Illness experiences due to communicable chronic conditions: integrative literature review

Experiências de adoecimento por condições crônicas transmissíveis: revisão integrativa da literatura

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Abstract

The objective of this article is to identify and describe the illness experiences of people living with communicable chronic conditions. An integrative literature review was carried out in May 2015 in the PubMed, the Literature in the Health Sciences in Latin America and the Caribbean (LILACS) and in the Scopus databases. Through the intersection of keywords and controlled descriptors, eight search strategies were conducted and resulted in the final selection of 12 articles, which were catalogued into two theme categories, in order to group matching themes: (1) experiences with communicable chronic conditions; (2) coping strategies for communicable chronicle diseases. Stigma was identified as the most impacting experience in subjects' lives, which reverberated negatives feelings. In spite of their illness, subjects adopted healthy lifestyle habits and found support on religiosity/spirituality and on the dimensionality of time as a way to live harmoniously with diseases. We also noticed that the support network (family, health services) plays a key role in the process of living with communicable chronicle diseases. Since the diagnostic, the subjects experience negative feelings and sensations not only because of the fragileness that the disease imposes on their body but also because of the maintenance of the condition, which make them more vulnerable to discrimination, prejudice and stigma. It becomes necessary to strengthen the support network around the subject, in order to encourage improvements in the quality of life of people living with communicable diseases. Keywords: Communicable Diseases; Communicable Chronic Conditions; Illness Experience.

Resumo

O objetivo deste artigo é identificar e descrever as experiências de adoecimento de pessoas que vivem com condições crônicas transmissíveis. Revisão integrativa da literatura foi realizada em maio de 2015 nas bases de dados PubMed, Literatura Latino-Americana e do Caribe em Ciências da Saúde (Lilacs) e Scopus. A partir do cruzamento de palavras-chave e de descritores controlados, foram adotadas oito estratégias de busca, que resultaram na seleção final de 12 artigos. Realizou-se fichamento dos artigos, sendo elaboradas duas categorias temáticas, tendo em vista o agrupamento de temas coincidentes: (1) experiências com as condições crônicas transmissíveis; e (2) estratégias de enfrentamento das condições crônicas transmissíveis. Identificou-se o estigma como sendo a experiência de maior impacto na vida dos sujeitos, o qual reverberou em sentimentos negativos. Apesar disso, os sujeitos adoecidos adotaram hábitos de vida saudáveis, bem como apoiaram-se na religiosidade/ espiritualidade e no dimensionamento do tempo como forma de harmonizar sua convivência com as doenças. Observou-se, ainda, que a rede de apoio (família, serviços de saúde) tem papel fundamental na vivência das condições crônicas transmissíveis. Os sujeitos experimentam sensações e sentimentos negativos desde o diagnóstico, seja pela fragilidade que a doença impõe ao seu organismo, seja pela manutenção da condição que os torna mais vulneráveis à discriminação, ao preconceito e ao estigma. Torna-se necessário fortalecer a rede de apoio em torno do sujeito, no sentido de favorecer a melhoria na qualidade de vida das pessoas que vivem com condições crônicas transmissíveis.

Palavras-chave: Doenças Transmissíveis; Condições Crônicas Transmissíveis; Experiência do Adoecimento.

Introduction

Diseases are characterized as common phenomena in the course of human life. As an experiment, they are continually in the interweaving of the particular dimension of the subject affected by social history, which reflects the socio-cultural context in which the illness is produced and interpreted (Souza et al., 2013). In this sense, subjects affected by a process of illness establish positions before the diseases, giving them meaning and developing a routine to deal with the event (Rabelo; Alves; Souza, 1999).

Regarding chronic conditions, although there are significant differences between noncommunicable and communicable diseases, these illnesses confront the diseased people and family similarly in regard to living with a permanent or long-term condition (Alencar, 2006).

In addition to the intrinsic biological aspects of chronic conditions, which require changes in the subject affected, some diseases need deeper adaptations from the social point of view, as it is the case of socially stigmatized diseases. Thereby, the Human immunodeficiency virus/acquired immunodeficiency syndrome (HIV/AIDS), tuberculosis (TB), leprosy and the viral hepatitis demand that the subject develops strategies to deal with the feelings of exclusion, prejudice and discrimination (Borestein et al., 2008; Garcia; Koyama, 2008; Sousa; Cruvinel, 2008; Touso et al., 2014).

The presence of social and human sciences in the field of collective health conforms as the structural column of the area, evoking collective studies and itself as social system to the understanding of what is health, as a state and as an object of study (Loyola, 2012). Therefore, it is thus necessary to advance further in producing knowledge in health social and human sciences, especially regarding the theoretical and methodological support for researches (Deslandes; Iriart, 2012).

Thus, there is a reason for the development of this integrative literature review, aiming at eliciting reflections on the process of illness in chronic communicable conditions as a way of contributing to the (re-)construction of social reality in the collective scope. The guiding question of this study is: "what senses are experienced by people affected by chronic communicable conditions?" The aim was to identify and describe, borrowing from national and international literature, the illness experiences of people living with chronic conditions.

Methodology

Since 1980, the integrative literature review has been described as a method of research that allows the synthesis of multiple published studies, including the development of relevant research supporting decision-making and improvement of clinical practice (Coriolano-Marinus et al., 2014; Mendes; Silveira; Galvão, 2008). In addition, it allows for the definition of concepts, the review of theories, the evaluation of evidence and the analysis of methodological issues on a particular theme (Whittemore; Knafl, 2005).

This study is configured as an integrative literature review whose guiding question was structured through the PICO strategy (Santos; Pimenta; Nobre, 2007): (P) Patient or Problem – subjects affected by chronic communicable conditions; (I) Intervention – personal experiences; (C) Comparison – does not apply to this study; (O) Outcome – feelings and changes in daily life as part of experiencing the chronic communicable condition.

The following steps were considered for the operation: problem identification; selection of sample to be reviewed; definition of the characteristics of the studies and their results; analysis of the information; discussion and interpretation of results; and presentation of the review (Lima, 2015). Aiming at reaching an appropriate refinement of the articles, the following criteria for inclusion was established: articles published between January 2010 and April 2015, prioritizing, thereby, more recent studies on the subject; scientific research classified as originals and indexed in the databases PubMed, Literature in the Health Sciences in Latin America and the Caribbean (LILACS) and Scopus; articles available in Portuguese, English and Spanish; and articles that answered the guiding question established in this integrative literature review.

Articles that were published prior to the year of 2010, systematic review research and/or integrative literature research, dissertations, theses, as well as publications of official records; and scientific research classified as originals, but those without people living with chronic conditions as subjects of study, were not included.

Two reviewers performed search for articles in different and independent times, in May 2015, in the PubMed, LILACS and Scopus databases. The cross between keywords and controlled descriptors was used to select publications, in order to maximize search strategies; favoring the refined and thorough selection of the articles.

For better understanding and visualization, the keywords were organized into groups (G1, G2, G3 and G4) and controlled descriptors – belonging to the Medical Subject Headings (MeSH) and the Health Sciences Descriptors (DeCS) – have been identified in parentheses, as specified in Chart 1:

Group	Keywords
Gı	("doenças bacterianas sexualmente transmissíveis"), ("doenças virais sexualmente transmissíveis"), ("doenças transmissíveis"), "doença crônica transmissível," "doenças crônicas transmissíveis," "doença contagiosa," "doença infectocontagiosa," "doenças infectocontagiosas," "doença infecciosa," "doenças infecciosas," "enfermidade transmissível," "enfermidades transmissíveis," "condição crônica," "condições crônicas," "condição crônica transmissível," "condições crônicas transmissíveis," casos crônicos," "quadros crônicos," ("doenças crônicas") and "moléstias crônicas."
G2	"processo de adoecimento," "processos de adoecimento," "processo de adoecer," "processos de adoecer," "processo do adoecimento," "processos do adoecimento," "processo do adoecer" and "processos do adoecer."
G3	"experiência do adoecimento," "experiências do adoecimento," "vivência do adoecimento," "vivências do adoecimento," "vivencia de adoecer" and "vivencias de adoecer."
G4	("pessoas"), "sujeitos," "sujeito," "indivíduo," "indivíduos," "pessoa," "pessoas," "pessoa vivendo com condições crônicas transmissíveis," "pessoas que vivem com condições crônicas transmissíveis," "pessoa vivendo com condição crônica transmissível" and "pessoas que vivem com condição crônica transmissível."

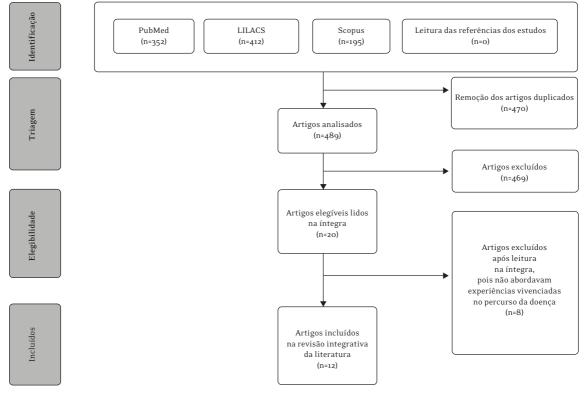
Chart I - Presentation of the keywords used in the article selection process as per grouping, Ribeirão Preto, 2015

Eight search strategies (E) were adopted, considering that, for the cross between keyword and controlled descriptors, a Boolean operator *OR* was used; among the strategies, Boolean operators *AND OR* were employed.

Thus, the following strategies were conducted: (E1) cross between the keywords and the controlled descriptors of "G1"; (E2) cross between the keywords of "G2"; (E3) cross between the keywords of "G3"; (E4) cross between the keywords and controlled descriptor of "G4"; (E5) cross between "E2" *OR* "E3"; (E6) cross between "E1" *AND* "E2" *AND* "E3"; (E7) cross between "E1" *AND* "E4"; (E8) cross between "E6" *AND* "E4." Due to the quantity of materials, these were stored in the online reference manager EndNote to facilitate the identification of articles.

Three hundred and fifty two articles were identified in PubMed, 412 in LILACS and 195 in Scopus. At the selection stage, duplicated work in each database and among each other were removed, remaining 489 articles. These, in turn, underwent the eligibility stage, in which the reading of the summaries was decisive and resulted in the selection of 20 publications. Successively, the peer reviewers did a full-text reading of the material, selecting 12 articles to compose the final sample of this integrative literature review. Figure 1 presents a flowchart concerning the process of selection of the articles in this study:

Figure 1 – Flowchart of the sampling of the integrative review, according to The PRISMA Group, Ribeirão Preto, 2016



Source: Moher et al., 2009

It is noteworthy that these articles were submitted to note-taking (Lima, 2015), to have the information organized and summarized in order to facilitate the production of thematic categories from the grouping of topics. Ethical issues in research have been respected, as well as the copyrights.

Results and discussion

Most articles - seven (58%) - were taken from the PubMed database, four (34%) from LILACS, and one (8%) from Scopus. Regarding languages, eight (67%) studies were published in English and four (34%) in Portuguese. Brazil was the country with the largest number of studies on the theme, with four (34%), followed by China, with three (25%), the United States of America, with two (17%), and the United Kingdom, South Africa and Thailand, with one study (8%) each.

Regarding the journals in which the studies were published, Social Science & Medicine concentrated the largest number - three (25%). The other nine journals (75%) - Qualitative Health Research; Issues in Mental Health Nursing; Health; AIDS Care; Journal of Family Psychology; Interface: Comunicação, Saúde, Educação; Revista da Escola de Enfermagem da USP; Escola Anna Nery Revista de Enfermagem; and Physis: Revista de Saúde Coletiva - presented one study each.

The grouping of topics from the selected articles enabled the construction of two topics: (1) experiences with chronic communicable conditions; and (2) coping strategies in patients with chronic conditions. Chart 2 describes the articles included in these categories, as well as the specifications related to the journal publication/year, title, authors, method, core idea and thematic category:

Chart 2 - Description of the articles per journal publication/year, authors, title, method, core idea and thematic	
category, Ribeirão Preto, 2016	

Published Journal (year)	Title	Authors	Method	Core idea	Thematic category
Social Science & Medicine (2015)	The stories we tell: Qualitative research interviews, talking technologies and the "normalisation" of life with HIV	Mazanderani and Paparini	Qualitative	Stigma and discrimination as difficult processes of living with AIDS; The normalization of AIDS as a strategy for combating the disease.	I
Escola Anna Nery Revista de Enfermagem (2014)	"Tuberculose multirresistente: integralidade da atenção à saúde na perspectiva discursiva" [Multidrug-resistant tuberculosis: integrality of health care in discursive perspective]	Ballestero et al.	Qualitative	Health care coordination as a weakener of the confrontation of multidrug-resistant tuberculosis (MDR TB).	I
Revista da Escola de Enfermagem da USP (2013)	"Convivendo com hepatite: repercussões no cotidiano do indivíduo infectado" [Living with hepatitis: repercussions on the daily life of the individual infected]	Teston, Silva and Marcon	Qualitative	Fear, anxiety and stigma as feelings experienced in the course of living with hepatitis B and C.	I
Social Science & Medicine (2012)	HIV and tuberculosis: the construction and management of double stigma	Daftary	Qualitative	Different levels of stigma experienced in living with TB and HIV/AIDS.	I
Qualitative Health Research (2012)	Living positively: the experiences of Thai women living with HIV/AIDS in Central Thailand	Liamputtong, Haritavom and Kiatying- Angsulee	Qualitative	Positive attitudes as a strategy for combating AIDS.	2

Chart 2 - Continuation

Published Journal (year)	Title	Authors	Method	Core idea	Thematic category
Social Science & Medicine (2012)	"Dying from" to "living with": framing institutions and the coping processes of African American women living with HIV/AIDS	Watkins-Hayes, Pittman-Gay and Beaman	Qualitative	The healthcare providers and institutions that protect people living with HIV (PLWA) as enhancers in the fight against AIDS.	2
Interface — Comunicação, Saúde, Educação (2012)	"A influência da religiosidade no conviver com o HIV" [The influence of religiosity in living with HIV]	Ferreira, Favoreto and Guimarães	Qualitative	Religiosity/spirituality as a strategy for combating HIV/ AIDS.	2
Issues in mental Health Nursing (2011)	Living in silence: a grounded theory study of vulnerability in the context of HIV infection	De Santis and Barroso	Qualitative	Negative experiences increase the personal sensation, as well as the social state of vulnerability of PLWA.	I
AIDS Care (2011)	In sickness and in health: a qualitative study of how Chinese women with HIV navigate stigma and negotiate disclosure within their marriages/ partnerships	Chen et al.	Qualitative	Stigma as a potential disorganizer to the social and familiar support to people living with AIDS.	1
Journal of Family Psychology (2011)	Facing HIV as a Family: Predicting Depressive Symptoms with Correlated Responses	Li et al.	Quantitative	Family support as a catalyst of the psychological well-being of PLWA.	I
Physis — Revista de Saúde Coletiva (2011)	" A análise da narrativa dos pacientes com HIV na construção da adesão terapêutica" [The narrative analysis of patients with HIV in the construction of therapeutic adhesion]	Ferreira and Favoreto	Qualitative	Protagonism as an enhancer in the fight against HIV.	2
Health (2010)	The phenomenology of time: lived experiences of people with HIV/AIDS in China	Zhou	Qualitative	Time as an ally in the construction and (re) signification of the experience of living with AIDS.	2

Taking the concept of hierarchy of evidence proposed by Melnyk and Fineout-Overholt (2011), an analysis of the information relevant to each study selected was conducted. From that, we observed that they all showed level IV of evidence, which refers to one descriptive or qualitative study.

Thematic category 1: experiences with chronic communicable conditions

The subjectivity of the disease is guided by the possibility of understanding an interior experience as problematic, from processes that transcend the

pure individual conjuncture, bypassing the social phenomenon (Nascimento, 2005). Regarding communicable conditions, the diseased person becomes more sensitive to the emotional problems resulting from losses, anxieties, fears, self-blaming and, especially, social stigmatization (Liamputtong; Haritavorn; Kiatying-Angsulee, 2012).

Studies such as the ones by Daftary (2012), De Santis and Barroso (2011), Chen et al. (2011), Li et al. (2011) and by Mazanderani and Paparini (2015) corroborate this understanding, revealing the stigma as the experience of the greatest impact on the lives of PLWA and TB.

It is stressed that the creation of the term stigma is attributed to the times of Ancient Greece, referring to bodily signs that showed something extraordinary or bad about the moral status of those who had them (Goffman, 1988). In the 1960s, the term gained new prominence from the reflections of Goffman (1988), which include the direct participation of society in the process of stigma formation. In this way:

[it] involves not so much a set of individuals that can be divided into two piles, the stigmatized one and the normal one, as a social process of two roles in which the individual participates in both, at least in some connections and in some stages of life. The normal and the stigmatized ones are not people, but prospects that are generated in social situations during mixed contacts, because of unfulfilled rules that are likely to act on the encounter (Goffman, 1988, p. 117).

The high prevalence of HIV/AIDS and TB in subjects considered on the margins of society (sex workers, men who have sex with men, women, people living in impoverished and overcrowded regions, immigrants) makes them even more vulnerable to the stigma and prejudice. The consequences of this phenomenon can undermine the control policies of these diseases, to the extent that they contribute to the low demand for HIV testing and TB tests and, above all, low adherence to treatments (Daftary, 2012).

Chen et al. (2011) analyzed the impact of the decision of women living with HIV/AIDS to disclose their pathological condition to their families. For these participants, the directions related to the stigma of the disease were more terrifying than the immediate threat to life, represented by a disease such as cancer. In this way, the disclosure of their diagnosis considered the nature and the quality of their personal relationships, and most of them privileged partners/spouses and close relatives (Chen et al., 2011).

Results in line were observed in the studies by De Santis and Barroso (2011) and by Liamputtong, Haritavorn and Kiatying-Angsulee (2012), in which PLWA revealed the need for concealing/hiding their diagnosis information, considering the feelings of shame and fear of others. Thus, they limited the sharing of that information to just a few family members.

The need to omit the health condition generated in subjects the feelings of denial of the diagnosis, fear of misunderstanding and abandonment by close people, depression and insecurity. Feelings that resulted, at times, in suicidal thoughts – predominantly in women –, considering that some female participants revealed to have physically attempted to take their own lives (Liamputtong; Haritavorn; Kiatying-Angsulee, 2012) and others adopted stances of not adhering to HIV/AIDS treatments, in an attempt to speed up the process of death by the disease (De Santis; Barroso, 2011).

If, on the one hand, the social stigma turns into feelings that weaken the experience of living with communicable diseases, on the other, they legitimate the feeling of segregation among the diseased subjects. Supported by this understanding, Daftary (2012) noted that subjects co-infected by HIV/AIDS and TB brought to the surface feelings of dual identity in relation to damages.

These dichotomous feelings invoked the construction of a positive self-identity, associated with the morally sane and correct, in which TB was naturalized, given its ability to affect a wider portion of the population and, above all, by its curable aspect. HIV/AIDS, in turn, raised the construction of negative self-identity, associated with immorality reflected from a deliberate action, with guilt and with the perpetuity of the disease (Daftary, 2012).

Furthermore, due to the intense experiences of stigma reported by participants in relation to HIV/AIDS, we noted that negative self-identity has become undesirable and therefore stigmatized, which, aggravated by the dual diagnosis, may have affected the way in which the subjects experienced, understood and shared the feelings of their illness (Daftary, 2012).

Although HIV/AIDS has been questioned in most studies, Teston, Silva and Marcon (2013) made similar observations in subjects living with hepatitis B and C. Most participants received the diagnosis of the disease during blood donation and revealed experiences such as fear, insecurity, powerlessness against the unknown, anguish in clarifying the way they contracted hepatitis and the anxiety related to the maintenance of the treatment.

Although the stigma is still set as one of the leading weakeners in living with communicable conditions, in particular HIV/AIDS, TB and hepatitis B and C, a reverberation of the senses of standardization/naturalization of these diseases as chronic conditions was observed, especially in the light of advances in technology and drug therapy.

In the study by Mazanderani and Paparini (2015), reports of normalization of HIV/AIDS were observed from cognitive and social points of view. The first increased, in participants, an adaptation to the unexpected diagnosis, as well as the incorporation of the disease to their lives in emotional and practical perspectives (treatments). Regarding social standards, participants revealed having a hard time engaging in daily activities (having a job, for example), affective relationships, and children (Mazanderani; Paparini, 2015).

From the abovementioned, one can infer that, although there is an attempt in the reverberation of HIV/AIDS as a chronic condition, the stigma that still persists in relation to communicable conditions weakens the concreteness of this ideology (Mazanderani; Paparini, 2015).

Thematic category 2: coping strategies of chronic communicable conditions

In general, chronic diseases result in disruptions in the lifestyle of individuals, turning into psychological and behavioral changes that require adaptation of life habits and strategies to deal with this new reality (Teston; Silva; Marcon, 2013).

The strategies adopted by Thai women living with HIV/AIDS are an example of this. To make

their life expectancy longer, they live positively with the adoption of habits considered beneficial to health, such as maintaining a healthy diet and exercising regularly (Liamputtong; Haritavorn; Kiatying-Angsulee, 2012). Similar results were observed in studies by Teston, Silva and Marcon (2013), considering that the subjects affected by hepatitis B and C, after being diagnosed, have adopted habits considered to be healthier and have reduced the consumption of alcohol.

In addition to the biological care, the close relationship between health and spirituality/religiosity gains prominence in the context of living with the chronic conditions, especially for providing emotional strengthening to the subject before the hardships imposed by the illness (Ferreira; Favoreto; Guimarães, 2012).

The study by Liamputtong, Haritavorn and Kiatying-Angsulee (2012), shows that Thai women – most adept to Buddhism – credited the acceptance of the disease to their belief in personal *karma*. The participants of the study conducted by Ferreira, Favoreto and Guimarães revealed religiosity (2012) to be used to explain their misfortune, explate the guilt of contagion and displace negative moral values experienced by these subjects.

The participants also highlighted positive aspects in relation to religion, such as: the spiritual support, religious forgiveness, religious collaborative participation, social connection and a benevolent redefinition of the stressor. However, the religious discontent, the presence of interpersonal conflicts with members of the religious group and doubts about the power of deities in the intervention of HIV/AIDS constituted the negative aspects of religiosity (Ferreira; Favoreto; Guimarães, 2012).

In this line of thinking, the process of living with HIV/AIDS was scaled after three periods: the linear, which corresponded to the interruption of life with the diagnosis of the disease; the relational, which was the time of sociocultural prioritization of family obligations in relation to the uncertainty of life; and the reconstructed, which was characterized as the moment when participants had the sense of self-realization, acceptance and happiness (Zhou, 2010).

The three dimensions are not necessarily correlated with the clinical course of HIV/AIDS, but reflected

the fluidity of their own awareness of the subject that may even have been shaped by various contextual factors (health, family relationships, social support, self-reflection) (Zhou, 2010). From this, living with HIV/AIDS began to be perceived as a phenomenon of living and growing, rather than dying deteriorating, which, to some extent, became the most useful time for these subjects, allowing the resumption of the protagonism of their lives (Zhou, 2010).

For Ferreira and Favoreto (2011), the perspective of protagonism refers to the action, dialogue and attitude of the subject prior to the diseases, HIV/AIDS in particular. Reports that pointed to the construction of new senses to life, the revaluation of aspects of health and self-care that were not considered before diagnosis were observed in this study. Senses of victory against the adversities of life were reverberated, in order to allocate HIV/AIDS as another obstacle to be overcome (Ferreira; Favoreto, 2011).

Taking the protagonism of their lives also denoted a relationship of complicity with the treatment, both from the point of view of commitment to the medication and the relationship with the health team. From this, it becomes necessary to understand the adhesion to the treatment as a mutable state, and not as a watertight condition of the subject. Therefore, adhesion becomes contextualized in the way of being, at the mercy of the daily variability, directly proportional to the movement of autonomy and protagonism of the subject (Ferreira; Favoreto, 2011).

In this perspective, the study by Watkins-Hayes, Pittman-Gay and Beaman (2012) noted that, since the diagnosis until the active management of life with HIV/AIDS, support institutions (hospitals, clinics and other services that offer care to diseased people) had a key role in the way the subjects determined and dealt with their health condition.

Living with HIV/AIDS, in addition to the emotional management and the physical symptoms of the disease, is, above all, living with previous experiences of pain and exclusion. Therefore, support institutions acted in order to help the subject to glimpse positive situations, regardless of the personal and environmental struggles, reinforcing the perseverance with the adversity of the illness (Watkins-Hayes; Pittman-Gay; Beaman, 2012). It is understandable that the confrontation, as well as the adaptation to physical, psychological, spiritual and social changes imposed by living with HIV/AIDS go through effective psychosocial support (family, friends, partners, institutional support groups). Therefore, healthcare providers should pay attention to the influences these changes promote in the lives of PLWA, especially those who lack social support, in order to minimize the negative impact on the health of these subjects (De Santis; Barroso, 2011).

However, the study by Ballestero et al. (2014) noted the lack of effective coordination between the services of the network of integral care for people living with MDR-TB. The limitedness of professional stances in relation to the negotiation and adequacy to the particularities of each subject and context, as well as the mismatch between the needs of the diseased people and the service organization ways, have further compromised adherence to treatment (Ballestero et al., 2014).

The family also fulfills a relevant role from the point of view of social support to people living with communicable diseases. In their study, Li et al. (2011) emphasized that the impact of HIV/AIDS can affect directly and indirectly the family context, and the quality of life of both patient and family is directly related to the way they deal with the stressful aspects of the disease.

Liamputtong, Haritavorn and Kiatying-Angsulee (2012) observed reports of family support to PLWA, especially at the moment of diagnosis, which resulted in positive feelings in relation to fighting the disease. However, Chen et al. reported negative experiences in relation to family support. One of the participants revealed to have been coerced by her spouse to abstain from work/employment in order to minimize the possibility of other people discovering her diagnosis of HIV/AIDS.

Although there are many challenges in living with chronic communicable diseases, much has been advanced, especially regarding the autonomy of the diseased people. At this moment, the social support network (family, health services) plays a fundamental role, and thus it has become a necessity to strengthen these social actors in order to promote further improvement in the quality of life of people affected by chronic conditions.

Final Remarks

This integrative literature review allowed for the observation that the experiences of people with communicable conditions, as well as their coping strategies, conform as themes explored by health social and human sciences, focusing on strengthening the actions of care.

In general, the studies aimed at understanding the phenomena related to the subjective and social dimension of the illness, transcending the biologizing logic of the objective character of the disease. They sought to describe and understand the positive and negative consequences of living with a chronic communicable condition in various sociocultural contexts.

Thus, it was possible to infer that the subjects, in particular those affected by HIV/AIDS, TB and hepatitis, experienced negative sensations and feelings since their diagnosis. This was both due to the fragility the disease had imposed on their bodies, as well as to the maintenance of their condition in contexts that make them even more vulnerable to discrimination, prejudice and social stigma.

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Contribution of the authors

Oliveira was responsible for designing, outlining and writing the report. Lima contributed to data collection and analysis, as well as to the critical review of the text. Faria, Ravanholi and Lopes contributed to data analysis and interpretation. Souza and Monroe contributed to the interpretation of the data, to the critical review of the text and to the approval of the version to be published.

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