Patient Care for Adolescents Chelsea Pankow

Over recent years, there has been a progressive shift in the way that health care quality is defined and measured. Patient-centered care—defined as "providing care that is respectful of, and individual responsive to, patient preferences, needs, and values and ensuring that patient values guide all clinical decisions"- is associated with improved clinical outcomes, efficiency, and patient satisfaction and has become a policy priority in the United States and other countries. The expanding field of patient-centered outcomes research has strengthened the voice of patients, resulting in numerous tools and indicators to measure health care quality from the patient's perspective.

Patient-centered care may be particularly important during adolescence-a formative period when lifelong behaviors and attitudes to health are acquired. However, the principles of patientcentered care need to be interpreted and applied in a way that meets the distinct developmental needs of this age group. As a starting point, adolescents want their voice to be heard. A recent study across eight European countries found that being listened to was rated the most important health care priority by children (up to 12 years), early adolescents (13–15 years), and older adolescents (16-18 years)ahead of not being in pain, not feeling scared, the presence of parents/family, and five other aspects of patient experience. From a legal perspective, the rights of adolescents to be listened to and participate in decisions about their care are enshrined in the United Nations Convention on the Rights of the Child (ratified by all UN member states except for the United States and Somalia).

Currently, many health professionals deliver genuinely patient-centered services that listen to, respect, engage, and empower their adolescent patients. However, efforts to ensure that all adolescents experience this level of care have been limited by the lack of a common conceptual framework for defining and measuring patient-centered adolescent care. Despite publication of numerous guidelines and quality standards, few validated quantitative indicators are available to measure and compare the quality of different services. This gap has also acted as a barrier to providing financial incentives for higher quality care.

Publication of a measurement framework for quality health care for adolescents in hospital, is an important step toward meeting this need. It contains a set of quantitative indicators of patient- and family-centered care for adolescents in hospital, which can be used to compare services and monitor progress over time. The conceptual framework in this article explicitly promotes adolescent friendly care as a common route toward better health outcomes, complementing the moral and legal arguments in favor of its adoption. In turn, adolescent friendly care is grounded in patient- and familycentered care, alongside the related constructs of evidence-informed care and positive care experience.

This framework gives a prominent voice to adolescents themselves: first, in the indicators used to assess patient experience and care processes and second, in the methods used to develop the framework. Rightly, this is positioned within a model of family-centered care. Whenever appropriate, parents, guardians, and other family members should be involved in the care of adolescents in hospital, and their presence is particularly valued by younger adolescents. It is also important to emphasize that listening to adolescents does absolve not parents and professionals of the responsibility to make decisions that are in the long-term best interest of those too young to be fully legally competent. However, none of these issues should be seen as barriers to engaging and listening to adolescent patients. As illustrated in the model by Sawyer et al, the quality of many aspects of adolescent care cannot be assessed without asking their views, and this

process is critical to greater health care engagement and improved health outcomes.

Initiatives to promote the voice of young have growing international people momentum: examples include the recent Guidelines on Child Friendly Healthcare, endorsed by 47 members of the Council of Europe; the You're Welcome quality standards for adolescent services in England; and ongoing global and regional work by the World Health Organization. Sadly, however, the quality of care experienced by many adolescents across the world continues to fall far short of these standards. Their voice is often excluded from patient surveys, while older adolescents and young adults report the poorest patient experience of any age group.

Learning to listen to adolescents forms the basis of working in partnership with them to ensure that health care services meet their distinct needs. This process has the potential to transform the quality of care they receive, their attitudes to health and health care, and eventually the poor health outcomes that many experience. Availability of quantitative data to inform this process is critical to the goal of delivering the patient-centered care that adolescents deserve.