HOW IS THE MEANING OF LIFE ARTICULATED IN PALLIATIVE CARE PATIENTS?

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Index

1. Abstract .................................................................p 1

2. Introduction .................................................................p 2-17
   2.1. Background .................................................................p 2-9
      2.1.1. A multidisciplinary context for the search for meaning .................p 2-4
      2.1.2. A conceptual context for the search for meaning ..................p 4-9
   2.2. Philosophic perspective .........................................................p 10-14
   2.3. Theoretic perspective .................................................................p 15-17

3. Aim .................................................................p 18

4. Methods .................................................................p 18-22

5. Results .................................................................p 23-54
   5.1. Extraction-synthesis from each interview .................................p 23-48
   5.2. Heuristic interpretation from all the interviews together ..................p 49
   5.3. Discussion of the findings .........................................................p 50-54

6. Discussion .................................................................p 55-59

7. Conclusion .................................................................p 60

8. References .................................................................p 61-65

9. Appendixes .................................................................p 66-71
1. ABSTRACT

**Background:** The human search for meaning has been studied from different disciplines; the psychologists have been the major contributors with approaches like logotherapy, existential therapy, psychospiritual therapy, etc. Other approaches have been art therapy, pastoral care and spiritual care. Yet, all the approaches have in common some key terms like transcendence, healing, wholeness, listening, meaning and spirituality. In the philosophic ground Gadamer’s hermeneutic explains the way the human beings construe meaning relating with others.

**Aim:** To know how the meaning of life is articulated in patients with terminal disease

**Design:** Qualitative-phenomenologic-interpretative influenced by Parse’s theory of Human Becoming

**Methodology:** 10 open interviews were undertaken (in 2006) with 10 participants recruited from three different settings using a purposive sample technique. The research was submitted previously to two ethics committees. The themes used in the interview had already appeared in a pilot study conducted in Malaga in 2004.

**Results:** In the 10 subjects meaning was construed through the shared experiences with significant people lived according to individual values while moving beyond hopes to transcend the disease’s experiences.

**Conclusions:** The finding obtained from this study produces a base of knowledge and “pre-understanding” (in Gadamerian terms) before starting a help-relationship with a palliative care patient.
To face death is to face the loss of meaning in our lives and the major pain is to end with the human relationships (Saunders 2003).

2.1 BACKGROUND

2.1.1. A multidisciplinary context for the search for meaning

The disciplines that have given major contributions to the explanation of the human search for meaning have been psychiatry and psychology. In one hand, some psychiatrists have been influenced by formal therapies, like Kissane, Clarke and Street (2001) who suggested the usage of pastoral counselling and cognitive therapy to overcome the *demoralization syndrome*; a diagnostic category that they proposed for the DSM IV characterized by hopelessness, loss of meaning and existential distress.

Chochinov (2003), also influenced by the formal school, supports Kissane, Clarke and Street (2001) new diagnostic category and adds Frankl’s logotherapy and dignity psychotherapy to manage the human search for meaning. Dignity psychotherapy focuses in improving the dying patients’ sense of worth, purpose and meaning.

Victor Frankl (2004) has been one of the major contributors in therapies based in the human search for meaning. His approach, logotherapy, is based in three philosophical and psychological concepts; freedom of will, will to meaning and meaning in life. The inspiration for this approach emerged during his staying in a concentration camp; he found that there were still sources of meaning and hope for human beings living in limit situations.

In the same line some other therapists use existential psychotherapy. This is new treatment approach that gives emphasis to the supreme preoccupations, these are; death,
freedom, existential isolation and meaningless. The psychiatrist or psychologist leaves the characteristic Freudian empiricism from the formal school to embark on an intuitive journey towards the universal human experiences; his labour can be comparable to a philosopher’s labour, helping the individuals to acknowledge something that they always knew (Yalom 2000). A similar but still different kind of therapy is the Psychospiritual therapy. As explained by Cunningham et al (2001), the term “psychospiritual” links mind and spirit, it takes to the conscience the spiritual dimension. In this sense, psychospiritual therapy is broader than existential therapy; it enhances, in a larger scheme, the human’s sense of meaning.

Art therapy, although it is younger than psychiatry or psychology, has a powerful knowledge to add to this multidisciplinary context. It has parts of its roots in psychoanalysis. The way it works is explained by a tripolar field where patient and therapist are connected by an image (eg a picture, a poem, a notebook, etc), this image communicates what is being experienced by the patient, it feeds his need for meaning, it facilitates a deeper understanding of the patient’s life, externalizes the transcendent realm and connects with the existential dimension (Connell 2001)

Chaplains and nurses contribute to the patients’ search for meaning through pastoral and spiritual care. The first one shares part of its knowledge with psychology (De Smet 2004) and is practiced by chaplains; the second one is linked with existentialism and philosophy and its use is shared by chaplains and nurses. Maaike and Hermsen (2004) explored the definitions of spirituality, religion and pastoral care in several palliative care journals from 1984 to 2002 and they concluded that there is not consensus in the literature; however some commonalities can be distinguished. In pastoral care, the
expert helps the patient to find answers to complex philosophical and theological questions, by helping the patient to find his own answers.

Yet, De Smet (2004) does not differentiate pastoral care from spiritual care, Cobb (as cited in Byrne 2002) advocates for an opposite direction and asserts that they are different. For his, spiritual care faces away from faith and moves towards the individual. Barbara Carroll (2000), sharing the same thesis, conducted a phenomenological study aiming to explore the nature of spirituality and spiritual care. She concluded that spiritual care helps the patient to re-appreciate life and find meaning in suffering and death.

Nurses have also contributed in other ways to the investigation of the patients’ search for meaning. Many nursing theorist have been influenced by existential philosophy and they have built their work from this base. Some of them are Watson, Travelbee, Leininger, Rogers, Newman, Benner and Parse (Tomey and Alliwood 1999)

The present dissertation has a solid base on a nursing theory influenced by the philosophic existentialism.

2.1.2. A conceptual context for the search for meaning

Some of the terms have already appeared in the way that the boundaries between the different disciplines have become thinner, transdisciplinary rather than multidisciplinary.

In the following section I am going to define key concepts like spirituality, meaning, transcendence, healing, wholeness and true presence. These concepts have been used indistinctly by one discipline or another.

Staring with a wide definition, the WHO (1990) defined spirituality as: “Those aspects of human life relating to experiences that transcend sensory phenomena. This is not the
same as ‘religious’, though for many people the spiritual dimension of their lives includes a religious component. The spiritual aspect of human life may be viewed as an integrating component, holding together the physical, psychological and social components. It is often perceived as being concerned with meaning and purpose and, for those nearing the end of life, this is commonly associated with a need of forgiveness, reconciliation and affirmation of worth”. The importance of this definition resides in the usage of relevant terms such as meaning, transcendence, wholeness (“it is an integrated component”) and healing (“affirmation of worth”); it gives a clue of what is coming next.

Although meaning is not such a wide concept, the capacity to construct meaning is of a high order; it attributes an existential or spiritual significance to an experience, elevating it beyond the physical perception (Glannon 2004). In this line, it is important to mention Cottingham’s (2004) vision. This author defines meaning from hermeneutics and says: “[...] for something to be meaningful to an agent, that agent must interpret it or construe it in a certain way” (Cottingham 2004, p. 22). He also declares that values, moral and spiritual are the principal criteria for a meaningful life. Activities like the artistic, the athletic and the intellectual, are also important due to the vision of their value in the whole; this is to say, the image (or the constructed meaning) the person has about the activity. Yet, the process of meaning construction does not stop here. In addition, meanings are not set; they rather are everchanging with new experiences (Parse as cited in Paillé and Pilkington 2002).

A term associated but, still different to meaning is transcendence. Glannon (2004) relates transcendence with the time perception. He asserts that in life threatening diseases, to transcend is to generate beliefs about such experience and move away from the future that produces fear to a timeless present. For the author to transcend is to take
a daily experience beyond its primary meaning, this is to change its meaning. Reed (1996) examines the concept of transcendence through three nursing theorists; Watson, Parse and Newman. For Watson transcendence is related to the human ontology (the essence of the person) and, in the nurse-patient relationship both experience transcendence and healing. Parse talks about co-transcendence, an intersubjective process which transforms the two parts. For her, in the patient-nurse relationship, the true presence (or being with the patient) mobilizes transcendence. For Newman the development of transcendence goes beyond time, space and physical concerns; it is a moral transformation which brings the person to a higher level of consciousness. The patient-nurse relationship helps the patients to achieve such awareness of the self. For Reed transcendence is a spiritual related concept which becomes evident in health experiences and confronting death, in this way, end of life experiences are transformed into healing. Still, What do we understand as healing?. According to Glannon (2004), the mind heals persons by making them whole again. Glannon`s conception of healing is related to his view of the human body, similar to Spinoza`s who says that “the mental and the physical are two modes or aspect of a single substance” (Spinoza as cited in Glannon 2004, p. 70). This is called monism, an alternative to Descartes`’s dualism or separated view of mind and body. Other authors like Neate and Neate (2001) see healing as a process of restoring energy balances which may be a different explanation (much more abstract) from the same phenomenon.

Stoter (1995) shared with Glannon (2004) similar meanings to describe healing, far from Neate and Neate (2001) conceptions. For him; healing is like a journey towards a mind, body and spirit unity. It is intrinsically connected with wholeness and it is featured by a personal peace, love of the self and openness.

It has been argued that through healing we achieve the wholeness. In the matter, Dossey
(1991) relates the concepts of mind, body, meaning and wholeness following David Bohm. The whole is the union of mind and body through meaning; in this way, meaning is like a bridge between mind and body. Dossey (1991) concludes that such an approach is needed to heal the patient.

In a narrative, a patient described her experience of healing while restoring the wholeness. For her, the patient-health professional relationship needs to meet two requisites; the patient wants and needs need to be acknowledged without any judgmental attitude (Murphy 2002). In the matter; being present in the one-to-one relationship has been described in different ways in the literature. The Human Becoming perspective (Parse 1999) talks about true presence, some synonyms are to bear witness to the other’s reality, to accompany and be with. To be truly present with a patient is not to direct or try to control his thoughts, choices or actions; rather, the nurse stays with the patient while he shows his own ways of being and reflects on the contradictions he has faced in the daily life. It is a skill developed by being attentive with the moment-to-moment shifts in meaning in the other person (Parse as cited in Aquino-Russell 2005, Paillé and Pilkington 2002). In the literature, similar conceptions have been found although less abstract. Reverend Burton (2002) defines what compassionate listening is; he says: “compassionate listening is a process where we hear with the heart the story of the other, while withholding judgment and maintaining appropriate boundaries” (Burton 2002, p 166). Yet, this definition is not very clear and concepts like “appropriate boundaries” need to be clarified. For Burton (2002), compassionate listening is also to accompany the patient through his pain until it is transformed into healing.

Cicely Saunders (2003) also talks about “being with” the other. She names the phenomenon “watch with me” meaning “be there”. According to her, watch with me
can help the patients to find a new meaning. She gives a religious connotation to the meaning construction between the two interacting parts, the patient and the carer. For her, the hermeneutic fusion of horizons (the achievement of a mutual comprehension) is seen as the awareness of Christ’s presence.

The main characteristic of “being with the other” is the intersubjectivity of the interpersonal relationship. Stoter (1995) states that healing is an aspect of spiritual care characterized by the partnership between the patient and the carer. For him, everyone involved in this relationship share a growing experience with mutual personal enhancement. Within this relationship love brings acceptance and understanding and shows his value with a touch, a word, eye contact or just being there. Cottingham (2004) gives importance to openness in the sense of being open to other people in order to achieve a truly meaningful life through genuine emotional interaction and critical dialogue with others. This is what he calls an integrated life.

The relationship between the exposed concepts is illustrated in the following figure (Fig. 1). It has been developed by the dissertation’s author in order to facilitate the comprehension of these key words.
Human beings build meaning through an open intersubjective spiral process. Meanings change continuously through transcendence which is represented in the diagram with an arrow; its pick reaches healing and fuses in the wholeness.

2.2 PHILOSOPHIC PERSPECTIVE

In this section the philosophical basis of the research will be explained in order to provide to the reader a clear and transparent research process, making explicit the
researcher’s inseparable intellectual influences.

Some scientific traditions understand that there is only one truth, “The Truth”, a truth that legitimizes the professional power. For Arrigo (Arrigo & Cody 2004) this scientific power comes from personal beliefs which are lived as a dictum; in this sense, Allen (1995) says that to fix meaning is an act of power. He appeals that scientific paradigms like positivism, objectivism and phenomenology are characterised by this linear and authoritative speech which defence the “objective interpretation” of the data.

In the same manner prescriptive theories are used in nursing. A prescriptive theory is a theory which precedes a research or a nursing care, this theory “tells you how to do the things”, this is a deductive process inherited from the traditional science, it relates to universal laws (“The Truth”) and theory testing (Roy 1995, Cody 2000).

Yet, other traditions believe that there is not one truth, these traditions sustain that there are many truths free from universal laws. Phenomenology peaks with Husserl (1900-1970) who believes in an objective and absolute truth which essence can be differentiated, set aside from everyday knowledge, through observation (Seymour and Clark 1998). In other words; Husserl distinguished between the presence of the object (a real object situated in space and time, an absolute truth) and the position of the object’s existence (also called the intentional object or the meaning that we give to this object, the everyday knowledge). The process of separating an object from its meaning was called phenomenological reduction; this process was influenced by the Cartesian dualism which contemplated separately subject and object. The major features from phenomenology come from this thesis; three concepts can summarize it. The first one is consciousness. Acts, objects, ideas and experiences “exist out there”, in the reality; when we are aware of them we construct their meaning, this is in Husserian terms, we position its existence in a non-physical dimension, they come through consciousness.
The act in which those objects situated in the reality come through consciousness and are provided of a subjective meaning, is called *intentionality*, this is the second concept. Such mechanism is possible thanks to a third concept, the *openness* character of the consciousness; as humans we are open to the world and, therefore, to the reality (Giorgi 2005).

Heidegger, later on, adopts a different approach and discards the phenomenological reduction. The main difference between Husserl and Heidegger is that for Husserl knowledge is achieved from an objectivist paradigm whereas for Heidegger knowledge is achieved from a relativist paradigm. The relativist position implies a “co-construction” of knowledge as the result of the interaction between the researcher and the participant; therefore it is called co-construction, because knowledge is constructed from the two interacting parts (Seymour and Clark 1998). Heidegger gives importance to the language as a medium through which meaning is established in human relationships (Pascoe 1996), such conception starts to produce a shift in the paradigm.

Hermeneutics goes beyond Husserian phenomenology and breaks the Cartesian Dualism (subject-object), its major contributor has been Gadamer and his master piece “True and method” (1975). For Gadamer, in contrast to the Husserian phenomenology, the meaning given to the objects does not occur through consciousness; it is rather given within a *historical, cultural and linguistic* context. The human being is not related to the world anymore through a process called consciousness; in the hermeneutic tradition the human being is “*in the world*”. Gadamer also adopts the term *openness* to explain the dialogue or process of making meaning through the interaction between the human being and the world. This is the process in which *understanding* happens and it is achieved with the *fusion of horizons*, this is, the researcher’s perspective fuses with the participant’s or read text’s perspective (“*the world*”). The two in interaction converge
and became an indissoluble whole. Yet, this process never ends and it is always open which implies that there is not an absolute truth (please, remember figure 1). The fusion of horizons has implicit another characteristic concept in hermeneutic philosophy; pre-understanding or prejudice. Our pre-understanding is our theoretical and conceptual assumptions (what Husserl called the everyday knowledge), we can never set aside it when we observe the reality (or the world, or the participants, or the texts we read) (Pascoe 1996; Annels 1996; Allen 1995). In this sense, Gadamer polished a metaphor originally from Schleiermacher (as discussed by Reed in Annels 1996); the hermeneutic circle which represents the art of understanding through the dynamic movement between the parts and the whole of the text we are interpreting. This idea has its pillars in the constructivist paradigm as explained by Guba and Lincoln (2000). Nevertheless, within this paradigm hermeneutics is contemplated as a methodology rather than a paradigm like we have been seeing it. In the matter, Allen (1995) argues about hermeneutic as a methodology. He states that in nursing, most of the texts are generated through interviews which may vary depending on the theoretical perspective used. The interview process must be justified on the basis of the theory and questions being addressed; the production of meaning through reading will be the core of the hermeneutic strategy, this is to say, the interpretation of the interview will be according to the hermeneutic fusion of horizons but the interview itself will be developed in accordance with the author’s theoretic influences, his intellectual pre-understandings. Allen (1995) in addition describes the criteria for validating a hermeneutic research. He distinguishes between process and consistency. Process refers to the conditions under which the interpretations were produced; the more democratic the conditions, the more trustworthy. On the other hand, two criteria are established for consistency. An internal criterion refers to the comparisons between the parts of the text and the whole text with
other texts and parts (this is the hermeneutic circle explained earlier). The strategy of returning to the subjects for validation do not secure the internal consistency as in hermeneutics the meaning is in the interaction between the reader and the text (or transcribed interview) not in the author’s head. Regarding to external validity; it has to do with identifying the text’s historical and linguistic context (Allen 1995).
Before continuing the discussion it is necessary to step backwards and contemplate the paradigmatic perspective.

The paradigm concept will be defined here in Kuhnnian terms. A paradigm is the vocabulary of a scientific community and reflects the way the scientist from this community think. A paradigm relates the words and phrases of a scientific community to the natural world, it construes meanings. These meanings are used to shape models which, in this turn, guide the theory construction (Kuhn 1987, Fawcett and Alligood 2005).

Guba and Lincoln (2000) distinguish four important paradigms in research; positivism, postpositivism, critic theory and constructivism. The last two ones emerge in the social science context. The present dissertation is created under a constructivist framework; one of the alternative paradigms that emerge after the critiques directed towards the positivism and postpositivism perspectives. The key thesis under the constructivist paradigm is that the reality is constructed; there is an indissoluble whole which is interacting continuously, hermeneutic, in this sense, is the research methodology used by those scientists who see the world through constructivism (Guba and Lincoln 2000).
Yet, within the four major paradigms described by Guba and Lincoln (2000), more alternative approaches can emerge. In the case of the constructivist paradigm an alternative one develops; the simultaneity paradigm. Parse said in 1987: “the fundamental beliefs of the simultaneity paradigm are that the human and the
environment are mutually and simultaneously interacting as a unity, that the human-universe-health process is more than a different from the sum of parts, and that health is an ever-changing process experienced by the human” (as cited in Parse 1999; p 11-12). Philosophy is the science’s mother; in the scientific development the start point is the paradigm, the philosophy. In the matter, one of the final destinations of the constructivist paradigm is the human science. Dilthey, the founder of the human science tradition (as cited in Baumann 2002 and Pilkington 2002) says that human sciences acknowledge the inner and the outer experience. In addition, Pilkington (2002) asserts that human science enhances the understanding of the multidimensional meanings inherent in the human existence. Mitchel and Cody (2002) conclude that those phenomenons that characterize the human science can not be adequately described, explained or analyzed through objectification. For these authors human science, art and hermeneutic are concepts intrinsically related; they sustain that, after all, the research outcomes are endowed with scientific meaning, scientific interpretation like a poetry is interpreted by a reader.

2.3. THEORETIC PERSPECTIVE

Rose Marie Rizzo Parse contemplates nursing as a human science and within the simultaneity paradigm she articulates a middle range theory; the human becoming theory. This theory won’t be used here in a prescriptive way; it rather will situate the research in a scientific nursing context. Parse’s theory will also provide a perspective to analyze the research findings.

The human becoming theory can be summarized in three principles; each of them has an associated theoretic concept (meaning, rhythmical patterns and transcendence respectively) and, at the same time, each concept is described by three other concepts.
All of them have roots in the hermeneutic thought.

The first principle says: “Structuring meaning [italics added] multidimensionally is cocreating reality through the languaging of valuing and imaging” (Parse 1981 as cited in Parse 1999, p. 6). This means that the human beings build their reality through the elections they do in the lived experiences. The human being cocreates the meaning of these experiences with the universe in a dialectic relationship. In this principle three more concepts complete the definition of meaning (Wesley 1995):

- Imaging: Means to shape the person’s knowledge in a prereflective-reflective level; this is, to concrete the experiences’ meaning. (Lee and Pilkington 1999, Parse as cited in Bunkers 2000, Parse 1999)

- Valuing: Is to confirm or not the beliefs through our perceptions and to confirm what is cherished in the prereflective-reflective knowings of imaging (Parse as cited in Bunkers 2000, Parse 1999). Choosing a determined situation help us to confirm our values (Rendon et al 1994).

- Languaging: The meaning of the experiences is constructed through the expression of thoughts (when we talk or when we move) or without them. This is a process of cocreating meaning with others (Bunkers 2000)

The second principle says: “Cocreating rhythmical patterns [italics added] of relating is living the paradoxical unity of revealing-concealing and enabling-limiting while connecting-separating” (Parse 1981 as cited in Parse 1999, p. 7). In this principle Parse goes further and adds that the meaning constructed in the dialectical relationship between the human being and his environment (or universe) is determined by contradictions that happen simultaneously. These contradictions happen in the daily life
when we relate with other people (Arrigo and Cody 2004), they are the following:

- **Revealing-concealing**: When we reveal some aspects of our self (e.g., values, feelings, beliefs), at the same time we are concealing others (Parse 1999, Bunkers 2000, Cody 2000).

- **Enabling-limiting**: There are infinite numbers of opportunities when we choose something and when we do it we enable ourselves with the decision we choose while, simultaneously, we limit ourselves with the opportunities or choices we refuse (Parse 1999).

- **Connecting-separating**: This means that when we connect with one of our human dimensions (or facets) we separate from others (e.g., when we are working we are not spending time with our family) (Wesley 1995). It is being with and apart from others, ideas, objects, and situations all at once (Parse as cited in Bunkers 2000). When we are with a person or a project, simultaneously we are away from other persons and projects (Cody 2000).

The third principle states: “*Cotranscending* [italics added] with the possibles is powering unique ways of originating in the process of transforming” (Parse 1981 as cited in Parse 1999, p. 7). This principle talks about aims and dreams overcome by the person (Wesley 1995). The principle is about transcendence which means moving beyond the moment with possibilities (Paillé and Pilkington 2002). Its three associated concepts are the following:

- **Powering**: Is the energizing force of forging ahead (Parse as cited in Bunkers 2000), it is “what moves a person towards a goal”. Powering leads to the self-affirmation in light of the possibility of non-being (Parse as cited in Lee and Pilkington 1999).
- **Originating**: It refers to carve the self uniqueness both alike and different from the others (Parse as cited in Paille and Pilkington 2002).
- **Transforming**: This is a concept related to evolve. Human beings change continuously and increase their diversity (Wesley 1995). It is the process of making the unfamiliar familiar in the way that personal perspectives shift (Bunkers 2000).

The following figure makes explicit the relation between the three principles, the associated core concepts and their respective descriptive concepts.

Fig. 2

<table>
<thead>
<tr>
<th>CORE CONCEPTS</th>
<th>FIRST PRINCIPLE</th>
<th>SECOND PRINCIPLE</th>
<th>THIRD PRINCIPLE</th>
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<tbody>
<tr>
<td>Imaging</td>
<td>Meaning</td>
<td>Rhythmical patterns</td>
<td>Transcendence</td>
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<td>Valuing</td>
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<td>Languaging</td>
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<tr>
<td></td>
<td>Revealing-concealing</td>
<td>Enable-limiting</td>
<td>Powering</td>
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<td>Connecting-separating</td>
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<td>Transforming</td>
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The way this theory will be used to help with the analysis of the results will be explained under the “analysis plan” section.
3. AIM

To know how the meaning of life is articulated in patients with terminal disease
4. METHODS

4.1 SETTING

Two teams were involved in this research. The palliative care team at the Virgen de la Arrixaca Hospital in Murcia and the onco-hematology team at Morales Meseguer Hospital in Murcia. Participants were approached in their homes, in the hospital and in the medical day centre.

4.2 PARTICIPANTS

The participants included had to meet the following criteria:

1. Do not feel that any harm can be done with the questions they have read in the information sheet
2. Have a prognosis less than six months
3. Have the cognitive as well as the physical capacity to consent whether they are taking part
4. Have pain or any other problematic symptom under control during the interview

All the patients who did not meet these criteria were excluded. The patients who spoke a language different to Spanish were included when an interpreter was available. Finally ten patients were included with ages ranging from 29 to 78. The interviews were conducted from January to October.

4.3 SAMPLING

The sample was obtained through a purposive sampling method congruent with the research’s paradigm and methodology. This is a characteristic method in qualitative
research; the aim was to sample a group of people with a particular characteristic, being at the end of their lives (Bowling 2002).

4.4 METHODS OF DATA COLLECTION

The information was collected through open interviews which lasted from seven to forty-five minutes. The themes were already used in a pilot study conducted in Malaga at CUDECA in 2004. Six participants were included in the pilot study which used the same theoretical background that the present dissertation. The results revealed that the six terminally ill patients re-shaped meanings like family, love and friends whereas their values changed as a result of life experiences rather than the disease experience. The questions asked then and their relationship with Parse’s principles can be seen in appendix 1.

The subject’s recruitment stopped when the data saturation was achieved, this is, when categories (or themes) started to reappear and produced no new information.

4.5 ETHICAL APPROACH

The study proposal was submitted to two different ethics committees; The Virgen de la Arrixaca Hospital ethics committee and the Morales Meseguer Hospital ethics committee. After obtaining their approval, the participants were doubly informed, verbal and written information were given. Consent was obtained signing a consent form (See appendix 2) after at least twenty four hours. The possibility of producing any harm was observed by the team members; in the matter, there was no need to follow up any participant.

4.6 RECRUITMENT METHODS
The participants were informed first by members of their health team; after this, written and verbal information as well as a consent form were given by the researcher.

4.7 ANALYSIS PLAN

Parse developed a research method in accordance with her theory. It has a phenomenological methodology as it is oriented to understand the person’s experiences and meanings described through words, symbols, metaphors, poetry or drawings. Parse understands that this kind of research is called basic research as the produced knowledge expands the base of the nursing science using a nursing language rather than adopting it from other disciplines (Parse 1999).

Parse’s research method includes the following three steps:

1º Dialogical engagement

Rather than an interview, the dialogical engagement is a discussion between the researcher and the participant in true presence. Yet, the researcher has named this process “open interview” to facilitate its comprehension. The dialogue is audiotaped or videotaped if possible (Parse 1999).

2º Extraction-synthesis

Here the research question arises. The essences of the dialogue or themes are articulated in a more abstract language, the research language, then it is expressed in a propositional statement and structures (Parse 1999, Baumann 2003, Huch and Bournes 2003, Bunkers 2003, Fawcet 2001).

3º Heuristic interpretation
The heuristic interpretation takes the research to a higher abstraction level. The processes of structural integration and conceptual interpretation move the discourse of the structure to the discourse of the theory (Parse 1999).

The interviews were read several times. In a first reading the experiences that threw light on the way the participant constructed his or her meaning were underlined. In successive readings core categories were identified. The categories were labelled in Parse’s terms (imaging, valuing, languaging, revealing-concealing, enabling-limiting, connecting-separating, powering, originating, transforming). This was to read “the parts”. Once the interview was synthesised for the dissertation’s findings “the whole was contemplated” and synthesised again in a proposition. The process of extraction and synthesis of each interview facilitated the analysis of all the interviews together; “the whole of each whole”.

In appendix 3 a practical guide to apply this research methodology has been developed by the dissertation’s author in order to facilitate its comprehension.

4.8 STEPS TO ENSURE INTERNAL CONSISTENCY IN A PIECE OF QUALITATIVE RESEARCH

After the pilot study’s experience in Malaga it was decided to send the interview themes previously in order to give to the participants’ time to think about the questions and decide freely to take part in the research. This technique would also reduce the recall bias.

In the other hand, during the interviews the technique of clarification was used in order to clarify any misunderstanding. During the interview’s analysis different parts within the same interview were compared to identify similarities and speech congruence; then
the different findings from the 10 interviews were again compared with the same finality following Allen’s criteria of internal validity (2005). According to this author, the strategy of returning to the subjects for validation do not secure the internal consistency as in hermeneutics the meaning is in the interaction between the reader and the text (or transcribed interview) not in the author’s head (Allen 2005).
5. RESULTS

5.1. EXTRACTION SYNTHESIS FROM EACH INTERVIEW

*Brian’s story*

Brian was a 71 year’s old retired man. He worked for 4 firms, one of it was developed by himself, in the other three he was the sales manager. Yet, he said that his real profession and vocation was bullfighter. He grew up in Seville where he developed his interest for the bulls. Being young he started to save money and travelled to Albacete (in central Spain) where he jumped inside a bullfight spontaneously, he described this experience as “a dream”, a year later he started to bullfight professionally. Brian’s interest for bulls came from his general interest for livestock, he also liked other animals, he had birds in his courtyard. At the age of 71 he used to follow bullfights on magazines and on TV. Other things that fulfilled Brian were the company of his wife, sons and great sons, to smoke, to drink wine and to live according to his values. He highlighted the following values; to be natural and simple (meaning to be “transparent and open” to others as he described it), to be honest (he related that he had the opportunity to steal money from his employees but he did not in spite of someone’s advices), to sleep with a peace of mind, not to harm anyone consciously, to be sensible and “to leave the door open to others” (meaning that he liked to be approachable). He expressed he felt “satisfied of living in peace […] a healthy and simple life”. Brian also described himself as an aggressive business man (he said this is an important quality in the business world) but, in the other hand, he was good with the people he worked with. In his relationships with others he remarked his parent’s education, values that he transmitted to his sons too. He remarked the importance of the dialogue in the family and the good harmony between its members. Brian also gave importance to the values
learned from the Catholic religion although he confessed that he did not believe in heaven and hell.

Other characteristics in his personality as described by him were to be helpful to people and to be independent in taking important decisions. Living with a terminal lung cancer he decided not to have a bronchoscopy done; in this point of his disease he wanted to “leave things as they were” (he said), he believed that any treatment or aggressive diagnostic technique would make worse the process. Brian explained how he saw this matter with a popular saying about a chicken, “the less that you annoy the chicken with a tumour in its neck the more it will live”. Overall, Brian talked about death with acceptance saying “I have lived all I have to leave” and expressing “when it comes I will accept it and that is all”.

*Essences in Brian’s language*

1. The family and the marriage are the most important experiences that satisfy a human being. Harmony, dialogue and respect define what a family is. What I learnt from my parents I have transmitted it to my son and daughters. I have also learned values from the catholic religion. (valuing and languaging)

2. I am who I am; honest, sensible, open, loyal, natural, easy, healthy, transparent, independent and worker. I am a bullfighter and a business man. I like animals. (originating and valuing)

3. I have taken important decisions in my life like stopping my studies, jumping into the bullfight’s world and closing a firm having to return to my employees the money they had earned. After this I started a new business by myself. (enabling-limiting)

4. To become a bullfighter was a big satisfaction to me as well as a big effort,

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1 The categories, labelled in Parse’s terms, behind the participant’s speech have been written in brackets in order to make visible the analysis process. Yet, this is not a usual practice in Human Becoming research pieces.
everything started because I liked livestock. To see how my son and daughters work and the harmony in their respective families also fulfils me as well as sleeping with a peace of mind. (powering)

5. To be honest was holy in my family. To me, death is acceptance; I believe that when we die we are ashes and rubbish like when a bull dies. I prefer to refuse any aggressive treatment, if we do not annoy the cancer I will live longer, like that popular saying about a chicken. (imaging)

Essences in the researcher’s language

1. Values are construed with the family and religion
2. The self is defined through personal values and professional roles
3. Important decisions arise within the professional world
4. Fulfilment emerges with personal goals reached
5. Values and death are concepts redefined and well-shaped.

Proposition

Meaning is constructed through values shared by the family and religion; chosen professional experiences and the fulfilment produced achieving personal goals being independent.

David’s story

David was a 76 years old man with a spinal cord cancer. He explained his cancer journey during the interview. Everything started years ago with terrible pains, after a bone scan a doctor diagnosed a spinal cord cancer. His wife was told the new curtly, “the thing is that your husband has a cancer” and, after a time, David was told he had a
cancer. David described that his major pain was the though of going to the theatre, he lived during a time suffering after being told that he had cancer. After this period, one of his daughters found a neurosurgeon that operated him, the intervention was successful and he started to walk with walking sticks, David experienced this as “walking as a robot”, he felt well for three years till he started to feel some discomfort again. David visited another doctor who said that to operate him again would not be possible, David expressed ironically that it was “as if the doctor was missing to say; die!”, another doctor from the same team said to him “what you have to do is to get use to live with the pain”. Years later he broke his hip, one of the doctors said to him “it is a surprise; people do not life such a long time with your disease” and David thought “what a way of cheering me up!”. Later on he was admitted to the hospital due to oedema. The doctor who received him in the emergency department talked to him about palliative care, David expressed that he was very grateful with this last doctor and with being referred to a palliative home care team. After his discharge he started to receive visits from this team, he was happy because he had his pain better controlled (in addition he had a pressure sore) and he could talk with the specialists. He was in a wheelchair then and needed a urine catheter.

Overall, he described his disease as “a spiral”, he expressed that it was “transforming him into dust”, that it was a “matter of luck”. He felt he had “no incentive” and he could only worry about the disease. David also expressed that his life was “stagnant” and that the disease had thrown his values out of reach.

During the interview David also talked about other experiences in his life. He started working as a crafts-man making nativity scenes. In his spare time and with his savings he learned accountancy and how to type so when he had to go to the military service he had the chance to be destined to the offices, he expressed that this was a “nice and
important experience” because he met a lot of different and nice people, he said that the military service “opened his horizons”. When he was finishing the service he though about staying there and become a professional soldier but he took the decision of leaving it. After this he started to work for a pharmaceutical firm, he said that to reach the post he reached (a manager) “fulfilled him” he did it because “he really wanted it” as he described and with his “efforts” and thanks to his “constancy”. Within this firm he started to work in a basic post, yet he wanted to learn more so he went to an academy, he expressed that he wanted to “overcome the fact of working with people with a poor education”; he said “the world should be something else or, at least, I wanted it to be something else”. He defined himself as a “hard worker”, “not lazy”. Another achievement he reached was an increase in his salary.

In his personal life his illusion was to get married with his girlfriend, to help his son and daughters to grow up and educate them, and to move from the town to the city where his kids would grow up in a different atmosphere.

For David family was synonym of “happiness” and “harmony”, he said, “[…] they give me all their affection and attention […] the family is everything or almost everything”, he received often visits and gifts from his son and daughters. In this context he talked about love, for him love was “the greatest thing”. David also expressed that faith helped him to go on as well as go to out to his son’s house. He felt that he did not live religion in the same way now that he was ill as he could not go to church. His wife and he were members from a religious group years ago, in this group the marriages used to meet regularly, help each other and talk about the kids’ education. He experienced this as “discovering a new world”.

In his time perception he felt that days were not too long, he though that watching TV and making cross-words helped.
Overall, David defined himself as a loyal, normal, without two faces and true.

*Essences in David’s language*

1. I am loyal, normal and true (originating)

2. I have achieved professional goals being worker and feeling like working, being constant and my commitment for studding also helped. (powering). Some of the important decisions that I have taken in my professional life have been; to leave the military service, to become a manager in a pharmaceutical firm and achieve an increase in my salary (enabling-limiting and transforming)

4. In my personal life to get married and to help my son and daughters to grow up has been my illusion as well as having a comfortable house (valuing and powering). Faith and going out to see my son helped me to go on.

3. The disease is a spiral, a matter of luck that transforms me into dust; it throws my values away and leaves me stagnant without any incentive. In the other hand; happiness, harmony, love, the greatest thing and affection describe what a family is (imaging).

5. Meeting new people during my military service opened my horizons. Later on, I discovered a new world being member of a religious group. (transforming).

*Essences in the researcher’s language*

2. His values and force to achieve goals describe how he is.

1. Moving beyond arises with efforts made in the professional world, felt illusions in a familiar context, relating himself with others and having faith.

3. Relevant decisions emerge with the possibility of going ahead in the familiar and the professional environment.

4. The meaning of the disease is construed feeling numb whereas the family is seeing as the centre of happiness.
5. Anecdotes about relating with others throw light to the lived experiences.

**Proposition**

Meaning is construed relating with others and achieving important goals overcoming the opportunities that arise living numb and happy simultaneously in the disease process.

**Janice’s story**

Janice was in her 70’s, she had been a housewife all her life. She did not like to go out, neither to watch TV nor listen to the radio nor music; she rather preferred to be at home with her sons and great sons. She felt she had worked a lot and considered herself an independent woman, she expressed; “I always liked to be independent and I have lived in my way”. She said that she had never had troubles with anyone. The most important thing were her sons and great sons, she said that they were her “satisfaction”, listening the mass on Sundays also satisfied her, she expressed; “the ten commandments say that we have to listen the mass and I carry out my obligation, believers’ life is like this, I think”. Janice felt that she had peace of mind because she had been good, she said; “the better you are the less you hurt people and the more tranquil you feel”. For her a bad person is a person who offends, who has bad thoughts and hurts the others, she said; “this is not satisfactory for a person”. Janice did not like to criticize the people; she also said that she is not a jealous person. When Janice was talking about how a good person should be she asserted that she felt satisfied of being as she had described herself.

Janice described what made her to go on with expressions like; “life makes you get by ahead […] God sends to each one […] He has sent me my illness […] the lord tests you […]” Janice said that these thoughts made her to feel better; she added that her husband, sons, her house and her life also helped her to go on, “although you were suffering, life
is kind and this makes you get by ahead again” she said. Janice expressed that she felt love, pity and worry for her family; pity and worry in the case that something happened to them. She saw her disease as “the biggest thing” it had happened to her, a “misfortune” and “the worst experience”, as described by herself. She talked about death in this way, “when my turn comes, that will be it” and, in the other hand; she compared life with a routine to face. Janice though she was going to live for a long time like her mother did who died at the age of 94.

Overall Janice felt that, after her disease, she had changed in many ways. She said that she had no illusions, one of her great daughters was going to get married shortly and Janice felt no illusion at all; “it was suppose to be the illusion of my life” she said. The time perception had also changed; she expressed, “one has no thought for tomorrow […]. I do not think like before and I do not do plans for tomorrow” she added that this way of seeing the time did not help her at all and she felt “more negative”. The disease had made her to be in “a bad humour” and be “rare” according to her confessions.

*Essences in Janice’s language*¹

1. My family, the Lord’s tests and life’s kindness help me to go on and feel better. (powering and transforming)

2. After my disease, I do not see the world in the same manner. I have not illusions; I only can live the present moment which makes me more negative, I feel I am rare. (enabling-limiting)

3. The family is a mixture of love, pity and worries. The disease is a misfortune, the worst experience and when death comes that will be it. Life is kind and a routine to face. (imaging)

4. I am independent, worker, pacific. I have peace of mind and I feel satisfied with
living like this. Other things that satisfy me are to listen to the mass on Sunday and the company of my family, the most important thing. I do not like TV, radio nor music, I neither like to go out. (valuing, originating and powering)

*Essences in the researcher’s language*

1. The family, religion and life push her to move beyond.
2. The disease imposes a new way of seeing the world through a negative attitude, lack of illusion in life, a feeling of being different and a change in the time perception.
3. The significance of family, disease, death and life emerge with ambivalence feelings and acceptance.
4. Satisfactions arise with living according to her values, spending time with her family and practicing religion.

*Proposition*

Meaning is construed moving beyond practicing one’s values with the family, religion and life, which are re-shaped through the disease experience.

*Bob’s story*

Bob was a 58 year’s old man; his cancer journey had started in 2001. One morning he had his coffee as usual and then he had a big rectal bleeding. The first year he was operated and he lived with neither pain nor discomfort for five or six months. After this period he started to feel a continuous pain. He felt he had to fight by his own; “[…] you have to go yourself, to fight yourself because you, yourself have to get the strength”. Bob expressed that the disease did not give him anything, he gave some examples; “Where does this pain come from? […]Why does it appear? […]”, I would like that some
persons explained to me why I have this pain; Why do I have this pain?. If I need this suffering to live this life then, tell me if this is life”. Bob felt that he had do nothing wrong to be suffering, he said; “If I have not killed anyone, Why should I be suffering, What have I done wrong?”. He also expressed that the disease had changed him; “before my life was simpler, now I feel aggressive with any thing” and that going on with it was an achievement.

Bob asserted that he had had a long and simple life, he said “I have not been a drug addict […], I have lived a simple life with my friends and so on […], I have been living as simple as possible and as good as possible, I have not troubled anyone […]. If I had to enjoy I enjoyed […] I think that you have to live life as you think life is”. His family and friends also contributed with him to live his life in his way; “We all have met, we have gone out […], for me this is living the life”. He added, “Life is very nice knowing how to live it”. He felt that during his life he had improved, he said “I have improved being more settled in life”. Bob declared that “his body”, “his energy”, “his blood”, “his nerves” and “life”, specifically “the family” and “friends” helped him to go on.

During the interview Bob narrated two extraordinary experiences. The day he was going to be operated for the first time he felt nausea and he failed to see the point, in this instant he saw a white figure with its arms like in a cross. He had similar experience years before when he was with a friend, months later after the extraordinary experience he discussed with his friend and his friend died in a motorbike accident. Bob added that at times he had visions or thoughts which happened. From these experiences he concluded; “there is SOMETHING […], no one can say that they have seen god […]; this experience has made me believe more in the persons, watch out, not in the church […] sometimes these experiences give some meaning to life but, other times life is rotten […], the persons do it rotten”
Essences in Bob’s language

1. I have not been a drugs addict, I have never troubled any one, my life has been simple. To enjoy with my family and friends is the way I think that life should be lived. (valuing)

2. Pain and suffering have no sense being a good man and having not killed anyone. The disease is an experience that I live myself, it is bad and hard. Life is enjoying with your people, simple and nice if you know how to live it. (imaging)

3. My energy, my body, my blood, my nerves, my life and my friends and family help me to go on and to go beyond the disease. Other life experiences that have helped me to change have been being settle in life and having the vision of a white being which helped me to believe more in persons. (powering and transforming)

4. The disease have changed me, I am not as simple as I was before (revealing-concealing)

Essences in the researcher’s language

1. The self emerges with personal values taken into a practical life.

2. Suffering arises with the no sense in the intimacy of the self whereas life is relating with others.

3. Moving beyond arises with the body, the soul, the relationships with significant people and spiritual life experiences.

4. Changes in who one is arise with the disease’s experience.

Proposition

Meaning is construed with the help of others, one’s strength and beliefs and taking one’s values into the practice to move beyond and transcend the no sense in suffering
leaving behind who one were.

Diana’s story

Diana was in her 70’s, she was a house wife and described herself as a “sensible” and “indoors woman”. Diana had lost a son with the age of 20 and she had four more. Her illusion and the most important thing were her sons and daughter, she liked to take her house forward, and look after her kinds; “I liked to take the house forward and smartened up my kids, my kids have been my madness […]”. She said that she had felt very happy helping her kids to grow up, she added “my husband and my sons and daughter are the only love”. The terms she used to describe what a family is were “the biggest thing”, “meetings” and “Union”. She perceived that life was “short” she also declared that “life was suffering”, yet, from the suffering she said that she had obtained “living in her way”. Diana expressed that she had also changed after the disease for better; “I have not got now that need for governing […] I see life differently […] I see life more simple now, less luxuries”. A part from helping her sons and daughter to grow up there were more experiences that pushed Diana ahead like faith and transmitting tranquillity and forbearance to her family; “[…] I appear stronger in front of them in order not to make them suffer” she explained. Although she did not feel right she was tranquil, she expressed; “I know that I am not right but I feel tranquil, […] I know that life is like this and I do not despair,” She said that to believe helped her to see this situation in this way; she expressed; “[…] I believe in God […] I believe a lot, I believe that there is a great beyond and I am not frighten of death […], I am frighten of suffering, […] I think I am going to see my son and my parents”.

Apart from the disease, Diana had experienced more changes in her life; in the past, when her twenty years old son died she sank. Now that she was ill Diana needed help to
be washed, she described her experience in this way; “I was active before, I could do my things, I used to go for walking […] and now I can not. Now I have to be washed […]. When you are in your awareness and you know that you are needed at home and you can not help, it is not easy”. Another big change that she lived in the past was the change from single to married; she said “It is a big, big, change”.

*Essences in Diana’s language*

1. The most important thing has been my sons, my daughter, my husband and taking my house forward. For me a family is union, meeting and love. Life is short and to live is to suffer although suffering helps me to live in my way. I feel tranquil because I believe in God, I think I will see my deceased relatives in the great beyond and I am not scared of death. (valuing, languaging and imaging)

2. Helping my sons and daughters, faith and transmitting tranquillity to my family help me to move beyond. (powering)

3. There are situations in life were I have changed. One is when a son died, I sunk then. After the disease I did not feel like governing anymore, I see life more simple now. Now that I am ill I feel badly but I am tranquil although it is hard not to help when you are needed because you have lost your activity and you need to be helped. Getting married also changed my life. (revealing-concealing and connecting-separating)

*Essences in the researcher’s language*

1. Tranquillity and living life authentically arise with relating the self with God and the family as love.

2. Moving beyond emerges with altruism, religion and transmitting tranquillity.

3. Losing control transforms who one were in who one is while the disease and getting
married connect with new ways of being.

**Proposition**

Meaning is constructed through the experienced tranquillity, relations with the family and God which facilitate to move beyond while the disease and suffering reveal new ways of living authentically.

**Mark’s story**

Mark got married when he was nineteen; he was 79 years old now. He had seven sons and daughters. He and his wife were the union point in his family, he said; “the day that we were not here, whether I die or my wife dies, it would not be the same, my sons would not meet as they do now”. Mark had been working hard all his life, he never learned to read and write; he worked as a builder, in the country, transporting vegetables, etc. He asserted that he was religious, this was a tradition that he inherited from his parents; he said; “When I pray I feel alright because when I was a child, my Dad used to sit down after dinner […] and we said our rosary every night with him […] I have teach my kids the same”. There were some experiences and persons that made Mark “to be at ease” or “to feel comfortable” as described by himself; like his wife, contributing monetarily to help his family, meeting all the family together for eating and enjoying, going to mass and weddings and baptizes; he said “we get on very well together”; the fact of being a good person also helped him to “feel comfortable”, he added “I go with my beautiful heart for the people”. He described that the best thing that had happened to him was to get married and to have his kids, he said that his illusion and achievement was to find a good job for his sons and helping them. Talking about his sons and daughters he said; “they are all very good […] I say to them ‘the day that there were disputes between the brothers or between the marriages, the house is over’.”
[…] I have teach them to be men, […] I wanted them to be with their wives at home, the best life, […] all of them have a good job […], and when they say ‘lets go out!’ I feel….”. He said that he was always there for his sons, his daughters and his friends.

Mark expressed that he held on his feelings about the disease to protect his family, he said, “I hold on. I pretend I am ok, although I know I am not, not to make my sons and my wife suffer”, Mark said that the “will power” also pushed him ahead; for Mark, an example of will power was “In the case that I decide not to go to Murcia and my wife wants to go then I say that I go”. Regarding to his disease he said that he did not feel that comfortable because he couldn’t walk as he used to.

*Essences in Mark’s language*

1. I am “at ease” when I pray or go to church for weddings and baptizes, when I meet with my family, with my wife, when I help my family and being a good man. My illusion and the most important thing has been my family, the union of the family. (valuing and transforming)

2. Holding on how I feel about the disease not to make suffer my family helps me to go on as well as my will power. (powering)

*Essences in the researcher’s language*

1. Feeling conformable emerges with living according to values.

2. Moving beyond surfaces with the need for protecting the loved people

*Proposition*

Meaning is construed through values shared with the family and helping and protecting the loved ones.
Michael’s story

Michael was 29 he decided to give up working in a familiar business to study a degree in maths; he said that he felt “liberated” after taking that decision. When he finished his degree he started to work as a professor. Michael had leukaemia, it appeared when he was 26, and then he had a bone marrow transplant. The transplant was successful and Michael re-made his life. He was with his girlfriend for more than ten years, they bought a house. He was in the hospital again because the leukaemia had been recurrent; the prognosis was bad although he did not know it from the doctors or his family who had decided to say nothing to him.

Michael liked to solve mathematic problems, going to the cinema, teaching, going out with his university and high school mates and playing computer games. Michael added that all the things he liked contributed to make him a more cultivated person. He said that he always had been a “positive person”, “sincere” and “open”; his principal values, as expressed by himself, were sincerity and honesty. For him to meet his girlfriend had been an important experience. Some personal achievements were to end up teaching, he said that he had achieve it “studying a lot and with his friends. I am there thanks to my friends”, he added that what pushed him to teach was the fact that he “liked it”. Another achievement was to have a flat with his girlfriend, he said “[…] to have a mortgage is an achievement nowadays”, he said that having a flat “fulfilled him” as well as being a maths teacher and having a nephew.

About life he said, “Life is like a walk, taking it the better that you can, […] ; living the day by day with your friends, your family, your girlfriend, your flat and your mortgage”. Friendship was “To receive and to give not waiting anything to be given back. To have a support every time you need it; to have someone there who listen”. He
expressed that family was “A big support. Family is to me the principal thing because they help you in everything you need, everything, everything, everything, everything […]”. Michael said that he was Christian, he expressed; “[...] there is some one above us [...] you are inferior to someone who is above you and can control absolutely everything. [...] It makes me feel ok because, presumably, he controls your destiny [...] and this makes me feel good”. In the same context, talking about the soul he said; “the soul is the interior [...] it is the spiritual part of each one we could say. [...] I think that when I die my soul will leave me and will go somewhere; where?, I do not know [...]”. He narrated one experience that made him feel that there was “something there helping him” like the experience of overcome the bone marrow transplant, he said that this experience reinforced his spirituality.

*Essences in Michael’s language*

1. I like going out with my friends, my girlfriend, maths, computer games, going to the cinema and teaching; they make me feel more cultivated. To meet my girlfriend, having a flat and a mortgage and teaching have been my achievements; my friends and liking to teach helped me to be a teacher. Having a flat and a nephew were experiences that fulfilled me. (powering and originating)

2. I am spiritual and religious, I believe in a superior being who controls my destiny and this makes me feel good. I also believe that my soul will go somewhere when I die. After overcoming the bone marrow transplant I reinforced my beliefs. When I decided to stop working I felt liberated. (languaging and transforming).

3. I am positive, honest, sincere and open. Life is like a walk, living the day by day. Friendship is to receive and to give, support and listening. The family is the principal support and help. (valuing and imaging)
Essences in the researcher’s language

1. Fulfilment arises with the achievement of personal goals, relating with others and being cultivated.

2. Transcendence emerges with a religious spirituality, survival experiences and feeling free.

3. The world’s vision surfaces with personal values and the supportive lived experiences shared with the family and friends day by day.

Proposition

Meaning is constructed through the pushing force of relating with close supportive people while feeling free and cultivated when achieving one’s goals and reinforcing spirituality through one’s values and survival experiences.

Jimmy’s story

Jimmy had been working most his life and he had little time to be at home with his family. He described that his life was “itinerant” because he had travelled a lot, he said, “When I had to go to Malaga I could stay there for a month before going back home, due to my work; I equally had to go to Seville, Córdoba and I did not come back home. I also went to France on my own to work in the vineyards”. Travelling, he had made a lot of friends and had lived different anecdotes; he said that he had learned about the differences between French and Spanish people. One of the things that marked Jimmy when he was living in France was the good times he spend meeting his friends after work, he said that it was important because “you share the same life with them, you know how they are […]”. For Jimmy his work was also important, he said that he felt happy when things were ok. His family was important to him too, he expressed, “out of
the family there are not many important people” he added about his family, “we are honest and good people”, for him a bad person was a lying person. For Jimmy life was “special” being healthy because “you could laugh of everything […] whether you have money or not” as expressed by himself. He said that he felt happy “telling jokes and talking about silly things which made you laugh […] and swearing”; for Jimmy special moments where those having money to eat.

Jimmy felt that his disease had affected his moral, he said “I was very comfortable and whether you want it or not the moral […] the fact of being working one day and from a day to another you are said ‘you are not going to work anymore in your life’ […] the moral goes down though you recuperate it afterwards, little by little; but in that moment, it goes down, you can sink”. When I asked him what had helped him to recuperate his moral he said; “Myself […]. Knowing what I have, I said to myself, ‘this won’t knock me out, I am going to go on myself’”.

During the interview Jimmy narrated many anecdotes with his friends about jokes, good times, drinks and work. In one of those anecdotes he explained how he faced a boss who was lying him and did not want to pay him, he said that he could do it thanks to his “temperament”, his “nerves”, “being honest”, “forward” and “not being afraid of anything”, he added, “if I have said that I am going to do something in this way […] I do not step backwards […] this is the way I am”.

An important achievement was an increase in his salary; he said “you get moral”.

_Essences in Jimmy’s language_

1. Sharing life moments with my friends, play jokes and talk is important to me. Family and work are also important (languaging)

2. What make me go on are my temperament, my nerves, my honesty, and moving
forward. The disease pushed my moral down but I recuperated it little by little. The achievement of an increase in my salary helped me one to “get my moral” once. (valuing, powering, revealing-concealing and transcending)

3. Life is itinerant and a healthy life is a life where you laugh. (imaging)

**Essences in the researcher’s language**

1. Meaning arises when we share life moments with those who make us laugh and the family.

2. Authenticity emerges with the need of moving beyond to re-construe oneself moral.

3. Meanings about life surface with work and health experiences.

**Proposition**

Meaning is construed through shared lived moments with others while laughing and moving beyond to transcend oneself moral in the context of work and health experiences.

**Noel’s story**

Noel was 50 years old. He said that the most important thing that had happened to him was to get married at the age of sixteen and to have two sons; he worked and fought to go ahead and have a house. But soon he had to leave his family and carry out the military service. When he came back he had changed; he said, “I started to drink there […] I confess I was alcoholic […] I walked the bad pathway” and his wife asked him to leave home. Noel expressed that “being alone he sunk even more into the oblivion” but, in the other hand he said, “I was happy because I had a lot of problems […] the process was going to be hard but I knew that my sons would not lack anything […] and I would be able to do what I wanted […] I was tranquil”. Noel started to spend his money and to
go out with his friends, he described that he was “deranged”. He was admitted to a alcoholics rehabilitation centre for two months and he hung on for six months, then he started to drink again till he went back with his wife and left her pregnant. He described this experience in this way; “But I did not go back to the habitual, this was an obligation, I did not want my wife to leave me. I did it for her…well; I did it for me, not to be alone […]”. In this period he was 30 and he expressed that then he “did not assimilate almost anything”. Noel continued and said to himself “The moment has come […] I have to do this for myself, not for my wife or my sons, not for nobody; but because I am destroying myself”.

During the alcoholics therapies he met more people and he and his wife started to meet out with them and drinking coke and other soft drinks. Noel expressed about this experience; “If you lean on people who drink you do not stop drinking, if you smell the alcohol you loose yourself”. Later he left the group and his wife again.

Noel explained that with 41 years old he was not the same, he did not fancy going out and working he felt that physically he was neither the same, he said “In spite all the things I had done I started to feel wrong, this is logic, about my sons, the others […]”. He added that he started to change because he started to think, “I was not used to think before” he stated. He found a partner they lived in a flat and he started to feel more “relax”, “we are well”, he explained.

Concluding he said that “he had to mark his life by his own” and that “time had made him change” he felt that he never had neither his parents nor his brothers support. After meeting his actual partner he started to enjoy travelling, fishing, motorcycling, etc. He declared that he felt satisfied because his family did not lack anything, they were good people and strong, he said “I have friends now”, he was happy seeing that his sister was ok. Noel considered he liked helping people at least economically.
1. When I got married I fought to go ahead. When I came back from the military service I started to drink and my wife noticed that I had changed, when she left me I sunk but, in the other hand I felt tranquil because I could do whatever I wanted. I stayed in an alcoholics centre for two months and six months later I started to drink again, I knew I was hurting myself. I had a group of friends from the alcoholic’s therapy but I also left them after a time. In that period I left pregnant my wife, I did it for myself, not to be alone anymore but we split up again. I realised that I had to go on for myself because I was destroying myself. Being 41 I realised I was not the same physically; I did not fancy going out anymore, I started to think, before I did not do it and I found a partner then, I felt relaxed, we are fine. The time has made me change, I like travelling now and watching motorcycling. I have had to mark my life on my own. (revealing-concealing, enabling-limiting, transforming and powering)

2. When I started to drink I started to “walk a bad pathway”, I was “deranged”, I “hardly assimilated anything”, I was “destroying myself”. (imaging)

3. To get married young and having two sons were important experiences to me. When I was older I started to think about everything I had done and I felt wrong. Now, I feel satisfied when my people do not lack anything and my sister is ok; I have friends now. I like helping people. (valuing and languaging)

Essences in the researcher’s language

1. Decisions, changes in the self and in one’s daily situations arise when problems appear and disappear while time, one’s efforts and thought reveal new ways of moving beyond individually.

2. Descriptions of hurting the self emerge with negative terms about one’s actions.
3. Important moments and altruism appear when one thinks about what were wrong and the lived situations with the family.

*Proposition*

Meaning is construed through the time and thoughts needed to solve individually one’s problems.

*Keith’s story*

Keith’s interview lasted for seven minutes, it was the shorter interview compared with the others. He preferred to be asked short questions and reply short answers. Keith was English, he had some properties in his country and when he retired he came to live to Spain with his wife. He said that he had lived “carrying on”, “keeping going”; for him life was “as it is”, “taking it as it comes”. He said that he lived the day by day but he also thought about the past and the future. He felt that he had always been the same and that it had to do with the way he was brought up. The most important thing for him were his sons, grand sons and his wife, he said that they sometimes made him feel “annoyed”, “comforting”, and that they were “always there”. Important values for him were honesty and reliability.

Keith expressed that we was a believer “I am not religious in a strict sense but I do believe”; when I asked him what the word soul and spirit meant to him he said “I do not think that we will die, the soul is the afterlife”, he added that to believe made him feel “secure” and “safe”. Finally he said that he had to take important decisions in the past, one of them was buying a house, and he did it “doing his best” as he described it.

*Essences in Keith’s language*

1. The family makes you feel annoyed, comfortable; you know that they are always
there. To believe in the afterlife makes you feel secure and safe. Life has to be lived as it comes (revealing-concealing and imaging)

2. The most important thing is my family and an important experience to me has been buying a house. To life in Spain has been an achievement for me. Honesty and reliability are important human values to me. (valuing, languaging and powering).

Essences in the researcher’s language

1. Encouraging feelings arise with family and afterlife beliefs.
2. Important experiences emerge with the family, home and personal values.

Proposition

Meaning is construed through encouraging feelings with the family, beliefs and the personal values given to achievements.

The ten propositions synthesise the interview’s essences in the researcher’s language.

The final ten propositions are presented in the figure 3. The finding from the study will be a major structure resulted from synthesising these ten minor structures.

Fig. 3

1. Meaning is constructed through values shared by the family and religion; chosen professional experiences and the fulfilment produced achieving personal goals being independent.

2. Meaning is construed relating with others and achieving important goals overcoming the opportunities that arise living numb and happy simultaneously in the disease process.

3. Meaning is construed moving beyond practicing one’s values with the family, religion and life, which are re-shaped through the disease experience.

4. Meaning is construed with the help of others, one’s strength and beliefs and taking one’s values into the practice to move beyond and transcend the no sense in suffering leaving behind who one were.
5. Meaning is constructed through the experienced tranquillity, relations with the family and God which facilitate to move beyond while the disease and suffering reveal new ways of living authentically.

6. Meaning is construed through values shared with the family and helping and protecting the loved ones.

7. Meaning is constructed through the pushing force of relating with close supportive people while feeling free and cultivated when achieving one’s goals and reinforcing spirituality through one’s values and survival experiences.

8. Meaning is construed through shared lived moments with others while laughing and moving beyond to transcend oneself moral in the context of work and health experiences.

9. Meaning is construed through the time and thoughts needed to solve individually one’s problems.

10. Meaning is construed through encouraging feelings with the family, beliefs and the personal values given to achievements.

**The study’s finding:**

Meaning is construed through the shared experiences with significant people lived according to individual values while moving beyond hopes to transcend the disease’s experiences.

**5. 2. HEURISTIC INTERPRETATION FROM ALL THE INTERVIEWS TOGETHER**

The following figure shows the evolution in the abstraction level from a simple language “the structure” towards a theoretic language “the conceptual integration”. The evolution of the concepts is presented both separately and in propositional statements.
### Core concepts

<table>
<thead>
<tr>
<th>Structure</th>
<th>Meanings</th>
<th>Conceptual Integration</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Shared experiences with significant people</td>
<td>1. cocreating meaning</td>
<td>1. Languaging</td>
</tr>
<tr>
<td>2. Living according to individual values</td>
<td>2. Reassuring beliefs</td>
<td>2. Valuing</td>
</tr>
<tr>
<td>3. Moving beyond hopes to transcend the disease’s experiences</td>
<td>3. Shifting personal perspectives</td>
<td>3. Transforming</td>
</tr>
</tbody>
</table>

### Structure

Meaning is construed through the shared experiences with significant people lived according to individual values while moving beyond hopes to transcend the disease’s experiences.

### Structural Transposition

Meaning is construed cocreating the reality and reassuring one’s beliefs while personal perspectives shift.

### Conceptual Integration

Meaning is construed through the languaging of valuing to transform the self.

### 5.3. DISCUSSION OF FINDINGS

*Shared experiences with significant people*

The first core concept, shared experiences with significant people, captures the essences of the participant’s language when they talk about their family and close friends. For example; for Brian the family was harmony, dialogue and respect. David added that family was happiness, love, affection and the greatest thing. Janice said that a family was a mixture of love, pity and worries.

Having a family and a home was one of the most important experiences described by the participants; for example, Bob, talking about his life, “a simple life”, said, “to enjoy with my family and friends is the way I think that life should be lived”. David said, “In
my personal life, to get married and to help my son and daughters to grow up has been my illusion as well as having a comfortable house”. Mark said that the most important thing for him was the union of the family. Janice said that listening to the mass on Sunday and the company of her family were the most important things. Diana expressed that the most important things for her were her sons, her husband and taking her house forward. Other participants talked about similar experiences with others. Michael (who was 29) talked in the same manner about her girlfriend and his University mates.. On the other hand, Jimmy, who had been far from his family most of his life due to his job, construed the reality relating with others; his work mattes, he said; “sharing life moments with my friends, play jokes and talk is important to me”, he also narrated several anecdotes that happened with his friends.

The concept of shared experiences with significant people has been conceptually integrated with languaging. Parse (1998 as cited in Bunkers 2000) writes; “languaging is signifying valued images through speaking-being silent and moving-being still” (Parse 1998, p. 40 cited in Burnkers 2000 p. 211); in addition, and as a clarification, Bunkers (2000) asserts that this is a process of cocreating meaning with others. This thesis is in accordance with the hermeneutic tradition which says that the meaning given to the situations is construed through a historical, cultural and linguistic context (Pascoe 1996; Annels 1996, Allen 1995). Allen (1995) wrote “[…] Language is created and reproduced socially and historically, it is a collective enterprise […]” (Allen 1995, p 176-177).

*Living according to individual values*

The second core concept, living according to individual values captures the subcategories of beliefs and autonomy.
When the participants described themselves they used their personal values. For example; for Keith honesty and reliability were important values. Noel talked about helping people, Michael said he was positive, open and sincere.

Often, individual values were transmitted through the family and religion; Brian’s said; “What I learnt from my parents I have transmitted it to my sons and daughters. I have also learned values from the catholic religion”.

Some participants had beliefs about the afterlife. Diana thought she was going to see her deceased relatives when she died and Michael believed that his soul would go somewhere too.

Another relevant value found was the autonomy. Autonomy has been understood here in terms of “being free to choose”. In this sense, Brian commented that he had decided not to receive any aggressive treatment; he was clear about what he wanted. Janice defined herself as an independent, worker, pacific woman. Noel had learned from his experiences and he thought that “he had to mark his life on his own”.

The core concept of living according to individual values has been conceptually integrated with valuing. Valuing is “to confirm or not the beliefs through our perceptions and to confirm what is cherished in the prereflective-reflective knowing of imaging” (Parse as cited in Bunkers 2000, Parse1999). Once more, going back to the hermeneutic thought, we find similarities. One of its pillars is the language (already commented) and also the historical and cultural contexts; in this sense, values and beliefs are inherent to the culture and the human history.

Moving beyond hopes to transcend the disease experiences

The third core concept captures the participants’ past achievements as well as revealing experiences which have helped them to transcend the disease experience.
Personal and professional achievements produce satisfaction and fulfilment and shift the personal perspectives. For Brian, becoming a bullfighter was a big satisfaction and, in the other hand, sleeping with a peace of mind and the harmony in his family also fulfilled him. David had achieved many professional goals; he described that he could do it because he was worker, he liked working and he was constant and committed to study. Jimmy and David talked about increases in their salaries as achievements. Jimmy said that this helped him to “get his moral”; he declared that his temperament, his nerves, his honesty and moving forward helped him to go on. Michael felt fulfilled being a teacher, having a nephew, having met his girlfriend and having a flat.

There were experiences other that achievements which changed the participant’s perspectives; these were revealing experiences. For example, Michael reinforced his beliefs after overcoming the bone marrow transplant. Noel said that after being alcoholic, what changed him was the pass of the time and starting to think. Bob described that his energy, his body, his blood, his nerves, his wife, his friends and his family helped him to go on and to go beyond the disease. He also had twice a revealing experience when he lost the point and saw a white being; since then he saw the persons in a different way. David described important experiences relating with people; first in the military service which “opened his horizons” as expressed by himself. Later he “discovered a new world” being member of a religious group. Michael asserted that going out with his friends, his girlfriend as well as maths and cinema made him to be more “cultivated”.

Religion helped in occasions to go on; Janice said “My family, the Lord’s tests and life’s kindness help me to go on and feel better”.

Diana expressed that helping her family, faith and transmitting tranquillity to her family helped her to move beyond. Mark had a similar perception, he said that holding on his
feelings about the disease not to hurt his family helped him to go on; he added that his will-power also helped.

These experiences influence the way the disease is understood. The core concept of moving beyond hopes to transcend the disease process has been conceptually integrated with transforming. Transforming in Parse’s terms is “the process of making the unfamiliar familiar in the way that personal perspectives shift” (Bunkers 2000); Parse adds “Humans change moment-to moment as they actualize dreams and hopes through inventing new ways to propel beyond what is to what is not yet” (Parse 1999, p. 8). Going back to the diagram at the beginning (Fig. 1), we can compare Parse’s Transforming with transcendence; “the white arrow” in the diagram.

Finally and interestingly it has been noted that Parse’s transforming is preceded by another core concept, powering. These two concepts are inter-related and indissoluble. Powering is the energizing force of going ahead (Parse as cited in Bunkers 2000), what the participants have described as “my nerves”, “my temperament”, and, on the other hand, the experiences and persons who have also helped them to go on like “my wife”, “religion”. “Moving beyond hopes to transcend the disease experiences” has been the core process of construing meaning in these ten terminally ill patients.
The first step to explore how palliative care patients constructed the meaning of their lives was to undertake an extensive literature review in 2005. Electronic databases as Web of Knowledge, Medline, Cinhal and Embase were searched. In addition, information was also collected at San Christopher’s hospice library, Franklins Willkins library and New Haunt House library at King’s College (London). The key words used were meaning of life, meaning of death, meaning construction, transcendence, spirituality, Parse, Gadamer, hermeneutics, phenomenology and palliative care. Studies which had applied Rose Marie Rizzo Parse’s research methodology to palliative care were also searched although none were found. Equally, there were no studies in palliative care influenced by the Human Becoming Theory. The journal Nursing Science Quarterly (Which Rose Marie Rizzo Parse is the editor) was hand searched from 1995 to 2005. All the relevant articles for the study have been included in this dissertation.

Many studies about the meaning construction explore the connexions between meaning and coping.

Lyren Chiu (2000) studied the phenomenon of transcendence of breast cancer in Taiwanese women. She was influenced by Leininger’s theory of culture care diversity and used a phenomenological research methodology (van Manen’s methodology). The conclusion obtained from her study was that transcendence was the capacity of a person to give meaning to suffering, leave attachment behind, open the self up accepting life and death and heal the self with compassion. In the present dissertation transcendence is captured in the category of “moving beyond hopes to transcend the disease
experiences”; in this sense, transcendence emerges in the daily life, in achievements and in spiritual experiences. The variety of situations in which transcendence happens shows the multicoloured nature of this phenomenon which is difficult to generalize.

Dobratz (2002) explains “the pattern of the becoming-self in death and dying” resulted from a study which examined the psychological adaptation of palliative care patients. She was influenced by Sor Callista Roy’s adaptation model. The pattern is shaped by “self integration, inner cognition, creation of personal meanings, and connection to other and a higher being” (Dobratz 2002, p 139). The author gives importance to the relationship with god, the use of conscious choices, relationships with others to construe meanings and the self-transcendence and its effects in well-being and coping. Similarly, the present dissertation has some points in common. The participants talked about religion, autonomy, relationships and “feeling good” in some situations (eg relating with significant others) which can be understood in terms of “well-being”. Interestingly, Post-White et al (1996) after a descriptive study about hope, spirituality, sense of coherence and quality of life in patients with Cancer, related hope with coping. They remark the importance of sustaining the patients’ hope (individually defined) which resides in their ability to find meaning and mobilize inner resources. In the matter, Breitbart and Heller (2003) designed an intervention meaning-centred for patients at the end of life. It lasted for eight weeks; they offered supportive psychotherapy to a control group and assessed the two groups before and after the interventions. The sense of meaning and “spiritual well-being” was enhanced in the meaning centred group after the intervention.

Tasker (2003) conducted a qualitative study using the narratives of five adult survivors of brain injury. Her research question was; How brain injury made sense of and, How
does this meaning-making process shape adjustment and adaptation?. The participants talked about other sources of meaning and relationships which were “extremely important” in the healing and coping process. She concluded that the participants ended up recognising their spirituality after the crisis and they needed to feel understood being listened. The importance of being listened appears once more in the literature; I will come back to this point later on.

Hsu and Kahn (2003) also relate adaptation with meaning construction in Taiwanese widows. They concluded that the human adaptation occurred in the form of endless cycles of meaning construction which allowed the past, present and future to appear simultaneously. With this process the widows could re-socialized. Here are similarities with the present dissertation; the phenomenon of relating with others appears again as well as the process of construing meaning through the lived experiences in the past, in the present and with future hopes and dreams.

Overall; these studies have pointed to existed connections between meaning and coping far from this research aim. However, they also give some examples of how people construe meaning in critic situations and give us a picture of the making-meaning process in human beings.

The only comparable study is the pilot study conducted in Malaga. Being influenced by Parse’s theory, the research methodology used was not the Parse research method, yet the results were similar. Importance was given to the relationships with others while individual values were continuously shaped by life events, nonetheless, the study did not make explicit how the participants transcended. The apparition of similar findings in the 2006 study enhances the study’s internal consistency. Equally, the similarities between the structures of the ten different propositions and, within each interview, in
each participant’s language; contribute to strength the internal consistency. On the other hand; the findings can not be extrapolated to similar populations as the uniqueness of each individual story is not repeatable.

The same interview protocol was used in the two studies (at Malaga 2004 and Murcia 2006). The researcher introduced herself and explained why she was conducting the study and why it was relevant. The usage of the same interview themes in both studies may have leaded to the similarities in the results; thereby it is proposed to change the questions or themes in futures researches and compare those findings with the present findings. In the matter it is important to mention that is has been difficult to outline the interview taking into account that in Spain there is a culture of death denial and it is delicate to talk and ask about death openly. Within the health context death is seeing as a failure (Azulay 2000; Rubio, Adalid and De Castro 2001), this lead to a culture of paternalism which results in the “social death” of the dying (Álvarez and Velasco, 2000). Because of this reason it has been difficult to access to palliative care patients. On the other hand there are also ethical concerns; can it be asked, How do you construe the meaning of your life? or, What is the meaning of your life? Not producing any harm?. The interview was developed taking into account these two obstacles and questions about meaning construction were asked indirectly as it can be seen in appendix 1.

In addition it was difficult to access to palliative care patients with diseases other than cancer since this service, to the date, is only offered to cancer patients and, on the other hand, the palliative care patients with diseases other that cancer are not identified as such by their health professionals due to the health professional’s deficit of knowledge about the end of life.
It has also to be acknowledged the process of translating fragments of the interviews (transcribed in Spanish) into English. Rather than a translation it has be an interpretation. Hughes, Saleem and Addington-Hall (2005) studied the cultural acceptability and appropriateness of an English end-of-life survey questionnaire (VOICES) translated into Bengali. They pointed out the importance that should be given to the vocabulary, shared meanings, cultural equivalence and the ways that people conceptualized health, death and dying. Having lived in England and being Spanish the researcher has taken into account cultural similarities in the two countries when the lived experiences were “interpreted” onto English. Kuhn (1983) also differentiated between translation and interpretation; for him an interpreter distinguishes those characteristics unknown for the persons who speak a language, characteristics without any equivalent terminology in the Spanish language.
7. CONCLUSION

This study makes explicit how the interviewed palliative care patients construe meanings through their values, important relationships in their lives and ways of transcendence; this last concept has been the core one. In the literature there have been described ways of being with the patient through this process; some examples are “to listen”, “to be in true presence with” and “to watch with” (Parse 1999, Saunders 2003). In addition, another therapeutic form of accompanying the dying is suggested; “the help-relationship”. In the health-illness process, the help-relationship is a human exchange in which the health professional captures the patient’s needs in order to help him to find new possibilities to face his actual situation. It is a human relationship which enhances the personal development. Some of the pre-requisites for the help-relationship are, to listen without any judgmental attitude, to be empathetic, to observe the non-verbal communication, to be authentic, etc (Cibanal 2003).

In conclusion, the finding obtained from this research, “Meaning is construed through the shared experiences with significant people lived according to individual values while moving beyond hopes to transcend the disease’s experiences” address this study’s aim “to know how the meaning of life is articulated in patients with terminal disease” and produces a base of knowledge and “pre-understanding” (in Gadamerian terms) before starting a help-relationship with a palliative care patient.
8. REFERENCES


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Appendix I

Relationship between the Parse’s principles and the possible questions that emerged during the interview

Principle 1: “Structuring meaning multidimensionally is cocreating reality through the languaging of valuing and imaging”

- How would you resume your life?
- Tell me about you
- Could you tell me an important story that has happened in your life?, What did it mean to you?
- What are your values?
- What is important to you? And, what does it mean to you?

Principle 2: “Cocreating rhythmical patterns of relating is living the paradoxical unity of revealing-concealing and enabling-limiting while connecting-separating”

- Could you tell me about important decisions that you had to take in the past and changed your life or the way you are?
- Have your values ever changed? Why?

Principle 3: “Cotranscending with the possibles is powering unique ways of originating in the process of transforming”

- What pushes you to move forward?
- Tell me about your achievements; how did you reach them?
- Tell me about experiences that supposed a change in your self
Appendix II

Consent Form and participant’s Information Sheet

CONSENT FORM

Patient identification number

Title of project: *Understanding how palliative care patients construe meaning*

Name of Researcher: 0440319

**initial box**

1. I confirm that I have read and understood the information sheet dated ………….for the above study and have had the opportunity to ask questions. □

2. I understand that my participation is voluntary and I am free to withdraw at any time, not giving any reason, not being affected my nursing care or legal rights. □

3. I understand that my confidential recorded interview may be looked at by 0440319. I give permission for 0440319 to have access to this recorded interview. □

4. I agree to take part in the above study.

Name of Patient                     Date                          Signature

Name of Researcher               Date                          Signature

(Adaptation from Consent Form Model COREC, 2003)
PATIENT INFORMATION SHEET

**Study about how palliative care patients construe meaning in their lives**

You are invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

1. **What is the purpose of the study?**

   The purpose of the study is to better understand how the palliative care patients give meaning to their lived experiences. With a deeper understanding of this perception we aim to improve the health professional-patient relationship, providing individualised nursing care according to our patients’ expectations.

   In order to reach this goal individual interviews will be recorded with questions as: Tell me a little bit about your life, Which experiences were the most important for you?, What are your values?, Have you ever changed? In which way?, etc. The patient is at liberty to terminate the interview at any stage.

   This study commenced in January 2006. The results will be available in January 2007. Copies of this research and its outcome can be obtained on request.

2. **Why have I been chosen?**

   You have been chosen because you meet the criteria of the study
   - The nature of your illness
   - Your symptoms are well controlled
   - You are receiving palliative cares
   - You have got the mental and physical capacities to choose freely your taking part in the study.

   Ten subjects will be included in total.

3. **Do I have to take part?**

   It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and you will be asked to sign a consent form. If you decide to take part you are free to withdraw at any time. In the case that you decide not to take part the standard of the care that you receive WILL NOT be affected.

   Should you feel unable to continue with the interview or find certain subject too difficult to talk you may stop or withdraw the interview at any time.
4. **What are the possible benefits of taking part?**

   The improvement of the cares offered to individuals experiencing similar health care issues enhancing the professionals’ understanding of their patients’ experiences.

5. **Will my taking part in this study be kept confidential?**

   If you decide to take part in the study your recorded interview will be kept in a secure place to which only the researcher will have access. All the information obtained will be confidential. The interviews will be assigned a different name to ensure anonymity.

7. **Who is organising the research?**

   This study’s idea emerged due to the lack of research published about the understanding and comprehension of our patients’ life perception. 0440319 is an MSc in Palliative Care student at King’s College (London). The present research is part of the MSc programme. 0440319 has undertaken similar researches in Almeria and Malaga in the past.

**For further information please contact**

0440319
Appendix III

A guide to understand Parse’s Research Method

1. Extract the categories from the interviews in the participant’s language

2. Transform these categories in the researcher’s language

3. Formulate a proposition (in the researcher’s language) with the purpose of synthesising the interview.

4. Repeat the explained process with the other interviews

5. Once each interview had been synthesised in a proposition, from the 10 resulted propositions a wider proposition is elaborated with the purpose of synthesising again. The resulting proposition from the ten other propositions is the research’s finding, also called “the structure”

6. From the structure the key concepts are separated and defined in a higher degree of abstraction, this is called “structural transposition”, then the resulting concepts are elevated again to an even higher level of abstraction but this time in the theory’s language; this is called “conceptual integration”

7. From the resulting concepts from the structural transposition a proposition is elaborated.

8. From the resulting concepts from the conceptual integration another proposition is elaborated.