The Seminar— Helping Families at Life's End Was it effective?

ALTH DEPARA

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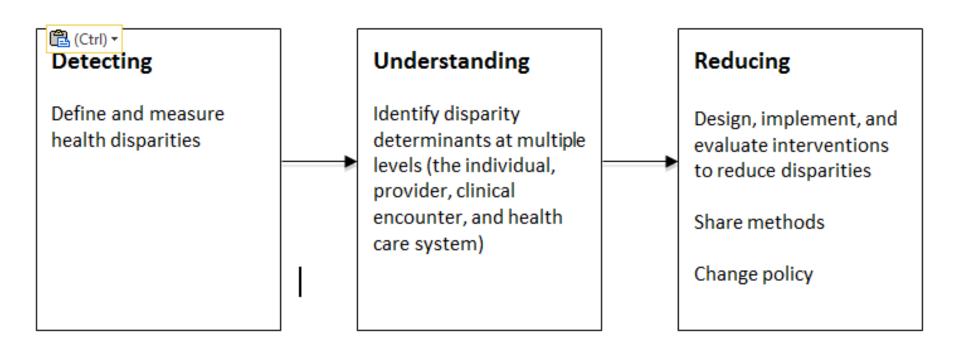
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Framework —

The three phases of health disparities research ¹





The hospice use disparity — Baltimore City

- 2012: 34% of deaths (~45% nationally)
 - •43% among white residents
 - •23% among African American residents
- Common barrier: lack of knowledge ²⁻⁹
- Suggested method: train community leaders 4,10
 - Religious leaders 7-9,11



Learning objectives

- 1. To describe the basic services offered by hospice, with an emphasis on hospice as an extra layer of support for families and caregivers, both before and after the patient's death.
- 2. To dispel two common myths about hospice.
 - a. Enrolling in hospice is giving up, medically and spiritually.
 - b. Hospice is experimental and/or designed to quicken death (institutional distrust).
- 3. To describe personal experiences with hospice.
- 4. To discuss basic strategies for talking to families near life's end, with an emphasis on normalizing emotion and asking open-ended questions.



Methods

- Post-seminar SurveyMonkey survey
- 13 questions, mostly open-ended
 - Acceptability
 - Perceived effectiveness
- Respondents (response rate 15%)
 - 82% female
 - 47% over the age of 60
 - 45% religious leaders

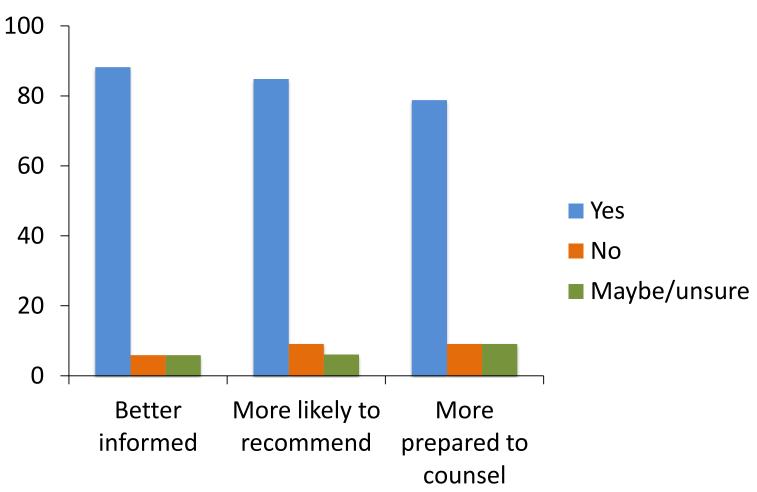


Acceptability — Need and desire for information

- "[The] information is vital."
- "We need to know about this for our members."
- "I believe the more correct knowledge we have allows the community to utilize services that enhance a good quality of life even as that life takes a turn toward the end of life."



Perceived effectiveness — Improved knowledge





Perceived effectiveness — Plan to share what they learned

- "A lot of good information...that I can use in my practice."
- "I feel better able to address the issues with family members because of all that was shared."
- I attended the seminar to learn "information on ways to help others and take that information back to my church."



Conclusions

- Need and desire for information
 - Opportunity to partner with the community
- Ready to share knowledge
 - Engage community leaders



References

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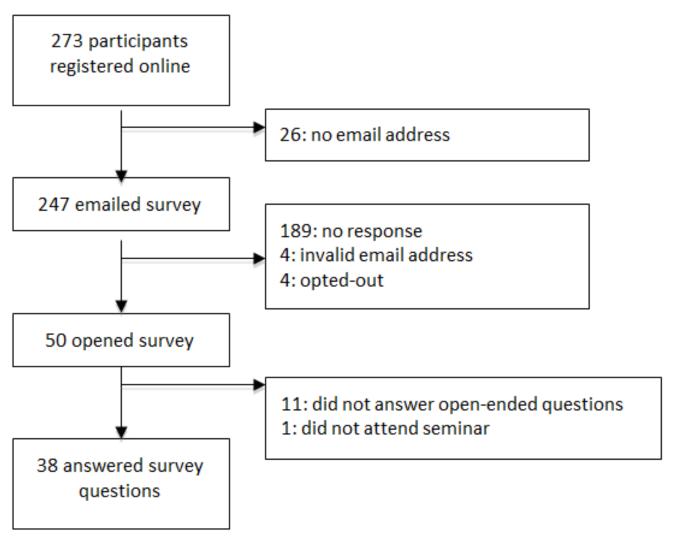


Survey Questions

- 1. What were you hoping to learn by attending the seminar?
- 2. What did you learn from the seminar?
- 3. Who is eligible for hospice?
- 4. What services are available to people enrolled in hospice? What services are available to their families?
- 5. After attending the seminar, do you feel better informed about the services offered by hospice? Why or why not?
- 6. After attending the seminar, would you be more likely to recommend a family member enroll in hospice? Why or why not?
- 7. After attending the seminar, do you feel more prepared to counsel families about end-of-life care? Why or why not?
- 8. From your perspective, what are common "myths" about hospice? Were these addressed in the seminar?
- 9. Would you participate in a similar event in the future? Why or why not?



Survey Participation





What services are available to patients enrolled in hospice? What services are available to their families?

	Frequency	Percent
Mentioned services from >1 discipline	20	63
Comfort care/pain management	14	44
Bereavement support/counseling	13	41
Nursing	12	38
Religious/chaplaincy support	11	34
Home care	11	34
Social work	9	28
Inpatient care	5	16
Volunteers	3	9



From your perspective, what are common 'myths' about hospice?

	Frequency	Percent
A patient only enrolls in hospice to die	9	28
Hospice is only for the patient	4	13
Hospice takes over control of a patient's care from the family	4	13
Hospice care is expensive	4	13
Enrolling in hospice means giving up	3	9
Hospice gives patients too many medications	3	9
Hospice is only for cancer patients	3	9

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