A Partner Relationship in Meeting the Needs of Patients and Their Families

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Abstract

A nurse is the first person who comes in contact with patients and their family members. She shares information with them by verbal and non-verbal communication, with the goal of establishing a good relationship and focusing her attention on the patient as a whole person. Nurse's sincere thoughts and feelings create a sense of security and open communication, which are key elements for providing healthcare and inclusion of the family in the decision-making process. A nurse who spends her time by the patient's side plans, implements, evaluates and documents the changes in the patient's condition. That way the healthcare is focused on meeting the physiological needs and maintaining stable condition of the patient. Struggle for life doesn't leave any time for the family to adjust to the new situation. Establishing the patient – family – nurse relationship is important not only in the beginning, but also during the whole treatment and decision-making process. When relationships within the family are stable, the family has an irreplaceable role in developing a sense of security and belonging for the patient.

Providing care for the patient is a priority for the healthcare team, whereas the most significant thing for the family are sincere and correct information about the patient's current condition, the effect of the applied therapy and the possible outcome of the treatment. Developing care philosophy focused on the family and the holistic approach includes assessment of the family's needs and the impact of the disease on its overall functioning. Cultural factors play a significant role in the ability to understand not only the patient's but also the family's point of view. Medical, ethical, legal and a whole range of other problems connected to the receiver and provider of services can be avoided by effective communication.

The purpose of this paper is to highlight the importance of a partner relationship, focusing on the family and the essential role of the nurse in decision-making.

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Introduction

Providing quality healthcare to the patient, cooperating with the family and establishing a good relationship in a multidisciplinary team are requirements nurses face in a holistic approach to the patient. Frequency and availability of information and discussion about the uncertainty of the prognosis help in creating a good working environment among healthcare team members and successful cooperation with the family. An illness is not stressful only for the suffering patient but also for family members and other persons from the patient's environment with whom he/she is in contact. The family's primary role is to support and protect its member throughout the course of the illness and the related decision-making process. This process is complex, the family considers it to be the most important one, but more importantly, the quality of service provision and the patient's quality of life depend on it. In deciding about procedures and interventions for the patient whose life is threatened, the recommended model is the joint decision-making, which includes clinicians, family members, relatives or a guardian, and it is important that all of them receive correct, valid and necessary information at the same time. Responsibility and decision-making are ethical issues. The family wants to actively participate in order to fulfil the wishes of the patient and expects open and sincere communication. In practice, a positive effect of family support on the outcome of a serious illness requiring intensive care has been recognised for decades. The role and participation of the nurse in decision-making is connected to the quality of health services, and the nurse's thoughtfulness and kindness towards the patient and the family contribute to the development of feelings of security and trust. Through her work by the patient's side and by providing comfortableness, gentle touch and information about any changes in the patient's condition, the nurse helps the family members develop an understanding of the patient's condition, as well as a perception of future development of the situation. By frequently following-up on the patient, the nurse becomes very well acquainted with the patient's personality.

Partnership Approach and Team Members

For the sake of cooperation within the team and a greater satisfaction of the patient and family members, members of a multidisciplinary team have to be responsible, properly trained, possess good communicational skills and be ready to hear other people and acknowledge their opinion. Nurses' skills imply more than just instrumental and technical skills and providing information to the patient - they also pertain to integration of affective and relational aspects of communication. Communication is the basis for ensuring satisfaction and understanding of expectations, it is to be conducted in detail, and often. Family members need to be given an opportunity to express their concern and seek clarification for anything that they do not understand during the discussion, in order to be able to make right decisions (1). Their needs and satisfaction depend on many factors, such as their social and economic situation, availability of health care or literacy. Anxiety that appears when someone is facing death can be alleviated through existential care, during which healthcare workers explore their own sense and values after witnessing the suffering of a patient whose life is threatened by an illness (2). In terminal patients, the comfort is made by sharing fears with the patient and the family (2), who have many unanswered questions, depending on their unique cultural, economic and religious background. Adequate and efficient communication among family members in the decision-making process protects the autonomy of the patient (3,4). In order for the nurses to be able to meet all the requirements in providing holistic care, they need to become actively involved in the discussion about the patient and in the actual decision-making process, which would result in greater satisfaction regarding communication with the family. It would also help alleviate

patients' fear, and prevent burnout in nurses. It is necessary to implement continuous training in communicational skills and the Nursing Act needs to be amended to include duties and competences, counselling and support for the patients' families and the development of a family-oriented concept (5,6). Without all-encompassing organizational dedication to the patient and the family, these challenges represent a barrier that prevents change of healthcare system culture. Care for the patient and the family is focused solely on the service provided to the users (7). Partnership approach acknowledges and attempts to use the knowledge and skills of both participants, and each brings a different, but potentially valuable and complementary relationship (8), which includes sharing ideas and mutual teaching (9).

Nurses and decision-making

Professionalism in nursing needs to reflect one's enjoyment in work. Nurses have to provide care by seeing the world through patients' eyes and meet their needs while sharing the experience of being hospitalised, developing a mutual partner relationship. Nurses have to be capable and willing to spend time with the patient and to be available to both the patient and their family. They should thoughtfully consider a person as an individual, not merely acquired compassion with the transfer of information in a non-verbal way, but also reacting to signs and expressing feelings of empathy. Nurses share their concerns and develop a feeling that each patient is an individual by actively listening to the patients and not by treating them as a number. They encourage inner strength and hope for accepting and implementing the therapy, increase motivation and raise the quality of their relationships.

Nurses are not always able to correctly asses and meet patient's needs (10), and they are often not included in the decision-making process (11,12). In their work, nurses encounter unsatisfactory communication and cooperation with doctors, which is a consequence of insufficient participation in the decision-making process and receiving information about the patient.

Nonparticipation in the decision-making and the lack of openness and dialogue arouses suspicion and distrust in the course and outcomes of the treatment, and deepens the feeling of anxiety and loneliness in family members in a time of a difficult existential situation. Nurses who devote more time to patients and members of their families have valuable information about the patient and the situation within the family. The family can share their concerns regarding the patient with them, and the outcomes of good communication are associated with stress reduction. Consequences of a lack of information are increased loneliness, insecurity and lack of understanding in the decision-making process. Nurses need more education in developing communication skills required for their work with a dying patient and his/her family (13). In those circumstances, a lack of trust and communication stimulate fear and patients become overwhelmed with anxiety and anger (2). Some nurses give patients and their families an opportunity to ask questions about issues that cause anxiety and hopelessness, or to talk about their feelings and desires for the future (2). When there is an increased likelihood that a patient will die, healthcare team members have to be ready to talk about it, because that is expected by the patient and his/her family.

Family and decision-making

A research conducted by Reesal Bath (2000) came to a conclusion that relatives need information but cannot always receive it from health professionals. Considering that they are in a state of physical and emotional exhaustion, it is unknown to what extent the patients are capable and competent to participate in the decision-making process, hence the responsibility is perceived as divided among those who are included in such process (14).

The lack of involvement of the family and lack of information, openness and reciprocity in decision-making leads to feelings of abandonment, inability to protect or support. A passive attitude in the process of decision-making can lead to anxiety and depression (15), whereas active involvement result in traumatic

stress symptoms (16). Interaction between the family, nurses and doctors is of vital importance, where mutual trust is crucial (17,18). A systematic approach enables expertise, communication skills, awareness, empathy and ability to adjust the plan to the relevant situation (19), which enables good cooperation with the family. The family needs to actively participate, plan and jointly make decisions regarding care provision to their loved-ones. Caregivers are faced with challenges regarding communication with the patients and providing information on their condition. The patient needs to choose to whom the information relating to his/her health can be provided. Providing information is a matter of privacy and wish which should be of utmost importance (20). Access to information about the patient's health condition, requirements and quality of relationship with the staff are the primary needs of the family, and meeting those needs is a primary responsibility of doctors and nurses in intensive care units, which is important for assessment of care quality (21). The family finds itself in a whirlpool of insecurity, shock, helplessness and confusion. The support is priceless (21). Little research has been conducted on interventions with families of critically ill patients, and almost no one has done anything to improve communication between the healthcare team and the patient's family (9). Nurses have a leading role in facilitating cooperation between the family physician, nurses, family members, applying a collaborative approach to the problem through planning and providing holistic care and integrating palliative care. Communication needs to be adjusted to suit each family individually. Monitoring of the protocol and application of standardized procedures in practice would help with the assessment for solving the patient's and the family's problems. Relatives of patients with carcinoma have different needs; however, their priority is quality care, in which they include their own perception and seek nurses' support. Relatives, in turn, provide immense support in reduction of stress and anxiety, and it is therefore important that the patient, while still able to do so, nominate a person who is to be informed about his/her condition. The family and the patient need time to realise that futile life-sustaining procedures are conduct to give time to the family to prepare itself for the final decision step by step (22-26). In such a way, providing care to the patient and caring for the family make up a unit in the process of joint decision-making (24).

Communication in the ER

Unexpected admission of a patient in the ER for the purposes of reanimation is a traumatic experience for the patient and his family, and it requires great support from the medical staff during and after the resuscitation. Important features of care for the family are presence and proximity of loved-one, meaningful information, support provided by the staff and comfort. After repeated but unsuccesful resuscitation, those who suddenly find themselves in mourning feel the need to see the body of their loved-ones and touch them, which enables them to better come to terms with their loss and ultimately helps them in the mourning process.. In such situations they want to hear (and ask for) an explanation regarding the circumstances of their loved-one's death but while they are in the state of shock, they cannot take in verbal information. Many authors also describe a psychological trauma experienced by the family members who were there when the resuscitation took place. In the aspect of healthcare providing, nurses meet basic human needs and consider that it is not possible to provide genuine holistic care in these situations. They often exhibit their inability to do so through insensitivity, disinterest, inhumanity and coldness (27). Determining the ability to make decisions on behalf of the weakened and exhausted patients depends on the assessment of the kind of help that caregivers can provide. The family is uncertain, they do not know what the patient knows or does not know, or what the patient him/herself would give their consent to or what they would be able to give their consent to. They often experience moments of hope related to improvement, but they also experience constant fear of deterioration or possible loss of loved-one, and confrontation with termination of treatment and acceptance of reality. Relatives suffer from mental disorders such as fear, depression, uncertainty,

helplessness and hopelessness, but they also struggle with financial difficulties, problems with their work or education, problems with the changing of roles in the family and social isolation. They often suffer from headache, back pain, sleeping disorders, fatigue, loss of appetite and reduction in physical strength (28) and they experience a high level of emotional stress (29,30).

Role of the Partner in Providing Support

Partners, relatives and close friends are not just advisors, but also a main source of support for patients with carcinoma (31) through provision of emotional stability and help during the treatment and in the patients' everyday functioning. For women suffering from breast cancer, partner's emotional support is of great significance and it alleviates their suffering. Not only does this feeling reduce stress, it also enhances the quality of life, boosts the self-esteem of these women and strengthens their trust in partner (32). Research has shown that in a situation in which one of the partners gets sick, it is the patient's partner who carries greater mental load than the patient him/her self (31), and their involvement in the decision-making process is the best way of providing support. Illness of a family member influences the balance in such a way that it comes to destabilisation and loss of security for all family members. They are faced with requirements caused by the disease, such as providing increased emotional support for the sick partner, redistributing life plans and taking on new tasks or roles within the family (33). Patients' partners seek and must receive emotional support in order to be able to carry their own burden and return to normal function.

Specificity of Communication with Elderly Patients

In an individual approach and contact with an elderly patient, a nurse needs to be familiar with what the patient believes, wants and whether he/she has any specific needs (34). The nurse encourages the patient not to lose hope, to accept the changes and to be persistent in order to achieve greater independence, (35) and also helps the patient in achieving his/her goals. Needs are changeable and dynamic, and in order to meet them, the nurse is expected to provide support as care coordinator (36). Life expectations of elderly patients are ever-growing, and conducting rehabilitation is a key factor in ensuring their independence and improvement of life quality after a traumatic event, in facing deterioration caused by a chronic health condition or in their preoccupation with the feeling of losing themselves (37). Developing a relationship of trust helps the patient in carrying out activities which he/she is capable of performing, in a right manner and in an environment in which he/she feels safe and has a sense of existence. A nurse recognises that through his/her knowledge and intuition, he/she has an irreplaceable role in assessing and providing motivation and support, encouraging and boosting of self-esteem, educating on self-care and helping in everyday activities, using different aids or demonstrating to the patients how to do a certain activity in a simpler way. Intuitive understanding of patients and their family members is a concept that nurses have recognized as a road towards better outcomes (38). Family members feel fulfilled and invest great effort in order for their loved-one to get the best possible care. Patients sometimes start feeling as if they are dependent on nurses, whose role is not sufficiently recognized. In order to achieve greater independence and progress, the method of providing rehabilitation is equally important as all the other interventions and procedures. Research has shown that some family members perceive a nurse based on their own experiences and stereotypes, and not based on the current situation, which does not contribute to the welfare of the patient and his/her motivation.

Conclusion

Nurses should invest more effort in order for the partner relationship to become better integrated in the standards of healthcare provision. The

prospect of family participation in the decision-making process depends on the organizational politics in the healthcare system. Genuine cooperation with patients and their families should be integrated in the organizational culture and more effort should be invested in cooperation with the family in order to further develop and change the rules of practice and encourage the initiative of the patient and family members to become included in the decision-making process. Nurses' dedication and their encouragement for a change to happen within their organizational units can result in change of the entire healthcare system

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References

1. Krimshtein NS, Carol A. Luhrs CA, Kathleen A, Puntillo KA, Cortez TB, Livote EE, Joan D, Penrod JD, Judith E, Nelson JE. Training Nurses for Interdisciplinary Communication with Families in the Intensive Care Unit: An Intervention. J Palliative Med 2011;14:1325-333.
2. Leung D, Esplen MJ, Peter E, Howell D, Rodin G, Fitch M. How haematological cancer nurses experience the threat of patients' Mortality. J Adv Nurs 2012; 68:2175–2184.
3. Foucault M. Afterword: the subject and power. In Michel Foucault: Beyond Structuralism and Hermeneutics (Dreyfus H & Rabinow P eds). University of Chicago Press, Chicago, IL, 1983. pp. 208–26.
4. Fowler C, Lee A. Re-writing motherhood: researching women's experiences of learning to mother for the first time. Aust J Adv Nurs 2004;22:39–44.
5. Zakon o sestrinstvu NN 121/03, 117/08, 57/11).
6. Pinkert C., Holtgräwe M., Remmers H. Needs of relatives of breast cancer patients: After repeated but unsuccesful resuscitation, those who suddenly find themselves in mourning feel the need to see the body of their loved-ones and touch them, which enables them to better come to terms with their loss and ultimately helps them in the mourning process. The perspectives of families and nurses. Eu J Oncology Nursing 2013;17:81e-87.
7. Abraham M., Moretz J.G. Implementing Patient- and Family-Centered Care: Part I – Understanding the Challenges. Pediatric Nursing 2012;38(1):44-7.
8. Davis H, Day C, Bidmead C. Working in Partnership with Parents: The Parent Adviser Model. The Psychological Corporation, London 2002.
9. Fowler C, Dunston R, Lee A, Rossiter C, McKenzie J. Reciprocal learning in partnership practice: an exploratory study of a home visiting. Studies in Continuing Education 2011;34: 99–112.
10. Ngo-Metzger Q, August KJ, Srinivasan M, Liao S, Meyskens FL. End-of-life care: guidelines for patient-centered communication. Am Fam Phys 2008;77:167-74.
11. Benbenishty J, Ganz FD, Lippert A, Bulow HH, Wennberg E, Henderson B, Svantesson M, Baras M, Phelan D, Maia P, Sprung CL. Nurse involvement in end-of-life decision making: the ETHICUS Study. Intensive Care Med. 2006;32(1):129–32.
12. Ferrand E, Lemaire F, Regnier B, Kuteifan K, Badet M, Asfar P, Jaber S, Chagnon JL, Renault A, Robert R, Pochard F, Herve C, Brun-Buisson C, Duvaldestin P; French RESSENTI Group. Discrepancies between perceptions by physicians and nursing staff of intensive care unit end-of-life decisions. Am J Respir Crit Care Med 2003; 167(10): 1310–315.

13. Ferrell BR, Dahlin C, Campbell ML, Paice JA, Malloy P, Virani R. End-of-life Nursing Education Consortium (ELNEC) training program: improving palliative care in critical care. Crit Care Nurs Q 2007; 30(3): 206–12.

14. Heyland DK, Frank C, Groll D, Pichora D, Dodek P, Rocker G, Gafni A. Understanding cardiopulmonary resuscitation decision making: perspectives of seriously ill hospitalized patients and family members. Chest 2006; 130: 419–28.

15. Anderson WG, Arnold RM, Angus DC, Bryce CL. Passive decision-making preference is associated with anxiety and depression in relatives of patients in the intensive care unit. J Crit Care 2009; 24:249–54.

16. Azoulay E, Pochard F, Kentish-Barnes N, Chevret S, Aboab J, Adrie C, Annane D, Bleichner G, Bollaert PE, Darmon M, Fassier T, Galliot R, Garrouste-Orgeas M, Goulenok C, Goldgran-Toledano D, Hayon J, Jourdain M, Kaidomar M, Laplace C, Larché J, Liotier J, Papazian L, Poisson C, Reignier J, Saidi F, Schlemmer B; FAMIREA Study Group. Risk of post-traumatic stress symptoms in family members of intensive care unit patients. Am J Respir Crit Care Med 2005; 171: 987–94.

17. Swigart V, Lidz C, Butteworth V, Arnold R. Letting go: family willingness to forgo life support. Heart Lung 1996;25:483–4.

18. Nelson JE, Cortez TB, Curtis JR, Lustbader DR, Mosenthal AC, Mulkerin C, Ray DE, Bassett R, Boss RD, Brasel KJ, Campbell ML, Weissman DE, Puntillo KA. Integrating palliative care in the ICU: the nurse in a leading role. J Hosp Palliat Nurs 2011;13(2):89–94.

19. Martinsen K. Care and vulnerability. Oslo: Akribe, 2006.

20. McCullough J, Schell-Chaple H. Maintaining Patients' Privacy and Confidentiality With Family Communications in the Intensive Care Unit. American Association of Critical-Care Nurses 2013;33(5):77-79.

21. Siddiqui S., Sheikh F., Kamal R. "What families want - an assessment of family expectations in the ICU". International Archives of Medicine 2011;4(21):2-5.

22. Norton SA, Tilden VP,T olle SW, Nelson CA, Eggman ST. Life support withdrawal: communication and conflict. Am J Crit Care 2003;12:548–5.

23. Wiegand D. In their own time: the family experience during the process of withdrawal of life-sustaining therapy. J Palliat Med 2008; 11:1115–121.

24. Lind R, Lorem G, Nortvedt P, Hevrøy O. Family members' experiences of 'wait and see' as a communication strategy in end-of-life decisions. Intensive Care Med 2011; 37:1143–1150.

25. Abbott KH, Sago JG, Breen CM, Abernethy AP, Tulsky JA. Families looking back: one year after discussion of withdrawal or withholding of life-sustaining support. Crit Care Med 2001; 29:197–201.

26. Schaefer KG., Block SD. Physician communication with families in the ICU: evidence-based strategies for improvement. Curr Opin Crit Care 2009;15:569–77.

27. Beckstrand RL, Lamoreaux N, Luthy KE, Macintosh JLB. Critical Care Nurses' Perceptions of End-of-Life Care Obstacles: Comparative 17-Year Data, Dimensions of Critical Care Nursing, 2017;36(2):94-105.

28. Stenberg U, Ruland CM, Miaskowski C. Review of the literature on the effects of caring for a patient with cancer. Psychooncology 2010;19(10):1013-25.

29. Foss KR, Tenholder MF. Expectations and needs of persons with family members in an intensive care unit as opposed to a general ward. South Med J 1993; 86(4):380-4.

30. LeClaire MM, Oakes JM, Weinert CR. Communication of prognostic information for critically ill patients. Chest 2005;128(3):1728-35.

31. Hasson-Ohayo I, Golldzweig G, Braun M, Galinsky D. Women with advanced breast cancer and their spouses: diversity of support and psychological distress. Psyhooncology.2010;19(11):1195-204.

32. Arora NK, Finney Rutten LJ, Gustafson DH, Moser R, Hawkins RP. Perceived helpfulness and impact of social support provided by family, friends, and health care providers to women newly diagnosed with breast cancer. Psychooncology 2007;16:474-86.

33. Fletcher KA, Lewis FM, Haberman MR. Cancer-related Concerns of Spouses of Women with Breast Cancer. Psychooncology. 2010;19(10):1094–1101.

34. Tyrrell EF, Levack WM, Ritchie LH, Keeling SM. Nursing contribution to the rehabilitation of older patients: patient and family perspectives. Journal of Advanced Nursing 2012;68(11):2466–476.

35. Sahlsten MJM, Larsson IE, Sjostrom B, Plos KA. Nurse strategies for optimising patient participation in nursing care. Scand J Caring Sci 2009;23(3):490–7.

36. Association of Rehabilitation Nurses (2010) About ARN. A Definition and Brief History of Rehabilitation Nursing. Retrieved from http://www.rehabnurse.org on 28 October 2010.

37. Long AF, Kneafsey R, Ryan J, Berry J, Howard R. Teamworking in Rehabilitation: Exploring the Role of the Nurse. English National Board for Nursing, Health Visiting and Midwifery, London, 2001.

38. Moretz JG, Abraham M. Implementing Patient- and Family-Centered Care: Part II - Strategies and Resources for Success. Pediatric Nursing, 2012; 38(2):106-110.