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How and what do laypeople learn about end-of-life care using narrative? A case study in educational research

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Abstract

Background: Studies have reported positive impacts from community engagement in end-of-life (EoL) care. However, few studies have used a narrative for health promotion. Thus, we examined how and what lay participants learned through an EoL care education program using narrative.

Methods: A case study in educational research was implemented through qualitative process evaluation. The program was conducted in a hospital in Japan. Participants living in the surrounding community were recruited by convenience sampling. We conducted 90-minute focus groups with participants at two and eight months after the completion of the program. All data were audio-recorded, transcribed verbatim, and analysed using thematic analysis.

Result: We identified five themes. First, participants reconstructed the concept of EoL care using their own experience and new knowledge gained in the program. Second, the stories in the program stimulated participants to recall their feelings and emotions, which caused catharsis effects. Third, the stories evoked other perspectives through metacognition. Fourth, their experience inspired altruism towards patients and their families at the EoL. Fifth, they reflected on their own deaths as an extension of their relationship with others. This learning process was consistent with Kolb's experiential learning. Their experience enabled lay participants to overcome the existential terror of death while using the narrative mode of thinking to perceive their relationship with others as a symbolic identity.

Conclusion: The educational program using narrative deepened lay participants' understanding of the concept of EoL care. Such programs have the potential to enhance community engagement in EoL care.

Keywords: *Lay-People Learning, Public Health, Palliative Care, Qualitative Research, Narrative Medicine*

Practice Highlights

- We developed an end-of-life (EoL) care education program using narrative, and have clarified how and what lay-people learned through the program.
- Interaction among laypeople inspired the five process; reconstructing their understanding, recalling emotions, evoking other perspectives, inspiring altruism and reflection on their own death.
- A narrative about end-of-life care created the opportunities to face the inconceivable death and deepened lay participants' understanding of the concept of EoL care.
- A narrative has the potential to enhance the engagement of the community in EoL care.

I. INTRODUCTION

The World Health Organization recommends that end-of-life (EoL) care be approached by integrating general population with hospital-level care (World Health Organization, 2014). While EoL care and health promotion are understood to belong to different categories (Rosenberg & Yates, 2010), there is a need for a more open societal attitude in facing and discussing death and dying (Kellehear, 2012). In addition to individuals who are receiving EoL care themselves, their family and social group also become aware of their own health and well-being in the context of life-limiting illnesses (Radbruch et al., 2009). However, laypeople

tend to experience more problems near death than medical professionals, such as stigma and loneliness, which might cause distress among patients and their families. Various education programs have been developed around the world to solve these problems.

Our review of published education programs for EoL care found that community resources have been used in a number of projects, such as naturally occurring social networks (Leonard, Horsfall, & Noonan, 2015; Mills, Rosenberg, & McInerney, 2015) and externally facilitated networks (Leonard et al., 2015). Community resources have also been used in direct support from trained community volunteers (Jack, Kirton, Birakurataki, & Merriman, 2011), and in programs such as work with schools (Hartley, 2012), businesses (Hall, Shucksmith, & Russell, 2013) and professionals (Richardson, 2002). Further, seed grants have been awarded to support community-led projects in the field of death, dying, loss and care (McLoughlin, 2013.). Conducting a program requires several areas of focus, such as writing a will and advance care planning (Seymour, Almack, Kennedy, & Froggatt, 2013), but can also involve exploring society's perception of death and dying through local or national conversation (Patterson & Hazelwood, 2014) or improving the experiences of those living with life-limiting illnesses (Mitchell & Burton, 2006). However, few studies have examined how laypeople learn in education programs.

Story-based learning (McQuiggan, Rowe, Lee, & Lester, 2008), which combines story contexts and pedagogical support strategies, may be an effective way to deliver an educational experience because laypeople are more likely to adopt the narrative mode over the logico-scientific mode of thinking (Clandinin & Connelly,

2000). Narratives are widely used in public health promotion in the UK (Talley, 2011). However, a systematic review of narrative-based interventions for health promotion concluded that more research is needed to determine how these interventions can best be used (Perrier & Martin Ginis, 2016). Process evaluation can allow the examination of participant views on the intervention, as well as investigation of any contextual factors and determination of the processes that mediate observed intervention effects (Al-HadiHasan, Callaghan, & Lymn, 2017). It is important to evaluate "how" laypeople learn in public health promotion, as the learning process uses narrative to improve health literacy.

II. METHODS

A. Aim
We clarified how lay participants learned through an EoL care education program using narrative.

B. Design
We conducted a case study in educational research (Creswell, 2012). The case was constructed by the interaction of laypersons and healthcare professionals, with a program constructed using narrative. Since our focus was on gaining an in-depth picture of the learning process through narrative among individuals, we involved only a series of cases in a community hospital. To focus on the learning process of lay participants, we undertook qualitative process evaluation using audio-recordings of the group dialogue in each session and focus group (FG). We reported in accordance with the consolidated criteria for reporting qualitative research guidelines (Tong, Sainsbury, & Craig, 2007).

Session	Date	Theme	Content	Assignment	Leading professional
1	24 Jul 2014	Sharing the experience of palliative care	Lecture: What is palliative care? Video: Narratives of cancer patients Group discussion	To write your understanding of palliative care based on the lecture and book readings	Physician
2	25 Sep 2014	Understanding the changes experienced by people who are facing death and discussing how we can support them	Lecture: Process of acceptance and active listening Group discussion	To write your understanding of the lecture and book readings	Nurse Medical social worker
3	27 Nov 2014	Engaging in decision making for your loved one	Lecture: Process of decision making Role play: Professionals conduct a brief role play of a case Group discussion	To reflect on one's view of life and death and thoughts for one's family, and to write these down in a letter	Physician Physical therapist
4	26 Feb 2015	Our view on life and death	Sharing the assignment from the previous session		Nurse Pharmacist

Table 1. Contents of the program

C. Setting of the Education Program

The study setting was a 150-bed hospital in Tokyo with a palliative care unit established in May 2014. We delivered a community education program to laypeople at the hospital to enhance their understanding of EoL care from July 2014 to February 2015. The learning outcome of the program was "to learn together about EoL care and to take action to promote health and well-being at the EoL based on one's own values". We adopted a narrative-centred approach as a learning strategy. Narrative-centred learning is defined as a narrative pedagogy that integrates methods such as case method teaching and problem-based learning to encourage self-directed learning and participant engagement (McQuiggan et al., 2008). Each session was 2 hours, during which the participants were engaged in constructing and telling stories in a small group. Healthcare professionals in the hospital played the role of facilitators, after prompting information from the lecture was given (Table 1). Participants were given an assignment at the end of each session to write their own story relating to the given topic. If a lay participant could not participate in the session, he or she was asked to watch a video recording of the session. We deliberately placed a 3-month interval between sessions with the expectation that participants would reflect on what they had learned from the sessions in their daily lives.

D. Participants

Using a community publication on health information produced by the hospital and convenience sampling, we recruited laypeople living in the catchment area of the hospital to attend all four sessions of the program (Babbie, 2007). Lay participants contacted the hospital after having seen an advertisement for the course in the community publication. The first author (JH, male) sent letters to the participants to confirm their willingness to participate in the study. We did not establish exclusion/inclusion criteria for literacy level or health status. Since JH and the third author (ND, female) had worked in the hospital, some lay participants knew JH and ND. Other participants built a proper relationship with JH and ND through the EoL program. At the start of the program, during the educational sessions, and during the FGs, we informed the participants that they were not obliged to talk and could leave if they became emotionally upset or experienced a breakdown.

E. Data Generation

All group dialogues during three sessions (excluding the fourth session in order that participants did not hesitate to share their own view on life and death) in a room of the hospital were audio-recorded to mainly focus on the learning process. Additionally, we conducted three 90-minute FGs, namely two FGs within one month after completion of the program and a third FG eight months after completion. JH facilitated the FGs using prompt questions and took field notes while preparing and conducting the program and in post-program FGs. All FGs were conducted in a quiet room in the hospital. All audio-recorded dialogue and FGs were transcribed verbatim by JH. We could not return the transcripts to lay participants because some participants were reluctant to do so. Accordingly, AO and healthcare professionals who joined the program checked for discrepancies between group dialogues during the three sessions and the verbatim transcriptions of the FGs. JH was a general physician in the hospital and a final-year PhD student at the time of data collection. JH had received training in qualitative research as part of the PhD program.

• What did you learn from the program?
• What did you experience in the program? Which of these experiences was the most impressive?
• What promoted your learning?
• How did you feel when attending the program? What made you feel this way?
• After the session, did you experience any changes? For example, in your behaviour or perspective?

Table 2. Prompting questions in FGs

F. Analysis

A thematic analysis was adapted for data analysis (Braun & Clarke, 2006). First, JH and second author (AO, female) separately read and deductively coded the transcripts. AO had undertaken qualitative research training by the time of data analysis in the UK. JH then created inductive codes based on the research questions and initial coding, with any disagreements with AO resolved by discussion. Once JH and AO agreed on the coding, all researchers discussed the themes that emerged from the codes and how these themes interacted until we were in full agreement. The whole process was iterative, which allowed us to achieve a richer interpretation of the data. Thus, researchers crystallised the data and confirmed the interpretation based on the field notes as a triangulation process.

III. RESULTS

A. Participants

Eighteen laypeople living in the local area of the hospital participated in this program. All participants were aged 50–70 years and all but one participant was female. The backgrounds of all participants and their

presence/absence in the four sessions and three FGs are shown in Table 3. Four lay participants watched the video because they could not participate in the session.

All cases of absence from the sessions or FGs were due to personal reasons of the participants.

Background of lay participants		Session 1	Session 2	Session 3	Session 4	FG 1	FG 2	FG 3
Gender	Age							
F	67	○	○	○	—	—	—	—
F	61	○	○	○	○	—	—	—
F	74	○	○	○	○	○	—	○
F	65	○	○	○	○	—	○	○
F	72	○	○	○	○	—	○	—
F	53	○	○	○	○	—	○	—
F	66	○	○	○	○	—	—	○
F	74	○	○	○	—	—	—	—
F	60	○	Video	○	—	○	—	—
F	51	○	○	—	○	○	—	—
F	69	○	○	Video	○	○	—	—
F	60	○	○	○	○	○	—	—
F	63	○	Video	Video	○	—	○	○
F	64	○	○	○	○	—	○	○
M	74	○	○	○	○	—	—	○
F	63	○	○	○	○	—	—	—
F	71	○	—	○	○	—	—	—
F	67	○	○	—	—	—	—	—

Note: FG 1, FG2 − Focus groups within one month after completing the program.
FG 3− Focus group eight months later after completing the program.

Table 3. Backgrounds of all participants and presence (○)/absence (−) in four sessions and three FGs

Themes	Sub-themes	Example of the texts
Reconstructing the concept of EoL care	Correcting the previous knowledge of palliative care	*"I thought that palliative care was the same as hospice care. However, my understanding of palliative care has changed since I was diagnosed with cancer and was advised that palliative care would start at the start of treatment."*
	Connecting the knowledge of palliative care with real world	*"I understood the connection with the community. Not many people know about community palliative care. I likewise did not know anything about these services before attending the program."*
	Contributing to the spread of knowledge on palliative care	*"I show photos of the books used in the program on my blog and have described what I learned in the program and my thoughts on palliative care. This has become my most popular post ever."*
Recalling feelings and emotions	Conflict between patient's hope and hospital rules	*"Because my husband pulled out the infusion needles himself, he was tied up to the bed and said that he was treated like a criminal. "*
	Regret regarding a late transition to palliative care	*"If I had known about palliative care earlier, I could have had him receive palliative care earlier."*
	Perplexity about an acquaintance discontinuing treatment	*"My teacher (living with metastatic breast cancer) says that she is thinking of stopping medical treatment because she thinks it is a waste of money and makes her feel guilty. I think that she should receive medical treatment for as long as she can."*
	Catharsis effect	*"My husband died two years ago. I think that I have become able to accept his death since attending the program. Learning and having a chance to learn have helped me to accept my mental condition of the past two years. I feel calm now."*

	Embarrassment in real experiences	"I have a friend in hospital. When I went to see her previously, we talked a lot about the many funny things that have happened in the past to help her remember. However, we did not talk much when I visited last time. I could not find the words when I noticed she was facing her own death. Since then I have been thinking about how I should behave in front of friends' family members and what I can do for my friend as a person."
Evoked other perspectives through metacognition	Differences between theirs' and others' perspectives	"I was impressed by the explanation about anger. I thought that I might be unable to accept anger."
		"The role plays allowed watchers to consider what they should do if they were put in the same situation. I think this was good."
	Differences among family members	"Because I only have sons, I get feelings of wishing I had a daughter like the oldest daughter who looks after her parents in the role play."
	Differences among professionals	"I think it is preferable that specialists help families overcome such difficulties."
Inspiring altruism	Motivation to commit to supporting others in EoL	"For me, I want cancer patients and their families to spend the rest of their lives in peace."
Reflecting on their own impending death	Mitigating their fear of death	"I don't think it is necessary to be afraid of death but I am confident that I have been living well up until now."
	Appreciation of others	"When I die, I want to say "thank you" to my family and friends."
		"I think that family members should mentally support the patient; so, it is better to ask them to look after me than to not ask at all."

Table 4. Emergent themes and sub-themes based on analysis of group dialogue and FGs

We focused on how laypeople learned in the program throughout the study. A total of 12 lay participants participated in the FGs. Through the analysis, we extracted five themes: reconstructing the concept of EoL care, recalling feelings and emotions, evoking other perspectives through metacognition, inspiring altruism, and reflection on one's own death (Table 4).

B. Theme Analysis

1) Reconstructing the concept of EoL care: The program deepened participants' understanding of the concept of EoL care by allowing them to compare their own experience with relatives or friends at the EoL and their image of EoL with those of other participants. Each session led participants to reconstruct their stories about the EoL. Triggered by these stories, participants discovered situations in their daily lives with a link to EoL, as follows.

"I thought that hospices were a place where morphine would be given to patients until their death. I have learned a lot about palliative care from the program, which has improved my understanding of palliative care."

Additionally, reading related books that were introduced in a series of sessions and dialogue with others allowed them to consolidate and articulate their previously vague understandings. For example, they generated a new understanding of EoL care by reflecting on such things as their own experience after gaining new knowledge about the difference between hospice care in a palliative care unit and the concept of EoL care, including its connection with the community and family/psychological support, and realisation of the spread of EoL care, as follows.

"I reached the conviction that I could receive family/psychological support. I have learned that if my husband is admitted to this hospital, I will also be supported as a family member."

Furthermore, their new-found understanding motivated them to contribute to disseminate the 'right' concept of EoL. On the other hand, some healthcare professionals who joined the small group dialogues as facilitators faced challenges in being unable to control the participants' story-telling.

2) Recalling feelings and emotions: Constructing stories stimulated participants to recall their inner experiences and emotions. As a result, participants verbalised their recalled feelings such as conflict, regret and perplexity in a group dialogue. This verbalisation of their emotions was a catharsis of the stress they had felt, as follows.

"My husband died two years ago. I think that I have become able to accept his death since attending the program. Learning and having a chance to learn have helped me to accept my mental condition of the past two years. I feel calm now."

Moreover, through the program, participants embodied emotions associated with their experience with relatives or friends at the EoL when recalling their internal

feelings. These narrative-based experiences widened their cognitive understanding of EoL care at the emotional level.

3) Evocation of other perspectives through metacognition: Specific external experiences during the sessions stimulated participants' interest. Additionally, by verbalising their interests, participants noticed their emotions, differences between their own and others' perspectives, and the context to which they belonged, such as families and professionals. Participants understood the need for expert assistance as they came to understand these perspectives. For example, participants showed appreciation to healthcare professionals for providing emotional support and management, which was given according to the different perspectives of different family members, as follows.

"I thought that families of cancer patients could not be as generous to patients' emotional changes, including anger as the family in the role play. I think it is preferable that specialists help families overcome such difficulties."

Through their cognition of other perspectives, they learnt how to access self-monitoring and self-representation as metacognition.

4) Inspiring altruism: Considering the understanding of EoL care inspired altruism as a latent need, defined as a desire that cannot be expected to articulate due to a lack of information (Langford, 1995). Participants expressed their understanding of EoL as stories through their participation in the program and their reading of books, which reminded them of their altruistic feelings, embedded as latent needs. Participants were motivated to commit to supporting patients and their families who were suffering at the EoL as volunteers.

"For me, I want cancer patients and their families to spend the rest of their lives in peace. And I have learned to feel compassion for families with cancer patients. It is important to support such families."

5) Reflecting on their own impending death: By gaining an understanding of EoL care, during which time they consulted with others who felt fear and anxiety regarding facing their death, participants started to anticipate their own deaths. This helped them to alleviate their fear and anxiety on the subject. In addition, they developed an appreciation for those on whom they will rely at their own EoL.

"I used to think that death was cruel, painful and scary, but I do not really think that now because there are people we can talk to as part of palliative care services. I don't think it is necessary to be afraid of death but I am confident that I have been living well up until now."

IV. DISCUSSION

We described laypeople's learning patterns through an EoL care education program, in which EoL care through narrative-centred learning and interactions with other participants inspired five processes, namely reconstructing their understanding, recalling emotions, evoking other perspectives, inspiring altruism and reflection on their own death. The process led them to convince that EoL was individual for every person and the EoL care was rooted in the understanding of their own life.

Lay participants learned not only about EoL care but also about the value of their own life in this education program. In previous studies of palliative education for healthcare professionals, undergraduate education on palliative care covers humanistic aspects and holistic views (Centeno, Ballesteros, Carrasco, & Arantzamendi, 2016; Horowitz, Gramling, & Quill, 2014). In graduate education, palliative care experts define comprehensive and essential palliative care competencies for internal medicine or family medicine residents, and residents improve their knowledge in a 2-week palliative rotation (Olden, Quill, Bordley, & Ladwig, 2009; Schaefer et al., 2014). In reality, it is nonetheless difficult for residents to alleviate the psychological distress felt by patients and families in palliative care (McFarland, Maki, & Holland, 2015). Considering this challenge, it is understandable that laypeople are more likely to harbour a stereotyped understanding of EoL and stigma around death compared to healthcare students or professionals. However, this study suggests that constructing stories enables lay participants to recognise their perception of the EoL and reflect on their own experience and feelings, similar to healthcare professionals (Arai et al., 2017). Narratives evoked participants' feelings and induced a catharsis of emotions after they expressed and verbalised these feelings. Through this process, lay participants acquired metacognition of death and dying by sharing and verbalising their own understanding and feelings about dying and well-being, which voluntarily promoted an altruistic desire to commit to EoL care and motivated them to contribute to disseminating the interpretation of EoL. In addition, they had opportunities to leverage their own existing experiences based on constructing stories, which is different from Kolb's experiential learning (Kolb, 1984). In previous health education programs, health professionals used information from standard epidemiological studies to change the misapprehensions

of laypeople (Allmark & Tod, 2006; McConnachie, Hunt, Emslie, Hart, & Watt, 2001; Prior, 2003). However, in addition to providing knowledge, encouraging participants to construct their own stories deepened their understanding of EoL care with respect to their own values.

While lay participants reflected on their own impending death, lay participants anticipated death as an extension of their own life and learned how healthcare professionals provide care to dying patients and their families through stories. Moreover, lay participants anticipated their own death with respect to their relationship with others. In social psychology, existential terrors, which are a basic psychological conflict that results from having a self-preservation instinct whilst realising that death is inevitable, can be managed by embracing cultural values or symbolic systems that provide enduring meaning and value to life (Curtis & Biran, 2001). A narrative-based program may provide laypeople with a sense that they are connected to someone, which will ultimately enable laypeople to deflect fear and manage their fear of death. Through this process, participants may attain an altruistic desire to express personal preferences for situations in which others benefit (Batson, 1997) because they realise the stress of the situation on others and develop respect for their well-being (Batson, 2010). Lay participants gained enhanced empathy for patients or their families who were suffering in the face of death and dying, which motivated altruistic behaviours to commit to EoL care.

Throughout the narrative-centred learning, rather than learning through structured knowledge in textbooks and lectures from healthcare professionals, lay participants reconstructed their own narratives consisting of a series of actions and stories describing concrete events and experiences. Bruner illustrated that there are two distinct modes of understanding (Bruner, 2009). The first is the logico-scientific mode of organised thinking based on reason. The second is the narrative mode associated with the creation of stories. People complementarily use the two cognitive modes to understand the world according to the situation. Laypeople are more likely to adopt the narrative mode in daily life. Through communication with others, laypeople realise how they understand the world they live in. However, healthcare professionals tend to use the logico-scientific mode in public health promotion for laypeople because they themselves learned through structured knowledge in textbooks. This leads to a mismatch between healthcare professionals and laypeople, and highlights the need to reflect on differences in modes of thinking when developing learning strategies. A chain or sequence of narratives from scattered experiences can be connected and arranged into an identifiable structure (Prins, Avraamidou, & Goedhart, 2017). In addition, stories motivate people to identify novel perceptual, emotional, and motivational experiences and are suited to alternative learning paradigms such as guided discovery (McQuiggan et al., 2008). Lay participants were able to enhance their understanding of the EoL through sharing and comparing their experiences with each other using the narrative mode. As a result, they acquired the metacognition and motivation to commit to the suffering of others.

A. Strengths and Limitations

There are three main limitations of this study. First, lay participants who participated in the program might be more open to learning about EoL among the general population. However, most participants initially misunderstood the concept of EoL care and some hesitated to share their experiences with relatives or friends at the EoL. This narrative-based approach was useful for such participants in deepening their understanding of EoL care and leading them to acknowledge that death is an extension of life. Second, two researchers (JH and ND) participated in developing the program and JH acted as a facilitator in the FGs. While we tried to provide a neutral environment and asked questions to encourage free speech, we may have asked inductive questions. Additionally, lay participants might have unconsciously or consciously mimicked the intentions of researchers due to self-selection bias and reporting bias because they agreed to participate in the study. To evaluate data credibility, JH, ND and another researcher (AO) who did not participate in running the program conducted a triangulation of the data (Walker, Holloway, & Wheeler, 2005). We assessed data that arose from free, frank and honest interactions and found that the group which included one particular researcher (JH) maintained a good relationship in which everyone asked frank questions or provided dissenting opinions. We might have missed critical views which could have been raised by other potential participants who were absent at the FGs. Third, we could not follow up on outcomes such as engaging community and social networks. Further study is needed to continue participation observations and follow-up to determine the longer-term outcomes of this narrative-based program.

V. CONCLUSION

We evaluated the process of a health education program on EoL care using the strategy of narrative-centred learning. Lay participants deepened their understanding of EoL care while reconstructing their knowledge, recalling their own experiences and emotions, evoking other perspectives, inspiring altruism and reflecting on

their own deaths. Such a program has the potential to enhance community engagement in EoL care.

Notes on Contributors

JH, AO and ND contributed to the design and implementation of the research, analysis of the results and writing of the manuscript.

Ethical Approval

This study was reviewed and approved by the ethical committee of the hospital (No. 69), which considered sampling, informed consent, and the confidentiality of participants. All participants provided written informed consent for participation and audio-recordings of the group dialogue and FGs.

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Declaration of Interest

The authors declare that they have no competing interests.

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