

ANALYSIS OF THE EXPERT PATIENT CONCEPT ACCORDING TO WALKER AND AVANT'S MODEL

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ABSTRACT

Objective: to analyze the Expert Patient concept in Walker and Avant's model.

Method: theoretical concept analysis conducted in November 2019 on national and international databases with a final sample of 21 studies, in which the following data were investigated: country, year of publication, area of knowledge, participants, concept, attributes, antecedents, and consequences. The quantitative data were analyzed in a simple descriptive way and the qualitative data were organized in figures. The concepts identified were processed with the aid of the *Interface de R pour Analyses Multidimensionnelles de Textes et de Questionnaires* software program.

Results: the United Kingdom (10; 47.6%) stood out, as well as the year 2015 (04; 19.1%), Nursing as the most evidenced area of knowledge (05; 23.8%), and patients as participants (18; 72.0%). With regard to the basic elements, care self-management (04;19.5%) was the most relevant attribute; in addition, the increase in the number of people with chronic diseases (10;18.5%) and social/community integration (14;24.5%) were evidenced as the most important antecedent and consequence, respectively. Additionally, the terms *expert patient*, *condition* and *health* stood out in the processing of the concepts presented in the studies included in the final sample.

Conclusion: concept analysis allowed determining the origin of the Expert Patient concept, the different fields of action of this subject, the self-care skills developed and their actual meaning, which is defined as an individual actively engaged in self-care and with the required skills to manage their clinical condition and help others in a similar situation.

DESCRIPTORS: Self-care. Health services. Participation of the patient. Patient safety. Concept formation.

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ANÁLISE DO CONCEITO DE PACIENTE EXPERT SEGUNDO O MODELO DE WALKER E AVANT

RESUMO

Objetivo: analisar o conceito de Paciente *Expert* no modelo de Walker e Avant.

Método: análise teórica de conceito realizada em novembro de 2019 em bases de dados nacionais e internacionais com amostra final de 21 estudos, nos quais investigaram-se o país, ano de publicação, área da saúde, participantes, conceito, atributos, antecedentes e consequentes. Os dados quantitativos foram analisados de forma descritiva simples e os qualitativos organizados em figuras. Os conceitos identificados foram processados com apoio do *software Interface de R pour Analyses Multidimensionnelles de Textes et de Questionnaires*.

Resultados: destacaram-se o Reino Unido (10;47,6%); o ano de 2015 (04;19,1%); a enfermagem como área de conhecimento mais evidenciada (05;23,8%); e pacientes como participantes (18;72,0%). A respeito dos elementos teóricos, a autogestão do cuidado (04;19,5%) foi o atributo que mais sobressaiu; evidenciaram-se, ainda, o aumento de pessoas com doenças crônicas (10;18,5%) como antecedente, a integração social/comunitária (14;24,5%) em meio aos consequentes, e os vocábulos *patient expert*, *condition* e *health* mediante o processamento dos conceitos apresentados pelos estudos incluídos na amostra final.

Conclusão: a análise conceitual permitiu determinar a origem do conceito Paciente *Expert*, os diferentes campos de atuação desse sujeito, as habilidades desenvolvidas em prol do autocuidado e o seu real significado, o qual é definido como um indivíduo ativo no seu autocuidado com habilidades necessárias para gerenciar sua condição clínica e auxiliar outros em situação semelhante.

DESCRITORES: Autocuidado. Serviços de saúde. Participação do paciente. Segurança do paciente. Formação de conceito.

ANÁLISIS DEL CONCEPTO DE PACIENTE EXPERTO CONFORME AL MODELO DE WALKER Y AVANT

RESUMEN

Objetivo: analizar el concepto de Paciente Experto del modelo de Walker y Avant.

Método: análisis teórico de concepto realizado en noviembre de 2019 en bases de datos nacionales e internacionales con una muestra final de 21 estudios, en los cuales se investigó lo siguiente: país, año de publicación, área de salud, participantes, concepto, atributos, antecedentes y elementos consecuentes. Los datos cuantitativos se analizaron en forma descriptiva simple y los cualitativos se organizaron en figuras. Los conceptos identificados se procesaron con la ayuda del *software Interface de R pour Analyses Multidimensionnelles de Textes et de Questionnaires*.

Resultados: se destacó lo siguiente: Reino Unido (10;47,6%); el año 2015 (04;19,1%); la Enfermería como área de conocimiento más evidenciada (05;23,8%); y pacientes como participantes (18;72,0%). Con respecto a los elementos teóricos, el automanejo del cuidado (04;19,5%) fue el atributo que más sobresalió; también se hizo evidente el aumento en la cantidad de personas con enfermedades crónicas (10;18,5%) como antecedente, la integración social/comunitaria (14;24,5%) entre los elementos consecuentes, y los vocablos *expert patient* (paciente experto), *condition* (patología) y *health* (salud) mediante el procesamiento de los conceptos presentados por los estudios incluídos en la muestra final.

Conclusión: el análisis conceptual permitió determinar el origen del concepto Paciente Experto, los diferentes campos de actuación de este sujeto, las habilidades desarrolladas en pos del autocuidado y su significado real, que se define como un individuo activo en materia de su autocuidado con las habilidades necesarias para manejar su patología clínica y ayudar a otras personas que se encuentran en una situación similar.

DESCRIPTORES: Autocuidado. Servicios de salud. Participación del paciente. Seguridad del paciente. Elaboración de un concepto.

INTRODUCTION

The theme of Patient Safety (PS) has been recognized and discussed worldwide, representing a global challenge for the health services and a priority for achieving care quality amidst the complexity of the work activities¹⁻³.

This situation results from the exponential increase in failures that can result in Adverse Events (AEs) in patients^{1,3-4}. It is worth highlighting that the care provided involves the context, the work organization implemented in this environment and the human factors^{2,5}.

From this perspective, the active participation of professionals, family members and patients themselves is indispensable, as these latter are at the center of the treatment process and continuously observe the entire series of actions taken aiming at their recovery and well-being. In addition, they have the opportunity to contribute to the promotion of their safety by providing diverse information and suggestions to improve care^{1-2,5-6}.

Various initiatives have been undertaken worldwide aimed at fostering patient-centered care, such as the "Patients for Patient Safety" program, promoted by the World Health Organization (WHO) to gather these patients and other individuals/institutions interested in PS through collaborations and partnerships⁷.

In Sweden, the National Health and Welfare Board and the Swedish Association of Local Authorities and Regions (SALAR) - representing the municipal health councils - emphasize a new perspective on the patient for improved quality and effectiveness of the services. In Finland, there are laws and decrees that recommend giving priority to participation of the patient, whereas in the United States of America (USA) a Joint Commission suggests that patients and their family members should seek information from health organizations in case of doubts^{1,5-6}.

Based on this focus/attention to patient as an active actor in care self-management, the term Expert Patient emerges to refer to those who have greater access to information through television shows that focus on health themes derived from the Internet with updated news and data, in addition to the development and availability of applications and/or software on digital platforms that present health-related reports in the format of games, e-books, videos and chats, among others^{5-6,8-10}.

However, it becomes pertinent to develop a horizontal relationship between patients and health professionals responsible for care promotion, in order to build a bond of trust in which patients feel confident and active in their health-disease process, to discuss their clinical condition and to provide support to other patients^{1,3,5-7,9-10}.

Therefore, the meaning of Expert Patient needs to be understood in its essence so as to contribute to the growth in this profile of health service users, as it will lead to the strengthening of an increasingly more holistic, participative, safe and high quality care. In addition, based on the understanding of the definition of Expert Patient, health professionals will have better opportunities to achieve more positive results in both individual and collective health care.

It is worth emphasizing that there are many interpretations for the term Expert Patient, related to its translation/adaptation into the language spoken in different countries, especially with regard to the different existing contexts governed by the health system and the local culture. Thus, it becomes fundamental to obtain a general overview about what the world literature presents on the Expert Patient concept using the investigation method proposed by concept theoretical analysis¹¹, in order for it to be appropriately apprehended and applied in the most diverse scenarios.

Therefore, the following question is formulated: what is the Expert Patient concept according to the scientific productions in health?; and the objective is to analyze the Expert Patient concept in Walker and Avant's model.

METHOD

This is a theoretical concept analysis as proposed by Walker and Avant, which addresses recent and/or little explored concepts in the literature. For such purpose, the research was structured in eight stages, namely: I) selecting the concept of interest; II) delineating the analysis goals and purposes; III) determining the possibilities of use of the concept; IV) defining the attributes; V) proposing/using a model case; VI) creating additional case(s); VII) identifying antecedents and consequences; and VIII) defining empirical frameworks¹¹.

Study selection was based on the recommendations for an integrative review¹² and was conducted in November 2019 on the following electronic indexing systems: Scientific Electronic Library Online (SciELO), PubMed, CINAHL, Scopus, Cochrane, Web of Science and Psycinfo, by using the Descriptors in health Sciences (*Descritores em Ciências da Saúde*, DeCS) and their respective Medical Subject Headings (MeSH): #1 - *Paciente Expert/Expert Patient*; #2 - *Autogestão/Self-management*; and #3 - *Serviços de Saúde/Health Services*, using the “AND/OR” Boolean operators in the following combinations: #1 AND #2 AND #3; #1 AND #3; #2 AND #3.

Publications available in full and dealing with the theme were included. Editorials, opinion articles and duplicate papers were excluded, as well as those that did not address the Expert Patient concept, in addition to those that only made their abstracts available for free access. It is noted that no time and/or language restrictions were applied.

A total of 8,392 studies were identified in the initial search and, after reading of titles and abstracts, full analysis and rigorous observation regarding the inclusion and exclusion criteria, a final sample of 21 publications was obtained as described in Figure 1, which shows the selection process.

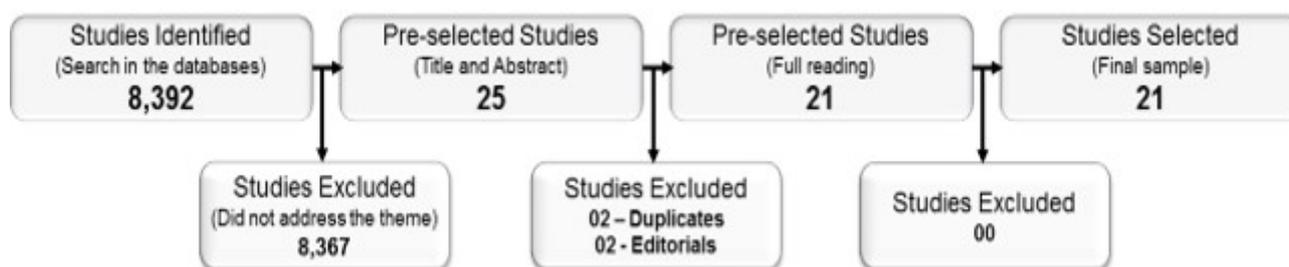


Figure 1 - Flowchart corresponding to the selection process of the studies. Natal, RN, Brazil, 2021.

The following indicators were used for evaluation of the studies: title; country; year of publication; health area evidenced (Nursing, Nutrition Science, Medicine and Dentistry, among others); participants (professors, students, professionals, patients, family members); concept(s) presented; characteristics/particularities related to the Expert Patient; aspects that contributed to the proximity and emergence of the term Expert Patient and, finally, consequences of applying the Expert Patient concept.

The data were organized and tabulated in *Microsoft Excel* 2016 spreadsheets in a simple descriptive manner and presented in tables and/or figures to facilitate interpretation and understanding of the investigated concept.

It is worth emphasizing that the concepts found in the studies selected were processed in the *Interface de R pour Analyses Multidimensionnelles de Textes et de Questionnaires* (IRAMUTEQ) software program¹³, with application of similarity analysis. This choice was motivated by the fact that this tool allows for a better interpretation of associations (proximities and distances) between the terms that make up the concept in a graphical manner, in addition to indicating which aspects have strong relationships between each other (as shown by the thickness of the connection line).

RESULTS

Among the 21 studies that comprised the final sample, the United Kingdom^{14–23} stood out as the country with the highest number of studies (10; 47.6%), followed by Brazil^{8,24}, China^{25–26}, Spain^{27–28} and the USA^{29–30} (02; 09.5% each), and then by South Africa³¹, Canada³² and Malawi³³ (01; 04.7% each). In relation to the publication year, 2015^{20–21,27,31} (04; 19,1%) stood out from the rest (Figure 2).

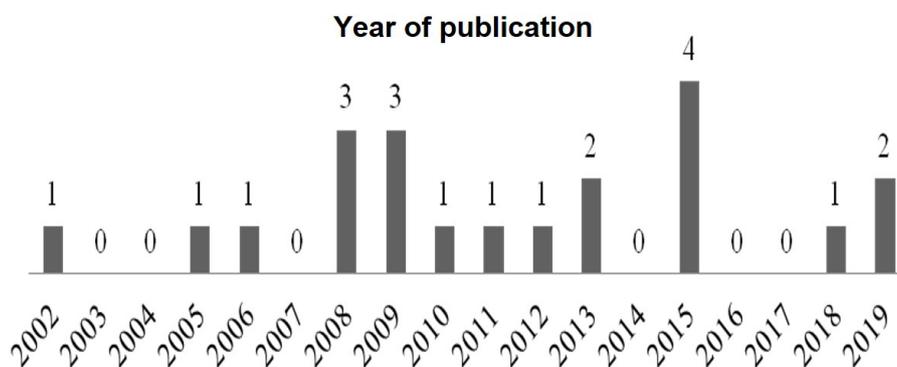


Figure 2 - Year of publication of the studies. Natal, RN, Brazil, 2021.

Although it has not been possible to identify the health area evidenced in all studies, only Nursing^{14,15,19,25,33} (05; 23.8%) was pointed out. Among participants, patients^{14–23,25,26,28–33} (18; 72.0%), nurses^{14,25,33} (03; 12.0%) and physicians²⁵ (01; 04.0%) were pointed out, and it is worth highlighting that the same profile of subjects was present in more than one study. In addition, a number theoretical-reflective studies^{8,10,13} (03; 12.0%) were evidenced without a specific participant sample. With regard to the attributes that address the terms that help characterize and build the investigated concept, Table 1 presents the most cited ones.

Table 1 - Attributes of the Expert Patient concept. Natal, RN, Brazil, 2021. (n=21)

Attribute	n	%
Care self-management ^{20,23,27–28}	04	19.5
Health self-management ^{16–17,26}	03	14.2
Self-care ^{19,29,32}	03	14.2
Empowerment in care ^{15,24,30}	03	14.2
Self-management of the disease ^{21–22}	02	09.5
Autonomy in care ^{25,31}	02	09.5
Reliable support source ^{18,33}	02	09.5
It promotes shared care ¹⁴	01	04.7
Digital native ⁸	01	04.7
Total	21	1000

The antecedents, which are factors that contributed to proximity and emergence of the concept, and consequences, which refer to results of applying and/or developing the concept, are shown in Table 2.

With regard to the concepts presented in the papers selected, Figure 3 graphically depicts a synthesis of the actual meaning of Expert Patient, with the words *expert patient*, *condition* and *health* standing out. It is worth noting that, as all studies have an English version published, it was decided to conduct data processing in this language.

Table 2 - Antecedents and consequences of the Expert Patient concept. Natal, RN, Brazil, 2021. (n=?)

Variable	n	%
Antecedents		
Increase in the number of people with chronic diseases ^{16-19,21,26,28-29,31-32}	10	18.5
High cost of treatment/medical care/health services ^{14,16,26,28-29,32}	07	12.9
Multimorbidities ^{16-19,21,26,28-29,31-32}	07	12.9
Social stigma ^{15,17,22-23,27,30,33}	07	12.9
Need for social support ^{15-16,22-23,30,33}	06	11.1
Shift in paradigm ^{8,22,27-28,30}	06	11.1
Access to information ^{18,23-25}	04	07.4
Search for alternative treatments ^{14,17,22,27}	04	07.4
Internet ^{8,23-24}	03	05.8
Consequences		
Social/Community integration ^{8,15-16,20-24,26-28,31-33}	14	24.5
Optimized relationship between patient and professional ^{14-15,19,21-22,24-25,28,30,33}	10	17.5
Improvement in self-esteem and quality of life ^{14-15,19,22,24,28,30-33}	10	17.5
Search for training/knowledge updates by the professionals ^{14,16,21,24-26,28,31}	08	14.0
Improvement in communication ^{8,16,18,23,25,27-28,32}	08	14.0
Development of the Expert Patient Program (EPP) ^{8,16-18,22-23,29}	07	12.8

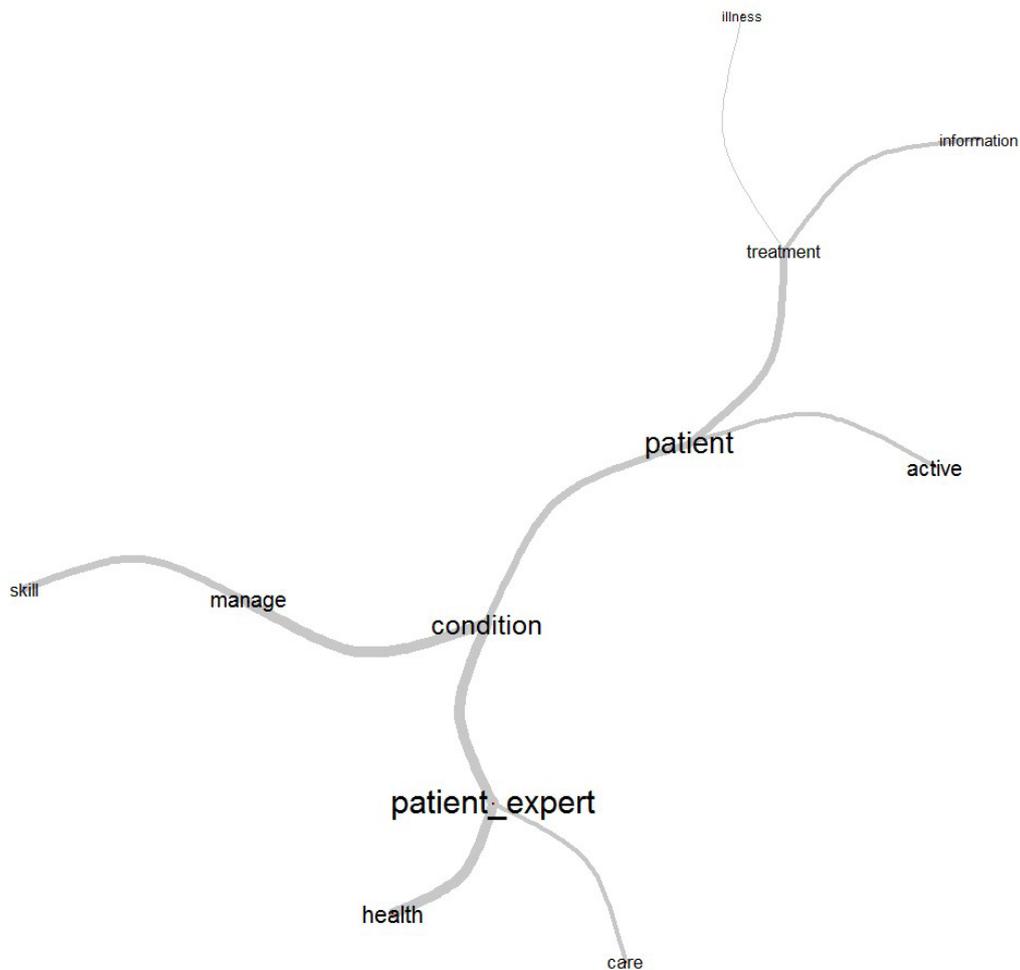


Figure 3 - Similarity analysis of the Expert Patient concept. Natal, RN, Brazil, 2021.

DISCUSSION

Although the approach to the term Expert Patient is considerably recent, global initiatives point to the importance of this subject in the health services and in their own self-management process. For example, the Expert Patients Programme (EPP) has been developed in the United Kingdom since 2002 as a pilot test to investigate how to place patients at the center of healthcare, which may justify the highest number of research studies conducted in that country^{9,20–21,34}.

It is noted that the fact that most of the studies were published in 2015 results from population aging, the worldwide increase in the number chronic diseases, and ease of access to the Internet, as well as from the idea, disseminated by the WHO, that patients need to be active in health self-management to facilitate the promotion of safe healthcare^{3,5,7–9,20,31}.

As for the area of knowledge, Nursing stood out for being the professional category with the highest number of studies, for being present in all health care levels, and for spending more time in direct and indirect activities with patients^{1,4,20,25}.

The most evidenced participants were patients since, in addition to the fact that the studies were focused on these individuals, it is observed that achieving better quality in the results of the actions undertaken by health institutions most of the times depends on understanding the perceptions and opinions of the main beneficiaries of this process, in order to optimize the strengths and create strategies to suppress/eliminate the existing weaknesses, as well as to enable patients to actively participate in their health-disease process^{5–6,20–21,25,31}.

In relation to the attributes identified, it is understood that they refer to at least four fundamental aspects that contribute to characterizing the Expert Patient concept, namely: search for information, initiative, knowledge sharing, and use of several forms of technology.

In this sense, the terms self-management of the disease, of health, and/or of care emphasize the idea that Expert Patients are able to manage their clinical condition based on the peculiarities of the activities of daily living by considering their possible limitations, those involved in the social context (family members, friends and neighbors, among others), and in the physical environment of their residence, so as to search reports that add knowledge on their disease and to develop measures that adjust to their particularities^{9–10,20–22,27}.

Self-knowledge is supposed to help Expert Patients to be increasingly more active subjects, as the expressions “self-care”, “autonomy in care” and “empowerment in care” reflect a patient who contributes with the health services by identifying and reporting the probable side effects of a given treatment, participating and/or leading health committees/boards, and favoring the creation of support groups^{9,14,25,30–31,34}.

It is noted that Expert Patients are important individuals not only for themselves but also for the health scope in general, as the aforementioned cooperations subsidize improvements in the healthcare, scientific, educational, political, economic and social spheres^{8–10,22,25,27–28,30}.

These assertions are in line with those of another two attributes of the Expert Patient concept, such as the one that promotes shared care and a reliable support source. Such properties support judgment on the issue whether Expert Patients are capable of participating with other patients and/or health professionals by reporting their experiences and empirical knowledge, facilitating decision-making for a therapeutic intervention, assisting in the elaboration of healthcare guidelines, and helping define the best research questions and develop studies that significantly contribute to the life of the target population^{9,14,20,29,30}.

To achieve these expectations, Expert Patients, also associated with the term digital natives, have tools that provide them with a vast field of knowledge through the use of Internet and, in multiple formats, including videos, scientific articles, blogs and news, among others, which enables them to be

updated about diverse information on their disease (definition, pathophysiology, diagnosis, prevention and treatment) and to transmit these data to other patients who do not have access to such knowledge, do not know how to use these sources and/or have limited literacy skills^{8,10,30}.

Although all these benefits are plausible, for the results to be really positive and promote relevant changes in patient care, it is extremely important that health professionals develop a horizontal trusting relationship, so that they can instruct patients regarding the places to search for news about their clinical condition, as well as encouraging them to be transformation agents within their care context and to express their perceptions and experiences to others, in addition to forming critical citizens with regard to their rights and duties^{8,20,25,27,30}.

The following model case is suggested to use the Expert Patient concept: a patient attends a collective consultation of the HiperDia group (individuals with hypertension and/or diabetes) scheduled for 9 a.m. and involving nurses, physicians, dentists, dietitians, physical educators, pharmacists and psychologists. During the meeting, at the invitation of the nurse in charge of the group, the patient briefly reports his life experiences in various contexts immediately after being diagnosed. Subsequently, the different areas of health knowledge take turns to provide advice and new information on how to deal well with such clinical conditions.

At the end of the discussion, the patient goes to the nurse's office to have his data/measures taken in order to update his registration and takes the opportunity to talk about the proposal of creating a municipal health council, showing interest in becoming one of the representatives of their neighborhood of residence. The patient is then sent to the team physician's office to obtain a new prescription and, during the conversation, he reports having noticed some blood pressure (BP) changes at dawn and states a suspicion that can be the result of a medication that he is taking, according to data from a video available on the Internet; the physician admits being unaware of this effect, substitutes the medication, says that he will perform a deeper search, and schedules a new consultation for the next day.

When leaving the care unit, the patient says goodbye, thanks the professionals for the care provided, and meets a childhood friend, who invites him for a casual meeting with their family members at a pizza house. Despite accepting the invitation, the patient makes it clear to his friend that he cannot overeat at the meal due to his clinical condition and because he has made some changes in his eating habits. When leaving the unit, the patient acts in various segments of society - health board, self-help groups, community activities in general - and helps other patients with similar diagnosis to share knowledge and practices, in addition to encouraging health promotion and prevention of associated diseases.

Conversely, there is the opposite case: the patient attends the collective consultation of the HiperDia group to update his registration data, obtain a new prescription and have access to the medications. When leaving the unit, he thanks for the care provided, meets a childhood friend and, at that moment, they schedule a meeting with their family members at the neighborhood pizza house.

With regard to the antecedents, the growing number of individuals with chronic diseases and/or multimorbidities, together with the increased costs of treatment, health services and medical care, represent aspects that contributed to the emergence of the Expert Patient concept, as it was shown that this new user profile is confident and able to be in control of his health-disease process by adopting behaviors that may help in his clinical and psychological improvement^{9,10,14,20-21,26,31}.

This perspective is facilitated by effective guidance provided by the professionals, which reduces the number of consultations in care centers, especially in the primary care setting; furthermore, it makes workers more available to early detect individuals with a given disease that is still not chronic and, through effective management, may reduce public expenses and help organize collective education programs for patients^{9-10,20-21,30-31}.

Based on these factors - epidemiological profile and financial resources - it is understood that the act of searching alternative therapeutic interventions represents an aspect that fostered materialization of the Expert Patient concept, as dialog with physicians and nurses, for example, enables patients to give their opinion and to report new measures that may improve their quality of life and are compatible with their socioeconomic conditions^{14,20–22,27,31}.

This proposal is based on other antecedents, such as access to information and the Internet, given the Expert Patients' predisposition to critical sense, as they are not satisfied only with the reports disseminated by health institutions. In addition to that, due to their lack of academic qualification in the area, Expert Patients present limited knowledge, which reinforces the idea of searching for clarifications^{8,24–25,30}.

Another issue is stigma and the need for social support, as certain chronic diseases are still devalued, marginalized and/or neglected by society. In contrast, Expert Patients know who to deal/cope with adversities by finding non-judgmental support and seeking for timely clarification about issues that are considered taboos^{15,20,22,27,30,33}.

However, a change of paradigm is noticed, in which the biological model of health is replaced by an approach centered on the patients, who actively participate in their the care process, becoming partners in healthcare by discussing and sharing knowledge with health professionals, caregivers, family members and other users^{8,22,26–27,30}.

With regard to the consequences of the investigated concept, improvement in self-esteem and quality of life was one of the results observed, resulting from greater acceptance of the disease, development of self-care skills, and strengthening of a proactive and reflexive posture^{14–15,22,26–27,30–31}.

This evolution is also the result of improved social/community integration, as Expert Patients recognize their limitations/potentialities and use them for their benefit, do not adopt a passive attitude and expose their thoughts with the purpose of helping others feel integrated^{8,15,20–22,24–25,27,31}.

It is observed that improvement in communication may be explained by raising awareness in these patients with regard to the lack of sufficient data about their clinical condition and, because of that, they need to know how to express themselves clearly and objectively. Likewise, they have the opportunity of disseminating this new knowledge to other people who are in a similar situation and thus become transformation agents^{8–10,25,27,30}.

This is due to the fact that the change occurring in the relationship between patients and/or their families also includes health professionals because a bond of cooperation is established, in which specialists seek to understand and approach, in an attentive manner, the patients' main concerns, priorities and doubts, placing them at a central position in care self-management and making them feel confident of their skills and capable of providing help in various contexts^{6,21,25}.

It is noted that the efforts by health professionals to participate in training sessions/knowledge updates reflects the peculiarity of Expert Patients, as these professionals are increasingly more prepared for any event raised by these patients and/or know how to act in the best possible way when they are not completely sure about a given instruction^{8–10,14,21,25–26,30–31}.

Creation of the EPP goes beyond a consequence, as it has an expanded meaning not only for Expert Patients but also for those surrounding them, since this program is directed to patients, tutors, graduate students and health professionals, all of them committed to contributing to a safer and higher quality care self-management^{8–10,16–18,22–23,29,34}.

It is emphasized that the EPP is not limited to educational purposes; instead, it also aims at planning and developing research studies with the active participation of Expert Patients, in order to identify and evaluate new treatments based on scientific evidence and to create tools to support health self-management^{9–10,34}.

Based on the similarity analysis, it was understood that Expert Patients have a strong relationship with their health condition and with being linked to a more active role in treatment of the disease through self-management^{8-10,27,30,34}.

One limitation of the current study is the restricted access to some surveys (either because only the abstract was available or because access required payment), which could provide data that would expand and/or strengthen diverse information from the other papers included in the final sample.

The following is suggested as a proposal for future research studies on Expert Patients: an analysis of the different contexts into which these individuals are inserted, in order to facilitate the existing concatenations that could interfere with or enhance development of this profile of health service user.

CONCLUSION

The model proposed by Walker and Avant for concept analysis enabled to determine the origin of the Expert Patient concept, the different fields of action of these subjects, the self-care skills developed and their actual meaning.

Therefore, Expert Patients are defined as individuals who assume an active/autonomous stance in their health-disease process, based on care/health/disease self-management, in addition to being able to develop and/or improve the skills required to manage their current clinical condition by searching diverse information on the best treatments several times, in addition to being digital natives and help others in a similar situation by promoting shared care, thus representing a reliable support source.

Hence, the current study presents subsidies to science because it brings to light importance of the appropriate use of the term Expert Patient, in order to improve quality of the health services and foster an increase in the number of patients with this profile. To this end, it is necessary to train current and future health professionals so as to facilitate identification/approach of these patients, in addition to assisting them in contributing to the promotion of care self-management among other individuals with similar characteristics.

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