Autonomy and adherence to individual with chronic renal disease

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Abstract The adherence of the sick individual is the main objective of this study, which was carried out through bibliographic review. Non adherence to therapeutical proposals is a frequent problem with medical, social and economic consequences for the involved sick individuals, services providers, and health system. It is possible to define and to quantify non adherence of individuals with chronic renal disease in regular hemodialysis programs evidenced in several indicators. The longer and more complex is the proposed treatment, the more frequent is non-adherence. Non-adherence increases mortality, morbidity, and costs of treatment. Causes for non-adherence are multi-factors, partially related to loss of control over personal life due to dependence. Individual's rehabilitation requires possible recovery of independence, autonomy in order to change a receiver susceptible to an imposed treatment into an active partner of a therapeutic intervention.

Proposed strategies involve negotiation with sick individual, a customized approach focused in the individual by using a biopsychosocial model.

Key words: Personal autonomy. Patient compliance. Chronic disease. Dialysis.

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The adherence of the sick person is the goal of this study, through literature review. But what is adherence? How is it assessed? What are its results? What are its causes and factors? What correlations can be established? What are its implications? What are the best strategies to optimize the adherence of people?

The sick, when feeling bad, seeks for an asset: health care. In acute situations, he hopes for symptomatic relief of symptoms: the cure. In these circumstances, an individual patient can demand prescription and their adherence to treatment may be compulsive [1].

Chronic conditions often occur concomitantly with little obvious manifestations or with the possibility of complications that still do not exist, but that are very

likely, both with indication for intervention and prescription. In chronic situations adherence to treatment is smaller [2].

Non-adherence is a frequent problem with medical, social and economic consequences for the sick people involved, as well as for service providers and the health system. One of the most studied examples regards to people with chronic renal disease (CRD) in regular hemodialysis program, the regularity and frequency of contact between them and the health care teams [3].

Hemodialysis may increase the length and quality of life of people with CRD, but is a complex process. People with CRD need to take a set of commitments, which includes the acceptance of programs and hours of dialysis, a prolonged continuous use of several drugs, food restriction, and fluid intake. These people are still subject to complications of the associated morbidities. Non-adherence is an important problem for this population, since it has been observed that almost a third of people were not adhering to at least one of three surveyed indicators [4] and others reported that at least 50% of dialysis population does not adhere to part of prescriptions made [5]. The extent of adhesion depends on how it is defined and measured.

Definition

There are several terms associated with adherence to treatment: compliance, adherence [6]. Of these, compliance was used until 2001 and is linked to the act of obeying orders, discipline in the face of physician's determinations, instructions and prohibitions [7]. In the context of use of this term, the ill person subjects passively to orders.

In the context of use of this term, the ill person subjects passively to orders. Adherence, contemporary term used in the context of negotiation, agreement, or covenant between patient and physician, is reported as expressing more or less identity between behavior and medical recommendations [8]. The World Health Organization (WHO) defines it as the sick person's behavior in taking medications, dieting, adopting lifestyles agreed with the physician [9]. This definition provides an implicit agreement with patient participation in managing the process.

Therefore, compliance means more than just following instructions: it results from a process of shared decision between the doctor, who knows the disease and treatment, and the patient who knows of his life, preferences, capabilities, and limitations in pursuing a particular plan. The adherence level will depend on the adoption and maintenance of behaviors that include personal management, control of therapeutic plan by the individual patient [10].

Evaluation

To evaluate the adherence indicators

and parameters are defined, whose specificity and sensitivity are not yet determined due to the multiple factors involved. There is currently some inconsistency in definition, lack of parameters standardization and lack of autonomy and adherence in people with chronic kidney disease evaluation of the validity of these indicators [11].

However, a cross-correlation has been found between the various indicators, promoting consistency in the indicators of non-adherence. However, a cross-correlation has been found between the various indicators, promoting consistency in the indicators of non-adherence. Commonly used are attendance and punctuality, interdialytic weight gain (> 5.7% dry weight), oral medication, hyperphosphatemia (P> 7.5 mg / dL) and hyperkalemia (K> 6.0 mEq / L) [12].

Results

It has been found that the various indicators show a frequency variation from country to country, with respect to structural conditions and the characteristics of the population. The non-adherence to dialysis is more common in the United States (7.9%) than in Europe, where it is negligible (0.6%). In Japan, the percentage increase in weight between two dialysis sessions is higher (34.5%) than in the other regions considered [12].

The non-adherence behavior is not distributed uniformly throughout the population. In a study of non-adherence to dialysis, it was found that 9.1% of the population accounted for more than 3% of faults, while others have not failed to attend planned sessions and may mean that non-adherence is a phenomenon restricted to a group of people[8].

In parallel, people with a non-adherence indicator to an item are more likely to have non-adherence to other items [13]. The association between various indicators of non-adherence can mean that non-adherence is not a behavior toward a specific item but rather a personal way of looking at the proposals received. As for medication, a study showed that on average, patients were prescribed 12 drugs [14]. This study used the combination and comparison of three methods of evaluation: report of the person, counting tablets and electronic control of container opening. It was found that adherence to oral medication remains the major difficulty. Other studies of adherence to medication showed that 93% of them adhered to medication for hypertension and 97%, to phosphate binders [15].

In a recent meta-analysis of nine tests, 40% of interventions to improve adherence to medication of short duration achieved this objective and caused improvement in at least one clinical data. For long-term medication, in 69 tests, 44% of the interventions improved adherence but only 24% had improvement of at least one clinical outcome. In these tests the effect

interventions were complex and included a combination of several techniques: nearest assistance, strengthening of information, reminders, self-control, enhancing autonomy, individual counseling, family intervention, psychotherapy, telephone monitoring, home support [16].

Correlations

It is possible to establish correlations with statistical significance between different variables. The younger age groups are correlated with less adherence [12,13]. Would this be due to greater tolerance to deviations, more self-confidence, greater willingness to take risks?

Those employed and married showed a greater frequency of hyperphosphatemia, a hydroelectrolytical disorder which conditions high phosphate levels in the blood, commonly associated with chronic kidney disease. It was found that people living with someone had better adherence to the duration of dialysis than those who lived alone[12]. Family support was positively correlated with the improvement of adhesion [17]. The smokers had a higher risk of non-adherence than non-smoker [12,13]. Does the smoker's status represent a relative devaluation between behavior and personal health?

The educational level, measured in years of schooling, showed no correlation with indicators of non-adherence. Perhaps more than academic education, existential perspective will count for this purpose? Before it had been found that among people with higher education, adherence was greater among those with family support. In those with less education, adherence was related to the support provided by professionals[18]. There are no studies comparing the correlation between different levels of education or illiteracy in this population.

Moreover, in contexts in which transport of the person is not always assured, the fact they being institutionalized, as it implies a schedule of times and transport, were correlated with greater adherence both as to attendance and punctuality.

Effects on morbidity and mortality

If a particular medication is not taken, its specific effect is not produced. A study conducted in 1,426 people with CRD (but not yet on dialysis) showed that the lowest levels of adherence were significantly correlated with higher rates of albuminuria and blood pressure [19].

It has been also found the relationship between non-adherence and morbidity evaluated by episodes of hospitalization [12], as well as increased risk of death in people with non-adherence [8,12,13]. In a comparison of multiple groups, it was noted that the differences in adherence to dialysis attendance could contribute to differences in mortality between countries, given that skipping a single dialysis session may expose the person to a higher risk of serious situations, such as hyper-hydration and hyperkalemia[20].

Economic effects

Considering the number of 340,261 people on dialysis in the United States in 1999, with 214 days of hospitalization per

100 patient years, with a daily cost of $1,300, and assuming that 25% of episodes of hospitalization were related to non-adherence , the corresponding annual cost would be 237 million dollars [21]. If the frequency of non-adherence was the same in Portugal for 9037 people on dialysis in 2007, the annual cost of hospitalization related to non-adherence would be 4.3 million Euros.

Factors

From the results and correlations has been tested the identification of causes and risk factors for non-adherence - which may depend on the individual patient, the provider or professionals; and even the characteristics of the illness and treatment.

The proposed factors, which are dependent on the sick person, are: cognitive deficits, lack of economic resources, access, knowledge about their disease and treatment, motivation to manage it, lack of confidence and self esteem (to be considered capable of making improvements in own procedure), lack of awareness of self-autonomy and the possibility of self-control of one's existence, lack of treatment expectations and consequences of non-adherence, certain beliefs and conceptions of life[22].

The factors that depend on the provider are many. Increased adhesion did not follow the increased clinic dimension [12]. Time pressure, less personalization and less personal care possibly could be implicated.

As for the factors depending on professionals, it was found that the presence of a dietician reduces non-adherence with interdialytic weight gain [12]. The care provided by nurses with more than two years of experience was correlated with a lower rate of shortening dialysis [12].

In a study of 79 people, a correlation was found between adherence and perceived satisfaction with the sick person's nephrologist [23], namely the physician's interest felt by the sick person.

Some characteristics of kidney disease and its treatment may contribute to non-adherence: chronicity; polymedication, the complexity of the medication regimen, lack of evidence or understanding of the justification for the need of certain medications and attitudes, and the need of continued and prolonged treatment [24].

Chronic diseases and their therapies represent an intrusion on people's lives, disrupting or interfering with the appreciated activities and life styles and habits [3]. Such circumstances may represent situations of tension. Tension because the person is equipment dependent, on the others that control it, but she/he wants her/his independence,

mastery of the issues that concern her/him. Tension because people occupy most of their time with the treatments and displacements required to achieve them, but they want to avoid domination or regulation of their lives by the treatment. Tension because people must meet schedules, dietary restrictions, treatment regimens, but must maintain self-control, autonomy for obtaining the inherent quality of life. These tensions require constant balancing between refusal and acceptance of control of rhythms, schedules, habits of life, between autonomy and adherence [5].

Strategies

The problem of non-adherence can be transformed into an opportunity for the physician to move from a paternalistic stance to one in which the sick person exercising personal control over his life, treatment, self-determination for achievement of autonomy. Heteronomy, translated into opinions, can interfere with self-esteem and demonstrate the dependence on third parties that define good and evil, is interference over autonomy [25].

Autonomy is mentioned more often in the context of authorization for certain actions and interventions in the very sick person, related to informed consent. But the right to autonomy is also to be able to refuse: the right to express their choices and conscious and unconscious omissions. Autonomy is the right to see respected the very way in which we live [26]. The more autonomous, the better the sick person feels. The awareness of autonomy is an improvement factor of well being, of satisfaction. And satisfaction is an adherence factor. The needs of independence and autonomy must be recognized, respected, and actively sought.

The personal relationship is an important point of adhesion and it should turn into an interaction between prescriber and patient, as a partnership in which both want to achieve the best results [27]. The quality of physician-patient relationship is one important determinant of adherence [9, 28]. Except in situations of danger to public health [29] (e.g., pulmonary tuberculosis), one cannot force people to accept all proposals, technically justified, made.

Thus, one should focus on the use of a sick person's collaborative approach (instead of policy), for the sharing of decisions improves adherence [30]. And arrange control by the patient, so that each option is not a 'doctor's orders', but his choice. Problems, solutions and alternatives must be presented to him, and the options discussed and negotiated, and approach control and adherence results. Some have successfully presented the person a graph, comparing their results with the average of the others and with the recommended values [31]. The therapeutic benefits of the proposals must be greater than the disadvantages and their goals, clear. The advantages of assuming a

behavior, taking a medication should be important to the person concerned. The patient must understand the importance of the proposal for himself [10].

In parallel, the contemporary perspectives of looking at disease are based on the biopsychosocial concept, introduced by Engel [32], that, in comparison with the old positivism derived from the biomechanical model considers the management of chronic diseases as an involvement of biological, psychological, and social factors. More recently the personalist model appeared, which treats the sick person as a whole, present with its project and narrative inherent in the relationship that transcends it[33]. The philosophy of this approach transforms the passive recipient of an imposed treatment into an active partner in therapeutic intervention [34]. From the analysis of correlations and their interpretations, set out in the preceding paragraphs, strategies have been proposed to improve the adherence [10], such as:

1. Choose biochemical and behavioral markers of non-adherence;
2. Identify and quantify non-adherence;
3. Listen to the patient;
4. Assess what each patient does and why he does it;
5. Identify barriers to adherence;
6. Present the problem; agree to standalone solution;
7. Individualize the proposed therapy: adapting the treatment plan in accordance with the needs and preferences of the person to change some behavior;
8. Add value to the treatment, medication, and positive effect on adherence to the person;
9. Assess the likelihood of adherence and seek the support of relatives, neighbors or others to improve. Involve available systems in the community. Involving available systems to the community;
10. Provide support information materials for the patient. Reinforce oral directions with written recommendations;
11. Reduce, where possible, the complexity of the proposed schemes;
12. Reinforce behaviors and results. Periodically inform the patient of results, the effect of their behavior;
13. Do not make judgments.

Final considerations

The frequency of non-adherence is high. The definition, evaluation, and application of indicators of non-adherence require greater standardization. There are numerous factors and causes that should be targeted for further characterization. The behavioral theories of non-adherence need more consistency.

Non-adherence contributes to increased morbidity and mortality of sick people. The increase in morbidity increases the consumption of health services and the corresponding expenditure. Increased autonomy improves adherence Some data suggest that the personalization of treatment increases adhesion. The relationship of physicians and other health professionals with sick people is critical in non-adherence. All these items require prospective studies with isolation of variables without bias.

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Resumen

Autonomía y adhesión en la persona con enfermedad renal crónica

El objeto del presente estudio es una revisión bibliográfica de la adhesión de la persona enferma. La carencia de adhesión a las propuestas terapéuticas es un problema frecuente con consecuencias médicas, sociales y económicas, para la gente enferma implicada, los servicios y el sistema de salud. Cuanto más complejo y prolongado es el tratamiento propuesto, más frecuente es la falta de adhesión. Ésta aumenta la mortalidad, y morbilidad y los costes de tratamiento. Las causas de no adhesión son multifactoriales, y están en parte relacionadas con la pérdida de control en la vida personal, con la dependencia. La rehabilitación de la persona exige la recuperación posible de la independencia, de la autonomía, de forma que transforme un receptor pasivo de un tratamiento impuesto, en un socio activo de una intervención terapéutica. Las estrategias propuestas implican la negociación con la persona enferma, un abordaje personalizado, centrado en esta persona enferma, usando un modelo biopsicosocial.

Palabras-clave: Autonomía personal. Cooperación del paciente. Enfermedad crónica. Diálisis.

Resumo

Autonomia e aderência na pessoa com doença renal crônica

A aderência da pessoa doente é o objetivo do presente estudo, realizado mediante revisão bibliográfica. A falta de aderência às propostas terapêuticas é problema frequente, com consequências médicas, sociais e econômicas para as pessoas doentes envolvidas, prestadores de serviços e sistema de saúde. Nas pessoas com doença renal crônica, em programa regular de hemodiálise, é possível definir e quantificar a não aderência, concretizada em vários indicadores. Quanto mais complexo e prolongado é o tratamento proposto, mais frequente é a não aderência. A não aderência aumenta a mortalidade, a morbilidade e os custos de tratamento. As causas de não aderência são multifatoriais, em parte relacionadas com a perda de controle sobre a vida pessoal, com a dependência. A reabilitação da pessoa exige a recuperação possível da independência, da autonomia, de forma a transformar um receptor passivo de um tratamento imposto num parceiro ativo de uma intervenção terapêutica. As estratégias propostas envolvem a negociação com a pessoa doente, uma abordagem personalizada, centrada na mesma, utilizando modelo biopsicossocial.

Palavras-chave: Autonomia pessoal. Cooperação do paciente. Doença crônica. Diálise.

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