

Original Article

How to Deal With Relatives of Patients Dying in the Hospital? Qualitative Content Analysis of Relatives' Experiences



Erica Witkamp, RN, PhD, Mirjam Droger, RN, Rien Janssens, PhD, Lia van Zuylen, MD, PhD, and Agnes van der Heide, MD, PhD

Department of Public Health (E.W., M.D., A.v.d.H.), Erasmus MC University Medical Center Rotterdam; Department of Medical Oncology (E.W., L.v.Z.), Erasmus MC Cancer Institute, Rotterdam; Faculty of Nursing and Center of Expertise in Care Innovations (E.W.), Rotterdam University of Applied Sciences, Rotterdam; and Department of Metamedica (M.D., R.J.), EMGO+, VU Medical Center, Amsterdam, The Netherlands

Abstract

Context. Hospital care and communication tend to be focused on the individual patient, and decision making is typically based on the principle of individual autonomy. It can be questioned whether this approach is adequate when a patient is terminally ill.

Objectives. Our aim was to explore the involvement and experiences of relatives in the hospital during the patient's last phase of life.

Methods. This study was embedded in a retrospective questionnaire study on the quality of dying of a consecutive sample of patients who died in a general university hospital in The Netherlands. We performed a secondary qualitative analysis of relatives' comments and answers to open questions. Relatives of 951 deceased adult patients were asked to complete a questionnaire; 451 questionnaires were returned and analyzed for this study.

Results. Relatives expressed a need for 1) comprehensible, timely, and sensitive information and communication, 2) involvement in decision making, 3) acknowledgment of their position, 4) being able to trust health care staff, and 5) rest and privacy. When relatives felt that their role had sufficiently been acknowledged by health care professionals (HCPs), their experiences were more positive.

Conclusion. Relatives emphasized their relation with the patient and their involvement in care of the patient dying in the hospital. An approach of HCPs to care based on the concept of individual autonomy seems inadequate. The role of relatives might be better addressed by the concept of relational autonomy, which provides HCPs with opportunities to create a relationship with relatives in care that optimally addresses the needs of patients. *J Pain Symptom Manage* 2016;52:235–242.

© 2016 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

Key Words

Relatives, family, experiences, hospital, end-of-life care, autonomy

Introduction

In The Netherlands, about one-third of all deaths occur in the hospital, a percentage that is lower than in many other European countries.^{1–4} Many of these deaths are caused by a chronic illness and are

preceded by a period in which the patient is in need of palliative care, including end-of-life decision making.^{5,6} In Western health care, decision making is mainly based on the principle of individual autonomy,^{7,8} which in philosophy is described as self-rule or independence and in legislation as the individual's

Address correspondence to: Erica Witkamp, RN, PhD, Department of Medical Oncology, Erasmus MC Cancer Institute, P.O. Box 5201, 3008 EA Rotterdam, The Netherlands. E-mail: f.witkamp@erasmusmc.nl

Accepted for publication: February 18, 2016.

right to decide on medical treatment.^{9–11} Although the Institute of Medicine in 2001 already stated that involving the patient's family and friends is a matter of course when providing patient-centered care,¹² health care professionals (HCPs) in the hospital usually only address the patient when making decisions on treatment and care. They assume that the patient is competent and able to decide for himself and will involve relatives only when needed.¹³ According to Quinlan,¹⁴ patients in hospital have a comprised autonomy, as they accommodate to the ethical, legal, and organizational context of the hospital. This is particularly the case at the end of life, when the physical and psychosocial condition deteriorates and patients are no longer able to optimally participate in decision making without the support of relatives.¹⁴ Many patients want their close relative to be informed about their illness and to involve them in major decisions at the end of life.^{15,16} Relatives in palliative care should be supported in caring for the patient and for their own well-being.⁶ Many studies have shown that timely information and communication enable patients and their relatives to prepare together for death and to strengthen their relationship. Furthermore, information and communication can help relatives prepare for surrogate decision making if needed.^{4,15,17–21} Particularly at the end of life, patients tend to think and act in relation to close family and friends.¹⁴ Therefore, it can be questioned whether the patient's individual autonomy is the most appropriate base for end-of-life care. To update, there is a gap in empirical research on patient and relative involvement at the end of life and the implications for HCPs.^{14,22} In this study, we aim to explore the involvement of relatives in the hospital during the patient's last phase of life as experienced by relatives.

Methods

Design and Setting

This study was embedded in a retrospective questionnaire study on palliative and terminal care in the hospital.²³ The original study was carried out in the Erasmus University Medical Center in The Netherlands. The questionnaire we used contained 93 closed- and open-ended questions, the latter being merely questions for clarification. For this article, we used a qualitative approach to study the answers and comments to 10 open questions about hospital care in the last days of life.

Participants

The study population included relatives of 951 consecutive adult patients who died between June 2009 and July 2012, after a hospitalization of at least 6 hours at 18 nonintensive care wards (Table 1). Ten to

Table 1
Characteristics of Patients and Relatives

Characteristics of Participants	N = 451
Patients	
Age: mean (SD)	69 (14)
Sex	
Male	58%
Female	42%
Marital state	
Shared household	63%
Living alone	37%
Diagnosis	
Cancer	51%
Noncancer	49%
Length hospitalization: mean (SD)	15 days (19)
Relatives	
Age: mean (SD)	57 (13)
Sex	
Male	30%
Female	69%
Relation to patient	
Partner/spouse	44%
Child (in law)	37%
Other	19%

13 weeks after the patient had died, the relatives were invited to participate in the study by completion of a questionnaire on the quality of dying in the hospital. For 68 (7%) patients, no relative could be traced. We received 451 completed questionnaires (response 51%). We assumed that by including all participants, the number and content of the comments would be sufficient to cover the full range of experiences.

Data Analysis

A qualitative inductive content method was used to systematically analyze the texts.^{24,25} After selection of the relevant questions, all comments were read by two researchers (F. E. W., S. M. D.). Because the comments of relatives often related to different questions, data were coded across all questions using the open coding method.^{25,26} Two researchers (F. E. W., S. M. D.) coded the data independently. The codes were discussed until consensus was reached. Twenty-six different codes were extracted and discussed and agreed on with two other researchers (A. H., R. J.). The codes were reassembled and restructured into categories (axial coding) and subsequently we discussed and decided on integrating and refining the categories into overarching themes (selective coding) (Table 2). In addition, we summarized the answers to the associated closed questions and counted the number of explanatory comments per question, using SPSS, version 21 (IBM Corp., Armonk, NY).

Ethical Considerations

Approval for this study was given by the Medical Ethical Research Committee of the Erasmus MC. According to Dutch legislation, written informed consent of the patients or respondents was not required

Table 2

Code Tree: Descriptive Themes, Categories, and Codes of Relatives' Experiences

Information and communication
Comprehensible
Clearly and to the point
Need to understand the situation and prognosis
Need to make informed choice
Timely
In time and at right moment
Initiated by professional
To be prepared
Sensitive
Sensitive for needs
Emotional support
Involvement in decision making
Deliberation
Opportunity to participate
Togetherness in discussion and decisions
Shared responsibility
Acknowledgment
Acknowledgment
Affirmation of person (patient and relative)
Relative's opinion
Relative's significance to the patient
Relative's complex role and position
Trust
Trustworthiness
Best possible care
Fulfill agreements
Being honest
Access
Accessibility of professionals when needed
Rest and privacy
Facilities
Private room
Intimacy
Rest
Stop invasive procedures
Presence
Relative's need to be with loved one
Support of the patient
Present at moment of death (not wanting the patient to die alone)

because data were gathered after patients' death and the study involved minimal risk or burden to the respondents. Participants were informed that all data would be anonymously analyzed.

Results

A total of 451 relatives gave 1931 explanations and comments to the 10 questions (Table 3). The experiences of relatives concerning their position and role could be summarized in five categories: 1) information and communication, 2) involvement in decision making, 3) acknowledgment, 4) trust, and 5) rest and privacy. Bereaved spouses and bereaved children reported experiences in all of these categories.

Information and Communication

Experiences with information and communication concerned comprehensibility, timeliness, and sensitivity.

Comprehensibility. Relatives reported that they had felt a need for comprehensible information about the patient's situation and prospects, to accompany the patient and to participate in decision making when needed. Physicians were expected to explain the patient's situation accurately and in an understandable way.

I was called in the morning when I was at my office, and they asked whether I could come that day, because her saturation was decreasing. Being a lay person I cannot be expected to understand that; I would have wanted them to be more clear, more pressing. (R104, sister, 54y)

Relatives experienced contradictory information from the multidisciplinary team as confusing:

Various doctors told us different things; this was very confusing (R914, wife, 55y).

They critically reported about situations in which they were not informed, or it had been difficult to get in touch with the physician, or where the physician had discussed the patient's impending death with the patient only. Relatives' need for information also concerned procedures after death.

Timeliness and Sensitivity. Timeliness, with an emphasis on "in time" and "proactive," was related to positive experiences concerning information and communication. Being informed and called in time enabled relatives, or would have enabled them, to prepare for imminent death, and to arrive in time at the ward to be with the patient in his final moments.

In the morning we were invited to meet with the physician at 4.30 PM; when we arrived at 4.15 PM he had just died (R50, father, 73y).

When relatives were informed proactively, they were satisfied, whereas they critically appraised situations in which they repeatedly had to ask for information. Furthermore, relatives reported about their preferences for being informed clearly and decisively, as well as in a sensitive way.

Only on the last day we realized that she was dying; we were only told that she was not doing well (R264, daughter, 60y).

Information after the patient's death had been helpful to get more clarity about what had happened in the final phase.

Involvement in Decision Making

Many relatives reported about their involvement in making medical decisions, either together with the patient or as representative when the patient was unable

Table 3
Closed- and Open-Ended Questions and Explanations

Quantitative Analysis (Answer: Yes)				Qualitative Analysis			
	Total, <i>n</i> = 451 (%)	Spouses, <i>n</i> = 217 (%)	Children, <i>n</i> = 150 (%)		Total, <i>n</i> = 451 (%)	Spouses, <i>n</i> = 217 (%)	Children, <i>n</i> = 150 (%)
Do you feel your presence was meaningful to your beloved during final 24 hours?	302 (67)	157 (72)	95 (63)	Can you explain your answer?	302 (67)	137 (63)	104 (69)
Was there, to your opinion sufficient nursing care during the final 24 hours?	358 (79)	179 (83)	114 (76)	Can you explain your answer?	209 (46)	90 (41)	76 (51)
Was there, to your opinion sufficient social and emotional support to you and to your beloved during the final 24 hours?	270 (60)	134 (62)	84 (56)	Can you explain your answer?	221 (49)	97 (45)	81 (64)
Did to your opinion the medical care change during the final days?	129 (29)	58 (27)	49 (33)	Can you explain your answer?	195 (43)	88 (41)	74 (49)
Do you believe you have sufficiently been involved in medical decisions?	308 (68)	144 (66)	107 (71)	Can you explain your answer?	176 (39)	82 (38)	73 (49)
Has the staff paid sufficient attention to the wishes and preferences of you and your beloved?	316 (70)	158 (73)	103 (69)	Can you explain your answer?	169 (37)	80 (37)	63 (42)
If you had not been present at the moment of death, would you have preferred to be present?	(<i>n</i> = 155) 116 (75)	(<i>n</i> = 54) 47 (87)	(<i>n</i> = 60) 42 (70)	Can you explain your answer?	(<i>n</i> = 155) 109 (70)	(<i>n</i> = 55) 36 (65)	(<i>n</i> = 60) 42 (70)
If you have had a postmortal discussion with the staff, did this meet your needs?	(<i>n</i> = 184) 145 (79)	(<i>n</i> = 106) 78 (74)	(<i>n</i> = 55) 39 (71)	Can you explain your answer?	(<i>n</i> = 184) 112 (61)	(<i>n</i> = 106) 67 (63)	(<i>n</i> = 55) 33 (60)
Do you believe the staff could have done more for you and your beloved during the final days?	65 (15)	23 (11)	30 (20)	Can you explain your answer?	207 (46)	93 (45)	75 (50)
Do you have general or additional comments?	n.a.	n.a.	n.a.	Do you have general or additional comments?	220 (48)	108 (50)	16 (11)

n.a. = not applicable.

to communicate; whether they had been given options to choose from on behalf of the patient, what these options were and what information they had received. Relatives who were satisfied concerning their role as the patient's representative in the decision making process had been clearly informed about the options and felt that they had made decisions together with the physician.

Every option was explained and decisions were shared (R185, wife, 77y),

Medical examinations etc. were communicated, but not discussed (R815, wife, 69y).

Relatives who stayed all day with the patient reported about sufficient opportunities to be involved in all decisions, whereas others had experienced difficulties in getting an appointment with the physician: "We were present all the time, so we could continuously interfere and discuss everything" (R503, daughter, 46 y). Relatives who had not been involved in the decision-making process reported that they felt neglected, that they could not agree with the decisions made, or did not understand these decisions: "I really had difficulty to convince them of his preferences (to die smoothly, without choking)" (R220, sister, 55y).

Acknowledgment

Relatives' need for "acknowledgement" refers to the experience that HCPs should do their best to affirm the patient as a person and the relative in his position and relation to the patient. Relatives were satisfied when they were treated with respect and reported on having easy, honest, and open communication with the medical and nursing staff; they were dissatisfied when they lacked such experiences. It was important for relatives that HCPs acknowledged their close involvement with and specific knowledge of the patient, his situation, his values and beliefs, and their significance to the patient.

They asked only him for information, but his answers were confusing and the staff did not understand him. I did, but they did not listen to me (R724, wife, 42y).

They did not ask me once about how she should be cared for (R263, husband, 47y).

Furthermore, relatives needed acknowledgment of their feelings of uncertainty regarding their position in the hospital. For example, it was seen as helpful to have a conversation with the nurse after the patient's death to be affirmed in the adequacy of their role and care. Acknowledgment of and respect for relatives also was important after the patient's death, for example, when confirming the patient's death,

discussing organ donation, offering condolences, and providing relatives time to say goodbye.

My mother died at 8.05 PM. After the physician established the death she only said the nurse would arrange all formalities, she said nothing further. This physician didn't offer her condolences to us. Me and my family have talked a lot about this (R30, son, 51y).

Trust

Trust concerned experiences about whether HCPs provided good care, or what relatives believed to encompass good care, whether HCPs did what they promised to do, and whether they did all they could to relieve the patient's suffering. Relatives reported about feeling stressed when they felt that the quality of care was insufficient: "We were asked to give her food and drinks. If we were not there the food just stood there, although she could not reach it" (R940, personal coach, 28y). Others felt confident when they left the patient knowing that he was in good hands: "If we wanted to go out for a while, we could leave him behind in good hands" (R7, daughter, 32y).

These experiences were often related to relatives' experienced knowledge and skills of the HCPs, for example, regarding symptom control and communication, attitudes toward the patient, such as showing respect and loving care, and to the availability of enough medical and nursing staff. Disagreement about medical decisions, both within the medical team and between the physician and the patient or relatives, affected relatives' feelings of confidence:

Five days before he died he asked for extra pain medication because he couldn't take it anymore. The physician refused, because he did not consider him to suffer "hopelessly." Who decides on that? The physician? Or the patient who feels that life is slipping away while he almost literally dies of his pain? (R56, daughter, 40y)

Rest and Privacy

Experiences concerning rest and privacy were related to having a private room for the patient, silence and privacy when receiving visitors, being able to share time and emotions and to be oneself.

There was not enough rest. Too much noise on the corridor and much agitation in the room of the patient!!! (R549, wife, 50y)

The final 24 hours, especially the very last hours, our "being together" was a positive experience. The nurses from the night shift were totally unaware of approaching death (R593, husband, 56y).

Rest also involved avoiding futile medical examinations, which were a burden for the patient: "Even

though we requested to bother him as little as possible, they were still carrying out many burdensome examinations" (R542, wife, 60y).

Relatives reported that being able to visit the patient every hour of the day was important, so that they could express their love and affection, support the patient in his last phase of life and meaningfully contribute to the patient's well-being. Therefore, the opportunity to stay during the nights and to have a meal and beverage at the bedside was important.

... he had been hospitalized shortly, and they supported him by allowing me, after his admission at night, to stay as long as I wanted to (R336, wife, 64y).

When having a private room, relatives reported about "being on their own" with the patient, which could either be experienced as being abandoned or as being respected in their privacy. This seemed to be related to undisclosed expectations about whether HCPs should proactively enter the patient's room or on the patient's or relatives' initiative.

Interpretation and Discussion

Bereaved relatives felt better able to represent the patient when they were acknowledged in their role as caregiver, representative, and close relative, and as such to be timely informed and involved in making decisions about treatment and care. Experiences were more positive when the patient was provided with optimal care and felt as comfortable as possible and when there was sufficient trust, privacy, and rest in end-of-life care.

Our findings are in line with recently published literature reviews.^{22,27} Virdun et al. identified five domains of what family members in Western societies stated as most important in end-of-life care in the hospital setting, that is, effective communication and shared decision making, expert care, respectful and compassionate care, trust and confidence in clinicians, and financial affairs.²⁷ Relatives in our study did not refer to financial affairs. Although patients in the U.S. may be confronted with health care costs, health insurance policy in The Netherlands protects patients and their relatives from such worries. Olding et al. identified from the literature five components of family involvement in patient-centered care, that is, presence, having needs met/being supported, communication, decision making, and contributing to care.²² Our data show the emphasis relatives put on acknowledgment of their relationship with the patient. Findings suggest that relatives have two distinguishable roles during the last phase of life of the patient in the acute care. First, HCPs should acknowledge that the patient's illness is also a problem of relatives.^{8,12,22,28} It is not an isolated, nor a

temporary event, but a highly stressful nonreversible situation that deeply affects the relative's life and future.⁸ Because of this, relatives need care and attention of hospital staff themselves, which extends to the period after the patient's death, when relatives realize that the patient has died and might need support in their bereavement process and in moving forward with their lives.²¹ Second, relatives have the role of caregiver and of advisor in complex decisions, and eventually may need to act as the patient's representative. During the last days of life, the physical and mental health of patients and their decision making capacity may fluctuate and gradually diminish, which demands flexibility of relatives in the role of representative.²⁹ Palliative care, therefore, also should support relatives in their role as an intermediary between the patient and HCPs, with the end goal of improving the quality of life and quality of dying for the patient. To represent the patient's interests in decision making when needed, relatives require timely information about the illness and options for treatment, to enable them to discuss preferences for treatment and care with the patient.^{19,20,30} Not all patients can be expected to completely inform their relatives, and research has shown that patients want to protect their relatives throughout the end-of-life experience.¹⁴ Therefore, HCPs should ask patients in a timely fashion to designate a relative to receive medical information.

In addition, the identity of severely ill patients shifts dramatically in the hospital, as compared to when they were still at home. Care in the hospital is often impersonal and fragmented and tends to reduce patients with full histories and relational identities into diseased body parts that are described and approached in medical jargon.⁸ Patients are connected to their relatives and these relationships shape their identity. Relatives are reminders that the patient is not merely a collection of dysfunctional body parts that require professional intervention, but a moral agent with a history and important relationships. Relatives are the constant factors in a changing plethora of HCPs.⁸ They enable the patient to maintain his identity, to live his personal life till the end, and to die in accordance with his values.

Our study shows that relatives of dying patients, that is, spouses as well as children, put effort into improving the quality of life at the end of life and the quality of dying of the patient. Because relatives know the patient best and want to ensure that his interests are respected as well as possible, relatives want to have an intermediary role between the patient and health care staff. HCPs' attitude, therefore, should support relatives' confidence in maintaining their caregiver role in an unknown place with unknown routines.^{4,19} Acknowledgment of relatives'

role and expertise toward patients at the end of life might be a prerequisite for other positive experiences. When HCPs acknowledge this role, comprehensive and timely information, involving relatives in decision making, and facilitating rest, privacy, and practical facilities might be a natural consequence. Relatives experiencing such supportive care in this study more often reported positively on the quality of care for the patient. Although this matches with the dimension "involvement of family and friends" of patient-centered care,¹² structural attention to relatives seems to be in contrast with current clinical practice in the hospital, for example, in attitudes of HCPs and in the organization of care.¹³ The focus in Western health care is on the individual patient, to the exclusion of the interests of others.⁸ Especially in North-Western countries, HCPs in hospitals do not prioritize attention to a patient's social network and structures of care might not be appropriate to do so.¹⁰ Hospital care is primarily focused on the individual autonomous patient, considering him to be rational and independent,⁹ and respecting his rights on information, confidentiality, and privacy.³¹ However, at the end of life, patients often think and act in relation to close family and friends.¹⁴ In this context, the concept of individual autonomy as one of the main principles in health care might fail. It is important to acknowledge that interdependence is inextricably tied to the human condition.²⁸ People are connected and involved with each other and patient autonomy is a relational phenomenon.^{14,32,33} The concept of relational autonomy, in which the patient and the relatives are seen as interdependent, is more appropriate in end-of-life care,³⁴ where the involvement of relatives is important in preserving or restoring an overall sense of patients' identity, agency, and selfhood.³⁵

Limitations and Strengths

A limitation of this study is that the research questions of the original study were focused on the patient, and not primarily on the experiences of relatives. The study was conducted in one hospital, and a majority of the participants were of Dutch origin, which may limit the generalizability of the findings. Furthermore, the study originally was not performed as a qualitative study; the qualitative design of this study, however, allowed for an in-depth analysis of all the comments. We found many similar comments within the 451 completed questionnaires, suggesting that we reached saturation of data.

Conclusion

This study shows that patient-centered hospital end-of-life care includes the acknowledgment of relatives

in their role of caregiver and representative of the patient, to inform them and to involve them in decision making. In addition, relatives need to be able to trust HCPs in providing good care. They also need practical support. Such acknowledgment and support enables them to take care of the patient and represent his interests at the end of life. This may conflict with an approach that is based on the principle of individual autonomy. Relational autonomy, considering patient and relative to be connected and interdependent, is probably a more appropriate concept in end-of-life care.

Disclosures and Acknowledgments

This study was financially supported by a grant from the Erasmus MC Medical Research Committee and the Tom and Josephine Rijckes Legacy Foundation, and neither had any involvement in the design and conduct of the study; collection, management, analysis, and interpretation of the data; and preparation, review, or approval of the article. All authors declare they have no competing interests.

References

1. Statistics Netherlands. Death certificate. Updated 2014. Available at: www.statline.cbs.nl/Statweb/search/?Q=overleden&LA=NL. Accessed June 6, 2014.
2. Cohen J, Bilsen J, Addington-Hall J, et al. Population-based study of dying in hospital in six European countries. *Palliat Med* 2008;22:702–710.
3. Houttekier D, Cohen J, Surkyn J, Deliens L. Study of recent and future trends in place of death in Belgium using death certificate data: a shift from hospitals to care homes. *BMC Public Health* 2011;11:228.
4. Mossin H, Landmark BT. Being present in hospital when the patient is dying—a grounded theory study of spouses experiences. *Eur J Oncol Nurs* 2011;15:382–389.
5. Dutch Comprehensive Cancer Center. Palliatieve zorg in beeld 2014 [Palliative care in the Netherlands.]. Available at: <http://www.netwerkpalliatievezorg.nl/rotterdam/Hulpverleners/Actueel/tabid/7998/ctl/Details/ArticleID/11194/mid/20832/IKNL-Rapport-Palliatieve-zorg-in-beeld.aspx>. Accessed April 25, 2014.
6. World Health Organization. Global atlas of palliative care at the end of life 2014. Available at: www.who.int. Accessed June 18, 2014.
7. O'Neill O. Autonomy, individuality and consent. In: *Autonomy and trust in bioethics*. Cambridge: Cambridge University Press, 2004.
8. Ho A. Relational autonomy or undue pressure? Family's role in medical decision making. *Scand J Caring Sci* 2008;22:128–135.
9. Feinberg J. Autonomy. In: Christman J, ed. *The inner citadel: Essays on individual autonomy*. Brattleboro, VT: Echo Point Books & Media, 1989:27–53.

10. Hancock K, Clayton JM, Parker SM, et al. Truth-telling in discussing prognosis in advanced life-limiting illnesses: a systematic review. *Palliat Med* 2007;21:507–517.
11. Patientenrecht-en-clientenrecht [Patient rights and client rights.]. Available at: <http://www.rijksoverheid.nl/onderwerpen/patientenrecht-en-clientenrecht>. Accessed October 14, 2014.
12. Institute of Medicine, Committee on Quality of Health Care in America. In: Crossing the quality chasm: A new health system for the 21st century. Washington DC: National Academies Press, 2001. Available at: <http://www.nap.edu/catalog/10027.html>. Accessed January 28, 2016.
13. Sokol DK. Don't forget the relatives. *BMJ* 2014;349:g7351.
14. Quinlan C. Patient autonomy at the end of life: Literature review 2009. Available at: ejournal.narotama.ac.id/files/Literature%20Review.pdf. Accessed September 12, 2014.
15. Heyland DK, Dodek P, Rocker G, et al. What matters most in end-of-life care: perceptions of seriously ill patients and their family members. *CMAJ* 2006;174:627–633.
16. General Medical Council. Treatment and care towards the end of life: Good practice in decision making. London: General Medical Council, 2010.
17. Young AJ, Rogers A, Dent L, Addington-Hall JM. Experiences of hospital care reported by bereaved relatives of patients after a stroke: a retrospective survey using the VOICES questionnaire. *J Adv Nurs* 2009;65:2161–2174.
18. Shinjo T, Morita T, Hirai K, et al. Care for imminently dying cancer patients: family members' experiences and recommendations. *J Clin Oncol* 2010;28:142–148.
19. Dosser I, Kennedy C. Family carers' experiences of support at the end of life: carers' and health professionals' views. *Int J Palliat Nurs* 2012;18:491–497.
20. Fritsch J, Petronio S, Helft PR, Torke AM. Making decisions for hospitalized older adults: ethical factors considered by family surrogates. *J Clin Ethics* 2013;24:125–134.
21. Clark K, Cain J, Campbell L, Byfieldt N. Caring for people dying in acute hospitals: a mixed-methods study to examine relative's perceptions of care. *Palliat Support Care* 2015;13:335–343.
22. Olding M, McMillan SE, Reeves S, et al. Patient and family involvement in adult critical and intensive care settings: a scoping review. *Health Expect* 2015.
23. Witkamp FE, Zuylen L, Maas PJ, et al. Improving the quality of palliative and terminal care in the hospital by a network of palliative care nurse champions: the study protocol of the PalTeC-H project. *BMC Health Serv Res* 2013;13:115.
24. Elo S, Kyngas H. The qualitative content analysis process. *J Adv Nurs* 2008;62:107–115.
25. Malterud K. Systematic text condensation: a strategy for qualitative analysis. *Scand J Public Health* 2012;40:795–805.
26. Boeije H. Analysis in qualitative research, 1st ed. London, UK: Sage, 2010.
27. Virdun C, Lockett T, Davidson PM, Phillips J. Dying in the hospital setting: a systematic review of quantitative studies identifying the elements of end-of-life care that patients and their families rank as being most important. *Palliat Med* 2015;29:774–796.
28. Verkerk MA. The care perspective and autonomy. *Med Health Care Philos* 2001;4:289–294.
29. Edwards SB, Olson K, Koop PM, Northcott HC. Patient and family caregiver decision making in the context of advanced cancer. *Cancer Nurs* 2012;35:178–186.
30. Workman S, Mann OE. 'No control whatsoever': end-of-life care on a medical teaching unit from the perspective of family members. *QJM* 2007;100:433–440.
31. Ells C, Hunt R, Chambers J. Relational autonomy as an essential part of patient-centered care. *Int J Fem Approaches Bioeth* 2011;4:79–101.
32. Landeweer E, Berghmans R, Elfahmi D, Goldsteen M. Collaboration in psychiatry, privacy and confidentiality revisited. *Int J Fem Approaches Bioeth* 2011;4:121–139.
33. Wilson F, Ingleton C, Gott M, Gardiner C. Autonomy and choice in palliative care: time for a new model? *J Adv Nurs* 2014;70:1020–1029.
34. Stanford Encyclopedia of Philosophy. Feminism-autonomy. Available at: <http://plato.stanford.edu/entries/feminism-autonomy/>. Accessed April 14, 2014.
35. Voskes Y, Kemper M, Landeweer EG, Widdershoven GA. Preventing seclusion in psychiatry: a care ethics perspective on the first five minutes at admission. *Nurs Ethics* 2014;21:766–773.