A new sense for living: a comprehensive study about the adaptation process following spinal cord injuries

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ABSTRACT
The present study explores and describes the adaptation phenomena following spinal cord injury, focusing on the applied strategies of adaptation and identifying the necessary nursing care. The research used a qualitative approach, applying the Grounded Theory as a methodological reference. A group of nine individuals who had spinal cord injuries, and who presented a successful adaptation to a new way of life, was assessed by means of semi-directed interviews. Documentary analyses about life histories were performed and the Grounded Theory was used for data analyses. The study allowed for the explanation of the adaptation phenomena following the event of the spinal cord injury, which highlighted the influence of the acceptance of a new meaning of life and the maintenance of the will to manage new situations and challenges stemming from the injury. The central subject of this study is the spiritual dimension of the individual. This anticipates a specific nursing intervention for people suffering from spinal cord injuries.

KEY WORDS
Spinal cord injuries.
Adaptation.
Rehabilitation.
Spirituality.

RESUMO
Este estudo teve como finalidade explorar e descrever o fenômeno de adaptação após lesão medular, enfatizando a explicação das estratégias de adaptação adotadas, e procurando identificar as implicações que têm nos cuidados de enfermagem. A metodologia utilizada foi a Qualitativa, tendo como referência metodológica a Grounded Theory. Para tal, foi dada voz ativa a nove indivíduos que sofreram lesão medular, com um percurso de adaptação de sucesso à nova condição, utilizando a entrevista semidirigida. Foi efetuado também análise documental de alguns relatos de vida, partindo para a análise dos dados à luz da Grounded Theory. Foi possível explicar o fenômeno de adaptação após lesão medular, sendo evidenciada a influência do encontro com um novo sentido da vida, na manutenção da disposição para gerir as consequências que advém do confronto com uma lesão medular. O tema central do estudo prende-se assim com a dimensão espiritual da pessoa, o que antevê uma intervenção de enfermagem específica nesta área, junto do indivíduo após lesão medular.

RESUMEN
Este estudio tuvo como finalidad explorar y describir el fenómeno de adaptación después de una lesión medular, enfatizando la explicación de las estrategias de adaptación utilizadas y buscando identificar las implicaciones que tienen en los cuidados de enfermería. La metodología utilizada fue la Cualitativa, teniendo como referencia metodológica la Grounded Theory. Para esto, fue dada voz activa a nueve individuos que sufrieron lesión medular, que atravesaron un periodo de adaptación con éxito en la nueva condición, utilizando la entrevista semiestructurada. Fue efectuado también un análisis documental de algunos relatos de vida, partiendo para el análisis de los datos a la luz de la Grounded Theory. Fue posible explicar el fenómeno de adaptación después de una lesión medular, colocando en evidenciada la influencia del encuentro con un nuevo sentido de la vida, en la manutención de la disposición para administrar las consecuencias que advienen del enfrentar una lesión medular. El tema central del estudio está relacionado con la dimensión espiritual de la Persona, lo que permite una intervención de enfermería específica en esta área, junto al individuo después de una lesión medular.

DESCRITORES
Traumatismos da medula espinal.
Adaptação.
Reabilitação.
Espiritualidade.

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INTRODUCTION

The number of people with spinal cord injuries has increased considerably in past years, a situation that is related to an increasing level of development in all countries. We know that its etiology relates predominantly to traffic accidents, although there are other important causes, such as work accidents and those sustained during leisure activities.

This type of injury emerges suddenly and unexpectedly, bringing with it an abundance of changes to the life of the victim, causing feelings of loss in all the spheres of life and changes in the corporeal, emotional and spiritual spheres\(^5\). Pecci, who became a paraplegic following an accident, states that

> paraplegia splits man apart. Everything is split in half. The man-spirit is the same. The man-will is the same. The man-love is the same. But they don’t move the man-legs [...] although they are together, they are apart\(^6\).

The spinal cord injury determines the sudden onset of a new personal reality, which forces the person to change and adapt the many roles and activities developed up until then.

Adaptation to this new condition will naturally depend on the type of injury and its prognosis, as well as other factors such as the type of personality and the social, educational and cultural levels. In addition, the post-injury rehabilitation program influences the patients’ ability to cope, as seen in the study\(^3\), encouraging the subjects to seek out strategies that will help them adapt to the new reality of their injury. In turn, this will lead to acknowledging the relevance of the work of the healthcare professionals, especially the nurses.

Giving meaning to the experience of being ill is commented on by the authors, to whom rehabilitation is a continuous, global process, […], helping the individuals and their families to face the experience of the disease, and giving it meaning\(^4\).

I deeply agree with this concept, as I believe that the mission of the caregiver is to help people create a way of living that is meaningful and compatible with their new situation, regardless of their physical condition or the nature of their problem\(^6\). Therefore, I consider that the care provided by the nurses in the rehabilitation period will have a fundamental role in the adaptation of the individuals following a spinal cord injury.

During the review of the literature related to the adaptation period after a spinal cord injury, I found two studies from Portugal\(^8\) regarding this phenomenon. One of them was a qualitative study, where the author attempted to comprehend the experiences of people with traumatic vertebral-spinal injuries, identifying several routes of adaptation to paraplegia. The study also detected a few knowledge gaps in the Portugal literature regarding the quality of life of these people, which resulted in a later study, which evaluated their quality of life using the MOS SF-36 scale. Both studies provided me with information about certain areas and encouraged me to further study other areas. When we provide care to these people as rehabilitation nurses, we notice that, while some of them respond awkwardly and experience permanent difficulties in adapting to their new condition, there are others who adopt a constructive attitude. As such, a question was raised: why do people react so differently following an event that creates limitations and forces them to be dependent on others? I drafted an initial question that became the study focus: How do people with spinal cord injuries adapt to their new condition? The answer to this question would require meeting the following goals: 1) Exploring and describing the adaptation phenomenon after a spinal cord injury, 2) Identifying and explaining the adaptation strategies after a spinal cord injury and 3) Reflecting on the nursing interventions focused on the strategies of adaptation used by people that have been victims of spinal cord injuries.

METHOD

I decided on the use of a qualitative method of study, since I intended to obtain details about the feelings, processes of thought and emotions related to the phenomenon of adaptation, which would allow the reflection on the different perspectives of the subjects who experienced them to be as exhaustive as possible. After reviewing the literature related to the phenomenon under investigation, I decided to explain the phenomenon of adaptation after a spinal cord injury in a theoretical way, using the Grounded Theory\(^7\) as my methodological reference.

Therefore, I started collecting data that would facilitate the comprehension and explanation of the phenomenon, attempting to select the best informants using the best techniques. This was made easier because data collection and data analysis overlapped. Since data collection for this Master’s degree thesis was not performed within a hospital context, the ethical issues of the fieldwork were analyzed by the Review Board of Instituto de Ciências Biomédicas Abel Salazar – Universidade do Porto, where the study was performed.

In accordance with the principles of Grounded Theory, the sample was not defined beforehand, but was built progressively\(^7-8\). I made an effort to find a population of individuals undergoing the process of adaptation to spinal cord injury, aided by the chief nurse of the Physical Medicine Service of the city of Oporto who had the ability to assist in the locating and selection of the first interviewees. This stage involved using a set of previous contacts in order to locate the key-informants.

With the data obtained from the initial interviews, I began their analysis, attempting to represent several points of view. New informants of different ages, types of injury and socio-professional situations (marital status, education, occupation and type of family) were then selected.
The criteria used to decide when to interrupt the sampling of different groups that are pertinent to it is the point of theoretical saturation; in this situation, this occurred when no new relevant data emerged, indicating that the properties and dimensions would be well-developed in this category, showing variation and and validation in relation to the other categories\cite{7-8}.

Therefore, the sample is made up of nine individuals with spinal cord injuries who have undergone a successful process of adaptation. This is an intentional sample, as I decided to choose those informants who had lived the experience, were willing to talk and were particularly intuitive towards their situation\cite{9}. The sample is also a snowball, because, when subjects matching these criteria were found, they were asked to indicate other people with similar characteristics\cite{10}.

The semi-structured interview was the main data collection technique used, and the questions were prepared according to the initial question of the investigation, with an interviewing scheme containing the following guiding questions, essentially based on the study goals\cite{11}: 1) How did you see your situation after the accident? What feelings did you experience? 2) What type of support did you have? 3) How did you become aware of the available resources? 4) How did you adjust to your injury? Which resources did you use? 5) Was there a nurse to help you during this process? How? 6) What kind of help would you like to have had from the nurses? 7) What does the adaptation to this new reality mean to you?

In addition to the interview, documents prepared by other people were used, including the documentary analysis related to life experiences from people who sustained spinal cord injuries and who narrated their personal stories in detail, as it was experienced, with their role being similar to that of the key-informant’s for an investigator\cite{7}.

Data analysis is the center of the Grounded Theory’s methodology, working according to the precepts of a study\cite{7}. The authors consider the coding, its central procedure, by proposing three types of coding: open, axial and selective, which are then executed during the analysis of the collected data.

As such, I started with open coding (data fragmentation), analyzing the data line-by-line as they were collected, in order to identify the existing processes. I attributed codes to each phrase or incident in the margins of the description to allow for easier identification. Some of the codes were attributed according to the participants’ language; others were built by me, according to the concepts derived from the data\cite{12}.

The next step involved grouping the contexts into categories. This happened whenever a group of concepts was related or had characteristics in common, and were therefore able to be grouped under the same category. The constant comparison of the concepts allowed us to generate the properties of the categories, starting by thinking about the conditions in which the category is minimized, the generated categories and their relations to other categories. The next step was the process of axial coding, in which I matched the categories with their subcategories. In contrast with open coding, which makes it possible to fragment the data, this type of coding made it possible to put them together again, establishing links among them and giving them new meanings. In this phase, I also sought answers to questions such as: how, why, how, and when.

As the coding progressed, the constant comparisons provided the accumulation of knowledge regarding the properties of the categories, thus producing integration. I moved on to the delimitation of the theory, disregarding categories and properties that were irrelevant and focusing my attention on the main categories. I started the process of selective coding, restraining the coding to aspects belonging to the core category and those significantly associated with it. The core category became the guide to the theoretical sample of the study\cite{7}.

Reaching this core category was therefore a complex process, followed by the comparison of the emerging theory with the existing literature regarding the investigated theme, attempting to perceive the similarities and the differences.

**RESULTS**

The emerging theory for the adaptation phenomenon

Six categories emerged from the data analysis, related to the adaptation phenomenon: 1) emotional response to the new situation, 2) difficulties encountered, 3) types of support, 4) awareness of the situation, 5) the organization of the resources and 6) the adaptation. There was also a central theme: finding a new meaning for life. I will proceed to the explanation of the studied phenomenon, according to the data analyzed.

The spinal cord injury in the life of the individual demands an emotional response from this individual. It indicates how the new circumstance is evaluated, with the impact phase of the injury being represented by a number of negative emotions associated with the situation\cite{13}.

There is a feeling of helplessness, of not being able to do anything to change the situation, of being tied to a bed and incapable of doing anything (E 7);

... fear, fear overall: can I take it? What will it be like for the family? Am I going to a hospital? How am I going to do it? How am I going to get there? How am I going to wash myself? How am I going to urinate? How? How? (E 6).

Such negative emotions decrease considerably in the post-impact phase, where positive emotions emerge, such as gratitude – expressed by the opportunity of giving new meaning to life within the confines of the new condition experienced, and also acceptance with the description of feeling well and calm:
People don’t know what’s good, like going to the bathroom and giving thanks every day. Everyday I’m thankful […] because we only care about vital everyday things when we don’t have them anymore (E 2);

So, I see myself more easily in a wheelchair than on foot. I feel well when I’m on foot, I see things in a new way, it relieves my back, I can stretch my legs, my muscles, but I think I couldn’t really walk well. I think the wheelchair is better (E 9).

The spinal cord injury, in addition to impacting the emotional sphere, will cause a number of difficulties due to the transformations undergone by the body, not only with physical implications but also affecting several aspects of the human life, such as psychological, socio-economic, and spiritual aspects, as well as those related to care and knowledge:

… feeling myself unable to do things. I don’t know, sitting up for the first time, sitting, brushing my teeth, combing my hair, picking things up, elimination… (E 1).

… a cottage where once we were kings, which I built, where I hung pictures, where I placed furniture, where I took things, and now I’m the one who’s taken there (E 6).

there’s this issue of independence, it’s like I want to do things but I have to wait… It’s the issue of autonomy, all those issues of the social life, like going out and being with friends (E 7).

People face a large number of obstacles that they never had to deal with before, needing support so that their world does not collapse and they can start dealing with the adversities imposed on them at this particular moment in their lives, with the purpose of maintaining their willingness to manage and cope with the new challenges that emerge. This support was particularly evident in participant’s spiritual sphere, which allows them to look at the implications of the injury as a new path that must be taken. It will provide opportunities to give a new meaning to life, which also allows them to have goals, to love and to be loved, and still find a reason to continue giving meaning to their existence in religion.

In my case, my children were the most decisive factor in my adaptation, since they need me… (E1)

My brother’s balance, Elisa’s lightness, my parents’ welcoming, all of that and just that, so natural, I became a balanced being, nourished by the love and caring of those people who are mine. This makes me walk […] (E 1).

At a certain point I thought: ‘This happened because of something special, which I couldn’t find yet! Everything in life has a reason for being’. I held onto that, spiritually (E 8).

It is worth noting other determining factors, namely certain individual psychological characteristics, such as self-control and self-confidence, which allowed them to control the new challenges effectively by believing that the change is an opportunity for personal growth instead of a threat to their safety, thus accepting a certain unpredictability in life.

I force myself to insist at every weak point […] I consider the limitations and attempt to lessen them. I analyze the conditions and decide to transform them(2).

Regarding the search for support, the need for social support was also perceived, due to the implied encouragement of healthy behaviors and by conveying the meaning of life:

It was essential for me, having all those people around me, being aware that things wouldn’t be different because I had had that problem. I mean, nothing changed. It’s not because of this problem that I won’t have friends, that I won’t have a family, that I won’t have a girlfriend, that I’ll stop being useful (E 5).

Regarding being aware of the situation, this aspect emerges progressively from the data that refer to this stage. How the person became aware was revealed mainly through questions posed about one’s situation and the realistic information provided by the healthcare professionals, with a particular emphasis on the weekends and exchanging experiences with people with the same type of injury:

…I never wanted them to hide anything from me. I always wanted them to be direct with me, and I wanted to know which opportunities I had (E 6);

…coming to the weekend events gradually prepared me for my future life (E 2);

…from that moment, I started meeting people who had been injured for longer and who led an independent life. I realized wait, there must be something new there, there must come a time when I won’t need my mother, my sister or my father to do things. I might be able to live alone and feel comfortable (E 9).

However, regarding the awareness of the situation, the things that people became aware of emerge, such as the necessity of having more autonomy, the inabilities and the remaining abilities, and the difficulties and the priorities.

…before my brother went to work, he took me to the bathroom and waited. There, I saw I wasn’t doing anything and I was a burden to him, so I said: no, I have to start doing things by myself (E 3);

…I had had the injury for about six months and I could foresee that my future was going to be as a tetraplegic, so, yes, I wanted to stabilize my body as much as possible (E 6).

After one is aware of the situation, it is possible to organize the resources, especially in the social-professional and healthcare areas, through behaviors of therapeutic compliance, with access to specialized healthcare services and adequate technical support.

Living alone is not a possibility. There’s a lady that lives with me, 24 hours a day (E 4).

A possibility of working with computers came up and I decided to take it. It was important to become professionally
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The organization stage peaks in the adaptation to their new condition of life, due to their willingness to manage their situation and the challenges imposed by it, using the conscious knowledge and choosing integration, which translates into physical, psychological and social adaptation\(^\text{10}\).

A central theme emerges in the present study: finding a new meaning for life, which is the end result of the analysis and explains a large part of the variation of the phenomenon of adaptation, summing up all the data into a pattern\(^\text{9}\). Indeed, I noticed that the route of adaptation of the victims of spinal cord injuries, especially regarding how they became aware of their new condition and organized the resources, was mainly influenced by the spiritual aspects of each person, which translates into the capacity of the person with such an injury to reorganize their existence by seeking a new meaning for life and finding it\(^\text{16}\).

This spiritual dimension was revealed to be the driving force of people who are willing to manage the consequences of their injury, setting goals to achieve in life, maintaining the hope that made it possible to plan actions for the future, regarding life and its aspects as gifts offered by the new condition, and also becoming more humane and friendly:

... when we're bound to a wheelchair, [...] we feel useless, it's important to feel useful again (...) with activities and goals, otherwise we can't set ourselves free... (E 1)

... I have a great lesson for life, which taught me that we must try to live every day, doing the best we can, in the long or the short term. Therefore, I try to do my best in everything. I'm happy with my life, with what I do, with what I have, and I'll let it flow. Whatever comes up will be good and I'll try to learn how to live with that\(^\text{44}\).

... I think I'm feeling a lot better. I used to be worried about doing things, in reaching for this and that, but not now. It's like, let it be and see what good things life will bring to me (E 9).

The emerging theory for nursing care

In order to facilitate reflection regarding the nursing interventions that focus on adaptation strategies, data related to nursing care were also evaluated, which resulted in the identification of two main areas, which constituted two categories: aid obtained from nurses during the process of adaptation, related to the care received, but also including the difficulties faced when receiving care; and the suggestions related to nursing interventions and the skills of the nurses that could make adaptation after spinal cord injury easier.

Acknowledging the emotions experienced during the impact phase of the injury and their need for emotional support were shown to be crucial to facilitate coping with this crisis through the acceptance of their current state. Nursing actions of determination\(^\text{10}\) also emerged from the data, expressed by the regular vigilance of the evolution of the health status, and also the evaluation of certain situations that demand attention during the hospitalization period:

... if they could see that a person was becoming more and more downhearted, they said. So, this is what happens (E 3), but also actions of service provision, which were associated with the establishment of useful and harmonious relationships with the nurses. These attributes were shown to be available and to improve the situation, comforting the patients when necessary:

... and there are nurses [...] that can sit down and stay with us, seeing if things are all right (E 1);

I could see everyone supporting me [...] that sort of caring, the smiles, the friendly words and comforting (E 2).

Regarding the awareness of the situation, this is particularly influenced by the present issues and the provision of realistic information, which is provided by the healthcare professionals in a systematic and educational way in accordance with themes related to health, but also through an anticipated orientation and series of explanations, which made certain future issues more understandable and clear. These issues are usually faced by people with spinal cord injuries, to the point of being suggested as nursing actions to be implemented after this type of injury:

... giving alternatives to the situation the person is involved in. Trying to explain that there will be changes, but explaining these changes and that it will be possible to overcome a difficult phase towards a phase that is better (E 5).

However, some situations emerged in which information was regarded as lacking in regards to preparation for the discharge:

It was like taking a step back at the moment of the discharge. And, once more, there was no preparation for the discharge... (E 7).

According to the data, management was also suggested as a nursing action which would facilitate the organization of the resources, especially on the social-professional and the healthcare levels, through behaviors of therapeutic compliance. Resources were focused on specialized healthcare services and adequate technical care as pre-organized teachings:

... I think these things [the teachings] should be planned (E 7), but also with the opportunity of contacting people with the same type of injury.

As mentioned above, the peak of this phase of the organization of resources translated into the adaptation of the person to their new condition, and is particularly influenced by finding a new meaning for life. The provision of service is suggested according to the data and the central theme of the study in the form of care and, more specifically, as encouragement, by conveying trust and hope:
...those were positive people who always gave me strength (E 5);

...another thing that the nursing team promoted was the collective experience, talks and outings. Not being afraid to leave (E 7).

Which strengthens my conviction about the importance of the nursing interventions being focused on the spiritual aspects of these people.

DISCUSSION

As seen, a spinal cord injury in the individual’s life will demand an emotional response that is initially translated as negative feelings which are progressively transformed, and can even turn into positive feelings of gratitude and acceptance. By acknowledging these emotions and the need for emotional support, the nurse performs a crucial role in helping the patient cope with this crisis and to resume a state that is comparable to the previous situation, or even better than it, through acceptance of their current health state. Therefore, it will be important to communicate empathy and understanding verbally, according to the experienced events, establishing trust and positive attention, listening to the patients’ concerns, helping them to recognize their negative feelings and encouraging them to express them, providing support in the different phases of suffering or when decisions need to be made, and discussing the emotional experiences with the individuals on a personal level.

In addition, the changes and losses as a result of the spinal cord injury on a physical level can be observed, since they cause several difficulties that are carried over into the several dimensions of human existence. Therefore, support is vital at this particular moment in life, with the goal of helping people maintain their willingness to manage and cope with the new challenges that they have to face, in preparation for a new phase of the organization of the available resources to face their new reality. In this phase, being helped by the nurses becomes fundamental to the search for knowledge about the required therapeutic regimen and their compliance with it, with the control of risks and symptoms, and also with their ability to participate in the healthcare procedures. In addition, our support in the decision-making process may make it easier to find new ways of being that are truly meaningful and compatible with their new situation. The rehabilitation of these people must be faced as a healthcare process that begins early and is comprehensive, holistic and educational. The rehabilitation nurse assumes the roles of educator, provider of care, advisor and consultant, often being responsible for elaborating the general rehabilitation plan[18].

The need for support was particularly evident in the spirituality of the victims of spiral cord injuries, which allowed me to visualize the implications of the injury as a route to be followed. This route offers an opportunity for giving new meaning to life, which caused me to reflect on the importance of the spiritual dimension in the life of these people and its influence on their health state. Indeed, the patients’ welfare varies over time, and the search for balance occurs according to the challenges posed by each situation. The victim should be aware that having a spinal cord injury does not necessarily means that the person has a disease, as long as the person maintains the desire to reach a state of balance that is characterized by controlling suffering, physical welfare, emotional and spiritual comfort. As such, I believe that providing service to people who experience the impact of a spinal cord injury must encompass a holistic perspective, where each person is considered as a whole with unique strengths and specific healthcare needs, which demand continual adaptation to the constant changes in the several dimensions of the person, including the spiritual dimension.

The growing acknowledgment of the influence of spirituality on the health status of the person is a known fact. Its importance is recognized by the Portuguese Government, through the National Health Plan 2004-2010: More Health for Everyone, Strategic Orientations[17]. Through the analysis of the current situation regarding spiritual and religious assistance, the plan alludes to the fact that hospitalization emerges as the moment that brings anthropological and spiritual questions to light, where people are faced with new processes even though they are not prepared to cope with and integrate them. This happens when the person has to face the reality of spinal cord injury, where the losses incurred result in the violation of the persona as a whole. The suffering is not only physical, but also spiritual, often followed by subjective states such as hopelessness or impotence.

From there, I moved on to building the perspective of which interventions the nurses should perform when providing care for a person as a whole on the long path of adaptation to a spinal cord injury, in order to help them redefine their lives and explore new opportunities. In this manner, they can emphasize the aspects related to the core category of the study: the meaning of life.

Therefore, I submit that nurses must be prepared to evaluate the subtle expression of the spiritual necessities of the spiral cord injury patient, especially when expressions of concern, loneliness and impotence emerge, in order to intervene accordingly. Also, it may be necessary to assist the individuals in expressing and relieving their anger appropriately, assuring them the availability of support in times of suffering. I am convinced that this type of care could also benefit them when the nurses share their spiritual perspective, especially regarding the meaning and purpose of life, which necessarily implies that the nurses become aware of their own spirituality.

We could also observe how important family and friends were, as well as the support groups, especially individuals who experienced the same type of injury. The spiritual resources and the availability of religious services in certain
situations were also important. Encouraging the individuals to review past events and relationships becomes important, as these could lessen the negative effects of the new condition and could even become a type of spiritual support. Promoting contact with people who have successfully adapted to the spinal cord injury will not only help people become more aware of the situation, but can also assist in the future organization of the available resources to cope with the new reality. We must also encourage these people to use their spiritual resources and to take part in religious services whenever they manifest this sort of desire.

With the results of this study, we also realized how important hope was in developing a positive perspective towards the new condition. Indeed, the maintenance of hope in individuals who live with this type of injury allows them to live more intensely, regardless of the imposed adversities\(^\text{19}\).

Therefore, it will be essential for nurses to develop competencies in promoting hope, helping these people to look beyond their immediate situation, avoiding the clouding of reality and directing their energy appropriately, by identifying the areas of hope in their life so that they can establish and review goals related to their object or hope more easily. Since these patients are admitted into hospitals quite often, the nurses may excel at the role of encouraging feelings of hope and the will to live, as they are constantly in contact with the patient, having the opportunity of providing emotional support and information about the condition and the treatment\(^\text{19}\).

**REFERENCES**


