

The reflection of the quality of life of people with Crohn's disease in nursing

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Abstract

OBJECTIVES: To determine the quality of life of patients with Crohn's disease and to determine if this is reflected by the quality of nursing care.

METHODS: For the purpose of this research, we used a generic standardized questionnaire of the quality of life, published by the World Health Organization (WHOQOL-100). The questionnaire was distributed among 100 patients with Crohn's disease and among 1456 members of healthy population. To analyze the results, we used the SPSS program and appropriate statistical methods.

RESULTS: The comparison of the domain scores of population standards in the Czech Republic and the respondents with Crohn's disease revealed a difference in the domain "physical condition", where the mean value was at the limit of the lower interval of the standard, and in the domain of "independence".

CONCLUSION: The results given in this study define the possibilities of nurses and their functioning associated with altered quality of life. An evaluation of the most affected areas allows nurses to determine an appropriate intervention. Providing nursing care, in accordance with the latest knowledge, must be based on the quality of life. This newly incorporated area offers healthcare professionals a new dimension for assessing and determining subsequent interventions.

INTRODUCTION

A better understanding of the quality of life of patients brings to a new perspective to nursing care. Although there are several definitions of quality, some of which date back to antiquity, nursing does not work with them exclusively. Nursing care cannot be limited only to performing certain procedures; it is also necessary to develop the field in the scope of contextual comprehension and, above all, with respect for human individuality. In order to fulfil this, it is necessary to know the context that may help to

reveal the determinants of quality of life. Knowing and understanding which areas of human life are most affected, in the context of endangered qualities, enables modern nurses to respond to emerging health care issues. One of the aims of nursing is to maintain, restore, and support an individual's health and development of self-sufficiency. This objective cannot be achieved only by implementation of learned procedures regardless of human individuality. Assessing treatment only on the quality of execution of a procedure is a sign of stagnation. A patient's quality of life is constantly changing and the concept of appropriate provided care must change with it.

The 'quality of life' concept is integral in nursing and is closely linked to the provision of meaningful nursing care. It allows care planning that provides the greatest benefit to the patient in accordance with their needs and preferences (Olišarová *et al.* 2013).

Crohn's disease occurs primarily in young people, the median is between 25 and 28 years. It is a chronic disease with periods of relapses and remissions (Češka *et al.* 2012). In the Czech Republic, there are 4–6 new cases per 100,000 inhabitants per year. The number of new cases in developed countries is increasing, especially among the population of older children and adolescents. Currently, there are both medical and surgical treatments, but it remains an incurable disease. Five to ten percent of patients suffer from severe and irreparable structural changes in the digestive tract, which results in a permanent disability. Therefore, it is necessary to address fully the 'quality of life' issues faced by patients who suffer from this disease.

MATERIAL AND METHODS

For the purpose of this research, we used a generic standardized quality of life questionnaire from the World Health Organization (WHOQOL-100). The questionnaire contained 100 items, covering six domains related to quality of life: (1) physical health, (2) mental level, (3) physical independence (self-sufficiency), (4) social relations, (5) environment, and (6) mental health. The questionnaire covers 24 aspects of life and has four items that evaluate overall quality of life and overall health.

The target groups were patients with Crohn's disease living in the Czech Republic. According to the latest available sources, the incidence of Crohn's disease ranges from 18 to 22 cases per 100,000 inhabitants per year. In absolute numbers, according to the latest data of the Institute of Health Information and Statistics (ÚZIS), there are 17,783 people with Crohn's disease (2011; ÚZIS data). The age distribution of patients suffering from this disease is known only in general terms. The largest group consists of those aged 15–30. Credible data on patient gender is not available. The starting point for the design of the sample was the population of the Czech Republic over 20 years old, which was, on 31/12/ 2011, 8,423,099 people (according to the data from the Czech Statistical Office). The number of patients with Crohn's disease was, as already mentioned, in 2011, according to the data of ÚZIS 17,783 persons, it means 0.21% of the total number of inhabitants of the Czech Republic over 20 years. This group represents the basic file for the needs of the research. The sample size was set at 100 people – patients with Crohn's disease, it means 0.56%. Given that the structure of the sample of the patients with Crohn's disease by gender and age is not known, the requirements for representativeness of a sample were not defined and the file was constructed by random selection, when the only requirement was the

presence of the diagnosis of Crohn's disease. Based on the above criteria the distribution of the questionnaires was managed by organizations that provide long-term care for large numbers of such patients (The Sisters of Mercy of Charles Borromeo Hospital, Prague, CZ, and The České Budějovice PLC Hospital, České Budějovice, CZ). Further help with the distribution was provided by the outpatient department of MUDr. Jelínek, (Klatovy, CZ). One-hundred and twenty questionnaires were distributed, of which, exactly the required 100, were returned. The response rate was therefore 83%. After an analysis for missing values in the questionnaires, with the upper limit set at 5%, no questionnaires were eliminated. Therefore, all 100 questionnaires were used.

For comparison purposes, a second (control) group was formed of healthy individuals chosen from the Czech Republic. The control group was established as a representative sample. There are 8,423,099 age appropriate inhabitants of the Czech Republic, i.e., aged ≥ 20 years. This age limit was chosen based on the limits of occurrence of Crohn's disease in the Czech Republic. The sample was subdivided according to gender and age. The respondents were divided into six, 10-year age groups. The highest age range was 70–79 years and above. Fifteen hundred questionnaires were distributed and 1456 were returned. The rate of return was 97%. After an analysis for missing values in the questionnaires, with the upper limit set at 5%, 15 questionnaires were excluded (1.03% of the control group). The final file, suitable for processing, numbered 1441 respondents.

Statistical methods

In the first phase, we carried out a preliminary descriptive and exploratory analysis of the individual items of the questionnaire WHOQOL-100, followed by an analysis of missing values, which showed, among other things, the number of questionnaire missing more than 5% of responses, and therefore needed to be excluded from analysis. For those questionnaires where the response rate was below the threshold, the missing entries values were replaced by answers generated using estimates adjusted by random residue and regression equations.

The next phase involved the calculation of the six domain scores from the WHOQOL-100. These were calculated as the average value of a variable number of the corresponding "facets".

The control group was represented by a large sample of healthy individuals chosen from the general population of the Czech Republic, as described in the user guide for the Czech version of the quality of life questionnaires from the World Health Organization (Dragomirecká and Bartoňová 2006).

Finally, we performed an actual analysis of the differences of the mean domain scores between the groups. Additionally, it was necessary to determine the distribution of variables entering analyses. This was done using

the Kolmogorov-Smirnov's test (at $p < 0.05$). Results showed that, due to an abnormal distribution of the variables in the healthy population (that entered all analyses comparing differences), it was necessary to use the non-parametric Mann-Whitney U test (at $p < 0.005$). In all analyses, we used the SPSS 15.0 program.

RESULTS

A sample of healthy individuals was compared with the standard for the Czech Republic. This standard is provided by the user guide of the Czech version of the quality of life questionnaires from the World Health Organization. The results of our research show that the average value of domain scores, for our control group of healthy individuals was consistent with the standards set by 2006 version of the manual (Table 1).

When comparing the domain score of the population standards in the Czech Republic and respondents with Crohn's disease, a difference was found in the domain "physical condition", where the mean value was at the lower limit of the interval of the norm (Table 2). The value of the domain score for "independence" was significantly below the norm.

The domain "physical condition" includes unpleasant physical sensations that a person may experience,

and demonstrates how these feelings disturb the individual's life. It is, for example, pain and how a person controls it, and how easily a person can achieve pain relief. With regard to pain, our patients with Crohn's disease had lower quality of life scores (Mann-Whitney's test, < 0.05). Conversely, a better quality of life, compared with the healthy population, was found in the facets: body image and appearance, mobility, social support, sexual activity, living environment, learning opportunities and skill training, natural environment, ease of transport, and conditions supporting spirituality.

The energy and fatigue facet focused on energy, zest for life and ability to perform the necessary tasks related to the activities of daily living. This facet was also assessed lower by those with Crohn's disease relative to the control group (Table 3).

Another domain that those with Crohn's disease evaluated differently than health individuals was "independence". This domain contains the following four facets: mobility, activities of daily living (ADL), addiction to drugs or medical procedures, and work performance.

Table 4 shows that respondents reported higher scores, compared with the healthy population, with regard to the mobility facet, but not as well with regard

Tab. 1. Comparison of domain scores of WHOQOL-100 CR relative to the population norms of the Czech Republic and of average score values in the control group used in the this research.

Domains	Norm interval			Healthy population N = 1141
	Lower threshold of the norm	Mean of the norm	Upper threshold of the norm	
Physical condition	14.3	15.4	16.5	14.9
Psychical experience	13.5	14.4	15.3	14.6
Independence	15.9	16.9	17.8	16.0
Social relations	14.0	15.1	16.1	15.2
Environment	13.8	14.6	15.4	14.8
Spirituality	12.2	13.9	15.6	13.0

Tab. 2. Description of the mean values of WHOQOL-100 facet scores and the differences between healthy individuals and Crohn's disease respondents (Mann-Whitney's test at $p < 0.05$).

Domains	Healthy population N = 1441			Crohn's disease N = 100			Mann-Whitney's U test
	Mean	Median	STD*	Mean	Median	STD*	
Physical condition	14.89	15.00	2.35	13.97	13.67	2.65	0.000
Psychical experience	14.57	14.60	1.94	14.65	14.80	1.96	0.595
Independence	16.05	16.50	2.48	14.55	14.75	2.50	0.000
Social relations	15.23	15.33	2.08	15.80	16.00	2.26	0.012
Environment	14.82	14.88	1.81	15.11	14.88	1.75	0.211
Spirituality	13.00	13.00	3.35	13.72	14.00	4.07	0.040

* Standard divergence

Tab. 3. Description of the mean values of facet scores on the WHOQOL-100 and the differences between those with Crohn's disease and healthy individuals (Mann-Whitney's test: $p < 0.05$)

Domain "physical condition"	Healthy population N = 1441			Crohn's disease N = 100			Mann-Whitney's U test
	Mean	Median	STD*	Mean	Median	STD*	
Facet 1 pain and discomfort	9.32	9.00	2.83	10.05	10.00	3.26	0.013
Facet 2 energy and fatigue	14.51	15.00	2.58	12.66	13.00	3.34	0.000
Facet 3 sleep and rest	15.49	16.00	3.15	15.31	16.00	3.76	0.986

* Standard deviation

Tab. 4. Description of the mean values of facet scores on the WHOQOL-100 and the differences between those with Crohn's disease and healthy individuals (Mann-Whitney's test: $p < 0.05$)

Domain "independence"	Healthy population N = 1441			Crohn's disease N = 100			Mann-Whitney's U test
	Mean	Median	STD*	Mean	Median	STD*	
Facet 9 mobility	15.84	16.00	3.10	16.71	17.50	3.20	0.002
Facet 10 ADL	15.91	16.00	2.64	15.32	16.00	3.05	0.068
Facet 11 dependency on drugs and treatment	7.47	6.00	3.60	13.28	13.00	4.16	0.000
Facet 12 work performance	15.91	16.00	2.77	15.44	16.00	3.16	0.105

Tab. 5. Question: To what extent does the quality of your life depend on taking medication or on medical care?

Sign	Absolute rate	Relative rate
1. at all	5	5.0%
2. a little	22	22.0%
3. moderately	25	25.0%
4. a lot	28	28.0%
5. at the most	19	19.0%
No answer	1	1.0%
Total	100	100%
Modus	3. moderately	
Mean	3.34343	
Standard deviation	1.16482	

Tab. 6. Question: To what extent do you need medication?

Sign	Absolute rate	Relative rate
1. at all	6	6%
2. rather not	9	9%
3. moderately	25	25%
4. rather yes	20	20%
5. completely	40	40%
No answer	0	0%
Total	100	100%
Modus	5. completely	
Mean	3.79	
Standard deviation	1.22715	

to the facet of dependence on drugs and treatments. As the table shows, the quality of life of the respondents is degraded by taking medicaments.

As an example of the protocol used, Table 5, shows a typical question processed with frequency values: "To what extent does the quality of your life depend on taking medication or medical care?" For a condition like Crohn's, the choice of "a lot" is not unexpected.

The predominant response to the question "How essential is the need for medication?" was "absolute" (Table 6). This means that the respondents who suffer from Crohn's disease are aware that the use of drugs limits their own lives to some extent.

When comparing the mean values of the facet and domain scores, with regard to demographic data such as gender, there were no statistically significant differences. In contrast, when comparing the same, with regard to the current health status of the respondents, we found statistically significant differences in the domain of "social relations" and the facets of 'social relations' and 'social support', with healthy individual reporting higher scores than those with Crohn's disease (Table 7). The frequency distribution, according to current health status, shows that from a total number of 95 respondents with Crohn's disease, 81 respondents reported feeling unhealthy, while only 14 reported feeling healthy. However, it should be noted that not all the respondents perceived the question the same way. Someone could have interpreted it to mean their current state regardless of the diagnosis of his or her long-term illness, and someone, on the other hand, someone else could interpret it to mean a general description of their current state of health, including their diagnosis.

Tab. 7. Description of the mean values of the facet scores on the WHOQOL-100 and the differences between those with Crohn's disease and healthy individuals (Mann-Whitney's test: $p < 0.05$).

Domain "social relations"	Mean		Median		STD*		Mann-Whitney's U test
	Ill N = 81	Healthy N = 14	Ill	Healthy	Ill	Healthy	
Facet 13 personal relations	15.94	17.50	16.00	18.00	2.32	1.40	0.017
Facet 14 social support	15.84	17.57	16.00	18.00	2.64	2.50	0.022
Facet 15 sexual activity	14.94	15.93	15.00	16.00	3.47	2.46	0.381

* Standard deviation

DISCUSSION

It is difficult to track and define the quality of life, especially in connection with nursing. However, finding limiting factors regarding the quality of human life is one of the objectives in the field of nursing. Based on this finding, it is possible to identify the needs and determine appropriate interventions. In the Czech Republic, there have been several studies focused on monitoring quality of life. Olišarová *et al.* (2013) pointed out that research in the Czech Republic, focused on quality of life, found that the monitoring quality of life is an important part of a comprehensive patient evaluation, since it can detect hidden problems.

In our research, we focused on a specific disease, which without doubt affects the quality of life of affected individuals. As indicated by Češka *et al.* (2012), it is a disease that occurs in periods of relapses and remissions of inflammation. The manifestation of the disease depends on the extent and location of the disease, as well as on the character of the local inflammatory changes. The latest available Czech statistics, from 2012 (Typltová 2013), reported that Crohn's disease constitutes 12% of all registered gastroenterological diseases. In 2012, 17.8 out of every one hundred thousand, or 18,749 people suffered from Crohn's disease in the Czech Republic. Compared to the number from 2005, this was an increase of 51%. This is an alarming increase in the number of people with this disease. Therefore, the probability that a nurse will encounter patients with this disease is clearly on the rise. Rendl and Tóthová (2013) reported that quality of life is directly related to a health problem regardless of its acute or chronic nature; however, patients with chronic diseases indicate, in most cases, that they have a higher quality of life than patients suffering from acute diseases do. This can be influenced by the adaptability to the disease.

In our research, we determined which domains were most affected relative to quality of life in patients with Crohn's disease. As mentioned, these were the domains "physical condition" and "independence". The domain "physical condition" is formed in the WHOQOL questionnaire by the facets of pain and discomfort, energy and fatigue, and sleep and rest. If we focus on the symp-

toms of Crohn's disease, which are derived from impairment in the gastrointestinal tract, we can observe pain, weight loss, diarrhoea, high temperature, fatigue and/or anaemia (Lukáš *et al.* 2005; Češka *et al.* 2012). It concerns the symptoms that are reflected in our research, respectively in the responses to the questionnaire. The same results were also drawn by Smith *et al.* (2002) when they investigated the influence of a nurse consultant on the quality of life of patients with non-specific intestinal inflammation. In their research, the quality of life of the respondents also reflected the symptoms of the disease. Additionally, disease symptoms can also affect the mental state of patients.

Pain was reported as statistically significant. It is therefore evident, that this annoying symptom interferes with the quality of life. Pain management is part of the overall, comprehensive treatment of Crohn's disease. This, however, requires the use of medication, which can also affect quality of life. Medication issues are reflected in the domain of "independence". This domain includes issues of addiction or dependence on medication and other treatments. Medications can affect quality of life in two ways. First, medications can have both negative and positive impacts on the quality of life. Our study suggests that respondents were dependent on medication and/or other medical procedures. Respondents reported that disease treatment interfered with their lives, regardless of whether it was medical or surgical treatment. The treatment of Crohn's disease also represents a considerable financial burden for patients. As reported by Yu *et al.* (2008), hospitalization of patients with Crohn's disease is a major constituent of the direct costs of medical care (in Europe, direct costs for the treatment of Crohn's disease represent 64–69% of the total costs). However, indirect costs, exemplified by reduced productivity in the work place are much higher. Understanding the determinants that affect the quality of life of patients with Crohn's disease was also the goal of a study by van der Have *et al.* (2014). Their meta-analysis showed that the most common determinants included absenteeism, increased activity of the disease, number of relapses, corticosteroid treatment and the number of hospitalizations. If we look on their findings, it is clear that these areas were also manifested in our results.

Another important symptom, although it is non-specific, was fatigue. This symptom was included in the quality of life assessment. Compared to healthy individuals, those with Crohn's disease reported feeling more tired and having less energy.

The "psychological experience" domain, which consisted of negative or positive feelings, there were no differences between those with Crohn's disease and healthy individuals. It is clear that this condition is largely affected by the stage of the disease, whether the respondents are in a period of remission or relapse. Although our research did not find a difference in quality of life in the domain "psychological experience" there have been several studies that reported a link between inflammatory bowel disease and mental health problems, such as anxiety or depression (Kurina *et al.* 2001; Mardini *et al.* 2004; Mittermaier *et al.* 2004).

The results of the questionnaire led us to ask the question; in what ways can a nurse positively affect a patient's quality of life? This issue was studied by Hernández-Sampelayo *et al.* (2010), with the goal of identifying scientific evidence regarding quality of care in the management of inflammatory bowel diseases, at the levels of structure, process, and outcome, in relation to nurses. The results showed that nurses play an important role in the care of patients with inflammatory bowel diseases. Many other studies have also dealt with finding answers for these questions. Finding new ways by which nurses can influence patients' quality of life is an important field of research in nursing. The interventions that nurses provide within the nursing process cannot be limited to interventions related to the disease itself or its symptoms. On this basis, it is also possible to develop standards and associated quality of care. It has also been confirmed by the Society of Gastroenterology Nurses and Associates (2014), which deals with developing the quality of the standards of clinical nursing practice in gastroenterology.

In an interventional study by Nightingale *et al.* (2000), 339 patients received educational materials about lifestyle, health promotion, medication, and diagnostic methods. Additionally, patients had access to a direct telephone line to a nurse specialist. The result was that hospital visits were reduced by 38% and average length of the stay in hospital was reduced by 19%. The number of patients in remission increased from 63% to 69%. As for access to information on inflammatory bowel diseases, patients' satisfaction improved. These numbers reflect the importance of nurses in patient education. According to the results of the research, it is evident, that the costs associated with treating these patients also diminished.

The domain, in which the respondents in our survey reported better quality of life in comparison with the healthy population, was the domain of "social relations". This may be related to the fact that patients with Crohn's disease have opportunities to socialize in support groups. Even here, the nurse can play a role, which

was pointed out by Leshem (2003). He pointed out that nurses play an important role in the formation and coordination of support groups for patients with non-specific inflammatory bowel diseases. He also makes recommendations for nurses to evaluate the quality of life, well-being, stress levels, and anxiety in patients. He also states that nurses have the experience, knowledge, and skills to organize and administer support groups.

CONCLUSION

This paper highlights the changes in the quality of life of people with Crohn's disease. These changes may not be obvious to health care professionals. When selecting appropriate interventions, these changes must be taken into consideration, and need to be reflected in the quality of nursing care. Crohn's disease is not just a disease of the digestive tract; it is a disease that also stigmatizes the patient. It interferes with a patient's everyday life and causes pain and discomfort. Compared with healthy individuals, those with Crohn's disease are more likely to suffer from fatigue or changes in vital energy, which to some extent is linked to lifelong treatment and lifestyle changes. In this respect, it should be noted that these factors directly affect the lives of patients and their families, as well as the labor market. By nature of the contemporary philosophy of nursing, which is based *inter alia* on holism, medical treatment and nursing care must be directed toward the whole person, including the bio-psycho-social and spiritual aspects. If nursing care is based on the latest knowledge, then it must be based on an assessment of quality of life. This newly incorporated area offers healthcare professionals a new dimension of assessing and determining subsequent interventions. It also opens up a new role for the nurse specialist in the field of gastroenterology, which requires highly professional and comprehensive nursing care. This care is based on evidence and established interventions with the combined goals of improved disease management and optimization of quality of life.

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