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ORIGINALES

Perception of sources of support that facilitate adherence to the treatments

Percepción de las fuentes de apoyo que facilitan la adherencia a los tratamientos

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ABSTRACT:

Introduction: Non-adherence to treatments increases the probability of therapeutic failure and unnecessary complications.
Objective: To explore the sources of support perceived by patients with chronic diseases that facilitate adherence to treatment.
Method: Qualitative descriptive study with a phenomenological approach, in which eight complex chronic patients were recruited, without distinction of gender or age, residents of Barcelona, and who, after evaluating pharmacological adherence with the Morisky-Green test and the test of Batalla resulted in being adherent to the therapeutic regimen. After which, two open questions were asked that were recorded on an audio device and transcribed verbatim. For data analysis, the method Colaizzi was used.
Results: Three thematic groups emerged: 1) Having family support; 2) Understanding of the disease and strategies that facilitate adherence to treatments; and 3) Relationship with reference professionals.
Conclusions: The most important source of support perceived by the participants is the family, coinciding with other authors. The finding of this study is that shows medicine and nursing are evidenced as instigators that promote their empowerment and as a recognized source of influence that has allowed their assimilation and training to adopt measures that help them follow the pharmacotherapeutic guidelines.

Key words: Patients; chronic disease; social support; compliance; treatment adherence.

RESUMEN:
Introducción: La falta de adherencia a los tratamientos aumenta la probabilidad de fracaso terapéutico y complicaciones innecesarias.
Objetivo: Explorar las fuentes de apoyo percibidas por los pacientes con enfermedades crónicas que les facilitan la adherencia a los tratamientos.
Método: Estudio cualitativo descriptivo con enfoque fenomenológico, en el que se reclutaron ocho pacientes crónicos complejos, sin distinción de género, ni edad, residentes en Barcelona, y que tras evaluar la adherencia farmacológica con los test de Morisky-Green y el test de Batalla diera como resultado ser adherente al régimen terapéutico. Tras lo cual se efectuaron dos preguntas abiertas que fueron grabadas en un dispositivo de audio y transcritas textualmente. Para el análisis de los datos, se utilizó el método Colaizzi.
Resultados: Surgieron tres grupos temáticos: 1) Tener el apoyo familiar; 2) Comprensión de la enfermedad y estrategias que facilitan la adhesión a los tratamientos; y 3) Relación con los profesionales de referencia.
Conclusiones: La fuente más importante de apoyo percibida por los participantes, es la familia, coincidiendo con otros autores. El hallazgo de este estudio, es que se evidencia a medicina y enfermería como instigadores que fomentan su empoderamiento y como fuente de influencia reconocida que ha permitido su asimilación y capacitación para adoptar medidas que les ayudan a seguir las pautas farmacoterapéuticas.

Palabras claves: Paciente; enfermedad crónica; apoyo social; cumplimiento; adherencia al tratamiento.

INTRODUCTION

Lack of adherence to therapeutic regimens is a prevalent and relevant problem. The World Health Organisation defined adherence as: "The patient's behaviour in relation to taking medication, following a diet or modifying lifestyle habits corresponds to the recommendations agreed with the health professional" [(1)]. This body also stressed that the measurement and evaluation of adherence to treatment is an ongoing need, which enables the planning of effective, efficient and quality treatments. According to the results of the European Health Survey in Spain 2020, 49.3% of men and 59.1% of women aged 15 and over have a perceived chronic illness or health problem [(2)] and these percentages increase with increasing age. In this context, failure to adequately follow therapeutic regimens is associated with a decrease in quality of life and life expectancy, which results in poorer control of the disease, increasing its complications, which leads to an increase in consultations, hospitalizations and complementary tests, with the consequent increase in healthcare costs.

There are many treatment-related factors that influence adherence: complexity, duration, treatment changes, previous treatment failures, availability of medical and nursing support for treatment, etc. In 2003, the WHO classified the factors involved in adherence into five dimensions: socio-economic factors, factors related to the health system and its professionals, factors related to the treatment, factors related to the pathology and factors related to the patient [(1).] According to Vlasnik, factors that may contribute to non-adherence include frequent changes in drug regimen, misunderstanding of prescribing instructions, limited medication education and forgetfulness [(3)]. Di Matteo, on the other hand, states that in some cases there is a direct influence between social support and adherence to different pharmacological treatments, diet or physical exercise [(4)]. Social support can facilitate effective coping by enhancing motivation to engage in adaptive behaviours [(5)]. Consequently, as it is influenced by many factors, no single intervention strategy or set of strategies has proven to be effective for all patients. For this reason, interventions aimed at adherence must be tailored to the particular requirements related to the disease

experienced by the patient, and to achieve this it is necessary to problem-solve with each patient and accurately assess not only adherence, but also the factors that influence adherence.

The aim of the present study is to explore the sources of support perceived by patients with chronic diseases that facilitate adherence to treatment, in order to find out their self-efficacy and the measures implemented that they consider to have provided them with a positive strategy in their adherence to treatment regimens.

MATERIAL AND METHODS

Study design

A descriptive qualitative study with a phenomenological approach was developed, due to the detailed information it provides on the phenomena explored from the perceptions of the people, which are centred on their experiences and situations, from the perspective in which they are involved [6]. In this sense Burns expresses that, although they are focused on understanding, they are also consistent with the philosophy of nursing [7].

Participants and inclusion criteria

The study sample was selected by purposive sampling and consisted of chronic patients, regardless of gender or age, living in Barcelona, who, due to their complexity, were identified in their HC as complex chronic patients (PCC) for a comprehensive approach to their multidimensional needs, centred on the patient and family [8], who took more than 5 medicines a day and who, after evaluating their pharmacological adherence with the Morisky-Green test [9] and the Batalla test [10] were found to be adherent to the therapeutic regimen.

Recruitment

Prior contact was facilitated by nursing professionals from the Poblenou basic health area (ABS), from the Litoral de Barcelona primary care service (SAP) and from the care support nurses of the Vall d'Hebron Hospital. Once selected, they were contacted by telephone, where the characteristics of the study were explained to them and they were invited to participate in the study. For those who agreed to participate, an appointment was arranged according to their preferences, either at the participant's own home or at a clinic in the center where they were visited. We conducted the study from May to December 2019. Confidentiality and methodological rigour were guaranteed, after signing the consent form. All participants received a written informed consent document containing all the characteristics of their participation and the objective of the study. They were informed that participation was strictly voluntary and of their right to revoke their authorisation to withdraw from the project, without any detriment of any kind.

Procedure

Two methods were used in parallel, one for its high sensitivity and the other for its high specificity [11]. The first one given to the participants was the Batalla test, which

addresses adherence based on the individual's knowledge of the disease, assuming that greater knowledge of the disease on their part represents a higher degree of adherence. This test consists of three questions; an incorrect answer qualifies the patient as non-adherent [12], while the Morisky-Green test is based on behaviour, i.e., the person's compliance with taking the prescribed medication. This test consists of 4 questions; an inadequate answer qualifies the patient as non-adherent; the patient was considered to be adherent if he/she answered correctly to all four questions [13].

After assessing pharmacological adherence with the Batalla test and the Morisky-Green test, eight participants were recruited who answered both tests correctly. An *ad hoc* questionnaire was used to describe the socio-demographic profile of the participants. (**Table 1**).

Table 1. Data and demographic characteristics of the participants (N = 8).

Code	Sex	Age	Marital status	Cohabit	Sons and sex	Medication
PT-1	M	80	Married	With wife	1 M y 1 F	>of 5
PT-2	M	82	Married	With wife	3 M	>of 5
PT-3	F	84	Widow	Only	1 F	>of 5
PT-4	F	81	Widow	Only	2 M	>of 5
PT-5	M	79	Widower	Caregiver	1 M	>of 5
PT-6	F	84	Married	With husband	1 F	>of 5
PT-7	M	15	Single	Mother and sister	0	>of 5
PT-8	F	18	Single	Parents	0	>of 5

Notes: M= Male; F= Female
Source: Own elaboration.

Once the results of both tests were verified and all participants were adherent to the treatment regimen, they were asked two open-ended questions: What do you think makes it easier for you to take your medication correctly? and What support do you perceive helps you in this regard? Responses were audio-recorded and transcribed verbatim, and completed when data saturation was reached. The estimated time to complete the data collection was approximately 30-50 minutes.

Data analysis

For the analysis of the data, the Colaizzi method was used [14], involving the search for and identification of common threads. After several full readings of the interviews, significant statements were identified and extracted by grouping and categorising the meanings into clusters of common themes, in order to finally uncover the phenomenon.

RESULTS

Of the eight participants in this study 4 (50%) were female and 4 (50%) were male. The mean age of the participants was 65.37 years. Two of them were adolescents (15 and 18 years old). The age range of the other six was between (79-84 years). Three

were living with a spouse and three were widowed and two were included in the home-based care programme (ATDOM). All met the inclusion criteria.

After analysing the information using the Colaizzi method [14], 39 significant statements were identified and organised into six descriptor codes and consolidated into five categories and three thematic groups: 1) Having family support; 2) Understanding the disease and strategies that facilitate adherence to treatment; 3) Relationship with the professionals of reference, as shown in (**Table 2**) and presented below.

Table 2. Description of thematic groups, categories and descriptor codes

Themes	Categories	Descriptor codes
1. Having Family support	1.1. Living with the family	Spousal support Parental support
	1.2. Contribution filial	Support from sons
2. Understanding the disease and strategies that facilitate adherence to treatment	2.1. Being informed	Receiving information and clarifying doubts
	2.2. Strategies and resources incorporated	Help from devices
3. Relationship with the professionals of reference	3.1. Relying on the professionals of reference	Feeling supported

Source: Own elaboration

Theme 1. Having Family support

Two categories are identified in this theme, reflecting the personal situation and circumstances of each participant and the differentiation of perceived support related to their age and family situation.

Living with the family

Spousal support: The three participants who live with their spouse expressed that their adherence to all treatments is due to the unconditional support they receive: *"The wife makes me take everything well. My wife always helped me and helps me [...] the number of pills I take every day, without her I don't know what I would have done" [PT-1]. "Having the wife [...] who takes good care of me and always worries" [PT-2]. "Having my husband by my side always [...] What is important here is who puts the pills in order in the box, so you don't make a mistake, the merit is theirs" [PT-6].* Two of them said that their spouses also helped them with food, changing the ways of cooking so that the types of food were healthier: *"It was hard for us to understand that after the attack there were things that I could no longer eat the same [...] when the sons come, my wife makes other things for me, [...] you see how much she takes care of me..." [PT-1]. [PT-1]. "I let the nurse take care of the meals and since then [...] I don't eat the stews I used to eat" [PT-2*]. Another aspect highlighted by [PT-1] and [PT-2] is the support they received when they had complications related to the disease or faced very difficult situations: *"The woman who always stays by my side, she wants me to do what the doctors say so that I don't have another bummer" [PT-1]. "She does*

everything so that I don't get sick, after the last scare she goes to the limit with everything" [PT-2]. Having the spouse's support and unconditional help was the main support perceived by the three participants who lived with their spouse. Feeling supported by their partner helped them to adapt to changes in their daily life and adherence to prescribed treatments.

Parental support is very important in adolescence, due to the distancing from parents that occurs at this age, the influence of the social environment is very great and can favour non-compliance and thus relapse. Participant [PT-7] is a 15-year-old adolescent who is undergoing cancer treatment for leukaemia and attributes his adherence to treatment to his mother, because she controls and intervenes to ensure that he follows the guidelines. *"My mother [...] is in charge of my medication, she always reminds me when my pills are due and she even went to school to give me the pills" [PT-7]. Participant [PT-8]* is an 18-year-old teenager who received a lung transplant as the most suitable option for her survival due to cystic fibrosis. This represented an abrupt change in her situation that made her become involved in her treatments under the supervision of her parents. *"My parents have been my support, it's been many years of realising that without them I wouldn't be the way I am [...] I usually organise my medication myself, with my parents" [PT-8].*

Contribution filial

This category relates to the support that participants living alone at home observe their sons giving them, in order for them to follow the therapeutic regimens. The support of sons is highlighted by two participants, both widows living alone at home, mentioning their satisfaction with the support they receive from their sons: "I have the daughter who lives next door and she comes every day [...] she takes care of everything and keeps an eye on everything" [PT-3]. *"My son comes when he gets off work, he brings me the things I need, the other one comes at weekends and prepares all the medicines for me every week, I can't complain, they are good, they are looking for someone who can come in the mornings, without them I don't know what I would do" [PT-4].* Participant [PT-6] although she said she felt supported by her husband, she also expressed that her daughter is a great support for both of them: *"Her husband [...] and her daughter who takes care of us [...] she comes to see us when she is not working, but if we need her or if we don't understand something, we call her and she comes [...] we are very good with her" [PT-6]*. Participant [PT-5] attributes this to the caregiver hired by his son, giving his son the value of having her: *"The lady who comes to my house who hired my son prepares it for me, [...] she can only come when she finishes work and on Saturdays, she was worried about me, [...] as she is not always with me, she is the one who takes care of everything" [PT-5]*.

Theme 2. Understanding the disease and strategies that facilitate adherence to treatment

Being informed

The experiences of the participants showed that being informed about their disease, their treatments and clarifying doubts is very important for their adherence to treatment. Seven participants considered that being informed and being able to clearly understand the guidelines and changes in treatments is very useful: *"There is one thing that is important for us and that is that my doctor and the nurse explain*

things to me so that we both know what they are saying, that we understand it without doctors' words" [PT-1]. "When I go to the doctor, I ask him things [...] I ask him everything I don't know and then he explains about the tests and if something changes [...] the nurse sometimes has to explain it to me again, [...] better to ask what not to do it wrong" [PT-2]. "When we go to the doctor or the nurse, they explain to us how we have to do it... the other day she took me off a medicine that I no longer needed because the tests came out better" [PT-3]. "The doctor [...] the other time she changed some of my medication and she explained all that to us until I understood" [PT-4]. The doctor [...] prescribes and also explains to the husband how to take them, so he does it well [...] if we need something we go and ask and that's it" [PT-6]. "When we come to visit, we take the opportunity to visit and see the nurses and I usually ask them my questions" [PT-7]. Participant [PT-8] has also used digital media to obtain information: *"At the beginning I asked a lot or looked it up on the internet, otherwise I wrote a message to my paediatrician or the nurses, or else I called the unit with my doubts" [PT-8]*. Having the facility to be able to consult with professionals when needed gives them security and reinforces adherence.

Strategies and resources incorporated

All participants are convinced that having the help of devices to facilitate adherence benefits them. Six of the participants report that they use pill boxes to organise their daily medication and point out that it helps them to avoid making mistakes: "*The pill box with everything I have to take for the week and it's perfect, a good invention, my daughter insisted and in the end it's better [...] not having the boxes on top of the cabinet" [PT-1]. "Every week we prepare and put the medicines in the little box so I can look at them, my wife does too" [PT-2]. "She gives me all the pills for the week, except for the Sintrom, which she tells me on the phone [...] because it has to be taken at the same time every day" [PT-3]. "My son prepares all the medicines in the box for me every week" [PT-4]. "Since everything is prepared in the box it goes well [...] when the lady is not here it is easy for me to know which pill, I have to take" [PT-5]. "Here what is very important is who puts the pills in order in the box so you can't make a mistake" [PT-6]*. Four participants also use the mobile phone alarm as a reminder to take medication: *"Since I put the alarm on my mobile phone so that it rings every day to take my Sintrom [...] I don't fail to take the pill at the same time, I give the phone and without touching it, it rings the next day" [PT-3]. "You see, I have to take this pill at the same time and as I am alone at that time, I put my mobile phone on so that it rings and I don't miss the time" [PT-5]. "My mother asks me every day if I have taken my pills and she also sets the alarm on her mobile phone" [PT-7]. "Sometimes I forget, so I have an alarm on my phone to remind me" [PT-8*].

Theme 3. Relationship with the professionals of reference

Relying on the professionals of reference

This category is related to the trust they place in the referring professionals and the support they perceive in their care. All the participants highlighted that they perceive the support of their doctors and nurses of reference and trust their judgement: *"Knowing that we can count on the doctor and the nurse helps a lot in everything [...] whenever we go I take the inhaler to review how I do it [...] between this and the paper he gave me it goes well" [PT-1]. "With frankness I tell you that both the doctor and the nurse I have are lovely, they care a lot and treat me very well" [PT-2]. "When we go to*

the doctor or the nurse [...] they know what they are doing" [PT-3]. "The other time he changed things for me about the medication [...] because if he does it, it's because he has to do it [...] but I ask the nurse who helps me to understand it better, because she explains and explains until when she asks me, she sees that I know it, she writes it down in big letters and I stick it on the fridge" [PT-4]. Participant [PT-5] refers that it was the nurse who realised that he was not taking his medication properly. *"One day when she came to my house, she was looking at what I was taking and asking me about the boxes and as they were almost the same and they were all together, I got confused, she helped me so that I didn't do it wrong, I talk to my son and they put everything in the little box every week, when the lady who comes is not there it is easy for me to know which pill I have to take" [PT-5]*. The home care setting has its own characteristics that require patient safety strategies adapted to their needs, which is why assessing risk factors through observation is an essential nursing tool that should always be used, as it allows us to identify their needs and detect dangers or shortcomings. as in this case, in which mistakes were made in taking medication and alternatives were sought with her son, to provide support and ensure proper adherence to treatment. The participant [PT-6] attributes the merit of her adherence to the medical criteria and the support received from her nurse to reinforce skills related to healthy habits that allow her to improve her state of health; *"The merit is theirs, the doctor who prescribes them and also explains to her husband how to take them, so he does well [...] the nurse has been explaining to us about the meals [...] I am lighter now [...] that's how I am doing, they have lowered my pills and that's good" [PT-6]*. This same participant describes another of the changes incorporated in her daily life, considering that the workshop recommended by her nurse has allowed the habitual incorporation of the exercises learned and with it the stimulation of staying active: *"I go out little because it is difficult for me and it is increasingly more difficult [...] the nurse [...] convinced me and I went to one of those gymnastics workshops and we both went, now we do them at home every day, sometimes I forget, but only a few" [PT-6]*. The participant [PT-7] relates the support of the professionals to the children's oncohaematology unit, where there is an atmosphere of complicity between the health professionals, the patients and the families*: "The nurses in the unit, when we come to visit we take advantage [...] to see the nurses and I usually ask them my doubts, without the nurses it would not be the same, they help us, it is not easy to understand my illness, in the unit they help us a lot" [PT-7].*

Paediatric nurses are well aware that cancer treatments can provoke emotional reactions of loss, decreased self-esteem and depression. In the case of the participant [PT-8] given its chronic complexity and the continuity of care that does not cease after transplantation. The support of health professionals is essential for the challenge of integration into daily life and to prevent and detect non-compliance with treatment: "I have been to the hospital so many times that I know everyone, in the unit they have always taken great care of me [...] my paediatrician and the nurses" [PT-8].

DISCUSSION

In this study, social support was shown to have an important relationship with adherence to treatment. The family was shown to be a key element, revealing that family support favours adherence to treatment, as they feel supported despite the difficulties they are going through, related to their situation, personal circumstances, age and family living environment. For participants living with a spouse, their partner's

support and unconditional help was the main perceived support, feeling supported by their partner helped them to adapt to changes in their daily lives and to adhere to the prescribed treatments. Another aspect they praise is the support they received when they faced very difficult situations or had complications related to the disease. For the participants living alone at home, the support that their sons give them to follow the treatment regimens properly is praised by all, because they have taken an active role in supporting them when it became necessary. In line with the above, other authors already stated that after the marital partners, the most important sources of support for the patients were their sons [15]. This support may also include a preventive provision that encourages self-reliance and independence to the extent possible [16], the aim is for sons to continue to see their parents as individuals who continue to have their own needs, rights and personal histories.

In adolescence, parental support is very important, due to the distancing from parents that occurs at this age, the influence of the social environment is very great and can favour non-compliance and thus relapse. For the two adolescent participants, their support has been and continues to be essential, as the illness and its treatment represented an abrupt change that forced them to become involved under the supervision of their parents. This stage is of vital importance, because it is when the structuring of the individual's personality takes place, through intense changes at different levels: physical, psychological, emotional and social. Body image becomes very important and many stop taking medication, partly because of the adverse effects of drugs on body image, and it is very important to prevent and detect this problem, in order to offer the necessary support to prevent relapse. In this area it is necessary to reinforce through rigorous improvement intervention, active treatment follow-up with age-appropriate monitoring questions [17]. Nursing is well aware of the refusal of medication by adolescent patients, who for various reasons do not comply with their medication regimen and to address this problem, they have developed different control and monitoring strategies such as the constant application of a medication compliance protocol [18]. Therefore, family and social support is perceived as a facilitating source of adherence. Wekland already highlighted the importance of family interactions, both in the origin and in the course and outcome of the illnesses [19], he also pointed out that the family alone, or in conjunction with other agents, had a major role to play in the onset of disease and that its influence on lifestyle changes and adherence to treatment was extremely important.

Understanding of the disease, acceptance of the treatments, availability of oral or written information, simplification of the therapeutic regimen, accessibility to medical and nursing professionals, individualised follow-up with face-to-face or home visits and in parallel with the family in order to provide a better approach, are actions that have favoured adherence.

Trusting and feeling supported by the professionals of reference for all participants is a recognised influence, the results show that person-centred care is an indispensable element for improving adherence in chronic patients. In this context Bosworth, et al, highlight the need for face-to-face interaction between the patient and the health professional with a triple purpose: Motivational, with the aim of reinforcing the importance of adherence, in order to achieve the desired therapeutic objective. Counselling, informing the patient of the necessary aspects for the appropriate use of treatments, based on shared decision making, considering the preferences of the patient and their caregivers [20]. For McMullen et al, medication appropriateness is

considered a very important tool for improving adherence and is one of their established domains of effective prescribing, a concept derived from therapeutic appropriateness that also incorporates the need for shared decision making with the patient and their caregivers [21].

In terms of the strategies and resources incorporated, the use of pill dispensers is the method most used by all, because they make it easier to organise weekly treatments in advance, the use of the mobile phone as a reminder to take doses, especially when it is a fixed schedule, and the warning alarm is of great help to them. Regarding digital means of consultation, only one of the participants reported using them. Strategies are part of the health empowerment of each individual, which is why it is necessary to involve the patient as an active part of the selection process, since, at the end of the day, it is the patient who makes the final decision on whether or not to take the medication. However, as non-adherence has a multifactorial origin and is a dynamic behaviour, which can change over time, it needs to be assessed periodically.

Limitations

The results cannot be universalised to the whole population, due to the small sample size, although it provides a unique insight into the experiences of the participants, and also because the research source is the interview, which focuses on the subjectivity of the informant.

CONCLUSIONS

There is no universal strategy that works to improve adherence for all patients and in all contexts. The most important source of support perceived by the participants is the family, spouse, sons and parents, in agreement with other authors. Patients who have a good relationship with medical and nursing professionals adhere better to treatments because they receive more information and alternatives. The finding of this study is that medical and nursing professionals are evidenced as instigators who foster their empowerment and demonstrate their empathic capacity, helping them to have a better understanding of their disease by promoting behavioural changes and using resources by incorporating devices that help them to follow pharmacotherapeutic guidelines. For all, having good communication gives them confidence and security and is a recognised source of influence that has enabled their assimilation and empowerment by the actions taken that facilitated their adherence.

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