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Quality of life in adults diagnosed with familial adenomatous polyposis and desmoid tumor.

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**PURPOSE:** The purpose of this study was to examine the health-related quality of life in a sample of Canadian adults diagnosed with familial adenomatous polyposis and desmoid tumor. **METHODS:** The study was conducted in two parts. Seven individuals participated in a focus group prior to a mail-out survey. A cross-sectional mail-out survey was administered to eligible individuals who were actively followed at the Familial Gastrointestinal Cancer Registry at Mount Sinai Hospital. **RESULTS:** Forty-one individuals (25 female and 16 male) were available to be contacted by the registry coordinator and 23 questionnaire packages were completed, resulting in a 56.1 percent participation rate. The results of this study demonstrated a reduced health-related quality of life for individuals living with familial adenomatous polyposis and desmoid tumor for over 10 years. The main predictors of health related quality of life in this analysis included marital status (married vs. not married), prior knowledge of desmoid tumor in the family, and current level of hopelessness ( $R(2) = 0.856$ ,  $df = 13$ ,  $F = 26.8$ ,  $P < 0.001$ ). The qualitative content analysis of themes from the focus group indicated that ongoing medical uncertainty and lack of information from health care professionals, isolation, and family communication were the main challenges in living with desmoid tumors. **CONCLUSIONS:** The findings from this study suggest that ongoing education of health care professionals is warranted and that information and support interventions may be beneficial to this clinical population.