

# Disease Management and the Patient's Role in This Process

## Hastalığın Yönetimi ve Hastanın Bu Süreçteki Rolü

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Geliş Tarihi/Received: 06.11.2015  
Kabul Tarihi/Accepted: 01.02.2016

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**ABSTRACT Objective:** With increasing life expectancy increases and chronic morbidity. Health authorities are making efforts to put into effect initiatives for organizing of effective medical monitoring of chronically ill patients. In Bulgaria, the chronically ill are tracked according to rules on a national level. The goal that we had set in this study was to understand the disease management process, emphasizing the involvement of the patient, as well as the quality of life. In addition we studied the experience of other countries undergoing reforms in the strategies and approaches for dealing with chronic diseases. **Material and Methods:** We used a qualitative method of research - focus groups that include different medical specialists. **Results:** In the discussions was considered the possibility for the patient to be a part of the team, but generally such a setting is not typical for our country. As a whole, the discussion regarding the concept of quality of life was tied for time and a relatively small number of topics were formulated in this regard. The role of the GP and the creation of multidisciplinary teams, cooperation between departments as a prerequisite for improving the quality of life of chronically ill patients were also discussed. **Conclusion:** Patient satisfaction is directly related to the active involvement and responsibility for their own health.

**Key Words:** Public health; chronic disease; patients

**ÖZET Amaç:** Beklenen ömürün uzaması ile birlikte kronik hastalıklar da artmaktadır. Sağlık uzmanları kronik hastaların etkili tıbbi takiplerini organize etmek için girişimlerde bulunup, çaba harcamaktadırlar. Bulgaristan'da kronik hastalar ulusal düzeyde konulan kurallara göre izleniyorlar. Çalışmamızın amacı, bu hastalıkların tedavi süreçlerini araştırmak, hastaya ilişkin yönleri üzerinde durmak ve böylece olabildiğince yaşam kalitesini artırmaktır. Ek olarak, diğer ülkelerdeki bu alandaki yenilikleri ve reform stratejilerini incelemeyi amaçladık. **Gereç ve Yöntemler:** Farklı tıp alanlarındaki uzmanları içeren araştırma odaklı grupların kalitatif yöntemini kullandık. **Bulgular:** Tartışmalarda hastayı ekibin bir üyesi olarak ele aldık, fakat bu durum bizim ülkemize özgü değildir. Bütün olarak tartışmada, yaşam kalitesini artırmaya yönelik sayıları az da olsa fikirlere yoğunlaşıldı. Genel sağlık hizmeti veren pratisyen doktorun multidisipliner ekipteki rolü ve bu hastaların yaşam kalitesini artırmak üzere departmanlar arasında işbirliği sağlanması üzerinde duruldu. **Sonuç:** Hastaların memnuniyeti, kendilerinin aktif olarak kronik hastalıkların yönetim sürecine katılmaları ve kendi sağlıklarıyla sorumlu olmaları ile doğrudan ilgilidir.

**Anahtar Kelimeler:** Halk sağlığı; kronik hastalık; hastalar

Türkiye Klinikleri J Health Sci 2016;1(3):157-162

With increasing life expectancy accumulates and chronic morbidity, data for this tendency is in the national and international health institutions in developed countries. Health authorities are making significant efforts to put into effect various initiatives over the past two decades, for organizing of effective medical monitoring of chron-

ically ill patients. In parallel, evidence is accumulated in the strategies for dealing with chronic diseases and challenges the effectiveness of existing approaches.<sup>1-4</sup>

In recent years the so called Chronic Care Model has established itself.<sup>5</sup> The model created in the U.S. in the 90s of the last century by Edward Wagner, is widely used in many countries nowadays. The program includes elements to improve healthcare at municipal level, health facility, practice and patients. In this process an active role as providers of medical services have the health professionals and the patients themselves.

In Bulgaria, the chronically ill are tracked according to rules of organizing and funding that are carried out on a national level and regulated by Decree 39 of the Ministry of Health and the National Framework Agreement.<sup>6,7</sup> The term “dispensary treatment” is used.

The goal that we had set in this study was to understand the involvement of the patient in the disease management process, emphasizing his important role in the effectiveness of the healing process, as well as the quality of life.

## MATERIAL AND METHODS

Qualitative research was performed by means of focus groups.

After written informed consent 60 participants took part. Five heterogeneous groups were formed, included general practitioners, specialists from different fields working in hospitals or in out-patients clinics; health managers; health economists and patients.

Each group had a moderator and co-moderator, an audiotape of the work in the focus groups, with subsequent transcription was made.

The analysis was done in several stages. First, each moderator individually selected specific phrases from the discussion, which were evaluated as key codes for specific opinions and positions. In the second stage, the coded information was sorted, again by each of the moderators, and categories were developed. Comparing the results from the

three moderators showed a high degree of agreement on the categories. In the third stage, the three moderators worked together to synthesize topics, and agree on the final analysis.

## RESULTS

Dispensary treatment of the chronically ill in the country is done on a voluntary basis, in that sense the position of the patient plays a significant role. In the focus group, the opinion circulates that patients remain passive.

*“... The patient is not participating; on the one hand, system rejects him, with this walking and waiting in consulting rooms ...”*

*“... In terms of the patient's rights; you as a doctor are not entitled to exercise pressure; and we come again to the willingness of the patient to assume their responsibility ...”*

In the discussions was considered the possibility for the patient to be a part of the team that is based on the assumption that patients are motivated to care for their condition, but generally such a setting is not typical for our country.

*“... We founded a training center for patients with diabetes, we have a very good organization, but attendance is low, as if patients are not used to this, and are not ready ...”*

These topics are logically related to taking personal responsibility for coping with the disease –

*“... The patient should be trained in order to enable him to take responsibility.”*

In the discussions is commented the issue of the so-called self-help groups, that are considered an efficient approach, but are not popular in the country.

*“.... The promotion makes sense and should be a national policy, general practitioners do in the conversation, but it's nice to make campaigns, to be a matter on national level... Schools for training of patients to be financed, to be established as a model, a policy, with media presentation an adjustment that the patient must be involved....”*

In the focus groups has been clearly outlined the opinion that it is necessary to significantly improve basic health education.

*"... There is a need to speak about people's health awareness... quality of life is individual, there are people that care about quality of life, but there are others who harm themselves and they burden the health system; assessment is very relative ..."*

As a whole, however, the discussion regarding the concept of quality of life was tied for time and a relatively small number of topics were formulated in this regard.

*"... The quality of life is a complex concept, patients need not only medical care but also social assistance, a psychologist, we speak of diets ..."*

*"... The care needs to be taken up by a multi-disciplinary team: psychologist, social worker, nurse; this is not just about treatment, but for the quality of life, risk factors, and campaigns for prevention of chronic diseases as well...."*

The understanding of the concept of quality of life is clear, but in an enclosed plan it remains good to know it. In practice, the quality of life is not evaluated, there is even missing criteria.

*"... Now we only register whether we did or not certain activities; no one cares about the patient's condition, about his state of mind, and everything is very difficult for him...."*

*"... We want to help teams develop in terms of nursing care, earlier there was home care, now you can barely get a nurse to come to your home, they rarely visit patients in their homes ...."*

This problem could be solved by setting standards and a comprehensive strategy for assessing the quality of life related to health. According to participants it is very essential for evaluation to be in conformity with contemporary approaches in the care for chronically ill - individual and holistic.

On the other hand is discussed the physician's responsibility that he has towards patients with a confirmed diagnosis and treatment of chronic diseases. The role of the GP and the creation of multidisciplinary teams, cooperation between de-

partments as a prerequisite for improving the quality of life of chronically ill patients were also discussed.

*".... Most important is the communication between the structures for the benefit of the patient ....."*

The discussion did not miss the importance of *health promotion, early diagnosis of socially significant diseases, purposeful demand and motivation for reducing removable risk factors, prevention of complications and rehabilitation.* These topics are directly associated with chronic diseases and their effective tracking, issues which at this stage are not enough in the focus of policies on taking care of the chronically ill. Dispensary is often limited to recurrent consultations and basic prescription of supporting medication.

## DISCUSSION

Focus groups have been described as a method of discussion, carefully planned, and the purpose is to gather information obtained in a tolerant and not threatening for participants' environment. This method can generate a lot of information, which is unachievable by the quantitative methods. In focus group discussions it is possible to understand the cognitive and emotional responses of the participants and to track the group dynamics. This data complements quantitative approaches to understanding the world. Unfortunately, quantitative and qualitative methods are often interpreted as conflicting rather than complementary strategies.

Our team chose this method as suitable for obtaining information about the attitudes, opinions, expectations and positions of the interested countries. The aim was to answer certain questions in terms of in-depth debate, discussion and analysis. This is particularly useful in understanding how certain countries consider specific cases, incidents, and they also help to fill gaps in people's understanding of their own problems. Researchers receive more detailed information, and the summary of the attitudes, beliefs and opinions can shape new ideas and lead to fully understanding certain issues.<sup>8</sup>

According to Bousquet et al., chronic diseases can be viewed as an expression of a common group of diseases with different risk factors, socio-economic determinants and accompanying illnesses. The authors focus on the development of multidisciplinary client-centered management of chronic diseases. Recommendations include the determination of the severity of the disease and control, and effective interventions and research to unite around carefully phenotyped patients who strictly follow medical standards. The patient should be placed in the center of the system. In order to improve health care worldwide and decrease inequality, an innovative approach is developed- "P4 medicine" for improving the management of chronic diseases. The expected results are: better support for patients; significant improvement in prevention and options for treatment; innovative health systems involving more activities in the patient's home; cost reduction and new interdisciplinary training program.<sup>9</sup>

Training programs for disease management have been the subject of discussion and focus groups consisting of patients with chronic diseases: asthma, diabetes, epilepsy, and cancer. Summarized topics resulting from the work of the focus groups concentrate on the following issues: dealing with fear and anxiety; need to trust the medical specialist and finding a balance between medical care and personal effort "to be a manager of your own case." Other important issues include knowledge about the next stages of the disease and knowledge about the characteristics of the disease, management skills of chronic illness and dealing with the accompanying mental and emotional problems. For patients these are important gaps which need to be filled. Generally people who suffer from diabetes and asthma are more informed than those who have epilepsy. This raises questions about the preparation of general practitioners and specialists to inform and educate patients how to control their disease. Primary care teams face daily challenges for chronically-ill people.<sup>10,11</sup>

Another aspect that corresponds with our study is the discussion of the relationship between quality of life and participation in initiatives sup-

porting patients. Those who participated in self-help groups are better adapted to living with the disease, while people in difficulty of their condition have trouble keeping a job and feel socially isolated.

These findings confirm the importance of psychosocial factors for chronic disease management and recognition of this aspect as equivalent in importance with the treatment itself. Data from this study shows how some people can successfully adapt to the illness of indefinite duration, while others face serious difficulties in coping with the disease and this has a negative impact on different areas of their lives. Another important social aspect of chronic diseases is recognized - the stigma of living with a disease such as epilepsy or cancer. Pragmatic perspective of the management of chronic diseases should reflect positively on all spheres of life of the individual patient.

Doctor-patient relationship is the most important element in the process of treatment and care. It is filled not only with medical significance, but also psycho-emotional, social and philosophical. Along with the diagnosis, treatment and the regime, very important aspects are trust and agreement between the two sides, the responsibilities of the patient, communicative exchange, being informed, support by the doctor, independency and reporting of personal uniqueness. Today we talk about "the patient-expert" in the healing process and this raises the question of patient's competence. The role of informed consent is directly related to the autonomy of choice, the therapeutic relationship, satisfaction and outcomes. It is believed that the more competent the patient, the more active and responsible he will be for his own health, style, and quality of life. In a study of Moreau et al., is treated the shared decision making as part of a client-centered care and the place of the patient in the course of his treatment and follow-up. Focus groups were conducted among patients for discussion of clinical studies on three different medical problems: care in the cases of hypertension, prostate cancer and breast cancer. The results allow for an expanded interpretation of the concept of client-centered

care by incorporating various integrative models for doctor-patient interaction.<sup>12</sup>

Most patients accept the decision as a shared decision, a carefully considered question and answer in interaction with the doctor who allows patients to be experts in getting more clear information, participation in the healing process, negotiating compromises with the opinion of the physician. This gives the patient the right to a second opinion and control even with the paternalistic model that is preferred by the elderly people. Facilitating factors (trust, qualitative non-verbal communication, and time for reflection) and obstacles/constraints (complex/emergency situations, inadequate scientific competence, failure to file an application, requirement, fear of information) are part of shared decision making. The role of counseling, patient's education and self-management skills are considered the Keys in the Chronic Care Model and the improvement of the condition of patients with chronic diseases.<sup>13,14</sup>

Study on the quality of the communication process is carried out by Moretti et al. Scientists have conducted a series of focus groups among patients in Italy, England, Belgium and Holland conducted under standard conditions. The aim of this study is to analyze the quality of doctor-patient communication from the perspective of patients and to provide new views on doctor-patient interaction in different European countries, which will contribute to the evolution of the patient-expert. Analysis of data from focus groups can contribute for a better understanding of the communicative behavior of doctors and patients' expectations for the development of interaction. The problem of quality of medical services is associated with satisfaction of the patients' professionalism of medical specialists' experts and effectiveness of the health system. An essential role in this process plays the so called "compliance", the result of a built trust, cooperation and satisfaction between doctors and patients on the one hand and the relationship between them and other health care institutions.<sup>15</sup>

Another important aspect is the role of the nurse as part of the medical team. In the article presented by I. Eijkelberg et al., is described an inno-

vative approach for providing care for chronically ill patients through a special nurse who was named head of shared care. Experience in applying this type of health care shows that this is a good solution for filling the gap between primary and secondary care. Such a practice nurse acts as a patient-level coordinator. The data obtained from the shared experiences of patients participating in the focus groups indicates the importance of this method in the study of working models of care for chronically ill patients through qualitative methods.<sup>14</sup>

The role of the nurse is important for persons in need of care at home, lonely or disadvantaged. Issues of this type of care are not resolved in our country. They are both on organizational level and on the level of education and training. Care includes two elements - medical supervision, care and support in dealing with the social aspects of life. Much of this care is provided by unqualified personnel working in national operative programs, after completing a short training course. Existing methodologies developed by the Ministry of Labour and Social Policy, in which the focus is customer care and improving his quality of life. Policies and procedures to protect the autonomy and independence of the person, and his personal data, and the development of an individual plan of care are developed. The needs for this kind of help then it comes to the aging population in Bulgaria, and the increase in the number of people that need long-term care requires a national strategy for specialized training of medical professionals to offer these activities.<sup>16</sup>

In our country the quality of life of chronically ill patients is directly related to health and social problems and insufficient funds set in the state budget for health. For those who have cancer this is a problem that they face daily. For patients even the question for allotting more money for prevention in an economic crisis is ambiguous. Studies discover a lowered social activity and quality of life, estimated as bad for two thirds of the examined patients with cancer. For 87.7% of the interviewed the disease is the leading event, bearing negative emotional charge, re-



duced self-esteem and opportunities for social adaptation.<sup>17</sup>

Data obtained from studies of numerous authors on the vital function of patients with cardiovascular disease showed a number of problem areas and major changes in the normal way of life of these people. The challenge for contemporary health care is with the treatment to reduce the impact of disease on the demands of everyday life, profession and family role, working for social adaptation and quality of life in the presence of chronic disease. The opinion that the monitoring of lifestyle is essential for its duration and satisfaction from achieving life goals is formed.<sup>2,18,19</sup>

## CONCLUSION

Patient satisfaction is directly related to the active involvement and responsibility for their own health, resulting in better health outcomes. Tack-

ling disease requires a better self-understanding by patients and a better understanding of the common causes of chronic diseases. The importance of adherence in the doctor-patient interaction plays an important role for the trust in the healing process and its optimal effectiveness.

Models offering health care for patients with chronic conditions integrate structures and experts from different fields who unite their efforts and resources for better quality of life despite the disease.

The information from such qualitative studies can be successfully used to create new strategies to improve health care, reduce the cost of health and achieve years of a satisfactory life of good quality.

The research in focus groups is planned within the project: **HO-04/2012** Public Health. Monitoring of chronic diseases - a multidisciplinary approach, funded by a competition inside a university for research projects of the Medical University of Plovdiv.

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