Patient-Centered Outcomes Research and Patient-Centered Care for Older Adults: A Perspective

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Abstract

Patient-centered care that reflects consumer-driven health care decision of an individual as opposed to collective or social choice—based health decision has many implications for clinical decision and resource allocation. With possession of required information and faced with appropriate assessment of preferences, older adults make better choices for their own health. However, one must acknowledge that patient-centered approach for older adults should effectively integrate tenets of value-based care to improve overall quality of care and societal well-being. In this perspective, I present the importance and challenges of patient-centered care and patient-centered outcomes research among older adults.

Keywords

patient-centered care, patient-centered outcomes research, aging, value in care, comparative effectiveness

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Introduction

Patient-centered outcomes research focuses the attention on patient's beliefs, preferences, and needs, in contrast to physician-centered care (Bardes, 2012; Frank, Basch, & Selby, 2014). Thus, active participation of the patient as a stakeholder is an essential element of patient-centered outcomes research. The Patient-Centered Outcomes Research Institute (PCORI) was established as part of the U.S. Patient Protection and Affordable Care Act of 2010 to fund comparative effectiveness research to improve quality and relevance of evidence and help patients, caregivers, clinicians, insurers, and policy makers make informed health decisions (Costlow, Landsittel, James, Kahn, & Morton, 2015). To understand and address the complex and unique health care needs of older adults, their participation in patient-centered outcomes research is essential. This perspective is arranged as following. I begin with a brief discussion regarding older adults and patient-centered care. This is followed by issues of involvement of older adults in patient-centered outcomes research, information seeking and informed decisions, and the challenges. Finally, I conclude with discussion regarding essence of patient-centered care for older adults in the era of aging U.S. population.

Older Adults and Patient-Centered Care

High-quality care, communications, and attention to the social context are essential elements of patient-centered care for older adults. The term "older adults" encompasses

a wide age range, and the health needs and preferences vary over this age spectrum (Ansah et al., 2015; De Beni et al., 2013; Yoshinaka et al., 2015). This difference in needs and preferences has important implications for informed decision making and for achieving quality and value in health care. Value is defined as the quality of care divided by the cost of care (Porter, 2010). The interdisciplinary nature of the geriatrics discipline puts it in a unique position to lead the integrated care for achieving patientcentered care among older adults by being responsive to their needs, preferences, chronic health conditions, and desired outcomes. However, many older adults continue to face geographic variation in the availability of integrated geriatric teams, especially those residing in rural areas (Aronson, 2015; Institute of Medicine [IOM], 2012; Kogan, Wilber, & Mosqueda, 2015).

Involvement of Older Adults in Patient-Centered Outcomes Research

The overriding goal of consumerism in health care is to improve efficiency and quality of care via prominent

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role for the patient (i.e., consumer) in health care choice. Patient-centered care and patient-centered outcomes research are at the core of this movement. An intricate and complex relationship exists between patient-centered outcomes research and patient-centered care in the context of issues related to care for older adults. The goal of patient-centered outcomes research is to generate information that can facilitate patient-centered care. This process is challenging as older adults often face barriers to research involvement due to functional limitations and comorbidity. Patient-centered care, in turn, focuses on the relationship between health care provider and patient as equal partners in making decisions about patient's health. This new model of health care demands that older adults have the necessary information to make informed choices regarding value of care (Jayadevappa & Chhatre, 2011; Kogan et al., 2015).

The PCORI emphasizes involving patient-stakeholders over the entire research spectrum: from identification of research question to dissemination of results, and this is atypical compared with the investigator-driven approach of traditional medical research (Frank et al., 2014). Older patient-stakeholders expressed multiple reasons for involving in research: helping future patients by sharing their experience and expertise, and feeling that direct involvement in research is healing and beneficial. Although health care providers believe that they are responsive to patient preferences, they may misinterpret preferences of older patients. Involvement of older patients is most relevant to preference-sensitive decisions in situations where there are multiple treatment choices, but no clear best evidence-based option.

Information Seeking and Informed Decisions

The technical and personal nature of health care poses a challenge to providing unbiased and symmetrical information to achieve expected benefits of consumerism. Information asymmetry between patients and health care providers regarding value and quality is inherent in health care. When patients become better informed, they become more knowledgeable. At the same time, patient-centered care may raise the possibility of disagreement and worsening of patient-provider communication, mutual frustration, and inefficient use of visit time.

Comprehensive, unbiased, and uniform health information from trusted source must be available and accessible to older patients as they mostly receive specific information during their visit with the health care provider. Many older adults have a sense of personal investment in their own well-being and are willing to devote time to understand their diagnosis and treatment. Thus, transparent communication between health care provider and patient is an essential element for achieving patient-centered care among older adults.

Challenges of Patient-Centered Care

Patient-centered care for older adults is a tool to ensure that the patient's voice is heard and his or her preferences are effectively incorporated, leading to informed decision making. As patient-centered care gains popularity, researchers and policy makers need to be cautious. Asymmetry of information and trust are the challenges faced by health care providers in guiding patients to the "right choice" of care, especially for older adults. Also, the level of patient involvement may depend on the sensitiveness of the preferences, and intensity and duration of the illness. For some illnesses, there is one clearly superior path, and patient preferences may play very little or no role in decision making. For example, a hip fracture or acute appendicitis will need surgery, and there is not much room for options. For many medical decisions, however, multiple paths exist that entail different combinations of treatment options and outcomes. Decisions about therapy for early stage prostate cancer and lipid-lowering medication for primary prevention of coronary heart disease are two good examples. In these cases, patient involvement in decision making adds substantial value (Barry & Edgman-Levitan, 2012; Edelman & Barron, 2016; Forsythe et al., 2015; Selby, Forsythe, & Sox, 2015).

Older patients seek information to understand the trade-offs involved regarding cost and quality of care so that they can participate in informed decision making. Incorporating transparency in health care costs (especially in nonmarket health care sector) and its sensitiveness for resource allocation remains a challenge to the patient-centered care model. Patient-centered care for older adults can play a vital role in health care policy, allocation of resources, and delivering appropriate care by effectively integrating patient and health care provider perspectives (Jayadevappa & Chhatre, 2011; Kogan et al., 2015).

Patient-Centered Care and Value-Based Care

As health systems move to value-based care, they are embracing trade-offs between quality of care and cost. Patient centeredness, safety, effectiveness, timeliness, efficiency, and equity are considered important attributes of value in care (IOM, 2001; Levit, Balogh, Nass, & Ganz, 2013; Young, Olsen, & McGinnis, 2010). Patient-centered care, through shared decision making and patient involvement in patient-centered outcomes research, is considered an important feature of value-based care. This movement has inspired "choosing wisely" campaign to eliminate overuse and misuse of health care services such as tests, procedures, or therapies. However, incorporating these

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measures to enhance quality of care and reduce cost for older adults is a challenge. Many of the quality of care metrics have focused on process-related measures that inform older adults little about the functional outcomes they might expect (Aronson, 2015; IOM, 2012; Kogan et al., 2015). An individual patient's needs and preferences influence the definition of value that is based on cultures or geographic regions. Involvement of older patients in patient-centered outcomes research can help in bridging the knowledge gap that currently exists. Therefore, the value-based care and patientcentered care must be considered together to improve quality of care among older adults. Patients' value may be fully expressed only when they are involved in their care, and this is possible when they are fully informed and engaged.

Future Considerations

Patients and other stakeholders are increasingly engaged in the planning and conduct of biomedical research (Barry & Edgman-Levitan, 2012; Edelman & Barron, 2016; Forsythe et al., 2015; Selby et al., 2015). Patient-centered outcomes research and patient-centered care are poised to substantially change how health questions are asked and how answers are pursued (Bardes, 2012; Costlow et al., 2015). Older adults are more likely to have complex health care needs, and thus, participation of older adults in patient-centered outcomes research is necessary to fulfill their unique health care requirements.

Patient centeredness revolves around a theme of respect. In the era of consumerism and value-driven health care, patients want to be involved in their care, rather than being told what to do. At the same time, patients also acknowledge the fact that health care providers and patients differ in terms of health knowledge. Patients, especially older adults, desire unbiased health information from health care providers. Those who oppose patient-centered care model are concerned over patients making unrealistic, uninformed, or detrimental demands regarding their care. It is clear that all stakeholders will benefit from clear and transparent guidelines regarding roles and evaluation of engagement. How well older patients and health care providers strike this balance is a challenge to patient-centered care for older adults. As with any structural change, successful adoption of patient-centered care involves multidimensional approach. As we embark on the path of value-based care, time is needed to ensure that expected improvements in quality of care are achieved. This fact, along with aging of the U.S. population and their specific health requirements, demands that patient-centered outcomes research must identify and corroborate multidimensional factors to achieve efficiency, equity, and quality of health care through patient-centered care.

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