The Challenges & Opportunities of Communicating the Hospice Volunteer Role to Organizational Outsiders

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Research & Background


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• White, Z. M., & Gilstrap, C. M. (2017). *“People just don’t understand”: Challenges communicating home hospice volunteer role experiences to organizational outsiders*. *Management Communication Quarterly*.

The Hospice Volunteer Role

• Roles are constructed by:
  • Expectations
  • Organizational requirements
  • Ongoing social interactions
    — Everyday
    — Internal
    — External
Outsiders may play a significant role in shaping volunteers’ role identity:
- Org. affiliation is symbolic, not financial
- Isolated work location
- Spend more time with patients than some IDT members but have much less clearly defined roles

Role identity and development may be complicated by others’ perception of volunteer work as:
- Physically tainted
- Culturally “different”
- Social costs of social stigma

What communication challenges do home hospice volunteers experience when communicating their role to hospice outsiders?
How do volunteers manage these role-related communication challenges?
• In-depth interviews
  – 38 hospice hospice volunteers (25 women ,13 men)
  – 9 different hospice organizations
  – Age 21 to 86 (M=63.55 years)
  – 3 months to 20 years (M=5.02) years of hospice volunteer experience
  – 4 major Communication Challenges

We’re Not Special—We’re Special

Communication Challenge: Convincing others anyone could fulfill the role.
  • Individual acclaim (“you must be a saint“)
  and
  • Distancing themselves from serving
    (“I couldn’t do that. I don’t see how you can do that.” “I can’t spend time around people are dying.”)

We’re Not Special—We’re Special

• Volunteers wanted to (but couldn’t) explain who they are and what they did:
  – Required no special qualifications
  – “Is not anything extraordinary”
  – “Is easier than people think”
**Denial Strategy**

Attempts to convince others the role did not require any special qualifications/capacities:

They say, “What do you do with hospice?’ They don’t understand for one thing. And then they will say, ‘Oh, you must be really special to be able to do that,’ and I’m like, ‘No, I am not! I am not any more special than anybody.”

**Reframing Strategy**

– Described their work as a “gift,” “calling,” a special capability of dealing with dying people” and “something I’m good at.”
– Refocused others’ attention on their individual ability and willingness to endure the stigma related to death and dying.

**Reframing Strategy**

Volunteers began describing themselves as unique because they possessed:

“the compassion enough to want to be around them. So I don’t see the stigma where some people have got it. I think too, it is personality because not everybody is cut out to do something like this.”
We’re Among the Living—We’re Among the Dying

Communication Challenge—Insider-Outsider differences about who they were serving.

“I never think of it as being around death. I’m around people who are in their lifetime’s last moments or months on Earth. I never think of it in any sort of negative way. Death, it’s a friend. I think hospice helps us come to a more healthy appreciation of what dying is all about.”

Outsiders’ orientation:

“I think generally, people just look at sickness and death, particularly, as being a fearsome thing. But you know, death is part of life. It doesn’t frighten me. So that’s the hardest part to explain to people who say, ‘I couldn’t do that or how do you do that.’”

— Volunteers conceived of death/dying as expected and necessary to life.
— Outsiders were believed to see death/dying as abnormal and distinct from the living process.
Redirected Identification Strategy

- Emphasized their connectedness with hospice patients, not hospice outsiders.
- “We’re all dying. I’m dying too.”
- “Everybody’s dying. You’re dying. I’m dying. There’s not a difference.”

Redirected Identification Strategy

- Blurred the distinction between volunteers and hospice patients. “It’s a process we’re all going through.”
- Disrupted others’ distancing of death by demonstrating their identification with patients.

It’s Enjoyable—It’s Depressing

- Communication Challenge: Overcoming others’ belief that volunteer experiences were nothing but depressing, tragic, and sad.

“...I think it is hard for people to think you want to hang out with a dying person. They think, ‘What could you possibly find that is good about that?’
It’s Enjoyable—It’s Depressing

• Difficulty articulating the “rewarding experiences” of their interactions:

“Once they find out [I’m a hospice volunteer] they ask, ‘Why would you want to do that?’ They can’t understand that family members and sick people, who are dying, can actually enjoy life as long as their pain’s controlled.”

• Risked judgment from others

“It’s most difficult to explain that you are wanting to do hospice volunteering instead of going to the lake. Or that you are doing that instead of going out to the bar. ‘You are taking that as your first choice compared to doing fun things for yourself? You would rather do that than this?’”

Camouflaging Role Experiences Strategy

– Silencing themselves, using euphemisms—“I have a hospice thing.”

– Avoiding discussions about interactions with patients—“no sense in explaining.”
Presence is Significant—Presence is Insignificant

• Communication Challenge: Justifying purpose of presence when no act on their part would prevent a patient’s death.

“We just visit and try to fulfill an emotional need. But other than that, it’s hard to say what we do, really. People just don’t understand. It’s difficult to explain because it’s not a material thing. It’s something that’s intangible.”

Innovation and Excellence in Advanced Illness at End of Life

Presence is Significant--Presence is Insignificant

Difficulty communicating the value of presence even when it won’t make a difference . . .

“You’re not doing anything. You just sit there for 5 hours when someone is going to die?”

Innovation and Excellence in Advanced Illness at End of Life

Shifting focus from doing to gaining

Gaining insight:

“People think there’s something wrong to be around dying people. But I have told others that I believe that when people are close to dying, that they are really close to a spiritual experience and sometimes when you are in the energy of somebody whose actually dying, and they are in a real positive feeling about it, that it’s just almost an enlightenment experience. It’s almost blissful.”

Innovation and Excellence in Advanced Illness at End of Life
Shifting focus from doing to gaining

Gaining authenticity:
“I think people are so real because it is towards the end of their life and so they are not going to make you feel good. I mean saying things to make you feel good. ‘This is it. I’m going to tell you what I’m thinking.’ I’m there. I’m not mincing words. It’s just real and I just like that because in today’s society, it’s not like that.”

Urgency as a sign of need and value:
“This is important. This is a timed thing. It has to be done now. It has got to be done before anything else has to happen. I can go to a movie later. Or I can go have fun later. This guy has this much time left. He has to have this done. He has to have me help him now, because there is no tomorrow. He needs that special, whatever it is, right now. It can’t wait.”

Self satisfaction of seeing immediate results of presence:
“You get a good sense you’ve accomplished something. You’ve been able to make a difference in somebody’s life that day. You know, it’s when you walk in, there could be all kinds of chaos going on and when you leave everybody is eating or kind of calmed down a little bit. And there’s a little bit more order and peace.”
Conclusions

• Volunteers faced challenges communicating:
  – Perceived role-specific skill set qualifications
  – Nature of the population they served
  – Prejudices of role-based, interactional experiences
  – Value of presence as an essential type of service

Takeaways

The importance and value of role-based communication training for volunteers:

(1) Discuss the recurring communication challenges and strategies to enhance identification

(2) Brainstorm strategies for connecting individual role experiences to
  – The Hospice Mission
  – The IDT
  – Value to Patients and Families
  – Personal Benefits
Takeaways

(3) Create ongoing “backstage” opportunities for volunteers to socialize and practice ongoing role development and identity

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