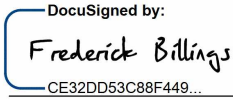
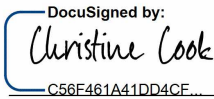



A COMPREHENSIVE REVIEW OF THE LITERATURE SURROUNDING THE
ADOLESCENT EXPERIENCE OF A PARENT'S AMYOTROPHIC LATERAL SCLEROSIS
OR FAMILIAL AMYOTROPHIC LATERAL SCLEROSIS DIAGNOSIS


By

Emily R. Johnson

RECOMMENDED: 
CE32DD53C88F449...
Dr. Frederick Billings


C56F461A41DD4CF...
Dr. Christine Cook


174D4DC2384B4A1...
Dr. Valerie Gifford, Advisory Committee Chair


C56F461A41DD4CF...
Dr. Christine Cook, Chair
School of Education Counseling Program

A Comprehensive Review of the Literature Surrounding the Adolescent Experience of a Parent's
Amyotrophic Lateral Sclerosis or Familial Amyotrophic Lateral Sclerosis Diagnosis

by

Emily R. Johnson

A Graduate Research Project Submitted to the
University of Alaska Fairbanks
In Partial fulfillment of the Requirements of the Degree of
Masters of Education in Counseling

Valerie Gifford, Ph.D.
Frederick J. Billings, Ph.D.
Christine Cook, Ph.D.

University of Alaska Fairbanks
Fairbanks, Alaska
Spring 2016

Abstract

Amyotrophic lateral sclerosis (ALS) is a neuro-muscular disease causing progressive paralysis and eventual death of the patient. Adolescent children who have a parent with ALS or other terminal illnesses have ability to comprehend the course of the disease's processes, death and the suffering of others, which often leads to the teen experiencing existential issues including loneliness, meaninglessness, a lack of personal freedom or responsibility, and a fear of death. The following research paper provides a thorough review of the literature surrounding the effects of a parental ALS diagnosis on adolescent development, existential concerns and grief response. Suggestions for resolving existential concerns and grief are presented. The knowledge gained from the literature review was used to create a web-based resource for adolescent children of ALS patients. The application and product portions of this paper contain a thorough description of the web-based resource, the information it contains, and ways that it can be useful to adolescents and members of their support system.

Table of Contents

	Page
Abstract	2
Table of Contents	3
Introduction	7
Available Resources	8
Purpose of the Literature Review	9
Rationale for an Adolescent Focus with an Existential Approach	9
Amyotrophic Lateral Sclerosis: An Overview	11
Symptoms of ALS	12
Limb-onset	12
Bulbar-onset	13
Epidemiology	13
Etiology	14
Familial ALS (FALS)	15
Special Concerns for Adolescents of ALS/FALS Patients	16
Genetic testing	16
Genetic counseling	17
Cognitive Abilities of Adolescents and Their Reactions to Grief and Loss	18
Current Research on Teens of Cancer Patients	19
Effects of a Long Term Illness of a Parent on an Adolescent	19
Grief Responses of Adolescents	21

Existential Theory: Introduction	22
Existential Principles	23
Existential Anxiety in Adolescents	23
Existential anxiety and adolescent identity	24
Existential Anxiety in Adolescents and ALS/FALS	25
Existential Loneliness	26
Existential Loneliness Experienced by the Parent and Effects on the Teen	27
Adolescent experience of loneliness with a parent's ALS/FALS	28
Combating Existential Loneliness in Adolescents	28
Families who do not communicate	29
Counseling for ALS/FALS	29
Families who communicate	30
Finding Meaning in Life Despite the Darkness of ALS/FALS	31
Lack of Meaning in an ALS/FALS Parent	32
Importance of Meaning in the Life of a Teenager	33
Effects of ALS/FALS on a meaning in life for adolescents	34
Assisting Youth in Creating Meaning in Life Despite ALS/FALS	35
Caregiving for ALS/FALS family members	35
Additional counseling	37
The Freedom and Responsibility to Confront ALS/FALS	38
Freedom and Responsibility of a Person with ALS/FALS	39
Freedom and Responsibility in Adolescents When a Parent has ALS/FALS	41
The Reality of Death	42

An Adolescent's Realization of Death as a Result of a Parent's ALS/FALS	43
Grief and Loss in Adolescents	45
Stages of Grief	46
Stages of grief and loss in teens with parents diagnosed with ALS/FALS	47
Normal Grief Responses	47
Abnormal Grief Responses	48
Interventions for Youth	49
Support from Parents, Adults and Grief Groups	49
Family Therapy	50
Dignity therapy	51
Creating Memories of the Deceased	52
Seeking Professional Assistance	53
Application of the Literature: An ALS/FALS Website	55
Existential Loneliness	56
Finding Meaning	56
Freedom and Responsibility	57
Reality of Death	57
Grief and Loss in Teens	58
Special Considerations for Adolescents of ALS/FALS Patients	58
Distributing the Website	59
Conclusion	59
References	61
Footnotes	70

A Comprehensive Review of the Literature Surrounding the Adolescent Experience of a Parent's Amyotrophic Lateral Sclerosis or Familial Amyotrophic Lateral Sclerosis Diagnosis

The psychological effects of a terminal disease is widespread and a predictable stressor facing communities, families, and individuals. Grief and loss associated with family and community member's passing away as a result of various types of cancer, autoimmune diseases, and illnesses, while predictable and inevitable, pose implications for the mental health of adolescents. In the United States, over two million youth under the age of 18 have experienced the loss of a parent (Christ, Siegel, & Christ, 2002). One such illness that can claim the life of a teen's loved one is Amyotrophic Lateral Sclerosis (ALS). Not only can this terrible disease cause the death of a loved one, but it also has the genetic potential to be passed on to younger generations (Hartzfeld et al., 2015; Pfister et al., 2013; Verma, 2014).

Introduction

ALS is a progressive, degenerative, neuromuscular disease that results from genetic mutations (Marangi & Traynor, 2014; Padhi, Banerjee, Gomes & Banerjee, 2014; Williams, Fitzhenry, Grant, Martyn & Kerr, 2013). The majority of cases are sporadic; however, 5-10% have been found to be passed genetically (Hartzfeld et al., 2015; Li et al., 2015; Pfister et al., 2013; Verma, 2014). Patients are typically diagnosed in adulthood and often succumb to the disease within three to five years (Padhi et al., 2014; Pagnini, Phillips, Bosma, Reece & Langer, 2015; Pfister et al., 2013; Roth-Kauffman & Niebauer, 2012). If the ALS patient has adolescent aged children, their diagnosis may prove to be problematic for the teen's normal development. Research has shown that contrary to common misconceptions, teens do in fact have the cognitive abilities to comprehend death, disease, and the pain and suffering of others (Faulkner & Davey, 2002; Phillips, 2014). A higher cognitive ability often leads adolescents to experience several

negative effects including an increase in struggles with existential concerns such as loneliness, lack of meaning and responsibility, and death anxiety which can affect the development of a normal identity (Berman, Weems & Stickle, 2006; Brassai, Piko, & Steger, 2013; Carlson, 2003; Ens & Bond, 2007; Phillips, 2014; Phillips & Lewis, 2015; Schultz, 2007). Cancer and ALS differ greatly in form; however, for the developing adolescent, the effects of losing a parent over a prolonged period of time are still applicable.

Available Resources

A thorough review of the literature, electronic resource sources and counseling support tools available to support adolescents who have a parent with ALS/FALS revealed limited mental health supports for this population. Resource dedicated to helping adolescents understand ALS and cope with the loss of their loved one to this disease have yet to be created.

Electronically, one blog, “Children of ALS” (2011), allows individuals to share their personal stories of living with a parent who was affected by ALS. “Children of ALS” does not share any grief resources, does not provide research based information regarding the experiences of the parent with the disease, or the effects of the disease on the emotional and cognitive development of the adolescent. Another blog, “ALS forums” (2015), allows individuals to ask and respond to questions about the disease. The authors of this forum discuss ALS/FALS; however, it is not the sole focus as other disorders and diseases are also discussed. This site is not informational, nor is it designed to cater to adolescent development. Furthermore, it does not provide resources for grief and loss. The ALS Association website (2015) provides research-based information on the biological and genetic aspects of the disease, and includes updates on the progress that scientists are making in finding a cure for the illness. While this information may be helpful to teens, this

site is not designed to provide resources specifically to teens who are living with a parent with the disease.

Purpose of the Literature Review

The guiding questions for the research project is based on adolescent development, what do teens experience when facing progressive losses from a parent being diagnosed with ALS/FLAS; how do they understand and experience these losses; and what helps them resolve the associated grief and loss? Therefore, the purpose of this research project is to (1) provide a comprehensive review of the literature surrounding existential issues created in an adolescent when their parent is diagnosed with a terminal illness, (2) discover the effects of the progressive losses and the parent's diagnosis on the teen's cognitive development, and (3) provide methods that could assist the adolescent in overcoming those issues. An overview of ALS and the cognitive development of adolescents are provided along with descriptions of common reactions to death, grief and loss. An in depth review of the literature provided insight into how a parent's ALS/FALS diagnosis and a teen's cognitive abilities effect the youth's development and mental health. The guiding psychological theory for this project is existentialism, and information will be given regarding how a parental diagnosis affects a teen's existential anxiety in each of the four principles of existential theory: loneliness, meaning, freedom and responsibility, and a realization of death.

Rationale for an Adolescent Focus with an Existential Approach

According to Piaget's theory of cognitive development, children enter the final stage of development, the formal operations stage, and acquire the ability to think abstractly between the ages of 11 and 12 (Parke & Gauvain, 2009). This change in cognitive ability allows for children to understand a world that is not confined in reality, create "ideal" circumstances, and consider

several possible solutions to problems (Parke & Gauvain, 2009; Santrock, 2014). They also begin to develop ideas for their future and create meaning, and they are able to think logically (Santrock, 2014). Simultaneously, according to Erickson, teens are also attempting to determine how they will live their lives, establish their goals, formulate their purpose, and further develop their identity (Berman et al., 2012; Santrock, 2014). If adolescents are able to explore their roles in a healthy way and create their own identity, they will create appropriate identities and live healthy lives (Santrock, 2014).

Teens have been found to have the cognitive abilities to be able to consider their purpose in life and understand death (Parke & Guavain, 2009; Santrock, 2014). Prior to this stage of development, children are not able to consider existential meaning, loneliness, freedom and responsibility or a fear of death because they cannot think abstractly (Santrock, 2014). Similarly, unlike younger children, teens are cognitively developed enough to begin creating a purpose and identity for themselves, which may lead to existential crises such as a sense of meaninglessness or a fear of death (Santrock, 2014). If, for some reason, a teen is unable to create a healthy identity, they will be at a greater risk for identity confusion which can potentially have negative consequences later in life (Berman et al., 2006; Brassai, Piko & Steger, 2012; Santrock, 2014). A terminal illness such as ALS/FALS, of a parent can affect this process (Garrow & Walker, 2001; Spillers, 2007). Consequently, this project focuses on adolescents due to their heightened risk for the emergence of problems in adulthood that stem from an unresolved existential crisis negatively affecting healthy development during this critical period as a result of losing a parent to ALS/FALS.

The research is used as a foundation for the creation an electronic, web-based resource for adolescents, their healthy parents, and other adults in the community who are working with

adolescents facing these issues. The website provides developmentally appropriate information about ALS/FALS, the existential anxiety felt by both the adolescents and terminally ill parent, as well as resources and suggestions to manage and cope with four main existential issues and the grief and loss felt before and after their parent dies.

Existential theory has four main principles that are realities all individuals will face: loneliness, meaninglessness, freedom and responsibility, and a realization of death (Albinsson & Strang, 2003; Frankel, 2006; Garrow & Walker, 2001; Spillers, 2007). Individuals who experience existential anxiety, typically do so in one of these four areas as they are some of the common issues involved in human life. These concerns usually arise around the age of 13, and if not addressed may lead to negative consequences later in life (Berman et al., 2006). Each principle can bring about its own struggles which can be exacerbated by the diagnosis of a parent's diagnosis of ALS/FALS.

Amyotrophic Lateral Sclerosis: An Overview

ALS, also known as Lou Gehrig's disease, is a degenerative neuromuscular disease in which motor neurons in the brain, spinal cord and motor cortex slowly die (Marangi & Traynor, 2014; Padhi et al., 2014; Williams et al., 2013). As a result of this loss, patients experience progressive paralysis; dysphonia, a difficulty to speak; and dysphagia, a difficulty swallowing (Padhi et al., 2014; Yu et al., 2014; Williams et al., 2013). ALS is considered to be a terminal illness. Patients usually suffer from respiratory failure caused by an inability to control and move muscles in the diaphragm and chest wall, which eventually causes patients to succumb to suffocation (Pagnini et al., 2015; Yu et al., 2014; Williams et al., 2013). While the majority of cases are considered to be sporadic in nature, research has found that a small percentage of cases are inherited genetically (Hartzfeld et al., 2015; Li et al., 2015; Pfister et al., 2013; Verma, 2014;

Yu et al., 2014). Currently, there is no cure for the disease. One pharmaceutical, Riluzole, has been proven to slow the symptoms and prolong life in individuals with ALS; however, it does not reverse the symptoms, and it only extends life by a few months (Padhi et al., 2014; Li et al., 2015; Roth-Kauffman & Niebauer, 2012; Williams et al., 2013).

Symptoms of ALS

Not all ALS cases will present the same. The disease typically begins to show symptoms in one of two ways, limb or bulbar (Roth-Kauffman & Niebauer, 2012; Williams et al., 2013).

Limb onset is more common than bulbar and accounts for almost 75% of all cases (Roth-Kauffman & Niebauer, 2012; Williams et al., 2013).

Limb-onset. Limb-onset of ALS is characterized by weakness developing primarily in the hands, arms, feet, or legs (Roth-Kauffman & Niebauer, 2012; Williams et al., 2013). Early symptoms may include frequent tripping or falling, muscle spasms, difficulty performing normal daily activities such as writing, climbing stairs, or standing up from a chair, stiffness, slowness, and a lack of coordination (Roth-Kauffman & Niebauer, 2012). Patients typically note that weakness begins in one hand, arm, leg, or foot (Roth-Kauffman & Niebauer, 2012). This initial weakness is followed by a loss of strength and control in the rest of the extremities and complete immobility (Pagnini et al., 2015; Roth-Kauffman & Niebauer, 2012). Immobility is followed by a weakening of the bulbar muscles, which leads to dysphagia, dysarthria, and eventually respiratory failure (Pagnini et al., 2015; Roth-Kauffman & Niebauer, 2012; Williams et al., 2013; Yu et al., 2014).

The average life span from diagnosis to death of a patient with limb-onset ALS is three to five years (Padhi et al., 2014; Pagnini et al., 2015; Pfister et al., 2013; Roth-Kauffman & Niebauer, 2012). The average age of onset for this form of ALS is between 55 and 65 (Pagnini

et al., 2015; Roth-Kauffman & Niebauer, 2012; Turner et al., 2010). Limb-onset ALS/FALS occurs in roughly two-thirds of patients (Cistaro et al., 2012).

Bulbar-onset. The second type of ALS onset is bulbar-onset. Instead of beginning in the extremities and moving towards the facial muscles, the degeneration of motor neurons begins in the bulbar region with the facial muscles (Roth-Kauffman & Niebauer, 2012). Patients typically notice a difficulty talking and swallowing initially (Roth-Kauffman & Niebauer, 2012; Williams et al., 2013). As the disease progresses, an inability to fully close the eyes and mouth, tongue weakness, slurred speech, and drooling is reported (Roth-Kauffman & Niebauer, 2012; Williams et al., 2013). With bulbar-onset ALS, there is a heightened risk for choking as chewing and swallowing food becomes progressively more difficult (Roth-Kauffman & Niebauer, 2012). As with limb-onset, patients with bulbar-onset eventually succumb to respiratory failure as they lose control of their diaphragm and chest muscles (Roth-Kauffman & Niebauer, 2012; Williams et al., 2013). The average age of onset of this form of ALS is 68 (Roth-Kauffman & Niebauer, 2012).

In general, the progression of bulbar-onset ALS is much quicker than limb-onset (Turner et al., 2010; Williams et al., 2013). The average prognosis is 33 months, although some patients have lived longer than four years (Turner et al., 2010). Research has found that 50% of patients with bulbar-onset who lose ambulatory function, will typically reach respiratory failure within three months of becoming immobile (Turner et al., 2010). Roughly one third of patients will develop bulbar-onset symptoms (Cistaro et al., 2012).

Epidemiology

Roughly 1.5 to 2.7 per 100,000 people are diagnosed with ALS in North America (Roth-Kauffman & Niebauer, 2012). Around the world, the prevalence rate is between two and nine individuals per 100,000 (Yu et al., 2014). While the disease can affect individuals at any age, it

most commonly develops between the ages of 55 and 65 (Roth-Kauffman & Niebauer, 2012; Williams et al., 2013). The disease has not been found to differentiate across cultures, and there is no difference between genders in the familial form (Roth-Kauffman & Niebauer, 2012). When the disease is sporadic however, it tends to affect males one and a half times more than females (Roth-Kauffman & Niebauer, 2012). Trends within the United States have found an increase of incidence with advanced age (Williams et al., 2013).

Etiology

For the most part, the cause of ALS remains unknown. Currently, there are no environmental factors that have been found to consistently cause ALS. Proposed risk factors for the development of the disease include physical trauma, exposure to solvents and metal vapors, and head injury (Pfister et al., 2013). However, there is not conclusive evidence dictating whether these environmental factors cause or put individuals at a higher risk for ALS (Pfister et al., 2013). Similarly, smoking, exercise, exposure to metals, fertilizers, pesticides, or formaldehyde and living next to industry or sewage treatment plants have been linked to several case studies, but the research is still inconclusive (Yu et al., 2014).

Although the research surrounding environmental factors remains inconclusive, researchers have confirmed that when certain genes mutate, motor neurons will begin to progressively degenerate, thus leading to ALS (Hartzfeld et al., 2015; Li et al., 2015; Padhi et al., 2014; Pfister et al., 2013; Verma, 2014). However, the cause of that mutation remains unknown (Wu et al., 2012; Yu et al., 2014). Trends have shown two ways in which the disease can emerge. The majority of ALS cases are sporadic. On average, 90% - 95% of all individuals who develop the disease are the only one in their family to do so (Hartzfeld et al., 2015; Li et al., 2015; Pfister

et al., 2013; Verma, 2014). However, roughly 5% - 10% of all cases are inherited (Hartefeld et al., 2015; Li et al., 2015; Pfister et al., 2013; Verma, 2014).

Familial ALS (FALS). In one study, Fang and colleagues (2009) examined the cause of death of children of roughly 6,671 patients who developed sporadic ALS in Sweden. Their results found that the children of these patients were 10 times more likely to develop the disease when compared to individuals not related to a sporadic ALS patient. It was noted that the younger the patient was when they were diagnosed with a sporadic case, the higher the risk the patient had of the case becoming familial (Fang et al., 2009). The average age of onset of the original ALS patient was 66, while the average age of onset for siblings was 57, and 54 for the children of the sporadic ALS patients. This data is consistent with other studies that also show that FALS has an earlier age of onset when ALS is inherited (Hartefeld et al., 2015; Roth-Kauffman & Niebauer, 2012).

Familial ALS occurs when two or more individuals in the same blood line develop the disease (Hartefeld et al., 2015; Pfister et al., 2013; Verma, 2014). Mutations in the SOD1, C9orf72, TDP-43, FUS/TLS, matrin 3, and angiogenin genes have been found in patients with FALS as well as Sporadic ALS (Li et al., 2015).¹ Currently, in the inherited cases, between 15-20% of all cases are linked to SOD1 mutations and roughly 40% are attributed to mutations in the C9orf72 gene (Li et al., 2015). The mutation of these genes has been found to be both autosomal dominant and autosomal recessive; yet in familial cases, it is most often autosomal dominant (Fang et al., 2009; Hartefeld, 2014; Pfister et al., 2013; Vucic, Nicholson, Chio, & Kierman, 2013). The development of the disease may not occur in all family members, and may even skip generations (Fang et al., 2009). However, because FALS is typically autosomal

dominant, there is a 50% chance that a parent with FALS could pass on the mutation to their children (Hartzfeld, 2014).

Special Concerns for Adolescents of ALS/FALS Patients

ALS has the potential of becoming a genetically transmitted disease (Fang et al., 2009). Although roughly 90% of all cases of ALS are sporadic, 10% of cases become familial (Hartzfeld, 2014), and research has found that children of sporadic ALS patients are ten times more likely to develop ALS than the general population (Fang et al., 2009). As previously mentioned, in the familial form, adolescents have a 50% chance of inheriting a mutated gene from their parent and developing the disease later in adulthood (Hartzfeld, 2014). Research has shown that children of cancer patients experience a perceived greater risk for developing cancer themselves which often leads to chronic stress and depression (Harris & Zakowsky, 2003).

Genetic testing. Genetic testing may help determine the cause of ALS in the family (Hartzfeld, 2014). However, this testing is typically performed on an individual who has been diagnosed with ALS and only about 50% of individuals with the familial trait will be identified (Hartzfeld, 2014). Researchers have not discovered all of the mutations that could lead to FALS; therefore if an individual has FALS but the genetic test is negative, the patient likely has a mutation that has not been discovered (Chio et al., 2013; Hartzfeld, 2014). Additionally, if a mutation is not discovered, genetic testing of family members would not be useful as the mutated gene causing the symptoms is unknown (Hartzfeld, 2014). If a mutation is discovered the biological family members who have not been diagnosed can be screened to determine if they have also inherited the mutation (Hartzfeld, 2014). Patients should keep in mind that positive test results do not determine the age of onset, symptoms of severity or progression rate (Chio et al., 2013).

Currently, testing adolescents under the age of 18 is not recommended as symptoms or mutations typically do not emerge until later in life (Hartzfeld, 2014). Genetic testing for all known FALS genes in an ALS patient costs roughly \$6,000 and is not typically covered by insurance (Hartzfeld, 2014). Researchers are still discovering genes that when mutated lead to ALS. As a result, results of genetic testing are often uncertain. If families decide to move forward with genetic testing, counseling is often required for subsequent family members to be tested (Hartzfeld, 2014).

Genetic counseling. Genetic counselors assist clients in considering the meaning of a positive or negative results and the risks and impact of the diagnosis (Hartzfeld, 2014). Genetic counselors should include a discussion of the uncertainties of genetic mutations with ALS, the possible presence of multiple mutations and the poor genotype and phenotypic correlation in genes (Chio et al., 2013). Additionally, prior to the test being performed, a psychological interview that discusses the patient's motivations for knowing, expectations, and family dynamics should be completed as well as personality assessments and screeners for depression, suicidal tendency and cognitive function (Chio et al., 2013). Some patients refuse to receive genetic testing for a variety of reasons including a fear of the results, inability to live with the known risk, and a wish to maintain hope (Chio et al., 2013). Similarly, some patients choose to receive testing in order to reduce anxiety, contribute to research, acquire knowledge for the benefit of their children, and to assist in future and reproductive planning (Chio et al., 2013). Positive results could require an individual to live with the knowledge that they may develop ALS in the future, and have the potential to pass the mutation along to their children. Negative results do not necessarily mean that an individual will not still develop the disease (Chio et al., 2013). Serious consideration and thought should take place before deciding to receive testing.

If their parent believes they may have inherited the disease and decides to receive testing the results could yield a number of possibilities. The finding of a genetic mutation still only leaves a 50% chance that an ALS patient's son or daughter will inherit the disease (Hartzfeld, 2014). Similarly, a negative result does not immediately mean that the adolescent will not develop the disease later in life, as the mutation of the parent's gene may not yet be known, or the adolescent may not have inherited the trait (Fang et al., 2009; Hartzfeld, 2014). Adults working with adolescents of ALS/FALS patients should be aware of the stress an adolescent may experience that results from the perception that they are at risk for developing a terminal illness (Harris & Zakowsky, 2003). Additionally, if a parent tests positive for a genetic mutation, a youth should be referred to a genetic counselor before being tested themselves (Hartzfeld, 2014).

Because adolescents of sporadic or familial ALS patients have a higher chance of developing FALS than the general population, this group must cope with the knowledge that they could develop a terminal illness later in life. They may be also simultaneously grieving the loss of loved one. Resources need to be made available to help them understand ALS/FALS as well as the accompanying emotions of grief and loss.

Cognitive Abilities of Adolescents and Their Reactions to Grief and Loss

Adolescence is a period of development that is characterized by change as young individuals begin to strive for and desire independence (Faulkner & Davey, 2002; Phillips, 2014). In addition to their more obvious physical growth, this group also experiences mental developments, which typically provide them with the cognitive capabilities and aptitude for abstract thought (Faulkner & Davey, 2002; Phillips, 2014). Research has shown that with this mental ability, they are able to comprehend the potential future outcomes of terminal diseases such as cancer more so than younger children (Phillips, 2014). It has also been found that

adolescents can understand the physical and emotional pain of another individual and that they have the increased cognitive and empathic capacities that allow them to be conscious of losses (Phillips, 2014).

Current Research on Teens of Cancer Patients

While minimal research is available to help assess how having a parent with ALS/FALS can affect an adolescent, a great deal of information has been found regarding the effects of terminal cancer of a parent on a teen. A diagnosis of terminal cancer of a parent may impede upon a youth's normal development as normal tasks may need to be placed on hold while the parent is receiving care (Phillips, 2014). Youth who are striving for independence and are attempting to form a personal identity are typically trying to pull away from their families (Faulkner & Davey, 2002). Yet if they are simultaneously experiencing the terminal cancer diagnosis of a parent, youth have been found to experience a conflict between the desire to become independent and the knowledge that they are needed by their families at home both physically and emotionally (Faulkner & Davey, 2002). Adolescents are more able to perform household tasks than younger children and are usually more physically capable to care for a parent. Doing so however, may detract from the time they spend with peers and participating in extracurricular activities, both of which support normal development (Faulkner & Davey, 2002; Phillips, 2014).

Effects of a Long Term Terminal Illness of a Parent on an Adolescent

The loss of a parent is one of the most stressful events a child or adolescent can experience in their life (Brent, Melhem, Masten, Porta & Payne, 2012; Gunther, Crandles, Williams & Swain, 1998; Phillips, 2014). In some cases, adolescents will experience the loss of a parent that is quick and not prolonged such as in the case of a terminal, progressive disease like

cancer or ALS/FALS. In these cases, youth react differently. Youth in these situations are considered to be at risk for depression, posttraumatic stress disorder (PTSD), and substance use (Brent et al., 2012). Research also indicates that teens who lose their parents suddenly will experience a lower peer attachment, diminished desire to pursue or continue an education, and a higher sense of hopelessness (Brent et al., 2012). Research indicates that teens who lose a parent suddenly will have negative consequences in adulthood if the grief, loss and trauma are not dealt with (Brent et al., 2012). Youth who do not receive interventions have a higher risk for bipolar disorder, anxiety disorders, depression, behavioral disorders, hopelessness and aggression in adulthood than youth who do receive interventions after a sudden loss (Brent et al., 2012). Bereaved youth who experience a sudden trauma have a very different experience than youth who lose a parent to a long-term terminal illness.

It has been found that teens who lose parents to a long-term illness such as cancer experience similar consequences to those teens who lose a parent suddenly (Gunther et al., 1998; Phillips, 2014). Youth who are losing a parent to a long-term illness have twice the risk of self-injury and higher instances of PTSD than their non-bereaved peers (Phillips, 2014). Because adolescents have the mental capabilities to understand their parent's cancer and the future outcomes, they have been found to experience higher levels of stress and anxiety at the illness of a parent than younger children (Faulkner & Davey, 2002; Phillips, 2014). Adolescents have also reported feelings of anger, despair, and social isolation during the final stages of their parent's illness (Sheehan et al., 2014). While stress levels have been found to be at their highest during the terminal stages of cancer, depression can last up to two years after the parent's death (Phillips, 2014; Sheehan et al., 2014). Research has also found that adolescents feel a sense of

loss prior to their parent dying from cancer. They report a loss of their healthy parent, of both parent's emotional and physical availability, and a loss of normalcy (Phillips, 2014).

Grief Responses of Adolescents

After a parent dies, adolescents have been found to present similar grief reactions to adults including feelings of disbelief, loss and emptiness, disturbed sleep, irritability and feelings of anger towards the deceased (Schultz, 2007). Additionally, adolescents who lose a parent have been found to have significantly higher levels of depression and anxiety in general, as well as higher disturbances in their cognitive and behavioral functioning in adulthood than the rest of the population (Schultz, 2007). Studies have shown that children who are in the process of losing a parent to the Human Immunodeficiency Virus (HIV) or the more advanced Acquired Immunodeficiency Syndrome (AIDS) particularly struggle after their parent is diagnosed. Adolescents of HIV/AIDS infected parents must balance the knowledge that their parent will die, while simultaneously attempting to live a normal life (Gunther et al., 1998; Zhang et al., 2009). The results of the research show that the experience of a loss over time varies greatly from that of a sudden loss.

While terminal cancer is a disease that differs greatly from ALS/FALS, adolescents are still faced with the loss of a parent and the way of life of which they were accustomed to. Phillips and Lewis (2015) interviewed several adolescents who were living with a terminally ill parent about their feelings surrounding their situation. Their study revealed several themes. Participants reported that they felt the weight of the world on their shoulders, which included loneliness, feeling as though their parent's illness would never end and a constant worrying. They also expressed that their parent's illness changed everything. Adolescents claimed that they had no energy, they had to take care of their parent, put up with "a lot", and had a grim outlook on life

(Phillips & Lewis, 2015). In addition, adolescents reported that they tried to not think about the illness, however when they felt they needed to, talking about their situation helped (Phillips & Lewis, 2014).

Teens losing a parent to ALS/FALS may be experiencing thoughts and feelings similar to adolescents who are losing a parent to terminal cancer. Loneliness, meaninglessness, freedom and responsibility, and the realization that all humans will die, are the basic principles of existential theory (Garrow & Walker, 2001; Spillers, 2007). These principles can be utilized as guidelines when assisting adolescents with their current and future grief and loss as well as with other struggles of losing a parent to ALS/FALS.

Existential Theory: Introduction

Existential theory attempts to reframe experiences on an individual level into a universal context (Spillers, 2007). Death, for example, is an inescapable, universal event for all human beings regardless of resources, genetics or personal choices. While it does emphasize the individual experience, this theory is also aimed at showing individuals how their personal life experiences and challenges bring them closer to the fundamental realities of the human condition (Spillers, 2007). The term 'existential' can be used to refer to existence itself, the meaning of that existence, and the desire of an individual to give meaning to their existence or their will to meaning (Frankel, 2006). Frustrations and neuroses occur in an individual when they discover problems in these areas. For example, if a person were to develop concern or despair over the worthwhileness of their life, this concern would be considered an existential distress or frustration (Frankel, 2006). Frustrations typically occur throughout the four principles of the theory.

Existential Principles

The four principles defined by existential theory are realities that humans face; loneliness, meaninglessness, freedom and responsibility, and death (Albinsson & Strang, 2003; Frankel, 2006; Garrow & Walker, 2001; Spillers, 2007). In essence, these principles are utilized to assist individuals by helping them search for their own truth throughout their lives with an open mind (Adams, 2014; Frankel, 2006). While resources in people's life such as family members, friends, or spiritual practices can support them along their journey, they are responsible for giving meaning and a purpose to their life, as well as for their attitudes and reactions to various challenges (Spillers, 2007).

Existential Anxiety in Adolescents

Existential anxiety (EA) is the way in which thoughts of life and death cause fear or concern in an individual (Berman, Weems, & Stickle, 2006; Ens & Bond, 2007). For example, people may experience a loss, and question whether their life has any ultimate importance or purpose (Berman et al., 2006). Similarly, feeling as though there is no, and will never be any, significant importance to existing, as well as a sense of guilt about not living up to personal potential can cause EA (Albinsson & Strang, 2003; Berman et al., 2006). When people are unsure about meaning in life, their choices and attitude, or if they fear death, they experience EA, which can have negative consequences on their physical and mental health including high levels of depression and anxiety as well as a negative view of the self, their future, and the world (Berman et al., 2006).

A common assumption is that adolescents do not experience EA because they do not have the cognitive capabilities and maturity to do so (Berman et al., 2006; Carlson, 2003). As previously noted, it has been found that adolescents do in fact have the cognitive capacity to

comprehend common life issues, have an insight into mortality, and experience other concerns that may lead to other EA such as a lack of meaning (Berman et al., 2006). Research has also found that these concerns begin to arise during adolescence becoming notable around the age of 13, and that fear of death is one of the most commonly reported fears in the age group as a whole (Berman et al., 2006).

Existential anxiety and adolescent identity. Forming a clear and personal identity is one of the most important developmental tasks youth face in adolescence (Berman et al., 2006; Schultz, 2007). The development of an identity is a continuous progress in which people establish personal beliefs about the self and perception of how others view them, and integrates these beliefs with personal values and a life direction (Schultz, 2007). When developing an identity in adolescence, a youth will start to determine their gender role, morals, religious preference, and peer group (Berman et al., 2006). Similarly, life goals and a general sense of direction are established providing the individual with some sort of meaning (Berman et al., 2006; Brassai, Piko & Steger, 2013).

Investigators have found that adolescents who are not actively engaged in forming a personal identity may experience some EA symptoms (Berman et al., 2006; Braassai et al., 2013). When adolescents lose a parent during this process, they will struggle in forming and maintaining their personal identity because they are not able to pause the process while they grieve (Schultz, 2007). The loss of a parent may affect the process as a whole, as parents provide both a guiding relationship and examples of an identity that teens can compare and contrast with their own (Schultz, 2007). Schultz (2007) found that adult women who lost their mothers during adolescence experienced a different perception of themselves before and after the loss, a need to replace the connection that was lost, and reported that death became a realistic

part of their everyday lives. In other words, they experienced an existential loneliness and a realization of death.

Existential Anxiety in Adolescents and ALS/FALS

Existentialism emphasizes individual existence, personal meaning, and a freedom and responsibility held by each individual (Albinsson & Strang, 2003; Frankel, 2006; Spillers, 2007); however, it also recognizes that some aspects of life such as race, family, and gender are uncontrollable (Carlson, 2003). Similarly, some situations in life are unavoidable by the individual. An adolescent has no control over a parent contracting a terminal illness such as ALS/FALS, nor do they have any control over whether or not the disease will be passed to them genetically in the future. This lack of control or knowledge can lead to several anxieties and cause the adolescent to experience an existential crisis. Spillers (2007) found that when experiencing a loss and when realizing that they may be faced with a disorder, adolescents may ask questions such as "...why am I the way that I am? What is the purpose of my life? How am I to live my life?" (p. 191). These questions can be addressed through an individual's search for meaning and resolution of the existential issues that arise while doing so.

Adolescents have the cognitive abilities to understand the eventual outcome of a terminal illness including the losses associated with the parent's illness progression and eventual death (Berman et al., 2006; Keeley, Generous, & Baldwin, 2014; Phillips, 2014). Furthermore, it is this cognitive ability that allows them to experience their own EA concerns (Berman et al., 2006; Carlson, 2003). Additionally, as a result of their EA experiences, teens are subjected to several negative side effects including depression, a lack of personal meaning, anxiety, and an incomplete personal identity that can affect them in adulthood (Berman et al., 2006; Cheng, Hasche, Huang, & Su, 2015; Phillips, 2014; Schultz, 2007). Therefore, it can be concluded that

adolescents may benefit from taking an existential approach to resolving crisis in their lives, such as the terminal illness of a parent, and the associated stages of grief and loss. This approach lends itself well to supporting adolescents through the likely manifestations of loneliness, loss of meaning, death anxiety and death avoidance that tend to result from a parent passing away from a terminal illness (Buxbaum & Brant, 2001; Carlson, 2003; Ens & Bond, 2007; Kubler-Ross & Kessler, 2005; Phillips, 2014; Phillips & Lewis, 2015).

Existential Loneliness

Existential loneliness differs greatly from the normative definition. Loneliness is typically meant as lacking connections or relationships or being socially isolated from other (Spillers, 2007). Instead, existential loneliness refers to a state of being in a physical body that is separate from all other entities (Sand & Strang, 2006; Spillers, 2007). Described as a universal to human existence, individuals recognize their loneliness when they realize that their attitudes, values, and background differ from other individuals (Mayers & Svartberg, 2001). Existential loneliness does not imply a social isolation or disconnection, but instead is a recognition that an individual is a separate entity from all other human beings (Spillers, 2007).

Similarly, this loneliness can be the catalyst that causes individuals to seek company and relationships with others (Albinsson & Strang, 2003; Sand & Strang, 2006). Existential theorists propose that the only certain aspect of life is death (Mayers & Svartberg, 2001). In an effort to escape the idea that humans will all die alone, individuals will attempt to distract themselves with tasks or relationships (Mayers & Svartberg, 2001). When a loss of one of those “distractions” or relationships occurs through either separation or death, loneliness emerges because individuals are reminded that they are separate from every other individual (Mayers & Svartberg, 2001). This loneliness can have an effect on teens of terminally ill parents.

Existential Loneliness Experienced by the Parent and Effects on the Teen

Ozanne, Graneheim and Strang (2012) interviewed several ALS patients in depth. They found that ALS patients suffer from several existential consequences including loneliness as a result of the changes they experience. It is important to note that not all patients will experience existential loneliness; however, this population is at a higher risk than the normal population for doing so (Ozanne et al., 2012). Some patients felt that they are both physically and existentially absent from their family members and the world around them. Simultaneously, patients had an intense fear being alone because they were dependent on their family members as caregivers. Patients reported that these feelings were especially high when they had children because they did not want to leave them when they died. Additionally, patients who came from families who found it difficult to talk to each other about the disease reported more feelings of loneliness. As a result of these feelings, ALS patients would pull away from their family members (Ozanne et al., 2012).

In addition to experiencing loneliness, the parent may also be struggling with grief as a result of the ALS/FALS diagnosis. The parent may be in denial regarding the situation, experience anger and turn it inward for having developed the disease, even though disease development was outside of the parent's control, or become depressed and feel empty (Kubler-Ross & Kessler, 2005). If the parent pulls away and becomes emotionally and physically unavailable to the teenaged child, the teen may experience feelings of grief, loss and loneliness (Buxbaum & Brant, 2001; Kubler-Ross & Kessler, 2005). Being unable to communicate with family members, especially teenage children, could have negative consequences for the parent and adolescent.

Adolescent experience of loneliness with a parent's ALS/FALS. When there is a lack of communication about the terminal illness of a parent or the family's situation itself, research has shown that the adolescent struggles to adjust (Sheehan et al., 2014). Authors note that depression and anxiety rates increase in adolescents who are not told about a parent's illness because they are not able to discuss their feelings. While this lack of communication is not solely the fault of the dying parent or the adolescent, both of whom are likely struggling with their own form of existential loneliness, reestablishing communication is crucial if they are to experience togetherness before the parent succumbs to the disease (Sand & Strang, 2006). The desire to be acknowledged and respected is a basic human need and can benefit both the ill parent and adolescent (Sand & Strang, 2006). A lack of communication about the illness itself or feelings surrounding it could cause family members to feel as though they are not being respected or acknowledged. As previously mentioned, adolescents will understand that something is wrong; however, if they are unable to discuss their feelings, they will experience an increase in anxiety and stress (Phillips, 2014; Sheehan et al., 2014). Additionally, teens will likely be conscious of their parent's physical and emotional pain, yet if they are unable to discuss it they will become distressed (Phillips, 2014). If an adolescent is unable to discuss these feelings and concerns, it will likely lead to existential loneliness. They will be cognitively aware of their parent's condition and prognosis, which will in turn likely make them aware of their own separateness, aloneness, and mortality. These realizations lead to existential loneliness (Spillers, 2007).

Combating Existential Loneliness in Adolescents

Death is seen by some as the event that symbolizes loneliness in all human beings (Sand & Strang, 2006). Death brings to light the inevitable separation from all other individuals and is usually when existential loneliness is felt the strongest (Sand & Strang, 2006). However,

adolescents who experience the death of a parent have reported that they experience loneliness while that parent is still alive (Albinsson & Strang, 2003; Phillips & Lewis, 2015). The teen's experience may be due in part to the loneliness the parent feels as a result of their illness which causes the parent to pull away from their family members and not discuss their personal feelings. It could also stem from the family as a whole not discussing emotions surrounding their situation (Albinsson & Strang, 2003; Ozanne et al., 2012).

Families who do not communicate. Teens who come from families that do not typically discuss their feelings surrounding death or a terminal illness will need an outlet to help them combat their own loneliness and avoid the negative consequences of existential loneliness. Research has shown that talking about feelings surrounding a parent's terminal illness, even if there is not much to say, can be beneficial to adolescents (Phillips & Lewis, 2015). The adolescent's social relations, including surviving family members, friends, and community members can provide support, understanding and warmth (Muselman & Wiggins, 2012). Spending time with and seeking support from others as well as talking about difficult subjects that may not be able to be discussed in the home have been found to be beneficial to adolescents living with a parent with a terminal illness (Phillips & Lewis, 2015). Adolescents have also reported that they found being able to play or participate in normal, enjoyable activities was beneficial as well (Phillips & Lewis, 2015). Adolescents may not be able to obtain support from family members; yet, if they are able to discuss their feelings surrounding death and connect with supportive individuals, they may be able to combat their own loneliness.

Counseling for ALS/FALS. If the adolescent has the resources to seek professional help, counseling has been found to be beneficial in aiding an adolescent by creating a healthy environment in which to handle stress and conflicts (Henderson & Thompson, 2011). Teens who

come from an environment in which a parent has been diagnosed with ALS/FALS, typically experience stress. If they are also in an environment that does not allow them to express their feelings regarding this illness, they will likely experience even more stress, anxiety and existential loneliness. Existential counselors can aid adolescents not only by providing someone to listen to and discuss these feelings with them, but also doing so in a genuine manner, and by giving them an unconditional positive regard and empathy (Byrd & Erford, 2014). Additionally, an existential counselor will assist a teen in becoming attuned to their feelings in the present, being aware of their own existence, enhancing their interpersonal relationships with others and discover a meaning to life (Byrd & Erford, 2014). This specific help may be able to assist an adolescent in combating their own existential loneliness as they are able to become more in touch with their existence, separateness, and meaning to life (Byrd & Erford, 2014).

Families who communicate. Not all families struggle with a lack of communication. If a teen comes from a family that openly discusses feelings and concerns they have the opportunity to avoid some of the anxiety and stress associated with having to remain silent. However, terminally ill parents sometimes feel as though they are not receiving support or respect from their family members (Ozanne et al., 2012) while simultaneously, their adolescent children are becoming aware of their existential loneliness as a loved one dies (Keeley et al., 2014; Mayers & Svartberg, 2001; Sand & Strang, 2006). Therefore, if a family is able to openly communicate about their feelings, it is important that they do so in order to avoid and combat the negative effects of existential loneliness.

Conversations with a dying loved one have proven to be very important to the adolescent's overall ability to cope with the death of a loved one after they have died (Albinsson & Strang, 2003; Keeley & Generous, 2014; Keeley et al., 2014). Through these final

conversations, individuals are able to embrace death and create comfort and support between the dying and surviving family members (Albinsson & Strang, 2003; Keeley et al., 2014). Keeley and colleagues (2014) interviewed 41 adolescents who had lost a loved one and asked them to provide suggestions to other adolescents about their final conversations. Participants recommended every day communication with the parent as a way to provide a sense of normalcy during the end of life transition. Treasuring the conversations with the parent after they had died were also reported to help the participants cope with the loss (Keeley et al., 2014). Some participants suggested spending time with the dying parent in order to avoid feelings of guilt and regret as a result of not doing so. In addition, teens also suggested expressing love for the dying parent through both verbal and nonverbal means. This could include actually telling the dying parent that they loved them, hugging or kissing them, or giving gifts or support. Participants in the study reported that these aspects of the conversations provided them support while the parent was still alive and helped them to adjust to their grief and loss (Keeley et al., 2014).

Being able to communicate about feelings of separateness, concern, and grief are ways in which to help combat existential loneliness. However, communicating within a family is not always an option for adolescents who are losing a parent to ALS/FALS. Resources such as social support, friends, other family members, or professional help have been found to help ease the stress and anxiety of not being able to discuss feelings. Existential counselors can aid an individual in overcoming these difficulties as well.

Finding Meaning in Life despite the Darkness of ALS/FALS

Frankel (2006) wrote that “He who knows the ‘why’ for his existence, will be able to bear almost any how” (p. 101). Existentialism posits that the human desire to find a meaning in life is the factor that motivates individuals to find fulfillment and growth (Frankel, 2006;

Spillers, 2007). Additionally, this driving force to find meaning is unique to each individual and allows for coherence and purpose (Richer & Ezer, 2000). Some theorists believe that when faced with negative circumstances, an individual will survive only if they are able to rise above those circumstances and give their existence a purpose (Carlson, 2003; Frankel, 2006). Existential theory proposes that when faced with challenges in life, individuals are tasked with embracing and accepting those challenges and finding their own personal meaning to their existence (Frankel, 2006; Spillers, 2007; Yalom, 2002). The meaning to existence will vary from person to person and from moment to moment (Frankel, 2006).

Suffering provides an opportunity for individuals to search for a purpose powerful enough for the individual to make sense of life and their situation (Frankel, 2006; Richer & Ezer, 2000). Outside support such as family, friends, and religion may assist an individual in their journey to find meaning; however, the work itself must be done by the individual (Spillers, 2007). Research has shown that those who have a sense of meaning in their lives experience more hopefulness, happiness and overall life satisfaction (Cheng et al., 2015). Conversely, a lack of personal meaning in one's life has shown to lead to several negative mental health issues severe alcoholism, a poor self-image and identity crises (Berman et al., 2006; Brassai et al., 2013; Cheng et al., 2015).

Lack of Meaning in an ALS/FALS Parent

Research has found that terminally ill patients occasionally experience a lack of meaning in their lives (Albinsson & Strang, 2003; Ozanne et al., 2012). Dementia patients for example, have reported a wish to die because they have no personal meaning and no chance to overcome their disease (Albinsson & Strang, 2003). ALS/FALS patients are faced with similar circumstances. Not all ALS/FALS patients will experience a lack of personal meaning; however,

they are at a higher risk than the normal population for doing so (Ozanne et al., 2012). Research has found that ALS/FALS patients struggle to maintain a purpose to their life after diagnosis (Ozanne et al., 2012). Patients report high levels of meaninglessness as well as an inability to find a purpose for life. Some patients will focus on the knowledge that their future is unknown, and therefore feel a sense of hopelessness, a fear of being a burden to family members, and as though there is no point to make any plans or continue relationships (Ozanne et al., 2012). High levels of anxiety and fear have also been reported over uncertainty of time remaining in life and about what the future will hold (Ozanne et al., 2012). As an ALS/FALS patient is struggling to find a meaning in life, their adolescent child may be doing so as well.

Importance of Meaning in the Life of a Teenager

Adolescents begin to construct a personal meaning early in their development and that meaning plays a role in the creation of their identity (Brassai et al, 2012; Brassai et al., 2013; Carlson, 2003). Research supports the positive correlation between a meaning in life and development (Brassai et al., 2012; Brassai et al., 2013; Carlson, 2003; Cheng et al., 2015; Frankel, 2006). Studies have found that teens create a meaning by comparing themselves to others, which then causes them to enhance, improve, and evaluate themselves (Brassai et al., 2013). However, research has also shown that those who fail to create a meaning are more likely to experience a loss of control and substance abuse in adulthood (Brassai et al., 2013; Cheng et al., 2015). In general, when an individual meaning in life is created in adolescence, the individual has been found to have a positive quality of life, psychological well-being, and fewer negative psychosomatic symptoms (Brassai et al., 2012; Brassai et al., 2013; Cheng et al., 2015; Frankel, 2006; Yalom, 2002).

Effects of ALS/FALS on a meaning in life for adolescents. As previously mentioned, adolescence is a key time for producing normal development. If a parent contracts a terminal illness like ALS/FAS, the teen is more likely to spend time at home because they are able to accept and perform household responsibilities such as completing chores, assisting in childcare and acting as caregiver, which in turn takes time away from their social interactions (Phillips, 2014; Zhang et al., 2009). This may affect a teen's development of a meaning as they are unable to compare and contrast themselves with friends and make change for a positive, personal meaning (Brassi et al., 2013).

Research has also found that the youth's parents play a key role in the development of meaning (Brassai et al., 2013). Parental support, or the amount the adolescent feels encouraged or appreciated has been found to have a positive effect on both male and female teens (Brassi et al., 2013). Parental warmth and involvement has been found to be positive in the formation of a meaning in both males and females as well, and especially so for girls when the father is being responsive (Brassi et al., 2013). Conversely, paternal demandingness for maturity, extreme control and over supervision have all been found to negatively affect the development of a meaning in girls (Brassi et al., 2013). This information is important for several reasons. If a parent of an adolescent is suffering from ALS/FALS, they may seek to maintain their own sense of meaning by attempting to overexert control over their families (Ozanne et al., 2012). This type of behavior by the parent will likely be seen as being over demanding by the adolescent and affect their ability to create meaning (Brassi et al., 2013). Conversely, they may attempt to pull away from their family members and isolate themselves as a result of their guilt and shame derived from their physical disabilities and need for dependence on others (Ozanne et al., 2012).

This may appear to the adolescent to be a lack of support which can also affect how they develop a personal meaning (Brassi et al., 2013).

The effects of a diagnosis of ALS/FALS of a parent can have an effect on both the parent's and their adolescent child's meaning of life. Because this is such a crucial time period for youth, they may need assistance in creating a meaning. There are a few ways in which to provide help to adolescents.

Assisting Youth in Creating Meaning in Life Despite ALS/FALS

There are several ways that youth can work to continue developing meaning in their lives despite living with a parent of ALS/FALS or losing them. As previously mentioned, spending time with friends and peers and learning from them can aid an adolescent in maintaining meaning (Brassai et al., 2013; Zheng et al., 2009). Unfortunately, research has found that if family members of a terminally ill individual attempt to ignore their situation, feelings of meaninglessness will deepen (Albinsson & Strang, 2003; Sand, Olsson & Strang, 2010; Weisser, Bristowe & Jackson, 2015).

Caregiving for ALS/FALS family members. Weisser and colleagues (2015) interviewed adults who chose to act as caregivers of family members who had contracted ALS and other motor neuron diseases. Participants reported that if they attempted to ignore their family member's situation, they experienced feelings of guilt for not helping their loved one. Conversely, if they chose to care for their family member, participants reported being able to build relationships with their loved one, felt as though they were able to live in the moment and enjoy life more, and considered the experience to be rewarding. The benefits of being a caregiver to their ALS patient was considered to outweigh the negative consequences (Weisser et al., 2015).

Other researchers have looked at family caregivers of patients with other terminal illnesses. Sand et al., (2010) interviewed family members of terminally ill cancer patients in palliative home care setting to discover their motives for caring for their dying loved ones, approximately one third of which were children of the dying individual (Sand et al., 2010). Participants reported that caring for their family member allowed them to maintain meaning in their lives. They explained that when faced with the impending loss of a loved one, meaninglessness stemmed from threats of unfairness and the disintegration of their family. The dying loved one's body, their family unit, autonomy, and basic beliefs about life were realized as being taken for granted, and the loss of them was astoundingly unfair. However, the majority of participants realized that if they were to confront the challenges placed before them that they would need to take responsibility to find meaning in their situation (Sand et al., 2010).

In an effort to maintain a sense of meaning, participants chose to spend time with their dying loved one and give back to them. In doing so they were able to provide comfort by maintaining daily routines and hope. They explained that by spending time with their loved one they enforced both a sense of togetherness and their personal relationships with the dying. They also reported personal growth as they had an opportunity to confront their own fears of death (Sand et al., 2010). Research on family members of dementia patients have yielded similar results. Meaningless in the adult children of the patient was combated through memories, daily routines, responsibility and relationships (Albinsson & Strang, 2003).

Researchers have found that by caring for their dying loved one, family members put themselves at risk for reactions such as stress, anger, sadness and pain that were difficult to cope with (Albinsson & Strang, 2003; Sand et al., 2010). However it was also noted that if they were unable to spend time with their loved one regularly, whether it be as a result of work, school, or

not living nearby or not wanting to, they experienced shame, guilt and a strong sense of meaninglessness that infiltrated their entire existence (Albinsson & Strang, 2003; Sand et al., 2010; Weisser et al., 2015). Participants reported that by countering their negative feelings and fears of death with feelings and tasks that represented and maintained life such as hope, dignity and joy, they were able establish and maintain a personal meaning despite the losses they were experiencing (Albinsson & Strang, 2003; Sand et al., 2010; Weisser et al., 2015).

Currently, there is no information on adolescent caregivers who are losing a parent to ALS/FALS specifically. However, adolescents who are losing a parent to ALS/FALS may be able to find meaning in caring for and spending time with their dying parent. Their relationships and sense of family togetherness may strengthen if they assist their ill parent (Albinsson & Strang, 2003; Sand et al., 2010; Weisser et al., 2015). Similarly, they can find hope in providing a normal setting for their loved ones and may find meaning in giving back to their loved one (Albinsson & Strang, 2003; Sand et al., 2010; Weisser et al., 2015).

Additional counseling. While options such as spending time with friends or peers, learning from a healthy parent or caring for a dying loved one may help an adolescent create and maintain meaning in life, they may need additional help. Counseling can also assist a teen find meaning (Frankel, 2006; Spillers, 2007). Existential counselors can listen and be present with the client and refrain from administering judgement on a teen (Spillers, 2007). An adolescent who is losing a parent to ALS/FALS may be struggling with several feelings such as shame, guilt and meaninglessness that stem from helping the dying parent or a similar reaction that comes with the stress of assisting a dying parent (Albinsson & Strang, 2003; Sand et al., 2010). Existential counselors can also assist adolescents in coping with the unfairness of their situation (Spillers,

2007). There are many ways in which a teen can combat feelings of meaninglessness. The responsibility to do so, lies with the youth.

The Freedom and Responsibility to Confront ALS/FALS

Existential theory proposes that each and every human being has a certain amount of freedom to construct their own reality, shape their lives how they please, and fulfill the destiny that they have chosen for themselves (Spillers, 2007). According to Yalom (2002) individuals create and shape themselves through their choices, actions, and failures to act. This is an unavoidable freedom and responsibility (Yalom, 2002). Similarly, existentialism gives each individual a responsibility to feel, think, and believe as they so choose, and to shoulder the responsibility for those beliefs (Frankel, 2006; Spillers, 2007). Individuals are forced to make choices in everyday life about things as minute as what to eat for breakfast, and as life-changing as where to live or whether to care for a dying loved one. These decisions are the individual's to make and they must take responsibility for them (Frankel, 2006; Sand et al., 2010). In some situations, life presents individuals with challenges and forces them to choose how they will react. These challenges give rise to the need for the individual to determine what matters most, and therefore help the individual to discover meaning (Frankel, 2006; Sand et al., 2010).

Existentialism does not imply that individuals are at fault for the challenges or struggles that happen to them as many life events are outside of one's control (Frankel, 2006; Spillers, 2007). While they are not held responsible for what happens, they are accountable for the reactions and attitudes that they have towards these negative circumstances (Frankel, 2006; Spillers, 2007). Negative reactions or attitudes to an undesirable situation often contribute to the individual's own suffering (Frankel, 2006; Spillers, 2007). For example, if an individual is faced with a negative situation and decides that they will blame others, they will likely wait for

someone else to rescue them, therefore becoming a spectator to their own problems (Spillers, 2007). Responsibility for one's attitudes, reactions, and decisions is critical in any type of change (Frankel; 2006; Spillers, 2007; Yalom, 2002).

Freedom and Responsibility of a Person with ALS/FALS

ALS/FALS currently has no cure (Li et al., 2015; Padhi et al., 2014; Roth-Kauffman & Niebauer, 2012). It is a slowly progressing neuromuscular disease that leaves the patient unwillingly dependent on others for survival (Ozanne et al., 2012). Therefore, it is not surprising that patients experience a lack of meaning in life and withdraw from their family and friends (Ozanne et al., 2012). Although existentialism does not blame the individual for the challenges that they must face in life, ALS/FALS patients have been found to experience feelings of guilt, shame, meaninglessness and loss, anxiety over death, and a lack of control in areas of everyday life (Ozanne et al., 2012). Additionally, patients have been found to experience a loss of religious belief, hopelessness because there is no cure, and feelings of bitterness and unfairness about their situation (Ozanne et al., 2012). Patients suffering from other terminal illnesses have been found to experience similar reactions (Albinsson & Strang, 2003). Dementia patients for example, have been found to experience a lack of hope and meaning and some express a wish to die (Albinsson & Strang, 2003). According to existentialism, individuals have the freedom to respond this way even if it has negatives consequences for those involved (Spillers, 2007). Each individual is different and will place a value on different aspects of life that give them meaning. If an ALS/FALS patient places value on other aspects of life, they may take on the responsibility to change their attitude (Ozanne et al., 2012).

Ozanne et al., (2012) found that despite their diagnosis, physical losses, and feelings of meaninglessness, the 19 ALS patients in their study were able to find a meaning to go on living

life in the time they had left. Researchers credit this change in attitude to a shift in the response that patients gave their situation. Patients explained that their choice to change their attitude and response to their situation despite their limitations and negative outlook stemmed from the meaning, support, happiness and strength they received from their family members and friends, especially their children and grandchildren. Patients reported that by simply being present with their loved ones, they were not accepting the disease, but accepted that they could make their situation they lived in and found happiness and meaning in those moments (Ozanne et al., 2012). Albinsson and Strang (2003) discovered that dementia patients were also able to find meaning in companionship and relationships. Patients recognized that they could either dwell on their anxiety, physical limitations and prognosis, or focus on the things that were most important to them (Albinsson & Strang, 2003; Ozanne et al., 2012). In having the freedom to make that decision, they were responsible for their own reaction to their situation.

The participants in Ozanne et al.'s (2012) study all had similar responses to their diagnosis and situation. It is important to reiterate that not all individuals will be able to find meaning as the feelings of guilt, shame, and the desire to be rescued can be very powerful and they may become spectators to their own situation (Frankel, 2006; Spillers, 2007). In an effort to understand their loved ones situation, teens should recognize that their parent is struggling with more than the physical limitations of the disease. Their parent's withdrawal, bitterness, issues with control, and negative outlook are consequences of their parent's existential struggle and reaction to their diagnosis and prognosis (Ozanne et al., 2012). These reactions and attitudes are not necessarily directed at the teen or other family members. Depending on their parent's values and meaning to life, they may be able continue to find meaning in life (Spillers, 2007).

Freedom and Responsibility in Adolescents When a Parent has ALS/FALS

In a similar way to their parents, youth have the freedom and responsibility to choose their reaction and attitude to uncontrollable situations. When faced with a parent's diagnosis of a terminal illness, youth experience anxiety, stress, shock, anger, irritability and depression (Albinsson & Strang, 2003; Buxbaum & Brant, 2001; Ens & Bond, 2007; Phillips, 2014; Rainville, Dumont, Simard, & Savard, 2012). Additionally, they experience existential meaninglessness and loneliness (Berman et al., 2006; Carlson, 2003; Phillips, 2014; Phillips & Lewis, 2015). Therefore, just as all other individuals have the freedom to control their reactions and attitudes, teens must find a way to do so as well.

Examples of freedom and responsibility can be seen in studies by Weisser et al., (2015), Sand et al., (2010) and Albinsson and Strang (2003) that were previously discussed. Family members of terminally ill patients were faced with a choice of whether or not to provide care to their dying loved ones. By being challenged with the knowledge that someone they loved and who was important to them was going to die, most of them responded by taking on the responsibility to spend time with their loved one and comfort them (Albinsson & Strang, 2003; Sand et al., 2010; Weisser et al., 2015). They made this decision despite the knowledge that they would likely be exposed to stress, pain, sadness and feelings of obligation and exhaustion yet in doing so, were able to protect themselves from negative emotions that would have allowed the fear of death and guilt to take over and threaten their existence (Albinsson & Strang, 2003; Sand et al., 2010; Weisser et al., 2015). Participants reported that if they had made the decision to ignore their situation and preserve other values such as spending time with friends or doing activities they enjoy outside the home, which is entirely within their freedom to do so, that they would have then had to battle feelings of guilt, shame, and loneliness (Albinsson & Strang, 2003;

Sand et al., 2010; Weisser et al., 2015). They chose to respond their situation in a manner that aligned with the meaning they gave to life which included loving and caring for family members as opposed to allowing that meaningless to take over and consume them (Albinsson & Strang, 2003; Sand, Olsson & Strang, 2010; Weisser, Bristowe & Jackson, 2015). Some participants reported that they decided to do what they did in an effort to help themselves as much as their loved ones (Sand et al., 2010).

The decisions described above are one way that teens can react to a parent developing ALS/FALS. As Frankel (2006) stated, “Life ultimately means taking responsibility to find the right answer to its problems and to fulfill the tasks which it constantly sets for each individual. These tasks, and therefore the meaning of life, differ from man to man and from moment to moment” (p. 98). Adolescents have the cognitive ability to understand their situation and, although they are still creating their own personal meaning to life, have the freedom to decide how they will react to their situation (Spillers, 2007). The feelings of meaninglessness, stress, and anxiety can be dealt with by helping and spending time with the dying loved one (Albinsson & Strang, 2003; Sand et al., 2010; Weisser et al., 2015), talking to friends or other family members (Ozanne et al., 2012; Phillips & Lewis, 2015), or by seeking existential counseling (Spillers, 2007; Cheng et al., 2015). Ultimately, it is up to the teen to take that responsibility and help themselves.

The Reality of Death

Death is one of the only guaranteed, obvious, and inescapable aspects of life (Spillers, 2007). According to existential theory however, a realization that death and life are interdependent is essential to discovering meaning in one’s life. (Garrow & Walker, 2001). If an individual is able to recognize that they are not immortal and that they will one day succumb to

death, they are then able to live a more authentic life (Albinsson & Strang, 2003; Ens & Bond, 2007; Garrow & Walker, 2001; Yalom, 2009). Those individuals who avoid a recognition that death is a reality have been found to do so by filling their lives with diversions and distractions, which causes them to self-alienate and experience anxiety related to their death (Spillers, 2007). Yalom (2002) wrote that “though the physicality of death destroys us, the idea of death may save us.” (p. 126). This realization has been found to motivate individuals to recognize their freedom and responsibility to take advantage of the opportunities of life before they encounter death (Albinsson & Strang, 2003; Garrow & Walker, 2001). A fear of death can also interfere with the ability to enjoy life (Yalom, 2009). Instead of seeking pleasure, individual’s attempt to avoid pain and thoughts of death (Yalom, 2009). Several events can lead to anxiety about death including the death of a loved one, contracting a life-threatening illness or experiencing a traumatic event such as being raped, fired, or robbed (Yalom, 2009).

In youth, grief has also been found to cause a greater concern for loved ones and empathy, a strengthening of communication skills, and tighter emotional bonds with others (Ens & Bond, 2007; Keeley & Generous, 2014). Research has found that individuals with a death awareness report not taking life, time, or people for granted; rather, they live in the present, and have priorities and values that allowing them to have meaning (Albinsson & Strang, 2003; Spillers, 2007).

An Adolescent’s Realization of Death as a Result of a Parent’s ALS/FALS

Adolescents recognize that death is permanent and universal early in their development (Berman et al., 2006; Ens & Bond, 2007; Yalom, 2009). Youth experience anxiety and stress about death as well of feelings of loneliness and meaninglessness as a normal part of their development (Berman et al., 2006). While death anxiety has the potential to alter how a youth

experiences life, research has shown that youth who experience the loss of a parent do not show significantly higher levels of death anxiety than youth who are not bereaved (Ens & Bond, 2007). Researchers suggest that teens who experience a familial death learn how to manage their negative emotions associated with death, how to use psychosocial resources, and are able to comprehend death differently, which lowers anxiety levels (Ens & Bond, 2007). Conversely, youth with little or no exposure to death experiences have been found to have higher levels of death anxiety compared to youth who have experienced loss (Ens & Bond, 2007).

Although teens of ALS patients are familiar with death, they may still experience death anxiety. ALS is a disease that progresses slowly, and death anxiety in teens may emerge during the early stages of their parent's illness if the teen has not experienced, previously, the death of a significant person in their lives. Yalom (2009) suggests finding meaning, living without regrets and creating meaningful relationships in order to overcome a fear of death. Utilizing personal freedom and responsibility to live according to priorities and appreciating life is happening instead of "asking why life is happening" has also proven to be helpful (Yalom, 2009).

ALS/FALS is an incurable, slowly progressing, terminal neuromuscular disease (Marangi & Traynor, 2014; Padhi et al., 2014). Patients who contract the disease may only survive one and a half years with bulbar-onset (Turner et al., 2010), or may have as many as five years with limb-onset (Padhi et al., 2014; Pagnini et al., 2015; Pfister et al., 2013; Roth-Kauffman & Niebauer, 2012). Therefore, over an extended period of time, children of ALS/FALS patients are likely to be living with a dying loved one for an extended period of time and are experiencing the gradual loss of normalcy including their parent's physical self, the support that was offered by the parent, and their time with friends (Ens & Bond, 2007). It is possible, that similarly to teens who live with a parent with advanced cancer, teens of ALS/FALS patients find ways in which to manage

their death anxiety and come to grips with the reality of death. Instead of succumbing to self-alienation and the anxiety associated with the realization of death, they become aware of its reality and find meaning in their lives. As a result, youth do not necessarily need assistance with accepting death as a part of life. Rather, they may require resources in handling their grief after their loved one has died.

Grief and Loss in Adolescents

Unfortunately, ALS/FALS is a terminal illness. Eventually, the adolescent will lose the parent to the disease. Research has shown that children and adolescents will react to a loss in similar ways to adults around them (Schultz, 2007; Walters, 2008). However, in the Western world, the majority of cultures still attempt to deny death and avoid the grief associated with it (Spillers, 2007; Walters, 2008). As a result, many individuals grow up sheltered from the pain of a loss (Walters, 2008). While youth of ALS/FALS patients have been found to recognize the reality of death in their home, the world around them may not be ready to accept their grief (Walters, 2008).

Studies have found that the loss of able-bodiedness can produce the same fear, avoidance and realization of death as the actual loss of life (Buxbaum & Brant, 2001; Spillers, 2007). Parents suffering from a disabling, terminal illness may be unable to be physically and emotionally available to adolescents (Buxbaum & Brant, 2001). ALS/FALS patients lose their “old-self” when they lose mobility and ability to function independently. Simultaneously, the parent may be struggling with existential loneliness and a lack of meaning, which may cause them to withdraw from their family members (Ozanne et al., 2012). The “new” parent will take the “old” parent’s place and cause several changes in an adolescent’s life, which may include a lack of physical and emotional support (Buxbaum & Brant, 2001; Spillers, 2007). With this type

of change, the grieving process for the teen of an ALS/FALS parent may begin years before the actual death of their parent. In addition, grief for the future may be felt as well (Spillers, 2007). Following a physical loss, adolescents have been found to grieve a loss of support, a change in living a “normal” situation, and decreased family income (Ens & Bond, 2007).

Stages of Grief

Kubler-Ross and Kessler (2005) discuss several stages of grief and loss that teens may experience after their parent dies. Initially, teens who are losing a parent to a terminal illness may be in the denial stage, and they may move through their life denying that their loved one is going to die. Once the loved one dies; however, teens may continue to experience denial and a disbelief that they will not see their parent again. Once individuals are able to accept the reality of their loss, they move into the second stage and become angry. Individuals may direct their anger at the family member who died or toward themselves for being unable to prevent the death. If individuals are able to recognize and manage their anger, they can overcome these difficult circumstances (Kubler-Ross & Kessler, 2005).

After recognizing feelings of anger, a person may move into the bargaining stage. Before the death, this stage may look like prayer asking for the loved one’s life to be spared. After the loss, this grief process may turn into “what if” statements, which are often accompanied by feelings of guilt. For example, a teen who has lost a parent to ALS may experience guilt and ask, “What if I had spent more time with them before they died?” Similarly, people may attempt to “bargain” away the pain, and they may be willing to try anything to remove feelings of hurt (Kubler-Ross & Kessler, 2005).

After attempting to bargain, individuals typically shift their focus to the present and experience the fourth stage: depression. This stage may feel as though it lasts forever, and it is

characterized by feelings of emptiness, withdrawal, and meaninglessness. This stage is natural. Authors note that the loss of a loved one is very depressing, especially after realizing that they will not come back and will not get better. Depression is often considered to be unhealthy. However, if depression is recognized as part of the healing process and the feelings of sadness and emptiness are used to help explore the loss completely, the depression will eventually ease as the individual gets stronger (Kubler-Ross & Kessler, 2014).

The last stage of grief and loss is acceptance. Instead of being completely “alright” individuals are able to accept their new reality without their loved ones. A person may never be “ok” with the loss of a loved one and will not like the new reality; however, they will learn to live with it. With this realization, individuals are able to begin to heal and adjust, realize that it was the loved one’s time to die, and that life continues to move forward (Kubler-Ross & Kessler, 2005).

Stages of grief and loss in teens with parents diagnosed with ALS/FALS. Teens of ALS/FALS patients are in a unique situation. As they progressively lose aspects of their parent, they may experience the stages of grief and loss multiple times before their parent dies (Buxbaum & Brant, 2001). If feelings of depression, meaninglessness, and loneliness arise, teens will need to overcome them in order to continue with healthy development later in life (Berman et al., 2006; Cheng, Hasche, Huang, & Su, 2015; Phillips, 2014; Schultz, 2007). The stages are important to keep in mind after the final loss of the parent’s life, as well as normal and abnormal grief responses.

Normal Grief Responses

In teens, a ‘normal’ grief response typically includes feelings of sadness, anger, shock, and numbness, emptiness, disbelief, depression, and confusion (Buxbaum & Brant, 2001; Ens &

Bond, 2007; Schultz, 2007). Changes in behavior as a result of a loss may include a lack of interest in school or activities, sleep disturbances, decreased appetite and keeping concerns inside (Buxbaum & Brant, 2001). Additionally, teens may experience difficulty sleeping, hallucinations, changes in study habits and a fear of intimacy (Ens & Bond, 2007). Teens often are under the impression that they are expected to act like adults; however, in the case of a loss they may feel frightened, powerless and dependent which can cause them to act out (Buxbaum & Brant, 2001). Teens may display anger at the loss, which may in turn lead to depression and punishment of the self or others (Buxbaum & Brant, 2001). Feelings of guilt may also lead to withdrawal, depression and poor behavior (Buxbaum & Brant, 2001). These responses may last days or a few weeks (Buxbaum & Brant, 2001).

Abnormal Grief Responses

If these symptoms last more than a few weeks and extend several months, the individual may be experiencing something more serious than a typical grief experience. Major depressive disorder (MDD) occurs when an individual experiences five of the following, daily for more than two weeks: depressed mood, lower levels of interest or pleasure, weight loss, insomnia, fatigue, worthlessness, thoughts or behaviors of suicide or a lower ability to concentrate or think (American Psychological Association, 2013). Dysthymia occurs when a depressed mood occurs for most of the day for more than a year in adolescents (APA, 2013). Along with the depressed mood at least two of the following must be present: poor appetite, insomnia, low energy, low self-esteem, poor concentration, or hopelessness (APA, 2013). The symptoms for both MDD and dysthymia become problematic and affect the individual's normal functioning (APA, 2013). Additionally, if the adolescent develops a fear of death, they may experience negative stress, anxiety and meaninglessness (Ens & Bond, 2007). If interventions are not put in place to assist the

teen with their unresolved grief in adolescence, disturbances may continue into adulthood (Buxbaum & Brant, 2001).

When distinguishing between grief and depression there are several differences to keep in mind. Grief typically involves emptiness and loss; whereas, a depressive episode involves a lack of happiness or pleasure (ALS Association, 2007; APA, 2013). Grief will also decrease over time and slowly present in waves as opposed to daily symptoms (APA, 2013). Unlike MDD or dysthymia, grief and the pain of a loss is often also accompanied with happiness and humor in between waves of sadness (APA, 2013). Additionally, depression disorders may include suicidal thoughts while bereaved individuals will likely only focus on the deceased (APA, 2013).

Interventions for Youth

The loss of a parent often creates a void in the world of a teen that is not easily filled (ALS Association, 2007; Buxbaum & Brant, 2001). When assisting youth in coping with and managing their grief and loss, research provides several suggestions. Open communication with the surviving parent has been found to positively impact the youth's ability to adjust to the loss and changes they have experienced (Buxbaum & Brant, 2001; Keeley et al., 2014; Muselman & Wiggins, 2012). In providing support, the surviving parent should also ensure that the child is aware that they are cared for and knows that they have someone to listen to them (ALS Association, 2007; Buxbaum & Brant, 2001; Muselman & Wiggins, 2012). Providing routine activities, ways to remember the deceased loved ones, and helping teens to feel important and involved has also proven to be beneficial to youth (Muselman & Wiggins, 2012).

Support from Parents, Adults and Grief Groups

If the surviving parent is unavailable to provide support for the teen, other adults may be able to take their place. Nurturing teachers or counselors in a school setting or other individuals

that the adolescent trusts and feels comfortable with can provide significant support to teens when they are outside of the home (Buxbaum & Brant, 2001). Teens need to know they are cared for, have someone to listen to them and to feel that they are important (Muselman & Wiggins, 2012). They may seek this support from individuals outside of the family if their surviving parent is unable to fill this need (Buxbaum & Brant, 2001). Bereavement practices and manifestation of grief may vary within cultures (Hardy-Bougere, 2008). A failure to utilize cultural practices after death may lead to unresolved feelings of loss (Hardy-Bougere, 2008). As a result, teens may benefit by connecting and receiving support from elders, family members, or community members, who are aware of cultural practices surrounding grief and loss, to bolster resiliency and healing within their cultural context.

If the family receives care from hospice, formal grief groups may be available to the child (Buxbaum & Brant, 2001). Additionally, individual or group counseling at school with the school counselor has been found to be a positive intervention for grief (Buxbaum & Brant, 2001). In general, group counseling for the loss of a parent has been found to allow individuals to share their experiences, reduce isolation, utilize an opportunity to express grief, normalize their experience and feelings and increase communication with family members, all of which are positive in assisting bereaved youth (Buxbaum & Brant, 2001; Hung & Rabin, 2009). Grief groups also provide a perceived sense of empathy and a surrogate support system for adolescents who may be lacking support from family members (Hung & Rabin 2009). Social support has proven to promote positive outcomes for bereaved youth (Hung & Rabin, 2009).

Family Therapy

Family therapy assists family members by prioritizing the family unit, helps to enhance communication and works to bring about the family's recognition of the emotional needs of its

individual members (Schuler et al., 2012). If a family is faced with a parent's diagnosis of ALS/FALS and individual members are struggling with overcoming the grief experienced as the ill parent loses physical and emotional availability, family therapy can help members overcome the negative complications of grief (Schuler et al., 2012). Family therapy with members of terminal cancer patients has shown to increase communication, decrease levels of stress and depression, and increased family functioning (Schuler et al., 2012). Family therapy can be administered within a number of theoretical orientations (Schuler et al., 2012). An existential family therapist may be able to assist family members with maintaining meaning, overcoming loneliness, or recognizing personal freedom and responsibility.

Dignity therapy. A more specific form of existential family therapy, that has shown to be beneficial before the ill parent dies, is dignity therapy. Dignity therapy involves the terminally ill patient, and it attempts decrease suffering by maintaining meaning, dignity and purpose (McClement et al., 2007). The sessions are recorded and given to family members after their loved one's death, and research indicates that these recorded sessions have been found to be helpful with overcoming grief and provide a source of comfort (McClement et al., 2007). Dignity therapy assists dying parents with their existential issues by helping them cope with their loneliness, finding meaning, and overcome their fear of death. As a result, pain and suffering is lessened (McClement et al., 2007). Family members and friends may also partake in dignity therapy by providing support and comfort during the therapy sessions (Bentley, O'Connor, Breen, & Kane, 2014). Although these interventions were found to decrease anxiety and depression, the emotional burden of caregiving was not relieved completely but was somewhat lessened (Bentley et al., 2014).

Creating Memories of the Deceased

Research has found that providing a youth with memories or keepsakes of a deceased parent can help them cope with grief and loss in a healthy way (Albinsson & Strang, 2003; Buxbaum & Brant, 2001; Henderson & Thompson, 2011; Hung & Rabin, 2009). An important aspect of the grieving process for children is to maintain a relationship with the lost parent by incorporating positive aspects of the parent into their own self-concept (Henderson & Thompson, 2011; Hung & Rabin, 2009). Creating a memory book or scrapbook with pictures of the deceased can aid the youth in remembering positive memories before the onset of the terminal illness (Buxbaum & Brant, 2001; Henderson & Thompson, 2011; Hung & Rabin, 2009). Studies have found that 60% of adolescents who were at risk for hospitalization from negative effects of their grief such as suicidal ideation, anger, withdrawal or depression were able to avoid being admitted through the use of a memory book (Buxbaum & Brant, 2001). Additionally, having the surviving parent assist the adolescent with memorializing activities such as talking about the deceased or passing on the deceased objects to the adolescent have proven to be helpful as well (Hung & Rabin, 2009). In a similar way, journaling about and writing letters to the deceased have found to be helpful as well (Musleman & Wiggins, 2012).

Another method that has proven helpful to youth attempting to cope with the loss of a parent is to have the dying parent become involved in the process. The dying parent could write letters or journals or record messages for their youth (Buxbaum & Brant, 2001). These could either be given to the youth immediately after the parent dies, or on an important day such as their graduation or wedding day (Buxbaum & Brant, 2001). In these messages, the parent may be able to explain their personal hardships and growth that resulted from their illness. For example, the parent could describe the loneliness and lack of meaning they experienced, how much they

loved their child, or give them advice for their future. These explanations have been found to be healing for adolescents (Buxbaum & Brant, 2001).

Seeking Professional Assistance

Existential counselors can assist adolescents after they have lost a parent. By providing a positive regard, genuineness, and empathy, a counselor could fill the role of a listener and build a relationship with the youth (Byrd & Erford, 2014). The counselor could assist an individual in making sense of the death by finding meaning in all that has happened and to see the positives of the situation (Muselman & Wiggins, 2012). Existential counselors will also focus on love, suffering, anxiety and death, which may assist the youth in becoming self-determining (Byrd & Erford, 2014). Doing so can in turn help them find meaning and allow them to take responsibility for themselves and their reactions (Byrd & Erford, 2014). Counselors can assist youth by encouraging them to be sensitive to their existence, attending to their feelings in the moment and enhancing relationships with loved ones and friends who are still alive (Byrd & Erford, 2014). In the situation of a loss, this may help youth to confront their feelings instead of avoiding them, and to overcome persistent feelings of anger, depression and guilt that may have serious consequences if not addressed (Buxbaum & Brant, 2001).

Some specific techniques that existential counselors may use include role playing, during which the client and therapist may act out different individuals (Byrd & Erford, 2014). Counselors may also use the empty chair technique, during which the client imagines someone they wish to speak with is sitting in the counseling session and can say what they need to and brainstorm different reactions the individual may have (Byrd & Erford, 2014). Spiritual discussions are not uncommon in existential settings and have also been found to assist adolescents in evaluating existence and meaning after a loss (Muselman & Wiggins, 2012).

Counselors can also assist adolescents in art therapy, which includes utilizing music, song lyrics, and creating self-portraits or pictures to overcome a loss (Muselman & Wiggins, 2012).

Existential counselors can provide several specific interventions that can assist an adolescent in overcoming their grief and loss. Frankel (2006) an existential theorist, developed logotherapy, a form of existential counseling that focuses on the meaning of existence and assists clients in finding their own meaning. Frankel believed that in situations with the absolute worst conditions, an individual may find the will to survive if they have a meaning and purpose to their existence, and that finding and fulfilling meaning is the primary motivation in an individual's life (Frankel, 2006). Logotherapy is designed to assist clients in recognizing the formation of vicious-cycles that lead to neuroses, shift their focus from self-centeredness to a larger meaning, and finding that meaning in work, in loving another person (Frankel, 2006). If an individual is struggling to find meaning, logotherapy can be used to remind them of the meaning they have given to their existence (Frankel, 2006). Instead of living without hardships and tension, Frankel proposed that logotherapy attempts to make the individual fully aware of their responsibility to what, for what, or to whom they deem themselves responsible (Frankel, 2006). The more an individual can forget themselves and dedicate their energy to a cause or a loved one, the more they can actualize themselves (Frankel, 2006). Although existential counseling typically works well within cultures because it focuses on universal experiences (Byrd & Erford, 2014), counselors must ensure that they are cultural competent before working with a particular ethnic group. Different ethnic groups may experience grief or loss uniquely and counselors should be prepared to assist in an appropriate way (Cowles, 1996; Hardy-Bougere, 2008).

Application of the Literature: An ALS/FALS Website

ALS/FALS is a disease that leads an individual to slowly lose all voluntary physical control of their body and eventually succumb to suffocation (Marangi & Traynor, 2014; Padhi et al., 2014; Pagnini et al., 2015). In the process, patients are likely to experience existential consequences such as loneliness, death anxiety, a lack of responsibility and sense of freedom, and a loss of meaning (Ozanne et al., 2012). Information from a review of current literature indicates that while the patient is combating these psychological struggles, their adolescent children are also likely to be experiencing similar existential problems that derive from their situation and their own personal development (Berman et al., 2006; Brassai et al., 2013; Carlson, 2003; Ens & Bond, 2007; Phillips & Lewis, 2015; Schultz, 2007; Walters, 2008). Because adolescents have the ability to cognitively understand the implications of ALS/FALS and are simultaneously attempting to develop cognitively and create an identity, adolescents will likely experience an increase in existential problems (Berman et al., 2006; Carlson, 2003; Ens & Bond, 2007; Phillips, 2014). Through combining information about youth development and existential concerns, coping techniques and methods for overcoming grief and loss, an online resource for adolescents was created. (<http://alsforteens.weebly.com/>)

The online resource provides information about ALS/FALS, the different onsets, its etiology and epidemiology, the sporadic versus familial types, and its implications for the patient. The literature review yielded research that supports sharing information with youth about a parent's illness, and it indicates open communication proves to be positive for an adolescent's mental health (Sheehan et al., 2014). Therefore, providing a resource for adolescents to gain knowledge about their situation will assist them in maintaining healthy development.

The online website also discusses existential problems that may arise in the adolescent as a result of their situation. Four tabs lead to information about loneliness, freedom and responsibility, meaning and the reality of death. Within these sections, the adolescents gain insight into the existential problems that their ill parent is facing. Additionally, teens are also provided with explanations for the root of some of their own existential problems and the potential effects on them. The research notes that teens experience existential issues in typical development situations when a parent is not diagnosed with ALS/FALS (Berman et al., 2006; Brassai et al., 2013). Moreover, studies also indicate that existential problems can be exacerbated by the terminal illness of a parent, which can affect a teen's mental health and in turn, normal identity development (Ens & Bond, 2007; Phillips & Lewis, 2015; Sand et al., 2012; Schultz, 2007). Suggestions for overcoming these existential issues are provided in each section.

Existential Loneliness

The section on loneliness defines and provides an explanation of existential loneliness and its effect on teens. Research has shown that communication with both family members and friends along with counseling can assist individuals in overcoming existential loneliness (Keeley et al., 2014; Sand & Strang, 2006; Sheehan et al., 2014). These coping methods will be discussed in an effort to provide teens with methods to manage their loneliness.

Finding Meaning

Information on the importance of giving meaning to life is presented. Youth will learn how a lack of meaning can affect their development, and methods to assist teens in finding meaning are given. Suggestions include spending time with and learning from friends, learning from a healthy parent or adult, assisting in caring for and spending time with their ill parent,

finding a meaningful project or area of work, and seeking professional help from an existential counselor (Brassai et al., 2013; Frankel, 2006; Sand et al., 2010; Zhang et al., 2009).

Freedom and Responsibility

A discussion on freedom and responsibility is provided for teens, which includes information about how attitudes and reactions to uncontrollable situations, such as a parent's illness, can affect a youth's mental health and overall meaning of life. Teens will be informed of their freedom to make their own decisions and to choose their own attitudes and reactions; however, they will also be made aware that their actions will have consequences. Research suggests the importance of teens not ignoring their situation and, instead, encourages that they respond in a way that does not lead them to experience guilt, shame, and death anxiety (Albinsson & Strang, 2003; Sand et al., 2010). The literature posits that a healthy response allows them to discover and enhance their meaning of life. Research has found that caring for and spending time with an ill parent and assisting in caring for them can help teens to recognize their own freedom and responsibility (Sand et al., 2010). This discussion and the various suggestions along with the associated rationales are presented on the website.

Reality of Death

A review of the literature found that within their normal development, teens will often develop death anxiety as they recognize that they, someday, will die (Berman et al., 2006; Ens & Bond, 2007; Spillers, 2007). Youth who experience the death of a parent have been found to have lower levels of death anxiety than non-bereaved youth, and it is suggested that these individuals have learned to use coping methods and psychosocial resources to understand death differently, which in turn, lowers their anxiety (Ens & Bond, 2007). Therefore, research suggests that teens who experience the death of a parent are already aware of death, and they are not at an

increased risk for death anxiety. Based on these findings, information about grief and loss is provided for teens.

Grief and Loss in Teens

In addition to information about existential crises, teens can also find information on grief and loss, and the five stages of grief. The normal grief response in teenagers, which includes difficulty sleeping, sadness, disbelief, anger, confusion, depression, hallucinations, fear of intimacy, and loneliness, will be presented, as well as information about the typical time frame for when these responses may begin. In cases of ALS/FALS, the teen may begin to experience the loss of their parent before they actually die, as the parent will be going through major physical changes. The teen may also begin to grieve the loss of what the future may have held and a loss of support they once received. Research suggests several methods that have proven successful in combating grief and loss including support from adults, the healthy parent, and grief groups as well as creating memories of the deceased and seeking professional assistance. These methods are presented to teens as resources that can be utilized as needed throughout their parent's illness and after their death.

Special Considerations for Adolescents of ALS/FALS Patients

Information is presented on genetic counseling for adolescents of ALS/FALS patients. Although it is not recommended that individuals under the age of 18 obtain genetic testing, youth may have concerns about their chances of inheriting the disease. A review of the literature found that genetic testing for ALS/FALS is not always accurate and that genetic counseling is recommended for any individual who is interested in pursuing testing. This section is solely informational.

Distributing the Website

Upon completion of this project, the website was distributed through several methods. The website was broadcasted through several social media outlets including Facebook, Instagram, and Twitter. In addition, it was distributed to the ALS Association, specifically the Evergreen chapter which supports the most northern area of the Northwest United States, including Alaska, Washington, Idaho, and Montana for possible inclusion on their websites. Lastly, the information was released to the Counselor Education and Supervision Network Listserv (CESNET) for the dissemination to counseling professionals, faculty and the students via their website.

The website provides information about ALS/FALS and existential issues, youth development and coping methods for teens in one resource. This site can assist the youth in handling the feelings associated with their situation. This particular website could also assist the healthy parent or other significant adults in the adolescent's life in understanding the teen's developmental and emotional experiences. The website as a whole reflects the information found by reviewing the literature and provides a comprehensive resource for adolescents experiencing existential problems that result from a parent suffering from ALS/FALS.

Conclusion

The loss of a parent is one of the most stressful events an adolescent will encounter. This literature review has found that if a loss of a parent to a progressive disease such as ALS/FALS occurs at such a crucial time for human development, the adolescent may be at risk for future negative consequences in adulthood. In normal situations, teens are already being confronted by existential issues such as managing their loneliness, recognizing their own freedom and responsibility in life, developing a sense of meaning and understanding the reality of death. If

they are attempting to cope with the diagnosis of ALS/FALS in a parent as well, these issues could be worsened by the knowledge of their parent's prognosis which in turn if not addressed, can lead to negative consequences later in life. The information in this literature review and comprehensive website can be useful to teens as it provides them with easily accessible information about their parent's illness, insight into their own cognitive development and existential issues, as well as resources to help resolve those concerns and cope with their grief and loss.

Frankel (2006) once wrote that "ultimately, man should not ask what the meaning of his life is, but rather he must recognize that it is he who is asked" (p. 131). A teen who is faced with successfully managing the diagnosis of ALS/FALS in their parent and inevitable death of their loved one is ultimately responsible for doing so. They have the freedom to determine what their existence will be (Frankel, 2006; Yalom, 2002). If they decide to alienate themselves, ignore death, and fail to find a purpose for themselves, they are within their right; to do so however, they will suffer the consequences of their decisions. If that youth is able to maintain a healthy attitude, find meaning, overcome their death anxiety and maintain healthy relationships, they will reap the rewards of a positive development and outlook in spite of their situation. By creating a meaning to their existence, adolescents may find peace in knowing they have found a means by which to live despite knowledge that their world will one day fade (Yalom, 2002). A person may find bliss in the face of suffering and desolation by seeking comfort in their loved ones; both real and lost (Frankel, 2006).

References

- Adams, M. (2014). Human development and existential counselling psychology. *Counselling Psychology Review, 29*(2), 34-42.
- Albinsson, L., & Strang, P. (2003). Existential concerns of families of late-stage dementia patients: Questions of freedom, choices, isolation, death, and meaning. *Journal of Palliative Medicine, 6*(3), 225-235. doi: 10.1089/109662103764978470
- ALS Association. (2007). *Loss & grief: A manual to help those living with ALS, their families, and those left behind*. St. Louis, MO: ALS Association.
- ALS Association. (2015) [Website]. Retrieved from <http://www.alsa.org/>
- ALS forums.com. (2015). [Web log comment]. Retrieved from <http://www.alsforums.com/forum/>
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Arlington, VA: Author.
- Bentley, B., O'Connor, M., Breen, L. J., & Kane, R. (2014). Feasibility, acceptability and potential effectiveness of dignity therapy for family carers of people with motor neurone disease. *BMC Palliative Care, 13*(12), 1-15. doi: 10.1186/1472-684x-13-12
- Berman, S. L., Weems, C. F., & Stickle, T. R. (2006). Existential anxiety in adolescents: Prevalence, structure, association with psychological symptoms and identity development. *Journal of Youth and Adolescence, 35*(3), 303-310. doi: 10.1007/s10964-006-9032-y
- Brassai, L., Piko, B. F., & Steger, M. F. (2012). Existential attitudes and eastern European adolescents' problem and health behaviors: Highlighting the role of the search for meaning in life. *The Psychological Record, 62*(4), 719-733.

- Brassai, L., Piko, B. F., & Steger M. F. (2013). Individual and parental factors related to meaning in life among Hungarian minority adolescents from Romania. *International Journal of Psychology, 48*(3), 308-315. doi: 10.1080/00207594.2011.645483
- Brent, D. A., Melhem, N. M., Masten, A. S., Porta, G., & Payne, M. W. (2012). Longitudinal effects of parental bereavement on adolescent developmental competence. *Journal of Clinical Child & Adolescent Psychology, 41*(6), 778-791. doi: 10.1080/15374416.2012.717871
- Buxbaum, L., & Brant, J. M. (2001). When a parent dies from cancer. *Clinical Journal of Oncology, 5*(4), 1-6.
- Byrd, R., & Erford, B. T. (2014). *Applying techniques to common encounters in school counseling: A case-based approach*. Upper Saddle River, NJ: Pearson.
- Carlson, L. A. (2003). Existential theory: The development of meaning should be inherent, authentic intentional act should serve to aid in the understanding of life experience. Helping school counselors attend to youth at risk for violence. *Professional School Counseling, 6*(5), 310-315.
- Cheng, M., Hasche, L., Huang, H., & Su, X. S. (2015). The effectiveness of a meaning-centered psychoeducational group intervention for college students. *Social Behavior and Personality, 43*(5), 741-756. doi: /10.2224/sbp.2014.43.5.741
- Children of ALS. (2011, April, 24). [Web log comment]. Retrieved from <http://childrenofals.blogspot.com/search/label/parents%20with%20ALS>
- Chio, A., Battistini, S., Calvo, A., Caponnetto, C., Conforti, F. L., Corb, M, ... Surbone, A. (2013). Genetic counseling in ALS: Facts, uncertainties and clinical suggestions. *Journal*

- of Neurology, Neurosurgery and Psychiatry*, 85(5), 478-485. doi: 10.1136/jnnp-2013-305546
- Christ, G. H., Siegel, K., & Christ, A. E. (2002). Adolescent grief: "It never really hit me... until it actually happened." *American Medical Association*, 288(10), 1269-1279.
- Cistaro, A., Valentini, M. C., Chio, A., Nobili, F., Valvo, A., Moglia, C... Pagani, M. (2012). Brain hypermetabolism in amyotrophic lateral sclerosis: A FDG PET study in ALS of spinal and bulbar onset. *European Journal of Nuclear Medicine & Molecular imaging*, 39(2), 251-259. doi: 10.1007/s00259-011-1979-6
- Cowles, K. V. (1996). Cultural perspectives of grief: An expanded concept analysis. *Journal of Advanced Nursing*, 23, 287-294.
- Ens, C., & Bond, J. B. (2007). Death anxiety in adolescents: The contributions of bereavement and religiosity. *Omega*, 55(3), 169-184. doi: 10.2190/OM.55.3.a
- Fang, F., Kamel, F., Lichtenstein, P., Bellocco, R., Sparen, P., Sandler, D., & Ye, W. (2009). Familial aggregation of amyotrophic lateral sclerosis. *Ann Neurol*, 66(1), 94-99. doi: 10.1002/ana.21580
- Faulkner, R. A., & Davey, M. (2002). Children and adolescents of cancer patients: The impact of cancer on the family. *The American Journal of Family Therapy*, 30(1), 63-72. doi: 10.1080/019261802753455651
- Frankl, V. E. (2006). *Man's search for meaning*. Boston, MA: Beacon Press.
- Garrow, S., & Walker, J. A. (2001). Existential group therapy and death anxiety. *Adultspan Journal*, 3(2), 77-87.

- Gunther, M., Crandles, S., Williams, G., & Swain, M. (1998). A placed called HOPE: Group psychotherapy for adolescents of parents with HIV/AIDS. *Child Welfare League of America, 77*(2), 251-271.
- Hardy-Bougere, M. (2008). Cultural manifestations of grief and bereavement: A clinical perspective. *Journal of Cultural Diversity, 15*(2), 66-69.
- Harris, C. A., & Zakowsky, S. G. (2003). Comparisons of distress in adolescents of cancer patients and controls. *Psycho-Oncology, 12*, 173-182. doi: 10.1002/pon.613
- Hartzfeld, D. (2014). *Familial amyotrophic lateral sclerosis (FALS) and genetic testing*. Retrieved from <http://www.alsa.org/about-als/genetic-testing-for-als.html>
- Hartzfeld, D. E. H., Siddique N., Victorson, D., O'Neill, S., Kinsley, L., & Siddique, T. (2015). Reproductive decision-making among individuals at risk or familial amyotrophic lateral sclerosis. *Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration, 16*, 114-119. doi: 10.3109/21678421.2014.951945
- Henderson, D. A., & Thompson, C. L (2011). *Counseling children* (8th ed.). Belmont, CA: Brooks/Cole, Cengage Learning.
- Hung, N. C., & Rabin, L. A. (2009). Comprehending childhood bereavement by parental suicide: A critical review of research on outcomes, grief processes, and interventions. *Death Studies, 33*(9), 781-814. doi: 10.1080/0748110903142357
- Keeley, M. P., & Generous, M. A. (2014). Advice from children and adolescents on final conversations with dying loved ones. *Death Studies, 38*, 308-314. doi:10.1080/07481187.2012.753556

Keeley, M. P., Generous, M. A., & Baldwin, P. K. (2014). Exploring children/adolescents' final conversations with dying family members. *Journal of Family Communication, 14*, 208-229. doi: 10.1080/15267431.2014.908198

Kubler-Ross, E., & Kessler, D. (2005). *On Grief and Grieving: Finding the Meaning of Grief Through the Five stages of Loss*. New York, NY: Scribner.

Li, Y., Balsubramanian, U., Cohen, D., Zhang, P-W., Mosmiller, E., Sattler, R., Maragakis, N. J., Rothstein, J. D. (2015). A comprehensive library of familial human amyotrophic lateral sclerosis induced pluripotent stem cells. *PLoS ONE, 10*(3), 1-13. doi: 10.1371/journal.pone.0118266

Marangi, G., & Traynor, B. J. (2014). Genetic causes of amyotrophic lateral sclerosis: New genetic analysis methodologies entailing new opportunities and challenges. *Brain Research, 1607*, 75-93. doi: 10.1016/j.brainres.2014.10.009

Mayers, A. M., & Svartberg, M. (2001). Existential loneliness: A review of the concept, its psychosocial precipitants and psychotherapeutic implications for HIV-infected women. *British Journal of Medical Psychology, 74*(4), 539-553.

McClement, S., Chochinov, H. V., Hack, T., Hassard, T., Kristjanson, L. J., & Harlos, M. (2007). Dignity therapy: Family member perspectives. *Journal of Palliative Medicine, 10*(5), 1076-1082. doi: 10.1089/jpm.2007.0002

Muselman D. M., & Wiggins, M. I. (2012). Spirituality and loss: Approaches for counseling grieving adolescents. *Counseling and Values, 57*(2), 229-240. doi: 10.1002/j.2161-007X.2012.00019.x

- Ozanne, A. O., Graneheim, U. H., & Strang, S. (2012). Finding meaning despite anxiety over life and death in amyotrophic lateral sclerosis patients. *Journal of Clinical Nursing, 22*, 2141-2149. doi: 10.1111/jocn.12071
- Padhi, A. K., Banerjee, K., Gomes, J., & Banerjee, M. (2014). Computational and functional characterization of angiogenin mutations and correlation with amyotrophic lateral sclerosis. *PLoS ONE, 9*(11), 1-8. doi:10.1371/journal.pone.0111963
- Pagnini, F., Phillips, D., Bosma, C. M., Reece, A., & Langer, E. (2015). Mindfulness, physical impairment and psychological well-being in people with amyotrophic lateral sclerosis. *Psychology & Health, 30*(5), 503-517. doi: 10.1080/08870446.2014.982652
- Parke, R. D., & Gauvain, M. (2009). *Child psychology: A contemporary viewpoint* (7th ed.). New York, NY: McGraw Hill Education.
- Pfister, T., Sekhon, R., White, M., Scott, P., Munro, S., Johnston, M., Karla, S., & Korngut, L. (2013). Familial amyotrophic lateral sclerosis in Alberta, Canada. *Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration, 14*, 273-277. doi: 10.3109/21678421.2012.754044
- Phillips, F. (2014). Adolescents living with a parent with advanced cancer: A review of the literature. *Psycho-Oncology, 23*, 1323-1339. doi: 10.1002/pon.3570
- Phillips, F., & Lewis, F. M. (2015). The adolescent's experience when a parent has advanced cancer: A qualitative inquiry. *Palliative Medicine, 29*(9), 851-858. doi: 10.1177/0269216315578989
- Rainville, F., Dumont, S., Simard, S., & Savard, M-H. (2012). Psychological distress among adolescents living with a parent with advanced cancer. *Journal of Psychosocial Oncology, 30*, 519-534. doi: 10.1080/07347332.2012.703765

- Richer, M-C., & Ezer, H. (2000). Understanding beliefs and meanings in the experience of cancer: A concept analysis. *Journal of Advanced Nursing*, 32(5), 1108-1115.
- Roth-Kauffman, M., & Niebauer, J. (2012). Amyotrophic lateral sclerosis: Diagnosis and appropriate management. *Clinician Reviews*, 22(7), 15-21. Retrieved from: <http://www.clinicianreviews.com/specialty-focus/genetics/article/amyotrophic-lateral-sclerosis-diagnosis-and-appropriate-management/2a7d25fc760dcce47c42358f7a78414a.html>
- Sand, L., & Strang P. (2006). Existential loneliness in a palliative home care setting. *Journal of Palliative Medicine*, 9(6), 1376-1387. doi: 10.1089/jpm.2006.9.1376
- Sand, L., Olsson, M., & Strang, P. (2010). What are motives of family members who take responsibility in palliative cancer care? *Mortality*, 15(1), 64-80. doi: 10.1080/13576270903537690
- Santrock, J. W. (2014). *Adolescence* (15th ed.). New York, NY: McGraw-Hill Education.
- Schuler, T. A., Zaider, T. I., & Kissane, D. W. (2012). Family grief therapy. *Family Matters*, (90), 77-86.
- Schultz, L. E. (2007). The influence of maternal loss on young women's experience of identity development in emerging adulthood. *Death Studies*, 31, 17-43. doi:10.1080/07448118600925401
- Sheehan, D. K., Druacker, C. B., Christ, G. H., Mayo, M. M., Hdeim, K., & Parish, S. (2014). Telling adolescents a parent is dying. *Journal of Palliative Medicine*, 17(5), 512-520. doi: 10.1089/jpm.2013.0344

- Spillers, C. S. (2007). An existential framework for understanding the counseling needs of clients. *American Journal of Speech-Language Pathology*, *16*, 191-197. doi: 1058-0360/07/1603-0191
- Turner, M. R., Scaber, J., Goodfellow, J. A., Lord, M. E., Marsden, R., & Talbot, K. (2010). The diagnostic pathway and prognosis in bulbar-onset amyotrophic lateral sclerosis. *Journal of Neurological Sciences*, *294*(1/2), 81-85. doi: 10.1016/j.jns.2010.03.028
- Verma, A. (2014) Tale of two diseases: Amyotrophic lateral sclerosis and frontotemporal dementia. *Neurology India*, *62*(4), 247-351. doi: 10.4103/0028.3886.141174
- Vucic, S., Nicholson, G. A., Chio, A., & Kiernan, M. C. (2013). Apparent anticipation in SOD1 familial amyotrophic lateral sclerosis. *Amyotrophic Lateral Sclerosis and Frontotemoral Degeneration*, *14*, 452-456. doi: 10.3109/21678421.2013.764569
- Walters, D. A. (2008). Grief and loss: Towards an existential phenomenology of child spirituality. *International Journal of Children's Spirituality*, *13*(3), 277-286. doi: 10.1080/13644360802236599
- Weisser, F., Bristowe, K., & Jackson, D. (2015) Experiences of burden, needs, rewards and resilience in family caregivers of people living with motor neurone disease/amyotrophic lateral sclerosis: A secondary thematic analysis of qualitative interviews. *Palliative Medicine*, *29*(8), 737-745. doi: 10.1177/0269216315575851
- Williams, J. R., Fitzhenry, D., Grant, L., Martyn, D. & Kerr, D. A. (2013). Diagnosis pathway for patients with amyotrophic lateral sclerosis: Retrospective analysis of the US medicare longitudinal claims database. *BMC Neurology*, *13*(1), 1-15. doi: 10.1186/1471-2377-13-160

- Wu, C-H., Fallini, C., Ticozzi, N., Keagle, P. J., Sapp, P. C., Piotrowska, K., ... Landers, J. E. (2012). Mutations in the proflin 1 gene cause familial amyotrophic lateral sclerosis. *Nature*, 488, 499-503. doi: 10.1038/nature11280
- Yalom, I. D. (2002). *The gift of therapy: An open letter to a new generation of therapists*. New York, NY: Harper Collins Publishers.
- Yalom, I. D. (2009). *Staring at the sun: Overcoming the terror of death*. San Francisco, CA: Jossey-Bass.
- Yu, Y., Su, F. C., Callaghan, B. C., Goutman, S. A., Batterman, S. A., & Geldman, E. L. (2014). Environmental risk factors and amyotrophic lateral sclerosis (ALS): A case-control study of ALS in Michigan. *PLoS ONE*, 9(6), 1-9. doi: 10.1371/journal.pone.0101186
- Zhang, L., Li, X., Kaljee, L., Fang, X., Lin, X., Zhao, G., Zhao, J., & Hong, Y. (2009). 'I felt I have grown up as an adult': Caregiving experience of children affected by HIV/AIDS in China. *Child: Care, Health & Development*, 35(4), 542-550. doi: 10.1111/j.1365-2214.2009.00973.x

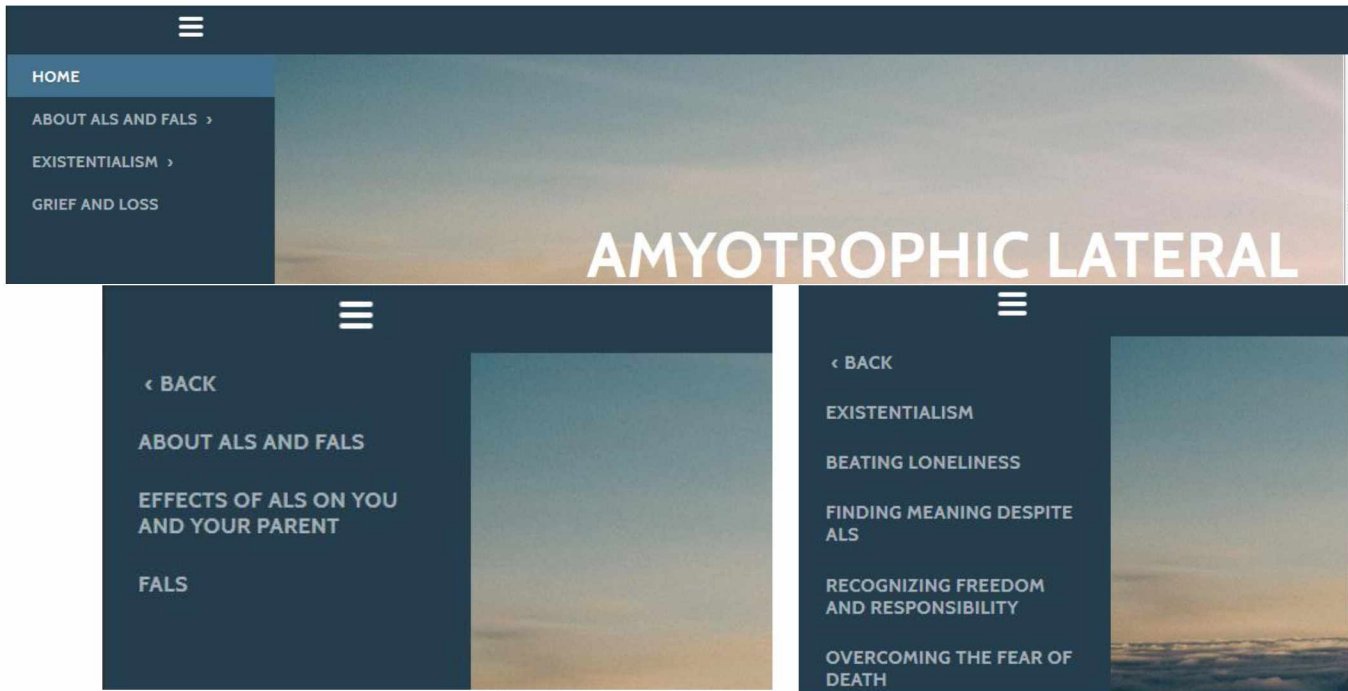
Footnotes

¹ Although technical information on genetic transferred disease is beyond the scope of this paper (and the author's personal expertise), it is added as an aid for those whose expertise requires more specific information.

Appendix

A review of the literature found that teens have the cognitive ability to comprehend death, illness, and the suffering of others (Faulkner & Davey 2002; Phillips, 2014). Research also supports providing information about a parent's illness and the surrounding existential concerns to adolescents (Phillips, 2014; Sheehan et al., 2014). Therefore, the information gleaned from the review of the literature surrounding a teen's experience of a parent's ALS/FALS diagnosis was used to create a web-based, existential resource. In this document, screenshots of the various pages within the website are provided along with a brief description of the rationale for the included information.

Screenshot: Navigation Tabs



Rationale: Breakdown of Navigation Tabs

By clicking on the three parallel lines in the upper left hand corner, teens can access the navigation tabs and the various pages within the website. For example, by clicking on the “About ALS and FALS” tab, the teen can find information about the disease, the “Effects of ALS on You and Your Parent”, and the “FALS” pages. Similarly, by clicking on the “Existentialism” tab, visitors can find the various pages about overcoming existential concerns.

Screenshot: Home Page



AMYOTROPHIC LATERAL SCLEROSIS

A Resource for Teens of Parents Diagnosed with ALS

"HE WHO KNOWS THE 'WHY' FOR HIS EXISTENCE, WILL BE ABLE TO BEAR ALMOST ANY 'HOW'" --VIKTOR FRANKEL

WHAT'S INSIDE

This website is a research based, existential resource for teens who learn a parent is diagnosed with amyotrophic lateral sclerosis (ALS) or familial amyotrophic lateral sclerosis (FALS).

Learning about a parent's diagnosis of ALS or FALS can lead to a number of different responses that are perfectly normal. As the disease progresses in your parent, you may experience other concerns such as loneliness; a lack of meaning, freedom or responsibility; and a fear of death. These feelings are not uncommon among adolescents who are in similar situations. However, if not dealt with, these concerns may lead to more serious consequences in adulthood.

This site provides information about how ALS and FALS will affect your parent physically and emotionally. It also provides explanations for some emotional reactions you may experience and suggestions for overcoming them. Information about grief, loss and coping strategies that may help you are also provided.

Dedicated to the memory of Lloyd A. Johnson
1958-2014
"I love you more"

Created by:

Emily R. Johnson

In Partial fulfillment of the Requirements of the Degree of
Masters of Education in Counseling
University of Alaska Fairbanks
May 2016

Rationale: Information Included on the Home Page

The home page of the website provides the title of the website as well as a brief description of the information found in the website. A user will be able to navigate using various tabs with specific information based on broad topics. The tabs appear in the upper left hand corner of the page and include the headings of “About ALS and FALS,” “Existentialism” and “Grief and Loss.” Specific information on the home page includes its title and a brief description of the information provided. The author’s information and a brief dedication are included as well.

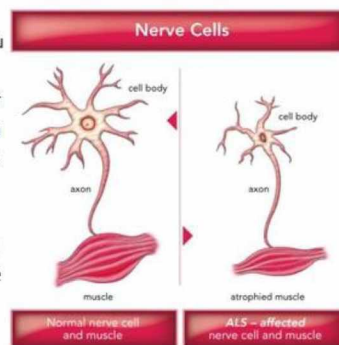
Screenshot: About ALS

ABOUT AMYOTROPHIC LATERAL SCLEROSIS

WHAT IS IT?

Amyotrophic lateral sclerosis, also known as Lou Gehrig's disease, is a progressive neuro-muscular disease. A genetic mutation in the person's body causes the neurons that move muscles in the brain, spine, and motor cortex to slowly die. When this happens, the brain is no longer able to tell the muscles to move, and patients slowly lose

the ability to control their physical movements. Over time the person becomes paralyzed and experiences difficulty swallowing and talking. ALS is a terminal disease meaning that the patient will eventually die. As the disease progresses further, patients lose control of their diaphragm and breathing muscles causing suffocation.



WHO GETS IT?

- ALS typically begins to develop between the ages of 55-65.
- The disease affects 2-9 out of 100,000 people around the world
- Sporadic cases affect males more than females
- The illness occurs in all cultures and races

WHAT CAUSES IT?

Researchers are still unsure what causes a person's genes to mutate and lead to ALS symptoms. Several proposed risk factors include severe physical trauma, exposure to metal vapors, smoking and head injuries. However, this evidence is not conclusive enough to say with certainty if these factors cause genes to mutate.

Currently, there is no cure for the disease. One prescription drug has shown to slow the progression of the disease, but it does not stop the progression completely.

TYPES OF ALS

SPORADIC ALS

- 90-95% of cases happen sporadically (randomly) and the patient is the only person in their family to develop the disease
- Symptoms develop between 55-65 years of age
- Children of sporadic ALS patients are 10 times more likely to also develop ALS than the rest of the population

FAMILIAL (FALS)

- 5-10% of cases are inherited cases, and more than one person in the family will develop the disease
- The younger the patient is diagnosed with a sporadic case, the more likely they are to pass on genetic mutation to their children
- FALS tends to appear earlier in life (50-55 years old)
- Disease may not occur in all family members and may skip entire generations

BULBAR-ONSET

- Muscle loss primarily occurs in the face and jaw
- About half of patients with bulbar-onset will lose the ability to walk and move their arms
- Life span is typically 2.5 years
- Bulbar-onset symptoms occur in roughly 1/3 of all patients (ALS and FALS combined)

SYMPTOMS

LIMB-ONSET

- Muscle loss noted in hands, feet, arms and legs
- Patients notice tripping, falling, difficulty writing or standing up, a lack of coordination, and muscle spasms
- Disease progresses inward from limbs, affecting facial and breathing muscles last
- Life span is typically 3-5 years after diagnosis
- Limb-onset symptoms occur in roughly 2/3 of all patients (ALS and FALS combined)

Rationale: Information Included on “About ALS” Page

The “About ALS” page provides teens with information about the disease itself. A general description of the disease and its progression are provided as well as descriptions of the various types: sporadic, familial, bulbar-onset and limb-onset. Additionally, the epidemiology and etiology of the disease are provided. This page is meant to provide an overview of the disease. The literature review supports sharing information about a parent’s terminal illness with youth and indicates open communication proves to be positive for an adolescent’s health (Phillips, 2014; Sheehan et al., 2014).

Screenshot: Effects of ALS on Your Parent and You

HOW ALS EFFECTS YOU AND YOUR PARENT

EMOTIONAL EFFECTS OF ALS ON YOUR PARENT AND YOU

YOUR PARENT'S EXPERIENCE

When people are diagnosed with a terminal illness a number of reactions may occur. It is not uncommon to experience a sense of denial, a lack of optimism or a sense of bitterness and unfairness. ALS patients may develop a fear of being alone as they lose physical mobility.

Some ALS patients experience several negative feelings. Anger and bitterness may result from the diagnosis itself and knowledge of future loss of life. Guilt may occur if they feel that they are the cause of their family's suffering. Feelings of shame may lead to isolation. Although they may fear being alone once they lose physical control of their bodies, ALS patients may try to make things easier for their loved ones by isolating in an attempt to cope with these feelings.

Death anxiety is not uncommon in ALS patients. Knowing that ALS has no cure and that they will die regardless may cause feelings of hopelessness. Because the future is unknown, your parent may feel that it is meaningless to make plans and relationships with others may be affected.

HOW ALS CAN AFFECT YOU

The loss of a parent may be one of the most stressful events of your teenage years. Stress and anxiety are not uncommon in teens who are losing a parent to a long term illness. Other reactions may include:

- Post Traumatic Stress Disorder (PTSD)
- Anger
- Despair
- Social Isolation
- Depression
- A Sense of Loss After Your Parent's Death
- A Sense of Loss Before Your Parent's Death
- Loss of a Healthy Parent's Physical and Emotional Availability
- Loss of support
- Loss of normalcy
- Grief

In addition to the above, it is common to experience existential concerns including loneliness, meaninglessness, a lack of freedom and a fear of death.

Rationale: Information Included on “Effects of ALS on Your Parent and You” Page

The “Effects of ALS on Your Parent and You” page provides information about possible emotional reactions that both the parent and teen may experience. The purpose of this page is to provide youth with knowledge about typical emotional responses of a parent after being diagnosed. It is also meant to give the youth an insight to some of the “normal” emotional reactions they may be experiencing. Research supports providing youth with information about their parent’s illness and experiences (Phillips, 2014; Sheehan et al., 2014).

Screenshot: FALS

FAMILIAL AMYOTROPHIC LATERAL SCLEROSIS

FALS

For the majority of cases, ALS develops randomly. Researchers do not know why genes mutate to cause disease. However, 5-10% of cases are passed genetically from parent to child. Some genetic mutations can be detected through genetic testing.

GENETIC TESTING

Genetic testing is typically performed on patients who already have a diagnosis of ALS or FALS. Researchers are still trying to determine which genes mutate leading to sporadic ALS and FALS. If a patient has been diagnosed with FALS, some genetic testing is available to see which gene is mutating and causing symptoms. However, because not all of the genetic mutations have been found, a person with FALS may receive test results that do not show any mutations at all.

If your parent has ALS or FALS and you want to be tested to see if you will inherit FALS, your ill parent needs to be tested first, and a mutation must be found. If a mutation is not found in a parent, it will be difficult to find a mutation in you because geneticists will not know which genetic tests to perform. If a mutation is found in your parent, only a 50% chance exists that you will also develop the disease. If you are tested and a mutation is found, there is no way to determine when symptoms will start to appear or how fast the disease will progress.

Genetic testing is not recommended for adolescents under the age of 18 as mutations in genes typically do not appear until later in life. Testing for all known FALS and ALS genes is expensive and usually costs around \$6,000. Because of the uncertainty of testing for this disease, counseling is typically required.

GENETIC COUNSELING

Prior to genetic tests being performed, counseling is usually required to discuss your motivations for knowing, expectations of your family, and screen for depression and suicidal tendencies. A conversation about the uncertainty of genetic testing for ALS or FALS and about what positive or negative results may mean typically occurs.

As a result of counseling you may decide against genetic testing. You may decide they do not want to know if you have the mutation, do not want to live with a positive result or want to maintain hope. Some people decide to receive testing to reduce anxiety, contribute to research, or use the information to benefit their children. If you test positive for ALS or FALS before you have children, you may use the information when deciding whether or not you will have children in the future.

Rationale: Information Included on the “FALS” Page

The “FALS” page provides specific information about the familial form of the disease. Information about genetic testing and counseling is provided. The literature review indicates that youth who lose a parent to a terminal illness experience a greater perceived risk for developing the disease themselves which can lead to chronic stress and depression (Harris & Zakowsky, 2003). This page is meant to be informational for youth who may be concerned about developing or inheriting the disease themselves.

Screenshot Existentialism



EXISTENTIALISM

EXISTENTIAL THEORY

In general, existential theory attempts to normalize human experiences. Every human experiences a form of loneliness, needs to find meaning in experiences and life, has a freedom and responsibility to make choices, and will one day die. It is not uncommon for people who experience a major loss or stressful event to feel lonely, experience meaninglessness, perceive a lack personal freedom or responsibility and fear death.

These symptoms lead to depression, stress, and anxiety. If not dealt with, issues later in life may also occur. It is important to work on these existential problems as soon as possible so as to avoid prolonging pain and complicated grief responses. Investigate below to see how a parent's diagnosis of ALS may lead to existential concerns in your life.

EXISTENTIAL CONCERNS

BEATING LONELINESS

Existential loneliness is somewhat different from 'normal' loneliness. This type of loneliness refers to the realization of being separate from all other people. People live, create values, and die physically separate from all other individuals. No one can create belief systems for you or accompany you after you die. This realization usually motivates people to create relationships with others.

To discover more about loneliness and ways to overcome it, click on the button above.

FINDING MEANING DESPITE ALS

When a person creates a meaning in their life, they also develop motivation and a purpose for living. Sometimes negative situations can cause a person to make sense of their life and purpose. Having a meaning can help people overcome challenges and negative circumstances. Not having a purpose or meaning can lead to negative consequences.

To learn more about how a lack of meaning can affect you and about ways to create meaning, click on the button above.

REALIZING FREEDOM & RESPONSIBILITY

Human beings has a certain amount of freedom to chose their reactions and attitudes to situations, determine their own future, and create their own life. People can feel, think, act, and believe as they choose.

To take a closer look at your own freedom and responsibility when your parent develops ALS, click on the button above.

OVERCOMING A FEAR OF DEATH

Death is one of the only guaranteed events in life. Some people develop fear and avoidance of death when they realize that they are not immortal. This development has not always been found to be the case in teens who lose a family member, because they have found ways to cope with their feelings of grief and loss.

To obtain more information on death and grief and loss in teens who are losing a parent to ALS, click on the button above.

Rationale: Information Included on the “Existentialism” Page

The “Existentialism” page provides an overview of existential theory and the four existential concerns that can arise in a teen from a parent’s ALS/FALS diagnosis. Research has found that teens experience existential concerns throughout the course of normal development; however, these concerns can be exacerbated by the terminal illness of a parent and, if not dealt with, can cause serious problems later in life (Berman, Weems & Stickle, 2006; Phillips, 2014; Schultz, 2007). This theoretical approach has been found to be beneficial in aiding adolescents in resolving crises in their lives that arise when a parent is diagnosed with a terminal illness (Buxbaum & Brant, 2001; Carlson, 2003; Ens & Bond, 2007; Phillips, 2014; Phillips & Lewis, 2015). Brief descriptions of existential loneliness, the importance of finding meaning, realizing freedom and responsibility, and overcoming a fear of death are presented for introductory purposes. Teens can click directly on the buttons to be taken to the other pages which provide more in depth descriptions of the four different areas, explanations for how these existential concerns can be affected by a parent’s ALS diagnosis and ways to overcome the possible existential concerns.

Screenshot: Beating Loneliness



BEATING LONELINESS

HOW ALS CAUSES LONELINESS

When a person is diagnosed with ALS, they may experience feelings of loneliness. The knowledge that they will become sick and face death while people around them remain healthy may cause them to pull away from their family members. It is important to note that this is not your parent's fault. Rather, your parent is simply struggling with realizing and overcoming feelings of loneliness.

Throughout life, when people realize that they are separate from others, they create relationships in an attempt to overcome feelings of loneliness. You have likely created relationships with your parents. However, if your parent is diagnosed with ALS and begins to pull away from family members, you may experience loneliness as well.

IF NOT DEALT WITH...

Avoiding communication about feelings of loneliness of a parent's ALS diagnosis can have negative consequences. Depression, stress, anxiety and feelings of disrespect may arise if loneliness is not discussed. If not dealt with, you may be at risk for substance abuse, guilt, and depression in adulthood. There are several ways to overcome loneliness and the side effects that come with it.

HOW TO BEAT LONELINESS

TALK ABOUT IT

If you are unable to discuss feelings and concerns at home, talk to people close to you about your feelings of loneliness and feelings surrounding your parent's disease. Friends, community members and other family members can provide support, understanding, comfort and warmth.

DISCUSS IT WITH FAMILY

Some families will have open communication about a parent's ALS diagnosis and associated loneliness. If this is the case in your life, talk with your dying parent. Conversations with dying loved ones are beneficial to both you and your parent, by providing a sense of normalcy and support while lessening guilt and anger. Talking may make it easier to cope with the loss as opposed to remaining silent.

SEEKING PROFESSIONAL HELP

Counseling can also be beneficial in resolving these losses. Existential counseling can provide a supportive person to listen and talk to you about the feelings of loneliness and concerns regarding your parent's illness. They will also have specific skills to help you overcome loneliness and cope with the loss you are experiencing.

Rationale: Information Included on the “Beating Loneliness” Page

The “Beating Loneliness” page provides an explanation for the possible feelings of loneliness that both a parent diagnosed with ALS and teen may be feeling. Information supported by research about the importance of overcoming loneliness is provided as well as suggestions for overcoming it (Keeley & Generous, 2014; Muselman & Wiggins; 2012; Phillips & Lewis, 2015). For example, communicating with family members and discussing feelings with others are two of the strategies provided.

Screenshot: Finding Meaning Despite ALS



FINDING MEANING DESPITE ALS

HOW ALS AFFECTS MEANING

Creating meaning is important. People who have purpose and meaning in their life tend to be more hopeful and happy. They are also less likely to struggle with alcoholism, poor self-image and other mental health issues in adulthood.

Normally, teens create meaning in their lives by comparing themselves to friends or other people, and by receiving support from their parents. If a parent develops ALS, this meaning making may be difficult to do. You may need to spend more time at home helping to care for your parent. If your parent is experiencing loneliness and is pulling away, support that you once had from this parent may change.

CAREGIVING

Ignoring a parent's ALS diagnosis can lead to meaninglessness. When faced with the impending loss of a loved one, several beliefs can lead to a lack of meaning or purpose including:

- Threat of unfairness
- Loss of a family unit
- Changes in beliefs about life
- Loss of the loved one's physical body
- Realization of taking life for granted
- Feelings of guilt, shame, stress, anger, sadness, pain
- Fear of death

Assisting in providing home care for a parent with ALS allows you to combat meaninglessness. Although caregiving can lead to stress and be difficult, family caregivers have found it to be worth it. Spending time with your ill parent helps with:

- Creating a sense of family togetherness
- Strengthening personal relationships with the dying
- Overcoming a fear of death
- Beating existential loneliness
- Creating personal growth
- Experiencing feelings of hope, joy and dignity
- Maintaining a meaning and purpose

OTHER WAYS TO FIND MEANING

- Spending time with friends and peers when time allows
- Spending time with your healthy parent
- Speaking with an existential counselor if possible
 - Existential counselors can assist you in finding meaning in life by listening, being present, and by not judging

THINGS TO REMEMBER...

- Each person must create their own personal meaning
 - No one can create meaning for you
- Caring for a parent may lead to stress, anger, sadness and pain which can be difficult to overcome
 - Spending time with loved ones help to overcome these feelings and maintain positive emotions such as hope and joy and decrease guilt and shame

Rationale: Information Included on the “Finding Meaning Despite ALS” Page

The “Finding Meaning Despite ALS” page provides information on the importance of making meaning as well as the consequences of meaninglessness in life. The research showed that failing to spend time with dying family members had negative consequences (Brassai, Piko & Steger, 2013; Sand, Olsson & Strang, 2010; Weisser, Bristowe & Jackson, 2015). The literature also strongly supported caregiving as a way in which to find and maintain meaning during a parent’s terminal illness (Brassai et al., 2013; Sand et al., 2010; Weisser et al., 2015). Both the benefits and possible negative side effects of caregiving are presented. The purpose of including the negative side effects is to be as transparent as possible with the youth, because research supports communication about a parent’s illness with teens (Sheehan et al., 2014). Other suggestions for finding meaning are provided as well.

Screenshot: Recognizing Freedom and Responsibility



RECOGNIZING FREEDOM AND RESPONSIBILITY

"You and you alone are responsible for the crucial aspects of your life situation, and only you have the power to change it. Even if you face overwhelming external restraints, you still have the freedom and the choice of adopting various attitudes toward those situations."

--Irvin Yalom

WHAT DOES IT MEAN

All people have the freedom to think, feel and believe as they choose. They are also free to determine how their reactions and attitudes to situations. Once a choice is made, that person has the responsibility of living with the rewards and consequences of that decision.

Your parent's ALS diagnosis is an uncontrollable life event. You are responsible for deciding how you will react and for choosing your attitude to your family's situation. You are also responsible for overcoming loneliness if you experience it and for creating meaning for your life. No one can make meaning for you.

FREEDOM, RESPONSIBILITY, AND ALS

When you learn about your parent's ALS diagnosis, you may experience stress, anxiety, depression, loneliness, and meaninglessness. But, you also have the choice to do something about these negative feelings. Feelings of meaningless and loneliness can be overcome. You are free to choose how you respond to your parent's diagnosis. You are also responsible for living with the consequences of that decision.

Choices that have proven to help overcome negative emotions that arise when a parent is diagnosed with ALS:

- Spend time with dying loved ones and family
- Assist in caregiving to overcome negative feelings of guilt, anger and depression,
- Communicate about feelings of loneliness with friends, healthy family members or dying parent
- Seek counseling

Rationale: Information Included on the “Recognizing Freedom and Responsibility Page

The “Recognizing Freedom and Responsibility” page provides a more in-depth explanation about the importance of recognizing personal freedom and responsibility. A quote by Irvin Yalom is presented to demonstrate this information as well. This page reminds teens that their parent’s illness is uncontrollable and that they have the power to choose their reaction and attitude toward their situation. A reminder of positive methods that can help overcome negative emotions associated with a parent’s ALS diagnosis are provided to prompt teens to make healthy decisions.

Screenshot: Overcoming the Fear of Death



OVERCOMING THE FEAR OF DEATH

REALIZING VS. AVOIDING DEATH

Creating meaning in life is partially dependent on realizing that death is inescapable. Recognizing that death will one day come, and acknowledging that death is a part of living, allows people to experience a more authentic and meaningful life. Those people who avoid death fill their lives with distractions and diversions that can cause them to alienate themselves and experience anxiety.

"Though the physicality of death destroys us, the idea of death may save us"

--*Irvin Yalom*

FEAR OF DEATH

A fear of death interferes with the enjoyment of life. Instead of focusing on positive aspects of life and seeking pleasure, individuals are focused on avoiding pain and loss.

Several experiences can invoke a fear of death. The death of a loved one, serious illness, and threat to personal safety can all lead to anxiety and fear of dying.

WAYS TO OVERCOME A FEAR OF DEATH

- Realize the difference between focusing on how life is and appreciating that life is
 - Instead of being concerned with life not being perfect, appreciate that life is happening
- Recognize your freedom and responsibility
 - Live according to your priorities
 - Use your freedom to do or not do what you wish
- Find meaning in life
- Create meaningful relationships
- Live with no regrets

IF YOU'VE EXPERIENCED A LOSS

If your parent is diagnosed with ALS or you have lost a loved one, you have experienced death. Grief during teenage years can lead to a greater empathy and concern for others, stronger emotional bonds, and better communication skills. Teens who experience a loss also are less likely to take life for granted.

While you may not experience a fear of death, there is a chance that you may still face feelings of grief and loss.

Rationale: Information Provided on the “Overcoming the Fear of Death” Page

The “Overcoming the Fear of Death” page provides an explanation about the different effects of realizing versus avoiding death on an individual. A quote by Irvin Yalom is presented to demonstrate this idea as well. A description of how a fear of death can occur and affect a teen’s life is presented as ways for overcoming that fear (Yalom, 2009). Research has found that teens who experience the loss of a loved one are less likely to experience death anxiety (Ens & Bond, 2007). This information is presented as well with a reminder that while death anxiety may not be an issue, grief and loss will still need to be dealt with. The purpose of providing this information, as supported by the literature review, is to continue to make teens aware of what they may be feeling as a result of their parent’s illness (Phillips 2014; Sheehan et al., 2014).

Screenshot: Grief and Loss



GRIEF AND LOSS

GRIEVING A PARENT WITH ALS

The loss of a parent can create a void that is not easily filled. Because ALS is a progressive disease, feelings of loss associated with changes in you parent's physical body and abilities, emotional support, and future may begin long before your parent actually dies. As your parent's disease progresses and changes occur, you may grieve the lifestyle and support that you once had.

In some cultures, many people attempt to deny death and the grief associated with it. Others may not understand the grief experienced by teens who lose a parent. Grieving the loss of a parent is normal and natural.

WHAT TO EXPECT: NORMAL VS. CONCERNING GRIEF REACTIONS

Grief may include feelings of sadness, depression, shock, anger, numbness, disbelief, depression and confusion. Sleep disturbances, decreased appetite and loss of interest in school or activities may also be present as you grieve. Your grief may feel overwhelming, painful, and exhausting. These responses may come in waves and may last days, a few weeks or even months after your loss. It is important to remember that you are free to have your own grief response and that it might be different from the response of others.

If your grief response lasts longer than a few months, it may be a sign that something else is occurring. A prolonged depressed mood, insomnia, thoughts of suicide, bitterness or self-isolation may be signs of major depressive disorder or dysthymia, both of which can have a negative impact on your overall health and functioning. If these symptoms occur, it is important to seek help.

STAGES OF GRIEF

As your parent progresses through their illness and you experience losses, you may move through the five stages of grief and loss before and after your parent dies.

1. Denial: In this stage, you are likely aware that your parent is dead; however, you may feel as though they are missing in your life and not really gone.
2. Anger: Once you recognize that your loved one is not coming back, you may experience anger at your parent, yourself or others for not being able to stop the illness. This anger is normal, and your realization of it can help you overcome your circumstances.
3. Bargaining: In the bargaining stage, you may ask questions such as "what if..." or you may feel guilty. You may think "if only I could be rid of my pain I will feel better." This thought process is natural.
4. Depression: After focusing on bargaining and thinking about the past, you will likely shift your focus to the present, which can lead to emptiness and meaninglessness. These feelings are normal. Losing a loved one and attempting to live a life without them is depressing. If you recognize your depression and embrace these feelings, they will eventually ease.
5. Acceptance: Losing a loved one is never easy. It may never feel as though your world is "right." However, learning to live a life without your loved one is a necessary step in adjusting and healing. Not doing so may lead to problems later in life.

Failing to move through these steps and obtaining acceptance may lead to problems later in life. See the suggestions below for overcoming grief and loss in a healthy way.

SUGGESTIONS TO AID IN OVERCOMING GRIEF AND LOSS

SUPPORT FROM OTHERS

- Talk with your healthy parent about your feelings and about your loss
 - Discuss happy memories of your deceased parent
- Talk with friends
- Talk with other adults that you are comfortable with such as mentors, coaches, religious members or teachers
- Connect with elders or family members within your culture for comfort, advice, guidance, and support as you grieve these losses

GRIEF GROUPS

- Allow members to share similar feelings and express grief
- Reduce feelings of isolation
- Provide a space to share experiences
- Serve as a support system

FAMILY THERAPY

- Can help strengthen communication
- May assist in recognizing the emotional needs of all members
- Gives support to ill parent and family members
- Decreases depression, stress and anxiety

MAKING MEMORIES

- Make a memory or photo book of your parent before their death
- Keep a few of your deceased parent's possessions as keepsakes
- Ask your ill parent to write letters or record messages for you before they die that can be opened or heard later in life

COUNSELING

- Seek support from school or existential counselors who can provide genuineness, empathy and understanding
- May help make sense of death by finding meaning in the situation
- Can assist you in processing feelings and enhancing relationships

Rationale: Included Information on the “Grief and Loss” Page

The “Grief and Loss” page provides information on the grief response for teenagers and a brief overview of the five stages of grief (Kubler-Ross & Kessler, 2005). Research shows that when losing a parent to a terminal illness, the grief process may begin before the parent dies (Buxbaum & Brant, 2001; Ens & Bond, 2007; Spillers, 2007). The loss of physical and emotional support of the parent as well as normalcy can lead to feelings of grief and loss throughout the progression of the disease (Buxbaum & Brant, 2001; Ens & Bond, 2007; Schuler, Zaider & Kisane, 2012; Spillers, 2007). Descriptions of normal and abnormal grief response are given so teens know what to expect and when to be concerned. The suggestions provided by the research for overcoming grief and loss are presented (Buxbaum & Brant, 2001; Byrd & Erford, 2014; Frankel, 2006; Hung & Rabin, 2009; McClement et al., 2007; Muselman & Wiggins, 2012). By providing teens with information about grief responses and ways to overcome them, an adolescent’s ability to avoid succumbing to abnormal grief responses that may have more severe consequences may be strengthened (American Psychological Association, 2013; Buxbaum & Brant, 2001; Ens & Bond, 2007).

Conclusion

The website provides information about ALS/FALS, existential issues, and coping methods for teens in one comprehensive resource. This site provides resources and suggestions that can assist the youth in overcoming the feelings associated with their situation. The website as a whole reflects the information found by reviewing the literature on ALS/FALS, adolescent development, grief and loss, and existential psychology. It provides a comprehensive resource for adolescents experiencing existential problems that result from a parent suffering with ALS/FALS.

References

- Albinsson, L., & Strang, P. (2003). Existential concerns of families of late-stage dementia patients: Questions of freedom, choices, isolation, death, and meaning. *Journal of Palliative Medicine, 6*(3), 225-235. doi: 10.1089/109662103764978470
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Arlington, VA: Author.
- Berman, S. L., Weems, C. F., & Stickle, T. R. (2006). Existential anxiety in adolescents: Prevalence, structure, association with psychological symptoms and identity development. *Journal of Youth and Adolescence, 35*(3), 303-310. doi: 10.1007/s10964-006-9032-y
- Brassai, L., Piko, B. F., & Steger M. F. (2013). Individual and parental factors related to meaning in life among Hungarian minority adolescents from Romania. *International Journal of Psychology, 48*(3), 308-315. doi: 10.1080/00207594.2011.645483
- Buxbaum, L., & Brant, J. M. (2001). When a parent dies from cancer. *Clinical Journal of Oncology, 5*(4), 1-6.
- Byrd, R., & Erford, B. T. (2014). *Applying techniques to common encounters in school counseling: A case-based approach*. Upper Saddle River, NJ: Pearson.
- Ens, C., & Bond, J. B. (2007). Death anxiety in adolescents: The contributions of bereavement and religiosity. *Omega, 55*(3), 169-184. doi: 10.2190/OM.55.3.a
- Faulkner, R. A., & Davey, M. (2002). Children and adolescents of cancer patients: The impact of cancer on the family. *The American Journal of Family Therapy, 30*(1), 63-72. doi: 10.1080/019261802753455651
- Frankl, V. E. (2006). *Man's search for meaning*. Boston, MA: Beacon Press.

- Hardy-Bougere, M. (2008). Cultural manifestations of grief and bereavement: A clinical perspective. *Journal of Cultural Diversity, 15*(2), 66-69.
- Harris, C. A., & Zakowsky, S. G. (2003). Comparisons of distress in adolescents of cancer patients and controls. *Psycho-Oncology, 12*, 173-182. doi: 10.1002/pon.613
- Hung, N. C., & Rabin, L. A. (2009). Comprehending childhood bereavement by parental suicide: A critical review of research on outcomes, grief processes, and interventions. *Death Studies, 33*(9), 781-814. doi: 10.1080/0748110903142357
- Keeley, M. P., & Generous, M. A. (2014). Advice from children and adolescents on final conversations with dying loved ones. *Death Studies, 38*, 308-314.
doi:10.1080/07481187.2012.753556
- Kubler-Ross, E., & Kessler, D. (2005). *On Grief and Grieving: Finding the Meaning of Grief Through the Five stages of Loss*. New York, NY: Scribner.
- McClement, S., Chochinov, H. V., Hack, T., Hassard, T., Kristjanson, L. J., & Harlos, M. (2007). Dignity therapy: Family member perspectives. *Journal of Palliative Medicine, 10*(5), 1076-1082. doi: 10.1089/jpm.2007.0002
- Muselman D. M., & Wiggins, M. I. (2012). Spirituality and loss: Approaches for counseling grieving adolescents. *Counseling and Values, 57*(2), 229-240. doi: 10.1002/j.2161-007X.2012.00019.x
- Phillips, F. (2014). Adolescents living with a parent with advanced cancer: A review of the literature. *Psycho-Oncology, 23*, 1323-1339. doi: 10.1002/pon.3570
- Phillips, F., & Lewis, F. M. (2015). The adolescent's experience when a parent has advanced cancer: A qualitative inquiry. *Palliative Medicine, 29*(9), 851-858. doi: 10.1177/0269216315578989

- Sand, L., Olsson, M., & Strang, P. (2010). What are motives of family members who take responsibility in palliative cancer care? *Mortality*, *15*(1), 64-80. doi: 10.1080/13576270903537690
- Schuler, T. A., Zaider, T. I., & Kissane, D. W. (2012). Family grief therapy. *Family Matters*, (90), 77-86.
- Schultz, L. E. (2007). The influence of maternal loss on young women's experience of identity development in emerging adulthood. *Death Studies*, *31*, 17-43. doi:10.1080/07448118600925401
- Sheehan, D. K., Druacker, C. B., Christ, G. H., Mayo, M. M., Hdeim, K., & Parish, S. (2014). Telling adolescents a parent is dying. *Journal of Palliative Medicine*, *17*(5), 512-520. doi: 10.1089/jpm.2013.0344
- Spillers, C. S. (2007). An existential framework for understanding the counseling needs of clients. *American Journal of Speech-Language Pathology*, *16*, 191-197. doi: 1058-0360/07/1603-0191
- Weisser, F., Bristowe, K., & Jackson, D. (2015) Experiences of burden, needs, rewards and resilience in family caregivers of people living with motor neurone disease/amyotrophic lateral sclerosis: A secondary thematic analysis of qualitative interviews. *Palliative Medicine*, *29*(8), 737-745. doi: 10.1177/0269216315575851
- Yalom, I. D. (2009). *Staring at the sun: Overcoming the terror of death*. San Francisco, CA: Jossey-Bass.