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Abstract: *The role of the intellectually disabled patient in their own health care decision-making is an under-investigated topic despite its serious ethical implications. Literature suggests that this vulnerable patient population faces barriers in communication in the pursuit of health care services. While communication challenges are numerous for the intellectually disabled patient, the ones surrounding health care decision-making seem to present serious ethical considerations. Inadequate research has been conducted to fully appreciate the experience of the intellectually disabled patient in regards to health care decision-making. Recognizing the vast gap in information on this important topic, further research is warranted.*

Keywords: *bioethical issues, patient rights, intellectual disability*

INTRODUCTION

The purpose of this literature review is to examine the role of intellectually disabled patients in health care decision-making. A description of the intellectually disabled patient will be presented to inform readers on the population being discussed. The paper will then examine the intellectually disabled patient as a health care consumer; challenges of patient-provider communication will be elaborated. The discussion of communication challenges faced by this population sets the stage to identify the ethical significance of the intellectually disabled patient and their role in health care decision-making. Acknowledgements are made that assessment of capacity is a relevant consideration for this patient population and their ability to make health care decisions. Finally, it is argued that additional research is warranted to understand the intellectually disabled patient and their experience with health care decision-making.

INTELLECTUAL DISABILITY

According to the President's Committee for People with Intellectual Disabilities (2010), intellectual disability (also referred to as mental retardation) affects approximately seven to eight million Americans. Characteristic of its diagnosis, those with intellectual disability experience varying limitations in intellectual functioning as well as limitations related to daily life skills; this diagnosis may be made through intelligence testing and assessment of support needs.¹ Once a population primarily housed in institutional settings, the intellectually disabled patient commonly resides and/or works in the community. Through various legislative and public policy advances, the intellectually disabled are increasingly included in society and protected from discrimination.

¹“Facts about Intellectual Disability,” Centers for Disease Control and Prevention (2005). Accessed Jun. 15, 2011, <http://www.cdc.gov/ncbddd/dd/ddmr.htm>

THE INTELLECTUALLY DISABLED PATIENT AS A HEALTH CARE CONSUMER

Consumers of health care services are diverse and include intellectually disabled patients. While extensive research is not available on the topic of intellectually disabled patients and their general experience with health care, available literature suggests that patient-provider communication challenges exist.² While patient-provider communication challenges are not unique to interactions between intellectually disabled patients and health care providers, the vulnerability of this particular patient population increases concern regarding these issues.

In one study³ researchers examined the identified gap in patient-provider communication among the intellectually disabled. In this study, higher-functioning adults with intellectual disability took part in focus groups and interviews; during these meetings, they were provided a forum to express preferences in regards to communication with health care providers. Preferences emerging from these sessions showed a patient population interested in having more time with their provider during consultation and having certain physical examinations demonstrated before they took place. Patients also expressed sincere concerns regarding triadic communication. The latter issue of triadic communication is particularly noteworthy.

During the previously mentioned study, intellectually disabled patients explained it was common practice for a support professional to attend medical appointments with them. The intellectually disabled patients did not seem to mind this fact, except their experience has shown that the physician will primarily address the support professional (versus themselves, the patients). The authors note that more favorable health care encounters could be achieved if communication were enhanced with intellectually disabled patients. Improved communication may augment the ability of these patients to exercise autonomy.⁴

Limited research is available on the topic of health care professionals and their competency in communicating with intellectually disabled patients. One study did examine this issue. In this study, training was offered to various health care professionals of diverse disciplines.⁵ The training design focused on providing education and hands-on experience in providing care to intellectually disabled patients. Despite all study participants having previously taken coursework focused on patient communication, none of the coursework focused on communication with patients having limited cognitive or verbal functioning.⁶ Results indicated that health care professionals in this study improved their knowledge of and interaction with intellectually disabled patients in regards to communication by receiving education on the subject.

In addition to communication challenges among intellectually disabled patients and health care providers, other potential problems for this patient population have been identified in the literature. For example, Tuffrey-Wijine highlights late presentation of illness, difficulties assessing symptoms, difficulties understanding illness and associated implications and ethical concerns regarding decision-making and consent to treatment as relevant issues for the intellectually disabled patient.⁷ Considering known communication challenges in the provision of care for intellectually disabled patients, Tuffrey-Wijine notes that significant ethical concerns exist in regards to health care decision-making for this patient population.⁸ For example, are intellectually disabled patients empowered to exercise autonomy? Do intellectually disabled patients feel comfortable expressing their preferences related to their own health care decisions? Do providers automatically assume intellectually disabled patients are unable to make health care decisions?

HEALTH CARE DECISION-MAKING

² Irene Tuffrey-Wijne, "The Preferred Place of Care for People Who Are Dying," *Learning Disability Practice* 12 no. 6 (2009): 16-21, <http://dx.doi.org/10.7748/ldp2009.07.12.6.16.c7125>; M. Wullink, W. Veldhuijzen, Lantman-de Valk van Schroyensteen, H., J. Metsemakers, and G. Dinant, "Doctor-Patient Communication with People with Intellectual Disability – A Qualitative Study," *BMC Family Practice* 10 no. 82 (2009), doi: 10.1186/1471-2296-10-82; S. Horrell, W. MacLean, and V. Conley, "Patient and Parent/Guardian Perspectives on Health Care of Adults with Mental Retardation," *Mental Retardation* 44 no. 4 (2006): 239-248; D. Harper and J. Wadsworth, "Improving Health Care Communication for Persons with Mental Retardation," *Public Health Reports* 107 no. 3 (1992): 297-302.

³ M. Wullink et al, "Doctor-Patient Communication."

⁴ Ibid.

⁵ D. Harper, "Improving Health Care Communication."

⁶ Ibid.

⁷ Irene Tuffrey-Wijne, "The Preferred Place."

⁸ Ibid.

While the intellectually disabled patient is indeed a health care consumer, their role is unclear in terms of their involvement in health care decisions.⁹ Some literature suggests that intellectually disabled patients are not involved in decisions related to their own health and associated care and treatment.¹⁰ In situations where it has been determined that proxy decision-makers should ultimately make health care choices for intellectually disabled patients, legitimate concerns exist on how this occurs. Researchers have examined the role of proxy decision-makers for individuals with disabilities residing in agency settings.

In the agency setting, employees have expressed legitimate concerns about reaching health care decisions based on the best interest and wishes of a patient, recognizing that such determinations are difficult to make.¹¹ While wishes of the patient have been identified as valued by employees making decisions on behalf of intellectually disabled patients, it is not clear that these wishes are adequately sought from the perspective of the patient.

Lohiya, Tan-Figueroa and Kohler acknowledge that end-of-life care for developmentally disabled patients could be improved by early and frequent communication with patients about best interests and desires.¹² However, a medical record review conducted at their agency demonstrated that out of 850 residents only two had completed an advance directive. According to the researchers, residents judged as mentally capable by their physician are informed on their right to formulate and execute an advance directive.¹³ Therefore, this particular study raises questions about the ways that individuals with disabilities are deemed capable, as well as questions related to how health care decisions are discussed with patients in agency settings. In a study of physicians in the Netherlands, physicians in agency settings were noted to commonly make end-of-life determinations for mentally handicapped patients.¹⁴ In the cases examined, 63 patients were "incompetent" and in 23 of these cases "there had been some communication with the patient."¹⁵ This study also raised several questions regarding generalizations about the patient population with comments such as the following in the text: "the life of mentally handicapped people is usually strongly influenced by the care of others because most of them are dependent on help with all types of activities" and "because most mentally handicapped patients are incompetent."¹⁶ It is unclear what criteria were used to arrive at the previous conclusions. The study did not indicate if a formal process were used to declare the patients incompetent or if these statements were assumptions related to the abilities of the patients who had a mental disability.

While it is not unreasonable to question the ability of an intellectually disabled patient to make a health care decision due to cognitive impairment, generalizations that this population cannot reach informed decisions are inaccurate. In studies examining the ability of intellectually disabled patients to make health care decisions, conclusions were made that suggest support and simplification in the decision-making process produced better results for the intellectually disabled patient.¹⁷ In addition, Cea and Fisher conclude that adults with mild intellectual disability and some with moderate intellectual disability demonstrate ability to provide adequate consent to basic treatments.¹⁸

THE DISCUSSION OF CAPACITY

Patients with intellectual disability should be involved in their own health care decisions when capable. The issue of the patient's capacity to make health care decisions is a worthy consideration. Despite what is known or unknown about the intellectually

⁹ K. Fisher, M. Green, F. Orkin, and V. Chinchilli, "A Content Analysis from a US Statewide Survey of Memorable Healthcare Decisions for Individuals with Intellectual Disability," *Journal of Intellectual & Developmental Disability* 34 no. 3 (2009): 258-265; C. Cea and C. Fisher, "Health Care Decision-Making by Adults with Mental Retardation," *Mental Retardation* 41 no. 2 (2003): 78-87.

¹⁰ K. Keywood et al, "Healthcare Decision-Making,"; G. van Thiel, J. van Delden, K. de Haan, and A. Huibers, "Retrospective Study of Doctors' 'End of life Decisions' in Caring for Mentally Handicapped People in Institutions in the Netherlands," *British Medical Journal* 315 no. 7100 (1997): 88-91.

¹¹ K. Fisher et al, "A Content Analysis,"; G. Lohiya, L. Tan-Figueroa, and H. Kohler, "End-of-Life Decisions in a Developmental Center – A Retrospective Study," *Western Journal of Medicine* 176 no. 1 (2002): 20-22.

¹² G. Lohiya et al, "End-of-life Decisions."

¹³ Ibid.

¹⁴ G. van Thiel et al, "Retrospective Study."

¹⁵ Ibid.

¹⁶ Ibid.

¹⁷ C. Cea et al, "Health Care Decision-Making,"; J. Wong, I. Clare, A. Holland, P. Watson, and M. Gunn, "The Capacity of People with a 'Mental Disability' to Make a Health Care Decision," *Psychological Medicine* 30 (2002): 295-306.

¹⁸ C. Cea et al, "Health Care Decision-Making."

disabled patient and their role in health care decision-making, there are recommendations accepted in the literature in regards to assessing and determining capacity. Widely accepted in literature are criteria for determining the ability to make health care decisions as outlined by Appelbaum and Grisso,¹⁹ which include the following criteria for assessing competence: communicating choices, understanding relevant information, appreciating the situation and its consequences and rationally manipulating information.

Capacity to make health care decisions should not be based on generalizations that someone is either capable or incapable of any and all decisions based on their status (intellectual or otherwise). The ability for a patient to make health care decisions may fluctuate and capacity may be demonstrated for some decisions and not others.²⁰ This longstanding acknowledgement is noteworthy as a reminder that despite having an intellectual disability, an immediate assumption of incapacity for involvement in health care decisions is not appropriate. As with all patients, an opportunity to assess capacity is warranted to ensure intellectually disabled patients are involved in their own health care decisions when possible.

Keywood and Flynn highlight inappropriate perceptions about those with intellectual disability.²¹ They note that it is often inaccurately assumed that intellectually disabled patients cannot consent for themselves. These assumptions, the authors argue, stem from beliefs that certain individuals by virtue of their status are incapable of making legal and valid health care decisions. Other scholars, such as Longmore, observe that nondisabled individuals often make erroneous assumptions that those living with disabilities view their own lives as diminished.²² The issue of ungrounded perceptions about the intellectually disabled is concerning because these inaccuracies could lead to barriers in the inclusion of intellectually disabled patients taking part in their own health care decisions.

CONCLUSION

While limited research exists on the intellectually disabled patient as a health care consumer that which does exist demonstrates communication challenges between the intellectually disabled patient and their health care provider. The risks of continued communication barriers for this patient population bring about several concerns, but a significantly noteworthy one is the risk of non-inclusion in health care decisions in instances where the intellectually disabled patient has the capacity to be involved.

Research on the intellectually disabled patient and health care decision-making is sparse. The ethical implications associated with this topic indicate a need for further research. Some research has been conducted which has tested the abilities of intellectually disabled patients to execute health care decisions. However, intellectually disabled patients are not being adequately studied to understand their experiences and involvement related to health care decision-making. To protect the rights and dignity of the intellectually disabled patient population, the role of these patients in health care decision-making deserves further exploration.

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¹⁹ P. Appelbaum and T. Grisso, "Assessing Patients' Capacities to Consent to Treatment," *New England Journal of Medicine* 319 no. 25 (1988): 1635-1638.

²⁰ K. Keywood et al, "Healthcare Decision-Making"; P. Appelbaum et al, "Assessing Patients' Capacities"; President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research (1982) "*Making Health Care Decisions: The Ethical and Legal Implications of Informed Consent in the Patient-Practitioner Relationship*." (Washington, D.C.: U.S. Government Printing Office).

²¹ K. Keywood et al, "Healthcare Decision-Making."

²² P. Longmore, "Medical Decision Making and People with Disabilities: A Clash of Cultures," *Journal of Law, Medicine & Ethics* 23 (1995): 82-87.

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