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Ethical dilemmas concerning autonomy when persons with dementia wish to live at home: a qualitative, hermeneutic study

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Abstract

Background: Caring for people with dementia living in their own homes is a challenging care issue that raises ethical dilemmas of how to balance autonomy with their safety and well-being. The theoretical framework for this study consisted of the concepts of autonomy, beneficence, non-maleficence, paternalism and from the ethics of care. The aim of this study was to explore ethical dilemmas concerning autonomy that were identified when persons with dementia wished to live at home.

Methods: This Norwegian study had a qualitative, hermeneutic design and was based on nine cases. Each case consisted of of a triad: the person with dementia, the family carer and the professional caregiver. Inclusion criteria for the persons with dementia were: (1) 67 years or older (2) diagnosed with dementia (3) Clinical Dementia Rating score 2 i.e. dementia of moderate degree (4) able to communicate verbally and (5) expressed a wish to live at home. The family carers and professional caregivers registered in the patients' records were included in the study. An interview guide was used in interviews with family carers and professional caregivers. Field notes were written after participant observation of interactions between persons with dementia and professional caregivers during morning care or activities at a day care centre. By means of deductive analysis, autonomy-related ethical dilemmas were identified. The final interpretation was based on perspectives from the theoretical framework.

Results: The analysis revealed three main ethical dilemmas: When the autonomy of the person with dementia conflicted with (1) the family carer's and professional caregiver's need to prevent harm (non-maleficence) (2) the beneficence of family carers and professional caregivers (3) the autonomy of the family carer.

Conclusions: In order to remain living in their own homes, people with dementia accepted their dependence on others in order to uphold their actual autonomy and live in accordance with their identified values. Paternalism could be justified in light of beneficence and non-maleficence and within an ethics of care.

Keywords: Autonomy, Dementia, Ethical dilemmas

Background

In Western culture, autonomy has a range of different meanings such as "... self-rule, self-determination, freedom of will, dignity, integrity, individuality, independence, responsibility and self- knowledge" ([1], p. 6). Autonomy is also identified with the qualities of intentional actions and being free from controlling influences. In medical ethics respect for autonomy is considered a fundamental principle [2]. Autonomy is a challenging issue in dementia care that needs to be understood in the context of caring for dependent persons [1, 3].

For most older people, autonomy is important for good quality of life [4, 5] as well as being able to live independently in their own homes unless limited by very poor health [6–8]. Even when institutionalized, participation in their own care is important [9–11]. Enabling people with dementia to remain involved in decision making is central to their self-determination and feelings of worth [12], in addition to promoting dignity, integrity and personhood [13–15]. Promoting autonomy is therefore considered an

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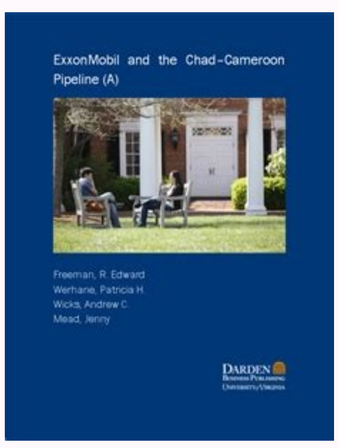

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intervention did not end until Jill left Mary's room, then not giving the call light to the patient was clearly during the intervention session and thus, Jill may not held liable for this incident.

What happens then if there was "negligence" performed by a PT while doing non-PT related tasks in the facility? What if Mary fell while Jill was helping another patient to the bathroom? Would Jill be liable for Mary's fall because she did not give Mary the call light? She may not be liable as a PT because there is NO patient-therapist duty. Would this kind of reasoning "on the spot" be considered negligence? Or would it be considered a reasonable action under the circumstances?

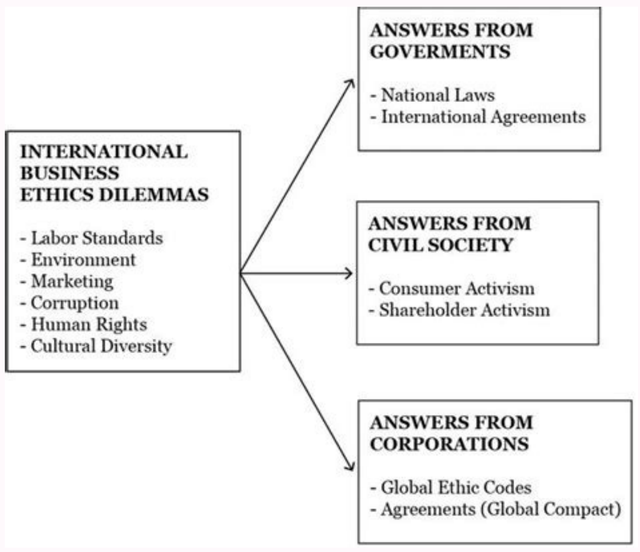
Is the Skilled Nursing Facility institution responsible for this incident? When the facility accepted Mary as a patient, it entered into a contract with her to provide care. The facility had a duty to provide Mary with medical care, while Mary has a duty to pay the establishment for the services rendered. This incident is clearly a breach of that contract, and as such, the facility failed to provide adequate care to Mary. Whether or not the facility may not be liable as a physical therapy professional, but the facility is liable in VR's capacity as an employee of the institution.

Element 2: Breach of Duty Standard of Care. The second element in determining negligence is whether Jill met the standard of care. Did she act in a reasonable manner given the circumstances as compared to what another prudent therapist would do? Jill's actions in this incident were not reasonable. Jill knew that Mary was a fall risk, and Jill knew that Mary was in need of assistance. Jill's intervention given to Mary (Turning the call light to a patient-friendly area) requires the skills and expertise of a physical therapist, and as such, Jill breached the standard of care. Would a PT who is not a nurse be liable for not giving the call light to the patient? Would the call light within Mary's reach, does that act of "negligence" fall within the scope of practice? Does Jill's act of omission violate the acceptable standard of care both of the facility and the APTA code of ethics? APTA Code of Ethics, Principle 3 reads: "PTs shall accept responsibility for the exercise of sound judgment." Not putting the call light close to the patient is obviously NOT sound judgment.

What would another prudent therapist do? Most likely, the therapist would make sure that the patient is safe and precautions have been put in place (i.e. making sure that the call light is within the patient's reach) before leaving the patient. If such is the standard of care, then Jill breached that standard of care. Jill's actions were not reasonable under the circumstances. Jill's actions did not reach a standard of care in skilled nursing facilities. The facility has a policy on call lights, which is clearly outlined in the Policy and Procedures manual. Jill clearly violated the standard of care of her profession and the facility.

Is the facility negligent in providing care within the acceptable standards? Whether the fall happened partially as a result of Jill's negligence, the facility may be liable for the fall as well. The facility may be negligent in providing care within the standards if it failed to provide care within acceptable standards. This argument may be strengthened by documentation which indicated that the facility was short-staffed that day (below the acceptable industry standards), and the evaluation of the patient's mental status was not performed by the nurse as mandated by the facility's policy. This argument may also be strengthened by evidence that the patient is at high fall risk and therefore extra measures should have been enforced to ensure the patient's safety.

Elements 3 and 4: Causation and Harm. The third element of negligence indicates that the action of the therapist caused the harm. The fourth element requires that harm actually occurred. Mary's fall was caused by Jill's failure to provide the call light to Mary. Mary did get up from her wheelchair despite previous instructions not to see that her call light was not placed within her reach and that there was no one around to call. It was reasonable to conclude that she would have not gotten up if the call light was within her reach. Mary's fall was caused by Jill's failure to provide the call light to Mary. Mary did get up from her wheelchair despite Jill's failure to provide the patient with a safe environment. Even if no direct causation cannot be established, the fact that the injury occurred while Jill was in charge of Mary's care is sufficient to establish causation. The doctrine of "res ipsa loquitur" ("the thing speaks for itself", which refers to situations where it is assumed that a person's injury was caused by negligence of another party, and the burden of proof is on the defendant to prove that he was not negligent). The fact that the patient suffered injuries which caused her death includes that the incident caused harm to the patient.



Case study

Case study

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This is the first in a new series whereby the ethical dimensions of a practice situation are discussed by two colleagues working in nursing and health care ethics. The author responds to their comments. This example comes from Japan.

Case history

Emiko Konishi
Saku University, Japan

Mrs A, an 88-year-old Japanese woman, was hospitalized with anemia, lower leg edema and ascites. She was living alone while receiving care in a day-care centre for elder people. Mrs A's only family was her daughter, who lived in the same town, but it was a day-care center worker who brought Mrs A to the hospital. The daughter arrived at the hospital later. The physician said to Mrs A: 'Your hemoglobin level six months ago was 12, but now it is only 4. Your anemia may possibly be caused by stomach bleeding so a thorough examination is absolutely necessary. If not treated, terrible problems might occur, and no treatment means you will likely die.' The patient, however, refused the treatment by saying that she was too old and the gastric camera was terrifying. The daughter also said, 'I want to respect my mother's decision. I know that her legs and her abdomen were swollen but because of her age I did not want her to be brought to hospital. As far as she does not want treatment, I agree with her.'

What should the nurses do and why?

First comment

Steven Edwards
University of Wales Swansea, UK

It seems reasonable to start by considering the patient's choice: should the nurses simply respect this? If patients refuse treatment it is normally difficult to justify compelling them to have it. Is this situation an exception to that general rule? Three things could lead one to say it is:

1) Since Mrs A is anaemic, with a haemoglobin level of only 4 g/dl, is this affecting her competence to make a decision about the situation? The nurse should give Mrs A more time to think about it and try to do something about her anaemia, for example, by offering a blood transfusion or iron by another route. She may well accept this and then be in a better position to make an informed decision about the option proposed by the doctor. She will certainly feel better too.
2) The reasons given by Mrs A for refusing the treatment also need further exploration. Why does she say she is too old? Does she think she simply does not deserve access to further treatment because she is a 'burden' on others? Also, why is she terrified of the gastric camera? Does she understand what this is? Again, these issues need to be explored with Mrs A in as calm a context as possible.
3) Since nurses and doctors are generally caring people who want to do the best for their patients, Mrs A's refusal of the treatment may make them feel as though they have failed in their duty to help her. The nurse's and doctor's caring instincts should lead them to pursue the strategies described in points 1 and

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CONTACT US If you have questions or comments about this Cookie Policy, please contact us at: eeri@eeri.org Find ethics case studies on bribery, sourcing, intellectual property, downsizing, and other topics in business ethics, corporate governance, and ethical leadership. (For permission to reprint articles, submit requests to ethics@scu.edu.) ICAS has published a series of case studies to help bring ethical problems to life:The CCAB has also published a series of ethical dilemmas case studies (2022), updated from previous editions, which illustrate how the Codes of Ethics of the CCAB bodies can be applied by:ICAS is one of the five members of the CCAB along with the ICAEW, ACCA, CIPFA and Chartered Accountants Ireland. The CCAB provides a forum for the five member bodies to work together collectively in the public interest on matters affecting the profession and the wider economy. What follows are three case studies taken from Bernard and Goodyear (1999). Try analyzing the cases from the perspective of a trainee and a supervisor. How does the ethical decision-making model presented in this module apply to the case? You might also want to talk with your supervisor, classmates, professors, or other practitioners about these cases. After the three cases are presented there are some questions that might guide your discussion. Vanessa has been a marriage and family therapist at an agency for six months. Gary, one of the other three therapists in the agency and the only other single therapist, is her clinical supervisor. It will take Vanessa 2 years under supervision to accrue the experience she needs to be eligible to sit for the state licensing examination for her LMFT. One evening Gary calls Vanessa to inquire whether she would like to go to a day-long workshop with him. The speaker for the workshop specializes in a kind of therapy in which Vanessa has expressed interest. Vanessa accepts and the workshop turns out to be an excellent professional experience. On the way home, Vanessa and Gary stop for dinner. Vanessa picks up the tab to thank Gary for including her. The following day Vanessa is sharing some of the experiences of the workshop with Camille, another therapist at the agency. When Camille asks, "Isn't Gary your supervisor?" Vanessa feels defensive and misunderstood. Later that day, Vanessa decides to go to her agency director and ask his opinion of the situation. He tells her not to be concerned about it and that Camille "worries about everything." During her next supervision session, Vanessa chooses not to mention either conversation to Gary (pp. 191-192). Margaret is a school counselor who has been assigned a trainee from the local university for the academic year. As she observes Noah work with elementary school children, she is increasingly impressed with his skills. She asks him to work with Peter, a nine-year-old, who has not adjusted well to his parents' recent divorce. Again, she is impressed with Noah's skill, his warmth and understanding, and ultimately, with the success he has in working with Peter. Margaret is a single parent who is concerned about her nine-year-old son. She decides to ask Noah to see him. Noah is complimented by her confidence in him. Margaret's son attends a different school, but she arranges to have Noah see him after school hours (p. 192). Ruth has been assigned to a local mental health hospital for her internship to work with patients who are preparing to be discharged. It is her first day at the site and she is meeting with her site supervisor. He gives her a form to fill out, which asks for information regarding her student malpractice insurance. When Ruth tells her supervisor that she does not carry such insurance, he advises her that it is their policy not to accept any student who does not have insurance. The supervisor also expresses some surprise because this has always been the hospital's policy and Ruth is not the first student to be assigned to them from her training program (p. 186). What are the main issues in the case?

What ethical issues are of concern in the case? Are there particular breaches of ethical principles? What are they? What can the supervisor do, if anything, to resolve the ethical problem(s) presented in the case? What can the trainee do, if anything, to resolve the ethical problem(s) presented in the case? Is there other information that might have been helpful in the resolution of this case? What could have been done to prevent the ethical problem from occurring in the first place? Test Your Knowledge What follows are 15 multiple choice items designed to test the knowledge that you have gained as a result of completing this module. Answers are provided at the end. Good Luck! The branch of philosophy that seeks to understand and to determine how human actions can be judged as right or wrong: epistemology eschatology pragmatism ethics teleology Which of the following is not a classification of ethical theories? Kantian Deontologism Consequentialism Pragmatism Virtue ethics Natural Law Are all of the following ethical theories and their brief definitions correct? Natural Law: Reflection on nature can lead one to discover principles of good and bad. Kantian Deontologism: An act must be performed because the act is apprpriate for everyone or conforms with moral law. Virtue Ethics: Certain character traits are appropriate and praiseworthy. They can be integrated into “practical wisdom” or “right reason.” Consequentialism: The rightness or wrongness of an action must be judged according to the effects that it produces. What ethical principle assumes the three standards of impartiality, equality, and reciprocity? Respecting autonomy Doing no harm (Nonmaleficience) Benefiting others (Beneficence) Being just (Justice) Being faithful (Fidelity) Your clinical supervisor shares his or her disclosure statement with you, giving you the opportunity to see the types of interventions that will be used in clinical supervision. You are given the opportunity to decide which, if any, of the interventions are uncomfortable to you. This process best complies with which ethical principle? Respecting autonomy Doing no harm (Nonmaleficience) Benefiting others (Beneficence) Being just (Justice) Being faithful (Fidelity) Your clinical supervisor shares information with others about your disclosures during supervision. The information shared was “personal” and had little if any bearing on your work with clients. What is the primary ethical principle violated by your supervisor? Respecting autonomy Doing no harm (Nonmaleficience) Benefiting others (Beneficence) Being just (Justice) Being faithful (Fidelity) Which of the following is not a purpose served by professional codes of ethics? They provide protection to consumers and further the professional stance of organizations. They provide a vehicle for professional identity. They provide a framework to resolve all ethical issues that might face a profession. They provide some means of defence for those who conscientiously practice within the ethical guidelines laid down by a particular profession. They provide evidence that a particular profession has a body of knowledge and skills that it can proclaim. Because ethical code development is a process driven by concensus and the fact that problematic issues developed outside of this process may have to be addressed within a code of ethics, we may view codes of ethics as “reactive” documents. An ethical decision-making model provides you with a set of guidelines for making ethical decisions. If you were facing a difficult ethical dilemma, after identifying the problem and the potential issues involved, what would be, using Corey’s model, one of the first places that you would look for assistance in the resolution of the dilemma Ethical guidelines Ethics scholarship supervisor and respected colleagues practicum class internship class Substantive due process Covers the relationship between supervisor and trainee. Trainees are made aware of their responsibilities and those of the supervisor during the clinical supervision process. The extent to which interactions between supervisor and trainee can be disclosed to others. Your clinical supervisor is also the instructor for one of your classes. Addresses the extent to which fair and consistent application of the criteria that governs your training program has been followed. Addresses the rights that you have as a participant in a training program. Dual relationship Covers the relationship between supervisor and trainee. Trainees are made aware of their responsibilities and those of the supervisor during the clinical supervision process. The extent to which interactions between supervisor and trainee can be disclosed to others. Your clinical supervisor is also the instructor for one of your classes. Addresses the extent to which fair and consistent application of the criteria that governs your training program has been followed. Addresses the rights that you have as a participant in a training program. Informed consent Covers the relationship between supervisor and trainee. Trainees are made aware of their responsibilities and those of the supervisor during the clinical supervision process. The extent to which interactions between supervisor and trainee can be disclosed to others. Your clinical supervisor is also the instructor for one of your classes. Addresses the extent to which fair and consistent application of the criteria that governs your training program has been followed. Addresses the rights that you have as a participant in a training program. Procedural due process Covers the relationship between supervisor and trainee. Trainees are made aware of their responsibilities and those of the supervisor during the clinical supervision process. The extent to which interactions between supervisor and trainee can be disclosed to others. Your clinical supervisor is also the instructor for one of your classes. Addresses the extent to which fair and consistent application of the criteria that governs your training program has been followed. Addresses the rights that you have as a participant in a training program. Confidentiality Covers the relationship between supervisor and trainee. Trainees are made aware of their responsibilities and those of the supervisor during the clinical supervision process. The extent to which interactions between supervisor and trainee can be disclosed to others. Your clinical supervisor is also the instructor for one of your classes. Addresses the extent to which fair and consistent application of the criteria that governs your training program has been followed. Addresses the rights that you have as a participant in a training program. Should a breach of ethics occur during your clinical supervision, one of the first steps that should be taken is to: file police charges. call your professional organization. talk to the appropriate person in either your academic department or in the agency in which you are working to determine the proper procedure for filing a grievance. report your supervisor to the state licensing board. do nothing. It was probably a mistake. 1: d; 2: c; 3: a; 4: d; 5: a; 6: e; 7: c; 8: a; 9: a; 10: d; 11: c; 12: a; 13: e; 14: b; 15: c;

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