CASE STUDY

End-of-Life communication with non-traditional families and lesbian, gay, bisexual and transgender patients for nurses

Julie E. Darby[1], Peggy Ward-Smith*[2]

[1] Department of Nursing, Baptist College of Health Sciences, Memphis, Tennessee, United States
[2] School of Nursing and Health Studies, University of Missouri-Kansas City, Kansas City, Missouri, United States

Received: August 10, 2016 **Accepted:** September 17, 2016 **Online Published:** September 23, 2016
DOI: 10.5430/cns.v4n4p40 **URL:** http://dx.doi.org/10.5430/cns.v4n4p40

ABSTRACT

Objective: The purpose of this article was to describe a concept synthesis on communication at end-of-life (EOL), and specifically when the family framework is non-traditional.
Methods: An electronic database search of online publications generically and within healthcare disciplines and education was performed. The terms communication, EOL communication, EOL, simulation, communication concept analysis, and EOL concept analysis, singularly and in all combinations were used. The search was limited to peer-reviewed articles, available through the University of Missouri-Kansas City library, written in English, and appeared to have a research focus, resulted in 24 articles which were reviewed for this concept analysis.
Results: Uses and definitions associated with communication during EOL were used to articulate the attributes, antecedents, consequences, and empirical referents. Model, borderline, and contrary cases were developed.
Conclusions: Communication is conceptually defined; a foundation for the development of an operational definition is begun. The use of appropriate and respectful communication, among and between interprofessionals, the patient, and his/her family members or emotionally attached persons enhances the ability to ensure that EOL desires are known and documented. This activity will improve the capability for healthcare professionals to provide appropriate and desired care.

Key Words: Communication, End-of-life, Interprofessional, Lesbian, gay, bisexual and transgender

1. INTRODUCTION

Communication between health care providers, a patient, and his/her family member(s) was initially identified in 2001 to have a direct effect on satisfaction with care.[1] The Institute for Healthcare Communication[2] posits that appropriate end-of-life (EOL) communication relieves distress, improves coping, and increases satisfaction. Yet, the ability to define or describe appropriate, effective communication at EOL remains elusive. According to Cartwright and colleagues,[3] in addition, there is a paucity of research focused on the EOL experiences among lesbian, gay, bisexual and transgender (LGBT) people. In 2004 there was an awareness of EOL care planning and need for respectful communication as critical elements, necessary to ensure that the care provided is respectful and valued, yet these interactions typically occur within brief encounters. Previous research has linked ineffective communication to medication errors,[4] increased morbidity and mortality,[5] increased length of inpatient hospital

*Correspondence: Peggy Ward-Smith; Email: wardsmithp@umkc.edu; Address: 2464 Charlotte Street, Kansas City, MO, 64108, United States.

stays,[6] and decreased work satisfaction among nurses.[7] In fact, as early as 2002 the Institute of Medicine (IOM) identified the ability to communicate appropriately and accurately as a quality standard.[8] While effective communication is always important, it is critical when providing EOL care. Despite these early results and recommendations, Granek and associates[9] describe EOL communication among the most difficult conversations in health care. Communication at EOL remains a challenge among healthcare providers.[10]

In instances where the patient, and family structure are non-traditional, an additional challenge in this scenario relates to the ability of the healthcare provider to communicate effectively, using generic titles, and in an unbiased manner in their presentation. Rawlings outlines and describes specific EOL concerns in this situations.[11] While the goal of any nursing care is to be holistic, competency with respect to sexuality is affected when negative attitudes or homophobia is present. Provision 1.3 of the American Nurses Association Code of Ethics for Nurses[12] requires nurses to provide care "with compassion and respect for the inherent dignity, worth, and unique attributes of every person" (p. 1). While challenging, this respect must be provided to all individuals, uniformly. The National End of Life Care Programme[13] provides approaches appropriate for use when the patient or family is non-traditional.

The use of effective interprofessional teams has been recognized as a critical component of high quality EOL care.[14] Communication, in this situation, is both verbal and nonverbal, and includes listening and presence.[15] Effective interprofessional communication has been associated with better resource-efficiency and care that is holistic and innovative.[16] In circumstances where the lifestyle choices of the patient vary from the social or cultural norm, clear and respectful communication may be challenging.[17,18] The purpose of this concept analysis is to explore the state of the science specific to communication between health care professionals when the patient receiving EOL care and their family members include significant individuals who are not related in typical, or traditional, patterns. Family, for the purpose of this analysis, will include individuals who live together, take care of each other, have an emotional attachment, and have many things in common. These individuals refer to each other as family members.[19]

2. Purpose of conducting a concept analysis

Walker and Avant[20] defined a concept analysis as the process by which the basic elements of a concept undergo a complete examination. The aim of a concept analysis is to clarify the definition and use of the phenomenon under investigation.[21] Identification of the attributes and characteristics provides a foundation from which research can identify, explore, and explain the theoretical relationships and the clinical application of the phenomenon. The initial step in a concept analysis is to perform a literature review. Thus, the attributes and characteristics are evidenced-based, and applicable toward research.

2.1 Literature review

The initial step included performing a review of the published literature to identify primary research studies focused on the topic of interest. These studies were used to define the concept, using operational definitions, and research results. Thus, terms similar or analogous to communication at EOL can be avoided, resulting in a clear, definable, and operational term. In this case, the initial review utilized the search engines of OVID, Academic Search Complete, PubMed, Medline through Ovid, CINAHL through Ebsco, and Google Scholar and the keywords of communication, EOL, and concept analysis in singularly and in all possible pairs. The search was limited to research articles published between 1960 and 2015, written in English, and published in the public domain. The results of this search identified 24 appropriate articles. Exemplars are presented in Table 1.

2.2 Uses of the concept

Communication, as a noun, is defined by the National Communication Organization (NCA) as the process by which information is exchanged between individuals. Communication, which can be verbal or nonverbal, has language specific to any discipline.[22] In health care settings clear, concise and appropriate verbal and non-verbal communication is necessary to provide error-free care.[23] In health care settings, communication must be interdisciplinary; this includes every healthcare provider, the patient, and his/her salient family member(s). Interprofessional collaboration is so dependent upon communication that the World Health Organization (WHO) includes interprofessional communication as a key element in the delivery of health care.[24]

A 1999 Milbank Report[25] identified 11 core principles that guide professionals who provide EOL care. These standards, adopted by many health care professional organizations, include being sensitive and respectful to the wishes of the patient and his/her family member(s). Results from a systematic review performed by Harding and colleagues,[17] which critiqued 22 interventions, concludes that EOL health care needs do not alter based on sexual orientation. However, heath care providers should be aware that there might be some unique needs for this group. Communication is the

only intervention that can facilitate care that is appropriate, respectful, and valued. Performing a concept analysis provides a mechanism to identify when, and how therapeutic communication can enhance the dying experience. This is particularly important when there is a paucity of literature focused on the EOL needs of individuals with non-traditional lifestyles.

Table 1. Exemplars from the review of the literature

Title	Author(s), Journal/Publication Source	Data Type	Level of Evidence
Exploring the Impact of Sexual Orientation on Experiences and Concerns about End of Life Care and on Bereavement for Lesbian, Gay and Bisexual Older People	Almack K, Seymour J, Bellamy G. *Sociology* DOI: 10.1 177/0038038510375739	Qualitative	Level VI
End-of-life Care Considerations for Gay, Lesbian, Bisexual, and Transgender Individuals	Rawlings D. *International Journal of Palliative Nursing* DOI: 10.12968/ijpn.2012.18.1.29	Qualitative	Level II
End-of-life Care for Gay, Lesbian, Bisexual and Transgender People	Cartwright C, Hughes M, Lienert T. *Culture, Health & Sexuality* DOI: 10.1080/13691058.2012.673639	Qualitative	Level VI
Lesbian, Gay, Bisexual and Transgender People's Attitudes to End-of-Life Decision-Making and Advance Care Planning	Hughes M, Cartwright C. *Australasian Journal on Ageing* DOI: 10.1111/ajag.12268	Mixed Methods	Level VI
Intensive Communication Skills Teaching for Specialist Training in Palliative Medicine: Development and Evaluation of an Experiential Workshop	Clayton JM, Adler JL, O'Callaghan A, et al. *Journal of Palliative Medicine* DOI: 10.1089/jpm.2011.0292	Quantitative	Level VI
LGBT People's Knowledge of and Preparedness to Discuss End-of-Life Options	Hughes M, Cartwritght CM. *Health and Social Care in the Community* DOI: 10.1111/hsc.12113	Quantitative	Level VII

2.3 Essential attributes

The key, or essential attributes for communication, in an EOL scenario, have been well defined by Kourkouta and Papathanasiou.[26] These attributes include: (1) an encounter between at least two individuals, (2) a mindfulness or an awareness that effort will be required of all individuals, (3) a willingness and the ability to listen, and (4) attentive to the use and meaning of verbal (words) or nonverbal (body language) to convey information.[27–31] When considering interprofessional communication, specific to health care professionals, additional attributes must be included. These include: (1) participants in the encounter are two or more health care providers and the goal of the encounter focuses on patient care; (2) the ability to learn from each other exists; (3) there is a respectful sharing of knowledge and expertise; (4) the experience is andragogical, or nonhierarchical; and (5) the goal of the encounter is focused on a health outcome for a patient for whose care the participants are responsible.[14,30,32,33]

2.4 Model

Placing the attributes listed above into a model (see Figure 1) display the circular nature of the phenomenon. Central to the model are patient outcomes. This is the focus of the communication, and the desired outcome. Within the outermost circle are the individuals involved in the communication. There must be at least two individuals involved; generally, there will be at least three (the patient, a family member, and a health care professional). Within this circle, and between the communicators, is sharing. This sharing includes the wishes, desires, and decisions of the patient and his/her family member(s). The sharing must include an effort to explain content, and a willingness to listen without bias. All communicators must be aware of their verbal and non-verbal communication and clarify any unclear verbal or non-verbal communication of any other communicator. Missing, ineffective, or unclear communication between these individuals will negatively affect the care provided.

Further within the circle is learning, which is a two-way communication event between patient outcomes and each communicator. Using patient outcome as a goal, each communicator has the ability to contribute and learn from this process. The communication must be respectful, nonhierarchical, and respectful. This communication process will: (1) assure that the desired patient goal is achieved, and (2) allow each communicator to learn. This learning will include how to respectfully assess the wishes and desires of individuals from sexual minority populations and what care differences there are when the family membership is non-traditional. Thus, immediate learning will improve the care of the patient, yet the content provided may be applicable in other scenarios. Ineffective or miscommunication at this point has a negative impact on the impending patient outcome and long-term consequences for the health care professional.

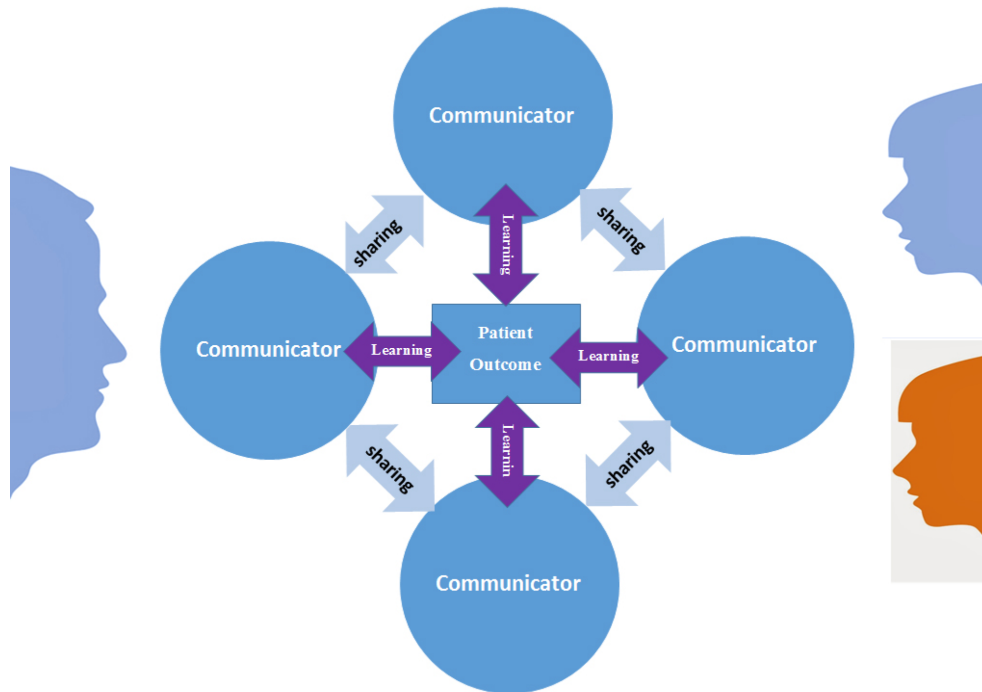

Figure 1.
Communication model

2.5 Cases

Walker and Avant[20] defined a model case as one that has all the defining attributes, and exemplifies the ideal for the concept under investigation. The authors have developed a model case to demonstrate the ideal scenario. From this, borderline, close, and contrary cases may be developed by the absence of a critical variable, such as pain control, or the addition of a compromising variable, such as relationship strife, to demonstrate the effect of incomplete application of the attributes.

Mr. Taylor is a 56 year-old male, admitted to the acute care facility three days ago for intractable pain treatment related to metastatic lung cancer. A retired veteran, Mr. Taylor resides with an Army buddy (Bob) in a subsidized apartment located in the center of the city. Estranged from his family, Mr. Taylor's self-identified family consists of Jerry, a friend from church, Margaret, Mr. Taylor's ex-sister in law and Bob. Mr. Taylor is presently disabled, although he will state that his employment has been "spotty" over the years. Mr. Taylor is not service-connected for any health care benefits. An initial team meeting was held to discuss further treatment decisions, pain control options, and discharge plans. Present at this meeting were Dr. Johnson, a hospitalist, Ms. Peters, the social worker assigned to Mr. Taylor, Ms. Ellie, RN, Margaret, and Bob.

Mr. Taylor expressed the desire to undergo no further treatment. He would like Bob to assume his health care decision-making process should he become unable to do so. He would like to die at home, although he recognizes that this may be problematic, a result of finances and lack of a support system. Pain control is Mr. Taylor's goal. Reviewing this scenario, Mr. Taylor has described his wishes and desires; these were heard by each communicator. His non-verbal communication supported pain being a concern, and his understanding that his health situation is not curable. Dr. Johnson explained various procedures that were options, yet clarified that these were palliative in nature when queried by Mr. Taylor. Interventions aimed at pain control were presented, and the benefits and barriers to these interventions were discussed.

Ms. Peters inquired about the safety of the home setting, the risks associated with having narcotics in the home, and if alcohol or other drugs were used. Margaret stated that she could be available to run errands and transport to medical appointments, but she could not do housekeeping or personal care. As the conversation began to include placement in an extended care facility, Bob became physically upset. Ms. Ellie probed the nature of this behavior. After much silence, it became apparent to Ms. Ellie that the relationship between Mr. Taylor and Bob went beyond friendship. Using a non-judgmental tone, and neutral words, Ms. Ellie allowed Mr. Taylor and Bob to describe their concerns. Uncertainty surrounded any alternate living situation. The ability for Bob to be present at any time and be included in all decisions for Mr. Taylor, if he resided in an institutional setting, was disconcerting. Ms. Peters was able to validate that the identified durable power of attorney for health care decisions would be honored in any setting, and that residents are able to identify individuals that may, or may not, visit. In reviewing this

scenario, learning was provided to Mr. Taylor and Bob.

In situations where the family unit is non-traditional, unique barriers exist.[34] In this circumstance, the ability for Bob to be present, and a contributing member of Mr. Taylor's health care decision process, was paramount to any treatment decision. Sharing of this information allowed learning to occur. Mr. Taylor and his family learned that the identified durable power of attorney could be any identified person, and that visitation policies in institutional settings do not bar non-traditional family members from any activity. The learning that occurred as a result of this sharing will allow the health care professionals to provide care to Mr. Taylor that is respectful and valued. These individuals also learned that when non-traditional family situations are present, any assessment needs to include probing questions to clarify wishes and desires. These queries need to be non-judgmental and the content needs to be included in care decisions. If learning did not occur, this scenario will repeat itself. If a communicator is not astute to non-verbal behavior, or if a communicator does not exhibit non-verbal behavior, the treatment plan will not reflect the wishes and desires of the patient. Thus, not only is the present scenario affected, future situations will also be unsatisfactorily resolved. In either case, the patient outcome is less than desired.

According to Walker and Avant,[20] a close case may be described as one in which the communication is not clear, yet the family members are capable of providing the care required. In this instance, remaining home may be an option, perhaps if Margaret was able to provide physical care. A borderline case may exist when a critical member of the patient's family is not included in the conversation. A contrary case may be best described as an assessment that assumes the family structure is traditional, or no accommodations are made for alternate life styles.

The development of cases exemplar, close, and contrary cases provide clinical examples for the concept under investigation. This bridges the research – practice gap which often hampers the use of theory to frame clinical practice and provides a model to display the relationship between theory and practice. The development of cases to articulate the concept prevents confusion, or misapplication of the concept where inappropriate as well as format research testing the relationships between the attributes.

3. Implications for nursing practice

According to Hughes and Cartwright,[18] EOL care for LGBT individuals has been viewed using HIV/AIDS research data. This may be explain why healthcare provider stigma and bias is a persistent challenge.[35] Research has identified personal support networks, including traditional and non-traditional members, as a key concern.[3,36] Rawlings[11] described incidences of delays in seeking treatment because of fear of discrimination or the necessity of hiding one's identity to avoid judgmental or biased treatment plans. As a profession, nursing has supported, served as a voice, and advocated for vulnerable individuals and populations, as required by the ANA Code of Ethics.[12] Legal rights and privileges are undergoing revision to include life-style options for LGBT individuals. Healthcare treatment discussions and decision-making needed to reflect these changes. That includes being respectful, inclusion, appropriate, and clear to all patients, and all family members, who seek care. Understanding and clarifying the concept of communication in EOL care, specifically for individuals who are LGBT, is the initial step in changing their healthcare experience.

Conflicts of Interest Disclosure

The authors declare they have no conflicts of interest.

References

[1] Wanzer MB, Booth-Butterfield M, Gruber K. Perceptions of health care providers' communication: relationships between patient-centered communication and satisfaction. Health Commun. 2004; 16: 363-383. PMid: 15265756. http://dx.doi.org/10.1207/S15327027HC1603_6

[2] Conversations at the End of Life | Institute for Healthcare Communication [Internet]. [cited 2015 Apr 17]. Available from: http://healthcarecomm.org/training/continuing-education-workshops/conversations-at-the-end-of-life/

[3] Cartwright C, Hughes M, Lienert T. End-of-life care for gay, lesbian, bisexual and transgender people. Cult. Health Sex. Int. J. Res. Interv. Care. 2012; 537-548.

[4] Rosenstein AH, O'Daniel M. Disruptive behavior and clinical outcomes: perceptions of nurses and physicians. Am. J. Nurs. 2005; 105: 54. PMid: 15659998. http://dx.doi.org/10.1097/00000446-200501000-00025

[5] O'Daniel M, Rosenstein AH. Professional communication and team collaboration. 2008 [cited 2015 Mar 13]. Available from: http://www.ncbi.nlm.nih.gov/books/NBK2637/

[6] Reeves S, Lewin S. Interprofessional collaboration in the hospital: strategies and meanings. J. Health Serv. Res. Policy. 2004; 9: 218-225. PMid: 15509407. http://dx.doi.org/10.1258/1355819042250140

[7] Rosenstein AH. Original Research: Nurse-physician relationships: impact on nurse satisfaction and retention. Am. J. Nurs. 2002; 102: 26-34. PMid: 12394075. http://dx.doi.org/10.1097/00000446-200206000-00040

[8] Institute of Medicine. Crossing the quality chasm: a new health system for the 21st century: 1st (first) Edition. National Academies Press; 2002.

[9] Granek L, Krzyzanowska MK, Tozer R, et al. Oncologists' strategies and barriers to effective communication about the end of life. J. Oncol. Pract. 2013; 9: e129-e135. PMid: 23942929. http://dx.doi.org/10.1200/JOP.2012.000800

[10] Clayton JM, Adler JL, O'Callaghan A, et al. Intensive communication skills teaching for specialist training in palliative medicine: development and evaluation of an experiential workshop. J. Palliat. Med. 2012; 15: 585-591. PMid: 22433021. http://dx.doi.org/10.1089/jpm.2011.0292

[11] Rawlings D. End-of-life care considerations for gay, lesbian, bisexual, and transgender individuals. Int. J. Palliat. Nurs. 2012; 18: 29-34. PMid: 22306717. http://dx.doi.org/10.12968/ijpn.2012.18.1.29

[12] Code of Ethics for Nurses [Internet]. [cited 2016 Aug 30]. Available from: http://www.nursingworld.org/MainMenuCategories/EthicsStandards/CodeofEthicsforNurses.aspx

[13] MacMillian. The route to success in end-of-life care: achieving quality for lesbian, gay, bisexual, and transgender people. [Internet]. 2009 [cited 2016 Aug 29]. Available from: http://www.macmillan.org.uk/documents/aboutus/health_professionals/endoflifecare-lgbtroutetosuccess.pdf

[14] Hartrick Doane G, Stajduhar K, Causton E, et al. End-of-life care and interprofessional communication: not simply a matter of "More". Health Interprofessional Pract. [Internet]. 2012 [cited 2015 Mar 12]. Available from: http://commons.pacificu.edu/hip/vol1/iss3/5

[15] Matzo ML, Sherman DW, Sheehan DC, et al. Communication skills for end-of-life nursing care: teaching strategies fromt eh ELNEC curriculum. (Cover story). Nurs. Educ. Perspect. 2003; 24: 176. PMid: 14528862.

[16] Firth-Cozens J. Multidisciplinary teamwork: the good,bad, and everything in between. Qual. Health Care QHC. 2001; 10: 65-66. PMid: 11389310. http://dx.doi.org/10.1136/qhc.10.2.65

[17] Harding R, Epiphaniou E, Chidgey-Clark J. Needs, experiences, and preferences of sexual minorities for end-of-life care and palliative care: a systematic review. J. Palliat. Med. 2012; 15: 602-611. PMid: 22401314. http://dx.doi.org/10.1089/jpm.2011.0279

[18] Hughes M, Cartwright C. LGBT people's knowledge of and preparedness to discuss end-of-life care planning options. Health Soc. Care Community. 2014; 22: 545-552. PMid: 24935483. http://dx.doi.org/10.1111/hsc.12113

[19] Poindexter CC, Valentine DP. An introduction to human services: values, methods, and populations served. 2nd edition. Belmont, CA: Cengage Learning; 2006.

[20] Walker LO, Avant KC. Strategies for theory construction in nursing. 5th edition. Boston: Prentice Hall; 2010.

[21] McEwen M, Wills EM. Theoretical basis for nursing. Philadelphia: Wolters Kluwer/Lippincott Williams & Wilkins; 2011.

[22] What is Communication? [Internet]. [cited 2015 Mar 14]. Available from: http://www.natcom.org/discipline/

[23] Hixson R. Communication. Ann. Psychother. Integr. Health. 2012; 15: 56-58.

[24] WHO | International Classification of Functioning, Disability and Health (ICF) Framework to facilitate interprofessional education and collaborative practice [Internet]. [cited 2015 Mar 14]. Available from: http://www.who.int/hrh/news/2014/hrh_icf_framework/en/

[25] Principles for Care of Patients at the End of Life [Internet]. [cited 2015 Dec 9]. Available from: http://www.milbank.org/uploads/documents/endoflife/#core

[26] Kourkouta L, Papathanasiou IV. Communication in nursing practice. Mater. Socio-Medica. 2014; 26: 65-67. PMid: 24757408. http://dx.doi.org/10.5455/msm.2014.26.65-67

[27] Brown KW, Ryan RM. The benefits of being present: mindfulness and its role in psychological well-being. J. Pers. Soc. Psychol. 2003; 84: 822-848. PMid: 12703651. http://dx.doi.org/10.1037/0022-3514.84.4.822

[28] Hays JS, Larson KH. Interacting with patients. Macmillan; 1963.

[29] Morse JM, Solberg SM, Neander WL, et al. Concepts of caring and caring as a concept. ANS Adv. Nurs. Sci. 1990; 13: 1. PMid: 2122796. http://dx.doi.org/10.1097/00012272-199009000-00002

[30] Olenick M, Allen LR, Smego RA. Interprofessional education: A concept analysis. Adv. Med. Educ. Pract. 2010; 1: 75-84. PMid: 23745066.

[31] Raphael-Grimm T. The art of communication in nursing and health care: an interdisciplinary approach. New York: Springer Publishing Company; 2014.

[32] Broers T, Teresa B, Cheryl P, et al. What's in a word? understanding "Interprofessional Collaboration" from the students' perspective. J. Res. Interprofessional Pract. Educ. 2009; 1: 3-7.

[33] Xyrichis A, Ream E. Teamwork: a concept analysis. J. Adv. Nurs. 2008; 61: 232-241. PMid: 18186914. http://dx.doi.org/10.1111/j.1365-2648.2007.04496.x

[34] Almack K, Seymour J, Bellamy G. Exploring the impact of sexual orientation on experiences and concerns about end of life care and on bereavement for lesbian, gay and bisexual older people. Sociology. 2010; 44: 908-924. http://dx.doi.org/10.1177/0038038510375739

[35] Kimmel DC, Rose T, David S. Lesbian, gay, bisexual, and transgender aging: research and clinical perspectives [Internet]. Columbia University Press; 2006 [cited 2015 Feb 26]. Available from: http://books.google.com.proxy.library.umkc.edu/books?hl=en&lr=&id=Ae39o9m66hIC&oi=fnd&pg=PR7&dq=end+of+life+lgbt&ots=bx3M6cKIM9&sig=6UKvBiXO-AZwhjo-FUIJRPDl3bA

[36] Hughes M, Cartwright C. Lesbian, gay, bisexual and transgender people's attitudes to end-of-life decision-making and advance care planning: LGBT people and advance care planning. Australas. J. Ageing. 2015; 34: 39-43. PMid: 26525446. http://dx.doi.org/10.1111/ajag.12268