



EDUCATIONAL RESOURCES

Whose Death is it Anyway?

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Learning Objectives

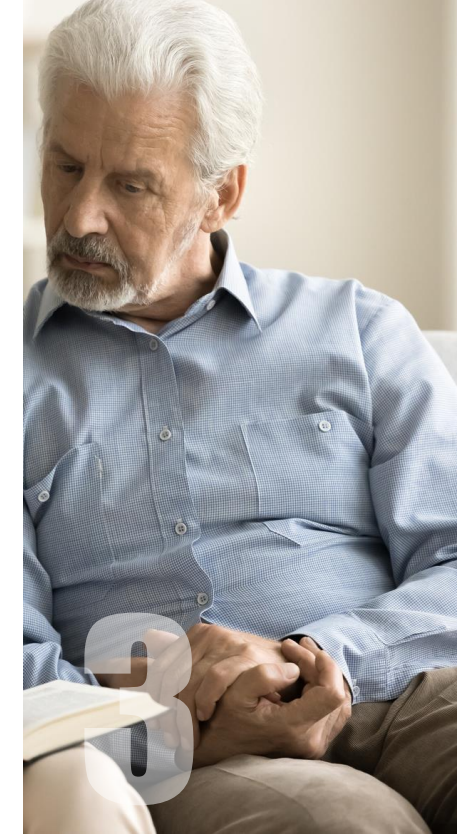
At the end of this activity the learner will be able to:



Understand death literacy and why it's important to talk about end-of-life care, dying and death openly.



Identify some of the challenges around death literacy and why our society is unprepared to discuss and plan for death.



Understand how the expansion of death literacy could improve end-of-life care for healthcare providers, our communities, friends, and families.

Agenda

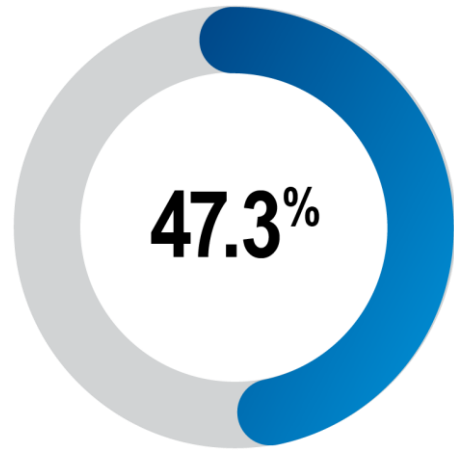
1. Life Event Planning
2. Review why care is often fragmented or unwanted
3. Case Studies
4. Identify what matters most and how it may impact the Care Plan
5. Implementing strategies to ensure better care
6. Interdisciplinary Team Impact



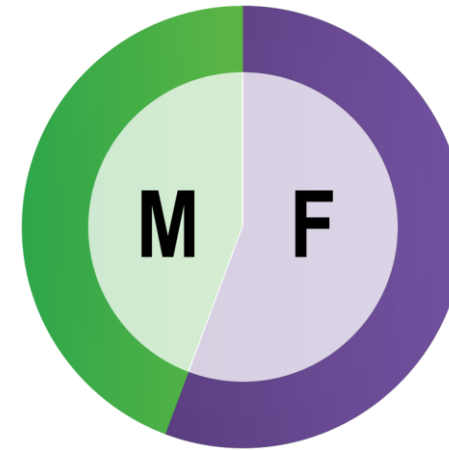
Life Event Planning

- Wedding
- Birth of a baby
- Graduations
- Birthdays
- Anniversary
- Retirement
- **End-of-Life Care Through Death**

Hospice Facts & Figures

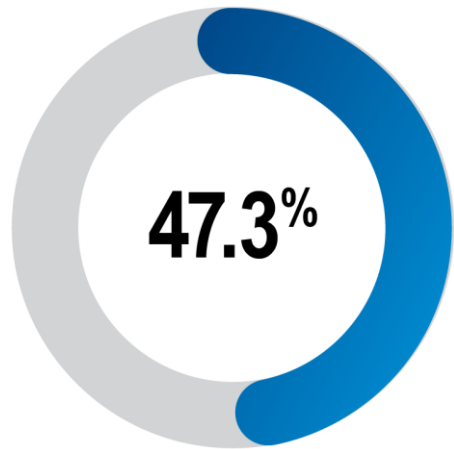


1.71 million / 47.3% Medicare beneficiaries enrolled in hospice

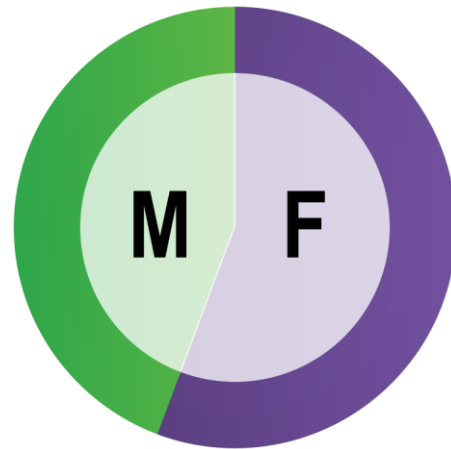


52.5% identified as female, 42.1% identified as male

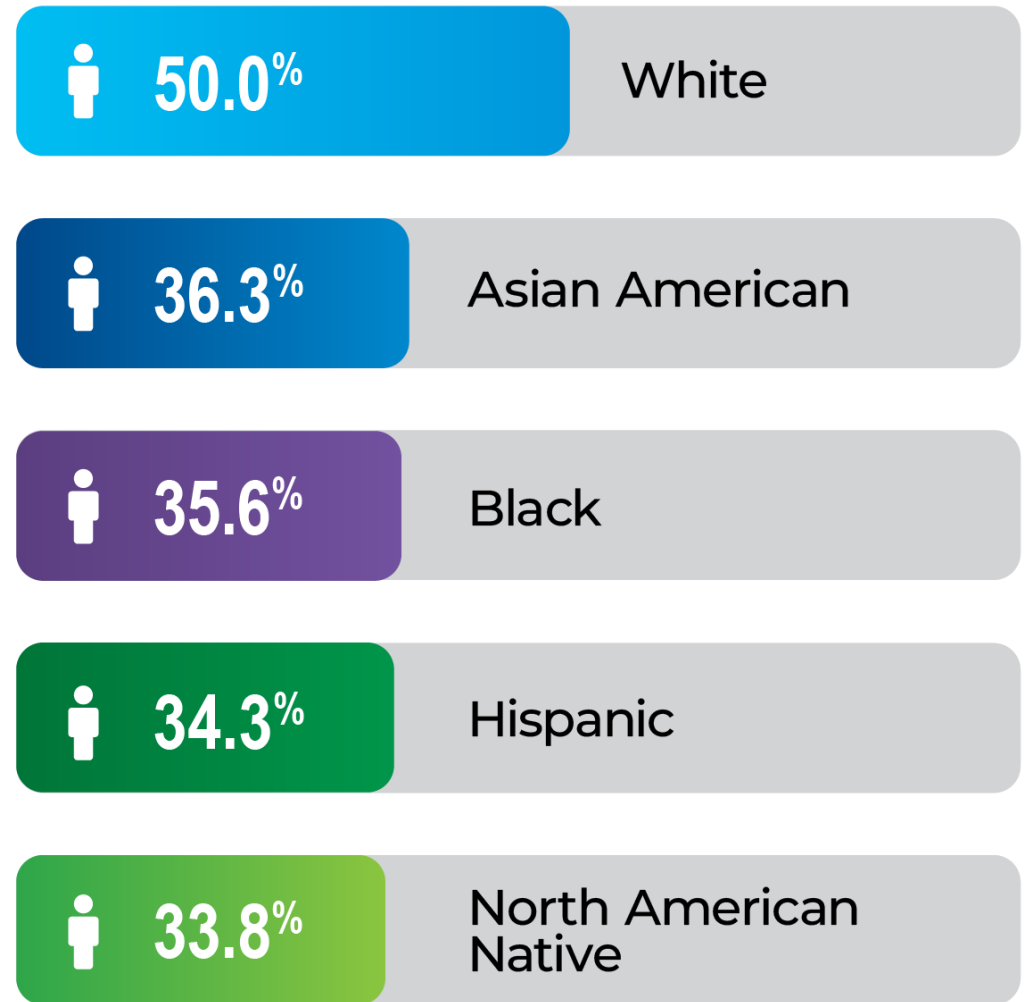
Hospice Facts & Figures



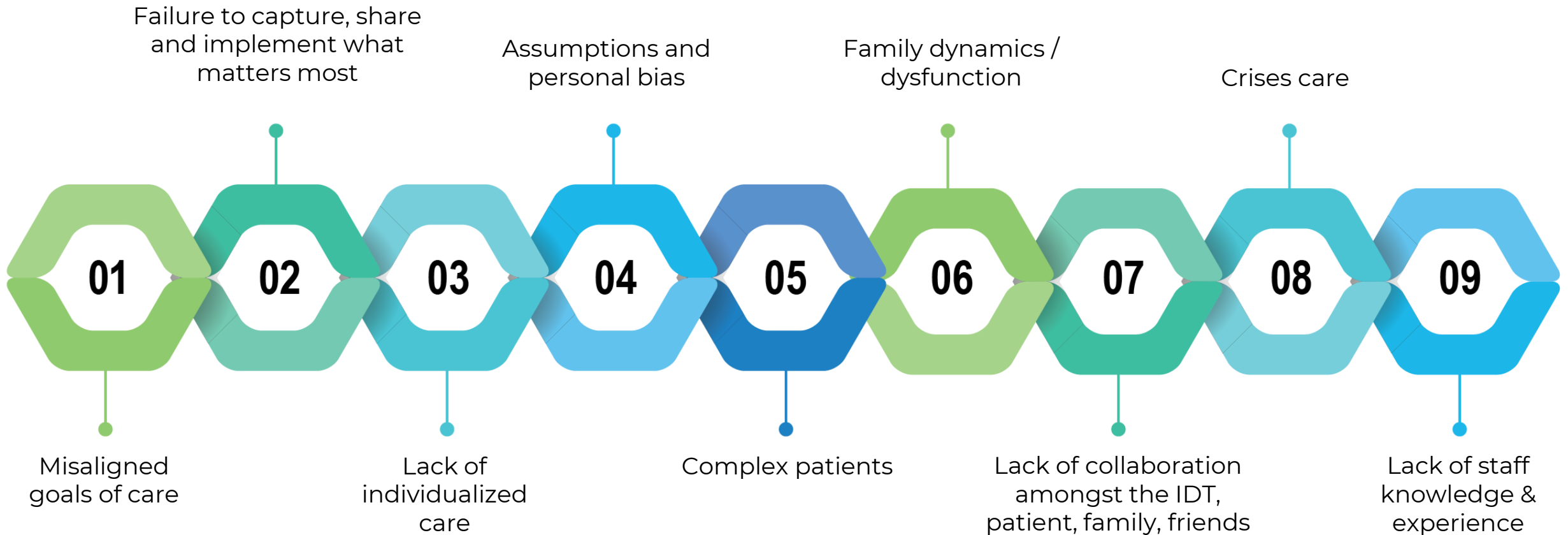
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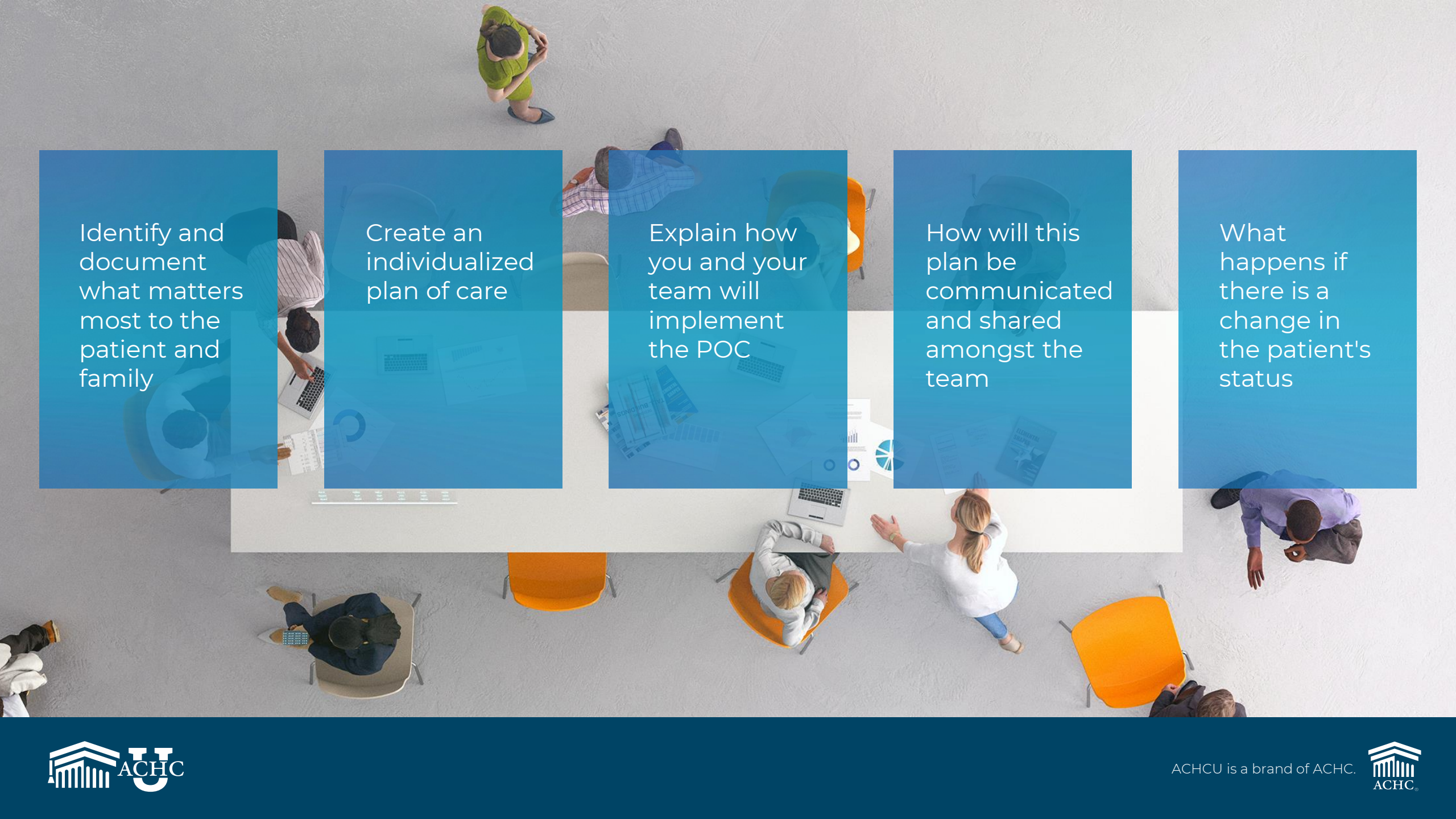


Why Care is Often Fragmented/Unwanted



Case Studies





Identify and document what matters most to the patient and family

Create an individualized plan of care

Explain how you and your team will implement the POC

How will this plan be communicated and shared amongst the team

What happens if there is a change in the patient's status



Name: Jack Middleton: 64-year-old
Diagnosis: Terminal COPD with co-morbid conditions, heart failure, A-fib, HTN, depression and anxiety.
Medications: Roxanol and Ativan PRN. His current frequency orders are SN 2xw, HHA 2xw, MSW 1xm, refuses chaplain services

Background:

Jack and daughter's want Jack to be able to remain in his home and he is adamant that he will NOT go back to the hospital. His biggest concern is air hunger and being dependent on others. Jack stated that he has no desire to stop smoking and does have an occasional drink.

Jack's two daughters moved him from his home state of Hawaii to the mid-west to be closer to them. He lives in a duplex beside his ex-wife. Jack is very angry about having a terminal diagnosis and about being moved away from his friends.

It has taken time for Jack to develop a relationship with the hospice team and currently he is only able to show anger or superficial emotions with them. His daughters do report that he is always angry and sharp with them. He and his ex-wife often have verbal arguments. Often, his oldest daughter is caught in the middle.

Jack continues to smoke but has signed a contract that states he will shut off his oxygen and only smoke outside. He exhibits shortness of breath with minimal exertion, depression, and agitation.

Scenario 1



Name: Jack Middleton: 64-year-old

Diagnosis: Terminal COPD with co-morbid conditions, heart failure, A-fib, HTN, depression and anxiety.

Medications: Roxanol and Ativan PRN. His current frequency orders are SN 2xw, HHA 2xw, MSW 1xm, refuses chaplain services

Recent IDT notes:

Over the last month Jack has had an increase in shortness of breath which now occurs at rest and requires HOB elevated 35 degrees to sleep. Jack is smoking less as he does not want to take off his oxygen. He continues to only require assistance with 3/6 ADLs despite the significant dyspnea. His youngest daughter is getting married next week, and Jack wants to go, however, his family doesn't think that he should due to his current state of health. There continues to be tension and arguments between Jack and the family.

Recent Events:

The hospice on-call RN receives a call late Saturday night, from the oldest daughter, stating that they are headed to the hospital to have Jack get a psych evaluation. She reports that he has had mental health issues for years and they just cannot handle him anymore. The nurse can hear Jack in the background yelling at the family that he is not going.

Name: Clyde Harris, 83-year-old

Diagnosis: Terminal CHF and co-morbid conditions that include COPD, diabetes, PVD, HTN, and CVA.

Medications: Insulin

Background:

Clyde made it very clear to his son and attending physician that he no longer wants to go to the hospital and just wants to be home. Clyde has old friends stop by from time to time to talk about the old days over a beer. Clyde lives alone, but his son, Jack, and his husband live three houses down. Clyde and Jack's husband are cordial, but Clyde does not feel comfortable receiving care from him.

Clyde can make his needs known and is A&Ox3 but has expressive dysphagia due to his stroke. He requires max assistance with 6/6 ADLs due to his left-sided paralysis. Clyde worked at the beef plant all his life and has always lived in the same house. His wife died several years ago, and Jack is his only child.

His son works at the same beef plant that Clyde did and goes to work at 7 am. He comes to Clyde's home every morning at 6 am, gets him out of bed via a Hoyer lift, and puts him in his recliner in the living room. He checks his blood sugar and administers his insulin. He gets Clyde breakfast and lunch and leaves them on the table by the recliner with a urinal, water, TV controls, and phone. He gets off work at 4:00 and heads to Clyde's to care for him.

Scenario 2

Name: Clyde Harris, 83-year-old

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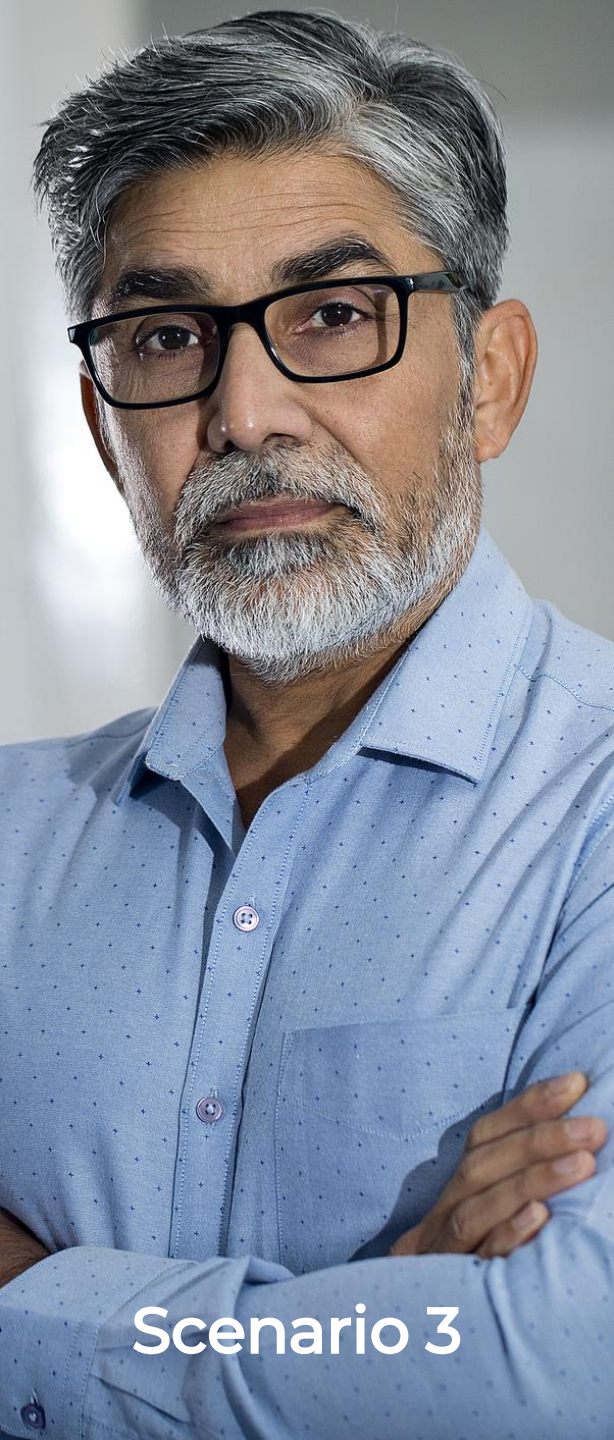
Medications: Insulin

Background (cont'd):

The hospice team has provided resources to Clyde and his son for additional caregiving services, but Clyde does not qualify for any program and does not have the financial means for private caregivers.

Recent IDT notes:

Over the last month Jack has had an increase in shortness of breath which now occurs at rest and requires HOB elevated 35 degrees to sleep. Jack is smoking less as he does not want to take off his oxygen. He continues to only require assistance with 3/6 ADLs despite the significant dyspnea. His youngest daughter is getting married next week, and Jack wants to go, however, his family doesn't think that he should due to his current state of health. There continues to be tension and arguments between Jack and the family.



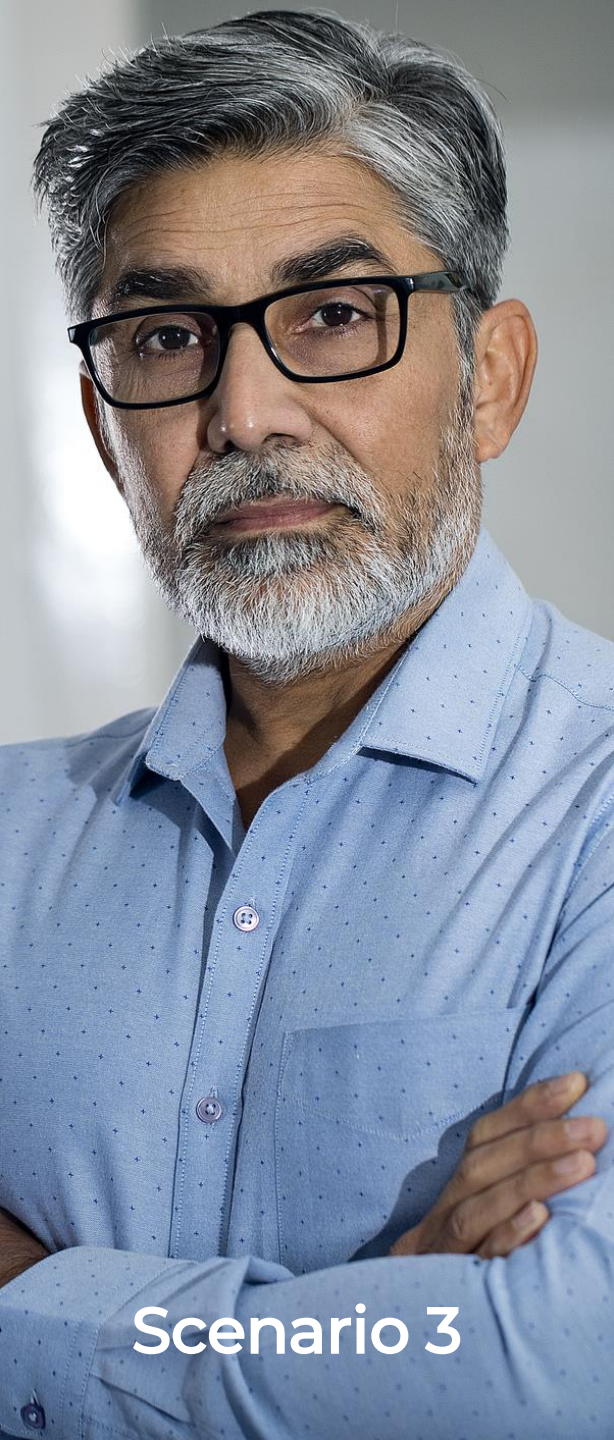
Name: Anil Agarwal, 73-year-old
Diagnosis: End-stage pancreatic cancer.
Medications: Roxanol

Background:

He lives with his wife of 52 years. His two sons, daughter-in-law, and 5 grandchildren are staying with them due to Mr. Agarwal's decline. Mr. Agarwal states that he no longer wants to go to the hospital, he wants to die at home with his family.

It is important to Mr. Agarwal and his family that he continues to practice his cultural and Hindu religious beliefs. He does not want outside people caring to his personal hygiene needs. The family worship daily, including lighting incense, prayer, and meditation at the start of the day. Mr. Agarwal spent many hours seeking out people from his past as a need to apologize for actions from his past. He is a very stoic man and the leader of his family.

Mr. Agarwal has declined rapidly since his admission to hospice and is now very cachectic with a weight of 78 pounds, is unable to eat, bedbound, requires maximum care for 6/6 ADLs, sleeps 20+ hours per day, he is confused, with periods of restlessness. Hospice has increased his SN frequency to 4xw.



Name: Anil Agarwal, 73-year-old
Diagnosis: End-stage pancreatic cancer.
Medications: Roxanol

Background (cont'd):

The hospice RN arrives at the patient's home to find that Mr. Agarwal is experiencing pain with a rating of 8/10 on a FLACC scale. He retrieves the Roxanol from the comfort kit to administer the ordered dosage and explain to the family the medication, side effects, dosage and frequency. The eldest son states that his father would refuse pain medication saying, "We want him to be awake and to conquer his pain, with the help from his family through prayer and meditation". The nurse explains that Mr. Agarwal doesn't have to be in pain, it is the role of hospice to help him die comfortably.

Implementing Strategies

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Understand & document the patient's wishes, goals, care preferences and priorities in the record

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06

Provide the **right care** at the **right time**.

07

Advocate for the patient and family.

Strategies that work!

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Adapt to changes and update the record.

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07 | Advocate for the patient and family.

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Strategies that work!

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10 | Team engagement to provide opportunity for staff to share and support each other.

Strategies that work!

Interdisciplinary Team Impact

- Identify and act on what matters most
- Consistent and coordinated care that aligns with what matters
- Achieve better patient outcomes
- Experience higher job satisfaction
- Understanding what your team is doing well
- Identify what your team needs to change to achieve better patient outcomes



Questions or comments?

References

1. Engage team members in generating ideas and problem solving
2. Rabow M, Hauser JM, Adams J. supporting family caregivers at the end of life. "they don't know what they don't know." JAMA 2004;291 (4):483-491.
3. NHPCO Facts & Figures 2023
4. Patient and Family Centered Care Organizational Self-Assessment Tool. (2023). <https://www.ihc.org/resources/Pages/Tools/PatientFamilyCenteredCareOrganizationalSelfAssessmentTool.aspx>
5. <https://theconversationproject.org>



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Thank you

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