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An abstract of
a thesis submitted to the Faculty of Emory College of Arts and Sciences
of Emory University in partial fulfillment
of the requirements of the degree of
Bachelor of Arts with Honors

Department of French and Italian Studies

2019

Abstract

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This thesis focuses on *Le Scaphandre et le Papillon (The Diving Bell and the Butterfly)* (1997) by Jean-Dominique Bauby, the former editor-in-chief of *Elle* who suffered a cerebrovascular accident that left his body paralyzed but his mind intact. Through the intervention of caregivers and forms of self-care, Bauby learns to come to terms with his new body in a dynamic healing process that emphasizes sensory experiences. Caregiving does not merely take the form of care by hospital personnel: it is delivered through friends and family, as well as through Bauby's own imagination. By facilitating the experience of sensation—whether that be physical, gustatory, or otherwise—caregivers help Bauby gain the autonomy necessary to find meaning in his new bodily state. This thesis largely addresses the phenomenological aspect of stroke survivorship with an emphasis on Locked-in Syndrome through a close reading of Bauby's memoir. While the clinical considerations of the memoir are addressed, the thesis emphasizes the phenomenological interpretation. Separated into overarching themes of dehumanization, attention to the spirit through attention to the body, and the rejection of the Cartesian model through imagined bodily experiences, a close reading of the text reveals the importance of caregiving in healing the spirit. This thesis begins with a representative literature review of the sources that analyze the memoir and subsequently explores the importance of caregiving in the maintenance of a lived body in addition to a mechanical one. This review of caregiving is then applied directly to *The Diving Bell and the Butterfly* and concludes with a discussion of the practical applications of humanistic inquiry in modern-day care in addition to their applicability to memoir.

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Acknowledgements

I sincerely thank my adviser, Dr. Bruyère, for the time and energy he invested in advising this thesis. I would also like to thank Dr. Coropceanu for encouraging me to pursue a thesis interdisciplinary in nature. I would like to thank Dr. Blanton as well for her input over the course of the writing of this thesis in addition to the narrative contributions she has made.

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Preface

Since entering college, I have had a passion for neuroscience and French literature, which led me to double major in biology and French studies. I never imagined that I would be able to merge my two majors because from an outsider's perspective, they run in parallel. When I took the class "Medical Neuropathology" through the Neuroscience and Behavioral Biology department, the professor introduced me to *The Diving Bell and the Butterfly* by showing the class the film on the last day. At that point, I had already begun exploring ideas for my thesis, but none of them had combined my two majors. Instantly, I was drawn to the memoir. It was a compelling piece full of optimism in a period of darkness, and I knew that I wanted to spend more time with it. As a student on the pre-medical track, the memoir is especially relevant because it allowed me to explore the health humanities. I decided to focus on the role of caregiving in *The Diving Bell and the Butterfly* because understanding the role that doctors, nurses, therapists, and the like play is vital to understanding patients' illness experiences in order to provide optimal care.

In this thesis, I provide an analysis of the role of caregiving in health through the use of a close reading of *The Diving Bell and the Butterfly.* I begin with an overview of the relevant literature published about the memoir. I then explore literature related to caregiving, and in the bulk of my thesis, I focus on various aspects of care specific to *The Diving Bell and the Butterfly*, including but not limited to that of direct medical care, indirect care from others, the spiritual component of healing, and the function of the imagination in healing. I then broaden my focus to include other stroke narratives with an emphasis on how the medical humanities impact modern-day clinical practice.

I. An Overview of the Existing Analyses

In *The Diving Bell and the Butterfly* by Jean-Dominique Bauby, writing serves as the healing process through which Bauby can understand his new body after a sudden break in continuity between his former, glamorous life as the editor in chief of *Elle* and his present, dependent one. It is through his writing that we observe themes of disability, embodiment, autonomy, and his connection to others. Central to the role of writing in the context of the memoir is the understanding of philosopher Georges Canguilhem's pedagogy of healing:

> La santé d'après la guérison n'est pas la santé antérieure. La conscience lucide du fait que guérir n'est pas revenir aide le malade dans sa recherche d'un état de moindre renonciation possible, en le libérant de la fixation à l'état antérieur. (Canguilhem 2002, 99)

> Health after healing is not the same health as before. The lucid consciousness of the fact that healing is not a return helps the patient in his search for the state of the least possible renunciation by liberating him from his fixation upon his previous state. (Canguilhem 2012, 66)

It is therefore important to understand health after his stroke not as a return to normalcy but rather as an establishment of a new way of understanding the self over time. In *The Diving Bell and the Butterfly*, writing acts as a medium to achieve this new state of health.

Hannah Thompson, professor at UC Berkley's school of public health, describes the memoir as an "autopathography," or a means through which to express one's illness and a way to regain autonomy (Thompson 2016, 81). Going a step further, Valerie Raoul, professor emeritus at the University of British Columbia, describes writing to be a way to "reconstruct" himself in the wake of a "rupture of continuity" (Raoul et al. 2001, 187). Implicated in this statement is that writing is a therapeutic process that results in healing oneself whereas as modern medicine attempts to return the body to its previous state. As described by Claire Boyle, lecturer in French at the University of Edinburgh, writing can be understood to be a "technology of the self," a term coined by French philosopher Michel Foucault. She elaborates:

> The crucial insight here is that the self recognises itself as malleable: the self is *altered* by the techniques that it applies to itself, which have ameliorating effects on its self-understanding, health, fitness, and more besides. A technology of self is thus a system comprising diverse techniques and behaviours for bringing about improvements to the condition of the self. (Boyle 2016, 95)

Writing can thus be understood to be an act of healing, a sort of "ritual" that is not a fight against locked-in syndrome (LIS) but rather an effort that allows Bauby to live *with* LIS rather than despite it, a distinction made in by Sakellariou, an occupational therapist, in "Creating In/Abilities for Eating" (Sakellariou 2015). Difficult as the process may be, neurologist Joost Haan writes that "there are no metaphors of battle, grief, or journey" (Haan 2013, 25). The nonlinear nature of the memoir, often characteristic of illness narratives, emphasizes that understanding his new situation is not a "journey," which would imply a clear starting and end point. Rather, Bauby jumps between writing about his present body to imagining scenarios to returning to his life before his stroke in order to compile his narrative.

The role of writing serves as the starting point for every theme in the memoir. As such, a network can be created between the themes with serving as a branching point (Figure 1).

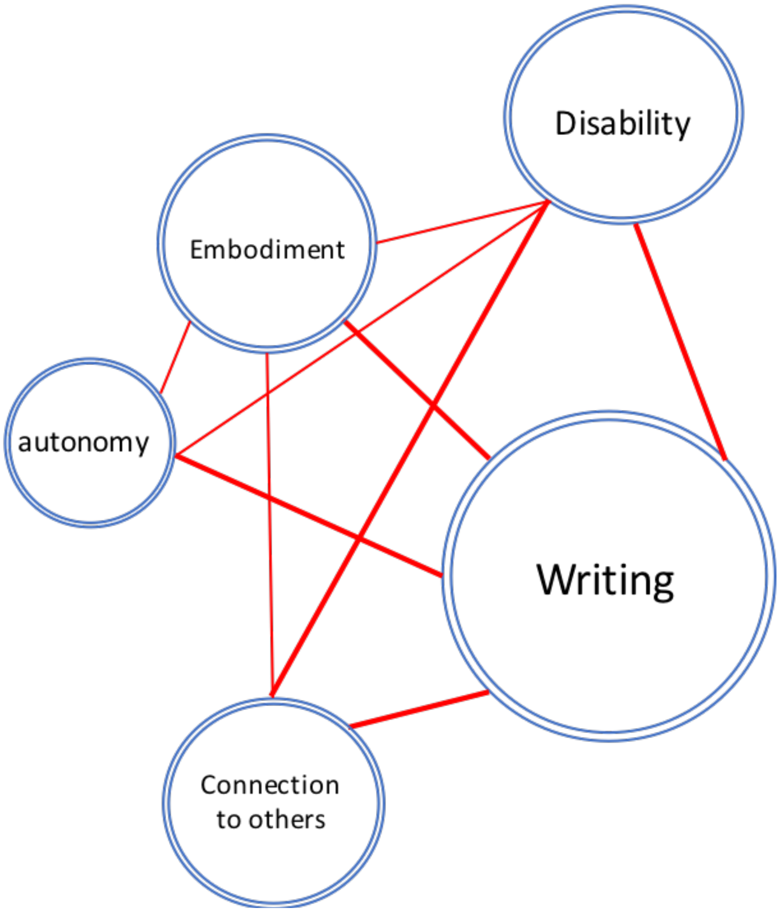

Figure 1: **A Network of Themes in Prior Analyses** The blue lines connect each of the themes back to writing in order to highlight its centrality. The relative size of each circle represents the relative emphasis I will put on each theme. The red lines represent the connections between the other themes, and the thickness of the lines represent the strength of the correlation between the two in this essay. The distance between points is not significant.

The most immediate connection is that of writing to disability. According to Thompson, Bauby sees himself as "un handicapé" ("a cripple") rather than "une personne handicapée," ("a handicapped person") implying that he sees disabled people as being less than human

(Thompson 2016, 80). He looks down upon them and therefore initially upon himself. Suddenly thrust into the situation of being totally paralyzed, he understands the perspective of the able-bodied gaze but also the perspective of being the target of the gaze. Yet he doesn't feel himself to be tragic. This is because he understands that being paralyzed is not so different from normality: his father, who is unable to leave the house due to his age-related frailty, is also "locked-in." Although his father is not deemed to be disabled, he is unable to interact with the outside world, much like Bauby (Thompson 2016). Bauby has to adjust to life as being disabled, and, according to G. Thomas Couser, professor at Hofstra University, "disability provides not the *subject* of his narrative but only its *motivation*" (Couser 2009, 40). Therefore, we can consider disability to be a vantage point for the narrative. His disability allows for him to see the world in a different light than before, thus acting as a vehicle rather than a central theme to the memoir. Tess Jewell of York University, likens Bauby's LIS to Tiresias, the Greek archetype of a blind seer who became blind by incurring the gods' wrath. She writes, "Tiresias is a perfect figure for the disablement and resulting insight of Bauby, as Bauby himself describes his condition in the light of classical punishments meted out by the gods against the guilty" (Jewell 2013, 113-114). Bauby's reference to angering the "gods of literature and neurology" could perhaps be a reference to the story of Tiresias, as they are both marked by disability and the ability to see beyond the present due to their disability. However, it is more likely that this turn of phrase was a joke rather than an allusion and that Jewell's interpretation is more of an analogy than an analysis of Bauby's text. Continuing with the theme of blindness, Jewell notes that in the film, Bauby's eyes were closed in the photograph of him as a child at Berck-sur-mer. She interprets this to mean that he was blind to his surroundings, including his friends and family, and that he was destined to return to Berck to gain sight of what is important in life (Jewell 2013).

Through writing, Bauby achieves a sense of autonomy. Medical doctor Robert S. Schwartz argues that writing is a form of complementary alternative medicine, which is a "treatment" that is not necessary to the treatment of the disease but rather aids in the healing process. It is not something prescribed by the doctor but rather a way for Bauby to take his health into his own hands (Schwartz 1998). Overboe, associate professor at Wilfrid Laurier University, argues that LIS does not cause Bauby's life to be compromised; instead, he tries to preserve himself through writing. Overboe writes that he himself was disabled and can thus attest to the fact that being in a helpless situation does not necessarily make a person's outlook on life bleak (Raoul et al. 2001). However, if we understand writing to be a technology of the self, it does not preserve him so much as change him for the better in the context of his disability. Instead of a preservation, it is an alteration. According to Tess Jewell, Bauby's writing stems from "a need to prove himself" as a reaction to colleagues in Paris spreading rumors about him being in a vegetative state (Jewell 2013, 111). Thompson calls this a pushback against the stigmatization of the disabled. Before his stroke, Bauby had also unwittingly felt an unwarranted sense of pity against the disabled, thereby denying them autonomy. For example, he smiled at a disabled person in Lourdes, and the latter's reaction was to stick out his tongue in order to prove that he is not helpless. Similarly, Bauby uses writing to communicate to others that he is not to be pitied and that his mental faculties are still intact (Thompson 2016). He seeks to "affirm that his new existence is still a form of life" (Jewell 2013, 111). Jewell, knowingly or not, alludes to the earlier quote by Canguilhem by emphasizing that Bauby has a *new* form of life instead of arguing that he is the same person as before.

Problematically, the movie, directed by Julian Schnabel, removes much of the autonomy he has in the memoir. Jewell writes:

> One of the most important changes that occurs with the adaptation of *Le scaphandre et le papillon* is that the film gives away moments of Bauby's agency to other characters, thus restricting even further his already limited abilities. In addition to the omission of the monthly bulletin, Bauby also no longer reads his letters to himself "in a daily ritual that gives the arrival of the post the character of a hushed and holy ceremony" (91)—one of the few physical abilities left to him—but instead listens to them being read by Céline. (Jewell 2013, 111)

As stated, the film reallocates the little autonomy he has to other characters, plunging his character into a helpless figure. He is denied the very same independence that he celebrates in the memoir. Furthermore, the film transforms him into a tragic character who inspires pity by neglecting his dark humor. For example, when he is being bathed, the voiceover laments his fate and ignores the "guilty pleasure from this total lapse into infancy" (*DBB* 24). By eliminating the sense of pleasure he feels on occasion, Schnabel imposes his own perception of the situation and thus removes Bauby's voice from the narrative. Moreover, Bauby communicates to his speech therapist that he wants to die, but no such request is present in the memoir. Bauby's lover, Florence Ben Soudan, "criticizes the film for inserting a declaration of despair." The "hope and humor" present throughout the memoir are omitted from the cinematic narrative, which denies the author his perception of his own experiences (Jewell 2013, 112). Schnabel further makes Bauby out to be a tragic character by taking the phrase "Etais-je aveugle ou sourd ou bien faut-il nécessairement la lumière d'un malheur pour éclairer un homme sous son vrai jour?" (Had I been blind and deaf, or does it take the harsh light of disaster to show a person's true nature?"

(83)) out of context (*DBB* 89). In the memoir, this quotation refers to his previous inability to see the depths of people he superficially knew, which were only brought to light due to his stroke. In this context, he does not see LIS in a negative light because it allows him to communicate better with acquaintances. However, Schnabel puts the quote into the context of Bauby regretting not having taken advantage of opportunities before his stroke. Schnabel justifies his decision by saying:

> It certainly could be about himself or us, I mean, he says, did it take the harsh light of disaster for me to find my true nature. And so until he was robbed of every other distraction other than the meditation on what it is to be alive, he wasn't born, in a sense. (quoted in Heidt 2009, 135).

Bauby's interpretation of his stroke is not the same as that of Schnabel: Bauby meditates that he had not properly understood his acquaintances whereas Schnabel claims that Bauby had not properly understood life. Through drastically changing Bauby's internal monologue, Schnabel removes the author from the narrative. Jewell also criticizes the film for showing others' emotions because it "removes [Bauby's] centrality to the narrative" (Jewell 2013, 120). However, this decision does not exclude his centrality because his narrative is partly based on the emotions and reactions of others. Nay, he writes the memoir *in response* to people calling him a vegetable. Therefore, it is impossible to exclude others from the narrative.

The creative license Schnabel takes becomes influential in others' interpretation of the memoir, as Pelaprat, professor at DePauw University, and Hartouni, professor at UC San Diego, believe that Bauby finds the process of rehabilitation in the medical setting to be "by and large

[…] humiliating, torturous, and dehumanizing" (Peleprat and Hartouni 2011, 391). There are indeed moments in which Bauby finds the medical system to be dehumanizing and self-congratulatory, such as when the ophthalmologist sews up his eye without explanation or when the neurologists applauds his ability to sit in a wheelchair. However, he appreciates Sandrine and his physical therapists, without whom he would not be able to communicate or regain physical function.

Embodiment is also a theme that allows Bauby to heal. However, there are some misconceptions about the connection between the mind and the body. Couser argues that the experience is "out of the body," not "of the body" (Couser 2009, 42). This statement implies that Bauby experiences LIS not through embodiment but rather through *dis*embodiment. Furthermore, Pelaprat and Hartouni adopt an interpretation based on cognitivism, or the idea that "what you call a "self" is not a *source* of mental experience; it is, rather, an *effect* of mental processes" (Pelaprat and Hartouni 2011, 395). They understand LIS through a Cartesian lens: instead of highlighting the connection between the mind and the body, they interpret LIS to be a mechanism by which to escape the confines of the body and allow for only the mind to work, which they believe to be the definition of one's existence. They go so far as to say that the diving bell is *not* a contraption that weighs him down but rather it is something that allows him to be a more authentic version of himself (Pelaprat and Hartouni 2011).

The general understanding is that the diving bell represents Bauby's body. The movie makes use of this standard interpretation, in which Bauby says that imagination and memory are the only means of escape. Other authors interpret the diving bell to connote a sense of entrapment and of being weighed down. For example, Berman, professor at the University of Albany, argues that the diving bell represents a "claustrophobic prison" but also a way to reach new depths (Berman 2013, 256). Berman acknowledges that the diving bell reflects the difficulty of Bauby's interactions with the outside world, but he also argues that it represents a way to reach a deeper understanding of life and of others. It takes Bauby into uncharted territory, but it can be a healing process in addition to the emotional weight we normally interpret it as being. A particularly distinctive interpretation comes from Overboe:

> The diving- bell, for me, does not represent Bauby's imprisonment by LIS but rather the oppressive practices of those who usually privilege an able-bodied perspective. They see the problems of lack of communication, of lesser embodiment and absence of selfhood, as residing with Bauby as a result of LIS. (Raoul et al. 2001, 193)

Using this interpretation, we can understand the diving bell to be *other* people and the environment around him. Through writing, Bauby is able to escape this lack of communication, gain autonomy, and become embodied in a way that makes him feel human instead of being reduced to the gaze.

If the diving bell represents oppression, either by his body or by his environment, then the butterfly represents freedom. According to Berman, "the butterfly symbolizes in literature, mythology, and folklore not only rebirth but also the soul" (Berman 2013, 263). Rebirth here is a key word because writing is a technology of the self: it is a way for Bauby to "rewrite" himself, to understand his new body and to learn to live in it. In that sense, the butterfly does represent a rebirth.

Returning to the idea of the technology of the self, Thompson argues that Bauby needs to come to terms with the fact that he is not the *Elle* man he was before. He needs to learn to live with his new body, and he does so through writing. He anthropomorphizes his alphabet, describing the letters as dancing around the room. Because his only way of communication is via his alphabet, the alphabet itself is embodied. Because the letters are embodied, we can see that his body and physicality are reflected in his writing, especially when we account for the fact that the memoir was written using eye blinks (Thompson 2016). Boyle elaborates on the idea of embodiment by saying that there are three types: the material, the remembered, and the imagined. The material refers to his body in its current state: painfully rigid. The remembered refers to his past life. In the movie, the sequences we see of him in flashbacks often involve motion. He is constantly walking or moving around a room, never stationary. The emphasis on mobility highlights what he primarily is concerned with in his past life. The imagined body emphasizes the sensorial and the sensual fantasies he has. For example, he imagines the Empress's dress and we can almost feel the fine texture of the material, hear its light rustling, and see the silky quality of her dress. He also imagines having seafood with Claude, and we notice the sensory experience of the food. More noticeably, we understand the sensuality of the scene in which he and Claude kiss and it becomes a tactile experience *of* the body. The movie includes first-person point of view shots, which connotes the idea that his new body is still able to experience sexual encounters such as this one (Boyle 2016). This thought leads into Jewell's criticism of society's perceptions about the sexuality of disabled individuals. She argues that people often understand disabled people to be asexual whereas the reality is that they still have sexual urges but cannot necessarily act upon them (Jewell 2013).

The final aspect of the network is that of writing's role in relation to communication with others, including with the people who were physically around him and with the reader or viewer. Thompson argues that writing is inherently interactive: in Bauby's case, communication necessarily requires the active involvement of the others around him. Writing is not a solitary process: Claude (or another third party) must be there. However, not everyone is great at using the writing system for communication, such as the friend who told him people were calling him a vegetable in the movie. Therefore, writing plays a crucial role in communicating with the people around him, and writing cannot happen without communication (Thompson 2016).

The movie centers around the engagement of the audience due to the first-person point of view. Some might argue that using this technique detracts from Bauby's individual experience, but Boyle writes:

> [Schnabel] creates a protagonist whose subjectivity is not so much 'entangled' with that of the viewing subject (in ways that may be ethically compromising) as quite self-consciously shared with others, and reaffirmed by them, thus allowing for Jean-Do to enmesh himself with these others on an equal basis as part of a wider community of sovereign subjects. (Boyle 2016, 97)

Boyle argues that the first-person point-of-view does not lessen Bauby's illness experience but rather allows us to understand his perspective, rather than to *become* Bauby. The use of "claustrophobic cinematography" helps us understand the feeling of being entrapped in the diving bell as well as the experience of feeling helpless in one's own body (Boyle 2016, 100). She takes the example of the neurologist at the beginning of the movie. He points his finger into Bauby's eye, which at this point is our eye. It feels like an imposition, and we cannot control it, much like he cannot. This form of embodiment helps us to understand his situation. Boyle goes on to say that the audience and the filmmakers are "accessories" to the memoir with which he can effectuate the technology of the self (Boyle 2016, 94). It allows for social recognition as well as cultivating a deeper relationship with his friends and family. Jewell agrees that using the first-person point of view is not problematic because Bauby writes in his memoir that a movie about his life would be entitled "The Eye" (Jewell 2013). Sarah J. Heidt, professor at Kenyon College, reinforces the legitimacy of this decision by noting that Bauby frequently uses the noun "on" in lieu of "je" or "vous." He invites the audience into his cocoon in order to escape his solitude but also to convey the experience to the readers/ viewers. Accepting the invitation entails reading the memoir but also being able to understand the lived experience (Heidt 2009).

I have summarized here some of the central themes in the memoir using prominent works that elaborate on them in depth. Although the body of literature is rather extensive, it is incomplete. Notably, the role of caregiving is only topically mentioned in the literature: Thompson alludes to the ophthalmologist's impersonal behavior when he does not explain what he is doing to Bauby's eye (Thompson 2016). Canam, assistant professor emerita at the University of British Columbia's School of Nursing, understands the memoir as an instrument that makes healthcare providers aware of their implicit biases against the disabled (Raoul et al. 2001). One study conducted by physician Anand B. Karnad was done in order to determine whether reading this book actually changed doctors' perspectives on patient care. The results showed that medical residents recognized that their compassion was lacking, and that, during small-group discussions, they deemed it important to spend extra time with patients (Karnad 1999). I have found these mentions of the role of caregiving to be brief and inadequate. In my thesis, I will elaborate on writing's role in caregiving in the healing process in *The Diving Bell and the Butterfly.*

II. The Influence of Caregiving on the Subjective Body

The gap in the outlined literature regards caregiving, which serves to bridge medicine and humanistic inquiry by focusing on the relational aspect of health. Without the caregivers present, Bauby would not have been able to communicate, have had a sense of autonomy, or have been able to heal on a spiritual level. Medical anthropologist Arthur Kleinman describes caregiving as being made up of several components: it involves lessening one's "pain and suffering," offering assistance with basic tasks such as walking, "protection, and emotional support" (Kleinman 2012, 1550). He argues that "care" is the root of caregiving, "implying cultivation of the person and the relationship through practices of attending, enacting, supporting, and collaborating" (Kleinman 2012, 1551). Collaboration in the sense of caregiving is a key element in *The Diving Bell and the Butterfly* because it allows Bauby the freedom to express himself and to heal. Medical anthropologist Annemarie Mol defines caring as a "tinkering with bodies, technologies and knowledge—and with people too" (Mol 2010, 12). Caregiving can therefore be understood to be a way of modifying a situation or a practice until an equilibrium is reached. This applies not only to treatment of the body but also of the spirit; tinkering does not merely involve treating symptoms but also the selfhood of the patient. As previously described, Foucault's technology of the self involves a remodeling of the self, or coming to a new understanding of the self based on an unforeseen circumstance. The definition Kleinman gives of caregiving closely mirrors this idea by involving others in reshaping the self. In the wake of Bauby's stroke, when his sense of self is precisely what is at stake, caregiving is a means through which Bauby can learn to understand his new circumstance.

Before addressing the humanistic side of Bauby's case, I would like to turn to the clinical side of healthcare, which lies at the base of caregiving. A number of clinical studies have been conducted regarding disparities between the caregivers' intentions and the patient's desires. Some studies have addressed the psychosocial implications of Locked-in Syndrome directly. While the subsequent studies involve scientific analysis and statistics and do not necessarily relate directly to memoir, they contain relevant clinical implications that are reflected in the memoir. For example, in line with what we see in *The Diving Bell and the Butterfly*, neuropsychologist Bruno et al. have shown that a large percentage of individuals with Locked-in Syndrome (LIS) are happy based on a number of psychological surveys. They found that 72% of patients were happy and 28% were not for the following reasons: anxiety, lack of recreational activities, lack of mobility, and lack of speech recovery. Most of the patients lived at home with a significant other, were religious, and were able to move their limbs to an extent. 82% cited that they were in a comfortable relationship, but only 21% reported that they participated in activities they found to be important. Those who were unhappy tended to be less healthy and they were more likely to be treated as being a hopeless case compared to the happy group. The article cites that those who were happy "succeeded in recalibrating, reprioritizing, and reorienting their needs and values, whereas the low raters cope poorly because they cannot shed the needs and values from their previous life" (Bruno et al. 2011, 6). Though the phrase "technology of the self" is not explicitly used in the text, they give the precise definition when describing patients determined to be happy. It also relates to Canguilhem's philosophy that there is no return to normal, and patients must learn to understand their new body. Therefore, utilizing a technology of the self, such as writing in Bauby's case, leads to a happier life and better patient outcomes.

If caregivers are unsure of their role or are not able to fulfill it, patients' lives can be compromised. Oftentimes, due to the nature of LIS, caregivers and healthcare providers make decisions without consulting the patient. For example, physical medicine and rehabilitation specialist Katz et al. describe a situation in which a doctor and the patient's son decided to allow the patient to be withdrawn from life support without consulting her, even though her mental faculties were intact. This example illustrates that issues can arise even when the caregiver (in this case, the son) has good intentions but possibly a lack of understanding of his mother's mental capabilities. Katz et al. conducted a longitudinal study in which data was gathered on patients with LIS in 1985 and again in 1990. In a study involving 17 patients, they found that caregivers reported occasional or seldom depression in 8 and 7 patients, respectively, and the remaining 2 were deemed to be chronically depressed. These data are in line with the previously mentioned study in which patients with LIS were generally happy. In this study, it was determined that the attitude of the caregiver is also involved in the health and happiness of the patient. They found that three of the patients showed a decline in health and determined it was due to the reluctance of caregivers to transfer them to a wheelchair (Katz et al. 1992).

Beth Han, doctor in the US Department of Health and Human Services, and Haley, professor at the University of South Florida, found similar results to those of Katz et al. when examining the mental health of caregivers of stroke survivors. There was a higher percentage of depressed caregivers compared to those who were not. They were primarily concerned with how the patient would be cared for in the future, and those with a stronger support system were less depressed than those without (Han and Haley 1999). Joan S. Grant, a researcher at the Rosalynn Carter Institute for Caregiving, et al. determined that after a stroke, the caregiver experiences a break in continuity similar to as the patient does. Thrown into an unexpected situation, they are unprepared and "report feelings of physical and emotional strain, being worried about themselves and care recipients, extreme tiredness, and losing self to caregiving" (Grant et al. 2014, 151). They attempt to do twice as much of the work as before and lose friends in the process. According to this study, caregivers should be given more information about their role, relationship, and sexual relationships from that point on in addition to resources that would help both them and the patient (Grant et al. 2014). In *The Diving Bell and the Butterfly*, we observe moments of frustration on the part of Sandrine, Sylvie, and Joséphine. These moments of frustration, at least temporarily, affect the care Bauby receives. Interestingly, Simon Kemp, a French professor at the University of Oxford, questions the validity of these studies about happiness by applying Bergson's principle of arousal; that is, the body must have a reaction for one to have an adequate emotional response. Kemp writes that because Bauby does not have access to his body, his emotions are attenuated, and that this attenuation apparent because the tone of the memoir is "stoical" (Kemp 2011, 74). Therefore, instead of believing that Bauby is at peace with his new body through thoughtful deliberation, Kemp argues that this peace stems in part from the inability to experience the physiological component of emotion.

In a literature compilation conducted by Krishnan, assistant professor at Emory University's Department of Rehabilitation Medicine, et al., they sought to determine the specific needs of stroke survivors as reported by caregivers. They found that each need fell into one of three categories: "body function needs," "activity and participatory needs," and "environmental needs" (Krishnan et al. 2017, 500). The body function needs included the need to improve mood, to control changes in behavior, and to better manage pain. In terms of activity and participatory needs, the stroke survivors are urged to lead a healthier lifestyle, be in touch with their spirituality, and become more independent in terms of motility. The overarching goal is to improve communication, "preserve the survivor's autonomy," and involve them in the decision-making processes (Krishnan et al. 2017, 501). As for environmental needs, the authors recommend better communication with healthcare providers and better support from family and friends. Environmental stressors can arise from inability to pay the healthcare bills and lack of a support network (Krishnan et al. 2017).

To better understand the role of caregiving in LIS specifically, I would like to take a look at caregiving in motor neuron disease, often referred to as amyotrophic lateral sclerosis (ALS). There are not many documents about caregiving as it relates to LIS, but there is ample literature regarding caregiving in relation to ALS. ALS is a suitable surrogate for LIS because it is a degenerative neurological disorder that results in total paralysis provided the patient lives long enough. (The major difference in symptomatology is that ALS is progressive whereas LIS is sudden. Regardless, it is suitable because in the context of *The Diving Bell and the Butterfly,* we are looking at the phenomenological relationship rather than the clinical dimension of caregiving. The phenomenological approach is crucial because it focuses on care not from a perspective of clinical efficacy but rather from the perspective of the patient.) A study Sakellariou et al. examines the role of caregiving through conducting joint interviews in which both the patient and the caregiver were present. The basis for conducting joint interviews is that they would reflect intersubjectivity, or "how humans share experiences and how they depend on each other to construct and make sense of these experiences" (Jackson 1998, 2002; quoted in Sakellariou et al. 2013, 1565). The caregiver is required to take on more responsibility than before, leading to shared experiencing that necessarily lead to intersubjectivity on the part of both parties. In one of the interviews, the patient barely spoke but was engaged in the conversation nonetheless through agreeing with her husband as he told their stories. He was able to lend his voice when she could not, leading to a shared experience. This phenomenon leads to a "heteroglossic world", or the presence of "the voices of people living with an illness and the voices of the healthcare providers, […] family, friends, work colleagues, and other social actors"

(Sakellariou et al. 2013, 1567). To elaborate, heteroglossia refers to the involvement of others' perspectives in a narrative. The perspective that others bring to the table becomes incorporated into the narrative, and therefore the narrative is constructed from many viewpoints (Sakellariou et al. 2013). Heteroglossia could lead to a loss of autonomy, which in Bauby's case, he tries to reclaim by writing a memoir to communicate his perspective.

The type of care one receives is often based on the caregivers' understanding of the definition of a body. Philosopher Drew Leder makes the distinction between the "dead body" and the "lived body." Modern medicine often relies on the former because it understands the body to be a machine made up of parts that must be mended. He explains that this concept arose from René Descartes, who revolutionized medicine through medicalizing the body. In his second meditation in "Meditations on First Philosophy," Descartes writes: "Well, the first thought to come to mind was that I had a face, hands, arms and the whole mechanical structure of limbs which can be seen in a corpse, and which I called the body" (Descartes, online access). We can see here that Descartes regards the physical body as being mechanistic, made up of moving parts like a machine rather than possessing life. Contrarily, Michel de Montaigne, a philosopher from the Renaissance rather than from the Enlightenment, understands two bodies, the conscious body and the unconscious one, rather than a division between the mind and the body. In "Of Practice," he writes:

> Il y a plusieurs animaux, et des hommes mesmes, apres qu'ils sont trespassez, ausquels on voit resserrer et remuer des muscles. Chacun sçait par experience qu'il y a des parties qui se branslent, dressent et couchent souvent sans son congé. Or ces passions qui ne nous touchent que par l'escorse, ne se peuvent dire nostres. Pour les faire nostres, il faut

> que l'homme y soit engagé tout entier ; et les douleurs que le pied ou la main sentent pendant que nous dormons, ne sont pas à nous. (Montaigne 1988, 376)

> There are many animals, and even men, whose muscles we can see contract and move after they are dead. Every man knows by experience that there are parts that often move, stand up, and lie down, without his leave. Now these passions which touch only the rind of us cannot be called ours. To make them ours, the whole man must be involved; and the pains which the foot or the hand feel while we are asleep are not ours. (Montaigne 1967, 271)

We can understand this passage to mean that there is a body that we control and one that we do not. Montaigne recognizes the difference between a body-as-corpse versus a lived body, saying that the corpse is one that we do not control whereas the lived body is the one of which we are in control. He is thus arguing for a division between bodies—the unconscious and the conscious—rather than between the body and the soul. Montaigne gives the example of epilepsy: the person having the seizure has their "soul and body […] buried in sleep" (Montaigne 1967, 270). Because he argues that they are both in sleep, he is making a case for the two being connected: the soul and the conscious body are buried in sleep while the unconscious one takes over. In the case of Bauby, he is not in control of his body physically, but he is in control of it mentally; therefore, his body can be thought of as one he experiences as well as one which he cannot control. That is, his anatomical body cannot be equated with his lived body. However, modern medicine is largely based on Descartes's description, as it examines parts of the body and focuses on their repair rather than on the humanistic implications of medical practice. As such, caring for the "Cartesian corpse" is a detached process upon which modern medicine in founded. Conversely, the "lived body" relies on intention rather than on biological processes. Leder describes "bodily intentionality" as a means "through which we constitute and respond to our world" (Leder 1992, 25).

Therefore, in order to heal, a caregiver must consider not only the mechanical body but also the lived one. In "Les Nouvelles Figures du Soin," philosophers Guillaume le Blanc and Frédéric Worms reference the work of philosopher and ethicist Virginie Pirard when they write:

> Se pose alors la question de savoir si le soin, en son fond même, relève d'une charge emotionnelle produite dans le jeu des relations humaines, en quel cas le soin pourra être pensé comme l'extension légitime d'un amour de l'autre, ou s'il peut être défini exclusivement comme travail, reconnu comme tel dans le champ des compétences professionnelles. (Le Blanc and Worms 2006, 78)

> The question then arises as to whether care, in its very essence, is an emotional charge produced by the interplay between human relations, in which case care could be thought of as a legitimate extension of a love for the other, or whether it can be defined exclusively as work, understood as such in the field of professional competencies. [personal translation]

This quote considers whether care stems from a love for the other or from duty, and both are true to an extent. For example, Sakellariou further considers caregiving regarding ALS when he writes about his experiences with his mother in "Creating In/Abilities for Eating." His mother tries to hold onto her past life in order to feel like herself, and she denies having a percutaneous endoscopic gastrostomy (PEG) for a long time despite it being the recommended course of action. Her family supplements her diet with grinding up pills and feeding her, and this intersubjectivity allows her to maintain autonomy rather than falling victim to her disease. It is not so much the food itself as the *act* of eating that allows her to maintain her sense of self, and her family is instrumental in doing so (Sakellariou 2015). This care stems from love for another because the family members are trying to prolong her life as she knows it (that is, her lived body) rather than forcing her to accept the PEG, which would make logical sense if we only consider the mechanical body.

It is therefore apt to postulate that caregiving necessarily involves an evolution of both the self and the relationship between the caregiver and the patient. Looking at ALS as a substitute for LIS also allows us to better explore what is meant by "the technology of the self." Sakellariou looked at a case study of a married couple in which the husband assists his wife with daily living in a way to preserve her autonomy and dignity as much as possible. Throughout her prognosis, they adapt to each circumstance, initially avoiding the PEG then preferring it over other options. They constantly adapt to the situation, thus embodying the very definition of the technology of the self but through a *shared* experience. Similar to Bauby, she "wants assistance for a lived body, not for a body-as-a-tool" (Sakellariou 2015, 1905). The intersubjectivity of the situation allows for her to experience a lived body that adapts to change, rather than experiencing a static, medicalized, "Cartesian corpse."

In conclusion, caregiving allows patients to experience the world in a way in which they could not otherwise. Caregiving lies at the crux of patient autonomy and self-actualization and thus plays a critical role in the process and maintenance of health. I will elucidate the role of caregiving in *The Diving Bell and the Butterfly* and how it facilitates redefining the self as well as reaching a new state of normalcy.

III. Means of Healing in *The Diving Bell and the Butterfly*

The *Diving Bell and the Butterfly* is a memoir composed by Jean-Dominique Bauby, the former editor-in-chief of *Elle* magazine. Bauby suffered a stroke in the brainstem, causing him to become totally paralyzed, though he was still able to blink and eventually was able to move his head. The brainstem is at the base of the brain and allows for the flow of sensory and motor signals to and from the rest of the brain in addition to controlling autonomic functions, such as breathing and heart rate. Complementarily, the cerebrum controls for higher-level functions, such as thought, emotions, and memory, among many other functions. Due to the location of Bauby's stroke, his body was severed from his mind, otherwise known as Locked-in Syndrome (LIS), which is named for the feeling of being "locked in" a totally paralyzed body that one cannot control. This feeling gave rise to the title of the memoir, as the diving bell represents the weight and constraining nature of his body and the butterfly refers to his mind. Bauby's only form of contact with the outside world consisted of eyeblinks, which was also compromised when one eye needed to be sewed shut due to the potential of his cornea developing an ulcer. His speech therapist, Sandrine, developed a communication system in which the letters of the French alphabet were arranged in order of frequency. Bauby was to blink when the person reading the alphabet aloud said the letter that he wanted. In this manner, Bauby was able to collaborate with a publishing agency, which sent Claude Mendibil to transcribe his memoir letter by letter. Bauby would wake up early every morning, memorize what he wanted to write word for word, and dictate the memoir through eyeblinks to Claude. Writing the memoir served to help him come to terms with his new situation in which he had no obvious autonomy and completely relied on others to provide for him. The memoir thus showcases an evolution of his adjustment, starting off relatively bleak, going through ups and downs, and eventually accepting his diagnosis and moving on. Bauby passed away mere days after its publication.

Caregiving plays a central role in many illness narratives, but it has an exceptionally large role when it comes to LIS, in which the patient is entirely dependent on the actions of others. The existing literature on *The Diving Bell and the Butterfly* has not addressed its central role to the narrative, focusing instead on questions surrounding disability, autonomy, and the metamorphosis into someone who accepts his condition. While these themes are indubitably central to the memoir, the involvement of others in healing has not retained the attention of those analyzing the memoir. Caregivers are the vehicle for healing in Bauby's case; the lack of intersubjectivity would preclude him from self-expression and communication, thereby rendering the previously explored themes obsolete.

Throughout the memoir, caregiving plays a central role because it affects not only Bauby's body but also his general wellbeing. We often imagine caregiving in a strictly clinical sense: caregivers—whether they be hospital staff or family members—are often associated with attending to the patient's ailment. Of course, in *The Diving Bell and the Butterfly*, there are notable examples of caregiving in the physical sense, but most of the caregiving involves healing the spirit independently or through the body. The caregivers are notably therapists, family members or friends, and his imagination. Instead of trying to return to normal, Bauby learns to understand his surroundings in a new light through redefining himself to reach that end. This persistent change in order to heal is defined by Foucault as a "technology of the self":

> [L]es techniques de soi […] permettent aux individus d'effectuer, seuls ou avec l'aide d'autres, un certain nombre d'opérations sur leur corps et leur âme, leurs pensées, leurs

> conduites, leur mode d'être ; de se transformer afin d'atteindre un certain état de bonheur, de pureté, de sagesse, de perfection ou d'immortalité. (Foucault 1994, 785)

> [T]echnologies of the self […] permit individuals to effect by their own means, or with the help of others, a certain number of operations on their own bodies and souls, thoughts, conduct, and way of being, so as to transform themselves in order to attain a certain state of happiness, purity, wisdom, perfection, or immortality. (Foucault 1988, 18)

The technology of the self is based in part on the concept of "le souci de soi," or "to be concerned with oneself" (Foucault 1994, 786; Foucault 1988, 19). We can translate this concept to *The Diving Bell and the Butterfly* because Bauby must be concerned with himself both physically and emotionally to bring about a change in the self. Caregiving, in its multiple forms, can therefore be understood as a vehicle for the concept of "the technology of the self" because it allows Bauby to transform in such a way that he is able to come to terms with his new state of being.

To begin, the act of writing itself is a form of caregiving. For Bauby, writing cannot be a solitary activity—given his dependence on others, it is inherently an intimate experience. Claude, his emissary, functions as an interlocutor between Bauby and the outside world: her presence, on which he is dependent for communication, lends him the autonomy that accompanies self-expression. He writes:

> Le grand cahier bleu dont elle remplit chaque recto d'une écriture bâtonnée et consciencieuse, la trousse d'écolière pleine de stylos de rechange, la pile de serviettes en

> papier prêtes aux pires expectorations et la bourse de raphia rouge où elle extrait de temps à autre la monnaie pour aller chercher un café. (137)

> The big blue notebook whose pages she fills with her neat, formal handwriting; the pencil case like the ones schoolchildren use, full of spare ballpoints; the heap of paper napkins ready for my worst coughing-and-spitting fits; and the red raffia purse in which she periodically rummages for coins for the coffee machine. (131)

In this sentence, Bauby highlights the various ways in which Claude acts as his caregiver. He first concentrates on the act of writing, then on her preparedness, then on her role as a physical caregiver, then on her own needs. She acts not only as someone who transcribes his book but also as someone who attends to his physical body when he has a coughing fit; therefore, she has a multifaceted role. The sentence reflects a hierarchy of her actions: she is first someone who allows him to write, then a caregiver in the traditional sense, and finally, someone who puts his needs ahead of her own because her personal actions are included at the end of the sentence. In the movie, when Bauby is making the agreement with the publishing company to write a book, a butterfly flies onto the publishing agent's lamp. The ability to express himself through writing is associated with a silent freedom, giving him hope and autonomy by having the unique opportunity to dictate his memoir. Continuing with the theme of writing, he writes that his physical therapist, Brigitte, "parcourt tout mon visage, la zone stérile qui me semble avoir la consistance d'un parchemin" ("Her warm fingers travel all over my face, including the numb zone, which seems to me to have the texture of parchment" (16).) The tenderness of the care he receives from his therapist is in direct contact with his writing, as he uses the metaphor “parchment” to refer to his face. Emory French professor Vincent Bruyère writes that this metaphor serves as a “surrogate continuity between seemingly incompatible bodily states—the body which is reparable and beyond repair, consciousness between confidence and despair” (Bruyère 2018, 99). The simple interface between Bauby’s former and current body occurs through caregiving, and it is because of caregiving that he is able to experience both bodies. This scene is Montaignian because it showcases two bodies: one that is outside of Bauby’s control and one that he experiences. This passage demonstrates how experiencing both bodies can be thought of as a technology of the self: the point of contact allows him to transition into accepting his new body.

In Bauby’s writing, one can observe his use of diction and syntax to criticize certain hospital staff members and their subpar role in caregiving. According to Leder, medical professionals often understand the body from a Cartesian point of view, which he calls “the Cartesian corpse.” Descartes medicalized the body, separating the mechanical body from the lived one, and modern medicine works on the basis of this model (Leder 1992). Canguilhem’s philosophy aligns with this idea, which states that:

> On peut dire que, pour le malade, la guérison est ce que lui doit la médecine, alors que pour la plupart des médecins, encore aujourd’hui, c’est le traitement le mieux étudié, expérimenté et essayé à ce jour que la médecine doit au malade. (Canguilhem 2002, 71)

> We can say that for the sick man, healing is what medicine owes him, while for most doctors, even today, what medicine owes the patient is the best-studied, best-tested, and most-used treatment currently available. (Canguilhem 2012, 54).

That is to say, medical personnel are less concerned with healing the lived body as they are with tending to the mechanical body. Throughout much of the memoir, the actions of the doctors align with Canguilhem's philosophy. They provide what they presume to be the best treatment while ignoring the illness as such. The methods they use therefore have the potential to be dehumanizing and disempowering, as they are concerned less with the patient's dignity than they are with their body. For example, when Bauby is first placed in the wheelchair, the neurologist exclaims, "vous êtes bon pour le fauteuil" (14-15). ("You can handle the wheelchair" (9).) The French phrase indicates a more passive and cruder construct than the English, as the French more literally translates to "you are good for the wheelchair." In English, the word "handle" assumes a sort of autonomy that is not present in the French because the word "handle" implies that he has a degree of control over the situation. Bauby being able to sit in the wheelchair was in fact a large victory—it was very possible for him to have gone into spasms, and the fact that he did not allowed him to travel the hospital. However, the positive news was not properly communicated to Bauby, and he felt the chair to be a setback to recovery rather than a prosthetic giving him the opportunity to travel. The passive syntax is also present in "Le bain" ("Bathtime"). Bauby employs the passive voice to describe his treatment: "je trouve cocasse d'être, à quarante-quatre ans, nettoyé, retourné, torché et langé comme un nourrisson" (22). ("I can find it amusing, in my forty-fifth year, to be cleaned up and turned over, to have my bottom wiped and swaddled like a newborn's" (16).) The passive voice indicates that he loses autonomy while being bathed, which cannot be regained in this situation, but he adds a sarcastic element when using vocabulary referring to infancy, implying that they treat him with less dignity than he merits. In addition, he refers to the orderlies as "gangsters" (15, 9) who put "le cadavre du gêneur" ("the nuisance's cadaver" (9) [modified translation]) in the trunk of their car. Because the orderlies handle his body unceremoniously, he uses brutish terminology to refer to them. In effect, the orderlies treat Bauby as a "Cartesian corpse" rather than as a lived body. Moreover, in the context of their handling his body, he uses the third person to talk about himself, calling his body "le cadavre," or *the* cadaver, removing his selfhood from the scenario (9). He goes on to call the personnel in the room "blouse[s] blanche[s] (15)" ("white coat[s]" (9)), employing synecdoche in order to reflect the doctors' disregard for his person. Bauby continues to use metaphors throughout his memoir to reflect the degree of dehumanization he experiences. The ophthalmologist who sews one of his eyes shut does so "comme on ravaude une paire de chaussettes" (59) ("as if he were darning a sock" (53).) This simile implies that the doctor is detached from the situation and treats Bauby as an inanimate object, one that is stepped on and mended so that he can be stepped on again. In the movie, we experience this scene through a first-person lens; the audience sees the world through Bauby's eye(s), and the camera focuses on his eye being sutured closed. The scene is mildly grotesque and tempts us to look away, but it exemplifies and communicates the horror and helplessness Bauby feels in this scene.

Dehumanization, whether conscious or not, in the memoir is not limited to healthcare providers; other patients in the hospital also express disregard for Bauby's personhood, focusing instead on his outward appearance. Bauby refers to these patients as "touristes," (tourists) who pass through the hospital to heal and reenter the world after a brief stay (37/ 31). He explains that patients in a coma are "une mauvaise conscience" ("guilty conscience") of whom everyone is aware but whom everyone prefers to ignore (37/ 31). Bauby describes his own ward as follows:

> Enfin, si l'on veut que cette peinture soit complète, il faut chercher un coin pour nous poser, volatiles aux ailes rompues, perroquets sans voix, oiseaux de malheur qui avons fait notre nid dans un couloir en cul-de-sac du service de neurologie. Bien sûr, nous déparons dans le paysage. Je sais trop bien le léger malaise que nous provoquons en traversant, raides et silencieux, un cercle de malades moins défavorisés. (38)

> And to complete the picture, a niche must be found for us, broken-winged birds, voiceless parrots, ravens of doom, who have made our nest in a dead-end corridor of the neurology department. Of course, we spoil the view. I am all too conscious of the slight uneasiness we cause as, rigid and mute, we make our way through a group of more fortunate patients. (32)

The self-deprecating language Bauby utilizes does not reflect his own perceptions of his ward but rather those of the other patients. He makes use of images of birds who have lost a part of their defining bodily functionality, which reflects the population of the ward. For example, we can take Bauby to be the parrot who has lost his voice—he is now rather a butterfly than a parrot. He cannot speak, but he can still fly due to his imagination being intact. Conversely, in the opinion of the tourists, he is "raide et silencieux" ("rigid and mute"), two terms that carry a negative connotation that imply a total lack of communication with others. The use of the word "cul-de-sac" ("dead-end") implies a point of no return. The phrase gives a bleak outlook on their condition; it is the belief of the "tourists" rather than of the patients that they have reached a dead-end. The other patients see the patients in the neurology wing as being helpless and aversive, invoking judgment rather than compassion. Bauby has a clear view of this judgment when he is receiving physical therapy:

> Chaque matin, je passe ainsi une demi-heure en suspension, en un hiératique garde-à-vous qui évoque l'apparition de la statue du Commandeur au dernier acte du *Don Juan* de Mozart. En dessous, ça rit, ça plaisante, ça s'interpelle. J'aimerais avoir ma part dans toute cette gaieté mais, dès que je pose mon œil unique sur eux, jeune homme, mamie, clochard détournent tous la tête et éprouvent un besoin urgent de contempler le détecteur d'incendie fixé au plafond. Les « touristes » doivent avoir très peur du feu. (39)

> Every morning I spend half an hour suspended this way, frozen to attention in a posture that must evoke the appearance of the Commendatore's statue in the second act of Mozart's Don Giovanni. Below, people laugh, joke, call out. I would like to be part of all this hilarity, but as soon as I direct my one eye toward them, young man, grandmother, homeless man turn away, feeling the sudden need to study the ceiling smoke detector. The "tourists" must be very worried about fire. (33) [modified translation]

Bauby has a literal bird's-eye view of the physical therapy room and observes himself being ostracized. He is literally, as well as socially, isolated from the rest of the patients. In French, the repetition of "ça," unavoidably translated as "they" in English, reinforces this separation. "Ça" implies a detachment from the patients below, as Bauby refers to the scene itself rather than the people involved. Because of this syntactical decision, we can infer Bauby's feeling of isolation from the other patients, including in the room in which caregiving is in its most obvious form. In the list of people observing him ("eux, jeune homme, mamie, clochard" / "them, young man, grandmother, homeless man"), Bauby does not use the conjunction "and," which would imply that the list ends. Through omitting this conjunction, Bauby implies that the list continues and is not limited to these three people. In French, it is unconventional to omit the word "the" (or some form of it) before nouns, though Bauby does so in his list of people. This omission implies that there is not just one person staring at him but rather an arbitrary number, as "the" would imply singularity. Canguilhem broaches the idea of exclusion from the lens of tuberculosis, which we can apply in Bauby's case due to the phenomenological relationship between tuberculosis and LIS:

> Les médecins avaient en quelque sorte intégré à leur conception de la maladie une réaction populaire d'effroi et de rejet, alors même qu'ils luttaient contre elle. […] La tuberculose était objet de terreur, comme l'avait été la lèpre au Moyen Age. Nommer la maladie en aggravait les symptômes. Car la maladie entraînait exclusion sociale autant que consomption organique. (Canguilhem 2002, 83-84)
>
> Doctors have somehow managed to integrate a popular reaction of dread and rejection into their conception of disease, even while they were struggling against it. […] Tuberculosis was a source of terror, much as leprosy was in the Middle Ages. Naming the disease would aggravate its symptoms, because the disease entailed social exclusion as much as organic consumption. (Canguilhem 2012, 59)

The patients in the physical therapy room are not necessarily scared of catching the disease, but the image of extreme disability perhaps scares them. Much as with tuberculosis or leprosy, the other patients reject Bauby from being part of the mirth which he can only observe from above. Although the naming of LIS itself does not constitute exclusion as it did in tuberculosis, the mere sight does. As a result, social exclusion as well as "organic consumption" (i.e. LIS itself) adversely impact Bauby's health.

However, most of the encounters Bauby writes about are not bleak. For example, Sandrine, his speech therapist, develops his alphabet so that he can communicate with others, and she frequently interacts with him. In the movie, Sandrine (renamed Henriette) appears frequently after he experiences bouts of guilt, depression or lamentations of the past. Often, there is an abrupt transition from these desolate scenes to Henriette holding the board that contains the letters of his alphabet. These transitions, or perhaps a lack thereof, convey that his alphabet provides him reprieve from desolate thoughts. Although these moments of depression are not present in the memoir, the switch from negativity to the alphabet highlights the central role of the alphabet in healing. Relatedly, it is the combination of physical therapy and speech therapy that essentializes the juncture between the mechanical body and the lived body. Leder writes: "To attend to the lived body is not to forsaken the tools and learning that Cartesian medicine has provided. It is merely to refuse to grant this mechanical wisdom the status of ruling paradigm" (Leder 1992, 31). We can therefore understand Sandrine's involvement as one which draws upon Cartesian ideology but employs it in such a way as to tend to the lived body. Instead of treating Bauby's body as a machine, she tends to the body that he can control rather than the unconscious one, using the Cartesian methodology to apply principles to a more Montaignian philosophy of the body. For Bauby's birthday, he was able to recite the alphabet, about which he writes: "on ne pouvait me faire de plus beau cadeau" (46) ("I could not have had a better present" (41).) The French literally translates to "one could not have made me a better present," and the distinction here is subtle but remarkable. The word “on” in French can take on the meaning “we,” and “faire” implies a creation. As such, this sentence implies that he and Sandrine were both part of the process of arriving at reciting the alphabet, thus demonstrating the intertwined nature of caregiving in accomplishing a goal that signifies autonomy (i.e. speech). Sandrine serves as source of hope during Bauby’s healing, and she plays a pivotal role as being both a formal and informal caregiver. She developed his alphabet and helps him to use it and to learn to speak again, demonstrating her role as a formal caregiver. However, she also acts as an informal caregiver in the movie when she helps him set up the phone in his room and talk to his publishing agent. She is a special caregiver in the sense that she fulfills this dual role; oftentimes, informal caregiving is limited to family, and her involvement in his personal life allows her to understand, to some degree, who he was both before and after the stroke.

Bauby’s friends and family also constitute caregivers, though not necessarily in the traditional sense. Regarding caregiving, Kleinman writes:

> It is a practice of empathic imagination, responsibility, witnessing, and solidarity with those in great need. It is a moral practice that makes caregivers, and at times even the care-receivers, more present and thereby fully human. (Kleinman 2010, online access)

In the chapter “Le rideau” (“Through a Glass, Darkly”), Bauby’s children must take on each of these roles. For children, imagination as a form of caregiving entails giving their father drawings to try to help him heal. They often draw pictures to put on his wall, such as when Théophile drew a Mickey with his tongue hanging out when his father could not open his mouth (22/ 16). This drawing is a form of caregiving because Théophile, if nothing else, reaches out to his father to try to promote his recovery through imagination. The familial gesture itself is a form of caregiving because Bauby has a support network that promotes healing. His daughter, Céleste, also draws a picture, which they then display on the wall (80/75). The mere act of offering Bauby a drawing is in and of itself an act of caregiving because it shows that he is still a father regardless of his condition. However, his children do not only play a role in emotional support but also in attending to his body:

> Avec des serviettes en papier, Théophile essuie, tout en marchant, les filets de salive qui s'écoulent de mes lèvres closes. Son geste est furtif, à la fois tendre et craintif comme s'il était en face d'un animal aux réactions imprévisibles. Dès que nous ralentissons, Celeste m'enserre la tête entre ses bras nus, couvre mon front de baisers sonores et répète : "c'est mon papa, c'est mon papa", a la manière d'une incantation. (75)

> As he walks, Théophile dabs with a Kleenex at the threads of saliva escaping my closed lips. His movements are tentative, at once tender and fearful, as if he were dealing with an animal of unpredictable reactions. As soon as we slow down, Céleste hugs my head in her bare arms, covers my forehead with noisy kisses, and says over and over, "You're my dad, you're my dad," as if in incantation. (69-70) [modified translation]

Théophile must assume the role of a caregiver (i.e. must assume responsibility, in Kleinman's terms) to his father, which places him in an uncomfortable position because he is trying to be helpful all the while understand that it is his father of whom he is taking care. This is an act of physical caregiving in which a family member must assume a novel role. Céleste also feels this pressure but stands with him in solidarity because she showers him with affection while repeating that he is her dad. This scene also evokes the quote from “Les Nouvelles Figures du Soin” because caregiving is a role that stems from love rather than duty in the context of Bauby with his children. Although the situation is apparently difficult for the children to process, they remain loving in his life and assume multiple roles, reinforcing that caregiving does not only refer to health-related care. We can also understand these offerings from his children as a cause of a deeper familial bond. Bauby writes that they begin to celebrate Father’s Day “pour attester, sans doute, qu’une ébauche, une ombre, un bout de papa, c’est encore un papa” (76). (“to affirm without a doubt that even a rough sketch, a shadow, a tiny fragment of a dad is still a dad” (70) [modified translation].) In celebrating this holiday for the first time, Bauby’s family becomes closer; his disability therefore leads to a deeper bond with his children, showing that caregiving can have a positive effect on relationships.

In the movie, we see others also caring for him. One of his friends reads him Balzac late into the night and falls asleep at his bedside. Claude and Céline (Sylvie), in addition to Henriette (Sandrine), act as interlocutors when Bauby wishes to speak to anyone on the phone. Near the end of the movie, Céline must help Bauby communicate with his former lover, Joséphine. Visibly upset, she nevertheless continues to translate even the most heart-wrenching phrases and leaves the room when Bauby asks to listen to Joséphine speak in private. When she returns, she communicates in tears that he would like to tell Joséphine, “chaque jour je t’attends” (“Each day I wait for you”) before hanging up the phone. In Céline’s case, caregiving is a form of self-sacrifice insofar as she endures emotional pain for the sake of his desire to speak to his lover. Another example of caregiving in the movie occurs when we see a scene of Bauby and Claude on a yacht in which she gifts him *The Count of Monte Cristo* by Alexandre Dumas, the book he had intended to rewrite.

(screen capture, 1:27:01)

After this gesture, Bauby imagines her descending into the depths of the ocean with him. Although her role had previously been confined to being an emissary, they have developed a bond, and the film demonstrates this connection by having her hold on to him as he sinks. As Claude is holding on to his diving bell as he descends into the ocean, we hear her say, “Ça m’est égale si vous m’ameniez avec vous au fond de l’océan parce que vous êtes aussi mon papillon.” (“I don’t mind you dragging me to the bottom of the ocean because you’re also my butterfly.”) While it is a dramatized scene, it nevertheless exemplifies the strength of Bauby’s social network. In particular, the scene highlights the relationship between Claude and Bauby that developed after his stroke, exemplifying that a deep bond can be formed with a caregiver who entered his life at a time when he was in a dependent state. We can therefore see that a profound relationship with a caregiver does not need to be established before a disabling event.

Bauby is also an agent of caregiving for himself. As is the case for many ALS patients, Bauby must constantly seek to adapt to the situation rather than adhering to the medical model of a return to normalcy, which Canguilhem describes as follows:

> D'où la tendance générale et constante à concevoir la guérison comme fin d'une perturbation et retour à l'ordre antérieur, ainsi qu'en témoignent tous les termes à préfixe *re-* qui servent à en décrire le processus : restaurer, restituer, rétablir, reconstituer, récupérer, recouvrir, etc. En ce sens, guérison implique la réversibilité des phénomènes dont la succession constituait la maladie ; c'est une variante des principes de conservation ou d'invariance sur lesquels sont fondées la mécanique et la cosmologie de l'époque classique. (Canguilhem 2002, 74-75).

> Thus emerged the general and persistent tendency to conceive the cure as an end to disturbance and a return to an anterior order, as attested by all the terms with the prefix "re" that serve to describe its process: "restore," "reconstruct", "reestablish", "reconstitute," "recuperate", "recover", and so on. In this sense, to cure implies the reversibility of phenomena whose sequence constitutes the disease; it is a variant of the principle of conservation or invariance on which classical mechanisms and cosmology are founded. (Canguilhem 2012, 55).

Instead of following the medical model, which implies reversibility, Bauby must seek to *redefine* himself rather than to restore a past life, made unavoidable by the nature of his condition.

The way in which Bauby cares for himself is largely through imagination, which allows him to come to terms with his new body. This method drastically contrasts Descartes's method of understanding the body, of which he writes in his second meditation in "Meditations of First Philosophy":

> [I]n general, everything relating to the nature of body, could be mere dreams […] [T]o say 'I will use my imagination to get to know more distinctly what I am' would seem to be as silly as saying 'I am now awake, and see some truth; but since my vision is not yet clear enough, I will deliberately fall asleep so that my dreams may provide a truer and clearer representation.' I thus realize that none of the things that the imagination enables me to grasp is at all relevant to this knowledge of myself which I possess[.] (Descartes 1984, online access)

Descartes understands knowing the self through imagination to be absurd, as understanding the self comes not through understanding the body but rather through reflecting on the body as an inanimate object that houses the soul. For Descartes, it is impossible to know that the body exists, but it is possible to know that one has thoughts; hence, he describes that "I" refers to "[a] thing that doubts, understands, affirms, denies, is willing, is unwilling, and also imagines and has sensory perceptions" (Descartes 1984, online access). Taking Descartes's philosophy and applying it to LIS, which is considered to be the epitome of the separation between the mind and the body, may seem intuitive, but Bauby's actual experience contradicts the separation of the mind from the body.[1] Bauby uses imagination to reconstruct his reality so that he understands how to use and experience his body regardless of his circumstance. Embodiment via imagination is the way through which he understands himself, as he has to readjust his conception of the self after the cerebrovascular accident. For example, Bauby anthropomorphizes his alphabet, prescribing it movement and fluidity which his own body lacks when he writes that the letters "main dans la main, [les lettres] traversent la chambre, tournent autour du lit, longent la fenêtre, serpentent sur le mur, vont jusqu'à la portent et repartent pour un tour" (25). ("hand in hand, the letters cross the room, whirl around the bed, sweep past the window, wriggle across the wall, swoop to the door, and return to begin again" (19).) Bauby's alphabet functions as a prosthetic because it is an extension of himself: he requires it to communicate with the outside world. By assigning the letters motion, he is also able to move around the room, if only in his imagination. The phrase "hand in hand" implies that there is a sense of continuity between the letters, that they all move in tandem and allow him to travel as well. In another attempt to maintain continuity, while being fed through a tube, Bauby uses his imagination to experience the meal rather than relying on watching the brown substance drip through the tube. He recreates meals and one of his friends sends him a recipe, which is another way in which non-medical caregiving is evident in the memoir (42/ 36-37). Furthermore, he assigns objects of his imagination a spiritual value by using religious language to write about them. Bauby describes the sausage he remembers from his childhood as "un objet sacré" (sacred object), thereby assigning the memory

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[1] Notably, Bauby must rely on intersubjectivity, or the presence of caregivers, to stay alive and be in possession of his mental faculties. Without caregiving and attention to his body, including for communication, Bauby would not be able to express his thoughts. The mind and the body cannot possibly be separated if he must rely on others to pay attention to his body.

of food that he experiences a spiritual identity (43/ personal translation). The act of imagining meals is a form of caregiving because it is a technology of the self: Bauby builds on past experiences to learn to experience a new body rather than relying merely on the sight of a bag of fluid. Although he has an ambivalent relationship toward God Himself, as demonstrated when he writes that Céleste prays to "son Seigneur" (19) ("her Lord" (13)), he nevertheless uses religious language in his writing to describe objects and people who provide him solace and healing. Indeed, he uses religious terminology to describe Empress Eugenia, who visited the hospital while it was still a children's hospital. Her visit was commemorated with an engraving, which he frequently visits and calls a "relique" (30). ("Relic" (24).) Bauby imagines her coming to life and caring for him:

> Elle ne m'a pas repoussé. Elle a passé ses doigts dans mes cheveux et m'a dit doucement : « Allons, mon enfant, il faut être très patient », avec un accent espagnol qui ressemblait à celui de la neurologue. Ce n'était plus l'impératrice des Français mais une divinité consolatrice à la façon de sainte Rita, la patronne des causes désespérées. (30)

> She did not send me away. She ran her fingers through my hair and said gently, "There, there, my child, you must be very patient," in a Spanish accent very like the neurologist's. She was no longer the empress of the French but a compassionate divinity in the manner of Saint Rita, patroness of lost causes. (24)

The language that Bauby uses, namely "divinity" and "saint," implies that he sees her as a comforting, religious figure. He sees the Empress as being his protector instead of God, as the language he uses to describe God (Seigneur instead of Dieu, Lord instead of God) invokes a hierarchy, with the Empress being above a Lord. In the movie, the Empress acts as a symbol of a living body as opposed to a stationary one, as seen in the following screen capture:

(screen capture, 0:47:01)

In this scene, the embodied Empress takes the foreground whereas her bust (that is, her inanimate, locked-in form) is seen in the background. While Bauby is narrating the scene, we hear Claude reciting the alphabet. This scene of the Empress therefore represents that embodiment is possible through the alphabet, much in the same way as the Empress comes to life when the inscription regarding her visit is read. However, her embodied form is relocated to the background when Bauby narrates: “Dans un reflet de la vitrine est apparu le visage d’un homme que semblait avoir séjourné dans un tonneau de dioxine” (30). (“Reflected in the glass I saw the head of a man who seemed to have emerged from a vat of formaldehyde" (24-25).)

(screen capture, 1:18:37)

At this point, Bauby is caught between the embodied and the disembodied self. He does not recognize his mechanical body, but at this point in the movie, he has experienced his lived body. It is at this moment that he must decide whether he will choose the body he controls or the one he does not. A few seconds after this screen capture, he jumps up, kisses the Empress (only in the movie), and they dance. This scene therefore represents that he has chosen to inhabit the body that he does control rather than resigning himself to be a Cartesian corpse. In addition to the Empress, the lighthouse by the hospital also acts as a guardian: "[c'était] élancé, robuste et rassurant […] je me suis tout de suite place sous la protection de ce symbole fraternel qui veille sur les marins comme sur les maladies, ces naufragés de la solitude" (34). ("[it was] tall, robust, and reassuring […] I placed myself at once under the protection of this brotherly symbol, guardian not just of sailors but of the sick—those castaways on the shores of loneliness" (28-

29).) Much like the Empress, Bauby describes the lighthouse as being a symbol for those who are sick and lonely, and he accepts it as a symbol of solace and protection. Instead of relying on a deity, he uses a variety of sources to feel more at peace. Finally, Bauby makes use of votive images to heal. Ex-voto are described as an offering of part of oneself in order to heal. They are often sculptures of body parts dedicated to deities as a plea for help or as a sign of gratitude once one is healed. According to philosopher Georges Didi-Huberman:

> Wax, as the material of all manner of *plasticities*, lends itself perfectly to the *labilities* of the symptom that the votive image tries magically to involute, to heal, to transfigure…Now, in this constant metamorphosis, it ceaselessly affirms its indestructible reference to what all this has in common: one might say it permits a *gain of flesh*, this flesh that it so perfectly imitates and to which it so obstinately returns… (Didi-Huberman, 9).

As we can see, votive images allow for lability and metamorphosis, and they are often used in religious contexts as an offering in exchange for health. These images are often, but not always, constructed of wax and look like the body part trying to be healed. They can also be physical offerings that represent a body part but do not necessarily resemble it. Bauby writes:

> En plus, j'ai dédié à mon larynx les petits sachets d'encens qui pendent à mon mur, ex-voto rapportés du Japon […] Si je suis avisé qu'à mon intention on a brûlé quelques cierges dans une chapelle bretonne ou psalmodié un mantra dans un temple népalais, j'assigne aussitôt un but précis à ces manifestations spirituelles. Ainsi j'ai confié mon œil

> droit à un marabout camerounais mandaté par une amie pour m'assurer la mansuétude des dieux africains. Pour les troubles de l'audition, je m'en remets aux bonnes relations qu'une belle-mère au cœur pieux entretient avec les moines d'une confrérie de Bordeaux (18-19).

> What is more, I have dedicated to my larynx the little packets of incense hanging on the wall, ex-voto brought back from Japan […] If they tell me that candles have been burned for my sake in a Breton chapel, or that a mantra has been chanted in a Nepalese temple, I at once give each of the spirits invoked a precise task. A woman I know enlisted a Cameroon holy man to procure me the goodwill of Africa's gods: I have assigned him my right eye. For my hearing problems I rely on the relationship between my devout mother-in-law and the monks of a Bordeaux brotherhood. (12-13) [modified translation]

In this passage, Bauby lists examples of caregiving done by others who try to heal him through their own spirituality or religion. Bauby appreciates the gesture and in turn takes their act of caregiving into his own hands by assigning body parts to each of the ex-voto. He partitions his body and uses the parts as offerings to various religions for healing. Although he does not necessarily have faith in any of the aforementioned religions, the act of donating parts of his body to each helps him to heal because he is in a position of autonomy by making the offering.

In conclusion, caregiving occurs in many forms, including through doctors and other hospital staff, friends, family, and Bauby's internal drive to heal using his imagination. Not all forms of caregiving are equally attentive to his mental health, and those in the context of the hospital are often more geared towards supporting his body. Because there is no cure for LIS, the other agents of caregiving offer more respite than do medical interventions. Largely due to caregiving, both externally and internally as a technology of the self, Bauby is able to conclude his memoir with optimism and an understanding of and appreciation for his new circumstances.

IV. Caregiving Narratives in a Rehabilitation Context

The role of caregiving in *The Diving Bell and the Butterfly* begs the questions as to whether caregiving on a humanistic level is present in modern-day stroke rehabilitation. How are patients treated beyond the corporeal? With limited time with each patient, it can be difficult to address this question in practice. Jean-Dominique Bauby received care partially through being able to write his book; his health concerns were addressed through non-conventional therapy, which eventually led to his adaptation to his new circumstance. While receiving this level of care is certainly a unique case, humanistic inquiry has been applied in modern-day caregiving as seen through treatment targeting emotions and through the use of narrative medicine.

Although it is difficult to directly involve the humanities in care, a number of studies have been done that assess patients' emotions and employ humanistic tools in order to improve the mood of both patients and home caregivers. Lutz, registered nurse and professor at the University of North Carolina Wilmington, et al. found that caregivers of stroke survivors do not have sufficient time to process the event and to immediately take on new responsibilities. In the American medical system, patients are often discharged relatively soon after the event, and the time to discharge has decreased over time, leading to patients being "discharged quicker and sicker" (Lutz et al. 2011, 1). A large part of the negative health-related outcomes in stroke survivors is directly correlated with caregiver health: caregivers are not given adequate time to prepare and therefore feel helpless. Having not had enough time to grasp the reality of the situation themselves in addition to not having had time to adjust their lifestyle and home to accommodate the stroke survivor's needs, caregivers often feel overwhelmed. When the stroke survivor is discharged without the caregiver having had time to prepare, the mental, and even physical, health of both the patient and the caregiver are compromised. The progression of stroke recovery comes in three steps: the “stroke crisis,” “expectations of recovery,” and the “crisis of discharge” (Lutz et al. 2011, 4). The “stroke crisis” phase is associated with the sudden spike in anxiety related to the event itself and the feeling of a loss of control. The “expectations of recovery” phase is marked by optimism of the patients regaining full control of their body. Caregivers and patients alike carry this optimism of a return to normal, but as we have seen with Canguilhem, there is no return to normal; rather, there is a coming to terms with a new normal. Clinicians focus more on this new normal than do the former: small improvements constitute large strides in recovery. However, at the “crisis of discharge,” survivors and caregivers begin to understand that there is no return to normal when the patients are being discharged without having fully recovered, and survivors are left feeling unprepared, frustrated, and angry:

> You know, it’s very humiliating to have to call somebody so you can go to the damn bathroom in the middle of the night. Just to go to the bathroom. Yeah, that’s when you know you’re really screwed up, when you have to call somebody to help you out with something that simple, something you take for granted your whole life. [P-13] (Lutz et al., 7)

This patient, once home, realizes that he has lost the autonomy he had before the stroke and that rehabilitation was not able to give him back his old life. These feelings of frustration lead to tense relationships with their caregivers and also an increase in depression, which in turn can negatively impact recovery. We see a similar phenomenon in *The Diving Bell and the Butterfly* when Bauby is being bathed:

> Un jour, je trouve cocasse d’être, à quarante-quatre ans, nettoyé, retourné, torché et langé comme un nourrisson. En pleine régression infantile, j’y prends même un trouble plaisir. Le lendemain, tout cela me semble le comble du pathétique, et une larme roule dans la mousse à raser qu’un aide-soignant étale sur mes joues. (22)

> One day, for example, I can find it amusing, in my forty-fifth year, to be cleaned up and turned over, to have my bottom wiped and swaddled like a newborn's. I even derive a guilty pleasure from this total lapse into infancy. But the next day, the same procedure seems to me unbearably sad, and a tear rolls down through the lather a nurse's aide spreads over my cheeks. (16-17)

Although Bauby is not being discharged per se, he experiences sadness because he has lost control of his body, and he is still coming to terms with the fact that he will not be able to make a full recovery. Bauby feels the stress of not being in control of his own body—of being totally at the mercy of a caregiver—leading to feelings of sadness not unique to his own narrative.

A study by Blanton, associate professor of rehabilitation medicine at Emory University’s school of medicine and founder and editor-in-chief of the *Journal of Humanities in Rehabilitation,* et al. addresses the concern of “carepartners” not being adequately prepared for taking on the responsibility of caring for a loved one. They found that carepartners often do not know how far to push the stroke survivor, often leading to interpersonal conflict, which is associated with reduced positive outcomes in patients. In their literature review, they found that patients who have a greater sense of perceived autonomy with caregivers who use less controlling language showed an increase in confidence, adherence to the treatment, and showed greater improvement on the whole. Using these principles, they constructed a study to improve patient outcomes. The patients used in the study had weakness in one arm, and the prescribed therapy involved wearing a mitt on the unaffected arm in order to promote using the affected arm to carry out tasks to regain motor function. The patients were required to attend ten constraint-induced movement therapy sessions for three hours at a time, preferably with the carepartner present. The carepartner was given a workbook that included strategies for caring for the stroke survivor and information about stroke, which they were to complete over the course of weeks. The researchers found that use of the workbook decreased depressive symptoms, fatigue, and family conflict in carepartners but showed no effect on carepartners' self-efficacy. Use of the workbook was also associated with better progress in the patients, building on the previously mentioned study by Lutz et al. that concluded that lack of preparedness and health on the part of the caregiver corresponded with more negative outcomes in patients (Blanton et al. 2018). Therefore, the introduction of resources for the caregiver and not only the patient lead to improved patient outcomes. Addressing the concerns of all parties involved through the use of engaging media enhances patient care and reduces stress on the family. In some ways, we can also consider *The Diving Bell and the Butterfly* to be a workbook. The act of creating the memoir was a way to cope, which, like the previously mentioned workbook, was a method through which a patient (i.e. Bauby) could better understand his diagnosis and learn to live with it. It is also possible that the memoir itself could serve as a workbook for others involved in stroke rehabilitation, whether that be the patient or the caregiver. The memoir demonstrates how someone was able to heal, and it could provide coping mechanisms for a patient in addition to methods of caregiving for the caregiver. The memoir could heighten caregivers' awareness of patients' concerns and desires which otherwise might go unnoticed. For example, in a panel discussion involving Maryanne Weatherill, a speech therapist and assistant professor at the University of West Georgia, Weatherill noted that the memoir heightened her sensitivity to details. She mentioned that while watching the movie, seeing the hospital employee turn off Bauby's television in the middle of a soccer game from a first-person perspective made her aware of the seemingly minute details that impact a patient's experience. This elevated awareness led her to pay more attention to non-clinical details in her practice (Laures-Gore and Weatherill 2019).

As exemplified by the aforementioned mentioned study by Blanton et al., addressing the family unit—that is, focusing on family-centered care just as much as patient-centered care—improves patient outcomes. In a piece regarding cultural competency, Kleinman argues that eliciting a patient's narrative through the use of a variety of questions helps to address the patient's concerns and ultimately provides better care for the patient. Much of this article is directed towards issues of cultural competency in the clinic, but it can be generalized to include all narratives. One of the main questions to address is, "what is at stake?" (Kleinman 2006, 1674) By finding out what the person's concerns are, clinicians can better direct their treatment. In a personal interview, Blanton gave the example of an older man who wanted to participate in one of her research studies. She began to address his mood and found that the main source of his grief was not his stroke but the passing of his wife. During that encounter, the man's son seemed disinterested, and finally, she directly asked him what his biggest concern was. Asking that question led to a discussion about the man's depression and his son's involvement in his recovery, which included driving forty-five minutes a day to take care of his father, all the while juggling his own family and work (Blanton, personal interview). The aforementioned case study demonstrates the importance of addressing the family unit rather than focusing solely on the patient because she might not have identified the source of the man's worries without involving the family. The man felt like his disability caused him to be a burden on his son, which in turn led to feelings of depression. When this concern in addition to his wife's passing was addressed, the treatment became more tailored to their needs. In reality, the bond between the patient and his sons became stronger because the sons were caring for him and visiting him more often than they had previously. Therefore, the act of caregiving transformed the familial relationship, likely in a positive way. Caring for the patient in this case also meant lessening the perceived burden on his son, which decreased the stress on the family, ultimately leading to improved patient outcomes. It is therefore crucial to evoke a narrative in order to understand who the patient is and to address their specific needs, leading to the best recovery possible.

Blanton explains that before addressing one's stroke and its repercussions, patients often want to make sure that physical therapists, as well as any other people involved in their recovery, know who they were before the stroke. They do not want the incident to be their defining feature, and sharing who they were before the stroke can create a closer bond between clinician and patient. She shared that one of her students did not immediately understand why a patient was talking about his past life as a plumber instead of working on his recovery. With limited time together, the student assumed that they were there to work, not socialize, but Blanton paraphrases the student's final understanding as follows:

> I realized that it was really important for him to tell me who he was. That he was somebody bigger than the stroke, and this wasn't just him, and these were his aspirations, and when I listened to him, it was just as important as the exercises I was doing. (Blanton, personal interview)

Therefore, understanding the patient's personal history, not just his medical one, allowed the student to better tailor the therapy, and the mere act of explaining his past reaffirmed in his own mind that the stroke did not define him. We see a similar phenomenon in the memoir. Although Bauby begins with his life after the stroke, he does not write about the actual incident until the penultimate chapter. Interspersed in the memoir are chapters that focus solely on his past life, ranging from his trip to Lourdes ("La trace du serpent"/ "Our Very Own Madonna") to his life as the editor-in-chief of *Elle* ("Les demoiselles de Hong Kong"/ "The Ladies of Hong Kong"). The structure of the memoir is nonlinear; it occurs outside of calendrical time and seeks to reconcile the past with the present. The nature of healing is not a straight path, and the chapters from various points in time serve to make readers understand both who he was before and after the stroke before being told the story of the stroke itself, allowing them to understand the stroke in the context of Bauby's life.

According to Blanton, addressing the question of "what gives you purpose?" is difficult but important in recovery. Rather than asking the question directly, it is important to elicit a narrative and have a conversation to reach that end (Blanton, personal interview). In a study conducted by Psarra and Kleftaras, professor of clinical psychology at the University of Thessaly, they found that having a meaning in life is negatively correlated with depression. Building on the work of Viktor Frankl, who founded logotherapy, they explain that "'Logotherapy' is a theoretical system of understanding the way people develop and maintain meaning in their lives" (Psarra and Kleftaras 2013, 81). This paradigm consists of three core values: the experiential, the creative, and the attitudinal. Psarra and Kleftaras apply these principles to stroke survivorship. The experiential focuses on gaining meaning through experiences. An example of an experiential value comes from *The Diving Bell and the Butterfly*:

> C’est dire le réconfort que je ressens deux fois par jour quand Sandrine frappe à la porte, passe une frimousse d’écureuil pris en faute et chasse d’un coup tous les mauvais esprits. Le scaphandre invisible qui m’enserre en permanence semble moins oppressant. […] Je profite de Sandrine pour avoir quelques proches en ligne et saisir au vol des bribes de vie, comme on attrape un papillon. (46-47)

> Which explains the gratification I feel twice daily when Sandrine knocks, pokes her small chipmunk face through the door, and at once sends all gloomy thoughts packing. The invisible and eternally imprisoning diving bell seems less oppressive. […] I take advantage of Sandrine's presence to be in touch with loved ones, to intercept and catch passing fragments of life, the way you catch a butterfly. (40-41)

This quotation comes from the chapter “L’ange gardien” (“Guardian Angel”), which refers to his speech therapist, Sandrine. The direct reference to his speech therapist as being a guardian angel illustrates the importance of caregiving on a patient’s general state of wellbeing. In the context of this quote, she is the only way through which he can communicate with the outside world, thereby being one of the few people who can tap into the “experiential value” previously described. Neglecting imagined experiences, which are not taken into consideration in Psarra’s and Kleftaras’s paper, Bauby’s experiences are nearly always tied to his ability to communicate. The experience of communication removes the diving bell, and Bauby introduces the butterfly when he describes having Sandrine be an interlocutor when he is communicating with others outside of the hospital on the phone. In the movie, after Henriette introduces the alphabet to

Bauby, the first-person point of view camera shifts upwards, and we can briefly observe a picture of a butterfly hung on his wall. The butterfly is often used as a metaphor for freedom in the memoir, and having these experiences through Sandrine (Henriette) allows him to escape the diving bell, adding experiential value to his life.

Blanton also shared a patient's narrative in which the patient's experiential values gave him meaning in life in the wake of his stroke. The patient had previously done manual labor but was unable to return to it due to his stroke. He expressed interest in the Episcopalian Church, and Blanton recommended taking a course in theology related to the church which she had taken before deciding to pursue physical therapy. He took the class and ended up becoming ordained as a deacon, and he spent the rest of his life dedicated to the church. Through evoking his narrative, Blanton was able to uncover his interests and lead him down the path of finding new meaning in his life when returning to normal is not an option (Blanton, personal interview). Logotherapy involves being able to look past the tragedy and gain meaning from the illness and to reach "his/her spiritual dimension," which Blanton's patient had done in the literal sense of the word (Psarra and Kleftaras 2013, 81).

The second component of logotherapy is being able to have creative value in one's life. The word "creative," in addition to referring to creative activities such as writing, also refers to building a life, with the paper giving examples such as "building a home" or "defending a belief" (Psarra and Kleftaras 2013, 81). The construction of *The Diving Bell and the Butterfly* itself can be thought of as a creative value because Bauby gives meaning to his life by dictating this memoir and sharing his experiences. The writing of the memoir is a way to heal, and he is able to look past his disability and assign meaning to it. He also keeps up a correspondence with many of the people he knows: this is both a way to express himself to avoid being deemed a "vegetable" and a way to create points of contact with others (81). This scenario can also be thought of as an experiential value because it creates and maintains relationships with others. When he reads letters from acquaintances that contemplate the meaning of life, he writes: "Leur légèreté masquait des profondeurs. Etais-je aveugle ou sourd ou bien faut-il nécessairement la lumière d'un malheur pour éclairer un homme sous son vrai jour ?"(89) ("Their small talk had masked hidden depths. Had I been blind and deaf, or does it take the harsh light of disaster to show a person's true nature?" (83)) Bauby gains meaning in his life from LIS because it allows him to communicate with others on a level he was unable to—or simply didn't—when he was able-bodied. The third value of logotherapy is attitudinal value, which refers to people finding meaning through being able to make their own decisions. Using the example from before, Bauby regains autonomy by rejecting the notion that he is a vegetable. To counter that widely-held notion in Paris, he begins a correspondence with many people to prove that he is not at the mercy of LIS. The study concludes that:

> [W]hen persons with physical disabilities possess a feeling of meaning and direction in life, have a clear sense of personal identity and responsibility for life, accept the inevitability of death and pursue new challenges in life, then they accept and cope better with their physical disability. On the contrary, when individuals experience an absence of meaning, goals and mission in their life and feelings of apathy, boredom and indifference about their life (existential vacuum), resulting from their physical disabilities, then it is more difficult for them to accept and adjust to those disabilities. (Psarra and Kleftaras 2013, 89)

As we have seen in the aforementioned narrative examples, the findings of this study reflect the actual lived experience of many patients with stroke-related disabilities. An example from the interview with Blanton involves a person who approached rehabilitation with doubt and despair. The patient was suffering from depression and easily became frustrated with having to wear the mitt on her unaffected hand because she was unable to do even minor tasks. Blanton, after having evaluated her self-efficacy, recommended that she wear the mitt only while they were together, and she focused on praise so that the patient would not feel like the task was pointless (Blanton, personal interview). This patient was more subject to the "existential vacuum" than those in the previous examples, but proper intervention can cause improved outcomes compared to those following a standardized treatment plan.

Helping patients to understand that there is not a return to a previous life involves a delicate balance of optimism and realism. Blanton explains that in stroke rehabilitation, it is difficult to know how much a given patient will improve because each comes to the table with different capabilities. After a certain period of time, patients will show less improvement, and some of them will turn to research studies in an attempt to "get back" their previous physical capabilities. However, Blanton and others must remind the patient that research will not cause a return to normal. She shared the story of a patient who would fly up to Atlanta to be in her research study. He appeared to be very enthusiastic, but after a while, he stopped answering her calls and discontinued the study. Once she finally got in touch with him, he explained that he had not been seeing the improvements he had hoped to see, and instead of spending hours a day to make small improvements, he preferred to spend that time with his family. This patient realized that he would have to accept a new state of health rather than returning to the former, but he could nevertheless find meaning in life (Blanton, personal interview).

In addition to physical therapists, medical doctors have recognized the importance of narrative medicine in their practice. Rita Charon, founder of the field of narrative medicine, writes:

> Along with scientific ability, physicians need the ability to listen to the narratives of the patient, grasp and honor their meanings, and be moved to act on the patient's behalf. This is narrative competence, that is, the competence that human beings use to absorb, interpret, and respond to stories. (Charon 2001, online access).

Narrative medicine is therefore a field that invites healthcare providers to actively listen to patients' narratives and to use reflection as a tool to maximize the healthcare providers' efficacy to most effectively treat the patients and alleviate their concerns and suffering. David H. Chestnut, an anesthesiologist, reflects on his own demeanor in a narrative piece on his interactions with patients. He reflects that he had been arrogant and brusque, and someone told him that he was being unkind with the staff and that he should try to work in a team. He also reflected that he became "impersonal and mechanical" (Chestnut 2017, 781). He describes an incident that made him realize his own shortcomings:

> One day I prepared to per- form a preanesthetic assessment on a woman who was scheduled to undergo surgery for breast cancer. Her surgeon was in the room talking with her, and so I waited outside the door. I became annoyed when 1 min stretched to 5 and then 10 min. I had other things to do. What were they talking about? But then I realized that the patient was crying, and the surgeon was listening and speaking with an

> extraordinary empathy that put me to shame. I learned a lesson in kindness from that surgeon. (Chestnut 2017, 781)

From this point on, Chestnut spent more time interacting with patients and getting to know them, thereby building a mutual trust. In a paper by rehabilitation specialists Stearns et al., the authors reflect on their own shortcomings in medical practice. They reflect on cases that have affected them and explore ways in which they would have handled the situation differently. For example, Carvalho writes:

> I learned some crucial lessons with this interaction: a foundation of trust is essential and it is important to tailor interventions to an individual's readiness for change. If I had fostered a collaborative environment with shared decision-making, it may have led to the development of a positive therapeutic alliance, which could have facilitated behavioral change. (Stearns et al. 2018, 3)

Engaging in narrative medicine allows doctors and other healthcare providers to identify their own shortcoming and to reflect on how to change their own practice, thereby ameliorating caregiving. Modern medicine expects acceptance of a diagnosis to be linear, but the reality is that there are ebbs and flows in acceptance. "An individual's readiness for change" can fluctuate throughout the healing process, and tailoring therapy at each stage of rehabilitation can only be done through eliciting the patient's narrative throughout the treatment. In *The Diving Bell and the Butterfly*, Bauby also experiences these fluctuations of acceptance. While he had been optimistic about his ability to communicate and had used imagined experiences to better experience his body, when he plays hangman with his son, his disgust at himself is renewed:

> Comment le dire? Est-ce monstrueux, inique, dégueulasse ou horrible ? Tout d’un coup, j’en crève. Les larmes affluent et de ma gorge s’échappe un spasme rauque qui fait tressaillir Théophile. N’aie pas peur, petit bonhomme, je t’aime. Toujours dans son pendu, il achève la partie. Encore deux lettres, il a gagné et j’ai perdu. Sur un coin de cahier il finit de dessiner la potence, la corde, et le supplicié. (77)

> There are no words to express it. Is my condition monstrous, iniquitous, revolting, or horrible? Suddenly I can take no more. Tears well and my throat emits a hoarse rattle that startles Théophile. Don't be scared, little man. I love you. Still engrossed in the game, he moves in for the kill. Two more letters: he has won and I have lost. On a corner of the page he completes his drawing of the gallows, the rope, and the condemned man. (71-72) [modified translation]

Bauby is unable to interact with his son beyond eyeblinks, and he laments the fact that he can no longer show physical affection like he had before. When he writes “j’en crève,” which is better translated to “it kills me” in order to carry the same connotation as the French, he is expressing strong revulsion at his condition. He also writes that Théophile draws “the condemned man,” which explicitly refers to the drawing on the paper but implicitly refers to Bauby. That is, he feels like he is condemned to not being able to express his love for his children, and his condition becomes an obstruction. While he had previously been optimistic, he becomes deeply saddened in this scene, showing the nonlinear nature of healing.

The humanities in clinical practice, though often unappreciated, has many practical implications, as stated by author and physician Frank Huyler:

> One answer is that the humanities, like science, are a tool. The humanities, broadly and imperfectly defined as they may be, nonetheless concede what the sciences resist—that we are irrational creatures much, if not all, of the time. Our collective values and beliefs may be eroded by evidence, but they are rarely overturned by it. […] In other words, studying the humanities in medicine is not about indulging in sentimentality, in earnest appeals for empathy that is often impossible to achieve. It's not about making doctors nicer, although few will complain if that happens. Instead, studying the humanities in medicine is about helping doctors and medical students become more aware, more insightful, more reflective, and— ultimately—more influential in shaping the trajectory of health care. […] And, finally, it is about providing an outlet for both emotional engagement and self-reflection in a culture that typically denies both, looks outward rather than inward, and too often ignores not only the personal costs but also the personal rewards of medical work. (Huyler 2013, 919)

Therefore, we cannot neglect the involvement of humanities in medical practice. As exemplified in *The Diving Bell and the Butterfly,* the humanities can act as a tool insofar as the memoir itself has a prosthetic dimension. The memoir is an extension of Bauby and serves as a healing device. Often considered merely to be a mechanism to enhance empathy, the humanities also bring self-reflection that engages healthcare providers in understanding the patient, thereby modifying clinical practice to align best with the patient’s needs. As demonstrated in *The Diving Bell and the Butterfly*, caregiving involves interacting with a patient in such a way that he or she may heal, not only on the corporeal level but also on the metaphysical. The patient is more than solely a body to be attended to, and use of a variety of caregiving techniques allows the patient to heal in a holistic sense.

In conclusion, *The Diving Bell and the Butterfly* is a memoir that highlights the importance of attentive caregiving. The ability to interact with Bauby in such a way as to promote his autonomy and to help him come to terms with his new body plays a crucial role in his recovery. By regarding his body as a lived body rather than simply a mechanical one, healthcare providers maintain his personhood. The memoir rejects the Cartesian notion of Locked-in Syndrome being the ultimate separation of the mind from the body, and Bauby’s experiences demonstrate that he has a lived body that serves to help him come to terms with his new state of being. Through his imagination, he constructs scenarios that allow him to heal, sometimes by creating votive images and other times by pure imagination, as is the case with his interactions with the Empress. The critical role of caregiving in rehabilitation of Bauby’s overall wellbeing serves to illustrate that attention to factors other than the corporeal impact health in every regard to one’s wellbeing. Therefore, it is imperative that caregivers consider every aspect of a patient’s life because it is at the juncture of the physical and the metaphysical that true healing takes place.

Bibliography

Bauby, Jean-Dominique. *The Diving Bell and the Butterfly.* Translated by Jeremy Leggatt. Vintage, 1998.

Bauby, Jean-Dominique. *Le Scaphandre et le Papillon.* Éditions Robert Laffont, 2007.

Berman, Jeffrey. *Dying in Character: Memoirs on the End of Life.* University of Massachusetts Press, 2013.

Blanton, Sarah, et al. “Family-Centered Care During Constraint-Induced Therapy After Chronic Stroke: A Feasibility Study.” *Rehabilitation Nursing,* vol. 00, no. 0, 2018, pp. 1-9.

Boyle, Claire. “Le Scaphandre et Le Papillon: Autopathography, the Locked-in Self, and Schnabel’s Cinema of Embodiment.” *L’Esprit Créateur,* vol. 56, no. 2, 2016, pp. 93-107.

Bruno, Marie-Aurélie et al. “A Survey on Self-Assessed Well-Being in a Cohort of Chronic Locked-in Syndrome Patients: Happy Majority, Miserable Minority.” *BMJ Open*, vol. 1, no. 1, 2011, pp. 1-9.

Bruyère, Vincent. *Perishability Fatigue: Forays into Environmental Loss and Decay.* Columbia University Press, 2018.

Canguilhem, Georges. *Ecrits sur la medicine.* Le Seuil, 2002.

Canguilhem, Georges. *Writings on Medicine.* Translated by Stefanos Geroulanos and Todd Meyers, Fordham University Press, 2012.

Charon, Rita. “Narrative Medicine: A Model for Empathy, Reflection, Profession, and Trust.” *JAMA*, vol. 286, no. 15, 2001, pp. 1897-1902.

Chestnut, David H. “On the Road to Professionalism.” *Anesthesiology: The Journal of the American Society of Anesthesiologists,* vol. 126, no. 5, 2017, pp. 780-786.

Couser, Thomas G. *Signifying Bodies: Disability in Contemporary Life Writing.* University of Michigan Press, 2009.

Descartes, René. *The Philosophical Writings of Descartes.* Vols. 1 and 2. Translated by John Cottingham, Robert Stoothoff, and Dugald Murdoch. Oxford; Cambridge: Cambridge University Press, 1984.

Didi-Huberman, Georges. "Ex-Voto: Image, Organ, Time." *L'Esprit Créateur,* translated by Gerald Moore, vol. 47, no. 3, 2007, pp. 7-16.

Foucault, Michel. "Technologies of the Self." *Technologies of the Self*, edited by Luther H. Martin, Huck Gutman, and Patrick H. Hutton, University of Massachusetts Press, 1988, pp. 16-49.

Foucault, Michel. "Les techniques de soi." *Dits et Écrits,* translated by Fabienne Durand-Bogaert, vol. 4, Gallimard, 1994, pp. 783-813.

Grant, Joan S., Caralise W. Hunt, and Laura Steadman. "Common Caregiver Issues and Nursing Interventions After a Stroke." *Stroke*, vol. 45, no. 8, 2014, pp. e151-153.

Haan, Joost. 2013. "Locked-in: The syndrome as depicted in literature." *Literature, Neurology, and Neuroscience: Neurological and Psychiatric Disorders,* edited by Stanley Finger, François Boller, and Anne Stiles, *Progress in Brain Research,* vol. 206, 2013, pp. 19–34.

Han, Beth and William E. Haley. "Family Caregiving for Patients With Stroke." *Stroke*, vol. 30, no. 7, 1999, pp. 1478-1485.

Heidt, Sarah J. ""Ça, c'est Moi": The Diving Bell and the Butterfly as Autobiographical Multitext." *Adaptation,* vol. 2, no. 2, 2009, pp. 125-148.

Huyler, Frank. "The Woman in the Mirror: Humanities in Medicine." *Academic Medicine,* vol. 8 8, no. 7, 2001, pp. 918-920.

Jewell, Tess. "Blinding the Screen: Visualizing Disability in Le Scaphandre et le Papillon." *Mosaic: A Journal for the Interdisciplinary Study of Literature,* vol. 46, no. 3, 2013, pp. 109-124.

Karnad, Anand B. "Humanistic Qualities in End-of-Life Care: Lessons from *The Diving Bell and the Butterfly: A Memoir of Life in Death*—Required Reading in an End-of-Life Care Curriculum for Internal Medicine Residents." *Journal of Palliative Medicine,* vol. 2, no. 4, 1999, pp. 411-416.

Katz, Richard T. et al. "Long-Term Survival, Prognosis, and Life-Care Planning for 29 Patients with Chronic Locked-in Syndrome." *Archives of Physical Medicine and Rehabilitation,* vol. 73, no. 5, 1992, pp. 403-408.

Kemp, Simon. "Bergson, Bauby and the Neuroscience of Emotion." *French Studies Bulletin,* vol. 32, no. 121, 2011, pp. 73-76.

Kleinman, Arthur and Peter Benson. "Anthropology in the clinic: The problem of cultural competency and how to fix it." *PloS Med,* vol. 3, no. 10, 2006, pp. 1673-1676.

Kleinman, Arthur. "Caregiving as Moral Experience." *The Lancet*, vol. 380, no. 9853, 2012, pp. 150-151.

Kleinman, Arthur. "Caregiving: The Odyssey of Becoming More Human." *The Lancet*, vol. 373, no. 9660, 2009, pp. 292-293.

Kleinman, Arthur. "On Caregiving." *Harvard Magazine,* 2010. https://harvardmagazine.com/2010/07/on-caregiving.

Krishnan, Shilpa et al. "Needs of Stroke Survivors as Perceived by Their Caregivers: A Scoping Review." *American Journal of Physical Medicine and Rehabilitation,* vol. 96, no. 7, 2017, pp. 487-505.

Le Blanc, Guillaume and Frédéric Worms. "Les nouvelles figures du soin." *Esprit*, 2006, pp. 77-79. Print.

Leder, Drew. "A Tale of Two Bodies: The Cartesian Corpse and the Lived Body." *The Body in Medical Thought and Practice,* edited by Drew Leder, Kluwer Academic Publishers, 1992, pp. 17-35. Print.

Lutz, Barbara J. et al. "The crisis of stroke: experiences of patients and their family caregivers." *Topic in stroke rehabilitation*, vol. 18, no. 6, 2011, pp. 786-797.

Mol, Annemarie. *The Logic of Care: Health and the Problem of Patient Choice.* Routledge, 2008.

Montaigne, Michel de. *Les essais.* Edited by Pierre Villey and Verdun L. Saulnier, Quadrige/PUF, 1988.

Montaigne, Michel de. *The complete works of Montaigne: essays, travel journal, letters.* Translated by Donald M. Frame, Standford University Press, 1967.

Pelaprat, Etienne and Valerie Hartouni. "The Neural Subject in Popular Culture and the End of Life." *Configurations,* vol. 19, no. 3, 2011, pp. 385-406.

Psarra, Evangelia and George Kleftaras. "Adaptation to Physical Disabilities: The Role of Meaning in Life and Depression." *The European Journal of Counselling Psychology,* vol. 2, no. 1, 2013, pp. 79-99.

Raoul, Valerie et al. "Narrating the Unspeakable: Interdisciplinary Readings of Jean-Dominique Bauby's The Diving Bell and the Butterfly." *Literature and Medicine,* vol. 20, no. 2, 2001, pp. 183-208.

Sakellariou, Dikaios. "Creating In/Abilities for Eating." 15 Jun. 2015. *Somatosphere.* Accessed 10 Feb. 2019. <http://somatosphere.net/2015/06/creating-inabilities-for-eating.html>

Sakellariou, Dikaios. “Enacting Varieties of Subjectivity Through Practices of Care: A Story of Living With Motor Neuron Disease.” *Qualitative Health Research,* vol. 26, no. 14, 2016, pp. 1902-1910.

Sakellariou, Dikaios, Gail Boniface, and Paul Brown. “Using Joint Interviews in a Narrative-Based Study on Illness Experiences.” *Qualitative Health Research,* vol. 23, no. 11, 2013, pp. 1563-1570.

Schwartz, Robert S. “The Diving Bell and the Butterfly: A memoir of life in death.” *New England Journal of Medicine,* vol. 339, no. 12, 1998, pp. 856-857.

Stearns, Zachary R., Marissa L. Carvalho, and Morven A. Ross. “Pitfalls and Pearls of Persistent Pain.” *The Journal of Humanities in Rehabilitation,* Emory University, 2018.

Thompson, Hannah. ““De Simple Malade j’étais Devenu Un Handicapé”: Interrogating the Construction of “Disability” in Jean-Dominique Bauby’s Le Scaphandre et Le Papillon.” *L’Esprit Créateur,* vol. 56, no. 2, 2016, pp. 79-92.

Non-Printed Sources

Blanton, Sarah. Personal Interview. 4 Mar 2019.

The Diving Bell and the Butterfly. Directed by Julian Schnabel. Miramax Films, 2007.

Laures-Gore, Jacqueline Sue and Maryanne Weatherill. Voices, Health and Humanities Film Series, 4 Mar 2019, Atlanta, GA. Panel discussion.