

A Developmental Examination of Patient Engagement and Quality of Care in Adolescent Oncology

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The Institute of Medicine places the patient at the center of their high-quality cancer care conceptual framework, arguing that supporting patient engagement within the cancer setting is the highest priority for the improvement of cancer care in the United States. Adolescent cancer patients make up a unique cancer group due to tumor biology, specific cancer-related challenges, and social and cognitive factors unique to this developmental period. Within adolescent medicine, there are two main approaches for achieving high-quality care and increased patient engagement – patient-centered care and family-centered care. The current study examined a sample of 80 adolescent cancer patients, and determined how engagement is associated with self-reported quality of care, and the moderating roles of models of care, patient age, and development. A cross-sectional survey design was utilized, and participants were recruited in-person at two local hospitals. Participants recruited for this study were diagnosed with their most recent cancer diagnosis between the ages of 10 and 20, were at least 3 months from their most recent diagnosis, and had finished active treatment in the last two years (if they were not currently receiving treatment). A combination of correlations, multiple linear regression, and moderation analyses were utilized. Overall, the study found no significant relationship between patient engagement and quality of care, and models of care and patient's age and development did not moderate this relationship. Participants reported experiencing patient-centered care more often than family-centered care, but family-centered care was significantly correlated with patient engagement. Finally, cognitive development was the only unique, significant predictor of patient engagement in the current study. These findings demonstrate the necessity of examining

adolescent cancer patients as their own unique group. Patient engagement does not play the same role in adolescents' perceptions of quality of care as we see in adults. Future research will need to further elucidate what aspects of their experience are important in improving quality of cancer care in adolescent cancer patients. The examination of developmental metrics was a novel aspect of the current study, and it exemplified the importance of development in adolescent cancer patients' experience, but also the need to examine multiple developmental metrics.