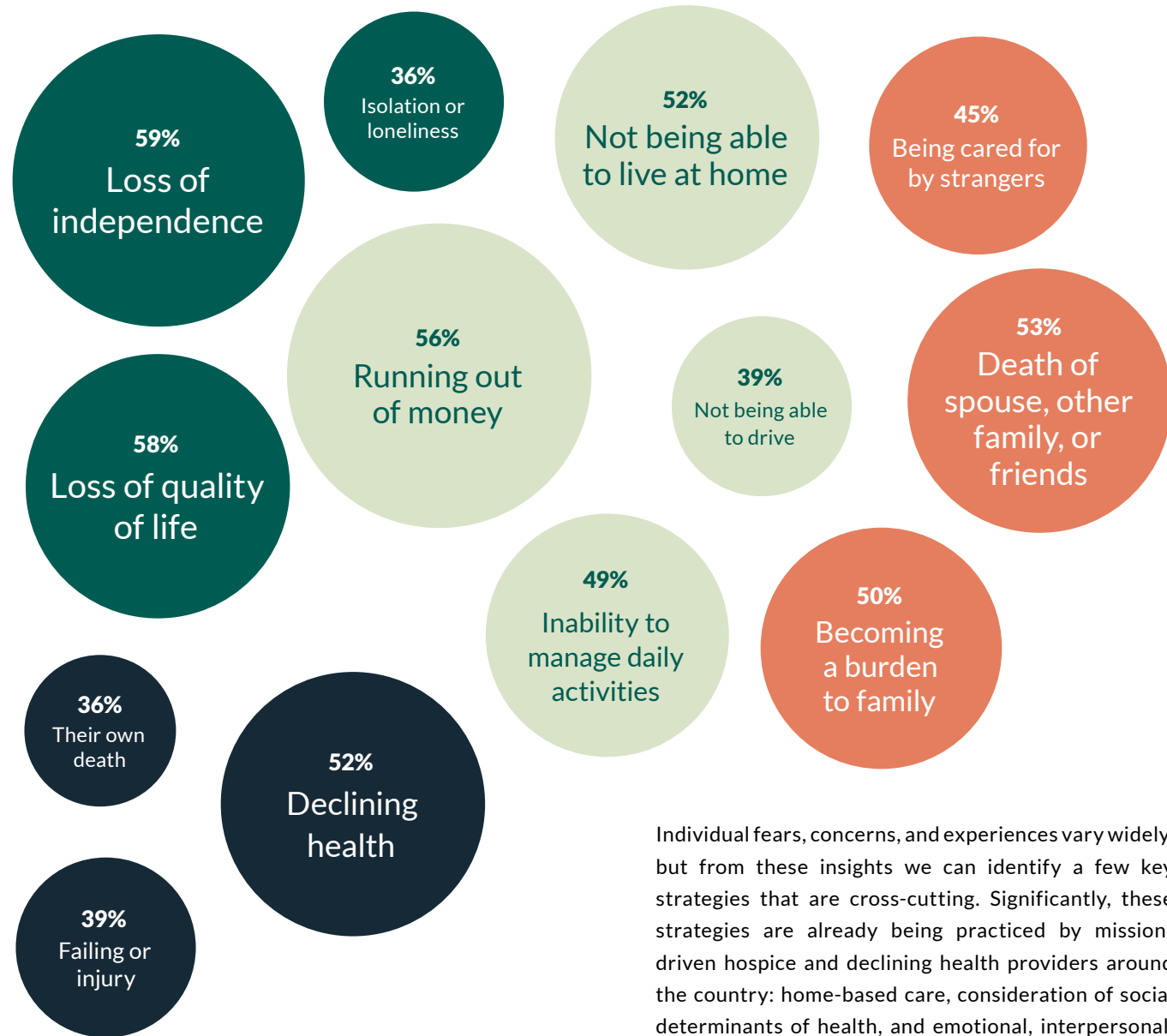
Health is only part of the picture

To build a healthcare system that is more responsive to the needs of an aging population, it is critical to look at the specific facets of aging that cause the most concern. Breaking down the NPHI survey data below, we can identify a number of key insights.

Top Concerns About Aging

59% Loss of independence

36% Isolation or loneliness

52% Not being able to live at home

45% Being cared for by strangers

56% Running out of money

39% Not being able to drive

53% Death of spouse, other family, or friends

58% Loss of quality of life

49% Inability to manage daily activities

50% Becoming a burden to family

36% Their own death

52% Declining health

39% Failing or injury

Individual fears, concerns, and experiences vary widely, but from these insights we can identify a few key strategies that are cross-cutting. Significantly, these strategies are already being practiced by mission-driven hospice and declining health providers around the country: home-based care, consideration of social determinants of health, and emotional, interpersonal, and spiritual support.

Aging in place

As has been noted previously, the vast majority of older Americans exhibit a clear preference for remaining at home as they age. This is unsurprising—home is where we feel most comfortable and safe. Yet, for increasing numbers of Americans, including those in older age ranges, having a stable, safe, place to live is becoming more challenging. Jennifer Molinsky, a researcher focused on housing for the aging population, noted[29] that, "Over 10 million households headed by someone 65 and over are cost burdened (paying more than a third of their income on housing); half of these pay more than 50 percent." Housing shortages and high prices represent a nationwide crisis across all age demographics, and for older adults, these financial burdens have a significant impact on health and well being.

On top of rising housing costs, financially-strapped older Americans may struggle to afford needed healthcare, foregoing medications or preventive visits to save money. A recent federal report[30] found that some 5 million Medicare beneficiaries struggle to afford their prescriptions, with Black and Latino adults over 65 being 1.5 to 2 times more likely to report difficulty affording prescriptions. The cumulative impact of such experiences, alongside the multifaceted influence of social determinants of health, contribute to the close correlation of life expectancy with wealth or poverty. By some estimates[31], the gap in life expectancy between the richest 1% and the poorest 1% of Americans is 14 years for men and 10 years for women.

Even for better-off Americans who can afford stable housing, aging at home is not necessarily safe or practical. One analysis[29] found that "less than 4% of homes offer a no-step entry, single-floor living, and wide enough doors and hallways to accommodate a wheelchair." The limited stock of such homes, and the high cost of renovating one's home to be more accessible, represent significant barriers to enabling more of the population to safely age at home. These challenges also point to the urgent need for greater access to quality, home-based care, which can help mitigate risks so that residents can remain in place for as long as possible.

Real Stories:
Suzy

Suzy is a devoted caregiver for her 96-year-old mother, who has been in and out of the hospital repeatedly as her health has declined in recent years. As challenging as the experience has been, she is unequivocal in her view that being a caregiver is a privilege, not a burden.

The practical and emotional difficulties that come with her role as a caregiver pale in comparison to her frustrations with the healthcare system and the staff members she interacts with. She speaks forcefully about the clear influence of money on healthcare, perceiving that the demands of seeing more patients with fewer staff members inevitably leads to a lack of empathy and compassion. Notably, she emphasizes that these issues have gotten significantly worse in recent years, and patients and their families have little power to change it.
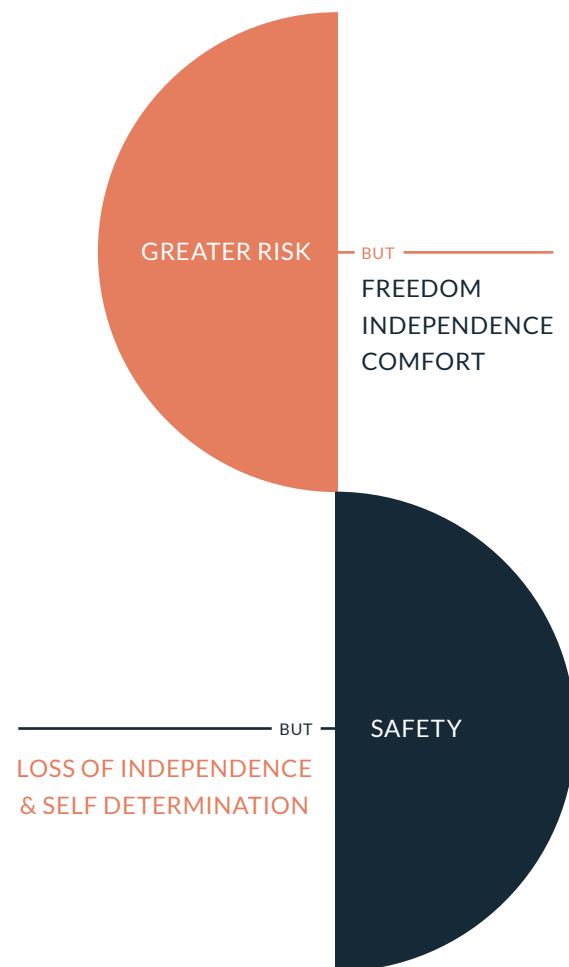
An outspoken advocate for "elder respect," she is meticulous about putting up pictures of her mother in the hospital room to remind staff that she is a human being. Still, her overall experience has felt transactional and dismissive, at a time when dignity and compassion should be top priorities.

> We're treated as transactions and disposable, and I think your Mom or your grandfather or whoever, they deserve better. We all deserve better because we're going to be in that position, too. That coldness, that dismissal is just really prevalent.

It takes a village

In addition to basic architectural considerations related to aging in place, a lack of cohesive, community-based support puts older Americans at even greater risk. Given the massive role that social determinants of health play in influencing health outcomes, it is critical that individuals who are aging at home have access to support for nutrition, transportation, and physical activity. Institutions like assisted living facilities account for many of these needs in their basic operational models, but given that the vast majority of Americans would prefer to remain at home, it is critical to bolster the availability of such services in the community. Currently, older Americans are forced to choose between the risks of living on their own terms at home and the safety that institutions can offer. Community-based support services offer a way out of this binary.

GREATER RISK — BUT —
FREEDOM
INDEPENDENCE
COMFORT

— BUT — SAFETY
LOSS OF INDEPENDENCE
& SELF DETERMINATION

On top of the more straightforward benefits of services like meal delivery, community-based services for adults who are aging in place can also help combat isolation and loneliness. The National Academy of Sciences[32] detailed the striking associations between isolation and loneliness and adverse health risks.

- About a quarter of adults over 65 are socially isolated, and nearly 50% report feeling lonely.

- Loneliness was associated with a 59% increased risk of functional decline and a 45% increased risk of death.

- Social isolation was associated with a 50% increased risk of developing dementia .

The paradox is that the individuals who are most isolated and at highest risk are, by definition, most likely to go unnoticed in the community. Without strong social and community ties, many older adults, particularly those with chronic health conditions that limit their mobility, may languish in their homes, disconnected from the kinds of support that might be most valuable. The National Academy of Sciences report notes, "nearly all persons who are 50 years of age or older interact with the health care system in some way...so this interaction may serve as a touchpoint to identify those who are isolated or lonely." This observation aligns with other research that has linked isolation with increased hospital readmissions and Medicare expenditures (though data on these points is mixed). Given the clear impact of isolation on health outcomes, and the healthcare system's unique position to intervene, it is critical that social connection be prioritized in support services for aging populations.

Researchers[5] have indicated that so-called "social prescribing" can be a valuable tool for intervening in cases of social isolation: "[social prescribing] is believed to result in better social and clinical outcomes for people with chronic conditions and their caretakers, [and] a more cost-efficient way to use health and social care." Yet, translating this recommendation into action has remained challenging. First, although social isolation may be associated with greater Medicare

expenditures and increased hospitalizations, other research suggests that high-risk, isolated populations may be less likely to use preventive healthcare, such as primary care visits or routine screenings. As a result, the patients who would benefit most from social prescribing in the primary care context may be hardest to reach.

Perhaps more importantly, the National Academy report notes that "...despite the promising nature of many community-based programs, this type of support often remains underused due to the weak or nonexistent link between health care practitioners and community-based services." A significant exception to this trend are "safety net" healthcare organizations that serve the needs of declining health and aging populations. Mission-driven hospices, specifically, tend to have deeper community ties, and may therefore be better equipped to connect high risk patients with community-based social support. One study[33] of 203 US hospice organizations (80% of which were nonprofit) found that more than 80% reported using internal funds to pay for non-clinical services not covered by Medicare. The most commonly reported expenses were for food, utilities, shelter, and funeral costs. Beyond paying for such support directly, the vast majority of these organizations "reported collaborating with community agencies to help patients and families to access available resources to obtain a similar range of basic necessities and services."

Another key facet of the nonprofit hospice model is the significant role that volunteers play. Given the largely charitable, volunteer-based roots of the hospice movement, the Medicare hospice benefit stipulates that volunteers should deliver 5% of total care hours. While many nonprofit providers that began as hospices have broadened their service lines to provide care for non-hospice patients, the presence of volunteers remains integral. These volunteers offer a wide range of non-medical services, from transportation to music and pet therapy to death doula programs. Such services have direct value for patients, caregivers, and families, but they also illustrate the deep ties nonprofits tend to have to the communities they serve. Because almost

all of the original hospices in the US were nonprofit, such organizations have often been operational for significantly longer than more recent for-profit competitors. The longevity of nonprofits has enabled them to develop deep roots in the community, and strong volunteer programs are a testament to that presence.

Hospice and end-of-life care will be discussed in more detail in the following chapter. However, it is critical to note that many hospice organizations have vastly expanded their service offerings across the care continuum, indicating that aging populations could benefit from engagement with community-based providers as a complement to their primary care and specialist teams. The multidisciplinary approach such organizations offer, alongside their deep connections to community support services, have significant potential to reduce isolation, address social determinants, and improve health outcomes.

Integrated Care

PALLIATIVE CARE

Specialist — Patient + Family — Primary Care
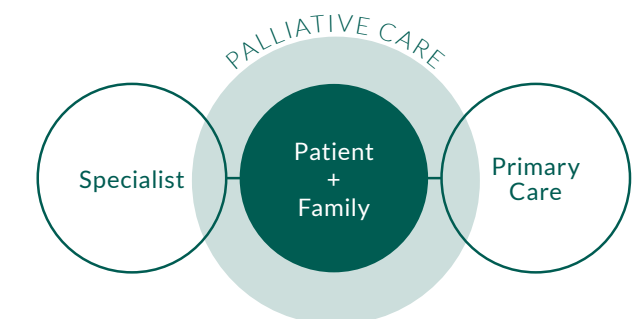
04

Dying, Death, and Grief

As challenging as aging and illness can be, nothing about human existence is more fundamentally incomprehensible than death. No matter one's religious or spiritual beliefs—or lack thereof—few of us can ever truly conceive of what it means to die until we're directly confronted with the possibility. This is a uniquely modern problem—the proportion of people who die suddenly or accidentally continues to shrink. And while that's a credit to modern safety regulations, hygiene, and medical advances, it's had the unintended consequence of forcing us to contemplate something we're by and large either unwilling or unable to truly process. Significantly, what people fear most about death is not death itself, or the afterlife, but how their death will affect others—financially, emotionally, practically. The grief of loved ones left behind, in other words, may be more painful to think about than our own needs.

"Life is pleasant.
Death is peaceful.
It's the transition that's troublesome."

Isaac Asimov

As life expectancy has increased and treatments for a variety of ailments, and even aging itself, have become more sophisticated, the experiences of declining health and death have become increasingly medicalized. While medicine has much to offer, it has not solved the fundamental reality of mortality. There will always come a point at which the potential for cure or recovery goes from slim, to remote, to non-existent. Physicians, particularly in certain specialties like oncology, may be reluctant to accept this diminished chance at a cure. As human beings, physicians feel invested in each patient's case, and as physicians, they are trained to use their knowledge to "solve" discrete problems. As a result, they are comfortable describing additional therapeutic options, or clinical trials a patient could join, but they are less comfortable accepting the reality of decline and death.

The role of physicians, and the healthcare system more broadly, in counseling patients about their options at the end of life is massive. In NPHI's survey,[2] about two-thirds of respondents said they would be comfortable talking about their end-of-life care wishes with a doctor or healthcare provider—more than spouses, priests and spiritual advisors, or other family members. About 75% of respondents believed Medicare should cover such conversations, yet only 14% reported having had a conversation with a healthcare provider about their end-of-life wishes and only 29% have documentation of their wishes.

These data points indicate a willingness to talk about death, and a desire to have such conversations in a healthcare context. Yet, simultaneously, we see very little follow-through to action, with the most commonly cited rationale being "I haven't gotten around to it" (56%). Part of the explanation appears rooted in the central theme of distrust. Even as most respondents report relatively high trust in doctors and nurses as individuals, they remain overwhelmingly distrustful of the healthcare system, particularly in the context of end-of-life care.

Deciding what matters

In order to improve the frequency and value of end-of-life planning conversations, it is essential to understand the specific concerns patients have. Asked what concerns them most about their own death, NPHI survey respondents rated "how my loved ones will be affected" (59%) and "missing the lives and events of others" (51%) highest, well above other options like "whether there is an afterlife" (28%) or "what will happen to my body after I die" (20%). Similarly, asked what is most important to them at the end of life, we see an emphasis on loved ones.

Significantly, the single lowest-rated factor surrounding end of life was "living as long as possible." A related question takes this insight a step further—only 13% of respondents said that "preventing death and extending life" should be the most important task for healthcare at the end of life. Of course, in a perfect world, we'd all

Thinking about the circumstances that might surround the end of your own life, how important is each of the following to you?

84%
Making sure family is not burdened by tough decisions about your care

83%
Making sure family is not burdened financially by your care

64% (Lowest-Rated)
Living as long as possible

want to live "as long as possible," but when considering the end of life, individual priorities appear to shift towards the impact on others[3], as well as comfort (85%) and peace (85%).

Another area that respondents place great emphasis on is where they will die.

The widespread preference for receiving care in the home and remaining at home throughout the aging process has been discussed throughout this document, and will be explored further in the next section. This preference for the "comforts of home" applies equally to the end-of-life context.

Where would you prefer to die?
Where do you think you are most likely to die?

Only 6% would prefer hospital...

...but 14% think they will

35% are not sure where they think they'll die

58% would prefer to die at home

but only 31% think they will

The original architects

As utilization of hospice care has risen in recent decades, public awareness of hospice has accordingly risen as well. According to NPHI's survey data,[2] 96% of respondents have at least heard of the term. Among respondents who have at least some familiarity, hospice is regarded favorably by three-quarters and, interestingly, there is a strong correlation between degree of familiarity and favorability ratings.

Percent selecting "5 – very positive" opinion on hospice care

Don't know much 9%

Knows a little 30%

Knows a lot 56%
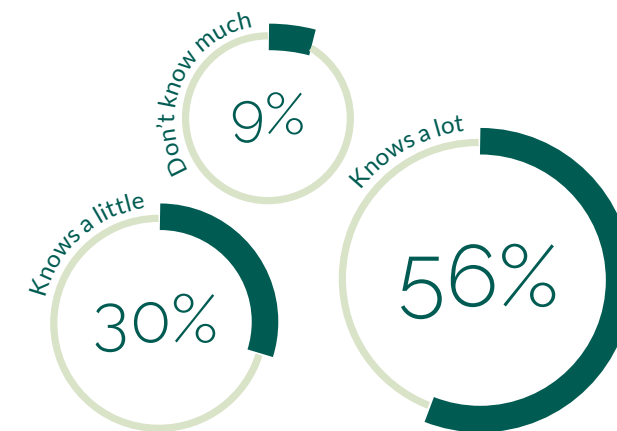
Such positive responses may conflict with the experience of some hospice professionals; anecdotes from interviews with those working in hospice often portray the word itself as triggering, and many go to great lengths to avoid mentioning "the h-word" in front of patients and families. A possible interpretation of this disconnect is that the moment hospice is introduced to a family is inevitably a moment of crisis, fear, confusion, or despair—particularly when, as is often the case, hospice referral happens in the final days of life. No matter how enlightened or open minded a patient and their loved ones might be about the prospect of death, the event itself remains tragic. Reflecting on the experience after the fact, families may be more likely to view the experience positively, which would explain the connection between firsthand experience, familiarity with hospice, and high favorability. Indeed, another common experience reported by hospice workers is families telling them, "I just wish we had called sooner."

Even as hospice utilization has increased nationwide, notable disparities exist between white and non-white communities. A 2020 Johns Hopkins study[34] found that:

"34.9% of Black study participants who died used hospice services over the study period, compared with 46.2% of white participants. Black Americans were significantly less likely than white Americans to use three or more days of hospice. Also, Black Americans were more likely to have multiple emergency room visits and hospitalizations, or to undergo intensive treatments in the last six months of life — regardless of the cause of death."

Given the historical injustices that Black communities have faced—particularly in the context of healthcare—it is unsurprising that there is hesitancy to opt for a service that will, by definition, involve the cessation of curative treatment. Yet, it is also well-established[35] that in many cases, patients on hospice actually live longer than similar patients who undergo intensive treatment.

The benefits of addressing these disparities extend beyond social justice. One study[36] found that "Medicare spends about 20% more on the last year of life for Black and Hispanic people than White people," suggesting that greater hospice utilization would have a significant impact on overall healthcare spending. Of course, all Medicare beneficiaries should be entitled to choose the care that aligns with their goals. Yet, in practice, more intensive treatment is often the default approach in end-of-life situations—less a choice patients make than something that happens to them.

"You'll go in there and they'll eat you alive...I hate to say [something] bad about hospitals, but it's true."

Black-owned hospice executive[37]

> "When hospice came, I would still go over there every day, but now I'm going over with my kids. I'm cooking, giving my grandmother a hug, saying a prayer. My caregiver role became totally different, it became more of a love giver."
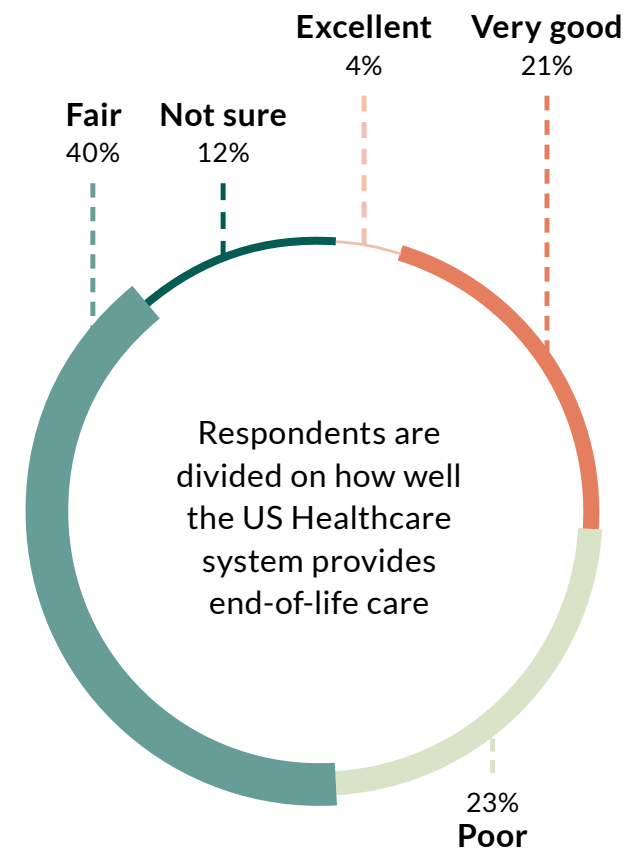
Real Stories:
Sally

Sally is a middle-aged Black woman who spent several months as the primary caregiver for her grandmother, who died after a long battle with cancer. She and her large, tight-knit family benefited greatly from the support of hospice during the final months of their grandmother's life.

Sally's family has always been close, but when their grandmother's health began to decline, they rallied around her and relied on each other for emotional support. As the matriarch of a large family, Sally's grandmother was known for her cooking, and never missed hosting holiday meals and family reunions. When her cancer became too advanced, doctors recommended hospice, and Sally was pleasantly surprised at how gentle and supportive the hospice team was. She cherished having the time to listen to her grandmother's stories and sensed that her grandmother was at peace with dying. The hospice team knew when death was approaching, and helped get the full family together to share stories and pray during the final days.

Sally recounts the story of this final chapter with a smile, emphasizing that it was joyful and peaceful for both her grandmother and her family members.

Communities over systems

Reviewing NPHI's survey data,[2] there is a clear tension between the overwhelmingly negative view respondents had of the healthcare system at large and the generally favorable view those same respondents had of hospice. Respondents were also divided over how well the healthcare system provides end of life care.

Excellent 4%   **Very good** 21%

Fair 40%   **Not sure** 12%

Respondents are divided on how well the US Healthcare system provides end-of-life care

23% **Poor**

The even distribution of "very good"/"excellent" and "poor," coupled with the very high number of "fair" or "not sure" ratings, suggest a wide variance in personal experiences with end-of-life healthcare. A 2023 *New York Times* article[38] highlighted the persistent reality of aggressive, invasive medical treatment at the end of life. The "comments" section of the article—while obviously anecdotal—includes hundreds of accounts of horrifying end-of-life experiences, an alarming number of which center on the role of financial incentives.

"...my 94 y/o father decided [my mother] should have the pacemaker so she did. She is a shut in, is in pain and there is not much joy in her life these days... Implanting the pacemaker was recommended by the hospital because they make [a] lot of money doing this procedure, this was not done to improve her quality of life."

"For my aunt, the cancer treatment was the "end" of a life she enjoyed and the beginning of a life no one would want."

"Make a living will, folks...[otherwise] you will become a living, breathing, suffering piggy bank for the medical community. And call hospice. They are experts and will remove your loved one from the grips of an out-of-control and profit based system that is regularly torturing people to death."

Hospice care has always occupied a unique place within the healthcare system. Its religious and charitable origins set it apart from other types of healthcare, yet many aspects of the hospice model are now being touted as the future of healthcare in general. Multidisciplinary teams, patient-centered care, shared decision-making, social determinants of health, home-based care—these principles are now mainstream among healthcare thought leaders, and may represent the future trajectory of healthcare. Hospice leaders have been advocating these same concepts for more than 50 years, suggesting that experts in end-of-life care may be well-suited to guide the rest of the field.

More specifically, given the problematic influence of financial incentives and profiteering, it is community-based hospice organizations that have the opportunity to be the leaders of this movement. This is not a moral argument about the virtue of nonprofit tax status as such. A wealth of evidence highlights the clear differences between nonprofits and for-profits, from frequency of visits to breadth of services to the types of patients cared for. The RAND Corporation conducted a study[39] to examine family experiences with both types of organizations and found that "caregivers whose family member received care in a not-for-profit hospice reported the best care experiences, generally followed by those who received care in a for-profit independent hospice. Those who received care in a for-profit state/regional chain or a for-profit national chain reported the worst care experiences."

Setting aside more general considerations about the role of profit in healthcare, the issue is particularly problematic in the hospice context. In an editorial response to the RAND study, one researcher summarized[40] the issue:

"Even if patients or their families experience poor quality care and wish to change hospice agencies (as one could with a physician or home health agency), the short time frame of hospice enrollment (one-quarter of patients are enrolled for a week or less) and the potential of disruption during an extremely stressful time make such switching of hospices essentially impossible. Because hospice is generally a once-in-a-lifetime experience for families, comparative experience does not exist and reporting deficiencies or quality concerns after a patient has died may seem futile."

These factors, in addition to the flat rate that Medicare pays for all hospice patients, present clear incentives for hospice companies to seek out lower-need patients and offer fewer services. By contrast, nonprofits are the experts at delivering quality care to the highest need patients, no matter what the financial consequences.

"It's not just about nonprofit versus for profit. It's about how much more we offer. We've been here for 25 years. We're going to be here for the next 25 years."
NPHI Member CEO[1]

Family and caregiver grief

An often overlooked aspect of hospice care is robust grief and bereavement support for families both before and after the patient has died. A number of studies have outlined the detrimental impact of grief on caregiver mental health. By some estimates,[41] about 20% of caregivers will experience psychiatric symptoms like depression or "complicated grief" after the loss of a loved one. As in many other aspects of healthcare, there are also noteworthy disparities in impact for the most vulnerable communities; one study noted that "Individuals with lower income, lower education, and those who are African Americans are also more likely to exhibit greater depression and complicated grief after the death."

Additional research[42] has noted that targeted interventions to address caregiver grief both before and after the death of the care recipient have led to reduced depression among caregivers. In particular, caregivers and families of Alzheimer's patients who received tailored grief support reported significantly greater resilience and lower rates of chronic depression than those in the control group. The study also found that these results were sustained for over a year, suggesting that early, sustained grief support is key to improving long-term mental health outcomes for caregivers.

Grief Support Intervention vs. Control Group

Resilience

| 60% | 42.9% |

Chronic Depression

| 7.8% | 17.9% |

● Intervention group   ● Control group
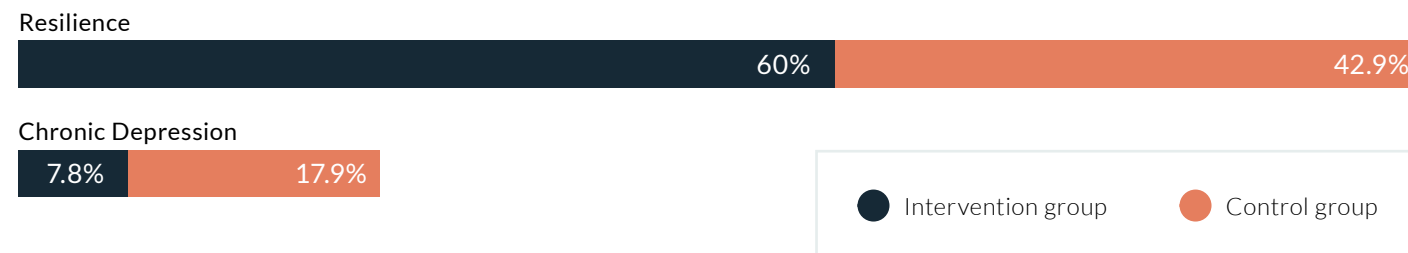
These positive outcomes demonstrate the potential benefits of greater hospice utilization, since the hospice model prioritizes grief support for caregivers and families. The inverse may also be true. In one study,[43] over 18 months of follow up, surviving spouses whose loved one underwent a life-sustaining treatment in the final month reported greater increases in depressive symptoms than those who did not.

There is also a significant body of research indicating that the impact of grief extends beyond mental health. By some estimates,[44] becoming a widow increases one's mortality risk by 48%, with a diverse, interconnected set of potential factors influencing that increase. On top of the emotional and mental strain associated with loss, surviving spouses must adapt to practical changes in their living circumstances and disruptions in their degree of social connection. Men, in particular, are less likely to have a close confidant than women, which may make them more vulnerable to adverse outcomes after losing a spouse.

Hospice providers have expertise providing end-of-life care not just for patients but for their caregivers and families as well, and studies suggest that such support has a positive influence on health outcomes for the bereaved. Nicholas Christakis[45] explored the relationship between spouse survival and hospice utilization, finding that both men and women whose partners had used hospice care lived longer after the partner's death than those who did not use hospice.

Given that hospice quality metrics rely heavily on family member satisfaction, often reported after the patient has died, it is unsurprising that nonprofit hospices perform significantly better than their for-profit counterparts. One study[46] examining the association between amount of volunteer support and family satisfaction found, "Bereaved family members in hospice programs that use a higher rate of direct volunteer patient care hours reported higher ratings of the quality of care for that hospice program." Similarly, lower rates of volunteer involvement were directly associated with lower "excellent" ratings from patients.

The complex experience of grief has clear implications for caregiver and family health and wellbeing. With half a century of experience delivering expert care at the end of life, nonprofit hospice organizations are uniquely equipped to address this challenge. Significantly, many nonprofit hospices extend their grief support offerings to the entire community, not just family members of patients they have served. Such comprehensive support is deeply interconnected to the role that philanthropy and volunteerism play in the nonprofit hospice model. As a result, increasing competition from for-profit providers poses a dire threat to long-term community grief support.
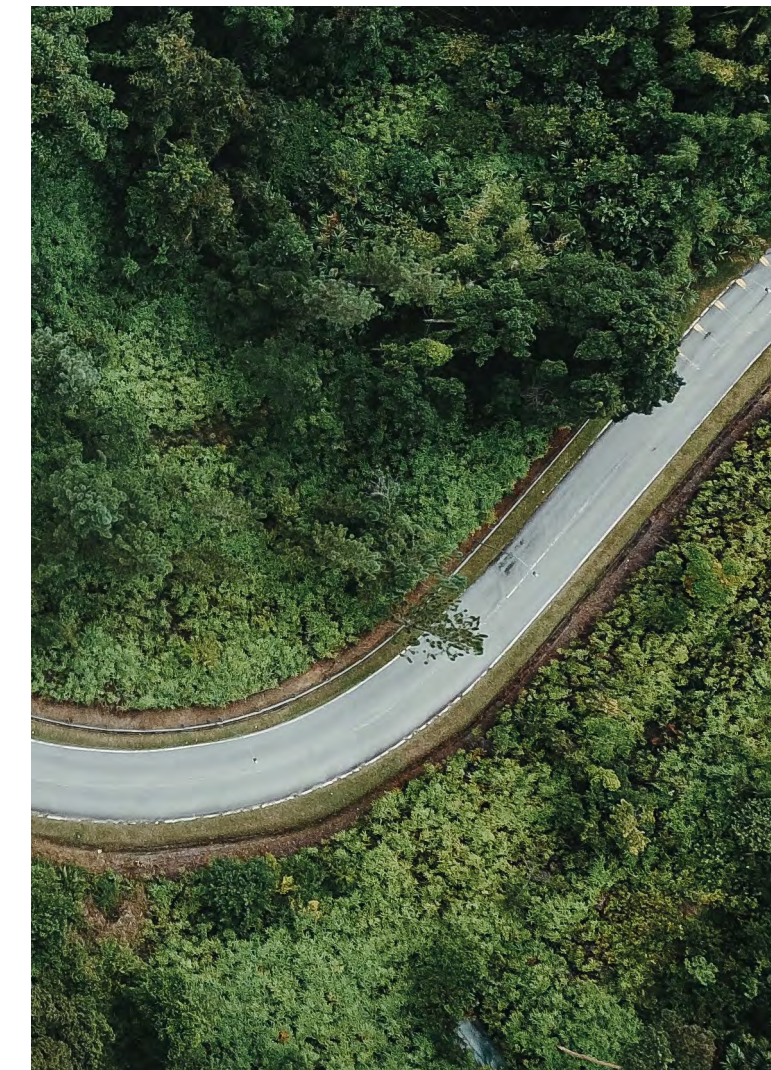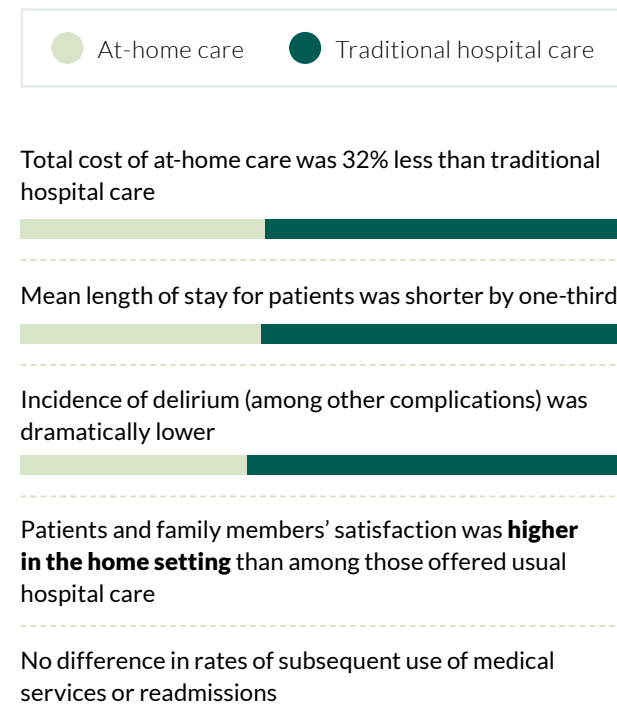
05

Home

Bringing it all back home

We are currently in the midst of a large-scale reorientation of healthcare that will increasingly focus on the home as a site of care. This is not new, of course. For hundreds of years, doctors routinely—and sometimes exclusively—made house calls to treat patients in their homes. As hospitals proliferated and expanded their outpatient service offerings, this trend reversed for much of the 20th century. A turning point came in the spring of 2020, when COVID-19 forced millions of people into quarantine, and healthcare providers scrambled to care for the huge influx of patients into hospitals around the country. As has been widely reported, routine, preventive care suffered greatly during the pandemic, with consequences we still cannot yet fully comprehend.

In the midst of this crisis, many states and insurance providers adjusted their regulations for telemedicine, to grant greater flexibility to patients and providers who were suddenly unable to access in-person care. These changes accelerated the already-growing boom in investment in virtual health solutions, and while utilization of telehealth has stabilized from its peak during the height of the pandemic, the impact appears to be lasting. A McKinsey report[47] found that:

- Telehealth utilization is now 38X greater than it was before the pandemic.

- Consumer and provider attitudes towards telehealth have improved.

- Venture capital investment in digital health has tripled compared to pre-pandemic numbers.

Beyond the explosion of interest in digital tools, in-person, home-based care is also experiencing growth and investment. One market forecast[48] reported that, "The U.S. home healthcare services market is projected to grow from $94.17 billion in 2022 to $153.19 billion by 2029..." Beyond the obvious patient benefits of convenience and comfort, providing care in the home has great potential for reducing costs to the system overall.

Advantages to home-based acute care[49]

| ● At-home care | ● Traditional hospital care |

Total cost of at-home care was 32% less than traditional hospital care

Mean length of stay for patients was shorter by one-third

Incidence of delirium (among other complications) was dramatically lower

Patients and family members' satisfaction was **higher in the home setting** than among those offered usual hospital care

No difference in rates of subsequent use of medical services or readmissions

For populations in declining health, particularly among the elderly, providing care in the home also offers unique insight into the non-medical factors influencing a patient's health. More than[50] 300,000 older Americans are hospitalized for a hip fracture each year, about 95% of which are caused by falls. In a population that is more likely to have issues with balance and be on multiple medications which may cause dizziness, it is essential that living quarters are designed with safety in mind.

Home visits from healthcare providers with expertise in this population present a critical opportunity to identify risks and implement safety adjustments. Further, home visits offer clinicians the opportunity to see where medications are stored, what food is available in the kitchen, and assess the cleanliness of the home, which can offer insight into the patient's mobility and self-efficacy. In short, home visits represent a crucial opportunity to address social determinants of health for high risk populations.

Despite the optimism and potential around digital solutions and home-based care, there are reasons to be wary of the rapid influx of investment in for-profit providers. As previously discussed, widespread distrust of the healthcare system appears to be linked to suspicions about profit-seeking. Further, the changes in regulation of telehealth during COVID-19, while a necessity, created a "black box" effect, where practices changed abruptly with little oversight.

As with the growth of the for-profit hospice industry, allowing the trajectory of the field of home health to be dictated by investment companies, national and regional chains, and start-ups could have the effect of eroding care quality. Meanwhile, nonprofit, community based organizations specializing in declining health have decades of expertise providing quality, home-based care to patients with complex needs. Payers and policymakers should look to such organizations as the vanguard of this transformation in healthcare.

Summarizing the essential meaning of home for those in declining health, Atul Gawande writes in *Being Mortal*: "Home is the one place where your own priorities hold sway. At home, you decide how you spend your time, how you share your space, and how you manage your possessions. Away from home, you don't." Across the entire continuum of care, a focus on home will shape the future of healthcare. Ensuring that this transformation serves patient wellbeing rather than shareholder value will require a coordinated nationwide movement led by the nonprofit, community-based organizations that have provided this type of care all along. Amplifying their values, vision, and expertise to key audiences—from providers to payers to policymakers to patients—is the first step.

> "Home is the one place where your own priorities hold sway. At home, you decide how you spend your time, how you share your space, and how you manage your possessions. Away from home, you don't."
>
> Gawande, *Being Mortal*

Real Stories:
Rosie

Rosie is a successful business owner and the sole caregiver for her mother, who is in the final stages of cancer. Her mother's declining health coincided with the outbreak of COVID, so Rosie invited her to move into her home, where she has lived ever since.

The biggest challenge for Rosie has been an intense feeling of isolation. She's always had a strained relationship with her mother, who can be critical and demanding, and the emotional impact of that dynamic feels even more acute now that she has totally reoriented her life and home to be a caregiver. An outgoing, social person who loves to entertain at her home, Rosie now feels completely cut off from her friends, hobbies, and children. Yet, for all her sacrifice and dedication, her mother is often hostile and judgemental. Rosie resents her brother, who refuses to help out but remains "the favorite child" in the eyes of her mother.

While Rosie has the financial means to bring in outside help, her mother's stubbornness makes this a non-starter, resulting in a "lose-lose" situation where both she and her mother are unhappy and overwhelmed.

"I would have a whole team here 24-7, but my mom would never...it's not that she wants only me, she's just a very private person...she never liked having people in her home."

Recommendations

Recommendation #1

If you see something, say something

Expand public relations and thought leadership efforts to speak out on issues beyond declining health and end-of-life care. When there is public outcry about pharma profiteering or corruption anywhere in the healthcare industry, use it as an opportunity for education about the advantages of choosing a community-based, mission driven provider. Such commentary doesn't need to be political—Americans across the ideological spectrum are looking for someone to trust.

Recommendation #2

Play the "long game"

Target schools and younger audiences for volunteer opportunities, death doula programs, staff recruitment, community engagement events, and educational programming. Taking a more outspoken stance on issues like healthcare and health equity could earn the trust of the next generation of caregivers and care seekers. The return on investment for this might be decades out, but as a field it is a critical component of changing the culture.

Recommendation #3

Connections across the continuum

Use the deep connections your organization has to other safety net healthcare and social services organizations to tell a new story about what community-based support looks like. Connections between values-aligned providers not only help patients find the support they need, they also establish the organization's role as a deeply entrenched part of the community that is here for the long haul. Knowing how to "speak the language" of organizations that share your values can help form new connections as well.

Recommendation #4

Honesty is the best policy

Patients say that they want honest guidance, and want that guidance from physicians. But most physicians, particularly specialists, aren't comfortable having those conversations. Organizations that specialize in declining health and end-of-life care have the firsthand experience and expertise to lead a culture shift within the broader healthcare community. Target medical schools, residents, and early-career physicians with data, messaging, and educational opportunities to highlight this disconnect and gain skills in handling Advanced Care Planning discussions.

Recommendation #5

Double down on social determinants

One way to sidestep public distrust of healthcare might be to lead with social determinants instead. By framing risks as environmental or situational, we can protect the pride of aging communities, who might not be ready to admit they need help. Hospices have a long tradition of connecting vulnerable patients to community-based support for non-medical needs, and even providing those services themselves. Emphasizing this aspect of what you provide reorients the topic in the public's mind, and potentially avoids two major triggers of distrust: profit-seeking and the healthcare industry.

Recommendation #6

Trusted messengers

The significant role of volunteers and donors in community-based, nonprofit organizations is a major point of differentiation from for-profits. These groups provide a valuable, diverse array of programs and services, and also serve as vital ambassadors for their organizations in the community. Often inspired to become donors and volunteers by their own experiences with loved ones, these community members have compelling stories to tell that can reframe the discussion for those who are less familiar with the subject. Further, volunteer and donor involvement is a clear manifestation of the deep, long-term community roots that nonprofits have. Formally training these individuals to be effective communicators and arming them with the data and messaging to become real-world advocates is a major—and potentially cost-effective—opportunity.

Recommendation #7

The "Good Housekeeping" effect

Awareness and consideration of the differences in quality and approach among providers is generally low. Simplifying the story through a public-facing "seal of approval"—with associated messaging and campaigns to define the meaning and value of NPHI membership in a more consumer-friendly format—could help mission-driven organizations stand out from the competition. Since there is a robust body of evidence demonstrating that NPHI members, and nonprofits more generally, outperform the field, there is a clear opportunity to translate complex quality metrics into a quick, identifiable symbol of excellence.

Recommendation #8

Defining grief support

While there is a wealth of research on the adverse impact of grief on the health and wellbeing of surviving caregivers and families, there is relatively little insight into the type and quality of grief support offered by hospice organizations. Encouraging Centers for Medicare and Medicaid Services and policymakers to more rigorously evaluate this aspect of hospice care can inform program design and service delivery, and would likely benefit community-based organizations that offer more robust grief and bereavement support. It is critical, however, that reimbursement for these services be linked to the depth and quality of the program, rather than a "bare minimum" standard that can be easy to implement to boost revenue.

Recommendation #9

More than six months

As hospice organizations expand their services upstream to provide palliative care to an ever-broader range of patients in declining health, Centers for Medicare and Medicaid Services should reimagine the hospice benefit to offer greater support across the continuum of advanced illness care, rather than tying it to a specific (and often hard to predict) life expectancy. In doing so, policymakers should be attentive to the unique benefits of community-based nonprofit providers, and structure benefits to be supportive of the long-term sustainability of those organizations.

Recommendation #10

Promoting accountability

Reforms to hospice payment methodology should focus on giving more accountability to providers for patient outcomes while eliminating opportunities to "game the system." Shifts in payment structure are critical to reducing the incentives that currently facilitate profiteering at the expense of patient wellbeing. Providers that serve as a "safety net" in their communities should be rewarded for the quality of care they provide to the patients with greatest need.

Recommendation #11

Demystify the day-to-day

Doing an audit of everything you offer—beyond what is mandated by Medicare—will reveal just how much of an impact you have. Meal delivery, transportation, pet therapy, grief support in the community—many organizations do this heroic work because they believe in it, but that doesn't always translate to compelling communications. Placing more emphasis on the full spectrum of what you offer to the community can reframe the conversation.

Recommendation #12

Make yourself comfortable

In many of the caregiver research conversations, participants gravitated towards the phrase "comfort care" as a clear, welcoming way to describe the kind of care their loved ones deserved. The moderators also offered alternative terms like palliative medicine, symptom management, and serious or advanced illness care, but participants either did not understand those terms or found them cold and clinical. Hospice was generally viewed favorably, but as other research has noted, it is often perceived as an option only in the final days or weeks of life. Additional large-scale, quantitative research could shed light on the most effective terminology for patients and caregivers across the continuum of declining health.

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