

ARTICLE

In-hospital delays for stroke care: losing sight of patient-centered care

Charles Ellis PhD

Associate Professor, Department of Health Sciences & Research, Medical University of South Carolina, Charleston, SC, USA

Abstract

The emergence of patient-centered care has offered a challenge for health professionals in some settings to fully engage patients in all stages of the care process. For example, stroke is a condition that requires urgent and comprehensive care. This comprehensive care may be provided to patients who are experiencing compromised cognitive and communication skills. In addition, “in-hospital delays” in care can occur during the process of evaluation and treatment. In-hospital delays in receipt of acute stroke care and the challenges of post-stroke cognitive and communication functioning can result in some patients having negative perceptions of the care process. This brief communication is an exploration of focus group data that suggest achieving the key elements of patient-centered care is challenging in acute care settings that provide care for complex conditions such as stroke.

Keywords

Clinical decision-making, communication, delays, long term outcomes, needs, patient-centered care, patient perceptions, person-centered medicine, preferences, respect, stroke, trust, values, whole person care

Correspondence address

Dr. Charles Ellis, Department of Health Sciences & Research, Medical University of South Carolina, 77 President St., MSC 700, Charleston, SC 29425-7000, USA. E-mail: ellisc@musc.edu

Accepted for publication: 21 January 2013

Introduction

Each year, approximately 795,000 Americans experience a stroke and at a cost of approximately 19 billion dollars [1]. These estimates are only a small percentage of the nearly 5 million individuals who suffer strokes worldwide [2]. Consequently, delivering the earliest treatment for acute stroke is a primary goal of clinicians charged with caring for stroke patients [3,4]. The use of recombinant tissue plasminogen activator (rTPA) within the first 3-hours from symptom onset is associated with decreased disability and improved long-term outcomes [5,6]. Unfortunately, many patients fail to seek medical care in a timely fashion and few patients arrive within the 3-hour window necessary to receive the benefit of rTPA [5,7].

However, there are some patients who arrive for timely care who still experience “in-hospital delays” in the receipt of their care [5,8-10]. A review of pre-hospital and in-hospital delays by Evenson and colleagues indicated that in-hospital delays can exist at several time points during the acute stroke care experience including: (a) time from emergency department arrival to an emergency department physician evaluation, (b) time to expert physician (neurologist) evaluation, (c) time to CT scan or interpretation and (d) time to rTPA administration when applicable [8]. It is critical to understand that the initial

management of patients with stroke is comprehensive and multifaceted and the process itself can contribute to delays in attempts to ensure evaluation accuracy and taking the proper steps to facilitate optimal outcomes.

Despite such attempts to achieve best outcomes, the patient’s perspective of the care process can be quite different from the healthcare providers, particularly in terms of the perceptions of in-hospital delays. Such delays can be perceived by the patient as “forgetting about the patient” at such time points where the patient is sitting and waiting for the next healthcare provider to appear, for diagnostic evaluation and interpretation of test results. This perception can be attributed to a lack of emphasis or focus on “patient-centered care”. Patient-centered care attempts to establish a relationship between patients and their families and their health providers that is based on respect for the patient and their wants, needs and preferences [11]. According to Bechtel and Ness, the 4 key elements of patient-centered care are: the whole person care, coordination and communication, patient support and empowerment and ready access [12]. More specifically, patient-centered medicine should have a specific focus on the patient’s experience with precedence given to what the patient prefers [13]. Therefore, in-hospital delays for early stroke care may be perceived as placing less emphasis on or “losing sight of patient-centered care” which seeks to have greater emphasis on the individual patient needs and

concerns, rather than those of the physician [14]. In this paper, we examine the issue of patient-centered care during the treatment of patients with stroke, specifically patient perspectives of patient-centered care.

Methods

Data reported in this paper were obtained from a focus group discussion as part of a larger study designed to examine delays in seeking treatment (DST) for stroke-related care. The larger study was reviewed and approved by the university institutional review board (IRB). The data reported here were collected from a focus group of 10 stroke survivors who had experienced a stroke within the past 2 years. Each participant in the group engaged in a discussion of their stroke experience with particular emphasis on their decision-making process to seek stroke care. As part of that discussion, participants revealed information about their hospital experiences for stroke care. These discussions serve as the basis for the information reported here.

Results

An analysis of the focus group transcripts suggests that some elements of patient-centered care were absent. Discussion relating to 3 key elements of patient-centered care emerged.

Whole Person Care - post-stroke communication and cognitive issues

A key component of patient-centered care is the concept of “whole person care”. Whole person care describes an understanding of the need to attend to the patient as a whole, not as a collection of body parts or with specific emphasis on one primary body [12]. In the case of stroke, particular emphasis is on resolution of the stroke and prevention of significant brain damage. In the early stages of care, less emphasis is placed on the secondary consequences of stroke such as communication and cognitive disorders. However, inadequate consideration of these issues leaves many patients with a poor understanding of their condition and the process that is ongoing to address their condition. Confusion and communication disorders are typical early symptoms of stroke but new to individuals experiencing the stroke as described by one patient:

“I had no physical manifestations other than; I could think but I couldn’t vocalize. And it was really, really confusing. Like he said, you’re driving and you can’t figure out how to put it in gear. I couldn’t talk to me wife. You know like, I knew what I wanted to say but I don’t know what I was saying.”

Because the primary objective of early stroke care is to stabilize the individual’s primary medical condition, less

attention is given to post-stroke consequences and patients are left with little understanding of the complex processes associated with stroke. More specifically, what may be perceived as frustrating in-hospital delays to the patient may be the normal care process to ensure the best outcome. However, it is important to note that research designed to examine barriers to patient-centered care among individuals with communication disorders suggests that patients and families expect to be allowed more time for post-stroke communication [15]. Consequently, there is concern that the primary goal of patient-centered care may be at odds with evidence-based medicine type approaches which have a primary focus on larger population groups [16]. However, more recent discussions increasingly indicate a potential complementarity of the two, given that good and meaningful outcomes should be defined primarily in terms of the individual patient.

Communication – provider communication about status/progress

A second component of patient-centered care is coordination and communication. In-hospital delays are often the result of the complex process associated with care decisions for individuals experiencing a potentially fatal event. According to Bechtel and Ness, many patients desire help in understanding the test results and treatment recommendations that will allow them to become involved in their care [12]. In an acute event such as stroke, this process can be complicated by the status of the patient and the nature of the impending diagnostic results. However, the perceptions of the patient can be primarily related to the length of the delay and the lack of information received, rather than their perceptions of the complexity of the care decisions as described by this particular patient:

“I sat on a gurney in the ER for 5 hours..... They sat me and I mean literally on a gurney and they took my vital signs and that was it. Oh we are going to admit you for overnight. I said, “Oh no you’re not”. So, that’s when they had the ambulance transfer me.

Similar to whole person issues, the primary objective is the diagnosis and treatment of stroke and delays may be required to ensure that the best possible outcome is achieved. Unfortunately, that may not be the perception of the patient who is frequently fatigued by the stroke event and the stroke care process as well as being mentally or physically compromised by the stroke itself.

Patient support and empowerment – trust and respect

Patients are believed to be able to manage their conditions better when they receive support and are empowered by the receipt of partnership decision, support for self-management and trust and respect [12]. More positive outcomes are expected when patients operate with the team *via* relationships that include effective communication and respect for their preferences.

Difficulties arise when patients have concerns about the credentials of the healthcare providers and when unacceptable communication has occurred, as described by this patient:

“Well I mean you are putting yourself in the hands of a professional. It’s like trying to tell a mechanic how to fix your car. I don’t know what you know as a professional so how am I going to tell you how to do your job..... I’m here because I don’t know what in the hell is going on between the ears. I need your help so. I know something is wrong but I need you to tell me what it is. If you are incapable of doing that; you’re just gonna put me on a gurney in a corner then maybe you need to refer me to somebody else then that’s what I need you to do.”

Central to patient-centered care are the wishes of the patient. However, this does not mean that the patient can receive whatever treatment he or she wants [12]. It does mean, however, that significant emphasis must be placed on ensuring that patients held significant trust and confidence in their healthcare providers. It is also important to note that patients may not be able to make accurate judgments of the clinical competency of healthcare providers and thus make judgments on other characteristics such as friendliness, timeliness, the quality of personal interactions and trust [17]. Therefore, to achieve quality personal interactions and obtain trust requires providers to engage in an ongoing accommodation of language and of cognitive or other barriers that may preclude effective decision-making. Patients and families expect to be treated with respect, regardless of the significance of their post-stroke condition [15].

Discussion

Engagement in patient-centered medicine during the acute treatment of diagnostically challenging conditions such as stroke can be difficult. Early management of stroke requires timely confirmation that the individual’s impairments are due to stroke and not another health condition, determination of the patient’s suitability for treatment with thrombolytic agents, diagnostic studies and evaluation of the patient-related history as well as all other relevant information [18]. Consequently, this complicated focus on early management may cause some healthcare providers to lose sight of the key elements of patient-centered care.

Evidence reported here suggests that this may be the case in some instances. However, the evidence reported here is only from the perspective of a few patients and does not consider the complexity of the ‘behind the scenes’ patient management issues. Regardless, patient perceptions of the process are influenced by the level of their engagement in the decision-making process, the trust in the patient management process and their perceived satisfaction with patient-provider communication. It is potentially not the delay itself that creates patient dissatisfaction, but the lack of communication regarding expected outcomes and the “next steps” that create

frustration during the evaluation process. Ultimately, patient-centered acute stroke care can be demanding and time consuming, given that such an approach requires the integration not only of the wishes of the patients, but also the clinical expertise of the care team which includes generalists and specialists who may have competing interests [17]. Consequently, the patient’s satisfaction and perception of the quality of the healthcare interaction may not include an accurate assessment of the technical competency of the healthcare provider [17].

This study is not without limitations. First, the data reported here emerged from only one focus group of 10 participants. Although the data appear adequately to reflect the early stroke management process, information from additional focus groups would further clarify issues related to patient centered-care. The primary goal of this project was not transferability, but at this stage simply a more basic exploration of patient-centered care. Second, this paper primarily emphasizes the 3 key components of patient-centered care (whole person care, coordination and communication and patient support and empowerment) [12]. More comprehensive studies and descriptions of patient-centered care currently exist in the literature and the many additional components of effective patient-centered care should be considered in future examinations of patient-centered care in stroke management [cf. 19-22].

Conclusions

Engagement in patient-centered care is not always an easy process. Some health conditions require complex and multifaceted care that complicates the process of engaging patients in patient-centered care. Future studies are needed to understand the barriers and facilitators of patient-centered care particularly for the treatment of complicated health conditions such as stroke.

Acknowledgements and Conflicts of Interest

The author was supported by a career development award (CDA # 07-012-3) from the Veterans Health Administration Health Services Research and Development program. The author reports no conflicts of interest.

References

- [1] Roger, V.L., Go, A.S., Lloyd-Jones, D.M., Benjamin, E.J., Berry, J.D., Borden, W.B., Bravata, D.M., Dai, S., Ford, E.S., Fox, C.S., *et al.* (2012). Executive summary: heart disease and stroke statistics - 2012 update: a report from the American Heart Association. *Circulation* 125 (1) 188-197.
- [2] World Health Organization. (2012). Global Burden of Stroke. Available at:

- http://www.who.int/cardiovascular_diseases/en/cvd_atlas_15_burden_stroke.pdf.
- [3] Moser, D.K., Kimble, L.P., Alberts, M.J., Alonzo, A., Croft, J.B., Dracup, K., Evenson, K.R., Go, A.S., Hand, M.M., Kothari, R.U., Mensah, G.A., Morris, D.L., Pancioli, A.M., Riegel, B. & Zerwic, J.J. (2006). Reducing delay in seeking treatment by patients with acute coronary syndrome and stroke: a scientific statement from the American Heart Association Council on cardiovascular nursing and stroke council. *Circulation* 114 (2) 168-182.
- [4] Duncan, P.W., Zorowitz, R., Bates, B., Choi, J.Y., Glasberg, J.J., Graham, G.D., Katz, R.C., Lamberty, K. & Reker, D. (2005). Management of Adult Stroke Rehabilitation Care: a clinical practice guideline. *Stroke* 36 (9) e100-143.
- [5] Morris, D.L., Rosamond, W., Madden, K., Schultz, C. & Hamilton, S. (2000). Prehospital and emergency department delays after acute stroke: the Genentech Stroke Presentation Survey. *Stroke* 31 (11) 2585-2590.
- [6] The National Institute of Neurological Disorders and Stroke rt-PA Stroke Study Group. (1995). Tissue plasminogen activator for acute ischemic stroke. *New England Journal of Medicine* 333 (24) 1581-1587.
- [7] Smith, M.A., Doliszny, K.M., Shahar, E., McGovern, P.G., Arnett, D.K. & Luepker, R.V. (1998). Delayed hospital arrival for acute stroke: the Minnesota Stroke Survey. *Annals of Internal Medicine* 129 (3) 190-196.
- [8] Evenson, K.R., Foraker, R.E., Morris, D.L. & Rosamond, W.D. (2009). A comprehensive review of prehospital and in-hospital delay times in acute stroke care. *International Journal of Stroke* 4 (3) 187-199.
- [9] Lacy, C.R., Suh, D.C., Bueno, M. & Kostis, J.B. (2001). Delay in presentation and evaluation for acute stroke: Stroke Time Registry for Outcomes Knowledge and Epidemiology (S.T.R.O.K.E.). *Stroke* 32 (1) 63-69.
- [10] Centers for Disease C, Prevention. (2007). Prehospital and hospital delays after stroke onset - United States, 2005-2006. *Morbidity and Mortality Weekly Report (MMWR)* 56 (19) 474-478.
- [11] Institute of Medicine (IOM). (2001). Crossing the Quality Chasm: A New Health System for the 21st Century. Washington, DC: National Academies Press.
- [12] Bechtel, C. & Ness, D.L. (2010). If you build it, will they come? Designing truly patient-centered health care. *Health Affairs (Millwood)* 29 (5) 914-920.
- [13] Krumholz, H.M. (2011). Patient-centered medicine: the next phase in health care. *Circulation: Cardiovascular Quality and Outcomes* 4 (4) 374-375.
- [14] Bardes, C.L. (2012). Defining "patient-centered medicine". *New England Journal of Medicine* 366 (9) 782-783.
- [15] Nordehn, G., Meredith, A. & Bye, L. (2006). A preliminary investigation of barriers to achieving patient-centered communication with patients who have stroke-related communication disorders. *Topics in Stroke Rehabilitation* 13 (1) 68-77.
- [16] Epstein, R.M. & Street, R.L., Jr. (2011). The values and value of patient-centered care. *Annals of Family Medicine* 9 (2) 100-103.
- [17] Kupfer, J.M. & Bond, E.U. (2012). Patient satisfaction and patient-centered care: necessary but not equal. *Journal of the American Medical Association* 308 (2) 139-140.
- [18] Adams, H.P., Jr., del Zoppo, G., Alberts, M.J., Bhatt, D.L., Brass, L., Furlan, A., Grubb, R.L., Higashida, R.T., Jauch, E.C., Kidwell, C., *et al.* (2007). Guidelines for the early management of adults with ischemic stroke: a guideline from the American Heart Association/American Stroke Association Stroke Council, Clinical Cardiology Council, Cardiovascular Radiology and Intervention Council, and the Atherosclerotic Peripheral Vascular Disease and Quality of Care Outcomes in Research Interdisciplinary Working Groups: the American Academy of Neurology affirms the value of this guideline as an educational tool for neurologists. *Stroke* 38 (5) 1655-1711.
- [19] Miles, A. & Mezzich, J.E. (2011). The care of the patient and the soul of the clinic: person-centered medicine as an emergent model of modern clinical practice. *International Journal of Person Centered Medicine* 1 (2) 207-222.
- [20] Miles, A. & Mezzich, J.E. (2011). The patient, the illness, the doctor, the decision: negotiating a 'new way' through person-centered medicine. *International Journal of Person Centered Medicine* 1 (4) 637-640.
- [21] Miles, A. & Mezzich, J.E. (2012). Person-centered medicine: addressing chronic illness and promoting future health. *International Journal of Person Centered Medicine* 2 (2) 149-152.
- [22] Miles, A. (2012). Person-centered medicine - at the intersection of science, ethics and humanism. *International Journal of Person Centered Medicine* 2 (3) 329-333.