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Quality of life in patients with chronic pancreatitis – Possibilities of measurement of the phenomenon in research

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ABSTRACT

Objective: To discover which of the measurement tools were used for the assessment of quality of life (QoL) in patients with chronic pancreatitis (CP); to search for a specific tool that was validated and standardized directly for CP; to summarize the main areas of symptomatology that dominated the decrease overall in QoL in patients with CP.
Methods: The method of the overall conceptualization approach was the analysis, comparison, critical discussion and summarization of the available results of studies researched between 2000 and 2014 in relevant databases. The analyzed studies were included in the selective sample according to predefined criteria. This paper presents the results of a partial objective regarding a comprehensive research project.
Results: The identified tools include the following questionnaires: SQUALA (1 study); SF-36 (4 studies); SF-12 (6 studies); EORTC QLQ-C30 in the form of QLQ-PAN26 (3 studies). A specific and new tool is PANQOLI (1 study). The most significant factor of decreased QoL included pain; other factors were: chronic diarrhoea, digestion issues, diabetes mellitus, severity and length of disease, number of relapses and comorbidities, loss of job, unemployment, early retirement, financial issues, sleeping issues, fatigue. On the contrary, the aetiology had no effect on QoL; the same applies to surgery or endoscopic therapies.
Conclusion: To assess QoL the following questionnaires were used: subjective QoL questionnaires specific for chronic diseases, and a questionnaire originally intended for patients with tumour diseases. This shows a degree of interest in the area of QoL in CP patients. The sum of the findings can be used for a comparison between domestic results and to identify the dominant CP symptoms. A great challenge is the standardization and linguistic validation of the PANQOLI questionnaire in the Czech sociocultural environment.

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Introduction

Chronic diseases present a serious issue of the current society, while morbidity is increasing. They include long-term diseases that are virtually incurable. Chronic pancreatitis (referred to as "CP") is defined as a constantly worsening inflammatory process affecting the functional gland parenchyma, which gradually causes its destruction and fibrotic restructuring. In later stages, the disease causes exocrine and eventually also endocrine pancreatic insufficiency [1, p. 682]. The symptomatology of this benign disease significantly decreases the quality of life in patients [2, p. 3]. CP is described as an exhausting, long-term disease with a number of uncomfortable symptoms, which are dominated by pain [3, p. 39]. CP is not a common disease, the incidence and prevalence rates vary geographically [4, p. 88], and the occurrence of the disease is slightly increasing. The TIGARO categorizes the disease as toxonutritive, idiopathic, genetic, autoimmune, recurrent acute pancreatitis and obstructive [5, p. 520, 6]. The most frequent symptoms, which also have a direct effect on quality of life in patients, include pain, losing weight, steatorrhoea, diarrhoea, subicterus or icterus of intestinal dyskinesia, nausea, vomiting and diabetes mellitus. The less frequent symptoms include pancreatic ascites, hydrothorax, thrombosis of the portal or linear vein with left-sided portal hypertension, bleeding in the upper parts of the digestive tract. Possible complications include origination of pseudocysts, abscesses, concrements of the pancreatic duct, inflammatory masses, obstructions or stenoses of the duodenum and biliary duct. Pain is the most frequent and dominant symptom of CP. Pain is indicated by 85–90% of patients [5, p. 520]. Painless form of the disease are indicated by only 10% of patients. Pancreatic pain is caused by a number of pathological mechanisms; its origin is of a multifactorial aetiology. The origin of pancreatic pain is an ongoing inflammation of the parenchyma, nerve inflammation, increased pressure in the pancreatic duct caused by obstruction leading to increased pressure in the pancreatic tissue, stenosis of the descending part of the duodenum and intrapancreatic part of the biliary duct and possible pressure on the pancreatic tissue and cystoid duct [4, p. 90, 6, p. 184–7]. The specifics of pancreatic pain were described in a review article by Chrastina and Bednářová [7]. The aetiology of this long-term disease is of a multifactorial nature. Relevant studies emphasize a coincidence of genetic, developmental and environmental factors. On their own, these factors do not present a sufficient cause for the origination of the disease and at the same time are not required for the disease to occur [8]. An exception is the hereditary, obstructive and probably also the autoimmune form, which the existence of the disease is clearly caused by a single, main etiologic factor [6].

To define the concept of "quality of life" (abbreviated as "QoL") is a very difficult task [9–11]. Presently, there is no single definition agreed on by all authors. The concept can be defined as a subjective assessment of an own life situation [10,12]. Available definitions of quality of life slightly differ; however, all of them are based around life satisfaction of an individual [11].

Quality of life is a holistic phenomenon [11, 13, p. 89]. It expresses a combination of experiencing personal wellbeing, satisfaction and frequently also a certain position within social stratification [13]. Kitrungroter and Cohen [14, p. 625], and Peters and Sellick [15, p. 525] understand quality of life as a "dynamic and subjective indicator of assessment of an individual's life". The element of the dynamic nature and multidimensionality is also indicated by Davidová et al. [16, p. 165], who describes the quality of life as a result of mutual interaction of social, health, economic and ecological conditions relating to the individual human being as well as to the social life. From a perspective of holistic understanding of an individual, the quality of life can also be defined as a "multidimensional and subjectively perceived construct, which influences all domains of an individual's life. Similarly, the level of QoL depends on whether the existing life conditions match the needs, wishes and desires"[14, p. 630]. It might be stated that the concept of QoL covers information about the physical, mental, social and spiritual condition of an individual [17,18] and is determined by a number of factors. These are life circumstances, health conditions and many others [11]. Other factors influencing quality of life include age, sex, race, education, marital status or present social situation, acknowledged values, economic situation, religion, cultural background, polymorbidity, etc. [10]. A sociological and philosophical perspective clarifies the achievement of personal goals, self-realization in the society, achievement of personal potential as a determinant of the resulting quality of an individual's life [11]. Quality of life is a purely subjective quantity [13,19], dynamic quantity [11,13] and depends on various circumstances, time and situations under which it is assessed [11]. Health-related quality of life (HRQoL concept) focuses on the areas of the overall quality of life that are affected by health or disease [12, p. 116]. This concept objectifies the effect of disease on the patient as perceived by the patient. This approach evaluates the impact of the symptoms of a disease in everyday activities of the patient, existence and degree of limitation perceived by the patient in connection with the disease [19]. Contemporary medicine considers the quality of life an appropriate indicator of physical, mental and social health [9]. Health-related quality of life issues are assessed by means of standardized questionnaires. This area uses three types of tools for HRQoL assessment – global, generic and specific. The application of the WHOQOL-BREF tool in various groups of patients is noted, e.g. by Bužgová et al. [20]. A priority in comprehensive recovery of patients with chronic diseases is to maximize the patients' functioning in everyday life and to achieve the highest possible level of overall satisfaction [21, p. 39]. The goal of each therapy is to eliminate the symptoms or at least decrease the discomfort caused by the disease [22,23]. In the context of the present health care system, the assessment of quality of life is a significant parameter of assessing the effectiveness of treatment and individualized interventions [11, p. 17, 20, p. 246, 23, p. 406]. The overall wellbeing subjectively perceived by the patient and the patient's functioning, are among the indicators that can be used to quantify the effect of various types of therapy and to assess their benefit for the patient [24, p. 1]. Pezzilli et al. [25] recommend routine application of quality of life questionnaires to assess the perception of overall satisfaction in patients with chronic pancreatitis in order to select those who require more intensive medical and

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