Person-Centered Care: A Definition and Essential Elements

The American Geriatrics Society Expert Panel on Person-Centered Care

Improving healthcare safety, quality, and coordination, as well as quality of life, are important aims of caring for older adults with multiple chronic conditions and/or functional limitations. Person-centered care is an approach to meeting these aims, but there are no standardized, agreed-upon parameters for delivering such care. The SCAN Foundation charged a team from the American Geriatrics Society (AGS) in collaboration with a research and clinical team from the Keck School of Medicine of the University of Southern California to provide the evidence base to support a definition of person-centered care and its essential elements. An interprofessional panel of experts in person-centered care principles and practices that the AGS convened developed this statement. **J Am Geriatr Soc 64:15–18, 2016.**

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Improving healthcare safety, quality, and coordination, as well as quality of life, are important aims of caring for older adults with multiple chronic conditions and/or functional limitations. Person-centered care is an approach to meeting these aims in a way that assures the primacy of individuals' health and life goals in their care planning and in their actual care. In its 2001 report, "Crossing the Quality Chasm: A New Health System for the 21st Century,"[1] the Institute of Medicine identified patient-centered care as one of the six pillars of quality health care and described it as "providing care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions." In recent years, the concept of having the person be the driving force in their healthcare decisions has evolved and gained momentum, and it is now largely considered the gold standard for health care across the United States and abroad.[2] There has also been a move toward using the term "person-centered," rather than "patient-centered," to encompass the entirety of a person's needs and preferences, beyond just the clinical or medical. Person-centered care can expand and shift a traditional healthcare model from one in which the physician or other provider is in the primary decision-making role to one that supports individual choice and autonomy in healthcare decisions. Yet, because person-centered care remains hard to define and operationalize, it could remain an aspirational goal that is not fully realized.

Despite a sizable and rapidly growing body of literature on person-centered care and the frequent inclusion of this term in health policy and research,[3] there is no standard, agreed-upon definition. This lack of consensus encompasses not only the definition of person-centered care, but also its core elements, best practices, and measures to assess effectiveness. Given the growing interest in person-centered care and calls for healthcare reforms that include expanding person-centered care practices,[4,5] a timely opportunity exists to establish standardized, accepted parameters of person-centered care so that everyone is speaking the same language and shares a common meaning. This is necessary so that there is a clear and consistent point of reference for provision of care, research, and policy.

Therefore, The SCAN Foundation (TSF), in keeping with its mission to advance a coordinated and easily navigated system of high-quality healthcare services for older adults that preserves dignity and independence, undertook a project to establish standards for the person-centered care model. TSF charged a team from the American Geriatrics Society (AGS), in collaboration with a research and clinical team from the Keck School of Medicine of the University of Southern California (USC), to provide the evidence base to support a definition of person-centered care and its essential elements.

METHODOLOGY

Project Components and Expert Panel

Project components included a comprehensive literature review, an environmental scan to identify person-centered

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care programs that might appear in the gray literature, qualitative interviews with nine community-based healthcare and social service organizations identified through the environmental scan as providing innovative approaches to person-centered care, and the formation of an interprofessional expert panel to review the research findings and develop a consensus definition of person-centered care and its essential elements. Ongoing TSF work on dignity-driven decision-making, focused on how models of care for older adults with chronic conditions and/or functional impairment are implemented, also informed this project.[6]

The expert panel consisted of 14 participants from around the country with expertise in person-centered care principles representing the fields of gerontology, geriatric medicine and oncology, gerontological social work and nursing, health policy and finance, law, long-term care delivery, and public health. The USC study team, TSF program staff, and AGS staff all provided input into the expert panel process, with the USC team facilitating an in-person meeting of the expert panel in February 2015 in Los Angeles, California.

Process

Fifteen definitions of person-centered care or similar terms, such as patient-centered, patient-directed, or person-focused care, were identified during the literature review and used as a foundation to draft a composite definition of person-centered care for chronically ill older adults with functional limitations. The draft definition was revised numerous times based on review and discussion among the project participants. All participants received a bibliography and summary of the literature review along with a worksheet to provide feedback on the draft definition and suggested essential elements of person-centered care. Feedback was compiled into a summary document that was distributed before the meeting, at which the expert panel discussed several iterations of the proposed definition of person-centered care. The resulting draft definition and its essential elements were subsequently circulated to the panel. Additional comments were considered and incorporated, and all panel members approved the final consensus definition (detailed below). In addition to developing the definition and identifying elements of person-centered care, the panel discussed effective implementation of and barriers to person-centered care in various practice settings. The panel's work is intended for use by healthcare providers, administrators, researchers, regulators, policy-makers, and consumer advocates.

DEFINITION AND ESSENTIAL ELEMENTS OF PERSON-CENTERED CARE FOR OLDER ADULTS WITH CHRONIC CONDITIONS AND/OR FUNCTIONAL LIMITATIONS

Definition

"Person-centered care" means that individuals' values and preferences are elicited and, once expressed, guide all aspects of their health care, supporting their realistic health and life goals. Person-centered care is achieved through a dynamic relationship among individuals, others who are important to them, and all relevant providers. This collaboration informs decision-making to the extent that the individual desires.

Elements Essential to Realizing This Definition

An individualized, goal-oriented care plan based on the person's preferences. A thorough medical, functional, and social assessment provides a foundation for the person and family to consider their goals. For some people, the assessment should be conducted in their place of residence.

Ongoing review of the person's goals and care plan. Reassessing the care plan on a regular basis helps to determine the plan's effectiveness, to address the person's evolving health and life goals, and to address changes in the person's medical, functional, psychological, or social status.

Care supported by an interprofessional team in which the person is an integral team member. The team must be flexible in composition and adaptable to changes in the person's health status, circumstances, and care and life goals.

One primary or lead point of contact on the healthcare team. Having one care provider who serves as a point of contact for the person and everyone involved in his or her care eases communication and facilitates continuity of care and transitions across care settings.

Active coordination among all healthcare and supportive service providers. Coordination among all providers assures that all services continue as seamlessly as possible, particularly when the person moves from one site of care (or residence) to another. The primary point of contact referenced above facilitates this.

Continual information sharing and integrated communication. Communication and information sharing may be accomplished through mechanisms such as the electronic health record and enhanced by careful listening and open communication between the person and everyone involved in his or her care.

Education and training for providers and, when appropriate, the person and those important to the person. Including the principles of person-centered care in the education and training of all healthcare providers contributes to their understanding of and commitment to providing person-centered care, including consistent recognition and maintenance of the person's autonomy. Health education of people receiving care and those important to them supports informed decision-making and self-determination.

Performance measurement and quality improvement using feedback from the person and caregivers. Measurable outcomes should focus on the successful implementation of care plans, evidence that the person's goals are being met, and evidence that efforts are being made to minimize difficulties during transitions between healthcare providers and across care settings.

IMPLEMENTATION OF PERSON-CENTERED CARE PRACTICES

Barriers to Implementation

Implementing a person-centered care approach requires significant core changes in the norms and expectations for

most healthcare systems. Several barriers stem from the concern of what can be realistically implemented in different practice settings. Some major barriers are thought to be:

Inconsistent terminology. In addition to adopting a standard definition of person-centered care, clarifying the meaning of key terms such as "goals," "preferences," and "values" will enable more consistent, system-wide delivery of person-centered care and will facilitate cross-study research, measurement, and sharing of best practices.

Traditional approaches to clinical practice. Although healthcare providers typically seek and incorporate input from individuals and those important to them, many providers still function in a traditional role of principal decision-maker.

Physician workload. Physicians need to be involved in person-centered care planning and implementation at some level, despite heavy clinical demands and time constraints. A well-coordinated interprofessional team can help to distribute the significant workload involved in managing the complex care of chronically ill older adults while bringing valuable perspectives and skills to person-centered care delivery.

Misaligned incentives. The team and health system that provides person-centered care and bears the cost of doing so may not be the beneficiaries of eventual cost savings, depending on the system and payment structure.

Identifying appropriate indicators. A focus on quality of life and amelioration of symptoms is a higher priority than attaining specific health metrics. Measures such as blood pressure and glycosylated hemoglobin are easy to obtain but do not measure person-centered outcomes. Quality indicators need to be defined for person-centered care for older adults with complex conditions or multiple comorbidities. A person-centered care plan may be the most significant quality indicator.

Provider concerns for risk and safety. When a person makes a decision that the healthcare provider strongly disagrees with and that puts the person at significant risk of death or worsening disability, it will bring up ethical and medico-legal concerns that will challenge the delivery of person-centered care and the promotion of the person's independence.

Lack of advance care planning. Many people, including those with dementia, have never discussed their care desires before becoming incapacitated, leaving providers and those important to the person to do their best to decide what the person would have wanted. People with dementia often lose capacity for this discussion long before death, meaning person-centered care is done by proxy during a significant portion of their lives.

Lack of payment structures that span healthcare and community-based organizations. Many older adults, particularly those who are frail and need long-term supportive services, require health and community-based resources. These are currently fragmented, without clear payment structures to promote coordination and comprehensive care.

Lack of continuity in health records. In many settings, there are multiple health records, some electronic and some not, and even when they are electronic, often they are not interoperable. This creates a significant challenge to communication and coordination among healthcare settings and providers.

Additional Considerations

Along with the essential elements previously described, the expert panel discussed some additional characteristics of person-centered care that support its effective implementation.

Communication focuses on interactions between the person and the provider, guided by an up-to-date care plan and an accurate understanding of the person's motivations, priorities, and preferences. An important aspect of communication and understanding involves a discussion about what the person wants to achieve (e.g., functional maintenance, improvement) as a specific, measurable, and realistic goal. Working with and educating individuals and their caregivers to set realistic goals, as well as how to achieve and periodically reevaluate and adjust these goals, is an important part of this process.

Team-based care is critical to person-centered care and needs to be supported by organizational leaders. The composition of teams needs to be flexible so they can respond to the individual's evolving needs and care and life goals.

Coordination involves explicit efforts to overcome difficulties in transitions between healthcare providers and across care settings. To accomplish this, it is important to identify the person with primary responsibility for the care plan and how the plan is communicated across settings and providers. A method for providing simultaneous access to care plans across the healthcare team needs to be established.

Environment includes an organizational culture that provides support and training in person-centered care practices for providers and identifies team members who are best suited for this type of care delivery.

In addition, organizations practicing person-centered care use measurement tools that focus on patient and caregiver satisfaction. Other measures of person-centered care could include integration and communication of health and long-term services and supports; system-level measurement of outcomes (e.g., avoidable hospital admissions), structures (e.g., organizational culture), and processes (e.g., individualized care planning); and individual-level outcomes, which could include mental health outcomes, caregiver stress and strain, patient satisfaction with role in decision-making and shaping care, alignment of goals with the care received, and goal attainment scaling.

SUMMARY

The definition and essential elements of person-centered care presented in this statement are based on findings in the literature and best practices identified through an environmental scan, with input from an interprofessional panel of experts in person-centered care principles and practices. Using a standardized definition and essential elements of person-centered care can assist healthcare providers, administrators, researchers, regulators, policy-makers, and consumer advocates in studying, implementing, and evaluating best practices in person-centered care. By identifying

the major barriers to implementing person-centered care, the healthcare system can move toward solutions. This definition and essential elements can be used to support the adoption of person-centered care practices across the nation and improve the quality of care for older adults, particularly those with complex healthcare needs.

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Conflict of Interest: Dr. Brummel-Smith was a former Geriatric Advisory Board member and consultant to SCAN Health Plan, which has some connection to TSF. Dr. Reuben has received occasional honoraria from the AGS for work such as Geriatrics at Your Fingertips. Dr. Tabbush has received several grants from TSF, including two for directing management programs and others for conducting research. Dr. Tinetti received funding from the John A. Hartford Foundation to develop and implement patient goals-directed care. Ms. Tumlinson is a grantee of TSF. Dr. Vladeck was a consultant to TSF from 2011 to 2014.

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