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# THE ROLE OF PATIENTS IN THE MANAGEMENT OF CHRONIC DISEASES: RESULTS OF THE FOCUS-GROUP STUDY

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## ABSTRACT

The management of chronic diseases shall be considered a priority in the work of the global international institutions, which are related to health policies. In the search for effective and efficient solutions for the treatment of chronic diseases, scientists are developing different programs. In Bulgaria the continuous monitoring of chronically ill people is defined with the term dispensarization. The objective of the research is to analyze the place and the role of patients in the monitoring of their chronic diseases and how the concept of quality of life relates to this process. Method The research in focus groups is planned within a research project on the monitoring of chronic diseases. Five group discussions were held. The number of participants in all focus groups was sixty. Results The two discussed directions - the active role of the patient and the focus on the results are weak links in the current organization of the care for the chronically ill people. The topic of creating and adopting an Act of the patient was also presented, in which to be paid attention to the evaluation of the quality of life. In general was brought the need for a clear delineation of the roles and the competencies of everyone involved in the monitoring process of chronic diseases. The chronic disease cannot be defined only as a medical problem, as there are economic and social, including political consequences. Conclusions The management of the chronic disease requires coordination of doctor-patient interaction, a model of partnership and trust in the relations, self-management of the condition by the patients and their inclusion in the health team. The most important step to achieve this goal is the education of the patients, increasing their knowledge and motivation, psycho-emotional support, instilling hope and faith in the capacity of the patients.

## UDC CODE & KEYWORDS

■ UDC: 614.2 ■ Health care system ■ Chronic care ■ Patient ■ Quality of life

## INTRODUCTION

The management of chronic diseases shall be considered a priority in the work of the global international institutions, which are related to health policies. Walters et al., (2012) defined the management of the disease as widely pragmatic approach aimed at chronic diseases through comprehensive care, including diagnosis, treatment and support, prevention, early detection and self-management. This multidisciplinary approach is united around the patient and his disease, and is adapted to his needs and specific environment.

In the search for effective and efficient solutions for the treatment of chronic diseases, scientists are developing different programs. In Bulgaria the continuous monitoring of chronically ill people is defined with the term dispensarization. An Ordinance is applied, which sets out the diseases that are tracked, who coordinates the process – GPs or a specialist; the number and frequency of the necessary examinations and the sources of funding.

According to J. Bousquet et al., (2011) the leading line is the transition to client-centered integrative care and multi-model and systematic approach to cope with chronic diseases in order to reduce the burden and the social impact on people and society (Bernard & Ryan). Putting the patient at the center of the system sets a number of challenges related to a change in thinking, the approaches to work and the modes of doctor-patient interaction.

The objective of the research is to analyze the place and the role of patients in the monitoring of their chronic diseases and how the concept of quality of life relates to this process.

### Method

The qualitative research in focus groups is planned within a research project on the monitoring of chronic diseases.

The selection of participants was made with the idea of a heterogeneous and informal group. The following categories of participants were invited in writing – physicians from primary care; specialists; health managers and patients.

A form of prior information about the process of conducting the focus groups was prepared, including written informed consent at enrollment. The group discussions were held in the period – January to June 2013.

Five group discussions were held. The number of participants in all focus groups was 60, as the distribution of the categories of participants and the duration of the work are presented in (Table 1).

Each group was moderated by host and co-host. Three researchers from the team were tasked to lead the focus groups to the previously identified four main themes. The key for the successful work of the participants was the establishing of the right atmosphere of shared trust and the discussion of different points of view. Of each focus group were made audio recordings, which at a later stage were transcribed. In total the operating time of the five groups was 06:10h.

The coding of the performance of the five groups was conducted in three steps, using thematic analysis. In the first stage each moderator separately encoded certain phrases from the statements of the participants. The goal was to formulate a

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Table 1: Monitoring of chronic diseases

| No. of group | N of participants | Gender | | GPs | Specialists | Patients | Institutions | | | Health managers |
|---|---|---|---|---|---|---|---|---|---|---|
| | | M | F | | | | RHI | BMA | RHIF | |
| 1 | 11 | 4 | 7 | 9 | | 1 | | 1 | | |
| 2 | 11 | 3 | 8 | 7 | | | | | 2 | 2 |
| 3 | 10 | 3 | 7 | 1 | 4 | 2 | | | | 3 |
| 4 | 13 | 4 | 9 | 1 | 4 | | | 1 | 2 | 5 |
| 5 | 15 | 3 | 12 | 3 | 2 | 1 | 1 | | 1 | 7 |
| TOTAL | 60 | 17 | 43 | 21 | 10 | 4 | 8 | | | 17 |

RHI - Regional Health Inspection
BMA - Bulgarian Medical Association
RHIF – Regional Health Insurance Fund

Source: Authors

set of topics that were considered as key issues for discussion. The second stage was to sort and summarize the topics into categories. There was an optimal saturation of the concepts in the formation of the categories. In the last stage were synthesized themes, a result from the joint work of the researchers, which were discussed and finalized as a result of the discussions in the focus groups.

## Results

The present organization for monitoring of chronically ill patients in Bulgaria – the dispensarization, is rigid with a fixed number of tests and examinations, which leads to the main theme, a consensus across all focus groups – “lack of individual approach”. The participants reported that the patient is rather isolated, and there is no flexibility in the monitoring of the disease.

In the foreground was displayed the theme on “the responsibility of the patients” in the process of tracking and their motivation. In most chronic diseases the patients are required to comply with certain mode of life as part of their therapy. In this line of thinking, the theme of their “basic health literacy” is essential.

An interesting discussion stimulated the theme on the “patient as part of the team”. This again goes back to the responsibility of the patient, but in the groups this theme was greatly enriched with the discussion of the patient awareness and the need for education of the patient. Here, there is a place not only for the education of a specific patient by a physician and/or a team, but also for the mass health education events, such as shows or media publications. In this context is discussed also the topic of self-help groups. The whole range of propositions reflects on the efficient use of resources not only in the health system, but also in the society as a whole. In our country, the education of the patient is not seen as a separate part of the overall treatment plan. The formation of self-help groups has been sporadic. There is lack of funding for such activities. The “schools” for the chronically ill could be a model, form of health policy that promotes the activation of patients. What is controversial is that in the focus groups prevailed the opinion that such health policy should happen again on national level, the opportunity to test models on regional levels was not adopted.

The discussions were directed to the necessary change in attitudes and respectively was brought the theme of “the implementation of a patient-centered approach”. The participants agreed on the idea of an early education of medical professionals in the approach, right from the student bench.

One of the themes discussed in all groups was “the quality of life”. This is directly related to the individualization of the process of tracking of the chronic diseases, because the attitude to the providing of the quality of life for a certain patient is not only related to the medical care, but also to rehabilitation and to social services. The participants in the focus groups inextricably linked the concept of quality of life with the holistic approach to health care. On the other hand, the quality of life of the patients with chronic diseases is widely accepted as a criterion for assessing the impact of medical care. Common in the groups was the opinion that it is necessary to be drawn up a strategy for assessing the quality of life in chronically ill patients by compiling and applying standards.

The two discussed directions - the active role of the patient and the focus on the results are weak links in the current organization of the care for the chronically ill people. Topics that should be more widely discussed and according to the participants in the focus groups the professional organizations need to be more involved. The same applies to the patient organizations, although their multitude often leads to diverging interests. The topic of creating and adopting an Act of the patient was also presented, in which to be paid attention to the evaluation of the quality of life. In general was brought the need for a clear delineation of the roles and the competencies of everyone involved in the monitoring process of chronic diseases. The chronic disease cannot be defined only as a medical problem, as there are economic and social, including political consequences.

## Discussion

The significant increase in the incidence of chronic diseases and their impact on the individuals and their families leads to the need for many countries to rethink the organization of the health systems by changing the focus from the diagnosis and the treatment of the patients to their conduct in the management of the disease and the prevention of its complications; there is a need of partnership with healthcare professionals and the deployment of initiatives to reduce the sense of isolation of the chronically ill people as weekly group seminars; individual support and multidisciplinary counseling based on primary medical practice (Johnston et al., 2012). In the same vein, in the present study was discussed the lack of individual approach and the isolation of the patient, as a fault of the organization for monitoring patients with chronic diseases.

Interesting are the topics discussed by health managers in the Netherlands, also in the conditions of focus-group discussions. The patterns of disease management in the primary medical care were analyzed – the barriers, the roles and the responsibilities of those involved in the process (Walters et al., 2012). There was a discussion on the ways to reform the health care in the direction of a general model focused on chronic diseases. They highlighted the need for client-centered care to be implied as a leading paradigm in the health system.

The comprehensive view on the health care system should include the perspective of the patients, their experience. In a qualitative study, Yen et. al., (2010), displayed the differences that doctors and people with serious, long-term illnesses have in terms of health problems and the approaches to find solutions (Baker et al., 2005).

The client-centered model offers several key dimensions: the understanding of the overall personality; discovery of common ground; incorporation of the prevention and the health promotion; enhancement of doctor-patient relationship and a realistic attitude. According to a study of Hudon et al., (2012), the management of chronic diseases expands the client-centered approach by incorporating new aspects/areas: the legitimacy of the experience, gained in the disease; the competence of the patients and their knowledge and offering hope and inclusion of the family physician as the patient's advocate in the process of care (Vadiee, 2012).

The challenge is in the new way of the provided health care and motivating the patients to assume personal responsibility for their own health. This reform concerns primarily a change in the thinking and behavior of the patient and the doctor, which is defined as a long and difficult road. The key changes, affecting patients, are: moving from passive (accepting) to active (responsible) role; participating as a member of the health team; adopting a new lifestyle, health education and behavior (Walters et al., 2012; Vadiee, 2012; Loss, 2010; Eckman et al., 2012).

There is a similarity to literature in the topics of the present study, which are related to the health literacy. The low health literacy discourages patients to do the necessary consultations and tests. This is in the basis of the understanding of the patients of their own illness, their ability to manage the risk factors and to change their health behavior. As a consequence is disrupted the cooperation between patients and health professionals. The bad cooperation with chronic diseases is regarded as a global problem and is even characterized as a "hidden epidemic", because it deteriorates the medical outcomes and thus adversely affects the quality of life of the patient, on the one hand, and, the health care costs, on the other hand (Booth et al., 2013).

The education of the patients has an important role in their active inclusion in the healing process. Their participation in the health team helps in the search for resources to deal with the disease and the improvement of the health status. The experience of the application of educational programs shows how the increased knowledge for the disease affects the lifestyle, and the change in the lifestyle affects the health outcomes. These new skills are especially effective for people with inadequate health literacy and for people with health education. The educational interventions seriously affect the health behavior and the personal responsibility of the patients (Spicer et al., 2012).

We could conclude that some of the themes in this study reflect the passive position given to patients in the present organization for tracking the chronically ill people, which is supported by disease-centered approach, applied by medical specialists. In the same vein could be interpreted the other themes, affecting the outcomes. Improving the quality of life of the patient is determined as the main objective of the programs for care of the chronically ill. Precisely the quality of life is seen as an aggregate for the success of a program. The chronic diseases, which are subject to medical follow-up programs, are characterized by their long course and inability to be cured. Since the cure could not be an objective, then the only option for us is to strive for quality of life, in order to be able to evaluate the treatment efforts. The problem has been widely discussed in the literature, with various proposed instruments for evaluation (Steinhaeuser et al., 2011; Meyer et al., 2013; Wensing et al., 2008; Taggart et al., 2011). In our country the quality of life is not measured formally as part of the follow-up programs of chronically ill patients. Not accidentally, during the discussions in the focus groups, was synthesized the view of individuality and subjectivity of the perception of quality of life, the difficulty in determining the standards and the evaluation criteria.

## CONCLUSION

In conclusion, the themes emerged in this study have showed the passive role of the patient in the current organization for tracking of the chronic diseases. Changes in the health policies should make the dispensary observation attractive for the patients; the implementation of mandatory activities not be regarded purely quantitative and in the practice to be used indicators in the assessment of the quality of life.

The management of the chronic disease requires coordination of doctor-patient interaction, a model of partnership and trust in the relations, self-management of the condition by the patients and their involvement in the health team. The most important step to achieve this goal is the education of the patients, increasing their knowledge and motivation, psycho-emotional support, instilling hope and faith in the capacity of the patients. The new role of the physician is to become a guide to the patients in their way to cope with the disease. The medical professionals are increasingly interested in the personal perspectives of the people according to their health status and what quality of life can be achieved in the presence of the relevant disease.

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