Empowering Patients' Right of Choice

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Our experience with hospice care: what we knew (and didn't)
Our Experience with Hospice

- What we knew, what we didn't, and our personal misconceptions.
This story is not unique.

- Thousands of patients and families are faced with this decision every day
- Many feel blind-sided and vulnerable when the onset of hospice care comes quickly
- Difficult for patients and families to receive education / resources before it's time to decide
What is the overall sentiment around end-of-life care?
People value comfort and peace towards end-of-life care.

- Being comfortable and without pain: 86%
- Making sure family is not burdened by tough decisions about your care: 84%
- Making sure family is not burdened financially by your care: 83%
- Making sure you receive the best medical care: 80%
- Being at peace spiritually: 76%
- Making sure you are surrounded by family: 67%
People want to spend their last days wherever they call home.

- At home: 58%
- Hospital: 6%
- Hospice: 4%
- Nursing: 1%
- Depends: 18%
- Not Sure: 12%
- Other: 2%

Emergence Creative Inc, and SIR. The National Partnership for Healthcare and Hospice Innovation, Washington, DC, 2022, pp. 1-87, Views and Experiences of Aging & End-of-Life Care in the US.
As people age, there’s often more worry about losing independence and quality of life rather than death itself.

59% Concerned about losing independence

33% Concerned about death itself

Emergence Creative Inc, and SJR. The National Partnership for Healthcare and Hospice Innovation, Washington, DC, 2022, pp. 1-87, Views and Experiences of Aging & End-of-Life Care in the US.
There is a clear alignment between what people want in end-of-life care, and what hospice provides.

So why is there a gap?
How familiar are people with hospice care?
Around 75% of people know very little about hospice care.

- A little: 55%
- A lot: 22%
- Have heard the term: 19%
- Not sure: 3%
- Have not heard the term before: 1%

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The majority of people who knew at least a little about hospice had a positive opinion about it.

- Very positive: 38%
- Somewhat positive: 36%
- Neutral: 15%
- Somewhat negative: 4%
- Very negative: 2%
- Mixed feelings: 5%
- Not sure: 1%

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As people learn more about hospice, they are more likely to have a positive opinion.

Percent of respondents selecting 'very positive' opinion on hospice

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Not only do people not know about hospice, but they also don't know they have a choice of who provides the care...
Why patient choice matters in hospice care
Ethical Considerations

- Respecting patient autonomy
- Support the right to make healthcare decisions
- People have the right to self-determination
Improved Outcomes

- Improves Patient Satisfaction and Trust
- Promotes Autonomy and Dignity
- Enhances Treatment Adherence
- Supports Mental and Emotional Well-being
Personalized Care

- Addressing Unique Cultural Needs
- Catering to Specific Care Requirements
- Facilitating Spiritual Comfort
Why are people not familiar with hospice and their rights?

Most familiarity comes from direct experience for a family member or loved one.

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The gaps in education and discovery of hospice care
What's the current status? Are we doing enough?
There are many misconceptions.

- Hospice is a place
- Hospice care is expensive
- Hospice is only for the elderly
- Choosing a hospice means giving up
- Someone else chooses a hospice for me
- You can't go back to curative treatment
Close to 50% feel people in the US have little control over decisions made about their end-of-life care.

Emergence Creative Inc. and SIR. The National Partnership for Healthcare and Hospice Innovation, Washington, DC, 2022, pp. 1–87, Views and Experiences of Aging & End-of-Life Care in the US.
The discovery gap: Current shortfalls
Nurses believe a lack of hospice knowledge among nursing home staff is a barrier to hospice enrollment.

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Nursing home patients eligible for hospice were not enrolled at the time of death

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What can we do to empower patient right of choice?
What can families, facilities, and hospices do?
For Facilities

- Provide comprehensive information
- Create cultural competency training programs
- Equip social workers & care planners
- Leverage technology
For Hospices

- Clear communication
- Establish workshops, webinars, and educational programs
- Equip staff with the right tools
- Simplify admission
For Patients

- Seek information
- Ask the right questions
- Seek second opinions
- Join support groups
Wrapping up
The Shift to At-home Care

- Hospice Care is the 2nd fastest growing healthcare segment nationwide, trailing only behind personal care.
- Shifting patient preferences, family involvement, and payer acceptance

"Impact of Home-Based Social Work Palliative Care on Hospital Use at the End of Life: A Hospice Provider Group–Outcome Evaluation." (Journal of Palliative Medicine, 2019)

"Hospice Care is the 2nd fastest growing healthcare segment nationwide, trailing only behind personal care." (Hospice News, 2022)
The more we empower patient right of choice, the more we empower autonomy, the more we empower dignity, the more we empower quality of life.
Thank you

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