

# MASTER THESIS

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## The Meaning-Making of Dying Experiences in Nursing Homes: A Critical Realist Systematic Literature Review

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## Dedication

This thesis is dedicated to my beloved grandmother C.T.C. Your unselfish love moulded me into who I am today, and I am grateful that you have imprinted in me that life is “*lux et caritas*”.



# Acknowledgement

To God be the honor and glory!

Reflecting on my journey over the past years, it was a fully loaded carousel ride. I left the Philippines a few years ago and ventured into a personal journey over to a whole different world than the one I grew up in. Now, Norway is my second home. My life has never been the same since then. At this point in the journey, I must no doubt offer my gratitude to several who have helped me along with it.

To Nord University and the faculty of Social Science, I present this personal thesis as a testament to my highest appreciation to your dedication and commitment. Your institution has helped develop my critical thinking and transform my way of seeing the world. I have much enjoyed my time learning with you.

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## Abstract

**Context.** Influenced by the critical realist philosophy, a social worker interested in dying believes in the idea that knowledge is fallible and half true; thus, there is a need for another perspective. That being said, knowing of a phenomenon on dying can be elicited in many ways. This study utilized published literature as a way of attaining knowledge on how terminally ill persons make meaning of their dying experiences in nursing homes.

**Purposes.** The general aim of this study was to produce explanations on the meaning-making of dying experiences in nursing homes through a critical realist systematic literature review. Alongside systematic reviewing, this study was specifically able to identify, describe and appraise surveyed literature; synthesize literature findings from primary studies; and finally, produce new knowledge out from the constructed synthesized themes.

**Methods.** A systematic search of the literature was carried out from February to July 2018 using databases, hand-searching, literature snowballing, and combining alternative search terms and search strategy operators. From the total search results, only 288 were considered potential literature. With the use of carefully constructed inclusion and exclusion criteria, it finally identified 2 relevant items of literature. These 2 pieces of literature were considered as primary studies and subsequently underwent quality (critical) appraisal. A thematic synthesis was used to synthesize the findings of the primary studies.

**Findings.** In the synthesis of 2 primary studies, it was found out that terminally ill persons make meaning of their dying experiences by: *(i)* indicating the villain that interrupts life; *(ii)* infusing personal efforts in meaning-making; *(iii)* adopting different ways to restore meaning to the dying experience; and *(iv)* placing meanings in the various aspects of life. Likewise, two contrasting issues emerged that have the impact on the meaning-making of terminally ill elderly people. These were institutional influence and spirituality. However, these issues were eventually fading as death approached. While the terminally ill persons were in their meaning-making process, they manifested the power of human agency by taking control of the situation. This innate agentive power became instrumental to the liberation and freedom from the constraints and limitations of being dying.

**Conclusion.** Through a critical realist systematic literature review, an insight into how terminally ill persons make meaning of their dying experiences in nursing homes has been made possible. The findings suggested that through the meaning-making efforts there remains an active human agentive power. In the pursuit of understanding terminally ill elderly persons and their experiences, it indicated that human agency must be at the prime of doing social work.

**Keywords:** meaning-making, terminally ill, dying, elderly people, nursing homes, critical realism, systematic literature review, critical appraisal, thematic synthesis.

# Table of Contents

<b>Dedication</b>	i
<b>Acknowledgement</b>	ii
<b>Abstract</b>	iii
<b>Table of Contents</b>	iv
<b>List of Figure</b>	vii
<b>Glossary of Terms &amp; Definitions</b>	viii
 <b>Chapter 1: Introduction</b>	 1
1.1 My Philosophical Tradition	4
1.2 Locating My Position in the Present Study	6
1.3 Transitional Summary	7
 <b>Chapter 2: What is Critical Realist SLR?</b>	 8
2.1 Purpose of the Literature Review	9
2.2 Protocol and Training	10
2.3 Searching the Literature	10
2.4 Practical Screen	11
2.5 Quality Appraisal	12
2.6 Data Extraction	12
2.7 Synthesis	13
2.8 Writing the Review	13
2.9 Transitional Summary	14
 <b>Chapter 3: Methods, Processes, and Ethics</b>	 15
3.1 Operationalization of Terms	15
3.1.1 Terminally Ill	15
3.1.2 Meaning-Making	16
3.1.3 Dying Experience	17
3.1.4 Nursing Homes	18
3.2 Search Strategies and Processes	19
3.2.1 Purposes of the Study	19
3.2.2 Protocol and Training	19
3.2.2.1 Learned Lesson One	20
3.2.2.2 Learned Lesson Two	20

3.2.2.3 Learned Lesson Three . . . . .	21
3.2.2.4 Learned Lesson Four . . . . .	21
3.2.2.5 Learned Lesson Five . . . . .	21
3.2.3 Searching the Literature . . . . .	22
3.2.4 Practical Screen . . . . .	24
3.2.4.1 Inclusion Criteria . . . . .	24
3.2.4.2 Exclusion Criteria . . . . .	25
3.2.5 Quality (Critical) Appraisal . . . . .	26
3.2.6 Data Extraction . . . . .	27
3.2.7 Synthesis . . . . .	28
3.2.8 The Writing of Systematic Literature Review . . . . .	30
3.3 Ethics Involved . . . . .	31
3.3.1 Objectivity: The Primary Ethics in the Selection Process . . . . .	32
3.3.2 Transparency: The Overarching Ethics . . . . .	32
3.3.3 Accuracy: The “Should Never” Missed Ethics . . . . .	32
3.3.4 Reflexivity: The Cornerstone Ethics . . . . .	33
3.4 Transitional Summary . . . . .	33
<b>Chapter 4: Results of the Systematic Literature Searching . . . . .</b>	<b>34</b>
4.1 The Informants . . . . .	36
4.2 Methodological Characteristics of the Primary Studies . . . . .	37
4.3 The Quality (Critical) Appraisal of the Primary Studies . . . . .	39
4.4 Transitional Summary . . . . .	41
<b>Chapter 5: The Constructed Synthesized Themes . . . . .</b>	<b>42</b>
5.1 Indicating the Villain that Interrupts Life . . . . .	43
5.2 Infusing Personal Efforts in Meaning-Making . . . . .	44
5.3 Adopting Different Ways to Restore Meaning to the Dying Experience . . . . .	46
5.4 Placing Meanings in the Various Aspects of Life . . . . .	49
5.5 Transitional Summary . . . . .	51
<b>Chapter 6: The New Expanded Knowledge . . . . .</b>	<b>52</b>
6.1 The Contrasting Issues . . . . .	52
6.2 New Understandings on the Meaning-Making of Dying Experience . . . . .	55
6.3 Transitional Summary . . . . .	59

<b>Chapter 7: Final Discussions</b>	60
7.1 Conclusion	60
7.2 Significance of the Study Results to Social Work	61
7.3 Limitations and Recommendations of the Study	62
7.4 Future Directions	63
7.5 My Personal Reflections in the Whole Journey	64
<b>Reference List</b>	i
<b>Appendix A:</b> The Eight Steps of Systematic Literature Review	vii
<b>Appendix B:</b> SPIDER and SPISDER Formats, Algorithms, and Searching Operators	viii
<b>Appendix C:</b> The Data Keeping Sheet, Duplicates, and the Coding System	ix
<b>Appendix D:</b> Flow Diagram of the Search Strategy Results	xv
<b>Appendix E:</b> Trends of the 288 Searched Literature in Terms of Publication Year	xvi
<b>Appendix F:</b> Methodological Characteristics of the Two Primary Qualitative Studies	xvii
<b>Appendix G:</b> Quality (Critical) Appraisals of the Two Primary Qualitative Studies	xviii
<b>Appendix H:</b> Illustration of the Thematic Synthesis Process in this Study	xix

## List of Figure

**Figure 1:**

Domains of Reality in Critical Realism, The Ontological & Epistemological Sources. 6



## Glossary of Terms & Definitions

**Data Extracting Form-** refers to a particular form a reviewer used during data gathering.

**Data Keeping Sheet-** it is where all selected literature enlisted after the selection process. It is constructed in a table format and includes a list of authors, dates, titles, coding system and personal remarks of the reviewer.

**Full-Text Review-** a process of assessing and critiquing literature starting from title sections down to the reference lists. In this study, a full-text review is applied to literature that has passed the inclusion and exclusion criteria.

**Search Strategy Operators-** refers to command operators used to expand or narrow the search results on databases. Operators include Boolean, Truncation symbols and wildcard word.

**Literature Sensitivity-** locating and retrieving as many literature items as possible from many sources in order not to miss potential literature sources, thereby achieving a comprehensive searching process in the pursuit of a systematic literature review.

**Literature Specificity-** an approach of carefully including potential literature that is relevant and fit for inclusion. Literature specificity happens after literature sensitivity.

**Potentially Eligible Literature-** refers to literature that has the potential ability to answer the research question and must undergo strict assessment by applying the selection criteria. Although it has the potential to be included, through stringent assessment it may end up being excluded.

**Primary Studies-** refers to literature items that ultimately are considered as sources of data to answer the research question. Primary studies are literature either qualitative or quantitative in nature depending on the constructed selection criteria. Furthermore, for any literature to be considered a primary study, it must undergo a full-text review and all inclusion criteria must apply.

**Selection Criteria-** refers to the criteria used for all types of systematic literature review. These criteria are vital since they assist a reviewer during an objective and careful selection of literature. Two types of criteria found in systematic literature review are inclusion criteria and exclusion criteria.

**Researcher-** this term is equally referred to a reviewer in the context of systematic literature review. The word researcher denotes my role in the present study, and for a term reviewer it signifies my role as the one reviewing the literature. These two terms are categorically the same in the context of my study, but it is more fitting to use the term “reviewer” to provide clarity and consistency.

## Chapter 1: Introduction

One of life's realities is dying. It is a part of life, as natural as being born (Kubler-Ross, 1975). It strikes anyone, anywhere, and anytime. Dying is not tangible, but it is veridical. If dying really strikes mankind, have we come to grasp the nature of it? Have we come to know the lives of dying persons, especially those living in nursing homes? How do they make meaning in dying?

My interest in understanding dying was stirred primarily by my experiences of the death of people I encountered in various nursing homes I worked at in the past years. These nursing homes had become a place of refuge and an extended abode for those terminally ill elderly people I took care of. As I took care of them, I noticed that they were of varying ages, engaged in many meaning-making efforts, in need of the different level of assistance, and ailing of various diagnoses. Nevertheless, in spite of these demographic variations, they will all eventually die. This observation is reflected in the words of McCormick and Conley saying, despite the "ambitious goals of healing... and curing, death is a natural and inevitable end of human life. All will die" (1995: 236). Such a strong statement imbued in my thoughts that nursing home residents are not exempt from this life's reality. However, if dying is a determined reality, is there no point that we have to understand it? I understood, then, that death is certain and dying is inescapable, but knowing it should not hold us against its inevitability. When living is important to elderly people so, too, is dying. To my argument, dying itself does not define the totality of a person, and it is vital to know how that person becomes in the whole dying process. I contend that there is more than being dying. As I pursued my interest, I found dying as one of the many events in nursing homes, yet I noticed the timing of it was hard to determine. It does neither happen every day nor come by schedule, and sometimes it arrives unexpectedly. And for that, my chance of understanding dying seems so little. Perhaps its mystery defines the boundary of my knowledge and draws a thin line of my wondering unless I become the dying.

Although dying is a universal reality in nursing homes (Österlind et al., 2011); it has been described as enigmatic to recognize (WHO, 2004). What is worse is that it has not drawn the same extent of inquiry and interest like of younger people (Hallberg, 2004; WHO, 2004) even though many of the old people die in institutions (Österlind et al., 2011). Several reasons justify the situation. One, the timing between an early and a late palliative phase has been ambiguous and gnostic (Jakobsson et al., 2006). Second, failure to expedite choices and some dying elderly people have trouble recognizing and expressing their needs (Holloway, 2009; Österlind et al., 2011). Given these realities, a concern is raised about the quality of attention provided to elderly people during the terminal stage of illness. In that aspect, social work is curious about this overwhelming observation towards elderly dying people in nursing homes.

Considering those observations, my interest in understanding dying people is not an interest that came up abruptly but rather was a constant interest, evoked in me every time I would be caring for them. As a social worker, I argue that how we understand elderly people in their dying affects the way we comprehend, care, and listen to them.

Issues surrounding dying are essential to tackle, and a social worker is well placed to undertake an effective involvement through the familiarity of personality development and functioning and approaches of helping people who face disabling difficulties (Smith, 2016). The flexibility of social work in recognizing and attempting to deal with the various needs of the dying and bereaved families has been considerable (ibid); however, it must not be taken for granted that constant knowledge about these clients and their experiences should be updated since experiences vary from person to person across time. I argue that often the social worker has been exposed to this kind of work in dying, it is nevertheless always timely and relevant that practice is guided by updating information within the field. I believe that knowledge on meaning-making of dying experiences must be generated to always impact the social work profession. That being said, whatever the knowledge this study produced, it is also congruent to the hopeful aim to inform and influence the social work and its practitioners in particular, and the society in general.

As I am interested in the phenomenon of dying, it also remains unclear to me how terminally ill elderly persons make meaning while contemplating imminent death. I argue that in their meaning-making we are drawn to know the person behind dying and not as a dying body. Despite my considerable exposure in nursing homes, my understanding of how elderly people make meaning is undisputedly meager. Hence, my interest to understand dying from the person's perspective was my first choice. With that in mind, I opted to conduct interviews with dying elderly persons in Norway. Sometime in September 2017, I began my field activity starting by sending correspondence to nursing homes regarding my study. However, this did not yield much despite my expectations to get positive answers. I sent my formal inquiries to these institutions but did not get significant feedback. By December 2017, I still had no one to interview. It seems being an outsider is a challenging position. Perhaps one reason is linked to Goffman's depiction of the nursing home as "a place of residence and work where a large number of like-situated individuals, cut off from the wider society for an appreciable period of time, together lead an enclosed, formally administered way of life" (Goffman, 1961: xiii cited in Davies, 1989: 77). Goffman's statement offers the idea of why it is so hard to get access to nursing homes. To my understanding, as nursing homes become embodied institutions, life continues to exist among dying elderly people. However, what is constituted in the daily lives and routines in nursing homes is not common knowledge for everybody. The knowledge of

how "total institution" works and how people interact with each other is off-limits to outsiders unless considered part of it. The daily culture of nursing homes indeed consists of private matters, not available for lay people, and even for people working in nursing homes only granted one has direct contact with another who is dying.

Also, as I further reflect on this situation, another reason is perhaps on a more personal level. Personally, while my fluency in Norwegian was not yet as I wished, I felt hindered in engaging with elderly people, especially those dying, who have difficulty in expressing themselves. To me, talking about dying is sensitive and so communication must be effective. Since advanced language proficiency was lacking on my part, it thus became a drawback and further positioned me as an outsider.

With dwindling hope, I nevertheless held on to the belief that there could be other ways to get answers for my research question. The hope of interviewing terminally ill Norwegian elderly people was no longer a viable option, so I began considering alternative ways than doing interviews. I believe the knowledge to understand terminally ill persons are not only confined to one method but transcend in many ways. My belief echoes one saying, "reality exists independent of human condition... and all the facts, observations, and data are theory-laden" (Rousseau, et. al. 2008 cited in Okoli, 2015:2). I contend that evidence or knowledge of the phenomenon come in diverse formats and, to me, the option of a literature review is amenable. It sounds like my choice is pragmatic and yes, it is indeed. Having said that, knowledge is not only extracted from spoken words or images, but also through texts found in the literature.

So, before embarking on my quest, first and foremost, I need to find dying persons and their stories from literature. However, how can we assure if there are pieces of literature on dying and meaning-making? How can I get to them? Where and what to start with? These questions make me realize that I must consider certain issues of practicality, logic, and manageability.

Concerning literature, authors like Hawkins (1991) claims that there has been an efflorescence of literature about death and dying, as well as, writings that talk about personal stories of illness and death. After Hawkins (1991), also Bingley and colleagues (2006) claim that narratives of persons facing an imminent death have been proliferated in the public domain. Both Hawkins (1991) and Bingley et al.'s (2006) assertion seems to justify there are indeed many pieces of literature discussing death and dying. Despite their claims, there is no defined knowledge on how much literature produced, particularly by social workers, that focuses on meaning-making of dying persons in nursing homes. And when literature on dying is diverse, it can also appear fragmented. According to Crossan and Apaydin, "fragmentation of the field prevents us from seeing the relations between these facets and ultimately impedes consolidation

of the field” (2010: 1154). In the same vein, Siddaway suggests that “it is not always clear what the overall picture is, or which results are most reliable and should be used as the basis for practice” (2014: 1) and worse, “runs the risk of conducting a redundant study” (Lange, 2014: 6-7). Bearing in mind these concerns, it is pertinent that a literature review should be carried out. In this study, therefore, a literature review is done systematically, thus referring to the term “systematic literature review or SLR.”

Alongside with my SLR, I intend to explore and describe the trends of the searched literature. Showing the extent of dying studies in the field and reporting methodologies and findings of the meaning-making of dying persons can bring the discipline into another level of clarity. In addition, to guide what kinds of literature should be collected, my systematic literature review will answer a central question: **“How do terminally ill persons make meaning of their dying experiences in nursing homes?”** This central question seeks to find answers encompassing discussion on the meaning-making of dying experience. Likewise, when I speak about the dying experience of terminally ill people, it should be clear from the very beginning that it refers to dying as a lived experience. In other words, being in the process of dying is a personal experience that terminally ill people experience in a given moment.

## 1.1 My Philosophical Tradition

Before moving forward in this study, determining my positionality within this research is of significance. Locating my stance has significant implications that extend beyond more than just theoretical understanding, but also influences the choice of my research design and ethics in the whole study process. My research stance becomes my personal compass as I am coming forward in knowing how the terminally ill persons make meaning of their dying experiences. Without it, I am left blinded and lose myself in a labyrinth of conflicting worldviews.

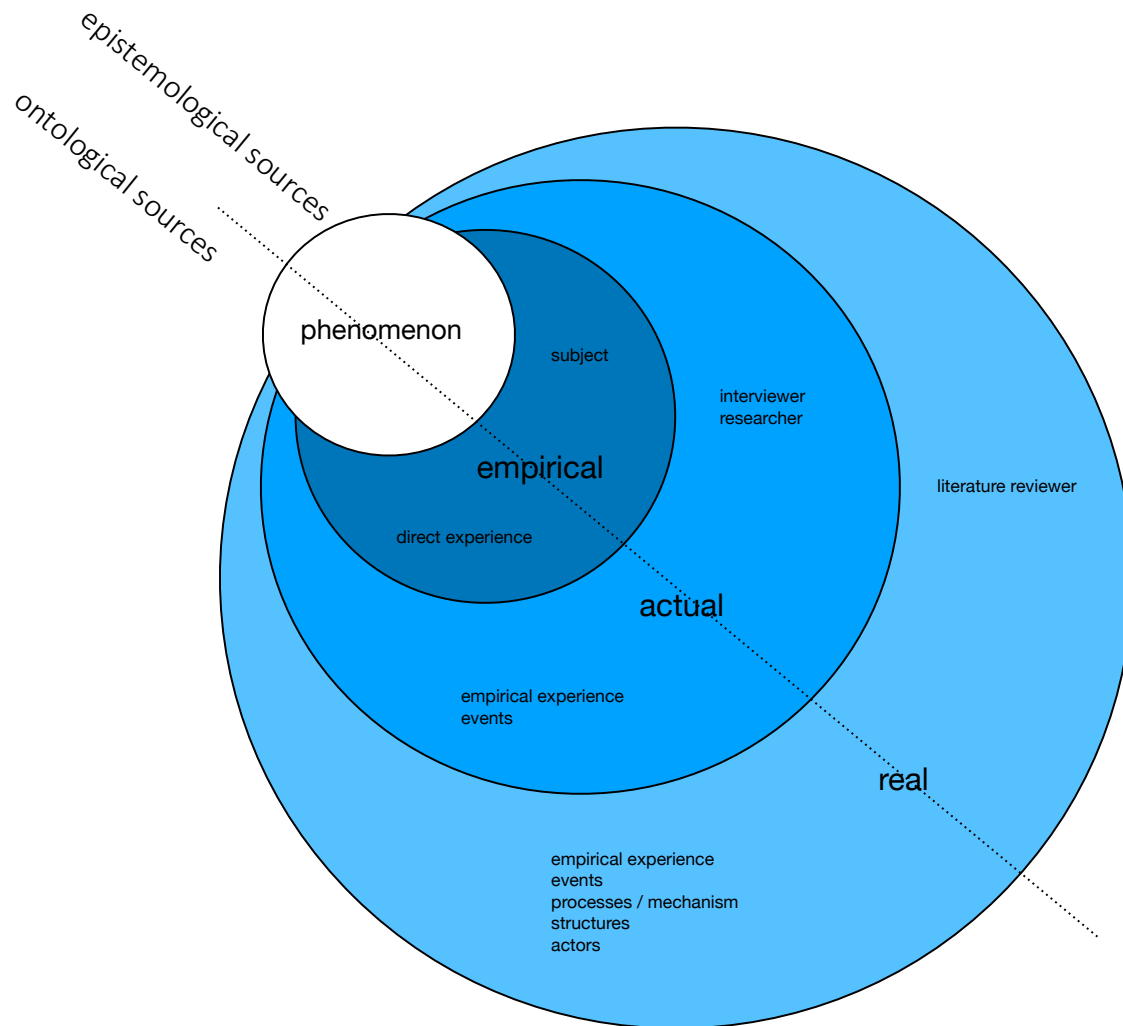
Influenced by my belief that there are other ways to gain understanding on a particular phenomenon, I venture to carry out SLR. Using literature towards understanding a phenomenon is actually a method supported by the critical realist tradition. Under this tradition, pieces of literature, if selected correctly, can yield knowledge, more or less, and elicit reflections on what is observed in reality (Okoli, 2015). And by knowing the reality, critical realism endorses the idea that *ontology precedes epistemology*. In other words, before acquiring knowledge of reality, one must acknowledge that reality itself exists in various spheres, otherwise knowledge is neither immediate nor possible. As I am following Critical Realism, there are essential tenets that I am aware of and that underlies my research stance. These are:

- With strong roots in ontological *realism*, critical realism believes that there exists a *reality* independent of the immediate human thought, and the experience of reality does

not always reside in a person but separate from themselves; thus, we can generate knowledge of it (Rousseau et al., 2008 cited in Okoli, 2015). The reality here refers to “whatever it is present in the universe (i.e., forces, structures, and so on) that causes the phenomenon we perceive with our senses” (Schwandt, 1997 cited in Maxwell, 2012: 3).

- Reality should be understood as *open layers*, which hints that there exists a world independent of our own perceptions and constructions. In effect, there is no absolute truth, no single correct understanding and no specific knowledge exists to explain a certain phenomenon in the world. Thus, knowledge, in that sense, is socially constructed, partial, incomplete and fallible thereby alternative perspectives are advocated (Bygstad and Munkvold, 2011; Maxwell, 2012).
- Reality is comprehended as being stratified in three domains: *empirical*, *actual*, and *real*. The real domain comprises structures and objects (physical or social) with capacities for behavior called mechanisms (Bygstad and Munkvold, 2011), and those mechanisms inject causal powers that either enable or constraint events we may observe both in the empirical and actual domains (Bhaskar, 1998b; Sayer, 2004). Please refer to *Figure 1* for illustration of ontological sources for each domain of reality.
- Concerning epistemology, critical realism is compatible with constructivism and interpretivism, and it highlights that knowledge produced of the few is of equal value with that of some other few (Maxwell, 2012). Since there is flexibility on epistemological origin under critical realism, I referred myself as most fitting to *constructivism* since reality is independent of the human mind and knowledge of reality is always a human and social construction (Crotty, 1998). I argue that understandings on meaning-making of dying experiences are subjective in a way that we can only better grasp if we go back to the source of knowledge which constructivism makes it possible. The reality of that knowledge contains descriptions and such descriptions are not mere copying, rather the different producers of knowledge constantly enhance how language creates reality (Putnam, 1999 cited in Maxwell, 2012). As I followed in this tradition, theoretical knowledge produced is considered as features reflecting the different domains of reality (Devitt, 2005 cited in Maxwell, 2012). I, thus, sustain a belief that mental states and attributes, meanings, and intentions of informants and authors found in the published literature, although not directly observed, can yet contain similar features found in other domains of reality. The thoughts being generated from the literature are representations of varied experiences; therefore, we can also seek these representations by *operationalizing* so that we can generate similar attributes and properties of experiences reflecting the reality in other domains (Maxwell, 2012; Okoli,

2015). Please refer to *Figure 1* for illustration of epistemological sources with respect to different domains of reality under critical realism.



**Figure 1:** Domains of Reality in Critical Realism, and The Ontological & Epistemological Sources

## 1.2 Locating My Position in the Present Study

In this study, pieces of literature are the sources of data that can generate answers for my research question. Under the critical realist tradition, the reality of the phenomenon is independent of the human mind and there exist many ways to know it. I, as a researcher in the field of social work, make use and review literature grounded on the belief that reality with its similar attributes and features can also be understood through texts and concepts. I situate myself in the domain of “the real” and am engaging in “the empirical” and “the actual” domains. The real domain is the immediate access to me as I am investigating a phenomenon under interest using literature. To cross both the empirical and actual, I must operate in such a way that I am able to recognize the context of what to seek, who to find, and where to explore. When

data has been accessed, I soon immersed into it and eventually generate knowledge taking a constructivist approach. Constructivist in the sense that reality is independent of human minds and knowledge of that reality is continuously a human and social construction (Crotty, 1998). As I situate myself in the real domain of reality, I seek truths by examining processes and mechanisms involved, experiences, events, structures, and actors between empirical and actual layers that have contributed to the creation of those truths. Further, I attempt to observe potential links, patterns, and unobservable reality “since an underlying reality provides the conditions of possibility both for actual events and perceived phenomena, recognizing and teasing apart the different layers of reality is a key ingredient for plausible and comprehensive social analysis” (Fiaz, 2014: 496).

### **1.3 Transitional Summary**

In this chapter, I have emphasized the focus of my study on meaning-making of the dying experience among terminally ill elderly people in nursing homes. Also, I have mentioned critical realism as my philosophical tradition. With this tradition, there was a belief that knowledge is fallible and half true. Hence, as a social worker, I will be using literature to produce alternative perspectives on the phenomenon under scrutiny. To make this happen, I have situated myself in the real domain with a constructivist approach investigating the mechanisms and processes involved, structures, experiences and events including the actors themselves. To be better understood on these concepts, there are expounding discussions found in the subsequent chapters. Meanwhile, to orient us more about how critical realist influences my systematic literature review, what it is and how to do it, I offer further discussions in chapter 2.



## **Chapter 2: What is Critical Realist SLR?**

This study follows the protocol of conducting SLR with critical realist considerations. A literature review that is done systematically contains the core characteristics of being clear, comprehensive, logical, rigorous and a reproducible method for finding, appraising, and synthesizing (Okoli and Schabram, 2010; Aveyard, 2014).

What then is the difference between systematic and a traditional literature review? Although a traditional literature review is one form of written appraisal, it does not imply a defined methodology (Jesson et al., 2011). Authors like Rousseau et al. consider this type of review “cherry-picking studies” (2008: 476). My understanding of “cherry-picking” is that there exists merely a selection of pieces of literature that have relevance to a topic being studied; hence, there is no inherent rigor to its method. Traditional literature reviews are restricted to literature already known to writers, authors, and researchers (Mallett et al., 2012). Consequently, the same scientific papers are often cited and may introduce bias in literature reviews (ibid). In contrast, systematically searching of literature involves a defined process to locate and collect an extensive scope of literature, present and synthesize the characteristics and findings of the results of the searched materials, using an evaluation and synthesis tools (Aveyard, 2014).

Considering that SLR occupies a place in social work (Kelly, 2012), the processes involved in doing systematic review should be done in a “comprehensive accumulation, transparent analysis and reflective interpretation of all studies” (Rousseau et al., 2008: 7). Likewise, as social work becomes “a contextually diverse profession (that) draws on received ideas from social and human science disciplines” (Preface by Healy in Hutchinson and Oltedal, 2014: 1), it is logical to say that social work itself operates and functions by studying multiple studies to produce knowledge. Thus, an SLR with critical realist considerations work as a compliment to summarize different philosophical paradigms from various disciplines (Okoli, 2015). That being said, a critical realist systematic literature in the field of social work searches beyond the particular subject domain, network, specialty, and allows a reviewer to incorporate diverse evidence that shed light on the subject of interest (Mallett et al., 2012; Okoli, 2015).

Critical realist SLRs are characterized by being objective and systematic (Okoli, 2015). They encompass a systematic search process to identify and locate potential literature sources, at the same time, a systematic presentation and synthesis of results (Siddaway, 2014). In the same way, there exists an unbiased selection process by being objective and looking on evidence based on its merits to answer the research question (ibid). To best achieve these characteristics in critical realist systematic reviews, Baumeister (2013) endorses adopting the mindset of a judge rather than of a lawyer. In other words, a reviewer is like a judge that should

skeptically assess the potential literature to decree the fairest judgment possible (Siddaway, 2014) and being rational, reasoning logically from evidence during the presentation and synthesis of results (Drobak and North, 2008). In contrast, “a lawyer’s approach to the evidence involves trying to make the best case for one side of the argument” (Siddaway, 2014: 1).

When results and synthesis have been achieved, one of the hallmarks in critical realist SLR is to explore the synthesized evidence and eventually produce new knowledge (Okoli, 2015). Baumeister and Leary (1997) call it “going-beyond” discussion. That is to say, the reviewer is required to expand the synthesized knowledge and develop new ideas beyond the apparent findings collected from the primary literature (Okoli, 2015).

In the quest of finding answers to a focused research question, SLR can find a consolidated knowledge from a body of research and present an analysis of collected literature available (Aveyard, 2014); thereby, in its all form, is “considered a piece of research” (Jesson et al., 2011). Conventional wisdom has it that SLR is not a research itself; however, if the criteria to consider are to answer a research question, then it is considered to be one. Likewise, standalone literature reviews are valuable research that unearths new insights and develops valuable theoretical contributions (Okoli, 2015). I argue that the systematic nature of literature reviewing involves methods and processes to answer a research question, then systematic literature reviewing, in that sense, inherent methodology. Hence, that underscores the claim of Jesson et al. (2011) that it is, thus, research in itself. SLR occupies a prominent place within the realm of scientific activity which must be acknowledged (Baumeister, 2013).

Primarily, for this study to be a piece of research in its own right, it must be of good quality. As such, it must adhere to a rigorous research process that improves the “methodological transparency of the review” (Gough and Elbourne, 2002 cited in Mallett et al., 2012: 447). Hence, a guide in conducting SLR must be followed. The methods employed in this study are the principles and processes developed by Okoli and Schabram (2010). More details about these processes are discussed in the succeeding sections. Please see *Appendix A* for additional visual illustration.

## **2.1 Purposes of the Literature Review**

At the onset of reviewing, the purpose of SLR should be cleared (Okoli, 2015). Generally, literature reviewing aims to collect appropriate literature and synthesize it in a way that it can address research questions (Siddaway, 2014). When reviewing is done systematically, there is assurance of objectivity and specificity to literature items being included but it is expected to get only a low number of results. While only a few primary studies may be included, these studies can nevertheless address a specific research question and provide a focus, but

qualitatively constructed findings to a focused study of interest. So, as far as social work is concerned, critical realist SLR “can reveal significant trends and practice implications through the synthesis of all available research in a given area (specificity and focus of interest), as well as identifying areas that need further research” (Boaz et al., 2002 cited in Kelly, 2012: 78). And while producing qualitative answers, it is also essential to note if the SLR leans towards either theory landscaping, theory contending or theory testing. As Okoli (2015) explains, a review that is theory landscaping documents empirical reality, taking note of actual reality and proposing new understandings in “real” reality. In other words, it creates understandings about a topic, theme or concept of interest. If theory contending is the aim, a critical realist reviewer is making an opinion to explain the unexplained empirical reality while in theory testing, a reviewer validates a specific theory of the antecedent cause of the phenomenon (ibid).

## **2.2 Protocol and Training**

This stage is simply the planning and “trial and error.” Once the purpose is set out clearly, a draft of a protocol on how to carry out the whole stage must be achieved. Here, a reviewer must undergo training, be acquainted with the conduct of the review and identify limitations and challenges while on training (Okoli and Schabram, 2010). My understanding of this stage is to ensure that a reviewer is equipped with the strategies needed to carry out the whole review. Fink (2005) comments that in an SLR there might be changes in the entire course, and to lessen the burden of changing and repeating documentation, a protocol is helpful to track changes and guarantee an explicit nature of work. Purposely, the protocol and training stage help a reviewer to formulate research questions, operationalizing the key terms, drafting a strategy protocol and taking down notes while gaining experience and learning under the process.

## **2.3 Searching the Literature**

The searching for literature should be done comprehensively. That said, a wide search on interdisciplinary databases is advised as suggested by the critical realist philosophy. Further, the act of searching for literature is placed on identifying empirical observations that give testimony to the actual events (Okoli, 2015). As a critical realist informed reviewer, I believe that knowledge is fallible and half-true, so in order to effectively produce the real underlying mechanisms of the phenomenon, a purposeful, wide search of evidence, and searching across the different school of thoughts is a need (ibid). To add, as the ultimate goal of SLR is to produce rich explanations, a reviewer should consider various ways and means to extract wide-range interdisciplinary databases and sources (ibid). This further implies that sourcing includes

books, journals, abstracts, and databases by using search strategy operators (Okoli and Schabram, 2010).

Levy and Ellis (2006) also suggest that a “backward and forward search” of literature, simply known as snowballing, is beneficial. The backward search involves studying the reference section of a highly relevant piece of literature while forward search involves getting all articles that have been cited in other relevant articles (Levy and Ellis, 2006). Now, in an instance where there are many results garnered during the searching of literature the next question would be: “When to stop the search?” As Levy and Ellis (2006) suggested, the importance of identifying the date range during the planning stage is a hint for a reviewer when to stop. When the literature search through whatever means generates the same reference articles all the time, then the exhaustion level has been reached (*ibid*). It is also a common knowledge that research publications are constantly emerging, so how can I solve this situation? To solve this potential problem, Okoli and Schabram (2010) explain that by regularly and rigorously recording the search histories, then a reviewer can periodically search the databases and detect whether there is any new reference literature relevant for inclusion.

## **2.4 Practical Screen**

It is expected that after literature searching from different sources, a vast amount of reference literature is collected; however, most of which is not eligible to address the research question (Okoli and Schabram, 2010). Therefore, the next step is a practical screen. For Okoli and Schabram (2010), a practical screen is manifested through reading the searched literature but requiring only to read the abstract and practically decide its potential for inclusion. Contrary to Okoli and Schabram (2010), the author Siddaway (2014) emphasizes to read both the title and abstract as these two sections of the literature gives the idea for potential eligibility for inclusion. If the title and abstract point to potential inclusion, then a reviewer should obtain the full-text version and read it judiciously (*ibid*). At this stage, although there is a vast collection of literature, a reviewer must continue to err on the side of literature sensitivity (*ibid*). In other words, a reviewer is continuously sifting and collecting as many literature items as possible from different sources in order not to miss potential literature.

Eventually, all potential articles that are collected during literature sensitivity will then undergo a strict evaluation. By undertaking the rigorous evaluation, a critical realist reviewer makes sure that all literature items are relevant and appropriate for inclusion, an approach known as literature specificity (*ibid*). To achieve literature specificity, a reviewer will apply a screening measure known as the inclusion and exclusion criteria as strictly and objectively as possible. These criteria have been influenced by the operationalization of key terms stem from

the research question and by the purposes of the literature review. Again, if these criteria are followed strictly and select literature objectively, a critical realist reviewer only obtains a highly relevant set of literature. Here, it is expected that highly relevant sources lead to high confidence in the conclusion of review (ibid).

## **2.5 Quality Appraisal**

All literature items included after a strict selection process are considered as “primary studies.” These primary studies are required to be appraised in such a manner that they meet the extent of quality standards since not all articles are of equal quality (Okoli and Schabram, 2010). So, the appraisal serves two purposes. Firstly, in case there is a low-quality standard that exists in the collected literature, the quality appraisal becomes a second screening to help eliminate literature that does not fully meet the standard requirement. Secondly, since the quality of a final review depends much on the quality of primary studies then it needs to be scored (Fink, 2005; Okoli and Schabram, 2010). However, for caution sake, the over-zealous exclusion of presumably low-quality articles has led to problems in past literature reviews (Rodgers and Hunter, 1994). To my understanding, due to over-zealous appraisal, the literature items are judged either included or excluded according to the scores each article gains in the scoring system but not on the merit of how each literature contributes to the findings of the study. On the contrary, Okoli and Schabram (2010) underscore the idea that not all reviews will eliminate literature based on their quality. So, what then is the objective of a quality appraisal? To answer this, it is necessary to appraise the quality of the included literature as a basis for confidence in the final results (Okoli and Schabram, 2010). Likewise, a critical realist perspective concurs with the idea that knowledge is fallible, so primary studies, in that case, need to be assessed according to the standards on how authors carried out the task and how they produce the results from the empirical studies (Okoli, 2015).

## **2.6 Data Extraction**

From a critical realist perspective, data that proposed explanations and showing relationships between concepts and the underlying structures or mechanism of the phenomenon are considered as data to be extracted (Okoli, 2015). The type of data to be extracted from each primary study is based on the research question established during the protocol phase (Okoli and Schabram, 2010). The data becomes the transcripts that will be stored in data extracting sheets. These data extracting sheets further include spaces to store details and comments of the reviewer. Subsequently, they are combined with the details of inclusion and exclusion criteria and quality appraisal as a full record during the synthesis stage (ibid).

## 2.7 Synthesis

When raw data are gathered from selected primary studies, the next procedure is synthesizing. In the words of Siddaway (2014), he explains that there are few considerations before deciding which synthesis approach is appropriate in a critical realist SLR. These considerations include (i) research question, (ii) primary purpose of the study, (iii) the nature of raw data collected during literature selections, and (iv) theoretical and empirical issues (ibid). Specifically, on theoretical and empirical issues, Bearman and Dawson (2013) further explain that a critical realist reviewer should stipulate which philosophical stance influences the whole SLR. By mentioning the stance, it helps readers to understand which view influences the reviewer during synthesis. In other words, the philosophical tradition shapes the way the reviewer understands the data.

As soon as the final criteria are considered, the primary studies are then processed for synthesis. During synthesis, when data contains qualitative and quantitative results, a meta-analysis is appropriate (Siddaway, 2010). If data presents qualitative results, a qualitative research synthesis is applicable wherein findings of each included primary study are synthesized and expanded into new understandings rather than merely summarizing and determining consistencies and differences (Siddaway, 2010; Aveyard, 2014).

## 2.8 Writing the Review

The presentation of an SLR "needs to be in sufficient detail" (Okoli and Schabram, 2010: 33). To achieve detail writing and reporting, I invoke a few things to consider. One, the philosophical stance needs to be considered as it influences not only the way a critical realist reviewer's view the study topic but also on the research design and ethics. Second, as long as the reviewer (i) adheres to the guidelines that outline in reporting systematic literature review; (ii) using flow diagram, figures and illustrations to support the contextual meaning of the texts; and (iii) getting inspirations from books and journals then the reviewer cannot go wrong (Siddaway, 2014).

Also, as technical writing is essential, there is another question that needs to be enlightened: "Should the reviewer use a first or third person in the writing of SLR?" To answer that question, Aveyard (2014) explains the matter of writing is a personal choice and in critical realist, SLR involves many authors, so it is appropriate to use "the first person" to indicate that a reviewer is the one reviewing the works of other authors. With that in mind, I agree with Aveyard (2014) in a way that to avoid confusing readers about "who says who" thus giving more clarity while readers advance the reading of the study.

Finally, since SLR is considered to be a piece of research, the output is expected to apply the principles and guidelines of searching, critiquing and analyzing the literature (Aveyard, 2014). For that reason, I believe that in a thesis writing submitted for an academic degree, there is no place for an “unsystematic review,” otherwise there can be no assurance that the study has been done rigorously and comprehensively.

## **2.9 Transitional Summary**

In this chapter, I have discussed critical realist SLR. Concerning the processes and methods, the eight steps of Okoli and Schabram (2010) have been explained which includes stating the purpose, doing the protocol and training, searching the literature, practical screen, quality appraisal, data extraction, synthesis, and writing the review. As much as we were already acquainted with the processes and methods, in the next chapter, I discuss how I applied it in my whole search of the literature. In the same way, I detail the ethics involved as I carried out the methods and processes of SLR.

## Chapter 3: Methods, Processes, and Ethics

In this chapter, I present the operationalization of key terms found in my research question and the undertakings of eighth methods and processes of SLR developed by Okoli and Schabram (2010). Also, this chapter addresses the concerns of practicability, logic, and manageability of doing SLR as I mentioned earlier in chapter 1.

### 3.1 Operationalization of Terms

Operationalization of key terms is important to help sort things out during the selection of literature. I argue that many terms may mean different meaning in different contexts. In order to avoid confusion for the readers, key terms must be clearly understood in the context of the present study (Aveyard, 2014). Equally, Siddaway (2014) explains that operationalizing key terms determine the boundary and focus of the study. As a critical realist informed reviewer, I believe that interdisciplinary searching must be done to collect valuable and potential empirical studies that can answer my study of interest; however, I am also aware that as I search literature from various sources, the results are overwhelming. To mitigate this problem, the clear operationalization of key terms helps in creating concise inclusion and exclusion criteria during the selection process. In effect, the selection process of literature is objectively attained and manageable. Thus, highly relevant literature leads to a more focus study and eventually achieving high confidence in the findings and conclusion of the review (Siddaway, 2014).

As a reminder, when I detail the key terms in this study, for example, the age of a terminally ill person, does it mean I am bound to the notions of ageism? Am I stereotyping that being old age equates terminally ill and death? My response is definitely no. I only detail the age bracket of a terminally ill person for the purpose of selecting eligible literature. Again, the more focused the study is, the greater confidence in the results; at the same time, the unbiased selection of literature is a distinctive feature of a systematic literature review.

Now, the terms inherent to my research question are important to be understood so as it set out the boundary and range of my study. Going back to my research question: “How do terminally ill persons make meaning of their dying experiences in nursing homes?”, I identified four key terms that need to be operationalized. These terms are: *terminally ill*, *meaning-making*, *dying experience*, and *nursing home*.

#### 3.1.1 Terminally Ill

In pieces of literature about death and dying, terminally ill is one of the many terms that has been defined somewhat variously. McCartney and Trau (1990) suggest that terminally ill is equally defined as “dying” or in a “terminal condition” due to its pathological origin wherein



causes are either injury, disease or illness, and in such degree of certainty there can be no health restoration or life-prolonging measures to hamper the natural course of death. Moreover, those that are permanently unconscious and in vegetative state or coma are therefore terminally ill because medical intervention is no longer necessary to restore health (McCartney and Trau, 1990). Another author, Lynn (1996), defines terminally ill as a person having a fatal illness with life expectancy of six months or less. Since McCartney and Trau (1990) and Lynn (1996) offer varying explanations, it is Hui and company (2014) have successfully fused the two definitions. According to Hui and company, terminally ill is a person with “a progressive life-limiting disease with a prognosis of months or less” (2014: 87). Though their definition is amenable, I have a reservation when it comes to studying dying experience. I argue that in studying the phenomenon of dying, it is essential to deliberately determine the context of “less” in words “months or less.” I further argue that “less” may mean weeks, days or hours. In whatever category it may be, the importance of considering the time in this context is crucial. I argue that it is crucial since there are terminally ill that have a life expectancy of days or hours and may have altered consciousness. If this situation happens in dying moments, then there is no assurance on the validity of their accounts. Similarly, with a prognosis of six months or less, there is no doubt that more dropouts in the respondents will be expected given the rapid changes and transitions in health conditions. I suggest that it is better to reconsider respondents that have received a diagnosis of life-limiting disease with little survival rate or those that are terminally ill but have few years, at least one year, months or weeks to live. By considering so, one is left with a clear-cut description of who are terminally ill in this study. Therefore, this study operationalizes terminally ill as a *conscious person with progressive life-limiting disease or dying with a life threshold of years, months, weeks or hours*. Any terminally ill that are unconscious or with hallucinations are not covered in this study since communication skills are diminished. Remember, the sharing of dying as a lived experience from a conscious person is essential; otherwise, the validation of the experience about the phenomenon is called into question.

### **3.1.2 Meaning-Making**

A person with a poor or deteriorating recovery of health status seems death highlights the end-point of biological life. In the face of imminent demise, meaning-making becomes generative and significant (Breitbart et al., 2004). A terminally ill person is aware that the body is immersed in the physical world not free from pain and limitation but warrants the person to further question, wander and search (Granados, 2006 cited in Ashfield, 2012). In other words, a person creates moments and meanings which intensify the more profound understanding of

life and existence. For a medical sociologist like Frank (1995), the deeper searching and wandering of the experience eventually creates a “new map” wherein the unfamiliar experience becomes gradually known to body and self. There are vast things to discover in life and in each instance, we tend to convey ourselves to make sense of whatever circumstance we may be (Frankl, 1962). Here, I must say, the meaning-making efforts of one who is terminally ill is not a small endeavor, but rather it takes courage, commitment, and conviction to reflect upon and take ownership of one’s own existence (Breitbart et al., 2004). As the person articulates the feelings and reasons, it is an attempt of giving voice to the whole experience (Frank, 1995). Hence, what the body speaks reflect a whole being. This study, then, is anchored on a fundamental belief that in the nexus between intellectual reasoning and one’s own feeling situates the sphere of meaning (Breitbart et al., 2004), and when the experience is articulated meanings evolve and being shared with the world (Kulas, 2001). In this study, meaning-making is understood as processes of recreating and representing the person’s perspectives on the world and self when undergoing a disruptive life occurrence. For a person to recover, there is a self-pursuing for meanings and meanings made are connected to the cultural and social context of the one experiencing it (Marcu, 2007). The phrases like *making-meaning*, *meaning-searching*, *meaning-finding*, *meaning-seeking*, *making-sense*, *making-out* are recognized as solicited terms for meaning-making.

### 3.1.3 Dying Experience

To grasp the essence of the experience, one must reflect in the past (van Manen, 1997). In my understanding of van Manen’s (1997) idea, to reflect on the past means to involve a mental or temporal recollection of events, able to think upon and make sense of the experience. I argue that we cannot account for the experience if we have not been exposed and immersed in given life events or phenomena in one way or another. Here, dying as a lived experience has a cluster of significance and as we reflectively gather components, we assign certain ways of memory to make sense (ibid). And within that memory contained no single, but clustered of meanings that describe the whole dying as a lived experience (ibid). In the same vein, Caputo explains that dying as a lived experience itself contains a “*plus ultra*” which means there is “*more than what is meant explicitly*” (1987: 40). In that case, if we consider the dying experience it does not only talk about being a terminally ill or in a living- dying phase, but it also speaks of the exterior things that contribute to the whole making sense of the event. Frank (1995) describes it as a complex embodiment of abstraction. So, in understanding dying as a lived experience one needs to consider a contributing story about “our neighbors...our parents, our children...quality of life, spirituality, culture, history, art, nature, loss, pain, prognosis, diagnosis, and ultimately all

other human lives” (Kulas, 2001: 14). In this study, the dying experience refers to the experience lived by those terminally ill or dying persons. The dying experience is understood as an experience with a cluster of meanings, embodiments of abstraction of a person’s life-world and a reflective story of the entire experience of being terminally ill in nursing homes. Furthermore, it refers to the entire story and journey of being a dying person in a nursing home from the time of diagnosis. By and through stories, dying experiences are either transformed into narratives, shared through telling, or even written in diaries. I also suggest that stories of dying experiences can either be shared individually or through a group. However, be aware that this study precludes the end-of-life or near-death experience which report hallucinations, with altered level consciousness or in a coma.

### 3.1.4 Nursing Homes

Historically, nursing homes were shelters called “gerocomeia” meaning a place that provided food and medical care for the elderly (Lascaratos et al., 2004). Fast track to the modern world, they become a “facility with a domestic-style environment that provides 24-hour functional support and care for persons who require assistance with ADL’s (activities of daily living) and who often have complex health needs and increased vulnerability” (Sanford et al., 2015: 183). Nursing homes are man-powered by both professionally and non-professionally trained caregivers that render care and support to those persons in need (Abel & Nelson, 1990). Yates-Bolton (2017) emphasizes that persons in nursing homes that have increased vulnerability are those frailties and require a greater level of input of care. To me, these persons are most likely represented by those elderly who are unable to care for themselves, needs assistance, with debilitating illnesses that have no chance of full recovery and those who are terminally ill. Additionally, these persons reside in nursing homes in a varied time span- either in short or long-term stay (Sanford et al., 2015). For Kasper, “the largest segment of the long-stay resident in the nursing home population, and potentially among the most difficult to transition back to the community, are those over age 65” (2005: 5). In this study, the nursing home context is thus explored as a residential facility that provides round-the-clock medical and personal assistance to those elderly, ages 65 and over, frail with a debilitating illness, diagnosed terminally ill with years or less survival rate. The phrases *residential care home*, *assisted-living facilities*, *home-for-the-aged*, *institutional care home*, *long-term care setting*, and *elderly home* are recognized as alternative phrases for a nursing home. Some literature mentions “home” referring to the original abode of dying persons where they, at the same time, receive services from professional staff is not fit as an alternative term for a nursing home. Likewise, the terms hospital, hospice, or even monasteries that took care of the dying persons are not included.

## **3.2 Search Strategies and Processes**

To achieve an effective strategy, the processes developed by Okoli and Schabram (2010) were applied. As I already discussed in chapter 2, the methods and processes serve as valuable means for searching, documenting, synthesizing, and reporting an SLR. The discussion of these processes follows hereafter.

### **3.2.1 Purposes of the Study**

This study was bound to answer a research question: “How do terminally ill persons make meaning of their dying experiences in nursing homes?” While this study was directed to a specific interest among terminally ill persons in nursing homes, it generally aimed to produce qualitative answers on the meaning-making of dying experiences. Moreover, since this study is considered as standalone and theory landscaping review, it provides answers by observing the empirical domain, noting actual domain, and eventually creating new knowledge about the meaning-making of dying experiences. To generate qualitative answers, this study was specifically able to:

- i. Identify and describe the searched literature collected from varied sources;
- ii. Describe the methodological characteristics and appraise the primary qualitative studies in order to know the rigor of how authors arrived their respective findings and conclusions;
- iii. Synthesize the original accounts of informants and actual findings of authors from primary qualitative studies to explore the meaning-making of dying experiences through constructed themes and;
- iv. Create an expanded knowledge out from the constructed synthesized themes.

### **3.2.2 Protocol and Training**

Personally, I consider this stage as a trial-and-error. No wonder why it is significant to undergo the protocol and training process, as this is where the fundamental learnings of exploring literature items and solving problems concerning strategies arise. I spent the entire month of January 2018 doing the protocol and training stage when I finally decided to conduct an SLR for my thesis. As I have described, my moments were all done by a back-and-forth pattern of reading literature, searching for references, writing on my notebook, typing my thoughts on a computer, and afterward changing or worse erasing it. This pattern of repetition is daunting, nevertheless this is the stage at which my various attempts and laborious practice of sifting, categorizing, and coding literature have been rewarded with practical learning outcomes. As I underwent this stage, I learned five lessons. Discussions are detailed below.

### **3.2.2.1 Learned Lesson One**

The formulation of the research question should be focused and specific. At first, my research question was formulated as follows: “How do terminally ill persons make meaning of their dying experiences?” What I learned was that the question had no focus, and it was broad in terms of setting. So, after several attempts at restructuring the question, I decided that my study would focus on the nursing home environment. With the inclusion of nursing home, the question becomes: “How do terminally ill persons make meaning of their dying experiences in nursing homes?” When my study concerns only terminally ill nursing home residents, then it only suggests that it refers to primarily nursing homes and all solicited terms as specified in the operationalization. It further means that it does not include settings like home, hospital, hospice, and monasteries. By doing so, the topic setting became more precise. The more focused a study is the greater chance of attaining confidence that can be placed in the findings and conclusion. The study begins with terminally ill in nursing homes, so it ends up explaining as well about terminally ill persons residing in nursing homes.

### **3.2.2.2 Learned Lesson Two**

The entire research question cannot be used to searching for literature to different databases. Or long phrases are not practical when searching for literature because the hit results will be overwhelming. In fact, not all results, have relevance to the actual topic being searched. Instead, derive an approach by using important key terms from the research question. To effectively carry out this task, I happened to explore the PICO framework as an approach to systematic review. PICO means “Participants, Intervention, Comparison, Outcomes, and Study Design.” There is a trend going on that systematic review and meta-analysis are the gold standards for doing research reviews (Clarke and Stewart, 1994 cited in Cooke et al., 2012). However, these standards are suitable for research that is of quantitative in nature. When I evaluated PICO, I found it unnecessary since the nature of my study is not quantitative but qualitative. In my interest as to finding a suitable approach, I encountered the SPIDER framework in the work of Cooke et al. (2012). SPIDER is an approach different from PICO. It means “Sample Population, Phenomenon of Interest, Design, Evaluated Outcomes, Research Type.” Again, my study pertains to meaning-making of dying experiences hence SPIDER format was of greater value. To illustrate how the research question is translated into SPIDER format, please see *Appendix B: Illustration 1*.

### 3.2.2.3 Learned Lesson Three

After the research question was formatted through the SPIDER approach, I used it for searching literature. The formula was: [S AND P of I] AND [(D OR E) AND R] or when translated *[terminally ill AND dying as lived experience] AND [(interview AND focus group AND case study AND narratives AND observational studies OR meaning-making) AND qualitative]*. I ran a trial with this formula on three databases namely, Google Scholar, PubMed, and NORA. Interestingly, there were several results garnered from Google Scholar and PubMed, while NORA gave no match results. Although this was a testing of the formula, it gave me an idea that different databases require different approaches, and some require simple search commands while others do not. In that case, the formula is not a fit-for-all strategy. Still on SPIDER, though its usefulness is notable for qualitative literature review, yet I have one criticism on it. My observation was that the SPIDER had no specification for the intended setting. For example, my research question has a focus on nursing home, and with a SPIDER format, it did not mention of any setting. So, I further developed the approach into SPISDER wherein the included “S” refers to the “Setting.” I argue that formatting the research question into SPISDER approach is beneficial because it highlights keywords and concepts needed so as to ease the laborious task of searching. Finally, to see how the research question is formatted into SPISDER format, please see *Appendix B: illustration 2*.

### 3.2.2.4 Learned Lesson Four

There is a great size of literature available online. To lessen the task of collecting huge and unnecessary literature for my study, I used the search strategy operators which include Boolean operators, truncations symbols and a wildcard word. Boolean operators like *AND*, and *OR* were used to limit or expand the search coverage in databases while truncation symbols like *( )*, *“ ”*, *\**, *[ ]* were utilized to minimize nuances in the search of the literature. Aside from that, I also used a wildcard word *mean\** to sift literature that contains the word mean on the title or in the abstract.

### 3.2.2.5 Learned Lesson Five

Online literature is abundant and to organize such a high number of literature items is important. I learned that creating a table for potential literature after the search will help to save the results. I further learned that information in a table must include authors, year of publication, title, and remarks such as why a literature is important, and any comments on whether the literature is included or excluded for full-text review. In doing so, managing a vast amount of literature was

easier, the retrieval of data was accessible, and the detection of duplicate materials became easier. To illustrate this, please refer to *Appendix C*.

### 3.2.3 Searching of Literature

In my searching for the literature, I combined three strategies namely, online database searching, hand-searching, and citation snowballing. These strategies are essential because they become a fundamental key to guarantee a good starting point in identifying studies, and ultimately for the actual result of the study (Wohlin, 2014). Following a critical realist perspective, the searching across multidisciplinary disciplines is necessary so that many perspectives are elicited to produce varied explanations (Okoli, 2015).

The online search of the literature was conducted between February to May 2018 from databases provided by Nord University and helsebiblioteket.no. My motivations behind the databases selection are in line with a critical realist philosophy to search across different school of thoughts as suggested by Okoli (2015). Since the topic area for study covers dying as a lived experience of terminally ill in nursing homes, biomedical literature items are of great advantage, so I opted to search in PubMed, Scopus, and MEDLINE; as well as, in the European MEDLINE extension known as EMBASE. To avail the effective combination of citation indexing and web technology, I searched the Web of Science. The Wiley Online Library, CINAHL, Sage Publications, Science Direct, and Taylor & Francis were utilized because of their extensive multidisciplinary collections of literature resources extending from health, medicine, social science to literature covering the field of humanities. In addition to that, Google Scholar was a benefit to locate grey literature. For electronic book sources, E-book Central and the Springer databases were explored as access to protocols, scientific documents, and reference works. For published theses and dissertations worldwide, ProQuest was of great help. DART was accessed to explore published theses in Europe, IDUNN for Scandinavian, and NORA for Norway. With regard to the worldwide digital library for scientific journals, JSTOR was a plus. Eventually, the Directory of Open Access for Journals (DOAJ) was used to accelerate the collection of potential literature.

During the retrieval of potential literature from online databases, I used keywords and concepts that are formatted in the SPISDER framework. Again, I do not use the exact phrase of the research question since it gives an overwhelming result. Boolean operators like *AND*, *OR*; truncation symbols like *()*, *“”*, *[ ]*, *\**; and wildcard “meaning” is transformed into *mean\** were all combined to either increase or delimit the scope. Specifically, I used *AND* in order to increase the specificity of the results while delimiting only to relevant reference. *OR* was used to increase both the sensitivity and results of the number of references. Truncation symbols like

( ), [ ] were used because of the complex combination of search statements (Briddon, 2002). The “ ” was used to connote one word, and the symbol \* was combined to a root word to cover a wide range of searching thus getting higher exponential results. To illustrate the actual algorithms and search strategy operators used for searching literature, please see *Appendix B: illustration 3*.

During an online database search, although literature items showed the titles and abstracts, some cannot be retrieved and worst not completely opened. To mitigate this situation, I used ENDNOTE x8 to expedite the search. At the same time, I requested professional assistance with access to other databases. With that effort, some were retrieved but there were few not entirely available. Those sets of literature that were not totally retrieved marked with “cannot be retrieved” or CR. Searched literature that were opened including those that were not were all recorded in the data keeping sheet. These include journals, books, book chapters, theses and dissertations, essays and a list of abstracts. Also, a coding system was utilized to determine the content of the searched literature. Please see *Appendix C* for reference.

On June 2018, I also conducted the hand-searching of literature. Hand-searching, according to Hopewell et al. (2007), is still a valuable element of the SLR protocol since other kinds of literature are not indexed correctly in other online databases. Following Hopewell et al. (2007), I argue that hand-searching ensures the selection of literature that may be overlooked or just poorly and inaccurately indexed. Moreover, it increases the chance that other major relevant sets of literature are not missed. Based on that reason, hand-searching was a supplemental strategy.

Aside from the databases and hand-searching, another technique was carried out in the month of July 2018 was literature “snowballing.” Snowballing includes backward and forward searching of literature. Snowballing, as a strategy, refers to assessing the reference list including the citations of particular study (Wohlin, 2014). In this study, I only conducted a backward search because of time constraint. Potential literature from the reference list of the primary studies considered highly relevant was marked, picked, and included in the data keeping sheet. This technique was repeated to the following primary studies that were included.

Given that literature items were obtained out from different sources, I observed that there were many similar sets of literature were repetitively collected, see *Appendix B* for the list of duplicates. By collecting many duplicates from different search strategies, I decided that my searching process has reached its exhaustion level as explained by Levy and Ellis (2006). The exhaustion level was my signal to stop the searching of literature regardless of how many literatures I collected. In comparison to other qualitative research, my SLR is not concerned with the sample size of literature. Although it was imperative that, under critical realist



philosophy, the cross-searching of multidisciplinary literature is carried out, the purpose of such action was to solicit explanations from various perspectives (Okoli, 2015). That being said, the determination of how many literature items are included is not the central concern of this SLR, but rather to produce thick explanations during construction of synthesis (ibid).

### **3.2.4 Practical Screen**

Given the possibility of huge results in the searching of literature, the practical screening in the form of inclusion and exclusion criteria supports the selection process. To determine if the criteria were understood well, I tested these criteria on the first 100 articles that I sifted from Google Scholar. Then, I made an adjustment to some criteria in order to become specific and objective during the retrieval process. With the new adjusted criteria, the first 100 articles were assessed again by doing a quick evaluation in the titles and abstracts. This process of quick assessment and comparing against the criteria was influenced by Siddaway (2014). Those papers considered relevant or most likely to be relevant were saved in the data keeping sheet using the Microsoft Word in my computer.

With respect to the making of inclusion and exclusion criteria, I made certain that it should be as objective and specific as possible. Siddaway (2014) explains that in order to achieve the specificity and objectivity in the criteria, a reviewer should adopt decisions based on theory and evidence. In other words, decisions included in the inclusion and exclusion criteria should be justified. As a result, ideas found in chapter 1 and the operationalization of key terms found in chapter 2 were pulled together to develop my inclusion and exclusion criteria. Also, there were some decisions in the criteria that were of course of practical reasons like the language of publications and the type of study to be included. These criteria were then applied all throughout the selection process of literature. Below are the inclusion and exclusion criteria.

#### **3.2.4.1 Inclusion Criteria**

- As the nature of my review was to landscape theories via exploring and explaining, I intend to include qualitative literature that discusses on meaning-making of dying experience as an evaluated outcome. Considering the time-constraint, qualitative studies were the sources to provide explanations via thick descriptions. In the case of a mixed type study, only the qualitative part will be considered.
- Articles that contained discussion on how dying persons make meaning of their dying experience. The making of meaning represents the intellectual reasoning, feelings and emotions, and all those mechanisms and attempts to give voice to the lived experience.

- Discussions about dying as a lived experience and were reflected in narratives, stories, interviews, participant observation, and case studies.
- Terminally ill persons that were aware of their condition, conscious and can able to share their experience were included. Also, those terminally ill or dying that have a prognosis of a few years, months, weeks, days or hours to live.
- Terminally ill persons with a progressive life-limiting disease and deteriorating health status. Likewise, those were dying elderly people in nursing homes.
- Age was from 65 years old and above following Kasper's (2005) claim. If no age indicated in a particular study, then context clues were elicited to satisfy this specific criterion. However, in such cases, a careful assessment and deliberation were done in order to support the inclusion.
- Residing in nursing homes, residential care homes, assisted living facilities, home-for-the-aged, institutional care homes, long-term care setting or elderly homes.
- Following Hawkins's claims in 1991 implying that many pieces of literature existed in the public domain, this study intended to collect literary articles 6 years backward from 1991. Hence, the search range was from 1985 until May 2018.
- Only English-published article so that there was no need for translation.
- Peer-reviewed materials and articles that underwent screening and passed the standard criteria for publications.
- Any research study that passed the standard requirements of the research committee board.

#### **3.2.4.2 Exclusion criteria**

- Articles that do not discuss the meaning-making of the dying experience as an evaluated outcome.
- Articles that discuss near-death or end-of-life experiences which reported that respondents were having a change in consciousness and hallucinating.
- Subjects or informants that were terminally ill but infants or young adult.
- Those terminally ill in hospitals, hospice, home, and monastery.
- Those terminally ill diagnosed with a progressively debilitating disease but cannot express their thoughts and feelings. Or any dying person in nursing home that was diagnosed with cognitive impairment.
- Those dying persons that were comatose or unconscious.
- Age was less than 65 years old.
- Articles that were published earlier than 1985.
- Scientific studies that were quantitative in nature.

- Articles that were published other than English.

Literature included after the selection process was surveyed through two rounds of full-text review. In the first-round of full-text review, literature was examined from title to conclusion but somewhat lenient to allow more pieces of literature into the next round of review. In the second-round full-text review, strict inclusion and exclusion selections were applied. In this study, the importance of conducting two rounds of the full-text review was to ensure that potential literature items were not missed or overlooked. I also argue that as a single author of this study there exists no other persons to control the selection process and by doing the two rounds full-text review, I had the chance to control which literature has to be included and excluded.

### **3.2.5 Quality (Critical) Appraisal**

After the practical screening, I conducted a constructive appraisal of the primary studies in the month of August 2018. Appraising is necessary for critical realist SLR because many articles are not of equal quality (Okoli and Schabram, 2010). For Siddaway (2014), there is no actual agreement on the best way to appraise the quality of literature. Based on Siddaway's idea, a novice researcher like me will have a hard time deciding on which appraisal tool is appropriate to use since there exist much. To mitigate this challenge on my part, I searched online and investigated which tools were available and can be of benefit to my study. During my search, I encountered an assessment tool with 11 specific questions developed by Greenwood et al. (2009) and eventually adopted in the systematic review found in the work of Zhang and Lee (2016). This 11-item rating scale was used for deciding as to whether the paper was further included or excluded according to the merit of the respective methodological quality (Zhang and Lee, 2016). However, I was hesitant to use this tool because it has a tendency to further disqualify primary studies that were presumed low-quality. Rodgers and Hunter (1994) explain that the over-zealous exclusion of a presumably low-quality study created a problem in the past. In accordance with that idea, my motivation behind appraising primary studies was to help me understand and critique the methodological limitations or biases of the authors in their respective studies. I had no intention to omit any study, but I allowed the assessment in order to give me an impression of which study has the methodological rigor, and which one has not. I further argue that if only high-quality studies remain included there was a risk that significant insights from presumably low-quality studies were excluded during the synthesis of the idea. As a resolution, I decided to keep the primary studies regardless of results of the quality

appraisal because, as Siddaway (2014) suggested, the worth of each study might only become distinguishable at the point of synthesis rather than at the point of appraisal.

Aside from the 11-item rating scale, I found another tool which I think was of greater advantage to my study. To aid my assessment, I adopted the assessment tool revised by Letts et al. (2007) entitled: “Critical Review Form– Qualitative Studies (Version 2.0).” This appraisal tool has a strength to critique and assesses the quality because it has more specific questions that evaluate critical components of the included primary studies compared to that of the 11-item rating scale. Components of the critical review tool by Letts and company (2007) include: Study Purpose, Literature, Study Design, Sampling, Data Collection, Data Analysis, and Conclusions and Implications. For each component, it contained a specific question to help a reviewer construct the assessment. Scoring was not numerical, but it was only on a “yes, no, and *not detailed answers*.” For illustration, please refer to *Appendix G*.

### **3.2.6 Data Extraction**

This stage of SLR was carried out between the months of August and September 2018. In the commencement of data extraction, first and foremost, the primary studies included were saved to my personal computer using Microsoft Word software. One primary study was converted directly to Word file while the other could not be. The primary study that was not converted directly to PDF was converted first and eventually saved. The primary studies were then labelled with author’s name and year of publication respectively. Vital information from each primary study was extracted separately using the data extracting form that I prepared. Information collected from primary studies were: Authors name, Date and Country, Aim or Purpose, Study Design, Setting, Number of Participants, Data Collection Method, Techniques used for Analysis and the Findings. Please see *Appendix F* on how the methodological summary was structured. After extraction of vital information, subsequent quality (critical) appraisals were carried out. Please see *Appendix G* for the results of the appraisals.

During my extraction of vital information, one issue I found difficult was determining what counts as “the data.” In my early discussion in chapter 2, I have mentioned that those data that proposed explanations and showing relationships between concepts, structures, and the underlying mechanisms of the phenomenon are considered as data (Okoli, 2015). In this study, stories of the informants and actual findings from authors were counted as data. I argue that stories and findings from each study were important to be collected since there encompassed information that justifies the weight of findings from the two authors. Hence, stories and findings comprised the data transcripts.

Now, as the data consisted of stories and findings from each study, the next stage was synthesis. In preparation for the synthesis stage, my data transcripts were transferred to QUIRKOS software. After the trial on how to use QUIRKOS, I found it difficult to operate. As a novice researcher, it did not provide me with the flexibility and visual comprehension that I needed for my own understanding of the data. Authors like St. John and Johnson (2000) explain that although qualitative analysis software can help in the coding and retrieval of deconstructed data, it has a risk of decontextualizing meaning. Out from that reason, I opted to use the manual method. Though it sounds like conventional, this way it worked for me. I printed out the data transcripts, putting pages on it, and numbered each line for easy tracing during synthesis. This technique was in line with Becker's suggestion to number the extracted data transcripts sequentially and using line numbers (Becker, 1986 cited in Silverman, 2011). Subsequently, I used different color markers to highlight the voices of the authors and the informants' verbatim accounts within the transcripts.

### **3.2.7 Synthesis**

The whole synthesis stage was carried in the months of October to December 2018. Based from the suggestions of Siddaway (2014) and Bearman and Dawson (2013), I considered that the type of my research question, purposes of my study, nature of primary studies, and my epistemological constructivist stance all leaned towards conducting a qualitative research synthesis. That being said, I found thematic synthesis, as a form of qualitative research synthesis to be an appropriate technique because it can integrate diverse ideas from various primary studies by grounding the understandings in the exactitudes of the situation and informants' contexts and perceptions (Thomas and Harden, 2008).

In line with my interest to seek understandings from the voices of terminally ill and the voices of authors in primary studies, thematic synthesis was a compliment. Using the original voices from the texts, it revealed the social world and contextual accounts of those involved. However, Wilkinson highlights that although voices reflecting the actual talks of terminally ill and authors reveal the lifeworld, there is a tendency that voices compounded in texts are "used as *"means of access"* to something that lies behind or beyond it, rather than treated as of interest in its own right" (2011: 174 cited in Silverman, 2011: 214) thereby thematic synthesis can "lose sight of where the data (coded) sit within the whole (transcripts)" (Bloor et al., 2001: 64 cited in Silverman, 2011: 215). In other words, when texts are not treated as a solid source of reality in reference to its original context, then it allows escaping of the original understanding of the phenomenon from what is actually meant. To solve this potential problem during my synthesis, my constructivist approach provided a remedy to this constraint by reinstating the originally

enacted findings and studying how realities found in texts as constructed by those informants and authors of the study. For Silverman (2011), constructionism looks on the mechanisms involved and observing what the voices say within the texts and around the texts. By considering texts as a mean of access to various realities, I too consider how these texts evolved and constructed within the contexts of those reality makers. In doing so, I examined the processes involved including potential links, patterns, and unobserved reality on how the knowledge is produced. In that way, I considered constructionism as a compliment to thematic synthesis under critical realist SLR.

Before recommencing my synthesis, I reminded myself to remain true to the original accounts and findings of the primary studies. I read three times the stories of informants and the findings of each study without any pre-constructed thoughts. My sole purpose was to immerse myself and be acquainted with the data. Likewise, noticing what they were trying to say. This technique was somehow related to naïve reading. After immersion, the synthesis techniques by Thomas and Harden (2008) were applied. Please see *Appendix H* for illustration.

In ***Stage 1***, the transcripts were freely coded line-by-line. As I inductively coded the data, there were times that each line contains not only one code but several. Here, I paid attention to wording, phrasing, content, consistency of ideas, and specificity of expressions. As I continued coding the texts, I came to engage with the informants and their life-worlds where they make meaning of their dying experiences. Additionally, I also began to engage how authors understand their whole experience from their individual standpoints. I became immersed in the different worlds of experiences converging into different patterns and metaphors. The entire process was time-consuming, mind-boggling, and exhausting, but on the other hand, I began to notice contrasts and similarities of ideas. This “noticing” of similar ideas is known as the “translation of concepts” (Thomas and Harden 2008: 5), meaning what is seen in one data can also be seen on the other, though subtly. Despite similarities, it cannot be denied that there were also contrasting perspectives. As I remained open to translational concepts, I, too, was vigilant on the differing thoughts emerging. At the end of this stage, I developed codes iteratively until I expanded or shortened as I felt it needed.

In ***Stage 2***, I carefully examined the translational concepts and double checked against the original transcripts if the codes I created were reflective of both terminally ill persons and authors accounts. Next, I grouped together all similar and coherent codes against contrasting concepts. Likewise, observing hidden realities, processes, and links involved as suggested by Fiaz (2014). Here, I used post-its and a wall to have a visual presentation and a grasping of meanings. Out from these grouping of codes, I eventually created tentative themes that can address my research question. It took me ten attempts in creating and changing themes until I

reached a point where everything made sense and was inlined with central themes. In this same process, my actions were dynamic because there were times when I went back to stage 1 to re-code the texts and regrouped the codes. It was a cyclical motion of understanding, but the more codes being created, the more perspectives I generated. Here, I was able to understand the data in a broader and wider angle.

Concerning the arrangement of my arguments within the constructed synthesized themes, there were four distinct voices included: the voices of the terminally ill persons, the authors of primary studies, my own voice, and the voices of other authors which I utilized to support my arguments. To identify the voices of the terminally ill persons and the authors of two primary studies, I *italicized* their original accounts. And to make sense the whole data synthesis, I looked for connections between them, noting differences, and finally as Jesson et al. (2011) suggested, collated and presented the data by telling a new story in a meaningful way.

In ***Stage 3***, I described this process as challenging because it required me to “go beyond” the constructed synthesized themes. According to Thomas and Harden (2008), this stage is important because it will reflect the ability of the reviewer to give new insights. In this stage, I observed and examined processes involve on how knowledge of reality produced both by the terminally ill persons in the empirical domain and by the authors in the actual domain. After a long process of constant checking between my constructed synthesized themes, I finally went further and produced new understandings that were still grounded in the hope to answer the same research question.

### **3.2.8 The Writing of Systematic Literature Review**

The organization of the whole paper is purposely arranged according to the manner in which my arguments were built up. If I have been transparent, systematic and rigorous, it is because I have followed the ideas of Okoli and Schabram (2010), Aveyard (2014), Siddaway (2014), Okoli (2015); as well as, reading different published systematic literature reviews online.

To indicate my voice in this study, I have personally chosen to use the “first person” as suggested by Aveyard (2014). I am conveyed that it is suitable to use the first person all throughout the discussion so that the readers will keep track and locate my arguments since systematic review deals with many authors of literature. Moreover, as I form my arguments, I am committed to a thought that the philosophy of the past is timeless. What I mean by this statement is that whatever the thinking of the past was, it always has relevance to the present. My conscious decision of taking a value of anything from the past coincides with Hubert Dreyfus’s philosophy that putting interest on “making the thinking of the past relevant to the contemplation of the present” (Dramer, 2017: 38). It is essential to me as a novice reviewer to

relate a text or group of texts “to current concerns rather than freezing it in the past” (ibid). I argue that the value of the texts in my primary qualitative studies, be it from the past or present, is appreciated if reading and understanding it gives a significant difference and brings relevance to the present world, we are living in. I am convinced that literature, either past or present, discussing the meaning-making of terminally ill, has in one way or another relevance, since the phenomenon of dying has never been a concern of one but always of many. It is, therefore, fitting too that a critical realist philosophy in SLR underlines its importance by intertwining the knowledge of the past and present literature to generate understandings on a certain issue, topic or phenomenon that has relevance for many and not of the few. Thus, all throughout this study, the readers will notice the inclusion of old references combined with recent references.

Again, I give value to past literature because there is something in them that informed the present. I value the old references because thinking and contemplating historically, in that way, I also think relevant. Hence, by considering the importance of the previous authors, I am able to bring my thinking forward. Similarly, in this study, I also appropriate considering the well-known idea of Isaac Newton (1675): “If I have seen further it is by standing on the shoulders of Giants.” To me, nothing is ever more beneficial than to build my understandings from the authors and experts that have gone before me. As I humbly consider myself a novice, yet I argue that even a novice can see farther if I stand on the shoulders of past researchers and theoreticians. By considering those ideas, it influenced the writing of my whole thesis. As an overview of the structure and organizations of the whole thesis, there are seven chapters included. The brief outline of each chapter is discussed in the following.

*Chapter 1* is an introduction.

*Chapter 2* entails a discussion about critical realist SLR.

*Chapter 3* details the methods, processes, and ethics.

*Chapter 4* highlights the results of the systematic literature search.

*Chapter 5* presents the constructed synthesized findings.

*Chapter 6* contains the new interpretation of the constructed synthesized findings.

*Chapter 7* includes the final discussions.

### **3.3 Ethics Involved**

With my early discussions on the potential significance of SLR found in chapters 1 and 2, indeed, I established the fact that there are benefits we can gain from applying it. As SLR is getting more attention with regard to its capacity to answer a research question, there are ethical issues we need to consider. Bear in mind that “preparing a systematic literature review is a form of research and should, therefore, be undertaken in a responsible manner to ensure integrity and



avoid misconduct” (Wager and Wiffen, 2011: 130). With the influence of critical realist philosophy, I have addressed four fundamental ethics as I conducted my SLR, and these are: *transparency, accuracy, objectivity, and reflexivity*.

### **3.3.1 Objectivity: The Primary Ethics in the Selection Process**

In the conduct of my SLR, I noticed that the robust nature of the procedure improved objectivity by using an approach that lessens the random error and bias. One example of this objectivity was done in the selection process of literature. By using the predefined selection criteria, literature items that fulfilled the inclusion criteria were thus retained. This approach maintained the objectivity by giving merits on the significant contribution the paper may have and not on the author (Siddaway, 2014). Siddaway (2014) suggests that the unbiased selection of literature avoids the notion that I include particular studies because I favor certain authors or excluding a particular study because I have disagreements on another writer or researcher. Likewise, the selected primary pieces of literature were appraised using a standard assessment instrument to determine the overall quality. In this way, readers of my review will “interpret the results and conclusion within the boundary of my inclusion and exclusion criteria” (Siddaway, 2014: 3).

### **3.3.2 Transparency: The Overarching Ethics**

The obligations to conduct and report the results accurately, the onus is placed entirely on me as the sole author of this research. My study utilized literary articles as the primary sources of my data. How I searched and came up with the literature was all done in a systematic way starting from the databases searching, library visits, and ending with literature snowballing. The product of my literature searching was saved in a “data keeping sheet”. The actual “data keeping sheet” is found in *Appendix C* for reference and transparency. Likewise, the processes of how I searched and selected the literature articles were summarized in a flow diagram, see *Appendix D*. As for data extraction from primary studies and how I generated the findings, both were then explained in an illustration, please see *Appendix F* and *Appendix H* respectively. Likewise, reporting of the data to my supervisor was carried out so that there will be assurance of supervision to each in every step of the process including data retrieval and processing.

### **3.3.3 Accuracy: The “Should Never” Missed Ethics**

To ensure accuracy in the data extraction, I treated the results of each primary study as they were in order not to deviate from the original thoughts of the authors and informants of the primary studies. Likewise, the primary studies did not undergo translation since texts were written in English. By adhering to the original nature of the texts means I did not apply any

force to distort the facts that will favor certain assumption. Instead, I chose to remain true to the contexts of each primary study. Subsequently, the findings and discussions section of each study were printed out. Direct quotations of informants and personal texts of each author were highlighted with assigned colors. The prime purpose of highlighting the texts with assigned colors was to efficiently guide me in determining who said the claim from the discussion of each primary study, thereby maintaining accuracy during the audit trail. In every quotation and claim that I lifted directly from the primary studies, a direct citation was done to honor the authors and informants. Since primary studies were already published in the public gazette, doing an accurate citation was the only mean I can mitigate the issue of consent in SLR.

### **3.3.4 Reflexivity: The Cornerstone Ethics**

The ethics of reflexivity in SLR is a cornerstone under a critical realist philosophy. As a reviewer of literature, reflexivity specifies my ability to observe and account for my own activity (Bhaskar, 1989 and 2011 cited in Price and Lotz-Sistka, 2016). In my research, not only am I reviewing but also engaging and taking part in the whole process. As I am gradually transformed by my own learning process, it enables me to grasp the phenomenon I am studying. Similarly, whatever learning and thinking I developed, it challenges existing assumptions that bring continual learnings in the whole process. All throughout my scientific study, I practiced reflexivity by posing questions along the way as a form of engagement between me, the authors, and informants found in the primary qualitative studies. Through reflexivity, it strengthens my questioning mind to challenge the hidden assumptions. It develops my ability of self-reflection as to why such things happen, what I do know and I do not know, and what I think and feel or just simply what I understand about my role within the whole discussion.

## **3.4 Transitional Summary**

To keep us on track, chapter 1 has clarified how I became interested in studying the meaning-making of terminally ill elderly people; likewise, I also detailed how critical realism influenced me. Chapter 2 has accounted for the details of what critical realist SLR is and how to practice it. It was also in chapter 2 that I presented the idea that systematic review itself is a piece of research in its own right. In this current chapter, I described how I carried out my SLR based on practicability, logic, and manageability; and as well as, detailing some learned lessons along the way. Moreover, I also detailed the ethics involved namely, objectivity, transparency, accuracy, and reflexivity. Discussions about the results of conducting SLR, a summary of the methodological characteristics and the appraisals of the primary qualitative studies are then seen in the next chapter.

## Chapter 4: Results of the Systematic Literature Searching

This chapter entails discussions that answer objectives *i* and *ii*. To start with, the search began by applying the algorithms in 19 databases. It then generated 2310 hits of literature. These 2310 were screened by reading the titles and abstracts while using the inclusion and exclusion criteria simultaneously. Eventually, there were 275 potential literature collected. Aside from databases searching, there were 24 articles collected through hand-searching. Combining the 275 and 24, the total collected literature items were 299. From the 299 results, 27 literary articles identified as duplicates. After the removal of duplicates, there were 272 pieces of literature left and underwent first-round full-text review. In the first-round full-text review, I examined the literature starting from the titles to conclusions. However, in the first-round review, my selection process was not too strict in order to allow more literary articles to be examined for another round of review. In effect, the total number of articles collected were 9. These 9 literary articles were examined for the second-round full-text review, but this time the selection criteria were applied strictly. The rationale behind my second-round full-text review was to judge whether the literature items successfully leveled my inclusion criteria; at the same time, ensuring an overview which literature satisfied inclusion or had the potential for exclusion. Starting from the title down to the conclusion, all texts were scrutinized. By doing so, I had finally sort out literature items that were totally included. At the end of this second-round of the review, only 2 literature items remained. Using the reference lists of these 2 primary qualitative studies, I only conducted backward snowballing because of time constraints. In the backward snowballing, there were 16 potential literary articles were added in the data keeping sheet. However, from the 16 potential literary articles, there were none that met the inclusion criteria; thus, all 16 articles were also excluded. For a visual illustration, please see *Appendix D* for a flow diagram of the search strategy results.

In summary, the 272 literary articles drawn from databases and hand-searching added to 16 articles drawn from backward snowballing. In total, there were 288 pieces of literature underwent full-text review. These 288 articles were composed of 192 journals, 32 books and book chapters, 60 theses and dissertations, 3 essays, and 1 list of abstracts. For reference, please refer to *Appendix C* and find for *small n's*.

Still on the 288 articles, it was noted that from 1985 to May 2018 there has been an increasing literature that discusses the themes of death and dying. This trend confirmed the claims of Hawkins (1991) and Bingley et al. (2006) that indeed there were increasing studies interested in death and dying. Based from my systematic literature searching, there were 5 identified articles published in the years 1985-1990, 25 articles between the years 1991-2000, 118 articles in years 2001-2010, and 140 articles from 2011 to May 2018. However, only few

literature reviews have been conducted that specializes on death and dying in nursing homes, and surprisingly there have never been carried out any SLRs with critical realist considerations done in the field of social work. To illustrate, the result on the trends of the 288 searched literary articles in terms of publication year, please see *Appendix E*.

Again, these 288 literature items were saved on a “data keeping sheet” using Microsoft Word and eventually underwent strict screening. Out of 288, 286 were excluded while only 2 literature items remained after the strict selection process. These 2 pieces of literature became my “*primary studies*.” Reasons for inclusion and exclusion were based on the selection criteria that I detailed earlier. The selection criteria were transformed into codes for easy retrieval of reasons as to why a particular study was included or excluded. To illustrate this please see *Appendix C* and find the coding system and the remarks section.

The 2 primary studies included are as follows:

- “Opening Doors: Understanding the Experience of Dying” by Kulas, Gail (2001).
- “Tending the Soul of the Terminally Ill” by Kang, Seung Hee (2006).

These 2 primary studies were the results of rigorous, objective, and specific selections. As a critical realist reviewer, I argue that even with a small number of primary studies included there still possibilities to answer my *focus* research question. I further argue that since the nature of my SLR leaned towards *qualitative* reviewing of primary studies and not on meta-analysis that requires a minimum number of studies, the aims were to collect appropriate literature, synthesize them and provide many perspectives on the meaning-making of dying experiences. In fact, it is not the nature of qualitative SLR that is much concern on the sample size of literature or how many informants included from each primary study. For that matter, SLRs, as Popay et al. (1998) explain, are much concern on the relevance of primary studies rather than the randomness and representativeness of literature. Here, the ultimate concern of qualitative SLR is how strong each primary study can generate many answers via thick explanations drawn from the various school of thoughts (Okoli, 2015). In other words, the merit is given on the strengths of these literature items to produce many answers, and if those pieces of literature illuminate the subjective meaning, behavior, actions, and perspectives of those being researched. The primary marker of qualitative SLR is to provide knowledge and evidence to inform policy and practice that privileges lay knowledge or subjective accounts (Popay et al., 1998). This study was interested in the meaningful qualitative explanations that may help us in understanding the meaning-making of those terminally ill in nursing homes from their context. To increase the use of the context as means of locating knowledge of those terminally ill and

supporting their subjective meaning, my epistemological *constructivist* approach was a complement whereby it examines the patterns and underlying reality that provides the conditions of possibility both for actual events and perceived phenomena (Fiaz, 2014).

Regarding the extracted data, I noticed a problem in one of the two primary studies. It came to my knowledge that not all informants were included as stipulated in my inclusion criteria. Although informants were categorically terminally ill, not all of them came from nursing homes. Such observation was found in the work of Kulas (2001). To mitigate this problem, I read the whole paper again and searching for context clues as what I had stated in my inclusion criteria. I found out that only a few of her informants leveled my inclusion. This situation further indicates that I will only retrieve stories and accounts of those qualified informants. However, in spite of this deviation, I still considered Kulas's (2001) work based on merit that it can give a potential contribution to my SLR. The study of Kulas (2001) includes 5 informants namely, Christine, Hank, Frances, William, and John. Out of 5, only Hank and Frances leveled the inclusion criteria. While in Kang's (2006) study, Mrs. Erickson is the standalone informant. In this study, there were 2 authors and 3 terminally ill elderly people were considered to be examined as reality makers during the synthesis stage.

Before synthesis, each primary study was printed out, fixed with pages and each line was sequentially numbered. There were 18 pages and 980 sequential line numbers for the transcripts of Kulas, Gail (2001) while 8 pages and 303 sequential line numbers for the transcripts of Kang, Seung Hee (2006). Next, I assigned labels to each author and informant. These labels were: for Kulas, Gail was ***Author Kulas***; for Kang, Seung Hee was ***Author Kang***; for Hank was ***Informant Hank***; for Frances was ***Informant Frances***; for Mrs. Erickson was ***Informant Mrs. Erickson***. As labels were done, I used five different color markers to mark and trace the accounts of the 2 authors and 3 informants. The color markers used were: for Kulas, Gail I used dark pink; for Kang, Seung Hee was light pink; for Hank was brown; for Frances was dark green; for Mrs. Erickson was light green.

## 4.1 The Informants

From the two primary qualitative studies, there were three unique stories of individuals who were terminally ill or dying, aware of their conditions, and living in nursing homes. These were the stories of Mrs. Erickson (72-year-old), Hank, and Frances. Although age was not specified for Hank and Frances, Kulas detailed that each "had gray hair and wrinkles" (2001: 116). Again, in my inclusion criteria, I have stipulated that even though age is not specified, but context clues will be observed in order to help me out decide if literature is included. Hence, I included Hank

and Frances based on the merit that they can contribute essential understandings about the meaning-making of dying experiences in nursing homes.

The first story was from Mrs. Erickson. She became a widow a few years prior. She had eight children in all, but two had died. She was a woman of stature with a voice of confidence and authority. Mrs. Erickson was an independent woman until she had several strokes and one episode left her completely blind. Her doctor commented that if another stroke should happen, it might cause her death. When she became blind, she was in total darkness. Her transition to a nursing home became a big adjustment.

Another was the story of Hank. He lived in a senior residence together with his wife. The manner Hank told his story was direct and upfront. He detailed his life having cancer and his hope of having a cure. Hank was hoping that his cancer will be cured, but later he realized that cure was no longer possible. When the reality became so clear, Hank set things ready. He arranged his funeral and sorted out his financial and legal affairs in a way all were in order.

Different from Hank and Mrs. Erickson was the story of Frances. She suffered from breast cancer, underwent several surgeries and radiation treatments. Although the doctor did not label her as dying at the beginning, for her, as long as cancer was there nothing could be done. Her story was unique because she never waited for the physician to diagnose her. Prior to all these treatments, she already felt a lump in her breast, but she waited for her doctor to discover it. However, right in that moment of her own discovery, she grasped the severity of her reality. For Frances, her situation was serious, and she was dying.

## **4.2 Methodological Characteristics of the Primary Studies**

In 2001, Kulas published her own master thesis exploring the experiences of dying in Canada via the university's publisher in cooperation with the Canadian National Library Congress while Kang presented a doctoral dissertation on the same theme in the year 2006. Unlike Kulas (2001), Kang (2006) never mentioned the location of the study in a manuscript published in the *Journal of Counselling, Psychotherapy, and Health*. The two authors have different backgrounds and so in their disciplines. Kulas (2001), as a nurse produced her own various understandings of dying experiences that contributed the field of nursing while Kang (2006) approached the phenomenon as a therapy counselor and contributed the field of marriage and family therapy. These two primary studies have a qualitative nature, and both authors adopted a phenomenological approach. In the study of Kulas (2001), she followed the philosophy of Heidegger which has roots on hermeneutic phenomenology. Kulas (2001) focused on consciousness and the essence of the phenomenon by exploring the existential and interpretive dimensions, paying attention to the "taken for granted" moments and interpreting the metaphors

and words used by a storyteller in the attempt of making sense of the lived experience. In the work of Kang (2006), both a counselor and storyteller co-created the meaning of the lived experience. Kang (2006) never assumed a detached self in the understanding of the phenomenon, but instead situated a conscious self and engaged to the descriptive details laid by a storyteller. Furthermore, Kang (2006) as a counselor sitting in a therapist-conducted consultation acknowledged a storyteller as an expert of the lived experience.

Kang's (2006) study has a clear description of one setting, while Kulas (2001) recruited informants from various settings. Concerning sample size, both studies had recruited a small number of informants. Kulas (2001) had five informants while Kang (2006) focused on one informant. The relevance of their informants was appropriate in relation to the focus of their individual study. Both studies contained a discussion on their sampling technique. Kulas (2001) and Kang (2006) mentioned how and where they recruited the informants. However, Kang (2006) failed to reason out the motivation behind why the study was having only one informant. In effect, there were no comparisons of how the dying experience was understood from one informant to another. However, Kang (2006) still addressed the research question of the study by utilizing a descriptive phenomenological approach.

Both authors gathered their data through audiotaped interviews. To my assessment, Kulas (2001) interviewed Hank twice and Frances only once because the gatekeepers did not allow her for the second interview. In the work of Kang (2006), the interview happened only once with Mrs. Erickson. To my argument, the importance of conducting several interviews elicits a chance to validate the data collected; whereby, in my assessment, Kulas (2001) acquired this validation benefit over Kang (2006). In the data collection, both authors did not use assistants or interpreters but at least conducted the interviews personally and acquired a direct impression towards the shared experiences. Both authors manifested, at least, the capacity of eliciting data through contact interviews. In respect to the use of field notes, it was only Kulas (2001) that utilized the importance of field notes which she eventually used as a supplement together with the recorded interviews during her analysis. To my view, it was just essential for Kulas (2001) that she had field notes since she conducted interviews in different settings and with various informants in varied times. Different from Kulas (2001), Kang (2006) never mentioned the use of field notes since Kang (2006) never reported the frequency of interview with the informant. However, sitting as a counselor in the conversation with the informant, Kang (2006) only mentioned about the recorded conversations. This implies that Kang (2006) was entirely dependent on the audio recording device and that it became a way of facilitating the analysis. Finally, in spite of variations in their manner of making the analysis, Kulas (2001) and Kang (2006) demonstrated their abilities to create and develop understandings

on the experiences of dying. As a result, Kulas (2001) through her hermeneutical style produced twelve insights while Kang (2006) developed eight themes through thematic analysis. To illustrate the summary of the methodological characteristics of both primary qualitative studies, please see *Appendix F*.

### **4.3 The Quality (Critical) Appraisal of the Primary Studies**

With the aid of the modified form produced by Letts et al. (2007), the two primary studies were appraised on seven vital criteria which cover from study purposes down to the conclusion section of each study. In addition, the appraisal was necessary for my study since both two primary qualitative studies were published in different publications. Kulas (2001) published her thesis in the university's own publication after the recommendation and approval of the research committee, but not in journal form. Kang (2006), however, disseminated the study through a journal publication which underwent peer review. By applying this quality (critical) appraisal tool, I determined the similarities and differences including the strengths and weaknesses between these two primary qualitative studies.

The first criterion was on **Study Purpose**. Kulas (2001) and Kang (2006) deliberately outlined the purposes of the study. The stated purposes were also in-lined with their research questions, hence there was a good start in each study respectively. In that way, readers could quickly capture the point of interest as well as to the direction of their individual work.

On the second criterion, both primary studies presented **Literature Reviews** which became the ground to justify their personal motivations to conduct their studies. Both authors presented compelling evidence with regard to discussions on relevant past researches and successfully relate their study by pointing out the gaps.

The third criterion was on **Study Design**. Both primary studies utilized a qualitative phenomenology in which, in my point of view, it was appropriate because both authors were actually compelled to produce understandings about dying experiences. Moreover, as both authors tried to seek understandings of dying as a lived experience, phenomenology helped them explore the emotions, ideas, and meanings inherent within the experiences of all informants. Kulas (2001) and Kang (2006) were able to enter into informants' life-worlds through interviews and were able to capture the essence of the shared experience.

Concerning the fourth criterion on **Sample and Sampling**, Kulas (2001) detailed her reasons regarding purposive sampling of informants while Kang (2006) failed to justify exactly as to why there had only one informant in the study. To my assessment, Kang's (2006) failure to explain further concerning the sample size cast doubt for the readers as to whether there was actually a reason to remain in one sample. In contrast to Kang (2006), Kulas (2001) explained



her decision to stop the sampling after she had reached a sufficient depth of information to support her study.

About the fifth criterion, **Data Collection**. Both primary studies had similar sample profiles and described sufficient background information about their respective informants. In effect, both authors established the credibility and suitability of their informants within the framework of their respective studies. However, in spite of similarities in the collected data, there found to be a difference with their study setting. Kulas (2001) allowed the selection of informants from various settings while Kang (2006) focused on one site. As they conducted interviews in their respective setting, both authors successfully obtained the informants' approval prior to the actual interviews. The way Kulas (2001) reached her informants was through an initial meeting with the gatekeepers and eventually got the chance to contact them. However, Kang (2006) failed to mention how the informant was recruited. With regard to data collection, both authors explained their roles in the whole data collection process, described their relationships with participants, and laid out their individual biases and assumptions before the commencement of data collection. However, comparing these two primary studies, I found Kulas (2001) possessed more procedural rigor than Kang (2006) since Kulas (2001) has detailed more narrative descriptions about her effort in carrying out the tasks pertinent to data collection.

The sixth criterion was on **Data Analysis**. The two primary studies successfully developed an inductive analysis from their data. Both authors mentioned the processes of coding, reflecting, categorizing, and understanding the data as a whole. More so, Kulas (2001) and Kang (2006) justified their methods used in analyzing the data with respect to their individual philosophical stances. Kulas (2001) followed a hermeneutic phenomenology that eventually led her to develop twelve themes in her understanding of dying experiences, while Kang (2006) followed the existential phenomenology which in turn gave eight themes describing the informant's experience. The manner of their arguments was all consistent with the data; and in effect, their ideas were inclusive and reflective of all the data that exists. That being said, Kulas (2001) and Kang (2006) showed the analytical rigor and brought emerging ideas into the fore. Admittedly, the new ideas and understandings produced from the two primary studies echo the two authors' efforts that their findings were formidable reflections of the phenomenon and reflective of those persons with a similar profile in a similar setting. However, in spite of these compliments to their works, yet I am of two minds about Kang's (2006) strategy in data collection, particularly in the interview section. I have mentioned elsewhere that Kang (2006) conducted the interview just once and never said of any follow-ups or validation of the data with the informants thus this made me question the confirmability of the interview data. I argue that even though Kang (2006) had one informant but still the

importance of validation of the data must be upheld to achieve confidence in the results. Unlike Kulas (2001), her detailed reporting carries a proof that her strategies were trustworthy.

The last criterion was on the **Conclusion and Implications of the Study**. Both authors clearly stipulated that their efforts in the study will tend to uncover the dying experiences and generate more understandings of the phenomenon. In that aspect, Kulas (2001) and Kang (2006) achieved the purposes of their study. They did not arrive at one sounding conclusion, but instead offered many perspectives which brought the readers into a horizon of many possibilities in viewing dying experiences. Essentially, Kulas (2001) and Kang (2006) were able to discuss and synthesize the data and finally highlighted their final statements in congruence with the findings they achieved. As a matter of fact, their conclusions brought impact and significance to their respective fields of specialties.

In conclusion, the primary qualitative studies were well designed and structured with meaningful and valuable findings. The purpose and background of each study were cleared and concise. The results were well analyzed. Kulas (2001) gave a hermeneutical understanding of the phenomenon while Kang (2006) produced a detailed discussion of the dying experience. To my assessment, both authors employed appropriate designs. The only downfall of Kang (2006) was on the method of data collection, wherein an explicit explanation was expected. Contrary to Kang (2006), Kulas (2001) detailed her justification and motivations to a greater degree in which readers can be able to understand her methods of data collection. Both studies have identified their limitations allowing scholars the chance to modify or further research on the same topic. Based on the result of this appraisal, I recognized that both studies successfully addressed their respective research questions. Although there were little variations in some areas of the criteria set by Letts et al. (2007), both authors never produced poor-quality literature. To illustrate the content summary of my quality (critical) appraisal, please see *Appendix G*.

#### **4.4 Transitional Summary**

In this chapter, I have detailed the searching strategy results using databases, hand-searching, and literature backward snowballing. Out from the many pieces of literature sifted from different sources, I end up with 2 literature items. These 2 primary studies were considered sources to answer my research question. Also, in this chapter, I have described the literature development that concerns dying studies; likewise, the methodological characteristics and quality (critical) appraisal. On the next chapter, I will present a discussion of my synthesized findings by applying a constructivist approach.

## Chapter 5: The Constructed Synthesized Themes

This chapter contains a discussion that addresses objective *iii*; at the same time, it is the product of undertaking stages 1 and 2 of the thematic synthesis by Thomas and Harden (2008). In stage 1, I created 115 codes which were then downsized to 4 synthesized themes as I undertook stage 2. In this chapter, feature only 4 final themes. The discussion entails the themes that are translational and emergent from the work of Kulas (2001) and Kang (2006).

The process of synthesizing became possible because of the three terminally ill persons: Hank, Frances, and Mrs. Erickson, who shared their personal stories. Likewise, the two authors: Kulas (2001) and Kang (2006), who have devoted their time to listening and understanding the plural possibilities of dying experiences. Moreover, as I am one with critical realist tradition, accessing the real domain of reality helped me to immerse in the dying experience. As an effect, the conceptual understandings that I have developed are the product of my textual engagement with the two authors situated in the actual domain and the terminally ill persons located within the empirical domain.

It was a challenge, however, at the start of my synthesis, since it would bring further insight than what these primary studies had yielded. The synthesized themes are my enlightenment as I am searching for answers to my research question. As I immersed in the data, I encountered difficulty while seeking direct and apparent themes to answer my scientific quest. However, as I reminded myself of how I operationalized earlier the terms *meaning-making* and *dying experience*, I realized that dying itself contains a cluster of meanings (van Manen, 1997) and a complex embodiment of abstractions (Frank, 1995). In other words, there were many concepts and ideas included in dying. As I attempted to understand the dying stories, an openness within myself was required in order to capture the meanings of the phenomenon of dying. Through my realizations, I allowed myself to be conscious to many possibilities of understanding during data immersion. As I reviewed the two qualitative primary studies, I then noticed that conversations of dying persons contemplate their past and present lives, recollection of events, the happy and sad thoughts, their possessions, their family, church, faith, and music. It all seems a conduit of past and present experiences and the mixture of abstract and hidden personal meanings. It is thus, in this chapter, that I develop my constructed concepts about their meaning-making efforts. I mentioned constructed because, under the constructivist approach, I understood and made sense of the possible understandings of their experiences, not only by my own thoughts but by the meaning they shared, accessed both in the empirical and actual realities. To bring coherence to my synthesis, I present themes that outline the flow of my constructed ideas.

## 5.1 Indicating the Villain that Interrupts Life

Based on the data, what I noticed was that in the advent of their making-meaning of their dying experiences, they tend to make sense by telling stories of the things, something new to them. They told their dying stories by reflecting in the past that involves mental or temporal recollection of events (van Manen, 1997) and eventually highlighting “villains” in such a way their listeners can understand before jumping to the climax. The author like Frank explains that terminally ill people “tell first the condition and later the self otherwise no one dares to listen” (1995: 61). Furthermore, the obvious observation found in the accounts of Hank, Frances, and Mrs. Erickson was that they found themselves in a situation trying to think about and deal with the new things in their lives. They think and deal with new things differently in order to attain a new perception of themselves, their conditions, and positions in the world they belong to (Frank, 1995).

Inherent in their stories was the revealing of something villain has come. They become the protagonist trying to guess the true name of the antagonist (ibid). Like Hank, he was direct and to the point in telling his story. He never thought of any reservation but was frank about his condition and said, “*it’s cancer*” (**Informant Hank P1/L15**). As he told his story, Kulas described him:

*“(Hank) spoke with a clear loud voice... it was as though he was driven by his need to teach me...to tell me what he knew, as though everything was ordered and defined”*  
(**Author Kulas P1/L12-18**).

The manner in which Hank opened his story involves a sense of conviction of what was the villain. He highlighted a disease that he dealt with until he was sure it was cancer.

Similar to Hank, Mrs. Erickson knew that her episodes of strokes were the reason for her being terminally ill. Her stroke made her life pass through hell. She was as if accepting her impending demise after she was told by a physician that “*another stroke might cause her death*” (**Author Kang P1/L18**). Earlier she had experienced several episodes of strokes, and they eventually became the reason for her blindness. Imagine how hard for her to lose her eyesight. For Mrs. Erickson, it was difficult “*not being able to see anything*” (**Informant Erickson P1/L32**). It was the episodes of strokes that changed her and even her ways of living each day.

For Hank and Mrs. Erickson, their clear convictions about their conditions were reflected in their ways of convincing the listeners about the knowledge passed on to them. Here, I argue that they are not trying to tell stories out of their imaginations but stories with defined concepts of “cancer,” “stroke,” and “blindness.” However, this was not the case with Frances. As Frances navigated her story, she started it not with a definite term but describing there was

something in her body. Though it was vague for her, still she said, “...*just a lump about here, which I knew was there...*” (**Informant Frances P3/L122-123**). In her sentiments, there was evidence of no clarity as to what was exactly the lump looks like, yet she knew it was serious. She never waited for her physician to determine her fate, but “*she called herself dying*” (**Author Kulas P3/L122**) and created “*a story about how she believed she was dying*” (**Author Kulas P3/L118**). What made Frances different from Hank and Mrs. Erickson was her personal conviction knowing that a “lump” signifies something serious. She knew that a lump became the villain although it was not yet defined what it really was.

For Hank, Frances, and Mrs. Erickson, their conditions and illnesses are villains in their lives, and living in a terminal illness means living with interruptions (Frank, 1995). As interruptions are present, they discover and make sense of their situations. Otherwise, if they will not speak of interruptions, they become silenced (ibid).

## 5.2 Infusing Personal Efforts in Meaning-Making

When a person is dying, one engages in the space of contending and challenging or for some just simply appraising the personal experience. For Hank, it was a moment not to succumb easily with cancer but to explore possibilities. At first, he explored what more to being than dying is. He told stories about the reality that he was dying and then other moments of high hopes of getting a cure from cancer. This contending behavior was reflected in his statement “*I have to do something about it myself*” (**Informant Hank P1/L16**). It was evident in Hank’s voice that he was trying to figure out and seek what was best. As if he was bargaining if he could find the chance for a cure. Does this mean that he wanted to be healthy again? It seems his own desire was compounded by the expectation that he can be healed. His desire was perhaps influenced by a “contemporary culture that treats health as the normal condition that people ought to (be) restored” (Frank, 1995: 77) and “requires bodies to be depressed and thus fixable” (Frank, 1995: 112). These contradictions were pointing to the “*multitude of tensions a person may be feeling*” (**Author Kulas P1/L46-47**). What I have observed in the data was, as if Hank was dancing between living and dying, and while he was dancing in uncertainties, he contended his illness with thoughts of possibilities.

While Hank was contending his cancer with hopes of a cure, Frances has a different approach towards her situation. Hers was different from the hope Hank wants. Frances knew from the beginning that something was present in her body. She knew that something unusual and strange was happening inside her, but she let it pass. It was reflected in her statements:

“... *I knew it (a lump) was there but which I didn’t tell her because I thought we’ll just let her find out for herself (physician)*” (**Informant Frances P3/L123-124**).

Perhaps in Frances's words, she was accepting of her fate that whatever it was, nothing could be done? Does this mean that Frances imagines her life as nothing getting better? Was she concerned about her body and her condition at all? Do her actions accounted for being passive? Does being passive meant neglecting the chance of medical interventions? It was evident in the data that Frances never acted immediately upon her discovery of a lump. Kulas described Frances's action "*...as though she was playing a harmless game...this game of hide and seek*" (**Author Kulas P3/L127-128**). On the contrary, behind Frances's action was a woman convinced that she was dying; more so, her behavior posed a challenge as to what usually the medicine dictates and operates for those assuming a sick role. Might Frances be certain of her death and believed that her mortality is unavoidable? By considering Frances's behavior, the author like Frank (1995) points out that Frances will not allow herself to be crowded by medical contingencies. For Frances, she trusted her intuition, believed in it, and challenged to what the medicine dictates. Furthermore, Kulas offered an alternative reason to justify her:

*"Maybe for Frances it was a game where she snickers as she played along with what medicine dictates...this seems but one way to create a space for herself in a medical system that overpowers, dictates and dominates people"* (**Author Kulas P3/L130-133**).

Different from them was Mrs. Erickson. She neither contended if there were alternatives to alleviate her condition nor played a hide and seek game to challenge medical hegemony, but she already knew the severity of her condition. She knew she was terminally ill and described her experience as "*It's hell...it's very very difficult, and it's very emotional*" (**Informant Erickson P1/L32**). Although she was in a place of difficulty and struggle, yet she managed to understand her situation and to make her adjust easily. She went through "*darkness*" (**Author Kang P1/L15**) but accepting of her fate as it was. In the early stage of her dying, she appraised her experience as 10 signifying intense difficulty until she rated it 4 signifying acceptance. The appraisal she made became a revelatory moment that helps her to move "*from hell to acceptance*" (**Author Kang P1/L26**). Mrs. Erickson met suffering head on and accepted her illness. Frank (1995) describes Mrs. Erickson's illness as a journey that become a quest.

For these three terminally ill people, the reality of dying elicits varied reactions. Although they are not free from pain and limitations, they still infuse personal efforts to make sense of the experience (Ashfield, 2012). As the dying experience is unique and individual, the outlooks and reactions of those dying may also be unique and personal (Saunders, 2003). Here, the contending efforts of Hank, by challenging to the constraints made by Frances, and even the appraising efforts of Mrs. Erickson are all varied personal reactions adopted by dying elderly people while they are in the space of meaning-making.

### 5.3 Adopting Different Ways to Restore Meaning to the Dying Experience

Terminally ill persons find ways to recover and restore meaning in their dying moments. Hank opened his sharing with his statement saying, *“that’s up to you... this is going to help me get the cure”* (**Informant Hank P1/L14**). His words suggested that in the act of his storytelling and sharing he found a cure. The cure he meant was not a cure from his own illness but something a cure he wanted for his inner self. Kulas described Hank’s action as:

*“In the process of dying, people are still in the process of redefining themselves, understanding who they are, and how they live... constantly creating meaning in their lives, meanings of their life and meanings of their dying and death. As though these stories are monuments that tell of the enduring significance of their life”* (**Author Kulas P8/L386-389**).

Not only the act of storytelling helped Hank find a cure, as he claimed it, but also the selling of his treasured possessions. He sold his car, musical equipment, and fiddles. All these things with value and significance. Following Wallendorf and Arnould (1988) and Belk (1988), these objects are important to Hank because they become storehouses of his personal meanings, extensions of himself, and reflections of his self-identity. But why does he sell them if those were of value and with significance? The author like Belk (1979) suggests that Hank’s action is seen as fulfilling the higher-order need for actualization. In this case, Hank is truly convinced that death is coming and by giving away his possessions is a symbolic action for an actualized being that is ready to find the right recipient for his valued things. By his act of finding recipients, in that sense, Hank is immortalized in the memories of those receivers (Stevenson and Kates, 1999). Furthermore, Kulas offered another possible reason for Hank’s action:

*“Preparing for death is as much about control as it is about dying...arriving at a place of preparedness is a process that never stops but constantly changes in personal meaning... readiness for death had taken on a different meaning in Hank’s life (and) it was more about preparing for others in the reality of his death.”* (**Author Kulas P8/L443-457**).

Here, as death comes near, I noticed that Hank never ceased his responsibility, and it only reflects perhaps his role as the head of the family that takes control.

Based on these observations, I sense that sharing of stories and selling away of valued possessions are among the many acts that dying elderly people utilize to restore themselves and finding meaning before they die. How Hank managed his journey moving forward was through stories and selling of valued possessions. Though death is irreversible in his case, Hank as an

actualized being finds ways to show control over his situation. All of Hank's actions suggest that after all *"preparation gives people direction and purpose"* (**Author Kulas P9/L484**).

Different from Hank was Mrs. Erickson. Her ways of restoring meaning for herself have been contributed to many factors. The one above all other factors was the support from her daughter. As Mrs. Erickson lived her life every day in darkness, her daughter was the core support. It was highlighted in her claim:

*"If I am really down, my daughter will come from work...otherwise, she talks to me on the phone and calms me down and even gets me laughing"* (**Informant Erickson P2/L52-53**).

I figure out that with Mrs. Erickson's situation inside her was a woman of vulnerability, and her daughter was a grace of support in times of her inner battle for restoration. Her daughter performed the role of a confidant and remained with her in finding a new meaning of what is happening. Here, I argue that behind her daughter's action lies a saying that "even when we feel that we can do absolutely nothing, we will still have to be prepared to stay" (Saunders, 2003: 4). In doing so, her daughter gave the feeling of reassurance and safety that comes from faithfulness for her mother (Saunders, 2003: 5). I am convinced though that between them there is a forging of a real confidence wherein Mrs. Erickson herself feels welcomed and accepted in the person whom she knew well. Aside from her daughter, music was also a great help to her. In her statement, *"I think of classics in religions...just a quiet music...the hymns"* (**Informant Erickson P5/L161**). Similarly, it was evident that music *"made her feel upbeat, happy and lively"* (**Author Kang P5/L160**). In that sense, music allows a direct connection, rediscovering and reintegrating of her inner self to her own body (Frank, 1995). The type of music she used to listen also reflects a strong connection to her faith, and her faith to the "Divine" made herself resilient and finding inner strength. Mrs. Erickson's spirituality was heavily noticed in her own efforts in dealing with the impending death. Spirituality, in that sense, influences her own continual process of making meaning. In effect, her making meaning that involves spirituality allows her to reappraise her illness as an opportunity for changing her own beliefs and goals, and more certain, her own faith (Park, 2013). However, this influence of spirituality in dying moments is contested. Kulas, in her own words, explains:

*"Spirituality often attempts to stabilize the uncertainty of life (and) belief in a high power absolved (a dying person) of the responsibility of dying...(thus) dying is interpreted as an event without being met by resistance"* (**Author Kulas P6/L303-309**).



In other words, spirituality may allow a dying person to see death as something not to be combated and passive in finding meaning because demise is already ordained and nothing more can be done.

It is also accounted that personal mantra has been one of the factors that facilitate change in the lives of dying people. Based on the data, I observed that the mantra became an internal synergy. The constant remembering of mantra by Mrs. Erickson becomes an unconscious chanting that keeps her mind at rests amidst dismantling thoughts (Bhawuk, 2003). In the end, her “*never ever giving up*” (**Informant Erickson P2/L71**) mantra kept her “*moving forward*” (**Author Kang P2/L68**) in the life remaining.

External support has also been evident in the data from which a terminally ill person draws encouragement. While Mrs. Erickson was in the nursing home, her statement of “*cooperation with the staff*” (**Informant Erickson P2/L49**) was an evidence of how an institution played a beneficial role for her in the whole process. As she got encouragement from nursing home staff, her church where she belongs has also been another network of support. However, although the two mentioned social networks were evident with Mrs. Erickson, yet it has not been so obvious to Hank and Frances. When Hank detailed his story of the significance of physicians and the healthcare system in his life and dying, he emphasized his needs nevertheless to take charge of his life. Hank still manifested his personal responsibility towards himself and the things around him. The presence of treatment institutions and the people working in it help Hank in his dying journey, yet Hank never belittles his ability to take control. However, in the case of Frances, she has a different experience with the institution that took care of her. Although she was not diagnosed as terminally ill in accordance with the physician’s diagnoses, Frances considered herself dying. She was dying basing from her belief that there was something serious happening in her body, yet the institution was so reserved about her situation and her diagnoses. In spite of that, Frances:

*“created a reality where she placated the medical establishment by letting them think they know about her and about her illness. Frances’s physician had not even told her she was dying. Yet she knew she was. Perhaps dying is not inextricably linked to a diagnosis (Author Kulas P3/L133-136).*

Support mechanisms have been evidently helpful for Hank and Mrs. Erickson, but sometimes they have their limitation like in the case of Frances. To my argument, situations like this indicate that external supports and networks can be of benefit and sometimes contradicting in ways how terminally ill people make meaning of their dying experiences.

Still from the data, these three terminally ill persons use the word “it.” In the story of Hank, he used “it” to identify cancer. Likewise, Frances used “it” to label a lump that eventually diagnosed as cancer, and Mrs. Erickson expressed “it” to identify her stroke that gave her blindness. Here, I argue that they used “it” in a context to justify what considered to be the villain; and thus, to ensure that the villain is understood by them. They use a certain language to “discuss (their) experiences in the world...and in order to speak about them, (and) place a label on them” (Flaming, 2000: 33). In other words, “it” as a label becomes a strategy. They use the word “it” to make sense and communicate themselves and towards the world (Flaming, 2000). I also argue that as they use the word “it,” it becomes a label to indicate *something* and to denote that *something* has nothing in possession over them and of their identities. For them, cancer, a lump, stroke, and blindness do not own them but are only part of their lives.

Though they are terminally ill, Hank, Frances, and Mrs. Erickson took charge, owned, and lived their dying experiences. They managed to find continuity in life through words, telling stories, relationships, networks and supports, and material belongings. So, the “different ways” that I am referring to here are counted as the coping mechanisms they had utilized to help them back to their own body, and as they back to their bodies they found their own way out of the struggle and discovering a continual balance in their everyday lives (Frank, 1995).

## **5.4 Placing Meanings in the Various Aspects of Life**

Terminally ill persons that are aware of their situations uttered that out of their dying experiences come diverse meanings emplaced in their lives. Meanings are made because of the consciousness of terminally ill persons, and in fact, they played a primary role in rectifying the discrepancies between the present situation and their personal desired goals (Park and Folkman, 1997). Together with the intrusive thoughts that deluge the minds of terminally ill persons, this pushes them to make efforts to review and reflect in order to be informed of what is now true and fantasy (Janoff-Bulman and Frieze, 1983 cited in Park and Folkman, 1997). I argue that these efforts prepare them to make new adjustments and accepting of a realistic situation. In effect, terminally ill persons continue sorting out information until change and reality have reached an accord (McCann et al., 1988 cited in Park and Folkman, 1997).

Like Hank, he clarified his personal goals and values by figuring out what would be his priority in life remains. In his words, “*I’m getting everything all set and ready before I die*” (*Informant Hank P8/L415*) sets a new tone. As Hank sets everything ready, I argue that he manifested a sense of empowerment within himself, an empowerment that comes out from him being an actualized person, by taking control and by being prepared. He made efforts to put things ready because he knew that his situation cannot be changed. He understood that the

reality of death was sure and biological life cannot be extended. By acting out his desired goal in accordance with what was the real situation, Hank distinguished the “what is now true and what is fantasy.” In doing so, he felt as if he was making a difference by putting and organizing essential things in place before his death. In return, Hank saw the meaning, purpose and was changed by his efforts. For the author like Sandstrom (2005), Hank’s experience provoked him to deeply reflect upon the essence of his life and goals for self.

As death draws near and heightens, terminally ill often derive growth and expansion. To my observation, growth and expansion were evident to Mrs. Erickson. Although she was physically dying, her experience rippled spiritual growth because she recast her struggles as it was like a spiritual journey (Frank, 1995). Clearly, Mrs. Erickson’s religiousness helps her to understand her own world and situation, and that suffering becomes bearable for her (Wuthnow, Christiano and Kuzlowski, 1980 cited in Park and Folkman, 1997). Here, the religious perspectives of Mrs. Erickson “provide meaning at the level of personal significance, causal explanation, coping and outcome” (Park and Folkman, 1997: 121). Spirituality, in such instance, stirs existential progression and expansion.

As the illness continuously unfolds and the health diminishes, terminally ill persons demand less of themselves (Sandstrom, 2005). Following the statement of Frances “*for goodness sakes we can’t live forever you know*” (**Informant Frances P5/L262-263**) and “*one thing about having cancer, nobody can do anything much about it... it is something that’s inevitable*” (**Informant Frances P6/L285-286**). To my observation, in her word of inevitable, she never reckoned death and its inevitable reality but accepting that her life will end. I further observed that acceptance does not require a demand for pursuing extensive life measures. Her sense of acceptance “has emerged as a valuable construct in understanding adjustment” (laChapelle et al., 2008: 202). Adjustment to what is inevitable settles herself into a realm where she never resists death but living in a present moment and gradually descends to what is destined.

More so, terminally ill persons often develop an awareness of relationship restoration (Sandstrom, 2005). This situation was evident to Mrs. Erickson. In her own words she said:

*“we have moment that we (family) disagree, but everybody does. It’s over and done...we talk it out and don’t bring it up again”* (**Informant Erickson P6/L193-194**).

Based on that data, I argue that this situation is forging a substantial relationship of “*mutuality and dialogue*” (**Author Kang P6/L184**). For Mrs. Erickson, restoring of familial relation rekindled meaning produced by a mutual understanding and dialogue to heal and to move forward. This idea revives a new meaning, as I understand it, is not an end in itself but

this further enhances continual closeness of the mutual relationship between a terminally ill and the loved ones. Such understanding is seen in Frankl's (1962) assertion highlighting that forged meaning becomes a catalyst for an enhanced sense of connectedness and that it just goes on in the present healing moment.

From these three dying experiences, it is evident that ordeals reconstruct and make a new meaning of life expressions in the various aspects of their lives. As terminally ill persons come to terms with their finitude, their search for meaning intensifies. In turn, that meaning gives a fresh new meaning towards themselves and others, and subsequently distinguishes what is true and what is fantasy. The achieved meanings aid them to see a new breath of existential perspectives and ultimately set them above from the expected fate (Frank, 1995).

## **5.5 Transitional Summary**

Through this chapter, I have presented the meaning-making efforts of terminally ill persons in nursing homes. There were four central themes made and reflecting the meaning-making efforts drawn from the synthesis of the two primary qualitative studies. Inherent in the themes were constructed ideas as I understood the life-worlds of Hank, Frances, and Mrs. Erickson together with the dynamic understanding of Kulas (2001) and Kang (2006). The themes were: indicating the villain that interrupts life, infusing personal efforts in meaning-making, adopting different ways to restore meaning to the dying experience, and placing meanings in the various aspects of life. As much as we have learned from this chapter, I invite you to chapter 6 as I present the expanded knowledge of the four constructed synthesized themes.

## Chapter 6: The Expanded Knowledge

This chapter discusses the expanded knowledge of the constructed synthesized themes; as well as, answers to objective *iv* of this study. This is also referred to as the “going-beyond” of stage 3 in the thematic synthesis by Thomas and Harden (2008). The product of undertaking stage 3 is the 2 new understandings out from the constructed synthesized themes. What I will discuss in this chapter still has a connection to the original research question.

Correspondingly, I have mentioned earlier that methodological summary and the results of quality (critical) appraisals were utilized to examine underlying issues thus achieving better hindsight in formulating my own arguments. In my observations of the data, I notice that the stories of Hank, Frances, and Mrs. Erickson are diverse and different from one another. Although they are in the same situation of dying, the embodied meanings weaved into their experiences were unique. As unique as their experiences are, are there hidden messages that I can bring to the fore? Also, bringing their voices together speaks not of a single dimension of meaning-making but of multiplicity and complexity of the whole experience. In the same way, the difference between how Kulas (2001) and Kang (2006) presented their findings offers me different perspectives on how I understand the context of meaning-making in dying. Instead of doing straightforward thinking, I explore and examine the phenomenon of interest from different angles just like the ambitious intention of critical realism of investigating reality in all possibilities and in a critical way.

### 6.1 The Contrasting Issues

Looking back to my constructed synthesized themes, I observed two emerging issues that have different sides. Firstly, an issue that pertains to institutional influence; and secondly, spirituality. On the first issue, the institution where one terminally ill resides may play an influential role in the whole meaning-making of dying experience. In Frances’s case, the institution represented by her physician was reserved concerning her diagnoses. Frances was not diagnosed as terminally ill, yet she believed she was dying. Though she was not diagnosed as dying, does this mean that she has no right to make out the abstract things to which she feels real? Is it really a need of diagnoses before a dying person makes meaning of the experience? I argue that Frances made a distinction in herself by creating a space to contend the hegemonic power of medicine and medical institutions. She never waited for her physician to let her know that she was dying. Frances knew that once she has cancer, there is nothing that could be done. The time she discovered a lump on her breast was the same time that she figured out that something was serious. She reacted to the reality that a lump means something though she never fully grasped if it was indeed cancer or not. It was her dire reaction upon her own discovery.

To my observation, Frances challenged the impression that one must act out before a person is diagnosed with such illness or disease. She never waited to be labeled terminally ill to believe she was dying. She defined herself and her situation in ways that do not trap her within the forms of repression and confess her own “truth” outside the boundaries of biomedical and therapeutic discourse (Sandstrom, 2005). Similarly, her ways created resistance against the loss of her personal autonomy and possibilities for personal action to which medicine and health institutions potentially do (Komesaroff, 1995). Contrary to Frances’s experience, Mrs. Erickson has a different story of a nursing home. In spite of her situation, she had the support of the staff. The role of a nursing home in Mrs. Erickson’s experience was different from that of Frances. A nursing home was portrayed as helpful to Mrs. Erickson’s situation.

Now, what seems intriguing to me is the juxtaposed influence of nursing home as seen in the data. To examine this issue, as a critical realists reviewer, I need not only to explore how this issue emerges but also how the authors derive the data. What has been the results in the primary qualitative studies each author has something to do about it. By reviewing back to my qualitative (critical) appraisal, I found out that Kulas (2001) has been allowed once in her interview with Frances. Could this be the reason that Kulas (2001) became partial in her findings? Perhaps in the mind of the physician sparks the idea that Kulas’s (2001) insistence and presence could be detrimental to Frances, and so the necessary measure should be done to protect Frances’s interest.

Consequently, by that incidence, Kulas (2001) made a strong emphasis on the controlling aspect of health institutions as represented by the physician. Such a focus can be considered a projection mechanism of Kulas (2001) because she was never allowed for another interview with Frances. Granted that the bases of Kulas’s (2001) action are speculatively correct, but Frances volunteered herself and decided to be interviewed in the first place. In Frances’s world, she believed she was dying and her efforts to make sense of everything was a way of coping.

In contrast, Kang’s (2006) work highlighted the positive impact of the institution on Mrs. Erickson’s experience of being terminally ill. Was there any reason to explain this observation? Again, my evaluation of Kang’s (2006) work highlighted that Kang (2006) had descriptive phenomenology research and the data was collected through a one-time interview. To my argument, there is a little advantage when research is done in descriptive phenomenology instead of a comparative. The reason is, it does not include so many opportunities to see varying perspectives and contrasting issues to focus on. There might be missed opportunities in seeing farther from the things the way they are. If only Kang (2006) explored more views, there might be more potential understandings to this issue.

Further, another problem was Kang's (2006) interview done only once; at the same time, the number of informants was limited to one. To me, Kang (2006) does not have the opportunity of seeing other angles to examine the data across different informants, thus offering a limited understanding of the findings. Or might it be that Kang (2006) as a counselor working in the nursing home only allowed portraying the good side of it? If this is true, this could be a reason for a possible bias presentation on the role of a nursing home. Granted there is bias, yet in the words of Mrs. Erickson were direct revelations that indeed a nursing home has been encouraging and supportive. As terminally ill, would Mrs. Erickson make any story just to portray the good side of a nursing home? What benefit would Mrs. Erickson get from this if she created a fictional reality? I doubt that Mrs. Erickson confabulated her accounts for the purpose of showcasing the good side of the institution that cared for her.

With these contrasting results concerning the impact of a nursing home in the meaning-making of the dying experience, I have found no more expounding reasons to justify what is behind the difference. What I have presented here is my explanations based on my objective assessment of the primary qualitative data. However, if this issue on the impact of a nursing home in the meaning-making of the dying experience can be further examined in a more focused study in the future, might we can draw extensive ideas and so grey areas on this issue will be clarified.

On the second issue, spirituality has varying effects on the meaning-making of the dying experience. In the story of Mrs. Erickson, it was clear that her faith and religion had impacted her coping ability and so her meaning-making efforts. In her darkness, struggles, and ordeal, all have been overcoming because of the spiritual influence that strengthens her ability to see the goodness in all the things she had been through. The fact that she was terminally ill, her faith keeps her moving from the shadow of darkness. Mrs. Erickson was showing that her spirituality became a source of positive growth despite a significant change happening within and around her. Spirituality, in that sense, imbues a life with meaning and fosters a life-changing transformation toward her goals and priorities (Frank, 1995; Park and Folkmann, 1997). Hence, the evidence of growth was prominent in her spiritual life. Perhaps this finding of a positive spiritual influence on Mrs. Erickson's dying experience may be slightly influenced by the author of the study itself. Kang (2006), as an author, maybe working as a counselor in a religious run institution to which in that case a nursing home was an example. Or maybe Kang (2006) was a pastoral counselor that was influenced by its professional training from a religious academic institution to which Kang (2006) acquired a degree as a counselor? If these were true, then, a professional bias from Kang's (2006) side may interplay in the presentation of the study results regarding the impact of spirituality on the meaning-making of dying experience. By

considering these things, so in what position that I have said these observations? Again, if I made such a remark, it would be because I look beyond the things more than what it means in Kang's (2006) study. As a critical realist reviewer, I am not only looking on finding answers to my research question but I, too, evaluate how such findings were drawn. So, the knowledge of how spirituality may influence Mrs. Erickson can be drawn from many possible reasons available in Kang's study; and for that, under epistemological constructivism, I am noting unobservable patterns and considering unseen links that may contribute to the creation of observable reality. Despite spirituality's positive impact on Mrs. Erickson, Kulas (2001) embossed another idea. For Kulas, spirituality *may* "affect dying...(and) dying is interpreted as an event without being met by resistance" (2001: 92). To my understanding, what Kulas (2001) meant was that terminally ill persons might become passive and just concede to the idea that death is determined thus dying is not contested. If so, that creates a discourse that a terminally ill may cease the continual efforts to re-create the self and finding of meaning in the life remaining. Kulas's (2001) ability to see this kind of perspective was because of a hermeneutic influence accompanied in her philosophical stance, wherein she saw more than what the eyes met. Her hermeneutical style of viewing other angles allowed her to see the other side of the coin. As much as Kulas's (2001) idea accounted to be a possible understanding of spiritual influence in the meaning-making of the dying experiences, I am of two minds, though. To my argument, I challenge Kulas's (2001) notion by questioning what if a spiritually terminally ill person has already settled after appraisal of a reality that death is not to be wrestled with but accepted as end fate, can it still be considered that a person is passive and have not challenged? Although there is a differing idea concerning spirituality, I never sense strong reasons from the data that can elaborate on my arguments. I suggest that if aspects of spirituality will be given serious attention then it can be an interesting topic to focus on future research.

## **6.2 New Understandings on the Meaning-Making of Dying Experience**

Even though different issues emerged in the synthesized themes nonetheless Hank, Frances, and Mrs. Erickson reveal valuable understandings of the efforts they manifested. Apparently, these efforts are processes that talk about how they make meaning of their dying experiences. However, there is no direct evidence that they have been through in the same trajectorial pathways of dying experience although all of them were terminally ill. What I have seen in the data is at least each experience is different and each person pursues dynamic strategies of meaning-making under different circumstances. This observation confirms to the claim of Saunders (2003) that death and dying are unique and personal. That being said, I argue that no



dying experience is either less or more than the other; thus, each dying experience holds a potential need to be listened to and respected.

Again, it is riveting to note that, despite uniquely different dying experiences, a compelling connection and message underlying their stories. In reference to the four synthesized themes, a prominent message that emerges is a manifestation that they, in one way or another, take control of their situations. This “taking control” is considered as another new understanding of how terminally ill persons make meaning of their dying experience. It is evident in the data that Hank, Frances, and Mrs. Erickson started sharing stories until to a point where they achieved meanings in the various aspects of their lives. This pattern is a piece of evidence that they are really exerting personal efforts while meaning-making of the whole dying experience.

Furthermore, it also brings enlightenment that as death heightens the two issues namely, the impact of nursing homes and spirituality were eventually fading. To make it clear, as death is nearing for Hank, Frances, and Mrs. Erickson, these issues are gradually fading and placed into the background. It is no longer as explicitly as overwhelming like before. The reason is they become more drawn to things that are most important to them such as the strengthening of relationships, legacy, meaning, and purpose. In other words, what becomes significant is the idea of, as I describe it, “*what is now and for the future*” that is set into the foreground. To exemplify, Hank fixed all the necessary things to order that his family would not be burdened with the responsibilities after his death. Frances found meaning and purpose by being grateful and by cherishing the life remains because she believed that death was part of life and inevitable. Mrs. Erickson established reconciliation and fostering good relationships with her family. All of these exemplify to what I consider “*what is now and for the future.*”

In the process of their taking control, I further argue that they gradually realized that physical life was eventually ending; likewise, seeing the failure of medicine to extend life beyond death. In my observation of the data, death changes the course of status quo and medicine has no power to reverse their dying conditions. Thus, the reality of finitude became bolder. As deaths’ reality heightened, specifically the two issues emerging were all gradually fading. What is interesting now is the emergence of unseen labels assimilated to the fact that death is approaching. These labels may create a distinction (Guilfoyle, 2012) between, on the one hand, being sick, vulnerable patient and dependent of total care (Frank, 1995) or “marginal persons and sources of ambiguity” (Sandstrom, 2005: 71) and, on the other hand, something of an opposing idea to which I call the anti-label. In these distinctions, Hank, Frances, and Mrs. Erickson stand in between. Undeniably, the reality of death consumed their thoughts and emotions in such a way there was a battle within them, but there was also a struggle to win the

battle. In my point of view, their bodies try to overcome the forces of uncertainties. Despite the uncertainties, Guilfoyle proposes that it is inherent to human nature the “intrinsic capacity to do something (and) capable of resisting” (2012: 12). However, in the advent of doing something and exercising resistance, Hank, Frances, and Mrs. Erickson must realize that to start their crossing over from the labels of dying towards the anti-label, they must recognize the multitude of their corporeal energies, capacities, forces, impulses, aspirations, and beliefs (Guilfoyle, 2012). In the same way, they must realize that nobody can do a crossing over for them, but only them alone. They must rely on their intrinsic human capacity to overturn the challenge (ibid).

I know that they can move under their own individual power, but “How?” At first, it seems not visible because I never found it within the text or direct quotations signaling that they have indeed attempted to cross over. But soon enough I was reminded that I am moving through the actual and empirical domains; at the same time, observing patterns, potential links, and unobserved reality. So, I come to know, then, that by and through the act of storytelling and sharing to those who listen was already an attempt of crossing over. Hank, Frances, and Mrs. Erickson engaged in processes of acting out meaningfully their dying experiences through their stories. The story was, in fact, an invitation for them to move towards the side of anti-label. This act of storying allowed them to recognize and to story their sides, and the author Frank describes it, “storytelling is less a work of reporting and more a process discovery” (2013: xvi). That being said, storytelling becomes a space that invites them to resist, thus rendering an articulation of the whole experience. I argue that their stories brought illumination to the things they were not attuned to in the very first place. They found this storying as a space to recall all events embodied in their journey. Such articulation strengthens and thickens their resistance. They were in a position that reifies a new platform for making a new story distinct from that of a sick, dying, dependent of total care, marginal persons, and sources of ambiguity. They exerted efforts to specify the villains that trigger the genesis of being dying. Above all, they gave voices to the whole experience (Frank, 1995).

In the advancement of their taking control, it was evident from their stories that Hank, Frances, and Mrs. Erickson subjugated their struggles and there was an interjection of resistance, as described by Guilfoyle (2012). For example, Hank contended his cancer, Frances challenged her possible diagnoses, and Mrs. Erickson sought out to overturn her darkness. Here, their efforts of subjugating and resisting bringing a space where these three terminally ill people can re-create and adjust their lives. To my observation, they are entering into space where they can infuse their personal efforts, and this is materialized through the invitation of stories. The storytelling becomes an alternative, readily available for them and they responded to it. In the act of their response, they become gradually conscious of the purpose why they are doing it and

so become fully realize the purpose of resistance (ibid). Gradually, they are crossing over towards the anti-label and striving to live consistently finding purpose, creating new meaning and direction. For the author like Frank (1995) explains that as they see themselves, they emplace meanings into their lives and maintain their identities to where they are most familiar with. And now, the known self and their voices remain (ibid).

In essence, they are taking control because they are higher than what their circumstances have told them, and they are taking ownership of their own body because for them “the body is the source of meaning and meaning creation... and it is the perspective that (they) bring to bear in the world” (Komesaroff, 1995: 14). Although they struggle at first to articulate the things not accustomed to and to the difficulties accompany to it, they never keep themselves in the shadow of their own impending demise. They seek out to help themselves to explore and manage the uncertainties of being terminally ill. In spite of adversities and struggles, they did the one thing: “focus on what is in (their) control as opposed to what is not” (Holiday & Hanselman, 2016: 27). Thereupon, I have come to realize that within their efforts of taking control all of these things seem to direct in an idea that even in moments of dying, terminally ill people in nursing homes manifest and exercise the agentive power inherent in them. They have used the power within, and by acting through it, that is the only time they become subjective, not objective in that sense (Crosby, 1996). If there is a slight constraint of human agency by structures around them yet agentive power exists and works because of such degree of personal choice (Fiaz, 2014). Equally, by working through the power within, Hank, Frances, and Mrs. Erickson, as explained by Crosby (1996), are accepting of themselves rather than refusing it; in their acceptance of themselves, they take possession of their lives; and as they make themselves their own, they come to belong to themselves in a new way.

Similarly, they take a stance and making a difference not for material but on the existential gain. For Breitbart et al. (2004), Hank, Frances, and Mrs. Erickson take courage and conviction to reflect upon and gradually take ownership of their own existence. They create a legacy, not of the physical but into the memories of those people who become their witnesses (Frank, 1995). They hold on to the self they are born with and not the self-ascribed after the illness or the labels of dying. They make efforts to overturn their condition and thus propel liberation and freedom from the discourses that place them to vulnerability. More importantly, they rely on their capacity for the agency. This inherent power enables them “to do, to refuse and to re-story” (Guilfoyle, 2012: 14) and re-invent themselves following shattering illness and suffering (Frank, 1995). Significantly, if the change is seen in the life of Hank, Frances, and Mrs. Erickson, it is not something new but characterizes recollection of the knowledge and embodied scars of identities to which they take hold and own (Frank, 1995). Their deep

searching and wandering in their experience eventually produce a “new map” in which the unfamiliar body once again known to them (ibid).

By and large, this “taking control” attributes the human agentive power of terminally ill elderly people. Though teeming with imminent death, they find an escape from possible restrictions and limitations of being dying by infusing the innate power. What has been seen in their meaning-making efforts is indications that, in one way or another, they continue constructing themselves neither for material nor physical gains, but instead for existential benefits. Now, through these understandings, we gain new insights into the lives of those terminally ill elderly people in nursing homes. Remember, whatever the explanations qualitatively produced are theories being landscaped to yield sensible answers as we are in our continual quest to comprehend dying experience. If I have seen this new knowledge more than from what is seen in the constructed synthesized themes, to me, I happened to see what Caputo mentioned the “*plus ultra*” or “*more than what is meant explicitly*” (1987: 40) about dying experience. While the “*plus ultra*” knowledge is significant, it is not meant to be generalized. Under critical realist philosophy, the knowledge produced is suggestive and alternative; likewise, only fractions of what lies beyond the vast horizons of understanding the dying experience.

### **6.3 Transitional Summary**

In this chapter, I have discussed the new message of human agency reflected in their ways and by taking control of their situations. It relayed to us a message that what merely is included in their collective meaning-making efforts signifies that there is more, something of beyond from what is the apparent knowledge they offered. Although there can be many possible constraints, terminally ill elderly people used their innate power of human agency to propel liberation and freedom from all constraints, and they do it not for material or physical but for existential gain. As much as this chapter has provided us with the new understanding of the meaning-making of the dying experiences, I invite you once more to my last chapter for final discussions.

## Chapter 7: Final Discussions

This chapter contains the conclusion, significance of the results to social work, limitations and recommendations, future directions and my personal reflections on the whole journey.

### 7.1 Conclusion

As a social worker, my curiosity over meaning-making processes in dying experience was amplified by my exposures in nursing homes I worked with. My curiosity was then a prime motivation to study dying. Along the way it became strenuous because of many uncertainties involved, thus placing me as an outsider in my quest to search for answers. Driven to pursue my interest, critical realism offered viable options in seeking understandings, thus searching for answers has been made possible. Critical realism informed me that the reality of the phenomenon is an open system, half true, and fallible; therefore, always requiring alternative perspectives to understand it. Following that belief, I ventured on SLR to answer my research question: *“How do terminally ill persons make meaning of their dying experiences in nursing homes?”* As I am one with the critical realist tradition, I argue that texts found in literature also create near reflections and understandings on the meaning-making of terminally ill elderly people. With the successful application of SLR, I concluded that terminally ill elderly people make meaning by: *(i)* indicating the villain that interrupts life; *(ii)* infusing personal efforts in meaning-making; *(iii)* adopting different ways to restore meaning to the dying experience; and, *(iv)* placing meanings in the various aspects of life. Also, two contrasting issues were surfacing in the meaning-making processes namely, institutional influence and spirituality. Although these issues, at first, may have impact but were eventually fading as death heightened. As they pursued the meaning-making processes, they manifested the human agentive power by taking control of the situation amidst impending death. This innate agentive power became instrumental in the liberation and freedom from the constraints and limitations of being dying.

With those findings, I happened to see the *plus ultra* of the dying experiences, and if I made it possible, it was because I stand on the shoulders of the past Giants. The sources of knowledge I presented, though literature produced in the past, helps inform our present. As we are always in a constant quest to understand the complexities of dying and the life of those terminally ill elderly people, we can only hope for is to find sensible answers. The answers I produced are constructed understandings not to generalize but suggestive in their own right, and just fractions against the whole knowledge of the dying experience. Again, the manner how we understand dying and those terminally ill affects the way we comprehend, care, and listen to them. I am convinced that the known wisdom from this study is always and continues to be highly relevant to me as a social worker, to social work, and to the readers anywhere.

## 7.2 Significance of the Study Results to Social Work

While there is a potential risk that terminally ill elderly people may fall as marginal persons and sources of ambiguity, the findings suggest that they have the “ability to symbolize and make use of the power of discourse” (Sandstrom, 2005: 71). As they are engaging in their meaning-making efforts, they maneuver the chaos and areas of discourses around them. They thereby communicate from spaces where they play with power, remake meanings, and manifest resistance. And for that, the lesson may give this to social work is that never neglect the creative capacities of terminally ill elderly people even in the moments of dying (Sandstrom, 2005). Although they face the looming end of life, they live a life brimmed with meaning, and they were living while dying (Ng, 2014). It also reminds social work not to abandon the terminally ill persons’ *subjectivity* that interplays in mitigating the everyday exigencies of human struggle (Sandstrom, 2005). Likewise, it reminds of the significance of meaning-making and living a meaningful life because it reflects the resilience, optimism, and well-being of those terminally ill in nursing homes (Ng, 2014). The findings further suggest that social work must focus on the central significance of meaning and processes of meaning-making so that it provides a vista for understanding dying on a more personal level (ibid). I argue that knowing them personally in their meaning-making we see a glimpse of who they are - the person they have become and not a dying person in a sick role. As social work practitioners enrich personal connections and forge a mutual relationship with terminally ill in the moments of their dying perhaps, they realize that in their actions they “*subjectifying the subject*” (Sandstrom, 2005). In other words, the placing of terminally ill people in the center of discourses, considering their choices and decisions, and putting their interest at best. Thus, it underscores the claim that human agency is at the prime of doing social work (Parsell et al., 2017).

In considering the importance of human agency, it is essential to note that terminally ill people in nursing homes are not passive objects to be gazed at, but constantly engaging in continual processes of discovering themselves and actively constructing a sense of self. The processes of their identity reconstruction are manifested in their many ways of restoring meaning and through their personal efforts linking their human action towards the broader social context. However, it is also imperative that as social work invests on human agency, it is worth to remember that each dying person is unique and individual. Human agency varies from person to person, despite the innate agentive power. Hence, I suggest that social workers need to reinforce agentive power within the sphere of a safe and therapeutic environment, honoring them with compassion, and treating them with respect and dignity (Kessler, 2007). In that way, they help by being a force for dying people to reflect on their finitude, motivates them to make the most of their lives, and finds meaning as something worthy of its own sake (Trisel, 2015).

### 7.3 Limitations and Recommendations of the Study

In this study, there are several limitations. I argue that detailing the limitations are necessary in order for the readers to balance their understanding as they go over this study. As I enumerated the limitations, I also included the corresponding recommendations.

1. The Author of this study was the only sole reviewer, thus there is a question of bias in the selection process of included literature. However, to mitigate this problem, the principle of objectivity during selection process was applied using concise inclusion and exclusion criteria to minimize biased selection as much as possible; and at the same time, constant reporting to my research supervisor was done for the purpose of monitoring. To mitigate this potential problem, I recommend that when applying SLRs there be at least two authors to perform a check and balance in the selection process; and thereby, improving internal control and selection.
2. Sources of data were only qualitative scientific pieces of literature. Thus, there is limited accommodation for other ideas. I, therefore, recommend that future studies to include quantitative studies, unpublished literature, and other sources like narrative reports and actual documentaries to collect a wide range of possible understandings.
3. The search range spanned from 1985 until May 2018. Any published materials after the month of May 2018 are not included. I recommend that in the future study, published literature after May 2018 should be included to ensure the expansion of new knowledge.
4. This study only utilized backward snowballing and does not include a forward snowballing because of time constraints. Thus, I recommend utilizing both forward and backward snowballing in the future literature reviews on death and dying studies in order to increase the chance of comprehensive literature search.
5. There was no expert contact done in this study because of time limitations. I am aware that by contacting experts in the field one needs ample time to get answers and responses. For future literature reviews, I recommend utilizing this method to increase the chance of comprehensive coverage of literature searching.
6. In this study, only terminally ill people that are conscious and with the capacity to share their experiences from nursing homes were included, thus it cannot generalize on the entire dying elder population. I recommend investigating dying elderly people with dementia. Also, expanding the coverage across various settings like home, hospice, palliative care centers, monasteries, and hospitals to increase comparative analysis; as well as, to accommodate diverse understandings from different fields, disciplines, and specialties.

## 7.4 Future Directions

In this section, I offer four thoughts that need to be considered for future directions in the field of social work. Each discussion is something related to what I have discovered in my study, thus worth suggesting.

Firstly, there is scant evidence of critical realist philosophy in the conduct of systematic literature review, specifically on dying studies by social workers. If the tradition of critical realism needs to be fully understood, most especially on the study of the social and cultural phenomenon, I suggest that critical realist philosophy should be continuously explored to comprehend the strengths and limitations of this tradition and further recommend how it can be improved.

Secondly, in this study, there is no clear and concrete grounding regarding the nursing homes impact during the making of meaning by elderly dying people. As much as I attempted to rationalize, it lies yet beyond the boundary of this study to determine the extent of the roles of nursing homes in the meaning-making of the dying experiences. It is, therefore, suggested to further study and favorably conduct SLR to understand this issue on a broader scale, thus illuminating the varied reasons.

Thirdly, as spirituality has been seen as important in this study, there is also a counteractive idea in relation to the meaning-making of dying elderly people in nursing homes. However, it is beyond the capacity of this study to investigate further the different ideas. I recommend that there is a need for reliable scientific research to illuminate the impact of spirituality among terminally ill elderly people. Furthermore, SLR must be done to acquire a wide range of scoping of ideas and perspectives across different setting and contexts.

Lastly, terminally ill persons manifest the determination to make themselves better even when the course of death is irreversible. This idea thus *further* invites the practice of social work to investigate concepts of agentive power among elderly dying people. The way we understand elderly dying people in nursing homes requires a consideration, particularly from social workers, whose interest lies with those vulnerable persons in the environment. Along with reconsidering the agentive power of dying persons, I *further* recommend investigating the ethics involving the care of dying in the present time. I say *present* in order to accommodate the generated knowledge of SLR into the context of the present time. Specifically, the ethics of personal autonomy and power, since I argue that when considering the agentive power, it may pose a challenge to the judgment and decision making of healthcare professionals being perceived as healers and caregivers. With this in mind, social workers need to revisit the ideas of the medical hegemonic power and structural influences towards terminally ill persons in nursing homes and produce solid *empirical* scientific results that can give light on this issue.



## 7.5 My Personal Reflections in the Whole Journey

As I attempt to seek and understand the experiences of dying expressed in literature it took me for a while to decipher what was really the essence of making sense the stories of Hank, Frances, and Mrs. Erickson. I have to admit that in discovering what I can learn was a task both daunting and challenging. If I had to describe it, it's a twist and turn of mind puzzle. Psychologically it may seem. There were times that it was exhausting, and eventually, I was drained. Worst, I sometimes ended up with plain understanding without critical minding and discovering the emergence beyond the data that I am seeing. Determined not to give up, I summoned certain ethics that was important as I searched- the ethics of reflexivity. I came to realize that this reflexivity is a cornerstone ethics in which I am reminded of me to question and to hold an inquisitive position as I am in my scientific journey. Out of reflexivity, I even discovered that when I have to understand dying people, I must acknowledge my own mortality in order to grasp the essence of hidden meanings. In this way, I avoided creating the unseen demarcation between them and me. It does, indeed, require an equal footing to appreciate the discovering of meanings about dying experiences. It does not need to be "other" in order to understand dying, but it is an invitation to reflect and appreciate the experience as if it also talks about my future death. It does further ignite bravery and openness that in life amidst impending death there is so much to be appreciated, and there is still a life worth living for. Contrary to the old notion that dying is the pointing towards the eternal end, I realized that dying people can still recreate an image the way they are likely to be remembered, perhaps not of physically but on existentially, as a form of legacy for those who become their witnesses in the moments of their dying. Here, even though my means of knowing Hank, Frances, and Mrs. Erickson were only through texts and descriptions made by Kulas (2001) and Kang (2006), yet they once again immortalized through textual symbolism and descriptions. Through it, I had a glimpse of unique dying experiences and created an imagination through textual constructions as if I am present to them and they are present to me.

Finally, I realized that human agency among dying can be one of the core concerns in the practice of social work. Human agency, based on my study, reflects that a person always has the capacity "to do, to act upon and to re-story" (Guilfoyle, 2012: 14). What Hank, Frances, and Mrs. Erickson portrayals were genial human agentive powers that overturned the vindictive discourses of struggles and limitations assimilated to as being dying. They proved that although they are slightly influenced by structures and processes around them, yet they manifested the sense of control that reflects their self-determination thus shaping once again their being, identity, and meaning in life. Alas! To me, they were the unsung heroes that rise above against the intrusive distinctions of being dying.

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# Appendix A

## The Eight Steps of Systematic Literature Review





# Appendix B

## SPIDER and SPISDER Formats, Algorithms, and Searching Operators

*Illustration 1: The **SPIDER** Approach to Systematic Qualitative Literature Review*

	APPROACH	SPECIFICATIONS
<b>S:</b>	Sample Population	Terminally Ill
<b>P of I:</b>	Phenomenon of Interest	Dying as a Lived Experience
<b>D:</b>	Design	Interview, Focus Group, Case Study, Narratives, Observation Studies
<b>E:</b>	Evaluated Outcomes	Meaning-Making
<b>R:</b>	Research Type	Qualitative or Mixed Type

*Illustration 2: The Improved **SPISDER** Approach to Systematic Qualitative Literature Review*

	APPROACH	SPECIFICATIONS	ALTERNATIVE/ RECOGNIZED TERMS & DESCRIPTIONS
<b>S:</b>	Sample Population	Terminally Ill	Dying, Moribund, Chronic Illness, Life-Limiting Disease, => 65 years old, Have Years, Months, Weeks, Days or Hours to Live and Conscious
<b>P of I:</b>	Phenomenon of Interest	Dying as a Lived Experience	Refers to Lived Experience as a Terminally Ill
<b>S:</b>	Setting	Nursing Home	Residential Care Home, Assisted Living Facilities Home-for-the-Aged, Institutional Care Home, Long-Term Care Setting, Elderly Home
<b>D:</b>	Design	Interview, Focus Group, Case Study, Narratives, Observation Studies	
<b>E:</b>	Evaluated Outcomes	Meaning-Making	Making Meaning, Meaning Searching, Meaning Finding, Meaning Seeking, Making Sense
<b>R:</b>	Research Type	Qualitative or Mixed Type	

*Illustration 3: The Combined **Algorithms** and **Search Strategy Operators** Used in Searching Literature*

COMBINATION	SPECIFICATIONS
Algorithm #1	terminally ill OR dying OR moribund AND (meaning* OR meaning making OR meaning searching OR meaning finding OR meaning seeking) AND (nursing home OR elderly home OR home-for-the-aged OR retirement home)
Algorithm #2	meaning* making AND dying AND experience
Algorithm #3	(meaning*making OR meaning searching) AND (dying OR terminally ill)
Algorithm #4	(terminally ill OR death) AND "meaning making" AND "experience" AND "nursing home"
Algorithm #5	"meaning making" AND "lived experience" AND (dying or terminally ill)
Algorithm #6	"meaning making" AND "dying experience"
Algorithm #7	"terminally ill" AND "meaning making" AND "lived experience" AND "nursing home"
Algorithm #8	[All terminally] AND [[All ill] OR [All dying]] AND [All "meaning making"] AND [All "experience"]
Algorithm #9	(terminally ill OR dying) AND "meaning making" AND "experience"
Algorithm #10	"meaning making" AND "lived experience" AND (terminally ill OR dying) AND "nursing home"
Algorithm #11	(terminally AND ill OR dying) AND "meaning making" AND "experience"
Algorithm #12	[All: terminally] AND [[All: ill] OR [All: dying]] AND [All: "meaning making"] AND [All: "experience"] AND [All: "nursing home"]
Algorithm #13	(mean* OR meaning making OR meaning seeking OR meaning searching OR meaning finding) AND (experience) AND (dying OR terminally ill) AND (nursing home)

# Appendix C

## The Data Keeping Sheet (288 Literature), Duplicates, and the Coding System

Author/s	Year	Title	Codes	Remarks
<b>JOURNALS (n=192)</b>				
Adorno, G.	2015	Between Two Worlds: Liminality and Late-Stage Cancer-Directed Therapy	NMM	Exclude
Addington-Hall, J. M. et al.	1991	Dying from Cancer: The Views of Bereaved Family and Friends About the Experiences of Terminally Ill Patients.	NMMP, NNH	Exclude
Ahern, S. et al.	2012	Advances in Health Sciences Education: Critically Ill Patients and End-of-Life Decision-Making: The Senior Medical Resident Experience	NTI	Exclude
Alon, S.	2010	Researching the Meaning of Life: Finding New Sources of Hope	NNH	Exclude
Anagnostopoulos, F. et al.	2011	Exploring Global Meaning in Greek Breast Cancer Patients: Validation of the Life Attitude Profile- Revised (LAP-R).	NNH	Exclude
Anbäcken, E-M. et al.	2015	Expressions of identity and Self in Daily Life at a Group Home for Older Persons with Dementia in Japan	NMMP, NTI	Exclude
Anderson, L.	2009	Pastoral Care and the Spiritual Formation of Older Persons	NMM	Exclude
Ardelt, M.	2008	In Search for Meaning: The Differential Role of Religion for Middle-Aged and Older Persons Diagnosed with a Life-Threatening Illness	NMM	Exclude
Audet, C. et al.	2015	Finding Meaning in Life While Living with HIV: Validation of a Novel HIV Meaningfulness Scale among HIV-Infected Participants Living in Tennessee	NNH	Exclude
Bailey, H. & Tilley, S.	2002	Storytelling and the interpretation of Meaning in Qualitative Research	NNH	Exclude
Bennett, E. et al.	2017	"I'll Do Anything to Maintain my Health": How Women Aged 65-94 Perceive, Experience, and Cope with their Aging Bodies	NMM	Exclude
Bergmann, D.	1992	Anna: Fully Alive in the Face of Death.	NNH, <65	Exclude
Berlin, A.	2016	A Heart Set on Living	NMM	Exclude
Berman, M. et al.	2013	Experience of Fear of Cancer Recurrence Among Early Stage Breast Survivors	CR	Exclude
Bernard, W. et al.	2014	The Role of Spirituality at End of Life in Nova Scotia's Black Community	NMMP, NNH	Exclude
Bickerstaff, K. et al.	2003	How Elderly Nursing Home Residents Transcend Losses of Later Life	NMMP, NTI	Exclude
Boston, P. et al.	2011	Existential Suffering in the Palliative Care Setting: An Integrated Literature Review	NTI, NNH	Exclude
Brady, E.M.	1999	Stories at the Hour of Our Death	CR	Exclude
Brayne, S. et al.	2008	End-of-Life Experiences and the Dying Process in Gloucestershire Nursing Home as Reported by Nurses and Care Assistants	NMM	Exclude
Breibart, W.	2001	Spirituality and Meaning in Supportive Care: Spirituality and Meaning Centered Group Psychotherapy interventions in Advanced Cancer	NTI	Exclude
Breibart, W. et al.	2004	Psychotherapeutic Interventions at the End of Life: A Focus on Meaning and Spirituality	NTI, NNH	Exclude
Briscoe, W. & Woodgate, R.	2009	Sustaining Self: The Lived Experience of Transition to Long-Term Ventilation	NTI, NNH	Exclude
Bruce, A. et al.	2011	Longing for Ground in a Ground (Less) World: A Qualitative Inquiry of Existential Suffering	NNH	Exclude
Butler, S. & Rosenblum B.	1991	Cancer in Two Voices	NNH	Exclude
Byock I.	1997	Dying Well: The Prospect for Growth at the End of Life.	NNH	Exclude
Bäärnhielm, S.	2004	Restructuring Illness Meaning Through the Clinical Encounter: A Process of Disruption and Coherence	NNH	Exclude
Cable-Williams, B. & Wilson, D.	2016	Dying and Death Within the Culture of Long-Term Care Facilities in Canada	NNH, <65	Exclude
Caldwell, R.	2005	At the Confluence of Memory and Meaning- Life Review with Older Adults and Families: Using Narrative Therapy and the Expressive Arts to Remember and Re-author Stories of Resilience	NMMP, NNH	Exclude
Campbell-Enns, H. & Woodgate, R.	2015	The Psychosocial Experiences of Women with Breast Cancer Across the Lifespan: A Systematic Review Protocol	NMM	Exclude
Cannaerts, N. et al.	2004	Palliative Care, Care for Life: A Study of the Specificity of Residential Palliative Care.	NNH	Exclude
Carlson, A.	2007	Death in the Nursing Home: Resident, Family, and Staff Perspectives	NMMP, NTI	Exclude
Chan, H. & Pang, S.	2007	Quality of Life Concerns and End-of-Life Preferences of Aged Persons in Long -Term Care Facilities	NNH	Exclude
Chao, C-S C et al.	2002	The Essence of Spirituality of Terminally Ill Patients.	NTI	Exclude
Chapman, S.A.	2006	A "New Materialist" Lens on Aging Well: Special Things in Later Life	NTI	Exclude
Cheng, J. et al.	2010	A Pilot Study on the Effectiveness of Anticipatory Grief Therapy for Elderly Facing the End of Life	NTI, NNH	Exclude
Chung, B.P.M. et al.	2017	Beyond Death and Dying: How Chinese Spouses Navigate the Final Days with Their Loved Ones Suffering from Terminal Cancer.	NTI, NNH	Exclude
Clifton, S.	2015	Theodicy, Disability, and Fragility: An Attempt to Find Meaning in the Aftermath of Quadriplegia	NNH	Exclude
Cohler, B.	1991	The Life Story and the Study of Resilience and Response to Adversity	NTI, NNH	Exclude
Coleman, N. et al.	2011	Psycho-Oncology Best Practice Guidelines and a Service Perspective: Conceptualizing the Fit and Towards Bridging the Gap	NMM	Exclude
Costello, J.	2001	Nursing Older Dying Patients: Findings from an Ethnographic Study of Death and Dying in Elderly Wards	NNH	Exclude
Coward, D.	1994	Meaning and Purpose in the Lives of Persons with AIDS	NNH	Exclude
Coward, D. et al.	2005	Transcending Breast Cancer: Making Meaning from Diagnosis and Treatment	NNH	Exclude
Coyle, N.	2006	The Hard Work of Living in the Face of Death	NMMP, NNH	Exclude
Daaleman, T. & Dobbs, D.	2010	Religiosity, Spirituality, and Death Attitudes in Chronically Ill Older Adults	NNH	Exclude
Dalmda, S. et al.	2012	The Meaning and Use of Spirituality Among African American Women Living with HIV/AIDS	NNH	Exclude
Djivre, S. et al.	2009	Five Residents Speak: The Meaning of Living with Dying in a Long-Term Care Home	NNH	Exclude
Docherty, D. & McCoil M. A.	2008	Illness Stories	NTI	Exclude
Drageset, J. et al.	2017	Crucial Aspects Promoting Meaning and Purpose in Life: Perceptions of Nursing Home Residents	NTI, NNH	Exclude
de Guzman, A. et al.	2009	Filipino Elderly's Sense of Reminiscence, Living Dispositions, and End-of-Life Views	NTI, NNH	Exclude
de Vries, B. et al.	2017	The Relationship Timeline: A Method for the Study of Shared Lived Experiences in Relational Contexts	NMM	Exclude
Ellingsen, S. et al.	2015	The Pendulum Time of Life: The Experience of Time, When Living with Severe Incurable Disease—A Phenomenological and Philosophical Study	NNH	Exclude
Ellingsen, S. et al.	2014	Being in Transit and in Transition: The Experience of Time at the Place When Living with Severe Incurable Disease- A Phenomenological Study	NNH	Exclude
Elofsson, L.C. & Ohlen, J.	2004	Meanings of Being Old and Living with Chronic Obstructive Pulmonary Disease	NTI	Exclude
Engle, V. et al.	2015	The Experience of Living Dying in a Nursing Home: Self Reports of Black and White Older Adults.	NMM	Exclude
Fang, M. et al.	2016	Culturally- Sensitive End of Life Care Scoping Review	NTI, NNH	Exclude
Froggatt, K. et al.	2011	A System Lifeworld Perspective on Dying in Long Term Care Settings for Older People: Contested States in Contested Places	NTI, NNH	Exclude

Funk, L. et al.	2015	What Family Caregivers Learn When Providing Care at the End of Life: A Qualitative Secondary Analysis of Multiple Datasets	MM	Exclude
Gallagher, A.	2008	A Pilot Evaluation of the Arts for Life Project in End-of-Life Care	MM	Exclude
Gamilij, T.	2003	The Macabre Style: Death Attitudes of Old-Age Home Residents in Israel	MM	Exclude
Garnett, M.	2003	Sustaining the Cocoon: The Emotional Inoculation Produced by Complementary Therapies in Palliative Care	MM	Exclude
Gerdner, L. et al.	2007	The Circle of Life: End-of-Life Care and Death Rituals Among Hmong-American Elders.	MM	Exclude
Genius, S. & Bronstein, J.	2016	Looking for "Normal": Sense Making in the Context of Health Disruption	NTI, NNH	Exclude
Goldsteen, A. et al.	2006	What is a Good Death? Terminally Ill Patients Dealing with Normative Expectations	NNH	Exclude
Goranson, A. et al.	2017	Dying is Unexpectedly Positive	NNH	Exclude
Guerrero-Torres, M. et al.	2017	Understanding Meaning in Life Interventions in Patients with Advanced Disease: A Systematic Review and Realist Synthesis	NNH	Exclude
Graffigna, G. et al.	2017	Recovering from Chronic Myeloid Leukemia: The Patient's Perspective Seen Through the Lens of Narrative Medicine	NTI, NNH	Exclude
Grew, F.	2017	The Soul's Legacy: A Program Designed to Help Prepare Senior Adults Cope with End-of-Life Existential Distress	NTI, NNH	Exclude
Gruenewald, D. & White, E.	2006	The Illness Experience of Older Adults Near the End of Life: A Systematic Review	CR	Exclude
Hack, T. et al.	2010	Learning from Dying Patients During Their Final Days: Life Reflections Gleaned from Dignity Therapy	NNH	Exclude
Halldorsdottir, S. & Hamrin, E.	1996	Experiencing Existential Changes: The Lived Experience of Having Cancer	NNH	Exclude
Hanson, L. et al.	2004	As Individual as Death Itself: A Focus Group of Terminal Care in Nursing Homes	MM	Exclude
Harris, H.	2008	Growing While Going: Spiritual Formation at the End of Life	NNH	Exclude
Harrop, E. et al.	2017	Managing, Making Sense of and Finding Meaning in Advanced Illness: A Qualitative Exploration of the Coping and Wellbeing Experiences of Patients with Lung Cancer	NNH	Exclude
Haug, S. et al.	2015	How Older People with Incurable Cancer Experience Daily Living: A Qualitative Study from Norway	NNH	Exclude
Hennings, J. & Froggatt, K.	2016	The Experiences of Family Caregivers of People with Advanced Dementia Living in Nursing Homes; a Specific Focus on Spouses: A Narrative Literature Review	NNH	Exclude
Hepworth, M.	2005	Aging Bodies: Images and Everyday Experience	NTI	Exclude
Hisham Hashim, H. et al.	2013	A Journey from the Known to the Unknown: A Qualitative Study Approach	NNH	Exclude
Ho, A. et al.	2013	Living and Dying with Dignity in Chinese Society: Perspectives of Older Palliative Care Patients in Hong Kong	NNH	Exclude
Ho, A. et al.	2016	Dignified Palliative Long-Term Care: An Interpretive Systemic Framework of End-of-Life Integrated Care Pathway for Terminally Ill Chinese Older Adults.	NNH	Exclude
Hold, J. et al.	2017	Opening Life's Gifts: Facing Death for a Second Time	NNH	Exclude
Holstein, M.	1997	Reflections on Death and Dying	NNH	Exclude
Hossain, M.S. & Gilbert, P.	2010	Concepts of Death: A Key to Our Adjustment	NNH	Exclude
Hughes, C. R. et al.	2014	Cultural Meaning-Making in the Journey from Diagnoses to End of Life	NNH	Exclude
Hunter, E.	2008	The Legacy of Cancer: The Importance of Passing Beliefs, Values & Positive Health Behaviors for Women with Cancer.	NNH	Exclude
Höök, K.	2009	Affective Loop Experiences: Designing for Interactional Embodiment	NNH	Exclude
Ironsides, P. et al	2003	Experiencing Chronic Illness: Co-creating New Understandings	NNH	Exclude
Jones, K.	2005	Diversities in Approach to End-of-Life: A Review from Britain of the Qualitative Review	NNH	Exclude
Jones, S.A.	1993	Personal Unity in Dying: Alternative Conceptions of the Meaning of Health.	CR	Exclude
Kang, S.	2006	Tending the Soul of Terminally Ill	AI	INCLUDE
Kaysen-Jones, J	2002	The Experience of Dying: An Ethnographic Nursing Home Study	NNH	Exclude
Keall, R. et al.	2011	Discussing Life Story, Forgiveness, Heritage, and Legacy with Patients	NNH	Exclude
Keall, R. et al.	2015	Therapeutic Life Review in Palliative Care: A Systematic Review of Quantitative Evaluations	NNH	Exclude
Kellehear, A.	2008	Dying as a Social Relationship: A Sociological Review of Debates on the Determination of Death	NNH	Exclude
Kenny, K. et al.	2017	Terminal Anticipation: Entanglements of Affect and Temporality in Living with Advanced Cancer	NNH	Exclude
Kimble, M. A.	1990	Aging and the Search for Meaning	NNH	Exclude
Knox, M. et al.	2017	Lost and Stranded: The Experience of Younger Adults with Advanced Cancer	NNH	Exclude
Koutiri, I. & Avdi, E.	2016	The Suspended Self: Liminality in Breast Cancer Narratives and Implications for Counselling	NNH	Exclude
Kutner, J. et al.	2009	Bereavement: Addressing Challenges Faced by Advanced Cancer Patients, Their Caregivers, and their Physicians	NNH	Exclude
Kvåle, K. & Synnes, O.	2017	Living with Life-Prolonging Chemotherapy- Control and Meaning Making in the Tension Between Life and Death	NNH	Exclude
Larson, D.G.	2005	Becky's Legacy: More Lessons	NNH	Exclude
Lawrence, M. & Repede, E.	2012	The Incidence of Deathbed Communications and Their Impact on the Dying Process	NNH	Exclude
Leal, I. et al.	2018	Interconnection: A Qualitative Analysis of Adjusting to Living with Renal Cell Carcinoma	NNH	Exclude
Lee, V. et al.	2006	Meaning-Making Intervention During Breast or Colorectal Cancer Treatment Improves Self-Esteem, Optimism, and Self-Efficacy	NNH	Exclude
Lee, V. & Loisel, C.G.	2012	The Salience of Existential Concerns Across the Cancer Control Continuum	NNH	Exclude
Leung, P.	2010	Autobiographical Timeline: A Narrative and Life Story Approach in Understanding Meaning-Making in Cancer Patients	NNH	Exclude
Liamputtong, P. et al.	2012	Living Positively: The Experience of Thai Women Living with HIV/AIDS in Central Thailand	NNH	Exclude
Li, Y. et al.	2015	Posttraumatic Growth and Demoralization After Cancer: The Effects of Patients' Meaning-Making	NNH	Exclude
Lin, H.	2008	Searching for Meaning: Narratives and Analysis of US-Resident Chinese Immigrants with Metastatic Cancer	NNH	Exclude
Lit, S.W.	2015	Dialectics and Transformations in Liminality: The Use of Narrative Therapy Groups with Terminal Cancer Patients in Hong Kong	NNH	Exclude
Lynn, J. et al.	1997	Perceptions by Family Members of the Dying Experience of Older and Seriously Ill Patients.	NNH	Exclude
la Cour, K. et al.	2004	Creating Connections to Life During Life-Threatening Illness: Creative Activity Experienced by Elderly People and Occupational Therapists	NNH	Exclude
la Cour, K. et al.	2009	Activity and Meaning Making in the Everyday Lives of People with Advanced Cancer	NNH	Exclude
la Cour, K. & Hansen, H.P.	2013	Aesthetic Engagements: "Being" in Everyday Life with Advanced Cancer	NNH	Exclude
Mackay, M.M. & Bluck, S.	2010	Meaning-Making in Memories: A Comparison of Memories Death Related and Low Point Life Experiences	NNH	Exclude

Madsen, R. & Uhrenfeldt, L.	2014	Palliative Patients' and Their Significance Others' Experiences of Transitions Concerning Organizational, Psychological and Existential Issues During the Course of Incurable Cancer: A Systematic Review Protocol	NNH	Exclude
Mamo, L.	2008	Death and Dying: Confluences of Emotion and Awareness	NNH	Exclude
Manning, L.	2014	Enduring as Lived Experience: Exploring the Essence of Spiritual Resilience for Women in Late Life	NMM	Exclude
Martino, M.L. & Freda, M.F.	2016	The Wound of the Border: The Liminality Condition of the Body and Psyche	NE	Exclude
Mayer, S.	1989	Meaning-Making Process Related to Temporality During Breast Cancer Traumatic Experience: The Clinical Use of Narrative to Promote a New Continuity of Life.	NNH	Exclude
McCormick, T. R., & Conley, B. J.	1995	Wholly Life: A New Perspective on Death	NNH	Exclude
McElchor-Beaupre, R.	2010	Patients' Perspectives on Dying and on the Care of Dying Patients.	NNH	Exclude
Menzfeld, M.	2017	Giving Voice and Choice to Children at the End-of-Life: An Exploration of Meaning and Legacy in Pediatric Palliative Care	NTI, NNH	Exclude
Menzfeld, M.	2016	Cultural Models of Dying	NNH	Exclude
Mesquita, A.C. et al.	2017	When the Dying Do Not Feel Tabooed: Perspectives of the Terminally Ill in Western Germany	NNH	Exclude
Mitchell, G.	1990	Spiritual Needs of Patients with Cancer in Palliative Care: An Integrative Review	NNH	Exclude
Morenen, R.	2005	The Lived Experience of Taking Life Day-by-Day in Later Life: Research Guided by Parse's Emergent Method	NMM	Exclude
Moreno, P. & Stanton, A.	2013	What is the Meaning of Life? Women's Spirituality at the End of Life Span.	NNH	Exclude
Noble, A. & Jones, C.	2005	Personal Growth During the Experience of Advanced Cancer: A Systematic Literature Review	NNH	Exclude
Ogle, K. & Hopper, K.	2005	Benefits of Narrative Therapy: Holistic Interventions at the End-of-Life.	NMM	Exclude
Ohmsorge, K. et al.	2014	End-of-Life Care for Older Adults	NTI, NNH	Exclude
Park, C. et al.	2013	What A Wish to Die Can Mean: Reasons, Meanings, and Functions of Wishes to Die, Reported from 30 Qualitative Case Studies of Terminally Ill Patients	NNH	Exclude
Pederson, S.N.	2008	Meaning Making and Psychological Adjustment Following Cancer: The Mediating Roles of Growth, Life Meaning, and Restored Just-World Beliefs.	NNH	Exclude
Peoples, H. et al.	2017	To Be Welcome: A Call for Narrative Interviewing Methods in Illness Context	NNH	Exclude
Pizzo, P.	2016	Managing Occupations in Everyday Life for People with Advanced Cancer Living at Home	NNH	Exclude
Pols, J. et al.	2017	Thoughts About Dying in America: Enhancing the Impact of One's Life Journey and Legacy by Also Planning for the End of Life.	NMM	Exclude
Poppito, S. et al.	2009	The Particularity of Dignity: Relational Engagement in Care at the End of Life	CR	Exclude
Pretorius, H.G. et al.,	2005	Therapeutic Bridges to Meaning: An Existential Qualitative Analysis of the Co-Creation of Meaning in Individual Meaning-Centered Psychotherapy	NNH	Exclude
Ramos, K.	2016	Meaning-making of a Group of South Africans in the Experience of Living with HIV: A Phenomenological Study	NNH	Exclude
Redhouse, R.	2015	Psychosocial Health of Older Adults with Cancer: Clinical Interventions Promoting Meaning and Value-Driven Behavior	NMM	Exclude
Rodriguez-Prat, A. et al.	2017	Life-Story, Meaning Making Through Dramathrapy in a Palliative Care Context	NNH	Exclude
Romanoff, B. & Thompson, B.	2006	Understanding Patients' Experiences of the Wish to Hasten Death: An Updated and Expanded Systematic Review and Meta-Ethnography	NNH	Exclude
Romo, R. et al.	2017	Meaning Construction in Palliative Care: The Use of Narrative, Ritual, and the Expressive Arts	NTI, NNH	Exclude
Ruijs, C. et al.	2013	Sense of Control in End-of-Life Decision Making	NNH	Exclude
Sanders, S. & Swails, P.	2011	Symptoms, Unbearability and the Nature of Suffering in Terminal Cancer Patients Dying at Home: A Prospective Primary Care Study	NNH	Exclude
Schwarz, J. & Coyle, N.	2006	A Quest for Meaning: Hospice Social Workers and Patients with End Stage Dementia	NNH	Exclude
Seeber, J.	2001	Can We Know What Terri Schiavo Would Have Wanted?	NNH	Exclude
Shin, J.	2015	Meaning in Long Term Care Settings: Victor Frankl's Contribution to Gerontology	NNH, <55	Exclude
Sherman, E. & Webb, T. A.	1994	The Self as Process in Late-Life Reminiscence: Spiritual Attributes.	NMMP, NTI	Exclude
Skaggs, B. & Barron, C.	2006	Searching for Meaning in Negative Events: Concept Analysis	NNH	Exclude
Skillbeck, J. et al.	2017	Making Sense of Frailty: An Ethnographic Study of the Experience of Older People Living Complex Health Problems	NMM	Exclude
Sloan, D.H. et al.	2017	The Influence of Relationship on the Meaning Making Process: Patients' Perspectives	NNH	Exclude
Solano, J.P., et al.	2016	Resilience and Hope During Advanced Disease: A Pilot Study with Metastatic Colorectal Cancer Patients	NNH	Exclude
Solomon, D. & Hansen, L.	2015	Living Through the End: The Phenomenon of Dying at Home	NNH	Exclude
Steinhauser, K. et al.	2009	Seriously Ill Patients' Discussions of Preparation and Life Completion: An Intervention to Assist with Transition at the End-of-Life	NNH	Exclude
Street, A.F. & Kissane, D. W.	2001	Constructions of Dignity in End of Life Care	NMM	Exclude
Stout, N.	1992	Living and Growing into Death.	NNH	Exclude
Swinnen, A.	2018	Writing to Make Ageing New: Dutch Poets' Understandings of Late-Life Creativity	NNH	Exclude
Synnes, O.	2015	Narratives of Nostalgia in the Face of Death: The Importance of Lighter Stories of the Past in Palliative Care.	NNH, <55	Exclude
St. James O'Connor, T. et al.	1997	Making the Most and Making Sense: Ethnographic Research on Spirituality in Palliative Care	NNH	Exclude
Tait, G.R. et al.	2010	Meaning and Legacy in the Terminally-Ill Elderly: Dignity Therapy and Its Impact on Patients and Health Professionals	NNH	Exclude
Tait, G.R. & Hodges, B.	2013	Residents Learning from a Narrative Experience with Dying Patients: A Qualitative Study	NTI	Exclude
Taughner, T.	2002	Helping Patients Search for Meaning in Their Lives.	NNH	Exclude
Taylor, E.	1995	Whys and Wherefores: Adult Patient Perspectives of the Meaning of Cancer	NNH	Exclude
Temple, M. & Gall, T.L.	2016	Working Through Existential Anxiety Toward Authenticity: A Spiritual Journey of Meaning Making	NNH	Exclude
Thoresen, L. et al.	2011	Medicine, Health Care and Philosophy: The Significance of Lifeworld and the Case of Hospice	NNH	Exclude
Tighe, M.	2011	Coping, Meaning and Symptom Experience: A Narrative Approach to the Overwhelming Impact of Breast Cancer in the First Year Following Diagnosis	NNH	Exclude
Timmins, F. et al.	2015	Serenity Spirituality Sessions: A Descriptive Qualitative Exploration of a Christian Resource Designed to Foster	NNH	Exclude
Timonen, V. & O'Dwyer, C.	2009	Spiritual Well Being Among Older People in Nursing Homes in Ireland	NMM	Exclude
Tishelman, C. et al.	2016	Living in Institutional Care: Residents' Experiences and Coping Strategies	NTI	Exclude
Thompson, N. et al.	2000	Beyond the Visual and Verbal: Using Participant-Produced Photographs in Research on the Surroundings for Care at the End-of-Life	NNH	Exclude
Thorne, S. et al.	2002	Death, Dying, and Bereavement in Relation to Older Individuals	NTI, NNH	Exclude
		Chronic Illness Experience: Insights from a Meta-study	NTI, NNH	Exclude

Vincent, W.	2010	Telling Stories in a Veterans' Life Review Group: Design, Pilot Study, and Evaluation	NTI	Exclude
Volker, D. & Wu, H.L.	2011	Cancer Patients' Preference for Control at the End-of-Life	MM	Exclude
van Wijngaarden, E. et al.	2017	A Captive, a Wreck, a Piece of Dirt	MMMP, NNH	Exclude
Waldrop, D. & Weeker, M. A.	2014	Final Decisions: How Hospice Enrollment Prompts Meaningful Choices About Life Closure	NNH	Exclude
Waldrop, D.P. et al.	2005	Final Transitions: Family Caregiving at the End of Life.	NTI	Exclude
Weingarten, K. & Worthen, M.	2018	The Solace of an Uncertain Future: Acute Illness, the Self, and Self-Care	MMMP, NNH	Exclude
Wenger, L.	2013	Living Under Assault: Men Making Sense of Cancer	NTI	Exclude
Wenrich, M. D. et al.	2001	Communicating with Dying Patients Within the Spectrum of Medical Care from Terminal Diagnosis to Death.	MMMP, NNH	Exclude
Widdershoven, G.	2001	Care, Cure and Interpersonal Understanding	NTI	Exclude
Wiener, L. et al.	2012	Cultural and Religious Considerations in Pediatric Palliative Care	NTI, NNH	Exclude
Willig, C.	2009	Unlike a Rock, a Tree, A Horse or an Angel...: Reflections on the Struggle for Meaning Through Writing During the Process of Cancer Diagnosis	NNH	Exclude
Whitaker, A.	2008	The Body as Existential Midpoint: the Aging and Dying Body of Nursing Home Residents	NTI	Exclude
Whitsitt, D.R.	2010	Illness and Meaning: A Review of Select Writings	NTI, NNH	Exclude
Wong, P.	2016	Meaning-Seeking, Self-Transcendence, and Well-Being	MM	Exclude
Wright, S. et al.	2015	Meaning-Centered Dream Work with Hospice Patients: A Pilot Study	NTI, NNH	Exclude
Xia, H., et al.	2018	Exploring Meaning in the Life of Chinese Breast Cancer Survivors	NNH	Exclude
Yardley, S.	2013	Interpreting Educational Evidence for Practice: Are Autopsies a Missed Educational Opportunity to Learn Core Palliative Care Principles?	NTI, NNH	Exclude
Zambano, S. et al.	2014	The Experiences, Coping Mechanisms, and Impact of Death and Dying on Palliative Medicine Specialists	MM	Exclude
Zhou, Y.R.	2010	The Phenomenology of Time: Lived Experiences of People with HIV/AIDS in China	NTI	Exclude
Östlund, U. et al.	2011	Dignity Conserving Care at the End-of-Life: A Narrative Review	MM	Exclude
<b>BOOK OR BOOK CHAPTERS (n=32)</b>				
Balk, D. et al.	2016	Chapter 24: The Psychology of Death and Dying in Later Life	NNH	Exclude
Balzer Riley, J.	2015	Communication in Nursing	MM	Exclude
Baxter Magolda, M. & King, P.	2012	Meaning Making and Self-Authorship.	NNH	Exclude
Berger, J.	2012	Music of the Soul: Composing Life Out of Loss	MM	Exclude
Berzoff, J. & Silverman, P.	2004	Living with Dying: A Handbook for End-of-Life Healthcare Practitioners	MM	Exclude
Butler, R. & Wiley, J.	2009	Reflections in Personal Construct Theory	MM	Exclude
Edmondson, R.	2015	Ageing, Insight and Wisdom: Meaning and Practice Across the Life Course	NNH	Exclude
Eschenbruch, N.	2007	Nursing Stories: Life and Death in a German Hospice	NNH	Exclude
Frank, A.	1995	The Wounded Story Teller	NNH	Exclude
Glicken, M.	2009	Chapter 16: Evidence-Based Practice with Disabilities, Terminal Illness, and Assisted Living for an Aging Population	MMMP, NNH	Exclude
Helge Hvid, A.K.	2012	Elderly Care in Transition: Management, Meaning and Identity Work: A Scandinavian Perspective	MM	Exclude
Johnston, N. & Scholler-Jaquis, A.	2007	Meaning in Suffering: Caring Practices in the Health Professions	MM	Exclude
Kegan, R. & Kegan, R.	2009	The Evolving Self	NNH	Exclude
Kellehear, A.	2014	The Inner Life of the Dying Person	NNH	Exclude
Leman-Stefanovic, I.	1987	Chapter 1: Reflecting on One's Own Death	NNH	Exclude
Madjar, J.	2001	Section 4: The Lived Experience of Pain in the Context of Clinical Practice	MM	Exclude
Meagher, D. & Balk, D	2013	Handbook of Thanatology: The Essential Body of Knowledge for the Study of Death, Dying & Bereavement.	NTI, NNH	Exclude
Menzfeld, M.	2018	Anthropology of Dying: A Participant Observation with Dying Persons in Germany	MM	Exclude
Mintz, S.	2011	Chapter 4: On the Rhetoric of Gloom and Joy: "In Turbulent Love with the World"	NTI, NNH	Exclude
Neimeyer, R.	2012	Chapter 19: Constructions of Death and Loss: A Personal and Professional Evolution	NNH	Exclude
Nelson-Becker, H.	2018	Espiritualidad Y Preparación Para La Muerte En La Vejez: Dying Well	NNH	Exclude
Pearce, M. et al.	2008	Spirituality and Health: Empirically Based Reflections on Recovery	NTI, NNH	Exclude
Prodromou, A.	2015	Navigating Loss in Women's Contemporary Memoir	NTI, NNH	Exclude
Rowles, G. & Chaudhury, H.	2005	Home and Identity in Late Life International Perspectives	MM	Exclude
Scheer, J.	2012	Chapter 18: Reconstructing After a Change in Health Status	NNH	Exclude
Shin, J. & Steger, M.	2014	Chapter 5: Promoting Meaning and Purpose in Life	NTI, NNH	Exclude
Starck, P.	2008	Theory of Meaning	NNH	Exclude
Synnes, O.	2016	Chapter: Storytelling as a Dignity Preserving Practice in Palliative Care	NTI, NNH	Exclude
Van Brussel, L. & Carpentier, N.	2017	Closing the Book of Life: The Hospice Discourse and the Construction of Dying	NNH	Exclude
Werth, J. & Blevins, D.	2008	Decision Making Near the End-of-Life: Issues, Developments & Future Directions	MM	Exclude
Wooten-Green, R.	2001	When the Dying Speaks: How to Listen to and Learn from Those Facing Death	NNH	Exclude
Young-Mason, J.	1997	The Patient's Voice: Experiences of Illness	NNH	Exclude
<b>THESIS / DISSERTATION (n=60)</b>				
Ahern, G.R.	2015	A Narrative Inquiry: Case Leaders' Perspectives on Resilience in Hospice Care.	NTI	Exclude
Baillinger, S.N.	2014	Slowing Down Time: An Exploration of Personal Life Extension Desirability as it Relates to Christian Religious Belief Systems and Religiosity	MM	Exclude
Barrington, C. et al.	2008	Exploring the Nature and Meaning of Art with Older Adults in Hospice	MM	Exclude
Barron, A.M.	2000	Life Meanings and the Experience of Cancer: Application of Newman's Research Method and Phenomenological Analysis	NNH	Exclude
Bell, S.N.	2008	Drawing on the End-of-Life: Art Therapy, Spirituality and Palliative Care	NNH	Exclude

Bern-Klug, M.	2003	The Social Construction of Dying in Nursing Homes: Implications for Social Work	MM	Exclude
Bleicher, H.J.	2011	The Experience of Counseling the Terminally Ill and the Best Counseling Practices	NTI, NNH	Exclude
Brown, T.	2015	Narratives of Perceived Social Support as a Mediator for Increased Coping Resources and Optimism Among Cancer Patients and Survivors	NNH	Exclude
Bruce, M.J.	2009	Creating and Finding Meaning in Visual and Written Texts Through Aesthetic Experience: Four Case Studies of Hospice Patients	NTI, NNH	Exclude
Dacher, J.E.	1997	Older Women's Narratives of Aging, Disability and Participation in Rehabilitation Program: A Phenomenological Study of Lived Experience	NNH	Exclude
David, P.	2008	The Last Chapter: A Phenomenological Study of Aging Holocaust Survivors' Views on their Own Dying and Death	NTI	Exclude
Djivre, S.	2008	The Meaning of Living with Dying in a Long-Term Care Home: A Phenomenological Study of the Experience of Six Older Nursing Home Residents	NNH	Exclude
Downs, K.	2014	Understanding the Experiences of Stage IV Breast Cancer: A Qualitative Inquiry of a Stage IV Diagnoses	MM	Exclude
Ebener, M.K.	1999	Older Adults Living with Chronic Pain: An Opportunity for Improvement	MM	Exclude
Elmslie, P.A.	2010	An Exploration of the Impact on Individuals Who Have Experienced Multiple Losses from Death Over Time	NTI, NNH	Exclude
Franchini, L.	2011	Postmortem Care: A Ritual Created by Medical Subculture	NTI	Exclude
Gordon, T.	2009	Living in the Memory of Loss: Exploring the Impact of Aggressive, Palliative, and Hospice Care and Surviving Loved Ones	NTI, NNH	Exclude
Grossman, S.	2007	The Role and Meaning of Spirituality Among Older Adults in Western Australia	NTI, NNH	Exclude
Hall, V.P.	2000	Bearing Witness to Suffering in HIV/AIDS: Constructing Meaning from Loss	NTI, NNH	Exclude
Hannum, S.M.	2013	Chronic Illness Narratives: Conceptualizations of a Cancer Diagnosis Among Chronically Ill Older Adults	NNH	Exclude
Heriot, C.S.	1991	A Descriptive Analysis of Experiences of Personal Meaning of Life Among Older Adults	NNH	Exclude
Holtslander, L.	2007	Searching for New Hope: A Grounded Theory of the Experienced of Hope for Older Women Who are Bereaved Palliative Caregivers	NNH	Exclude
Imai, H.	2013	Death Acceptance and Intimate Relationships	MM	Exclude
Johnston, N.	2003	Finding Meaning in Adversity	NTI, NNH	Exclude
Jungers, C.	2007	Lived Experiences: An Examination of Older Adults' Late-Stage, Life-Span Ecological Transition from a Home Residence to an Assisted Living Facility	NTI	Exclude
Kahn, D.	1990	Living in a Nursing Home: Experiences of Suffering and Meaning in Old Age	NTI	Exclude
Keall R.M.	2014	Enhancing Existential and Spiritual Care for Palliative Care Patients from Both the Patient and Nurse	MM	Exclude
Källström, K. & Inga, L.	2009	Att Levat nara Döden: Patienters och Vårdpersonals Erfarenheter inom Hospicevård	MM	Exclude
Kulas, G.	2001	Opening Doors: Understanding Experiences of Dying	MM	Exclude
Lark, E.	2014	Making Space for Dying: Portraits of living with Dying	MM	Exclude
McGovern, J.	2012	Couplehood and the Phenomenology of Meaning for Older Couples Living with Dementia	NNH	Exclude
McSherry, C.	2008	The Inner Life at the End of Life	NTI, NNH	Exclude
Moheet, S.	2013	Islamic Middle Eastern Perspectives on Bereavement, Grief and Mourning	MM	Exclude
Morrissey, M.B.	2011	Suffering and Decision Making Among Seriously Ill Elderly Women	MM	Exclude
Nieto, B.	2005	Narratives of Facing Personal Mortality in the Breast Cancer Experience of Mexican-American Women.	MM	Exclude
Ng, P.	2014	For Whom the Bell Tolls: Meaning Making at the End of Life Among Chinese Terminal Cancer Patients in Hong Kong	NNH	Exclude
Noyes, L.	2001	Stories of the Oldest-Old as They Come to Face Death	NNH	Exclude
Pattinson, N.	2011	Cancer Patients Care at the End of Life in a Critical Care Environment: Perspectives of Families, Patients & Practitioners	NNH	Exclude
Percy, P.E.	2016	Mourning and Transformation: A Phenomenological Study of Living Through the Journey of Grief	NNH	Exclude
Pfaffman, S.	2014	Conversations with Senior Adults About Spirituality, Death and Dying	MM	Exclude
Pogge, S. M.	2013	The Experience of Living with Chronic Illness: A Heuristic Study	NNH	Exclude
Powell, K.	2010	The Relation of Search for and Presence of Meaning in Life to Attitudes About Death	NNH	Exclude
Pypser, S.M.	2003	The Lived Experience of Facing the End of Life in an Inpatient Hospice Environment	NNH	Exclude
Ruhl, S.	2014	Stories Do the Work... Pursuing an Embodied and Aesthetic Orientation for Hospice Care	NTI	Exclude
Savage-Stevens, S.E.	2003	Meaning in the Lives of Older Women: An Analysis with Hardiness, Health and Personal Projects	NTI, NNH	Exclude
Simon, S. R.	2006	Unfinished Journeys: Elder Learners in an Assisted Living Facility	MM	Exclude
Shetzer, L.	2007	Confronting Aging and Serious Illness through Journaling: A Study of Writing as Therapy	NNH, <63	Exclude
Sladden, C.	2015	Living and Dying with Colorectal Cancer: The Experience & Management of a Mortal Illness	NNH	Exclude
Solimeo, S. L.	2005	Living with Parkinson's Disease: Narratives and the Practices of Embodiment Among Elder Iowans	NNH	Exclude
Steigman, I.	2007	Journey into the Numinous: A Grounded Theory Exploration of the Stages and Meaning of Death Awareness Development	MM	Exclude
Stinson, A.	2013	Spiritual Life Review with Older Adults: Finding Meaning in Late Life Development	NTI	Exclude
Suk-erb, W.	2014	Resilience and Coping: The Perspectives of Cancer Patients' Family, Caregivers and Medical Volunteers at Khampramong Monastery, Thailand	MM	Exclude
Tambini, R.	2007	A Qualitative Investigation on the Phenomenological Experience of Alzheimer's Disease from Patient Perspective	NNH	Exclude
Taylor, A.	2009	Integrating the Mind and the Body: Examining the Role of Counselling Psychology for Individuals with Physical Health Problems	NNH	Exclude
Toombs, S.K.	2004	Living and Dying with Dignity: Reflections on Lived Experience	NNH	Exclude
Waddell, E.L.	2012	Residents' Meaning and Purpose in Life in Senior Communal Living Alternatives	NNH	Exclude
Walker, S.	2016	Finding a Voice at the End of Life: Exploring Preferred Place of Death in a Hospice Context	NNH	Exclude
Wiseman, R.	2015	Eudaimonia: Examining the Use of Narrative Reconstruction During Life Review	NNH	Exclude
Yates-Bolton, N.	2018	Meaning and Purpose in Care Home (Nursing) Life	NNH	Exclude
Zucker, D.M.	1999	Two Contrasting Cases of Men's Experiences with Chronic Coronary Heart Disease Post 1985	NNH	Exclude
ESSAY (n=3)				
Stern, P.	2008	Places for People to Die: The Unacknowledged Truth About Nursing Homes	MM	Exclude
Fresh Air	2016	Hospice Chaplain Reflects on Life, Death and the Strength of the Human Soul	NNH	Exclude
Wilson, E.	2008	Grief: The Defining and Inevitable Journey	NTI	Exclude

ABSTRACTS (n=1)	2013	Abstracts of the IPOS 15 <sup>th</sup> World Congress of Psycho-Oncology	Exclude
Society of Psycho-Oncology			
<b>Summary:</b>			
Journals	n= 192		
Book or Book Chapters	n= 32		
Dissertations/Thesis	n= 60		
Essay	n= 3		
List of Abstract	n= 1		
<b>TOTAL</b>	<b>288</b>		

MMMP, NNH

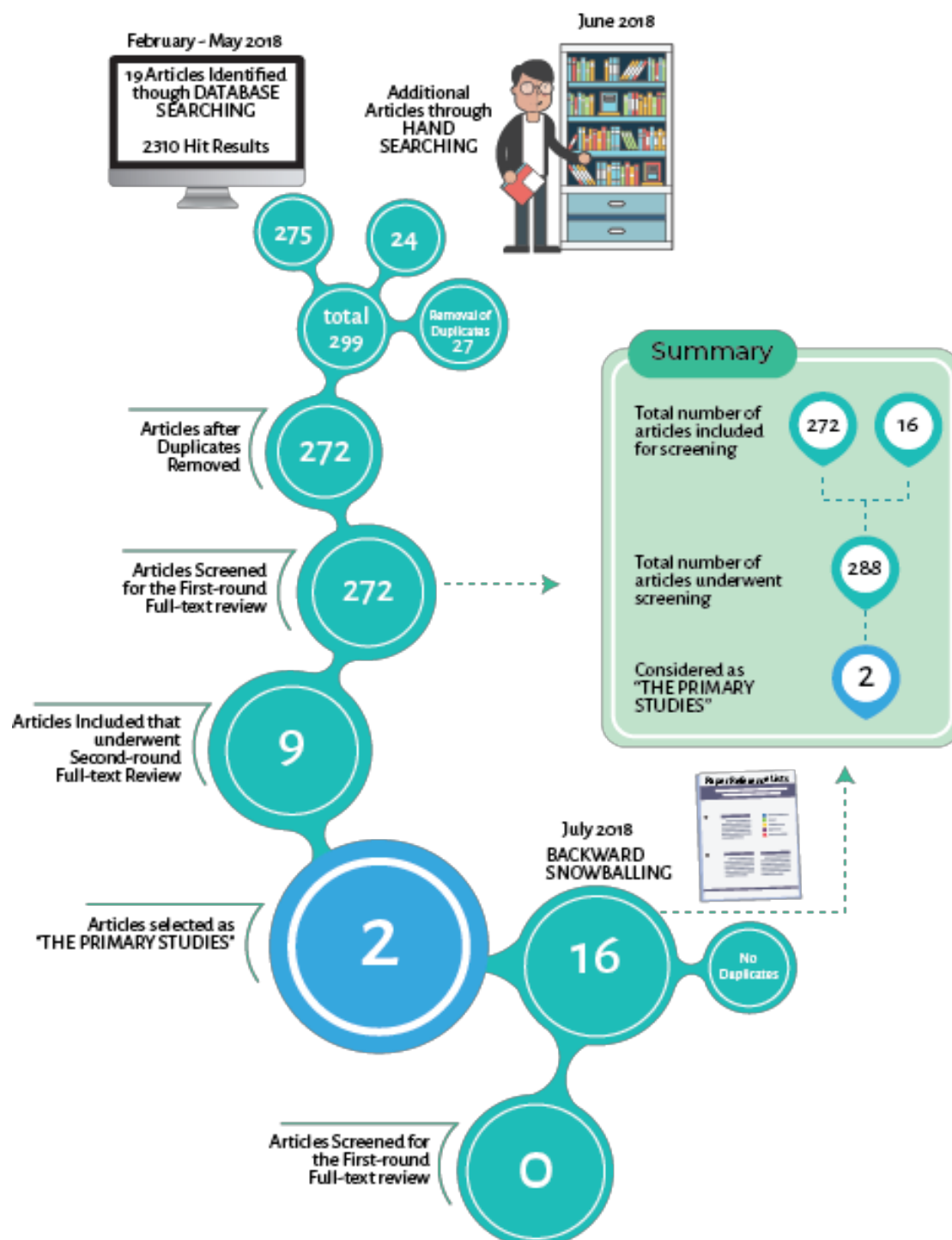
DUPLICATES (n=27)	2008	In Search for Meaning: The Differential Role of Religion for Middle-Aged and Older Persons Diagnosed with a Life-Threatening Illness	
Ardelt, M. et al.	2011	Existential Suffering in the Palliative Care Setting: An Integrated Literature Review	
Boston, P et al.	1999	Stories at the Hour of Our Death	
Brady, E.M.	2009	Creating and Finding Meaning in Visual and Written Texts Through Aesthetic Experience: Four Case Studies of Hospice Patients	
Bruce, M.J.	2014	Understanding the Experiences of Stage IV Breast Cancer: A Qualitative Inquiry of a Stage IV Diagnoses	
Downs, K.	2017	Crucial Aspects Promoting Meaning and Purpose in Life: Perceptions of Nursing Home Residents	
Drageset, J. et al.	2009	Filipino Elderly's Sense of Reminiscence, Living Dispositions, and End-of-Life Views	
de Guzman, A. et al.	2008	Growing While Going: Spiritual Formation at the End of Life	
Harris, H.	2015	How Older People with Incurable Cancer Experience Daily Living: A Qualitative Study from Norway	
Haug, S.H. et al.	2003	Experiencing Chronic Illness: Co-creating New Understandings	
Ironsides, P. et al	2017	Lost and Stranded: The Experience of Younger Adults with Advanced Cancer	
Knox, M.K et al.	2014	Making Space for Dying: Portraits of Living with Dying	
Lark, E.	2013	Aesthetic Engagements: "Being" in Everyday Life with Advanced Cancer	
la Cour, K & Hansen, H.P.	2009	Activity and Meaning Making in the everyday Lives of People with Advanced Cancer	
la Cour, K. et al.	2010	Meaning-Making in Memories: A Comparison of Memories Death Related and Low Point Life Experiences	
Mackay, M.M. & Bluck, S.	2016	Meaning-Making Process Related to Temporality During Breast Cancer Traumatic Experience: The Clinical Use of Narrative to Promote a New Continuity of Life.	
Martino, M.L. & Freda, M.F.	2011	Suffering and Decision Making Among Seriously Ill Elderly Women	
Morrissey, M.B.	2016	Mourning and Transformation: A Phenomenological Study of Living Through the Journey of Grief	
Percy, P.E.	2013	The Experience of Living with Chronic Illness: A Heuristic Study	
Pogge, S.M.	2015	Life-story: Meaning Making Through Dramatherapy in a Palliative Care Context	
Redhouse, R.	2014	Promoting Meaning and Purpose in Life	
Shin, J. & Steger, M.	2006	Searching for Meaning in Negative Events: Concept Analysis	
Skaggs, B. & Barron, C.	2015	Living Through the End: The Phenomenon of Dying at Home	
Solomon, D. & Hansen, L.	2009	Seriously Ill Patients' Discussions of Preparation and Life Completion: An Intervention to Assist with Transition at the End of Life	
Steinhauser, K. & Alexander, S.	2014	Resilience and Coping: The Perspectives of Cancer Patients, Family, Caregivers and Medical Volunteers at Khampramong Monastery, Thailand	
Suk-erb, W.	2017	A Captive, a Wreck, a Piece of Dirt	
van Wijngaarden, E. et al.	2015	Meaning-centered Dream work with Hospice Patients: A Pilot Study	
Wright, S. et al.			

The CODING SYSTEM	Codes	Explanations	Counts (N= 288)
	MMMP	- the discussion or focus of the literature is not on making meaning among terminally ill in nursing home.	61
	NNH	- setting is not in nursing home or alike.	106
	NTI	- participants or informants in the study are not terminally ill or does not coincide with the inclusion criteria of this study.	29
	MMMP, NNH	- participants or informants are terminally ill but the discussion is not on making meaning and the setting is not in nursing home or alike.	12
	MMMP, NTI	- the setting is in nursing home and alike, but the discussion is not focus on making meaning among terminally ill.	7
	NNH, <65	- the discussion or focus of the literature is on making meaning but not in nursing home. Though terminally ill but not above 65-year-old.	6
	NTI, NNH	- the discussion or focus of the literature is on making meaning but not in nursing home. The participants or informants are not terminally ill.	50
	GM	- the study is quantitative.	2
	NTI	- the literature talks about making meaning in dying but the verbatim accounts of terminally ill in nursing home cannot be traced in the findings or conclusion.	4
	NE	- the literature is not in English.	2
	AIOP	- all or almost inclusion criteria are present in the literature.	2
	CR	- there is available abstract of the literature but during full-text review cannot be retrieved or opened in spite of means to find the whole content.	7



## Appendix D

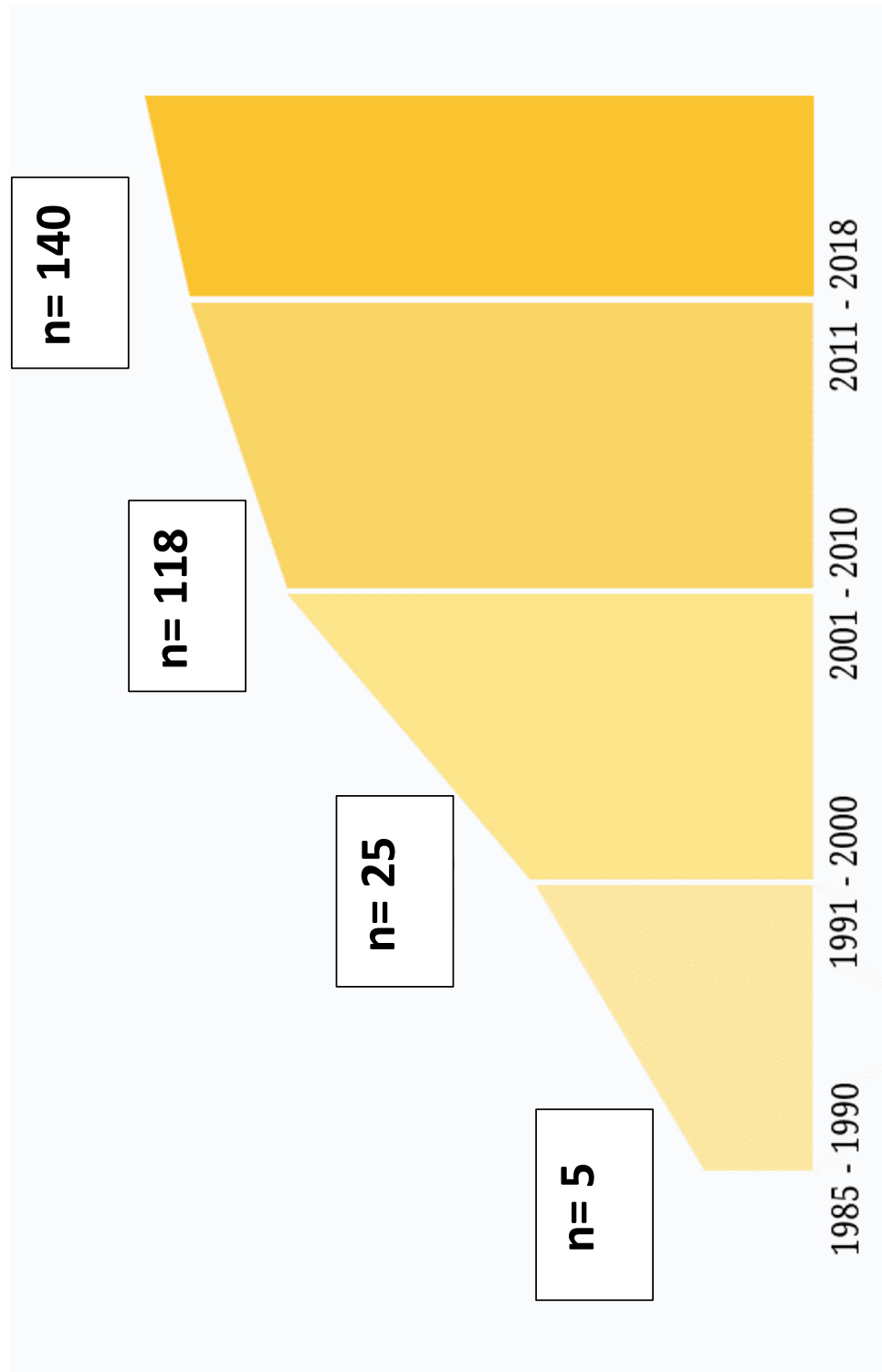
### Flow Diagram of the Search Strategy Results





## Appendix E

Trends of the 288 Searched Literature in Terms of Publication Year



# Appendix F

## Methodological Characteristics of the Two Primary Qualitative Studies

Author/ Date & Country	Aim	Design	Settings	Number of Informants	Data Collection Method /Analysis	Findings
Kulas, Gail/ 2001, Canada	To enter into a relationship with dying and generate understanding of their experiences.	Hermeneutical Phenomenology	-Senior's residence -Long-term institution -Informant's home	(5) William Christine Hank James Frances	Audiotape interview / Hermeneutical Analysis	<b>Themes:</b> 1. The Experience of Dying 2. Inevitable Destiny 3. Reflection on a Life that has Been Lived 4. "You Kinda Try to be Prepared" 5. Hoping 6. "My Body" 7. Influenced of Medical Landscapes 8. "I'm Still Living" 9. "You've Got to Live with a Little Bit of Pain" 10. Aging and Dying 11. Living On 12. The Other Vistas
Kang, Seung Hee/ 2006, not mentioned	To explore one's journey towards the unknown and to understand how one sees the end of life and how one is growing into fullness in the journey.	Descriptive Phenomenology	-Nursing Home	(1) Mrs. Erickson	Audiotape interview / Thematic Analysis	<b>Themes:</b> 1. Movement from Hell to Acceptance 2. Coping Mechanism 3. Image, Metaphor, Stories and Others Embedded in Mrs. Erickson's Experience. 4. Mrs. Erickson's Jesus with <i>Homoousion</i> 5. The Process of Mrs. Erickson's Spiritual Growth 6. Music as an Element that Gave Mrs. Erickson's Life 7. Mrs. Erickson's meaning of Life 8. Will to Live Until Death.

# Appendix G

## Quality (Critical) Appraisals of the Two Primary Qualitative Studies

Critical Review Components	*Questions	Kulas (2001)	Kang (2006)
STUDY PURPOSE	*Was the purpose and/or research question stated clearly?	Yes	Yes
LITERATURE	*Was relevant background literature reviewed?	Yes	Yes
STUDY DESIGN	*What was the design?	Hermeneutical Phenomenology	Descriptive Phenomenology
	*Was a theoretical perspective identified?	Yes	Yes
	*Method/s used?	Interview	Interview
SAMPLING	*Was the process of purposeful selection described?	Yes	No
	*Was sampling done until redundancy in the data was reached?	Not Addressed	Not Addressed
	*Was informed consent obtained?	Yes	Yes
DATA COLLECTION	*Clear and complete description of site?	Yes	Yes
	*Clear and complete description of participants?	Yes	Yes
	*Role of researcher and relationship with participants described?	Yes	Yes
	*Identification of assumptions and biases of researcher described?	Yes	Yes
	*Procedural rigor was used in the data collection?	Yes	Not Addressed
DATA ANALYSIS	*Data analysis were inductive?	Yes	Yes
	*Findings were consistent with and reflective of the data?	Yes	Yes
	*Decision trail developed?	Yes	Yes
	*Process of analyzing the data were described adequately?	Yes	Yes
	*Did a meaningful picture of the phenomenon Under study emerge?	Yes	Yes
	*Was there overall credibility?	Yes	Yes
	*Was there overall transferability?	Yes	Yes
	*Was there overall dependability?	Yes	Yes
	*Was there overall confirmability?	Yes	Yes
CONCLUSIONS & IMPLICATIONS	*Conclusions were appropriate given the study findings?	Yes	Yes
	*The findings contributed to theory development and future practice or research?	Yes	Yes

# Appendix H

## Illustration of the Thematic Synthesis Process in this Study

