Original Research

DOI: 10.5152/cjms.2021.2162

A MULTIDIMENSIONAL APPROACH TO CHRONIC DISEASE MANAGEMENT: PATIENT HEALTH ENGAGEMENT MODEL

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Received Date: 30.06.2020

Accepted Date: 06.12.2020

How to cite: Usta D, Korkmaz F. A multidimensional approach to chronic disease management: The Patient Health Engagement Model. Cyprus J Med Sci 2021; DOI: 10.5152/cjms.2021.2162

This article has been accepted for publication and undergone full peer review but has not been through the copyediting, typesetting, pagination and proofreading process, which may lead to differences between this version and the Version of Record. Please how to cite: Bağrıaçık E, Bostanoğlu H. Determination Of Nurses' Perception Status For Nursing Diagnoses. Cyprus J Med Sci 2021; DOI: 10.5152/cjms.2021.1568 - Available online at <https://cyprusjmedsci.com/EN>

A multidimensional approach to chronic disease management: The Patient Health Engagement Model

Abstract

Chronic disease management is a complex process that requires adaptation to unfamiliar lifestyle changes and long-term treatment, starting from the diagnosis until the end of life. In this case, healthcare professionals should inform the patient about the process, support their self-management skills, and adopt the appropriate approach, taking into account their emotional responses and perceptions about the disease process. The Patient Health Engagement Model is the most current person-centered care approach that is based on strengthening the patient's active role in maintaining chronic disease self-management. The model reveals that the patient undergoes sequential phases (blackout, arousal, adhesion, and eudaimonic project) according to the critical situations experienced in the process. By defining the phases, the model enables healthcare professionals to determine the patient's needs in terms of cognitive, emotional, and behavioral dimensions, plan individualized care, and integrate the patient as an active member of the healthcare team. Therefore, it is aimed to describe patient's experiences in chronic disease management starting from diagnosis, introduce the Patient Health Engagement Model, and discuss its use in chronic disease management. It is thought that this review will guide the nurses in our country to use the model in chronic disease management and will provide an effective approach to clinical practice.

Keywords: chronic disease, nursing, self-management, patient engagement

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INTRODUCTION

Chronic diseases are irreversible conditions that have a long duration, slow progression [1], which do not fully recover [2]. The World Health Organization reported that in 2016 71% of global deaths were due to chronic diseases [3], and this number would rise to 22.2 million in 2030 [3]. Studies in Turkey have found that 86% of deaths occur due to chronic diseases [4]. Therefore, the results demonstrate that chronic disease management has become a worldwide issue due to the high prevalence and mortality rates.

In addition to being a common problem, chronic diseases typically cause irreversible changes in the long term [5]. Reduction/loss of physical function and independence, limitation of daily life activities, matters in family roles, and coping difficulties are the main challenges [6]. These changes have indicated that the chronic disease process and related complications are not effectively managed. For individuals to manage their chronic conditions, they mainly need to comply with medical treatment, make changes to life patterns, and deal with psychological problems caused by the disease [7]. As a result, it is expected that individuals with chronic disease will adopt an approach in which they fulfill their responsibilities.

The Patient Health Engagement model is the most current approach and is highly recommended to maintain chronic disease self-management of where the patient takes individual responsibility and an active role during his/her care [8]. Accordingly, this article aims to discuss the use of the Patient Health Engagement Model (PHE Model) addressing cognitive, emotional, and behavioral dimensions in the chronic disease process. The topic will be discussed under two main sections of (i) the chronic disease management process and (ii) the use of the PHE Model in chronic disease self-management.

Chronic disease management: A lifelong development process

Chronic disease management is a developmental process in which a person adapts to live with a lifelong chronic condition [9]. This process appears with the individual becoming aware of a range of physiologic changes and symptoms in their body. The person initially may not attach importance to these changes but expect that they will get better; however, when symptoms do not disappear, they try to figure out the cause of the problems and associate with some realities. Symptoms with unknown causes may result in an individual's fear of losing health. To cope with this situation, they may take responsibility for their health in an attempt to resolve symptoms themselves. For example, they may use nonprescription analgesics to relieve pain, try medications used by other patients, or orient toward alternative medicine. When the person accepts that they cannot manage their symptoms, they utilize the healthcare services.

With an active role while managing symptoms until they attend the healthcare services, the patients mainly adopt a passive role during the diagnosis stage because they depend on health professionals to learn and recognize the cause of the changes they cannot manage. Additionally, due to the uncertainty they experience anxiety, have difficulty in perceiving health information and play a dependent role, by leaving most decisions to health professionals and relatives [10]. In this process, the priority for both patient and healthcare professionals is to complete diagnostic tests in the shortest time possible and to begin treatment [11]. During the diagnosis

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period, it was showed that patients experience problems in treatment adherence, they delay doctor's appointments, and are hospitalized repeatedly [12, 13]. All these results reveal the difficulties in chronic disease management when the patient has limited responsibility in this stage.

When encountering the new symptoms and dealing with the diagnosis, patients follow a self-management process where they accept the chronic condition and take responsibility for their health. Self-management is defined as individuals undertaking the tasks necessary to live well with one or more chronic situations [14]. This process requires adapting to a new nutritional pattern that most patients are not used to, performing regular physical activity, attending routine check-ups and repeating diagnostic tests, continuing the recommended medication treatment, and adapting self-monitoring behaviors to daily life [15]. It may be difficult for most patients to adjust to the complicated process [16], additionally, they require motivation to sustain these behaviors through life [17]. Effective self-management of chronic diseases ensures early awareness of newly-occurring symptoms, reduced attendance in emergency services, and lengthened survival durations which reflect in public health in the long term positively [18]. The ineffective self-management cause maladaptations to new behavior patterns, frequent admissions to emergency services due to noncompliance with medical treatment, and reduction in quality of life [19].

Previous studies have emphasized that patient education methods focusing on cognitive/behavioral levels that require the passive role of the patient are mainly used to sustain effective self-management dealing with treatment adherence [20, 21]. However, patient education is not sufficient to sustain adherence to treatment and lifestyle changes and generally was conducted spontaneously, without planning or determining individual goals [22]. As a result, planned interventions remain limited in ensuring patients' desire to take responsibility for their health and to continue their self-management skills through life [21]. The patient's motivation should be considered for effective self-management because the patient being able to give meaning to the chronic disease in the emotional dimension ensures the development of internal control focus and behavior changes that can be sustained for life [23]. For this reason, interventions for effective self-management including the cognitive, behavioral, and emotional levels will provide the most effective outcomes [24, 25]. Thus, concepts targeting giving a more active role to the patient based on cooperation between the patient and health professionals, involving patients in clinical decision making, supporting self-management, and allowing to plan individualized care in three levels have gained importance [26].

There are plenty of terms introduced in the last years highlighting patients' active role gradually [27-30]. In line with this, through the concepts of patient compliance, adherence, involvement, participation, activation, and empowerment support the active role of the patient, but most of these concepts can be used interchangeably and define patient's different roles in the process [27, 29, 30]. Finally, patient engagement is introduced as uniting all approaches under one roof, embracing a holistic view by considering individuals' needs in cognitive, emotional, and behavioral levels [31]. Different from others, patient engagement creates a cooperative atmosphere between individuals and health professionals [32], strengthening patients by

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expanding viewpoints to include their experiences and aiming for them to have more “words” in healthcare services delivery [33]. Focusing on developing the health knowledge, skills, and desire of patients managing their health, it addresses on protecting the health and gaining healthy life habits [34].

The patient engagement concept has provided positive clinical outcomes [21]. A range of results has presented that patient engagement facilitated for healthcare professionals to become easily aware of the patient’s needs, improve clinical outcomes, enhance treatment adherence and compliance to healthy life habits, increase awareness about risky life behaviors which reduce complications and contributed to the sustainability of the healthcare system [11, 28, 33, 35-37]. Finally, the ‘Patient Health Engagement Model’ was introduced based on several qualitative studies to define how individuals can become engaged in the care process [33].

PHE Model for chronic disease self-management

The Patient Health Engagement Model aims to assess the patient’s attitude to chronic disease management, readiness to manage care, and sense-making related to the disease [28]. The model supports the patient on cognitive, emotional, and behavioral levels; not only facilitate obtaining health-related information and self-management skills but also maintaining the emotional balance of the chronic care continuum [35]. Additionally, the model ensures the collaboration between the patient and the healthcare team in which the patient mainly make health decisions and managing their care, and this experience is combined with the knowledge accumulation of healthcare professionals. Therefore, the patient and health professionals form a partnership about the decision-making process [38]. From this aspect, the Patient Health Engagement Model can be qualified as being more comprehensive than other chronic care approaches.

The Patient Health Engagement Model reveals that individuals pass through phases in sequence according to critical events (like diagnostic testing, the occurrence of new symptoms, compliance with a new treatment, recurrence of disease) experienced during the process after receiving chronic disease diagnosis [11]. Dealing with these unexpected critical events causes severe stress and anxiety in the patient most of the time. This situation may negatively affect the patient’s desire to undertake active self-care and to participate in decisions related to treatment. As a result, healthcare professionals should determine the patient’s engagement phase and plan individualized interventions. The phases describing patients’ specific experiences are followed as blackout, arousal, adhesion, and eudaimonic project [39].

1. Blackout: The blackout position is where the patient is emotionally fragile due to a newly-occurring critical event (like diagnosis, the occurrence of a new symptom or recurrence) with the difficulty of facing a new reality [39, 40]. The patient initially feels shocked, fearful, anxious, and panicked due to the unexpected situation and unable to manage the health condition which results in loss of control in his/her health [41]. All these negative emotions cause difficulty in the transformation of this new health information into understanding, interpretation, and behavior; in other words, “cognitive blindness”. In the blackout phase, the patient tends to leave decisions related to the chronic disease process to health professionals

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with superior professional knowledge and skills and takes a passive role [40, 42]. At this point, the most basic expectation of the patient is to receive information about the disease from a trusted healthcare professional.

2. Arousal: In the arousal phase, the patient gains initial awareness in emotional terms after diagnosis. However, they display excessive sensitivity to every clinical symptom in the body and are always tense; as a result, each new symptom qualifies as an ‘alarm bell’ [40]. Compared to blackout, patients have obtained superficial health information; however, this information is still abstract. This is because fear and anxiety continue so the behavior does not reflect their health knowledge and they have difficulty sustaining new life habits [39, 43]. As a result, in this new adjustment process, the patient frequently needs to ask doctors/nurses whether they are correctly doing what they have been told or not [43]. In this phase, although there are positive effects of medication treatment, the most common problem is treatment noncompliance [42]. They encounter problems in adjusting the prescribed medication doses, self-administering invasive medications, or taking multiple doses. This may cause worsening of disease symptoms, lowering of quality of life, and disengagement of daily life activities [43].

3. Adhesion: In the adhesion phase, the patient has better-developed health literacy levels and chronic disease management skills compared to the blackout and arousal phases and becomes more stable emotionally [40]. The patient accepts the negative feelings caused by the diagnosis and the disease process but still does not have full autonomy about self-management. In particular situations with any change in life habits (going on holidays, travel for work, etc.) they may experience difficulties sustaining their disease management skills adapted to routine life [39] because the patient has not fully understood the rationale for the treatment plan. As a result, the patient may require motivation to sustain the new health behavior in stressful situations or during unexpected changes in lifestyle [41]. In the adhesion, the patient begins to recognize the importance of playing an active role in chronic disease management. This first awareness of the identity role of the patient is the pioneer of the final eudaimonic project phase.

4. Eudaimonic project: In the eudaimonic project phase, the patient has fully adjusted to the process from the start with skills obtained related to the cognitive, emotional, and behavioral dimensions. Individuals in this phase do not identify themselves as ‘patients’; in other words, ‘being a patient’ is an experience from their past. The individual succeeds in engaging chronic disease management skills within their daily routine and does not feel stress and anxiety due to changes experienced; contrarily they are hopeful about their health status and future [42]. The patient has developed an internal control focus to sustain emotional development and aims to reflect this skill in future life plans [44]. Different from the adhesion, patients in this position pay attention to changes in daily routines including what they eat, create appropriate conditions for taking medications, and continue to exercise [40]. The patient is specialized in chronic disease management and becomes an active member of the health team. For example, based on their own experiences they predict the requirements and expectations of other patients in similar conditions and may offer recommendations to healthcare professionals. Thus, they contribute to developing the quality of healthcare services.

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Patient health engagement journey: Transitions from phases

It is important to determine which engagement stage the patient is in for chronic disease management. Identifying the positions ensures nurses in determining which aspects the patient requires support for, setting individualized care goals, identifying factors that may be obstacles to gaining self-management skills, strengthening the patient's autonomy in decision-making, engaging the family in the care management and providing appropriate coping support to the patient [11]. In the process from the blackout to the eudaimonic project position, patients' experiences and possible approaches of nurses are given below.

From the blackout to arousal phase

The basic approach in the shift from blackout to arousal phase is to support the patient's health literacy, provide health information required by the patient, ensure they can manage negative feelings, and establish a trust relationship with the patient [40]. The trust relationship supports patients in resolving the feelings of shock, fear, and emotional confusion experienced after diagnosis. Due to the uncertainty, patients need to frequently ask a trusted healthcare professional about the disease and treatment. As a result, it should be ensured that the patient can communicate with the doctor or nurse whenever required (e.g., telephone, message applications) and receive answers to questions. To adapt the treatment and new lifestyle, the patient should be supported in the cognitive aspect considering the readiness level, and the basic health information should be given progressively. In this progress, it is recommended that organizing informative sessions about the disease, providing written/visual material at the patient's health literacy level, performing individual health-coaching, maintaining effective communication with doctors and nurses, and referring patients to the psychological counseling [40].

From arousal to adhesion phase

The shift from arousal to adhesion initially requires the patient to have self-confidence about developing self-management skills [40]. In the arousal phase, healthcare professionals are an important reference point for patients [41], because patients need the knowledge and skills of healthcare professionals to set health goals for their conditions. If effective support is provided, the patient develops self-confidence and becomes able to adapt the skills with enhanced health literacy and emotional strength. To sustain these behaviors and support independence, it is necessary to maintain a patient's motivation to manage this process [37]. Additionally, each new symptom may cause excessive responses so the patient needs to be supported at an emotional level; for instance, opportunities must be created for expressing their feelings and listening to the patient. Shifting to the adhesion phase, it is recommended that patients be referred to accessible scientific health-related information resources, meet with other patients with the same chronic disease to share experiences, keep a chronic disease diary recording knowledge, experiences and feelings related to disease management, review mobile applications to monitor and record information related to the disease (e.g., test results, medication doses and times, appointment dates) and use to-do lists to monitor implementations in the treatment management process [40].

From adhesion to the eudaimonic project phase

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From adhesion to the eudaimonic project, patients should have adopted and maintained the basic aim of care and healthy life for the future [43]. In the adhesion, the main focus is still disease and treatment; as a result, patients limit daily life activities and social experiences. However, in the eudaimonic project position, the chronic disease should be accepted as a natural part of life with a full adjustment to the changes and an appropriate environment be created in all conditions to complete sustainable self-management skills with patient's active role [35]. In this development, the patient begins to perceive chronic disease management as a part of life and describe it as gaining a new identity [45]. As a result, nurses should support the patient in making new plans for the future, even if limited compared to life before the diagnosis of chronic disease [46]. Furthermore, it is recommended that referring patients to scientific meetings related to the chronic disease, organizing home-based services for continuity of care, and encouraging patients to utilize web-based applications where they can share their disease experienced (e.g., forums, portals) [35].

Previous studies have shown that PHE Model is effective in chronic disease management. The PHE Model developed the skills of obtaining online health information and increased treatment compliance [47], revealed the greatest difficulty in type 2 diabetes was adapting to new life habits and that the emotional requirements of patients were mostly ignored [43], and was beneficial to understand the complicated experiences of lupus patients and to plan care specific to the person [42]. Additionally, the cognitive, emotional, and behavioral development process can be evaluated with the "Patient Health Engagement Scale" created based on the PHE Model by Graffigna et al. in 2015 [31]. The scale has had validity-reliability studies performed in Chinese [48], Spanish [49], and Turkish [50] languages with ordinal alpha values of 0.89, 0.85, and 0.80, respectively. Comprising five items, the Patient Engagement Scale has ordinal structure and can easily be answered by the patient. The scale easily determines the patients' engagement position and enable healthcare professionals to plan individualized interventions based on the patient's needs in continuous care.

CONCLUSION

Chronic diseases are leading conditions of reductions in quality of life, increases health-related costs, and shortening life expectancy worldwide. After the initial diagnosis, chronic diseases should be managed by the patient himself for lifelong; thus, strengthening the patient is the key factor to ensure the sustainability of the care process.

Chronic disease management requires patients to adjust complicated treatments and unfamiliar new lifestyle habits. Additionally, every individual has different attitudes to disease and subjective disease experiences; as a result, the patient should be dealt with using a multidimensional approach from cognitive, emotional, and behavioral aspects. At this point, the PHE Model strongly highlights patients' subjective experiences (knowledge about their health, feelings related to the process, and ability to self-care). In the healthcare team, nurses have a coordinating role in providing chronic care. For this reason, embracing PHE Model in chronic care will enable nurses to easily figure out their patients' needs and plan individualized care.

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The four sequential phases define the causes behind the patient's thoughts, attitudes, and behaviors by revealing the specific features of the engagement position. With these elaborations, the patient's coping skills can be strengthened easing their ability to play an effective role in the healthcare services. Thus, patients who have difficulties in developing self-management skills can be identified before entering the high-risk group, and cooperation can be established with the patient. Although different care needs may be required for each condition, the self-management approaches of chronic diseases are similar. Therefore, it is thought that the PHE Model may ensure effective self-management for all chronic diseases. As a result, the PHE Model is considered to be an effective approach for sustainable chronic disease management and is recommended for integration into clinical practice.

Acknowledgment: None declared.

MAIN POINTS

- Chronic disease management requires life-long adherence to complex changes, therefore patients' attitudes and subjective experiences should be taken into account to sustain the care process.
- After being diagnosed with chronic disease, each patient goes through engagement phases with specific characteristics of cognitive, emotional, and behavioral aspects.
- Determining the engagement phases enables healthcare professionals to define the patient's unique needs, provide individualized care, and integrate the patient as an active member of the healthcare team.

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