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Dying from cancer in the 21st century

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Table of contents

In memory of my beloved father
who taught me the beauty of life

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Preface

Last November I attended my supervisor, Professor Carla Willig's seminar on preparation for the viva. We discussed the questions that are most likely to be asked in a viva and we worked in pairs to try and answer them. The question that still haunts me is the following: "What makes your research original?". I decided that in the Preface, I will try and review what I consider to be the contribution of my research by presenting a concise summary of my research findings, and then adding how they relate to the other parts of this portfolio: the Critical Literature Review and the Case Study.

My research argument was born when I was doing my clinical training hours for the Qualification in Counselling Psychology in a Palliative Care Unit in Athens, Greece. I felt that I needed to be given the time and space to reflect upon my experience of having worked therapeutically with individuals who were dying with terminal cancer. I felt that the experience of working therapeutically with individuals at the end of their lives was very enriching and of great value both to the individual and to the therapist. I wanted to be given a chance to speak about these people, how they feel, what is of concern to them and their reality, and I designed a research proposal with these objectives in mind.

Having completed my research, now, I can see that the first parameter that makes my research original is its design. I decided that I wanted to bracket off most of my interventions as a researcher so I refrained from the construction of a semi-structured interview schedule, since even that could exert guidance into what I would have wanted to gather as information. I felt that even minimal contributions of mine would have a guiding power towards predetermined ends, these being either the findings of previous research, or theoretical perspectives, or even my own personal agenda. I was more than happy to find the unstructured research design in Smith, Flowers & Larkin's (2009) book on Interpretative Phenomenological Analysis. The design and the analysis of IPA were very attractive to me because IPA approaches phenomena from an insider's perspective, valuing and respecting the way participants talk about their experience as they live it. I only used an opening question, this being: "how do you feel about coming here to receive palliative care", and I allowed the participants' reflexivity to evolve.

The first superordinate theme that my analysis brought forward was the common tendency in my four participants to define who they were. All opened up the interaction with me the psychologist-researcher by introducing the fact that they had received a terminal diagnosis, that their cancer had spread to various organs, they gave very many details about the treatments they had received so far, and all implied, but not stated openly, that palliative care meant there was no more hope for a cure, or the restitution of their previous good health. I named this 1st subtheme the medical diagnosis as identity.

The 2nd subtheme which was the most elaborated upon and occupied most of the interview time was their need to review their identity, to speak about who they are now and who they have been throughout their lives. It feels as though in the face of personal demise, the dying person uses every opportunity offered to speak about himself/herself, to reconstruct his/her life narrative so that a sense of closure can be reached. Living with dying seems to presuppose the hard work of meaning reconstruction through recollection. Whilst constructing their life narrative, my participants communicated the life philosophies by which they lived. All spoke about high values which guided the course of their lives, making their lives shine under the lights of purpose and meaning.

This process of reminiscence of who they had been, noted in all of my participants, was punctuated by the tendency to process traumas and traumatic events from their lives in the here and now. This was noted as the 3rd subtheme and it revealed that the life review narrative was not a work of embellishment and beautification, but old pains and traumas were revisited in the attempt to find their place not in a chronological sequence but in a sequence of meaningfulness and a better understanding of the self.

The second superordinate theme was entitled the experience of suffering from terminal cancer, that is, the reality of living with terminal cancer to which the individuals have to adapt. The 1st subtheme is the somatic suffering from the excruciating pain that accompanies terminal cancer. The accompanying pain necessitates a whole new relationship with the body. The body of the past, full of vitality and mobility now brings pain and suffering which is impossible to tackle, to handle, to live with. Willig described this experience of the body as a “damaged container that may self-destruct and destroy [the] self along with it” (2009, p. 186). The 2nd subtheme comprises all other areas of suffering apart from physical pain, all those things that ‘get heavier day by day’ as one of my participants said, ranging from physical weakness, fevers, immobility, to emotions of hopelessness, terror, or disorientation. The title I gave to this subtheme is ‘limitations of cancer: getting familiar with the body which suffers’. The 3rd subtheme is the suffering from coming to terms with the terminal diagnosis, or ‘negotiating terminal cancer’. Here I collated all data that had to do with the terminal diagnosis per se, from the breaking of news, to its cognitive processing, how fantasy is deployed, and lastly the emotional consolation in accepting that dying is a common reality for us all.

The third superordinate theme introduces the nature of relatedness towards others. To the 1st subtheme I gave the title ‘the need to show and receive kindness’. Relationships particularly with friends are valued highly. Past impasses in relationships are sorted out and an emotional opening toward the other with kindness is noted. Another issue with respect to relatedness towards others is the negotiation of dependency now that cancer has advanced versus the independence of their previous identity. This tension between these two experiential dimensions comprises the 2nd subtheme of my analysis.

The fourth superordinate theme is titled ‘the confrontation with death’. It includes as its 1st subtheme the participants’ attitudes towards death, the 2nd subtheme collates thoughts about how the life of their closed ones will be affected by their death and try to foresee what they need to do whilst still alive to alleviate additional burdens to their loved ones whilst the 3rd subtheme which I found most inspiring has to do with thoughts about death and the beyond or where do we go after death, or what it might be like.

These are my IPA findings. The experience of living with dying, with knowing that you are dying seems to have these dimensions. I am content not only because my findings resonate with other research findings, not only because I completed a study with Greek participants giving to my findings a transcultural perspective, but most of all because, by utilising IPA, I was enabled to see beyond Kubler-Ross' five emotional stages, which have prevailed in the study of this phenomenon for decades. So my research could be considered original in all these respects.

Another area of originality is a methodological novelty that I attempted which is to impose a second analysis on my collected data, that of Foucauldian Discourse Analysis. Having adopted the epistemological position of critical realism, I was able to delineate a space of convergence for the two methods of analysis, namely IPA and FDA. Critical realism stands midway between social structures with real powers and effects on the one hand, and free and unrestricted agency of the individual on the other. Critical realism would support that we are both constrained and free to choose a course of action. My IPA analysis explored the experience of the individual but how uncontaminated it is to the prevalent cultural discourses that surround the phenomenon of living with dying from terminal cancer? How unaffected were my participants by the language they used to describe their experience? Language is considered the ultimate storage place of limitations and possibilities for describing a phenomenon and for expressing oneself. Language guides, dictates and allows only certain statements to be expressed, considered as true in specific cultural and historical periods. Investigating prevalent linguistic structures, or discourses, reveal how we process and appreciate a phenomenon.

I literally fell in love with discourse studies, devouring not just books and articles on discourse analysis, critical health psychology, deconstruction, French philosophy and lastly Foucault's writings themselves. I arrived at FDA not only because I tried to have a rounded understanding of what other qualitative methodologies can contribute, but in a bottom-up fashion. During an interview with one of my participants I witnessed the struggle, both cognitive and mostly emotional, to come to terms with the psychosomatic hypothesis for the genesis of cancer. I witnessed my participant's struggle to find a position within this discourse that blames the person for having invited to his life cancer because of his own 'wrong' doings. He reviewed all his life as a series of emotional traumas that he unconsciously internalised and operated as potential causes for his cancer. Not only was he suffering, not only was he dying, but he had to apologise for all those things that were his ownmost. I felt that he was stripped of his individuality and his personal history, offering them as verification to a highly misunderstood hypothesis that cancer is caused by unconscious psychological conflicts. So, I could add to the question about the originality of my research that the data guided me, the researcher, to the choice of an additional method of analysis, the FDA.

My FDA findings tackle both the discourse of psychology along which I was inviting the participants to speak as opposed to the medical discourse which stands indifferent to the subjective experience and imposes a particular language for communicating with the patients, and the discourses that are relevant to my research questions. My research questions intended to explore the construction of the discursive objects of cancer, dying and death. The 1st discourse focused on how terminal cancer is constructed. It is constructed in silence, we don’t want to talk about terminal cancer because it reminds us that the almighty biomedical model failed and did not cure it. Also, terminal cancer is constructed at the level of the individual as a great defeat: the individual, despite his/her vehement efforts in fighting this war against cancer have failed to win the war.

The discourse on dying constructs it as a strictly private affair not to be shared with others in any way. The dying individual is left with minimal knowledge about what to expect, the dying process itself, and is left in bewilderment to expect his/her death. Think about giving birth, in contrast, how much information and the breadth of linguistic means the biomedical model has to offer to the public. Death is a strictly private affair left to the individual to discover the course of the actual process or how to be in the liminal space of living whilst dying.

The last discursive constructions I investigated were centred on the available discourses around death. Here I pinpointed the discourse of bravery whereby the individual courageously and dynamically, with poetic allusions, faces up to his/her upcoming end, and the discourse of the heart which constructs the beyond death as a shelter of love for the reunion with the ones who loved each other in life.

The conclusion of my research argues that if individuals are supported in processing and reflecting upon the reifications from dominant discourses that weigh heavily upon them, they can regain the capacity to relate to their own mortality in a uniquely personal and authentic way. We, as counselling psychologists, can be of assistance in this process by fostering recollection and reflectivity so that the person regains a sense of his/her agency. To this end, my IPA findings can be translated as particular needs of the dying individual: to remember who s/he is, what s/he has been through, his/her life values and personal philosophy, in short be reminded of his/her identity; or the need to be close to others with kindness and support; or the need to speak about what her/his heart desires most in an imaginary quest of what it might look like ‘after’ her/his death. Working therapeutically along these objectives can offer a rich and empowering experience to the dying individual.

The Critical Literature Review I worked on considers the question that haunted one of my research participants with respect to whether cancer can be considered psychosomatic. With reference to the history of psychosomatic illnesses in psychoanalytic literature, the review concludes that cancer should not be classified as psychosomatic unless we consider all illness as psychosomatic which leads us to an evasive argument that does not contribute anything to our understanding.

The case study I am including here presents the therapeutic work with a woman diagnosed with terminal cancer, who I saw for 12 sessions. The course of the therapy with Amanda [the name is a pseudonym] is analysed with reference to the deployment of two schools of psychotherapy, namely client-centred therapy and systemic family therapy, the principles of which are discussed in sufficient length to show how they can complement each other. I conclude with a critical consideration of the manualised therapeutic interventions for the dying individual that have been devised and I take the position along Van Deurzen (2009) that psychotherapy is more of an art than a mechanistic science.

Part 1: The research

“The subjective experiences of people approaching death, when entering palliative care”

Abstract

Purpose: The purpose of this research is the study of the subjective experiences of individuals who enter palliative care knowing that they are approaching the end of their lives. Posing a research question on death and dying in 2018 is not an easy task. The researcher has to open up a space for her/his question through literature that extends in history and moves through interdisciplinary fields. I found that the idea of the fear of death is a formative central concept for the topic of death and dying that, if followed along the lines of its development, again historically and through conceptualizations from various fields, can provide a coherent and solid review of the topic. Placing the concept of the fear of death under examination enabled me to think about the subjective experiences of people who are facing the imminent end of their lives, in different ways than those suggested by ‘the fear of death’ hypothesis. I ‘bracketed off’ this hypothesis and I was freed to follow the much richer accounts of the present research’s participants in terms of distinct constellations of thoughts, feelings, and emotions that are experienced when leading a life knowing that you are dying, but also of expectations and requirements to be in a certain way, to think in a certain way, and to act in a certain way as dictated by dominant discourses.

Methods: Four participants were interviewed and two methods of analyses were imposed on the participants’ accounts, namely Interpretative Phenomenological Analysis (IPA) and Foucauldian Discourse Analysis (FDA). Special care for their epistemological complementarity was given.

Results: IPA revealed 4 superordinate themes with 3 subthemes each. The superordinate themes are self-presentation, suffering, relatedness and confrontation with death, which, as suggested in the conclusion, can be read as the special psychological needs of individuals who live-with-dying. The FDA findings, on the

other hand, added significant implications on individuals' experience by revealing the hidden powers of dominant discourses on cancer, death, and dying.

Introduction

The idea of the present piece of research stemmed from verbal communication held with members of staff of a Palliative Care Unit in Greece, I was doing my training as a Counselling Psychologist. There seemed to be an 'established' consensus that when dealing with advanced stage cancer patients' issues related to their imminent death, we would witness the fear of death in various configurations in their speech, their affect, and their behaviour. The underlying thought is fairly simple: "we all fear death, therefore the ones closer to its prospect must be experiencing much greater fear of death". From the position I had, where I was in greater emotional contact with these patients -than for instance the palliative care doctors or the nurses- I was gaining a much greater spectrum of emotional responses far richer, much more intense, exerting magnetic capture in their subtle variations, than the expected fear which I felt I wanted to put in words. Without embellishing the situation that would subtract from the pain and suffering -both physical and emotional– that these individuals with advanced stage cancer are facing up to, and without subtracting from the necessitated competences of the counselling psychologist who has to prove that her/his psychotherapeutic work is still of some value to these individuals, I strongly hold that we should investigate in greater detail the projection involved in the line of thought that I mentioned before, that when people are closer to death they are in much greater fear than the rest of us who are not yet in such proximity. This assumed fear works in at least two ways: it differentiates the non-dying from those actually dying, and the fear assumed to be experienced by the dying ensures that they are kept at an obvious distance. The assumed fear is projected onto the dying individuals as an explanatory scheme of their emotional lives. Nevertheless, projection is a defence mechanism whereby one's beliefs, values or other subjective processes are unwittingly ascribed to others (Reber, 1985). As with most defence mechanisms, projection has blinding effects, causing the silence of the other to whom projections are targeted and results in his/her distortion. The 'projected onto' other –in our case the dying individual- is left with no actual interlocutors open and available to him/her who could really hear what s/he is saying.

This is what this project of mine is all about: ‘listening to what the other is saying’, much in line with the mentality of psychotherapeutic literature and practice, much in line with getting to know the other, allowing him/her space to unfold, to speak, to broaden his/her spectrum of thoughts and emotions, and finally to develop as a person. I have studied and practiced extensively systemic family psychotherapy and I must admit that at this very moment of my writing, I realise that all there is to psychotherapy is to enable the individual to shake off other people’s projections, whether these being parents, larger familial systems, institutions we find ourselves a part of from a young age but also when much older, in marriages, in careers, in all aspects of human contact. Enabled by my own psychoanalysis, through training and my private practice, I feel that I have been open to listen to dying peoples’ voices and what they were actually saying, and all that they said I wish to return with this project.

What has been said so far comprises a psychological view on the topic of dying and death. Yet there are other views that will be considered here also: historical, sociological, anthropological even, but most of all the assets from existential philosophy on the topic of death and dying. Gaining knowledge and insights from all these areas will frame a post-modern approach to my topic by coming to appreciate better the history of the prevalent discourses of today about death and dying.

A post-modern approach is achieved by the simultaneous look at the individual level and the socio-cultural level. On the one hand we have the uniquely private experience of dying related to the universal process of our decay, while on the other we have the cultural framing of the experience of the way we have come to think and feel towards death and dying in our present times, in Western societies. Trying to think beyond binaries, the individual or the society, it will be argued throughout that one loops into the other, creating the experience *with* the related discourse/s. Since experience is mediated by the socio-cultural asset of language, we would expect that there is no discourse-free experiencing. On the contrary, discourses constrain how the experience is talked about by providing a context but also the linguistic means in order to be shaped in a particular way.

A conversation between History and Psychoanalysis

The idea of considering the different conversations that different academic fields stage among them, came to me after studying the first part of the *Handbook of Death and Dying* (2003) -edited by C.D. Bryant- which is composed by different chapters written by experts specialising in various areas -such as anthropology, history, psychology, sociology, and religion- and analyse the problematique of death from their own perspective.

The opening chapter of the two volumes *Handbook of Death and Dying* (2003) edited by C.D. Bryant, is written by Moore and Williamson (p. 3-13) –a counsellor and a sociologist- and introduces *fear* as the “most common response of humans to death” (2003, p. 3). Around this central premise the authors’ argument unfolds and they trace it back historically as the explanatory motivation for the development of magic and religion from Christianity to Buddhism and Hinduism, social order and organization, the emergence of philosophy from the rationalisations of death in Greek philosophy coming down to the “obsessive fear of death during the Middle ages” (Moore & Williamson, 2003, p. 9), the return of the belief of a mechanically ordered universe in the era of Descartes and later of Kant, to the search for meaning of the finite life of Existential philosophy. They continue that modernity should also be looked at as “the modern project [which] involves overcoming the historical human impotence in the face of death” (ibid). The “sanitization” of the death of modernity, through the developments in medicine, shows the distance from actual death that present times exhibit by relying on hospitals and other operationalisations for the handling of deaths. This is also another -the modern- way of managing the fear of death. They conclude that “evidence suggests that [all] human progress is indeed ultimately driven by the fear of death” (ibid, p. 11).

There are a number of fallacies in Moore and Williamson’ argument that need addressing. First and foremost, they seem to confound a phylogenetic characteristic of the human species with the fear of death. Citing the anthropologist Becker (1973), the authors agree with him that the fear of death “haunts the *human animal* like nothing else” (ibid, p. 3). Life preservation and fleeing from danger, or else predatory anxiety, are phylogenetic characteristics, biologically automated, common not only to the human species but to all species of living organisms in general. The argument that this automated response qualifies as fear of death, is doubtable and reductive. Fear of death presupposes a degree of conscious awareness and reflexivity characteristic of the human species exclusively, that cannot be subsumed and reduced under a biological reflex.

If this fallacy is resolved and they qualify their position on the fear of death of humans along the conditions of conscious awareness and reflexivity, another one arises with respect to its assumed universality. The argument would hold that all people throughout human history have experienced fear of death in the same way as we, the post-moderns, do. In other words, the emotion of the fear of death is culturally and historically unmediated to the point of assuming it being the same for the entire human species in general. It is difficult to assume this historical and universal continuity especially if we take into consideration historiographies on death such as Aries'.

Aries (1981) –a French historian who investigated the Western attitudes toward death by studying the European representations of death in literary, liturgical, testamentary, epigraphic, and iconographic sources (ibid) from the early Christian era to the present day- distinguished five death models during the last millennium in Europe that exemplify well-defined attitudes towards death. Not only do these distinct historical periods exhibit unique rituals and other artistic social expressions, but they also represent distinct ways by which people living in these historical periods experienced and understood death (Wood & Williamson, 2003). Aries (1981) names '*tame death*' the deeply inscribed, in both the actions of the dying and those present in the death, readiness of the person who was about to die to take the responsibility of his death and allow time for preparation, contemplation and prayer (Wood & Williamson, 2003). Death, in its accepted familiarity and nearness, was taking place in the bed of the dying, surrounded by family members, neighbours, and children. It was not experienced as devastatingly emotional -which is an attitude met in modern and postmodern western societies- but people accepted their imminent end with sorrow to be succeeded by the honest and spontaneous relinquishment from life in front of fate and nature (Aries, 1981). This position of acceptance meant the recourse to the rituals of death and dying, which were simple and familiar, laying death out visibly and publicly. It was a death model dominant in the eleventh century and disappeared completely by seventeenth century.

By the end of the Middle Ages, however, a significant change occurred in the European death attitudes, and was exemplified in ‘the Book of Life’ that was often draped around the neck of the dead and contained a written account of the sins and deeds of the dying individual. Much like “a passport, or rather like a bank book to be presented at the gates of eternity” (Aries, 2009, p. 33), the Book of Life symbolises the increasing relationship “between death and the biography of each individual” (ibid, p. 38). The attitude of ‘*one’s own death*’ is the second historical attitude Aries saw in the European history. By the end of the Middle Ages death and relation to death acquired two important characteristics: the death-bed process acquired a dramatic emotional character, and the importance of the self, along with his/her sins and deeds, for the fate of the deceased emerged.

The late sixteenth century and up until the eighteenth century witnessed the development of *the remote and imminent* death model. It is in this period during which the fear of death arose (Robben, 2004), despite the rise of rationalism, science and technology (Aries, 1981). Death was returning to a savage state (ibid) inaugurating the modern flight from death. At the same time, death because of its newly established remoteness became fascinating: “has aroused the same strange curiosity, the same fantasies, the same perverse deviations and eroticism, which is why this model of death is called ‘remote and imminent death’” (ibid., in Robben, 2004, p. 44). This model is exemplified in the artistic tendencies found in the centuries of the Renaissance (approximately from the fourteenth to the sixteenth centuries) and the Baroque period (approximately from sixteenth century to late seventeenth century) and assigned a meaning to death ‘confused’ with pleasure (Aries, 1981, p. 373). The macabre death becomes a predominant theme in all artistic expressions, revealing extreme complaisance before the spectacles of death, suffering and torture (Aries, 2009, p. 57). From the literature we can read poetry preoccupied with details related to bodily decay, such as the following:

> “There is naught but filthiness,

> Mucus, spittle, rottenness,
> Stinking, rotten excrement.
> Consider the products of nature…
> You will see that each man brings
> Stinking matter, loathsome things
> From his body constantly" (de Nesson, "Vigile les morts", in Aries, 2008, p. 121).

The macabre preoccupation gave way to the Romantic death, of the early nineteenth century, and the birth of intense emotions towards death. In *Jane Eyre* by Charlotte Bronte (1847) we read the following stance towards the imminent death of the character Helen:

> "I am very happy, Jane; and when you hear that I am dead, you must be sure and not grieve: there is nothing to grieve about. We all must die one day, and the illness which is removing me is not painful; it is gentle and gradual: my mind is at rest." (Bronte, 1847, in Aries, 2008, p. 434-435).

The romantic death period witnesses another change in the death model exemplified in intense emotions towards death, now '*the death of the other*' (Aries, 1976/2009). According to Aries, what we see in romantic literature is a historical mentality towards death which is characterized by intolerance for the death of loved ones, the desire for and certainty of reunion with the deceased after death, and finally admiration for death as a phenomenon with intrinsic beauty (Aries, 2008, p. 442). Moving closer to the twentieth century, Aries (2009, p. 67) traces the experience of 'hysterical mourning' as in Mark Twain's (1893) *The Californian's Tale* where a man had never accepted the death of his wife and awaited her impossible return.

The fifth death model according to Aries' (2008) historical analysis is the '*invisible death'*. It is the model of our period, of our times, the modern attitude. Death is medicalised, that is death becomes a technical phenomenon that must be kept out of sight and out of reach and in the wards of the hospital. Mourning for the death of loved ones is shameful and forbidden (Aries, 2009) and should take place in the secrecy of the lonely privacy of the bereavement. Aries notes that the cause of this interdict is the maxim of happiness, “the moral duty and the social obligation to contribute to the collective happiness by avoiding any cause of sadness….by appearing to be always happy, even if in the depths of despair” (Aries, 2009, p. 93-94).

Having reviewed one of the most important and influential works in the historiography of death and dying that is Aries’ *The hour of our death* (1977), I have established in my argument that there is historical variation in the experience of death and therefore we cannot consider fear of death as the sole and predominant response throughout history. As we saw, death had been experienced with familiarity, infatuation, as a beauty, with calmness, but also with exuberant fear and avoidance as is the case in our times. The argument of historical relativity poses questions to be answered by all theories that propose universal models of human functioning. To what extent can we read the fear of death as a universal response? Aries would refute such an argument based on his analysis. But in order to prove the counterargument of the fear of death being socially constructed we must have a look at psychoanalysis in order to clarify the nature of this fear, or else what kind of fear is it?

I consider it important to review the fundamental theses of psychoanalysis upon which all subsequent theories, about the fear of death, rely. Freud studied pathological phenomena and distinguished four fundamental concepts -with their respective functioning in the psyche of the individual- which relate to the fear of death, namely: anxiety, fear, phobia, and the death instinct.

Considering each concept separately and along the chronological order of their development, Freud thought at the beginning that *anxiety* was an alternative mode of release of instinctual energies which were denied expression by the secondary agencies of the psychic apparatus (Boothby, 1991). Morally unacceptable desires were repressed and so were the libido invested in them. Although hysteria can be explained by this model of repression, *phobias* cannot. In phobias it is the anxiety which produces repression, since anxiety is a signal of danger to the ego. In *Inhibitions, Symptoms, and Anxiety* (Freud 1926, SE 20) Freud distinguished anxiety from *fear* in terms of the absence or presence of an object, and accordingly anxiety has a quality of indefiniteness and is lacking a concrete object.

The danger that anxiety responds to, therefore, is not related to a threatening object or situation but more to an overflow of internal excitation (Boothby, 1991), that the threatened ego is called forth to manage. Unless managed, the ego becomes "vulnerable to disintegration" (Boothby, 1991, p. 143). The *death instinct*, on the other hand, was a concept devised by Freud to grasp better those acts that reintroduce anxious tensions to the psyche. These acts include recurrent traumatic dreams, repetitive games by children of painful losses, and the problem of masochism. All three types of symptoms seemed to "indicate an order of satisfaction '*Beyond the pleasure principle*'_ (Freud 1920, SE 18) a paradoxical pleasure in pain" (Boothby, 1991, p. 3), and even more the operation of a fundamental force at the level of an *instinct*. There must exist a primordial drive towards death, Freud (1920, SE 18) conceptualised, that instead of psychological harmony and equilibrium, tends towards conflict and disintegration. Death instinct shares an equal standing to that of Eros -or libido- in the psychic apparatus. It is responsible for all aggression and destructiveness of human beings, who are primarily self-destructive. "Freud was not simply concerned to expose a general tendency toward aggressivity and destructiveness in human beings. The thrust of Freud's idea was to conceive of a force of self-destructiveness, a primordial aggressivity toward oneself, from which aggressivity toward others is ultimately derived" (Boothby, 1991, p. 11) and Boothby continues "to fail to see that it is one's own death that is at stake in the death drive is to miss the point entirely" (ibid).

The Freudian distinctions among the four concepts of *anxiety, phobia, fear***,** and *death instinct*, that I just presented, frame a different understanding of the fear of death than commonly understood. The fear of death is a conscious fear, or a fear we can be consciously aware of. Now if the argument for the universality of the fear of death claims its functioning at an unconscious level, then the ones who argue about an unconscious fear of death are confusing it with the death instinct which is a completely different object. The death instinct operates at the level of the unconscious and when it signals anxiety -which distracts the homeostatic mechanics of the libido- calls for discharge along self-destructive and not life-enhancing ways. Laplanche (1988) supports that before a murderous discharge occurs the unconscious drive is at first instance turned toward the subject aiming at killing oneself. Again, if the argument about the fear of death intends to establish avoidance as a response for this fear, it misses the whole point of the Freudian conceptualisation. Accordingly, the argument of the fear of death cannot claim that it is a universal fear because it cannot function as the death instinct since its response is not avoidance but self-destructiveness. So, the argument of the fear of death must be implying only avoidance as a response which would categorise it at the level of a reflex of our biological constitution.

We saw the inconsistencies of the fear of death argument at the level of Freudian psychoanalytic theory which is presupposed for validation. We saw that according to Freud the fear of death presupposes conscious awareness, which operates at the level of conscious reflectivity (ego functioning), and since it has and targets a specific object as death it leans towards being more like a phobia.

With these two points in mind, the one drawn from Aries on the historical relativity of the concept of death and the Freudian theory that distinguishes the fear of death as a conscious phobia and not a death instinct, it can be seen that Moore and Williamson's argument (2003) for the all-pervasive fear of death in designing the course of human history fails to convince. Unsubstantiated as it is, their argument could be further refuted by counter-arguing that we could equally consider *the will to life* to have been the motivating force of the whole human civilization, which could be better supported by the psychoanalytic concept of sublimation.

A conversation between anthropology and sociology

The complexity of mortuary rites throughout human history and in all societies comes to add to what I argued for in the previous section that there is much more invested of the human psychological economy when facing death than an instinctual fear of death would suggest.

Anthropological research has witnessed great diversity in funeral rituals throughout history and cross-culturally, and there had always been actions showing a certain culturally relative emotion towards the dead who was to be buried. Death places certain duties on the community which the dead person belongs to and this has been a universal response to death throughout human history. We can recall from the beginnings of history the Greek ancient drama of Antigone (Sophocles 442/41 BC), where Antigone defied state law to fulfil the duty of burial to her brother -Polydefkis- and she was punished with the loss of her own life. We can recall and speculate about the ideological structures towards the dead of the ancient Egyptian civilization with the pyramids as symbols of greatness that still impress.

The first interpretation of mortuary rituals as seen through the lenses of anthropology - such as Frazer's (1913) and Tylor's (1871)- was that they established the origins of all religions. In mortuary rituals we find historically the foundations of religions because of the constructs of the soul and the settlement of the afterlife that were devised along these practices. The human mind in the birth of civilization, these anthropologists argued, experienced fear and in the workings of his/her imagination the concepts of soul and of the afterlife were invented. Here we note one of the big fallacies of early anthropology in that in attempting to explain the intense emotional reaction to the death of an intimate, as seen in most cultures, anthropologists assumed common emotional reactions to all humans.

Huntington and Metcalf (1991) warn us against assigning universal values across different cultures. We have to be cautious in doing that because as Durkheim (1965) emphasised, the complexity of the collective life out-powers the individual. Instead it would be more consistent to restrict ourselves in speaking about common practices across cultures. A legitimate position, accordingly, would notice that *weeping* when confronted with deaths is such a common practice. The extent to which, however, we could assume the same emotional experience is doubtful.

Radcliffe-Brown (1964) studied weeping in the secluded Andaman islanders and noted how wailing had a certain symbolism across different occasions, which was socially imposed as mandatory for all members of the ethnic group. Further, he argued that it was the very practice of weeping that would lead the participants to feel the appropriate emotion and not the other way round. He wrote, in particular:

> "…ceremonial customs are the means by which the society acts upon its individual members and keeps alive in their minds a certain system of sentiments" (Radcliffe-Brown, 1964, p. 324, cited in Huntington & Metcalf, 1991, p. 27).

On the same line of argument as that of Durkheim's (1965) who stressed that emotional reactions to death do not replace structure but on the contrary result from structure, Radcliffe-Brown (1964) supported a sociological theory with an empirical base in contrast to that of Tylor and Frazer. The origin of all religion was not to be explained by reference to a universal emotional system that unfolds when people confront death, but "men create[-d] eschatology to rationalize their ritual behaviour at mourning" (Huntington & Metcalf, 1991, p. 33). In other words, according to Radcliffe-Brown (1964) the social rituals of a community should be investigated for having produced the elaborate religious rationalisations, and not a trans-historical and universal emotional system as assumed by the fear of death argument.

To relate back to my original question about the necessity of experiencing fear of death as a trans-human and trans-cultural reaction, anthropological findings reply negatively. To support further, the study by Geertz (1960) on a Javanese tribe noted that the proper emotional state at funerals was affectless, not showing any great terror against death and being able to handle it with little anxiety. With all these in mind we are led to agree with Huntington and Metcalf that:

> "although we [can] clearly recognise emotions that are familiar to us, the range of acceptable emotions and the precise constellation of sentiments appropriate to the situation of death are tied up with the unique institutions and concepts of each society" (1991, p43).

Accordingly, the theories of anthropology that have been mostly influenced by psychology and psychoanalysis such as Malinowski's (1925), Becker's (1973), or Lifton and Olson's (1974) and have used as their fundamental premise the fear of death commit the fallacy of evolutionism, inherited to them since the beginnings of the demarcation of anthropology. Evolutionism locates one's own society at the peak of human development (Fabian, 1973) and accordingly the researcher who commits this fallacy sees other cultures through the lenses of his/her own cultural specific ideas and values and interprets them not in their own light but with reference to his/her own cultural values. In this line of thought, the fear of death thesis should be considered as such an evolutionistic thesis. Not only evolutionism, but also the fact that even psychoanalysis can be considered a product of our times and our western culture, we cannot hold its assumptions as pertaining to all cultures and at all times without running the risk of applying them retrospectively and therefore being easily refutable.

But even if we do apply the insights from psychoanalysis in explaining phenomena such as death and dying in other cultures, as we said in the previous section there seems to be confusion around the use of the concept of the fear of death -as of conscious or unconscious awareness- that hinders our understanding of the concept. To recapitulate, Freud spoke of an amorphous anxiety as the signal of the unconscious operation of the death instinct; its employment, now, as an explanatory concept by anthropology, presupposes its manifestation in the consciousness, which would counter the assumptions of the Freudian theory. Moreover, are we to assume in addition that the only manifestation of the death instinct is as a fear of death? That is another point that needs further elaboration and clarification as it shakes the anthropological argument.

Malinowski (1925) was perceptive of that problem and added that the universal fear of death should be complemented by an equally universal denial of death through beliefs in immortality, religion, and the eternal spirit. He combined psychoanalytic theory with ethnographic data and he came up with a theory about the birth of religion out of a conscious experience, such as the view of the body which is no longer alive. The sequence in his thought must have been that the view of the dead body created fear which had to be soothed by the creation of ideas that negated the finality of this sight; a process that must have been performed consciously, however.

Becker (1973) undertook the project of designing the trajectory of how the fear of death became unconscious through repression, assuming that if left conscious it would have paralyzing effects on people' evolution. We can see the confusion between a conscious and unconscious fear of death in Becker's argument since he claims that at some point this fear must have been conscious and cultural processes lost in history repressed it. Lifton and Olson (1974) also consider the belief in immortality as a universal response to the fear of death and proclaimed various different modes that have been devised towards symbolic immortality, ranging from biological immortality (the production of offspring), creative immortality through knowledge and the arts, to theological immortality with beliefs in resurrection or rebirth. Again, it could be counter-argued that any other concept -such as the will to life- could stand up for all these cultural developments equally well.

A conversation between philosophy and existentialism

The review of the anthropological debate over the fear of death led me to the study of the philosophical arguments and systems of thought that western societies throughout history have devised in dealing with death. Having cleared up the distinction between a conscious and unconscious fear of death, I will focus on the theorisations of the conscious fear of death through the lenses of philosophy.

The meticulous argumentation of philosophical inquiries throughout western history has come up with important systems of thought about death, which will be considered here. I will start with the Platonic theory from Ancient Greece and the choice for doing so and to not include the Pre-Socratics or other ancient schools of thought from other parts of the world is based on the fact that they are not as systematic, complete, and concretely philosophical as Plato’s theory. Plato inquired into, via the philosophic questioning of Socrates, definitions of particular excellences such as courage, soundness of mind, piety and more, in his attempt to show that ignorance is the reason for all wrongdoing. Building up from the content of our sensations, Plato abstracted more and more till the point where no more abstraction was possible. “What is piety?’, ‘What is beauty?’ or ‘What is equality?’ were a few of the questions he asked and which he answered by reference to the ultimate abstractions, to the ideas, or the Forms, that are the unchanging, irreducible ideas of things reached only through the intellect. Kraut (1999) describes succinctly how Plato’s thought evolved about the Form of Beauty (*Symposium*):

> “One develops a love for this Form by ascending through various stages of emotional attachment and understanding. Beginning with an attraction to the beauty of one person’s body, one gradually develops an appreciation for the beauty present in all other beautiful bodies; then one’s recognition of the beauty in people’s souls takes on increasing strength, and leads to a deeper attachment to the beauty of customs, laws, and systems of knowledge; and this process of emotional growth and deepening insight eventually culminates in the discovery of the eternal and changeless beauty of Beauty itself” (Kraut, 1999, p. 711).

Plato’s metaphysical theory about death starts at about here. People’s souls contain the knowledge of Forms, of the abstract ideas and accordingly through questioning they can recollect what they once knew and forgot. Death, now, by separating the body from the soul, the body with its perturbations from the soul which contains all possible wisdom, should not be feared but on the contrary should be looked at with “an attitude of fearlessness and hopeful anticipation” (Taylor, 2003, p26).

Hellenist Epicurus (341-271 B.C.), another important and highly influential philosopher for his understanding of death, introduced a ‘sophism’ (Gkikas, 1985) according to which humans should not care about death as there is no death when we are alive and when we are dead we cannot reflect upon the fact that we are dead. His argument was based upon his empiricist theory of knowledge whereby our sensations as stimulated by thin layers of atoms of external objects become the sources which guarantee reality and truth. As in the situation of death we will not have our sensations intact, we will not be able to have knowledge of that reality. In other words, since we cannot know anything when dead we are not justified in worrying about what comes after death. The soul perishes when the body dies (Yalom, 2008). There is no soul independent from the body. All there is, is knowledge through sensations and that which had been called soul does not have abilities for knowledge, therefore it cannot exist. The fear of death should not be of concern to us as there is no way we can perceive of death when alive.

Implicit in his theory of knowledge is his system of arguments about ethics. Epicurus preached hedonistic ethics (Sedley, 1999) with pleasure being our innate natural goal and pain the only evil we will experience in life. The goal of philosophy is to show how pleasure can be maximized (‘the Epicurean good life’, ibid, p270) and pleasure becomes more secure through a simple way of life that minimizes the chances of pain. In this line, thoughts about death and immortality cause anxiety in the human soul and should be avoided.

With the widespread flourishing of Christianity the problem of death acquired its full metaphysical treatment. Philosophy lost its prerogative over the issues of good life and death. Christianity, equally with all other religions, settled these matters with the promise of an afterlife and the immortality of the soul. During the Middle Ages the question of the body and its relation to the immortal soul entered the picture of Christian theology formulated into the idea of the resurrection of the body (Taylor, 2003). St. Thomas Aquinas (1225-1274) supported the resurrection thesis where at some point in the future the body will be resurrected and reunited with the soul “and at that time the person is reestablished and enjoys eternal life through the grace of God” (Taylor, 2003, p27).

More and more the issues related to death started to revolve around emotions -and in particular around faith- while they were distanced from knowledge. Consolation became the main target and not the consistent argumentation. “Faith is … a matter of the heart, not of the soul” writes Taylor (2003, p27) in describing these periods of human thought that discovered consolation in faith and with it strong emotional images about reunions of the soul with the body, of the deceased with other loved ones, of the deceased with a Divine Being who frees and consoles from earthly suffering. This will be the starting point for the philosophical tenet of existentialism to be found much later in time in the history of philosophy.

Much like the debate between Platonism and Epicureanism, the history of Western philosophy witnessed another similar debate -before the birth of existentialism- the well-known debate between rationalism and empiricism. This debate, prevalent mostly in Anglo-Saxon philosophy, has its roots in the philosophy of Descartes (1596-1650), whose doctrine of “I think, therefore I am” (Meditations, 1641) establishes the dualism of body and mind -as two separate and distinct entities- as the main proposition of the debate. Through the method of the doubt, Descartes came to see that the testimony of the senses can deceive us; what he cannot doubt about, however, is the fact that something which is called ‘I’ does the thinking and accordingly must exist. It is upon this ‘I’’s abilities, its thinking which cannot be doubted, that the whole of true and reliable knowledge can be built up.

On the contrary, the empiricist tradition, which found one of its main representatives in Hume’s (1711-1776) writings, is highly skeptical of unobservable entities such as the mind and the soul. His position is that our ideas are copies of impressions we receive through the senses, while our experience of our mental faculties for which we have no sense impression are a variety of mental states -such as intellect, judging, willing, doubting, and emotion. We have no impression of a separately existing substance that supports all these mental activities (Taylor, 2003) and accordingly there is no ground for supporting that such a thing as the mind or the soul exists. Hume’s skepticism questioned further the arguments about the immortality of the mind or of the soul. It is an impression received from the senses that everything in the universe is subject to change and even more to decay. On which grounds could we suppose that the mind or the soul could violate these universal principles? Hume’s reply was that “judging on the basis of experience, we ought to conclude that the fate of all else within the order of nature befalls what we call mind or soul as well. When the body dies… so do we, including our mind or soul” (Taylor, 2003, p30).

It seems that the arguments of Descartes and Hume are much more refined versions of the old binary about the supremacy of the body in knowledge or the supremacy of the mind (or the soul), as inherited by the philosophy of Plato and Epicurus. And the critique of Existential Philosophy has been exactly this that traditional philosophy ignored the philosophy of subjectivity to the benefit of a philosophy about the universe or a philosophy about the products of the mind (Mounier, 1988).

Existentialism, on the contrary, is the philosophy of subjectivity. What existentialism proposes is a refocus of philosophy on human existence, the ‘being’ of the humans. “Philosophers and scientists emptied the world from human existence” (Mounier, 1988, p. 199), emptied the world from that which exists before it comes to know, Kierkegaard (1841) argued against Hegel and his philosophical system which objectified human subjectivity. The primary duty of philosophy is to awaken the human subject from the ‘sleep’ (Mounier, 1988, p. 200) of having been an object of philosophical and scientific investigations. And when the human subject awakens and looks at himself/herself existentially, he/she sees the contingency of his/her being in that there is nothing that binds his/her existence with any kind of certainty. The existential subject, contrary to the subject of the idealist philosophies, is not in accord with nature, the god, or the Absolute. The existential subject works hard to find order and meaning:

> “Any order and meaning, if there are to be any, must be created by individual effort and resolve, and created anew by each individual all the time” (Gray, 1951, p115).

This capacity as well as the duty of the being of humans is the quality of transcendence that Heidegger (1962) spoke about as the essence of Dasein.

Abandoned in a contingent world, the human being is shaken by existential anxiety that s/he is constantly trying to shut out, plunging himself/herself into the in-authenticity of everyday life. For Jaspers (cited in Gray, 1951, p. 118) there are ‘boundary situations’, however, in a person’s life that are inescapable and constitutive for a genuine life. The boundary situations lead the individual to the realisation that everything depends on him/her, welcomes this unaided and unconsoled way of being, accepts that genuineness is not fulfilment (ibid, p. 121), and opens up to a way of living where intensification and clarification of life’s possibilities from moment to moment is adhered to. These boundary situations are our confrontation with feelings of guilt, with experiences of suffering, in cases of conflict, confrontations with chance, and of course our confrontation with our own death. From all boundary situations the most extreme confrontation is with our own death:

> “the painful fact of human finitude, the inevitability of death, can alone make living meaningful and significant” (Gray, 1951, p. 118).

Heidegger (1962) emphasised even more that our mortality can be regarded as a fountain of possibility and potentiality. Confronting our own death springs up ‘existential dread’ (Jaspers, cited in Gray, 1951, p. 120) -*conscious existential dread* as to relate back to my question that had been central throughout this literature review. The common way of reacting to this dread is through an escape from this truth, towards making it a public event, something that happens to everybody indiscriminately: “we strive to make death just another event among many” (Gray, 1951, p. 120) and we get lost in the impersonal “the They”, or the impersonal others. It is an escape from our personal responsibility, blunting all this intense conscious feeling, which when open to experience in full can lead the individual to authentic existence. Being-unto-death is a way of life that first of all isolates from the impersonal “the They” and throws the individual back to himself/herself, “it offers him the possibility of becoming a personality” (Gray, 1951, p. 123). Becoming a personality means living with resoluteness, the resoluteness of leaving behind “the banality of existence in society” (ibid, p. 124) and reaching that point of self-understanding and self-knowledge that individual existence must be given meaning through one’s own efforts.

A conversation with psychology

Even though existentialism taught the necessity for an individualised response to the dread of existence when facing death, psychology operationalised the concept of the fear of death in order to speak about percentages in the general population. Subsuming without differentiation under the same heading anxiety, fear, and threat in relation to death, research on attitudes towards death has brought about a great number of assessment scales that assess “the fear of dying and/or death as a relatively stable personality disposition (trait)” (Neimeyer, Moser, and Wittkowski, 2003, p. 47). The distance between psychology and philosophy is more than evident; whilst philosophy analyses a particular existential situation such as the experience of dread in the face of death, psychology generalises to all people the experience of the fear of death, making it a personality trait with varying degrees of intensity and discomfort. It is neither guided by any theory (Neimeyer, Moser, and Wittkowski, 2003, p. 47) and no definition or course of emotional events are explained.

Psychology, by subscribing to being a science, adopted the mechanics of science with neglect for consistent foundation at the level of theory. We saw earlier in this introduction how consistent psychoanalysis had tried to be with respect to the conscious fear of death and unconscious anxiety in relation to death. We saw in my discussion of existentialism its deep rooted theoretical discussion with philosophy in its history that gave rise to a new concept that is the existential dread toward death. Psychology (mainstream psychology, that is) aspiring to reach the status of science, embraced statistics in order to be able to speak about large numbers of the population and accordingly fell short of constructing fine distinctions in its objects of study. The claim for a scientific psychology was a product of the twentieth century which noted the birth of demography, as Foucault (1979) pointed out. Demography, or the statistics of the population, does not only count and predict births and mortality, life expectancy and longevity, but imposes the mentality of uniformity across the whole population: we people are similar, countable, and predictable.

It is important that we take a closer look at the questions that compose various ‘fear of death’ scales in order to proceed with my analysis of psychology’s research on attitudes toward death. The first scale to be devised to measure fear of death was *The Death Anxiety Scale* (DAS) by Templer (1970), consisting of 15 true/false statements of the type “-I am very much afraid to die” and “-The sight of a dead body is horrifying to me” (cited in Neimeyer, Moser, and Wittkowski, 2003, p. 49). Due to problems in the interpretation of scores the DAS scale had been devised and largely replaced by *The Revised Death Anxiety Scale* (RDAS) of Thorson and Powell (1994). It is now a 25-item scale, where the respondent confirms agreement or disagreement on a 5-point scale. The statements included are of the type “-I am not afraid of a long, slow dying”, “-Never feeling anything again after I die upsets me”, and “-I am looking forward to new life after I die” (ibid. p. 38). *The Collett-Lester Fear of Death Scale* (CLFD; Collett & Lester, 1969) is composed of four subscales and differentiates fear of death from the process of dying, both subscales attributed to the self and to others. It is a 36-item scale rated according to agreement on a 6-point Likert scale. Sample statements include: “-I would avoid death at all costs” (Death of Self subscale), “-I would avoid a friend who was dying” (Dying of Others subscale), and “-The pain involved in dying frightens me” (Dying of Self subscale) (cited in Neimeyer, 1994, p. 58).

Death attitudes research moved gradually into the construction of scales that are based on more theoretically consistent grounds, such as *The Threat Index* scale (TI) by Krieger, Epting, and Leitner (1974) which is based on Kelly's (1955) personal construct theory. The index utilises the basic ideas of Kelly's Personal Construct Theory (ibid) whereby the goal of a person's living is to accurately anticipate events in the world through the use of bipolar personal constructs. The index attempts to assess the extent to which a person's construct system is structured to anticipate death, and it is argued that: "death would be threatening to a person in proportion to the amount of systematic reorganisation that would be necessary in order to construe death as a personal reality, as part of the self" (Rigdon, et.al. 1979, p.247). Another important theory-led scale is *The Death Attitude Profile-Revised* scale (DAP-R) of Wong, Reker, and Gesser (1994) which is a 32-item scale in which the respondent indicates agreement or disagreement on a 7-point Likert scale. Statements included are of the type: "-I believe that I will be in heaven after I die", "-Death should be viewed as a natural, undeniable, and unavoidable event", and "-Whenever the thought of death enters my mind, I try to push it away" (cited in Neimeyer, 1994, p147). DAP-R utilises the existentialist perspective on the fear of death whereby we are motivated to pursue personal meaning (Frankl, 1965), with the developmental stage theory of Erikson (1963) and in particular the late adulthood stage of 'integrity versus despair', and Kubler-Ross's (1969) trajectory in accepting death stage theory. The DAP-R scale identifies three distinct types of death acceptance based upon life-views: neutral acceptance asserts death as an integral part of life, approach acceptance implies a belief in a happy afterlife and accordingly assesses religious beliefs, and escape acceptance of death as a resort away from life's pain and misery.

What have we come to know through the complex research designs that the administration of these scales have generated? First of all, that age was not found to be a significant correlate of death anxiety (Pollak, 1979), but rather it is dependent upon the severity of physical health problems, history of psychological distress, weak religious beliefs, and low personal resilience (Fortner & Neimeyer, 1999). Gender, also, is unrelated to fear of death even for older adults (ibid). The elderly exhibit less fear of death and dying as compared to middle-aged people (Gesser et.al. 1987-1988). With respect to illness and fear of death, studies have found no direct relationship between levels of physical well-being and fear of death (Baum, 1983, Baum &

Boxley, 1984), no substantial differences between psychotic patients versus neurotic patients on death anxiety (Feifel & Herman, 1973); also, deep religious commitment (Bivens et.al., 1994) and the belief in the afterlife (Ochsmann, 1984) ameliorate conscious fear of death, whilst persons who accept death as a natural part of life express less intense fear of dying and death (Tomer & Eliason, 2000).

The knowledge we gain from death attitudes research is more or less general statistics that do not enlighten any further than commonsensical understanding. There is nothing wrong with commonsensical understandings of phenomena and social representations methodology take them very seriously (Moscovici & Markova, 1998), but they are not posed as objective truths as attitude research aspired to claim of them. In particular, however, attitude research, as Potter and Wetherell (1987) argued, faces broad difficulties that are not easy to overcome. Firstly, attitude research relies upon decontextualised utterances which are put forth for agreement or disagreement. For instance the statement from the DAS scale "-The sight of a dead body is horrifying to me" is to be answered without any reference to context. One respondent might relate to having viewed a loved one dead and answer negatively while another might relate to an unfamiliar dead body and respond positively. Potter and Wetherell warn us that even a small amount of additional information about the context "can throw into question what, at first, appears to be reasonable interpretation of a person's utterance" (1987, p48). Attitude theory is indifferent to context because it assumes that there is such a thing as 'an attitude', an enduring and underlying mental entity, which is consulted when persons are asked to talk about it or will behave in accordance with it when situations allow. Discourse analysis, on the contrary, has shown that we deploy discourses -and not attitudes- that are not necessarily consistent and coherent (Potter & Wetherell, 1987, p. 49), but function, or do things in our communication with others. To illustrate, from the CLFD scale the statement we read: "-I would avoid death at all costs" and it seems difficult to imagine how it could be answered favourably or not. There are hidden assumptions, as Potter and Wetherell (1987) would suggest, for example, that we usually avoid what we most fear, in this case death. Nevertheless, an advanced cancer patient with unmanageable pain would respond negatively as s/he would be looking forward to their end with an aspiration for pain relief, while s/he might respond positively if s/he was pain free. Variability of accounts is not taken into consideration by the decontextualised scales of assumed static and constant attitude research. Moreover, attitude research assumes that an attitude is separate from the 'object of thought', that is the object of thought to be studied is assumed to be a simple and already present entity. Discourse analysts, on the contrary, have seen that the very object of research is formulated and constructed within discourse (Potter & Wetherell, 1987, p. 51), and the produced accounts usually intermingle description, explanation and evaluation (ibid, p. 52) making it impossible to distinguish the object of thought from the offered judgment about it. Potter and Wetherell warn that if a researcher wants to investigate a social phenomenon, s/he should be attentive to "how description and explanation are meshed together and how different kinds of explanations assume different kinds of objects or supply the social world with varying objects" (1987, p. 52).

The shortcomings of attitude research and of the 'technology' of measurement, to recapitulate, are their complete disregard for the *context* within which a statement from a questionnaire will be understood, that attitudes are assumed as independent entities to be simply described while it has been shown how *intermingled* they are with evaluations and explanations and accordingly cannot be considered stable across situations, the doubtful *translation* of respondents' replies into the analysts' categories, and lastly, the *variability* of the produced accounts in terms of what the deployed discourses intend to do.

So where do we stand in terms of the fear of death concept and the conversation with psychology I just concluded? Potter and Wetherell's (1987) critique of attitude research falls heavy upon the ambitions of the 'technology' of measurement. Not only are there limitations at the level of the construction of the various scales but more so there are distortions at the level of the knowledge we gain. Without context and without considering variation the returned knowledge is distorted and not objective or verifiable as it claims to be. The 'turn to discourse' paradigm in psychology and radical research since 1980s, on the other hand, had as its effects a swift turn to the study of how scientists talk about what they do (Parker, 2015, p. 2), and a gradual but steady disregard of the human subject. Parker (2015) wonders whether psychology and psychological knowledge since deconstruction are nothing more than endless processes of critique. There seem to be a complex problem to be resolved by the principles of contemporary psychology.

Discourse analysis tends to resist the temptation of building up a new ‘social psychology’ that would rest on more secure foundations (Parker, 2015). As a result, however, with the ‘new paradigm’, especially after the predominance of post-structuralist theory, a form of ‘anti-humanism’ emerged (ibid, p. 3) which is dismissive of agency or of the struggle individuals undertake in order to make meaning. Parker (2015) notes that the deconstruction introduced by the social constructionist and discursive movements in psychology reversed scientific priorities. He argues that in order to claim a status of scientific knowledge contemporary research in psychology should become attentive to three aspects about its practice. Firstly, subjectivity needs to be understood much more broadly than a distant, simple and voluntaristic entity. Our assumptions about subjectivity should be looked at with a question mark (or ‘under erasure’) and we should also include understandings about the kinds of subjectivity discourses allow, or how the interaction with the researcher facilitated or blocked the research process. Secondly, we should be cautious of our interpretations as they are guided by implicit theories of the self and the world we should become conscious of. Thirdly, we need to be attentive to the “way knowledge is intertwined with power” (Parker, 2015, p. 26) becoming able, that is, to critically evaluate the knowledge we produce. Important researchers who conceptualise psychological research along these lines include the works of Harper’s (as in Harper & Thompson, 2011), of Reavey’s (as in Cromby, Harper, & Reavey, 2013), or of Frosh’s (as in 2010).

A conversation with existential psychotherapy

By opening up a conversation with existential psychotherapy, I intend to touch upon that aspect of psychological theory and practice that usually stands apart from mainstream psychological research. The focus here is subjectivity per se; the struggles of the subject to relate to the world of meanings and produce something meaningful for himself/herself. I will focus here on the clinical setting of psychotherapy in order to have a closer look at the more intimate manifestations of a concept such as the fear of death. Existential psychotherapy is not a consented upon specific therapeutic practice, but many different therapeutic practices have evolved out of the meticulous study of existential philosophy. I will focus on the American Existentialist School and mainly on Yalom (1981, 1987) because he talked extensively about our confrontation with death, and on the British School of Existential Analysis and its leading representative, van Deutzen (1998, 2002a), whose views on human life are stimulating and can be enlightening when confronting death.

According to the American Existentialist School psychological difficulties arise out of internal conflicts with the ‘givens’ of existence (May & Yalom, 1989). According to Yalom (1981), these ‘givens’ of existence are the inevitable and inescapable confrontations the individual will have in the course of his/her life with death, freedom, isolation, and meaninglessness. The fact that we will die, the fact that we are free and the sole responsible ones to design our own lives out of groundlessness, the fact that we can reflect and see our ultimate isolation –our loneliness- despite our wishes to relate to others, and the fact we must construct our own meaning for our lives, these all are substantial and formative experiences in everybody’s life with unique implications for each one of us and our trajectories. Not all of us are courageous enough to resolve these confrontations successfully and it is here that problems of psychopathology arise.

More importantly, it is our confrontation with our death that can cause insurmountable difficulties to our emotional well-being. The terrible truth of our private, un-sharable, inevitable death is the ‘terror’ (May & Yalom, 1989, p. 377) that, unless transcended leads to psychopathology. “Symptoms and maladaptive character structure have their origin in the […] terror of death” (ibid), and accordingly, for existential psychotherapy the individual is fearful of and suffers from the awareness of this ultimate existential truth. The fear of death constitutes a primary source of anxiety: “it is present early in life, it is instrumental in shaping character structure, and it continues throughout life to generate anxiety that results in manifest distress and the erection of psychological defenses” (ibid). The existential therapist tries to alleviate these “crippling levels of anxiety” (ibid, p. 388) but not eliminate them. Life and death cannot be faced without anxiety; the question in therapy is to use this anxiety constructively.

Van Deurzen would doubt Yalom's (1981) overemphasis on the fear of death as the primary source of anxiety which exerts formative forces upon the entire personality structure of the individual. She would consider death among the life challenges, among the tensions that we meet in life. To dispel the anxiety produced by the tensions met in life, individuals try to lose themselves in the certainty of shared cultural practices fantasising about a perfect and problem-free life (Cooper, 2012, p. 110). For van Deurzen (1997) psychological difficulties are but self-deceptions, products of misguided philosophies of life (Cooper, 2012). The aim of existential therapy, according to van Deurzen (1997), is to help clients face up to the reality of their situation, resolve their self-deceptions, and come to terms with life in all its contradictions: "to immerse themselves in life rather than evading their troubles" (Cooper, 2012, p110).

The existential psychotherapist relies upon three fundamental principles about human nature. Human beings have capacities and they should be trusted when working therapeutically. The first principle of existential psychotherapy is the belief in the capacity of human nature to create meaning and order (van Deurzen, 2002) in spite of life's unpredictability and meaninglessness. The second principle is the belief that human nature has internal flexibility and is able to find direction and motivation even when facing up to existential 'givens' or limitations (ibid). The third principle stems from the belief in the capacity of human beings to live constructively and be creative within their existential limitations without losing ground and contact with reality (ibid).

According to existential psychotherapy, the fear of death is conceptualised very differently from the conceptualisations we have met so far. The fear of death is manageable, tameable, allowing for unique resolutions when confronted. It does not carry with it the austerity of philosophical definitions. It is not as incapacitating as the fear we meet in history, in anthropology and in sociology. It is a conscious fear, not as in psychoanalysis, of which we can become aware of and do something actively about. It is in this space that is opened up within the system of thought of existential psychotherapy that research questions can be posed affording the necessary freedom to the individuals to come up with unique resolutions in their confrontations with this 'given' of existence. Especially when death is not a distant possibility projected in the future but much closer, as in the case I want to study, the principles of existential psychotherapy kindles hopes that a lot more can be found other than fear towards death. And this is so because individuals struggle for meaning, can show personal direction even in the worst of situations, but most of all they are able to bear meaningfully even their own imminent death.

As this review predicts, prevalent ways of talking about death, or ‘discourses’, are also to be met in the speech of dying individuals. According to contemporary discourse analysts we are spoken by our cultures and their languages equally well as we are speaking (Lupton, 2012). Discourses provide the means for making sense of a phenomenon, they are all these abstract principles that define a phenomenon, and they are embedded in our historically specific cultural settings. But even within these determinations, individuals can create something of their own, that will speak of their own individuality and of their unique situation, and this research project allows this space for the individual to be unravelled.

Concluding argument

From what has been discussed so far I have established the following premises with respect to the argument about the ubiquity of the fear of death:

Premise 1: Fear of death is not a historically unchanged given. Reliable historiographers (e.g. Aries, 2008) who investigated death in the Western world found that fear of death can be traced fairly recently in history, since the 19th century and onwards.

Premise 2: Fear of death is not a psychologically universal given either. I pointed out the misunderstandings of the Freudian theory (1920, 1926) with respect to conscious or unconscious fear of death. If unconscious it is not fear but anxiety, and if conscious it would fall more under the category of phobia since the object of death is definite.

Premise 3: Fear of death is not an anthropological given even. Fairly recent anthropological arguments (i.e. Huntington & Metcalf, 1991; Fabian, 1973; Radcliffe-Brown, 1964) emphasise that we cannot claim a universal emotional system but historically relative communal or societal practices that give rise to specific emotions.

Premise 4: In the history of philosophy, death and related to death emotions had received various explanations (i.e. Plato, or Epicurus). Historical trajectories detached death and related to death emotions from the faculties of knowledge and became matters of concern of religious faith.

Premise 5: Fear of death became a matter of philosophical concern with Existential Philosophy (i.e. Kierkegaard, 1841; Heidegger, 1962). The consciously experienced anxiety that accompanies the awareness of our mortality can change a whole life course towards authenticity.

Premise 6: For psychology the fear of death is a universal human emotion that can be measured and the results can be compared between them. Attitude research, however, by looking for unchanging mental entities, consistent and coherent, independent from context or interaction, is not able to live up to its aspirations and accordingly its project is undermined and doubtful.

Premise 7: For psychotherapy and in particular existential psychotherapy, confrontation with death can open up possibilities for grounding a more realistic way of living, away from self-deceptions.

From all of the above, I would argue that death should be seen as socially and culturally constructed and so are death related emotions, such as fear. Much like a ‘cultural ethos’ (Geertz, 1973), every society in history has a distinct culture which includes a ‘death ethos’. “Death ethos” (Kearl, 1989 cited in Hayslip, 2003) is a culture’s stance towards death and death related issues, and it is composed of a variety of discourses, understood by all its members. It is reflected in the linguistic repertoires of a culture, in its entire societal practices, in activities and settings which embrace death.

Pursuing a research on death and dying in 2018 means adhering to an ‘epoche’ which has gained the strength to look upon the issue of death. Around the 1950s and with the silence-breaking writings of Gorer’s (1955) death as pornography, of Feifel’s (1959) psychological perspective on the repression of death, and Aries’s (1974) historiography on Western attitudes towards death, we witness a significant turn in the history of Western civilizations with respect to death: the dominant regime around death was revealed and spoken about. It was the regime of silence and hiding of death, of a privatized death restricted to the immediate family, of the lonely and isolated dying person, who would be attended by medical specialists while s/he would die in the premises of the hospital. The bureaucratised, medicalised and hospitalised death came to be considered since then as a “dehumanised” death (Prior, 1989, p5). The dominant discourse of death was constituted by the social processes of the entire array of legal, religious and political practices, characteristic of all those processes being the condemnation of the dying in loneliness and silence. Living in a body that belongs to medical science and shorn of his/her sociopolitical existence, the dying individual was caught up in a disadvantaged discursive position compared to the living.

Prior (1989), adopting Foucault’s analysis (1979), argued that to claim that death was hidden for most of the 20th century is to ignore that at least three disciplines focused on death throughout the century, namely: demography, pathology, and sociology. Demography considers death as rates of mortality and comes up with statistics around and about the fate of the species (Prior, 1989, p7). Pathology deploys the body as a machine metaphor and “this isolated, detached and mortal machine was viewed as a thing to be treated, reconstructed, repaired, improved, and acted on" (ibid, p9). Sociology, lastly, studied death -and in particular suicide- under the prism of social causation attempting to come up with objective law-like regularities of human affairs in its entirety. To be more accurate then, according to Prior (1989), the 20th century offered objective and scientific data about mortality, disease, and death causation but nothing was mentioned about the meaning of the world or of the objects within it (Weber, 1948, cited in Prior, 1989, p11). What was historically witnessed from the 1950s and onwards, in other words, was a refocus of the object of death from being a study on objective mortality towards the subjective "examination of the meanings and sensibilities of those involved in the processes of death and dying" (Prior, 1989, p11).

This turn towards the dying individual and the uniqueness of his/her experience which has been noted in history since the 1950s will be looked at in the following section. Particular emphasis is given to the most recent qualitative research on the subject because this will assist in framing my own qualitative research questions and also because the latest research on the field is primarily qualitative, revealing a turn in the focus from quantitative to qualitative, in trying to gain, in other words, an insider's perspective on the phenomenon.

Literature review of research into the experiential phenomenon

A review of research on the experience of living whilst knowing that dying is imminent, reveals not only important but also ambivalent findings. The study of Wrubel et.al. (2009), that utilised narrative analysis on the accounts of individuals who were asked about how they lived their lives with terminal illness having received a prognosis that ranged from about six months to one year of life, brought about an interesting finding. Participants split almost in half (n_1=19/32 and n_2=13/32) with respect to whether they experienced their lifeworlds uninterrupted and interrupted in dealing with the fact that their lives would soon come to a closure. This finding is important since it reveals a binary in the very experience of living knowing that you are dying: either the individuals will experience their lifeworld uninterrupted and maintained as exemplified in maintaining relational ties to their close ones, holding onto spiritual concerns, setting specific goals and continuing to work towards them, or they will experience their life interrupted. And it is a finding that perplexes the literature which was founded upon the premise that the end of life phase imposes distinct challenges on all aspects of the human biopsychosocial functioning. If that is the case then we should expect unanimous reactions of lifeworld disruption, much like Bury (1982) has predicated for the experience of serious illness as it becomes a landmark in any person’s life. What is intriguing in the research of Wrubel et al. (2009) is that almost half of the participants did not experience imminent death as upsetting, disrupting, or devastating. There seems to be something of a different quality in the topic of death that we investigate other than unanimous reactions. Rodin and Zimmermann (2008) speak openly about the ‘unique opportunities’ (ibid, p.181) that might be triggered in a dramatic alteration of a life course, and accordingly the end of living experience may facilitate “a process of constructive transformation” (ibid, p182); the phenomenon has been extensively studied by Tedeschi and Calhoun (1995) and named ‘posttraumatic growth’.

Recapitulating, between unanimous reactions and individual uniqueness lies a continuum of experience that a lot can be worked out and negotiated both at the level of the individual but also at the level of interaction with others, with society, with culture. It is the aim of my study to unravel the qualities of the dying experience when looked at from the perspective of the individual who is about to die, but equally so when the phenomenon is seen from the perspective of prevalent discourses specific to Western societies of 2018.

Considering each perspective separately, phenomenological studies reveal important experiential dimensions for the individual who lives knowing that her/his end due to terminal cancer is approaching. The meta-synthetic piece of research of Willig and Wirth (2018), studied the most recent (between the years 2011-2016) researches (n=23 studies with 318-332 participants) on the phenomenon and came up with the following experiential dimensions of living with terminal cancer. The four master themes that the study traced are the following. First is the master theme of *trauma* and captures the catastrophic interruption that the terminal cancer diagnosis has on a person's life. The affect that accompanies this news is negative and the individual experiences vulnerability and a lack of emotional and physical safety. Existential anxiety goes together with the sudden emergence of awareness of the individual's mortality. The second master theme is named *liminality* (Latin for threshold), capturing the quality of experience whereby the person feels like s/he inhabits a distinct space of living whilst awaiting dying. Liminality is a distinct experiential dimension in the sense that the individual occupies a 'waiting' room where time "becomes both all important and meaningless at the same time" (ibid, p233). Liminality expresses the ambiguity between the two positions the individual is called to inhabit at the same time: the position of full living and the position of non-existing in this world any longer, a state which leads to experiencing feelings of disorientation. The two positions also correspond to distinct sociocultural statuses adding to experiencing strains that demand continuous negotiation. The concept of continuous negotiation has been comprehensively described by Corr, Nabe, and Corr (2000) in their research on coping with dying. Four areas for coping have been identified: the physical, the psychological, the social and the spiritual. Physical coping comprises the care for the minimisation of physical distress; psychological coping revolves around negotiating emotions of security, autonomy, and richness in living; social coping requires the management of attachment relationships to others but also toward social activities and social roles; and spiritual coping which centres on maintaining or finding meaningfulness and connectedness in living, whilst dealing with issues around transcendence and hope. This comprehensive description of tasks to be handled within this liminal space of existence in between living and dying has been supported by the research of Coyle (2006) which was artfully titled *The hard work of living in the face of death*.

The third master-theme that Willig and Wirth' meta-synthetic study (2018) found was the noted effort of the dying individuals to *hold on to life*. The experiential negotiation of this dimension fluctuates between staying connected to life as they knew it so far and "(resisting) being torn away from all that made life meaningful and worthwhile in the past" (ibid, p234). It is a purposeful action that uses emotional and physical energy on the part of the individual and is exemplified in holding on to treatments and the anxiety that accompanies these procedures, focusing on the little pleasures of daily life, and investing in a sense of future no matter its extent. The fourth meta-theme the research revealed was the *impact of terminal cancer* on the patient's day-to-day life. Captured within a web of progressive losses such as loss of control over one's body, loss of dignity, loss of energy, loss of independence and more, the individual cancer patient is called to adapt to these losses that deteriorate day by day.

These phenomenological findings are important as they delineate the picture of the experience of living whilst knowing that the individual is dying, with reference to characteristic dimensions or qualities of the very experience from an insider's point of view. They do not claim the status of objective knowledge that positivist research has acclaimed and has established as its purpose, but instead phenomenological findings invite knowledge from those who experience the phenomenon -that is their thoughts and feelings- along with the involved relativism (Willig, 2008, p. 70) that this epistemological stance implies. Willig and Wirth' (2018) work argues that the relationship among the master themes is complex and seems to follow a dialectic of loss and gain of the type: "There is the loss of connection with the world of the living through Liminality on the one hand, and on the other there is the gain of a sense of connection through companionship and solidarity with fellow patients that becomes available through Life as a Cancer Patient as well the heightened sense of belonging and attachment found in Holding on to Life" (ibid, p. 234). The phenomenological picture of the experience we are considering is much richer than assumed by most of the positivist research that had dominated the field which usually depict the experience as characterised by inescapable suffering. If we take a closer look at stage theories, such as Kubler-Ross's (1969) stage theory we see not only an fixation with suffering through the various emotional stages that the dying person is going through, but also a normative way a person should relate to his/her experience of dying. Kubler-Ross's theory has prevailed and had produced a ubiquitous discourse about the emotional trajectory of dying. The sequential process of the 'right' way to die follows five stages that of denial, anger, bargaining, depression and acceptance. We still meet expressions in the literature that reflect the normative dimension of the stage theory, or else the 'right' way people should be dying, expressions such as 'nonaccepting', 'in denial', or 'having difficulty letting go' (Wright, 2003). By contrast, phenomenological research emphasises the insiders' perspective and not the 'objective' observation of outsiders. Outsiders, usually being health professionals, look at the dying individuals through 'projecting' onto them what they expect to see. On the other hand, an insider's perspective pays attention to the ill individual himself/herself and the way s/he describes his/her experience. Accordingly, the theoretical perspectives that had been developed in the past –like Kubler-Ross's (1969) emotional trajectory or Pattison's (1977) psychosocial needs theory of the dying- reflect the epistemological viewpoint of a different epoch (Nissim et.al., 2012). And the phenomenology of the dying experience by advanced cancer reveals a much richer constellation of emotions and feelings –much like a 'mosaic' in form, that can occur simultaneously and not in serial transition (Copp, 1998)- which unfold in a dialectic of loss and gain (Willig & Wirth, 2018) within the dimension of conscious awareness to be talked about openly when the individuals are directly asked. In this line, the pervasive old thesis about being in denial out of fear of death should be replaced by theses about fluctuating and contradictory "self-states" (Rodin, Zimmerman et.al, 2007, p185) whereby death awareness can coexist with strong emotions such as the will to live. The study by Rodin, Zimmerman et al (2007) with over 300 patients with metastatic cancer showed that the hypotheses about the inevitability of death anxiety and ubiquitous intolerability of death awareness is refuted as almost all of the patients could manage death anxiety whilst still finding life meaningful and purposeful. In this line the researchers argue that static concepts such as 'denial of death' underestimate the multiplicity, fluctuation and variable integration of the individual's dying experience (Rodin & Zimmerman, 2008, p186).

With Kastenbaum's argument (1996, in McTiernan & O'Connell, 2015) that humans are not inherently anxious about death but learn to be through socialisation, I will turn my focus now on the cultural assets of our epoch, or the prevalent discourses on dying from terminal cancer. Social psychological theories such as the social learning theory that Kastenbaum implies, or social cognition theories of planned behaviour converge on the model of the human subject they both share. According to them, the individuals acquire socially available assumptions about phenomena which in turn shape their behaviours. More recent social constructionist theories, however, have argued that mainstream social psychological theories overemphasise the role of cognitions and neglect the social context within which behaviours unfold (Willig, 2000). Instead of looking for fixed entities in the minds of individuals that operate as explanations of their behaviours, instead of searching for the inner thoughts that are considered as guiding behaviours, social constructionist critics -by building upon research findings whereby cognitions are not consistent, stable and predictive of behaviour (Willig, 2000, p548)- trust that a much better predictor of individuals' behaviours is the culturally available explanations of phenomena. Cognitive inconsistencies or dissonances can be better explained by the fact that "any one individual .... is likely to draw on different and often contradictory arguments in order to make sense of their experiences in different social contexts" (ibid, p548). Exploring the available discourses that surround a phenomenon can not only account for the inconsistencies of people's behaviours but also reveal the social, cultural and historical practices of the phenomenon. In this line, I now move onto the analysis of the discourses that surround dying from terminal cancer.

Following the Foucauldian (1977) conception of discourse, a discourse is the reconstruction of fundamental claims of knowledge as to what is allowed or restricted from being considered as true knowledge in particular historical periods. Analysing a discourse is a process, which seeks to understand which statements are legitimated and which are excluded (Whitney & Smith, 2010, p70) according to which regime of true knowledge, and the relations of power which permeate these regimes. The biomedical discourse is the fundamental framework for understanding death and dying (Kaufman, 1992) in our epoch. Both death and dying are defined as technical problems assigned to the institutions of medicine for management and tackling. The natural event of death is defined as a condition which must be treated and controlled by medicine; it is handed to the medical gaze to account for the clinical signs of the disease that caused the death. When death eventually emerges it is considered a ‘failure’ of biomedicine (Whitney & Smith, 2010, p73). Death is not considered a natural part of life but something that must be resisted and intervened upon (ibid). From the point of death and onwards, bureaucratic mechanisms take over for the efficient management of the dead individual. Existence becomes encapsulated within a file containing various medical and legal documents (ibid, p74), stripped of any uniqueness or individuality, applauding bureaucratic efficiency instead.

There are at least five primary assumptions (Nettleton, 2006, in Whitney & Smith, 2010) that the biomedical model puts forward with respect to the life and death of human beings. The first assumption is that there is a mind-body dualism with the body leading a distinct life from that of the mind. The second assumption is that the body operates as a machine to be repaired by expert doctors. The third assumption stems from the previous ones and emphasise the technological imperative inherent in medicine (Whitney & Smith, 2010, p71). The fourth assumption wants the explanations of diseases to be exclusively biological. The fifth assumption understands the causation of diseases from either the perspective of pathology or epidemiology (ibid, p72). From all the above we can conclude that the individual patient acquires the status of an *object* in the biomedical discourse (Rich, et.al. 2008). It is fairly recently that the Western biomedical discourse has turned its gaze to the introduction of the patient as a subject in the medical encounter. Catalysts in this movement of awareness and sensitisation have been Kubler-Ross’ (1969) work on death and dying, and Saunders’ development of the concept of ‘total pain’ (in Whitney & Smith, 2010, p74) as opposed to the sole physical pain of the ‘modernist’ (Rich et.al., 2008) biomedical discourse.

Having reviewed the prevalent discourses or the culturally available arguments that surround death and dying at present, I would like to turn now to the last field of recent discursive research on the subject, which follows a fine distinction that Willig (2000) points out. This is the focus on how subjectivity, which is constituted by discourses and practices, accounts for that very process via his/her more private meaning-making actions. We want to explore more the management of internalised discourses by individuals, and in this way understand better the relationship between discourse, practice, subjectivity and experience (Willig, 2000, p554). This is the point where discourse analysis converges with phenomenological research: not only do discourses constitute subjects by allocating specific positions for them within their limits, but also subjects have unquestionable possibilities to reflect upon their discursive constitution, resist and even rebel against the discourses' predetermined positions.

The scope of research along these parameters is the exploration of the social and psychological consequences of being positioned within dominant discourses associated with cancer and in particular terminal cancer. What is investigated by research of this kind is what can be said and done from within particular discourses but also what can be felt, thought, and experienced from within the available, the allocated, subject positions of these discourses (Willig, 2011, p. 898). The discourses surrounding cancer carry with them powerful imperatives, the most important of which is the imperative to 'think positively', demonstrating good and unshakable faith in the belief that "every problem can be solved" (ibid). Cancer patients are required to remain as cheerful and optimistic as possible (Wortman & Dunkel-Shetter, 1979, in Willig, 2011, p. 899). They are asked to declare a war and fight against it (Lupton, 1994) and so cancer is constructed as an enemy (Sontag, 1991). Cancer patients must accept their illness as a challenge, an opportunity even (Ehrenreich, 2009, in Willig, 2011, p. 899), to rethink their lives in search of the cause of their cancer. Cancer legitimates attributions of responsibility to the patient as being the patient's own creation out of his/her inner weakness and self-destructiveness (Stacey, 1997).

It can be seen that the confrontation with cancer is a highly individualised affair that demands more than merely the care for its possible cure. Cancer patients work hard to explain, to find meaning, and to relate meaningfully with this illness. They are required to produce narratives, "serviceable narratives" (Willig, 2009), to communicate to others and through them to comfort themselves. Frank (1995) produced a typology of narratives the most famous and widely used ones being the ones where good health is restituted, and the more refined being the ones that are offered to the public and describe the person's quest for meaning. What is the situation however when good health restitution is not the case? What about the terminal diagnosis? The individuals who live while knowing that they are dying are not serviced by the existing narratives: restitution of their health is not an option and despite having fought the war against cancer the winner is the illness. They have rethought their life and have made changes to the style of their life, having incorporated the imperative of personal responsibility into the way they relate to themselves and to their life so far. Still terminal cancer appeared and it has to be managed in addition. Two papers by Willig (2009, 2015) are relevant within this context and will conclude this section. Willig (2009, p. 188) argues that confrontation with one's own mortality is a confrontation with the limits of life itself: and life is uncertain, unpredictable and to a large extent uncontrollable. The bravery of facing up to one's mortality and not averting away the gaze when confronted with the fact that time is both limited and imminent, that there is no more future, can result in an encounter with being's authenticity (Heidegger, 1996). Therefore, we could expect that embarking upon the exploration of living-with-dying would bring forth highly idiosyncratic ways (Willig, 2015, p. 423) of making sense of this phase in a person's life; that it is not so much a shared experience but rather an individual challenge to be met in different ways by different people.

Concluding this literature review, I trust that I presented most of the challenges that a research on the subject of dying faces. It remains for the data of this research to find their place in this picture of research that has been constructed so far.

My research questions

My research questions -with all the above in mind- are the following:

1. How do cancer patients who enter palliative care –that is as they know that they are approaching the end of their lives- make sense of this major life transition and how is this reflected in the way they speak about themselves?
2. How do socially available ways of talking construct the phenomenon of dying and how are these deployed in the speech of the participants?

On the nature of subjective experiencing

Unless I delineate the nature of the subjective experience within the limitations set by the arguments of post-modernity, my research proposal would be incomplete and arbitrary. I will claim that there is a space to theorise subjective experience that is not deconstructed by the postmodern critique as essentialist and from there subjectivity can be looked at. The phenomenological tradition can fulfil this role of providing a space that is immune to the deconstructive efforts to do away with the essentialist claims of modernity about an autonomous, fully rational and purposeful subjectivity. The position will take serious consideration of the postmodern critique, however, by recognising the importance of historical and cultural specificity as well as the power of language when speaking about human affairs.

The postmodernist discussion about the human subject revolves around the deconstruction of the subject as the indubitable point of reference for thought and action, and as the locus of freedom and truth (Lovlie, 1992). The argument holds that when we speak about personal thoughts, intentions or authentic choices, we presuppose the principle of interior unity that holds our lives together as personal and private lives. The principle of unity is presupposed as that which binds my life together making it my own and not anyone else's. The created binary between the external and the internal reality carries with it the whole history of Western philosophy, of Western epistemology. The deconstruction of the binaries was Derrida's philosophical goal arguing that we should try and break down the oppositions that our thinking has inherited and which ensures the survival of metaphysics in our thinking, of the sort matter/spirit, subject/object, body/soul etc. (Sarup, 1993, p38). The binaries are characterised by their tendency to reserve a special place in the hierarchy for the one of the two terms while the second term is considered a subordinate. For Derrida this tendency for the creation of hierarchical binaries is metaphysical because it reflects the construction of the whole of Western philosophy for a secure and stable origin from which all other concepts emerge. Accordingly, Derrida used to call 'metaphysical' any thought-system, which depended upon a foundation, a ground, or a first principle (Sarup, 1993, p37), or a 'logocentric' system of thought which leads us to think that there is reason, or 'logos' that orders the universe including our psychological makeup (Lovlie, 1992, p123).

According to this line of thinking, the notion of subjectivity as formulated since the epistemological project of the Enlightenment as the autonomous, reasonable and purposeful entity that can live an authentic life towards the actualisation of inherent potentials violates the limitations set by the determinations of language, culture and historical specificity, and is nothing more than a fiction. To unpack the argument, the deconstructive reading of the historical definitions of subjectivity brings to the fore a subject who masters both self and nature, who is identical with the inner sense of self, who is capable of good enough self-knowledge. This discourse on subjectivity as mastery, identity and self-knowledge (Lumsden, 2007) forgets that we are formed by the language and the world that we come to inhabit, that we are primarily subjects of language: "a language that the subject is not the cause of, but which it must use to understand itself" (ibid, p. 39).

The powers of history, language, and culture and accordingly the undermining of the subject of the Enlightenment –or the free, intellectual agent whose thinking processes were considered unaffected by historical and cultural circumstances (Sarup, 1993)- had been largely revealed in the historiography that Foucault produced. The absolute substitution of the subject by impersonal systems of power, or discourses, marks Foucault's contribution to the history of thought structures along which we are directed to think and live. His argument for the 'marginalisation of the subject' (Gutting, 2005, p. 33) is guided by the premise that individuals operate in existing conceptual environments that determine and limit them in ways they cannot even be aware of. The goals of history, accordingly, should be the discovery of these conceptual environments, the operative discourses that direct and limit what can be thought of and allowed to be done at a given time period.

Post-modernism, therefore, puts forward a distinct epistemology. Polkinghorne (1992) distinguishes four characteristics of the post-modern epistemology, namely foundationlessness, fragmentariness, constructivism and neopragmatism. Considering each one in turn, *foundationlessness* of all knowledge resolves the old philosophical binary between empiricism (that knowledge arises from our infallible sense experiences) and idealism (that we get true knowledge through the imposition of our cognitive capacities upon reality) towards a new direction. Stressing the historically contingent nature of all knowledge, postmodernism admits that there is no way we can step out from our "biological makeup, cultural assumptions and language games in which we are immersed" (ibid, p. 149) and access an independent reality. Accordingly we have to accept that we have no sure epistemological foundation upon which knowledge can be built (ibid).

To the old assumption which considered the real as a single and integrated system, postmodernism counters the *fragmentariness* of reality, or that the real should be seen as "a disunited, fragmented accumulation of disparate elements and events" (ibid, p149). It is nothing more than a 'totalising' discourse (ibid), that we impose upon reality, and that constructs the real as a single and integrated system whose general laws knowledge should aim at discovering. Instead, we would have to restrict our ambitions to discovering unique sets of multiple forces operative at particular places and times and develop an understanding of the real as being in flux and in continuous change, rather than static. Polkinghorne quoting Rorty (1989), points out that not only is reality relative as it is constructed by location and time but the interpretative schemes used to understand reality "vary according to location and time" (Polkinghorne, 1992, p. 149), interpretative schemes understood as all those linguistic systems that stand between reality and experience. From all the above, the postmodern epistemological argument sustains that there is no ground upon which to evaluate the truth among diverse language and explanatory systems. In fact, considering truth as 'tidy' (Polkinghorne, 1992, p. 150) and unitary should be seen as "misguided leftover [-s] from modernity" (ibid).

What postmodernism puts forth is *constructivism* which represents human knowledge at the level of individual functioning as a construction built out of the interplay among a person's cognitive processes (language use included) and "embodied interactions with the world of material objects, others and the self" (ibid). Human experience does not reproduce accurate pictures of the real but "meaningful interpretations" (ibid) of it, recognising the powers our biological makeup and the interpretative patterns (discourses) characteristic of our historical, cultural and social environments, have upon the process of getting to know something. This complex amalgam of forces produces knowledge, which is relative to history and culture but also dependent upon the biological makeup of our perceiving abilities.

Postmodern epistemology is a “negative” epistemology (ibid, p. 151) in the sense that it does not give priority to any type of knowledge as more valid and reliable as compared to other more limited ones. All truth claims rest on the same ground of evaluation and have equal standing with each other. Polkinghorne (1992) recognises that the relativism inherent in the negative epistemology of postmodernism needs to be resolved through the provision of criteria in order to be able to evaluate truth claims and judgements about human actions. The position of *neopragmatism* can fulfil these conditions, according to Polkinghorne (1992, p. 151). Neopragmatism does not intend to come up with a theory of truth that would correspond to reality; instead, it limits itself with respect to the modernist ambitions accepting that we can only come up with criteria of truth which would merely fulfil intended purposes. Accepting that there is no way by which we can ascertain that the picture of the real we construct actually corresponds to the reality ‘out there’, neopragmatism produces pragmatic knowledge that accomplishes ends effectively, that “functions successfully in guiding human action to fulfil intended purposes” (ibid). In other words, the criteria of truth claims rely upon the success with which our interpretative patterns, both individual and collective, can capture the perceived regularities of reality to the extent that they allow us to accomplish our purposes. The more open we are with respect to our interpretative schemes the better we are equipped and able to capture the complexity that exists in the world. As for sciences and the production of knowledge, sciences should collect, organise, and distribute the results of their efforts which are by definition always limited in scope without aiming to discover universal and unchanging laws of the world. All knowledge statements in this way carry the limitations bound by locale and time, making them consistent with the arguments of postmodernity for relativism and historical specificity for all of what we know as true. We should be proceeding with our lives in this world at this specific time and place by considering what we know more like ‘case studies’ and not universal laws with secure foundations.

The critiques discussed so far provide the context for my purpose of describing subjective experience. The postmodern understanding of the individual undermines first and foremost the modernist assumptions about a unitary entity which can relate to himself/herself in an unmediated way and produce authentic and transparent accounts of himself/herself. The historically relative subject that postmodernity argues for renews our interest and zest to get to know him/her. The subject of postmodernity opens up new possibilities for knowledge. If we relate back to my literature review which aimed at refuting the universality of the fear of death argument, the subject of postmodernity is not determined by a universally unchanged emotional system. In this line of argument, we reclaim a subject of whom we know little about but also about the way s/he relates to himself/herself. And we renew our interest in getting to know more about how this subject relates to the end of his/her life in this historically specific epoche.

But how can we speak about subjectivity through the recourse to discursive reading? The problem of the place of subjectivity in the postmodern theories is the following: if we are produced as subjects through language, are we still subjects of language or objects of it? Even more, ethical dilemmas arise around questions such as: if we are constructions of prevalent discourses as exemplified by various institutions like the family, school, society, history, or simply language itself, how can we speak about agency, self-directedness, and personal choices?

Existential phenomenology, which derives from the refined writings of Heidegger in doing away with the metaphysics of former phenomenology, seems able to resolve the impasses that postmodernity stumbles on. Although a philosophical movement born in the midst of late modernity, existential phenomenology was able to answer questions about subjectivity and its relation to the world in a way that can satisfy the preconditions of the postmodern critiques. The fundamental premise of the existential phenomenological theorising that the subject is ineradicably connected to others and the world around it (Frie, 2003) resolves the binary of self/world or subjectivity/objectivity that required an answer from every philosophical thought system since the very birth of philosophy. Not only that but existential phenomenology additionally embraces themes around subjectivity such as agency, autonomy and authenticity (ibid, p. 16), which are considered fundamental for explaining individual change or for bestowing upon the subject the ability to choose one course of action over another. Frie (2003) reframes that we need to conceptualise a subject with a self developed out of, and dependent upon, interaction with history, culture, and language -as postmodernism argues for- but also a self who maintains a sense of cohesion and identity from within. Existential phenomenology can fulfil this aim of re-establishing a self with capacities by supporting that despite the limitations we have with respect to our embodiment or our biological makeup, despite the historically and culturally specific schemata through which we perceive phenomena of the world, there is uniqueness and wealth in subjective experience as provided by the distinct constellation of experiences of each one's life (Spinelli, 2005).

To reconstruct the premises of the existentially phenomenological arguments about the binary of subjectivity/objectivity we arrive at the following outline:

1. Subjectivity is not the unitary and detached rationality which imposes its capacities upon the world and in this way produces knowledge. Subjectivity is already in the world, in an immersed way connected with the world. S/he adopts the cognitive structures and language, characteristic of his/her era along which s/he reads the phenomena of the world. We are able to give accounts of the world because we are in the world and part and parcel of the world.
2. Subjectivity is not the unitary subject of knowledge that builds knowledge about the world through the gathered sense data s/he collects via his/her senses. All that subjectivity has in its powers are his/her interpretative abilities which according to the previous premise are shared interpretative abilities of and for these sense data. We cannot reach, in our interpretative efforts, the truth about the world but we create approximations of it according to our historical and linguistic equipment.
3. Subjectivity is equipped with the powerful force of reflexivity in his/her existential movement towards creating meaning. Spinelli elaborates on this point: "We cannot tolerate meaninglessness. Through a variety of in-built species invariants and experientially derived mental frameworks, we attempt to stamp our experiences with meaning" (2005, p. 10).
4. The uniqueness of subjectivity is re-established, however, by virtue of the unique constellation of experiences each one of us is called to meaningfully reflect upon, and in this way diversity among us is ensured.

5. Finally and with respect to the internal coherence of the self to which we have immediate access, existential phenomenology argues that we come to get to know and define ourselves by virtue of our comparisons with all those “not-I”s we come to relate to throughout our lives. Spinelli (2005, p. 95) names this process ‘self-construction’, a continuous construction of ourselves which we engage in throughout our lives. The relative constancy of ourselves that we experience at the same time is the result of a process of “sedimentation”, Spinelli (ibid) adds. The process of sedimentation incorporates past experience, current mood and future expectations (Spinelli, 2007, p. 34) at any given instance of the active deployment of reflection.

I have attempted to reconstruct the fundamental lines of theorising about subjective experiencing as developed in the contemporary philosophical scene. I believe that I have managed to answer satisfactorily that the phenomenological framework is not only particularly relevant to the study of subjective experiencing, but also that its findings are innovative and original today since the distinctive understanding it provides about the subject as unique but also immersed in the world at the same time. Doing research employing the Interpretative Phenomenological method of Analysis, more particularly, means focusing upon the interpretations of phenomena that individuals provide when asked to give accounts about their experience. In consistency with the postmodern critique about truth and the real - and in opposition to the premises of the research of the natural sciences which aims at arriving at universal laws- interpretative phenomenological research maintains that its findings are approximations of the phenomenon under study thus renewing our interest for understanding human affairs. The parameters to be studied in my research are how individuals relate to the knowledge that they are approaching the end of their lives, in 2018, in Greece, whilst I will be utilising and reflecting upon what is known so far about this phenomenon.

It is not only that which is attempted however. A discursive reading of my findings is proposed employing Foucauldian Discourse Analysis, recognising the strengths and wealth of postmodern critiques, these being the inescapable determinations of language and history when approaching the study of a phenomenon. Dominant discourses -or the community-available forms of linguistic structures- which have the power to shape and limit what we can think, say, and do, and also what can be done to us (Colahan, et.al., 2014), will be considered in depth and their implications for subjectivity will be accounted for. As I discuss in the methodology section which follows, I propose a dual focus for looking at the phenomenon of dying: at the level of the experiencing individual via a phenomenological reading, and at the level of discourses and the allocated subject positions of the phenomenon via a discursive reading. The two analytical foci complement each other not only conceptually but also in producing a consistent philosophical position whereby the existentially phenomenological subject survives the critiques of postmodernity, as was shown in this section.

Situating the present study in the “Awareness of dying” body of research

The “Awareness of dying” body of research started off with the work of Glaser and Strauss in 1965 which introduced the title of ‘awareness of dying’ and with it the concept of “awareness contexts” (Stacey et al. 2019, p. 212). Glaser and Strauss (1965) conducted intensive fieldwork combining observation (i.e. attendance of staff meetings) and interviews with patients and members of staff at six hospitals in the San Francisco Bay area, U.S. The theory they developed from this extensive investigation “presented an eye-opening view of how patient care was affected by the awareness level of the dying process by nurses, physicians, and patients” (Andrews, 2015, p. 2). It is a theory ‘grounded’ in the collected data aiming to explain the variability in social interaction in a particular socio-historical context (Wells, 1995). Standing in sharp contrast to the structuralist and functionalist theories of sociology that are too abstract and accordingly not able to be tested, the grounded theory methodology that Glaser and Strauss (1965, 1967) developed is guided by the collection of dense qualitative data through which –they argue- social interaction can be explained. Grounded theory is able to discover those elements that are necessary for every sociological theory as it is able to account for structural conditions, consequences, deviances, norms, processes, patterns and systems (Wells, 1995, p. 34) characteristic of the social interaction under study. It is this variability in social interaction that is argued that grounded theory can capture.

There are four categories of ‘awareness of dying’ that Glaser and Strauss (1965) found, which are reproduced interactively and sustained by both institutional and organisational norms (Stacey et al. 2019). The context, firstly, of *closed awareness* is a context in which patients are not aware of their impending death. Even though staff members understand that the patient is dying, they carefully cooperate with each other to avoid arousing the patient’s suspicions. The tactics relied on for the concealment include giving incorrect or partial diagnosis, manipulating the conversation so that the patient can make an optimistic interpretation of his/her situation, and spending little time with him/her in order to minimise the possibility of revealing the truth (Glaser & Strauss, 1965). In the context of closed awareness, the patient holds the false belief of recovery and accordingly is not allowed the benefit of choosing how to close his/her life. Also, friends and relatives by guarding against not revealing the secret cannot openly express their grief in the presence of their loved one (Andrews, 2015). There comes a time, however, that patients become suspicious that they may be dying. In *suspicion awareness* patients become suspicious that physicians and nurses believe them to be dying and engage in various strategies in order to confirm their suspicions. These strategies include announcing their impending death for the purpose of checking the reaction of staff members, or attaching significance to every word and gesture of staff members. Nurses and physicians, in return, interact with the suspicious patient by sending a clear message that they are too busy to answer his/her questions and usually direct him/her to another member of staff (ibid). The atmosphere of communication in the suspicious context of awareness among patients, relatives and staff is an atmosphere of tension, and can easily evolve into the context of mutual pretence. The *mutual pretence* context is formed when everyone involved knows that the patient is dying but they pretend otherwise. “There may be some comfort in mutual pretence and all people involved must be careful to maintain this fragile illusion” (Andrews, 2015, p. 3), and for this purpose the strategy mostly relied on is that of conversing on safe topics whilst if anything threatens the ‘fragile illusion’ everyone pretends that it did not happen. Mutual pretence has the potential to cause considerable stress for both relatives and staff, yet its atmosphere is generally one of serenity. The mutual pretence context is challenged, inevitably, by obvious physical deterioration of the patient and at this point the patient makes the transition to open awareness. In the *open awareness* context staff and patients recognise that the patient’s condition is terminal and act on this awareness relatively openly. “As patients become more aware of and take more responsibility for the dying trajectory, nurses and physicians expect them to behave with dignity and refrain from displaying their emotions” (ibid, p3). In open awareness Glaser and Strauss (1965) found that the staff had expectations about the appropriate way to die and even more they were active in encouraging an ‘acceptable’ way to die (Andrews, 2015). Open awareness gives to patients the opportunity to close their lives according to their own personal thoughts and desires, whilst enabling open communication with their relatives.

The four contexts of awareness of dying that Glaser and Strauss (1965) formulated, represent the reality of the Western world of the 70s. In everyday practice today, even though nurses and physicians continue to control information and so the awareness context, attitudes and practices towards disclosure have changed dramatically to the point of legislating in favour of the patient’s right to informed consent (Field & Copp, 1999). Despite the ideological shift towards disclosure and openness in communication with people who are dying, it is still a challenge to describe how such disclosure is accomplished. Taylor (1988) found that physicians effectively communicate a patient’s diagnosis in only 10% of cases, and that physicians develop a sort of personal routine for communicating their diagnoses instead of adapting their responses to each person. Even more, Copp (1999) saw that patients, during the course of their dying, engaged in different levels of awareness following more of a private psychological logic, according to what they considered tolerable at different stages. What these two studies imply is that even if the context of open awareness is adhered to by both physicians and patients, neither of the two can handle it with ease. Copp (1999), in this line of argument, concludes that awareness should not be considered as a stable attribute altogether. Among the reasons why awareness should not be considered a stable attribute of awareness contexts, the reports of Timmermans (1994) stress that Glaser and Strauss’ (1965) contexts of awareness of dying are overly cognitive in nature, ignoring the importance of emotionality. Timmermans (1994) proposed that open awareness should be considered along with the variable of emotionality resulting in three distinct manifestations of open awareness: suspended open awareness, uncertain open awareness, and active open awareness. In the *suspended*, the information is disregarded by patients and relatives as overly pessimistic or simply false, whilst physicians and nurses see those involved in the suspended manifestation are in a state of denial. The context of *uncertain* open awareness utilises uncertainty about the outcome to maintain hope in the interactive exchanges between medical professionals and patients and family members. For example, "the nurses and doctors do not feel the need to discuss the coming death with the patient, but they can discuss death-related matters" (Field & Copp, 1999, p. 465) and in this way they leave a margin for hope. The *active* open awareness context is created when all involved parties understand and accept that death is unavoidable and try to come to terms with this. Field and Copp (1999) considering all of the above arguments conclude that open awareness is both ambiguous and conditional as patients appear "to move 'in' and 'out' of open awareness, one moment recognising, acknowledging and preparing for their death, and at a subsequent time apparently denying that they are dying" (ibid, p. 466). Accordingly, we must admit that it is not a matter of doctors controlling the information given to the dying patient but patients can still exercise control over how they receive and manage emotionally the awareness of dying.

Where are we left, then, with respect to the body of research on 'awareness of dying' just presented? We are left with detailed accounts about the formation of different contexts of awareness in the interaction between patients and medical professionals. They can be enlightening of the social manifestations of interactions at the different awareness contexts. The detailed accounts can explain the variability in interaction when information about dying is communicated or not in the social context of a hospital, and in this way they manage to portray the complexity of social life. Portraying the complexity of social life in a systematic and understandable way renders it meaningful (Wells, 1995, p. 36). The detailed accounts of interactions that Glaser and Strauss' (1965, 1967) methodology of grounded theory was able to systematise, explain how and why people behave in certain ways when interacting with each other. In other words what grounded theory is able to capture is more of the social processes involved in a topic of interest rather than the nature of the experience of the involved individuals per se, which is captured better by phenomenological methods of inquiry (Willig, 2008, p. 47).

I propose that for my own research the method of Interpretative Phenomenological Analysis is more suitable compared to grounded theory, as it aims to explore individuals' perceptions and experiences when they are aware that they are dying. The aim of my research is the examination of the idiographic, implying the investigation of the cognitive, the linguistic, the affective and the physical being (Pringle et al., 2011) of the individuals. I would argue that gaining insight into the individual is better served by IPA as it is able to approach each individual case in its own terms and to do justice to this individuality whilst at the same time providing insights about the commonalities shared in the experience. Even though the experience must be considered bounded by social interactions and processes (Willig, 2008, p. 70) which legitimate grounded theory to be considered as a main method for analysis, still IPA is more attuned with the psychological aspects of the experience and accordingly more suitable for my research goals.

With respect to the question of choice over different methodologies between Foucauldian Discourse Analysis and grounded theory, now, FDA -as will be presented in the subsequent sections- subscribes to a social constructionist epistemology which aspires to examine not just social problems but the creation of all social life (Fine, 1993) by addressing their institutional formulation. FDA, moreover, asks how social problems are constructed and turns its gaze on the dynamic and historical processes of the social system in total. Lastly, FDA assists the researcher in asking questions of the sort: “Why are some patterns of action defined as ‘problematic’, while others are ‘normalized?” (ibid, p. 75), and come up with answers concerning the historical principles according to which social life is built. Grounded theory, on the other hand, studies the interaction of agents in different social contexts which, although valuable in its own terms, is different from the discovery of the abstract discourses that dominate and govern social life in distinct historical moments that FDA aspires to reveal.

On the particularities of Greek culture

The present research is designed and run for the Greek population and accordingly it is important to account for the Greek cultural particularities on the issues of death and dying. The history of Greece unfolds from the glorious ancient times that established, among others, philosophy and democracy, to the succession of the Roman Empire’s reign, and the Byzantine Empire’s times that embraced and promoted the Christian religion to the population (during the 6th century A.D.). In 1054 the Great Schism of the Christian Church occurred and Byzantium became the centre of the Eastern Orthodox Church (Mystakidou, et.al. 2004-2005). From 1453-1821 Byzantium fell under the Ottoman yoke. The Turkish reign had always been experienced by the Greeks as an oppressive occupation and in 1821 an organised revolt of the Greeks began, which resulted in the birth of the Greek nation-state. For these reasons Greece could not follow the historical movement of Enlightenment that took place in Western Europe and advanced rational individualism. Instead, Greece maintained the idea of community much longer, suggesting a strong sense of place, proximity, moral order and solidarity (Tziovas, 2003). The dominant ideology in Greece considered the basic social unit not the autonomous individual but the extended family (ibid) adhering in this way more to a “collective, traditional ethos” (ibid, p. 21) rather than the ethos of individualism. The importance of extended families comes down to the present in the family still being considered as the strongest support system (Mystakidou et al. 1996; Mystakidou et al. 2009) seen when all responsibilities for the care of a sick member of the family are assumed by close relatives. Accordingly, in the disclosure practices about terminal illness in Greece we can still find instances of concealment out of the need of relatives “to protect” the patient from the bad news (Mystakidou et.al., 2009; Mystakidou et.al., 2003) despite the international medical protocols.

“Individualism in Greece has remained atrophic due to the fact that national identity has been defined defensively in relation to a hostile ‘other’” (Tziovas, 2003, p. 27) a “hostile ‘other’” which throughout Greek history took various faces: the neighbouring Turks, the West, minorities, immigrants and so on. Residues of a difficult past, Greeks invented themselves as inhabitants of a specific region, with a history that relates them back to their ancient ancestors, believers in a religion -Christian Orthodox religion- that differentiated and defined who they were in the critical period of their self-formation as contemporary Greeks when under the sovereign reign of the Ottoman Empire. The early constructions of the Greek identity was characterised by a defensive conception (ibid) that differentiated strongly ‘us’ from ‘them’.

The ‘us’ that the Christian Orthodox religion differentiates is an ‘us’ which communes on a highly ritualistic and symbolic religious practice. The Orthodox religion is practiced today much as it was practiced hundreds of years ago. We witness no change in the practices, the archaic Greek language being used, the hymns being sung, or even the attire wore by the priests who are exclusively male. With respect to death and dying, the Christian Orthodox dogma holds that the deceased will be accepted by God and be blessed with eternal life. On the demand of the dying patient, a priest might be invited to the deathbed of the dying individual to pray for him/her and administer the last Holy Communion. The burial at the cemetery closest to the place of residence of the deceased begins in the church of the cemetery where relatives and friends gather to attend the funeral. The closing act at the day of the burial is the gathering over coffee – known as the 'consolation coffee' - to commemorate the deceased and pay respect and condolences to his/her close ones. After the burial, memorial services take place on the ninth day, the fortieth day, after six months, and finally every year after the death. On these particular days the closest relatives visit the grave with flowers, light the candle of the grave, request a priest to say a prayer for the consolation of the deceased, and distribute among them the specially prepared boiled wheat mixed with fruits and sugar ('kolliva') to eat and commemorate the deceased. It is expected that the closer females of the deceased (i.e. mother, wife, daughter/s) will wear black clothes for at least six months; in rural places we can still find women who mourn their deceased and wear black clothes throughout their lives. The purpose of all these rituals is to help the soul of the deceased in the transitory course from life to death, whilst assuring God's forgiveness for all of the deceased's sins. Through these rituals the Greek Orthodox Church facilitates the living in a way of coping with death and progressing towards bereavement, whilst to the dead person it attributes a representation of becoming sacred (Mystakidou, et al., 2004-2005) and eternal.

The fundamental principles of the Greek Orthodox religious dogma that differentiate it from all other forms of religion are the following (Pallis, 1985, p43-44):

1. God is highly personal (not an abstract idea) of a tripartite essence composed by God-Father, Jesus Christ the Son, and the Holy Spirit
2. The world is God's creation and a gift from God to humans
3. Human beings are created according to the image of God
4. Christian virtue arises not from knowledge and wisdom, but from the heart through love, whilst
5. All humans are equals among themselves and children of God-Father

The differences of the Greek Orthodox Church from other forms of Christianity mainly have to do with the insistence on the continuation of the preaching of the Apostles, Christ's pupils and their Holy writings, and accordingly it is believed that it advocates the right and true Christian faith. The Greek Orthodox Church defended this archaic form of Christianity against the Catholic reformations which led to the Great Schism of the Eastern from the Western (Roman Catholic) Christian Churches. In my own school textbook on the Christian Orthodox religion we read the following statement that I think captures the difference between the two Churches: "Orthodoxy tries to elevate the earth to the sky, while Roman-Catholicism tries to impress by bringing the sky down to the earth" (Father Metallinos, 1985, p. 131). This, despite its conceit, tries to convey the humility with which Christian Orthodox believers should approach the deity, but also supports what was mentioned earlier about the dichotomy between 'us' and 'them', which characterises Greek society.

Nevertheless, Greek society has increasingly become ethnically, religiously, and culturally diverse due to its being a member state of the European Union and partaking in the socio-political processes that result from a globalised economy. The Greek society is losing its strong collective cultural identity based on "the ideals of a historically inherited ethos, a shared tradition, and a common past" (Tziovas, 2003, p. 28) and much like most of the countries of the Western world nowadays takes on an ideology more open towards the other. Not only that, but the Greek society of the 21st century, by following the broad-minded cosmopolitanism of its political decisions to belong to the European Union, subscribed to the dislocation of cultures from the old way of living that was bound to specific geographic regions. The natural connections between peoples and places have certainly become eroded in the contemporary era which is characterised by global cultural homogenisation (Clifford, 1988, cited in Gupta & Ferguson, 1992). The world of our times is culturally, socially, and economically interconnected and interdependent (Gupta & Ferguson, 1992). To relate back to the topic of the present research, we can see the worldwide spread of the hospice and palliative care movement which focuses on decreasing pain and suffering, both emotional and physical, whilst improving quality of life for both patients and their families (Meier, et.al., 2016). There are inherent values that are transferred across borders with the palliative care movement coming to be considered as true and morally right worldwide. The old dichotomy between 'we' and the 'others', therefore, is becoming more and more blurred, erasing the cultural distinctiveness of geographical places.. Ferguson (1990 cited in Gupta & Ferguson, 1992) proposes to the shaking project of cultural anthropology of our times the investigation of different ‘cultural styles’. Anthropological research on ‘Cultural styles’ means searching for a logic of surface practices, “without necessarily mapping such practices onto a ‘total way of life’ encompassing values, beliefs, attitudes, et cetera, in the usual concept of culture” (Gupta & Ferguson, 1992, p19).

How are we, therefore, to approach the rich phenomenological data of cultural studies in the present? How are we to relate to the information that I have just presented about Greek culture to the present research project? First of all, we can relate to cultural information as the history of a culture which makes available social practices to which the individual subject relates with varying degrees of respect and devotion. We should be looking for unique and individualised receptions of these old traditions and not general cultural values. This perspective is consistent with the phenomenological viewpoint of this research which directs towards the ‘bracketing off’ of preconceived theoretical models which tends to leave out and forget that an individual creates unique constellations of meaning out of his/her unique life history.

What would Foucault’s arguments, on the other hand, tell us about the history of cultural traditions, bearing in mind that late Foucault was interested in broad societal constructions which guide towards particular ways of living? Foucault’s analyses of madness and the birth of the clinic, criminal punishment and the invention of the institution of prison, and the contemporary stance towards human sexuality, refer to historical “workings of a [an overall] culture rather than a specific level of a given culture” (Patton, 1999, p. 537) and accordingly his arguments extend beyond the limits of particular cultures. Foucault’s historiography is primarily political (May, 2005) focusing on historically developed structures of managing and controlling human experience. Whilst he shares with cultural studies the importance of societal processes constituting the subject, Foucault diverts his study of history interrogating those categories within which an experience is articulated (ibid, p. 306) and in this way he questions the history of thinking in particular ways itself. We see that Foucault’s projects run deeper analyses to those provided through the investigation of the history of cultural traditions, questioning the very categories we use to understand and speak about experience which we consider as natural. Out of these processes the individual is constituted by and not the cultural processes which if utilised can only describe general characteristics of the individual. Even though the cultural processes perspective can provide ‘thick descriptions’ (Geertz, 2003) of characteristics that can compose the distinct reality of an individual, Foucault’s directions on researching topics of interest stress that the determining forces of our civilisation run on much deeper levels and have to do with what we come to consider as true in particular historical periods.

Methodology and procedures

Research design

The present research on the subjective experiences of individuals who are approaching the end of their lives with advanced cancer and accordingly entered palliative care was designed for the Greek population by recruiting patients of the Palliative Care Unit of the University Hospital Areteion of Athens, Greece, an outpatient unit of medical day-care handling conditions of pain management where patients self-refer. The literature review of Greek psychological research on the subject showed that no phenomenological qualitative studies have been undertaken on the subject, but mainly quantitative research focusing on psychological difficulties as measured by standardised scales (i.e. Mystakidou et al. 2014, 2009, 2010). It was designed to be a single methodology study, an IPA research, with an unstructured interview schedule (Smith, et al. 2009, p. 69). During the data collection phase I turned toward a dual focus methodology, paying special attention to the manifestations of the FDA focus on participants' accounts. The research design respected the sensitivity of the condition of the participants and was framed in a single core interview question to be asked at the beginning of each interview investigating what the particular experience of living with advanced cancer and coming for palliative care mean to the individuals. Appropriate linguistic adaptations for better communication in the Greek language formed my introduction as follows:

> "-Welcome. My name is Eugenia and I'm a Counselling Psychologist. I'm inviting you to talk about how you feel about coming for palliative care. Having read the Participant Information Sheet of the study you know that I'm researching the subjective experiences of individuals who come for palliative care, that is, what this experience means to you. You can answer this question in whichever way you'd like. Our interview can be finished at any point you'd like and I'd like to remind you that if you experience any distress you can ask for the Counselling Services of Unit. Now we'll sign the consent form on two copies and we'll start the recorder".

There is a noticeable semantic overlapping in the Greek language in the expressions “-what does it mean to you....” and “-how do you feel about....” which I resolved by including both in my introduction so that a clearer understanding between me and the participants could be established.

Because the material sought for was emotionally sensitive, special care was given to not producing additional distress for the participants. In this line and during the designing of the study it was agreed with the Palliative Care Unit in Greece that up to six sessions of therapy could be offered post-research to participants in cases that experiences of distress arose. During the interview and the data collection phases, participants were emotionally supported by the attitude towards them that I adopted, which relied on the principles of client-centred therapy which are emotionally facilitative and cultivate an atmosphere of holding of the individual. Additionally, the standard procedures of research, such as written and verbal consent and debriefing, the right to withdraw consent at any time without this affecting the availability of support post-research, plus the offered possibility to read the transcript and consent to what would be included for analysis, were carefully designed in order to safeguard against causing unintended harm.

Ethical considerations

As explained in the previous section, special care for ethical considerations was given in all phases of the research. Due to the fact that the participants who were recruited are vulnerable individuals, the application that I submitted to the Senate Research Ethics Committee of the University, was very detailed and particular care was given to the construction of the Participant’s Information Sheet (see Appendix 3). All the documents that were given to participants (information sheet, consent form, and acknowledgement) were composed in both the English and Greek languages and had been approved by the respective Ethical Committees. The completed proposal for the study, including all the documents that address the participants had been approved by the Senate Research Ethics Committee of the City, University of London, and the Research Committee of the National & Kapodistrian University of Athens, Medical

School, Areteion Hospital (see Appendixes 1, 2, 3, 4, 5, & 6). Both boards permission was required as the study falls under the category of being a cross-cultural research. For the construction of my proposals and everything related to my research documents I utilised the directions of the *Code of human research ethics*. (British Psychological Society, 1990), the *Code of ethics and conduct* (British Psychological Society, 2009), the *HCPC Standards of Conduct, Performance & Ethics* (2012), and the *City University Guidelines on Human Research Ethics* (2014).

The ethical issues that pertained to my project were that I would be inviting vulnerable people to discuss their experience, which could elicit painful emotions. I have thought extensively on this topic and came up with a design that would provide post-research support and I have agreed with the Director of the Palliative Unit in Greece to offer a more structured framework of six sessions for participants who might be in need of psychological support. In order to avoid the ethical conflict of dual relationships, participants would be referred to the other psychologists of the Unit for their post-research therapeutic sessions. I also trusted that myself conducting the interview along the principles of client-centred therapy, I would be able to provide the participants with a holding environment where emotional turmoil could be processed as it arose. All of the interviews had difficult moments with emotional intensity but I was able to follow the emotional pacing of the individual by managing a position informed by the principles of client-centred therapy. In all interviews an atmosphere of trust and warmth was created and they ended with participants reporting feeling understood and more empowered. No one requested post-research psychological support sessions.

Another issue of ethics was consideration of the benefit the participants would gain from participating in this study. It is an issue of ethics since these individuals are vulnerable and with fragile emotionality, and they should be gaining something out of the research condition that has some meaning to them. I stressed to the Unit’s staff who did the sampling and in the Participant Information Sheet that participation in this research was an opportunity for the individuals to reflect upon their experiences with an experienced Counselling Psychologist practitioner who would listen to them carefully and with therapeutic responsiveness. It was further communicated that reflection assists meaning-making of difficult life situations, fosters a better sense of control over the situation, and is emotionally empowering.

With respect to the ethical considerations of the greater field of Palliative Care the study, it was argued, could contribute insights by getting to know more of the particular needs, themes, and concerns of advanced cancer patients. Not only psychologists but medical staff could benefit from the extracted knowledge in getting to know their target patients better and design how to better approach them and respond to their needs. Furthermore, supportive group work for palliative care staff would enable them to handle effectively the impact of working with the emotional needs of dying patients which may elicit strong emotions for them as well. Also, the insights of the research could inform relatives and carers of the dying individuals and more effective practices could be designed towards their support.

Recruitment

A sample size of four participants was agreed as sufficient with my principal Supervisor of City, University of London, Professor Carla Willig, since two distinct analyses would be imposed upon the interviews with them. Even though the sample size was small, what was sought for in qualitative research was depth of knowledge and not breadth (Smith & Osborn, 2008). The sample had to be fairly homogeneous in terms of experiencing the condition to be studied and for that purposive sampling (Smith & Osborn, 2008) was followed. Accordingly, all participants were individuals who suffered from advanced cancer and entered palliative care for pain management, that is they were approaching the end of their lives.

Inclusion criteria for the study were that the participants should have intact mental capacities, know that they are approaching the end of their lives due to advanced cancer, and express willingness to participate. Accordingly, an exclusion criterion was that individuals who suffered from delirium (Breitbart & Alki, 2009) -present in advanced cancer patients to a degree of 85% (Caraceni et al, 2000)- which seriously hindered their mental abilities of conscientiousness, attention, cognition and perception were not informed about the research. Another exclusion criterion was that the individual did not know that s/he had limited time left, a situation fairly frequent in Greece where only the family members know the truth about the patient's condition. An additional exclusion criterion for participation included severe incapacitation from psychiatric disorders (depression, anxiety, phobia, or post-traumatic stress disorder), and dementia since in both conditions individuals' ability to consent is significantly impaired. All of the exclusion criteria of the study were designed under the ethical guidance of not causing emotional harm and not becoming discriminatory to any aspect of participants' characteristics.

Candidates who were informed about the research and were asked to participate had to be able to endure participation both physically and mentally. The inclusion criteria, in other words, were having intact mental abilities and not experiencing conditions related to cancer cognitive disorders such as delirium (Breitbart & Alki, 2009) or cognitive failures due to chemotherapy (Hurria et al. 2007). The screening was undertaken by the Palliative Care Team -a multi-disciplinary team consisting of a GP, a nurse and a psychologist- and upon their agreement information was given to the patients for the research run at the premises of the Unit by an experienced Counselling Psychologist. Candidates, next, were handed the Participation Information Sheet while they were informed that they would be asked a single question to be answered in whichever way they wished.
Four participants were recruited who were interviewed for at most an hour of duration. The characteristics of the participants are the following:

Name	**Sex**	**Age**	**Marital status**	**Educational level**	**Ca**
Chris	M	64	Divorced	Primary education	Lung cancer with metastases
Barbara	F	74	Widow and now living with male partner	Secondary education	Bowel cancer
Adam	M	54	Single	Further education/ University degrees	Tonsil cancer with bone metastasis
Dora	F	53	Divorced	Primary education	Hepatocellular cancer

Two males and two females were interviewed, with ages ranging from early to late adulthood, from various educational levels and distinct marital statuses. All of them at the time of the interview were able to walk with minimum assistance, and had been screened for not having cognitive impairments.

Interview procedure

Candidates were informed about the study that was run in the Unit, were given brief descriptions about its nature and how it could be of benefit to them, were given copies of the Participant Information Sheets, and were advised that if interested to arrange an appointment with the researcher –me- on their next visit to the Unit and the doctors, which usually took place every fortnight. On meeting them for the interview, I welcomed them and I explained the rationale, the aim and the nature of the study in plain language. They were told that it is a study which aims to identify the needs and concerns of individuals who enter Palliative Care. I reminded them that it is required that we tape our interview session, that the interviews will be transcribed verbatim, safeguarding their anonymity and only extracts of their accounts will be utilised in the actual study. Then, participants were given the consent form (Appendix 2) to sign and a copy to take with them.

The interviews were initiated by me asking the single question and recommended that the question be answered in whichever way they wanted. The interviews evolved at the pace of the participant and the topics covered were decided by the participants themselves. No interview looked like the next. Each interview had its own distinct dynamic which at times felt like nothing common would come up in my analyses. I was sensitive not to assume excessive vulnerability of the participants and so I maintained an open attitude towards them and their concerns leaving it to them to explore their personal issues –thoughts, fears, worries, memories- related to their existential position. Adapting an informed client-centred therapy attitude by myself towards all of the participants facilitated the unfolding of personal material in an atmosphere marked by empathy and unconditional positive regard.

The interviews were concluded when the topics of concern were exhausted and I sensed that the participants had covered what they wanted to say. I thanked them and handed to them the Acknowledgement Sheet which recapitulated the purpose of the study and how the produced material will be handled (taped and transcribed), how anonymity will be safeguarded, and that if in need of psychological support post-research, counselling was available.

Reflexivity on the research procedures and analytic strategy

Finlay (2002) wrote: "as qualitative researchers, we understand that the researcher is a central figure who influences the collection, selection, and interpretation of data" (p. 531), and I will utilise this section to reflect upon my own contributions at all stages of the research process. Doing qualitative research means that it is the researcher with her/his knowledge, experiences, and personal meanings who sets the stage and invites participants to unfold their own knowledge, experiences, and personal meanings on a topic. Meanings of both the researcher and the researched are negotiated within the context of qualitative research and the unique understanding that is developed in an interview is an end result that bridges both parties' inputs. This section, therefore, will be a reflection on me as the researcher and my own contributions to the study.

The idea for this research came out of a need of mine Ihad since I was a Trainee Counselling Psychologist and was doing my clinical hours in the Palliative Care Unit, in Athens, Greece. My need was to learn more and accordingly be more effective as a therapist to the service of individuals who are approaching the end of their lives. Whilst in training I relied a lot on my clinical supervision on how to perform therapeutic work with these clients. As I was building up more trust on my therapeutic abilities in working with this client group, I realised that I wanted to investigate their special needs and find a way to give them a voice. This research idea was born out of my own difficulties in trying to find a way to connect with the dying individual, as the available resources were both limited and case specific.

The realisation of my idea into a research project had to resolve important challenges. The first challenge was that it was a sensitive research designed to be run on a vulnerable population. With vulnerability should be understood that the targeted individuals experience diminished autonomy due to physiological and psychological factors but also because of changes in their social status (Silva, 1995 in Liamputtong, 2007). Coyle and Wright (1996) question the ethical approval given to researchers who are not sufficiently equipped to address sensitive issues which can cause resultant distress. Verging towards ‘unethical’ (ibid, p. 432) practice, the researcher who does not know how to facilitate emotional states, who does not know how to be supportive, understanding, accepting, and non-argumentative, can do harm. It is important therefore that not only the researcher but also the researched benefit from the interview process. In order to safeguard the best interest of the participants my research design - as mentioned earlier- specified that only one question would be asked which could be answered in whichever way the participant wanted, whilst the unfold of the information would rely upon the utilisation of basic counselling skills of the humanistic psychotherapy ethos.

During the recruitment phase of the research I spent time explaining and guiding the nurse and the doctor of the Palliative Care Team of the Unit, who would be doing the recruitment, on the purposes of the research as that it would be of importance to further the knowledge we have on the needs of the dying individual, and also of the possibilities of being a rewarding experience for the individual. The communication between me, the nurse, and the doctor was very good as we knew each other for some time and have worked as a team together since my training with them. As I was told, the individuals who were approached volunteered their participation and none rejected it.

The scheduled appointments I arranged with the four individuals who were approached for participation were held at the premises of the Palliative Care Unit at convenient times to them. I proceeded with the steps that I described in the previous sections, including the reassurance that they had read the Participant Information Sheet, the signing of the consent form, and the agreed operation of the tape recorder. My stance towards them was marked by an open and warm attitude as well as by demonstrations of my unconditional acceptance of them through being attentive and responsive to whatever they felt like bringing up with me. The first interviewee was complaining of suffering from tremendous pains and was reserved at the beginning of the interview, only talking about his condition and the difficulties in managing his pain. When I asked him what is of importance to him to include in this research, he opened up. The second interviewee was emotional at the beginning and with her we made contact over her feelings of disempowerment. With the third participant from the start we spoke about himself and his personal history. The interview with the fourth participant developed smoothly and at the end she expressed a feeling of completion, of having said everything to me.

Evaluating the quality of the interviews, I made a serious decision with respect to whether I should recruit more participants. I decided that I would value all four interviews as they developed, each one seen under its own light and in its unique dynamics. Not all participants, however, spoke about the same things, to the same extent or depth. That was another big challenge I faced when analysing the texts, of how I was to find common ground in this material that looked so different to each other. This is where I felt that the unstructured interview schedule I followed, which was so carefully planned, respecting the sensitivity of the researched material as well as the vulnerability of these individuals, was verging towards a serious difficulty of extracting common themes. What kept me from considering my project a failure was my curiosity and my feeling that something of importance had taken place in these interviews. My curiosity led me to proceed with the IPA analysis anyway following the guidelines of Smith, Flowers, and Larkin (2009). I worked on each interview with the same enthusiasm, extracting its themes line by line, meticulously and thoroughly. When I started abstracting away from the particular data and handling the themes I started developing arguments about what was going on that was common to all interviews. I found that the superordinate themes were not only interesting but also revealing of central aspects of the experience I was studying. It was also very rewarding personally that I was able to conduct a worthwhile piece of research.

Having developed my IPA superordinate themes, I returned back to the data to come up with their exact phrasing. Working on a model for the translation of the data from the Greek language to English, I followed Fryer et al.’s (2011) suggestions whereby the analysis of the data should be done in the language that was spoken. Greek is my mother tongue and I have been raised and live within Greek culture, whilst my knowledge of the English language and British culture is really good as I have graduated from British universities and institutions. I felt secure in undertaking the translation myself and consulting with a native speaker of English when difficulties in the translation arose. Of the first decisions to make when translating is whether to follow a ‘literal’ or a ‘free’ translation (Birbili, 2000) model. A literal translation performs a word-by-word translation and could be seen as doing more justice to what participants have said which can, however, hinder the readability of the text (ibid). On the other hand, the free translation model which shows greater care for the readability of the data runs the risk of losing information from the original text (ibid). Consistent with the social constructivist view on language which a Foucauldian viewpoint supports, language should not be considered as a transparent medium of meaning or that “the same meaning in the source language can be found in all target languages” (Larkin et.al. 2007, p. 468). Instead, each language has abilities to create unique formations of meaning and, accordingly, not only the visible meaning but also the hidden meaning - stemming from the particularities of the distinct culture - should be cared for in the translation of a text from one language to another. With these two differentiations in mind - between literal and free translation and the visible versus the hidden meaning of a language – I approached and proceeded with the translation of my data. The translation I developed tried to do justice to both what the participants said exactly and the cultural particularities of their sayings, the equivalents of which I tried to find so that the English reader could understand and relate to them. For instance, I tried to keep the poetic style of expression that one of my participants employed, trying to translate it in the style of poetic expression in the English language, producing something of the sort “I’ve lived like an eagle, I’ll die like an eagle” instead of “I was an eagle, I’ll die like an eagle” which is the exact translation from Greek.

Immersed in my data, coding and translating, I started making refined observations about and around them. My enthusiasm for qualitative research had familiarised me with the possibilities different methods offer. The data analysis I was performing revealed a pattern that could not be caught by IPA. A very important and non-dismissible discursive construction was deployed by one of my participants which affected the whole structure of his narrative. Through discussions about his serious health problem with knowledgeable experts, the participant was familiarised with the discursive construction of cancer as being “psychosomatic”. The method that could capture and enlighten how the cancer discourse is constructed, is Foucauldian Discourse Analysis. FDA can reveal the discursive resources within a particular culture and give insights into the ways in which these set up subject positions (Johnson et. al. 2004, p363), in my case the subject position of the patient who is to be blamed for his cancer. I consulted my Supervisor at this stage and we decided that I would also undertake an FDA analysis on the data.

Doing a Foucauldian Discourse Analysis means first and foremost opening up the picture of the topic of interest and to start looking at the social and the historical. The exercise for the mind in doing an FDA is to capture how we have come to think about phenomena the way that we do. The Foucauldian analyst invites scepticism into his/her system of thought, speculating about the very conditions of what is accepted as true. Influenced by my readings which were rich and diverse, and following the guidelines of doing FDA according to Willig (2008, 2012, 2015) [presented in greater detail in the sections that follow] I believe I was able to shake off the well-established categories we use in understanding and speaking about cancer, death, and dying, and trace the distinct discourses we most often deploy.

The last stage of the present research had to do with managing its methodological issues –both epistemological and ontological- when utilising analyses from distinct paradigms, as phenomenology and discourse analysis are. It is fairly recent that the joining together of qualitative methodologies from different epistemological paradigms has been introduced and attempted. I would like to note that the turn to the blending of various analysing methods is not an ambition of the researcher. Being informed by the kind of knowledge each qualitative method can provide, the researcher can listen more carefully to his/her data and appropriate his/her methodological decisions by applying more suitable methods of analysis. I approached the researched material carefully to consider what was expressed in my participants' accounts and I discovered material that was suitable for a different kind of analysis, namely FDA. I would say that my data guided my decisions, my data guided me.

Reflexivity on myself and the ‘emotional labour’ undertaken during the research

‘Emotional labour’ theory was developed by Hochschild (1983) and refers to the management of emotions during work done for a wage considered an indispensable part of the requirements for the particular occupation. The requirements of the job usually involve face-to-face interaction with clients, towards whom an emotional state is intended (Steinberg & Figart, 1999 cited in Dickson-Swift et al. 2009, p. 63). Flight attendants, for example, are required to manage their emotions in favour of a pleasant and welcoming attitude towards clients. Acknowledging the importance of emotions in research and the emotion work the researcher undertakes, the western philosophy of science is challenged as it “judges emotions to be the anathema to academic research” (Dickson-Swift et.al., 2009, p. 63). This section focuses on the emotion work I undertook during this research, arguing that the distinct type of information that I provide here reveals its emotional impact and adds to the transparency and trustworthiness values for any qualitative research.

The main attitude required of a researcher by a research on sensitive topics should reflect considerable control over the processes the participant is invited to take part in. The research processes communicate to the participant that the framework can be trusted, as it meets the requirements of being scientific and not ordinary interaction. The Universities, the Ethics Committees, the Hospital, add to the authorisation of the researcher to conduct and profess the process. I felt comfortable in representing all these authorising units as they approved of my professionalism. However, this professional face had to be dropped when in contact with participants. While interviewing, I felt that I had to give to the participants the confidence that they were the experts on their own experience of which I was interested in learning about. This is a challenging switch in the interaction with an individual - which I also experience in my clinical practice- of communicating effectively that it is the individual, and his/her thoughts and emotions, which are of interest and not my expertise in giving advice on how another person should be. During the interviews quite often I felt that I had to reassure my participants that they could express themselves - in whichever way they wanted - on whatever they would like to include as an answer to my research question. This freedom handed to the participants was received with scepticism. They often interrupted their speech to ask me about my interest in what they were saying and every time I reassured them that I was interested in what they wanted to talk about.

As the interviews focused on deeper issues that had to do with the way each one related to his/her impending end it was very challenging to maintain a facade of emotional control and not allow my sadness and tears to be shown. I chose to remain by their side, to be with them, without revealing that it was painful to me also to realise that soon these individuals would leave this life, their loved ones would experience their absence, how empty their place in the world would be. Thoughts full of feelings went through the whole of me, which I tried to control and suppress, focusing on the here and now of my interaction with the individual. These thoughts and feelings became all alive again when I was doing the transcription of the interviews. Tears, questions about the futility of things, thoughts about the generosity of my participants in giving me their wisdom, physical exhaustion, coming to terms with the contradiction that I was doing this research with a direction towards life while my participants were moving towards death, and most of all handling their material with appropriate care as to cherish the trust they had shown to me, were some of the emotional reactions I went through and which I found myself in need of managing effectively.

Standing with empathy next to another person who is suffering and trying to carefully work with him/her on something that will be of value and from which the person can benefit (Rowling, 1999) is not easy to accomplish. The researcher should have clear in his/her mind the difference between empathy and sympathy, whereby empathy is the ability to feel 'with' another whilst sympathy is feeling 'for' another (ibid, p. 179). Empathy presupposes a degree of distance from the material of the suffering individual that allows for the provision of support to the individual. Sympathy, on the contrary, does not allow this distance; the person who experiences sympathy towards the suffering of another gets involved massively with the emotional material of the other person, loses the boundary and feels overwhelmed. My training in systemic psychotherapy and my personal analysis taught me this crucial difference and I can still recall my training tutor's words telling me: '- this is not yours' hinting that I was getting too involved with the material of my client. Nevertheless, the ‘art’ - I would say - of empathy is a process that has its own dangers. Psychotherapists’ compassion fatigue (Figley, 2002) has been spotted as the type of burnout pertinent to the professions of psychological therapies and is associated with ‘a sense of helplessness’ (ibid, p. 1436), exemplified as feelings of frustration, impatience, anger towards clients, increased boredom or lack of focus, hoping for certain clients to cancel their appointments, increased fatigue, decreased motivation, and experiencing decreased fulfilment and enjoyment with one’s work (Barnett et al. 2006 cited in Barnett, 2007). Compassion fatigue comes about when the therapist overlooks or ignores his/her own emotional needs considering them not to be as important as those of his/her clients. Therapists - much like all people- have their own ‘blind spots’ that can bleed when triggered. Self-care efforts are important and should be seriously attended to. These efforts can include, among others - along with personal therapy and supervision (Barnett, 2007)- rest, time-outs, and even the use of humour (Shuler, 2001 cited in Mann, 2004).

Conducting this research even though I did not experience compassion fatigue I could feel that I needed to rest after each interview to recuperate my emotional strength reminding myself that each interview was successful as the participant was able to take something of value for himself/herself. The participants were emotionally touched up gently as I wanted to touch them, they were not isolated but were listened to, and they were not objectified by my efforts to research a topic. All these aspects I found very rewarding for my performance and strengthened me. These thoughts that I had are very similar to what Shuler (2001 cited in Mann, 2004) advises as a self-care strategy which reframes or cognitively restructures difficult experiences into demanding competencies that are sufficiently developed. This coping strategy was of particular help to me as I am very much motivated towards the care of others. The unique constellation of events of my personal life familiarised me since my early youth with loss, with losing beloved others. Dimoula (1971), a Greek poet, wrote: “I’ve learnt to find hands and let go of hands”, and her words resonate with my experience of loss, of what it means to me to love, to love deeply and being called to live onwards without my loved ones who meant the world to me. It is true that living after a loss is painful; it is true that you doubt your emotional strength in living a life empty from the beloveds’ presence. Most of all it is true that the whole world changes as it becomes strange, rough, a poorer world. These marks –my own wounds, or ‘blind spots’- are both my biographical identity and my long struggle in letting go of the beloved ‘hands’ that departed from this life and finding other hands to love again. This is the story of my own life, stated briefly but I believe in dense meaning.

It is also important to include in this reflexivity part the fact that during the phase of analysis of my data I was diagnosed and treated for breast cancer. All of a sudden I was relating to my material from an insider’s point of view. ‘Insider research’ has been defined as the study of one’s own social group or society (Naples, 2003 cited in Greene, 2014) seen from the point of view of anthropological ethnography. It has been argued that there are both advantages and disadvantages in insider research. The most important advantage of insider research is the better understanding of the cognitive, emotional and psychological precepts of participants (Greene, 2014). My participants -in my case- became more familiar as now I could not only know what they had gone through but also experience treatment effects, the anxiety over cure and the frequent medical testing in which you come face-to-face with your desire to live a longer life. An important disadvantage, on the other hand, is researcher bias whereby the researcher’s personal beliefs, experiences and values influence the methodology, design, or the results of the study (ibid). Awareness of the potential of personal biases creeping into the research through conscious and effortful reflexion, can avert the biases effects and even reverse them into assets if laid out in the open and discussed thoroughly. In my case, I treated my personal experiences as additional information to the investigated experience, especially with respect to the threats to identity the illness poses and the needs for identity reassurance by significant others. The support I received from my Supervisor, Professor Carla Willig, was crucial for my continuing and completing this research project. I was turning to her for support and encouragement which I received plentifully. I will never forget when, having finished the protocol treatments for breast cancer, I was able to travel again and have a supervision session. Seeing her through her glass door I found it very difficult to control my not becoming emotional and a sob came out of me revealing both my emotional pain and a feeling of relief. I could recognise myself again!

I would like to turn now to the investigation of the theoretical and methodological assumptions of the present research which employed both Interpretative Phenomenological Analysis and Foucauldian Discourse Analysis for the analysis of four interviews given by individuals who had incurable cancer and entered palliative care, experiencing, therefore, the imminence of their end.

Methodology

Theoretical and methodological assumptions of Interpretative Phenomenological Analysis (IPA)

Interpretative Phenomenological Analysis (IPA) is a research method devised particularly for psychology and psychological phenomena (Smith, 1996), and sets as its objects for investigation all those experiences that are of some significance to an individual. Major life transitions are usually considered as these significant experiences since they necessitate from the part of the individual a “considerable amount of reflecting, thinking, and feeling as they work through what it means” (Smith, Larkin & Flowers 2009, p. 3). There are at least three assumptions about human nature but also about the nature of human communication that are implied. First of all is the premise of the human capacity for sense-making of their experiences to be unravelled in private and communicated to the others at a second stage. Second, the other, the researcher, in trying to make sense of the individual with whom s/he communicates in order to get to know what the participant is experiencing, is involved in a double hermeneutic, a double interpretative act, in relation to his/her own more refined sense-making of the less refined sense-making that the participant engages in. Self-consciousness and systematicity are the two principles that distinguish the less from the more refined sense-making. Third, through our shared humanity we are able not only to communicate our experiences but also to relate to the other by proximity and are able to explore similarities and differences with the experiences of other people.

IPA is *phenomenological, hermeneutic* and *idiographic*. Presenting brief histories for each of these terms that would assist their better understanding, Husserl was the first philosopher to have talked about the phenomenological attitude of knowing ourselves and the world through the intentional structure we can experience when we think. We are able to reflect upon our own process of thinking, turning our gaze inwards, that is, away from the objects of the world and towards our perception of those objects (Smith, Larkin & Flowers 2009, p. 12). In order to reach the terrain of experience, the individual should be cautious of the need to bracket off preconceptions and assumptions about the nature of a phenomenon. The aim of phenomenological inquiry is to reach the experience per se, this "set of invariant properties underneath the subjective perception of individual manifestations of [something]" (Smith, Larkin & Flowers 2009, p. 14), of any phenomenon.

While Husserl established a method of investigation of the contents of consciousness, Heidegger reflected about the content of human consciousness per se. This content is no other than Being (Dasein) itself, the existential givens of our being-ness. Which are: our worldliness, or our openness to the world "with the practical activities and relationships which we are caught up in" (Smith, Larkin & Flowers 2009, p. 17), our capacity for reflexive awareness distinct and exclusively referring to human beings and always directed towards meaning-making, with a clear sense of our selfhood and our separateness from others, but always in relation to something and someone (which is our fundamental intersubjectivity). What Heidegger contributes to phenomenological inquiry is that it is a hermeneutic method, in other words, interpretative. Interpretation is not a secondary act but an indispensable and inescapable condition of the human Being, "which … exists as long as it interprets" (Thanassas, 2004, p. 50). Accordingly, the very Phenomenology of Being is hermeneutics wherein interpreting and understanding acquires an existential meaning. The hermeneutic understanding of any text or whichever object of our experience, is cyclical (Smith, Larkin & Flowers, 2009, p. 28) moving from the part to the whole and then for understanding the whole we move back to the part and the particular. Hermeneutics in that way repudiates the project of grounding knowledge in some "indubitable, self-justifying acquaintance with things" (Smith, 2005, p. 283), or of us having unmediated access to reality. Instead, in our attempts to know something we interpret.

IPA is also idiographic, that is, it is concerned with the particular (Smith, Larkin & Flowers, 2009, p. 29), the particular of human experience in its meaning making dimension, and this is presented in its respective depth. In contrast to the ‘nomothetic’ approach prevailing in psychology for most of the years of its development and establishment, the phenomenological tradition offers detailed understanding of individual cases. IPA does not make claims at the level of a whole population aiming to establish general laws of human behaviour (Smith, Larkin & Flowers, 2009, p. 29), but it attempts in its practice to establish a distinct understanding of experiential phenomena: an understanding that will do justice to the depth of the experience of an individual through detailed accounts. IPA is not theory-driven with preconceived hypotheses to be tested, but its analysis allows for an experience to be expressed in its own terms rather than according to predefined understandings (Smith, Larkin & Flowers, 2009, p. 32). What IPA produces and poses as new knowledge are patterns of meaning (Smith, Larkin & Flowers, 2009, p. 38) generated by individuals who reflect upon their experience.

The capable IPA researcher, in analysing this kind of material can come up with accounts of meaning-making experiences that can add, challenge, even refute what we already know about a phenomenon. The reached patterns of meaning as selected via small and purposively-selected samples of individuals who experience a phenomenon, have the ability to present an experience not only in greater depth but also in greater variation. In IPA we look both for shared themes but also for variations of themes that not only challenge the interpretative abilities of the individual researcher but the way that the very phenomenon has been understood so far, though from within overshadowing generalisations.

Theoretical and methodological assumptions of Foucauldian Discourse Analysis (FDA)

As its name suggests, Foucauldian Discourse Analysis (FDA) is devised along the understanding of the social and the individual that Foucault introduced in his works of archaeological and genealogical historiography. The archaeological historiography of Foucault allowed him to discover periods of “epistemic convergence across related sciences and disciplines” (Conway, 2005, p. 241). These periods shared significant agreement on the general conditions and criteria of truth, knowledge and certainty

(Conway, 2005), forming distinct discursive practices of science. His genealogical investigations, on which he focused in his later works, studied the intricate power relations that inform discursive practices. The pairing of power and knowledge that Foucault saw in discursive practices was historically looked at in the definitions of madness, criminality and sexual deviancy, and accordingly he accounted for the origin of their institutionalisation.

Foucault, however, admitted that the goal of his writings had not been the analysis of phenomena of power but to create a history of the different modes by which human beings are made subjects (Foucault, 1982). He provided three modes of objectification of the subject in history. The first objectification of the individual subject came from societal "dividing practices" such as the isolation of the lepers in the Middle Ages or the confinement of the poor and the insane in the eighteenth century, but also the rise of modern psychiatry in the hospitals, prisons, clinics of the nineteenth and twentieth centuries. The "dividing practices" are techniques of domination that combine science with the practice of exclusion, offering to the subject both a social but also a personal identity (Rabinow, 1991, p. 8). The constituted subject, of these works of Foucault is that of a victim caught up in the processes of objectification and constraint as is the case of prisoners and of mental patients.

The second mode of objectification of the subject is through "scientific classification". Here the relation to domination is more "oblique" (Rabinow, 1991, p. 10) and the connections drawn are not as direct as the previous mode's works suggest. This second mode of objectifying subjectivity follows the historical way in which discourses are transformed into disciplines. Linguistics, economics or biology -'the human sciences'- according to Foucault (1966) had been considered as progressing and refining themselves through history. Foucault (1966), on the contrary, found abrupt changes in the course of their histories that display 'conceptual discontinuity' (Rabinow, 1991, p. 9) from the respective disciplines that preceded them. What we draw from this second mode of the constituted subject is that there can be no single theory about a universal subjectivity to be discovered, or as a matter of fact the ambition for a trans-historical subject is fallacious. How people think, talk and theorise about themselves "as language users, productive labourers and material entities helps shape the capacities and limits of their subjectivities" (McWhorter, 2005, p. 224), and are both culturally and historically relative.

The third mode of objectification that Foucault worked on was "subjectification". He studied all those processes of self-formation in which the person - in contrast to the two modes already discussed- is active (Rabinow, 1991, p. 11). This self-formation has a long genealogy and Foucault was principally concerned with isolating those techniques through which the person engages in active self-formation (Rabinow, 1991, p. 11). Included in the modern, post-Enlightenment society, example of these techniques is the very process of self-understanding, as mediated by an external authority figure, be s/he confessor or psychoanalyst (Rabinow, 1991, p. 11). Overall, they can be considered as "ethical practices" (McWhorter, 2005, p. 224) since they aim at establishing oneself in an ethos of a self-aware life.

Foucault, in his investigations about the ways subjectivity has been constructed in history and for which he found the three modes of objectification, operationalised the concept of discourse. Foucauldian Discourse Analysis deploys this fundamental concept of historically dominating discourse. Discourse and discourses are historical constructs whose power influences all levels of our social and private lives. At the level of the individual or from a micro-sociological perspective, discourses enable and constrain what can be said, by whom, where and when (Parker, 1992). At the level of the wider social or from a macro-sociological perspective, discourses privilege versions of social reality which legitimate existing power relations and social structures (Willig, 2015) and are exemplified in institutions. FDA, therefore, is a historical inquiry that aims to pinpoint mechanisms of power by offering a description of their functioning and the ways they define specific subject positions for the individuals addressed by the discourses (Arribas-Ayllon & Walkerdine, 2008). It is this recognition of the "genealogical background" (Arribas-Ayllon & Walkerdine, 2008, p. 100) of the object of study, that is, the "wider politics" that the phenomenon belong to, (Arribas-Ayllon & Walkerdine, 2008, p. 101) that is of interest in a Foucauldian Discourse Analysis, inviting us "to think differently about the present by taking a position outside our current regimes of truth" (Arribas-Ayllon & Walkerdine, 2008, p101).

In practice, the FDA researcher is interested to know the “discursive economy” (Willig, 2015, p. 154) of the phenomenon under study, that is the different sets of statements that construct an object, and by consequence the array of positions prescribed for the individuals to occupy. “Discourses offer subject positions which, when taken up, have implications for subjectivity and experience”, Willig writes (2015, p. 154), reminding us that discourses weigh heavy with predetermined positions for subjectivity which have implications for what, how, and the way they speak about experience. The way to proceed with FDA is through the study of language and language use. For FDA, the power of discourse is so extensive that it can construct the very position of the speaker in what can be said or not, felt or not, done or not. Accordingly, the discursive constructions reached at an FDA have implications for the ways we experience ourselves, our own selfhood, and what we feel as our subjective experience. When we deploy a discourse we are entangled in repertoires of meaning that affect the nature of our experience but also what we feel about ourselves, and we can actually feel that we are “‘sick’ or ‘healthy’, ‘normal’ or abnormal’, ‘disabled’ or ‘able-bodied’” (Willig, 2015, p. 164). Willig’s model (2008, 2015) of FDA has been followed in the present study.

The framework for combining the two methodologies

I argue that the two methodologies I employed not only enlighten different aspects of the phenomenon of death and dying that I studied but that they can also work complementarily to each other, each one contributing to our understanding of what is missing from the other.

Foucauldian Discourse Analysis utilises a social constructionist perspective where the social, the cultural and the historical situatedness of a phenomenon are underlined. FDA opens up our horizons of understanding with respect to the historically relative nature of things, the historicity of the phenomenon itself, and the “analytics of power” (Foucault, 1975) involved. The effects of dominant discourses on subjectivity are tremendous; not only do discourses prescribe positions for the subjects within their spectrum of influence, but they also dictate the kind of subject that is appropriate to deploy them. The individual subject is restricted with respect to his/her capability of independent agency to such an extent that unless consciously reflected upon and resisted there is nothing other than the subjectification that the discourse allows. Seen through the lens of the concept of discourse, the individual subject is a historical end product with specific abilities and limits. The deconstructive critique of postmodernism casts doubts upon the individual of modernity by shaking the grounds of truth about his/her rationality, autonomy, and fundamental unity, making him/her a product of the modern scientific-technological paradigm (Lewis, 2003). Conceptualizing the individual from a social constructionist perspective we use the word 'individual' under erasure since all that we considered as indicative of its nature are discursive prescriptions. Nevertheless, the individual is capable of reflection and it is at this level of personal experience that the individual can resist the restraining subject positions of a discourse, or choose between conflicting discourses.

It is in this opened space of experience that Interpretative Phenomenological Analysis is able to contribute. IPA enables us to explore the quality of an experience and in this way achieve a better understanding as to 'what it is like' to be living through a particular phenomenon. IPA is able to enlighten the process of self-formation and to answer questions that FDA cannot account for as to how we can resist dominant discourses or allow alternative subject positions to emerge. Late Foucault, when facing this impasse, spoke about the need for self-stylisation to a work of art (Foucault, 1983), through the "laborious cultivation of skill, knowledge and insight" (McWhorter, 2005, p. 225) in order to be able to think differently from the way society, culture, and personal history have led one to think.

The argument for the complementarity of these two methodologies rests exactly on the limitations each one has: the disregard of the experiential in FDA, and the disregard of the social in IPA. The epistemological questions with respect to which we can support the complementarity of IPA and FDA are discussed next.

Epistemological reflexivity

In order to clarify the epistemological basis of the present research, I am making use of the three epistemological questions that the researcher should be able to answer in relation to the quality of knowledge s/he aims at. Following Willig's (2008, 2012) invitation to researchers to frame their epistemological position, we should be clear first of all about the kind of knowledge that the methodology is able to produce. My answer to this first epistemological question is that my intentions were and are to give voice to people's accounts that are close to the end of their lives, having been given a definite time limit as the passage to palliative care signifies. These subjective experiences are invested with the validity of *phenomenological knowledge*, that is, no claim is being made about their accuracy or as reflecting something real that holds true for all people in related situations, as for example the theory of the stages of grief does. It is knowledge about "the quality and texture of the participant's experience" (Willig, 2012, p. 11) that allows individuality of the experience, hints towards broader and new concepts, while it admits a different level of awareness to the individual who speaks a language of immediacy without theories or pre-given deductive concepts. For instance, individuals in their speech communicate their experience as it is immediately felt. The qualitative research exercise for the researcher is to decipher, to make sense of, these experiential accounts without subsuming their novelty under verifiable hypothesis drawn from existing theories; in other words, the qualitative researcher should engage in a deductive type of reasoning. Again utilising an idea of Willig's (2012), the phenomenological researcher assumes that there is more than one world to be studied and a phenomenon can be experienced in many different ways producing something of uniqueness for each individual.

Yet, as we people are able to communicate with each other with words and through language, we are not solipsistic beings living in closed-up vacuums. Language carries significations and social representations that we all share in our understanding. There are more or less stable linguistic structures that not only guide our expression but also what we express through them. A *social constructionist knowledge* is a knowledge of the way things are spoken about, of the socially available ways of talking about a phenomenon that shape the way we construct and talk about our experience. Even more, the use of language carries certain ways of constructing the world, which not only are our common ground for understanding each other but also construct our very experience through the means it offers to us. While socially constructed knowledge usually subscribes to relativism, where there is nothing outside of language, nothing that stands independently from language and its social constructions such as an independent reality described more or less truthfully, still we can talk about qualified positions of relativism. To answer, therefore, the question of what kind of knowledge I assume my research to produce, I would say that it will aim to uncover those all-powerful constructions, or discourses, these individuals who know that they are dying deploy in their accounts.

The second question has to do with the assumptions that methodologies make about the world (Willig, 2008, 2012). ‘What is there to know?’ we ask here and we want to know about the nature of the world that we study, or my methodology’s assumptions about the ontological status of things in our world. What I do not assume is that there are universal psychological processes common to all people that my research will discover. What I talk about are the experiences of my participants as they come up in their, loaded by discourses, accounts. Experiences and not facts about their personal worlds or their psychological condition, I explain, and nothing more than that. And these experiences are then considered for possible commonalities so as to form a coherent narrative that would speak about them. Accordingly, the ontological position for my research is not a naïve realist one. Subscribing to the respective assumptions of both phenomenology and social constructionism, the world of my study does not have the fixedness of a hard reality to be discovered. Instead, I am aware that my findings are historically relative to the world I live in, to the year and era that I live, relative and relevant to the available discourses to the times we live. With respect to the phenomenological assumptions made in this project, the experiential worlds to be presented carry a mark of individuality that by definition undermine the generation of any law-like conclusions.

The third question concerning the epistemological stance for any research project (Willig, 2008, 2012) asks about the level of involvement the methodology assigns to the researcher. Interpretative Phenomenological Analysis by its definition promotes the role of the researcher’s involvement to that of being indispensable. The researcher is not only involved in the acquisition and direction of the researched material, but also actively interprets what s/he finds by referring to his/her own understanding. Reflectively recognizing how the researcher is actively entangled in the knowledge production of a given piece of research is a necessary process in qualitative research which enlightens the whole project. With respect to social constructionist methodology, the researcher co-constructs with the participants an understanding of where the participants stand in relation to prevalent discourses. More specifically, the researcher has to be reflective about the way s/he is positioning the participant and how this might have shaped the interview (Willig, 2012).

Ontological resolution: the case of Critical Realism

The two methodologies employed in the present study propose two distinct epistemological points of view with respect to the kind of knowledge they produce. In addition, they are driven by two distinct ontological positions with respect to the nature of the world and external reality they assume. Interpretative Phenomenological Analysis in assuming the privacy of experience subscribes to an ontological position with respect to an independent reality of private thoughts and feelings adhering to an ontology that leans towards realism (Finlay, 2009). With respect to language, IPA treats language as a more or less transparent medium that can give access to subjective feelings and experiences. Finlay (2009) rightfully asks how phenomenology can survive in the postmodern world of plurality and historicity which supports a relativist ontology. Acknowledging the merits of phenomenological research and having in mind that postmodern research with its emphasis on discourse has lost access to the personal and the experiential, phenomenological research can contribute answers to the questions that discursive research cannot; in particular why individuals adopt certain discourses and not others, how change at the level of the individual comes about, or how issues related to embodiment can be communicated and accounted for. Therefore, a qualified realist position and not naïve realism can be a standpoint for phenomenological research that would take into consideration that there are socio-political and historical aspects of reality which are not able to analyse and affect the way people talk and experience themselves.

Foucauldian Discourse Analysis’ ontological position, on the other hand, is relativist: there is no single reality to be grasped, approached, or reached independent from discursive constructions relative in history, communicated through language, limiting what can be said and done within the framework they form. There is no single world out there as realists argue, but numerous worlds, “numerous versions of the world” (Willig, 2008, p. 126) that do not stay constant for ever but are subjected to change and transformation. The impasses FDA faces by following a relativist ontology are with respect to the material aspects of our living which cannot be subsumed under the discursive. This non-discursive material aspect of our lives is generated by “relatively enduring structures that may be biochemical, economic or social (Willig, 1999 cited in Sims-Schouten, Riley & Willig, 2007, p. 103). Aspects of our living such as these have “extra-discursive ontology” (Sims-Schouten, Riley & Willig, 2007, p. 103), leading us to adopt a critical realist stance on ontological matters. Critical realism is this qualified position that allows for independent structures such as institutions, material conditions and factors related to embodiment to exist outside discursive constructions. The questions that relativist ontology cannot answer are: why an individual deploys particular discourses and not others, or how embodiment with its particular manifestations for each individual affect the individual, or how institutions affect certain living conditions with what they support or provide, or how material conditions (such as poverty or war) affect with extra discursive factors the lives of individuals.

Critical realism forms a space in which both methodologies can meet, and this is the ontological stance of the present research. Critical realism provides the ground for the blending of distinct methodologies by emphasizing that the point is not which methods should be combined with which, but that the decision should depend on explicit theorising about the research and the nature of the object of its investigations, providing the appropriate contextualisation of the forces and properties involved, paying attention to temporal sequencing and interaction of powers, and lastly, offering critical contextualisation of actors’ accounts (Elger, 2012). Accordingly, what will legitimate the pluralism of methods in a research project is on the one hand this knowledgeable attitude from the part of the researcher that there are extra-discursive realms that cannot be subordinated to discourses, and on the other hand, that the meanings humans attribute to their actions while being essential features of social research are not sufficient as there are social structures with real powers and effects (Elger, 2012) that constrain or enable the agential possibilities for action. These extra-discursive factors, these relatively enduring structures, that have been identified as operating in addition are the effects of embodiment (Cromby & Nightingale, 1999), the power of institutions, and materiality (Willig, 1999) whether biochemical, economic or social.

Analysis

IPA analysis

Superordinate theme 1: Presentation of the self
Subtheme 1: The medicalised body as identity
Subtheme 2: Review of identity and philosophy of life
Subtheme 3: Revival of early traumas

Superordinate theme 2: The experience of suffering
Subtheme 1: The somatic suffering – the excruciating pain
Subtheme 2: The limitations of cancer: getting familiar with the body that suffers
Subtheme 3: Negotiating terminal cancer

Superordinate theme 3: Issues around relatedness
Subtheme 1: Need for receiving and giving kindness
Subtheme 2: Dependency versus independence

Superordinate theme 4: Confronting death
Subtheme 1: Attitudes towards death
Subtheme 2: Thinking about life after their deaths
Subtheme 3: Speaking about death and the beyond

Superordinate theme 1: Presentation of the self

The most prominent characteristic in the speech extracts of my participants was their wish to relate to themselves by presenting who they are. The accounts about themselves and their course of life were detailed and comprehensive. The subthemes of this topic were that they introduced themselves through their illness, they proceeded with presenting their identity, and in a few of them there was a marked tendency to review early life traumas.

Subtheme 1: The medical diagnosis as identity

Participants introduced who they are by reference to their medical condition. Their self schema carried with it the trauma of the terminal cancer diagnosis, which is expressed in the deployment of medical terminology. The presented self-descriptions utilise medical terms, repeated in the sequence by which they had been introduced to them or had been experienced by them, revealing limited processing.

> "So, it [the cancer] started at the 3rd vertebra and the lung, after the robotics it was cleaned but after the sixth mon[-th], three months that the CAT [scan] was done, that is I started having pains … in the hip, the leg until up to the knee, so the CATs were done and it had left, it had moved down to the 10th and 12th vertebra, we did a treatment … at this moment that we are talking it has moved on to the cervical [vertebrae]… now I am undertaking treatment, 2nd day today, I did it and I just came out… I'll do 5-6 [treatments] just for a holding it back" (**Chris** 1.6-1.12 & 1.23-1.25).

The picture we get in this quote is of an individual bombarded by somatic experiences and medical vocabularies which he is trying to process cognitively and incorporate into his felt sense of and about himself. The individual reproduces what he has been told about his condition in a way that reveals vulnerability, futility and impotence (Frank, 1995, p. 97). The tense used is that of incessant present in a form of "and then" (ibid, p. 103) revealing that "consciousness has given up the struggle for sovereignty over [his] own experience" (ibid, p. 104) by coming up with meaningful abstractions of the type '-my situation has worsened despite having undertaken a series of treatments'. In short, the produced chaotic narrative attempts to communicate the "horrible" (ibid, p. 112) per se, difficult to follow without getting lost in the details that are provided with it.

With the same narrative characteristics, another participant presented her identity. Two extracts are presented from the same participant. The first is the initial introduction of herself to me in which we can see both the identity presentation at work along medicalised terminology, but also the chaotic characteristics of the produced narrative.

> "I have depression… I had depression before… I didn't go out I didn't want to, em I don't have friends, [I'm] only [with] my family, that is my sister and her daughters… I don't go out and I didn't go out before that is em and now it's even worse 'cause I'm sad now, very much so, with what has come upon me 'cause I feel very tired and I can't, I can't speak out" (**Dora** 1.1-1.8).

This second extract has to do with the narration of the terminal cancer diagnosis. Here we can follow some hesitant attempts at emotional processing of the terminal diagnosis.

> "...and so I was forced to get issued with my health booklet [for the poor] so that I can do medical tests
> Gina: mmm
> Dora: I said to myself it will be useful to me, I am just a human being, until I did the tests and I saw that I have [multi] cellular carcinoma that was it … [she is crying]
> Gina: Mmm (compassionate and in low voice) … it is as though you are saying this came up as well?
> Dora: (crying even more intensely)
> Gina: Yes
> Dora: This
> Gina: Mmm, does it scare you?
> Dora: It scares me, yes" (**Dora** 3.44-4.7).

Dora's introduction is emotional and moving. In her tears we read something more: emotional pain and fear. We get the sense that when the medicalised language is deployed the involved emotionality is emotional pain and fear. Both emotions are implied in the experience of a trauma, and this subtheme resonates with research that has stressed how deeply traumatic the terminal cancer diagnosis is (Willig & Wirth, 2018).

Subtheme 2: Review of identity and philosophy of life

There is a tendency in all of them to present and get a hold of their known identities. They speak about who they were, what they did, what they accomplished. They 'revisit' their known selves in a way that does justice to what they did in their lives and why they did it. They expose the philosophy of their lives. The narratives are detailed, aiming at unity and coherence with meaningful connotations that disclose the philosophy of their lives.

Barbara's identity gives supremacy to her role as a mother and her life project which was the establishment of a semi-independent house for young adults with learning difficulties like her younger daughter.

> "I raised four children and all four … had a good time. Knock on wood, none got left behind, that is, they developed, got an education, jobs, and my Fay [who has learning difficulties] even better than all [of them], she is my youngest, so I have this satisfaction… that is the fact that four children passed through my hands and all four of them did very very well isn't this satisfying? …and the most difficult my Fay who joined in [the society] properly" (**Barbara** 3.2-3.15).

> "We got together, eight of us, I brought them together, one of them was an engineer, myself not [involved] in the finances but in the overall coordination, for the finances we had assigned another person from the group and we d… we built this house [of semi-independent living for children with learning difficulties] that we are running for 20 years now solely handling the costs ourselves" (**Barbara** 2.2-2.7).

> "Because we are the No. 1 semi-independent living [house]"
> (**Barbara** 8.48-8.49).

> "...and they smile and they look happy when they say this is our home that... em... and may I say that if we hadn't established it and if my [other] daughter was here and married with her two children, Fay [her daughter who has learning difficulties] would have been dependent that is I say even if she took her to her house to take care of her, she would have been like a "tsonta" [a Greek word which literally means 'an attachment' and in the context of my participant's speech means that someone lives upon the grace of another] to her sister's house, now she has a personal life, while at her sister's house she would have waited for them to take her out, she would have waited for the one or the other (…) and so on and so forth" (**Barbara** 11.37-11.46).

The presentation of herself concluded with the admittance that the project of her life had been creating a comfortable and independent living for her younger daughter who has learning difficulties. In between her lines she explained that her life project was a dedication to a higher goal and she does not feel that she sacrificed her life. We get a sense of her philosophy of life in the quotes that follow:

> "I do not have another life, all my life was set up in this project"
> (**Barbara** 10.7).

> "Gina: Your life project?
> Barbara: Yes my life project! But I didn't, didn't, didn't (…) I have never felt deprived of anything, because whatever I was giving from myself I gave it somewhere I wanted to, I liked giving it away, so I wouldn't say that I sacrificed myself for anyone, I don't feel like "ah poor me that I sacrificed, that I did this or the other". No! It was my

> choice and it was an attribute of my disposition to do so" (**Barbara** 10.7-10.17).

Another point in Barbara's narrative that reflects her philosophy of life is her relationship with her daughter, and the principles that characterise this relationship. With noteworthy clarity in her expression that we usually see in the speech of people who have had long-term psychotherapy, Barbara says:

> "I wish for her to be pleased I don't care about anything else, because I am who I am and I don't expect from Fay [her daughter who has learning difficulties] nor from anyone else to make me someone, I am who I am… and why shouldn't I feel this way? I don't understand it, haven't I struggled my whole life, have I not worked for, like '800' years? … haven't I raised children? Took care of my elderly?" (**Barbara** 14.2-14.11).

The culminating point of her philosophy of life is this final quote by her. She speaks about her openness towards others and the enjoyment in having made relationships which are rewarding and where one stands up for the other.

> "...so it is well-known since forever that my door is open to everyone, the refrigerator is open for anyone who feels hungry, and so I was never left alone and I was always able to resolve my issues through all these people, because this is life: give and take and that's why I don't have any complaint" (**Barbara** 10.31-10.36).

Adam also presents himself through his accomplishments and professional achievements. He offered me detailed accounts of his accomplishments which portrayed both pride and contentment. He communicates a sense of fulfilment as seen in his opening statement:

> "You know, I am very happy with my life … I have worked hard, I have travelled a lot, I have studied" (**Adam** 1.11-1.15).

> “I started off working at a young age, when I first went to acting school, I was also working at a factory so that (...) I graduated from Veaki [acting school], then I enrolled at the National [theatre] (...) and afterwards I completed two programmes on [film] direction, that was before I got involved with the other… I enrolled at the University, I studied Political Sciences here, [in Greece], and then all alone again and working -who could support my studies anyway and stuff like this- I went abroad, I got a scholarship after the first year from Onassio [a Scholarship Foundation] and in this way… I’ve made it, three years, I went to Heidelberg in Germany, I studied anthropology, there that is after my studies in Political Sciences I studied Anthropology, I liked that” (**Adam** 1.18-2.11).

His philosophy of life is marked by the presentation of his abilities that gave himhigh reputation and professional prominence.

> “Because I had lived abroad and I was an anthropologist I was able to understand the specific culture of each country … let’s say the ways in which the Greeks of Argentina are different, the 3rd generation Greeks of the Soviet Union are different, and the ways the Greeks of Canada or of Australia are different, it is a puzzle any way you see it” (**Adam** 3.48-4.4).

> “I have worked very many years in radio, establishing a communication network, that is, everybody knows this radio cast: intellectuals, professors, businessmen, that is I am, from all over the world of Hellenism, even in Egypt, this is my job, daily” (**Adam** 4.8-4.12).

Dora’s presentation of herself moves in a completely different emotional direction. She has not done much to be proud of but the desire to present herself is there, genuine and no doubt frank.

> “I have depression [indistinct] and I had [depression] before [indistinct], I didn’t go out I didn’t want to go out, I don’t have friends, that is, only my family that is my sister, I get along with her daughters, I don’t go out” (**Dora** 1.1-1.5).

> “I don’t, I don’t talk I am not a person who… what I want to say even in my own family I don’t say much… I want to talk and I can’t get my words out I am not an open person, my sister talks and she gets them out of her chest, I can’t talk, I can’t” (**Dora** 1.8-1.20).

The third participant, Chris, similarly embarked on self-presentation. He was also informative, open and sincere. From the beginning he introduced his most prominent identity characteristic that he is a strong person who has faced up to difficult situations.

> “I am a really strong person, I have faced up to difficulties” (**Chris** 2.24-2.25).

> “...and tough jobs I have held, years before I was working in construction, later, for the remaining part of my life I worked as a waiter, lived at night, I am a very tough person with responsibilities and with… that’s why I know what pain means, if you don’t try hard you do nothing” (**Chris** 2.27-2.33).

He describes himself as a simple man who had been able to find his way in life, adapt to little and to plenty, to happy and to difficult circumstances. And this adaptability is of value which he recognises as such, more like an answer to the question of living.

> “I am a simple man… I was not, that is I didn’t want much, I didn’t, I could survive with little and with much ok I have lived my life, I can’t say I haven’t lived my life, both happy and

> difficult moments, and I have lived my life a little I haven't… and with my joys and with, that is I was a strong person" (**Chris** 3.34-3.40).

Chris's review draws on another attribute of his character that of being a 'devotee' - in Greek it is called "meraklis", the person who does everything with care and commitment-

> "In everything that I do I am a great meraklis [=devotee] you know what the word 'meraklis' [devotee] means? Everything that I do I'll do it 'meraklidika' [like a devotee], that's it. Otherwise I don't bother with doing it" (**Chris** 15.24-15.28).

He expresses a genuine gripe in the following two quotes in which he appears to be asking life itself for a reply. The tension is about accepting that he had always been a good person with a philosophy of life that valued relatedness and openness to the needs of others. It is for this reason he suggests that he deserves a good end to his life. Still he has to put up with the pain of cancer that has depleted his stamina and that feels much like a punishment.

> "A pleasant person I was always, always a person of amusement, always a person of mirth, with my house always open, you know, em... to be going through such pain this last year?, everything is over now" (**Chris** 3.44-3.47).

> "I never gave as to get with the goal of getting back, anything, if someone wants he'll give you, so, yes I feel that life has done me an injustice… yes, but we take life as it comes, this is life, it is not fair, this is how we should be taking it" (**Chris** 6.32-6.38).

Subtheme 3: Revival of early traumas

This subtheme has been noted in two out of the four participants. It could signify that there is a tendency of the internal emotional life to reprocess old traumas along with the present trauma of the terminal diagnosis. Old, mainly childhood, traumas are revisited in the participants' narratives suggesting that these traumas are emotionally revived. Here, the produced narratives are more chaotic, requesting from the psychologist-interviewer her contributions with knowledge or with emotional comfort.

> Adam: "[after the diagnosis of the tumour] I went to Agio Savva [Oncological Hospital] to a psychiatrist [name], I have another very good psychiatrist [name] anyway who is a child-psychiatrist, but even more… anyway a few friends that I respect –these are my friends- that is I never followed systematic psychotherapy and all that, but now while ill they helped me... em... because all of them, the oncologist without knowing anything and another oncologist and my other one told me and the psychiatrists that my illness is ... you die in six years, it incubates gradually within years and a great part of it is psychosomatic, that is, it is definitely psychosomatic" (**Adam** 4.28-4.46).

The psychosomatic hypothesis about the genesis of cancer leads Adam into a completely different frame of mind as is depicted in his narration. It takes him from the responsible, independent and achieving individual that he is, to a person who is willing to review his emotional pains throughout his life, without really understanding why he does it. I can sense the 'dizziness' that the psychosomatic hypothesis brings to him. We can note that he is losing his sense of agency over his life while he is trying to trace back over the mistakes of his life that have caused his cancer. This resulted in Adam's inability to think about his approaching death and to relate to himself in a more personalised way. This hypothesis decentres him, leaving him victimised and in emotional pain; he does not know how to handle it and he offers it up for explanations and contributions, even to his psychologist-interviewer. He stands on completely different ground than the other participants who, having not received this ‘intellectual’ explanation for their condition, are more able to create meaning and make sense by reference to more ‘holding’ (with the sense of providing comfort and consolation) philosophies which are psychologically more fruitful and which they are proud to share with others (e.g. Chris’s and Barbara’s philosophies of life from superordinate 1 subtheme 2).

With the above comment in mind, we read the following quote of Adam in which we can note how dedication and care are translated to stuck-ness, inertia, personal pain, an invitation for cancer, as though good health is a result of a happy-go-lucky way of living.

> “...but I got stuck there [trying to help his parents come to terms with having lost their means of support] in order to reassure them, that is I got stuck even though I had my personal life I got stuck, that is in order to keep them alive and the problems started, that’s about it, huge pressure, great huge pressure, oh oh unimaginable, afterwards they calmed down, as for myself nothing held me there and, that is, I refused that place where I grew up, I refused all these things” (**Adam** 5.43-5.50).

In the quote that follows there is an explicit association of the breakup of his relationship as another small death, which further suggests that Adam is struggling emotionally to understand what he himself did that caused his psychosomatic cancer.

> “Another difficult area I want to talk about is a great love, that lasted, it started when we were really young, we believed in the same things it was a deep emotional process that lasted for a long time almost 10 years, we lived together, let’s say, 8, 9 years but it ‘blew out around the corner’, that is it ended, but it was crucial to me and when it ended it was also another painful death” (**Adam** 6.3-6.11).

And he continues:

> “...and you know this is where a breach happened which was stronger I’m telling you, then, after, time passed... em... I understood that I couldn’t do another relationship easily… I did but … it was a mistake, I can’t lie to myself… but at a deeper level I wanted my independence, you know, I liked that” (**Adam** 6.17-6.25).

The breach refers to the gap between consciousness and unconsciousness as suggested by the psychosomatic hypothesis for the genesis of cancer. He is hesitant to admit that after the breakup of his relationship he preferred a lonely life after a conscious decision, or as a preference. He measures himself against the standards of good emotional health and presumes that he must be lacking something important here.

In the following, Adam tries to make sense of the conscious-unconscious binary. His phrasing is confusing, reflecting his struggle with words to make meaning, to understand what has been projected onto him by his ‘intellectual’ interlocutors:

> “The body while the mind processes and all these and the soul it looks like the body and the soul didn’t want that at all” (**Adam** 6.13-6.15).

In what follows he admits that he has not done systematic psychotherapy with a feeling of guilt as I sensed it. Hesitantly he states that he is consciously aware of being in need of psychotherapy now, during his illness.

> “But I haven’t done systematic psychotherapy, I felt that I needed it now during my illness a lot … especially with the metastasis in the bones” (**Adam** 7.12-7.17).

The last trauma he presents in support of the psychosomatic hypothesis is his present everyday life. His references to exact dates when various unfortunate events happened that affected the health of his parents, seem to be an attempt to understand the six years incubation of his own illness. In particular we read in the last quote that I include, a repetition of the same number of years (six years) that he was told was the incubation period of his cancer.

> “’cos my elderly [parents] had started falling ill and someone had to take care of them, myself an only child, they started, the story with my parents grew heavy... em... and had started having illnesses, you know, this at the beginning of the decade of the 90s, 92, 93” (**Adam** 3.21-3.25).

> “...and suddenly [higher tone of voice] my mother got a stroke, she is 69 years old, and she gets paralysed [undecipherable], my father from advanced Parkinson’s started gradually to collapse so all this I had to handle them on a regular daily basis ”
>
> (**Adam** 4.13-4.18).

> “I have gathered some money, I’m finished financially that is from the illnesses, the hospitals, that is I’m telling you for six and a half years now our lives are around hospitals every time it’s the one or the other, the one or the other” (**Adam** 4.24-4.28).

Dora, in a similar spirit, opens up painful memories from her childhood years:

> “My mother as well [like herself] takes medication because since she was young she had problems with her nerves… em she had been hospitalised in various… hospitals, since I was young I remember it… she had suicidal tendencies… and in general I remember she was going in and out of hospitals” (**Dora** 2.5-2.13).

> “I remember a number of things, she wanted to hang herself with a belt, from the neck, to hang it from the banister and

> tighten it and things like that, not very many but even these have left a mark on me (…) em I was … 12 [years old] I was, I was in school, primary school, and I was going through all this" (**Dora** 2.18-2.24).

> "...and my father was also ill… he had arteriosclerosis what's it called? And it affected his nerves also, a bit later, because they were hospitalised together" (**Dora** 2.44-2.48).

> "We were working, she worked, my sister, worked and I was at home taking care of the house and our younger brother because he was young and this is how things passed" (**Dora** 3.23-3.26).

Dora admits she received insufficient parenting during her formative years. She relates a sense of loneliness in saying "we grew up all alone" (Dora: 3.7).

> "We were visiting them and they were together [both mother and father] in the hospital... em... in essence I can say that we [the three children] grew up all alone" (**Dora** 3.5-3.7).

The same emotional tone is retained as her narration continues to describe her grown up years:

> "I, then, grew up I got married it didn't work out, later I worked as a stitcher… em... then the business that I worked for closed down, I worked in various other small businesses until I couldn't find a job any longer" (**Dora** 3.36-3.38).

In the following quote, Dora draws an association, a painful association, between her mother's depression and her own. She sees a resemblance, which suggests that despite having suffered so much from her mother's depression, she replicates it.

> "The window cover, said my mom, 'should we open it to have a view?' I said let it be closed a bit longer for me to sleep, I

> don’t do it for any reason, I don’t want it open, and I say to myself look how it turned now, my mother used to do these things [stay in the room with closed window covers] and now it is me doing it” (**Dora** 4.42-4.46).

I picked that up during our interview and I intervened therapeutically trying to differentiate what she is going through right now, owing to her cancer, from the psychiatric condition of her mother’s. I felt that my intervention was welcomed and it changed the tone of the interview. The extract is the following:

> “Gina: Yours is depression or you need time to relax and take it [her cancer] in?
> Dora: Mine is depression but also a ‘taking it in’, because still I can’t believe what has happened to me” (**Dora** 4.49-5.3).

What can be seen in the experiential dimension of both Dora’s and Adam’s, is that there is a revival of old traumas now during this difficult, critical, and terminal phase of their illness. This emotional tone reveals that the current traumatisation by the terminal cancer diagnosis brings about an intense sense of vulnerability for the individual, that can awaken old traumas from the entire life course of the individual that press for meaningful re-appreciation. As a finding it resonates with the aspect of the experience of living with the awareness of dying that stresses the inevitable trauma of the terminal diagnosis (Willig & Wirth, 2018). The emotional power of the terminal diagnosis is such, we would continue, that old traumas are reawakened adding more to the already demanding strains the individual is called to cope with.

Superordinate theme 2: The experience of suffering

The experience of suffering from advanced stage cancer comprises three main aspects. These are: the somatic suffering or managing excruciating pain, the limitations of cancer or getting familiar with the body that gets delimited, and coming to terms with the terminal cancer. These findings resonate with the experiential dimension of living “life as a cancer patient”, a heading of the meta-synthetic analysis of phenomenological studies on the experience of living with dying by Willig & Wirth (2018). They capture the quality of experience of an individual's day-to-day life marked by a range of losses.

Subtheme 1: The somatic suffering - the excruciating pain

The ceaseless pain of advanced stage cancer is a powerful common theme. It is a new experience to which they are called to relate. Their bodies are out of any control, in pain, and all efforts of self-soothing have failed. They turn to palliative medicine as an ultimate solution. The unknown features of their body in excruciating pain lead the individual to despair and on the verge of wishing their immediate death: an existential position that stems from the realisation that the body does not function in its known way, as it used to. They have to bid farewell to their strong selves.

> "...and I get the pains, evil pains I don't know what kind of pains, I have never felt such pains before" (**Dora** 4.7-4.9).

> "The problem is the Pains! How I will endure as long as it lasts with fewer pains or none this is it" (**Chris** 2.2.-2.4).

> "But the pain remains... em... we have reached a year now using 120 [mg] adhesives and 1200 [mg] lollipops, nothing. At times it is little, at times greater, it is still the same thing" (**Chris** 1.19-1.23).

> "I can bear the pains a great deal but I can't, at a point I can't when the whole of this side here gets numb, things are unbearable, that is to get asleep for half an hour to wake up from the pains and this thing over and over again" (**Chris** 2.11-2.16).

The pain of advanced cancer overpowers the individual's stamina. In an obvious contradiction in the words of Chris ('I can endure pain but this cannot be endured'

2.33), the individual tries to convey the uniqueness of the experience that defeats him/her. Here we see a chaotic element in the narration of the individual who suffers and tries to find the words to communicate his/her experience. S/he has to move beyond the given means of linguistic expression and create new schemes of expression.

> "I can endure [the pain], but this thing cannot be endured, it cannot be endured, that is honestly if it wasn't that I have my daughter's marriage shortly… I would have killed myself, that far, so that this thing is over ..." (**Chris** 2.33-2.41).

For Adam, the experience of cancer pain leads him to feel as though he is losing it, clearly referring to losing his mind within a physical condition that transcends what he can endure.

> "...what I am afraid of is when my everyday life changes, when the quality of my everyday life, only this, when I am in extreme pain -I can't- I need others to, I cannot even support myself, there, there I am losing it, there the problem overpowers me" (**Adam** 7.28-7.34).

And I conclude this section with two more quotes on the experience of pain of advanced stage cancer:

> "The problem of mine at this moment, because of the pain, and I emphasise it, if I did not have the pains I wouldn't have any problem, neither with my ex-wife, I would put up with it" (**Chris** 7.42-7.45).

> "Ok I could try to hope for, ok to hope for that all these processes, em, treatments in one way or another to hope for let's say two years ok to be given by life, two more years ok, now if it's three or one and a half it doesn't matter, I don't think it says much, ok to hold myself for as long as it is

> possible, yes I want that, but not to suffer like this" (**Chris** 11.28-11.34).

What we clearly see as the pinnacle idea of this subtheme is the necessity for the advancement of palliative care. The development of this medical speciality needs to be given its deserved respect and recognised status among the different areas of medicine. In Greece, in particular, it is only in the last couple of years that Palliative Care has been established as an independent Department in the National University of Athens, School of Medicine, which shows a change towards this direction.

Subtheme 2: The limitations of cancer: getting familiar with the body that suffers

Although the excruciating pain is a major component of the experience of advanced stage cancer there is more to its felt sense. There are operations, treatments and the harsh reality that things do not get better but deteriorate that are added to the experience of cancer pain. In this subtheme I have collated interview extracts that describe primarily the physical deterioration of the previously known healthy body and everyday life with terminal cancer. Chris described this experience in the following:

> "...and every day that it passes things get heavier" (**Chris** 9.14-9.18).

The daily management of the symptoms of terminal cancer are the new limitations that are placed on their activities which have to be handled both physically and emotionally:

> "Now, you see, I cannot go for a walk anymore I get tired easily, I want to go for a walk to the shops and look at the windows
> Gina: Yes, this can be tiring, yes

> Dora: But it is tiring, afterwards I have to be in bed I cannot be in bed, this annoys me I don’t want to be in bed all the time I want to be standing up
> Gina: Yes
> Dora: It tires me, it tires me, many things tire me…” (**Dora** 7.9-7.20).

> “I don’t go out in the sunshine I get fevers when I go out in the sun (…) so, out of necessity we don’t go out …” (**Dora** 7.27-7.30).

> “For two months I was in bed all the time, I couldn’t rise, that is I was having a fever and I couldn’t do… I wanted the A/C to be on and lie down because I was not feeling well, I felt I was dying or I was fading away” (**Dora** 8.26-8.31).

> “When I left the hospital and I was suffering too much, in between being asleep and awake, that is, I was suffering they would take me out of bed, a friend of mine was living with me, they would set me on the couch and I’d fall, she wanted to give me some chamomile tea with a tea-spoon and I would get sick and had great pains and so on and so forth” (**Barbara** 15.21-15.26).

Bearing with the bodily deterioration is one side of the experiential constellation of living with the limitations of terminal cancer. There are additionally cognitions, emotions, and fantasies that are affected by the reality of limitations due to terminal cancer. In the extracts that follow, we witness the emotional processing of futility and disillusionment.

> “But I know first-hand that it is a finished story, that is it doesn’t take anything more, even if we do go through another robotics procedure again it might be futile” (**Chris** 1.27-1.30).

> "I'm disillusioned… there comes a time which I know and I'm sure, I say '-you are not doing anything', the doctors, the doctors, all doctors are trying to calm you down with calmness, alas if every doctor would say to you 'you are dying', but this bloody cancer instead of leav[-ing]..., it is very difficult for someone to recover and we all know it, and this is the case whether you have money, or you are poor you are in the same position, so you are, since the moment that I know that, we know that salvation with the meaning of Salvation there is not, so what if you live for two months, what for six, what even for two years, this is my opinion I'm speaking generally, I'm making an argument, it is the same thing, you may live a little less, a heart attack and it's over, so as not to be a burden" (**Chris** 2.43-3.8).

Processing terminal cancer at all levels of human functioning is demanding and difficult. It requires emotional strength to bear the tremendous truth of not recovering. Chris uses the word 'Salvation' a strong religious word in his attempt to communicate the despair he experiences in handling, in managing, the imposed limitations of terminal cancer. The word 'Salvation' and its meaning as wishing to be saved from the evil and harm of terminal cancer reveals how deeply painful, how emotionally painful, the experience is. Barbara adds another component to how the experience is felt by referring to the workings of fantasy. Having undertaken a serious operation, she describes what she felt which included feelings of fear and disorientation, sensations of coldness and pain, but also fantasies of absolute terror:

> "I remembered this terrible feeling I had the first time I was operated on (...) I was tightened up, I was feeling cold, and I was in pain and I said now I am at EAT-ESA [the interrogation and imprisonment headquarters during the junta in Greece, 1967-1974] that's it I'm finished, I had the memories of the coup d'état –I went through all these 'good' [ironic] things in my life- I could hear someone shouting and was saying 'don't talk' don't do etc. I said I must be in EAT-ESA that's it it's

> over, until the doctor came and told me this and that, so after I was operated on for a hernia ... [she said to her daughter:] ‘-look my child, the recuperation room is there and as soon as you see me talk to me, tell me that you are here and ok it will not matter if I’m in pain, it will not matter if I am tightened up, I just to hear your voice, nothing more” (**Barbara** 16.1-16.16).

Subtheme 3: Negotiating terminal cancer

When a person gets to know that there is nothing more to be done towards the cancer’s cure, s/he enters a realm of not-knowing, not knowing what to expect, not knowing what to hope for, overall the insecurity of not knowing where they are standing. This difficult and demanding reality, by virtue of the facts, is described in the quotes that follow. We note in these extracts how the individual responds to the terminal cancer diagnosis with numbed internal sadness that accompanies the instructed resignation from hope for cure; we note how terminal cancer is negotiated in fantasy and cognitively; we note, lastly, the achieved reconciliation with the matters of fact that resolves the experiential impasse which brings comfort and soothing.

> “There is nothing that can be done ‘cos I have failure… and the doctor told me [undecipherable] in Athens, that in any place on earth I go, no operation can be done” (**Dora** 4.12-4.16).

> “They told me to undertake chemotherapy, I did [undecipherable] yes but I was in great pain and the gastroenterologist I visited afterwards, that is, he told me that these [treatments] are like bombs for the liver… ‘they’ll destroy it’. He said that is why I was in so much pain so I stopped them and I take only Fenicine vitamins and that is only with these what I can do and with the [food] supplements that

> Mrs [name of Palliative Care Doctor] gave me and the vitamin that she said helps” (**Dora** 4.18-4.27).

> “I’m afraid that if I took that again [the chemotherapy treatment], I would be in great pain I couldn’t …they hurt” (**Dora** 5.38-5.39).

> “When they told me to go back to the... em... the surgery I decided I won’t” (**Barbara** 15.49-16.1).

The processing of facts described above brings about the following emotional reactions: internal incommunicable sadness, a stance of resignation, and a turn to the outside for recognition of their efforts and strength.

> “em... and now is even worse, that is I’m sad, I’m very very sad with what has happened to me because I feel very tired I can’t, I can’t talk” (**Dora** 1.5-1.8).

> “’cos there is no life for which I could say ok I’ll get better and we move on as we were 20 years ago... em... there is no [future]! I have given up that I’ll get better… to bear it as much as I can” (**Chris** 7.24-7.30).

> “...and I have gone through all these processes [diagnosis and treatments for the bone metastasis] but I faced them as you can see with strength” (**Adam** 7.17-7.19).

The witnessed negotiation expands to all levels of human functioning. There is negotiation at the level of fantasy as in Barbara’s quote which follows, there is cognitive negotiation as in Chris’s case, and there is also emotional negotiation:

> “Anyway, being in between being awake and asleep (…) I said “mom let’s get over this tonight” meaning take me I’m leaving. In the morning I did not remember anything and I got out of

> bed without understanding how I got up while I couldn’t and I went to the kitchen and I prepared chamomile tea and I ate a cracker, my friend said “is that you?”! So, I was telling her about this and she told me because she is also “ok since you like believing in this its ok” I told her my mom didn’t want to take me with her and she let me go to the kitchen” (**Barbara** 15.21-15.36).

> “Now, and when a person is, has lived his life, 35 years, in the night, let’s say, or he has seen so much, he can see clearly he doesn’t need, I think, the doctor to persuade him ‘-don’t worry it’s ok you’ll recover don’t bother’ he can see things clearly that they [the difficulties] come, that they approach... em... ok ‘-accept them as they come, that’s life” (**Chris** 4.23-4.30).

> “…this... em... and at times I feel down, at times I feel better, as is normal for every person, sometimes I say it’s ok that’s it, sometimes I say oh oh why? Em how could it be different? That’s about it” (**Barbara** 1.8-1.10).

The negotiation culminates in the consolation, comfort, and recognition of the existential position. Our common existential given that we will all leave this life at last, this inescapable truth, brings consolation; it is a thought which brings breathing space to the immobilising not-knowing position they are called to occupy.

> “Em... now I have to realise that I’m dying and to die as dignified as possible, that’s about it, and without great pain I don’t want anything more than that, what else isn’t it so that all of us will leave” (**Barbara** 10.18-10.21).

Superordinate theme 3: Issues around relatedness

Two main subthemes have been found with respect to ‘relatedness in advanced stage of cancer patients’ experience’. The subthemes are: the need for kindness and support, and managing the binary of dependency versus independence.

Subtheme 1: Need for receiving and giving kindness

The relationships with others are seen under a distinct light. Their support is a shelter against loneliness, fear, and not being able to support their physical deterioration themselves. The others become recipients of gratitude and deep love. There is an emotional tension, however, between being with loved ones and friends and enjoying their company, and on the other hand wanting to be alone in grief contemplating the terminal diagnosis.

> “I have a great circle of friends not only acquaintances but essential ones who did not leave me at all, that is without being, because they know me and that I’m very independent, None of them is very intervening, didn’t leave me not for a minute to…[discontinued thought] ” . (**Adam** 6.48-7.3).

> “My friends coped [with her illness] well, they stood by me very well and this has been really good for me, they still stand by me…. I don’t have any complaint” (**Barbara** 1.15-1.19).

> “It is true we will leave this world, yet I’m lucky because I have friends, I’m very lucky, I can’t say the opposite, because this is luck. However I worked all my life on that, I can’t say, but no one betrayed me, that is when I gave I took back, and I’m lucky because there is no chance of being alone at home” (**Barbara** 10.21-10.27).

> “Some friends that I value, these are my friends, I didn’t, that is, I have never done psychotherapy systematically and stuff like that, but now in my illness they helped me” (**Adam** 4.37-4.40).

> “I’ve lived, I’m 69 years old and these years were both good and bad, I believe I have not hurt anyone in my life… the whole world loves me, that is my close ones, my relatives, even the strangers and friends, because I have many many acquaintances and huge friends. All love me ok.... I’m content, I am I can firmly state this” (**Chris** 4.15-4.19).

Past impasses in relationships are reappraised and receive different solutions. Chris is no longer the bitter husband who got a divorce from his wife because they could not find the common ground to be together. He treats the memory of their marriage with noticeable care and concern, openly admitting that he has an equal share of the responsibility for the break-up of their marriage.

> “All of us make [mistakes], all of us do, so what, who am I, a Saint? And you were the one to blame? We go by searching. “A rock doesn’t come out by one, it needs two” [a Greek expression that in English would be like ‘it takes two to tango’] . I was to blame as well, I was a man working at night, I have done bullshit in my life, ok, what should I be doing now? Trying to blame the other, you, so as to avoid my own responsibilities? No, the responsibilities are shared and it might be that I have even more” (**Chris** 8.1-8.8).

Friendships and relationships are valued with notable kindness and deep appreciation. Yet, there is a tension in their need for closeness and their need for being alone, for providing a space to themselves to contemplate what is going on in their lives. In plain language, Dora tries to convey:

> “Em... I am not in a good mood… friends of my brother and girlfriends come by and I don’t want to spea[-k]… but I don’t want to ... and bring my brother to a difficult situation by not being in the company … and so out of necessity I sit with them, of course this is for good it doesn’t hurt me, but I prefer no one to come because I don’t, don’t want company, I don’t want it” (**Dora** 5.10-5.23).

Subtheme 2: Dependency versus independence

A significant change in all of them that has to be handled both physically and emotionally is reconciliation with dependency. From feeling independent and with full control of their bodies they have to accept the dependency on others for their daily support. This new existential reality is not easily accepted.

> “Gina: Would you feel safer to have a person living with you?
> Chris: Certainly, look, em... we could name it out of necessity now I’ll… most probably for the remaining time, how should I say it, I will live in the same house with my [ex-] wife ok it is something a person doesn’t easily accept and didn’t I tell you that our relations had always been good, if she became ill I would [also] stand by her” (**Chris** 5.9-5.16).

> “Necessarily, if I was well it wouldn’t happen ok … I say necessarily because it’s me that I’m in need of her, ok” (**Chris** 5.37-5.38 & 5.41-5.42).

> “... when I’m in great pain and I can’t, I’m in need of others, I can’t even support myself” (**Adam** 7.31-7.32).

Others’ availability to assist them is valued greatly, although we can sense that it is not easy for them to accept their new existential condition of being in need of others for their daily functioning:

> "I've told her [her mother] that I cannot get tired, I cannot do various things because..., she sees me when I'm in pain, let's say, when I have fever, she understands. She says "-what is going on my child?" but she doesn't know exactly what is going on, I haven't, I haven't told her anything... [I can see] she is sad now while before she was more indifferent, she was, I don't know maybe it was her illness (...) "-should I fetch you an orange juice, should I fetch you something?" (**Dora** 17.36-17.40 & 17.42-17.48).

> "Yes I can't say, they'll take me shopping and this and that (...) '-may I take you out [her name] Barbara to go for dinner?' '-we won't go out, take me to the super market to shop ... to buy things' (...) they know that I can't do much but they also know that if something happens I'll call half the Athenian population for help, that I can't do much is well known" (Barbara 13.6-13.11 & 13.16-13.19).

Despite the willingness of others to be of support, the deterioration of functioning as time goes by is recognised with sorrow:

> "Em... gradually I see that every day that passes I can't be only by myself… to be doing all these that, no, all these that I could anyway, to keep going anyway, that is to take a taxi and come here, to to... like I used to two months ago, before three, before four [months]" (**Chris** 4.49-5.5).

Superordinate theme 4: Confronting death

This superordinate theme was constructed by three subthemes as these emerged in the analysis of the speeches of my research participants. This superordinate theme includes: attitudes towards death with a note on gender, thinking about life after their death and what preparations are made, and finally speaking about death and the beyond.

Subtheme 1: Attitudes towards death

All four participants touched upon their own attitude towards death with small and furtive references. This cannot pass unnoticed; the fact that they are trying to convey something of an emotional quality in terms of how they relate to their deaths with furtive references suggests that not only are we not used to discussing matters related to personal death with others and openly, but also that the available means of expression are poor. Nevertheless, the participants did touch upon this topic and even beautiful phrases came out, as in Chris's eagle "I was born an eagle and I'll die like an eagle" (Chris 10.47).

The two men said the following:

> "I am not afraid, I am not afraid" (**Adam**, 7.28).

> "…it's ok, let's say, since life brought 'this' to me, what can I do, I'm trying to face up to it as much as I can" (**Chris** 11.20-11.22).

> "'cause I was never afraid either of life or of death, nothing, nothing, that is I believe that I was born an eagle and I'll die like an eagle" (**Chris** 10.45-10.47).

While the two women said:

> "Now, I am afraid of death, I'm afraid of him [death is a male gendered word in Greek], what should I do? Em... I want to accept it because let's talk about it at times it affect[-s], but I have prolonged it and I say since it is not today let's enjoy

> today, I went to the wedding also, and I danced also" (**Barbara** 13.22-13.26).

> "Gina: Mmm does it scare you?
> Dora: It scares me, yes" (**Dora** 4.6-4.7).

What could be roughly noted from these extracts is that men tend to be more combative when facing death while women are more emotional. It is an interesting finding since it appears to be placing the fear of death argument in a sociological perspective. There is an issue of gender involved with its respective socialisation, which should be noted, despite the fact that my sample size was small.

Subtheme 2: Thinking about life after their deaths

I noted a difference in readiness to deal with thoughts around their deaths and what will follow their deaths. Two of my participants were better prepared to deal with these issues while the remaining two did not seem ready to open up. The hesitant ones were the intellectual man who had received extensive education, and the woman who had the gloomiest childhood and adult life. Both of them were discussed under subtheme 1.3 as instances of going through a revival of trauma.

Dora, the melancholic lady, said:

> "Em I take … Ladose and Strinox and I sleep thank God, I sleep and I forget myself… because I don't want to keep thinking about my problem, it upsets me" (**Dora** 4.34-4.38).

Revealing her wish not to think more deeply about her condition and related aspects of her death.

Adam utilising another psychological strategy, said:

> “If now that I’m ill and I can’t, I can’t go to [name of National Television Channel] to do my job I’ll die that is this is the only thing that keeps me going and supports me psychologically and so on, and another thing is that while others, let us say, would have left, would have preferred to, look to me is, it keeps me going even if I would have to go crawling” (**Adam** 6.41-6.47).

Adam’s quote reveals the difficulty he is having in accepting that fact that sooner or later he will not be able to go to work. With the phrase ‘if (...) I can’t go (...) to do my job I’ll die’ he discloses an internal processing around the issue of mastery and control over his condition. It is not the illness that delimits him, but his active involvement in his illness. In other words, what he is going through is due to his accountability and not due to the illness itself. What this suggests is that he feels that the cause of his death will not be his illness but the fact he will not be able to go to work any longer. Adam tries hard to regain control of his life. His work is an area that he controls, whereas his illness is out of anyone’s control. He admits that his work supports him psychologically, nothing else has this effect. He suggests that he would even crawl to work if he had to, because ... and here the words of Dora could complete his sentence ‘I don’t want to keep thinking of my problem’ (Dora 4.38).

The picture is different for the other two individuals. For Barbara the announcement of her death is not easy to handle and she admits being anxious of how her death will affect her loved ones.

> “But I’m anxious… ‘cos George is there, ‘cos of where I’ll leave Fay [her daughter who has learning difficulties], it is not easy to know the announcement of your death, that’s all” (**Barbara** 10.37-10.41).

Chris wants to attend the wedding of his daughter because he knows that if he dies before the wedding, his daughter will be expected to be in mourning for at least three years. During this period it would not be culturally acceptable for her to marry. Chris shows an ability to project his thought and imagination to what is to follow his death:

> “The wedding that is to take place shortly, it’s done out of the fear that I’m dying ‘cos afterwards my daughter at least for 2-3 years there will be no chance for my daughter to consider marrying” (**Chris** 9.47-9.50).

Furthermore, Chris has settled issues related to his belongings by passing them on to his daughter. He is able to envisage a good future for his daughter after his passing and, as he explains, he wouldn’t put his own welfare before her good future.

> “The only thing that I could say … I had a house in the village which I could sell so as to have [a more comfortable present life], but I didn’t do that, but I passed them to the child, everything, let’s say, that’s until I sell them, to deny from my child a certain property?… That is the only thing that I had which I didn’t have now under her name, two months now it is under her name so, to deny all these from her so as to have my personal wellbeing by... em... by not going to the house and live for as long as I’ll live with her mother [his divorced wife] in case that this affects me?” (**Chris** 6.48-7.11).

The only issue he will leave incomplete is his house, the one he lives in currently, which his heirs will have to empty:

> “I’ll leave it like this, filled [his house]… this abeyance will remain an abeyance with respect to this matter, that is, of the [his] house” (**Chris** 14.23-14.26).

In full awareness that his health is deteriorating day by day, Chris wishes a dignified posture on the day of his daughter’s wedding. Being able to attend the moment of happiness of his daughter is the only thing he wishes for, admitting that seeing her happy will fill him with strength and a sense of personal completion.

> “...and even to be able to be standing with my walking stick like I am I am at this moment here in front of you... em... I’m not asking for more but to be like this until the day [his daughter’s wedding] for this this happy moment let’s say, because I will also leave afterwards with greater strength and more complete” (**Chris** 10.25-10.30).

Subtheme 3: Speaking about death and the beyond

This last theme has great significance as it relates to thoughts and feelings about death from an existential position. Additionally, it reflects what one can secretly wish for the realm of the beyond. The extracts that follow come from the two participants who showed greater emotional readiness to deal with the matters around their death.

Chris shows his familiarisation with his imminent death by sharing with me a philosophical stance of accepting life and what it brings along. I cannot but associate his stance with the existential position of being-in-the-world.

> “I am used to taking life as it comes, not only now that I have the problem but even before the problem existed” (**Chris** 10.41-10.43).

And under the same light, he wishes to bargain with death -as one bargains with a friend- in order to be given less time to live but not to suffer any longer:

> “I don’t care about death, I’m not afraid of death, I’m speaking to you honestly, I’m not afraid of him… all of us will die, I told you again, what if it’s two months, 10 or five could you bring him closer and it’s ok to make a deal? Instead of two years to be two months but not to be in such great pain I have no problem, this is not my problem” (**Chris** 4.2-4.10).

The female perspective on this subtheme of speaking about death and the beyond opens up new possibilities for expression. Barbara, in distinctively poetic and moving language, says:

> "Death is death, that we all have to face and nobody likes it, yes, and it is that I'm not religious to believe oh I'll go this way or that way, I am not, I was not taught to, I don't know, may all those who believe, I'm not looking down on them, never, because they have something, but I don't, so ok how could I know what is to come, nobody knows what is to come". (**Barbara** 14.41-14.47).

Reflecting on her emotions, however, she develops a beautiful picture for the beyond as the meeting place with the beloved. She will conclude with a tension between believing in the beyond completely which she resolves immediately afterwards with a Kierkegaardian leap:

> "What my heart says because I want to, is that all those that I loved I will meet them, it's impossible I'm saying because what has existed here in life is love... em... it is impossible not to see my brother whom I loved, my mother, my father, my friends... em... my husband, ok I didn't have an intimate connection I don't care but all those whom I loved is it possible not to see them again? It is impossible, I say, because love stays, that's about it! My children not to see them again? If not so then why? That's about it, since there is love, this love, I'll find it again. Em... on a deeper level though it does not comfort me because I'm not certain about it hihihi [low laugh]" (**Barbara** 15.1-15.12).

> "So let me feel this way, and that's why I'm saying for all those who go to church and they do what they do it is good that they go since it pleases them, because no I never spoil it for

> them since it pleases them, yet I can’t take something out of it but I take out whatever I can” (**Barbara** 15.43-15.48).

I choose to conclude the IPA analysis section with the following quote which I think is very beautiful. Barbara ends her interview with the following rhetorical question. It is not a question that can receive a definite answer; its value lies in the emotional comfort it can provide and in its logical consistency. Barbara says that we cannot foreclose our hope for the existence of the beyond since we cannot logically refute life after death.

> “That’s why I’m telling you it is impossible not to find them [the dead members of her family] again since we love each other... is it possible not to meet again?” (**Barbara** 17.1-17.2).

Foucauldian Discourse Analysis

Foucauldian Discourse Analysis is a form of inquiry about the particular ways through which we see our world. Historical specificity is an important way with which FDA looks at the world, arguing that the present is not a continuation from the past that evolves through a pattern of greater and greater refinement. Foucault affirmed the difference between the past and the present in his genealogical historiographies which demonstrated the foreignness of the past (Sarup, 1993) and accordingly undermined the grand narrative of historical continuity. Another way FDA looks at the world centres upon the relationship between language, world, and individuals. Language does not picture and represent the world via its deployment by an individual mind. Language, instead, makes things happen in the world and within the individual mind. Language is constructive in building up objects, worlds, minds and social relations (Wetherell, 2001) and accordingly is constitutive of social life. Accounts about the world -or discourses- when widely shared become social realities. An account about a worldly event "enters the discursive economy to be circulated, exchanged, stifled, marginalised or, perhaps, come to dominate over other possible accounts and is thus marked as the 'definitive truth'" (Wetherell, 2001, p. 16). Combining the two ways of looking at things according to FDA, what we know as true is a culturally and historically relative product of the pervasive discourses we live by and are communicated in and through language. Not only with respect to what we consider true, but also the very understanding we have about the individual is also a product of prevalent historically-relative discourses. A third way of looking at things that comes about from the previous two is the unique understanding that FDA suggests for the individual subject. Discourses construct subjects as well as objects (Willig, 2015). Discourses, that is, allocate positions for the subjects with certain duties and rights that interweave the definitions of individuals with issues of power, politics and morality. Subject positions have implications for subjectivity since they carry with them moral orders of rights and duties that the individual takes on as well when s/he deploys a certain discourse. Accordingly, the very psychological realities of individuals are constructed by discourses exerting discursive effects upon their cognitions and emotions, upon their experiencing in general.

The first stage in doing a Foucauldian Discourse Analysis comprises the identification of discursive objects (Willig, 2001, 2008, 2015) in the texts and how they are constructed through language. Discursive objects are linguistic formations of terms which, if interrogated, betray the structures, the broader discourses, we use to perceive reality (Mills, 2003). The discursive constructions of objects, accordingly, can be located within wider discourses, or distinct systems of thought. This stage of abstraction from discursive constructions to wider systems of discourses, is the second stage in an FDA analysis (Willig, 2001, 2008, 2015). The third stage, according to Willig (2001, 2008, 2015), for doing an FDA analysis is drawing a closer examination of the context of the different constructions of objects taking place. In this stage, therefore, we interrogate what is the function of the discursive construction within the wider context of the social interaction: does it fulfil a purpose in the interaction? The fourth stage when doing FDA comprises the identification of the various subject positions the deployed discourses allocate to the individual users. Or else, we ask about the duties and rights allowed for those who use the discourse. The fifth stage is concerned with deciphering the relationship between discourse and action. Here we want to know the possibilities for action -what can be said or done- approved by the discursive constructions and the subject positions of the discourse. The final, sixth, stage of FDA analysis explores the relationship between discourse and subjectivities. We are asking here about the kinds of psychological realities the discourses give rise to, and we mean the ways of experiencing, the emotional and cognitive aspects of experiencing, looked at from within the limits imposed by the discourses.

The FDA analysis that follows is divided into two parts. The first part is an introductory FDA analysis with important findings about the social interaction my research itself posed to the participants. I noticed a tension, even a struggle, in all participants to shake off the effects of the medical discourse. My invitation to adopt and elaborate along the discourse of psychology showed the difficulties individuals with advanced cancer face when requested to relate to the type of subjectivity the discourse of psychology allocates. Being refused individuality by the medical discourse, participants tried hard to open up a linguistic space that would accept as being of equal importance their subjective contributions through their own understanding of their situation.

Introductory FDA analysis

With respect to the discursive context my research question opened up, the inviting question “How do you feel about coming for palliative care?” communicated to the participants at least three ideas. Firstly, that there is a difference between ordinary medical practice and palliative care. Ordinary medical practice centres on the cure of a disease, while palliative care centres on the soothing of symptoms of a disease no longer considered curable. Secondly, that this is a significant transition which must have affected the way they experience their lives. Thirdly, they are the experts in knowing and speaking about their thoughts and feelings and not anyone else, and accordingly what they will say is important and worth listening to. These important discursive constructions that I communicated with my research question to the participants were drawn from the socially available and morally appropriate ways of talking about terminal cancer of both the medical and the psychological discourses. The setting that I created reversed the supremacy, however, that we usually find with respect to these two discourses whereby the medical discourse overpowers, with its significance, importance, and austerity all other discourses. I did not ask for instance “what is your opinion about palliative care?” or “what do you think about palliative care?” where both questions operate from within the supreme moral order of medical discourse. Even though, I introduced a medically technical term, as palliative care is - with its effects of obscurity, impersonality, unfamiliarity, mystification even, as well as remoteness from everyday language- its authority, its supremacy is undermined by giving primacy to the individuals and their emotional experiences. I asked about emotions, thoughts, and feelings: the contents of the psychological discourse.

The psychology discourse and the definitions it provides on what it means to be a human as having an internal reality of thoughts and emotions that can be reflected upon and communicated to others, in short a humanist discourse of the self, delineate the shared space of meanings from which we began our social interaction. Following Rose (1996, p. 4), this conception of the individual as characterised by “profound inwardness” should be seen as a historical construction and not an ontological given. It is a construction of the discourse of psychology which has produced an historically specific understanding of personhood. The “psy-complex” (Rose, 1985) of sciences related to the psychological wellbeing has played a constitutive role in the subjectification of individuals, or otherwise, in what is considered an individual subject. In its most historically recent manifestations, the individual subject of the 20th century is portrayed in the ethic of an autonomous selfhood (Rose, 1996, p. 17), who through pedagogies of self-fulfilment strives autonomously to realise his/her individualised subjectivity. In accord, I positioned my research participants along these understandings about human subjectivity that the psychology discourse puts forth, namely:

1. That they are the owners of a profound inwardness that can be communicated to outsiders
2. That this profound inwardness can be accessed if reflected upon
3. The content of this inwardness are thoughts and emotions which organise unique experiences
4. That they and only they are the experts of their experiences, and
5. That their experiences are unique, as much as they have unique individualities themselves.

The subject positionings that the discourse of psychology allocates for deployment run counter to the ones allocated by the medical discourse. The positions of the medical discourse silence any expression of the subjective self and his/her meaning-making possibilities. Instead it treats the individual as an object who carries a disease, the management and cure of which are its aims. The study of disease in terms of biological, chemical, cellular or genetic factors that cause physical changes in the body (Crossley, 2000), imposes the position to the individual as that of the carrier of an impersonal disease rendering him/her invisible and passive in the face of experts' practice. Itself captive by a strictly positivist scientific methodology, the medical discourse affords to its users the practice of management of bodily symptoms via a solution-focused approach. It deploys obscure linguistic and interactive patterns aiming at affirming its distance from all other forms of social interaction and accordingly its privileged status. In sort, the medical discourse epitomises the following discursive constructions:

1. The split between the body and the mind, treating the former as an object to which its technologies are directed,

2. The individual is considered a patient and no interest is shown in the subjective experiencing of his/her disease,
3. With reference to its higher social status, the medical discourse deploys unique linguistic and interactive patterns to which the individual patient has to familiarise himself/herself with, make use of, and comply with.

FDA analysis refines the sets of assumptions that even a one-statement question –as was the one I used- communicate. The abovementioned assumptions marked the space of the social interaction and communication between myself and the participants. The participants understood my question as no one requested any clarification or additional guidance. What is noticeable, however, is the way each participant made the transition I was inviting them to make from the medical to the psychological discourse. These findings I present in this section.

Considering each participant's introduction in turn, Chris started off with a long presentation of his medical condition (**Chris** 1.4-1.30): the location of his cancer and its spread after a few months, the operations he undertook, and the state of his palliative treatment, as in: "a year now we have come to have around 120mg, or so, of self-adhesives and lollipops of 1200s, nothing, sometimes it's a bit less [the pain] sometimes is more, still it's the same thing" (**Chris** 1.20-1.23). His speech is full of medical technical terms in an attempt to accord his experience with the medical discourse, and in this way communicate how serious his condition is. By describing his condition with the austerity of the medical terminology, Chris made use of the high numbers of his pain killers' appliances in order to convey the level of his pain in an 'objective' way, the truth of which cannot be doubted. This was further supported by the use of the medical abbreviations such as 'robotics' (**Chris** 1.8 & 1.29) when he described the difficult operations he undertook, 'CAT' (1 **Chris**.9 & 1.10) scans, and the numbering of vertebrae in which his cancer is located (**Chris** 1.7 & 1.11). Medical facts were coming together in his speech in order to substantiate with credibility, authority, and reliability his personal experience of excruciating pain. By deploying the medical terminology Chris was able to describe his experience of pain and the condition of his bodily needs due to the advancement of the illness. The medical discourse positions the individual as an object of observation and description, and so Chris, by utilising medical terminology, simply describes his situation. I commented that he is describing an experience of pain and that while he is experiencing so much pain, he is still functioning with relative composure. His reply marked the transition from the medical discourse to the psychology discourse by saying: “because I’m trying, because I’m a person who can put up with pain” (**Chris**, 2.7-2.8). Offering reflective elaboration upon his experience of pain, Chris moved towards the positions of the psychology discourse that allow for a meaningful relationship to individual subjectivity through reference to his/her unique biography. Chris continued “- I have done difficult vocations, for many years I was in construction, then for all my life a waiter at night, I am a strong person having handled responsibilities … that is why I know what pain is and unless you hurt you do nothing, I can bear it [the pain]” (**Chris** 2.27-2.29 & 2.32-2.33). The possibilities for action afforded -or how it can be achieved- to the transition from the medical to the psychological discourse are exactly the possibilities of reflectively elaborating an experience from within the whole range of the individual’s biography, attaching to it not only sequence but also its investment with meaning.

For Adam the transition to the psychological discourse was done much earlier. Adam right away began his interview with a general introduction about himself and his biography, or his sense of personhood. He said: “you know, I am a person that’s very happy with my life … I have worked hard, I have travelled a lot, I have had a good education” (**Adam** 1.10-1.14). Adam, unlike Chris, gave priority to his own experience from within the limits of the psychological discourse, positioning himself as the sole expert of his unique experience. The narrative that Adam produced in reply to my question about how he feels about entering palliative care shows a good grasp of the different positioning that the two discourses -the medical and the psychological- allocate, and utilised my invitation for self-reflection from the very beginning. The individual, who had been erased from his/her subjectivity in his/her confrontation with the biomedical model of human functioning, found new opportunities for his/her subjectivity when the psychology discourse was embraced. Adam’s narrative about himself and his life unfolded following a historical plot that was chronologically linear, goal-oriented, and self-fulfilling. And these qualities should be understood in juxtaposition to the qualities of expression allowed by the medical discourse where only scientific facts of tests and treatments are assessed, devoid from any reference to the individuality of the patient, his/her history, all together qualities of expression that are disempowering.

Barbara adapted to the psychological discourse positioning by giving a personalised narrative of the situation she finds herself being in. She said: “So, it is three years now that I have this illness, I was hoping at the beginning that it might get better then I understood that it couldn’t. Em, I’m trying to make the rest of my life as much as it is possible for lesser pain and being more useful” (**Barbara** 1.2-1.6). Barbara produced an account that gave credit to her personal understanding of her terminal illness and her approaching end. Unique when compared with the way the other three participants made the transition towards the psychology discourse, Barbara portrayed a balanced positioning between the two discourses combining both the objectivity of facts of the medical discourse with the emphasis on subjective individuality of the psychological discourse. The implications for her subjectivity of this midway positioning between the two discourses are that she regains a sense of mastery of the situation she has found herself in. I would name her positioning an empowered position of mastery, and it is more clearly traced much later in her interview when she described the course of her illness and the decisions she had to make about it. Barbara said: “when they told me to go again for, to the surgery, when I decided that *I won’t*, I remembered the horrible feeling I had the first time that I was operated on...” (**Barbara**, 15.49-16.2). We can see how Barbara resisted being the passive recipient of the medical discourse’s functioning, allowing herself a space to evaluate the pros and cons of the suggested treatments and make a decision. Since the treatment’s implementation would have uncertain results in terms of its success, Barbara defied the authority of the medical discourse and stayed with a position of personal responsibility. Barbara’s stance towards the medical discourse is sceptical and in this way the presentation of herself is such that much greater responsibility for her condition is allowed to her. It is exactly this point which, following Crossley (2000, p. 29), differentiates modernist medical discourse from postmodernist medical discourse. The biomedical dominance is challenged in our postmodern era by patients who are experienced subjects and not passive recipients, who can contribute knowledge and take an active role in decisions.

On exactly the opposite end, Dora utilised to its extremity the psychiatric discourse. She introduced herself in the following way: “I have depression… I had depression before… I didn’t go out I didn’t want to, em I don’t have friends, [I’m] only [with] my family, that is my sister and her daughters…” (**Dora** 1.1-1.4). Dora understood the psychological invitation of mine from within the framework of psychiatric discourse known to her well enough since her early adulthood. Stacked with the psychiatric diagnosis that she was given for which she was prescribed regular medication, Dora deciphered the invitation for interaction under the psychological discourse as another instance of being positioned by psychiatry. From this discursive position everything Dora said was framed in such a way as to support her psychiatric diagnosis. She positions herself as a sufferer of clinical depression and according to her understanding of the diagnosis her secluded way of living and her loneliness verify that she measures less than the normal others who go out and have friends. Self-effaced under the weight of the psychiatric diagnosis, Dora is totally disempowered of relating to her subjectivity -or her profound inwardness- offered by the psychology discourse. Dora continued: “…and now it is even worse, that is I’m sad now very much with what has come to me [her terminal cancer] because I feel very tired, I can’t, can’t talk, I’m not a person who … I want to say even in my family I don’t say much… I can’t get them out [the words], I don’t talk I’m not an open person” (**Dora** 1.5-1.19). We can see in this extract the difficulty Dora has in reclaiming a relationship to her subjectivity that is not reified either by her psychiatric diagnosis or her medical condition. She states openly that she is not able to talk about what is going on in and with her, and she is implying that she cannot find the words to express herself since her relationship to herself is objectified under the weight of a psychiatric diagnosis. Neither can she talk about her medical condition and the way she feels about it since medical discourse does not equip those who deploy it with linguistic means for personal expression. We managed this interview via description of facts at the beginning, reliance on empathic understanding, ‘lending’ of words as to what can be expressed under the psychological discourse, but also exemplifying the position that relates self, personal history, thoughts, and feelings in meaningful appreciations.

In this section, I analysed the transition from the medical discourse to the psychological discourse which I invited my research participants to make. As shown, it was not an easy transition but revealed a serious tension in shaking off the objectifying powers that the medical discourse imposes upon individual subjectivity. More like a struggle, all participants tried to challenge the effects of the medical discourse and attempted to reclaim a position to relate to their subjectivity. The struggle between the two discourses, in other words, was a struggle between the dehumanising positioning of the medical discourse where the individual is simply a carrier of a disease to be managed, and the positioning of the psychological discourse which emphasises the emotional and cognitive processing of unique life worlds. All four participants, nevertheless, reviewed with me the course of their lives. Dora recalled her difficult childhood years with both her parents lost in the labyrinths of psychiatric illness. Adam recollected the course of his professional career, his respectable education, his familial and private life. Chris, too, was able to shake off the reifying powers of medical discourse and recollected his life, his unfortunate but with potential marriage, and his valuable relationship to his daughter. Barbara, lastly, produced a narrative rich in details of the greatest challenge she had faced in her life, namely the upbringing of her daughter with learning difficulties.

Main FDA analysis

Having delineated the context that my research question formed for the interaction with my research participants, I move on now to the main body of findings of FDA analysis. According to my research question the discursive objects of cancer, dying, and death were selected as the objects of inquiry. For these three discursive objects all implicit and explicit references to them were pointed out in the texts of the interviews with the four participants; similarities and differences were found that allowed for a combined reading of each discursive object. The three discursive objects were further interrogated, according to Willig’s six-stage model for FDA analysis, for the identification of wider discourses, the intended action within the actual context that the texts were produced, the subject positions allocated, the possibilities for action allowed, and finally the implications carried for subjectivity.

The FDA analysis produced the following findings:

The discourse of terminal cancer

1.a. Silencing the evil : the failed medical discourse

Cancer as a word was mentioned openly and stated only once in the four texts of the four participants! It is referred to and is not uttered openly, through a series of ‘it’s, ‘this’s’, or ‘thing’s’ revealing that there are still operative prohibitions in cancer definitions with respect to its open naming. Sontag (1978) had seen in her analysis of illnesses that linguistic practices of omission carry with them a kind of ‘mythological’ reasoning: cancer is considered an evil so refraining from its naming can prevent a catastrophe. The omission of the word cancer from everyday communication is not only a practice with long history, but also a cross-cultural practice. “The unspoken word”, “the C word”, “the something nasty”, “the big C”, or “the cruel C” (Stacey, 1997, p. 66), are all expressions to be met in the English language that replace the actual wording of cancer, while in Greek we usually get the expression “eparati nosos”, phrased in the old and formal Greek language, meaning the ‘cursed and incurable’ disease.

In support of the abovementioned points, I cite the omissions in the speech of each participant. For Chris, cancer is an unknown entity, an indefinite ‘it’, which gives terrible pain. He said: “*it* started in the basis of the 3rd vertebra and the lungs… but after six months….it has left and had come down to the 10th with 12th vertebra” (Chris, 1.6-1.11), and after a few lines he said: “-At this moment *it* has gone to the neck” (Chris, 1.23-1.24). This thing, this ‘it’ which gives pains, terrible and unbearable pains which cannot be borne, is evil, the absolute evil so that Chris is willing at times to take his own life in order to put an end to this torture. He said: “-this thing cannot be borne; I’m telling you honestly if it wasn’t for my daughter’s marriage… I would have killed myself, to this extent, so that it would be over...” (Chris, 2.33-2.41).

Adam’s narrative implies cancer with the words “tumour” (Adam, 4.29) and with “the disease” (Adam, 4.43) that grew in him gradually over time (Adam, 4.44). Without expanding further but fleetingly he mentioned “bone metastasis” (Adam, 7.17) to convey the terminal nature of his condition. He described himself in the present with the vague expression “now that I’m sick” (Adam, 4.8 & 6.41). Adam’s scattered words about his condition, about suffering from terminal cancer, remind us of the chaotic type of narratives that Frank (1995) isolated. Adam a man of strong determination to make things happen in his life, with a long dedication to intellectual cultivation, can find ‘no discernible causality’ (Frank 1995, p. 97) for what he is going through now. He is living the chaos (Frank 1995, p. 98) of advanced state cancer and the words to express himself fail him.

For Barbara cancer is “the disease” (Barbara, 1.3) which she had hoped could have been cured “but after a point I understood that it wouldn’t” (Barbara, 1.3-1.4). The incurable cancer, from which Barbara suffers, is the cause of a series of references in her speech of the form ‘I cannot do anymore’. More specifically, Barbara explained: “-...because [name of her younger daughter who has learning difficulties] has to go out and I can’t [escort her]” (Barbara, 7.50-8.1), or in the “-they [her friends] know that I can’t [be of active help] (Barbara 13.16), or “-until I got ill... I was very active” (Barbara, 7.13), or “most of them [friends of hers] are also ill like me... two of them are like me, and two have died...” (Barbara, 5.30-5.31), or lastly “-I couldn’t go to the day of the opening for the known reasons” (Barbara, 9.10-9.11). All these statements are phrased in a language of loss; Barbara regrets that she is no longer active and healthy but instead is ill from terminal cancer which restricts and confines what she is able to do.

Dora, now, much like all other participants, refrained from naming cancer. It is the ‘this’ in her following words: “I am really sad nowadays with this that has happened to me” (Dora, 1.6-1.7). Cancer is the ‘problem’ in her saying: “I take Ladose and Stilnox and I sleep, thank God, I sleep and I forget... because I don’t want to remember my problem, it makes me sad” (Dora, 4.34-4.38). In contrast to the other participants, Dora does not want to think about how serious her condition is. She prefers to retreat to the world of dreams for comfort and consolation. She knows that her cancer is terminal from what her doctors told her, that “in any place in the world you’d go to, no operation could be done” (Dora, 4.15-4.16); she knows that her cancer is terminal by the “evil pains” (Dora, 4.8) she gets that she has never experienced before; she knows her cancer is terminal by the fever she got for two months that kept her in bed for all that period. She knows and in speaking to me about it she chose to say more with her tears than with her words. And they were inviting tears that brought us closer in a genuine emotional connection that moved us both!

Scattered words describing scattered experiences are the discursive construction of terminal cancer. They draw from the discourse of medicine which has now failed. There are so many words, victorious narratives that praise the capacities of medical science. All these having failed leave behind silence, mythology, or magical thinking as shown in the silencing of the evil cancer word. Sontag (1978) argued that since death has lost its meaning in advanced industrial societies, that it has become "a meaningless event" (ibid, p. 8), cancer as a synonym for death has to be hidden. The action orientation, or the function, of the terminal cancer discourse, by not being allocated a satisfactory linguistic repertoire, operates as to glorify the existing medical discourse which offers extensive linguistic expression of its triumph. There is no space for linguistic expression offered to those individuals that the triumphant medical discourse has failed. In this way, the discursive repertoires remain unaffected by the challenges posed by the incurable, the fatal cancer. The subject position allocated in this dialogue with the victorious medical discourse is a secretive one. Individuals who suffer from advanced cancer and are about to die have no rights to speak about their condition, and they cannot find adequate linguistic resources for doing so. We could say that a regime of silence is imposed on them, closing down not only opportunities for any meaningful action about their condition, but it also closes down the very possibility for self-expression. The implications for subjectivity as seen in the words of my participants are demoralising. Chris is flirting with the idea of suicide, Dora finds retreat in psychiatric medication and in her fantasy world, Adam's chaotic narrative develops around scattered words that hide away the way that he relates to his upcoming end of his life journey, while Barbara constructs herself in the memory of when she was fit and healthy.

1.b. Terminal cancer in a context of war: The great defeat

The discourse of cancer is primarily a discourse of war. Military metaphors are mainly deployed when speaking about cancer and considering the appropriate attitude towards it. The cancer patient opens a war against his/her physical disease. Keeping in mind that cancer’s major social representation is that of the “biggest enemy” (Sontag, 1978, p. 69), the battle that the individual has to fight is relentless. A cancer patient is not a patient who suffers from a disease, s/he is a warrior, who has to have a fighting spirit, who has to have hope that s/he will win (Lupton, 2012), who is not allowed to give up (Willig, 2011, p. 899). In spite of the treatment ordeals, in spite of the suffering from the symptoms of the disease itself, the cancer patient is required to be optimistic, emotionally strong, with a coping attitude, and even cheerful (Lupton, 2012).

Positioned by the discourse of war as warriors against the ‘biggest enemy’, individual cancer patients have to display a fighting spirit and optimism in winning the war against their cancer. The participants of the present research have lost the war; their cancer is advancing and instead of hoping that their old good health will be restored, they are required to face up to their upcoming deaths. All four participants of my research positioned themselves as the defeated and communicated feelings of defeat. Moreover, they attributed to themselves the cause for losing the war and terminal cancer became a retribution for omissions, negligence, or in other words things they themselves did wrong. “Why me?”, “but why?”, “what have I done to deserve this?” are phrases or even sentences they directed to themselves and they answered from this mobilised self-blaming position. Sontag (1978) writes: “But ‘Why me?’ (meaning “It’s not fair”) is the question of many who learn they have cancer” (ibid, p. 38), and very nicely relates how quests for answers lead one to feel that s/he must have done something wrong for which cancer is a retribution. We should not forget that cancer has been associated, since the beginning of the 20th century, with certain personality characteristics, these being: insufficient passion, repressed sexuality, inhibition, non-spontaneity, incapability of expressing anger (Sontag, 1978, p. 21), and these constructions are still operative in the context of our social communication. Not only that, Sontag (1978, p. 43) argues, but also cancer expresses character, a will to sickness spoken through the body. These are powerful social representations of cancer and I witnessed them running through the narratives of my participants.

For Chris, defeat was communicated in his saying: “-ok I can hope for ... that these therapies will ... give me two more years, let’s say that life gives me two more years... I don’t think it says much...” (Chris, 11.29-11.34). Even the significant period of two years of life has no impact on the feelings of defeat of Chris. For him, his present life has no source of any pleasure, he admitted "-[I lead] just a life" (Chris, 3.30), and later on he said: "-there is nothing I can dream of, nothing" (Chris, 8.37-8.38). Defeated and blaming of himself is revealed in the following also: "-I am of a rare character... I can give my soul for the other without thinking about whether I'll get anything back... so *yes life had not been fair to me*" (Chris, 6.29-6.34). Chris is apologetic to his internal self-blaming –the enforced implication for subjectivity of the military discourse- that he had always been good to others, had lived a righteous life, but still he is suffering. His suffering, this defeat, cannot be explained by Chris. He tried attributing the defeat of his war against his cancer to himself, but since he cannot find what he has done wrong, the cause for his defeat is experienced as an injustice that life itself has done to him. His complaint cannot be directed to anything in particular but to life itself and accordingly he said: "-ok since life brought me this what can I do I'm trying to face up to it" (Chris, 11.20-11.22).

When she recounted her terminal cancer diagnosis Dora, next, communicated her defeat by drawing an irony that her fate played to her. For Dora the dimension of cancer as an injustice was revealed when she said: "-I worked in various factories until I couldn't find a job any longer... so I was issued with this health booklet [for those who do not have a job and cannot be insured] so that I do a medical check-up....I said to myself it will be useful... until I took those tests and it showed up [undecipherable] carcinoma that was....[she bursts into tears]" (Dora, 3.41-3.50). Dora decided to take care of herself and being unable to afford proper medical insurance she requested the issuing of the health booklet for the financially poor. Moving towards making her life better by taking better care of her physical health, she took her medical tests and found out ironically that she was suffering from a kind of cancer that was inoperable but also that the prescribed chemotherapies did not work for her and she had to discontinue them. These experiences positioned Dora as the defeated in her war against her advanced cancer. Her tears, her embodied expressivity, communicated how powerless she felt in dealing with all these adversities that defied the discourse of war against cancer.

With respect to advanced cancer being a defeat in a war, Adam came up with a much more sophisticated and even more disempowering position than admitting an injustice done to him. The psychoanalytic discourse has contributed an explanation of cancer as being psychosomatic. Adam accepted being positioned according to this explanation and in this way he constructed his advanced cancer as a personal yet consciously unintentional failure. He produced a very interesting narrative from within the subject position of the psychoanalytic discourse which I present in greater length. Adam said: "-because all, even my oncologist who did not know, the one oncologist and the other told me, and the psychiatrists, that my illness, you die in six years, it develops gradually over time and a big part of it is psychosomatic, that is *it is certainly psychosomatic*" (Adam, 4.41-4.46). Being introduced to the psychosomatic explanation by respectable medical practitioners, Adam was positioned as a powerless object for specialised inspection. Unconscious motives, now, caused his defeat against his cancer. From this point onwards the whole structure of Adam's narrative changed, systematising his life experiences as a series of traumas that must have caused his cancer, standing in sharp contrast to his earlier language of conscious rational activity and accomplishments; now his language became passive and afflicted, a language of defeat. He reviewed the history of his parents and their difficulties in making a living in Greece after the civil war. The emotionally painful break up of relationships with his father's relatives who made claims on their belongings. Adam said that all these painful events "became a tremendous discrepancy, conflict that is" (Adam, 5.25-5.26), that caused his getting stuck: "-but I got stuck there [with his parents] in order to comfort them although I had my own life, I got stuck because I wanted to help them stay alive" (Adam, 543-5.46), the pressure on him was "tremendously extreme pressure... unimaginable" (Adam, 547-5.48). Another source of emotional pain was his long-term relationship with a woman which ended; he compared this end to "another painful death" (Adam, 6.11). Then he drew a distinction that captured the exact nature of what he was trying to understand and come to terms with, after being given the psychosomatic cancer diagnosis: "-while the mind processes and all these and so does the soul, it seems that the body and the soul did not want it [the relationship break up] at all" (Adam, 6.13-6.15). Adam identified three levels of operation inside of him: the physical, the emotional as is the functioning of the soul, and the rational thinking of the mind. The physical is mysterious, unknown, hiding from any conscious effort the knowledge of what its needs are, which are its wants and wills. The emotional or the soul is also opaque and obscure with hidden needs and wishes not accessible to conscious reflection. While the rational is the part which we have conscious knowledge of and we can be certain of knowing our needs, the physical and the emotional have hidden and unconscious ways of expressing their needs. Adam is trying to comprehend the discourse of the unconscious which was offered to him as an explanatory frame for the aetiology of his cancer. He wants to understand what went wrong and why he is condemned to a premature death. And in his attempts to understand he produces an interesting anthropology about the human functioning. The subject position of the discourse of the unconscious he is pressed to occupy by the authority of so many specialists is confusing, puzzling and bewildering. He is forced under its weight to lose himself, the knowledge and certainty about himself that he had portrayed at the beginning of our interview. The implications of the unconscious as an explanatory concept for his subjectivity are overwhelming and shattering. He is called to doubt all that he held certain about himself and the way he has led his life. Hesitantly, he tried out a different construction with me, a distinct space for his subjectivity when he spoke about his need to be independent. If I was to stick with the discourse of the unconscious that is causing cancer, I would not have allowed the following interactive exchange. He continued saying that after the break-up of his ten-year relationship "a deep fracture" (Adam, 6.17) happened inside of him which as years went by he "understood that I couldn't easily make another relationship" (Adam, 6.19-6.20), deeply he wanted and he has chosen his independence. He admitted that he wanted and he preferred his independence "on a much deeper level I wanted my independence, I liked that" (Adam, 6.24-6.25), and with this statement Adam was able to shake off the blockage upon his subjectivity that the discourse of the unconscious imposed. From within the limits of building up an understanding between us and myself operating with the assumptions of the psychology discourse as I presented them in the introductory section of my FDA analysis, Adam was enabled to voice for himself a subject position more consistent with his self. He was no longer the docile recipient of the powerful discourse but an agent with a preference.

Barbara communicates a sense of defeat as well, but is unique in the way that she overcomes it. She said: "-at times I say that's it [I'm dying] but it doesn't matter, at other times I say [to myself] oh my God why?" (Barbara, 1.9-1.10). The way out of the self-blaming construction Barbara finds draws from the discourse of natural development. She produced the following perspective when she said: "-now in one way or another, now that the children have left, and my own [parents] have died, I have gone through all these long before that [her own illness]" (Barbara, 1.13-1.15), admitting that her life has run its course starting with the care of her children, then the care of her dying parents, and now she can expect her own end. Much later in her account the same perspective comes up again when she said: "...because I am who I am and I am not expecting from [name of her daughter who has learning difficulties] not from anyone else to make me someone; I am whatever I am... Haven't I struggled my whole life? Haven't I worked for '1000' years? Haven't I raised children? Haven't I taken care of my elders?" (Barbara, 14.3-14.11). In this series of questions, we witness how Barbara is struggling to shake off the self-blaming positioning of the discourse on cancer as war. Seeing her life in the context of developmental accomplishments adds to Barbara a unique dimension in the way she relates to her terminal cancer, as compared to that of the other three participants. Under this positioning of the full course of life discourse, she is enabled to see her life and so her death as natural processes, as parts in the process of successions, as parts of the same process with a beginning and so with an end, which gives to the individual a rational distance from the emotional self-blaming characteristic of the terminal cancer discourse. The individual feels empowered by counting a series of developmental goals and so s/he can resist self-blaming.

These discursive constructions of terminal cancer as a defeat revealed the self-blaming element of the discourse of cancer. The veiled argument would hold that since medical discourse has tried out all possible treatments, the cause of terminal cancer must be located in another variable, and that variable is the individual himself/herself. Sontag (1978, p. 55) supports that the turn to the psychology of the individual sufferer is led by the powerful fantasy that spirit can cure matter, that a state of mind can alter the course of physical illness, that a determined will can win the battle against any illness. Insightfully, she continues: "Theories that diseases are caused by mental states and can be cured by will power are always an index of how much is *not* understood about the physical terrain of a disease" (Sontag, 1978, p. 55). Not only can the fantasy about the will causing illness be detected in the self-blaming cancer discourse, but also the triumphant medical discourse is left to its status unquestioned. It is impossible for the medical discourse to be unable to all-powerfully cure, not to have all the answers. It is in the individual character that the answer to the question of the cause of terminal cancer should be looked for. The action orientation of the self-blaming discourse for terminal cancer is the quest for responsibility, the ultimate responsibility “both for falling ill and for getting well” (Sontag, 1978, p. 57). This powerful construction of terminal cancer is to be found under the militaristic rhetoric that almost inevitably accompanies cancer. The individual is responsible for having invited cancer into his/her life (Willig, 2009) and it is his/her responsibility to fight back against it. S/he has to be focused on winning (Stribbe, 1997) this war against death, that is, maintaining an optimistic stance throughout the course of treatment. My participants have lost this war; their cancer has not succumbed and they know that their death is near. Since there is no one and nothing to blame and the medical discourse leaves out of its radiant status of omnipotent cure all casualties, the terminally ill blame themselves, and the course of their lives. The allocated subject position in the terminal cancer as defeat discourse has only duties and responsibilities. The individual has the duty of suffering not only the severe physical symptoms of advanced cancer but the emotional self-blaming suffering. The legitimate form of behaving from within the limits of this particular discourse is that of constant mourning over the lost war. No reflexivity is allowed, supported, or enhanced that could ease this emotional blaming. The individual subjectivity is caught up in the lost war discursive construction and from this point of view only the great defeat can be seen.

Dying as a strictly private affair

The discursive constructions of dying in the four texts were laconic but with dense significations. It is a difficult realisation, the individual is checking out his/her strengths and readiness daily in an effort to be prepared for death. They live in a distinct realm, as that of an extension of their lives. Willig and Wirth (2018) named this transitional space, this distinct realm, “liminal space”, the liminal space wherein the individual experiences being between two worlds: the world of the living and the world of the dead. Doctors usually do not say much; more or less they leave the individual guessing as to what is to come. The individual has to sort out for himself/herself that s/he is dying. There is a lot of daily anxiety around dying: “is this my final day?”, “how will I know?”. The discourse created around dying is that it is a private affair that the individual has to go through alone and in wonder. The discourse of dying as a strictly private affair positions the dying individual as an object in bewilderment equipped with the minimum of information and knowledge as to how to handle the situation s/he is facing. The linguistic repertoires are very poor as will also be seen in the analysis that follows. In our post-industrialised societies, it is only a few professionals who have the right to know, who are prepared and equipped to do something with and for the dying individual. We know nothing about the course of dying itself, because death is not a topic to be touched upon in Western societies by the unassigned. What my FDA analysis revealed is that dying is a strictly private affair that the individual has to handle by himself/herself. Much work is needed, however, from the individual. The dying process is demanding: emotionally first of all in that they admit being in need of support, second physically as seen in their worries about having a dignified death with minimal pain, and third practically with the preparations that have to be taken care of.

In Adam's account there are two references that had to do with dying. The first had to do with the realisation that his end was approaching when he said "especially after the [diagnosis of] bone metastasis" (Adam, 7.17) implying the change of the realm he had to occupy from then on, a move from hoping for his cure to facing up to his death. He was left in this realm of knowing that he is dying, without knowing on the other hand what he will have to come to terms with. Adam continued: "-what I am afraid of is when the quality of my everyday life changes... that is when I'm in extreme pain I cannot I am in need of others, I cannot even support myself, there, there I'm losing it, the problem overpowers me..." (Adam, 7.29-7.33). Pain and suffering, dependence on others, feelings of despair all these are left for the individual to discover by himself/herself. The secondary diagnosis of bone metastasis that signifies the final countdown was offered to Adam with minimal support for what he will have to meet head-on. In between his lines he looked for the reassurance he was missing "-and I have gone through all these processes, but as you can see I've gone through all these with *strength*" (Adam, 7.18-7.19). Adam is making a statement here that the realm of the dying is not the realm of the strange. The social representations of the dying depict them as unfamiliar, whom we do not know how to approach, whom we face with bewilderment towards their needs. They are treated as others, unknown, unfamiliar, as strange. The realm of the dying is demanding and needs emotional strength, Adam guides us to see. And at times this emotional strength is very difficult to find, to generate. Adam admits that “I have never done psychotherapy systematically” (Adam, 7.9-7.10) although he had close friends that were well-known psychiatrists and psychologists with whom he had held important discussions still he has not done systematic psychotherapy “but I felt that I needed it very much now in my illness” (Adam, 7.13-7.15). Dying exhausts the emotional strengths of the individual. It is well-established that psychotherapy soothes emotional pain and it is this precisely that Adam realises that he needs.

Barbara, was much more aware of her dying and from the very beginning of her account she introduced it. She said: “-I am trying to do this extension of my life as much as it can be pain-free and useful” (Barbara, 1.4-1.6). Barbara reveals that she is experiencing this phase of her life as an extension; an extension, not actual life; an extension that can only be useful, that if it has to have a purpose that is of usefulness to others. No space is allowed for reflecting upon mortality, for processing emotionally this last period of our lives which is of utmost importance to our selfhood. Barbara warns: “-it is not an easy thing to be informed of your own death” (Barbara, 10.40-10.41) and as she is not elaborating further it is revealed how deeply private the affair of dying is. The individual retreats to a descriptive language and Barbara offers us a nice picture of what it means to live while knowing that you are dying: “-but I have postponed it [her death] and I’m saying [to her self] since it is not today let’s live today, I went to the wedding also and I danced also” (Barbara, 13.24-13.26). Barbara discloses the negotiation, the conscious negotiation, inherent in the dying process; the individual questions each day of his/her life whether it is his/her last, weighting up his/her physical strengths and emotional readiness. It is a difficult realisation, Barbara explained, coming to terms with the fact of your own dying and, visualising her end, wished for a good death. She described: “-em now I have to realise that I’m dying, and that [I’d like to] die with dignity and without much pain, that’s about it, I don’t want anything more” (Barbara, 10.18-10.20).

Dora was locked up in her silence. Her references to her experience of dying were implicit and emotional. From the beginning she said: “-I have depression... and I had [depression] before... [the diagnosis of her advanced cancer]” (Dora, 1.1-1.2), and her depression, as she will hesitantly explain, is understood as a fact in that she is not an extrovert person, she is unable to speak out and “break free” (Dora, 1.19), as her sister does. Dora accepted the positioning of the psychiatric discourse and repeated the diagnosis of depression that she had received, as the sole explanatory framework for whatever she was experiencing. In my interaction with her and realising how disempowered her subjectivity was from embracing the discourse of psychiatry, I offered alternative positioning to her, mainly drawn from the discourse of psychology. First, I drew the distinction between emotional depression and natural sadness about her condition. Second, her need for loneliness was analysed as her way to come to grips with what was going on in her life and the fact that she had received very unfortunate news about her health and her very existence. I would say that I offered her different positionings that were more empowering of her subjectivity as they captured better the different aspects of her experience. My contribution to our interaction is shown in the following: “Gina: -if we name it depression when what is going on here is that we say farewell to our good health it is too much. We will name it grief, we will name it sadness” (Dora, 5.11-5.14). Dora was a good listener and incorporated these distinctions, these different positions, into her fragile and weakened subjectivity. Soon she produced the following statement: “-mine is depression *but* I’m also trying to come to grips with ... because still I cannot believe what has come to me” (Dora, 5.1-5.3). My contribution legitimated different experiences for Dora. She was enabled to relate through different positions to her experience and she found a way to mention how deeply affected she is by the fact that she has received a terminal cancer diagnosis. The discourse for the dying –much like the psychiatric discourse- allows few linguistic resources for self-expression. The heavy label of dying –much like the label of insanity- precludes the language of the fully-functioning individual. The consequences of both discourses for subjectivity are not only disempowering but even incapacitating. The individual is silenced and condemned to segregating loneliness and the isolation of experiencing something strictly private.

Chris’s constructions of his awareness that he was dying came through an imaginary dialogue with his doctor: “-things are obvious, it is not necessary for the doctor to tell you ‘-its ok you’ll be fine, don’t worry’, you can see where things are getting at gradually, so just accept them, that’s life” (Chris, 4.26-4.30). He is negotiating the process of his dying around the limits of the communication with his doctors, who will not say openly ‘oh you are dying’. The patient has to guess that his/her end is approaching. Chris explained: “-there comes a time of which I know and I’m sure of, that nothing really can be done [there is no cure for his condition] the doctors are doctors, they are trying to calm you down in a good and peaceful way, imagine if a doctor was to tell you at first sight ‘- you are dying’” (Chris, 2.46-2.49). Yet Chris can see that day by day his health is getting worse “-slowly, slowly every day that passes I see that I cannot do things alone that I could do... two months ago, three, or four [months ago]” (Chris, 4.49-5.5). With this realisation in mind, Chris made necessary preparations for this last period of his life. He was about to move to his ex-wife’s house, a decision made by the whole family so that he would not be alone to face up to the needs of his gradual physical deterioration. He took care of matters of inheritance. Chris was looking forward to being alive for the wedding of his daughter, a wedding that is staged somehow in a rush out of “the fear that I might die ‘cause if so it would mean that for at least two or three years my daughter wouldn’t think about marriage” (Chris, 9.48-9.50). He acknowledged that this marriage will make him feel fulfilled: “’cause I will be able to leave stronger, more fulfilled” (Chris, 10.29-10.30). All these preparations, this plan of exiting the stage of life, are worked out in strict privacy.

What I traced in my analysis of dying as a discursive construction is the fact that it is considered an affair that is strictly private to the individual. Accordingly each one of my participants contributed something unique to the whole picture. Adam contributed the emotional needs of the dying individual; Barbara contributed the everyday negotiation with dying; Dora demonstrated the linguistic poverty met in the discourse of dying; Chris contributed the readiness in accommodating the changes that have to be made in the dying individual’s life. What can be safely argued from a discourse analytic perspective is that the discourse on dying is a strictly private affair. According to this discourse the individual is expected to figure out for himself/herself under a veil of secrecy all that there is to know, do, feel, and experience during this closing phase of his/her life. This solitude that I am trying to describe here reminds me of a few verses of a poem by K. Dimoula which describe how the human touch is missing in old age and that the elders are left without a caress when they cry. She writes: “... as for the elders, that is the old aged ones –whatever is not spring is already old nowadays- the old theories should hold. Do not embrace them! Let them burst out from weeping until they cannot breathe anymore...” (Dimoula, “The rare gift”, 1994). Similarly those who are dying should not be touched but be left in despair to figure out for themselves how they should approach their closing act. They are called to bear in absolute privacy and silence the most important period in a person’s life which is his/her farewell.

Discursive constructions about death: the discourse of bravery and the discourse of the heart

Discursive constructions around death had been the most difficult of the three to be expressed. It seems that ideas about death are not usually discussed with others, and pertain to a realm that is very personal to the individual. Not all participants spoke of thoughts and ideas about death. The ones who did, however, regained their emotional strength and reassured themselves that they had answers to innermost questions.

Dora did not express any thoughts about death. Locked up in her psychiatric diagnosis of depression, she did not reveal any deep feelings or wishes about her upcoming death. The only consolation she drew was from her psychiatric medication that offered her the possibility of a good sleep so that she would not have to think about anything.

Adam did not produce thoughts or ideas about death either. He admitted, though, that he was not afraid to die. The context of Adam's production was important and revealing: "-Gina: -you have made a long and precious journey.... Adam: -yes, yes, em... I am not afraid, I am not afraid..." (Adam, 7.26-7.28). Having communicated to Adam a subject position drawn from the discourse of psychology which portrayed care and admiration towards him, Adam was enabled to relate to his subjectivity empowered and content. From this perspective he could recount his impending death without fear but with strength. Providing a context that valued the narrative of his whole life restored a position of subjectivity in him which facilitated him in experiencing his upcoming death differently. He could open up to other possible experiences that resulted in communicating feelings of contentment and existential fulfilment.

Chris produced many thoughts about death that he had thought of before and simply reviewed them with me. He said: "-I don't care about death, I am not afraid of death, honestly, I'm not afraid of him... we will all die, and I told you before, what if two months, 10, or five months, could you get him closer ... and come up with an arrangement instead of two years to be two months but with no pains... I don't have a problem ... I have lived, I'm 69 years old I have lived for good and for bad, I believe for good I haven’t caused any harm to anyone in my life” (Chris, 4.2-4.13). Chris personifies death and wants to make an arrangement, an agreement, with him to live less but with no pain. Chris adopts the social representations of a human-like death and stages imaginary conversations with him, playing in his fantasy both parts. This discursive construction of death as a human-like entity attributes to Chris better control of his situation. He is addressing death as a person, as an equal, and asks from him absolution upon the basis of having led a life that is virtuous and just towards the others. Chris’s narrative as it evolved in time and depth brought to the fore additional constructs of death. It brought about the discourse of bravery that reassured him about his personal strengths. He said: “I was never afraid neither of life nor of death, of nothing, nothing, I believe that I was born an eagle and I’ll die like an eagle!” (Chris 10.45-10.47). It is a very powerful poetic metaphor that Chris finds and he relates to his experience in this most existentially important moment of his life. He is an eagle, a symbol of freedom and independence, a symbol of fearless living and of fearless dying. The discourse of bravery which alludes to the metaphors of a warrior of life, positions Chris in mastery of the circumstances. Not only a warrior in life but also a warrior when facing his great exit from life, the discourse of bravery through its poetic constructions can empower the individual in gaining a sense of control of a fateful and accordingly immobilising event as death is.

For Barbara death is constructed through much more rational effort. She said: “-Death is death and we all have to face up to it and no one likes it, and it is that I’m not a religious person to believe that I’ll go here or there, I’m not [religious], they didn’t teach me of that, I don’t know, those who believe are blessed, I’m not snobbish about [them], they have something to hold on to, but I don’t, so ok whatever comes, how could I know... no one knows” (Barbara, 14.41-14.47). Barbara draws two distinctions with respect to her constructions of death. The first distinction is between agnosticism and religiosity with herself leaning towards the religiously agnostic side although appreciating the comfort that religion offers to the ones who believe. The discourse of religion gives definite answers about death that as Barbara notices soothes anxieties and reaffirms a sense of control to the individual. Barbara resists the positions of religiosity, however, since its theological grounding relies on belief. She is not persuaded by these religious beliefs. Yet, there are different constructions of death Barbara drew from. They are drawn from the discourse of the heart, as I conceptualised it, after having proposed to her a dualist distinction between the mind and the heart. Our interaction was follow: “Gina: -But what does your heart say, though? Ok, you are not religious but how do you feel about... Barbara: -What my heart tells me because I want to, is that all those I loved I will meet them, it is impossible I’m saying since all that there is in life is love, em... it is impossible not to see my brother whom I loved, my mother, my father, my friends... It is impossible not to [see them again in the beyond] because love stays, that’s it. Not to see my children again? Then for what [what was the whole life for]? Since this love exists I must be able to find it again... em... but this is not consoling me totally as I’m not certain about it [she laughs meaningfully]” (Barbara, 14.48-15.12). Then onwards and until the very end of our conversation Barbara described the quality of the relationship with her first daughter, their intimate communication which is able to shake off fear, moments of ultimate happiness and sharing. Her very last thought is affirmative now: “-that’s why I’m telling you it is impossible not to find them again since we love each other” (Barbara, 17.1-17.2). Myself, experiencing in the interview with Barbara the impasse she found herself in, with respect to subject positions of religiosity versus agnosticism which operate at the level of rational thinking, I suggested a dualist construction between emotions and thoughts. The old dichotomous discourse of mind-body was introduced in my attempt to assist Barbara in seeing death from different positions. And the ideas that she related to this distinction were constructive in regaining hope and a point of view that were proportionate to her understanding of her experience.

The discursive constructions about death despite being really difficult to be uttered revealed two important discourses. Chris deploys the discourse of bravery in relating to his death, while Barbara deploys the discourse of the heart. With the discourse of bravery, Chris is able to regain his character determination which was violently ‘robbed’ from him when the medical omnipotence collapsed and there was nothing left for him to hope for. He draws from a poetic metaphor and gives himself a strong and free identity. The subject position allocated by the poetry discourse offers to the individual a space from which to see himself/herself and his/her life as the author of the course of events. Authors and owners of their lives are the subject positions that the discourse of bravery constructs. The rights allowed by this positioning are the freedom from censorship as well as the deployment of the capacities of imagination and fantasy. The possibilities for action the subject position of the bravery discourse permit is that of a dignified relating to the self by honouring the self and the individual’s identity. Dignity, emotional strength, pride, are all internal experiences that the individual who deploys the discourse returns to himself/herself. We could reliably speculate that these qualities of a person’s identity are shaken when the discourse of the almighty medicine of cure breaks down.

The discourse of the heart that Barbara’s discursive constructions drew from in her attempts to describe the beyond, the beyond her death, is a discourse that defies the limitations of rationality. Seeing Barbara struggling between the constructions of religiosity and agnosticism I offered to her the option of the heart which she incorporated into her system of thought and produced a construct of unique beauty. Love, the ultimate value in life for Barbara, is constructed as unassailable, as untouchable, as indestructible by the natural course of death and decay. Love cannot fade away, cannot die, but continues living even after the physical perishing of the beloved. The discourse of the heart is a powerful discourse of continuity and purposefulness of life. The action orientation accompanying the deployment of the discourse of the heart is the re-establishment of meaningfulness and trust in the processes of life. Accordingly, the subject position the discourse of the heart allocates is that of gazing at the end of life empowered by meaningfulness and purposefulness. The deployment of the discourse of the heart, we could speculate, positions the individual as capable of retaining meaningfulness and purposefulness in life even when leading to these last phases of his/her life.

I will conclude my FDA analysis with the recognition that dying is a difficult and demanding period in a person’s life with unique issues and problems that require the person’s attention and emotional energy to tackle. The present analysis revealed, from the perspective of prevalent cultural discourses, important struggles the individual has to undertake and resolve which add up to the experiential realm the IPA analysis uncovered.

Discussion

It has been argued that the research which focuses on the lived experience of living-with-dying reveals idiosyncratic findings of such great variability that it is impossible to impose a homogenising methodological move in order to identify shared themes across interview transcripts (Willig, 2015). Accordingly, the deployment of phenomenological methodologies which aspire to come up with shared themes in the meaning-making of the experience of encountering one's own mortality is an endeavour which does not do justice to the subtle meanings that the experience encompassed. I could not agree more with these propositions and suggestions for a researching process appropriate for this experience which cannot be exhausted or appreciated by cognitive references with their emotional overtones that are aimed at unrefined research practices. I could not agree more with the findings of Willig's (2015) piece of research that the experience of living with a terminal cancer diagnosis entails both universal aspects, such as that death awareness challenges the individual's ways of coping with his/her life, but it is mainly idiosyncratic in the way that this universal challenge is managed. My position is informed by the nature of my findings and recent literature, and both support that it is precisely this characteristic of the experience of moving towards death, that of being profoundly individual, being intimately personal, being utterly one's ownmost, that necessitates the idiosyncratic to be taken under serious consideration and theorisation.

The research design that I formulated and submitted for approval to the City, University of London, was carefully studied and the decision for unstructured interviews initiated with a single question was led by analogous ideas that would respect both the universality of the experience and its idiosyncratic characteristic. The texts that were gathered were rich and rewarding as the participants opened up issues of personal concern at their own pace, depth, and extent. The Interpretative Phenomenological Analysis that was practiced on the interview data firstly, revealed interesting findings that can enlighten further the experience of living while knowing that you are dying. I trust that the universal as well as the idiosyncratic emerged with equal importance. The Foucauldian Discourse Analysis that was imposed on the data secondly, elaborates on the cultural and historically specific factors of what is expected from the dying individual in the current formations of Western societies. We could argue that with the FDA analysis the universal aspect of the phenomenon is enlightened from within the linguistic limitations that participants tried to articulate what they go through. The two analyses complement each other moving from the individual experiential to the discursive socio-cultural. For a better understanding of the way that the two analyses complement each other we can consider “the linguistic and social fabric of any given community as a framework for potentially individualised production of meanings” (Colahan et al., 2012, p. 3). The individualised productions can then become “habits of thought” (Parker & Shotter, 1990 cited in Colahan et al., 2012, p. 4) that loop back to the dominant discourses via recycled daily interaction (ibid), and through this reciprocal process the phenomenological is bound with the social constructionist.

Synthesising my findings, the IPA analysis revealed above all a general tendency drawn from the emotional world of the individuals who experience the final phase of their lives, to present who they are. The presentation of selfhood, the presentation of the individual’s identity was found to be a common theme in all four participants and rich and detailed narratives were produced. Not only were narratives produced about cancer diagnosis, treatments, and the disillusioned persistence of terminal cancer, but more so coherent accounts of who they are and who they have become in the course of their lives. The identity narratives reproduced the autobiographical past in plots that were characterised by the striving for unity, purpose and meaning. Barbara presented her identity in a narrative about a conscientious individual who committed herself to the care of others. Adam led a life of high professional goals which he reached and derived great pleasure from that. Chris, a man who developed himself through the hard work of survival, even though he had received minimal education still produced a narrative that referred to the values of an honourable and respectful stance in life. Dora’s melancholic life was reviewed from the distance of recognition that her life had always been difficult. The need to present their identity through extensive references to the course of their lives was notable even though the degree of meaning-making varied. It is important here to utilise the distinction that McAdams and McLean (2013) draw of the degree of meaning-making processing in narrating identities, this ranging from no-meaning (as is the case of Dora), to learning from concrete lessons (as is the case with the ex-wife of Chris who agreed to care for him during the last phase of his life and is valued highly by him), to gaining deep insight about life (as is for instance the case of Barbara who reached thoughts about love as the ultimate value in life). In these meaning-making processes we can see clearly the striving of narrative identities for unity, meaning, and purpose.

In the literature we trace long discussions about the nature of narrative identity being or not constitutive of an individual's identity. The narrative approach rests on the assumption that narratives are not reflections of identities but are constitutive of identities, lives and problems (Bruner, 1986, 1987, 1991, cited in Carr, 1998). The theory of narrativity supports that the unity of the self resides in the unity of a narrative which links birth to life to death as a narrative beginning to middle to end (MacIntyre, 2007). Even more, MacIntyre argues that "stories are lived before they are told" (MacIntyre, 2007, p. 212), and extensive research have been done on the adaptational role of stories to experiences of suffering, and their developmental maturation within the course of life (McAdams and McLean, 2013), have been extensively deployed and supported. On the other hand the counterargument holds that primarily it takes a self to experience one's life as a story (Zahavi, 2005, cited in Capek, 2017), that is, a self that's able to differentiate self from non-self who has experienced already his/her agency in courses of action. Tengelyi (2004), further, points out that the course of life is much richer than what is fixed in a narrative, a fixation received by the mode of operation of narratives, this being the "retrospective attitude of storytelling" (ibid, cited in Capek, 2017). Tengelyi (2004) in this line distinguishes between retrospective storytelling and future-oriented acting, emphasising that future-oriented acting is more of an 'adventure' in its encounter with alterity, with otherness. This debate led me to think that retrospective storytelling or the narration of identity is a distinct experiential dimension to be met in moments of crises in a person's life. These moments are certainly the moments of confrontation with death as is the case with my research participants.

Medical sociology has for many years argued that confrontations with serious illness, such as cancer, operate as a biographical disruption (Bury, 1982) which necessitates biographical reworking towards a new identity, a renegotiated identity (Mathieson & Stam, 1995). What is implied here is the active reflexivity that gathers all these new aspects of the experience of self with and in illness –ranging from bodily changes, physical and emotional suffering, adaptations to new medical realities, experiencing the self as a patient- coming up with a new revised narrative about the self. In the FDA analysis we saw, nevertheless, that not only are narratives not constructed exclusively by the experiential dimensions of a phenomenon, but more dimensions are added such as the ways that the phenomenon per se is constructed socially and historically, exemplified in the available means for linguistic expression. Accordingly, the renegotiated identity of medical sociology disregards the discursive context that leads and requests from the individual to renegotiate his/her identity. A more comprehensive argumentation on the nature of the produced narrative about illness and identity, we find in Willig (2009) with her concept of “serviceable narrative”. A ‘serviceable narrative’ is a narrative under construction and revision, an open and unfixed narrative, which reveals that meaning-making, is a work in progress. It is sensitive to context or else its unity, meaning, and coherence are affected by pervasive alternative narratives as reproduced in the interaction with others. Willig (2009) noted among the alternative narratives the “imperative to think positively” (ibid, p. 185, Lupton, 1994) that restricts thoughts and constructions about mortality as unacceptable, the “moral discourse” (ibid) whereby the patient is blamed for having invited the illness to his/her life via his/her wrong doings or negligence, and the binary between self and body, the latter experienced as alien with the power to destroy the self along with it.

Where does this long detour into the problematique of narrative identity lead us with respect to my research findings? The notable tendency for the presentation of the self and life history produces narratives that strive for meaning, unity, and coherence within the context of interaction, not only with others but also with the prevalent discourses (i.e. the reworking of Adam’s whole life history along the demands of the psychosomatic hypothesis about the genesis of cancer). They are not fixed but they are tried out in interactional social spaces. They are fragile with respect to their unity and vulnerable to the effect of alternative interpretations. This hard work of seminal existential importance for the psychological wellbeing of the individual was witnessed in the present research also. The important characteristic of participants’ narratives was that they had to incorporate closure within them, or the fact that there was no more available time as in a future to be considered and looked ahead to. There was a changed relationship with time (Willig, 2015) that disconnected the present from the future which also affected the reminiscence of the past as no more of the same is expected (ibid). Because of all these characteristics, the narratives of individuals who are facing the end of their lives are able to reach up to high values of living, such as kindness, love, care for others, or a considerate position towards a life of doing good.

The extent that was given to identity narratives is analogous to the nature of the information gathered by the interviews. Most of the gathered material was idiosyncratic as it focused on detailed accounts of life histories and individual identity work. To a significant but much lesser extent the rest of the IPA findings were brought forward as common themes and we should be reminded that the interviews were unstructured with minimum direction as to the kind of information to be collected. The experience of suffering, primarily somatic suffering, was found to be common in the experience of all participants who had received a terminal cancer diagnosis. The body and its symptomatic experiences -usually of extreme and unbearable pain- is an alien body, a foreign body, an unknown body that needs to be learnt anew. Willig (2009) described the experience of the foreign body as the experience of “a damaged container” (ibid, p. 186) that threatens to destruct and destroy the familiar sense of self of each individual. Negotiating terminal cancer was another common subtheme that collated characteristic dimensions of the experience ranging from experiences of disorientation and insecurity to fantasies of complete and paralysing terror, which are soothed with reference to the common human fate. What is revealed here is a trajectory of thoughts and emotions that surrounds this existential conscientiousness of the end which is approaching. I would be cautious to consider a linear stage-evolving process such as the model of Kubler-Ross’s (1969). More so the trajectory is an active attempt to soothe the emotional turmoil through meaningful and factual rationalisations restoring a sense of purpose to the uncontrollable which is the personal death. In this line, I tend to ascribe to a reading of my findings that is more existentially informed, whereby the confrontation with death as an inescapable predicament of human nature necessitates conscientious and reflective action. This kind of action is the production of an identity narrative as it has emerged as a primary superordinate theme in this research. Instead of the fluctuation of emotions in a variety of forms, evolving in a linear fashion or the operation of a series of psychological defence mechanisms (Nissim et.al, 2012, p. 379), the existential overview of the phenomenon stresses that the confrontation with one’s mortality leads to the inescapable cognitive and emotional management of this facticity which is primarily idiosyncratic and unique for each individual.

Another dimension of the experience of living while knowing that you are dying that was brought on by the IPA analysis was that of relatedness towards others. Two subthemes explained the collated extracts: the need for receiving and giving kindness, and the tension between independence and needs for dependence, now and because of the symptoms of the illness. Friendships and relationships are talked about with notable kindness and deep appreciation. As a finding it is internally consistent with the thoughts about the beyond that came forward when contemplation about what follows a person's death was touched upon. Deep feelings of love and appreciation of loving relationships are valued highly during these last phases of a person's life, considered as the true wealth that accompanies the dying person toward his/her end. This is an important finding not probed sufficiently in the current research literature. In contrast, many allusions of this dimension toward kindness are made in literature and in memoirs from psychotherapy with individuals who are dying like de Hennezel's (1999) *Intimate Death*. The other dimension of relatedness in the lives of individuals who suffer from advanced cancer is the tension experienced between holding onto independent functioning while their strengths are deteriorating due to the illness. The tension is experienced as a serious threat to the loss of a dignified daily subsistence. As a finding it resonates with the constellation of losses that the individual experiences whilst being a cancer patient of advanced stage (Willig & Wirth, 2018).

The last finding of my IPA analysis considers death and how the participants relate to their own deaths. Attitudes towards death, actions instigated because of their approaching death, and thoughts about beyond their death comprise the subthemes of this finding. Less ready to come up with thoughts and emotions about death were the two participants who were experiencing past traumas as unfinished business. De Hennezel (1999) offers an understanding about the revival of old traumas when new ones are recounted which is psychoanalytically minded and whereby insufficient processing of original traumas –or repression of traumatic experiences- result in cumulative revival. Most of the information on this superordinate theme came from the other two participants. Both were thinking about their legacy after their death and were taking actions towards settling everyday matters for their loved ones. The importance of leaving a lasting positive legacy had been emphasised in research (Nissim et al., 2012) and it was found as a concern in my research also. I consider, nevertheless, that the production of ideas about the beyond of what can follow a person's death, the afterlife, that were elicited by one of my participants is highly insightful and elaborates eloquently on what other researchers say about finding and holding onto hope and purpose when living with death awareness. The participant devised the afterlife as a space to meet her loved ones, as a space of and for love. Moestrup et al (2015) argued that these ideas are comforting, presenting death in a less fearful way, and are primarily idiosyncratic, that is they are created out of the individual's fantasy and carry a very subjective overtone.

Subjective experience does not evolve in a vacuum of internality. It is situated, as I have argued already, within socio-cultural contexts mediated by language. My FDA analysis investigated the linguistic constructions of terminal cancer, dying, and death. These objects were judged as the most pertinent to the present analysis. The linguistic construction of terminal cancer, firstly, as followed in the participants' accounts revealed how the failed all-powerful medical discourse and the defeat in the war against cancer build up positions for subjectivity that press towards secrecy, silence, disillusionment, personal culpability, defeatism, and resignation. The individual who suffers from terminal cancer has to be silenced because his/her very existence shakes the omnipotent mythology of medicine. This discursive process is revealed in the limited linguistic repertoires offered for personal expression to the individuals who undergo terminal phases of cancer and accordingly approach the end of their lives. Cancer is almost always sited in a language of positive thinking and a military, or at-war, attitude. When cancer persists and restitution is not an option, the linguistic repertoires become impoverished and social interactions are caught up in bewilderment. As we saw, only one of my participants mentioned cancer as a word and the illness was mostly implied, inviting the interlocutor into a secretive exchange. I speculated, furthermore, that feelings of defeat and self-blaming arise as a result of being positioned along the discursive constructions of cancer. Since the cure of cancer is constructed as relying, besides medical treatments, on the fighting spirit of the individual, the terminal cancer patient relates to himself/herself with feelings of defeat and blame for not having fought hard enough. The issue of mortality from within this discursive framework that wants medicine capable of all cures, for defying mortality, is obstructed from expression and experience and the individual is allowed only the positions of feeling defeated and disempowered. From within the limits of the medical discourse, the individual cannot find a way to relate to himself/herself and his/her mortality. As we saw in the analysis section, the invitation of communicating along the lines of the discourse of psychology which permits and advances reflexivity, the individual can be enabled to resist these discursive positions and come up with more personal solutions as the IPA analysis revealed.

Another construction of my FDA investigation was that of dying. It is argued that in the present socio-historical period of our Western world dying is constructed as a strictly private affair. The dying individual in social solitude is dictated that his/her dying is an affair to handle all by himself/herself, being offered a minimal space with highly impoverished linguistic repertoires to communicate with others of his/her dying. Under a veil of secrecy and privacy the dying individuals get alienated from social life, left alone in ignorance and the least guidance to guess about his/her end. The constructed discursive space around dying leaves the dying individuals in enforced loneliness not only disempowered but also alienated from humane ways of relating to them. The dying are met with pity, sympathy, and, because of these, avoidance. It has been argued that Western cultures do not share a common cultural understanding about death and believe that it is very subjective and left to the individual to develop a way to deal with death (Moestrup et al, 2015). Particularly this construction of death and dying as being solely subjective Foucault would argue to be a social discourse allowing a certain way to think about, talk about, and act towards death and dying. This argument is consistent with what we said earlier in the discussion of IPA findings and the idiosyncratic character of the experience of living with dying. It is consistent as it accords with the discursive construction of privacy and isolation towards the dying individual that our Western societies press for through prevalent discourses. The dual-focus methodology I have employed enlightens both realms: not only the experiential realm at the level of the individual, but also the social realms highlighting the available discourses, or “forms of structured language” (Colahan, et al, 2012, p. 2) to be found in any linguistic community.

The last object of my FDA investigation was death itself and the discourses that surround its construction and from which individuals draw in order to speak about death. Two discourses were pinpointed in my analysis: the discourse of bravery and the discourse of the heart. The discourse of bravery shares similarities with a vehement attitude against misfortune and positions the individual as a warrior. No wonder, it had been deployed by the male participants of my research. The bravery discourse emphasises fearless living and fearless dying and in its linguistic construction, that is usually poetic, the individual user regains a sense of mastery and control over the circumstances. The discourse of the heart, on the other hand, which I also traced, is a discourse which values continuity and purposefulness of life by reference to the imperishable of love. It is a construction which empowers and strengthens the individual as it allows him/her a space from which to see death not as mere nothingness and devoid of any meaning. We should not forget that the individual dying from terminal cancer feels defeated and blames himself/herself for having lost the war according to the discursive constructions of cancer and in this line death is envisioned as a punishment for his/her wrong doings which leads to emotional numbness and fear. The discourse of the heart enables a vantage point on death that is not punishing but reassuring of some purpose which is also psychologically comforting.

Conclusion

The findings of my research can be interpreted as hidden powers and psychological needs. The Foucauldian Discourse Analysis brought to the fore the existence of dominant discourses that exert powerful effects on subjective experience that are most often hidden. How cancer and terminal cancer in particular are talked about, how dying and death are constructed, compose the hidden forces of dominant discourses which decisively affect how individuals relate to their experience. Raising awareness of how linguistic practices shape both social consent and individual experience can empower for alternative positions by resisting the hidden powers of discourses. On the other hand, the Interpretative Phenomenological Analysis complements with the actual accounts of the experience from within the viewpoint of the individual himself/herself. The commonalities of the phenomenological experience can be translated at the level of psychology as needs to be considered and effective action towards meeting them be designed. Among the needs that were pinpointed we could include the need for presenting the self, the need for showing and receiving kindness, or for being with others while at the same time wishing to be lonely to contemplate what they are going through.

With respect to the limitations of the present research, I am aware that the number of my participants is small. Even though the cases discussed have been chosen in terms of diversity on levels such as sex, educational level, marital state, and socio-economic status, still I believe that a larger number of participants -also recruited from different palliative centres- would increase the credibility of my findings. Moreover, the fact that I investigated the phenomenon of living-with-dying in a different culture –the Greek culture- and significant similarities were shown to operate under the common Westernised post-industrialised background, still more work could be done on cultural differences that would enlighten with alternative ‘habits of thought’ (Parker & Shotter, 1990 cited in Colahan et al, 2012, p. 4) that can have lessening effects on the hidden powers of dominant discourses. Contrasts and comparisons among different cultures could further enlighten how the phenomenon is received in broader historical contexts.

Evaluating my research, I trust that I demonstrated sufficiently how deeply involved in “the cyclical process of critical reflection” (Willig, 2012, p. 24) I was by questioning my topic and my interpretations from the beginning until the end. Since the beginning I embarked upon a main argument that opened up a distinct space for investigation away from ‘the fear of death’ argument, then I constructed alternative hypotheses, I proceeded afterwards with the actual design of my research, and during the first analysis of my data I decided to further analyse my data with an additional methodology that was more sensitive to the context, the social context with its available linguistic repertoires that enable but also restrict what can talked about, the way it can be talked about, and how these affect subjectivity. Special commitment was given to conceptualising how both methodologies can be combined and their generated insights were utilised both independently but also complementarily to each other. To the best of my understanding of the criteria of good qualitative research (Yardley, 2015) I was able to show sensitivity to the context both in the review of existing knowledge but also in the context of my hypotheses per se. When I was gathering my data I decided to take additional action to meet a better understanding of the participants’ context from which they understood their experience. Accordingly, the analysis that I produced –which added FDA analysis to the IPA analysis- was more insightful, more consistent with the very experience of my participants, more coherent towards the objects of my study.

And may I add as a final note a quote that I value greatly, and I believe sufficiently covers my own attitudes towards my topic and contributes to the conceptual transparency of what I, as the researcher, think about the phenomenon which I studied. It is a quote from the French psychologist-psychoanalyst, de Hennezel (1998), who had worked for many years with individuals who lived knowing that they were dying and in just a paragraph detects the imposed privacy towards the dying individual which I found in my FDA analysis, the need for kindness and love which I found in my IPA analysis, and also alternative positionings for both the dying individuals and the ones who interact with them; in short, it is a valuable quote and it reads as follow:

> “Even when one enters final helplessness, one can still love and feel loved... The ending of the life of someone you love can allow you to

accompany that person to the very last step. How many of us grasp this opportunity? Instead of looking oncoming death squarely in the face, we behave as if it will never come. We lie to one another, we lie to ourselves, and instead of giving voice to the essential, instead of exchanging words of love, or gratitude, or forgiveness, instead of leaning on one another for support in the extraordinary "crossing" that is the death of someone we love, pooling all the wisdom, the humour, and the love of which we're capable for the moment of actual encounter, we allow this final, essential, unique moment of life to be mired in silence and solitude" (de Hennezel, 1998, p. xiv-xv).

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Part 2: Critical Literature Review

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Appendix 1

CITY UNIVERSITY
LONDON

Title of Study: “The subjective experiences of people approaching death, when entering palliative care”

PARTICIPANT INFORMATION SHEET

We would like to invite you to take part in a research study. Before you decide whether you would like to take part it is important that you understand why the research is being done and what it would involve for you. 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.

What is the purpose of the study?
The study is about how people feel when they enter palliative care. It is very likely that you experience very difficult feelings at this stage of your life which you feel that you cannot share with anyone or no one understands. The purpose of this study is to better understand how people who enter palliative care make sense of this event, having in mind that you must have experienced a tremendous change in the way you perceived yourself after the diagnosis of having cancer. Entering palliative care with the physical pain central in your worries, thoughts and feelings, you must be experiencing additional difficulties in the way you experience yourself. The purpose of the study is to note and understand these difficulties.

It is done as part of my Doctorate degree in Counselling Psychology with the City University, London, UK. It intends to discover the needs, issues and concerns of people like you who are entering palliative care. In a comfortable and warm atmosphere with an experienced Counselling Psychologist you will be interviewed for about an hour. The interview will be taped for further processing. The processing could show that people like you who enter Palliative Care have common worries and difficulties and so get to know better the ways other people respond to your needs and difficult emotions.

Why have I been invited?
This information about the research is given to all patients of the Palliative Care Unit who are capable of managing the interview process. Participation in the study is open to everyone interested independently of age or gender. As long as you feel mentally and physically able to discuss issues about yourself you are more than welcome to declare your interest to participate. The study will involve 8 – 10 participants.

Do I have to take part?
Participation in the project is voluntary, and you can choose not to participate in part or the entire project. You can withdraw at any stage of the project without consequences.

It is up to you to decide whether or not to take part. If you decide to take part you will be asked to sign a form that you have understood what the interview is all about (consent form). If you decide to take part you are still free to opt out at any time and without giving any reason why.

During the interview you can stop as frequent as you want or even terminate the process at any time you feel pressed.

What will happen if I take part?

If you decide to participate it would mean that we hold an hour session together in which we will discuss the issues of your concern during this phase of your life. You will be free to talk about whatever you want and in whatever way you want to. I would appreciate getting to know more of you and your concerns. We will commence by you answering the simple question of "how do you feel about entering palliative care?". I will try to create an atmosphere between us of trust and care. It is very likely that we will focus on issues of mortality, pain, illness, cancer, diagnosis, approaching the end of life, or saying goodbye to loved ones and life in general.

The interview will be taped in order to be processed by a qualitative research method which looks for common topics in the concerns of people.

The session will be held here at the premises of the Palliative Care Unit.

What do I have to do?

Our work will start by you answering the question of "how do you feel about entering palliative care?" in any way you like, or say whatever comes to mind. I am not going to ask you to do anything else.

What are the possible disadvantages and risks of taking part?

You may well become emotionally distressed as a result of reflecting on your experience and for this reason you are provided the following list of services and organisations that provide psychological support.

- You can turn for support to the psychotherapeutic services of the Unit for six sessions.
- The National Help Line for People with Cancer. Ethnikh Grammh Bohtheias gia Atoma me Karkino: 1069
- Centre of psychosocial support for cancer patients: Hellenic Cancer Association. Kentro psychokoinwnikhs yposthrixhs gia karkinopatheis: Ellhnikh Antikarkinikh Etaireia: 210 6464598
- Centre "Ellie Lampeti": Hellenic Mastology Association. Kentro "Ellh Lampeth", Ellhnikh Etaireia Mastologias: 210 7773112
- Palliative Care. "Agapan" for cancer patients. Anakoufistikh symponetikh parhgorhtikh agwgh, Swmateio "Agapan" gia karkinopatheis: 210 7291079.

What are the possible benefits of taking part?

By participating in this research you will find a place and time to open up topics of your concern that we do not usually talk about with others out of fear and concern not to hurt them.

I am an experienced Counselling Psychologist and we can work out whatever arises in a warm and caring atmosphere.

In addition to personal gains, your contribution to the study will help to enlighten the scientific community about how people who are going through this phase of their lives feel, think, and make sense of their difficulties.

What will happen when the research study stops?

The interview will be typed word by word, translated to English, and processed. The material will be safely and securely kept until the final assessment of my Doctorate Thesis, and then will be kept for ten years as publications might follow. After ten years, they will be destroyed, safeguarding your anonymity and confidentiality.

Will my taking part in the study be kept confidential?

I am bound by The Code of Human Research Ethics (British Psychological Society, 2012) and the HCPC Standards of Conduct, Performance & Ethics (2012) and the City University Framework for Good Practice in Research (2010) on how to handle sensitive material. I will take good care in protecting the confidentiality of your material.

More specifically, access to your interview material will have only myself and my two Supervisors. Your name or any other identifying details will not be shown to anyone. Then extracts of the interviews will be included in my doctoral thesis and will be given for assessment to the authorised assessors of the City University, London, UK. When my thesis is completed the audio and written material will be kept for ten years and then will be destroyed so that no other person has any access to them.

If during the interview you reveal experiences that indicate that you have not been treated well or that harm may have come to you as a result of your treatment at the hospital I would advise you to contact the special independent complains office at the Areteion Hospital called the Office of Citizen's Support which is located on the main premises of the Hospital. This unit is entirely independent from the staff of the hospital.

What will happen to results of the research study?

My study will be submitted for assessment to City University, London, UK, and when successful, a possible number of publications in scientific journals will be produced. In all future uses of your material rest assured that your identity will not be revealed.

If you are interested in the results of the study you can access me in my personal email [redacted] at any time!

What will happen if I don't want to carry on with the study?

You can stop as many times as you like the interview or even terminate the process if you feel pressed. You can also withdraw your consent from the study and not have your material included for further processing. No explanation is needed and there will be no consequence in any respect. Unfortunately during the phase of the write up of the dissertation I will not be able to exclude your interview with me.

What if there is a problem?

If you have any problems with this study you can contact the Secretary of the Palliative Care Unit, Areteion General Hospital, Korinthias 27, Ambelokipoi 11526, Athens, Greece, telephone: [redacted], and the Head of the Unit [redacted], MD, will be notified.

Additionally, if you would like to complain about any aspect of the study, City University London has established a complaints procedure via the Secretary to the University's Senate Research Ethics Committee. To complain about the study, you need to phone [redacted] You can then ask to speak to the Secretary to Senate Research Ethics Committee and inform them that the name of the project is: "The subjective experiences of people approaching death, when entering palliative care".

You could also write to the Secretary at:

[redacted]
Secretary to Senate Research Ethics Committee
Research Office, E214
City University London

Northampton Square
London
EC1V 0HB
[redacted]

Who has reviewed the study?

This study has been approved by City University London, Senate Research Ethics Committee and the Research Committee of the National & Kapodistrian University of Athens, Medical School, Areteion Hospital.

Further information and contact details

If you have any inquiries about the research you can access me directly:

- Eugenia Giannikaki, Chartered Counselling Psychologist: [redacted]

For your information my Supervisor is the following and her email to be contacted is also included:

- Professor [redacted], City University London, UK, [redacted]

Thank you for taking the time to read this information sheet.

In Greek:

CITY UNIVERSITY LONDON

Τίτλος έρευνας: «Οι υποκειμενικές εμπειρίες των ατόμων που πλησιάζουν το τέλος της ζωής τους και μπαίνουν σε ανακουφιστική αγωγή»

Πληροφορίες για τον υποψήφιο συμμετέχοντα

Θα θέλαμε να σας προσκαλέσουμε να συμμετάσχετε σε μια έρευνα. Πριν αποφασίσετε είναι σημαντικό να κατανοήσετε γιατί γίνεται η έρευνα και τι καλείστε να κάνετε εσείς. Παρακαλούμε διαβάστε τις παρακάτω πληροφορίες και συζητήστε αν θέλετε πάνω σ αυτές. Ρωτήστε μας αν κάτι δεν είναι ξεκάθαρο ή αν θέλετε παραπάνω πληροφορίες.

Σκοπός της έρευνας

Η έρευνα θα εξετάσει πως αισθάνονται τα άτομα που έρχονται για ανακουφιστική αγωγή. Είναι πολύ πιθανό να νιώθεις πολύ δύσκολα συναισθήματα σε αυτή την φάση της ζωής σου που δεν μπορείς να μοιραστείς με κανένα ή κανένας δεν καταλαβαίνει. Ο σκοπός της έρευνας είναι να κατανοήσει καλύτερα πως τα άτομα που ξεκινούν ανακουφιστική αγωγή αντιλαμβάνονται αυτό το γεγονός, γνωρίζοντας ότι έχεις υποστεί μια τεράστια αλλαγή στον τρόπο που βιώνεις τον εαυτό σου μετά την διάγνωση ότι έχεις καρκίνο. Ξεκινώντας ανακουφιστική αγωγή με κύριο θέμα τον πόνο στις αγωνίες σου, τις σκέψεις και τα συναισθήματα σου, θα πρέπει να έχεις πρόσθετες δυσκολίες στον τρόπο που νιώθεις τον εαυτό σου. Ο σκοπός αυτής της έρευνας είναι να σημειώσει και να κατανοήσει αυτές τις δυσκολίες.

Διεξάγεται στο πλαίσιο του Διδακτορικού μου στην Συμβουλευτική Ψυχολογία με το Πανεπιστήμιο City του Λονδίνου, στην Αγγλία. Στοχεύει να ερευνήσει τις ανάγκες, τους προβληματισμούς, τα γενικότερα θέματα που απασχολούν τα άτομα που έρχονται για ανακουφιστική αγωγή. Σε μια ατμόσφαιρα ζεστή με μια έμπειρη Συμβουλευτική Ψυχολόγο θα κάνουμε μια ωριαία κουβέντα. Η συνέντευξη θα ηχογραφηθεί για περαιτέρω ανάλυση. Η ανάλυση μπορεί να μας δείξει κατά ποσό άτομα σαν εσένα που έρχονται για ανακουφιστική αγωγή έχουν κοινές αγωνίες και δυσκολίες και έτσι να κατανοήσουμε καλυτέρα πως οι άλλοι άνθρωποι μπορούν να σταθούν καλυτέρα στις ανάγκες σου και τα δύσκολα συναισθήματα.

Γιατί εγώ;

Η πληροφόρηση για την ερευνά αυτή δίνεται σε όλους τους ασθενείς της Μονάδας Ανακουφιστικής Αγωγής που μπορούν να ανταπεξέλθουν στην συνέντευξη. Η συμμετοχή στην έρευνα είναι ανοιχτή στον κάθε ενδιαφερόμενο ανεξάρτητα από ηλικία ή φύλο, μόνο στο βαθμό που μπορεί να διαχειριστεί σωματικά και διανοητικά μια συζήτηση πάνω σ αυτά που τον/την απασχολούν. Η έρευνα αποτελείται από 8-10 συνεντεύξεις.

Πρέπει να συμμετάσχω;

Η συμμέτοχη στην έρευνα είναι εθελοντική και μπορείς να αποφασίσεις να μην συμμετάσχεις. Μπορείς να αποχωρήσεις από την διαδικασία όποτε θελήσεις χωρίς επιπτώσεις.

Εσύ θα αποφασίσεις να συμμετάσχεις ή όχι. Αν αποφασίσεις να συμμετάσχεις θα σου ζητήσω να υπογράψεις ένα έντυπο ότι έχεις καταλάβει γιατί γίνεται αυτή η συνέντευξη (έντυπο συγκατάθεσης). Ακόμα και αν αποφασίσεις να συμμετάσχεις και κατά την διάρκεια αλλάξεις γνώμη μπορείς να το κάνεις.

Κατά την διάρκεια της συνέντευξης μπορείς να σταματήσεις την διαδικασία όσο συχνά θέλεις ή ακόμα και να διακόψουμε τελείως αν αισθανθείς ότι πιέζεσαι.

Τι θα γίνει αν αποφασίσω να συμμετάσχω;

Αν αποφασίσεις να συμμετάσχεις θα έχουμε μια ωριαία συνεδρία μαζί στην οποία θα συζητήσουμε ότι σε απασχολεί αυτή την περίοδο της ζωής σου. Θα είσαι ελεύθερος/η να μιλήσεις για ότι θέλεις με όποιο τρόπο θέλεις. Θα ήθελα να σε γνωρίσω καλυτέρα και εσένα και τα ζητήματα που σε απασχολούν. Θα ξεκινήσουμε με το να μου απαντήσεις στην απλή ερώτηση του «πως νιώθεις που έρχεσαι για ανακουφιστική αγωγή». Θα προσπαθήσω να καλλιεργήσω μια ατμόσφαιρα μεταξύ μας εμπιστοσύνης και φροντίδας. Η συζήτηση μας είναι πολύ πιθανό να συμπεριλάβει θέματα όπως η θνητότητα, ο πόνος, η αρρώστια, ο καρκίνος, πλησιάζοντας το τέλος της ζωής, αποχαιρετώντας τους αγαπημένους.

Η συνέντευξη θα ηχογραφηθεί για να αναλυθεί με ποιοτική μέθοδο που εντοπίζει κοινή θεματολογία στις αγωνίες των ατόμων.

Όλες οι συνεδρίες θα γίνουν στον χώρο της Μονάδας Ανακούφισης Πόνου.

Τι πρέπει να κάνω;

Η συνέντευξη μαζί σου θα ξεκινήσει με το να σε ρωτήσω «πως νιώθεις που έρχεσαι για ανακουφιστική αγωγή» με όποιο τρόπο θέλεις ή με ότι έρχεται στο μυαλό. Δεν θα σε ρωτήσω τίποτα άλλο.

Θα με επιβαρύνει αυτή η έρευνα με κάποιο τρόπο;

Είναι πιθανό να νιώσεις ψυχική αναστάτωση ως αποτέλεσμα της εμβάθυνσης στην εμπειρία σου και για αυτό το λόγο σου δίνω την παρακάτω λίστα υπηρεσιών και οργανισμών που προσφέρουν ψυχολογική υποστήριξη.

- Μπορείς να ζητήσεις υποστήριξη από την υπηρεσία ψυχοθεραπείας της Μονάδας για έξι συνεδρίες.
- Την Εθνική Γραμμή Βοήθειας για Άτομα με Καρκίνο: 1069
- Κέντρο Ψυχοκοινωνικής Υποστήριξης για Καρκινοπαθείς: 210 6464598
- Κέντρο «Έλλη Λαμπέτη» Ελληνική Εταιρεία Μαστολογίας: 210 7773112
- Ανακουφιστική Συμπονετική Παρηγορητική Αγωγή. Σωματείο «Αγαπάν» 210 7291079

Ποια τα πιθανά οφέλη της συμμετοχής μου;

Η συμμέτοχη σου σε αυτή την έρευνα μπορεί να σε βοηθήσει να βρεις ένα χώρο και ένα χρόνο να μιλήσεις για αυτά που σε απασχολούν και που συνήθως δεν μιλάμε από φόβο και έγνοια μην πληγώσουμε τους άλλους.

Είμαι έμπειρη Συμβουλευτική Ψυχολόγος και μπορούμε να διαχειριστούμε ότι προκύψει σε μια ατμόσφαιρα ζεστή και με απόλυτη αποδοχή.

Πέραν όμως από τα προσωπικά οφέλη, η συνεισφορά σου στην έρευνα θα βοηθήσει την επιστημονική κοινότητα να δει πιο καθαρά πως άτομα που διανύουν αυτή την φάση της ζωής τους νιώθουν, σκάφτονται, και νοηματοδοτούν τις δυσκολίες τους.

Τι θα γίνει όταν ολοκληρωθεί η έρευνα;

Η συνέντευξη θα καταγράφει αυτολεξεί, θα μεταφραστεί στα Αγγλικά, θα αναλυθεί, και κοινά θέματα θα αναδυθούν από όλες τις 8-10 συνεντεύξεις της μελέτης. Το υλικό θα κρατηθεί σε μέρος ασφαλές που θα έχω μόνο εγώ πρόσβαση εωσότου η Διδακτορική μου διατριβή αξιολογηθεί από το Πανεπιστήμιο. Μετά θα κρατηθεί σε ασφαλές μέρος για δέκα χρόνια σε περίπτωση που ακολουθήσουν δημοσιεύσεις σε επιστημονικά περιοδικά, κατόπιν θα καταστραφεί ώστε να διαφυλαχτεί η ταυτότητα των συμμετεχόντων.

Η συμμετοχή μου θα είναι εμπιστευτική;

Δεσμεύομαι από τον Ηθικό Κώδικα για την Έρευνα με Άτομα, της Βρετανικής Ψυχολογικής Εταιρείας (2012), και τους Κανόνες Συμπεριφοράς, Παράστασης και Ηθικής των Επαγγελματιών Υγείας και Φροντίδας της Αγγλίας (2012), καθώς και το Πλαίσιο Ορθής Έρευνας του Πανεπιστήμιου City του Λονδίνου (2010) για την διαχείριση ευαίσθητου υλικού. Η ασφαλής διαχείριση της εμπιστευτικότητας του υλικού σου είναι πρωτίστη μου υπευθυνότητα και θα το διαφυλάξω με μεγάλη φροντίδα.

Πιο συγκεκριμένα, πρόσβαση στην συνέντευξη σου θα έχω εγώ και οι δυο Επόπτες μου. Το όνομα σου καθώς και κάθε λεπτομέρεια της ταυτότητας σου δεν θα αποκαλυφθεί σε κανέναν. Μόνο αποσπάσματα των συνεντεύξεων θα συμπεριληφθούν στην Διδακτορική μου διατριβή και θα δοθεί για εξέταση στους Εξεταστές του Πανεπιστήμιου City του Λονδίνου, της Αγγλίας. Μετά την επιτυχή αξιολόγηση της το ηχητικό και γραπτό υλικό θα κρατηθεί σε ασφαλές μέρος για δέκα χρόνια. Μετά την πάροδο των πέντε ετών θα καταστραφεί ώστε να διαφυλαχτεί το ότι κάνεις άλλος δεν θα έχει ποτέ πρόσβαση σ αυτό.

Αν κατά την διάρκεια της συνέντευξης μου εμπιστευτείς εμπειρίες κατά τις οποίες η θεραπεία σου δεν ήταν σωστή ή ακόμα κ επιζήμια από το Νοσοκομείο θα σε συμβούλευα να επικοινωνήσεις με το γραφείο παραπόνων του Αρεταιείου Νοσοκομείου που ονομάζεται Γραφείο Υποστήριξης του Πολίτη και εδρεύει στο κυρίως κτίριο του Νοσοκομείου. Το Γραφείο είναι τελείως ανεξάρτητο από το προσωπικό του νοσοκομείου.

Τι θα γίνουν τα αποτελέσματα της έρευνας;

Η έρευνα θα κατατεθεί για αξιολόγηση στο Πανεπιστήμιο City του Λονδίνου, της Αγγλίας, και μετά την επιτυχή αξιολόγηση της ένας αριθμός δημοσιεύσεων θα ακολουθητέε σε επιστημονικά περιοδικά. Ακόμα και για τις μελλοντικές δημοσιεύσεις θα προσπαθώ να διαφυλάξω την ταυτότητα σας.

Αν ενδιαφέρεστε για τα αποτελέσματα της μελέτης αυτής μπορείτε να επικοινωνήσετε μαζί μου στο προσωπικό μου emai[redacted]

Τι γίνεται αν δεν θέλω να συνεχίσω;

Έχετε κάθε δικαίωμα να άρετε την συγκατάθεση σας να χρησιμοποιηθεί το υλικό σας στην μελέτη ανά πάσα στιγμή. Δεν χρειάζεται καμία εξήγηση και δεν θα υπάρξει καμία συνέπεια. Δυστυχώς κατά την διάρκεια της συγγραφής της μελέτης δεν θα μπορώ να παραλείψω το την συνέντευξη σας.

Και αν υπάρξει κάποιο πρόβλημα;

Για το όποιο ζήτημα ανακύψει μπορείτε να επικοινωνήσετε με την Γραμματεία της Μονάδας Ανακουφιστικής Αγωγής, Αρεταίειο Γενικό Νοσοκομείο, Κορινθίας 27, Αμπελόκηποι 11526, Αθήνα, στο τηλέφωνο[redacted], και η Καθηγήτρια κα[redacted] θα ειδοποιηθεί. Επιπρόσθετα, αν θέλετε να παραπονεθείτε για όποιο θέμα της έρευνας, το Πανεπιστήμιο του City έχει θεσπίσει διαδικασίες παραπόνων μέσω της Γραμματείας της Συγκλήτου του Πανεπιστήμιου της Επιτροπής Ηθικής Έρευνας. Για τα παράπονα σας καλέστε το τηλέφωνο [redacted]. Κατόπιν ζητήστε να μιλήστε με την Γραμματέα της Συγκλήτου του Πανεπιστήμιου της Επιτροπής Ηθικής Έρευνας και πληροφορήστε τους τον τίτλο της έρευνας: «Οι υποκειμενικές εμπειρίες των ατόμων που πλησιάζουν το τέλος της ζωής τους και μπαίνουν σε ανακουφιστική αγωγή».

Μπορείτε επίσης να γράψετε στην ακόλουθη διεύθυνση:

[redacted]
Secretary to Senate Research Ethics Committee

Research Office, E214
City University London
Northampton Square
London
EC1V 0HB
Email: [redacted]

Ποιος έχει εγκρίνει αυτή την έρευνα;

Η έρευνα έχει εγκριθεί από το Πανεπιστήμιο City του Λονδίνου, της Αγγλίας, Τομέας Ψυχολογίας Επιτροπή Ηθικής της Έρευνας.

Περισσότερες πληροφορίες και στοιχειά επικοινωνίας:

Για όποια περαιτέρω πληροφορία μπορείτε να επικοινωνήσετε μαζί μου απευθείας:

- Ευγενία Γιαννικάκη, Εγκεκριμένη Συμβουλευτική Ψυχολόγος, [redacted] και στο [redacted].

Προς πληροφόρηση σας η Επόπτρια μου είναι η ακόλουθη και παραθέτω και τα στοιχειά επικοινωνίας της:

- Καθηγήτρια [redacted], City University London, UK, [redacted]

Ευχαριστώ για τον χρόνο σας που διαβάσετε αυτές τις πληροφορίες.

Appendix 2

CITY UNIVERSITY
LONDON

Title of Study: “The subjective experiences of people approaching death, when entering palliative care”

PARTICIPANT CONSENT FORM

I (please print your first and last names) ________________________________ agree to take part in a research project conducted by Ms Eugenia Giannikaki for her Doctorate in Counselling Psychology at City University, UK. I understand that participation will consist of my taking part in a face-to-face interview with Ms Giannikaki. I understand that this interview will be tape-recorded and transcribed at a later stage and that the information I provide in my interview will be used for the completion of Ms Giannikaki’s doctorate and in any publications that emerge from her doctoral thesis.

I understand that the general purpose of the present research project is to explore the subjective experiences of individuals who go through palliative care.

I understand that participation in this research is voluntary and unpaid.

I understand that any information I provide will ensure that my identity is not revealed and only for research purposes in Ms Giannikaki’s doctoral thesis and in any future publications in which I will be identified by a number or pseudonym. My name and other identifying information will only be known to Ms Giannikaki and her supervisors.

I understand that all information I provide will be stored securely for the duration of the present study and will be destroyed after ten years.

I reserve the right to withdraw my participation at any point without giving reasons for this and without incurring any consequences.

I confirm that I have had the opportunity to ask as many questions as I have needed about this project and my participation in it.

I understand that the researcher and her supervisor will continue to be available in the event that I have further queries about this project and about my participation in it.

Participant’s Signature: ______________________________

Date: ____________________________________

Researcher’s signature: ____________________________________

Date: ____________________________________

Please provide a postal address or email address below if you wish to receive a summary of the main findings when these become available.

For any queries relating to this research project and your participation in it, please contact:

Researcher

[redacted],
DPsych Researcher and Chartered Counselling Psychologist
[redacted]

Academic Supervisor:
Name:
Business Address:
Tel.:
Email:

In Greek:

CITY UNIVERSITY
LONDON

Τίτλος έρευνας: «Οι υποκειμενικές εμπειρίες των ατόμων που πλησιάζουν το τέλος της ζωής τους και μπαίνουν σε ανακουφιστική αγωγή»

ΕΓΓΡΑΦΟ ΣΥΓΚΑΤΑΘΕΣΗΣ

Εγώ ο/η (παρακαλώ συμπληρώστε το ονοματεπώνυμο σας) ______________________________ αποδέχομαι να συμμετάσχω στην ερευνητική μελέτη της κας Ευγενίας Γιαννικάκη για την απόκτηση Διδακτορικού Τίτλου στην Συμβουλευτική Ψυχολογία με το Πανεπιστήμιο City του Λονδίνου, στην Αγγλία. Κατανοώ ότι η συμμέτοχη μου θα είναι μια κατ’ ιδίαν συνέντευξη με την κα Γιαννικάκη. Κατανοώ ότι η συζήτηση θα ηχογραφηθεί και καταγράφει αυτολεξεί σε μετέπειτα χρόνο καθώς και ότι οι πληροφορίες που θα δώσω θα χρησιμοποιηθούν για την ολοκλήρωση της Διδακτορικής Διατριβής της κα Γιαννικάκη αλλά και σε μελλοντικές δημοσιεύσεις που θα προκύψουν από την μελέτη αυτή.

Κατανοώ ότι ο σκοπός της έρευνας είναι η ανάδυση των υποκειμενικών εμπειριών των ατόμων που έρχονται για Ανακουφιστική Αγωγή.

Κατανοώ ότι η συμμέτοχη μου είναι εθελοντική και χωρίς χρηματική απολαβή.

Κατανοώ ότι όποια πληροφορία δώσω θα διαφυλάξει την ταυτότητα μου και θα χρησιμοποιηθεί μόνο για τους ερευνητικούς σκοπούς της διδακτορικής μελέτης της κα Γιαννικάκη και ότι σε μελλοντικές δημοσιεύσεις θα αναφέρομαι με ψευδώνυμο ή με αριθμό. Το όνομα μου καθώς και όποιες προσωπικές πληροφορίες θα είναι γνώστες μόνο στην κα Γιαννικάκη και στους Επόπτες της.

Κατανοώ ότι όλες οι πληροφορίες που θα δώσω θα αποθηκευτούν σε ασφαλές μέρος και θα καταστραφούν μετά την πάροδο δέκα ετών.

Επιφυλάσσομαι του δικαιώματος μου να άρω την συμμέτοχη μου αν το θελήσω χωρίς να δώσω εξηγήσεις και χωρίς να έχω επιπτώσεις.

Επιβεβαιώνω ότι είχα την ευκαιρία να κάνω ερωτήσεις διασαφηνιστικές για την έρευνα αυτή και για την συμμέτοχη μου σε αυτή.

Κατανοώ ότι η ερευνήτρια και η Επόπτης της θα είναι στη διάθεση μου αν θελήσω περαιτέρω διευκρινήσεις για την έρευνα και την συμμέτοχη μου σε αυτή.

Υπογραφή Συμμετέχοντα: ______________________________

Ημερομηνία: __________________________________

Υπογραφή Ερευνητή: __________________________________

Ημερομηνία: __________________________________

Αν επιθυμείται να μάθετε για τα αποτελέσματα της έρευνας αυτής συμπληρώστε την διεύθυνση σας ή το email σας.

____

____

Για περαιτέρω διευκρινήσεις για την έρευνα και την συμμέτοχη σας σε αυτή, παρακαλώ επικοινωνήστε:

Ερευνήτρια:

[redacted]
DPsych Ερευνήτρια και Εγκεκριμένη Συμβουλευτική Ψυχολόγος
[redacted]

Ακαδημαϊκός Επόπτης: Professor [redacted]

Email: [redacted]

Appendix 3

CITY UNIVERSITY
LONDON

Title of Study: “The subjective experiences of people approaching death, when entering palliative care”

Acknowledgement Letter

Date:

Dear <Name of participant>,

Ref: Your participation to my research project.

Thank you for taking part in my research project on the subjective experiences of individuals who go through palliative care. I would like to reassure you that your participation is being kept confidential and that both the tape-recording and the transcription of your interview with me are kept under lock and key and that these materials are only accessible by me and by my supervisors. Furthermore, I would like to take this opportunity to remind you that if you wish to talk to someone about your thoughts and feelings after your interview with me then you are more than welcome to contact the Unit to arrange for an appointment with the psychologist who will be more than willing to offer you her help at no charge. In the event that you feel the need to talk to a healthcare professional before you start your therapeutic work with the Unit’s psychologist you can contact the National Helpline for People with Cancer and their Carers on 1069 (charged at national rates for calls to landlines).

Please be advised that I am available for any queries or further information about my research project and I would be very happy to hear from you.

Kindest regards,

[redacted],
Researcher and Chartered Counselling Psychologist
[redacted]

*If you would like to complain about any aspect of the study, please contact the Secretary to the University’s Senate Research Ethics Committee on [redacted] or via email:
[redacted]

In Greek:

CITY UNIVERSITY
LONDON

Τίτλος έρευνας: «Οι υποκειμενικές εμπειρίες των ατόμων που πλησιάζουν το τέλος της ζωής τους και μπαίνουν σε ανακουφιστική αγωγή»

Ευχαριστίες

Ημερομηνία :
Αγαπητέ/η (όνομα συμμετέχοντα),

Για την συμμετοχή σου στην έρευνα μου.

Σ ευχαριστώ που έλαβες μέρος στην ερευνητική μου μελέτη πάνω στις υποκειμενικές εμπειρίες ατόμων που μπαίνουν σε ανακουφιστική αγωγή. Θα ήθελα να σε διαβεβαιώσω ότι η συμμετοχή σου είναι εμπιστευτική και η ηχογράφηση που κάναμε καθώς και η κατά λέξη καταγραφή της θα φλεχτούν κλειδωμένα ενώ πρόσβαση στα αρχεία αυτά θα έχουν μόνο εγώ και οι Επόπτες μου. Επιπλέον, θα ήθελα να σου υπενθυμίσω ότι αν επιθυμείς να μιλήσεις με κάποιον για τις σκέψεις σου και τα συναισθήματα σου μετά την συνέντευξη μας είσαι ευπρόσδεκτος/η να επικοινωνήσεις με την Μονάδα για να κανονίσεις ραντεβού με την ψυχολόγο που είναι πολύ πρόθυμη να προσφέρει την βοήθεια της, χωρίς καμιά επιβάρυνση. Αν πάλι νιώσεις την ανάγκη για κάτι πιο επείγον πριν την επομένη συνάντηση με την ψυχολόγο της Μονάδας μπορείς να επικοινωνήσεις με την Εθνική Γραμμή Βοήθειας για Άτομα με Καρκίνο και τους Φροντιστές τους στο 1069 (απλή χρέωση προς σταθερά).

Είμαι στη διάθεση σου για όποια ερώτηση ή διευκρίνηση χρειαστείς για την ερευνητική μου δουλεία και με χαρά να στην απαντήσω.

Με φιλικούς χαιρετισμούς,

[redacted],
Ερευνήτρια και Εγκεκριμένη Συμβουλευτική Ψυχολόγος
[redacted]

*Σε περίπτωση που θα ήθελες να παραπονεθείς για κάποιο τμήμα της έρευνας αυτής μπορείς να επικοινωνήσεις με την Γραμματεία της Συγκλήτου Ηθικής της Έρευνας του Πανεπιστήμιου City, του Λονδίνου, Αγγλίας στο τηλέφωνο [redacted] ή στο email: [redacted]

Appendix 4

CITY UNIVERSITY
LONDON

Title of Study: “The subjective experiences of people approaching death, when entering palliative care”

Referral Protocol

In cases of physical, emotional or sexual harm the following public boards and private agencies can be contacted in Greece:

For Children’ emotional and physical health:

- To Hamogelo tou Paidiou: http://www.hamogelo.gr telephone: 1056
- EPSYPE: http://www.epsype.gr telephone: 8018011177

For abused women:

- Kentro kakopoihmenhs gunaikas: 210 5235318, 210 4112091, 210 3220900
- Grammh kata ths oikogeneiakhs bias “Dipla sou”: 800 1188881
- Stegh kakopoihmenhs gynaikas kai anhlikou kouritsiou (Thessalonikh): 2310 528483, 2310 519594

For University students’ psychological services:

- Sumbouleutiko kentro foithtwn Panepisthmiou Athhnwn: 210 7277553, 210 7277554
- Kentro sthrixhs foithtwn Panepisthmiou Makedonias: 2310 891406
- Yphresia symboyloy psychikhs ugeias Oikonomikou Panepisthmiou Athhnwn: 210 8203239
- Symbouleutiko kentro Panepisthmiou Peiraia: 210 4142042, 210 4142043
- Symbouleutiko kentro Panepisthmiou Iwanninwn: 26510 96600

Social services lines:

- Koinwnikh yphresia TEI Athhnwn: 210 5385128, internal 5128
- Grammh psychologikhs yposthrixhs strateushmwn, Geniko Epiteleioy Ethnikhs Amunas: military 800114551, air force 8001145552, navy 8001145553
- Monada epeigousas thlephwnikhs anagkhs: 210 7222333 (Aiginiteio Psychiatric Hosital)
- Ethniko kentro ameshs koinwnikhs bohtheias (EKAKB): 197

Services for cancer patients:

- Kentro psychokoinwnikhs yposthrixhs gia karkinopatheis: Ellhnikh Antikarkinikh Etaireia: 210 6464598
- Kentro “Ellh Lampeth”, Ellhnikh Etaireia Mastologias: 210 7773112
- Anakoufistikh symponetikh parhgorhtikh agwgh, Swmateio “Agapan” gia karkinopatheis: 210 7291079.

For AIDS patients:

- Thlephwnikh grammh gia to AIDS Nosokomeio L. Suggros: 210 7222222
- Institouto psychikhs kai sexualikhs ygeias: 210 7797979

For drug and alcohol abuse:

- OKANA: 1031
- ITHAKH: 1145
- Monada apexarthshs toxikomanwn & alcoolikwn: 210 3617089.