Health-related quality of life (HRQOL) is defined as the impact of an illness, medical therapy, or health service on the ability to participate and have satisfaction in the physical, psychological, and social experiences of life [1]. HRQOL is particularly important to adolescents and young adults with special healthcare needs (AYASHCN) as they begin preparing to transition to adult-based care. In a 2016 study that used a Delphi method to identify healthcare transition outcomes most important to AYASHCN, achieving optimal quality of life (QOL) was rated highest, followed by a multitude of areas such as understanding the condition, medication knowledge and adherence, self-management, understanding health insurance, avoidance of unnecessary hospitalization, and having a social network [2].

A growing body of research on adolescents and young adults (AYA) populations has documented the connections between HRQOL and health outcomes. AYA perceived self-efficacy—predicted all QOL domains in a survey of 292 AYA with a variety of chronic illnesses [3]. Perceived self-efficacy, in turn, has been associated with greater adherence to treatment regimens and better glycemic control among adolescents with Type 1 diabetes [4], whereas engaging in more health-promoting behaviors has been associated with more favorable QOL [5]. Conversely, poor HRQOL has been linked with higher levels of anxiety [6,7]; higher levels of depressive symptoms; lower subjective wellbeing, self-esteem, and psychosocial functioning [7]; and poorer physical health [8]. AYASHCN identified as nonadherent have reported poorer health perceptions, self-esteem, mental health, family cohesion, and more limitations in social and school activities related to physical, emotional, and behavioral problems. Collectively, these findings suggest that empirically based assessment of HRQOL in the clinical setting may help identify those AYA at the highest risk for behavior, emotional, and school difficulties and nonadherence [8].

In this issue of the Journal of Adolescent Health, Singh et al. report on differences in adolescent self-reported HRQOL and parent-proxy reports of HRQOL in Jamaican adolescents [9]. Two hundred twenty six parent/adolescent pairs (130 with asthma, human immunodeficiency virus, insulin-dependent diabetes mellitus, or sickle cell disease and 96 healthy peers), mean age 14.9 ± 2.8 years, completed the Pediatric Quality of Life Inventory (PedsQLTM4.0 SF15) generic core scale and General Well-Being modules, resulting in three QOL summary scores: (1) psychosocial health, (2) physical health, and (3) the total score. Parent-proxies overestimated total QOL and physical QOL subscales as compared to adolescent reports regardless of whether the adolescent had a chronic illness. Parent-proxy report for adolescents with insulin-dependent diabetes mellitus and asthma was higher in several QOL domains, whereas there were no significant discrepancies for youth with sickle cell disease or human immunodeficiency virus. Although prior studies have acknowledged discrepant adolescent and parent-proxy HRQOL reports [10,11], the Singh et al. study provides new information about HRQOL in Jamaican youth, noting the cultural context may uniquely influence reports of HRQOL. However, Singh et al. did not include measures unique to Jamaican culture, which makes interpretation of differences across studies from different countries difficult. Future research is needed to further explore the impact of cultural context on HRQOL reporting and other factors influencing family responses on reports, or adolescent discomfort in disclosing concerns. It is helpful to further explore these discrepancies to obtain a comprehensive view of adolescent functioning and inform clinical interventions. Awareness of
cultural background and possible influences in reporting could open a conversation within the family regarding patient functioning and delineate adolescent and parent concerns.

Once specific QOL concerns are identified, interventions and recommendations can help improve QOL in various domains. Although there is little guidance on using QOL in various domains. Although there is little guidance on using QOL in various domains. Although there is little guidance on using QOL findings to inform intervention planning [12], a pilot program for QOL assessment and intervention planning in a group of adolescents who were on dialysis highlighted the need for QOL assessment with a follow-up discussion and intervention planning to see subsequent improvement in QOL [12]. Interventions could be broad and education-based if QOL scores and discussion uncover misunderstandings or misperceptions among family members regarding aspects of health. As familial social support has been related to treatment adherence in adolescents with chronic illness [13], a general parent-adolescent communication intervention may be broadly beneficial for adolescents with chronic illness.

Interventions may also be specific and based on domain-specific scores. For example, concerns in the physical domain could be relayed to the medical team for support with regimen management or referral for physical therapy; a meta-analysis for adolescents with cancer [14] found that exercise interventions had positive effects on generic QOL. Low emotional domain scores could highlight the need for referral to a mental health professional to further assess and treat emotional concerns (e.g., anxiety or depression). Working with a mental health professional was one of the most frequently chosen QOL interventions [12] and a review of psychologist-led interventions in adults with cancer found resulting improvement in depression, anxiety, PTSD, and/or QOL [15]. AYA with low scores in the social domain might benefit from connection with families who have similar medical conditions, attendance at chronic illness-specific camps, or mental health interventions. A review of impacts of chronic illness–based camps for children and adolescents found some consistency in improved social outcomes [16]. Low scores in the school domain could prompt interventions with the school (e.g., obtaining a 504 Plan for accommodations based on medical needs). Neul [12] found that academic planning and support was one of the most chosen QOL interventions in a sample of patients on dialysis. Ideally, interventions in any of these areas would yield an improvement in QOL and subsequent physical and/or mental health improvements.

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References