

# Coping strategies towards people with multiple sclerosis, throughout their life experience

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## ABSTRACT

**Introduction:** Multiple Sclerosis is the most common neurological disease on the population aged 20 to 30. But it counts with scarce published qualitative and scientific evidence, and the information that could be found, does not cover the topics developed herein. **Objective:** Understand coping strategies through the life experience of people living with Multiple sclerosis who belong to the Corporación Pacientes Esclerosis Múltiple (Corporation of Multiple Sclerosis Patients Talca) Talca, Chile. **Methodology:** Descriptive phenomenological study with qualitative approach. Seven people over the age of 18 participated, who had been diagnosed with Multiple Sclerosis. Semi-structural in-depth interviews were held, selected by non-probabilistic sampling of convenience until the saturation of data. Throughout the whole research, the ethical principles of Ezequiel Emanuel were respected. **Results:** People with Multiple Sclerosis report from their own life experience regarding coping strategies such as personal predisposition; Self-esteem and Functionality acquired through support networks (mainly family and health-care staff). **Conclusions:** The life experiences of people with MS are different and vary from person to person, depending on countless bio-psycho-social factors, but, within these factors, coping strategies stand out whether they are innate or acquired, added to other characteristics such as sex and age, amongst others.

**Key Words:** Stereotype; Ageing; Students; Health Sciences. (DeCS).

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## INTRODUCTION

According to the Federación Internacional de Esclerosis Múltiple (MSIF) (Multiple Sclerosis International Foundation or MSIF)<sup>(1)</sup>, currently there are 2,300,000 people who suffer from Multiple Sclerosis (MS) throughout the world, being one of the most common neurological diseases on the population aged 20 to 30. With the understanding that MS as a neurodegenerative and demyelinating disease that affects the central nervous system, causing damage to the myelin sheaths, which are lipoprotein structures that recover the nerve cells, whose role is to protect and increase the propagation of nervous impulse. Upon such sheaths being damaged, it affects the sensorial and motor function of all the different nerves of the body, which reflects within the different signs and symptoms that begin to appear in the people who have the disease, such as fatigue, dysarthria, pain, hemiparesis, spasms, shaking and paresthesia<sup>(2)</sup>. Due to these symptoms, it is hypothesized that their quality of life could be affected. Studies have proven that, as the disease progresses, there is a decrease in quality of life and in work productivity, and an increase in all costs associated to healthcare attention<sup>(3)</sup>.

The Ministerio de Salud de Chile (Minister of Health of Chile)<sup>(4)</sup>, determined that MS generates a disease burden of 329 years lost, as Disability Adjusted Life Years (or DALYs), which is relevant, since it affects people at the beginning of their professional career, a period which corresponds with the most productive economical period, also, generating a great impact at the economic level.

The situation at the regional level is not far from what was mentioned in the previous paragraphs, that is, the statistical information counted with currently is scarce when it comes to MS. But, according to public records of the Hospital Regional de Talca (HRT) (Regional Hospital of Talca)<sup>(5)</sup>, the total number of those attended due to MS was of 35 people. In spite of this statistical information regarding MS, there exists scarce evidence when it comes to published qualitative and scientific evidence, and the information that could be found, does not cover the topics developed herein. All the above indicates there are studies that show aspects such as chronicity, progression, and singularity of MS<sup>(6)</sup>, as well as the experience in regards to the diagnosis, and, additionally, in relation to the meaning for the caretaker of people with this disease<sup>(7)</sup>. Also, there are some quantitative studies related to the coping strategies of MS<sup>(8-9)</sup>. However, there is still much scientific evidence and/or published studies that are not known, which the research team was not able to locate it during the literature search, that account for these coping strategies and the experience lived by people with MS. Thus, the relevance of this research, since this disease creates limitation regarding the autonomy of people, due to its neurodegenerative characteristic, the vast range of signs and symptoms in people who have MS and due to its chronic and progressive nature, which often interfere with an effective psychosocial adjustment. Apart

from the physical limitations and/or cognitive deterioration, people with MS can experience different affections, such as depression, decrease and retreat from support networks and the loss of bodily and work-orientated functions<sup>(10)</sup>. However, some people are able to confront their situation in a positive manner and enjoy life<sup>(11)</sup>. Therefore, it is necessary to study the speeches given by the protagonists about life experiences from a holistic point of view and with the need to understand the experience of carrying this disease<sup>(8)</sup>.

This research recognizes the studies of Husserl<sup>(12)</sup> as theoretical basis, who points out that all object experiences take place in a course of experiences, where each participant retains past experiences and anticipates new ones parting from real experiences, focused on describing what the participants have in common when they experience a determined situation, in order to comprehend the nature of their actions. As has already been indicated, this study is not only centered on the life experience but also moves towards understanding the coping strategies that arise from these people, and from nursing. Callista Roy defines the coping process as innate or acquired models of acting before the changes produced by the environment, with the understanding that those determined innate are the ones genetically determined, being automatic processes, while the acquired coping strategies are created throughout methods<sup>(13-14)</sup>.

On the basis of the above, the objective of this research is to understand the coping strategies throughout the life experience of people with MS who belong to the Corporation of Multiple Sclerosis Patients Talca, Chile.

## METHODOLOGY

### *Participants*

Qualitative study with phenomenological approach<sup>(15)</sup>, using E. Husserl as a theoretical reference<sup>(12)</sup>. The referential and methodological framework for this research is based on the premises of Huberman and Miles<sup>(16)</sup>, who propose an analysis under three guidelines or related sub-processes, which are: data reduction, presentation of data, and presentation of the conclusions, and their verification. Seven people participated in this research who met the following selection criteria: being diagnosed with MS, belonging to the Corporation of Multiple Sclerosis Patients Talca, Chile, aged eighteen or older, and having obtained a score higher or equal to thirteen points in the abbreviated Mini-Mental Test<sup>(17)</sup>. The final n of participants was determined by using the data saturation criteria<sup>(15)</sup>.

### *Instruments and procedures*

For the development of this research, a verification test was performed in order to prove the comprehension of the questions by the interviewee, determine interview times, understand some of the possible reactions and responses

of the participating people. This verification test was performed by interviewing two people whose results were not incorporated for the final analysis of the study. Later, seven semi-structured in-depth interviews were performed, selected by non-probabilistic sampling of convenience<sup>(16)</sup>. Each interview had an approximate length of one hour and was performed in the home of the participants, which gave them peace of mind and trust, in order to share deliver their stories in more detail. The interview was performed depending on the availability of the interviewees, between the months of December 2016 and January 2017. First of all, introductory questions were performed, with the purpose of establishing trust between the interviewee and interviewer. Then, a test known as Mini-mental Abbreviated test was applied, which consists of 6 questions that assess temporal and spatial orientation, short and long-term memory, executive capability and visual constructive capacity<sup>(17)</sup>. This test was utilized to detect cognitive deterioration and observe its evolution in patients with neurological alterations. The total score of the application of this test was 19 points and it is considered altered if the score is less than 13 points. On this occasion, it was used in order to decrease biases and comply with ethical criteria of the research, following the process was continued with those who obtained a score higher or equal to 13 points, to finally perform the semi-structured interview.

The research questions were: How has the experience of living with Multiple Sclerosis been? What has been your approach to this disease?; based on your life experience, How has your experience been in regards to the care provided by the healthcare staff?

Throughout the entire research, the seven ethical principles of E. Emanuel were respected<sup>(19)</sup> and obtained the approval of the Committee of Methodological Evaluation (CEM-UCM by its acronym in Spanish) of the Faculty of Health Science of the Universidad Católica del Maule. All interviews were recorded, with prior acceptance and signed informed consent, using a digital recorder and then transcribed word by word. Prior to the beginning of the analysis, the research team approached the participants once again to corroborate their experience throughout their discourses, which is known as to go back to the source<sup>(20)</sup>.

## RESULTS

Huberman and Miles<sup>(16)</sup> were the methodological referents for the analysis of the results obtained, which are presented in dimensions that were developed from categories a priori, each one of with its pertinent sub-dimensions, that is, 1) Life Experience Dimension; sub-dimensions: symptomatology, diagnosis, treatment, and role of the healthcare staff, and 2) Coping Strategies Dimension; sub-dimensions: innate and acquired. The most significant and repetitive was obtained from each one of the former dimensions and sub-dimensions, thereby forming the data analysis, which was performed throughout data triangulation<sup>(21)</sup>; this data triangulation

originated from the revision of the theoretical framework, going back to the source and the analysis of the discourses, which gave way for the comprehension of the phenomenon being studied and validate the results. Likewise, the mains discoveries are described below:

### 1) Life Experience Dimension

a) One of the most relevant aspects within the context of life experience for these people with MS is the symptomatology. Throughout their expressions, different results can be observed. One of them is progressive limitation in daily life activities (functionality) perceived by these people, as can be reflected in the following anecdote: "I have noticed that I do not function the same as before. I used to be able to be out on the street all day perfectly, gave talks to companies without any problem, but nowadays I forget words, I do not retain information, I forget everything. I get tired and only function for a short time, and then I need to sit down since I cannot be standing up, so I have to rest. I need to throw myself on the bed for a while, throwing myself on the bed is like... obtaining a little energy to continue with my daily routine, I feel as if I am not the same person that before" (E4, 725-734). Additionally, in regards to my life experience, I also see a reflection of an alteration of my family and environment, which is shown in the following statement: "I was not doing well, neither was he, when one person gets sick, the entire family gets sick" (E4, 197-199). Another aspect that stood out is the effect in regards to the emotional environment that must be dealt with, upon consulting them in regards to their life experience of life with MS, they come up with phrases like: "Everything is pretty much ok, or everything is fine as far as can be expected, but that does not imply that I haven't had strong outbreaks, it does not imply that I have wanted to throw everything to the gutter (laughs), eh... it's difficult to begin to notice that one begins to do things, which before were normal to you, and get to the point in which it costs us a little more work, but it's the same, everything is pretty much ok, but it costs more" (E5, 8-17). Finally, in the discourses arise the late consultation due to unspecified symptoms of this illness, as mentioned in the following anecdote: "I used to get up early to work, and then one day I woke up with my hands numb, I thought that was weird, it had never happened to me, the same thing happened on the second day, my hands fell numb; on the third day it was less, but I sat on the bed and felt as if I was tired and thought it was weird, it felt like when you get home tired, very tired, so I barely got up, showered, but I felt very tired throughout that whole time. More days passed by and I felt very tired and I began to see something that looked like spots with some sort of white around the parts, and I thought to myself that was weird, because I began to associate my hands being tired and then began to see that" (E4, 23-36).

b) In regards to the experience lived pertaining to the diagnosis, different aspects can be observed such

as uncertainty in regards to the disease and everything pertaining to it, as is indicated in this anecdote: "And no, and it costs, for me it was super difficult, I think it was the first part where the diagnosis is given, that I didn't know where it might go, and just as you were saying, if I think about what is going to happen after, what will I have, if I am going to be handicapped, I have no idea. I think that it is to begin to know the disease and start thinking on those types of things, but that is my first impression with the disease" (E2, 704-712). Then, an emotional impact is identified (upon being diagnosed), since, upon asking the participants about their life experience with MS, some of their answers were the following: "Awful, horrible, horrible, as a matter of fact, the worst minute was when I saw the results of the tests" (E3, 118-120). Finally, in this sub-dimension we begin to see the comparison to their life before, as is mentioned in the following extract of the interview: "Because, previously, I used to arrive from work, to do my things, see my daughters, my plants, because my house is surrounded by plants. Now, I am always asking for them to be watered, help me with this or that, please, please, please... ¡Oh! ¡Horrible! ¡Horrible! ¡Horrible! How am I going to feel good? ...How am I going to accept an illness with which I am barely able to water my plants, take a shower, with rods?" (E7, 208-216).

c) In regards to treatment the experiences lived by these people reflect different results such as the refusal to have an invasive treatment from the users, which mentioned it in different anecdotes: "No, it hurts, I reject every time I am going to get the injection, it is uncomfortable, before, it was every day, now it's three times a day" (E1, 120-122). "I feel a little bit of panic when it comes to needles, then, they told me that they had to inject me and that was horrible" (E3, 198-200). Also, the complete therapy given during the treatment are also mentioned: "I began with a random treatment for the disease, such treatment has to do with cannabis, then, it was the change of medication, the treatment with cannabis and get out of the snag, it changed my panorama" (E3, 221-226). Another aspect related to the treatment is the expectation and hope of life granted by the treatment, people report it as "Beneficial, because I am alive, for example, to get injected is beneficial since I am alive" (E6, 224-225). "Of course, my wife, at the end of the month, whenever she gets like that, she injects herself and "kazaam!". It is as if she injected me with a boost" (E4, 1093-1095). Finally, it was detected that the majority of the people interviewed expressed an uncertainty in regards to the treatment, since they ignored if the diagnosis was favorable or unfavorable; this is shown in the following anecdotes: How am I going stay like this? but nothing appears here, unfortunately, it is too late, you are in a progressive phase, and there is no medication for your phase, there are many medication but not for your stage of the illness, " (E7 152-164).

d) As the last sub-dimension, you can find the role of the healthcare staff, which shows differences in the public and

private system, as has been mentioned in these interview extracts: "When I was diagnosed and I mentioned that I was treated by a fairly good staff, where not only was I treated by a neurologist, but by nurses and there was a team of doctors from different specialties to guide you, help you, and inform you; what did not happen to me here in Talca, but did happen in Santiago and happens to me a lot with the people of the corporation, all of a sudden when we begin to talk I notice how different my reality is than the one they live" (E3, 232-242). Another common topic that is frequently mentioned by people is the lack of empathy and affection, which can be translated into inhumane attention, which is shown in the following statement: "They offer a terrible service, I do not know why they are like that, if you go there sick! You are a patient, I mean, why treat people that way?, as if you get in the way" (E7, 539-542). "If I was standing up, the Doctor was sitting down –Don E6, -Doctor, how are you? – and he just said, fine, "how is Don E6 doing"?, none of that. Those are small details that make a difference" (E6. 257-260). But we must reveal that some of the statements show an improvement in service: "I think that I am not the only one, I believe they treat all patients that way, like that, in this manner! And now, that the hospital, the care is improving, becoming a little more humane, because of where we are in here and talked to every one, and I think because of that he has become more humane" (E5, 489-495). "It is what he is now, the "doctor" is providing care very similar to that he provides in the clinic, but now, because we have the corporation and he was given a warning, it is practically the same, because when I go to the clinic, we talk, he makes the tests, everything is good as well, but now in the hospital he is behaving like that and giving me the same care he provides in the clinic" (E5, 921-931). Another aspect worth pointing out is the delivery of less information in regards to the disease, which is reflected in the following anecdote: "What can I say? I wish they would support us more, I don't know, maybe they could give us more ... information about the disease" (E7, 318-320).

## **2) Strategies of coping throughout their life experience**

a) In regards to coping strategies, the innate strategies were found, from which you can see different ones such a negation in regards to the illness: "Mmm, no not yet, I still do not assume it, no because I think like that, that due to a miracle I will be able to walk a little bit" (E7, 191-193). Another innate strategy is the acceptance of the need for help expressed by the participant: "I do not want that my life depends on the illness, is something that I say but I do have a disease that I cannot let control me, if I feel bad I just need to let somebody know, I cannot remain alone and think it will go away, because things begin to accumulate. Another thing I learned is that I need to ask for help, that I cannot remain by myself and act as if "I can"" (E2, 716-724). Another innate strategy identified by the participants is the need of a multidisciplinary team, as stated in the following statement:

"What staff, if only the Doctor treats me? Nobody, I do not even know the current nurse, because I think she works after three in the afternoon. If I go to see the Doctor at ten in the morning, I am not going stay until three in the afternoon in order to talk to her, so I do not know her" (E7, 272-277). The last innate strategy that emerges from the talks with the people is that of acceptance, relating to the whole process of the disease as something normal: "I address it as if life went on as normal, as if life continued to be normal, nothing is going on here, in other words, I wanted things to be normal, but I always had pain and all that" (E4, 714-717; E3, 32-33).

b)Also, the other type of coping strategies are those that are acquired, from which you can rescue different forms such as complementary therapy, the participants referred to reiki, Bach flowers, cannabis and yoga use. "This is since July, I go with a therapist who uses Bach flowers, I love that woman" (E5, 769-771). Another strategy is the participation in the multiple sclerosis corporation, as has been expressed by the patients: "I have been learning throughout the people of the corporation" (E1, 25-26). "That is why we get together once a month and... we get to know each other and give feedback, in other words, we get to know the disease as... well, patients, not by looking it up on the Internet, but throughout life', in other words... I think it is a great idea that we did all of this for the corporation" (E4, 485-490). "Of course, yes, if the meetings, I go to all of them, there we breathe deep and encourage one another" (E7, 425-427). Another form of coping is the family support network, and generally, the statements mention: "Similar support from my husband, from my family, well my family knew 3 years after I was diagnosed, they knew when I was in treatment" (E5, 228-231). Professional support is also included as a strategy in order to face multiple sclerosis and everything related to it, expressed in the following manner: "It's not a small issue, I think it's important to go to a psychologist where I can see how to deal with this, while I was in Santiago still, I began to go to therapy with a Psychologist" (E3, 280-285). Another strategy is spiritual support as was stated: "Well, I am a person who has faith and all I say is, well, I can take a bag of pills daily or when I used to inject myself, I could be injecting myself 24 hours injection after injection, but if that is not God's will. It does not matter how much medication I take, I will not be the same" (E5, 45-52). The last strategy refers to emotional support given by the healthcare staff, where people give more value to emotional support as mentioned in the following interview: "I wish they were more humane, for them to put themselves in our shoes (pause), because...nobody is free" (E5, 838-839). "Look, I feel that when I was diagnosed, I felt as if the doctor was hugging me and I cried on her shoulder, in other words, yes, in that sense, it is because she is very empathetic" (E3, 444-448). There is also a need shown for psychological support: "If somebody is embarrassed and I fell as if now I am through that, that happens, I cry a lot, I feel that I have some sort of depression and need psychological help, so that somebody talks to me right there" (E4, 725-738).

## DISCUSSION

With the intention of clarifying the general objective, which is to get to know the coping strategies through the life experience of people with MS who are member of the Corporation of Multiple Sclerosis Patients Talca, Chile, the discussion is theoretically focused on the descriptive phenomenon of Husserl<sup>(12)</sup> in order to explain the life experience, and in Roy<sup>(13- 14)</sup>, in order to sustain from nursing, the coping strategies.

Throughout data analysis we can see that the people interviewed, upon being exposed to the stimuli (diagnosed with MS, different signs and symptoms, treatment, outbreaks, amongst other crisis associated to the pathology), their environment totally changes confronting reactions of adaptation, depending on each life experience<sup>(13)</sup> and also associated to different constraints such as support networks, the socio economic level, educational level, amongst others. These factors are constraints, and they contrast each other with what was exposed in the research by Lara and Kirchner<sup>(9)</sup> in Spain, where it is shown that the main problems presented by people with MS are physical limitations, labor problems, and lack of projection in regards to the future, reason why the support networks and protective factors take a role that is relevant when it comes to deal with the disease, aspects that appear in the statement of the participants.

In addition to the foregoing, at the Roy theory level <sup>(13- 14)</sup>, the importance of the nursing professional stands out in regards to adaptation, whose sole purpose is to help people in their effort to adapt in order to have their environment under control<sup>(13)</sup>.

After the data analysis, the researchers state that almost all of the people interviewed need more support or encouragement by the health personnel in general. In regards to this last item, the evidence obtained in this research shows a greater requirement of the patients in regards to the support provided by the professionals; nonetheless, there exists aspects that were not evaluated in this study such as the work load of the healthcare personnel, number of users assigned per professional, amongst others, areas which are also influencing the results obtained, thus opening, a line of future research.

Likewise, based on the fundamental philosophy of Husserl<sup>(12)</sup>, it is understood that the remote experiences of the participants has largely influenced in the final experience that the person may have with his illness, considering that such person who may have had a satisfactory experience in regards to his illness (personal or family-related), upon getting to know their current diagnosis or prognosis, could satisfactorily anticipate those possible results they may have with the current disease. Additionally, those people who many have had an unsatisfactory experience with their disease, whether it be personal or of their family circle, the most probable thing is that negative mental set-ups are anticipated of the possible results that they may have with their current illness. Just like that, people with MS anticipate

possible results in the evolution of their illness. Therefore, it is relevant for the nursing professionals to be able to work so that the nursing experience of people with MS is as satisfactory as possible, using for this, means that give integrality to the care proved by the healthcare personnel, providing care focused on people which includes psychological, affective, and emotional aspects. These efforts on improving the current care model would play a fundamental role so that people with MS could dispose of relatively satisfactory experiences during their illness, which could modify their mental set-ups, provoking that the current experience of MS could be efficient, so that, in the future, if exposed to another difficult stimulus or experience the people will be able to face it in a better way.

According to the arguments of Roy<sup>(14)</sup>, people react throughout cognitive and emotional channels, the processing of sensory information, learning, criteria and emotions. If a comparison with results obtained in this study is made, it agrees with the fact that the reaction of people in regards to the diagnosis and progression of MS is conditioned by the attitude of the professional who gives the diagnosis and the attitude of the people upon receiving it, the information delivered by the team, the individual search of information by different means (mainly Internet) and the empathy of the family and healthcare team, all of this is what would primarily condition the coping strategy.

Another important component that stands out in regards to life experiences of the Corporation of Multiple Sclerosis Patients Talca is the limitation of daily life activities in regards to functionality, in other words, performing daily functions, or being able to work. As it has been pointed out by some experts, the prevalence severity of shaking in patients with MS, which affects their quality of life as well and also reflects an increase in the rate of unemployment, which leads to an increase in the degree of disability, thus, confirming that the shaking could considerably reduce the quality of life and daily role of each person<sup>(22)</sup>. Another impact that these people may perceive due to their illness falls within the emotional environment. Researchers suggest, hypothetically, that people with disabilities can maintain reasonable levels of quality of life<sup>(23-24)</sup>. The results of this research show that people with MS said that it is not easy to deal with this disease, however, they are able to overcome the crisis, outbreaks and progression of the disease. Also, according to a great variety of unspecified symptoms shown by MS, people mention resorting late to health services, which implies that this disease is diagnosed in a more advanced stage, which influences in their treatment. Such statement is related to other studies<sup>(11)</sup>, which refer to the fact that MS has neurodegenerative characteristics, and a great variety of signs and symptoms that people experience that besides being of a chronic and progressive nature, they imply a great deal of objectivity regarding the symptoms of the disease.

Given the different life experiences in regards to the MS diagnosis, some relevant aspects are present and stand

out, such as is the uncertainty due to lack of knowledge about the disease at the time they get the news, which leads to an emotional distress, in which the majority of those interviewed mention to be unaware of its progression and their future in regards to the disease. Experts also show, similar to the results of this study, that the effects of chronicity give the people feelings of sadness and helplessness and the progression of the disease with feelings of uncertainty in regards to their future due to lack of knowledge about MS<sup>(6-24)</sup>.

Also, one of the treatment alternatives that this pathology has is throughout the use of invasive medication (injection), such alternative generates rejection since the frequent punctures produce pain and discomfort which conditions adherence to the treatment, thus, influencing their quality of life. Moreover, it is added that this type of treatment is not permanent due to the variability of the disease, reason why many patients should change treatment every so often, causing uncertainty. Though the treatment is a palliative tool to treat MS, people with this pathology when having access to it and knowing it exists, to treat and relieve their symptoms, they perceive the treatment as an expectation and hope of life, since it gives them independence in their daily life; therefore, giving the treatment an added value. Also, many of them include the complementary therapy in order to improve the final result and get a better quality of life. Something similar to what has been stated, was described in another study throughout the experiences lived by people who suffer from certain chronic illnesses<sup>(25)</sup>, including the meaning given to the illness by the people, which influences in their health and in the proper adherence to the treatment, as can be seen in the different perspectives that people with MS have about the treatment.

In regards to coping strategies, the innate and acquired strategies have been defined herein<sup>(14)</sup>, those present the most often were strong denial in regards to the disease, simulating that nothing has changed in order to not think in the changes and consequences that come along with the pathology upon being diagnosed or what must be faced in the future. So, their mind isolated the stimulus and was able to not get so distressed by the whole process. While this aspect is classified as an innate strategy, due to the fact that the person opts for carrying out that thought, the contrast of the other great majority, is the acceptance of the disease relating it as a new and real condition which must be faced, being one more change, amongst many others which must be faced on a daily basis as is mentioned by Lara and Kirchner<sup>(9)</sup>, in their study in which the majority of the participants used the coping strategy towards the illness as a solution to the problems and performing a positive reevaluation to his change. Something similar happens to the patients in the Corporation of Multiple Sclerosis Patients Talca who accepted to require help, as a reevaluation of this need in order to obtain a better quality of life. Continuing with the term of positive reevaluation<sup>(9)</sup>, the acquired coping strategies given that in this manner the

patients can obtain emotional support or encouragement of what they have to face in order to look at the disease as an obstacle to overcome, but in a positive manner and with the proper tools. One of these strategies is complementary therapy which is mentioned once again as an added value to the nursing process, also adding participation within the Corporation of Multiple Sclerosis Patients Talca, in which it is agreed upon 100% between the participants, who point out that it is a fundamental pillar in regards to the coping of the disease, since they can share their daily life experiences with people, and receive mutual support.

Additionally, the other strategies used by the patients in order to face the disease keep a relation, first, with the support provided by their families, since it represents a fundamental pillar throughout the duration of the disease. It is also relevant, in order to face the disease, the support provided by their employment, whether it be by co-workers or administrative staff. Apart from these strategies, the importance given to religion, faith in God and/or protective figure is added, being considered as support in a moment of crisis.

Finally, it is pointed out that the participants declare a need for greater emotional support and humane care, given the characteristics of the disease (chronic, progressive ailment and with a great variability of signs and symptoms) that must be faced throughout their life, reason why there is a clear need for the care of a multidisciplinary team to provide complete support. Therefore, experts refer to the patients who stopped the treatment in the fourth quarter had received less frequent psychological attention than persistent patients, while the adhering patients had received care at home and under informal situations more frequently than the non-adherent patients; therefore, it is of great importance to get care from a multi-disciplinary team, which means, humane and kind care given to the patients<sup>(26)</sup>.

## ADVANTAGES AND LIMITATIONS

The research team explains the advantages of this study: a) the need for empirical evidence from the participants within the Corporation of Multiple Sclerosis Patients Talca, and their support in the development of this study; b) the different types of training received by the research team (research modules, training for intervention during crisis in charge of a psychologist); c) have access to a library system with current data bases such as WOS, SCOPUS, PubMed, amongst others; d) the availability of the Faculty of Health Sciences for the review by an external commission named Methodological Evaluation Commission (CEM-UCM).

Not using software such as ATLAS.ti, or others to analyze data, is recognized as a limitation, which gives way to a future search for other qualitative research tools to be able to respond to the issue being studied.

## FINAL CONSIDERATIONS

Based on the analysis of the data obtained and with the purpose of giving answers to the general purpose of the research, it can be concluded that the coping strategies, from the life experience lived by people with MS, are present in an innate and acquired manner. Innate strategies in the beginning tend towards denial and physiological responses such as the outburst into tears at the moment of diagnosis and during the course of the disease, especially with outbreaks and associated complications. Upon several years passing from the diagnosis there is agreement since the majority of the people keep an attitude of acceptance. And, in regards to acquired strategies, one is recurring to family support and interdependence and support from networks as well as the support from the participation in the Corporation of Multiple Sclerosis Patients Talca.

The life experiences of people with MS are diverse and vary from person to person, depending on a great deal of countless factors such as bio-psychosocial ones. However, within these factors the following stand out: innate coping strategies such as personal pre-disposition; self-esteem and functionality; and all those acquired, for example: support networks (mainly pertaining to the family and healthcare personnel); age at diagnosis; educational and socioeconomic level; and type of treatment.

Finally, but no less relevant, is to mention that the MS disease is still being studied, reason why there is a need to increase the wealth of knowledge since the quantity of studies in regards to this is scarce, especially when dealing with research centered on the psychological and emotional aspects that come along with the disease diagnosis and treatment, which are usually obtained during the literature search, studies that cover almost exclusively that which deals with the disease from a bio-medical context, reason why it is a challenge for nursing to consider studies that incorporate, with a social and integral sense, the health of people that present chronic and degenerative diseases, such as is the case with MS, contributing to the health systems in regards to the care that such people require in regards to certain unique and special care, that improve the quality of care.

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