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Our Care Wishes – Adults with Congenital Heart Disease (OCW-ACHD)

The majority of patients born with congenital heart disease (CHD) survive to adulthood. However, these adults with CHD, particularly those with more complex disease, remain at high risk for ongoing chronic illness and premature death. Although survival and life expectancy are certainly increased, published average life expectancy for a patient with moderate to severely complex forms of CHD ranges from 37-54 years of age. Despite this risk, most adult CHD (ACHD) patients have never discussed their end-of-life (EOL) care wishes prior to being hospitalized with end stage or life-threatening illness. As a result, they are more likely to receive aggressive medical care and die while hospitalized than other patients with chronic illnesses. Advance Care Planning (ACP) is the process of choosing a substitute decision maker and outlining preferences for the types of medical care preferred when nearing or at end of life. ACP improves quality of life, leads to earlier referral to supportive care, decreases the use of aggressive medical interventions at the end of life and improves the quality of death. Current ACHD society guidelines advocate that patients and providers engage in ACP discussion. Other studies demonstrate that ACHD patients desire early ACP discussion. However, for a variety of reasons, these discussions rarely occur. No tools currently exist to aid in ACP for the ACHD population. Most available tools are geared towards elderly patients. We think that the availability of an online ACP tool that is designed specifically for the ACHD population will increase patient understanding of, participation in and completion of ACP. Working within a patient-centered framework, we plan to modify an available, existing online ACP tool to the unique needs of ACHD patients and to ascertain the feasibility, acceptance, and effectiveness of an ACHD-specific ACP tool. Study results will eventually support a future, large scale trial randomized trial to evaluate the use of this ACHD-specific ACP tool on the quantity and quality of ACP discussions and impact on quality of life and EOL care in this population.