Abstract: The objective of the article is to demonstrate how Palliative Care (PC) can be included in the theory of the Model of Human Occupation (MOHO). The philosophy of Palliative Care focuses on a client-centered approach like the Model of Human Occupation in Occupational Therapy (OT). The definition of Palliative Care and the role of OT in this camp are presented. A theoretical comparison was made of the perspective and theory of MOHO for Later Adulthood to Palliative Care, focused in dying persons. A non systematic review bibliography was made. The Occupational Therapist based on MOHO can evaluate and help the client to maintain or re-gain his/her Occupational identity, and life story. In the other hand, the Occupational therapist should help the client to accomplish their last wishes and live with quality of life till the last moment. It is possible to apply MOHO in PC but evidence is necessary.

Key words: occupational therapy, dying person, client centered-approach, last wishes.

Resumo: O objectivo do artigo é demonstrar como os Cuidados Paliativos (CP) podem ser incluídos na teoria do Modelo de Ocupação Humana (MOHO). A filosofia dos Cuidados Paliativos baseia-se na Abordagem Central do Cliente tal como o MOHO em Terapia Ocupacional (TO). A definição de Cuidados Paliativos e o papel da TO neste campo são apresentados. Uma comparação teórica foi feita da perspectiva e teoria do MOHO acerca da Terceira Idade para os Cuidados Paliativos, destacando-se os doentes terminais. Uma revisão bibliográfica não sistemática foi feita. O Terapeuta Ocupacional baseado no MOHO pode avaliar e ajudar o cliente a manter ou recuperar o/a seu/sua identidade Ocupacional, e a sua história de vida. Por outro lado, o Terapeuta Ocupacional deve ajudar o cliente a cumprir os seus últimos desejos e a viver com qualidade de vida até ao momento final. É possível aplicar o MOHO em CP mas evidência científica é necessária.

Palavras-Chave: Terapia Ocupacional, doente terminal, abordagem central no cliente, últimos desejos de vida.
Palliative care is an active and strict health care that combines science and humanism.

The World Health Organization (2002) presents Palliative care as “an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual”. The patient can be elderly, an adult or a child.

The Portuguese Association of Palliative Care (2006) defines palliative care as an active solution for extended, advanced, incurable and progressive illness that attempts to prevent consequent suffering and to provide the best quality of life possible to dying persons and their families. Palliative care is interdisciplinary: it involves actively controlling symptoms, while efficiently communicating with the patient and his/her family. Therefore it involves different disciplines from the health field, which must work with common aims, e.g: Medicine, Occupational Therapy, Psychology, Social Work, Religion, Physiotherapy, animators, medical aids and volunteers.(Pessini & Bertachini, 2005).

The principles of Palliative Care are: not to hasten or delay death; offer relief of pain and other symptoms; integrate psychological and spiritual aspects in the treatment; and offer support to the family during the disease and after the death (Moraes, 2009; Neto, 2010). Palliative care is client-centered, rather than disease-focused. (Twycross, 2002).

The client that receives Palliative Care is not necessarily a dying person but the dying persons and serious diseases are priority in this kind of care (Davies, 2004, Meireles, 2008). The disease in Palliative Care is defined as progressive when the symptoms manifest themselves in a progressive and multiple way; advanced, when the prognosis is limited; and incurable when there is no predicable answer to the treatment (Costa, 2002, cited by Bernardo, 2005).
Among the several terminal diseases identified in the 21st century, which can be developed at any age, are included: malign neoplasies, advanced organ failure (cardiac, renal, hepatic, respiratory, etc); AIDS and degenerative neurological diseases, namely Alzheimer's and Parkinson's. (Meireles, 2008; Maciel, 2006; Pushpangadan et al, 1996; Secpal, 2002).

The clients that receive Palliative Care are not defined exclusively by the diagnosis; there are concomitant complex symptoms and needs that overwhelm the normal capacity of hospital services (Soares, 2006, Neto, 2010). Palliative Care, which is integrated as part of treatment from the time of the disease diagnosis, grows as long as the disease’s process does too (Maciel and Othero, 2009).

Florianni and Schramm (2007) bring the concept “terminal care” as a kind of care inside Palliative Care, related to the support of the patient in the last days or hours of his life, with the finality to offer the person a dignifying death (Moraes, 2009). The terminal illness is an advanced stage of a disease with an unfavourable prognosis and no known cure (Macedo & Malheiro, 1999). We can see that the dying person has reached a stage of his/her disease so advanced that it is no longer beyond the possibility of a cure or treatment, rendering main organs insufficient and death imminent. In fact, the terminally ill is the status of a person expected to die between 3 to 6 months from a specific condition (Neto, 2010; Secpal; 2002, Mc Graw, 2002, cited by Free Dictionary, 2011). The number of people with advanced terminal disease is increasing due to greater control of the diseases nowadays and the related advance of science.

The definition of terminal illness has an established scale since advanced incurable disease, terminal illness, until agony, according to Polo (2007). The advanced incurable disease refers to the progressive and gradual effect to the autonomy and quality of life that will grow to death in a medium data. The terminal illness refers to the advanced disease in the gradual and irreversible phases, with multiple symptoms, emotional impact, loss of autonomy,
weakness or incapacity to answer, of which the prognosis is limited to weeks or months, in the context of progressive fragility. Agony is the phase that is behind death, with intense physical deterioration, extreme debility, cognitive alterations; of which the prognosis is limited to hours or days.

This article is focused especially on the dying person. The overall aim of this study, built with non-systematic review, is to suggest and start the reflection of an integration of Palliative Care in the theory of the Model of Human Occupation (MOHO), specifically the terminal illness phase and the role of Occupational therapy.

Occupational therapy as a science of occupation, growing in variety of health areas, has a role in Palliative Care (Costa, 2009, Othero, 2010, O’Brien, 2001) and its importance has been promoted since the 1970s (Picard & Magno, 1982; Pizzi, 1983; Pizzi, 1984; Lloyd, 1989, cited by Teo, 2009; Gammage, Shanahan, & McMahon, 1976).

According to The Portuguese Association of Occupational Therapists (APTO, 2005), the Occupational Therapist is the health professional job that ‘qualifies to the occupation in order to promote health and welfare’. Occupational Therapists believe that engaging in occupations underlies quality of life (AOTA, 2011). Occupational therapy acts beyond the limitations of the person. It is known how diseases, like cancer, can bring significant limitations to person’s daily life. Rehabilitation is an integrated part of Palliative Care, searching the realization of the most potential of autonomy and independence (Twycross, 2000). Occupational therapy intervention is worthy at any stage of an illness from primary diagnosis, through attempts at curative treatment, to palliation and finally terminal illness (Sutton, 1992, Penfold, 1996).

According to Othero (2010), the main objectives of Occupational Therapy in Palliative care are: maintenance of the meaningful activities of the client; promotion of positive stimulus for the quotidien enrichment; orientation and realization of comfort measures and
symptoms control (e.g.: anxiety, dyspnea); adaptation and training of the activities of daily life (autonomy and independence), creation of communication, expression of possibilities and the exercise of creativity; creation of spaces of joy and interaction, between patients, familiars and team. The Occupational Therapist can work with the client until the last moment of his/her life and even in the after-death, through connections, letters or visiting the family with the team. With the dying person the focus of intervention is essentially the increase of quality of life (Mingardi, Monti, Hartmann and Castellani, 2007).

The Occupational Therapist, based on a conceptual model, starts his/her intervention with the evaluation that surrounds the client’s entire life story. He/She identifies the most significant activities of the clients and the evolved limitations. Then the therapeutic and individual plan is stabilized and the role of Occupational Therapy is therefore essential, as in the context of limitations since life cannot lose its sense. Through Occupational Therapists, possibilities and space are created for the exercise of occupations, as physical and emotional conditions. This way the client and his family can maintain or restore their significant activities and his/her action beyond the world. (Othero and Costa, 2007; Othero, 2008; Goretti; 2006; Costa, 2009; Mingardi, Monti, Hartmann and Castellani, 2007).

The philosophy of Palliative Care, related to terminal care, focuses on a client-centered approach, like the one that is defended by the Model of Human Occupation (Kielhofner, 2002), one of the theory Models of Occupational Therapy (Costa, 2009, Kielhofner and Forsyth, 1997).

The Model of Human Occupation, the first model built in Occupational Therapy with incorporated ideas from systems theory, is evidenced as the most widely used occupation-based model in all over the world (Kielhofner and Forsyth, 1997; Brown, Rodger, Brown &Roever, 2005; Haglund, Ekbladh, Thorell & Hallberg, 2000; Law&McColl, 1989; NBCOT,
Kielhofner says MOHO “seeks to explain how occupation is motivated, patterned and performed”. The human occupation, seen as a broad and integrated in MOHO, is the doing of play, work and activities of daily life, within a temporal, physical, and social cultural context.

MOHO has the vision of the occupation as an interaction between the men and the context that emerges in the biological innate need, of domain and control of the owner’s surroundings and that is in the basis of the development and change in the person’s life (Kielhofner, 2002, Kielhofner & Forsyth, 2006, McMillan, 2006). In order to shape their abilities, self-concepts, and identities people are supported to do occupation, in the model’s view (Forsyth & Kielhofner, 2003).

The Model of Human Occupation sees each client as a unique individual whose characteristics determine the nature of the objectives and therapeutic strategies. It also considers how the client has a central mechanism of change and acts, thinks and feels. When someone works, plays and performs activities of daily life, he/she shows his/her capacities, patterns of living, thinking and interaction. Therefore, the Therapist can have an understanding of the client’s perspective and situation.

The principles of the client-centered approach define therapy as a process that encompasses the client’s respective information and behavior in active patterns, where therapeutic strategies and objectives are defined (Sumsion, 1999). MOHO focuses the Therapist on the individuality of the client and brings concepts that allow a deep evaluation of the situation and the perspective of the client. On the other hand MOHO conceptualizes the doing, thinking and feeling as a dynamic center in therapy (Kielhofner, 2002). The Occupational Therapist that practices client-centered approach, has the opportunity to use the competences to help the client to go through his/her objectives, opening the context to
meaningful occupations (Bouça, 2002; O’Brien, 2001). Otherwise, an Occupational Therapist that understands deeply the meaning of occupation makes a powerful contribution to the dying person (AOTA, 2011) as the Occupational engagement seems vital to the well-being of the dying person (Lyons, Orozovic, Davis and Newman, 2002).

The terminal illness can be seen as a Catastrophic Change. This concept, explained by the Model of Human Occupation (Kielhofner, 2002) refers to a stage of change that occurs in a person’s life when internal and external circumstances dramatically alter their Occupational situation, requiring a fundamental reorganization. This Catastrophic Change leads to a determinate end, reflecting a precipitating catastrophic change with no choice.

The theory of MOHO (2002, 2008) presented about the Later Adulthood, in the chapter “Doing and Becoming: Occupational Change and Development”, can be adapted and applied to the palliative care client. Although there are some studies with the role of Occupational Therapy and the importance of occupation in end’s life care (Bye, 1998; Picard & Magno, 1982; Pizzi, 1984; Pizzi & Briggs, 2004; Rahman, 2000; Tiggs & Sherman, 1983, cited by AOTA, 2011; Lyons et al, 2002; Gammage, Shanahan, & McMahon, 1976), there are no found studies with the application of MOHO in Palliative Care.

Volition, habituation and performance capacity are the three basic interrelated components of how humans are conceptualized in MOHO (Kielhofner, 2002).

Life is shaped by changes in lifestyle, especially in the elderly years when one can verify the diminished faculties, choices and social interactions (Santana et al., 2008). This disruption is also seen in the dying person. The volition, as a pattern of thoughts and feelings of the owner and his/her world, where is a fundamental need to act, is seen in this stage of life as an important help for the orientation of many choices and decisions faced by lifestyle changes (Kielhofner, 2002, Kielhofner and Forsyth,1997). The choices can be either activity choices or Occupational choices. Activity choices are the ones people can make in a limited
period of future time, like ordinarily, minutes, hours and days. This type of choice for action influences the course of life. On the other side Occupational choices involve more commitment and are related to Occupational roles starting a new project or habit (Kielhofner and Forsyth, 1997; Barret and Kielhofner, 1998). As an elderly may be embarrassed on realizing the choices of his activity, namely due to lack of transportation (Santana et al., 2010), institutions, money and colleagues, the dying person can also feel embarrassed in the realization of activities due to the pain of continuing an “aggressive” medicine, with excessive clinical interventions when a cure is no longer possible. The alteration of expectations and future plans is also one of the causes of suffering for the dying person (Bernardo, 2005), where the choices are reduced. The dying person's loss of physical and mental ability as well as any opportunity to use those abilities influences his or her Personal Causation. Kielhofner tells how this term is totally related with one’s sense of competence and effectiveness. Both older adult and the dying person are often shaped with losses of capacity and lack of opportunities to use abilities, which can therefore lead to a diminution of personal causation. It is important that the person minimizes the loss of competence and life-roles (Johnson, 1984; Strong, 1989; Strong et al., 1994, cited by Müllesdorf, 2000) and redefine them. Occupational therapy intervention with success, relies on understanding how clients perceive themselves and make decisions to engage in activities with volition as the generator of these perceptions and decisions (Barret et al, 1998). Volitional narratives give sense to the past experience of the dying person associating the events of life with the themes of personal causation, value and interest (Jonsson, Kielhofner, & Borell, 1997).

Values, as things that are meaningful for someone, go through some transformations and they have a dominant influence in their Occupational choices (Kielhofner, 2002). Those transformations depend on the circumstances of their life, both past and present, and in this particular case, the terminal disease. No one have the same values exactly (Mentrup, Niehaus,
Kielhofner 1999). Pessini (2002) affirms that the suffering, so related to terminal disease, is subjective and related to the values. Palliative Care has the role of giving sense to the suffering of the person (Bernardo, 2005). The Occupational Therapist should discover the particular way how the client experience and express his/her values and how it influences his or her Occupational life and constitutes a strength or weakness for adapting in the face of the disease (Mentrup, Niehaus, Kielhofner 1999).

Habituation is the internalized readiness to exhibit consistent patterns of behavior. In the dying person this process involves the adaptation of interiorized behavioral patterns, in the familiar ambient context. The change of roles in the elderly is most of the time involuntary and disagreeable, and undeniably the same in the face of terminal disease. When we are facing a terminal disease we are in new territory, which we cannot call a “habit”.

The roles related to family change, as well as the context of these roles, especially when the use of a hospital comes into play. Here, the afflicted has less energy, for instance, to take care of any children, as new roles are transferred when introducing the afflicted to a hospital environment in addition to the new roles transferred due to the illness in general. The changes in the environment and in the capacities of the client represent a big challenge to the habits developed for a long period of time in a stabilized environment (Kielhofner, 2002, 2008).

To the dying person, namely the terminal elderly person, time spent with children and grandchildren can be very important. The relationship with adult children can be an important source of help. When an elderly person becomes seriously ill, the role is switched and it is mainly the children who assume responsibility for their parents. This inversion of roles is often complex and challenging for the ones involved (Kielhofner, 2002). Another important role in later adulthood is friendship. The dying person may feel the need to have friends around him or her. On one hand, it is not necessary for this to be an
extensive circle of friends, but the patient may feel the will to say goodbye to the people he/she loved in life. On the other hand, a terminal illness in adulthood can enhance the impact that death has on family and friends. Such a loss at an advanced stage in life can be devastating for a partner, and bring loneliness and depression. Besides feeling and sharing life, the surviving partner should solve or take care of the things done by the person in life prior to their death (Kielhofner, 2002, 2008).

The worker role is a very important role to the person. Even beyond ordinary retirement age some people continue to work (Kielhofner, 2002, 2008). It is interesting to see in the study of Costa (2009) that dying persons, between 50-80 years old, said that “work” was the most important thing besides family, health and security.

Kielhofner and Forsyth (1997) present the example of a habit of everyday behavior: greetings. Greeting others is generally automatic in the everyday life. In the dying person it may be the last time the person will do that, turning it into a special and important moment. The Occupational Therapist can help in the farewell process, opening communication windows and helping in the expression of emotions and feelings making use of diverse activities (Othero, 2010; Kübler-Ross, 1969). By the other hand, the Occupational Therapist is able to help in the transition between occupational living roles to the sick role in palliative care (Dawson, 1993, Gammage, Shanahan, & McMahon, 1976)

The Performance Capacity, the 3rd base concept of MOHO, includes the ability to do things proportionately to the state of the patient's physical and mental well-being, underlying objectives and the matching subjective experience. A human being shows an amazing capacity to use his own body to alter the external world and to perform he must require body and mind capacities (Kielhofner and Forsyth, 1997). In the dying person, a fast decline in the ability to perform is identified, due to the difficulties in their motor, sensory, emotional, cognitive, or communication skills (AOTA, 2011). Age-related changes and the
terminal illness are unique to each person. The impact of those limitations must be reduced through the client’s adaptation to habits and the client’s unique context (Kielhofner, 2002).

The nature of the subjective phenomenon and its importance on performance is pointed out by the concept of the Living Body. It must not be forgotten that the client of palliative care, even if comatose, has a Living body. It is presupposed that the body is living and the mind is incorporated. After all, the knowledge, which the client has of himself or herself and the world surrounding him or her, is acquired through the body, which has conscious characteristics that we would normally reserve for the mind (Kielhofner, 2002).

On the approach of Occupational Therapy to the Palliative Care client, based on the Model of Human Occupation, the influence of culture cannot be neglected. Culture is defined by beliefs and perceptions, values, norms, customs and behaviors that are shared by one group or society and passed from generation to generation through formal and informal education (Kielhofner, 2002).

The dying person, and the persons surrounding him, are facing the imminence of death, a theme considered taboo in many cultures. Accompanying the “time of dying” requires the acceptance of the inevitable death (Bernardo, 2005, Twycross, 2002). The way each person perceives death, however, varies from culture to culture. The vision of an impending death and the construction of its collective identity constitute one of the most relevant elements to the formation of a common cultural tradition. All of us possess a cultural heritage that defines our vision of death. (Santos, 2008; Coelho and Falcão, 2006) Our actual interpretations of death are part of the heritage that the previous generations and ancient cultures bequeath to us (Santos, 2008).

With occupation seen as the capacity to do, feel and think about what it has done, the concept that the individual has of death may effectively influence what the individual thinks, feels or does.
Chattopadhyay and Simon, 2008, cited by Blank (2011) affirm that culture is crucial. Culture creates the context within which individuals experience life and understand moral meaning of illness, suffering, and death. Not all face death as something painful and the end of the existence of a human being.

It seems to the dying person to show and gain even more relevance to remember, synthesize, and tell his or her life story, than in the remaining stages of life. The individual, according to MOHO (2002), develops an identity and competence through the participation in occupations during the process of building and adaptation of his/her Occupational life, and this sense of identity and competence is threatened by the imminence of death. Actually, the client, with terminal illness, can feel that he or she is losing his/her dominance and control of his/her surroundings while as Costa (1995) say: “They want to continue to be themselves”. The Occupational identity, presented by Kielhofner (2002), as the composite sense of self and his/her wishes to become an Occupational being, related to his/her Occupational participation, is in fact, threatened.

Terminal diagnosis does not mean life has ended, as Ira Byock (1996), a leader in palliative care, cited by Wrubel, Acree, Goodman and Folkman (2009), affirms. The dying person feels his/her time decreasing, and when there is personal acceptance of the disease and the pain is controlled by Palliative Care, the client wants to enjoy the last moments of life, with the most possible meaning. All the elements of the multidisciplinary team, in which the Occupational Therapist is included, effectively have an important role in the contribution to the client’s objective and quality of life (Maciel and Othero, 2009; Trump, Zahoransky, & Siebert, 2005). Cooper (1992) suggests that what differs and separates the Occupational therapy from all other professionals is the knowledge and management of purposeful occupations. Arini and Othero (2011) present the case of a client, 66 years old, accompanied
for 16 months, in domiciliary palliative care, where it was possible to rescue the autonomy, the doing and the life story of the client, through Occupational therapy intervention.

Despite the definition of the concepts of MOHO pointing to the dying person, mostly pointing to the elderly dying person, it must not be forgotten that in all age groups terminal diseases exist, where it will always be necessary to act with the intrinsic dignity and respect of Palliative Care. The Occupational Therapist can lead the client, whether a child or an elderly person, toward the fulfillment of their last desires and occupations in life. The human occupation is a central strength to the development and change in health and welfare.

The Occupational Therapy process must be driven carefully. The Occupational Therapist needs to work in the immediate present and be able to redefine their goals and objectives often (Dawson, 1993) adapting each session to the performance capacity. It should not be forgotten after all, that, in Palliative Care, often this will be the last time this process is applied. HOPE (2004) tells about the experience of rapid changes of people with cancer and about the need to be especially responsive to those changing needs. This can be extended to all Palliative Care clients.

The last dying wish, as an activity choice, can be related to all the client has built in his Occupational story and it may be an element of significance to his/her past life. In fact, in same cases, it is possible to maintain meaningful activities until the last breath, through music and lecture resources as exemplified by Othero (2010). In the study of Costa (2009) it is included the case of a dying person who’s one last wish expressed to the Occupational Therapist was to find music of John Denver, an important singer to hers in her entire life. The Occupational Therapist offered his cd in her last birthday and adapted the hospitalar context to allow the cd listening. However, sometimes, listening to the life stories of the dying person and their conviction about things that are of value can be meaningful enough to patients (Boog, 2008).
According to MOHO it’s possible to understand that in the end’s life is important to have a meaning life behind. If not Occupational Therapists have the role to help the clients to find that meaning through this model. If the Occupational Therapist contributes during this process, we can compare it to what was defined by Bye (1998), as the essential phenomenon that guides the Occupational therapy practices of clients with terminal illness: “Affirmation of life: Preparation for death”. Therefore, the remaining life of the client is valued, the client is helped to live the present better, the client’s right of self-determination is recognized, and the client is helped in getting ready for the approximation of their death. Agreeing with Jaques & Hasselkus (2004), when the client is aware of his/her eminent death, the occupations that she/he chooses to engage get a special meaning. The biggest challenge to the Occupational Therapist is to help the client live effectively (Ferrer and Santos, cited by Othero, 2010) and actively until death.

**Conclusion:**

In a further edition of the Model of Human Occupation - Theory and Application it is suggested that a chapter or sub-chapter to Palliative Care be opened. Case studies with MOHO need to be applied.

In fact, at all ages, Palliative Care can be needed and have serious illness requiring special care and attention. It is a catastrophic change that affects the persons’ volition, habituation and Performance Capacity. Therefore it affects all human life, where the human occupation is central.

Occupational Therapy, with the MOHO fundamentals, can have the special role of helping a person to get back or maintain his/her Occupational identity as his/her life story and redefine life roles. The Occupational Therapist can help the client to realize his/her last wishes and work directly with their quality of life until the last moment.
References:


