

Review

The nature of decision-making for persons with delirium

— A preliminary review on the issue of advance directives and proxy consent —

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Abstract

The purpose of this paper was to explore the nature and process of decision-making for persons with delirium. Decision-making situations for patients with delirium involve persons with delirium, their surrogate decision-makers, their significant others, and health care professionals who are responsible for supporting patients and family to make their right decisions. Brock's (1994) three-principle (the advance directives, the substituted judgment, and the best interest) may facilitate health care professionals to support sound decision making for patients with delirium and family. When invasiveness of procedure or research protocol is considerably higher than usual care, special attention should be sought for such instance—not only a conventional approach of proxy consent, but also an effort to validate authentic assent of patients with delirium, such as modified consent forms and processes. Potential conflicts between advance directives and surrogate decision making needs to be explored in further research. Exploration of the nature of consent and decision-making process for persons with delirium would expand the horizon of the body of knowledge relating to practice, education, and research of health care professionals.

Key words : delirium, decision-making, consent, assent, proxy, advance directives

Introduction

Decision making for the care of persons with delirium, or acute confusion, is one of the most complex issues in health care. Health care professionals are required to be sensitive to those persons' needs, to support and facilitate a sound decision making in accordance with their preferences and best interest. When those persons are hospitalized and acutely confused (delirious) or cognitively impaired, they are incompetent to make a sound choice for themselves. When invasiveness and complexity of procedures are higher than usual care, persons with delirium may not understand such difficult and complex information, or implications and possible consequences following invasive procedures. Special attention should be sought for such instances—not only a traditional method of obtaining consent

from proxy but also an effort to validate authentic assent of persons with delirium. A certain channel to validate delirious persons' preferences or will is generally available and accessible to their significant others or familiar persons if they could use a simple communication.

Delirium is a transient mental syndrome with an abrupt onset and unpredictably fluctuating symptoms that are contrary to the symptoms of dementia that generally develop gradually over months and years. Symptoms of delirium are characterized as global impairment in cognitive functions, a reduced level of consciousness, attentional abnormalities, and increased or decreased psychomotor activities (Foreman, 1993; Lipowski, 1990; Neelon, 1990). Prediction (if at all possible), or early diagnosis and timely interventions are essential to the care of patients with delirium

in general; however, predicting and preparing to its onset is quite difficult for health care professionals (Foreman, 1993; Neelon et al., 1992).

Delirium is often times associated with physiological conditions such as dysfunction of the autonomic nervous system, acute medical, physiological, or toxic conditions, which decreases patients' information processing ability and memory performance. Stressful psychosocial or environmental conditions such as unplanned hospitalization, emergent procedures or critical care often exacerbate nonadaptive, restless, or unsafe behaviors. Unfortunately, patients and their family members, under such conditions, have to make a treatment decisions that may significantly affect their lives. Examples of such decision-making may include a choice of aggressive treatment plans, organ transplantation, institutional placement or relocation, or even end-of-life care decisions.

Despite the significance of such decision making, fewer studies in these decades have focused on ethical issues related to decision making for persons with delirium as compared to those issues related to persons with dementia. Value structures and decision making processes of persons with delirium involved in complex situations remain unexplored in the literature. The purpose of this review paper was to explore the nature and process of decision-making for persons with delirium, where the situations may involve patients' surrogate decision-makers and health care professionals who are responsible and accountable for supporting patients to make their right decisions or their best interest.

Subjective Experience of Delirium

Researchers have identified and reported subjective experience of delirium that helps health care professionals to understand the right approach to the care of patients with delirium. These studies imply that even in the midst of delirium (judged as "incompetent" by health care professionals), persons with delirium seem to have channels to communicate with other persons and remember their surrounding people, environment, and events. For example, in an interview of ten patients who underwent coronary artery bypass surgery, they were asked to reflect upon their experience of confusion in their intensive care

unit stay (Laitinen, 1996). The patients remembered their confusion as a significant and incomprehensible experience. Anxiety was the most prominent emotional response in the experience of being on the threshold between awareness and unawareness. Nurses' closeness and presence to patients was underscored by these patients.

Additionally, recurrent themes of subjective experience of delirium were also extracted (Schofield, 1997; Andersson et al., 2002). For example, they reported they had vivid visual or auditory hallucinations, or unpleasant and fearful memories, being trapped in incomprehensible experiences. Some of their present and past experiences were mixed up. They felt detached or feared the loss of control, but tried to get a grip on their experience of confusion. They tried to seek information about delirium, explanations about what happened and who were surrounding them. Some of them felt loss of memory and were reluctant to discuss about their experience, but the rest of them tried to make sense of having been delirious.

Whether these patients could communicate their preferences depends upon their level of cognitive status as well as health care professionals' sensitivity to their care needs. It is recommended that health care professionals and family members provide them with orienting cues to connect to their real world in a meaningful way while assuring and validating their emotional responses.

Decision-Making Principles for Patients with Delirium

As a theoretical perspective of this paper, the following section explains Brock's (1994) three-principle that guides health care professionals to weigh decision-making alternatives for patients with delirium. Brock's (1994) three-principle is ordered in the following manner: The advance directives principle; the substituted judgment principle; and the best interest principle. These principles state that the decision should follow advance directives when they are available and effective (clearly and directly address the decision in issue). When advance directives are unavailable but surrogate decision-makers are available, the decisions should be made by the surrogates who are knowledgeable about the patients' values and typical preferences in given

circumstances. When the surrogate decision-maker has limited or no knowledge of the patient's values or preferences, or no advance directives are available, an alternative decision should be guided by a principle that best promotes and protects the patient's interests (Brock, 1994).

Brock's (1994) three-principle is presumably helpful for health care professionals to support sound decision making for patients with delirium. Situations related to delirium, however, could be more complex than one can imagine; the three alternatives may not be useful in the situations that involve persons with delirium and family. Complexity of decision making for persons with delirium makes it more challenging for health care professionals to maintain their ethical and moral integrity.

Consent by Patient and Proxy

Health care professionals are required to consider what is morally and ethically right or wrong for a specific person in a specific care-providing setting and circumstance. They are also required to obtain consent from any patients undergoing any hospital care such as traditional as well as innovative treatment and procedures, research protocol, or student practicum. Consent is not only a completion of a document but a process of decision making that includes full disclosure of relevant information, potential benefits and risks, alternatives, and possible consequences. It is also a process of communication among patients, family, and health care professionals to ensure that health care is provided in consistent with patients' preferences (Teno et al., 1994).

The final decision should be made based on the patients' freedom of choice (i.e., voluntary nature of decision). Informed consent ultimately aims at securing and respecting patients' right to self-determination, patients' autonomy, and their authenticity of decision making and preferences to promote their well-being. Cognitively impairment of persons with dementia and delirium poses challenges to health care professionals because the notion of autonomy and authenticity of their decision making becomes blurred and questionable.

Consent for those persons with delirium is much difficult than that of persons with dementia. First, an abrupt onset and fluctuating nature of delirium probably make it difficult to assess patients' cognitive and decision mak-

ing competence. The level of consciousness or competence changes over the time, thus health care professionals' inaccurate or unreliable assessment may easily result. Second, delirium is often associated with emergent or critical conditions that necessitate urgent decision making on subsequent treatments. Lack of time may hinder meaningful and thoughtful decision making process, thus totally affecting patients' and their family's authentic consent questionable.

Alternatives to consent usually include advance directives (made by persons who, in this case, patients with delirium were once competent and are currently incompetent) or proxy consent (made by their surrogate decision makers). Advance directives are, however, not necessarily ready to be used for persons with delirium who may be critically or acutely ill in a real world setting. For example, advance directives may not have been prepared in advance or in a timely manner. On the other extreme, advance directives may have been prepared in advance, but the prepared directives may not be applicable to the current situation, or may not be fully compatible with the current preference of the persons (if they were able to make a sound decision and able to verbalize their preferences).

Proxy consent has often been used as an alternative to advance directives. Meaningful proxy consent, however, can be challenging because surrogate decision-makers may not be able to make a "right" decision for those persons with delirium. The outcome of the proxy consent may be incongruent with the current preferences of persons with delirium, even if these persons' preferences might be implied from their advance directives or by considering their "best interest" with family or close persons who are familiar with them.

Invasiveness and Complexity of Procedures

Careful examination on the assumptions of proxy consent is warranted, especially when a procedure is invasive or complex. In an effort to assess agreements of decision-making patterns between patients and their proxy decision-makers, clinical treatment vignettes were utilized in several studies. One of the study findings revealed that the proxy decision-makers' choice had agreed with the patients' choice at a low rate, or simply by chance, regardless of the previous discussion with the patients on their treatment prefer-

ences (Gerety et al., 1993). In another study, patients with dementia, their proxies, and healthy older persons (as a control group) were asked to rate their preferences to hypothetical options in four types of hypothetical research projects (Sachs et al., 1994). The patients with dementia were less willing to participate in hypothetical studies when the invasiveness of the study procedures increased. This study result validated a certain level of decision-making competence among those persons with dementia. Proxy and healthy older persons were more willing to give consent than those persons with dementia. The methodology of hypothetical vignettes provides valuable information regarding persons' preferences and attitudes; however, its limitation lies in "hypothetical," unreal circumstances provided in vignettes.

One clinical epidemiologic study focused on the issue surrounding consent for persons with delirium in a real world situation (Auerswald et al., 1997). In this study, rigor criteria were developed and utilized for a retrospective medical record review. Individualized interviews from nurses and attending physicians were also carried out to obtain supplementary information from them. The study findings revealed a high rate (19%) of procedures without documented consent, lack of cognitive and decisional capacity assessment, and inconsistent use of surrogate decision-making. Failure in obtaining consent was predicted by the presence of delirium and less invasiveness of procedures. A design of the study, a retrospective review of the medical records, may limit the generalizability of the study findings, as the study authors admitted. Health care document may not necessarily reflect actual consent processes: patients and health care professionals may have different satisfaction or totally opposite perspectives on consent process that was documented in medical record. For example, a detailed document of consent that appear to be excellent might be written only from a health care professional's perspective; a patient might not be satisfied with the consent process nor had found it helpful or meaningful.

The level of competence of nursing home residents needs to be carefully assessed and documented before obtaining their consent. Several studies on nursing home residents (in most cases, residents with dementia) revealed that they do not have enough level of cogni-

tion and capacity to give a meaningful consent, as evidenced by an examination of their mental status or decision-making capacities toward hypothetical clinical vignettes with typical treatment options (Agarwal et al., 1996; Fitten, et al., 1990; Fitten et al., 1990). An examination of the mental status of nursing home residents on admission and on a regular basis is warranted in order to make comparison against their baseline status. These studies, again, have limitations that lie in the methodologies of hypothetical clinical vignettes instead of real life situations. Hypothetical questions may lack reality or relevance to these nursing home residents, which may have resulted in false outcomes, underestimation or overestimation of competence.

Health Care Professionals' Sensitivity to Patient Care Needs

Health care professionals are reported to fail recognizing or underestimating patients' incompetence; thus, they fail involving surrogate decision-makers to important decision makings for patients (Barton et al., 1996; Fitten et al., 1990). Physicians' judgments on patients' competency showed high agreement (kappa coefficient = 1.0) for controls (normal elderly subjects) but significantly low agreement (kappa = .14) for Alzheimer's disease patients (Marson et al., 1997). On the other hand, some health care professionals have reliable and accurate intuitive sense to judge patients' cognitive capacity. Resident physicians and nurses have intuitive judgments on patients' cognition, judgment, and decision-making capacity that highly correlated (weighted kappa coefficients > 0.76) with the mental status score of the 200 patients in the intensive care unit (Cohen et al., 1993).

The latter finding (Cohen et al., 1993) implies that health care professionals in acute care settings may have accurate assessment ability toward a need for surrogate decision-makers. However, actual statistics in this regard was not examined in this study. The results of these studies are inconclusive in terms of health care professionals' ability to assess patients' competency. Further research examining the types of professionals, educational backgrounds, practice settings, institutional policies, or persons' characteristics such as responsiveness and sensitivities to patients is warranted; these variables are potential factors that influence the assessment of patients'

level of competence.

Standardized Scales and Modified Consent Processes

Standardized assessment scales tools have been developed for incompetent patients, including schizophrenia and dementia. The first example is the MacArthur Competence Assessment Tool-Treatment (MacCAT-T) (Grisso et al., 1997) that was developed for clinicians to measure mainly schizophrenic patients' cognitive skills. The MacCAT-T measures following abilities: understanding information relevant to their condition and the recommended treatment; reasoning about the potential risks and benefits of their choices; appreciating the nature of their situation and the consequences of their choices; and expressing a choice.

Another example is the Hopkins Competency Assessment Test (HCAT) (Janofsky et al., 1992), a brief instrument to evaluate the patients' competency to give informed consent or write advance directives. The HCAT consists of a short essay and a questionnaire for determining patients' understanding of the essay. The MacCAT-T and the HCAT are reported to have a high inter-rater reliability, and have satisfactory clinical utility (easy to administer) and criterion validity (high correlation with mental state examinations). These standardized instruments are valuable assets to assess patients' decision-making competence.

A simple technical modification in consent forms, or improvement of readability of forms, should be helpful for elderly to understand easily what is written in consent forms. Consent forms should be short in length, typed in a larger font, and written in easy and readable sentences for cognitively impaired elders (Ratzen, 1985). In a study of a simplified consent format with an illustrated storybook and a simplified text version, study participants were able to comprehend high- and low-risk vignettes better than a standard text version (Tymchuk et al., 1988). In fact, patient participants who received simplified or story book format (regardless the level of high- or low-risk vignettes) scored higher in subsequent memory performance test conducted after a week later as compared to those participants who received high-risk vignettes in standard version (Tymchuk et al., 1988).

Another proposed technique is a two-part consent process that ensures a subject's

comprehension of the provided information. Ratzen (1985) proposed a two-part consent form that contains a questionnaire (a test) assessing a subject's actual understanding of information in a consent form. If the subject passes the test, researchers or health care professionals leave a copy of the test with the subject. If the subject does not pass the test, the subject will receive an oral explanation again to retake the test. A more sophisticated example of the two-part consent process is a method of a preliminary research participation experience (a week try-out) proposed (Rikkert et al., 1997). These researchers conducted a study of fluid balance in geriatric patients using a week try-out method in obtaining the participants' consent. The results showed an improvement in the participants' capacity to consent, while enabling an acceptable participation rate. Through these modified consent processes, either by a two-part consent form or a week try-out experience, researchers and health care professionals are more likely to obtain a valid and authentic consent from a cognitively impaired and incompetent individual.

Summary: Toward Evidence-based Practice

The review of the studies related to the process of consent and decision-making for persons with cognitive impairment revealed that the majority of the population studied was nursing home residents and persons with dementia, with little attention to persons with delirium.

The frequency of documentation related to informed consent or proxy consent in persons with delirium was very low. Health care professionals need to be aware of the strengths and limitations of the above mentioned study methods, including hypothetical vignettes, standardized instruments, and modified consent processes. The limitation of hypothetical clinical vignettes includes irrelevance to the real world situations involving patients, families, and health care professionals. The actual clinical situations and contexts are obviously more complicated than those hypothetical vignettes. This warrants more investigative efforts, focusing on those persons with delirium in real world situations and contexts.

Standardized instruments may facilitate valid and sound assessment of the cognitively impaired persons; however, limitations of

instruments and standardization have to be noted as they are designed to measure for specific phenomenon of specific population in specific settings. Health care professionals' intuitive flexibility, critical thinking skills, and expertise in assessing patients' decision-making competence need to be developed throughout fundamental education as well as continuing education. Nurses are one of the health care professionals who are privileged to be at patients' bedside most frequently and longer period. Nurses, thus, are expected to be patients' advocates who have sensitivity to patients' needs and cultural and individual diversity in optimizing their health experiences.

Implications for Further Research and Theory Development

The complexity of real-life situations involving persons with delirium may limit the utility of Brock's (1994) three principles (the advance directives, the substituted judgment, and the best interests), as Brock indicated, despite its value as a practical guideline for health care professionals. In the literature, persons with delirium were not well studied as compared to persons with dementia, in terms of the ambiguous concept of "autonomy" and "authenticity" of decision making. The frequently of usage and outcome of advance directives for those persons with delirium are not well known in the literature, either.

Different from persons with dementia, advance directives for persons with delirium are not likely to be prepared in a timely manner partly probably due to an abrupt onset of delirium symptoms in acute care settings. Even if advance directives were developed previously by those persons who were competent at that time, those directives may be irrelevant to their current real-life concerns and needs, or may be incongruent with their current preferences. Advance directives may also conflict with the preference of the surrogate decision-makers since their levels of consciousness, cognition, and competence of persons with delirium may fluctuate significantly. Assuring valid and meaningful consent for persons with delirium is likely to be difficult.

Well being and quality of life of delirious persons and their families may be seriously affected by how consent process unfolds.

Health care professionals should be dealing with challenging issues in their daily clinical practice, but such information has not been systematically explored in detail in the literature. An identification of the nature of the issue, qualitative and exploratory research on morally and ethically difficult situations, would facilitate the development of theory that explains the phenomena and knowledge related to the care of persons with delirium.

Potential methodologies for such qualitative inquiry may include participant observation, document and chart reviews, and in-depth interview of patients, family, and health care professionals. Participant observation and a brief interview would be helpful to understand the patient's experience if a patient is presently delirious. In-depth interview would help explore their experience and identify their needs in the episode of delirium if a patient was delirious at a certain point in the past and is presently competent. The following research questions may facilitate our further inquiry to this area of study.

- How frequently advance directives are used and followed in critical care settings? What is the pattern of their use, and process of the decision making in relation to the care of persons with delirium?
- How fluctuating levels of consciousness, cognition, and competence in decision making may affect well-being and quality of life of persons with delirium and their family?
- What is the nature of the conflict between advance directives (of a patient who was once competent and is currently incompetent) and proxy consent? How advance directives are overridden by proxy, health care professionals, or "best interest" thinkers?
- What is the nature of meaningful consent process for persons with delirium? When is the best timing of the consent and decision-making? What are the guiding principles, guidelines, and standards that are used by health care professionals in given institutions?
- How cultural and individual diversity of patients, family, and health care professionals affect the process of consent? What approach is culturally appropriate and sensitive?

Conclusions

The above-mentioned research questions potentially have unique significance to the knowledge development in the area of ethical issues and the care of persons with delirium. The concepts of autonomy, self-determination, authenticity of decision making, and well-being of patients with delirium have been in the area of "gray zone." We have no single right answer to these kinds of questions. Potential conflicts among advance directives and surrogate decision making, as well as how we weigh one option from the other have not been well explored in the literature. Exploration of the nature of consent and decision-making process for persons with delirium, their surrogate decision-makers, and health care professionals would expand the horizon of the body of knowledge relating to nursing practice, education, and research.

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