SENSE-MAKING IN THEORY AND PRACTICE: A METATHEORETICAL FOUNDATION AND APPLICATION FOR HEALTH INFORMATION SEEKING

BY

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THESIS

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ABSTRACT

This thesis attempts to provide deeper historical and theoretical grounding for sense-making, thereby illustrating its applicability to practical information seeking research.

In Chapter One I trace the philosophical origins of Brenda Dervin's theory known as "sense making," reaching beyond current scholarship that locates the origins of sense-making in twentieth-century Phenomenology and Communication theory and find its rich ontological, epistemological, and etymological heritage that dates back to the Pre-Socratics. After exploring sense-making's Greek roots, I examine sense-making's philosophical undercurrents found in *Hegel's Phenomenology of Spirit* (1807), where he also returns to the simplicity of the Greeks for his concept of sense.

With Chapter Two I explore sense-making methodology and find, in light of the Greek and Hegelian dialectic, a dialogical bridge connecting sense-making's theory with pragmatic uses. This bridge between Dervin's situation and use occupies a distinct position in sense-making theory. Moreover, building upon Brenda Dervin's model of sense-making, I use her metaphors of gap and bridge analogy to discuss the dialectic and dialogic components of sense making.

The purpose of Chapter Three is pragmatic – to gain insight into the online information-seeking needs, experiences, and motivation of first-degree relatives (FDRs) of breast cancer survivors through the lens of sense-making. This research analyses four questions: 1) information-seeking behavior among FDRs of cancer survivors compared to survivors and to undiagnosed, non-related online cancer information seekers in the general population, 2) types of and places where information is sought, 3) barriers or gaps and satisfaction rates FDRs face in

their cancer information quest, and 4) types and degrees of cancer information and resources FDRs want and use in their information search for themselves and other family members.

An online survey instrument designed to investigate these questions was developed and pilot tested. Via an email communication, the Susan Love Breast Cancer Research Foundation distributed 322,000 invitations to its membership to complete the survey, and from March 24th to April 5th 10,692 women agreed to take the survey with 8,804 volunteers actually completing survey responses. Of the 8,804 surveys, 95% of FDRs have searched for cancer information online, and 84% of FDRs use the Internet as a sense-making tool for additional information they have received from doctors or nurses. FDRs report needing much more information than either survivors or family/friends in ten out of fifteen categories related to breast and ovarian cancer. When searching for cancer information online, FDRs also rank highest in several of sense-making's emotional levels: uncertainty, confusion, frustration, doubt, and disappointment than do either survivors or friends and family.

The sense-making process has existed in theory and praxis since the early Greeks. In applying sense–making's theory to a contemporary problem, the survey reveals unaddressed situations and gaps of FDRs' information search process. FDRs are a highly motivated group of online information seekers whose needs are largely unaddressed as a result of gaps in available online information targeted to address their specific needs. Since FDRs represent a quarter of the population, further research addressing their specific online information needs and experiences is necessary.

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Lastly, I appreciate the time and level of commitment that 9,200 volunteers provided in thoughtful feedback on my survey. I am grateful for insights they rendered into their information seeking experiences and for their generosity of spirit. The words of one anonymous participant characterize this Army of Women: *"anything to help another woman in her journey or quest for authentic knowledge."* (Participant #1598).

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INTRODUCTION

The central activities of the information seeking theory called sense-making are seeking, processing, creating, and using information whereby sense-making is the process and sense or understanding is the result of that process. (Dervin, 1992) Within the theory of information seeking, sense-making study appropriates the metaphor of gap-bridging from both a methodological and heuristic or investigative perspective to explain the phenomena of how individuals interpret information in order to make sense of it. Unfortunately, "philosophical knowledge has been very neglected in IS [information science] and the epistemological and metatheoretical views have seldom been formulated or analyzed" (Hjorland, 620). Scholars agree that the field of Library Science must deepen and enrich its theoretical and philosophical discussions so that it embraces the possibilities of disparate approaches, and so that in recognizing its limitations it transcends them. This thesis attempts to provide deeper historical and theoretical grounding for sense-making, thereby illustrating its applicability to practical information seeking research.

Chapter One

Sense making operates on three levels of abstraction: metatheory, methodology, and method (Dervin, 1992). This thesis attempts to make a deeper philosophical and metatheoretical connection in Chapter One. In the first part of this chapter, I trace the philosophical origins of sense making metatheory beyond the assumed origins in twentieth-century Phenomenology to its rich ontological, epistemological, and etymological heritage that

dates back to the Pre-Socratics. In addition, Chapter One examines sense-making's more recent philosophical undercurrents best articulated within *Hegel's Phenomenology of Spirit* (1807), where the nineteenth century German philosopher returns to the simplicity of the Greeks for his concept of sense.

Chapter Two

Chapter Two explores sense-making methodology in light of the dialectical and dialogical bridge connecting sense-making's philosophy and theory with its pragmatic uses. In Chapter Two, I build upon Brenda Dervin's 1999 model of sense-making and borrow her metaphors of gap and bridge analogy to discuss the dialectic and dialogic components of sense making. The dialectic, I believe, is the bridge between situation and use, and it therefore occupies a distinct position in sense-making theory. Sense-making's dialectical bridge connects theory and its philosophical origins discussed in Chapter One with sense-making in practice explored in Chapter Three. I believe the gap is the absence, the void, and the alienation where truth/meaning/sense should be and is not. It arises in all cognitive activity when the mind struggles to move from uncertainty to certainty. In this chapter, I specifically link sense-making's core concepts discussed in Brenda Dervin's works—her gaps, acknowledgement of becoming, "verbings", concept of movement within time-space, and the role of power—to their earlier sources in Phenomenology and in Hegel's dialectic. Furthermore, I call upon Mikhail Bakhtin's concept of the "dialogic" or dialogue in order to read Dervin's theory of sense-making not simply as influenced by philosophical works of the past but more so as a dialogic body of writings that extends in two directions: Dervin's ideas about sense-making communicate with

Hegel's <u>Phenomenology</u> such that they are informed by Hegel's work and also inform his work, albeit through the mind of the reader or communicator.

Chapter Three

While Chapter One discusses sense-making metatheory and Chapter Two explores sense-making methodology, Chapter Three addresses sense-making's method via a pragmatic example. The Greeks, Hegel, Bakhtin, and Dervin lend a philosophical foundation and give structure to practical everyday sense-making and information seeking. Therefore, I transition from the philosophical and methodological concepts of sense-making to the study of how first-degree relatives of breast and ovarian cancer make sense of their online information-seeking needs and experiences. (Henceforth, I refer to these relatives as FDRs). The National Institutes of Health defines FDRs as parents, children, brothers, and sisters.

Chapter Three uses an online survey to glimpse the un-addressed and perhaps misunderstood online information needs of FDRs of cancer survivors so that the health information environment can address a growing population of online cancer information seekers and understand what this population of Internet users most wants or needs from the websites they visit for cancer information. Because statistics show that an increasing number of Americans use the internet for health information, knowing what those information needs are will help healthcare providers, librarians, community health organizers, and website content developers gain a well-rounded picture of the health needs of its community members.

Additionally, Chapter Three reviews the literature and addresses gaps in health information seeking research. For example, the first gap lies in the lack of research about supporters of cancer patients. Very little online information appears to have been designed and

provided specifically for caregivers (Chalmers,1996; Chalmers, 2001; Pecchioni, 2007). The second research gap exists in studies examining the information-seeking needs, motivation, or behavior of FDRs of cancer survivors. "Few studies have especially concentrated on the information needs of their family members. An implication for further research, therefore, is that qualitative and quantitative studies could be used in order to establish more fully the information needs of family members of women with breast cancer" and ovarian cancer (Rees & Bath, 2000). If philosophical models inform library and information science, fewer gaps would exist because researchers would have a model or theoretical structure to follow, thereby lessening gaps and bridging theory and praxis, situation and use.

Conclusion

In summary, this thesis explores the theory of sense-making from both metatheoretical and methodological levels, and applies this theory in empirical research focused on FDRs of cancer patients and survivors. The main tenets of sense-making theory —gap-bridging, the notion of becoming, a focus on "verbings" and movement, and the role of power—find their sources in philosophical movements such as Phenomenology, in the discipline of Philosophy, in Wolfgang Iser's gap theory in Reader Response literary criticism, and in twentieth-century Russian Formalism's verbal strategies. Yet, sense-making's roots trace to ideas first articulated in Hegel's <u>Phenomenology of Spirit</u>. I propose that the dialect already exists as a simplified version of Dervin's fifteen or more sense-making themes, and argue that the dialectic constitutes the bridge between the protagonist's sense-making situation-gap-use based on Brenda Dervin's original conception.

In reality, the Internet can have positive effects on relatives of cancer survivors. Cancer, the most common cause of death in the United States for people under age 65, is the second most common cause overall, preceded only by heart disease. One in two males and one in three females will face a cancer diagnosis. The overall costs of cancer rose to 219 billion in 2007. Furthermore, lack of health insurance prevents 24% of Americans from receiving optimal health care (ACS Cancer Facts, 2008). Thus, this thesis uses sense-making theory as a lens through which to view gaps between cancer information needs and actual information available to FDRs who use the internet. The hope exists that results of the study will improve not only content and availability of information for internet users but also reduce health care costs since informed health consumers can reduce health care burdens through prevention and faster recovery times (O'Rourke and Tuokko, 2000).

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CHAPTER ONE

SENSE-MAKING IN LIGHT OF THE GREEKS AND IN THE SPIRIT OF HEGEL

Introduction

The act of sense-making and its metaphors of a protagonist moving through time and space in order to bridge a gap dates back to humankind's oral heritage. As written language developed, oral epic tradition moved to the recorded word. Homer's epic poems represent this first surviving instance of written texts. Homer (c. 750-700 BC) in book XI of *The Odyssey* has his epic hero, Odysseus, journey into the world of the dead where he encounters the physical and ontological gap that separates both the living and dead worlds. When Homer's hero reaches the world of the dead that lies beyond the Stream of Ocean, Odysseus stands on the edge of the world of the living where he consciously recognizes the space between himself and the underworld, the world of the dead. While journeying through the underworld, Odysseus encounters the soul of Elpenor, a fallen comrade: "Thus we sat facing each other across the trench exchanging joyless words, I on one side, with my sword stretched out above the blood, and on the other the ghost of my comrade pouring out his tale" (11.82-84). After this conversation, Odysseus meets his dead mother who asks: "My child, how did you come here to this murky realm, you who are still alive? This is no easy place for living eyes to find. For between you and us flow wide rivers and fearful waters" (11.155-158). These two emotional meetings between Odysseus and his beloved comrade and his dear mother represent early examples of sense-making.

As his main goal, Odysseus embarks on an information seeking and sense-making journey to the Halls of Hades ultimately to question the spirit of the blind Theban prophet, Teiresias, who, upon their first encounter, similarly wonders: "What has brought you, the man of misfortune, to forsake the sunlight and to visit the dead in this joyless place?" (11.85-90). Of course, it is Odysseus's incredible need to figure out how to get back home to Ithaca that compels him to undertake the hazardous quest. In reply, the prophet orders him to "step back from the trench and hold your keen sword aside, so that I can drink the blood [from the sacrificial sheep] and prophecy the truth to you" (11.90-95).

Yet, even after he finally gains the practical insight he has sought from Teiresias in the underworld, Odysseus struggles to make sense of deeper concepts such as what death means on several levels, i.e., physical, emotional, and spiritual. When he tells his mother that "I long to reach you, so that even in Hell we may throw our loving arms round each other," the reader and Odysseus recognize the physical barrier that divides life and death since his mother slips through the embrace. In the course of his visit, Odysseus's mother explains many things to him and calms his grief by making sense of his confusion and questions. As he leaves, she orders him to "bear in mind all you have learnt here" (11.220-224).

Virgil (70-19 BC) in his *Aeneid* similarly repeats the unforgettable scene of the hero bridging the gap between worlds. Before Aeneas can discover "truth sunk in depths of earth and gloom," he must journey down the dark road to Tartarus, the deep gloomy abyss residing in the lowest depths of the underworld. Before he descends into the "Jaws of Hades," he must first cross the slimy Tartarean Acheron:

> There in mud and murk seethes the Abyss, enormous and engulfing, choking forth all its sludge into Cocytus. Here there is a warden of the crossing, who watches over the river

water. He is the dreaded Charon: a ragged figure, filthy, repulsive, with white hair copious and unkempt covering his chin, eyes which are stark points of flame, and a dirty garment hanging from his shoulders. Charon punts his boat with his pole or trims the sails, and so he ferries every soul on his dusky coracle . . . The souls stood begging to be the first to make the crossing, and stretched their arms out in longing for the further shore (156).

Like Odysseus, the souls Aeneas encounters wonder what adventures could bring a living man to cross the great void, and they ask him pointedly "what fortune has been pressing on you that you should visit the sunless homes of gloom in this land of dark confusion?" (163). Aeneas successfully bridges the gap Virgil depicts metaphorically as treacherous waters separating one world from another. Just as the soul of Odysseus's mother imparts information, so, Aeneas journeys to the underworld to glean information from his father. Even though Aeneas bridges the gap on a physical level, he encounters a barrier on the metaphysical level when he laments "Father, o' let me, let me clasp your hand! Do not slip from my embrace!" Virgil continues: "Three times he tried to cast his arms about his father's neck; but three times the clasp was vain and the wraith escaped his hands, like airy dreams or the melting of a dream" (168). Like Odysseus who struggles to make sense of this experience and gains deeper insight from his mother's words, so Aeneas moves from anguish and confusion into understanding as his father "revealed each truth in due order" (169).

For the Greeks, Chaos, a "yawning void," constitutes the beginning of all things. Bards of Greek oral tradition and myths captured the notion of the "yawning void" so that poets could later write about it in Greek genres such as epic, poetry, and drama. These literary genres formed by poets represent early attempts to illustrate sense-making by both protagonists and antagonists

and their gap-bridging activities. The Greeks, and afterwards the Romans, used literature as the mode to explore information seeking and sense-making and to bridge the gap or void between confusion and insight about the origins of life and meaning of existence. Thereafter, in the centuries following Homer, Plato (429-347 BC) by his dialogues further defines in depth and breadth the philosophical concepts of sense and understanding using the Socratic method.

In Part One of Chapter One, I trace the philosophical origins of sense-making beyond its twentieth-century foundation in phenomenology to its rich etymological, epistemological, and ideological heritage that dates back to Homer and the Pre-Socratic era. Part Two of Chapter One links sense-making's concepts discussed and developed by Brenda Dervin in her works— the presence of gaps, acknowledgement of becoming, concept of movement within time-space— to their earlier sources in phenomenology best articulated within Hegel's *Phenomenology of Spirit* (1807) and his debt to Greek philosophy.

Part One: Greek Roots of the Word Sense

Etymology of the Word Sense (Noos/Nous)

In this section, I follow sense-making's roots to an ancient Greek term for sense and explore how the evolution of this Greek term relates to the theoretical foundations of sense-making and information seeking within the field of library and information science. I believe that the concept of sense-making as found in contemporary library science traces its linguistic and conceptual origins to two early Greek words for sense: *noos* and *nóein*. The noun is pronounced as *noos* in English (*vóos* –Ancient Greek spelling) and its corresponding verb is pronounced as *nóein* in English (*vóεiv* –Ancient Greek spelling). *A Lexicon of the Homeric Dialect* defines the first meaning of *noos* as "mind" and defines a second meaning as "sense"

(Cunliffe, 1963). According to ancient Greek etymology, *noos* evolves into new meanings, and eventually later Greeks spelled it as *nous*. In Kurt von Fritz's classic study, linguistic changes in the noun led to the creation of a new corresponding verb, *nóein* (1943). Thus, from its first written instance in Homer's poetry, the connotation and spelling of the word *noos* evolves over a long period of time into *nous*, which gradually came to mean the thoughts of one's consciousness. Eventually, in Parmenides's (520-460 BCE) poetic fragments, *noos* indicates an act of reasoning and is spelled *nous*.

As we see above, *noos* (νóos) and its infinitive *nóein* (νóϵιν) simultaneously means *sense* and *mind* in fourth-century Greece. Etymologically, the word *noos* probably derives from the root meaning "to sniff" or "to smell" since the Greeks initially believed that the mind was an organ, a concrete object (Snell, 1960; von Fritz, 1943). As the Greeks began to think of the mind, or *noos*, as more than a noun and more than just an organ of the body, the word assumed attributes belonging to adjectives and verbs. By the stage in semantic development found in the Homeric poems, the concept of *noos* more closely relates to vision rather than smell because the term has shifted to mean "to realize or to understand a situation"(Snell, 1960). The infinitive form of *noos* thus reflects "the image-making mind and also the act of image-making, and finally it is the individual image, the thought" (Snell, 1960). Therefore, if the first meaning of *noos* as a noun is "sense," the second meaning of *noos* is "mind." In a similar vein, it follows that if *nóein* is the act of sense-making or knowing through the sense organs, *nóein* also refers to the sense-making mind. This connotation of the word occurs "mainly where recognition of an object leads to the realization of a situation, especially a situation of great importance or emotional impact" (von Fritz, 1943).

The Greeks were the first to combine nouns and verbs to create abstract concepts. The trend of turning nouns into verbs or verbs into nouns, whose seeds or forms existed in primitive speech, comes into use in fourth-century Greece. In the slow and complex evolution of Greek language, "the verb and the noun were blended into one, and the three basic forms of the noun—name, concrete, and abstract noun" were combined to form the concept (Snell, 1960). For the ancient Greeks, some words representing thought process are often linked in peculiar combinations such that "nouns which are derived from verbs occasionally denote, at one and the same time, an organ, its function, and its effect" (Snell, 1960). Thus the germination of sense-making grows to connote more than the visceral organ's ability to sense external stimuli and develops into the deeper mental function.

Homer and Sense

Greek literature begins with Homer since there is no existent written work predating the *Iliad* and the *Odyssey*. Classicists argue that analysis of the term *noos* prior to Homer leads to "linguistic speculation" (von Fritz, 1943). Even within the Homeric poems, the Greek language shows evidence of evolving sophistication of thought. The words for sense—*noos* and *nóein* − develop several derivative connotations whose meanings appear in pre-Socratic philosophy.

In Homer, both noun and verb terms for sense come to mean insight —seeing on an intellectual level. Therefore, *nóein* or *noos* means the deeper realization when the mind corrects a mistaken identification. For example, the recognition that the person appearing in the shape of an old woman is in fact the goddess Aphrodite is not the result of a clearer vision of the external form since the appearance has not changed but results when the intellect penetrates beyond appearances to a truth. Homer linguistically shifts the meaning of a term to account for the

mind's insight into a truth and to account for his particular view of an instance within the phenomenal world.

Mikhail Bakhtin, Russian linguist and literary critic, explains this evolution in thought, symbolized within and by a word, as the existence of conflicting discourses. This new meaning of the Homeric word represents "the co-existence of socio-ideological contradictions between the present and the past, between differing epochs of the past." Because the "languages of heteroglossia [distinct or different types of speech] intersect each other in a variety of ways," rather than exclude each other, the multiple meanings of *noos/nous* "cohabit" and are "juxtaposed to one another" such that they are "interrelated dialogically" with older versions of the word (Bakhtin, 1981). Thus, it is possible that Homer's depiction of *noos* as insight can coexist with the other connotation of the word as sight. This co-mingling of meanings yields a deeper understanding for the reader of the hero's situation within the epic poem.

Parmenides and Sense

Parmenides' fragments mark the most important turning point in the evolution of both *vóos/nous* and pre-Socratic philosophy (von Fritz, 1943). Parmenides, a sixth century Greek poet, native of Elea, and teacher of Pythagoras, wrote his philosophy in verse form as revelations spoken through the words of a goddess (Kennedy, 1994). In Parmenides' time and during the centuries following Homer, his *noos* (now spelled *nous*) means acquiring knowledge—information seeking and even more specifically, sense-making, as library science would later call this behavior. Additionally, a new Greek infinitive, *nóein*, evolves to account for the meaning connected with the noun's greater activity as it develops into a verb.

Parmenides's extant fragments of his untitled poem, of which only 150 lines survive of the supposed 3000 line poem, illustrate his concept of sense-making or reason which he historically calls *nous*. For example, a goddess tells Parmenides which "road of inquiry" he should follow with his reason and from which roads he must keep away. "These roads, as a majority of the fragments clearly show, are roads or lines of discursive thinking, expressing itself in judgments, arguments, and conclusions (von Fritz, 1943; Snell, 1960). Since reason (*nous*) is to follow one of three roads and to stay away from the others, there can be no doubt that discursive thinking and reasoning are part of the function of sense-making. What for Homer is intuitive understanding becomes for Parmenides logical reasoning in the function of sense-making (*nous*).

Furthermore, inherent in the discussion of logical reasoning is the notion of the gap that reason must cross as it journeys towards truth and knowledge by information seeking and sense-making. Parmenides remains one of the earliest philospher-scientists to discuss the "unbridgeable abyss between the two 'worlds'" (Popper, 1998). Like Homer, Parmenides contrasts the world of facts and truth with the world of opinions or appearance. The hero of this philosophical poem follows in the Homeric epic tradition as he journeys across a seemingly unbridgeable gap from the mortal world into the immortal world. There the Parmenidean hero passes through "Gates of the paths of Night and Day, /and they are bound together by a lintel and a stone threshold. /They are high in the sky, blocked by mighty doors . . . that "spread open, creating a widening gap" (Herman 2004, 1.11-1.18). Here the goddess welcomes the hero, promising to teach him "well-rounded Truth as well as the opinions of mortals, for which there is no true evidence" (1.29-1.30). For Parmenides, his reasoning is his sense-making used to bridge

the gap between *doxa,* the world of opinion, and reality or the "thing in itself" that lies beyond or across the gap.

Sense-Making and Philosophical Thought

An understanding of these ancient terms offers insight into the evolution from pre-philosophical to philosophical thought. In particular, the ancient Greek development of the meaning of such words (*nous* and *nóein*) influenced the development of early epistemology. Scholars have shown that "a great number of modern philosophical terms in this field are either directly borrowed from the Greeks or translated from their language (von Fritz, 1943). The Greek classicist and linguist Von Fritz could not have been referring to the theory of sense-making contained within the theory of information seeking as we now know it in library and information science (LIS) when he made this claim in 1943, since LIS was just beginning to establish a foothold as a discipline in its own right. Yet, his statement rings true today as I explain in the following discussion.

The more complex extension of sense (*noos*) as both insight and meaning illustrated in the Homeric poems paves the way for pre-Socratic philosophy's distinction between appearance and reality. The pre-Socratic philosophers with the extension of *noos* to *nous* and to its verb equivalent differentiate between the phenomenal world perceived through the sometimes-fallible senses and the real world behind or beyond sensory perception. (Plato would later call this truth the world of the Forms.)

Parmenides raises the level of discussion about both sense and sense-making from its previous concern with how things appear in reality to a more formal theory. This formal theory contains elements that resemble modern sense-making in LIS. For Parmenides, if mortals fail to

use their reason (*nous)* correctly, they fail to reach real truth (Curd, 1991). Parmenides teaches

that reason (*nous)* can lead one astray if it takes the wrong path. His goddess suggests that

"helplessness guides their wandering *nous"* or reason, so that it is connected with opinion (*doxa*)

rather than truth (*aletheia*) (B6.5-6). "The implication is that mortals, having failed to keep their

thought from the forbidden route, are guided by a mistaken, deceived and altogether helpless

noos (*nous*)" (Curd, 1991). Moreover, the poem's use of a route along which one journey's for

knowledge is similar to Brenda Dervin's notion of the protagonist's sense-making journey. For

Parmenides and sense-making, the route of inquiry along which one searches for knowledge

indicates the quest is as important as the final outcome. That one can lose the path and become

lost on the way is symbolic of the confusion one encounters on the sense-making journey. The

key to Parmenides and the reason he remains important to philosophy and, I believe, to the

philosophical foundations of modern sense-making is that he claims reasoning and knowing

(*noein*) depend not on experience of appearances, which can lead the mind astray, but depends

on the real essence of being. For Parmenides and sense-making theory developed in

contemporary library science, the journey towards being rather than to non-being is the real

journey of true sense-making that leads to knowledge and understanding rather than to a journey

down the dark path of confusion and frustration characterized by conflating knowledge and

belief, being and appearance (B8.34-36).

  These distinctions between the world of truth and the world of opinion eventually lead to

distinctions between subject/object and mind/body. For example, Plato's idealistic world of

Forms stretches beyond an unbridgeable gap separating humankind's many sensible forms.

Unfortunately, Plato's distinction between subject and object later evolves into sixteenth-century

Cartesian dualism and to nineteenth-century phenomenology's subsequent discussions of the

subject/object dilemma. Furthermore, in light of this discussion of the Greek roots of sense-making in LIS, it is worthwhile pointing out that there is an etymological connection between the word for sense in both Greek and Latin. Interestingly, the Latin for sense, *sensus*, means both the physical senses and the understanding or reason. Thus, even after Plato, with the Romans the Latin word maintains the organic whole comprising mind and body; the connection has not yet splintered (Cassell, 1968). More importantly, the dichotomy between the concrete sense of sight and the abstract notion of insight sets up a natural opposition in which each side is understood better in terms of the other. Hegel's Phenomenology of concrete and abstract—beings and Being – partly arises out of Greek dichotomies found in words such as sense.

Part Two: Sense-Making and Hegel's Phenomenology

Although the etymology of the word sense-making dates back to classical Greece, the theory of sense-making as it grew within the field of communication studies was not articulated as theory and methodology until the 1970s. Since then, the notion of sense-making has gradually moved from a generalized communication-based methodology over to the library and information science discipline where it inspires discussions in the studies of information needs and uses. Brenda Dervin, a professor of communications and researcher in the field of library and information science, defines sense-making metatheory "as behavior, both internal (i.e., cognitive) and external (i.e., procedural), which allows the individual to construct and design his/her movement through time-space" (1983). Dervin defines the central activities of sense-making as seeking, processing, creating, and using information whereby sense making is the process, and sense or understanding is the result of that process. Within the theory of information seeking, sense-making study appropriates the metaphor of gap-bridging from both a

methodological and heuristic perspective to explain the phenomena of how individuals interpret information in order to make sense of it or come to conclusions.

Brenda Dervin's article, "On studying information seeking methodologically," mentions her debt to four philosophers whose teachings informed her thought in the development of ideas for her article "Sense-Making Metatheory and Methodology": Pierre Bourdieu (1930-2002), Michel Foucault (1926-1984), Hans-Georg Gadamer (1900-2002), and Jurgen Habermas (1929). Dervin states that "the term sense-making seemed to emerge in the early years of the phenomenological tradition although I have not yet located what I consider a first use" of the term sense-making. After careful study, I realize that what all four philosophers above hold in common with Brenda Dervin and her concept of sense-making are their ties to Hegel. If one steps back past phenomenologists such as Martin Heigegger (1889-1976) and Edmund Husserl (1859-1968) to view the thoughts of their predecessor, Hegel, one sees that all the various recent philosophical influences upon sense-making lead back not merely to Bourdieu, Foucault, Gadamer, and Habermas but trace their original source in Hegel's writings.

Professor Birger Hjorland asserts that the discipline of library science must deepen and enrich its theoretical and philosophical discussions so that it may entertain the possibilities of disparate approaches, and also that it may recognize its limitations in order to transcend them (Hjorland, 1998). He observes that scholars concerned with the theoretical structure upon which the field of library science rests take care to acknowledge that:

> Philosophical knowledge has been very neglected in IS [Information Science] and the epistemological and metatheoretical views have seldom been formulated or analyzed. Instead of conscious analysis such views have mostly been unconscious attitudes by information scientists. It is important for IS to raise its theoretical and philosophical

level, the better to understand the limitations and possibilities of different approaches

(Hjorland, 1998).

Rather than seek independence from existing theories and knowledge within other disciplines, Hjorland calls LIS to embrace its interdisciplinary roots and to discuss the eclectic theoretical foundation upon which the field rests "because it is important to base a discipline on a proper philosophical framework" (Hjorland, 2004; 2005).

Hegel's Recovery of an Ancient Idea

G.W.F. Hegel (1770-1831) rejects Immanuel Kant's *Critique of Pure Reason* (1724-1804) on the grounds that it forbids the possibility of knowledge of the Absolute, or Truth, prior to experiencing it, i.e. *a priori*. Therefore, such a Kantian claim that one can only know the world of appearances and not the things themselves limits knowing to the world of perception. Kant's thinking in this way is similar to the earlier Humean system since David Hume (1711-1776) argued that one can only know one's own perceptions. Hegel responds through "his attempt at recovery of an ancient way of philosophical knowing that he sees obscured within the contemporary "age of criticism" (Bristow, 2007). I discuss Hegel's position in detail in this section.

What is phenomenology—this ancient Greek way of knowing that Hegel discusses? The word *phanomenologie*, comes from the Greek *logos* meaning word, reason or theory and *phainomenon* meaning appearance. "The Greek word *phainomenon* means what shows itself, the self-showing, the manifest" (Snell, 1960). Since appearances may not always be reality as in the Homeric instance where the old woman is actually the goddess Aphrodite, the word *phainomenon* can also mean what eventually becomes plain to see or seems (Inwood, 1996;

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Snell, 1960; von Fritz, 1943). Phenomenology, then, is the study of appearances both literally

and metaphorically. Realization of a situation designated by the Homeric *noein* is quite similar

to phenomenology, which, in turn, is similar to sense-making's original definition of "situational

awareness" found in communication theory since both the Homeric and modern concept result in

a vivid impression that enters the mind from the outside environment. Moreover, Homer's

characters place together external events or images so that each element adds to a growing

understanding of a situation. This "self-showing of beings is the starting point of all

phenomenological investigation" (Brogan, 2005). As a division of philosophy, phenomenology

explores the concept of sense; thinkers such as Aristotle and Heidegger begin philosophy with

the mind's act of sense-making.

Like the early Greeks and their concept of *nous*, Hegel believes consciousness grasps

knowledge of objects through both sense perception and understanding. Hegel complains of

Kant's epistemological Idealism that it is a bridge leading only to the hidden things and thus can

be built out of nothing else but concepts. Hegel rejects this gossamer-like bridge and builds what

he believes to be a sturdy frame. From the later Greeks, Hegel borrows and is influenced by "the

Idea" —after Plato's "Ideas"—which constitute the forms or the archetypes of things themselves

(Kant A313, B370). But Hegel's "Idea" as the combination of essence and existence aligns itself

more closely to the Homeric concept of sense as *nous*. Consequently, he attempts to heal the

fragmentation that occurred with Descartes, separating objects of the senses and objects of the

understanding. His solution to bridge the gap that results from Cartesian dualism separating the

subject from the object is the "recovery of the ancient Idea, now very much obscured—obscured

now in particular by the events and culture that characterize the 'modern' in time and the

'northwestern' in space," since Cartesian dualism covers up rather than reveals the Idea

(Bristow, 2007). Philosophers after Hegel such as Habermas, Gadamer, Husserl, and Heidegger similarly return to Greek philosophy for their understanding of meaning—or what library science likes to call "sense-making." For instance Gadamer gains a deeper understanding of hermeneutics, the study and interpretation of written texts, when he returns to the old Greek manuscripts. He writes that "if we wish to do justice to the subject, the hermeneutics of the human sciences . . . lead us back into the problems of classical metaphysics" and Plato, in particular (Gadamer, 1989). Dervin remarks vaguely of Gadamer. She refers to his *Truth and Method* but only mentions that his "treatment of philosophical hermeneutics in its relationship to method propelled my own quest" (Dervin, 1999). Similarly, she remarks that Habermas has influenced her thoughts on sense-making (Dervin, 1999). Yet, in speaking of his *Lifeworld and System,* she is equally vague as she states: "Habermas whose focus on the development of communication-based theorizing of social structure have proved both foil and fodder"

Though the Greeks first invented the concept of image-making from the same word meaning both mind and sense (*nous*), the actual use of sense-making with its corresponding concept does not supposedly appear in the literature until the twentieth century, according to Dervin. Professor Dervin states that "The term sense-making seemed to emerge in the early years of the phenomenological tradition, although I have not yet located what I consider a first use" (Dervin, 1999). Dervin does not cite which "early phenomenologists" coined the term "sense-making" nor does she specifically mention early phenomenologists. She has, however, mentioned secondary sources who do interpret the phenomenologists. According to T.D. Wilson, one source for Dervin's concept of sense-making was social phenomenology, specifically Blumer's symbolic interactionism (Wilson,1999). Wilson states "the source of Dervin's ideas on sense making have links to and much in common with phenomenology. For

example, George Herbert Mead, Blumer's teacher, studied in Freiberg, and must have come into contact with the ideas that led Husserl to develop phenomenology as a philosophical discipline in the same institution" (Wilson, 1999). In following Professor Wilson's lead linking early phenonemologists to Dervin's sense-making, I explore Edmund Husserl's *Logical Investigations* and find he speaks of the "sense-making of knowledge," and that he further declares: "the sense of a statement survives the elimination of the perception" (Husserl, 2001). For Husserl, meaning lies not in the act of perception, since perception changes both over time and with each varied perspective, but in the percept or judgment of the perception. What seems a "first use" of the term sense-making that I find in Husserl's work does not tightly link Dervin's concept of sense-making with Husserl's. For Husserl, "sense" is meaning that cannot always be identified with sensory experience. Of course, this meaning of sense takes us back to the Homeric and Greek concept of sense as *nous* discussed earlier. Perhaps Dervin came to know phenomenology in reading these scholars' interpretations of phenomenology and in reading the later philosophers such as Habermas, Gadamer, Bourdieu, Foucault who came after and reacted against the early phenomenology movement.

Dervin cites Pierre Bourdieu as another influence upon her concept of sense-making. Pierre Bourdieu, French professor of sociology at the College de France who built upon the theories of Husserl, uses the term "meaning-making" rather than sense-making to explain his theory of *habitus,* or the combination of objective social structures into an individual subjective structure of action for the agent or actor. Dervin states that his "focus on practices as habitus has informed Sense-Making's attention to social structure manifested in practice" (Dervin, 1999). Bourdieu states that:

The notion of habitus has been used innumerable times in the past, by authors as different as Hegel, Husserl, Weber, Durkheim, and (Marcel) Mauss, all of whom used it in a more or less methodical way. However, it seems to me that, in all cases, those who used the notion did so with the same theoretical intention in mind…. I wanted to insist on the *generative capacities* of dispositions, it being understood that these are acquired, socially constituted dispositions…. I wanted to emphasize that this "creative," active, inventive capacity was not that of a transcendental subject in the idealist tradition, but that of an active agent…. I wanted to insist on the "primacy of practical reason" that Fichte spoke of, and to clarify the specific categories of this reason . . . (Bourdieu, 1990).

Therefore, like his Greek predecessors, Bourdieu, too, engages in reconciling the objective with the subjective to reach the middle ground that comprises understanding. He bridges the gap between subject and object when he introduces the concept *habitus,* or acquired characteristics of a given class, as a unifying principle. Interestingly, habitus is the Latin translation of the Greek word "hexis" [English pronunciation] which Aristotle used to explain those acquired characteristics or habits of a virtuous life—prudence, justice, fortitude, and temperance.

Sense-Making in the Shadow of Hegel

Foucault claims to have escaped Hegel. His philosophy seems an attempt to flee Hegelian thinking, but he ultimately confesses "We have to determine the extent to which our anti-Hegelianism is possibly one of his tricks directed against us, at the end of which he stands, motionless, waiting for us" (Foucault, 1983). Since the nineteenth century, one can never escape Hegel, and Foucault recognizes that his thinking in *The Discourse on Language* slams into, reacts against and sometimes even coincides with, Hegeliansim. Of Hegel's philosophy Foucault

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remarks that it is "The path along which we may escape Hegel, keep our distance, and along which we shall find ourselves brought back to him, only from a different angle, and then finally, be forced to leave him behind, once more" (1983). It seems to me that this is the point at which sense-making begins to exist in the most modern theoretical use as metatheory within the Contemporary Period. Sense-making asks, as does Foucault, that if philosophy must begin with absolute discourse, what, then, is the meaning of the individual person's existence as she arises and moves amidst a society, a social class, and a struggle? Thinkers such as Foucault, Bourdieu, and Habermas rearticulate Hegel so that he becomes more palatable and understandable for the twentieth century and beyond. Of course "Mind is always in the world, and social (Taylor, 1999). All this Hegel brilliantly pioneered," although credit for such thought falls to later thinkers who rephrase Hegel in a slightly more understandable way. Edmund Husserl may have been the first to revive the term sense-making from its original Greek meaning, and Pierre Bourdieu introduced the idea of "meaning-making," similarly pulling from Greek roots. However, the many facets comprising modern day sense-making in LIS trace their contemporary philosophical roots to their predecessor, Frederick Hegel and ultimately to Greek thought and sense-making.

Conclusion

Ultimately, sense-making's roots trace to ideas first articulated by Homer and that later surfaces in Hegel's *Phenomenology of Spirit.* Homer transforms the meaning of *noos* through his literary depiction so that the word assumes multifaceted and abstract meanings and becomes a new way to conceptualize perception and knowing. Scholars come to understand the linguistic evolution of a word such as sense-making when they juxtapose texts so they may dialogue with

past and/or future works. In this way, the linguistic and etymological differences in the notion *noos/nous* found in *The Odyssey* or the Parmenidean fragments are free not only to contradict but also to communicate similarities in "dialogic" interrelationship.

Hegel dips into Greek philosophy for his understanding of sense so that he may soundly argue his position against Kant and Cartesian dualism, and he moves beyond them to develop his system of metaphysics and epistemology. His conviction that humankind could bridge the gap between the absolute spirit of beings and Absolute Spirit plays out in his *Phenomenology of Spirit*. Spirit, Hegel's protagonist, is similar to Dervin's actor because they each embark on an information-seeking quest for truths or Truth. In comparing similarities between Dervin's and Hegel's theories, one cannot help but pull into dialogue many interrelated teachings, such as those by Gadamer, Bourdieu, Husserl, Habermas, and Heidegger because their points of view inform and are informed by those who came before and by those texts yet to be written.

In his humorous yet serious article, "We Don't Need a Philosophy of Library and Information Science: We're Confused Enough Already," Jim Zwadlo argues that the "con-fusion" of ideas within library and information science is worth seeking. The fusion of ideas in the interdisciplinary field is what makes library science an evolving and rich field capable of morphing and growing with the cultural times. Yet, in the same article, Zwadlo observes that contemporary library and information science theorists such as John Budd, Gary and Marie Radford, and Archie Dick propose a new philosophy for LIS based on phenomenology, or a work of an individual such as Foucault, "or a combination of approaches united by opposition to positivism. However, Zwaldo mistakenly believes their proposals imply that a power struggle is the way to choose philosophies, with a new philosophy adopted through a kind of cultural coup" (Zwaldo, 1997). I disagree with Zwaldo's latter charge in that a careful reading of Budd,

Radford, and Dick reveals that they are not proposing a new philosophy for LIS that can replace an older, less useful philosophy, but rather, these modern theorists merely take care to point out strains of either philosophical movements or individual philosophers whose ideas come to the fore and ground library science. The ideas already exist in LIS, and like artifacts long buried, remain unnoticed until brought to light. That Radford, Dick, and Budd are imposing a philosophy upon LIS is a backward way to read their work. In many cases, one cannot propose a philosophy for LIS when the philosophical framework that grounds the very nature of LIS is, in Heidegger's words "always already present."

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CHAPTER TWO

DIALECTIC AND DIALOGIC AS BRIDGES FOR SENSE MAKING

Introduction

In Chapter One I explored the philosophical origins of sense-making theory beyond the assumed origins in twentieth-century phenomenology and later communication studies to its rich etymological and epistemological ancestry in the Pre-Socratic era and connected the past with sense-making's more recent philosophical undercurrents further elaborated and articulated within *Hegel's Phenomenology of Spirit* (1807).

Chapter Two takes a closer look at sense making's methodology which I argue involves a dialectical bridge (bridge one) that connects the metatheory—or philosophy—with practice. I posit the Greek dialectic, transformed through Hegel, as the glue that binds sense-making's core concepts discussed and developed by Brenda Dervin in her works: the presence of gaps, acknowledgement of becoming, focus on "verbings," concept of movement within time-space, and the role of power. Finally, Chapter Two discusses the dialogic as a bridge (bridge two) between discourses integral to the process of becoming—or coming to knowledge and sense; I situate sense making methodology inside the dialogic process, or the act of dialogue.

Sense making and sense unmaking are inherent to the human condition since all individuals either consciously or unconsciously construct meaning by cognitively bridging gaps in worlds. For, as Aristotle says in his *Metaphysics* "All men by nature desire to know" (*Metaph*., A, 980 A I.). The gap-bridging metaphor lends a methodological and heuristic structure with which to posit questions about how people interpret information and make sense

of it. By pulling in George Lakoff and Mark Johnson's (1980) ideas of metaphor analysis using graphical illustrations, Brenda Dervin illustrates how people interpret and make sense of information through similar image schemes. Her highly cited diagram of sense-making features a protagonist who must bridge a gap to reach the other side; the conceptual metaphor illustrates the cognitive process of thought as it moves from uncertainty to clarity. According to Dervin, the sense making approach to information seeking is primarily a methodology that provides a conceptual framework. In Dervin's "On studying information seeking methodologically: the implications of connecting metatheory to method," she remarks that methodology: "is highly contested, much abused, and frequently ignored. . . It is, thus, either collapsed into method or collapsed into metatheory and in either locale it disappears" (Dervin, 1999). Professor T. D. Wilson observes that confusion exists between methodology and method because "people write about 'methodology' when all they are doing is describing the choice of method for a study, or simply describing the method chosen… to state one's methodological position is to describe one's view of the nature of reality" (Wilson, 2002). Indeed, methodology acts as the bridge between metatheory and method, thereby connecting theory and practice. Borrowing the bridge analogy, it is my intent in this chapter to connect sense-making theory and its philosophical origins discussed in Chapter One with sense-making in practice explored in Chapter Three. Chapter Two, then, acts as a bridge, and the bridge or methodology of sense-making is the concept of the dialectic and, through extension, the dialogic.

Chapter One explored sense making 'metatheory', or theory about a theory. The Oxford English Dictionary defines the prefix meta- as "beyond, above, at a higher level" and as such, metatheory belongs to the philosophical specialty of epistemology and ontology (OED). Methodology is subsumed under metatheory and similarly stems from philosophy.

Methodology is the branch of philosophy that analyzes the principles and procedures of inquiry in a particular discipline (Stanford Dictionary of Philosophy).

Dervin extracts fifteen major metatheoretical themes found within sense-making, some of which I have addressed in Chapter One. Ironically, in her words, "we are drowning in concepts, variables, methods, theories." In an attempt to simplify "the laundry list of concepts and theories and methods" of sense-making methodology, I recognize that each of these themes are simply a component of the Hegelian dialectic. In short, Hegel's dialectic, or commonly known as the Hegelian triad consisting of thesis, antithesis, and synthesis, "accounts for all movement and change, both in the world and in our thought about it. It also explains why things, as well as our thoughts, systematically cohere with each other" (Inwood, 1996). The dialectic, I believe, occupies a distinct position in sense-making theory. Therefore, the conceptual framework or model for sense-making methodology must take into account its dialectical underpinnings within theory. When one understands the dialectic, one immediately recognizes the "laundry list" of themes found within current sense-making and recognizes that the list falls under the dialectical umbrella. Further, I will explain how the dialectic, holding within its very nature the components of sense-making, connects the metatheory and method of sense making.

Therefore, Chapter Two adheres to the following organization: In Part One, I return to the Greeks this time to examine their concept of the dialectic and its role in communication and knowledge and to show how the components that comprise sense-making methatheory and methodology stem from these classical ancient roots. In Part Two, I address sense making's theory of movement through time and space as a concept which consequently already exists in Hegel's dialectic. Then, in Part Two, I also explore how sense making's theory of "verbing" similarly exists in the process of dialectical becoming, as Hegel's modern use of the dialectic

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pulls from the Greeks and provides a contemporary framework for the additional themes of "becoming" found in sense-making methodology. I discuss how the dialectic acts as a bridge between sense-making metatheory and method because the dialectic is the very methodology comprising sense-making. Finally, in Part Three, I analyze Dervin's theory of sense-making not simply as it is influenced by ancient concepts or by philosophical works of the past, including Hegel's successors Edmund Husserl (1859-1938) and Martin Heidegger (1889-1976), but I read her works as a dialogic body of writings that extend temporally back to the past, exist in the present, and reach into the future, albeit through the mind of the reader.

Part One: Sense-Making Methodology and the Greek Dialectic

Over thirty years ago Curtis Wright stated in his essay "The Immateriality of Information" that "the American librarian has never been comfortable with philosophy . . . [and] he has clearly become a cracker barrel philosopher, for library literature knows virtually nothing but cook book concepts and department store notions of 'philosophy'" (Wright, 1976). Since many thoughtful scholars in the library and information science field of present day are patiently and painstakingly paving a theoretical grounding for the field, most would disagree with Wright's statement that the librarian is merely a "cracker barrel philosopher." However, I do agree with Wright's suggestion urging librarians "to go back to the freshness and vigor of the Greek intellectual outlook . . . because the problems of librarianship are both human and complicated, and sorely need the help of philosophy" (Wright, 1976).

For the early Greek, dialectic is the act of reasoning or disputation through question and answer. The first role of dialectic occurred within the art of critical examination into truth through discussion or debate. The concept derives from a Greek infinitive which means "to

converse with someone" or "to discourse" (Janssens, 1968). According to Aristotle (384 BC-322 BC), Zeno of Elea (ca. 490 BC? – 430 BC) "invented" the dialectic. Yet, it is possible to trace the etymology of dialectic to an earlier use in Homer's eighth century B.C.E. epic poem, the *Iliad.* Homer's use of dialectic reveals that the verb signifies a slightly different meaning of: "to converse with oneself" or "to deliberate" (Janssens, 1968). For example, in Book XI (405-415) of the *Iliad,* Odysseus asks: "But what need for this debate in my heart?" At this moment in the *Iliad*, the Argives have deserted Odysseus in battle, and the hero considers both sides of his dilemma and what fate could possibly befall him. He weighs his options thus: "A great dishonor if I turn and run in fear of their numbers: but worse if I am caught isolated." He comes to a clear answer when he states: "I know it is cowards who keep clear of fighting, while the brave man in battle has every duty to stand his ground in strength, and kill or be killed" (405-415). Classics scholar Emile Janssens explains that Homer's use of the verb form of dialectic bears similarities to the later Latin word *legere* which means "to choose, to gather up" so that Homer's hero exercises a conscious choice in his deliberation or debate with himself (1968). Dervin would label the Homeric example a "sense-making instance" wherein the hero faces a dire situation and stops to cognitively weigh whether to stay or flee before he consciously acts upon his decision.

Socrates incorporates this Homeric idea of the dialectic—the art of deliberation or discrimination of ideas into his practice of philosophy. The well-known Socratic dialectic refers to his conversational method of question and answer to arrive at knowledge and truth. Plato's *Phaedrus* (370 B.C) gives the Socratic definition when Socrates says:

> Now I myself, Phaedrus, am a lover of these processes of division and bringing together, as aids to speech and thought; and if I think any other man is able to see things that can

naturally be collected into one and divided into many, him I follow after and 'walk in

his footsteps as if he were a god.' (266b).

In Plato's example, dialectic means not the art of leading a discussion, but rather, a way of

philosophizing and thinking whereby the individual moves towards insight (see Dervin, 1993).

Eventually, this dialectical way of reasoning or sense making evolves from technique or method

into methodology pervading his system of philosophy. By 380 B.C. Plato writes in Book VII of

the *Republic*: "And by master of dialectic do you also mean one who demands an account of the

essence of each thing?" (531d-536d). Dialectic ceases as the art of argumentation and rhetorical

methods used by the Sophists as an eristic, or art of disputation. Plato thus restricts the meaning

of dialectic, and defines it as the movement of the mind in search of truth. It becomes synthesis

when Plato writes "For he who is capable of synthetic view is a dialectician" (531d-536d).

Janssens explains that once the philosopher's task lies in contemplation of the Highest Good, the

dialectic rises from the Socratic method to the level of philosophy (Janssens, 1968).

Later, in Aristotle's works on logic, such as the *Topics* and *Metaphysics*, dialectic

assumes a "propaedeutic mission" and becomes "an art of discovery," and because of that it

directs the way toward the principles of all the sciences" (Janssens, 1968). In contrast to the

dialectic as the object of philosophy in Plato, Aristotle interprets the dialectic's place as the

object of science, and the dialectic becomes the ultimate form of common sense because it

requires reasoning from premises that are probable and generally accepted.

Hegel's contribution to the Greek dialectic, then, lies in his ability to synthesize the

Platonic dialectic as the art of philosophy and the methodology through which one seeks truth or

the highest Good with the seemingly opposite Aristotelian concept of dialectic as the facts of

science operating within the horizon of common sense. Hegel's recreation of the Platonic thesis

and the Aristotelian antithesis results in his synthesis wherein a new concept of dialect arises.

Part Two: Sense-Making Methodology Borrows from Hegel

G. W. F. Hegel's (1770 – 1831) modern use of the dialectic stems from the Greeks and

provides a framework for contemporary sense-making's many themes and terms. Hegel believed

three elements are essential to the dialectic and which I shall explore further below as they

pertain to sense-making: First, for Hegel, thinking involves thinking of essences. Second,

thinking involves contradictions or opposites. Third, contradictions are united through synthesis.

The first element essential to the dialectic, and I believe inherent in sense making, is that

thinking involves thinking about essences. Essence is the process of coming to know a thing or a

truth as it is in itself. Essence is implied, then, when Hegel defined the dialectic as the logical

pattern that thought must follow. In his view, the fundamental aspect of reality—dialectical

movement —pertains to and involves the essence of things. For Hegel, "that which exists . . . is

the movement of knowing which recognizes itself for the first time in the dialectic of motion

with which Greek thought began its course" (Gadamer, 1989). Sense-making likewise focuses

on the process that thought follows, and it assumes "that humans and their worlds are constantly

evolving and becoming" (Dervin, 1999). In making sense of the realities of everyday living, in

trying to understand the flux of things, the catastrophes of events, a person comes to understand

through reasoning, instruction, and experience the meaning of his/her reality. Like Odysseus, an

individual journeys on an epic quest toward making sense of the reality of things (essence).

The second element necessary for both the Hegelian dialectic and sense-making

methodology requires movement across time and space because each is aware of a protagonist

not only as static, inflexible, and rigid individual but also as fluid, flexible and creative across time. The movement or activity required in "sense-making" is also a central activity of Hegel's protagonist, Spirit, which can never be at rest but must always engage in moving forward (Hegel, 1977). "The movement of a being that immediately is, consists partly in becoming an other than itself, and thus becoming its own immanent content" so that it can return to itself or be "taken back into itself" once consciousness has "passed over into its higher truth" (Hegel, 1977). Hegel views this dialectical movement as a "course that generates itself, going forth from, and returning to, itself (*PS* 65). Such movement contains various moments between static and active being. Similarly, sense-making methodology focuses on movement through time and space and assumes "humans are involved in a constant journey through sense-makings and sense-unmakings" (Dervin, 1999). Zeno, the Greek philosopher, explains that "the reason why dialectic first seizes upon motion as its object lies in the fact that dialectic is itself this motion; or put another way, motion is the dialectic of all that is" (Gadamer, 1976).

Thus, the Hegelian dialectic provides a foundation upon which the sense-making moments of activity rest. Hegel worked out his own dialectic methodology by pulling from both the Greeks and from Johann Gottleib Fichte's (1762-1814), who had explored the concept of thesis, antithesis, and synthesis. In his *Early Philosophical Writings*, Fichte asks: "How is it possible to trace all the actions of the mind back to an act of connecting? How is synthesis conceivable without presupposing thesis and antithesis?" (Fichte, 1988) Hegel uniquely transformed Fichte's thought into his dialectical triad. Even Hegel's metaphysics similarly concerns itself with bridging the gap between appearance and reality. Thus, in studying sense-making, one realizes that it pulls ideas from the Hegelian dialect. His thesis, antithesis and synthesis represent the abstract, epistemological concepts found in Dervin's grounded terms of

situation, gap, and outcome. Dervin's protagonist as situated in time-place, mirrors Hegels

abstract concept of thesis. Hegel's thesis is the part where the dialectic begins. Here,

consciousness moves on its truth-seeking journey towards evolution and, ultimately, Absolute

Truth. Moreover, just as Dervin's protagonist faces a gap or barrier and similar to the

protagonist in fiction who must battle his antagonist (such as man against nature, man against

man, or man against himself), so too, Hegel's dialectic shows that consciousness always

encounters its antithesis or contradictory point of view. Faced with two contradictory ideas or

conflicting evidence in the thesis and antithesis, synthesis becomes unavoidable after struggle

and reconciliation. In the Hegelian triad, synthesis becomes the new thesis as the dialectic

continues a re-occurrance (Hegel, 1977).

Contradictions that occur in the Hegelian triad are essential to both sense-making and the

dialectic. Gadamer explains that the attempt to speak of motion as "all that is" leads to

contradiction.   Hegel taught that thought moves forward through a process of contradiction and

the reconciliation of contradiction. Sense-making theory captures the contradiction nicely

because it views individuals "as potentially static across time-space (as manifested in

inflexibility, habit, rigidity, stability) or fluid across time-space (as manifested in flexibility,

randomness, innovation, creativity)" (Dervin, 1999). Thus, sense-making's requirements clearly

already exist in the dialectic.

Another theme within sense-making theory calls attention to movement across time and

space because it is aware of the protagonist not only as static, inflexible, and rigid but also as one

who manifests a fluid, flexible, and creative being across time. "Humans are involved in a

constant journey through sense-makings and sense-unmakings" (Dervin, 1999). The movement

or activity required in "sense-making" is also a central activity integral to reader-response theory

where "meaning is no longer an object to be defined but is an effect to be experienced" —that effect depends upon the active participation of the reader (Eagleton, 1996). Moreover, the reader's expectation of meaning, what Dervin calls sense-making, is continuously adjusted so that meaning is the total movement of reading. So, too, Hegel's protagonist, Spirit, can never be at rest but must always engage in moving forward (6.11). "The movement of a being that immediately is, consists partly in becoming an other than itself, and thus becoming its own immanent content," so that it can return to itself, or be "taken back into itself" once consciousness has "passed over into its higher truth" (33.53). Hegel views this dialectical movement as a "course that generates itself, going forth from, and returning to, itself (40.65). Like sense-making, such movement contains various moments between static and active.

Dervin prefers to think of sense making in terms of a triangle consisting of situation-gap-use/outcome in order to capture the individual's cognitive movement. Hegel calls this sense-making moment nothing other than the becoming of consciousness where the process of perception and truth run its course. "This course, a perpetual alternation of determining what is true and then setting aside this determining, constitutes, strictly speaking, the steady everyday life and activity of perceptual consciousness, a consciousness that fancies itself to be moving in the realm of truth . . . and advances to the outcome (*PS* 68). In this dialectical "moment it [consciousness] is conscious only of this one determinateness as the truth, and then in turn of the opposite one" so that understanding can "bring together, and thereby supersede, the thoughts of those non-entities" (*PS* 68). Like the sense-making model where the individual repeats the cycle of sense-making in many moments throughout the course of a day and one's life, so too, in Hegel's dialectic, "the individual is thrown back to the beginning and drawn once again into the same cycle which supersedes itself in each moment as a whole" (*PS* 71).

Dervin's protagonist—i.e. individual users or information seekers—and Hegel's protagonist—i.e. consciousness or spirit, constantly repeat the sense-making cycle but only as individual consciousness transformed by previous experiences and knowledge.

Furthermore, Hegel and sense-making call attention to the notion of "becoming" as a growth in consciousness that enables individuals to bridge the gap between ideas or cognitive moments. Sense-making acknowledges the growth of an individual and the interconnectedness of the entire person—mind, body, spirit. Emotions, for example, play a role in outcomes because people think and work best when they feel good about themselves. Because confusion, fear, and anxiety lead to counterproductive outcomes or decisions, sense-making moments remain an important and even necessary time to disagree, question or clarify emotions, experiences, ideas, becoming (Dervin, 1983). The sense-making method of understanding even suggests individuals seek out "sites of maximum agreement as well as maximum disagreement" in order to gather the full perspective. This Hegelian dialectic of opposites is what sense-making calls "the circling of perspectives" (Dervin, 1983).

Part Three: Sense-Making's Dialogic

Sense-making is a bridge between discourses. A dialogic work refers to any work that carries on a dialogue or discourse with other texts, as the Russian philosopher Mikhail Bakhtin explains in his *Dialogic Imagination*. Like phenomenology and its corresponding twentieth-century literary theory known as reader-response theory, sense-making attempts to understand the human condition of mental processes through connections or dialogue that does not simply extend beyond or respond to previous works; sense-making's dialogue informs and is informed by works that came before it and by works yet to come. When Dervin states that: "there are

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different 'readings' (and Sense-Making assumes there always will be) these must themselves be put in dialogue rather than making one reading central" (1999), she restates a basic concept of literary theory. Just as there are several meanings of a word or line of poetry, so too, there are multiple interpretations of a text, such as a Marxist or a feminist reading. The different interpretations of which Dervin and reader-response literary theory imply depend on what implicit knowledge, experience, and opinions readers bring to their reading of a text, and how they elect to read between the lines or the gaps as Wolfgang Iser (1926-2007) observes (1978). Furthermore, those multiple meanings and interpretations, either within the same text or between two or more texts, must speak to each other. Sense-making and literary theory borrow this notion from Hans-Georg Gadamer, intellectual descendant of phenomenologists Hegel, Husserl, and Heidegger, who argues in *Truth and Method* (1960) that interpretation of past literature stems from a dialogue between past and present. Gadamer takes the original use of hermeneutics as it was applied to the interpretation of biblical texts, sometimes called biblical exegesis, and uses this method in unearthing meanings within secular texts. For Gadamer, one's understanding cannot journey into the past and into dialogue with previous texts without taking present understanding along (Eagleton, 1996). In a similar vein, Russian literary critic Mikhail Bakhtin, in *Dialogic Imagination* (1986), holds that dialogic works commune with past works and anticipate dialogues with future works (1981).

Another facet of sense-making is the metaphor of gap-bridging to explain the mind's successful arrival at sense or meaning. Brenda Dervin states that "Sense-Making thrusts itself between chaos and order, structure and person, facts and illusions, external worlds and inner, universals and particulars" and that the individual human being, whom she terms the protagonist, attempts to "construct bridges over a gappy reality" (Dervin, 1999). To revive the Greek notion

that the human mind is the origin and center of all meaning, phenomenology focuses on objects

as they appear to consciousness in order to bypass the problem of the gap between subject and

object, or consciousness and the world. Gadamer's *Truth and Method* discusses phenomenology

and literary criticism in light of the German word "Dasein—"being there," or "being in the

world." Dasein as a concept stresses consciousness as mediator between the objective world and

one's inner thoughts, feelings, questions, anxiety, etc.

Like reader-oriented literary criticism and sense-making theory, phenomenology

emphasizes the individual perceiver's central role in determining sense or meaning to fill gaps.

This turn toward the subject in philosophy manifests itself in the reader-oriented literary theory

called reader-response that began in the late 1960s. Reader response critic Wolfgang Iser

teaches that the narrative "gaps" are the absent details or connections within a work that the

reader must fill in from experience. However, no story can ever provide enough detail to prevent

gaps, so the reader must bridge the gap and thus complete the work within consciousness. The

text, then, becomes part of a reader's own experience. Indeed, the literary landscape of Western

culture's history is littered with protagonists such as Odysseus and Aeneas who bridge external

and internal gaps, whether literally or metaphorically, on their truth seeking, sense-making

journeys in synthesis towards wholeness or home. Later readers of these works actively fill in

the blanks or gaps in order to create their own sense and understanding as they dialogue with

texts.

Because humans are constantly in the process of becoming, sense-making theory

concentrates on movement. The shift away from nouns and noun-based interpretations to "a

focus on verbings," Dervin's term, offers a different entry for the search for systematic

understandings of the human condition" and "the patterns that emerge may pertain to fluidities in

sense-makings and unmakings opening up a new kind of theorizing" (Dervin, 1999). In fact, this new kind of theorizing that Dervin posits about verb emphasis in her body of scholarship already existed long before in Russian formalism, a form of literary criticism popular in the early twentieth century. Russian formalists such as Roman Jakobson (1896-1982) and Mikhail Bakhtin (1895-1975) focused on the "verbal strategies" that make a work literary. In "redirecting attention from authors to verbal 'devices,' they claim that 'the device is the only hero of literature'" (Culler, 2000). Sense-making, too, claims this identical focus. The formalists focus attention on action rather than on subject. For example, instead of asking "what does Homer say here?" formalists ask: "what adventures befall the epic in this poem by Homer?" The careful reader of Homer and Virgil notices that the interview questions Odysseus and Aeneas ask and are asked consist of this similar marked attention on action rather than on subject. For instance, the dead ask of Odysseus "how did you come here to this murky realm, you who are still alive?" Of Aeneas in Book II, they ask: "What fortune has been pressing on you that you should visit the sunless homes of gloom in this land of dark confusion" (l. 519-550)? Dervin asks similar verb-based questions in her sense-making research so that her focus is on "the verbings" by which sense is made and unmade. Sense-making frees research from the implicit assumption that there is one right way to produce knowledge (1999). Dervin, like Russian formalist literary criticism that preceded her, moves away from nouns and substances to concentrate on verbs and processes so that she can now declare that "verbing creates knowledge."

In the methodological model of Hegel's dialectic, "thought passes over from the subject into the predicate" because when one thinks the predicate—the verb, the act—one penetrates into the essence of the subject, or that which the subject itself is. In this way, the mind actively comes

to know the thing in itself. Therefore, Russian Formalism, Hegelianism, and Dervin speak of the same phenomenons with different vocabularies and points of view.

Like sense-making theory and Russian formalism, Hegel bases his entire *Phenomenology of Spirit* on sense-making's similar theme that humans are always in a state of becoming. "Becoming" is associated for Hegel with Heraclitus, who posited that everything is in a state of becoming and flux rather than in static being. Because later German thinkers following Hegel preferred to think in terms of the verb "becoming" rather than focus on the static being, they consequently applied "becoming" to the self-unfolding development of history and consciousness (Inwood, 1996).

A final facet of sense-making worth recognizing from a philosophical perspective is the recognition of power. Dervin acknowledges that Paulo Freire (1921-1997) and Jurgen Habermas influenced her ideas about power. For both Freire and Habermas, power depends upon truth. Yet, in tracing the discourse of power back to Hegel's *Phenomenology* and his writings about the Unhappy Consciousness, one notices the origin of the Master-Slave dialectic where consciousness, deprived of truth or the freedom to search for truth, results in loss of power. Hegel explains that this unequal balance of power, what he terms Master-Slave dialectic, plays out in both individuals and in society as a whole. Philosophical scholars after Hegel, such as Friedrich Nietzsche (1844-1900), Karl Marx, Foucault, Freire, and Habermas, continue the discussion of power, freedom, oppression, and truth of which Hegel writes in the *Phenomenology of Spirit*. Freire observes that the lack of value for individuals in society is nothing other than a power struggle. Likewise, Dervin and sense-making views this unequal balance as "forces of power in society and organizations, forces that prescribe acceptable

answers and make disagreeing with them, even in the face of one's own experience, a scary and risky thing to do" (Dervin, 1998).

Furthermore, sense-making specifically recognizes opposition or antithesis when it posits that "movement across time-space implies energy and calls attention to forces that not only impel and facilitate movement but also those that constrain, hinder, and limit movement" (1999). Similarly, in Hegel's dialectic, the movement or activity of consciousness involves a relationship of two extremes of force and passivity. Force "stands as actively present, while confronting it is a passive actuality: the two sides are in relation with each other, but both have also withdrawn . . . in the moving interplay of their mutual opposition" (Houlgate, 1998). Hegel, like Heraclitus, views opposition and conflict as forces necessary for the activity of becoming, and they are inherent in the evolution of consciousness toward Absolute Truth. All human interactions in sense-making similarly use a variety of synonyms to indicate the concept of force such as constraints, barriers, motivation, power, and societal power. In Hegel's chapter on "Force and Understanding," he agrees with the sense-making recognition that force blocks and propels understanding: "In the surface play of Forces everything negates and cancels everything, but the true background is wholly positive. This whole background consists of pure Notions which are part of the Subject's innermost self-consciousness" (*PS* 514-515). Force or power does not realize itself automatically. It needs to be "solicited" by another force. Force and power pervade the human condition.

As the individual moves forward in time toward making sense of situations, experiences, readings, and events or finding meaning in the simple or complex processes of thought, the information seeker constructs bridges using different verbings in order to arrive at outcomes. Verbings include "cognitions, thoughts, and conclusions; attitudes, beliefs, and values; feelings,

emotions and intuitions; and memories, stories and narratives (Dervin and Frenette, 2003 239). However, is it not time to move away from the fifteen or more themes or thought processes of Dervin's to a simpler approach since she herself admits that "we are all drowning" in theories, methods, and concepts? Who among us can remember the myriad of fifteen or more themes or steps in sense-making? Likewise, theories of philosophy and literature need consolidation to help librarians and readers.

Conclusion

In summation, the main tenants of sense-making—gap-bridging, the notion of becoming, a focus on "verbings" and movement, and the role of power—find their source in modern and postmodern philosophical movements such as phenomenology, Wolfgang Iser's gap theory in reader-response literary criticism, and twentieth-century Russian formalism's verbal strategies. Yet, in the final analysis, even the modern / post-modern theories rest on the original concepts of the Greek philosophers. Layers of philosophical constructs obscure contemporary readers' debt to the Greeks. If library science is to thrive as a discipline, it will build on Greek thought and move forward into the future always maintaining a clear historical continuity for library theory, readers, and patrons.

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CHAPTER THREE

ONLINE INFORMATION EXPERIENCES OF BREAST AND OVARIAN

CANCER FIRST-DEGREE RELATIVES

Introduction

"I feel that knowledge is power. The more you know, the better informed you are. You know what questions to ask your doctor, and once you start putting the battle plan together, the more equipped you are to fight." (Survey Participant #8004)

"I live in daily *fear* of contracting cancer as every one of my aunts and one uncle (maternal and paternal) died of some form of the disease. Most feared by me is ovarian cancer as a cousin and at least two aunts died from it.   Breast cancer is also a killer in my family and I feel as though I am a ticking time bomb, particularly now that I have been uninsured for four years due to "preexisting conditions" and high cholesterol and weight." (Survey Participant #8094)

"I have a PhD in health education, so I feel like I can evaluate online info well. There's a *Gap*, though, between info that's too simple & info that's in the medical journals." (Survey Participant #90)

"I think the biggest *gap* of information is related to preventative measures. Everyone wants cures, but I want to start with preventing before it ever happens. I would like to

see more major companies, businesses and organizations increase their focus on preventative measures." (Survey Participant #4958)

"During my most recent searches, I found there was too much information that seemed to be *disconnected*. In caring for a 1st degree relative with metastatic breast cancer as well as ovarian cancer, I found it frustrating trying to find information I could put to use immediately such as nutrition, meditation, and exercise as it relates to cancer treatment." (Survey Participant #3172)

"I have been researching breast cancer and it's causes/treatments since 1987 when my older sister who was only 30 years young at the time was diagnosed and had a double mastectomy. Previously, my Mom, became a survivor of breast cancer, however her two sister[s] and own mother were not so lucky since they were diagnosed in the 70's instead of the 80's like my Mom. What a difference a decade makes! That is why I find the internet such a wonderful blessing in searching for medical information, I no longer have to wait for a doctors appointment or spend [an] hour researching in a library. I can comfortable seek the information I desire and then take what I've found to my doctor to discuss what they know about a particular discovery on the road to a cure or a new treatment." (Survey Participant #8065)

Chapter Three of this thesis takes the theoretic and methodological lens of Brenda Dervin's concept of sense-making and shines it on the problem of health information seeking via an online survey. The survey provides a glimpse into the un-addressed and perhaps

misunderstood online information needs of first-degree relatives of cancer survivors so that the

health information environment can address this growing population of online cancer

information seekers and understand what this population of internet users most wants or needs

from the websites they visit for cancer information. One in three Americans will face a

diagnosis of cancer at some point in life, and the relatives of those individuals affected by the

disease face a growing information need for cancer information. Because statistics show that an

increasing number of Americans use the internet for health information, knowing what those

information needs are will help healthcare providers, librarians, and community health

organizers and website content developers with a more well-rounded picture of the health needs

of its community members.

The prevalence and accessibility of the internet raises questions of what health benefits

this powerful medium offers first-degree relatives of breast and ovarian cancer survivors. The

Pew Internet and American Life Project estimates that between 75 and 80 percent of internet

users search for health information online (Fox, 2003, 2009). Approximately 31% of e-patients

indicate that medical advice or information found on the internet has significantly helped them

(Fox, 2009). The Internet serves as a conduit for cancer-related information and support.

Moreover, studies indicate that internet use by cancer patients has been linked to increases in

social support, coping, and sense of community, and internet use by patients has also been linked

to decreases in loneliness and anxiety (Madara and White, 1997; Mills and Sullivan, 1999).

Although recent research provides an empowering picture of the impact that the internet

can have on cancer patients, three important gaps exist in the literature. The first gap involves

the focus of previous research which addressed the impact of internet use on cancer patients, not

cancer survivors. The American Cancer Society defines survivorship from the point of diagnosis

throughout the balance of life. Thus, most research on cancer survivors' information needs and sources has focused on early phases of survivorship (i.e. near diagnosis and during treatment) (Bloom, 2002). One review found that only 10% of catalogued studies (9 of 92) assessed current needs of post-treatment cancer survivors (Jemal et al., 2006). Even fewer studies report online information seeking behavior of cancer survivors (Meyer, 2007; Rutten et al., 2005). A anonymous survey participant summarizes the scholarship above:

> "As a cancer survivor, I use the internet to look for symptoms of recurrence and ways to prevent recurrence. There seems to be plenty of information about symptoms, etc. while you are in treatment. However there is much less information about living as a cancer survivor." (Survey participant #8578)

Online cancer information and support for *survivors* [my emphasis] is an under-analyzed area. Information addressing the online needs of this group may serve an important function to those seeking information, care, and support of cancer survivors and their families since the number of survivors increases with internet use and the availability of online resources (Rimer, 2005).

The second gap in the literature lies in the lack of research about supporters of cancer patients. Such supporters, some of whom are caregivers, undergo high levels of stress and depression and require assistance in terms of personal coping and caring for patients (Nikoletti, 2003; O'Rourke and Tuokko, 2000; Rolland, 2005; Marziali et al., 2005; Marton, 2009). As a means of coping and diminishing stress and depression, such supporters are common seekers of online health information and support. In fact, caregivers are more likely than patients themselves to conduct online health-related searches, using the information for their own understanding and to pass such information along to the cancer patients for whom they care (Fox, 2007; Pecchioni and Sparks, 2007; Abrahamson et al., 2008; James et al., 2008). Because

"carers also tended to act as 'gate keepers' of information and constantly sought information as a means of coping," some researchers conclude that caregivers are able to bridge the cultural and digital gap in a way that many health professionals cannot (James et al.). For example, one study found that few patients (4.8%) but a high proportion of caregivers (48%) accessed the internet directly for cancer information. Roughly half (50%) of the patients used internet information provided by someone else, generally a family member (James et al.). Unfortunately, very little online information appears to have been designed and provided specifically for caregivers (Chalmers, 1996; Chalmers, 2001; Pecchioni, 2007).

A third research gap exists in studies examining the information-seeking needs, motivation or behavior of first-degree relatives of cancer survivors. First-degree relatives are defined by the National Institute of Health as parents, children, brothers, and sisters (Genetics Home Reference, 2009). "Few studies have especially concentrated on the information needs of their family members. An implication for further research, therefore, is that qualitative and quantitative studies could be used in order to establish more fully the information needs of family members of women with breast cancer" (Rees and Bath, 2000). Since first-degree relatives are at an increased risk of developing cancer because of their genetic predisposition and family history, the awareness of a heightened cancer risk among this group adds another dimension to their information seeking and motivation such that not only do they seek information for a relative diagnosed with cancer, but they also seek information for themselves (Audrian et al., 1995; Chalmers, 2001; Pecchioni, 2007).

Literature Review

A history of breast cancer places first-degree relatives in a moderate to high risk category (Ziogas et al., 2000). One can assume that a similar risk exists for first-degree relatives of ovarian cancer. The minimum relative risk for women with primary relatives is estimated to be twice that of the general population (McCredie et al., 1997; Negri et al., 1997; Sellers et al., 1999). Also, first-degree relatives of women with breast cancer have substantially higher scores of mood disturbance than women with breast cancer (Lerman et al., 1996; Audrain et al., 1995; Chalmers et. al., 2003; Hopwood et al., 1998; Lerman et al., 1996; Lloyd et al., 1996). No research exists discussing mood disturbances among women with a family history of ovarian cancer. Women with a family history of breast cancer have reported feelings of vulnerability to breast cancer (Herbert-Croteau et al., 1997). Only in rare cases do relatives of cancer patients receive adequate psychological support from health professionals in terms of managing the consequences of the relative's illness and mastering their own fears (Faller et al., 1995).

To date, there is little understanding of the information and support needs of first-degree relatives of breast cancer survivors (Chalmers, 1996; Rees and Bath, 2000). There is no research delving into the information and support needs of FDRs of ovarian cancer. Support for first-degree relatives focus primarily on genetic counseling for younger women (Audrain et al., 1998; Hallowell et al., 1997; Hopwood et al., 1998; Lerman et al., 1996; Lloyd et al., 1996; Tessaro et al., 1997), whereas only a few studies identify information needs of women not seeking genetic counseling (Chalmers et al., 1996; Richardson et al.; Breast Cancer Info Link 1998; Stacey, 2002). The information needs of relatives are individualized and specific to personal situations (Breast Cancer Info Link, 1998). Recent studies of women with primary relatives with breast cancer conclude that first-degree relatives have moderate to high level needs for information and

support, yet these needs are not well met (Stacey et al., 2002; Chalmers et al., 2003). High-level

information needs include information about personal risk (Audrain et al.,1995; Chalmers et al.,

2003; Richardon et. al., 1994), genetic testing, and prevention (Audrain et al., 1995; Chalmers et

al., 2001, Chalmers et al., 2003; Hallowell et al.; Lloyd et al., 1996). The most frequently sought

information needs of FDRs included breast self-exam, mammography, breast cancer risk factors,

and lifestyle prevention measures (Breast Cancer Info Link, 1998). Women under age 50 want

information on breast cancer screening, risk of breast cancer, lifestyle options to lower risk, and

hormone replacement therapy and women over 50 wanted additional information on

chemoprevention; more than 75% of high risk women want more information to help make

decisions about prevention, benefits, and risks (Stacey et al.).

 While little research exists documenting the information needs of first-degree relatives of

breast cancer survivors, even fewer studies examine the *online* information needs of these blood

relatives (Kirschning, 2006). The Abramson Cancer Center of the University of Pennsylvania

reported in 2002 that more family members belonged to their main user group website than did

patients; one third of the web members were family members compared to one sixth patient

membership (www.oncolink.com; Kirschning et al.).

 The focus of Chapter Three, therefore, lies in assessing first-degree relatives' online

information-seeking needs, experiences, and motivations as compared with survivors and

"others" such as spouses or friends. The following research questions guided the study described

below:

 Research Question 1. How often and to what extent do first-degree relatives seek online

 information about cancer as compared to both non-related, undiagnosed online cancer

information seekers and to cancer survivors/patients? Cancer information seeking is

defined as having ever searched for information.

Research Question 2. Where do information-seeking first-degree relatives of breast and

ovarian cancer survivors turn when looking for quality cancer information online? Is

there a difference between where FDRs would prefer to go in contrast to where they

actually sought information?

Research Question 3. What barriers or gaps do FDRs face in their cancer information

quest? How do FDRs of breast and ovarian cancer survivors rate their satisfaction with

the existing online cancer information environment? Are there points of concern about

the information environment that stand out against others?

Research Question 4. How do FDRs bridge their gaps in information in order to make

sense of their situation? What types of cancer information and resources do FDRs use to

search for themselves and other family members in order to answer their questions? How

do FDRs of cancer survivors compare with other groups in terms of motivated usage of

online cancer information resources? Are there differences between active and passive

information-seeking?

Methods of Current Study

An online survey was the data gathering technique employed for this study. The online

questionnaire (see Appendix A) was developed to elicit information to address the research

questions above, and to explore potential relationships between the online information seeker

with the FDR, cancer survivor, and "others"—non-related, cancer-free participants who also seek

breast and ovarian cancer information, so that results give a comprehensive picture of who is

seeking information and how such searching might differ among particular groups.

The thirty-four item survey instrument was designed to take ten minutes to complete and

was subdivided into four blocks: introductory questions, information searching, experiences, and

types of information needed. Demographic information about participants was also collected.

Several categories were adapted from published research studies, a detailed review of the

literature, and Abrahamson et al.'s (2008) earlier quantitative study of lay information mediary

behavior in online health information seeking. Research Question 3 asks participants what

barriers or gaps they face in their cancer information quest. This section of the questionnaire

applies sense-making's core concept of the cognitive gap: "how they see their situations, past,

present, and future—and how they move to construct sense and make meaning of these

situations" (Dervin, 1989). Emotions are intricately interwoven into how individuals perceive

and strategize crossing their information gaps. According to Dervin, "Sense-making mandates

attention not only to the material embodiment of knowing, but to the emotional/feeling framings

of knowing as well" (Dervin, 1998). Research Question 4 examines how breast and ovarian

cancer information seekers bridge gaps in order to make sense of their situation. Section 4 of the

questionnaire attempts to uncover materials or resources individuals require to successfully

construct and cross their cognitive bridge (Dervin, 1989). The project was reviewed and

approved by the University of Illinois Institutional Review Board (IRB) on July 22, 2009 as

study #10010.

Pilot Studies

The researcher conducted two pilot studies before running the survey. The first pilot study in February 2009 consisted of a convenience sample of graduate library and information science students from UIUC and several volunteer librarians at the National Library of Medicine. The second pilot survey was sent by the Minnesota Ovarian Cancer Alliance via an email link to their support group "daughters of women with ovarian cancer." Questionnaire wording changes were made to each pilot survey improve question clarity.

Final Survey distribution

The Susan Love Breast Cancer Research Foundation accepted and distributed the link to the final survey via an email to approximately 322,000 volunteers in the Love/Avon Army of Women. The mission of the Dr. Susan Love Research Foundation which launched in 2008 through a large grant from the Avon Foundation for Women is to eradicate breast cancer through research and education. (About the Foundation, 2010). The Love/Avon Army of Women (www.armyofwomen.org.) is an internet-based program that unites laboratory researchers with women willing to participate in research studies related to breast cancer. The Army enables women of all ages, ethnicities, and levels of breast cancer risk to participate in research studies focused on understanding the cause of and means to prevent breast cancer before it starts.

Results

The survey was open for participation from March 24th through April 14th. Over ten thousand women agreed to take the survey (10,692), and 9,200 volunteers actually consented and completed the survey within the three week time period. The University of Illinois Urbana-

Champaign server collected and downloaded the data into an Excel spreadsheet. Data calculations performed using MySQL. Three main groups were compared so that results give a comprehensive picture of who is seeking information and how such searching might differ among particular groups: FDRs (25%), survivors (31%), and undiagnosed, non-blood relatives (42%). (Table 1, Figure 1.)

Research Question 1: Online Information-seeking Prevalence Among First-Degree Relatives

Characteristics of the Respondents:

Significantly more women (n=8,780) than men (n=129) took part, with 291 participants not indicating gender. Over 25% (n = 2,263) online survey participants were FDRs. Most FDRs were female (n = 2,234, 97%), age 55-64 (n = 702, 30%), and white (n = 2,122, 94%). (Table 1, Figures 1, 2, 3). 95% of FDRs have searched for cancer information online as compared to 97% of survivor participants and compared to 86% of participants who are neither diagnosed with cancer nor related by blood to someone with cancer, i.e. friends or family (Figure 3). 70% of FDRs search for cancer information for themselves. 15% report another person asked the FDR to search for information on her/his behalf, and 38% of FDRs, interested in another's situation, volunteered to search for information.

Only 1% (n =30) of FDRs report having ever searched for breast or ovarian cancer information for a spouse or partner. 57% (n =1,315) of FDRs indicate they have searched for cancer information for a fellow FDR family member. In contrast, 18% of survivors and 7% of friends and family have sought information for a FDR family member. Only 5% (n = 125) of

FDRs report searching for family members by marriage who are non-blood relatives. 23% (n=529) of FDRs have searched for information for friends. (Figure 5)

Research Question 2: FDR's Actual and Preferred Sources of Information

When participants were asked "What motivated you to search for breast or ovarian cancer information," 70% of FDRs indicated they were searching for themselves (in contrast to 94% survivors and 56% friends/family). 15% of FDRs indicated they were asked to find information for someone else (Survivors: 15%, Friends/Family 10%). 38% of FDRs responded they were interested in the person's situation and volunteered to search for information (in contrast to 22% survivors and 23% friends/family).

The survey asked participants to indicate all websites or online sources they would *prefer* to use online to find information. When asked "In your most recent search for breast or ovarian cancer information, where is the first place you looked for this type of information," FDRs indicated the following: Google (45%), WebMD (19%), a specific breast or ovarian cancer site (12%), Other (8%), Mayo.com (6%), Cancer.gov (3%), Yahoo Health, MEDLINE/MEDLINE Plus, Wikipedia, Library, Clinicaltrials.gov, and Holistic/Alternative treatment sites ranked at or below 1%. A majority of FDRs (86%) state these sites are where they first turn for online cancer information and also where they would actually prefer to visit. Table 3, Figure 5 shows the responses to survey questions related to online sources.

Research Question 3: FDR's Information-seeking Experiences

On their most recent online breast or ovarian cancer information search, 80% of FDRs found the information they needed, but 56 % indicate it took effort to find the information, while

only 50% report having understood the information, 60% have concerns about the quality of information found, and 53% state the information they found was not specific enough. 84% of FDRs use the internet to advance and explore the information they receive from doctors or nurses. (Table 4, Figure 6)

When searching online for information related to breast or ovarian cancer, FDRs experience more uncertainty(28%), confusion (17%), frustration (14%), doubt (7%), and disappointment (7%) than do either survivors or friends and family. In contrast, survivors report higher levels of optimism (20%), clarity (58%), and satisfaction (27%) than either FDRs or non-FDR family and friends. (Table 5, Figure 7)

Research Question 4: FDRs' Types of Information Needs

A fifteen- item checklist assesses the degree of information needs. Respondents indicated three levels of need in response to this statement: *At this time, do you feel you need more information about (item).* Responses included: *I need no more information, some more information, or much more information.* The fifteen items are organized into seven distinct categories and themes for analysis (see Appendix A).

Overall, FDRs indicate they need much more information than do survivors or non-FDR family and friends. In a list of fifteen information areas, FDRs report wanting "much more" information than do the other groups in the following areas: Screening and detection (22%), prevention (37%), genetic testing (36%), genetic counseling (29%), symptoms of concern (32%), food and nutrition as related to cancer (37%), physical fitness (28%), medical financial aid and insurance information (28%), online support groups for relatives (14%), complementary or alternative treatment (35%). Table 6.

Discussion

The current study explores and compares the online information seeking needs and experiences among three main groups: first-degree relatives, cancer survivors, and family/friends. Women are more active than men in online health information-seeking (85% compared with 75%) and in their use of online support groups (63% compared with 46%) (Madara and White, 1997; Mills and Sullivan, 1999; Fox, 2007). For instance, Dr. Susan Love's Army of Women blog recently reported that 86% of its online searchers and survey takers were women who had never been diagnosed with cancer; they were seeking information for themselves and loved ones (www.Armyofwomen.org, 2009). Similarly, the Abramson Cancer Center of the University of Pennsylvania reported in 2002 that more family members belonged to their main user group website than did patients; one third of the web members were family members compared to one sixth patient membership (www.oncolink.com; Kirschning et al.). This survey concurs with previous studies and reveals that 68% of survey volunteers in the Army of Women have never received a cancer diagnosis.

The sense-making approach and method was tied to a specific situational moment in time-space when survey participants were asked about their most recent online breast or ovarian cancer information seeking experiences and activities (Dervin, 1983). The survey measured the "gaps" in participants' experiences in finding cancer information online by asking a series of questions:

- On my most recent breast or ovarian cancer search, I found the information I needed.

- I understand the cancer information I find on the internet.

- When I do find breast or ovarian cancer information on the internet, I am concerned about the quality of information.

- The breast or ovarian cancer information I find on the internet is specific enough for me.

- I use the internet to help understand or explore further the breast or ovarian cancer information I get from doctors or nurses.

Participants responded by marking whether they strongly agree, agree, disagree, or strongly disagree with the statements. Similarly, participants were asked whether they needed "no more information," "some more information," or "much more information" as it relates to a fifteen-item checklist consisting of potential areas of information related to breast and ovarian cancer: "Thinking about your breast or ovarian cancer information questions at this time, how much more information do you feel you need?" The survey questions attempted to target where the information seeking gaps exist that prevent FDR from moving forward. Sense-making assumes that the quest for information begins with these barriers or blocks along the road to making sense of a situation such as cancer.

As highly motivated information seekers, the online searching activity of FDRs closely follows cancer survivors in that 95% of FDRs represented in this survey have sought breast or ovarian cancer information online compared to the 97% of cancer survivors who have ever searched for information online.

A majority of FDRs, 57%, seek online cancer information for their blood relatives. Perhaps the high number of FDRs searching for other FDRs stems from the fact that either they are caring for a relative with breast or ovarian cancer or because they are seeking information for undiagnosed relatives. These results correspond with studies that discovered caregivers are more

likely than patients themselves to conduct online health-related searches, using the information for their own understanding and to pass such information on to cancer patients for whom they care (Pew Internet; Pecchioni and Sparks, 2007; Abrahamson et al., 2008; James et al., 2008). In comparison, survivors and family/friends tend not to be avid information seekers for their FDR blood relatives since only 18% of cancer survivors and 8% of family friends have ever searched online for information for FDRs.

FDRs tend to be critical and experienced when selecting first sites to visit for information. A majority of FDRs begin their search with Google (45%), as do survivors (38%) and friends/family (43%). Yet, FDRs also use trusted sites such as WebMd and MedlinePlus and Mayo.com. Many FDRs directly select a specific breast or ovarian cancer site as their first site to visit for information; their information seeking behavior may be the result of experiences and exposure in the healthcare environment while caring for a relative with cancer. 83% of FDRs use the internet to explore further the information they receive from doctors or nurses as do 90% of cancer survivors.

Searching for cancer information online can be a highly emotional experience. Sense-making accounts for the feelings inherent in the information search process by incorporating Carol Kuhlthau's "model of the information search process" (Kulthau, 2004). According to Kulthau's model, feelings accompany thoughts and actions in each stage of an individual's information seeking journey. Kulthau lists the feelings inherent to the search process: uncertainty, optimism, confusion, frustration, doubt, clarity, confidence, relief, and satisfaction/dissatisfaction. This survey reframes and rephrases Kulthau's chart (her figure 3.2) found in her text *Making Meaning* when survey participants were asked about whether they encountered these feelings on their most recent online cancer search. (see table 5, figure 7)

When asked directly about the emotions experienced during their online search process, FDRs score highest in all negatively charged emotions. They report more uncertainty, confusion, frustration, doubt, and disappointment than do either survivors or family/friends when they search for information on the internet. A survey participant remarked:

> "My particular area of interest is Triple Negative Breast Cancer--all is gloom and doom-- not sure how current the information on the Internet is--Internet is very depressing on this subject (i.e. TNBC is a death sentence.) Also, since ovarian cancer is so deadly, am frustrated to not find more information on signs and symptoms." (Participant #8293)

FDRs also report higher levels of confusion than do either the survivors' group or the family/friend categories. Yet one cancer information seeker in the family group remarked of her difficulty and confusion seeking information:

> "It is difficult to obtain a balanced view of cancer and treatments available from the internet because the information is not always as current as that provided by a progressive medical facility. My husband has been recently diagnosed with cancer and we have found ourselves staying away from the internet because it is actually more confusing than helpful when trying to make health treatment decisions. We have found the doctors and nurses we deal with to be much more helpful. While we would like a combination of holistic and traditional therapies, it is difficult to find sources on the internet which combine both when you are seeking information. Once you have decided what your path will be, the internet is helpful in being a wealth of information but you have to know what it is you are looking for" (Participant #2196).

In contrast, survivors report highest feelings of satisfaction, confidence, optimism and clarity than do FDRs or family/friends in the information search process either because they find the

information they seek or because the information re-confirms what they have learned from doctors and nurses.

Though they have never received a cancer diagnosis, FDR information seeking needs surpass that of cancer survivors and family/friends. Recent studies of women with primary relatives with breast cancer conclude that first-degree relatives have moderate to high level needs for information and support, yet these needs are not well met (Stacey et al., 2002; Chalmers et al., 2003). FDRs are more concerned about specificity and quality of their information. 56% indicate it took effort to find the information. 60% are concerned about quality of information once they find it. For example, one survey participant remarked "I don't do health related searches on the internet because I don't know which information to trust. I rely on talking with my doctor when I have questions" (Participant #2071). The results also indicate it takes FDR longer than survivors and family/friends to locate the information they are seeking. When they do find the information they seek, they are more concerned than either survivors or family/friends about the quality of the information they find. Moreover, a larger percentage of FDRs state the information they found was not specific enough. In contrast, only 37% of survivors state that the information they find online is not specific enough. For example, one survey respondent remarked that "Though the information was good, I felt as though it was too general and wanted something more specific to my age group and ethnicity." (Participant #8022) Perhaps one reason for survivor satisfaction with the information they find lies in the fact that more research and resources target cancer patients and survivors' information needs.

High-level information needs include information about personal risk (Audrain et al.; Chalmers et al.; Richardon et. al.) and prevention (Audrain et al.; Chalmers et al., 2001, Chalmers et al., 2003; Hallowell et al.; Lloyd et al.). For instance, one survey respondent

commented: "It is very difficult to find specific information on certain symptoms and on prevention. Oncologists don't seem very educated when it comes to alternative treatments and nutrition and supplements" (Participant #8645).   Another study reported high level information need revolves around discussions of genetic testing. Clearly FDRs need more information about this grey area (Audrain et al.; Chalmers et al., 2001, Chalmers et al., 2003; Hallowell et al.; Lloyd et al.). A significantly larger number of FDRs report needing *much* more information about genetic testing, genetic counseling, prevention, screening, food and nutrition than do either survivors or friends/family. A survey respondent remarked: "I lost two aunts and a cousin within the past three years and even though I am tempted by genetic testing, I feel too uncertain about the potential for insurance companies to abuse the information" (Participant #7964)

The most frequently sought information needs of FDRs included breast self-exam, mammography, breast cancer risk factors, and lifestyle prevention measures (Breast Cancer Info Link, 1998). A survey respondent concurs with this mandate when she states:

"Specific education (not just an overview), hands-on detection training w/ props, etc. needs to be available and mandatory at the high school level. Early detection means teaching the prevention skills at a younger age. Knowledge is power." (Participant #8624)

Another participant suggests:

"I would like to see breast cancer awareness as far down as high school. When I was in high school, 1974, a teacher died from breast cancer. She was only 26 years old. The women physical education teachers brought in a speaker on breast cancer. As a teacher myself, I have brought in speakers to speak to our females on breast cancer.   Since I am

teaching in the elementary level, I am not [no] longer provided this program. I would

like to see a state or national wide awareness for high school girls." (Participant #8101)

Because sense-making research focuses on the individual's situation, these results focus on what

the audience member needs rather than on "campaigns" and "message" elements; "the important

utility of the situational approach is in practice (Dervin, 1983). In essence, findings of this study

will provide practitioners with insights about how to be both efficient and effective in their

online communicating efforts.

Limitations

While the study had an enormous response relative to other published studies of health

information seeking, it was a small response rate as a percentage of those invited (2.7%). The

population was also limited to the membership of one particular community, the Army of

Women (although there is anecdotal evidence that it was redistributed more widely). For these

reasons, the results should not be generalized to a broader population. However, the respondents

did exhibit substantial diversity in age, ethnicity, and geographic distribution.

Survey question number thirty four, the final question, was left as an open comment box

for participants to contribute any clarifications of their answers to the prior items, and other

thoughts or concerns. This resulted in approximately 420 pages of participant comments, and

time-constraints prevent an analysis. I intend to analyze the data in question thirty four and to

pursue the rich and thoughtful comments provided by participants because I believe they provide

clues to the information seeking experiences not only of FDRs but also of survivors and

friends/family.

Also, when asking about emotions encountered during the information search process, I failed to provide a box for fear. Carol Kuhlthau does not include fear as one of her emotions in the information-seeking journey. Many survey participants noted my omission in the comment box, such that I began to notice the theme of fear running as an underlying thread throughout the comments.

Future Research

This research presents a glimpse into the largely unaddressed online breast and ovarian cancer information needs, sources, and experiences of FDRs. Future research should unearth deeper information needs of this large online population of women. Future research may also address the fear factor inherent in information seeking in general, and it could address the related topic of information avoidance (Lambert, 2009; Miles, 2008).

Moreover, additional research in areas other than breast and ovarian cancer is also necessary, as is exploration of FDRs' internet information experiences within minority populations. Research beyond this web survey might also include qualitative interviews as a follow-up study informed by the results of the online questionnaire. Interviews with tied pairs of blood relatives would lend insight into the synergy between these two information seeking groups. The value of a qualitative interview process that both complements and supplements information seeking experiences and needs lies in the different perspectives and perceptions that relatives provide.

Conclusion

Results from this current study have implications for health practitioners, researchers, and state and local funding agencies. The Internet can have positive effects on relatives of cancer survivors, survivors, and others such as spouses and friends. For people under the age of 65, cancer is the most common cause of death in the United States, and it is the second most common cause of death for all ages, followed only by heart disease (Jemal et al., 2006). One in two males and one in three females will face a cancer diagnosis. One in four deaths in the USA results from cancer. The overall costs of cancer rose to 219 billion in 2007. Furthermore, lack of health insurance prevents 24% of Americans from receiving optimal health care. (ACS Cancer facts, 2008 check 2009).

Libraries play a vital role in providing Internet services to the public. All Americans deserve access to online information related to health and cancer since access to health information changes lives for the better. Statistics show that "over 80 percent of the [Internet] users said they made a change in their diet after using library computers," and the same study also revealed that "those living below the poverty line—families of four with an income of $22,000 or less—had the highest use of library computers" (http://cis.washington.edu/usimpact/projects/us-public-library-study/)

This paper attempts to expose some gaps between cancer information needs and actual information available to FDRs with the intent that such results will improve not only content and availability of information for relatives, but that it will also reduce health care costs in the long run since informed health consumers can reduce health care burdens (O'Rourke and Tuokko). The biggest increase in internet use from 2005 to 2009 lies in the 70-75 age bracket, with just one fourth of the age group online in 2005 compared with 45% of this age group online in 2008

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(Pew, 2008). By understanding the online information needs of FDRs, researchers and practitioners can begin to create more specific health care information.

Moreover, this research provides a glimpse into the un-addressed and perhaps misunderstood online information needs of first-degree relatives of cancer survivors so that the health information environment can address a growing population of online cancer information seekers and understand what this population of internet users most wants or needs from the websites they visit for cancer information. Furthermore, one in three Americans experiences a cancer diagnosis at some point in life. The growing numbers of caregivers of individuals face the need for cancer information. Because statistics show that an increasing number of Americans use the internet for health information, knowing what those information needs are will help healthcare providers, librarians, and community health organizers and website content developers gain a more well-rounded picture of the health needs of its community members.

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TABLES AND FIGURES

Research Question 1: Online Information-seeking prevalence among First-Degree Relatives

Table 1. Respondent Characteristics

| Gender		Total	FDRs	Survivors	Friends/Family	Others
Male		129	29	36	45	18
Female		8780	2234	2749	3672	94
misc.		291				
Age						
18-24		436	90	71	251	23
25-34		1138	312	93	721	11
35-44		1437	376	329	708	22
45-54		2558	679	834	995	42
55-64		2905	702	1139	1005	41
65+		909	189	432	270	13
Ethnicity		Total	FDRs	Survivors	Friends/Family	
African American		157	31	51	71	
Asian		94	19	36	36	
Hispanic		207	48	50	104	
Multi-Ethnic		49	8	14	27	
Native American		22	2	6	14	
Pacific Islander		13	5	3	4	
White		8278	2122	2605	3432	
Others		274	55	77	123	
Cancer Status						
FDRs		2309				
Survivors		2856				
Family / Friend		3874				
Other		123				

Figure 1. Cancer Status
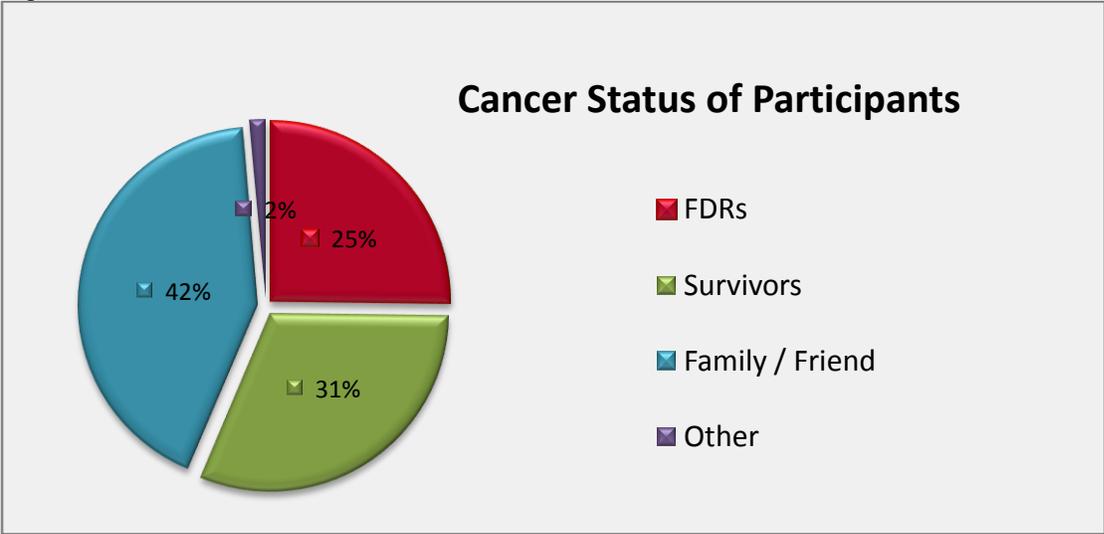
Figure 2. Age
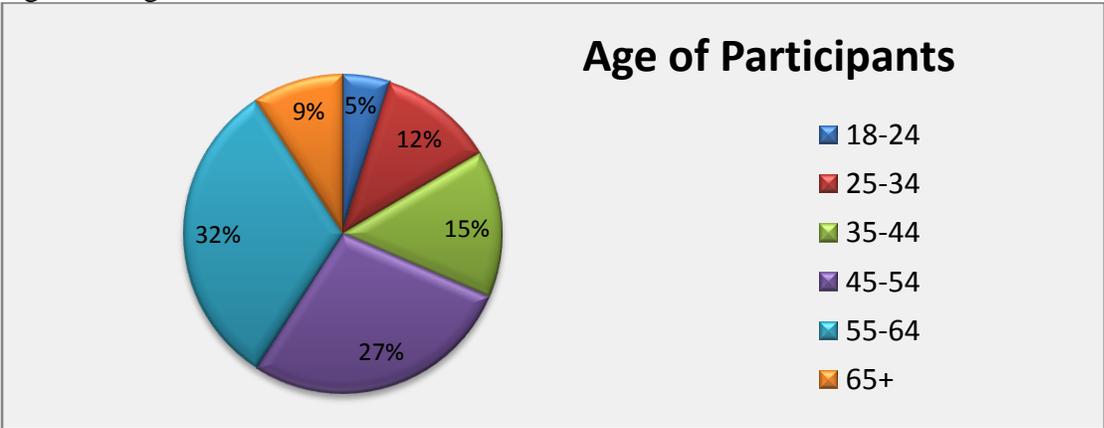
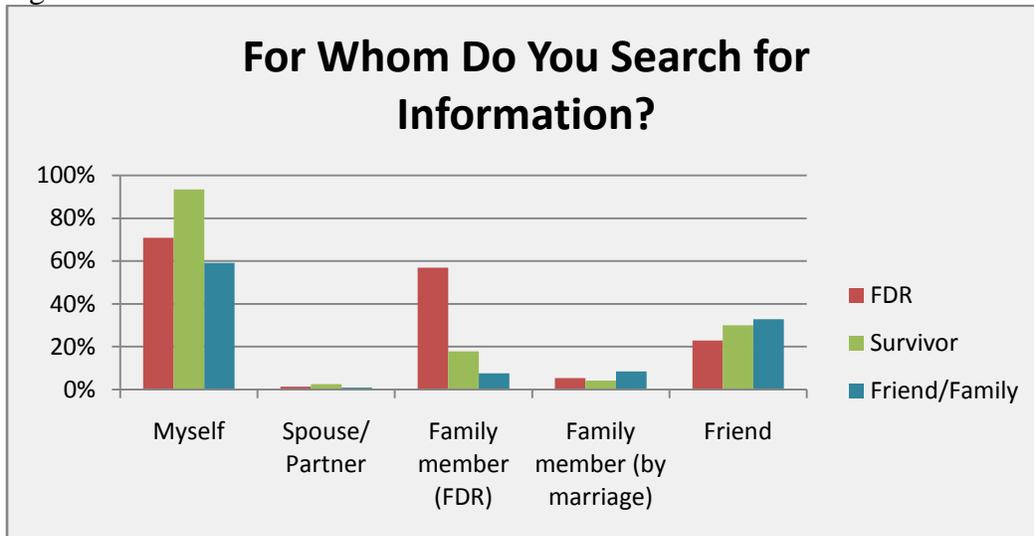Figure 3. FDRs who have Searched for Cancer Info Online
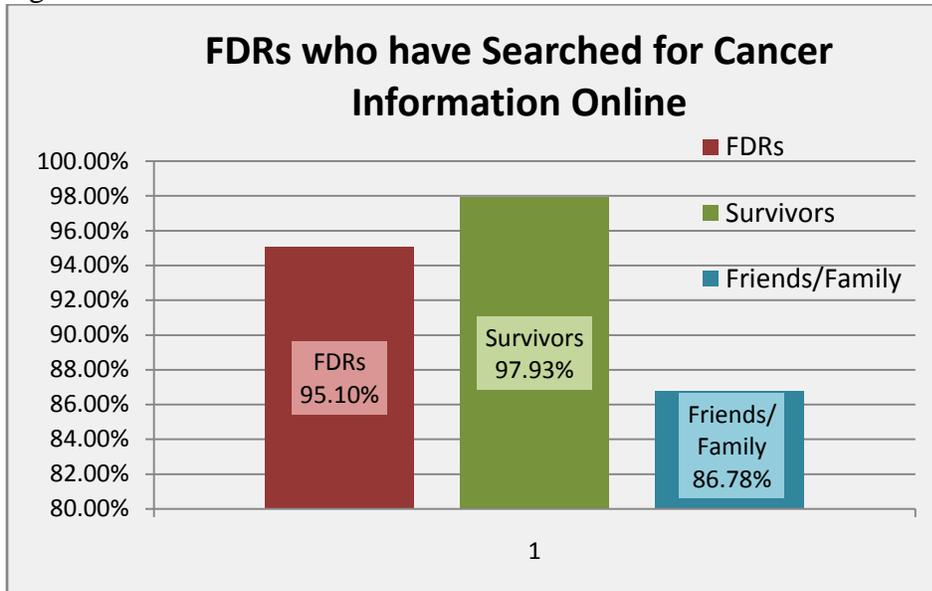
Table 2. For Whom do You Search?

Searching for Information	FDR	Survivor	Friend/Family
Myself	70.85%	93.48%	59.21%
Spouse/ Partner	1.29%	2.52%	0.95%
Family member (FDR)	56.95%	17.85%	7.61%
Family member (by marriage)	5.41%	4.20%	8.44%
Friend	22.91%	30.07%	32.78%
Other	3.37%	3.04%	12.08%

Figure 4. For Whom do You Search?



Research Question 2: FDR's Actual and Preferred Sources of Information

Table 3. First Place to Search for Information

First Place to Search	FDRs	Survivors	Friends/Family
Specific breast/ovarian site	12.31%	25.65%	6.10%
Cancer.gov	2.94%	4.47%	2.50%
Clinicaltrials.gov	0.31%	0.54%	0.13%
Google	45.50%	38.18%	42.52%
Holistic /Alternative treatment	0.36%	0.94%	0.35%
Library website	0.09%	0.18%	0.30%
Mayo.com	6.02%	4.36%	6.72%
MEDLINE Plus	1.34%	1.12%	2.12%
WebMD	19.09%	12.50%	21.27%
Wikipedia	0.71%	0.40%	0.75%
Yahoo Health	0.58%	0.76%	0.59%
Other	8.07%	9.65%	8.43%

Figure 5. First Place to Search for Information
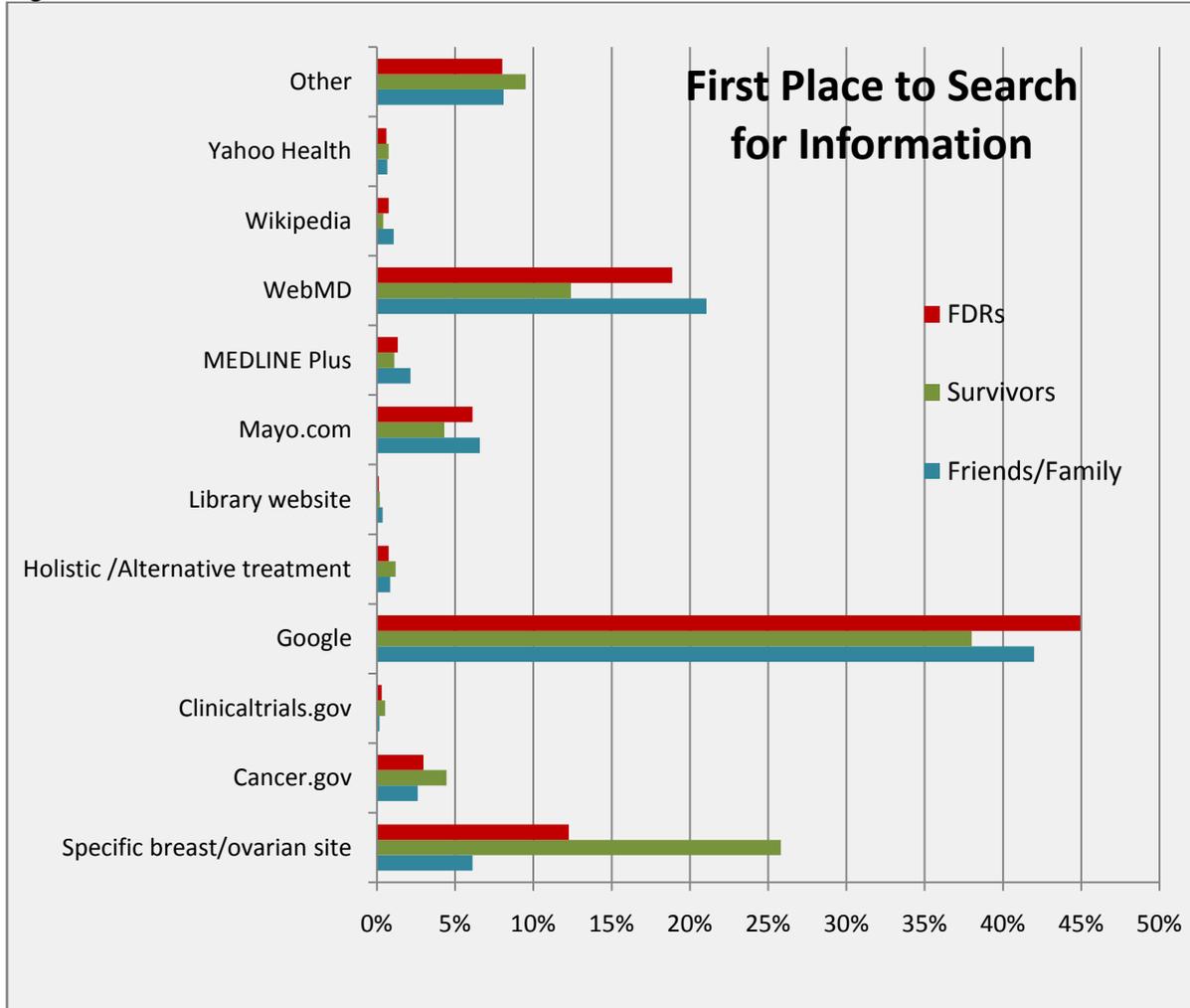
Research Question 3: FDR's Information-seeking Experiences

Table 4. Internet Searching Experiences

| On my most recent breast or ovarian cancer search, . . .	FDRs	Survivors	Friends/Family
I found the information I needed.	80.55%	84.59%	76.54%
It took effort to get the information I needed.	55.74%	51.89%	549.77%
I understood the information I found	49.81%	57.57%	57.25%
I was concerned about the quality of information.	60.55%	58.25%	58.47%
Information was NOT specific enough for me.	53.17%	63.20%	66.99%
I explored further the information from doctors/nurses.	82.68%	89.99%	69.00%

Figure 6. Internet Experiences

Internet Experiences:
On my most recent breast or ovarian cancer search, . . .
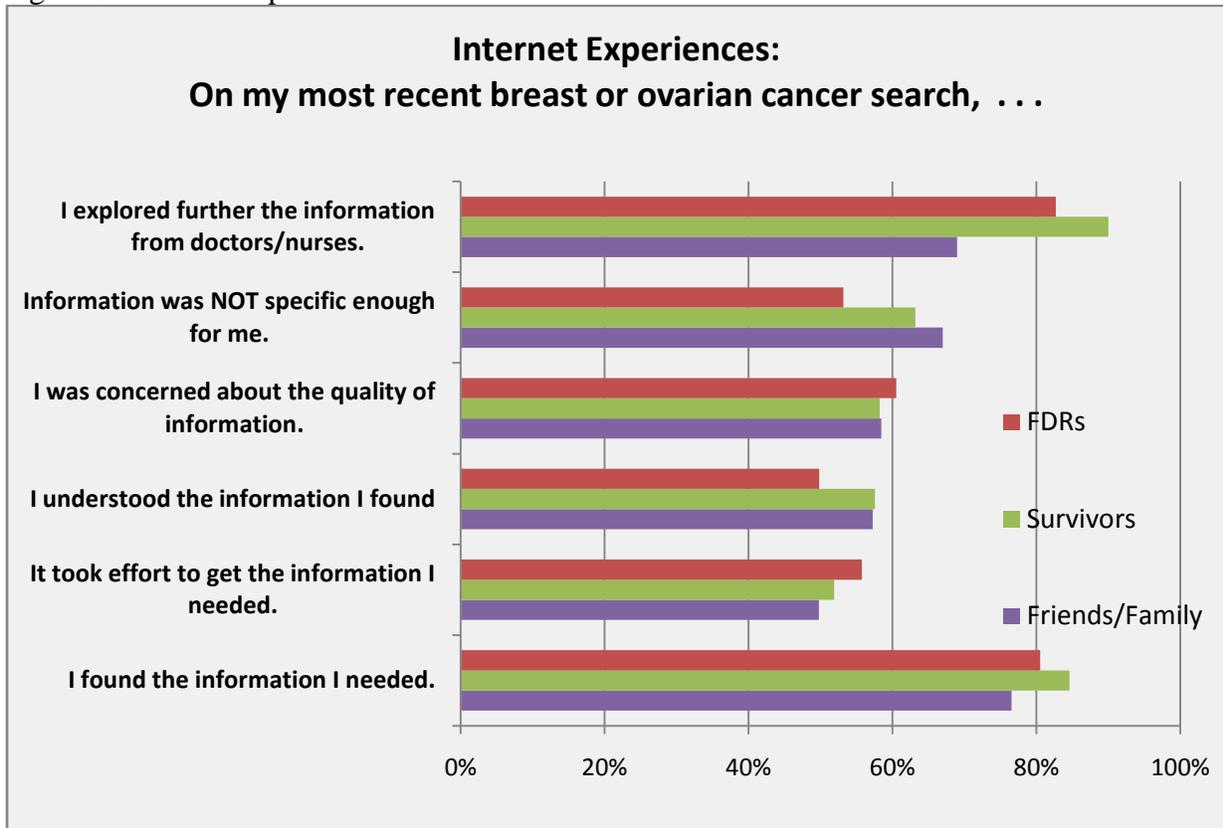
Table 5.Sense-Making Emotions

Sense-making Emotions	FDRs	Survivors	Friends/Family
Disappointment	7.54%	6.62%	4.85%
Satisfaction	21.91%	27.10%	20.62%
Relief	7.02%	9.56%	8.67%
Confidence	8.45%	14.71%	9.06%
Clarity	56.43%	58.47%	52.87%
Doubt	6.89%	6.65%	6.09%
Frustration	14.25%	13.48%	10.61%
Confusion	17.32%	13.41%	13.58%
Optimism	13.43%	19.82%	11.75%
Uncertainty	27.80%	24.51%	24.32%

Figure 7. Sense-Making Emotions

Sense-making Emotions During Search

Based on Kulthau's Feelings During Search Process

Categories (top to bottom): Uncertainty, Optimism, Confusion, Frustration, Doubt, Clarity, Confidence, Relief, Satisfaction, Disappointment

Legend:
- FDRs
- Survivors
- Friends/Family
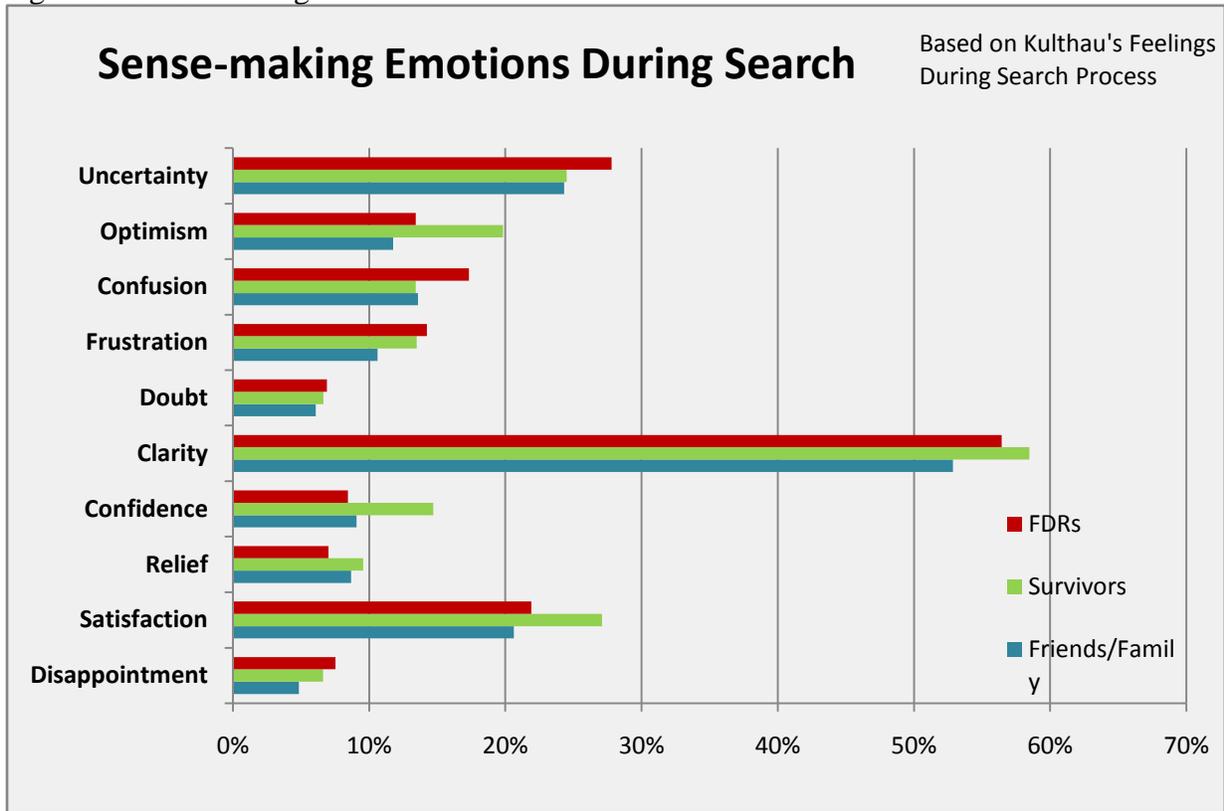
Figure 8. FDRs need much more information about . . .

FDRs need "much more" information about . . .

Legend:
- FDRs
- Survivors
- Friends/Family

Categories (top to bottom):
- Complementary /alternative…
- Online support groups - relatives
- Online support groups - survivors
- Medical aid / Insurance
- Meditation
- Physical Fitness
- Food, nutrition, diet
- Symptoms of concern
- Medical advances
- Long-term side effects
- Decreasing risk of recurrence
- Genetic Counseling
- Genetic Testing
- Prevention
- screening /detection methods:

X-axis: 0%, 10%, 20%, 30%, 40%, 50%

APPENDIX A: SURVEY INSTRUMENT

1. Please indicate your breast or ovarian cancer status:
   - ☐ I have been diagnosed with breast or ovarian cancer at some point in my life.
   - ☐ I have NOT been diagnosed with breast or ovarian cancer, but I am a first-degree relative (parent, child, brother, or sister) of someone either alive or deceased who has been diagnosed with breast or ovarian cancer.
   - ☐ I have NOT been diagnosed with cancer and am NOT a first-degree relative of someone diagnosed with breast or ovarian cancer.
   - ☐ Other, please specify: [text box]

2. Have you ever searched the internet for breast or ovarian cancer information?
   - ☐ Yes
   - ☐ No

3. When was your most recent online search regarding breast or ovarian cancer?
   - ☐ Within the last year
   - ☐ Within the last month
   - ☐ Within the last week
   - ☐ Other, please specify: [text box]

4. I have searched for breast or ovarian cancer information for (check all that apply):
   - ☐ Myself
   - ☐ Spouse or partner
   - ☐ Family member (first-degree relative)
   - ☐ Family member (by marriage)
   - ☐ Friend
   - ☐ Other, please specify: [text box]

5. What motivated you to search for breast or ovarian cancer information?
   - ☐ I am searching for myself
   - ☐ I was asked to find information for someone else
   - ☐ I am interested in the person's situation and volunteered
   - ☐ I am interested in the person's situation but do not plan to share the information with them.
   - ☐ Other, please specify: [text box]

6. In your most recent search for breast or ovarian cancer information, where is the first place you looked for this type of information?
   - ☐ A specific breast or ovarian cancer site
   - ☐ Cancer.gov
   - ☐ Centerwatch.com
   - ☐ Clinicaltrials.gov
   - ☐ Google
   - ☐ Holistic or Alternative cancer treatment website
   - ☐ Library website
   - ☐ Mayo.com
   - ☐ MEDLINE Plus
   - ☐ WebMD
   - ☐ Wikipedia
   - ☐ Yahoo Health
   - ☐ Other, please specify: [text box]

7. Is this the place you normally look for breast or ovarian cancer information or other health information?
   ☐ Yes
   ☐ No
If no, please list where you most frequently look for health information: [text box]

8 During my most recent search, I felt: (check all that apply)

☐ ☐ Uncertainty

☐ ☐ Optimism

☐ ☐ Confusion

☐ ☐ Frustration

☐ ☐ Doubt

☐ ☐ Clarity (or more informed)

☐ ☐ Confidence

☐ ☐ Relief

☐ ☐ Satisfaction

☐ ☐ Disappointment

In the following set of questions there is a statement about your Internet searching related to breast or ovarian cancer. Please indicate to what extent you agree with each statement.

	Strongly agree	Agree	Disagree	Strongly disagree
9. On my most recent breast or ovarian cancer search, I found the information I needed.	☐	☐	☐	☐
10. On my most recent breast or ovarian cancer search, it took effort to get the information I needed.	☐	☐	☐	☐
11. I understand the cancer information I find on the internet.	☐	☐	☐	☐
12. When I do find breast or ovarian cancer information on the internet, I am concerned about the quality of information.	☐	☐	☐	☐
13. The breast or ovarian cancer information I find on the internet is specific enough for me.	☐	☐	☐	☐
14. I use the internet to help understand or explore further the breast or ovarian cancer information I get from doctors or nurses.	☐	☐	☐	☐

Thinking about your breast or ovarian cancer information questions at this time, how much more information do you feel you need? For the topics listed below, indicate whether you would like none, some, or more information.

	No more information	Some more information	Much more information
15. Breast or ovarian cancer screening and detection methods	☐	☐	☐
16. Prevention	☐	☐	☐
17. Decreasing risk of recurrence	☐	☐	☐
18. Genetic Testing	☐	☐	☐
19. Genetic Counseling	☐	☐	☐
20. Long-term side effects of cancer treatment	☐	☐	☐
21. Symptoms of concern	☐	☐	☐
22. Food, nutrition, or diet as it relates to cancer	☐	☐	☐
23. Physical Fitness and cancer	☐	☐	☐
24. Meditation exercises	☐	☐	☐
25. Medical financial aid/ Insurance information	☐	☐	☐
26. Online support groups for survivors or patients	☐	☐	☐
27. Online support groups for relatives	☐	☐	☐
28. Medical advances in cancer treatment	☐	☐	☐
29. Complementary or alternative treatment or centers	☐	☐	☐

30. Please indicate your gender:
    ☐ Male
    ☐ Female

31. Please check your age category below:
    a. 18-24
    b. 25-34
    c. 35-44
    d. 45-54
    e. 55-64
    f. 65+

32. What category best describes your racial/ethnic background? Select only one.
    a. African American
    b. Asian
    c. Pacific Islander
    d. Hispanic/Latino
    e. Multiethnic
    f. Native American
    g. White (non-Hispanic)
    h. Other, please specify

33. In what country do you live? [text field]

34. Please feel free to explain any of your above answers further and/or add additional comments. Please do not type personally identifying information in the question space. [text field]

APPENDIX B: RECRUITING MESSAGE AND CONSENT SCREEN

The Survey Recruitment message

Are you the first-degree relative of someone with breast or ovarian cancer (parent, child, brother, or sister)?   Are you searching for breast or ovarian cancer information online, and having trouble finding it?

I am studying the Internet experiences of first-degree relatives of people with breast and ovarian cancer for a thesis project at the University of Illinois, Urbana-Champaign. The National Institutes of Health defines first-degree relatives as parents, children, brothers, and sisters. The information will be used to help understand what information people need most from cancer information web sites. The survey will take approximately 10 minutes to complete.

If you are over 18 years old, please click here to learn more about this important study:

[URL for survey consent screen]

Thanks,

Margaret Gross, M.S. student
Email: gross12@illinois.edu
Graduate School of Library & Information Science, University of Illinois
Urbana-Champaign

This message text will be posted on the following cancer information web site:
Army of Women: www.armyofwomen.org

Consent screen:

Online Breast and Ovarian Cancer Information Needs Survey

Margaret Gross, a student in the Graduate School of Library and Information Science at the University of Illinois, is conducting this research for her graduate thesis. The information obtained will be used to study the information needs of first-degree relatives of breast and ovarian cancer survivors. The National Institutes of Health defines a first-degree relative as a parent, child, brother, or sister. The survey will take approximately 10 minutes to complete.

Completion of this survey is voluntary. Please feel free to stop the survey if you feel it causes stress or discomfort. We do not collect personal information that could identify you. You may not directly benefit from participation in this survey, however, your answers and opinions, when collected and analyzed in the groups' results, may lead to greater understanding of first-degree relatives' desires to find online breast and ovarian cancer information. Summarized findings

from the survey may be shared with other researchers. You may print a copy of this form for your records. You must be at least 18 years old to participate in this survey.

If you have questions or concerns about the survey, you may contact the researcher, Margaret Gross, via email (gross12@illinois.edu) or phone (+1 760-224-7470). If you have any questions about your rights as a participant in this study, please contact the University of Illinois Institutional Review Board at +1 217-333-2670 (collect calls accepted if you identify yourself as a research participant) or via email at irb@illinois.edu.

I consent to participate [button] – [go to survey instrument]
I decline to participate [button] – [redirect to site]