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Université de Montréal

The experience of knowing without sharing the proximity of death due to cancer for family  
members in the Basque Country

par

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Mémoire présenté à la Faculté des études supérieures  
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Faculté des études supérieures

Ce mémoire intitulé :

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présenté par :

Amaia Sáenz de Ormijana

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This Master's Thesis titled:

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## Sommaire

Le cancer à la phase terminale est toujours un défi pour la stabilité d'une famille. Les difficultés dérivées de cette situation peuvent amener la famille à vivre une nouvelle dynamique dans laquelle la communication est limitée et les sujets reliés à la mort sont évités. La décision des proches de s'entendre avec l'équipe de santé pour éviter de donner l'information sur le diagnostic fatal à la personne malade est connue dans la littérature scientifique comme le phénomène de la « Conspiration du Silence ». Cette décision est encore assez répandue chez certaines familles basques. Le but de l'étude est de décrire, selon une approche phénoménologique, l'expérience de membres de la famille au Pays Basque qui habitent avec une personne vivant la phase terminale d'un cancer et qui ont décidé de cacher l'information du diagnostic fatal à la personne malade. À partir de la perspective de l'Humain en devenir de Parse, l'étudiante chercheuse a choisi une approche méthodologique qualitative dans laquelle elle fait partie intégrante du contexte et dans laquelle elle co-participe à la construction de la description de l'expérience avec les participantes. Les données ont été recueillies à l'aide d'entrevues en profondeur avec trois personnes. Malgré que nous ayons invité tous les membres des familles à participer, les entrevues ont été réalisées avec le membre de la famille identifié comme étant la personne avec le plus de responsabilités dans le soin de la personne malade. L'analyse et l'interprétation des données ont été réalisées à partir de la méthode de Giorgi (1997). L'expérience de « connaître sans partager » a été décrite par les trois membres des familles, sur la base de l'interaction entre trois éléments du système familial : (1) croyances et valeurs, (2) rôles et leur distribution dans le système familial et (3) dynamiques familiales de communication et fonctionnement. La façon dont les membres de la famille ont exprimé la signification de l'expérience « connaître sans partager » peut être décrite à partir des trois thèmes suivants : (1) « protection de la personne la plus faible », (2)

« affirmation de l'équilibre par la routine » (3) « maintien de l'espoir ». La dynamique de la protection est basée sur la croyance qu'une personne gravement malade n'est pas capable de prendre les décisions pour elle-même et cette dynamique est renforcée par la mise en priorité de l'assistance bienveillante plutôt que l'autonomie personnelle. Cette priorité ramène la famille aux attitudes selon lesquelles la soignante familiale se sent obligée de protéger la personne malade de la douleur et de la souffrance, entre autres, en ne l'informant pas de la mort prochaine. Le fait de garder les émotions et les discussions inconfortables hors de la vie courante aide la soignante à avoir la sensation de maîtrise et de maintien de la stabilité familiale. Finalement, le maintien de l'espoir, pour la soignante et la personne malade, paraît agir comme une défense contre la souffrance pour chacun. De notre point de vue et à la suite de cette étude, la personne malade décide aussi jusqu'à un certain moment d'agir de la même façon silencieuse et décide alors de garder la même attitude de protection auprès de la famille. Nous sentons que l'expression « Conspiration du Silence » n'inclut pas le niveau de conscience de la personne malade. Ainsi, nous proposons l'expression « Accord sur le silence ». Cette étude offre aux infirmières des éléments de réflexion pour être vraiment présentes auprès des membres de ces familles en les accompagnant lors de leurs processus de vie. La recherche dans l'avenir devrait être développée afin d'élargir les possibilités pour ces expériences familiales de trouver un espace et un sens dans l'univers des professionnels de la santé. Mots clés : membres de famille, phase terminale du cancer, mort, communication, recherche qualitative.

## Summary

Cancer in a non-curable stage is always a threat to the stability of a family. Difficulties imposed by this situation can lead the family to implement new dynamics where communication is restricted and death issues avoided. Relatives' decision to collude with the health care team in order to keep the information on fatal prognosis from the ill member is what the literature has named as the phenomenon of the "Conspiracy of Silence", still quite a common phenomenon among families from a Basque culture. The goal of this study is to describe, using a phenomenological approach, the experience of family members in the Basque Country who live with a person who is in the terminal phase of cancer and who, while knowing it, have decided not to share with him/her the information about his/her upcoming death. Using Parse's conception of the Human Becoming, the researcher takes a qualitative methodological stance where she is an integrate part of the context in which she co-constitutes and co-constructs with participants the description of the reality being shared at the time of the meetings. Data were collected through in-depth interviews with one member of three families, self-identified as the person with the largest responsibility in the care of the dying relative, although we invited several members to participate. Analysis and interpretation of the data were developed on the basis of Giorgi's (1997) method. The experience of "Knowing without sharing" may be described by the three carers participating in the study, on the basis of the interaction among three sets of elements: (1) values and beliefs, (2) roles and their assignment within the family system and (3) family communication and functioning dynamics or patterns. As family members expressed it, the meaning of the experience of "knowing without sharing" could be described as: (1) "protecting the weak", (2) "reassuring the equilibrium provided by normality" and (3) "maintaining hope". Dynamics of protection are based on the belief that a

person, being ill, is not capable of making good decisions for himself/herself and are reinforced by the value of beneficence over autonomy. This leads family members to attitudes where the carer feels obligated to protect the ill member from the pain and damage of suffering among other things, from the pain of knowing. Keeping emotions and feelings as well as uncomfortable conversations out of the everyday life seems to help carers gain a sense of control and ability to maintain everything the way it has always been. Finally, hope for self and the ill person, seems to act as a protecting shield against suffering for each. From what we heard in this study, it is also the ill member himself/herself who, at a certain point, decides to exert the same protective attitude towards his/her relatives by deciding to collude with them and not talk about difficult issues. From this stance, we feel that the expression “Conspiracy of Silence” does not take into account the patient illness awareness. Hence we are proposing the expression “Agreement on Silence”. This study is intended to provide nurses with hints that would help them be truly present to these family members and openly and wisely accompany them along their life-processes. Further research needs to be developed in order to deepen and widen the possibilities for these families’ experience to make sense in the health professionals’ own environment. Keywords: family carers, terminal phase of cancer, death, communication, qualitative research.

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**1<sup>ST</sup> CHAPTER**  
**THE PROBLEM**

## The phenomenon of interest

The diagnosis of cancer in a non-curable stage is always a threat to the stability of a family. Family's interaction patterns, as every other element of the family structure and functioning, is influenced by the proximity of death. Difficulties imposed by this situation can lead the family to implement new patterns or dynamics where communication is restricted and death issues avoided. Relatives' decision to collude with the health care team in order to keep the information on fatal prognosis away from the ill member is what the literature has named as the phenomenon of the "Conspiracy of Silence" (Costello, 2000; Krisman-Scott, 2000; Roser, 1994; Rubiales, del Valle, García, Garávís, Rey, Vecino, Hernansanz & López-Lara, 2000).

Despite the cancer mortality decrease brought by the rapid development of treatment techniques over the past 20 years, the augmented life expectancy in 1<sup>st</sup> world societies has increased the morbidity and mortality rates assigned to this disease (Oberleitner, 2001). In the Basque Country, cancer constitutes the main cause of death for men and women between the ages of forty-five and seventy-four (Gobierno Vasco, 2002). Like in every other region in Spain, there has been an increasing number of deaths caused by cancer and other life-shortening illnesses. In 1998, malignant tumours were known to affect 182 individuals per 100.000 (Gobierno Vasco, 2002). According to the studies by Vincent and Mirand (cited by Cooley & Moriarty, 1997), in the next two decades three out of four families will experience cancer.

Like any other life-shortening illness, cancer influences the family system. The fears and threats that an illness of this kind brings into the system may disturb its day-to-day life and dynamics. A life-threatening illness may cause a breakdown in a family's life cycle, in its

regular developmental history (Wright & Nagy, 1993). As the illness generates new needs and demands, it stops everyday life events from taking place and, instead, establishes new role distributions and new interaction patterns as well as new rituals and behaviours to be adopted by all family members (Chapman & Pepler, 1997; Moules & Amundson, 1997; Wright & Nagy, 1993).

Family members' reaction to the situation can be influenced by several elements such as: family dynamics, interaction patterns, communication skills, attachments, beliefs about death and dying, role assignment, etc. All of these factors exert also great influence on family members' attitude towards communication (Kristjanson & Ashcroft, 1994; Lev & McCorke, 1998; Plante, 1995; Wright & Nagy, 1993). Families can find it difficult to establish open and clear communication patterns. Uncertainties about death, cultural taboos and norms (Bruera, Neumann, Mazzocato, Stiefel, & Sala, 2000), stress and anxiety, preconceived ideas about cancer and the dying process, as well as myths such as (Fallowfield, 1997) "What you do not know does not hurt you" might contribute to this challenge (Fallowfield, 1997) and to generate secret keeping attitudes.

Interrelationships and communication with a dying relative constitute the basic foundation for the development of family support, both for the ill member and for the other members (Kristjanson & Ashcroft, 1994; Kristjanson et al, 1996; McEnroe, 1996; Sales et al., 1992). On one side, when difficulties that make communication poor are found, the positive effects of family support seem to be cancelled out, role reassignment becomes a problem and family cohesion is threatened (Ell, 1996). On the other hand, in the context of terminal illness, open communication contributes to increase marital adjustment and psychosocial functioning, as well as to the development of several coping strategies (Cooley & Moriarty, 1997).

However, keeping a fatal prognosis secret within the family fulfils several functions and allows the development of different relationships among members. Conspiracies of silence are very often intended to protect the ill member and the rest of the members from suffering, from the emotional and psychological damage caused by “unbearable” reality and by the threat of death (Hodgson, Higginson, McDonnell & Butters, 1997; Lev & McCorke, 1998; Wright & Nagy, 1993). Nevertheless, the conspiracy of silence can also accomplish other unconsciously intended functions such as resistance to change (Grolvick, 1983), calm and equanimity (Fallowfield, 1997) or limiting distress (Lev & McCorke, 1998).

In addition to all the determining factors identified, cultural and social values and beliefs have also clear influences on care practices (Andershed & Ternstedt, 1999). Dying and losing a loved one are highly culturally influenced experiences (Ali, Khalil & Yousef, 1993; Donnelly, 1995; Koenig & Gates-Williams, 1995; Leonard, Schrader, McTavish, Cumming, & Cumming, 1995; Talamantes, Lawler et Espino, 1995). Cultural values, norms and beliefs determine the way different individuals from different contexts live the experience of the proximity of death. Different studies have found important differences in the ethical and moral values that sustain the decision making process either held by the family members, the patient or the health care professionals (Bruera & Newman, 2000; Brusamolino & Surbone, 1997; Fallowfield, 1997; Kagawa Singer, 1998; Maciejewski, 1997). These studies found the tendency among latino cultures to deny death and keep it taboo (Blackhall et al., 1995). Especially in Mediterranean countries, those same studies have remarked families’ willingness to hide the information about fatal prognosis from the patient (Bruera et al., 2000; Fallowfield, 1997; Field & Copp, 1999; Porta, Busquet, & Jariod, 1997; Zakotnik, 1997). In a culture where death is denied, always set aside from social conversations and hidden away, the threat

of a loved one's impending death can actually bring more changes into the family than the illness itself.

While working in home-care community services, the tendency among Basque-Mediterranean families to withhold fatal prognosis and prognosis information from the "patient" him/her self strongly attracted my attention. From what I observed, family members who were aware of the diagnosis felt helpless when the ill member tried to express his/her concerns about the future or even about death. Besides, the patient him/herself found it hard to both, express feelings, fears, emotions or needs and, at the same time, watch other members suffer in the darkness of the imposed silence. When such communication patterns are developed, on one hand, people experiencing proximity of death can feel lonely (Husebo, 1997), anxious and stressed (Fallowfield, 1997). They themselves find new difficulties coping with the situation and relating to death (Husebo, 1997). On the other hand, other members of the family feel helpless, nervous, irritable and can actually develop higher levels of stress than the ill member (Houston & Kendall, 1992).

The family dynamics created by the decision of withholding information places the health professionals working with them in a very peculiar situation. Nurses are usually asked to conceal the information together with other health care professionals and the family members who decide to conspire. This narrowly defined space for movement that is left for health professionals poses important ethical dilemmas for these professionals. Health professionals are often under high pressure as they face the uncertainty of whether the ill member knows or does not know (McGrath, Yates, Clinton & Hart, 1999; Quill, 2002). They are caught between family members' decision to conceal and the patient's right to know, without even being able to verbally explore this last issue with him/her.

The situation is never easy and so it usually invites professionals to place themselves in direct opposition to it. From our own clinical practice, how many times have we labelled a family consciously sustaining a conspiracy of silence as pathological? Family dynamics sustaining a conspiracy of silence are indeed usually considered pathological by health care professionals (Blackhall, Murphy, Frank, Michel, & Azen, 1995; Quill, 2002; Rosser, 1994). Promoting communication between family members seems to be a crucial aspect of family-based intervention (Lev & McCorke, 1998), and so, in the last years, breaking up the patterns where conspiracy is installed seems to be the rule governing palliative care family interventions. However, sounder training and deeper knowledge is still to be developed on the subject (Hilton, 1996; Hodgson et al., 1997; Lev & McCorke, 1998). Health professionals also need to face and work through their own values on family communication and death in order to be able to respect and move along family's decision. This would allow nurses to accompany families along this process, no matter what their decision concerning communication is, and hopefully without feelings of suffering, helplessness or frustration (McGrath et al., 1999).

An individual's quality of life whether in the process of dying or losing a loved one is definitively influenced by factors such as family's communication patterns, rituals, beliefs or myths and taboos. According to Parse (1998), the nurse's goal is to participate in a way to contribute to quality of life as defined by each individual. Family members cocreate their reality based upon their values and beliefs, and so enable possibilities as they "language" their perspective on the experience.

To acknowledge the essence of the lived experience as described by each individual constitutes the goal of the phenomenological approach (Rose, Beeby, & Parker, 1995). In accordance to the basic three assumptions of her Theory, Parse (1998) encourages nurses to

develop research from this methodological perspective as this position strongly relates to her Theory's basic assumptions which promote understanding and accompanying individuals along their experiences from the meaning assigned to them and the quality of life as defined by them (Parse, 1998).

As a contribution to Nursing Science, this study is intended to obtain a sound understanding of the phenomenon from the point of view of the family members who choose not to disclose the fatal prognosis of one of them. This understanding of the phenomenon will help nurses accompany families during the process of losing an important other while keeping him/her away from acknowledging his/her oncoming death. From Parse's (1998) vision on quality of life, when facing the experience of fatal illness, health professionals need to set aside their role of curers and direct their caring efforts towards the achievement of the highest possible quality of life. Quality of care is therefore one of the substantive elements contributing to the quality of life of an individual in the process of dying. As identified by several previous research studies, communication and the establishment of trusting relationships with health professionals as well as with family members constitute a key element for the completion of this goal (Kristjanson & Ashcroft, 1994; Lev & McCorke, 1998).

Up to now, not much research has been developed on the experience of accompanying dying patients and their families. Besides this, most of that scarce research literature on the subject has been developed on anglosaxon culture contexts and so non-anglo contexts lack research efforts on the subject. Trans-cultural research studies are thus to be implemented in order to provide culturally sensitive care as a response to the exigencies of a multi-ethnicity increasing society. The study here presented aims to develop, from a qualitative approach,

sounder knowledge on Basque-Spanish family members' experience of knowing without sharing the proximity of death when losing a loved one.

The situation where relatives are aware of the ill member's fatal prognosis but decide to hide it from him/her is what has been named by the literature as the phenomenon of the "Conspiracy of silence" (Costello, 2000; Miyaji, 1993; Porta et al., 1997), and, since no author has been found to talk about this experience in terms of "Knowing without sharing", the literature review has been performed by using that former term, "Conspiracy of Silence". Nevertheless, and from a sound analysis of it, we firmly believe this term itself already implies some kind of moral negative judgement towards the group (family, friends, health care team) sustaining it. The definition of the term "Conspiracy" according to a dictionary talks about harmful or illegal motives of the conspirators (Hornby, 2000). This whole process of analysis and reflection led us to consciously decide not to use the term "Conspiracy of silence" for our text, but rather to call it the experience of "Knowing without sharing" and, from this more non-judgemental way of approaching it, conduct our work. Besides this theoretical distance with relevant literature, in this study, the student researcher is not interested per se in knowing the strategies put in practice by family members to keep the fatal prognosis secret, but rather on how family members live this experience. These are the reasons why, for this study, this phenomenon has been identified as the experience of "Knowing without sharing" the proximity of death, and not "Conspiracy of silence".

As the rates of slow dying, in contrast to sudden dying, illness, such as cancer, continue to increase in our society, the number of families who, facing a loved one's terminal phase of cancer, deal with this situation also increases. Sound investigation of these family members' experience will allow health professionals to better understand it in order to meet

the needs of both, patients and their significant others. Understanding the phenomenon of knowing without sharing the proximity of death in the experience of losing a loved one will enable nurses to empathetically accompany families along the dying process. Moreover, this understanding about Basque-Spanish family members' experience could contribute to the delivery of a more culturally specific care. The quality of care, being both the individual's health experience and the goal of the palliative health care, will be attained.

#### Goal of the study

The goal of this study is to describe, following a phenomenological approach, the experience of family members in the Basque Country who live with a person who is in the terminal phase of cancer and who, while knowing it, have decided not to share with him/her the information about his/her upcoming death. Emphasis is therefore put on family members who live with the person (spouse and/or adult children) and not the patient him/herself.

#### Research question

What meaning do family members resident in the Basque Country, who live with a person who is in the terminal phase of cancer give to the experience of knowing without sharing the information about the upcoming death of that member?

**2<sup>ND</sup> CHAPTER**  
**LITERATURE REVIEW**

The literature review presented here covers four issues: (1) Parse's Human Becoming Theory (Parse, 1998), as the theoretical basis for the study, (2) families and the experience of cancer in terminal stage, focusing mainly on communication issues, (3) the phenomenon of "Conspiracy of silence", and (4) the culture and its influence on the phenomenon.

#### Parse's conception of the Human Becoming

Rosemary Rizzo Parse's Human Becoming Theory (Parse, 1998) provides the theoretical basis for this research project. The Human Becoming Theory contributes to the orientation of the study in relation to its roots, its justification and the appropriateness of the approach used in the interviews. This theory is also going to be of value through the interpretation of the meaning ascribed to the experience by family members. The Human Becoming Theory provides a very broad, respectful and flexible basis for nurses on accompanying individuals and families through their life experiences in the way they choose. When working on subjects such as a loved one's loss, emotional communication patterns and styles and moments of suffering, such an approach might help nurses better understand and more easily respect those choices made by family members. The student researcher also found this theory suitable to her values and beliefs and to her way of understanding the phenomenon.

From the perspective of Parse's Human Becoming Theory (Parse, 1998), "the human being coexists while coconstitutes rhythmical patterns of relation with the universe that, through the human being's valuing and imaging, openly reflect the meanings he/she freely chooses and assigns in situations"(p. 11). Health is constituted by the "cocreated process of becoming as experienced and described by the person, family and community" (p. 11). This "human becoming" is therefore the central phenomenon to nursing and nurses' efforts are to be focused on quality of life as defined and determined by each individual. Nurses are to

accompany human beings on their process of becoming by providing them with their true presence as they help them illuminate meaning and move beyond their possibles.

Several research studies have been developed in the field of the experience of dying from the Human Becoming Perspective (Lee & Pilkington, 1999) and even from a family's experience perspective (Cody, 1994). Nevertheless, the experience of knowing without sharing the information on fatal prognosis and the diverse issues surrounding communication in the care of the dying have not been acknowledged. Thus, the literature review here presented does not reflect that perspective on the subject of interest. Nevertheless, other research studies found to be pertinent and to provide a wider perspective (mainly, social and psychological) on the phenomenon of interest have been used for the purpose of more knowledgeably approaching it. The development of new studies in that field would provide nurses with new elements allowing a closer understanding of the phenomenon.

### Families and the experience of cancer and dying

#### *The family and the experience of cancer and dying*

According to the systemic view presented by the Calgary Family Model (Wright & Leahey, 1994), a life-threatening illness such as cancer will influence all the elements of the family's structure and functioning. At the same time, family's characteristics, structure and functioning will also have an influence on the way the family lives the experience (Wright & Leahey, 1987).

Family members' beliefs and attitudes regarding illness, cancer and death, play an important role in the way the system responds to the situation of a loved one's oncoming death (Leonard et al., 1995). Besides, several family functioning dimensions may also have an

impact on their lived experience. Family's histories and the ways in which those histories influenced previous illness experiences will affect the way the system and its members will respond to this new situation (Kristjanson et al., 1996). Family's communication styles and patterns have also been shown to have an influence on its members' coping ability with a life threatening illness (Kristjanson and Ashcroft, 1994).

Cooley and Moriarty (1997) found that most of the studies developed on the subject of the impact of an adult's cancer diagnosis and treatment on family functioning, related to the development of new interventions and the promotion of adjustment strategies, but a lack of knowledge on the impact of the diagnosis on family members was acknowledged. Quint Benoliel (1983) in a literature review on nursing research on death, dying and terminal illness also suggested that continued investigation within this field is critical to the development of knowledge on the experience of life-threatening illness, especially family members' experience as it was identified as one of the neglected areas.

#### *Family communication through the cancer experience*

The family is supposed to be the environment where the patient feels more free to communicate in an open way (Gotcher, 1992). Nevertheless, this is not always the case. The disclosure of a cancer related fatal prognosis can often affect communication within a family system (Kristjanson & al., 1996) and render it difficult for every member. In a study conducted by Zhang and Siminoff (2003) with over 37 lung cancer patients and 40 family caregivers, 65% were found to face communication problems within the family as result of the terminal stage situation. Many of them recognized avoiding conversations over difficult issues as one of their strategies to cope with the situation. Hilton (1994) goes even further as she considers communication problems inherent to advanced cancer late stages.

From a theoretical analysis on family communication in advanced illness contexts developed by Kinghorn (2001), several factors related to the experience of living a loved one's upcoming death and one's own death were identified as having an influence on communication in the family system. Family's previous experiences of disease, cancer, death or even loss, behavioural patterns, patient's characteristics such as age, role assigned in the family, held beliefs and values, or finally, cultural aspects are considered to essentially condition the communication patterns that the family system is going to establish when facing the terminal phase of cancer (Kinghorn, 2001).

Another determining factor for the communication patterns in families living a loved one's terminal phase of cancer was found to be the patient's level of awareness (Field & Copp, 1999; Hinton, 1998). As defined in "About Death and Dying", a classic work by Glaser and Strauss (1965), awareness of dying is the conscious recognition of one's impending death. These authors identified four major types of awareness contexts which would also have major influences on the patients' experiences of dying: (1) closed awareness where health care professionals and relatives kept the patient ignorant of his/her stage, (2) suspicion awareness where although not informed the patient knew of the situation and tried to get people to confirm the suspicion, (3) mutual pretence where although knowing it patient and family members were colluding to pretend everything was ok, and (4) open awareness where everybody knew about the proximity of death and had the permission to openly address the subject (p. 11). Obvious indicators of the proximity of death, such as unexpected visits from relatives and friends, changes in family members' attitudes and the decline of patient's health condition, help patients make up their own diagnosis and explanation of the situation and very often turn from closed to suspicion awareness state. From the literature review performed by

Field and Copp (1999) on dying awareness, patients in the terminal phase of cancer move along the spectrum of these four types of awareness as they are not constant in their emotional and cognitive responses. Even when open awareness is established, patients seem to move in and out that stage establishing different patterns of communication as he/she tries to exert control on awareness. Thus, communication patterns established in the family also suffer several variations as the patient expresses different interaction needs at different moments along the process (Field & Copp, 1999), as he/she moves “inbetween spaces” (Pandolfi, cited by Gordon 1994, p. 283).

Family communication patterns are very much in relation to the type of awareness of the proximity of death established for and by the system. In “open” communication dynamics, the information is shared among the family members and the patient, and so are thoughts, feelings and emotions. In “closed” communication or non-disclosure communication styles, information is hidden away from the patient and he/she, as well as all other members of the family, are prevented from expressing themselves in terms of sadness, grief, pain, fears... This last situation, where relatives are aware of the ill member’s fatal prognosis but decide to hide it away from him/her is what has been identified as the phenomenon of the “Conspiracy of silence” (Costello, 2000; Miyaji, 1993; Porta et al., 1997), or what we have called the experience of “Knowing without sharing”.

In summary, there is much literature describing the aspects of family communication having an influence on family members’ experience during the terminal phase of cancer. However, more research needs to be developed on family members’ experience. Family members’ perception of the quality of life provided by the non-disclosing dynamics when living the experience of the terminal phase of cancer and the way it is provided through

different ways of communicating have not been studied in depth. More research on the subject of non-disclosing family members' experience still needs to be developed in order to gain a deeper understanding of the phenomenon.

### Conspiracy of silence

It is mainly in Mediterranean cultures that physicians tend to meet with the family members before they actually visit the patient. Initially informing the family members constitutes one of the most common information disclosure strategies found in palliative care clinical practice (Rubiales et al, 2002). In this highly culturally influenced situation, family members might take advantage of their privileged position and ask the doctor to collude with them in keeping the difficult information away from patient. The study by Costello (2000) provides evidence of such collusion.

Most of the times, the collusion between relatives and the health care team is intended, primarily, to protect the ill member, and secondarily to protect the whole system (Rosser, 1994). Collusion is intended to protect the patient from the harm of bad news (Costello, 2000; Miyaji, 1993) but whether it is the patient who needs to be protected or the colluding members still remains an issue for further study. McGuire and Faulkner, cited by Rosser (1994, p. 14), call it an "act of love".

Focusing on non-disclosure communication patterns, an analysis of the situation can be implemented both from the patients' and from the relatives' perspectives. On one hand, patients seem sometimes reluctant to share information or feelings with his/her loved ones in an attempt to protect them from the harm of knowing or not to upset them. On the other hand, family members might tend to encourage the ill member to conceal his/her feelings. They

themselves tend to “hide feelings and keep a smiling face” as if nothing happened (Kübler-Ross, 1969, p. 160). Reality is hidden as to protect the patient, and both patient and family members act as if not talking were going to diminish the consequences of the disease (Gotcher, 1992). Avoidance of the psychological distress brought up by difficult information and the proximity of a loved one’s death is clearly reflected upon in these patterns (Zhang & Siminoff, 2003).

Such difficulties in communication among family members have an effect on the psychosocial well-being of both patients and family members (De Valck & Van de Woestijne, 1996; Gordon, 1994). The existence of a taboo topic that may restrain family’s communication patterns seems to contribute to the suffering of the person (Halldorsdottir & Hamrin, 1996). According to the literature review performed by McEnroe (1996), family communication and interaction patterns seem to have an effect either to enhance or to restrict family members’ ability to adapt and to stick together. When patients decide to talk to their family members but are faced with no interaction from the other members, health problems start to increase (Gotcher, 1992).

There is no consensus in the literature about the appropriateness or non-appropriateness of disclosing the information on fatal diagnosis in relation to patient’s well being. According to some authors, collusion may have negative effects on the patient as it does not protect him/her but rather isolates him/her (Fallowfield, Jenkins & Beveridge, 2002). Besides, there is little evidence to suggest that the disclosure of a fatal prognosis will have negative effects on the individual (Kinghorn, 2001).

Still, information concealment among family members should not always be seen as a pathological issue. Defence mechanisms, considered by Rosser (1994) to be a sort of coping

mechanisms, related to family communication patterns such as concealment, denial or evasion might sometimes be necessary for the ongoing functioning and development of the family system (Schrök, 1980). Salander, Bergenheim and Henriksson (1996, p. 993) talked about the creation of “protection and hope” as “to build on an illusion which palliates the strain” of the fatal prognosis on a grounded theory research based on the experience of thirty patients with malignant gliomas. From this perspective, patients may decide to keep a certain way of thinking so as to be able to tolerate the situation (Bishara, Loew, Forest & Rapin, 1997; Gordon, 1994). From the analysis of several family’s perspectives within the Italian context, Gordon (1994) also identified non-disclosing patterns as one of the most suitable strategies to allow the patient to maintain tranquillity and hope. According to Meyza (1997), sometimes patients may prefer not to talk as a way of avoiding conversations over uncontrollable issues. Especially vulnerable patients may create an illusion as a way to find “meaning, mastery and self-enhancement” (p. 993). Along with this certain way of thinking, the patient may decide to transform the information received in a more bearable way or to avoid any kind of difficult information. In addition to this, in the study by Salander et al. (1996), 16 patients reported having agreed with their partner not to “pose vital questions” as an attempt “to keep threatening information away to protect their own hope” (p. 990).

In summary, opinions and attitudes towards conspiracy of silence found in the literature are diverse and even contradicting. On one side, Harris, cited by Rosser (1994, p. 13), affirms that physicians’ collusion surrounding non-disclosed fatal prognosis with relatives implies “that the patient is unable to exercise self control” and it denies the “patient’s adult status” as well as his/her right to make decisions concerning his/her ending life period. In the British context, Doyle, cited by Rosser (1994, p. 13), argues that family members have no

right to know before the patient has explained how it is difficult for him/her to deal with the information. On the other hand, Stedeford, cited by Rosser (1994, p. 13), agrees with collusion as he explains that sometimes patients do not want to know and so, in those situations, family members should be the people informed initially. According to health care professionals' vision on truth-telling and disclosure of fatal prognosis, difficulties arise mainly when the family members are told but the patient is not (Costello, 2000) and the patient's willingness to know has not been addressed.

Consensus is nevertheless achieved in the literature in relation to the need for further research in the domain of communication and decision making at the end of life (Blackhall et al, 1995; Kagawa-Singer, 1998; Teasdale & Kent, 1995). Family members' and patient's meanings to the situation, values and beliefs need to be acknowledged so as to allow a deeper understanding of the decisions made. Family members' experience of keeping the prognosis secret within the system has not been soundly investigated and so the impact of that decision on the members is still a field for further study. Whether sharing the information or concealing it, family members' experience is to be tackled by research studies as professionals' opportunity to develop more adequate intervention strategies at the end of life.

#### Culture, cancer and death

From the beliefs, ideas and meanings transmitted by culture (Ali et al., 1993; Annas, 1994; De Valck & Van de Woetijne, 1996; Donnelly, 1995; Leininger, 1991, 1977; Leonard et al., 1995; McEnroe, 1996; Porta et al., 1997), the individual and the family develop a singular and unique way of viewing, understanding and analysing the world, which will also influence the meaning they ascribe to their life experiences, including health experiences (Leininger, 1991). The culturally influenced meanings assigned by the individual and/or the family to the

diagnosis of cancer and death are strongly connected to the way they respond to it (Koenig & Gates-Williams, 1995). Besides a way of viewing the world, culture also provides the individual with a way of behaving. Attitudes and behaviours are therefore better understood within the social context in which they take place (Porta et al., 1997).

In relation to family members' lived experience of cancer, this aspect of the cultural influence becomes of special importance when dealing with an ill member's upcoming death and the delivery of fatal prognosis. Behaviours such as the interactions between health care professional and patients and/or family members are highly dependant on the cultural perspectives they all hold in relation to cancer, death, communication, roles, expectations, ethical and moral aspects of care... (Leonard et al., 1995).

According to Donnelly (1995, p. 5) cultures pertaining to the so-called Western society share a common popular belief about cancer whereby the person is thought to be "invaded by alien cells" and it is equalled to death. In that same context, the person diagnosed with cancer is viewed, by the population as well as by the health care professionals, as the patient with (Donnelly, 1995, p. 6) the "smallest competency, highest dependency, most depression and morbidity rates".

As stated above, death and beliefs about death play an important role on the experience of terminal stage cancer. Previously, death was seen as a natural part of life, whereas nowadays health professionals might consider death as a failure of the system (Adelbratt & Strang, 2000). Nevertheless, in the last 30 years, attitudes towards death have undergone radical changes following the hospice movement and the creation of the palliative care services in the Western culture. In the last 30 years, beliefs about death and dying have sensitively changed mainly in the North-American culture where now an open communication

cancer culture is promoted. Kellehear, cited by Costello (2000, p. 404) establishes that for a “good death to occur, the dying patient needs to be fully aware of the situation so that he/she can consciously play the dying role in a reciprocal social form”. Supporting this idea, Yalom, cited by Adelbratt & Strang (2000) affirms “we can not overlook the reality of death. When death is excluded, life becomes impoverished. Recognition of death contributes to a sense of poignancy to life” (p. 501).

Adelbratt and Strang, (2000, p. 500) affirm that “a shift towards a more eclectic and interactive model of death and dying” is taking place in our society. But this movement is not taking place in the same way all over the Western society. North-Americans’ value of autonomy pushes them to move much faster in that direction than what Mediterranean values, such as beneficence, family connectedness or protection of the ill, do.

The Latino population within the United States has been shown to be less willing to know about prognosis (Kagawa-Singer, 1995). They have also been shown to hold more family centred decision making models in contrast to North-American or even North-European cultures where the individual centred approach is encouraged (Candib, 2002). Within a family centred culture, the power assigned to the individual’s autonomy decreases as more value is given to the harmonious family functioning over its members’ individuality (Blackhall et al, 1995; Fallowfield, 1997; Maciejewski, 1997). Several other studies have also put light on the difference in cultural values between European cultures where the value of beneficence seems to overrule the health care decision making policies, and America, where it is patient’s autonomy that does it (Bruera & Newman, 2000; Brusamolino & Surbone, 1997).

Should we focus our attention on the European Mediterranean culture? As an integral part of the Western society, European culture is known to be death denying. As demonstrated

by Porta et al. (1997, p. 117), in Mediterranean cultures cancer is still “associated with a strongly reactive negative image” and death still remains a taboo subject. Within this culture, death is to remain unknown and frightening, people postpone the question of death and feel unprepared for it (Adelbratt & Strang, 2000), in opposition to the Anglo-American culture where openly speaking is valued, defended and protected (Candib, 2002; Wright & Leahey, 1994). As an example, in Italy, from a study by Field and Copp (1999) closed awareness was promoted. In Slovenia, in his discussion about communication with cancer patients, Zakotnik (1997) also affirms that this same death denying and closed awareness attitudes were culturally promoted. In Porta et al.’s (1997) study conducted in Spain, most respondents agreed that patients should not be informed of their diagnosis. A study developed by Fainsinger, Núñez-Olarte & Demoissac, (2003) among Canadian and Spanish cancer patients even found some differences between the two groups on the values attached by participants to disclosure and their cognitions. Spanish participants were much more reluctant to open and full disclosure and cognitions.

Nevertheless, the adoption of a non-disclosing attitude is a decision that emerges from a certain cultural context which includes health care professionals (Candib, 2002). Following the American shift towards patient autonomy and truth disclosure in the 1960’s, European health care policies tried to catch up on that philosophy by imposing it in the European context (Candib, 2002). What this meant was that, suddenly conspiracies of silence were to be broken and family members’ demands for collusion were to be refused by professionals. Nevertheless, from an analytical point of view, it could be argued that policies that encourage the systematic break down of this type of family dynamics do not take into consideration the beliefs, values and meanings family members have put into that choice. This non-respectful attitude may lead

to a very paternalistic way of caring, where health care professionals believe they know best for the family members. This approach to end of life decision making may be just as paternalistic as the truth-withholding attitude previously held (Blackhall et al, 1995; Candib, 2002).

There is still a dearth of literature on non-anglo people and their experiences related to health care (Grabowski & Frantz, 1992-93). Up to now, just three studies have been found that describe the Spanish cultural perspective on patient, terminal illness experience and interaction with the health care professional (Porta et al, 1997), and so more research is needed within this field.

In a study developed by Porta et al. (1997) among 151 Spanish health care professionals (family doctors and community nurses); although they recognized that problems came up when patients were not informed of the nature of their illness, it is important to make the reader aware that most of the professionals who participated in the study (61% of physicians and 66% of nurses) agreed on the opinion that patients should not be told their diagnosis (Porta et al., 1997). Estapé et al. (1992) in a study conducted with 167 cancer patients and 380 health care professionals, as well as Lopez de Maturana, Morago, San Emeterio, Gorostiza & Olaskoaga (1993) in their study of 300 health care professionals, also supported these results, as they acknowledged both physician's reticence to disclose truthful information and health care professionals' difficulties to care for dying patients. Centeno-Cortés and Núñez-Olarte (1994), through their study of 97 Spanish cancer patients, found out that one third of the patients were not aware of their diagnosis, another third suspected it and one last third knew about it. In that same study, it was also found that only a third of the informed patients asked for more information. On the other hand, 42% of the patients who had

not been informed of their diagnosis explicitly expressed not wanting any more information. Conspiracy of silence seemed to exert an important influence on this situation (Centeno-Cortés & Núñez-Olarte, 1994). From her work on Italian contexts, Gordon (1994) identified physicians' reluctance to open disclosing of fatal prognosis from their belief that: "telling somebody is like a condemnation that could destroy all hope and make it be like it was all over" (p, 291).

From Leininger's (1991) transcultural approach to care, human beings of any culture have the right to have their cultural values and beliefs respected and taken into account by the health care system. To ensure this, health care professionals are to be open-minded for culturally dependant ways of caring to be developed. Should we not assume all cultures to be alike but rather recognize and acknowledge the differences among them, in order to perform high quality culturally sensitive care (Koenig & Gates-Williams, 1995; Leininger, 1991). Research on culturally influenced issues, that takes values and beliefs into consideration is needed in order to attain this goal.

#### *Ethical aspects of the phenomenon*

The conspiracy of silence is also a very complex ethical issue. When dealing with critical issues such as the care of the dying and how it should be provided, either by family members or by professionals, ethics plays a crucial role. From a very general ethical view, patients have the right to know but they also have the right to abstain from knowing (Salander et al., 1996). Up to now, this literature review has presented some evidence mostly on the negative impacts the fact of not being aware of the fatality of the prognosis could have on patients, but evidence also exists to support the fact that some patients may prefer to keep conversations away from emotionally difficult issues such as death or the negative outcomes

of their illness (Jarrett & Payne, 1995). Kübler-Ross, cited by Costello, (2000, p. 404), affirmed that “sometimes it is not acceptable to provide the whole truth”. According to Porta et al. in 1997, 40% of patients in the study who did not receive information about illness did not want to get any more information. Yet, in most cases, the patient suspects, knows or wants to know the diagnosis (Porta et al., 1997), but consciously decides to maintain the subject taboo.

The situation could also be approached from an analysis on the power-control relationships established by all the participants. It is widely known that information gives power. Information helps health care professionals place themselves in control positions from where clinical situations seem to be more easily dealt with. The amount of information disclosed and the way it is provided contribute to increase health care professionals’ power. Information concealing may prevent individuals from making their own decisions, which, in the end seems to facilitate the professionals’ job. There is even a third party to this situation, that is, the family members. Family members’ sense of losing control when facing a loved one’s death as well as their need to place themselves in a higher position from where they can protect the ill member, invites them to pursue power acquisition by controlling the information being shared (Thomson, Melia & Boyd, 2000).

Ethical dilemmas with respect to this situation arise. The patient’s right to know and the carer’s, whether family member or professional, duty to care enter a painful conflict. From Thomson et al.’s (2000) analysis of the situation, carer’s sense of protection over the ill individual puts him/her in situations where patient’s right to know is overlooked. Carers may just want to protect the ill member but the concealing-colluding situation might also be protecting them from the emotional burden of the loved one’s grief (Thomson et al., 2000).

However, deeper analysis can be performed on the situation following different ethical models. When aiming at this, we should always bear in mind that “ethical decision making”, whether at the end of life or at any other point of the life cycle, “is based on the values of a culture” (Kagawa-Singer, 1998, p. 1754). The reviewed literature pertains mainly to the American society. In this society, the prevailing decision making model is the Contractual/Community Model, where the outstanding value sustaining the model is patient’s autonomy. Principles of beneficence, non-maleficence and justice also play a role in this model but are always considered to be second ordered (Brooke Hamilton, 2001). When applying this decision making model to palliative care and the field of communication and information management, truth telling appears to be strongly related to the respect for the person’s autonomy, and therefore becomes one of the top-grading values in clinical decision making (Brooke Hamilton, 2001). Following the American society’s value interpretation, it should also be acknowledged that within a system where autonomy is mostly valued, individual centred decision making processes are followed (Blackhall et al, 1995).

From this perspective, individual’s ability and competence to choose what he/she wants and thinks is best for him/her, as well as to act according to it, overrule the decision making process. Truth telling being the provision of relevant information necessary to make free choices becomes then of major priority for the health care system. The two physician-centred values such as non-maleficence (do no harm) and beneficence (do the best for the patient) remain behind patient’s autonomy as it is understood that, when having the appropriate information, the individual will be freely choosing what he/she identifies as the best option. It is at the point of the appropriateness of the information and the amount of it where ethical dilemmas appear.

Nevertheless the priority order established by this Contractual/Community Model for the set of values sustaining Clinical Decision Making is highly affected by culture. Values are culturally dependant elements and so cannot be left out of the analysis of an ethically sensitive situation such as the phenomenon of Conspiracy of Silence.

It is not just a matter of whether to use the term cancer or tumour (Salander et al., 1996) but rather of providing the family system with the opportunity to live the experience of terminal phase of cancer in a way that mostly fulfils their expectations and reduces their suffering. As Costello (2000, p.403) affirms, the maxim “dying patients should be told everything they want to know” is said to guide physicians’ decisions on disclosure. Nevertheless, there are two basic questions that arise from this maxim and which, again, pose new doubts for the professionals: “(1) how much of the truth should the patient be told?, and (2) is it always ethical and appropriate to give patients less information than they need?” (p. 403). Should we always be clear about the focus of the health care provided, always on the patient and never on the professional (Rosser, 1994), and ethical dilemmas will, in a certain way, be more easily approached.

#### *Cultural context of the phenomenon*

The study will be conducted in the city of Vitoria, located in the Basque Country, in the Northern Region of Spain. Being a Mediterranean country, Spain, and so the Basque Country, share the so-called Mediterranean culture. Within this context, values and beliefs about illness, family and death are of special importance when trying to understand families’ experience of losing a loved one. Cultural issues such as protection directed towards the person who is going to die (Fallowfield, 1997; Salander, Bergenheim, Bergström & Henriksson, 1998), physicians’ “deified” value (Korec & Andrakova, 1997), supremacy of

beneficence over autonomy (Brusamolino & Surbone, 1997), death avoidance and denial... are all very commonly observed. These elements invite families and health professionals to show attitudes and behaviours very different to the ones that could be identified in the Anglosaxon culture (Bruera et al., 2000).

Caregiving of relatives in the Mediterranean culture shows also several other particularities that make it significantly different to other cultures. In Latino cultures, family members play a first line role in the care of their dying. Ill members facing the final days of their lives are never left alone, whether at home or at the hospital. Relatives organize their schedules in order to spend most of the time with the person. Arrangements are usually made among family members so that the ill person is always accompanied by someone close to him/her. This situation poses obstacles for the physician to meet with the patient in a one to one encounter. This difficulty seems to contribute to the family collusion attitude, as relatives are always present on doctors' rounds or visits (Estapé et al, 1992; Rubiales, 2002).

The fact that no hospices exist in the Basque Country is mainly based on this phenomenon of family closeness. Most of the family members living with somebody who is in the terminal phase of an illness are encouraged by the health care team to keep that person at home as long as they feel capable of managing the situation, whether physically, psychologically or emotionally. Advanced home-care services have emerged in the last 10 years to support this movement of terminally-ill people into the community. Families tend to follow this movement by taking advantage of the services offered, so terminally-ill people tend to spend at their relatives (Estapé et al., 1992).

Within this family-centred-care context, health care professionals seem to more openly accept family members' decision making in the care of the dying. A sudden shift toward the

supremacy of patient's autonomy on this process would not seem have positive effects when having in mind the important role culture plays in the situation (Etapé et al, 1992).

In the Basque Country there are no data on the incidence of this phenomenon of conspiracy of silence. Just López de Maturana et al.'s study on 300 general practitioners (1993) in Bizkaia (Basque Country) reported physicians' reluctance toward truth disclosure, confirming the results obtained by other studies in the rest of Spain (Centeno-Cortés & Núñez-Olarte, 1994; Estapé et al, 1992). From the experience of the professionals working in the palliative care unit at Txagorritxu Hospital, around 15% of the subjects who are diagnosed with cancer and are given short-life expectancy prognosis are not informed by their relatives of their condition. When the ill person is over 65-70 years old this percentage seems to increase up to 80%. All these data are just based on individual clinical experiences and so constitute the outcome of a very subjective evaluation. They should just serve to orient the reader but never to support any of the evidence obtained in this work.

Assuming that individuals from different cultures will all respond in the same way when facing a loved one's loss is described by Wright, Cohen & Caroselli (1997) as a "disrespectful and irresponsible" attitude. Based on their culture, family members and patients develop their own interpretation of the cancer experience and the proximity of death (Donnelly, 1995). The function of the health care professional when working with a family who suffers is then to decode this interpretation and help the family assign a new meaning to it in a way that it reduces suffering and improves family's quality of life. Understanding this interpretation based on the recognition of the family's cultural context, and acting as a mediator between the family and the health care system are both of them recognized nurses' tasks when caring for patients and families as cultural human beings (Donnelly, 1995).

Cultural aspects' influences on the experience of dying and losing a loved one have been fairly extensively studied among Anglo-Saxon countries and some Mediterranean ones. Nevertheless, the impact of those aspects on relatives' decision of non-disclosing fatal prognosis to ill members still remains a challenge not only for clinicians but also for researchers. Exploring the challenge will surely help health care professionals develop a more culturally sensitive caring approach that will allow a more respectful and comprehensive attitude toward this situation.

A study that provides Basque-Mediterranean family members with a space and a place to talk about this experience as lived by them seems, therefore, necessary for contributing to both fields of the health care domain. A phenomenological study on Basque family members' experience of not sharing with the ill member the information about the proximity of death is presented here as a response to this identified need. The next chapter will present the method developed for our study.

**3<sup>RD</sup> CHAPTER**  
**THE RESEARCH METHOD**

In this chapter, the basic methodological elements for the implementation of the study such as the type of study, the participants and the context, the researcher's role, the data collection strategy, the data analysis strategy and the ethical considerations are presented. The theoretical bases of the phenomenological approach are also presented in this section.

#### Type of study

The phenomenological approach allows the study to attain its goal as it encourages the acknowledgement of the essence of the experiences as lived by the participants. Deeper knowledge about family members' experience of living with a relative who is in the terminal phase of cancer while having decided not to give him/her the information about his/her incoming death, as family members would describe it (Giorgi, 1997), might then be presumably achieved through this research method.

#### Phenomenological approach

"Phenomenology is not just a research method but also a philosophy and an approach" (Omery, 1983). In 1900, Edmund Husserl started the development of what we know today as phenomenology. From then until now, several philosophers, such as Heidegger and Gadamer, have followed his thought and have contributed to the emergence of this way of understanding the world and the human being by bringing new and diverting perspectives on the term "Phenomenology".

Phenomenology is nowadays understood and defined from two different perspectives. In one hand, "in relation to experience", phenomenology means a specific subjective or personal knowledge which implies a certain resistance to the scientific analysis. In the other hand, the notion of phenomenology as the "science of phenomena" gives the term a much more research oriented sense, since it implies the study of the

structures of the conscience (Giorgi, 1997). This latter meaning is what constitutes the basis of what we nowadays understand by the phenomenological research method.

#### *Purpose of the phenomenological approach*

From the second meaning attached to the concept of phenomenology that we just presented, Rose, Beeby and Parker (1995) explain that phenomenology is intended to “explicate the structure or essence of the lived experience of a phenomenon in the search for the unity of meaning which is the identification of the essence of a phenomenon, and its accurate description through the everyday lived experience”. As Patton (1990) states it, phenomenological inquiry should always be intended to find an answer to the question: “What is the structure and the essence of this phenomenon?” (p. 69).

Simplifying this definition, Omery (1983) states that the phenomenological approach “attempts to study the human experience as it is lived (...), intends to investigate and describe all phenomena, including the human experience in the way these appear”. This same author also describes the way in which phenomenology approaches its purpose, as it describes “the total systematic structure of lived experience including the meaning that these experiences had for the individuals who participated in them”. As presented by Giorgi (1997) “phenomenology works on the phenomenon of the conscience calling upon individual’s lived experiences” (free translation).

#### *Congruence between the phenomenological approach and the Nursing Science*

Several authors have acknowledged the mutual relationship between the phenomenological approach and the discipline of Nursing. Humanistic fundamentals to both of them are the main common elements that sustain the congruence between the approach and the discipline (Smith, cited by Rose, Beeby, & Parker, 1995). Caring in the human health experience from a holistic perspective, as the cornerstone of the discipline

situates the Science of Nursing in the need to utilize a research method that is mainly focused on the lived experience, in order to develop knowledge that is valuable for its practice. Knaak, cited by Rose, Beeby and Parker (1995) argues about the values nurses and phenomenologists share and the way they are implicitly reflected upon the data collecting strategies they both use, which emphasize observation, interviews, interaction and interpersonal relationships. As this author expresses it, these methods based on shared values can help phenomenology and Nursing “fully appreciate the patient’s or participants’ perception of events”.

Phenomenology is also given credit in the discipline of Nursing for the contribution this research method can make to the Nursing Science. These contributions can mainly be identified within two areas (Rose, Beeby, & Parker, 1995): (1) the theoretical underpinnings of the discipline, and (2) the knowledge for practice.

In relation to the theoretical underpinnings of the discipline, phenomenology contributes to concept clarification through the insights gained from a study of the lived experience. Concepts are understood to be the precursors of theory and so phenomenology can in the end help develop the supportive elements of knowledge development. Moreover, knowledge for practice has been defined by Schlotfeldt, cited by Rose, Beeby and Parker (1995) as “the knowledge that professionals must gain from relevant data concerning each person being served”, being his/her lived experience an important part of it. Phenomenology can thus contribute to achieve a closer understanding to these experiences and can help nurses learn and develop their practice knowledge through their everyday practice.

According to Parse’s view on Nursing Research, phenomenological approach allows a better understanding of the experience as it is lived by the individual, and will lead the nurses to the path of illuminating meaning, while synchronizing rhythms towards

moving beyond the possible. An open naïve approach to an individual's experience constitutes the foundation of Parse's Theory of Human Becoming main practice element which is true presence (Parse, 1998).

#### The definition

The experience of knowing without sharing is described for this study as the situation lived by family members who consciously know a member's fatal prognosis and/or prognosis and decide not to share this information with that ill member.

#### Researcher's role

From a phenomenological approach, the researcher is to show a natural inquiring attitude that would allow him/her to naively approach the phenomenon as lived and experienced by the person. He/she is to recognize his/her preconceived expectations, presuppositions or operational definitions and acknowledge their potential limitation of his/her capacity to understand the data being collected from the perspective of the participants in the experience (Patton, 1990). Student researcher's preconceptions, ideas, experiences and beliefs around the subject are presented on Annexe A. As Omery (1983) states it, the researcher's main concern is to "understand both the cognitive subjective perspective of the person who has the experience and the effect that experience has on the lived experience behavior of that individual". The researcher is then to be completely present to the participant in order to actively listen to what the latter is expressing through language and to the meaning he/she is assigning to the lived experience of the phenomenon.

In order for the researcher to have access to the participants' lived experience and the meanings assigned to it, it is necessary to develop a relationship solidly supported on

mutual trust. This relationship and the confidence participants can show in the researcher can only be achieved through this latter's real interest in the participant's experience.

#### Development of the study

The study was conducted in the city of Vitoria, Spain. Participants in the study were identified by the professionals of the Palliative Care Unit, at Txagorritxu Hospital from the Basque Public Health Service. The recruitment process started with the nurse or the doctor's invitation to the family members' to participate in the study. Once families had agreed to have a meeting with the student researcher, she then set an appointment with them where she explained the aim of the study and the process to be followed. In that same meeting, the student researcher handed the informed consent out to the family and, in the case the family accepted to participate, arrangements were made on the date for the interview.

#### Participants and context of the study

In agreement with the phenomenological approach the student researcher uses a purpose sampling. The student researcher therefore selects the participants in the study according to the purpose of it. The population for the study is then constituted of families living with a person in the terminal phase of cancer and who have decided not to share the information about the fatality of the diagnosis with the ill-member.

Several criteria for selecting the participants (families and family members) were used. First of all, families who had decided not to share the information about the proximity of death with the ill member were referred to the student researcher by the palliative care team. Families who had decided to share the information with the patient did not take part in the study, as the aim was not to compare two different experiences but to deepen in the understanding and description of just one of them (the one related to information withholding).

Secondly, from these families first contacted by the palliative care team, just those willing to participate in the study were selected. Finally, within those families willing to participate, members aged 18 or older who describe themselves as significant people for the ill member took part in the interviews. Relatives living through the experience of sustaining a conspiracy of silence when losing a loved one are assumed to be the best informants for the achievement of an understanding of this phenomenon.

### *Recruitment*

Participants were not easy to recruit. The recruiting time period (July 2002-September 2003) was presumably extensive enough as to allow enough contacts. Nevertheless, the final number of participating families shows the important difficulties this process imposed on the study. The subject of the study being the experience of not sharing information seemed to be an important element in families' decisions not to collaborate in the study, not to share their experience with the researcher. Around twenty families were invited by the palliative care team to meet the researcher and get some more information about the study. Just six of these twenty actually agreed to that meeting. Three out of these six families finally accepted to participate in the study. Besides all these difficulties, and although all members recognizing themselves as significant in the caring process were invited, just one carer for each family appeared at the time of the interviews. Difficulties with the schedules and with the burden of care seemed to be the reasons for any more members being able to show up.

Data were therefore collected through interviews (Morse, 1987) with one adult member of 3 families living the experience of withholding information from a member who is shortly going to die. They each were met twice.

### *Participants in the study<sup>1</sup>*

Characteristics of the chosen sample are here presented as the detailed description of the sample provides the context, essential for understanding the phenomenological description of the phenomenon. According to Morse (1992, p. 31) “context is a source of data, meaning and understanding”. No one experience makes sense without a context to place it in and so characteristics of the setting need to be acknowledged in order to gain a close understanding of the experience. The researcher is never to consider the context familiar but rather unknown as a way to approach it from a more free and open perspective (Morse, 1987).

#### Family X

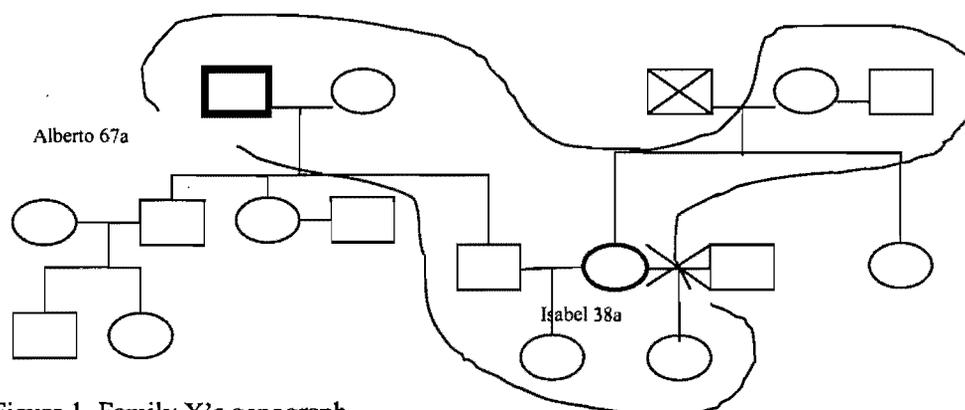


Figure 1. Family X's genograph

We meet family X at one of Alberto's admission to hospital upon referred. Family X lives in a small village next to Bilbao. Alberto, 67 years-old, was diagnosed a lung cancer six months ago. He has two sons and a daughter. Right now it is his youngest son's wife who takes care and responsibility for him. It is with her, Isabel, 38 years-old, that we hold the interviews.

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<sup>1</sup>Note: All names and demographical data have been encrypted to ensure confidentiality

Alberto is now retired but has worked as a kitchen chef. Family X pertains to middle-class socio-economical level. Alberto and his wife seem to have a difficult relationship. They have been together for over 15 years but each one of them has created his/her own day to day life. Alberto does not seem to be close to his oldest two siblings either.

As Alberto was diagnosed, he was given the discharge report and took a taxi home. He concealed the information about it and pretended not being aware and tried to keep everything the same. It was finally his daughter-in-law, Isabel, who decided to go and meet the doctor. The doctor himself advised Isabel not to reveal the information as they were afraid Alberto could do something to hurt himself. As she was informed of the situation, she and her husband met with the rest of the family and decided to take both Alberto and his wife home with them, and take care of him till his last day.

As Alberto was made aware of this decision, he pretended not to know anything and declined all responsibility over his health. From then onwards, he seemed to delegate his whole decision making responsibility on his son and his daughter in law. Alberto was not given any treatment but he was admitted to hospital several times for pain and dyspnea relief.

We first meet Isabel during one of Alberto's admissions to hospital. The first interview took place at the palliative care unit just two months before Alberto's death and five months after diagnosis. He has again been admitted to hospital and she felt overwhelmed. We talked and listened to her. We explained the project to her and asked for her collaboration. The first interview allowed us to establish the trust relationship with her, although we do not get the chance to talk about the subject. The second interview took place at the same unit nine days after Alberto's death and the third one three months after the second interview.

## Family Y

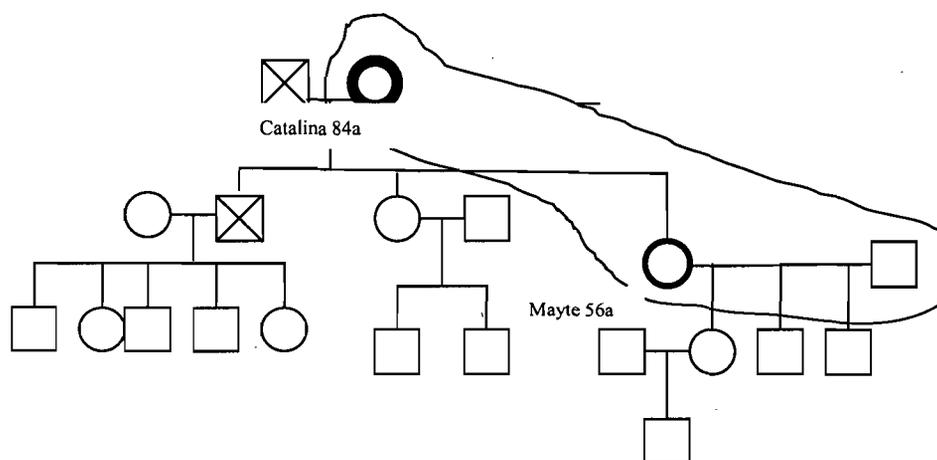


Figure 2. Family Y's genograph

Family Y is referred to us by the palliative care team. They live in Bilbao. Catalina is 84 and was diagnosed a liver cancer eight months ago. Catalina's husband died of a lung cancer two years ago and so did her eldest son just four years ago. Catalina has been living with Mayte, 56 years-old, her second daughter, and her husband since that last loss. As Mayte expresses it, neither Catalina nor she have been able to overcome these two losses and their grief. It is with Mayte that we hold our interviews.

Catalina was a house-wife for her whole life. Family Y comes from a middle-class socio-economical level. Catalina seemed to hold a close relationship with her daughter. At the time we meet Mayte she looked tired and expressed feelings of caregiver's burnout.

Catalina has not been admitted to hospital ever since the time of the diagnosis. Her age and the advanced stage of the tumor made doctors decide not to give her any treatment. The decision to hide the information from Catalina appears to be contrary to the doctors' advice.

The three interviews we held with Mayte took place at her apartment. The first one, which for reasons of respect towards Mayte's integrity we did not tape (she was too emotionally burdened and just could not stop crying), took place six months after the

diagnosis, the second one, a month later and the last, one month after the death. Trust was firmly established from the first interview.

Family Z

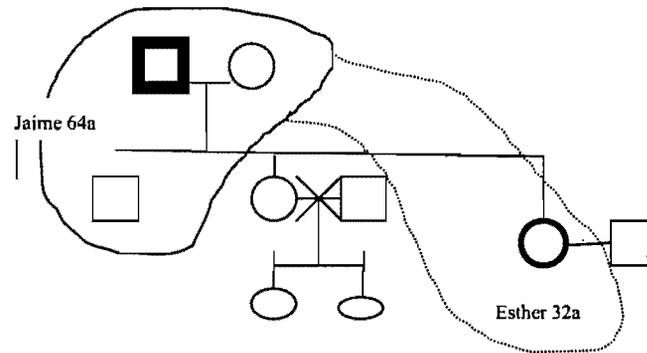


Figure 3. Family Z's genograph

Family Z lives in a large village in the province of Bizkaia. Jaime, 64 years-old, has three siblings. We meet family Z as Jaime was admitted to hospital for pain relief. He was diagnosed bone cancer 9 months ago and now suffered from severe pain. As Jaime was admitted to hospital I became his nurse in charge and establish a nice trust relationship with him and his family. As a staff nurse, I found caring for him difficult at times since he showed reluctance to express pain or suffering, concealing it even from us, the staff.

The interviews are held with Esther, Jaime's youngest daughter. She has been living outside of her parent's home for ten years now but seems to have taken the entire responsibility for the situation. Jaime's wife has been chronically sick for decades, and so it has always been the rest of the family who actually took care of her.

Jaime has worked at a metallurgical factory for over 30 years and was now getting ready to retire. Esther, 32 years-old, worked as a sales assistant. Family Z comes from a middle-low socio-economical class.

The first interview took place at the hospital 9 months after diagnosis and just three days before his death. The second one took place at a public park at the village where Esther lives, one month after the death.

### *Declining families*

Besides the three families that actually took part in the study, the palliative care team referred three other families to the student researcher during the time of recruitment. The first family denied participating as the project was explained to them on the phone. The caregiver explained, caring for her father was too time-consuming to be able to make any arrangements to come and meet with the researcher. This reason, not having any time left, was also pointed out by the second declining family for not participating. Finally, a third family was excluded from the study after the first meeting since the daughter with whom we met and the only member in the family willing to participate, did not agree with the rest of the members on their concealing attitude. She was totally opposed to it, offered every reason for considering it painful for her father and showed evident signs of suffering throughout the situation.

### Data collection strategy

The data collection method used for this study was the semi-structured interview. At the beginning, it was intended to develop conjoint interviews as relationships, interactions and dynamics among family members were thought to provide a wider perspective on the experience (Wright and Leahey, 1994). Finally, no more than one family member showed up at the time of the interviews and so conjoint interviews never took place. Nevertheless, the Calgary Family Model served as a guide for a systemic approach and the use of systemic questions allowed for acquisition of a much more family centered meaning to the experience.

Two to three interviews were held with each family member. The first interview was always intended to develop the trust relationship with the family. For two of the families, this first interview actually served as an emotional drainage space and moment. The second and/or third interviews were always conducted after the analysis of the first and/or the second one had been finished so participants would be given the chance to modify, criticize and/or confirm interpretations.

A two-hour time limit was established for every encounter so as to keep the focus of the interview on the subject of interest. The interviews were audio taped and transcribed, although moments of crying and profound emotional expression were omitted. Transcriptions underwent a double-checking process to assure their fidelity to the original source.

Participants were asked to fully describe the lived experience, and to express the meaning assigned to this experience as well as the insight developed from that experience. Descriptions were intended to be very detailed, avoiding as much as possible the use of generalizations and abstractions (Giorgi, 1997).

A guide for the development of the interviews was developed by the student researcher guided by the Calgary Family Model systemic approach. When developing the guide for the interview, several considerations regarding the characteristics of the questions were kept in mind in order to achieve the purpose of the study such as open-ending and avoidance of technical language, which would allow informants to feel more comfortable, confident and secure. The guide is presented in Annexe B.

All the interviews were conducted by the student researcher. She tried to maintain a stance of learner at all times having in mind it was actually the informant who was the expert on the situation. Interviews were mostly initiated using a very broad open-ended

question (Would you please tell me about your experience of acknowledging a relative's fatal prognosis?) which seemed to help informants concentrate on the subject. Once in the subject, the student researcher posed questions based on the informants' story and description of the experience to gain a deeper understanding of it: "how is this equilibrium that you were just talking about important for you all?" or "How does this not-talking attitude help you stay that close to each other?". It was this type of questions that helped the student researcher and participant construct the essence of the lived experience (Halldorsdottir et Hamrin, 1996). During the interviews, there were also moments when the main interest of the study had to be set aside in order to develop emotional support for participants. Tools such as positive rewarding, silence and touch were then used for this purpose.

The interviews took place wherever the family decided to, whether it was the palliative care unit, their own home or a public park. All the interviews took place at least six months after diagnosis, and so family dynamics were established (Doka, 1995-1996) and initial crises period dealt with. Without planning it this way, all second and third interviews took place after the ill member's death. We were aware of the influence this fact may have had on our study but different circumstances around the palliative care unit and the recruitment process made this difficult to be done differently.

The quality of data was assured by the development of the interviews and the sound analysis performed on them. Saturation of information was not achieved in this study. Nevertheless a deep description and understanding of the essence of the lived experience of knowing without sharing in families living the terminal phase of cancer was presumably attained and assured by the composition of the group of participants. Although we are aware of the increased richness that a higher number and diversity (more members of the

same family together) of participants could have provided our results with, we believe this study provides valid knowledge on the subject.

#### Data analysis strategy

Based on the literature reviewed, a decision was made to follow Giorgi's method for the development of this study (Omery, 1983; Rose, Beeby, & Parker, 1995; Tatano, 1994). This method presents diverse characteristics that make it more appropriate for the phenomenon of interest of this study. Giorgi (Omery, 1983) recognizes the existence of 6 steps that constitute the process of his method and that were actually followed by the student researcher:

- i. The interviews with the participants allowed the accomplishment of a naïve description of the phenomena,
- ii. The process of transcribing the audio taped material itself as well as several in depth readings of the transcripts helped the researcher and her co-analyzers gain a sense of the whole (both co analyzers were Masters-level registered Spanish nurses),
- iii. Deep and detailed readings of each transcript allowed the student researcher and her two co-analyzers identify main themes and sub-themes as well as structural elements to the phenomenon. The main researcher analyzed all the texts from all the three families while each co-analyzer did just two of them. Co-analyzer A worked on family X and Y while co-analyzer B worked on family X and Z. Once each one of us has come up with a list of codes for family X, this list was exchanged and similarities and differences were studied. This process lead to the construction of a new code list from which quotations were renamed following this new chart of agreement. Analyses on family Y and Z's texts were constructed on the basis of that same list but allowing it to grow and explode as new themes emerged. The synthesis and re-elaboration

process for the codes followed the same steps for these two last families as explained for family X,

- iv. As the student researcher's codes and interpretations were criticized and questioned by the co-analyzers, redundancies were eliminated, ideas clarified and/or meanings elaborated by relating them to each other and to the whole,
- v. Having gathered the information, the student researcher reconstructed reality on the basis of her interpretation of that information with the participants' help. To do so, once the student researcher had integrated her insights and been able to express them in a written format, she went back to participants and asked them to confirm her understanding (Patton, 1990). Once all the material had been analyzed and interpretations offered to the participants for modification and/or clarification, the student researcher transformed the meaning obtained from concrete language into the language or concepts of science,
- vi. Organization and enunciation of raw data within the language of the discipline  
Therefore, data are to be put in words from the language of the discipline so that they can contribute to that discipline's body of knowledge from a scientific frame,
- vii. Finally, the student researcher integrated and synthesized the insights into a descriptive structure which is to be presented to the scientific community through this paper and through an oral presentation at a national nursing research congress in Zaragoza (Spain).

Data analysis was conducted following an evident inductive approach. Once texts had been read over and over again and all three co-analyzers felt familiar and comfortable with, coding process started. Bearing the study goals in mind, codes were ascribed to each extract of the texts which seem to have a meaning of significance to those goals.

As codes were created, a full and detailed description of their meaning as well as the differences to other codes considered close but distinct were written down in the form of memos. When all three co-analyzers had finished up the coding process of the texts assigned to them, code lists along were put together and contrasted. Redundancies were eliminated always keeping the code with sounder and clearer definition. Where discrepancies were found, discussions took place based on contrast and comparison of citations assigned to each code. Where new codes appeared, and once redundancies eliminated, decision to keep or discard them were also made based upon ascribed citations. This whole code-consensus process was guided by the goals of the study. A list holding seventy-nine codes (eg. “talking is no good”, “I am moving at your pace”, “afraid of news”, “hope”, “loss of equilibrium”, “threaten rel to news”...) was finally agreed and accepted by three co-analyzers. Once consensus was achieved over the list of codes, these were grouped into different sets, what we call “families” regarding their meaning and their level of abstraction. Eleven families were finally constructed (eg. “equilibrium”, “hope”, “protection”, “roles, “dynamics”...). Finally, visual networks were drawn by using these families as connecting nodes. All nodes were put up on a global network and space was used for placing similar and more related elements together. From here, three more concrete networks were drawn each one leading to one of the three final core meanings to the experience. As a closure to the process, first drawn network was reconstructed by pasting the three smaller scale networks already finished. Again, visual and space orientation were used to put all these three together in a way it could give meaning to the experience and answer the research question, and which finally led to the figures as presented on this final report. Interviews were developed in Spanish and so were subsequent transcriptions. Data analysis, either by anyone of the three analyzers (research student and two co-analyzers) was therefore

done over these Spanish-written texts. Spanish being the mother language for all three co-analyzers, discussions following individual analysis were also conducted in Spanish. Translation took place just at the end of the process when citations had to be extracted and presented for final report. One of the co-analyzers being fluent in English, at both popular and academical levels, was the hint for trying to assure fidelity between Spanish and English wordings of participant family members' expressions. In spite of all the measures adopted aiming at assuring maximum fidelity regarding languaging, when dealing with meaning it could sometimes not positively (100%) be assured as it was observed that, in itself, the process of translation clearly constitutes a process of interpretation, where elements such as translator's culture, background, values and beliefs... seemed to be of remarking relevance. Maximum efforts were put into assuring rigor and validity of the translation process and both co-translators having been also co-analyzers of the data seemed to help very much in this sense.

Data analysis was performed over software Atlas-ti version 4.2 (built 058).

#### Criteria for validity and rigor

Transferability being the potential capacity assigned to the results to be critically implemented in other similar clinical situations, was, for this study, ensured by a very detailed description of the participants' characteristics and contexts.

Data validity for this study was ensured (Morse, 1987) by researchers' "trip back" to participants and their contexts. As she did so, she looked for participants' understanding of her own interpretation of their reality. This is, ensuring data were valid for those people's reality from her own perspective on the phenomenon.

Regarding the scientific rigor of the study and mainly of the analytical process, a diary was kept day to day in order to reflect researchers' decision making process and

provide validity to the interpretations being constructed. Every code renaming, every code-family construction, every higher-level category elaboration was reflected in that diary as well as the critical thinking process that was leading the researcher to make that decision. Researcher's perspective on the phenomenon and her stance towards the research project were also reflected in that diary as well as in this document as part of the reflexivity criteria this kind of research demands in order for its results to be scientifically valid.

### Ethical considerations

The ethical considerations of the present research project were evaluated and approved by two different organisms: The Ethics Committee for the Health Sciences Sector (Comité d'Éthique Sectoriel en Sciences de la Santé), at the University of Montreal, and the Committee for Evaluation of Clinical Trials at the Txagorritxu Hospital, Vitoria, Spain. As explained before, informed and written consent was obtained from the participants prior to the beginning the study, and withdrawal from the study was permitted at all times for participants who could wish to do so. The informed consent form is presented in Annexe C. Confidentiality of the information gathered was assured and maintained throughout the study.

Given the very special characteristics of the moment in life participants were going through, several considerations were to be made when developing the interviews and interacting with the informants. The student researcher was aware of the possible consequences the interviews could have on the participants, since they might stimulate self-reflection, reappraisal or catharsis. In any case, no one participant actually expressed need of special support besides the one provided by the student researcher during the interviews. To the contrary, the three of them showed gratefulness for the job being done and the time and attention dedicated to them. The attention from the palliative care team as

well as from all other resources remained in place and no other demand was placed upon the system.

#### Limits to the study

For our findings to be understandable and useful for the reader, we have considered essentially important to put them in context and present them in a very narrow connection to the three participating families' experiences. Nevertheless, we also believe in the radical importance for these results to be valid and contributing to the knowledge of the discipline, to situate them within the research context where they have been produced. As presented in this chapter, this work was carefully designed and the decision making process was well founded. Nevertheless, this research work presents limitations which have not been yet presented but which we believe the reader should also be aware of as they also constitute the research context for the results.

The first limit to our study was coming from the fact that for all the three families just the main carer showed up for the interviews. By using the systemic approach for our questions and interview approach, we were able to acquire a much more family-focused understanding of the experience but it was, in any case, a hard task to do and also up to a point, a certain limit for our findings.

Right from the beginning, it was clear for the research team that saturation was not the goal of our project. We did not intend to generalize our findings nor did we aim to prove any previously-established hypothesis. Bearing this in mind, the project had been designed for 4 to 6 families as participants. A second limitation of this study is the very small number of participating families. Difficulties surrounding the recruitment process by the palliative care team as well as several families' reluctance to talk about the difficult

situation they were going through were identified as the main causes for this lack of participants.

A third limit of this study might seem to be in relation to the literature review. Although many resources were available from the University of Montreal Library Services, the phenomenon under study (known as “Conspiracy of Silence”) seemed to be an old-fashioned subject for the Anglo-Saxon authors who had been working on it for the 80’s and 90’s but were not concerned about it anymore. This phenomenon was shown by the reviewed literature to be very soundly founded within the Mediterranean culture but unluckily enough, this is not the most powerful region in regards to research productivity. Authors and studies reviewed are thus not as updated as we would have wished and the amount of literature we were able to use not as large as we might have hoped. As Grabowski and Frantz already pointed it out in 1992, there is a dearth of literature on non-anglo population in relation to health experiences.

## **4<sup>TH</sup> CHAPTER**

### **THE RESULTS**

This chapter is intended to answer the research question: What meaning do family members residents in the Basque Country, who live with a person who is in the terminal phase of cancer give to the experience of knowing without sharing the information about the upcoming death of that member? From the analysis of the information gathered during the interviews with three families going through that experience, the results will get the reader closer to the meaning given by those participants to the experience of “Knowing without sharing”.

Although we hold an integral and holistic meaning of the term “experience”, in order for the reader to understand what we interpret the experience to mean for these three families, we have synthesized our interpretations and present them according to the following pattern. First of all, we will present and explain the three main elements that shape and build the meaning of the experience. Secondly, we will introduce the reader to the structure of the meaning itself, this is, the way those three elements relate to each other and sustain what these three families have lived and what it meant for them. Thirdly and finally, we will offer the reader an interpretation of the main themes and sub-themes that compound the meaning, clearly supported upon that structure, of the experience of “Knowing without sharing” as the participants presented it to us.

From a holistic and integral conception of the term “experience”, we accept it is of a much higher complexity than the sum of its elements. Not even the interrelationships among the elements have the potential to explain the experience at its integrity. What these three families have lived, as they have presented it to us, goes far beyond elements and interrelationships. Therefore, dividing it into elements will necessarily imply missing a sense of its understanding. Nevertheless, we feel obligated to present it in a way so that the reader can gain access to its understanding. Although we are aware of the limitations this imposes for the results of the study, and after hours of discussion, we believe this

presentation to be the easiest and simplest one for an outside spectator to understand what these three families have shared with us.

As we approached these three families' experiences, we felt the need to recognize, understand and apprehend their own language. In order for us to move a bit more comfortably within their own wording and interpreting of their living, we needed to submerge ourselves into their own life contexts. Direct quotations from transcripts are therefore here intended to illustrate their experience as we interpret it. Conceptual maps and diagrams will also try to help us build a closer image to these three families' meaning of "Knowing without sharing".

#### The elements

The roots to the experience of "Knowing without sharing", as these three families have presented it to us, consist on three essential sets of elements: (1) values, (2) roles, and (3) family dynamics. Understanding what these three sets of elements imply for the three families' meaning of what they lived through becomes essential for the comprehension of the whole.

All the three experiences participants shared with us were different from one another but they shared some common elements which kept emerging when trying to give sense to them. From our analytical perspective, those elements were of a very high and complex diversity and so a decision had to be made in order to organize them and make them understandable within the context of the experience. From Parse's Theory of the Human Becoming, values and beliefs become, through the valuing and imaging, essential elements of the family's coconstruction of their reality. Calgary's family model also supports this structure to our analysis as it itself sustains its own understanding of family functioning and dynamics, certain family structural elements such as values and beliefs,

roles. Other authors in the field of Family Nursing also support this way of giving sense to our data by acknowledging this relationship as different values and beliefs are shown to be behind different family dynamics (Candib, 2002; Kinghorn, 2001; Leonard et al, 1995; Quill, 2002).

It is not our goal here to define the terms themselves (value, family dynamics and/or role). Neither is it our goal to present each and every one of the roles, dynamics and values having an influence on each one of these three families' experience. As we present these three sets of elements, we aim to draw a picture of the basic components of the structure to the experience of "Knowing without sharing" for the three participating families. We intend to show the reader how these families give it a sense and explain the nature of the meaning. Therefore, we will here just present the values, roles and dynamics essential to these three families' understanding of their own experience.

From what these three families have taught us, it seems clear that the way they live the experience is determined by what they value. The meaning they assign to their everyday life elements is influenced by their own perspective on reality. But also, the way they approach their reality is influenced by the meaning they give to those elements. The beliefs sustained by these values will be more deeply explained in the third section of this chapter since they essentially constitute the essence of the meaning given by these three families to their experience.

### *Values*

As we approach these three families' experience of "Knowing without sharing" we identify five central values related to the experience: (1) beneficence vs. autonomy, (2) care, (3) suffering, (4) hope, and (5) the system's normality and equilibrium. We will here focus our attention on the meaning the three families assign to these values, which in a way

will imply discussion about certain beliefs implicitly related to those values. Nevertheless, the main beliefs sustained by these three families' values will be presented later on this chapter as the themes constructing their meaning to the experience.

First of all, the hierarchy of the values of autonomy and beneficence seems to be clearly in favour of this latest one. For these three families, when a diagnosis is given out, beneficence seems to be of a much higher importance than autonomy. It is something not even questioned or doubted. Within the three participating families it seems to be taken for granted that trying to do what is thought to be better for someone is of higher importance than letting that individual decide for him/herself:

“We had already told him in such a way that he now could admit that somebody else would make decisions and take care of him. And from then on, he let us do” Fam X (P1:509-512)

“Yes, of course, making decisions for her is one of the most important, although difficult, tasks within my role of carer. Now that she can't, somebody else has to and that is me (...) but she has never been like this before. No, no. She has always been a very haughty lady but now that she has become older and with this that she knows she has got on her (...)”  
Fam Y (P10: 432-435)

“Sometimes I see myself too prepotent but in the end I really feel capable of making decisions and giving my family some equilibrium” Fam Z  
(P11: 88-89)

At these three family members' experiences, “family's autonomy” seems to be favoured in comparison to individual's autonomy.

Family relationships, when one of its members becomes sick, seem therefore to be based upon the value of beneficence rather than autonomy. As we will see later on in this chapter, this way of understanding those two values very much influences the way these

families conceive the roles of carer and recipient (in this case, the person diagnosed with cancer), and so the way they implement and develop care.

Secondly, from the three families' experience, care is valued and conceived as protection and prevention from suffering. Caring is therefore being attentive to the menaces that could harm the other as the way to protect him/her. What the other is protected from or what is considered suffering, is defined by the caring person. For the three carers who participated in the study, suffering is represented not only by the physical pain but also by the emotional distress potentially brought up by "bad news". As these family members explain it, being diagnosed of cancer already implies a way of suffering and not being aware of it avoids that pain. Having to face a loved one's death seems to be the most stressful element on the whole experience; caring seems to soothe:

"If we told him, he would have died. We made that decision for him to be happier because it is already difficult enough for a son to be aware of his father's death and we did not want to make it any tougher, if they both would have been aware of it (...) it would have been the worst" Fam X (P1: 638-642)

"She is just a little baby, she is just a little baby. How can I possibly tell her that she is dying? I can not do that to her (...) and when I see her at the doctor's sitting there on the chair and looking at me (...) how am I going to do that to her?" Fam Y (P5: 151-152, 154)

"Caring for him? What was it about? It was about being with him and showing him I loved him and that he meant for me more than he could ever imagine. It was being with him and managing the situation in a way so that it would not hurt them, or hurt them as least as possible. It was not just being there physically with him but being attentive to anything around him so that he would feel as comfortable as possible" Fam Z (P7: 252-258)

“I am always in advance of everything we do and everywhere we go. I try to have all the information before him and have everything under control so that he does not suffer” Fam Z (P11: 455-457)

As we see from these three family members’ voices, suffering is to be avoided and care is the best way to do so, no matter what the implications of that way of caring are.

Thirdly, as we approach the issue of suffering within the experience of “Knowing without sharing”, death becomes a central element. Death is viewed by these families as the highest difficulty to face when protecting somebody from suffering and emotional pain. Nevertheless, it does not seem to be death itself that is hard to deal with. In fact, from what these three families have shared with us, death is so strongly avoided that in the end it is an issue nobody needs to confront, neither the person with cancer nor other family members. Mostly everything around it, whether it is talking about it, expressing fear or anxiety towards it or even mentioning it, becomes an issue for the family system:

“When she asks me about her symptoms and how things are going and I tell her everything will be all right? I think it alleviates her, she feels recomforted and I think that is exactly what she wants to hear from me. With all she’s got on her, I can not put anything else on top of that and so it has to be me who withholds the bad news” Fam Y (P10: 268-270)

“No, no, we decided not to talk about it as a way to avoid everyone’s suffering, so that we each would not see the other one’s suffering. We all knew he was going to die but if I told my sister “Dad is dying”, I knew that would hurt her and so we did not talk. I did not want to see my sister suffer. And this same thing happened with everybody else in the family. We all knew it was going to happen and we were all suffering for it but it was just a matter of not suffering more than what was just unavoidable. And with my dad, exactly the same thing happened. We did not want him to see us suffer and so we did not talk to him about it” Fam Z (P7: 65-81)

Fourthly, we shall here introduce these three family members' view of "hope". As we will see later on in this chapter, the way these families conceive "hope" and the meaning they assign to it seems to evolve along the process of terminality. As these families express it, being aware of one's own death could imply that that person has given up in the fight for life and the consequent loss of hope. In any case, as they express it, keeping hope and helping the other one keep it becomes one of the most important ways of caring for the ill member. Keeping hope therefore represents another protection mechanism these families seem to use in their fight against suffering, this is, another way of caring for the ill member:

"It would have been such a defeat for him to know he was dying... his whole life had been a defeat and now that he had a family, that he was being taken care of... we were at least to keep that hope for him, hope for him to be happy, for things to stay as they were, for worries to be left aside." Fam X (P1: 1129-1134)

"It is easier for her like that (keeping hope), on her way she keeps fighting. If she knew the truth, that information, the truth, it would have killed her by now, she would not be here right now" Fam Y (P10: 239-244)

"If I told my mom she is dying I would feel like smashing her against the floor. How am I going to do that to her? During all this time that we have been telling her half truths, we have had very nice moments together, we have told jokes, we have gone shopping, we have gone for walks to the riverside... all that we would not have had it if she knew she was dying. How can I take that hope away from her. I have no right to do that to her. All those special moments are the only positive side of this whole thing" Fam Y (P5: 800-805)

"What was hope for him? (firmly looking on researcher's eyes) Just knowing we were not going to suffer" Fam Z (P7: 445-446)

“If he feels strong enough as to stand up for the news that he is going to die soon, then you tell him. But if he does not, then you respect him and help him keep hope” Fam Z (P11: 824-826)

Finally, death also represents a threat to the equilibrium of the family. This equilibrium is mainly provided by each family’s normality and by the sense of control this normality allows in the members as everything is known, familiar. Death being the unique, a totally uncontrollable and unpredictable event in human’s life, imposes serious challenges to the system’s equilibrium as normality is endangered. The diagnosis of cancer itself already represents a major change in these families’ life process. As fatal prognosis (or the announcement of the proximity of death) is delivered, families’ normality is strongly modified and new functioning dynamics need to be put in place in order for the system to maintain its equilibrium. Normality is therefore endangered, control is lost and the equilibrium of the system seriously threatened:

“It was something we had always done and we did not want to let the situation change it.(...) We acted as if nothing were going on (...)” Fam X (P1: 1020-1021, 1029-1030)

“By keeping things within our normal limits, I got to spend some very special moments with my mom. If we had let things change, those moments would have never taken place” Fam Y (P10: 573-579)

“And most important of all, no matter what happened we had to stay together and keep functioning as the family we had always been before” Fam Z (P11: 134-136)

“Our relationship, just the same, we talked about the same things, did the same things, nothing special. We did not want to change our way of being for him. We did not want things to change and he did not understand why we had to change” Fam Z (P7: 768-770)

Once we have gone over the main values these three families seem to hold around the experience and in order to understand the basis of it, it is essential that we take a closer

look at the roles assigned within the family system and the way they are distributed, as well as the family dynamics narrowly connected to this type of assignment. Although we are aware that every role assigned in the system is largely modified by one of its member's diagnosis of cancer in a non-curable stage, for the purpose of this study we will solely focus our attention on two of them: (1) the role of carer, and (2) the role of care recipient, this is, the member "being cared for".

### *Roles*

The diagnosis of cancer in a non-curable stage allows the assignment of two essential roles within the family system. On one hand, the new situation allows one of the family members to take on the responsibility for the care of the member who is diagnosed. On the other hand, the difficult diagnosis assigns the ill member the role of the "being taken care of", even when he/she has not been told about his/her new condition. This role distribution is socially and culturally legitimated by the way care is conceived. As we have seen before, care and the way these three families understand it firmly sustain this role assignment. Besides, as we see it, this role distribution is also clearly permitted by the way these three families conceive family relationships and care, suffering and hope, death and communication. What this means is that even when this role assignment is first set out by the situation itself, it shortly becomes a tacit agreement among all family members.

Power and control are the main tools the carer holds in order to develop the tasks assigned to her role (we will here talk about the carer as "her" since all the three carers interviewed were women). Having the power and the control over the situation seems to place her at an "upper" position compared not only to the recipient, for whom she is to be responsible, but to the rest of the members in the family. What this role implies for the carer is that she will be responsible for everything concerning care towards the sick family

member. She is to do hands on work but, what is more important for us here, she is legitimated to make every decision concerning the recipient, no matter whether he/she can do that for him/herself. If we were to word this cultural belief: “as you become sick, your competence and ability to decide for yourself are seriously diminished and even cancelled. Therefore, it is me who knows better than you what is best for you”, which would complement the belief related to the value of beneficence explained before. From this “upper” position, the carer seems to control and guide the flow and expression of feelings and emotions, and establish and modify family dynamics of functioning and communication. It is usually she who decides what is to be talked about with the recipient and how “risky” subjects such as physical decline, symptom control, doctors’ visits, drug intake... are to be presented to him/her:

“I need to take care of him, his medication, his breakfast, my daughter, the house (...)” Fam X (P1: 177-180)

(To somebody else in the family) “What I will surely not let you do is show him not even a minimum bit of your pain and suffering, I will not let you nor anybody else show sadness to him” Fam X (P1: 1056-1059)

“Yes, I have made all the decisions for him. The only one I did not make was at the time of the haemorrhage” Fam X (P1: 506-507)

“And, right from the beginning, I had to speak up and say: if a house is to be well organized then someone is to rule over it and, it was not that I wanted to do it, but in the end I got it” Fam X (P1: 578-582)

“You have to make them (the other members in the family) see things and tell them: you are to go this way or the other way, or do this, or do that” Fam X (P1: 1021-1023)

“Yes, making decisions for her is just part of my role as carer although it is not always easy” Fam Y (P10: 432-435)

“Yes, once they fall sick, I have the power to decide for them (...), they are more subordinated to us (...) and that allows me to make decisions for them (...)” Fam Y (P10: 412, 423, 435)

“I feel responsible for them (...) maybe it is because I feel stronger than them” Fam Z (P11: 48-49)

“Yes, it was me who made the decision not to talk because I have become the owner of the visits to the doctor’s, I am responsible for avoiding... (...) because if my sister goes to the doctor’s and they tell her something (...) no, that hurts her too much. If they say it to me (...) well, I don’t mind having to put up with it” Fam Z (P11: 289-291, 298-300)

“It has been me right from the first moment. I have not let my sister or my mom do it because I feel I am the one who sets the equilibrium in the family. I have always been stronger than them and now I do not want to let them see my suffering (...) and they also expect that from me” Fam Z (P11: 99-106, 132)

“When I am home, I call them every three hours because I need to know, I need to be present in every aspect of the situation (...) I do it, I do it, I do it because I need to do it” [...] “When I think he is ok, then I go and try to solve other things as I try to make everything be ok” Fam Z (P11: 329-331, 344, 349-351)

“Because I know I can do it, I can organize things, I can arrange things. I know I can keep it under control” Fam Z (P11: 851-853)

On the other side, the ill member is assigned and finally assumes the recipient’s role which in itself comprises a passive and submissive role. The illness and the proximity of his/her death seem to take away his/her ability to rule over his/her own life and so he/she is to decline every responsibility on the carer. He/she is then considered to be the “weak” member of the family for whom everybody is to act protectively. If we compared the recipient’s position in relation to the one adopted by the carer, we would observe that

the diagnosis places the ill member at an “inferior” position so that he/she is to depend on his/her carer for his/her own functioning:

“Well, yes. It was difficult at the beginning. Someone who has always done what he has wanted to, who has had no limits or rules (...) and now suddenly he is to submit himself to somebody else (...) yes, it was hard at the beginning, he would not let me take care of him” Fam X (P1: 221-224)

“She is just a baby, a little baby” Fam Y (P5: 152)

“It is now that they have become older and that they feel their resources and abilities are under ours, that they let us take care of them and decide for them (...) when they started to feel their strengths were fewer than ours they let us take over” Fam Y (P10: 80-82, 404-406)

“He always let us do, right from the beginning he could have asked the doctor but he did not, he let me do everything for him (...) he adopted a very submissive role” Fam Z (P11: 421-423, 428-429)

“He does not want to know, he does not want to know, he just wants me to cheer him up and tell him everything will be alright” Fam Z (P11: 483-485)

As we can see from these quotations, there are some differences among these three families’ experiences in regards to the way the recipient’s role is assumed by the sick member. For Family Z, the sick member not only quickly accepts his role but also even contributes to this role distribution setting. However, for family X sick member, the process does not seem that easy and he first rejects being taken care of although his own physical decline soon drives him to a situation where he is to firmly adopt his new role within the family system. This role distribution assumption process will be more deeply explained later on this chapter.

Nevertheless, as we will also see later on this chapter and from our interpretation of the three family members’ meaning to the experience, who is who at this “role play” is not

always that clear. As the illness progresses and the ill member increases his/her level of awareness, he/she also seems to take on a protecting role. He/she continues to play the same role although every family member seems to be clearly informed that he/she knows what is going on. This seems also to be a way in which the ill member cares for his/her closest ones, including the “official carers”:

“What was hope for him? Knowing we were not going to suffer” Fam Z (P7: 445-446)

“He knew what was going on but did not want to make us suffer, he would hide his own pain or suffering so that we also would not suffer for him (...) it was a mutual protection, I protected my dad and he protected me, I protected my mom and she protected me (...) everybody seemed to protect everybody” Fam Z (P7: 117-120, 123-128)

“What he does not want is us to see his pain. I don’t know, maybe because it is him, because he is the father, because he is to show stronger than anybody else (...) or maybe that is exactly the same thing I do with my family” Fam Z (P11: 491-494)

### *Family dynamics*

Once the two roles are clearly assigned in relation to the family goals, family patterns of functioning and communication are to be adapted to the new situation. As we have seen before normality plays a crucial role in this experience as it contributes to the equilibrium of the family system. Anything that has been there before, that is already familiar and/or that the system is used to deal with is what constitutes normality. Previous patterns, whether on functioning or on communication, are then essential elements for each family’s normality. When approaching each one of the three families, we found it really important to be aware of previous role and task distributions, limits and boundaries, bonds and relationships, styles and patterns of communication, etc. All these elements seemed to be of large relevance for the understanding of the new patterns established after the

diagnosis. These new dynamics seem to be always intended to procure stability and support to the system in a way so that minimum changes are to be made and previous ways of functioning and communicating can now still be valid.

As we have just seen, these three sets of elements, values, roles and family dynamics, compose the basic structure of the meaning given to the experience of “Knowing without sharing” by the three participating family members. Nevertheless, these three sets are interconnected in a way that sustains that meaning. This is, these three elements each on their own, can not explain what the experience means for those families. It is now necessary to understand the way they relate to each other in order to move on to a higher complexity level where the meaning of the whole is achieved.

#### The structure

Once we have introduced the elements composing the structure to the meaning of the experience, it is now time to explain the structure itself. The way these three sets of elements are placed within the diagram as well as the way they relate to each other constitute the structure to the meaning of the experience of “Knowing without sharing”.

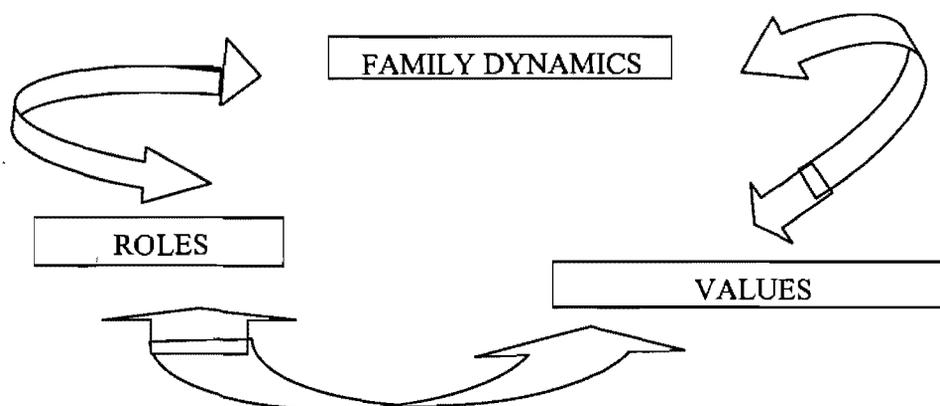


Figure 4. Basic elements composing the structure to the meaning of the experience

From what we see on Figure 1, the three sets of elements, values and beliefs, roles and family dynamics, are inherently interconnected. What this diagram tries to explain is that elements represented share circular and reciprocal rather than linear and one-way relationships among them. No one element on the picture would exist if the other two were not there. The presence of each one of the three allows the existence of the other two, at the same time these two set the space for the first one to come up on the scene. As a Spanish old saying reads: “Who comes first: the egg or the hen? There would be no eggs without hens but there would not be any hens if there were no eggs”.

Values and beliefs held by these three families, such as “children should care for their parents”, “women in the family should be responsible for care” or “the ill member should be cared for by other family members”, seem to be narrowly connected to families’ communication and functioning patterns as well as to the roles enabling these dynamics to take place. As they present it, these family members’ ways of understanding family relationships, care, death, hope, change and equilibrium, and so on, leads them to certain dynamics where protection of the ill member becomes a central goal as the main way of caring for the loved ill one. At the same time, for these protection and concealing dynamics to take place, role assignment needs to be put in place so that someone in the family can be assigned an “upper, more powerful” position from where protecting attitudes towards the recipient can be implemented. Again, for this type of role assignment to be put in place, terms such as care, death, protection, normality... need to be conceived and valued in a way that allows it to happen.

#### *Level of illness awareness*

Yet there is one last element that seems to play a crucial role in the development and onset of these dynamics. This is the ill member’s level of illness awareness. From our

understanding of the term “level of awareness”, this is more related to the acceptance and assumption of reality than to the fact of knowing about it. This is, we are here talking of awareness not at a cognitive level of whether the person has got the idea in his/her mind but rather whether he/she is conscious of what that means to his/her life and acts according to it. From what we have listened to on these three carers’ story telling, the family system’s level of awareness of what is going on and what it will shortly imply exerts a vital influence on the way these three sets of elements that compound the structure to the experience relate to each other. When higher levels of awareness, both on the carer and on the recipient according to the carers, are present, things start to appear clearer in everyone’s mind, each member of the system finds it easier to assume their role and act upon it. Also, when physical decline is accepted and fight against the unavoidable left aside, the boundaries for care, hope, suffering and normality seem to be more clearly drawn. Nevertheless, the level of awareness is not here exclusively addressed to the ill member but rather to the whole family system. Although these two evolve at different rhythms, they both have got something to say on the dynamics established and the meaning given to the situation, as we will see along this chapter.

The ill member’s level of illness awareness clearly influences the way the whole family lives the experience. As he/she shows a more aware attitude, family dynamics and functioning seem to be more clearly stated and established. To the contrary, when the ill member moves back and forth between acceptance and rejection, awareness and unconsciousness, fight for living and giving up, the family system finds it harder to make a statement, to establish any kind of caring dynamics, and to exert control. On the same way, and up to a certain point when physical decline and empirical evidence become undeniable, the ill member’s level of awareness is also influenced by the family system’s position in face of the situation, by their readiness to accept it:

“Yes she knows she is going to die and, to tell the truth, she is afraid. But sometimes, when she sees medication is not working, she is taking more and more every time (...) she asks me: ‘what are these doctors doing that does not work for me? This is nothing good that I have got on me. I know I am going to die’” Fam Y (P10: 138-139)

“When she’s got just a little thin thread where to grab on to, she says: ‘tell me my daughter, am I going to recover from this?, I am, right?’ (...) And when she feels worse she asks me to take her to the hospital where ‘those very nice doctors-she says-will treat me and heal me’ (...) ‘it’s just you who knows the truth’”. Fam Y (P10: 141-142, 157-159, 23-24)

“And there is a fight there when she says: ‘I feel sick and I know I am going to die but I need to hold some hope because I don’t want to die’.(...) And I feel so bad in this situation, I feel such an anguish (...) I do not know what to say or how to react” Fam Y (P10: 167-169, 172-174)

It seems clear for the three family members that the ill member knows about his/her approaching death shortly after diagnosis disclosure to the rest of the family. What does not appear so evident is that he/she actually reacts as he/she knew it, this is, that he/she actually verbalizes what feels, thinks, believes or worries about. This un-controlled situation seems to be an important stressor for the care provider:

“I sat with him and he told me: ‘you know, my daughter? It is sometimes better not to know about things’. He never said it again but never talked about it again either” Fam X (P1: 858-860)

“Some days before he died he came up to me and said: ‘I want to thank you for all you have done for me, there is nothing else you can do for me now’”. Fam X (P1: 877-879)

“Other times when he asked us he was clearly looking for hope and for our protection” Fam X (P1: 392-394)

“I don’t think she’s ever lost track of what was going on” Fam Y (P5: 18-19)

“Just some days ago she told me she was not going to last very much longer, she knew she was dying” Fam Y (P10: 129-130)

“He knew it, he clearly knew it, he was not dumm. (...) I know he knew it (...) it was just that he pretended he didn’t in order to protect us” Fam Z (P7: 449-450, 461-462)

Finally, from what we understand, the carer’s level of awareness is also of vital importance as it clearly exerts an influence over the dynamics established and therefore, the ill member’s level of awareness:

“Listen, on the first phase, doctors tell you about his diagnosis and prognosis, you go home and start thinking about it but still can’t believe it and you see that same reaction on the rest of the family. They act as if nothing were going on because they just don’t believe it” Fam X (P3: 71-79)

“They did not believe it, they did not believe it. I used to ask my husband: ‘But, are you aware of what is going on with your dad?’ And he would say ‘Yes, I am’ but he was not.” Fam X (P3: 111-115)

“Up to that moment I had pretended I did not know anything, nothing was actually going on, it was just some polyps and doctors were wrong...(…) I lived up with that illusion in my head, it would just be some polyps and everything would be all right” Fam Y (P10: 9-10, 12-14)

“When they told me it was lung cancer (...) the whole world fell on top of me. No way in the world I could have imagined that. Not my dad, not him. I had always thought anybody else could die: my neighbour, my aunt, my uncle... anybody but him or my dad or my sister... it took me sometime to assimilate it” Fam Z (P7: 724-729)

“I already knew my dad had cancer and it was still hard for me to listen to the doctor say he had it, what his life expectancy was... and it is still difficult to me when they say they need to put medication up to control his pain” Fam Z (P11: 785-789)

Within our participating families' experiences as described by the main carers, we have been able to identify three different dynamics clearly linked to the level of awareness. When presented back to them in our second interviews, they have all recognized it, and although each carer added their own nuances to the whole, felt themselves identified with it.

These three dynamics do not necessarily follow each other linearly and they are not on a non-return flow. Rather, carers recognize their family moving back and forth from one dynamics to another and even found it difficult to set the time limits between them.

For the first dynamics, a family member is informed of the diagnosis and fatal prognosis where the patient is not, but, as the three participating members have told us, none of them is actually "fully aware" of the situation. Grabbing onto thoughts such as "there is no way he/she can leave us now" or "there must be a way out of this for him/her" seems to help the system cope. From here, deciding not to inform the patient, to act as if nothing were going on and to hope everything will be alright, does not seem so difficult to understand. "Not talking about what we don't firmly believe" appears as the most coherent pattern of communication in this situation. Whether it is the carer, the dying person or the whole system that establishes this not-talking strategy is not clear but what really seems clear for family X and Z is that both patients are also espousing this attitude. We have named this first dynamics as "Nobody knows, nobody talks":

(After being admitted for 8 days and receiving the diagnosis of liver cancer, Alberto goes home on his own and does not tell his family about it. He has been given the report and he has read it but he pretends he has not understood what it is written on it and what it means) "The doctor then called home and, wondering why nobody had showed up at his office, asked us: 'Did he not say anything to you? Did he not tell you to come and meet me as soon as possible?' He had gone out of the hospital

with the discharge report in his hand and got home and said there was nothing new to his situation, just a new pill he had to start taking". Fam X (P1: 308-313)

"Listen, on the first phase, doctors tell you about his diagnosis and prognosis, you go home and start thinking about it but still can't believe it and you see that same reaction in the rest of the family. They act as if nothing were going on because they just don't believe it" Fam X (P3: 71-79)

"From the moment of diagnosis, he decided to give up, he did not even want to ask. We even went for the chemotherapy and there, he was feeling so sick that he told me: 'I would rather be dead than go through this, let's go home' and then I asked him: 'do you want to talk about it?' he turned his face away from me and never said anything else about it" Fam Z (P11: 473-479)

"If he has decided not to ask and not to know, I respect that, right? I respect him. Like I said before, I have decided not to talk and that is why I avoid it but if he ever wants to talk... I already tried it when we first started chemotherapy to see what he thought about it, what he felt like but there he clearly told me he did not want to know" Fam Z (P11: 884-889)

At the second dynamics, both patient and his/her relatives' level of awareness starts to increase as the illness progresses and the patient's physical decline becomes evident. Once the "Not talking" communication pattern is established, and for things to remain similar to normality and therefore under control, the system holds onto their decision to keep the subject of death away from conversations. Nevertheless, the patient who has entered a suspicion (awareness) state as Glaser and Strauss (1965) call it, might feel in need to have his/her suspicions confirmed and start to pose questions in a very indirect way. The family member seems to identify this patient's need but decides not to give him/her that information as she believes this might be more harmful for as the patient. The

three carers do not take the opportunity to talk since as they have recognized it, they lack the ability and the personal resources to hold a conversation about the subject. They therefore, hold a concealing attitude (see except Fam X + Y) based both on their own needs and on their interpretation about the recipient's needs. On the other side, the patient seems to pose his/her questions without expecting much as an answer. He/she does not want to harm his/her relatives by making them talk about it. Up to a point we could also say, by what these three family members have shared with us, that the patient him/herself might not want to hear what they may have to tell, and so even when they say "I have got cancer" or "What do I have?" they would then immediately leave the room or turn their head away. This is what we, from our interpretation of the carer's meaning to the experience, have called the "We know; you do not want to know" dynamics:

"He would come up to me and say: 'I have got cancer' and turn his head away to the window and I would say: 'Yes, or appendicitis, why do you say that?' Then he would talk to me about all his symptoms and I would tell them about many other illnesses he could have with those same symptoms but which were not cancer" Fam X (P3: 202-207)

"She would then complain and ask: 'But what do I have? What do I have that is killing me?' and she would leave the room and I would not answer her" Fam Y (P5: 529-530)

"She would come up to me and tell me: 'I think I am dying' and I would tell her: 'Yes mom, you are going to die but I am also. It will be God who decides about that but yes, you are going to die mainly because you are 68. Look at me, I am 48 and I could also die tomorrow' and then she would change subjects" Fam Y (P: 257-263)

Thirdly and finally, when the patient gets his/her suspicions confirmed, either by his/her physical decline or even by family's reluctance to answer to his/her questions, he/she then seems to decide not to pose anymore questions as to move on with the

dynamics established by his/her family, and protect them. This third dynamics is what we have called the “We all know but let’s not talk about it” pattern:

“He used to say: ‘I am just hoping that Dr Rodriguez will heal me because I really do think they care for me’” Fam X (P1: 846-850)

“She knew what was going on but decided not to ask about it anymore. On those days, we went out for walks, went shopping, visited our former house in the village... we did things that maybe we would not have done in any other way” Fam Y (P10: 48-53)

Besides these just introduced elements allowing each other to exist and exert an influence on the experience, it is important to note that it all takes place and makes sense within a certain context which also legitimates the situation. As explained earlier in the second chapter, within the Basque culture death is not a subject to be talked about, it is denied and kept out of social conversations. Relatives are entitled to be informed by doctors before the patient him/herself and the value of beneficence is of larger weight than autonomy. From a socio-cultural perspective, this Basque context openly invites this type of family dynamics to be put in place.

Having explained all this, it is easily understandable that the analysis performed on the transcripts from the interviews with these three family members was substantially performed following an interpretative method and not a categorical one. No one element exploring the meaning of the experience of these three families seemed to be of more importance than any other one but rather none could be explained without the presence of the other one. As stated at the beginning of this chapter, the experience is of a higher complexity than the sum of its parts.

## The meaning

Once we have had a look at the basis of the experience and got a sense of the elements that compose the backstage and the way that backstage is displayed and works, we may now try to approach the meaning of the experience itself as it is lived by the three participating family members

Common to these three families, we have been able to identify three main themes to the meaning given by them to the experience of “knowing without sharing”: (1) protecting the weak, (2) reassuring the equilibrium of the system, and (3) keeping hope.

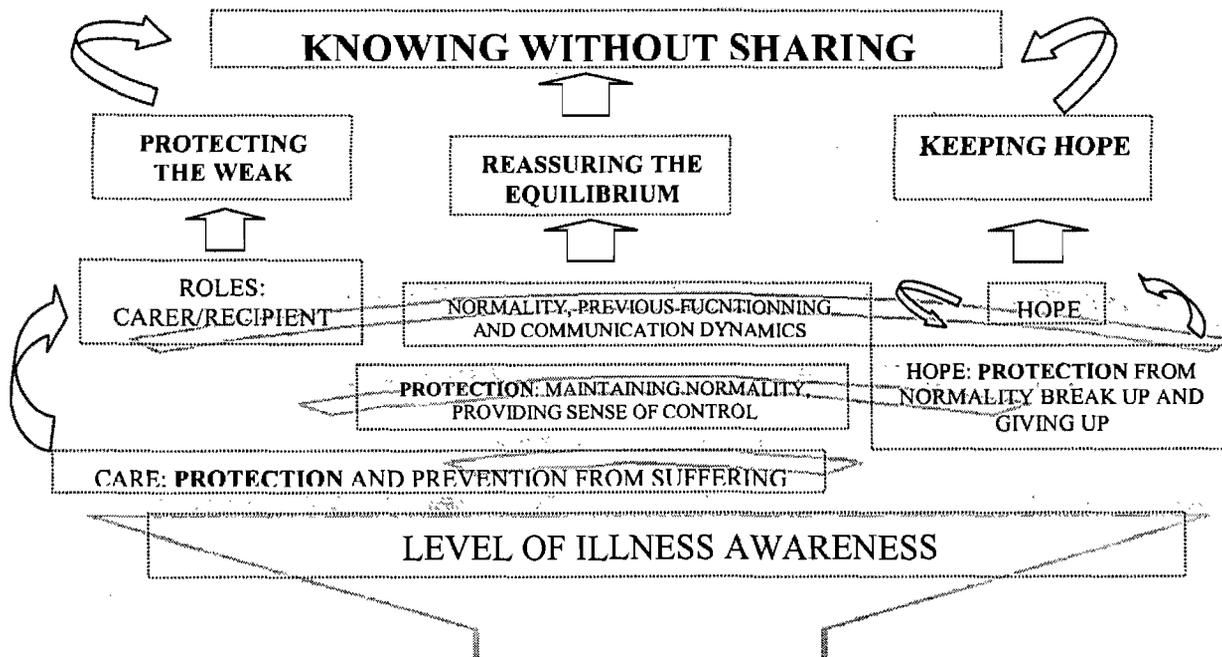


Figure 5. The meaning of the experience of “Knowing without sharing”. Conceptual map

Before deepening into each one of these three main themes, let’s have a look at the conceptual map where both the structure and the meaning are shown to be inherently connected.

All the elements shown in the picture are being presented in closed and isolated frames. Dotted lines for these frames intend to represent the idea that they are not separate and independent items but rather inherently connected whether among them or with the essence of the meaning of the experience itself (background of the picture).

Lines and arrows between items are meant to clarify the explanations given below so that the reader may more easily follow them. Nevertheless, as we understand the experience from what the three carers have shared with us, each item would represent a drop of water within a cloud: the cloud would not be a cloud without the drops and it would be different to any other cloud just by having those certain drops and not any other one, nor one more, nor one less.

The element represented in the box at the bottom of the picture is not solely connected to protection, care and hope but rather to the whole picture. System's level of illness awareness seems to support not only the dynamics themselves but also the flow and the rhythm of their onset.

As stated before, the analysis performed on the transcripts of the interviews is more interpretative than categorical. Therefore, themes and sub-themes as presented here do not necessarily hold a vertical structure but rather a circular one. They all reciprocally feed each other and even sustain the meaning given by the three participating family members to the experience as a whole.

Up to now, the central elements to the experience and the structure to the experience those elements form have been presented. The core, the meaning of the experience, this structure and its elements shape, is now to be introduced. From the three participating carers' wording, we have gained access to their valuing and imaging. This valuing and imaging is, from the transcripts, clearly described by these three families'

belief systems. Values, roles and dynamics seem to inform beliefs and consequently these latest ones seem to picture the meaning of the experience. This is the reason why nearly all the sub-themes to the themes, representing the meaning of the experience, are worded as beliefs and analyzed and interpreted from there.

<u>Themes</u>	<u>Sub-themes</u>
1. Protecting the weak from suffering	1.1. Diagnosis enables me to care for you 1.2. I love you and so I take care of you 1.3. Caring for you means protecting you from what I consider suffering 1.4. We protect each other
2. Reassuring the equilibrium of the family system	2.1. Death is a threat to the system 2.2. Normality and previous dynamics provide a sense of control 2.3. Not talking about death will maintain normality, sustain the equilibrium and help me keep control
3. Keeping everyone's hope following the level of awareness	3.1. Hoping for nothing to change 3.2. I also need hope 3.3. Hope prevents suffering 3.4. Talking about death destroys hope and makes me, as caregiver, feel guilty for hurting you

### *1. Protecting the weak from suffering*

#### 1.1. Diagnosis enables me to care for you

Cancer diagnosis and fatal prognosis legitimate the onset of protection dynamics. Death is socially considered as one of the most difficult issues to deal with in life and so compassion appears to be easily implemented towards the individual who is now known to

be dying soon. Even the way health care professionals deal with the information at the time of its delivery contributes to this role assignment and therefore to the onset of protection dynamics. When families are informed in first place and on the outside of the patient's room he/she is put in a position where he/she is to adopt a passive role, where he/she is not considered to be strong enough as to manage and live up with the information about his/her upcoming death. While the investigations are being done on him/her, he/she is given a more active role but once the diagnosis and fatal prognosis are assured, family members take this responsibility on. From then and onwards, visits to the doctors are always under the main family carer's control, the patient being sometimes even left out of those visits (what we call "family visits"). Results from ongoing investigations and information about illness progression are then kept away from him or her. This change in role assignments and family members' attitude towards him/her seems to inform the ill member about new circumstances under which he/she seems to adapt to the new situation by accepting this passive role and letting the other members do and decide for him/her.

In this situation, these three carers adopt their protecting attitude based on the belief: "Diagnosis and fatal prognosis allow me to care for you". He/she is to leave his/her decisions up to somebody else. The diagnosis enables other relatives to take on the responsibility for the ill member's decisions and actions. The ill member then becomes the "weak" member in the family towards whom everybody else, supposed to be and show strong, is to exert protection. Diagnosis itself but also the way it is disclosed enables then the onset of this new role assignment. As this new role assignment develops dynamics of protection start to show up on the scene:

"And I come back home from the hospital after talking to his surgeon and I sit and talk to him [...], 'it is not a matter of you having something, it is just that they have told us your hip is not ok, your liver is not ok, you are getting older, your blood sugar or whatever you call it, grandma suffers

from thyroid, she can't work and her legs are getting worse, what if she falls sick? Who will take care of you? Your daughter is leaving now, are you taking care of her? No, I can't- he said. Then you need to think about going and living at one of your sons' place or having one of your sons come over and live with you. And then he said: talk to grandma. We have already talked to her and she can't be running out to the ER every other day and you won't be able to do that with her either. That is true -he said- I won't be able to take care of her... and that is how he accepted that we take over...". Fam X (P1: 480-496)

"Yes, of course, making decisions for her is one of the most important, although difficult, tasks within my role of carer. Now that she can't, somebody else has to and that is me (...) but she has never been like this before. No, no. She has always been a very haughty lady but now that she has become older and with this that she knows she has got on her..."  
Fam Y (P10: 432-435)

## 1.2. I love you and so I take care of you

Caring for someone is understood by the three participating carers to be the best way to show love and appreciation for that person: "loving you means protecting you from what I consider suffering for you and deciding for you what is good for you". As by "natural laws" parents take care of their children, relatives in these three families take care of their dying loved one. Certain dynamics of love and appreciation are now allowed due to the proximity of death. The socially and culturally basic belief such as: "I love you and so I care for you" is now transformed into "I take care of you because I love you", me, at an active role, being the one who makes decisions for you, at a passive and submissive role:

"We had already told him in such a way that he now could admit that somebody else would make decisions and take care of him. And from then on, he let us do" Fam X (P1:509-512)

“Caring? Caring for my dad, what was it for me? It was about showing him that I loved him, that I loved him, that I loved him, that I loved him, it was mainly that to me, show him that he meant more than he could ever have imagined, right? It was not just being physically there and say ‘here I am’. While I was there I was not thinking ‘I want to get out of here’ not at all, when I was with him I felt great, I was ok because I could feel he was ok and he knew I loved him and somehow he also showed me he also hended me by being there, right? He also wanted me to be there. It was caring for him, loving him. Caring for him was loving him and show him that...” Family Z (P7: 252-262)

### 1.3. Caring for you means protecting you from what I consider suffering

As we have previously stated, for these three families protection represents the most valuable way of caring for their loved one. For protection attitudes to be exerted there need to be some contextual, whether external or internal, elements considered potentially harmful or suffering from which somebody is to be protected. Suffering and what constitutes it depends very much on each individual’s and family system’s values, beliefs and previous experiences. The meaning assigned to it clearly influences the dynamics established when having to manage with a situation such as a member’s fatal prognosis. From these three families’ voices, death and everything it implies is seen as a threat, and information concealing as the best way to protect the system and the ill member from that menace. Protection and information concealing start then to develop within the family system and allow the onset of protection dynamics:

“Because I know her well, and, I don’t know, considering her situation, her age, her level of understanding... I thought the truth would be too harmful to her because she was going to... and maybe telling her just half a truth would protect her...” Family Y (P10: 35-40)

“Caring for him? [...] What was it about? It was being with him and managing the situation in a way so that it would not hurt them, or hurt

them as least as possible. It was not just being there physically with him but being attentive to anything around him so that he would feel as most comfortable as possible” Fam Z (P7: 262-266)

For these three families, suffering is represented by death and the threat of loss. Once fatal prognosis has been established and physical decline starts to show up, the participants begin to accept the fact that death is not avoidable. Protection is therefore directed towards what can be actually avoided, this is, talking about death. Collusion dynamics are then installed. But by this time, the ill member has already been put aside and so the decision about what implies suffering for him/her is already made by the rest of the family. As these three carers explain it, it is mainly them who decide what the recipient of their care is to be protected from: “Taking care of you means protecting you from what I consider suffering”.

“If we told him, he would have died. We made that decision for him to be happier because it is already difficult enough for a son to be aware of his father’s death and we did not want to make it any tougher, if they both would have been aware of it... it would have been the worst” Fam X (P1: 638-642)

“No, no, we decided not to talk about it as a way to avoid every other one’s suffering, so that we each would not see the other one’s suffering. We all knew he was going to die but if I told my sister “Dad is dying”, I knew that would hurt her and so we did not talk. I did not want to see my sister suffer. And this same thing happened with everybody else in the family. We all knew it was going to happen and we were all suffering for it but it was just a matter of not suffering more than what was just unavoidable. And with my dad, exactly the same thing happened again. We did not want him to see us suffer and so we did not talk to him about it” Fam Z (P7: 65-81)

#### 1.4. We protect each other

While protection is addressed towards the ill member, the people surrounding him/her are to show strength and serenity all along the process. At a much more intimate level, carers from these three families show their own fragility and suffering throughout the process. Hence, they recognize exerting this protection also towards themselves as a way of protection from suffering that would allow them to maintain their position as a strong and serene carer. At the same time, the three carers receive a certain protection from the ill member. By accepting the not talking dynamics, the ill member also seems to prevent his/her carer's suffering:

“No, it is not that easy. Every time I need to decide something for her I start wondering: Who am I doing it for? For her or for me?” Fam Y (P10: 440-442)

“It is not hope just for him, but also for me” Fam X (P3: 255-256)

“It is really hard even for us, as carers, to be aware of a loved one's oncoming death” Fam X (P3: 844-845)

“I could see myself on her, I saw myself reflected on her face” Fam Y (P5: 154-157)

“I don't know maybe it was all about me feeling better by hiding the truth to them” Fam Z (P11: 305-306)

This recognition of the mutual protection exerted both by the carer and the ill member seems to be one of the main sustaining elements to this dynamics as it seems to show shared responsibility, by all members including the ill one, on the decision of “not sharing”.

From this just presented perspective, the first theme could be worded as “Protecting the weak” as long as we understand the term “weak” to be implicitly talking both about the ill member and the rest of the family members themselves, including the main carer.

Nevertheless, this protecting attitude is directed not only from the rest of the family towards the ill member but also, from what we have seen in these three families' experience, from the patient towards his/her relatives. As in our dynamics, which we have named "We all know but not talk about it", protection and concealing are espoused by the ill person: he/she is also showing a caring attitude towards the rest of the family members. By deciding to move along with what it is decided for him/her by the others, the ill person is protecting the others from the harm of change, trying to keep normality and to maintain hope for them. We could then affirm that, from these three families' experience, protection attitudes seem to be bi-directional, this is, protection seems to flow both from the family system towards the patient and from the patient towards the family system:

"Whether it was him or me that I was trying to protect... there I am not sure" Fam X (P3: 736-738)

"He knew what was going on but did not want to make us suffer, he would hide his own pain or suffering so that we also would not suffer for him (...) it was a mutual protection, I protected my dad and he protected me, I protected my mom and she protected me (...) everybody seemed to protect everybody" Fam Z (P7: 117-120, 123-128)

"What he does not want is us to see his pain. I don't know, maybe because it is him, because he is the father, because he is to show stronger than anybody else... or maybe that is exactly the same thing I do with my family" Fam Z (P11: 491-494)

Protection seems to be the central element for these three families' meaning to the experience of "Knowing without sharing". The diagnosis of fatal prognosis clearly enables the onset of protection dynamics where the ill member is to be cared for somebody else in the family. Caring for someone understood as a way to show love and appreciation, as well as a culturally established moral obligation, allows the carer to decide for the recipient what is best for him/her and to protect him/her from what she considers suffering. When

death is certainly at the end of the road and it is neatly assumed that it will not be avoidable, it seems for the three family members that suffering brought up by it can somehow be limited by not talking about it. But who is this protection directed to, the ill member or the rest of the family does not seem so obvious. Our three carers openly recognized needing also that protection for themselves to be able to cope with the situation and feeling the patient's protection as he/she decides to respect their decision and follow their rules.

## *2. Reassuring the equilibrium*

### 2.1. Death is a threat to the family system

Delivery of fatal diagnosis and prognosis within a family system seems to have a clear influence on their life experience, on their family dynamics, on the relationships among them, on their habits, on their everyday life... All these elements seem also to shape and singularize every family system in a way that makes each and every one of them unique and different to any other one. Those elements also tend to constitute the foundations for that family system's normality, this is they represent the parameters by which the members in the system shall be looking at the outside world, elaborating their judgement and acting upon them:

“We decide not to talk about it. It was something we had always done and we did not want to let the situation change it. (...) We acted as if nothing were going on...” Fam X (P1: 1019-1021, 1029-1030)

“It was not a very explicit decision. We did not sit around the table and said: ‘we won't talk about it’ but it was decided not to... Why? It was clear for all of us. We had never talked about death and suffering at home and we did not want to let it (death) take over our lives” Fam Z (P11: 808-812)

## 2.2. Normality and previous dynamics provide a sense of control -

Besides providing a point where to look out from, normality also clearly exerts an equilibrium function for the family system. This is, as the members of the family system share a common language and meaning to that language, know and function according to the same rules, norms, limits and look at the world from similar perspectives, the equilibrium of the family system, as it is provided and developed by its members, seems to be assured. Very often parameters for normality have not been explicitly set within the family systems. All its members have learned to function in such way and so that is what is “normal” for them, but they can’t identify the elements when we ask them about them. In any case, even when not explicitly agreed upon, those elements constitute the family system’s normality and contribute to its equilibrium.

“Our relationship, just the same, we talked about the same things, did the same things, nothing special. We did not want to change our way of being for him. We did not want things to change and he did not understand why we had to change” Fam Z (P7: 768-770)

Nevertheless, normality not only provides equilibrium to the family system but also a sense of control of the situation being lived through. When the context, the characters and the elements on scene are known and familiar, the whole family system acquires a sense of control over the situation that helps them move along and function as a family system within their normality. Feeling in control of a situation helps the members in the family system identify and act upon their role, make judgements and decisions based upon their values, beliefs and previous experiences and learn and adapt to the new oncoming needs:

“And most important of all, no matter what happened we had to stay together and keep functioning as the family we had always been before”  
Fam Z (P11: 134-136)

When an event as difficult to handle as the possible loss of a member comes into the scene, the family dynamics, relationships, habits, rules, limits, roles... are shaken. Changes need to be implemented within the family system for it to adapt to the new situation and move on with it. Normality is thus threatened. Its foundations need to relocate themselves and the equilibrium seems to be in danger. New roles need to be adopted and assigned for someone to be taken care of and someone to be caring for, everyday work or leisure activities and schedules need to be reorganized, relationships need to be reinforced for the system to be emotionally strong and sustaining... As all these elements become different and not familiar to the family system, the sense of control is lost for them. The members of the system then might start to feel useless, powerless and even senseless. Not only is the equilibrium of the family system being threatened by the announce of the loss, new boundaries to normality shall also now be installed according to this new element on the scene:

“By keeping things within our normal limits, I got to spend some very special moments with my mom. If we had let things change, those moments would have never taken place” Fam Y (P10: 573-579)

“If we had talked about it, then it (death) would have taken over our lives and his life, the very short time of his life he still had left” Fam Z (P11: 815-817)

The loss of control seems almost total for these three families in this situation. Many elements are not to be under their determination. Not even the information is. Now it is the illness itself and its progress that will define the new parameters for normality. Health care professionals are the ones holding the information about the illness but no one holds any information about the way the illness will progress, the symptoms that will have to be acknowledged and treated, the time of death, its circumstances, or what will come after it. This lack of information just seems to exacerbate this sense of loss of control:

“We don’t know when it is going to be, what it will look like, yes, they keep telling us she won’t suffer but how do I know it is her last moment? I feel lost and this feeling just increases as time passes by and death gets closer” Fam Y (P10: 273-276)

2.3. Not talking about death will maintain normality, sustain the equilibrium and help me, as caregiver, keep control

In such a situation where so many elements seem to be out of the family system’s control, it is not hard to understand that the family as a system develops functioning dynamics intended to maintain, or at least try to maintain, a minimum level of normality, a very basic equilibrium for its survival. As we have said before, loss of control is evident over elements such as illness progression or symptom control. It will actually be them who will have an influence on the system and not the system be controlling any part of them, as these families express it. What these three carers clearly identify as being under their control is the communication patterns and style established within the system:

“She knew what was going on but decided not to ask about it anymore. On those days, we went out for walks, went shopping, visited our former house in the village... we did things that maybe we would not have done in any other way” Fam Y (P10: 48-53)

At this point, previous patterns seem to play a crucial role. In families where communication, flow of information and emotional expression has not constituted a part of their normality, where communication has always been developed at instrumental, informational and/or normative levels, having to deal with such an emotionally heavy situation such as the loss of a member will not be easily attained. If normality is to be assured, then communication needs to stay within its previous boundaries. “Closed” communication styles are then strongly protected by the participating three family

members as they try to maintain their normality and assure their equilibrium as systems. If things are to be normal, they need to stay as close as possible as the way they were before.

The ill member's level of illness awareness clearly plays a role in the way the whole family lives the experience. As he/she shows a more aware attitude, family dynamics and family functioning seem to be more clearly stated and established. To the contrary, when the ill member moves back and forth between acceptance and rejection, awareness and unconsciousness, fight for living and giving up, the family system finds it harder to make a statement, and control more difficult to be exerted:

“And there is a fight there: ‘I feel sick and I know I am going to die but I need to hold some hope because I don't want to die’. (...) And I feel so bad in this situation, I feel such an anguish... I do not know what to say or how to react” Fam Y (P10: 167-169, 172-174)

Even though this closed communication pattern might be seen as a non-protective attitude; from an outside point, it was from what the three family members have shared with us. As they decide not to talk, not to openly share the information, not to show and share feelings and emotions, they protect the ill member and themselves from suffering, as they say it, but they also protect the normality of their family system. Besides exerting some kind of control over the situation, by not talking about the fatal prognosis of the illness or the incoming death, they intend to maintain and assure their previous communication patterns and style and the equilibrium to their family system.

As we have seen before, the ill member is not the only element in the family system that is protected. Family's normality is also strongly protected as it provides the equilibrium to the system that is now being endangered by the threat of death and suffering. Avoiding it in conversations and trying to keep emotions and feelings away from

the everyday issues seem to be the ways in which these three families have intended to keep sense of control, maintain normality and assure equilibrium.

### *3. Keeping everyone's hope following the level of awareness*

Yet there is another element that also gets the protection from the family dynamics established. This is hope. Yes, keeping hope can be considered as another way of caring and even as a way of assuring the equilibrium of the system. Yes, keeping hope is in any case another kind of protection. And so, why is it being treated as a separate theme? It is because of the very special connotations these three family members give to it. The way these three carers conceive, define and move around the issue of hope has made us reflect about it and so we feel obligated to present the results of those discussions with these three carers to the reader. We believe it to be of central importance for the reader and the nursing professional to understand the wholeness of the experience as it is lived and described by our participants.

From what we have introduced on the first section of this chapter, the value given to the term "hope" seems to be of special connotations in these three families' experiences. The Oxford Advanced Learners' Dictionary (2000) defines "hope" as the "belief that something you want will happen". What is being hoped for, who actually hopes for and what hope means and allows as it is maintained within the family system are the three main issues this analysis aims to explore.

#### **3.1. Hoping for nothing to change**

As any other element within these three families' experiences, hope also varies along the process as levels of awareness vary. Right at the beginning, when diagnosis and fatal prognosis have yet been recently disclosed, family carers recognize to be hoping for the doctors to be wrong. At this time, when not sharing communication patterns are

established, the belief that “he/she looks too healthy to die, doctors must be wrong, there must be a mistake somewhere, he/she can’t be dying” clearly imposes this kind of dynamics. Hope is therefore here directed towards illness and death and responsibility for keeping it falls almost entirely on the main carer. Besides, as these families explain it, keeping hope within the family system allows the gradual acceptance of what it is to come. There is thus a paradox these families live at this time: “hoping for death not to occur helps us assume that it is definitely going to happen”. The protection mechanism hope seems to play within this dynamics is here clearly addressed to other family members rather than the ill one. Him/her not being aware of the situation makes things easier for the rest as he/she is not to be hopeful for anything:

“It would have been such a defeat for him to know he was dying... his whole life had been a defeat and now that he had a family, that he was being taken care of... we were at least to keep that hope for him, hope for him to be happy, for things to stay as they were, for worries to be left aside.” Fam X (P1: 1129-1134)

“He knew it, he clearly knew it, he was not dumm. (...) I know he knew it... it was just that he pretended he didn’t in order to protect us” Fam Z (P7: 449-450, 461-462)

As time goes by and the ill member’s physical decline becomes evident, the focus of hope is now reset on normality. As the three carers shared with us, once fatal prognosis is assumed and everybody seems to be consciously aware of it, the system hopes for things to stay the same, for their normality to be protected and maintained. Keeping hope can also be understood as a way to exert control over the situation:

“She knew what was going on but decided not to ask about it anymore. On those days, we went out for walks, went shopping, visited our former house in the village... we did things that maybe we would not have done in any other way” Fam Y (P10: 48-53)

As we have just seen, the notion of hope is for these three families of very high relevance within the meaning assigned to their experience but it is such just in the way they conceive and experience it, and not in the way any outsider could understand it.

### 3.2. I also need hope

Whose hope are we talking about? Who keeps hope? From what the three carers have shared with us it is actually the whole system's hope that is here being protected. The first easy answer to the question seems to be that it is the ill member's hope that is being protected. Nevertheless, what these three carers have openly recognized when holding the interviews with them is the fact that it is also their own hope that gets protection from this dynamics. As they get emotionally involved in the situation they identify their own need to stay alert and face the situation with their own weapons, this is hope and protection; hope, as they realize they also need to hold on to something on their everyday role and functioning; protection, as they clearly recognize feeling guilty for destroying hope. As they decide to collude information and not share it, hope is protected:

“Up to that moment I had pretended I did not know anything, nothing was actually going on, it was juts some polyps and doctors were wrong...(…) I lived up with that illusion in my head, it would just be some polyps and everything would be all right” Fam Y (P10: 9-10, 12-14)

### 3.3. Hope prevents suffering

What is keeping hope then intended for? As these three family members present it, keeping hope seems to diminish the suffering in the whole system. Believing things will not change too much or at least not as much as for the system to lose power to exert some kind of control over the situation seems to avoid suffering and prevent the ill member from thinking and reflecting about his/her oncoming death, this is, as our three family members

see it, from giving up. As they express it, delivering care to someone as you believe nothing you do will help in anyway is not easily affordable. Believing what you do will avoid and prevent suffering, increase quality of life or even help maintain some kind of sense of control over the situation seems to be much more helpful. This is where these three carers express hope is addressed towards prevention of suffering no matter whose or what kind it is.

#### 3.4. Talking about death destroys hope and makes me, as carer, feel guilty for hurting you

Keeping hope is therefore intended to protect the other one and me from the harm of the announced death. The three carers felt responsible for this and went even further along the way when they explained to us what it meant for them not to keep hope. When death issues are put on top of the table, they, as carers, seem to feel guilty for hurting the ill member, for destroying his/her hope. In fact, as they expressed it, when the patient openly showed feelings of sadness and desperations related to the loss of hope, they recognized feeling guilty for it as they felt they had not been “good carers”. Talking about one’s death implies everybody recognizing the ill member’s awareness of his/her own death, and thus, that the protection mechanism of keeping hope has failed. When death is kept away from everyday life and conversations, care, as a protection and hope-sustaining mechanism is successfully performed. It is thus not just about protecting the other one but also about not hurting him/her:

“It is easier for her like that (keeping hope), on her way she keeps fighting. If she knew the truth, that information, the truth, it would have killed her by now, she would not be here right now” Fam Y (P10: 239-244)

“If I told my mom she is dying I would feel like smashing her against the floor. How am I going to do that to her? During all this time that we have been telling her half truths, we have had very nice moments together, we

have told jokes, we have gone shopping, we have gone for walks to the riverside... all that we would not have had it if she knew she was dying. How can I take that hope away from her. I have no right to do that to her. All those special moments are the only positive side of this whole thing”  
Fam Y (P5: 800-805)

For these three family carers hope does not seem to be static but rather to move and modify along with the illness and awareness state progression. Whether it is by holding onto beliefs such as “doctors went wrong” and/or “he/she will not die” or by holding onto “things will not change that much”, for these three families, hope is clearly intended to protect, both the ill person and the whole family system, from suffering.

In summary, this fourth chapter answers the question “What meaning do families living with a relative in the terminal phase of cancer give to the experience of knowing without sharing?”. Being aware that at the end everyone in the family knows about the fatality of the prognosis and the proximity of death, not letting information circulate around the table and keeping conversations away from such difficult issues as emotions or feelings of sadness, grieving or rage seems to be a way of protection. As we have seen, within this dynamics, protection is directed towards the member who is going to die, towards the system’s normality and equilibrium, towards hope and, finally, towards the rest of the system. Proximity of death and all the emotional issues around it seem a threat to the system, a too difficult to handle breakthrough in their previous functioning and communication patterns. Loss of control and loss of hope seem also to be at the bottom of their fears. A way to live through this experience that provides reassurance, sense of control, avoidance of difficult conversations and maintenance of previous dynamics seems therefore to be the shortcut out of this situation for these three family members. Protection, normality and hope are thus the three main elements these three families could summarize their experience with.

When sharing their experiences, the three family members coconstructed their reality on the experience of “Knowing without sharing” with us. These three family members seemed to be co-creating their reality based upon their valuing of cancer, suffering and death, family duty and care, and their imaging of normality, silence and hope. All these elements seem to be at the bases of these three participants’ forms of relating with each other as well as with their universe, and so therefore seem to open up the possibles for them participants to give sense to their experience and make decisions. “Protecting the weak”, “Reassuring the equilibrium” and “Keeping hope” seem to emerge as the three main rhythmical patterns by which these participants seem to coexist with their universe as they live through the experience of “Knowing without sharing”.

**5<sup>th</sup> CHAPTER**

**DISCUSSION**

The following chapter introduces the discussion of the main results obtained from the analysis of the information gathered during the interviews with the three participating family members. As seen in the fourth chapter, the results just presented answer the research question: What meaning do family members residents in the Basque Country, who live with a person who is in the terminal phase of cancer give to the experience of knowing without disclosing the information about the incoming death of that member? The discussion is now intended to get a closer look at the main three themes that give sense to the meaning of the experience in the light of the reviewed literature: (1) protecting the weak, (2) reassuring the equilibrium, and (3) keeping hope. First of all results will be presented in the light of Parse's Theory of Human Becoming. Secondly, main themes and sub-themes of these results will be compared and contrasted to the main authors' ideas and previous studies. A brief discussion over the method will follow. Finally, implications of the results for nursing practice and research will be offered.

#### In the light of the Human Becoming Theory

From Parse's Theory of Human Becoming (Parse, 1998), the human cocreates reality as he/she openly and freely chooses meaning. Right from the beginning of this project, this idea clearly guided the researchers' way of thinking and so the design and implementation of the project itself. We were therefore not interested in the phenomenon of "Conspiracy of Silence" itself, but rather in the meaning families gave to their experience of "Knowing without sharing". As the analysis on the interviews with three family members developed was being performed, we were able to identify not just the meaning assigned to the experience by the participants but also, and mainly, the values and beliefs that actually seemed to sustain that meaning. By being attentive to these three families' valuing and imaging we were able to achieve our goal and gain a closer look at

their reality, their meaning to the experience, the way they cocreated reality based upon their values, beliefs and previous experiences.

As we have tried to present it in the previous chapter, the three participating family members openly shared with us what it meant for them to live with a relative in the terminal phase of cancer while having decided not to share with him/her the information about his/her fatal prognosis. As we now see it and in the light of the Human Becoming Theory, the openness these three family members showed when sharing their meaning to the experience with us was mainly allowed by our true presence, our true interest on their way of understanding, giving sense and therefore living through this experience. This free and opened construction of meaning to the experience the human being lives is what Parse calls the cocreation of reality.

As we truly approached these family members and listened to their way of living the experiences, we started to understand their meaning and therefore their way of cocreating their own reality. Reflection upon the data throughout analysis and interpretation led us to one last idea which we think would be interesting to share with the reader and discuss about. From an outsider's point of view, several authors have named this experience of knowing without sharing as the "Conspiracy of Silence". By being truly present and listening and trying to understand the way these three families conceived and gave meaning to their experience, we now dare to propose keeping it the "A silent agreement on Silence".

Indeed, with the understanding of what the three family members have shared with us, it seems difficult for us to keep on using the term "Conspiracy of Silence" as it is presented in some of the literature previously reviewed. As we have seen through the dialogue with the carers, the ill member somehow agrees on silence as he/she also tends to protect his/her relatives from the harm of bad news. These three family members concurred

on the fact that the ill member was aware of his/her diagnosis and either consciously or unconsciously decided to collude and not talk about issues such as fatal prognosis or death. The experience, in the way these three carers have explained it to us, looks much more like a tacit, silent agreement than like a conspiracy. The protection dynamics established within the family system has not got one single direction but is rather reciprocally addressed. It was by being truly present and listening to their meaning of the experience that we came up with this new way of wording the phenomenon "A silent agreement on Silence".

If we consider this three family members' experience as a tacit and silent agreement, we could here be dealing with a paradox as worded by Parse (1998). As, by not sharing information and/or emotions and feelings, family members try to instillate silence in the system's dynamics, they silently agree on that silence-agreement. Just because they have been able to identify the possible harm caused by the absence of silence, they silently decide to keep silence in the core of their lives.

Also the rest of the structure of the meaning identified in this study reflects the process of Parse's Human Becoming Theory. In the previous chapter, we have scented the structure the family members seem to sustain the cocreation of their reality upon. Values and beliefs are basic elements within that structure. The way these three family members chose to view and value their world was narrowly connected to what they lived. The way these carers conceived the care they offered, the relationships and communication styles they developed, and the value of suffering and hope in the way they held it gave the experience of "Knowing without sharing" a very unique meaning. As Parse would word it, these families' valuing and imaging firmly sustain their meaning to the experience, their own and unique coconstruction of their reality.

Moreover, when making decisions and/or choosing among options, it was evident for us, researchers, that the way each family lived their experience clearly reflected the

possibles they were faced with. From their own understanding of values such as care, protection, suffering or hope, some options were being opened for them as other ones were getting closed. The way these three family members viewed their world and understood their relationship with it enabled some options to be present in their lives and limited other ones. By choosing options and making decisions on their everyday life concerning issues surrounding care and/or communication, each carer was also looking forward, constructing new perspectives for their oncoming future. As Parse would word it, these three caregivers cotranscended multidimensionally with their possibles as they made decisions and beard responsibility for them.

The three participating family members and the researchers understood the theme “Protecting the weak” as a way of caring and relating to each other within the family system. As these three families established this dynamics they were coconstructing their reality by coconstituting patterns of relating. It was, again, their meaning to the experience, based upon their possibles, their valuing and their imaging, that was actually supporting this pattern of relating. Nevertheless, this pattern of relating also seemed to give sense to these families’ meaning to the experience. As we expressed it before, the decisions they made seemed to guide the options they opened for themselves when developing new perspective for their future.

The importance given by the three family members to their normality could also be understood from Parse’s third assumption of her Human Becoming Theory. As the Theory expresses it, the members of the three families coexisted while they co-constituted rhythmical patterns with their universe. Normality was therefore representing their way of coexisting with the meaning assigned by them to their reality and possibles. For them and in the light of the Human Becoming Theory, “Reassuring the equilibrium”, this is, trying to make things stay stable as they protected their normality, was a way to assure their

rhythmical patterns of relationship with their universe were being perpetuated and put to safe.

The third theme or meaning found on the experience, as these three family members shared it with us, was also narrowly connected to this third assumption. "Keeping hope" in the way these three carers understood it was clearly intended to safeguard their patterns of relationship. Both communication styles and everyday normality were being menaced by the proximity of death. Pretending nothing had changed nor was it going to change seemed to provide these three carers with a more powerful sense of control over their own reality and the options they could picture for their future. Maintaining their own rhythmicity in their relationships with their world helped these three family members cotranscend with their possibles and power their unique ways of transforming, becoming and moving along their experience.

By cocreating rhythmical patterns with their universe, the three family members also showed us their unique and distinct ways of living the three paradoxical unities presented in the Human Becoming Theory. The way these three carers conceive and live the paradox revealing-concealing seems quite evident for the researchers. Establishing a communication pattern where certain subjects are not to be mentioned and other ones are to be specifically said in a certain manner, moment and place in order for the system's rhythmical patterns of relating to be safeguarded, clearly reflects this first paradox. The second paradox may also be clearly identified as the family system, by the rules, norms, role assignments established upon their valuing and imaging on the experience, openly limits but also enables each individual's autonomy. In the case of the roles assigned to each member in the system, they seem to define the functions and tasks each one of them is to develop but also which ones he/she is not to and how he/she should not perform them. Finally, but from the researchers' point of view to the basis of the whole experience, the

paradox of connecting-separating is also represented in these three families' experiences. Being aware of a relative's death allows the onset of certain dynamics as the whole family system feels the need to be close to him/her while knowing the separation is just round the corner. They all expressed feeling very closely connected to the ill person and to the rest of the members as they knew separation was unavoidable. Another paradox enabled by these participants' cocreation of their meaning to the experience was the one brought up by hope. As they express it, as diagnosis and fatal prognosis were disclosed to them, hope for the ill member not to die helped them assume the fact that he was certainly going to die and live up with it.

From what these three family members have shared with us, we have been able to draw up some hints on their experience and the meaning they assigned to it. Nevertheless, it is now even clearer for us that even when sharing some common points among the three families, each and everyone of them expresses differences which make their experience distinct and unique. By valuing and imaging in different ways, each system assigns different meanings to what they live, therefore coconstructing different realities. Different meanings also influence the cocreation of different patterns of relationship with the universe and unique ways of living the unitary paradoxes of connecting-separating, enabling-limiting and revealing-concealing. These different ways in which the three family members relate to their universes also seem to have an influence in the options they imagine and the decisions they make based upon those options. The way they cotranscend multidimensionally is thus also unique to them. This whole process, as we have just presented it, is what Parse calls the human becoming and, as she presents it, it is human-living-health.

### Dialoguing with previous authors and their studies

In order to facilitate the reader's understanding of this section of the chapter, when discussing our results with other authors' previous studies, we shall follow the same guide as we did on chapter IV. This is, we will start by talking about the influence of values, beliefs and previous experiences on the meaning assigned to the experience of "Knowing without sharing", then move on to talk about the three main themes identified ("Protecting the weak", "Reassuring the equilibrium" and "Keeping hope"), and finally share our reflections upon the results obtained in comparison with other authors' ideas.

#### *Influence of values, roles and family dynamics*

As presented in the previous chapter, our three family members have clearly shown us the connection between how they live the experience of knowing without sharing and what their understanding and beliefs towards certain elements are. What their understanding of suffering and death was, how they conceived and viewed hope or what meaning they assigned to care have been shown to be central elements to these three families' experiences and even to our understanding of it. Many authors support this idea as they argue about the influence of families' beliefs and attitudes on the experiences they live and the meaning they assign to it (Candib, 2002; Kinghorn, 2001; Leonard et al., 1995; Quill, 2002).

Pointing in that same direction, from what these three carers have shared with us, how their ill loved one had managed with difficult situations and what kind of family dynamics had been established seemed to be key points when making decisions for this upcoming event. From a theoretical analysis on family communication in advanced illness contexts, Kinghorn (1996) explains how families' previous histories in relation to health

issues and difficult-to-deal-with communication situations seem to have a very strong relationship with the meaning they are able to assign to what they live in their everyday.

These same authors as well as Kristjanson et al. (1996) specifically studied the influence of previous communication patterns. We can now say that our three families' attitude towards communication is just being reaffirmed by those previous results. As in those authors' studies, by not openly sharing the information within the system, the three participating families just tried to maintain their previous communication patterns and styles (Kristjanson & Ashcroft, 1994). Emotional communication had never been developed within the family before and difficult times such as the loss of one of their loved ones did not seem the most appropriate moment for things to change that much.

The Calgary Family Model, based upon the General Systems Theory, supports this understanding of the roots to the phenomenon. Following Wright and Leahey's (1994) ideas, all elements in a family system (structure and functioning) suffer the influence of a life-threatening illness. As in our participating families, roles, norms, boundaries, tasks, as well as communication and relationship patterns are hit and shaken by the impact of the oncoming loss.

One of the main elements we identified as being part of the roots to our participants' meaning of their experience of "Knowing without sharing" was autonomy and the way they valued and gave meaning to it. Autonomy for these participants was very much more tightly attached to the family as a system than to the individual him/herself. Tacit cultural norms which also sustain this hierarchy of values have been extensively discussed in the literature always supporting the idea that no one single vision of autonomy exists, and so no one way of giving meaning to it should be privileged over the rest (Candib, 2002). American model of patient's autonomy and individual decision making has been severely criticized by several authors as they argue that patients are left in

isolation and not always provided the resources needed to adopt new decisions (Quill, 2002). The situation becomes even more difficult when patients and/or families from non-American cultures and so their vision on autonomy, family relationships and caring are so dramatically different (Quill, 2002): In these situations, health care professionals' maximum caution around the subject is encouraged: "Just the patient and the family are the expert interpreters of their unique history as individuals and as a family in the context of their culture" (Quill, 2002, p. 232).

Caregiver's role and attitude are also two culturally very highly influenced elements of family structure and functioning (Quill, 2002). Based on cultural interpretation of values such as autonomy or beneficence and concepts such as caring and family connectedness and duty, caregiver's protecting attitude is easily understandable. Besides this sounding, Gordon (1994), in her in-depth analysis of Italian phenomena of communication around illness, also provides another pillar for supporting this kind of attitudes. As she explains it, from Mediterranean but also Catholic vision, the world is always highly hierarchically organized as there is always "someone higher than oneself and someone lower than oneself" (p. 305). From there, illness puts the individual in a lower, weaker, more vulnerable position where he/she is to be cared for someone at a higher position and "be kept in the dark or ignorant about certain matters" (Gordon, 1994, p. 305). The Basque Country being a region pertaining to the Mediterranean culture and radically influenced by Catholic religion could give some more sense to our findings in our three participating families.

Although we could identify some common elements (most of which have been presented here) to our participants' meaning of the experience, we also found differences among them which made every family single and unique in the way they lived and understood what they had to live. Those differences could only be explained by

understanding each family as a unique system with its unique elements and its unique way of functioning. In his dissertation about autonomy and culture within the health care arena, Quill (2002) emphasizes the need to bear in mind each family's cultural uniqueness in order to be very cautious and attentive to American culture supremacy.

According to the Calgary Family Model (Wright and Leahey, 1994), it seems that family's characteristics, structure and functioning also have a word to say in the experience they live, as they make every family unique and therefore every family's experience and meaning to it, different to any other one's.

Another element which we found to be important in the communication styles and patterns established by our three participating families when living through the experience of "Knowing without sharing" was the level of awareness, both of the ill person (from the point of view of the carer) and of the rest of the members. From what we have found within these three families it seems clear for us that it is not only the ill member's level of awareness but also the rest of the family members' that has got an influence on the way they live the experience. Field and Copp (1999), in a literature review on the subject of family communication at the end of life, also talk about it as one of the most influencing elements when establishing communication patterns within the family. These two authors clearly mention the influence the ill member's level of awareness has, not only on communication, but also on functioning and relationship dynamics. In our three families' experiences, it all seemed to function as a rhythmical pattern, and both, the ill member and his/her relatives, seemed to move along the wave as they tried to respond to the other one's needs. What was not that clear for us was the assumption that just the ill member would be guiding the flow. From a systemic point of view, the whole family would be moving along as they struggled to live the everyday.

As we have shown in the previous chapter, our three families go through three different dynamics along the experience of losing a loved one. All three dynamics seem to be based upon protection attitudes and the not-talking strategy we have just presented. Nevertheless, it seems clear for us that it is the level of illness awareness, both the ill member's and the rest of the family's, which actually allows the progression of these three dynamics. This finding of us in the way our three participating families have presented it to us has not been found in the literature reviewed. From what these three family members have shared with us, the level of illness awareness is not something that can be imposed. Each individual draws reality in his/her own way, faces this reality of his/her according to his/her own resources and progresses on the process at his/her own rhythm. Bearing this in mind, it shall be health care professionals' task to identify these rhythms and accompany our clients as we move along their wave. Understanding the flow of these dynamics when identifying the need for protection attitudes to be put in place both by the ill member and his/her relatives shall help us.

#### *Protecting the weak*

There seems to be a consensus in the literature reviewed about protection attitudes when looking at experiences of relatives caring for a dying loved one (Costello, 2000; Miyaji, 1993; Gotcher, 1992; Kinghorn, 2001; McEnroe, 1996; Rosser, 1994; Salander, Bergenheim & Henriksson, 1996; Thomson et al 2000). Candib (2002) clearly points at this cultural value when she recognizes both children's protecting attitude towards their elders and, reciprocally, 'elders' acceptance and treasuring of that caring" (p. 220). As other authors name it, caring for a close one becomes an "act of love" (Gordon, 1994, p. 300).

Where no such consensus has been found is on whether this protection attitude holds a positive or a negative impact on the family's experience. From most Anglo-Saxon authors, this protection is just the reflection of a very paternalistic way of caring where patient's autonomy gets no respect from the rest of the family (Blackhall et al, 1995; Candib, 2002). In some other Mediterranean author's opinion and from our participants' voices, things do not look the same. As we presented it before, for them it is the value of beneficence which actually prevails and it is from there that they choose their options, make their decisions and act upon (Brooke Hamilton, 2001; Brusamolino & Surbone, 1997).

Not talking about death and trying to keep issues surrounding it away from everyday conversations has been identified by our three participating carers as the most valuable way of protecting their ill relative. They all recognize being aware that although information has not been openly shared with the ill member, he/she finally knows what to expect as he/she observes his/her ongoing physical decline. Thus, they all agree that it is not the fact of not knowing but mainly of keeping it, and the suffering it brings along, away from their day to day life what matters to them. This finding has already been pointed out by some of the authors reviewed and they all seem to agree on the fact that it is not a matter of not knowing but rather of keeping conversations and everyday life away from suffering (Costello, 2000; Field & Copp, 1999; Glasser & Strauss, 1965; Gotcher, 1992).

But this not talking dynamics does not appear to be solely established by the rest of the family members but also by the ill person him/herself. As we have seen in our results, when he/she decides not to ask for any more information or to take on the role assigned to him/her by the system, he/she also seems to be executing a protection attitude towards his/her family. As Dr Kübler-Ross already pointed in one of her first publications back in

1969, collusion as a protection mechanism does not seem to be exerted just by the family system but also by the person who is going to die and, although not formally informed, is firmly aware of his/her near future. More recently Gordon (1994) explains how the ill member's reluctance to ask his/her relatives difficult questions as he/she knows his/her family already knows and they are protecting him/her. There is still one more author who goes even further by affirming that, when not showing any more active attitude, the ill member actually wishes to protect and not burden his/her family (Candib, 2002).

There is large controversy within the literature reviewed concerning this not talking attitude. Some authors strongly defend the negative effects of it as they believe it poses more difficulties for the family to go along with the process (De Valck & Van des Woetijne, 1996; Halldorsdottir & Hamrin, 1996), it diminishes their cohesion (McEnroe, 1996) and it may even isolate the patient from its environment (Kinghorn, 2001). We have not been able to find these same results in our work. Our family members have talked about their experience in their own words and always showed a very careful attitude towards their relatives. The ill member's isolation could not be assessed by the research team since we did not interview them. Cohesion among the family members was not identified either. Nevertheless, the ill member's meaning to the experience has not been addressed for this study and, although we are aware of the difficulties it poses, we believe it would be a great contribution to our understanding of the process from a systemic perspective.

On the other side, several authors have reflected about the positive effects of this not talking attitude. Candib (2002) sets up the space for reflection upon this protection attitude when she points out the fact that disengagement might sometimes be an autonomous decision as some elders might decide not to decide. In any case, several positive outcomes to this protective attitude are also found in the literature. Gotcher

(1992), on his study on 102 cancer patients receiving chemotherapy, found silence to be a protective attitude towards the ill member. Also Salander, Bergenheim and Henrikson (1996) talked about it as a strategy for the creation of protection and hope as to palliate the strain of the fatal prognosis. Schrök (1980) talks about this protecting attitude of not talking as a necessary mechanism for the system to keep functioning as such. Finally, from Meyza's discussion about truth-telling and communication with cancer patients in Poland (1997), recognized avoiding conversations about unavoidable issues such as death and fatal prognosis as a way to find meaning, mastery and self-enhancement in a situation where these three elements seem to be out of control.

A situation where death comes certainly along the way seems to impose difficulties for every member in the family, including the one who, taking on the responsibility for caring and making decisions, is to show strong and powerful. Several authors reflect upon the difficulties the carer is to face when dealing with a relative's terminal phase (Candib, 1992; Gordon, 1994; McCorkle et al., 1998). Our three carers recognized having difficulties themselves and even up to a point being in need of protection from the harm of fatal prognosis information. Thomson et al. (2000) already pointed this out when they reflected upon the direction towards which the protection dynamics were being set up. In their opinion, the carer him/herself also benefits from that protection attitude as he/she also needs to keep hope and pretend everything stays the same, which seems to be consistent with our results on mutual protection.

### *Reassuring the equilibrium*

From what the three family members in our study shared with us, death seems to be a threat for the system's normality and, therefore, its equilibrium. This idea has been very often presented within the literature as several previous studies have proved it to be a clear

disruption in everyday life (Jarrett and Payne, 1995; Sales, Schulz and Piegel, 1992). Leonard et al. (1995) affirmed that death was understood by participants to break their stability by shaking all elements of their quotidianity.

The loss of equilibrium brought up by the announcement of death that was so clearly identified by our three participating members has been extensively described in the literature reviewed. On their side, our members talked about the sense of loss of control and the need to resituate themselves within an everyday changing situation in order to gain more strength and recover lost normality and the equilibrium for the system. Halldorsdotir and Hamrin (1996) on their phenomenological study on nine cancer patients, showed the large impact the oncoming loss of a loved one had on family members' goals, roles and place in society. As these authors explain it, the participants described feeling vulnerable as they needed to redefine their role within the family and their place in society.

Acting as if nothing had happened seemed to be one of the strategies put in place by our three participating family members in order to safeguard their normality and equilibrium. Trying to make everyday activities similar to previous situations, trying for the roles not to be too soundly modified or for communication styles and patterns to be kept at the same level seemed to be mechanisms to keep suffering away. In the same way, our three participating family members recognized not talking as a protection attitude, trying to make things stay as if nothing were going on was identified as a mechanism for trying to maintain normality and assure the equilibrium of the system. Kübler-Ross on her work "From Death and Dying" (1969) already reflected upon this issue and also presented it as a strategy used by families when dealing with the oncoming loss of a loved one. Gordon (1994) on his analysis on Italian contexts, talks about the hope offered in terminal situations and directed towards sustaining the need for "nothing to change" and life to go on "as normally as possible" (p. 300).

As seen before, not talking about difficult issues such as death or suffering is the most easily identified strategy for families to protect the ill member, but also to keep things the same. When death and suffering are kept away from conversations in families where communication has never been developed at emotional levels, roles, boundaries, relationships and functioning rules and norms are kept the same. Schrök (1980) talked about this concealing attitude necessary for the ongoing functioning of the system in families going through the experience of losing a loved one.

### *Keeping hope*

Our third and final theme of the three participating families' meaning to the experience of "Knowing without sharing" had to deal with hope, its value within this situation and family's attitude towards it. From our three carers' experience, protecting hope was seen as a way of caring, and, at the same time, destroying the other one's expectations was seen as a way of mistreat and fail to care. Several authors mention it as a basic element for the carer to feel capable of assuming his/her role and taking care of the ill member. There is quite an agreement within the reviewed literature concerning families' need to protect hope and keep it alive as a way to maintain their functioning and to face the everyday (Gordon, 1994). In this sense, McCorkle et al. (1998) talk about the carer's attitude to protect his/her hope. But it does not seem to be just the carer who feels the need to protect it. On her study on thirty newly diagnosed patients, Salander et al. (1998) explain how the ill member shows reluctant to pose vital questions as a way to protect his/her own hope.

When reading through the literature around end of life family experiences, hope was a concept that kept emerging. One of the most interesting discussions we could invite

the reader to enter deals with the concept's multiple and diverse meanings and ways of presenting itself in such a difficult situation as a loved one's loss.

On one hand, Elliot and Olver (2002) performed an analysis on the subject of hope following 23 cancer patient's perceptions and experiences, and concluded assuming and giving credibility to those very various forms of hope, even when some of them could seem unreasonable to health care professionals. They even identified the presence of different forms of hope as illness progressed and the patient became aware of his/her difficult prognosis. These same authors argue for health care professionals working on palliative care settings to be aware of this diversity and show respect and acceptance towards them, whether they fitted within our "healthy" schemas or not. Even though health care professionals might sometimes find those forms of hope unreasonable, we need to be aware that they might be preventing the family system from sinking, regressing, isolating or shiding into death (Kübler-Ross, 1969). The family's and the individual's right to hope are to be respected and preserved (Gordon, 1994).

On the other hand, many authors actually agree on the fact that, besides having all those different meanings and forms, in situations of terminality hope is almost always directed towards normality and family's equilibrium (Bishara, Loew, Forest, Fabre & Rapin, 1997; Elliott & Olver, 2002; Gordon, 1994; Kübler-Ross, 1969). Following one of theses authors' findings, relatives of individuals at terminal stages of cancer (Gordon, 1994), hope for "things to stay the same, the family to stay together" (p. 300) as "living the continuity of the family, sustaining life as normal as possible, actualizes the hope of life, of continuity" (p. 309).

As the participants in our study expressed, telling somebody about his/her certain close death might bring up feelings of guilt as the information provider takes hope radically away from the ill individual's life experience (Gordon, 1994). Several authors

talk here about the value of uncertainty as an essential element for life. Eliminating uncertainty, knowing one has no future, cancels out one's present" (Gordon, 1994, p. 293). From here, implicit communication and understanding seem already sufficient and, mostly for Mediterranean cultures, even more relation, warm and open (Gordon, 1994).

When hope is protected and maintained, no matter what form it takes or what meaning families give to it, "good death" as this "protecting families" define it, is more easily achieved. When hope stays at the scene, the "good ending is not felt or acknowledged as an ending but rather lived as if life continues as normally as possible until the end arrives" (Gordon, p. 300).

### *Final reflections*

Right from the beginning of this project, our standing point in regards to the experience of "Knowing without sharing" seemed to be clearly set. Holding a very respectful attitude, being ready to be truly present to families and their stories, assuming no one position was of sounder judgement than other ones and believing each family had the right to think, feel and act upon their own values, no matter what this appeared to our eyes, looked totally helpful for developing this research project.

After setting the idea down and reflecting upon it for several weeks, the second step of the project took place, this is, the literature review. At this point, our neat and clearly established standing point started to tremble. From an overall view, Anglo-Saxon and North-American works tended to hold a very negative opinion towards the phenomenon and they even name it by using very negatively loaded terms: "Conspiracy of Silence". Understanding where those studies had been developed (non-Mediterranean cultures) and what research perspective they had used (mostly post-positivism) was a wonderful hint for us which also gave even more power to our research decision making process. Taking

some time to reflect on it seemed at that time to be our best option in order to be able to develop our project from a phenomenological perspective, also guided by Parse's Theory of the Human Becoming and the Calgary Family Model.

This time for reflection but, most importantly, the opportunity to be truly present and listening to these three families' story of suffering and pain finally gave us the tools to get closer to the meaning to the experience and be able to present it here to the reader in a way that looks as more similar as possible to what these three families generously shared with us.

Now that our research project is coming to an end, and after some time for reflection on our results, we can positively affirm that for these three family members the experience of "Knowing without sharing" has much more to do with a tacit (Gordon, 1994) silent "Agreement on Silence" than with a "Conspiracy of Silence".

Although all the elements presented as well as the structure linking them and their meaning seem to be common to the three families, it is also true that each one of those family systems holds a different way of living that experience. This particular way of experiencing their life events is highly influenced by every family's reality and their ability to experience it in a certain way, always different to any other family system's. What they live, and how they live it seems to exert an influence on the way they conceive their world and the way they look at it. Also, the way they conceive their world and look at it clearly influence the way they live their life experiences. In the end, what this means is that each family's reality, each family's experience and the meaning they assign to it, is unique and solely understandable from the deep and profound respect and comprehension of their history and previous experiences. Therefore, what we shall present here is not the answer to every family's difficulties, not the magical and universal recipe for nurses working in the palliative care field. Rather, our interpretation of the meaning these three carers shared

with us is intended to open doors, allow diversity and enable understanding from the respect to the difference.

We do not here intend to judge as good and appropriate what these three families lived and to the meaning they assigned to it. But we are certainly not here to criticize them, inhibit them or even punish them. We believe that from a more open and wider standing point health care professionals will find it much easier to move along these families' wave. The lack of communication within a family system does not necessarily represent a failure to cope. When working with families facing the terminal stage cancer experience, health care professionals should not base their work upon any preconceptions on families' best way to cope with such a situation (Doka, 1995-96; Leonard & al., 1995). Lack of research and training in this field are the main difficulties health care professionals need to overcome when facing these situations (Quill, 2002). Sometimes patients decide to conceal their thoughts and their feelings as they detect the difficulties in his/her family and want to protect them (Gotcher, 1992). From Parse's Human Becoming Theory as well as from an ethical perspective, health care professionals should respect patient's choice not to talk, whether to protect his/her loved ones or to protect him/herself, while they could work with the family rhythm to see other possibles.

#### Discussion over the method

Having in mind the very special characteristics of the families participating in this study and the very particular circumstances they were undergoing at the time of the interviews, there are several methodological issues that arose along the development of the study and that we find interesting for discussion at this point. We will be presenting the two of them that we have found more enriching and interesting for academic purposes.

First methodological issue deals with the fact that almost all second but certainly all third interviews with the participating family members took place after the ill member's decease. As it was previously designed, all interviews were to take place at the time the family system was going through the experience, this is, before the actual loss took place. Living through the experience at the time of sharing what it was like with an outsider was believed by the student researcher to be the closest report possible of the meaning ascribed to it. Nevertheless, things have turned out differently and new insights have been gained from it. This being a qualitative study, emergence of both results and process had to be on the forefront of the research design as it finally happened to be. What had been planned by the team did not match participants' needs and/or possibilities and so adjustments had to be made for the method to generate the richest information possible. Letting the method and the design follow participants' patterns and rhythm seemed to help provide most meaningful and sound data to the study. Interviews held at the time the ill family member was still alive seemed, to the student researcher, to require a much big effort to conduct and try to keep close to the subject of interest. Levels of anxiety and stress amongst participants seemed to be much higher than at those interviews where death had already occurred. To the contrary, interviews held after decease were much easier to focus on the subject and participating family members seemed to be much more relaxed and open to share their experience but mostly their time and their feelings and memories. On the other hand, participants expressed their gratitude towards the student researcher for the feeling of being cared for not only as caregivers completing their socially-valued duty of care but also as human beings who had suffered a very important loss. This feeling seemed to be nurtured by the fact of holding those interviews when the ill member was not there anymore and so the only person to be cared for by the system (here represented by the student researcher) was the participant herself. The method did not follow the plan as

previously designed but letting it follow participants' flow seemed to be of high relevance to the richness of its results.

The second and last methodological issue we would like to discuss about for the purpose of this report deals with the fact that, for one of the participating family systems, the student researcher happened to be the clinical nurse for the ill member at that family. Ethical considerations regarding this case were cautiously observed and examined by both the student researcher and the nurse supervisor at the clinical ward and arrangements were made for those criteria to be respected. No difficulties arose but rather to the contrary, the participating member explicitly expressed her gratitude towards the student researcher for being her the nurse on charge for his father at the ward. No difficulties had to be faced by the student researcher in regards to holding both, clinician and researcher's, roles at the same situation. First interview took place in the regular form as it had happened with former participants. Once this first interview had been developed and due to the small size of the health care services at the local level, the student nurse was assigned this patient. She then first entered the situation wearing a researcher's hat and then had to switch to the clinician's one. In this sense, having very sound information about the family system, their functioning, their dynamics and their way of experiencing what they were going through was of enormous help to the nurse on providing them with their clinical care. Time and family's difficulties with hospitalization were respected and so two last interviews with the participating member were actually scheduled for the time when the patient was to be discharged back at home. What actually happened was that he died soon after returning home and so interviews finally took place after his decease. Far from posing new difficulties to the student researcher/nurse, this situation actually provided the nurse with very useful information and tools for caring for that family system. Being quite aware of the limitations a practice such an in-depth interview has for everyday clinical practice,

reflections were made around the usefulness and pertinence of in-depth assessments of family systems and their functioning as a way to actually help health care professionals better perform. On the researcher's side, the fact of having, as a nurse, other spaces and times, different to the research interview, to share with the family actually made research interviews easier to focus on the subject. For the relative who participated in them, it seemed quite clear that the student researcher was there at that time to learn about their not-sharing experience and so other subject were not brought up to the conversation. Actually what the student researcher observed was that the participant took less time and effort to switch roles than what she herself actually did. Whether with this one family or with any of the other two participating in the study, the ethical dilemma of dealing with difficult experiences of people while doing it "just for research" kept coming up. The student researcher found it difficult to sometimes try to keep the interviews focused on the subject of interest when difficult and suffering emotions and feelings were being disclose. The boundaries between researcher and clinician's role did not seem to be that clear when regarded from an ethical perspective. This difficulty led to many stops and silences on the audio-recordings and to even the acceptance of the impossibility to talk about certain subjects with some of the participants. In this sense, ethical compromise and human respect was always put forward at the student researcher's decision making process.

#### Implications of the results of the study

##### *Implications for Nursing practice*

Bearing in mind the small size of the sample participating in the study and the inquiry perspective from which it has been developed, the results here presented do not intend to generalize or create and sustain formal theory but rather to pose questions and

invite to reflection, open doors to diversity, and develop more respectful attitudes towards these family functioning patterns in nurses working in the palliative care setting.

However, there are some implications for everyday nursing practice we could try to discretely point out and which are surely related to reflective practice. As we have seen along the fourth chapter, family members in this study recognize their own limits and difficulties to talk about death or even face situations where death might be a subject to be brought up to conversations. Bearing in mind, these difficulties seem one of the largest obstacles for communication, whether sharing or not sharing, in these three participants' experiences, it should be nurses' responsibility to try and help them develop abilities, personal resources and even strategies for facing these obstacles. Facilitating communication among members of a family going through a situation where one of them is shortly going to die would greatly contribute to their quality of life as they would increase their sense of control over the situation.

From Parse's Theory of Human Becoming nurses are to exert true presence with their clients as they develop their professional practice. This true presence allows the nurse to help the individual cocreate his/her own reality s he/she structures meaning through the languaging of valuing and imaging. The results presented in this work may give the nurses some hints on the valuing and imaging as well as on the languaging of families going through an experience such as "Knowing without sharing". Family members participating in the study seem to have taken advantage of our true presence in the interviews by cocreating their own reality and presenting it to us on their own words.

These three families' meaning of the experience, as they have openly shared with us, may help nurses identify the paradoxical units these families move along with as they (1) reveal but also conceal information, feelings and emotions, (2) enable but also limit

each individual's autonomy and decision making ability and responsibility, and (3) connect but also start to separate from their loved ones' physical presence.

Nurses' access to families' meaning of the experience, enabled by their true presence, may finally contribute to power unique ways of transforming for each system. Linguaging the meaning and identifying the paradoxes seems to contribute to illuminating new possibilities and moving beyond the present moment. As they feel comfortable to share their experience with us, they seem to feel capable of looking ahead from now as they themselves give meaning to their new life experience.

#### *Implications for Nursing research*

Three main areas of interest for future research had been identified along this study. First, and related to non-achievement of saturation by this study, further research needs to be developed on this same subject. We believe that by taking into account a larger number of participating families' experiences, the understanding of the experience of "Knowing without Sharing" could actually grow in depth and richness at illustrating its meaning for those families.

Secondly, in this study the level of illness awareness on both the ill member and his/her relatives was found to be of significant relevance to the evolving rhythm of the whole system along the experience. We believe it would be interesting to develop further research in this direction so that more evidence is found and new strategies can be developed for professionals in the practice field dealing with this kind of situations.

Thirdly and finally, these health care professionals' role, attitude as well as the effectiveness of their interventions when dealing with families going through the experience of "Knowing without Sharing" should also constitute a field of interest for further research. Health care professionals' lack of knowledge and training as well as

emotional and psychological difficulties when dealing with this kind of families have been well documented along our work. Further research should attain to provide them with useful and helpful knowledge in this sense.

This study has just opened up new questions for nurses to reflect upon their practice when facing situations of terminality. Development of further studies which would include a higher diversity of concealing families is strongly encouraged for the acquaintance of sounder knowledge within this field. Although this study could be difficult to realize since we had difficulties recruiting families and family members.

We, as nurses, are part of several different communities, this is, the nursing workforce, our colleagues at work, our unit within the institution, the health institution itself, our families and, how not, our Basque culture. Just the same way we understand the fact that we work and behave under the either explicit or implicit norms from the Nursing College, our colleagues' approval, the protocols in our unit, the rules for the institution, we also need to be aware that our own family history as well as our basque ethnicity will also contribute to our way of seeing the world, our way of valuing and imagining it and, therefore, the possibles that we open ourselves for when coconstructing our everyday. This issue becomes of maximal relevance when working with families who do not behave the way "we think they should for their own best". They themselves also pertain to different communities and so their reality is also valued and imagined from there. What this means is that, bearing in mind those contexts, theirs and ours, are not the same, our realities might not be the same either. No one reality is more powerful than any other one, but us, as health care professionals, are responsible for giving response to other people's needs in a way that is useful to them and contributes to their own way of conceiving their life and constructing their own quality of life, which in the end constitutes our goal.

Still talking about the context we as nurses develop our professional practice on an everyday basis, there are also some critical issues to be brought up into our contexts as to invite colleagues to reflect and discuss about. Although it was not a goal of the study, all three families somehow evaluated the services received and expressed their gratitude towards the palliative care team and to all health care professionals involved in the care of their dying loved one. Nevertheless, some remarks were made regarding the ways in which diagnoses were disclosed, communication issues tackled and family dynamics judged and even reprobated. It is here that reflection over our own practice should be opened up for discussion, and maybe change and growth towards more helpful but also respectful attitudes.

The analysis on these three families' meaning of their experience of "Knowing without sharing" is just intended to be a small contribution to the vast field of palliative care nursing research. It slightly tries to contribute to previous work done on communication issues surrounding families' experience of terminality. Nevertheless, more research is to be implemented in order to generate deeper understanding and a wider spectrum of possibles for nurses to be aware of when dealing with this kind of professional challenges.

Further studies on these families' meaning of terms such as "protection", "equilibrium" and "hope" need to be put in place as to allow nurses to more truly and openly accompany them as they move along with their life experience.

## **CONCLUSIONS**

From what these three family members have generously shared with us, we can now talk about their experience of “Knowing without sharing” not as a Conspiracy of Silence but rather as a silent Agreement on Silence. Every member of the family seems to be aware of the others’ awareness, including the ill member, but they all, either conscious or unconsciously, decide to act as if they were not. The decision is then made in order for death and suffering to be kept away from conversations, when they clearly feel those issues can not be put aside of that period of their lives.

Care understood as protection and prevention from suffering is the main element giving sense to these families’ meaning to the experience.

Loss of normality (carried around by changes within the family patterns of communication and functioning), loss of control and loss of hope are seen as threatens to the equilibrium of the system brought around by what is evidently out of control, this is, death. Death being an uncontrollable issue, and loss of normality and hope being power and control diminishing elements are therefore to be avoided in these three families’ way of living through the experience. The whole system is to be protected from it and not talking about it seems to be the most appropriate way they have been able to find for doing that.

But this whole protection dynamics is not spontaneously generated. Values and beliefs, whether family or socially constructed, around death, care, hope, family relationships and so on, contribute to each family’s construction of the meaning to the experience. Previous family patterns of functioning, communicating and relating also exert large influence on the present moment as they represent what is normal, familiar and easily set under control for these three families. Finally and inherently connected to these two elements, role distribution within the family also seems to be of high relevance to these three families’ meaning to the experience. A certain kind of role assignment where the ill

member is set at a lower submissive position in regards to his/her carer allows protection dynamics to take place and be easily developed.

But this whole meaning to the experience for these three family members would not make any sense if it were contextualized within the culture they pertain to. Socio-culturally assigned meanings to values such as autonomy and beneficence, care, death or hope sustain these three families' understanding of their world and, therefore, of the experience of "Knowing without sharing".

Just by holding an opened, culturally oriented true presence to families going through experiences close to a loved one's loss shall nurses be able to accompany and help them become along their way.

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## **ANNEXES**

## Annexe A

Personal experiences around the subject, preconceived ideas and origin of the study

Before any of my Nursing training or clinical experience began, I went through the experience of losing my grandmother. My family's decision was exactly that of withholding information about the diagnosis of cancer and the fatal prognosis to grandma, who was 76 years-old. Accompanying her during the process and even on the final moments as well as suffering the pain of this loss along with my relatives gave me the opportunity to experience the loss of a loved one who did not know and therefore who was not allowed to talk about her upcoming death. This personal experience has surely conditioned my interest for the subject. If I reflect back upon this interest of mine, I can say that this is what constitutes the origin of this study.

During my short work experience, I've had the opportunity to get in touch with families going through the experience of losing a loved one. Sudden deaths, elderly adults' death, children's death, chronically ill person's death... they are all different experiences of loss. Death and dying process brought on by cancer in the family constitute also a clear experience of losing a loved one. Still there are several elements that characterize and differentiate it from the rest and that have made it specially interesting for me.

I consider losing an important other as being one of the most challenging as well as learning experiences every human being can live. The family patterns created around this event can have a definitive impact on this experience. Information about death can be considered from many different angles and so therefore families can deal with it in many different ways. Concealing it can be one of these information managing ways.

In my opinion, on the one hand, withholding information as a way to protect the patient from the suffering caused by the information is actually the way families avoid discomforting discussions about the subject of illness, suffering, death and loss can bring to their lives. Fear and anxiety caused by these subjects invite the family to adopt concealing attitudes, without even being conscious of their own feelings and the impact they are having on their attitudes and reactions towards the sick individual. On the other hand, this kind of decisions are usually the consequence of previous family dynamics and so help maintain the coherency and the equilibrium through times of crisis like the one fatal prognosis can cause.

Based on all of these experiences explained above, it has been just during the last year that this attitude of mine towards conspiracy of silence has remarkably shifted from a very opposing position to a more accepting one. Just two years ago, I used to hold quite a devaluating attitude towards families conspiring since I understood that they were just preventing the ill member from choosing his/her own way of living his/her last days and dying. Right now, further education and lots of reading on the subject have provided me with a much more open and tolerating attitude from where I am aware of the many factors such as family dynamics, culture, values, beliefs that also play a role in the situation. This wider perspective on the subject allows me to greater respect families' choice and to more naïvely approach them in order to understand. Conspiracy of silence is not a mistake anymore for me but rather a family's chosen way to deal with a very difficult situation. Health care professionals are therefore not just to break up this type of dynamics but rather to stay close to the families and accompany them on the way they express the need of support. I believe health care professionals can help families move on to disclose and share information always in the family's own rhythm but keeping clearly in mind that this is just one of the possibilities the family has and not the only one or the correct one.

## Annexe B

Interview guide

1. Would you please tell me about the experience of acknowledging the close loss of a relative?
2. Tell me about what is like to not tell all?
  - 2.a. How do you feel about this experience?
  - 2.b. How do you, in this family, handle this situation?
3. What kind of feelings do you have now, when relating to the person who is ill? (to each one of the participants)
  - 3.a. How do you think your ill relative feels?
  - 3.b. Tell me more about the circumstances the decision was made at and the extent to which other people were involved?
4. What kind of help / support from the health care professionals would you like for you in this situation?
  - 4.a. What kind of help would you like your ill relative to have?
5. Is there anything else you might find important for you in this experience that we have not had the chance to talk about and that you would like to share with me today?

## Annexe C

Information to participants

**TITLE OF THE STUDY:** The experience of knowing without telling the proximity of death due to cancer in families living in the Basque Country

**RESEARCHERS:**

**Amaia Sàenz de Ormijana Hernández**, B.Sc., student in the Master's in Nursing program, Faculty of Nursing, University of Montreal

Address: [information retirée / information withdrawn] Telephone: [information retirée / information withdrawn]

**Jacinthe Pepin**, Ph.D., nurse, research director. Telephone: [information retirée / information withdrawn]

Note. The research team does not pertain to the palliative care unit.

**INTRODUCTION:** The number of deaths caused by cancer has been increasing over the past ten years. More and more families are faced with the threat of losing a loved one through the terminal phase of cancer. Living through a loved one's terminal phase represents an experience and a challenge for both the person who is ill and his/her family. When going through this experience, all family members, including he/she who is ill, develop diverse strategies which imply changes in family patterns and functioning which will help them manage and move along. Deciding how to handle the information about the fatality of the prognosis in the family is one of the many tasks that are to be performed by family members. Like any other one, the decision of not sharing the information with the person who is ill has been shown in the literature to be a critical one. No research study has been developed on family's experience of knowing without sharing the proximity of a relative's death due to cancer in the Basque Country. This study is aimed to gain a deeper understanding of this family's experience. A close look at the experience

as it is lived by families will give health care professionals the opportunity to provide better quality care as they feel more capable of respecting family's decision, and, therefore, can better accompany families through this experience. No judgement is to be developed over family's decision. It is not researcher's goal to make families change their decision. On the contrary, it is her purpose to better understand the experience the family goes through from the basis that their decision is just as respectable as any other decision.

**GOAL OF THE STUDY:** To gain a deeper understanding of the experience of knowing without telling the proximity of death as it is lived by family members in families living in the Basque Country.

**PARTICIPATION IN THE STUDY:** Families who wish to participate will be asked to share their experience with the student researcher. Three to four families will initially be invited to take part in the study. The information will be collected through two interviews which will be held by the student researcher with two or more adult family members. The first interview will last no longer than two hours and the second one, just two to three weeks later, no longer than an hour, always depending on family's desire to talk and share their lived experience. The first interview is aimed to gain an understanding of family's experience as it is lived by them. The second one will be held with the purpose of giving the family a second opportunity to make comments or express feelings that could not be presented at the time of the first interview or even to modify some of the information shared on the first interview. This second interview is also for the student researcher to make sure that she has clearly understood what the family wanted to express to her. Interviews will take place wherever the family decides to and finds it more convenient, whether it is at the hospital, at home... The interviews will need to be audiotaped for the sole purpose of its later analysis in the context of this present research. No person not

pertaining to the research team (as specified above) will have access to the information. Once the results are obtained they will be written down in a way that no participant will be identified. The tapes will be kept in a locked cabinet at the student researcher's study room and they will be erased as soon as they are transcribed.

Although getting in touch with the families through the palliative care unit, the information obtained directly from each family will not be shared with the health care team in that unit. Results of the study, presented in a way that will assure participants' confidentiality, will be passed onto the team only once the study is finished and approved by the Faculty of Nursing at the University of Montreal, which will, at least, take six months from the time of the first interview.

**PARTICIPATING CONDITIONS:** Willingness to share the experience, the feelings and the needs related to it, is an essential element for collaboration. In order to take part in the study it is necessary for you to be at least 18 years-old and consider yourself to be someone important in the life of the person who is ill. Accepting to participate in the study does not necessarily mean having to remain attached to that decision all along the three weeks. Anyone willing to abandon the study will always be openly accepted to do so without any implications, nor from the researcher nor from any other professionals clinically involved since they will not be informed of the process. In no case will this decision prejudice the care that your family member has a right to receive.

Emotional support and care for both the family members who take part and those who do not will continue to be provided by the palliative care team. If needed during the meetings, support will also be offered by the student researcher. Other available support resources from the Basque Health Care System will be made available to the family upon need.

**ADVANTAGES OF PARTICIPATING IN THE STUDY:** Families willing to participate in the study will have an opportunity to share their experience, feelings, emotions, hopes and illusions, difficulties, threats... with the nurse researcher.

The results of the study will help health care professionals improve the quality of care they provide to families living through the experience of losing a loved one, as they will gain a deeper understanding of family's experience. Families might therefore feel better accompanied and supported through this process.

**RISKS AND DISADVANTAGES OF PARTICIPATING IN THE STUDY:.** Taking part in this study will ask families to meet with the student researcher during three hours in total and to talk about their experience, which might for some people be difficult to deal with. Support, emotional and instrumental, from other professionals will continue to be provided regardless of the participation.

The results of the study will be written down in a research report which will pertain to the Faculty of Nursing, at the University of Montreal. A scientific article might be published in a professional periodical. In any case, confidentiality will always be assured.

**VOLUNTARY PARTICIPATION AND WITHDRAWAL OR EXCLUSION FROM THE STUDY:** Your participation is completely voluntary. You are free to withdraw from the study at any time without having to justify your decision and without any consequence on the care you or your relative receives.

In case you decide to withdraw from the study, you need to let Amaia Saenz de Ormijana know, just by phone or when meeting for the interviews. The student researcher might exclude you from the study in case you or her do not consider it appropriate to continue in it or you might

think that by doing so you might get harmed. In any case, support will be offered from the resources available.

All along the study, you will be given any new information that could come up and which could make you reconsider your decision to participate, before that information has any implications for you.

**RULES FOR THE FAILURE OF THE STUDY:** In case the study would fail to go all the way to its end, support from the resources available in the health care system will be assured and will continue to be provided.

**CONFIDENTIALITY OF THE INFORMATION:** Confidentiality of the information provided by the participants will be assured. No names or personal data (such as address, telephone number) will be reported. It will just be the student researcher who knows the identity of the participants, since fake names will be used for transcriptions and the writing of the research report. Just the student researcher will have access to the tapes. Once interviews transcribed using fake names, a collaborating nurse researcher will contribute to the analysis of those transcriptions. Both transcriptions and tapes will be destroyed as soon as the study is finished.

**QUESTIONS ABOUT THE STUDY:** In case you have any questions about this study, please do not hesitate to communicate with Amaia Sàenz de Ormijana at [information retirée / information withdrawn]. In case of urgent need please call [information retirée / information withdrawn].

**ETHICS:** This research work has been assessed and approved by two Ethical Committees, one at the University of Montreal and one at Txagorritxu Hospital. In case you still have any doubts about your participation in the study, please do not hesitate to get in touch with Sagrario Martinez, member of this last committee, at [information retirée / information withdrawn].

## INFORMED CONSENT FORM

Title of the study: The experience of knowing without telling the proximity of death due to cancer in families living in the Basque Country.

Main researcher: AMAIA SÀENZ DE ORMIJANA HERNÁNDEZ

I, (participant's name in capital letters).....

.....  
 declare having understood the information attached to this form and from which I have been given a copy, having talked about it with (researcher's name in capital letters).....and having had my questions answered and understood the goal, the nature, the advantages, the risks and the disadvantages of the study itself.

After having thought about it for a reasonable time period, I freely accept to participate in the study. I know I can abandon it at any time without any inconvenience or consequence for me.

Participant's signature.....Date.....

I, (researcher's name in capital letters).....

declare having explained the goal, the nature, the advantages, the risks and the disadvantages of the study itself to (participant's name in capital letters)

.....  
 Researcher's signature.....Date.....

Witness not-associated to the study (name in capital letters)

.....  
 Witness' signature.....Date.....

**ANNEXE D**

Canadian Ethical Approval

Spanish Ethical Approval

Université   
de Montréal



COMITÉ D'ETHIQUE DE LA RECHERCHE DES SCIENCES DE LA SANTÉ (CERSS)

CERTIFICAT D'ETHIQUE

**Titre du projet :** « The experience of knowing without sharing the fatal prognosis due to cancer in families in the Basque country »

**Sous la direction de :** Jacinthe Pépin

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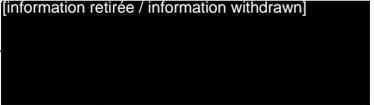
À la réunion du 18 mars 2002, six membres du CERSS étaient présents. Ce sont : la présidente du comité et experte en éthique, la représentante de la Faculté de pharmacie, la représentante de la Faculté des sciences infirmières, l'experte en droit, la représentante des étudiants, et le représentant du public.

Ils ont jugé le projet mentionné ci-haut conforme aux règles d'éthique de la recherche sur les êtres humains.

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Ce certificat est émis pour la période du : 12 août 2002 au 12 août 2003.

[information retirée / information withdrawn]



Jocelyne St-Amand, Ph.D.  
Présidente, CERSS  
Faculté des sciences infirmières  
Tél.: (514) 343-7619

Le 12 août 2002.

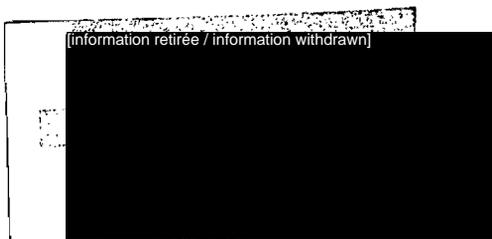


La comisión de investigación del hospital Txagorritxu de Vitoria-Gasteiz (Osakidetza), tras estudio y valoración del proyecto de investigación titulado " **La experiencia de conocer sin compartir el pronóstico fatal en relación con el cáncer en el País Vasco**", presentado por **D<sup>a</sup>. Amala Saéz de Ormljana** para su realización en este hospital considera que:

1. El citado estudio es de interés para la mejora de la asistencia ofrecida en este hospital.
2. El nivel científico del proyecto es de calidad suficiente para su realización.
3. Se dispone de la infraestructura técnica para llevar a cabo el proyecto planteado.

Por tanto, esta comisión acuerda autorizar la realización de dicho proyecto en los terminos en que se ha presentado.

En Vitoria-Gasteiz, a 31 de Julio de 2002



Fdo.: Dra. Dña. Marianela Hernández

Presidenta Comisión Investigación - Txagorritxu