

A Multidimensional Approach to Chronic Disease Management: The Patient Health Engagement Model

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Abstract

Chronic disease management is a complex process which that requires adaptation to unfamiliar lifestyle changes and long-term treatment, starting from 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 by taking into account the patient's emotional responses and perceptions about their disease process. The Patient Health Engagement (PHE) Model is the most current person-centered care approach which 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 this process. By defining these phases, the model enables healthcare professionals to determine the patient's cognitive, emotional, and behavioral needs, plan individualized care, and integrate the patient as an active member of the healthcare team. Therefore, the aim is to describe the patient's experiences in chronic disease management starting from diagnosis, to introduce the PHE Model, and to discuss its use in chronic disease management. It is expected that this review will guide nurses in using this model in chronic disease management and will provide an effective approach to clinical practice.

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

INTRODUCTION

Chronic diseases are irreversible conditions with a long duration, slow progression,¹ and never fully recovered from.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 by 2030.³ Studies in Turkey have found that 86% of deaths occur due to chronic diseases.⁴ Therefore, these results demonstrate that chronic disease management has become a worldwide issue due to its high prevalence and mortality rates.

In addition to being a common problem, chronic diseases typically cause irreversible changes in the long term.⁵ The main challenges are reduction/loss of physical function and independence, limitation of daily life activities, matters in family roles, and coping difficulties.⁶

These changes have indicated that chronic disease and its complications are not effectively managed. As a challenging process, chronic disease management fundamentally relies on the patient's self-control, which requires individuals to adapt to unfamiliar lifestyle patterns, to comply with medical treatment, and to deal with psychological problems.⁷ However, each individual has different perceptions and unique needs in managing their chronic diseases. For this reason, a multidimensional care approach is required to fulfill the patients' demands and to support their active role.

There have been plenty of terms introduced in recent years highlighting the patients' active roles.⁸⁻¹¹ In line with this, 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 they define

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the patient's different roles in the process.^{8,10,11} Lately, the patient engagement concept was introduced as uniting all approaches under one roof, embracing a holistic view by considering individuals' needs at cognitive, emotional, and behavioral levels.¹² Differing from other concepts, patient engagement creates a cooperative atmosphere between individuals and health professionals,¹³ strengthening patients by expanding viewpoints to include their experiences and aiming for them to have more "words" in healthcare services delivery.¹⁴ Targeting on developing health knowledge, skills, and the desire of patients to manage their health, it focuses on protecting health and gaining healthy lifestyle habits.¹⁵

Derived from the patient engagement concept, the Patient Health Engagement (PHE) Model is the most up-to-date approach and is highly recommended in order to maintain chronic disease self-management where the patient takes individual responsibility and an active role during his/her care.¹⁶ Accordingly, this article aimed to discuss the use of the PHE Model addressing cognitive, emotional, and behavioral dimensions in the chronic disease process. This topic is 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 long-term developmental process in which a person adapts to live with a lifelong condition.¹⁷ 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 and will expect that they will get better; however, when symptoms do not disappear, they try to figure out the cause of these 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 their 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.

Until patients seek healthcare services while managing their symptoms, they 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 uncertainty, they experience anxiety, have difficulty in perceiving health information and play a dependent role by leaving most decisions to health professionals and their relatives.¹⁸ In this process, the priority for both the patient and the healthcare professionals is to complete diagnostic tests in the shortest time possible and to begin treatment.¹⁹ During the diagnosis period, it was shown that patients experience problems in treatment adherence, they delay doctor's appointments, and are hospitalized repeatedly.^{20,21} These outcomes underline the difficulties in chronic disease management when the patient has limited responsibility in this stage.

When encountering 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 an individual undertaking tasks necessary to live well

with one or more chronic situations.²² This inevitable process requires adapting to a new nutritional pattern which 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 into daily life.²³ It may be difficult for most individuals to adjust to this complicated process,²⁴ since they need to adopt a new role as a patient. Additionally, they require motivation in order to sustain these behaviors throughout their life.²⁵ Effective self-management ensures early awareness of newly-occurring symptoms, reduced attendance to emergency services, and lengthened survival durations, which reflect positively in public health in the long term.²⁶ Ineffective self-management may cause maladaptation to new behavior patterns, more frequent admissions to emergency services due to noncompliance with medical treatment, and reduced quality of life.²⁷

Previous studies have emphasized that patient education methods focusing on cognitive/behavioral dimensions that require a passive role of the patient are mainly used to enhance self-management.^{28,29} However, patient education methods remained insufficient to sustain adherence to treatment and lifestyle changes and generally were conducted spontaneously, without planning or determining individual goals.³⁰ As a result, planned interventions remain limited in ensuring the patients' desires to take responsibility for their health and to continue their self-management skills throughout life.²⁹ Motivation should be considered for effective self-management because the patient being able to give meaning to their chronic disease in an emotional dimension ensures the development of internal control focus and behavioral changes which can be sustained for life.³¹ For this reason, interventions for effective self-management including the cognitive, behavioral, and emotional dimensions will provide the most effective outcomes.^{32,33} 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 planning individualized care in three dimensions have gained importance.³⁴

Along this path, the patient engagement concept offers a multi-faceted and dynamic nature¹² which encourages individuals to embrace an active role by combining their knowledge, abilities, and willingness to manage their care in order to promote positive health outcomes. With its broader view, patient engagement provides a comprehensive approach in different fields such as chronic care management,³⁵ patient safety practices,³⁶ and health information technologies.³⁷ Additionally, a range of results have shown that patient engagement allowed healthcare professionals to become more easily aware of the patient's needs, improved clinical outcomes, enhanced treatment adherence and compliance to healthy lifestyle habits, increased awareness about risky lifestyle behaviors, all of which reduce complications and contributed to the sustainability of the healthcare system.^{9,14,19,38-40} Finally, the "PHE Model" was introduced based on several qualitative studies revealing how individuals become engaged in their own care process.¹⁴

PHE Model for Chronic Disease Self-Management

The PHE Model aims to assess the patient's attitude to chronic disease management, readiness to manage care, and understanding related to their disease.⁹ The model supports the patient at cognitive, emotional,

and behavioral dimensions; not only facilitating obtaining health-related information and self-management skills, but also maintaining the emotional balance of the chronic care continuum.³⁸ Additionally, the model ensures the collaboration between the patient and the healthcare team, in which the patient mainly makes health decisions and manages their care, and this experience is combined with the knowledge of the healthcare professionals. Therefore, the patient and health professionals form a partnership regarding the decision-making process.⁴¹ From this aspect, the PHE Model can be stated to be more comprehensive than other chronic care approaches.

The PHE Model reveals that individuals pass through phases in sequence according to critical events (e.g., diagnostic testing process, the occurrence of new symptoms, compliance with a new treatment, recurrence of the disease) experienced during the process after receiving a chronic disease diagnosis.¹⁹ Dealing with these unexpected critical events usually causes severe stress and anxiety for the patient. 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 as follows: blackout, arousal, adhesion, and eudaimonic project.⁴²

1. Blackout: The blackout phase is where the patient is emotionally fragile due to a newly-occurring critical event (e.g., a new diagnosis, occurrence of new symptoms, or recurrence) with the difficulty of facing a new reality.^{42,43} The patient initially feels shocked, fearful, anxious, and panicked due to the unexpected situation and they feel unable to manage the health condition which results in a loss of control in his/her health.⁴⁵ 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 the health professionals with superior professional knowledge and skills and takes a passive role.^{44,46} At this point, the most basic expectation of the patient is to receive information about the about the disease and treatment from a trusted healthcare professional and feel understood.

2. Arousal: In the arousal phase, the patient gains initial awareness in emotional terms after their 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".⁴³ Compared to the 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 lifestyle habits.^{35,42} 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.³⁵ In this phase, although there are positive effects of medication treatment, the most common problem is treatment non-compliance.⁴⁵ They encounter problems in adjusting the prescribed medication doses, self-administering invasive medications, or taking multiple doses. This may cause a worsening of their disease symptoms, lowering of their quality of life, and a disengagement of daily life activities.³⁵

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 emotionally stable.⁴³ The patient accepts the negative feelings caused by the caused by the disease but still lacks full autonomy over self-management. In particular situations with any change in lifestyle habits (e.g., going on holidays, traveling for work), they may experience difficulties sustaining their disease management skills adapted to their routine life⁴² because the patient has not fully grasped the rationale for their treatment plan. As a result, the patient may require motivation to sustain their new health behavior in stressful situations or during unexpected changes in lifestyle.⁴⁴ In the adhesion phase, the patient begins to recognize the importance of playing an active role in their chronic disease management. This first awareness of the identity role is the starting point 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 the changes experienced; on the contrary, they are hopeful about their health status and the future.⁴⁵ The patient has developed an internal control focus to sustain emotional development and aims to reflect this skill in their future life plans.⁴⁶ Unlike the adhesion, patients in this phase pay attention to changes in their daily routines including what they eat, creating appropriate conditions for taking medications, and continuing to exercise.⁴³ The patient is specialized in their 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.

Patient Health Engagement Journey: Transitions from Phases

It is important to determine which engagement phase the patient is in for chronic disease management. Identifying the positions enables nurses to determine which aspects the patient requires support for, setting individualized care goals, identifying factors which 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.¹⁹ From the blackout to the eudaimonic project phases, patients' experiences and possible approaches of nurses are detailed below.

From Blackout to the Arousal Phase

The basic approach in the shift from blackout to the arousal phase involves supporting health literacy, providing health information, ensuring that patients can manage negative feelings, and establishing a trusting relationship.⁴³ The trust relationship supports patients in resolving their feelings of shock, fear, and emotional confusion experienced after diagnosis. Due to uncertainty, patients need to frequently ask a trusted healthcare professional about their disease about their disease and treatment process. 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. The patient should be supported in the cognitive aspect considering their readiness, and the basic health information should be given progressively. In this progress, it is recommended to organize informative sessions about the disease, provide written/visual material at the patient’s health literacy level, perform individual health-coaching, maintain effective communication with doctors and nurses, and refer patients to psychological counseling.⁴³

From the Arousal to the Adhesion Phase

The shift from arousal to adhesion initially requires the patient to have self-confidence in developing self-management skills.⁴³ In the arousal phase, healthcare professionals are an important reference point for patients,⁴⁴ 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 their 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.⁴⁰ Additionally, each new symptom may cause excessive responses so the patient needs to be supported emotionally; for instance, opportunities must be created for patients to express their feelings. It is also recommended that referring patients to accessible scientific health-related information resources, meeting with other patients with the same chronic disease to share experiences, keeping a chronic disease diary recording their knowledge, experiences and feelings related to disease management, reviewing mobile applications to monitor and record information related to the disease (e.g., test results, medication doses and times, appointment dates) and using to-do lists to monitor implementations in their treatment management process.⁴³

From Adhesion to the Eudaimonic Project Phase

From adhesion to the eudaimonic project, patients should have adopted and maintained the basic aims of their care and healthy lifestyle for the future.³⁵ In the adhesion stage, the main focus is still their disease and its 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 their life with a full adjustment to the changes and an appropriate environment should be created in all conditions to complete the sustainable self-management skills with the patient’s active role.³⁸ In this development, the patient begins to perceive chronic disease management as a part of their life and describe it as gaining a new identity.⁴⁷ 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 their chronic disease.⁴⁸ Furthermore, it is recommended to refer patients to scientific meetings related to their chronic disease, organize home-based services for continuity of care, and encourage patients to utilize web-based applications where they can share their disease experienced (e.g., forums, portals).³⁸ Figure 1 demonstrates the engagement phases according to the cognitive, behavioral and emotional dimensions of the model.

Multiple studies have investigated the effects of interventions targeting patient engagement and the PHE Model’s role in chronic disease management. Menichetti and Graffigna⁹ (2017) identified the relationship between patient engagement and the patient’s online health-seeking behaviors. Their cross-sectional study conducted with 352 Italian chronic patients showed that when healthcare professionals support patients’ autonomy, patients become more engaged in their own healthcare and developed online health information-seeking behaviors. Consequently, chronic patients’ emotional elaboration influenced their

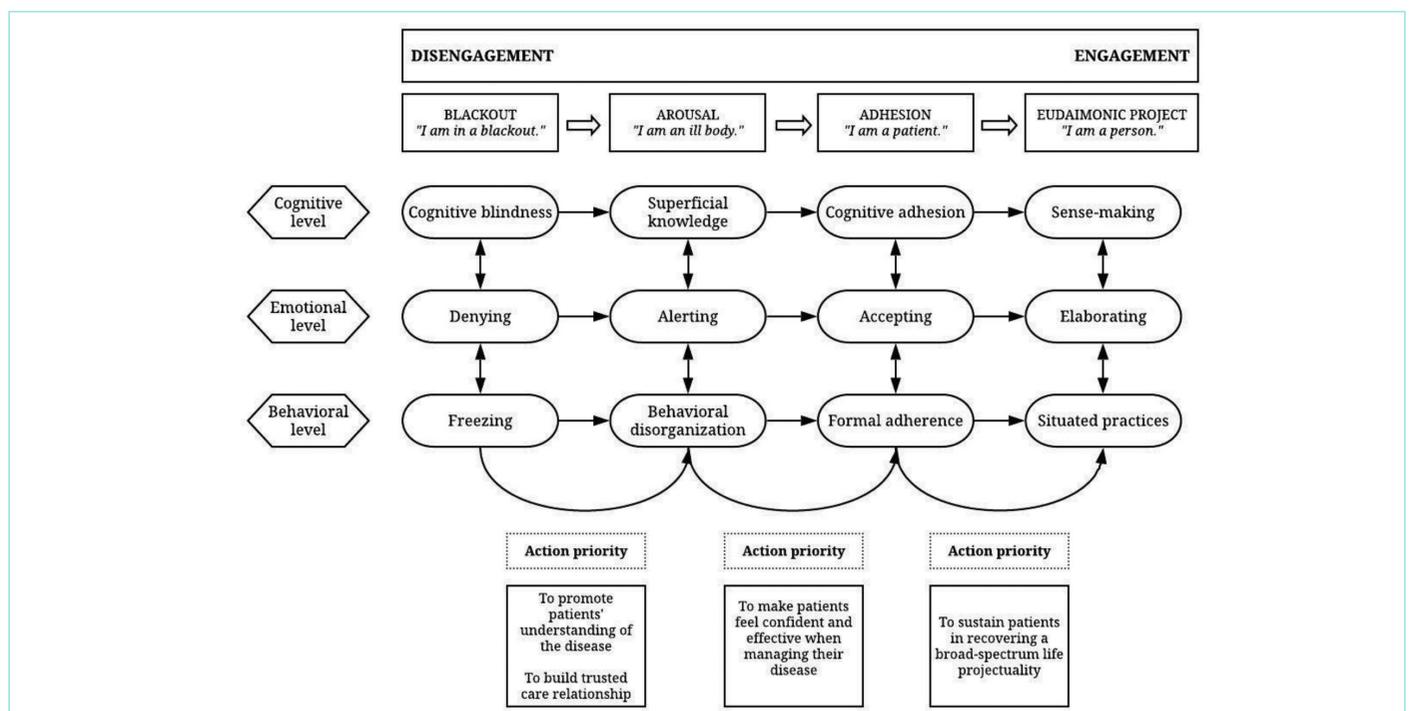


Figure 1. Patient engagement phases based on the Patient Health Engagement Model

ability to participate in care management, and it was recommended to provide reliable online health resources to individuals.⁴⁹

Mazzoni et al.⁴⁵ (2018) suggested that patients with systemic lupus erythematosus (SLE) experience a challenging process when living with their disease and self-managing their care. Therefore, they conducted a qualitative study and aimed to determine the SLE patients' engagement process by describing care management experiences. With four focus groups and ten in-depth individual interviews from various European countries, the authors claimed that patients who could reframe their needs in cognitive, emotional, and behavioral dimensions became more engaged in their care. Thus, the PHE Model represented an adequate framework to figure out the SLE patients' engagement process and plan individualized care.⁴⁵

Barello et al.⁴⁶ (2015) used a grounded theory approach to reveal the characteristics of the patient-doctor relationship and patient engagement with twenty-two in-depth interviews conducted with thirteen heart failure (HF) patients, five physicians, and four caregivers. The results shed light on the HF patients' engagement experiences and strongly underlined the doctors' essential role in fostering the patients' ability to engage in their care. Moreover, the early phases of the engagement process suggested the need for a paternalistic approach because the patients were more prone to delegate clinical decision making to the physicians. It was proposed that HF patients not only need cognitive and behavioral support but also emotional elaboration is crucial for engaging in care.⁴⁶

Graffigna et al.³⁵ (2014) suggested that patient engagement has become a key factor in improving type-2 diabetes patients' self-care management skills. With twenty-nine uncontrolled type-2 diabetes patients, a narrative qualitative study, in which they kept a one-week diary, was conducted to better understand their experiences of disease management. It was revealed that the greatest difficulty of patients was adapting to new lifestyle habits and that their emotional needs were mostly ignored. Also, the model led to the discovery of numerous unmet needs in different engagement phases and identified possible types of support in the cognitive, emotional, and behavioral dimensions. As a result, the PHE Model provided a strong framework to deeply understand type-2 diabetes patients' self-management experiences.³⁵

Additionally, the cognitive, emotional, and behavioral development process can be evaluated with Patient Health Engagement Scale (PHE-s) based on the PHE Model by Graffigna et al.¹² in 2015. The scale has had validity-reliability studies performed in the Chinese⁵⁰, Spanish⁵¹, and Turkish⁵² languages with ordinal alpha values of 0.89, 0.85, and 0.80, respectively. Comprising five items, the PHE-s has an ordinal structure and can easily be answered by the patient. The scale rapidly determines the patients' engagement position and enables healthcare professionals to plan individualized interventions based on the patient's needs in continuous care.

CONCLUSION

Chronic diseases reduce the quality of life, increase health-related costs, and shorten life expectancy worldwide. After the initial diagnosis, chronic diseases should be managed by the patient throughout their

life; thus, strengthening the patient is the key factor to ensure the sustainability of this care process.

Chronic disease self-management requires patients to adjust to complicated treatments and new and unfamiliar lifestyle habits. Additionally, each individual has different attitudes towards their 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 their ability to self-care). The four sequential phases define the causes behind the patient's thoughts, attitudes, and behaviors by revealing the specific features of the engagement process. With these elaborations, the patient's management skills can be strengthened, easing their ability to play an effective role in the healthcare services. Thus, patients with 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.

Future research based on the utilization of the PHE Model is highly recommended. For instance, designing web-based applications with interventions specific to the engagement phases, developing post-discharge patient follow-up protocols, and defining the interventions for different integrated contexts (i.e. other chronic conditions, acute situations, or supporting health-protective behaviors). In addition, nurses have a coordinating role in providing chronic care in the healthcare team. Accordingly, arrangements in the clinical practice aimed at increasing nurses' awareness of using this evidence-based model and reorganizing the outpatient chronic care follow-ups by adopting a patient engagement approach are also recommended.

MAIN POINTS

- Chronic disease management requires life-long adherence to complex changes, therefore, the patients' attitudes and subjective experiences should be taken into account in order to provide continuous care.
- After being diagnosed with a 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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