Course of Crohn's disease prior to establishment of the diagnosis.


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BACKGROUND: The course of Crohn's disease prior to the establishment of the diagnosis is widely unknown. Therefore, we instigated a survey amongst newly diagnosed patients. PATIENTS AND METHODS: Patients diagnosed with CD less than 12 months before enrollment were included. Data on demography, social status, time interval to diagnosis, symptoms, and health care service use were collected in a retrospective, web-based, census. Patients were contacted in cooperation with two organizations: a German patients' organization (Deutsche Morbus Crohn/Colitis ulcerosa Vereinigung e.V. [DCCV]) and a professional organization of German gastroenterologists (Berufsverband der Niedergelassenen Gastroenterologen Deutschlands e.V. [bng]). Study participation was anonymous by use of a transaction number. RESULTS: The median interval period between onset of first symptoms and diagnosis was 13 months. During this time, participants reported having five doctor consultations on average, with 44% of them having a mean of 1.5 hospitalizations. 65% were unfit for work with a 14 day median (2 to 480 days) due to their symptoms. A mean (+/-SD) of 8.6 (+/- 7.1) diagnostic tests were performed before the diagnosis was established. Overall health state was judged as temporarily bad or very bad by 84% of the participants. Age at diagnosis, characteristic symptoms, and localization of the disease for the participants did not differ from previously reported international data. DISCUSSION: This web-based survey shows a substantial time interval of over one year until diagnosis of Crohn's disease amongst the study participants. This period is characterized by both psychological stress and impaired ability to work.