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# Hidden on Campus: The Impact of Parental Illness on the College Student Experience

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Hidden on Campus: The Impact of Parental Illness on the College Student Experience

by

Molly R. Wilensky

A THESIS

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# Hidden on Campus: The Impact of Parental Illness on the College Student Experience

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It is unknown how many traditionally-aged college students experience the impact of parental illness immediately prior to or at some point during their time at an institution. Literature related to attachment and coping and identities/relationships provided a framework for understanding family dynamics and traditional experiences for students transitioning to a collegiate environment. Literature related to familial or parental illness provides some insight regarding the impact of illness on the college student experience; however, this research relies primarily on retrospective studies and quantitative data. What little research exists largely fails to portray the voices and subjective experiences of students coping with this challenging experience. Therefore, the results of this study contribute to the limited research that exists and provides valuable insight into not only what some students experience, but also what future research should address.

This qualitative study utilized a constructivist paradigm to examine the unique experiences of three traditionally-aged undergraduate students who had a parent develop a significant illness at most, 12 months prior to their transition to Midwest Regional University. Midwest Regional University is a four-year public research institution located in the Midwest region of the United States. Qualitative interviews were conducted utilizing two semi-structured interviews with three undergraduate students

who identified as experiencing the impact of parental illness as a college student.

Overall, findings indicated this atypical and challenging life event did affect many aspects of their collegiate experience. This study illuminated practical recommendations for supporting these students, as well as direction for future research.

## **Dedication**

*For the students who feel marginalized in holding this identity as they pursue and persist in higher education; I hope you can, or will eventually, acknowledge the ways in which your struggles have profoundly shaped you and helped you grow.*

## **Acknowledgements**

To the three participants who chose to be vulnerable and share their stories with me, I cannot thank you enough. Your experiences and challenges are such important considerations for higher education and have deeply impacted my desire to continue to establish and contribute to the current research. I wish you and your families the very best.

To Dr. Debra Mullen, your individualized attention and commitment to providing me with valuable feedback has significantly impacted my final year of graduate school and my desire to pursue research within the field. Your constant validation has been an important source of support as I navigated separating my participants' experiences from my own. A special thanks to my peer reviewers, who supplemented Dr. Mullen's feedback and helped me stay accountable through the process.

To my Career Services at CBA and Drake families, thank you for supporting me through my own experience with parental illness. I don't know where I would be without your continual understanding and encouragement. My desire to pursue student affairs developed and was nurtured in these two environments. A special thank you to my mentors, who continue to inspire and challenge me. Words cannot express how incredibly grateful I am for your support and guidance.

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support you needed. And finally, to my incredible dad, whose grit and positivity inspires me every day. You have profoundly shaped every part of me and my life. Thank you for inspiring me to pursue this field and this research.

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## Chapter 1

### Introduction

There is a significant body of higher education research that explores how parental attachment influences the traditionally-aged college student's adjustment to the collegiate environment, as the majority of traditionally-aged college students make this developmental transition with some degree of parental attachment. Literature explores how students cope with this transition and how new relationships and identities are formed as students engage more autonomously within academic and social situations. However, these bodies of research largely fail to account for how unique familial challenges, such as a family member's development of a significant illness, complicate what is often seen as a traditional transitional experience.

According to Schmidt and Welsh (2010):

When a crisis such as a family member's illness arises...normative concerns may become interrupted, exaggerated, or difficult to navigate, and the student's adjustment may suffer. Alternatively, it is possible that such an event would cause the student to cope more effectively in light of the bigger issue at home. (p. 397)

Schmidt and Welsh's (2010) findings suggest the impact of a family member's illness can be positive, negative, or both. Regardless, these students experience adjustment differently than peers who do not have these challenges. While their study doesn't directly attend to parental illness, their findings hold important implications for what factors might lead to positive adjustment and what factors might contribute to poorer adjustment.

Crandall, Ruggero, Bain, and Kilmer (2014) examined parental illness specifically in exploring the adjustment difficulties and caregiving burdens faced by college students with a parent diagnosed with a bipolar or depressive disorder. Although rarely publicly acknowledged, “students on college campuses often come from families where one or more parent has been affected by a bipolar or depressive disorder” (p. 53). Their findings suggest these students do have more difficulty adjusting to college, largely related to their increased caregiving responsibilities. Maunu and Stein (2010) also explored the role of parental mental illness on the college student experience and how faith and spirituality relates to meaning-making of parental illness. They, too, acknowledged how little has been done to explore this student population and their experiences. The three aforementioned articles demonstrate not only that these students have significantly different concerns that complicate adjusting to and participating in the traditional college experience, but also that this student population is invisible and under-researched.

### **Purpose Statement**

The purpose of this study was to examine the impact of parental illness on the traditionally-aged college student experience at a public, four-year institution. Many studies have examined the experience of children or adults who had a parent develop a significant illness, and many studies have explored attachment theory, coping, and identity/relationships, but very little research has identified how this experience impacts the collegiate experience for traditionally-aged students. I wanted to explore this atypical stressful event to illuminate an experience that is typically invisible.

### **Significance of Study**

Parental illness has a profound, unique, and often invisible impact on the traditionally-aged college student experience. Although researchers explore traditional transitions and ways of navigating roles within the familial unit and the collegiate environment, they ignore circumstances – such as parental illness – that complicate this experience. Of the three articles that specifically attend to the impact of parental or familial illness (Schmidt & Welsh, 2010; Crandall et al., 2014; Maunu & Stein, 2010) on the college student experience, only Maunu and Stein (2010) utilized a qualitative research design. Therefore, this study is be formative in establishing a strong body of research that illuminates the voices and experiences of this unique student population. In addition, this study provides educators and administrators with insight regarding which institutional resources might need additional attention or promotion.

### **Research Questions**

The grand tour question was: What is the impact of parental illness on the traditionally-aged college student experience at a public, four-year institution? In order to identify the experiences and challenges faced by this invisible and overlooked population, the following sub-questions were established:

- What are traditionally-aged college students' initial feelings and concerns when they learn of their parent's significant illness given their role in the family and the context surrounding the development of the illness?
- How has the development of their parent's significant illness impacted their collegiate experience?
- In what ways have they sought and received support within and outside of the institution?

- What can institutions do to support these students' unique needs?

This study was established to provide students the opportunity to reflect on their unique experiences as traditionally-aged college students who have had a parent develop a significant illness and how that has impacted their time in college, and for student affairs practitioners to understand this student population's unique needs and identify institutional resources that can assist this invisible population.

### **Research Design**

This study was conducted using a constructivist paradigm and a narrative analysis methodology and examined the subjective experiences of this population at a large, public research university in the Midwest. I chose this methodology to allow participants' voices to illuminate the ways in which they recognize and manage their experiences. Semi-structured interviews allowed me to collect meaningful data that reflected elements of common and unique experiences related to the impact of parental illness on participants' collegiate experiences.

### **Definition of Terms**

The following are terms used throughout this report to describe the impact of parental illness on the college student experience. These definitions help specify conditions for participation in this study and provide additional insight regarding the experiences of this population.

*Home:* This term refers to where the family – including the participant and their parent with a significant illness – lived together as a unit. If parents have separated, this may or may not be the primary residence of the student.

*Parent:* I use this term to refer to either a biological parent or step-parent who has played a significant role in the life of the participant prior to and during their collegiate experience.

*Significant Illness:* For the purpose of this research, significant illness was defined as a mental or physical illness or disability diagnosed by a medical professional that is either chronic or terminal and developed at some point during, or at most 12 months prior to, the participant's collegiate experience.

*Traditionally-Aged Student:* I have identified a traditionally-aged student as a student who is 19-22 years old.

*Transitional Period:* For the purpose of this research, transitional period is defined as the first semester of college, in which students are living on campus and are separated from the familial unit.

### **Delimitations**

I set boundaries for the study, which serve as delimitations of the research. Age of the participants, the type of illness developed by the participants' parents, and when the participants' parents developed their illness, all served as criteria in determining participant eligibility. The methodology and research design were chosen to provide an authentic account of the experiences and needs of students who have a parent develop a significant illness during their collegiate experience. Study volunteers were contacted and scheduled on a first-response basis in order to maintain equal opportunity for eligible students to participate. Surveys and other quantitative data procurement practices were not utilized because they do not provide authentic accounts of participants' experiences

and needs. All participants were students at the same large, public research institution in the Midwest.

### **Limitations**

My positionality as a researcher with a similar experience as the participants could be identified as a limitation. While one of my parents has a significant illness that strongly impacted my collegiate experience, the development of this illness occurred before I was born. Therefore, while I understand some of the challenges my participants experienced, I can never fully understand their unique circumstances.

This study featured a sample of three students from similar racial and geographical backgrounds and who have a parent with a significant physical illness. Two of the three participants identify as men, which led to a gender imbalance in the study. While the participant sample was small, which could be regarded as a limitation, I was able to gather significant insight into what some students who share this identity experience. The purpose of this qualitative study was not to encapsulate and generalize the challenges associated with parental illness on the college student experience; instead, it was to provide insight into unique challenges and concerns.

Since I identify in many ways with the population I explored, I had preconceived notions regarding how my participants understood and coped with the challenge of having a parent develop a significant illness. Therefore, I utilized two peer reviewers and conducted member checks to ensure my bias did not impact the reporting of my findings. My participants necessarily framed their stories and experiences to fit the questions within and outside of my semi-structured interview protocol. Therefore, it is possible my

questions suggested they interpret or make meaning of their experience in ways they might not have otherwise considered.

Time was another limitation in the study. As this study was a graduation requirement, conceived and carried out during one academic year, solicitation of participants and a comprehensive exploration of their experiences were limited.

### **Conclusion**

Higher education in the United States often fails to acknowledge the role of the familial unit in students' collegiate experiences. What little is acknowledged about this role fails to account for the impact of parental illness on the college student experience – a burden that impacts both social and academic experiences for students.

## **Chapter 2**

### **Literature Review**

In a review of the literature explored on this topic, four themes emerged: attachment and coping, identities/relationships, literature related to familial or parental illness, and parental illness within higher education. These four themes provide a general understanding of how students navigate the independence and autonomy afforded by a traditional, residential collegiate experience. This literature provides important insight and foundational knowledge regarding college student development and adjustment. Therefore, it is important to consider what we know about the typical student's experience in order to develop a stronger understanding of how a unique circumstance, such as the impact of parental illness, might challenge what we know and how we establish support for all students.

#### **Attachment and Coping**

The adolescent-parent relationship as it relates to college students has been explored for more than 20 years, with separation-individuation being explored as a function of adjustment. Findings suggest "adolescents who are securely attached to their parents are thought to more easily negotiate the process of individuation and to adjust to new situations such as the college environment" (as cited in Schultheiss & Blustein, 1994, p. 249). In addition, a "close emotional bond with parents is related to a positive family concept, a positive social self-concept, emotional well-being, self-esteem, and life satisfaction" (as cited in Schultheiss & Blustein, 1994, p. 249). These findings indicate the importance of considering parental attachment within the context of the college transition.

Schultheiss and Blustein (1994) also identified the impact of differences in context and gender on separation and attachment. Their study found that attitudinal dependency, the sharing of similar attitudes and beliefs, and emotional attachment to both parents, likely promotes effective progress in the development of purpose and academic independence for women. In addition, what Schultheiss and Blustein (1994) defined as conflictual independence – an “absence of guilt, anxiety, resentment, and anger in the adolescent-parent relationship” – was not an important factor for women (p. 253). For men, psychological separation and parental attachment were not significantly related to college student development. However, conflictual independence was important – men with conflict absent in their parental relationships were found to often be more adaptive in their functioning (Schultheiss & Blustein, 1994).

Overall, Schultheiss and Blustein (1994) suggested “additional research is needed to assist in identifying the essential contextual factors for various developmental and adjustment variables in clarifying their unique association with family relationship factors” (p. 254). For students in the transitional period who experience a parent developing a significant illness, secure attachment and a close emotional bond might exacerbate the impact of this experience, alter the parental-adolescent relationship, and make it more difficult for students to achieve the typical stage of individuation. Given the call for increased attention focused on contextual factors that influence development and adjustment, as well as the fact that research is inconclusive regarding the role of conflictual independence, and the notion that conflictual independence might not be possible after such a shift in the parental-adolescent relationship, it is important that

research explore the impact of parental illness on the traditionally-aged college student experience.

Lapsley and Edgerton (2002) also explored components of the adolescent-parent relationship as it relates to attachment, separation-individuation, and college adjustment. Their findings suggested, “the developmental task for the young adult is to flexibly manage the ongoing dialectic between separation and connectedness, while avoiding the undesirable outcomes of fusion and enmeshment, on the one hand, and complete detachment and isolation, on the other” (Lapsley & Edgerton, 2002). This process is influenced by the physical separation college students and parents experience during the transitional period, and the fact that students must make important decisions regarding their career and identity more independently than other larger decisions, such as where to pursue postsecondary education.

Lapsley and Edgerton’s (2002) findings, that conflictual independence from parents could result in a secure attachment style, align with and support the conclusions made by Schultheiss and Blustein (1994). Lapsley and Edgerton (2002) concluded that conflictual independence also relates to and informs how college students form and make sense of relationships with others; college students with secure attachment are less likely to have preoccupied attachment that makes them question whether they are unlovable or unworthy. Their findings also suggested that positive feelings regarding parental separation, conflictual independence, was the best predictor of adult attachment style and positive social and emotional college adjustment.

This additional support for the value and importance of conflictual independence provides further evidence that students who do have conflictual dependence – in terms of

attitudinal, functional, or emotional dependency – have more difficulty adjusting in college. Since students who experience one of their parents developing a significant illness might find themselves becoming more dependent on their parental relationship(s), it is important to understand what these students experience and how the collegiate environment can provide resources to improve their adjustment. The literature does not address this type of dependence, nor does it explore the reverse: ill parents becoming more dependent on the student, thus inhibiting the development of independence.

Research conducted by Wei, Heppner, and Mallinckrodt (2003) adds to the aforementioned findings by looking more specifically at college students' perceived ability to cope, rather than adjustment, related to parental attachment and psychological distress. Their results suggested perceived coping mediates the relationship between attachment anxiety and psychological distress. In addition, psychological distress can be predicted by attachment anxiety and avoidance. More specifically, "persons with anxious and avoidant attachment appraise their coping capabilities across problems in general as more ineffective" (Wei et al., 2003, p. 445). After making these conclusions, the authors made recommendations about how to assist students struggling with attachment and coping.

Wei et al. (2003) suggested a focus on increasing students' coping effectiveness could help minimize their distress. Helping students to acknowledge the relationship between poor coping strategies and their attachment patterns can be an important first step in either creating better coping strategies or increasing awareness of how to effectively use coping strategies effectively. This research, therefore, illuminates the importance of understanding the strategies students use when coping with their parent

developing a significant illness. It is important to acknowledge that since parental attachment might be impacted and altered by this experience, students' coping strategies may also change. Helping students understand this relationship can create awareness and hopefully lead to the development of new and effective coping strategies.

Secure parental attachment is related to successful college adjustment (Lapsley & Edgerton, 2002; Schultheiss & Blustein 1994), and coping strategies (Wei et al., 2003). Hiester, Nordstrom, and Swenson (2009) acknowledged the importance of parental relationships in the college transition process and focused more specifically on how these relationships are impacted and renegotiated within the context of students' transition to college during the first semester. These authors focused on this time frame because it is seen as "an important developmental milestone...and journey into emerging adulthood" (as cited in Hiester et al., 2009, p. 521). Adolescents have more autonomy and responsibility to balance their social and academic responsibilities within the collegiate environment. At the same time, they are often exploring their identity within a context completely different from their familial unit. Like Schultheiss and Blustein (1994), Hiester et al. (2009) explored differences in parental attachment for male students compared to female students.

Their findings, that "parental attachment was significantly related to self-competence, psychological distress, and college adjustment" (Hiester et al., 2009, p. 534) echoed previous research (Lapsley & Edgerton, 2002; Schultheiss & Blustein 1994; Wei et al, 2003). In contrast to findings by Schultheiss and Blustein (1994), gender differences did not appear to impact separation-individuation, and, therefore, parental attachment (Hiester et al., 2009). Men and women did not have significant differences in

reported levels of parental trust, communication, or alienation. According to Hiester et al. (2009), “male and female college students who perceived a more secure attachment to parents (higher trust and communication and less anger and alienation) perceived themselves as more competent, experienced less psychological distress, and experienced better adjustment to college” (p. 535). While gender differences were not seen in these results, patterns of influence related to parental attachment were evident by other findings from these authors.

According to Hiester et al. (2009), “both male and female students who felt angry with and alienated from their parents were more likely to perceive themselves negatively and report adjustment difficulties” (p. 535). Men who have these adjustment experiences might, however, have a bolstered sense of independence, which could positively impact college adjustment. Women might feel inadequately supported from an emotional standpoint and therefore may have more difficulty adjusting. While these experiences may not be reflective of every male or female student, Hiester et al. (2009) suggested it is important to explore the ways in which gender might influence parental attachment. They also suggested that the influence of parental attachment on adjustment might not be a linear relationship; successful or unsuccessful college adjustment may have an impact on parental attachment.

Hiester et al.’s (2009) findings suggest it is important to acknowledge how the transition to college affects parental attachment and adjustment. At the same time, their study does not acknowledge how a stressful life event, such as a parent developing a significant illness during this transitional period, might complicate the typical factors influencing parental attachment and adjustment. Adjustment and parental attachment are

found to play a significant role in the transition to college; therefore, exploring factors that complicate and make the transitional experience challenging should be a focus for student affairs practitioners.

### **Identities/Relationships**

Skowron, Wester, and Azen (2004) also explored the connections between family relationships and college adjustment. They, too, suggested, “the relative success with which an individual manages the stress inherent to university life may be tied to experiences in family relationships regarding emotional regulation, support, and opportunities for autonomy” (Skowron et al., 2004). Citing Bowen (1978), they introduced the concept of differentiation of self, or the “balance of both autonomy and connection” (Skowron et al., 2004). In their exploration of the literature, Skowron et al. (2004) illuminated research suggesting both male and female students who are more differentiated from their family can better cope with stress, act more autonomously, and experience better psychological adjustment. Their findings supported this prior research and indicated “the association between college related stress and actual level of personal adjustment is accounted for, in part, by one’s capacity to regulate emotional reactivity, maintain connections with others, avoid emotional cutoff, and yet take I positions in important relationships” (Skowron et al., 2004, p. 75). Since the impact of parental illness can affect the mediating components identified by Skowron et al. (2004), literature about differentiation of self should be considered when exploring this topic.

Rosenberger (2011) discussed another type of differentiation of self in identifying the importance of students creating new peer relationships and “the awareness, development, and establishment of boundaries between their own emerging sense of self

and others in their lives” (p. 11). While it is clear from Skowron et al. (2004) and the research they cited that differentiation of self from the family unit is impactful, Rosenberger (2011) suggested identity formation is also complicated by new experiences with interpersonal relationships. He identified two developmental challenges: “the process of self-discovery and the need to socialize or interact with others in the environment to satisfy certain needs” (Rosenberger, 2011, p. 13). Further, Rosenberger (2011) discussed how many students experience an environment in which their parents are not present in a daily capacity and that this allows the student to make their own decisions and discover their internal resources. In addition, he also discussed the fact that “students must identify others within the community with whom they can comfortably interact” (Rosenberger, 2011, p. 13).

While Rosenberger (2011) explicitly identified the population he wrote about as traditional-age college students, he made a latent assumption that these students have successfully transitioned from their family in identifying that their transitional struggles stem from the challenges of developing new interpersonal relationships. Students who experience the impact of parental illness challenge Rosenberger’s (2011) findings. Although these students’ parents may not be physically present on a daily basis, their struggles and needs might be constant considerations. Also, since this population is often invisible, they may not be able to identify others who might understand their concerns and/or preoccupations. While Rosenberger (2011) and others identified developmental and transitional concerns, their suggestions for student affairs professionals’ consideration and support are not all encompassing.

Coping, adjustment, differentiation, and transition experiences can be significantly different and produce different stressors that have been largely unexplored in the literature. According to Frazier and Schauben (1994), “the few studies that have assessed the prevalence of more traumatic life events reveal that a considerable number of students...have faced major life crises either before or during college” (“Introduction,” para. 2). Frazier and Schauben (1994) looked at how female college students experienced stressful life events and psychological adjustment. They suggested existing research typically generates a list of potential crises or stressors, often ignoring significant issues faced by students. Results of their study indicated that 20% of the 282 female undergraduate student participants experienced the death of a partner, friend, or family member and felt it was “the most stressful life event they had ever experienced” (Frazier & Schauben, 1994, “Results,” para. 3). The fact that death of a family member is included, but the impact of parental illness on the college experience is not, provides further evidence that there are significant student experiences that remain invisible holistically and in unique aspects of the college experience.

### **Literature Related to Familial or Parental Illness**

Williams and Corrigan (1992) are some of the first researchers who explored and published the impact of parental alcoholism and mental illness on undergraduate and graduate students. Their findings suggested participants who felt they came from a dysfunctional family “had lower self-esteem, greater depression, and more social anxiety than peers from perceived ‘normal’ families” (Williams & Corrigan, 1992, p. 411). In addition, even children who only perceived that their parent abused alcohol or were mentally ill had more difficulty with adjustment. They also found that social support

served as a mediator, with depression and anxiety being less prevalent for subjects with strong support systems. Since the period of transition to college often involves the formation of a support system, students experiencing the impact of parental illness while in the beginning stages of collegiate transition might have more difficulty adjusting successfully.

There is a large gap in the literature exploring this topic after Williams and Corrigan (1992) published their findings. Schmidt and Welsh (2010), nearly 20 years later, researched the adjustment experiences of university students facing chronic or terminal illness of a family member. They directly acknowledged the lack of research regarding this unique challenge for college students, as the research has typically only examined the experiences of spouses or the patients themselves. According to Schmidt and Welsh (2010):

Because college students are generally at a crossroad in their identity development, the predictors of...well-being and adjustment during a time of crisis intersect with the move toward autonomy that is typical of individuals at this phase of life. Attachment, coping style, and social support are among variables that have been found to be integral to subjective well-being in this time of transition. But for college students coping with the illness of a family member, it is unclear [how] subjective well-being or...specific illness-related variables will play a...role. (p. 397)

Their research explored well-being and adjustment variables and also provided recommendations for counseling and how to help students facing this burden.

Typically, students entering the college environment attempt to and do gain independence from family. In this process, they navigate new social and academic concerns and develop a new sense of self. Schmidt and Welsh (2010) argued:

When a crisis such as a family members' illness arises, these normative concerns may become interrupted, exaggerated, or difficult to navigate, and the student's adjustment may suffer. Alternatively, it is possible that such an event would cause the student to cope more effectively in light of the bigger issue at home. (p. 397)

The authors referenced literature related to attachment, coping, and social support to showcase how these variables related to college adjustment and subjective well-being. The results of their study demonstrate how the impact of familial illness influences these factors.

Schmidt and Welsh's (2010) findings produced evidence for both positive and negative impact on adjustment to college while coping with a family member's illness. They suggested "for individuals who do not have adequate coping mechanisms in place prior to a crisis such as a family member's illness, subjective well-being is likely to suffer when the perception of that crisis is particularly severe" (Schmidt & Welsh, 2010, p. 403). These individuals generally had a high level of perception of their family member's illness and perhaps having a more salient awareness contributed to poor adjustment for these students. On the other hand, another group of students was more emotionally distant regarding their family member's illness. These students had a more positive affect and were less likely to use denial or emotional venting as forms of coping. While this group still had low scores on social support, college adjustment, and life

satisfaction, and therefore may still have been suffering significantly, it is possible they had some ability to cope effectively.

The researchers' use of an open-ended Internet survey, as opposed to the quantitative methods utilized by most of the prior, related research, allowed them to collect reflections that extend beyond conclusions regarding the aforementioned variables. For example, participants were able to share that their social adjustment and experiences often involved a negative experience such as "withdrawing from friends or having limited time to spend with friends because of family demands" (Schmidt & Welsh, 2010, p. 403). Other students shared experiences of positive social adjustment wherein they developed stronger relationships with friends or relied more on their social support. In terms of academic adjustment, students also had two conflicting types of experiences (Schmidt & Welsh, 2010). About half of the students had additional motivation to perform well academically, whereas the other half found it difficult to concentrate or spend time on academics. In terms of personal adjustment, more students experienced negative personal or emotional change. These students often cited feeling burdened by the illness. Students who experienced positive effects shared feelings of growing from the hardship (Schmidt & Welsh, 2010).

Overall, Schmidt and Welsh (2010) suggested that those "working with individuals dealing with a family member's illness strike the appropriate balance between acknowledging the stress of their unique situation and focusing on enhancing relationship attachments, social support, and coping" (p. 404). The impact of familial illness of students can vary based on variables such as adjustment, attachment, and coping, as well as the relationship between the student and the family member, and the severity of the

illness. These differences provide evidence for the importance of hearing more student voices regarding their experiences with this type of crisis. The fact that “university students as a group have not been studied regarding this challenge,” despite evidence of a significant impact on the collegiate experience, is concerning and identifies a shortcoming in the services and support provided by higher education institutions (Schmidt & Welsh, 2010, p. 398). Therefore, it is important that research continues to explore the experiences of students dealing with this stressful life event.

Maunu and Stein (2010) added to the literature by exploring the personal loss of nine undergraduate students with a mentally ill parent. They, too, examined coping skills; however, they specifically looked at how this unique experience impacts students’ religious faith and spirituality. The authors suggested the impact of mental illness can be substantial, as the personal loss associated with a family member’s mental illness can be as significant as loss related to death of a family member (as cited in Maunu & Stein, 2010). Participants were split into two groups: a larger loss group and a smaller loss group, with placement based on the amount of personal loss identified by the participants. Findings suggested there are “five types of personal loss that included loss of social roles, loss of former relationships, loss of sense of self, loss of normal routine, and loss of a sense of the future” (Maunu & Stein, 2010).

In terms of faith journey, participants in the smaller loss group were more content with their spirituality whereas participants in the larger loss group tended to share that they were unsure of their spiritual journey (Maunu & Stein, 2010). Most participants identified some degree of spiritual struggle related to coping with their parent’s mental illness, with those in the smaller loss group feeling less of a struggle and those in the

larger loss group having divine, interpersonal, and intrapersonal spiritual struggles. Participants in the larger loss group were more skeptical of normal romantic relationships and marriage and also felt impacted more in both an emotional and physical aspect. Both groups identified having a lack of trust in others (Maunu & Stein, 2010).

Despite these negative consequences related to coping with the loss associated with having a parent with a mental illness, most participants identified that they had become “independent,” “stronger,” and “humble” (Maunu & Stein, 2010). Participants in the larger loss group reported fewer positive interpretations of their struggles. Both groups of participants, overall, shared negative and positive outcomes. These findings suggest it is important to acknowledge the individual differences of students while also exploring their shared experience related to loss and illness. Maunu and Stein’s (2010) study “underscores the resilience of young adults who cope with their parents’ mental illness and the potential role that stress-related personal growth might play in their lives” (p. 653). It is important to recognize that illness, whether physical or mental, can produce intense feelings of loss even though typically loss is only associated with death.

Crandall et al. (2014), like Maunu and Stein (2010), also explored the impact of parental mental illness on college students. Their research stemmed from the fact that “college campuses often host students who come from families where one or more parent has been affected by a bipolar or depressive disorder” (Crandall et al., 2014, p. 47) and utilized semi-structured interviews and self-report measures to examine students’ experiences of caregiving burden. While it is unknown how many students have this experience, 20.8% of individuals in the U.S. experience a depressive or bipolar disorder during their lifetime (as cited in Crandall et al., 2014). The authors shared that it is also

unknown what impact these mental illnesses have on a family and, in particular, offspring. Prior research suggests these offspring are at a greater risk of experiencing mental illness, in the form of depression or anxiety, especially when there is conflict within the family, or suicidal behavior (as cited in Crandall et al., 2014). It is important to consider how this can complicate a student's transition to college.

Their findings provide support for a significant impact on the college student experience. Crandall et al. (2014) found students who have a parent with mental illness reported significantly poorer adjustment compared to students coming from a family where a mood disorder was not present. In addition, these students reported an increased caregiving burden. While some of these students were also affected by mood disorders, all students in this situation may benefit from additional support and resources, according to Crandall et al. (2014). They suggested "psychoeducation groups...focused on coping with an ill family member may be an approach to helping students who face these burdens" (as cited in Crandall et al., 2014, p. 56).

### **Retrospective Studies.**

A few studies explore the impact of mental or physical illness from a retrospective view, in which adults or adolescents reflect on their experiences coping with this hardship as adolescents or children, respectively. Klimes-Dougan and Lee (2008), after assessing 139 young adults in a longitudinal study, suggested offspring of parents, particularly mothers with mood disorders, have an increased risk for suicide. Stoeckel, Weissbrod, and Ahrens (2014) utilized undergraduate participants to explore the association of dispositional gratitude, characteristics of parental illness, and family characteristics with depression and anxiety. Participants were split into two groups - all

lived apart from their family of origin - and provided a glimpse into their experiences growing up with an ill or healthy parent. Their research holds important implications for the impact of parental illness on the college student experience, as how children experience growing up often affects their life post-living at home.

Stoeckel et al. (2014) suggested that children often become leaders in the household when parents are ill; “Children will be ‘parentified,’ taking on more responsibility than appropriate in order to compensate for their parents’ deficiencies” (as cited in Stoeckel et al., 2014, p. 1). While they identified negative consequences, such as being “parentified” and having trouble with adjustment, Stoeckel et al. (2014) also suggested the impact of parental illness could be positive, with adults having more empathy, stronger familial relationships, and viewing loss in an optimistic way. The authors identified the concept of dispositional gratitude, a “life orientation towards noticing and appreciating the positive” (as cited in Stoeckel et. al, 2014, p. 2). Their findings, like those of Maunu and Stein (2010) and Schmidt and Welsh (2010), suggest this experience can have a positive impact despite evidence of difficulty.

In addition, Stoeckel et al.’s (2014) findings provide additional insight into what students may experience if they have an ill parent. Stoeckel et al. (2014) suggested dispositional gratitude moderates the internalization of the event, evidenced by depression, anxiety, and family quality of life, illuminates ways in which students can adapt to the situation, cope more effectively, and utilize resiliency. Challenges faced by students as a result of familial disruption and new role demands still include lower psychological well-being and more social, behavior, and academic struggles, according to Stoeckel et al. (2014), consistent with previously identified research on this topic. While

the experiences of their participants help explain the ways in which children can be impacted by a parental illness, they do not directly reference the undergraduate student experience under these same circumstances. The findings of Stoeckel et al. (2014) do, however, suggest these individuals have additional burdens that are sometimes experienced negatively and positively, impacting students' role in the family and their priorities.

In a study exploring emotional and behavioral functioning of cancer patients and their family members, Visser et al. (2005) provided both the perspective of children, aged 4-18, impacted by parental illness, and the parent's perception of the child's functioning. This research, conducted in the Netherlands, illuminated the importance of ill parents recognizing the needs and concerns of their children. Visser et al. (2005) suggested boys might have more difficulty expressing themselves and their feelings because of their language and social-emotional maturity, thereby fueling more distress. In addition, they found that girls tended to have more caretaking responsibilities and be more involved in providing emotional support, especially for ill mothers. In these ways, girls often experienced more of a burden (Visser et al., 2005). This concept is similar to that of being "parentified," as identified by Stoeckel et al. (2014, p. 1). Daughters, according to Visser et al. (2005), also tended to experience more sensitivity related to stress and interpersonal concerns, making them less likely to effectively cope with parental illness. Overall, the results of Visser et al. (2005) suggested problems for children coping with parental cancer tend to be internalized in the form of anxiety or depression compared to externalized problems in the form of aggression or delinquency.

Kinsella and Anderson (1996) also utilized a retrospective approach as they explored the impact of mentally ill adults on offspring and siblings. They suggested:

Mental illness is, by its very nature, a familial experience. A single family member may exhibit symptoms, receive a diagnosis, and undergo treatment, but because of the interdependence that exists within a family system, each and every family member is affected in some specific way. (Kinsella & Anderson, 1996, "Introduction," para. 2)

While offspring and siblings ranged in age from 27-56, well beyond the traditional college age, the three themes that emerged from their findings, coping skills, needs, and strengths, mirror what has been established in the literature as components of the impact of familial illness.

In terms of coping skills, participants discussed both healthy and unhealthy methods of coping (Kinsella & Anderson, 1996). Kinsella and Anderson (1996) described coping skills identified by the participants, including: attempting to escape their environment, either physically or mentally, seeking support, objectifying the illness, acquiring information, relying on spirituality, self-censoring, and self-isolation. Participants also shared their needs, which included a desire for information/explanation, support groups/normalization, individual attention and attention to emotions, and inclusion in the treatment process. Strengths established by participants as they coped with familial mental illness included independence, creativity, empathy, resiliency, assertiveness, and spirituality (Kinsella & Anderson, 1996). Kinsella and Anderson's (1996) research bolstered evidence for the unique needs of this underserved population. They suggested "siblings and offspring in particular remain largely without appropriate

services that could enhance their ability to adapt and cope with the burden of mental illness” (as cited in Kinsella & Anderson, 1996, “Implications & Recommendations,” para. 1). Despite indication of positive coping mechanisms, it is clear that family members have additional burdens and challenges to overcome when coping with familial illness.

### **Parental Illness Within Higher Education**

Some institutions, such as Purdue University, and others with chapters of Students of Ailing Mothers & Fathers Support Network, a national support network for “college students supporting college students grieving the illness or death of a loved one” (Students of AMF, 2015), have publicly acknowledged how the role of grief related to death or family illness can impact the collegiate experience. According to a Purdue professor, as cited by Neubert (2012), “even though losing a loved one or being away from a seriously ill parent is common for college students, many can feel isolated when balancing school and family issues” (para. 1). Identifying this experience as “common” is difficult when the number of students experiencing it is not tracked.

Servaty-Seib, a psychologist and professor, also identified some of the social and academic challenges. Students often internalize their stress and sadness because they don’t want it to define their peer relationships. They typically feel a sense of guilt, either from their focus on academics or financial issues (as cited in Neubert, 2012). Servaty-Seib suggested:

Balancing the role as academic-focused student and the child of someone who is very ill is not easy. Often, well-meaning parents don’t communicate about the illness or daily problems to their children because they are protecting them. Sick

family members often request that the student stay at school and focus on being a student. But then the student is at school worrying. And when the student is home, then they are worried about academic challenges. (as cited in Neubert, 2012, para. 5)

While some schools provide official grief absence policies and have relevant student groups, in addition to counseling services, not all do. At large institutions, these policies can make a difference in these students' lives (Neubert, 2012). Hamilton, the Assistant Dean of Students at Purdue, shared that students experiencing this hardship "...are forced to grow up faster when they need to be home on weekends to help care for a sick parent or younger siblings. It is very hard on them and can affect their success as a student" (as cited in Neubert, 2012, para. 9).

Although grief absence policies do not always provide a sufficient amount of sanctioned time away from collegiate responsibilities, institutions typically acknowledge death as a legitimate occurrence that deserves accommodations. What this group makes clear is that there is, just now, a push for students coping with significant, often prolonged illness, to have their experiences acknowledged. This can be difficult logistically, as illness can have a lasting impact and does not always have a clear "end."

While the experience of transition to the collegiate environment has been explored, nuanced challenges associated with unique individual and familial circumstances are, for the most part, ignored. The little research that does focus on these challenges, more specifically those that result from having a parent with a significant illness, is largely quantitative. Only one article identified in the review of literature

directly related to this particular experience utilized a qualitative approach and included the voices of participants.

It is important to recognize that the same challenges – anxiety, depression, difficulty coping, caregiving burden, adjustment difficulty, and more – have been identified consistently by the literature exploring the concept of the impact of parental illness. Some key areas, however, have not been explored and should be examined in order to best serve this population. Albeit limited, the literature has examined the positive and negative aspects experienced by both children and college students. Much of this research does not discuss how living in an environment outside the family unit in which the illness is prevalent alters these experiences. What research exists is overwhelmingly quantitative, providing findings that, although significant, fail to introduce voices speaking to the impact of parental illness.

Children younger than 19 are significantly impacted by this experience, but they often have different concerns, both personally and educationally. The college student experience is particularly unique because these individuals are encouraged and expected to adopt a lifestyle of independence, both socially and academically, in order to truly take advantage of the “college experience.” When a parent becomes ill, priorities might shift back to the family unit, straining adjustment and success in what is usually a completely separate environment. This study is valuable in that it identified and explored a significant life event that mediates the traditional transition to college and the overall collegiate experience.

## Chapter 3

### Methodology

#### Introduction

This qualitative study not only illuminated the impact of parental illness on the traditionally-aged college student experience – an experience the literature has overwhelmingly failed to capture – but also utilized participants’ voices to generate an understanding of a personal experience that has historically been distorted through self-report measures, inventories, and tests. What *are* the feelings and concerns of these students when their parent’s significant illness first develops and throughout its existence? How is their family and their personal life affected given their role as a traditionally-aged collegiate student? What support systems are utilized and how can institutions of higher education effectively provide resources that can assist students who encounter these challenges?

A qualitative approach is one in which the researcher makes observations and allows others to develop and share their own experiences. Researchers then attempt “to make sense of, or interpret phenomena in terms of the meanings people bring to them” (Denzin & Lincoln, 2000, p. 3). This qualitative study utilized a constructivist approach with a narrative analysis to reflect the socially constructed reality (Mertens, 2010) of students who experience the significant illness of a parent. This research paradigm and approach were chosen intentionally in conjunction with the interview approach. This study utilized a semi-structured interview approach to garner information from three participants (Mertens, 2010, p. 20). This interview approach allowed participants to

articulate their own experiences and perceptions of the way their parent's illness has impacted their identity and role as a traditionally-aged college student.

### **Researcher Paradigm**

Research paradigms are intricately linked not only to how the researcher is situated in the world, but also to how the researcher makes meaning of the world. Therefore, the researcher's philosophy and methodological approach to a study is important because it reflects both a desired approach to research and the conscious and unconscious biases and predilections inherent in and compatible with a research framework (Maxwell, 2005). As previously identified, I, and this particular study, operated from a constructivist paradigm.

According to Crotty (1998), "what constructivism claims is that meanings are constructed by human beings as they engage with the world they are interpreting" (p. 43). This approach values the perspective of the individual, who provides a contextual account of their experiences. Therefore, the knowledge produced inherently reflects a unique worldview (Jones, Torres, & Arminio, 2006). Researchers are also involved in interpretation, as they make meaning of the research through their own lens, values, and life experiences (Mertens, 2010). According to Guba and Lincoln (2005), "the ontological assumption associated with constructivism [is] that reality is not absolute, but is socially constructed and that multiple realities exist that are time and context dependent" (as cited in Mertens, 2010, p. 226). The constructivist paradigm necessarily impacts the research approach, as the approach must be consistent with the philosophy of the paradigm and provide a way for participants to share their stories and realities. I utilized the constructivist paradigm in that the stories shared by the participants were co-

constructed. I influenced what the participants shared in determining the research questions, developing the semi-structured interview protocol, and sharing parts of my own story. Participants made meaning of their experiences through the lens I established.

### **Research Approach**

Narrative analysis complements the constructivist paradigm because of its focus on meaning making. In addition, narrative analysis provides and values unique stories while also exploring the ways in which individuals choose to share these stories (Mertens, 2010). According to Chase, Denzin, & Lincoln (2005):

People grow to *constitute* the empirical material that interviews need if they are to understand how people create meanings out of events in their lives. To think of an interviewee as a narrator is to make a conceptual shift away from the idea that interviewees have answers to researchers' questions and toward the idea that interviewees are narrators with stories to tell and voices of their own. (p. 218)

Although all participants have an overall shared identity, unique circumstances such as the type of significant parental illness, the relationship of the student to their ill parent, and the length of the illness, among others, impact not only the saliency of the identity but also their story.

The narrative approach requires an interpretive process in which “rather than locating distinct themes *across* interviews, narrative researchers listen first to the voices *within* each narrative” (Chase, Denzin, & Lincoln, 2005, p. 221). Therefore, this research approach contributes to both individual and collective experiences, attending to the nuances experienced by individuals and establishing support mechanisms useful for the overall population.

## **Participants**

The participant criterion for this study was both restrictive and liberal. The criterion was restrictive in that the population was limited to traditionally-aged (19-22) undergraduate students who have a parent with a significant illness. The criterion was liberal in that significant illness is a relatively open definition. As stated in chapter 1: for the purpose of this research, significant illness was defined as a mental or physical illness or disability diagnosed by a medical professional that is either chronic or terminal and developed at some point either immediately prior to or during the participant's collegiate experience.

Recruitment of participants was conducted via snowball sampling and outreach to campus Academic Advisers. In the technique of snowball sampling, I started with one potential participant. Then, I asked that person to identify others who might share the experience that made them eligible for the study. According to Esterberg (2002), "in this way, [the] sample 'snowballs.' In fact, for 'hidden' populations...this may be the only way to recruit interviewees" (p. 93). A student who had already disclosed to me that her dad developed cancer during her first semester at Midwest Regional University (MRU) was approached first via email regarding the study. A few weeks later, the faculty advisor sent a recruitment email to all Academic Advisers at MRU.

The student who had already disclosed having this experience did not respond to the email. Meanwhile, the Academic Advisers were asked to reach out to any students who they knew of who might fit the participant criteria. From this initial recruitment approach, five students volunteered to participate. Three of these students met the study criteria, while two did not. The first ineligible student's parent developed their

significant illness many years prior to them entering college. The second ineligible student was not yet 19. In attempt to expand the number of participants after confirming the three initial volunteers were eligible and interested in participating, the faculty advisor reached out to the Director of Residential Life, fraternity and sorority house directors and advisors, and to a student organization that serves families with cancer. These staff members marketed the opportunity to participate in the study. No more students volunteered to participate after these additional recruitment measures were taken.

Participants were incentivized to participate through a one in three chance of winning a \$25 gift card to a local restaurant. To avoid bias, participants were chosen on a first-response basis. While I had no direct prior relationships with the participants, I did have indirect ties to two participants. My roommate referred one participant to the research study. Another participant was a member of a group I have worked with for over a year. However, I did not interact with this participant in any capacity prior to the interview process. The advisor of the group encouraged the student to participate in the study and referred him to me. Basic demographic information for each participant is listed in Table 1.

Table 1. *Participant Demographic Information*

Interview	Pseudonym	Age	Sex	Race	Year	Major
1	Andrew	21	Male	White	Junior	Anthropology
2	Lisa	20	Female	White	Sophomore	Pre-Secondary Education (Social Science)
3	Jacob	19	Male	White	Freshman	Marketing

Although the two sets of interviews did not focus on these demographic characteristics, it is important to again acknowledge some of the similarities and differences between participants. All participants' permanent residences were in the state of Nebraska. In addition, all participants identified as White/Caucasian. The majority of the participants were male, but all participants varied in age and major. Table 2 includes information regarding the participants' ill parent.

Table 2. *Parental Illness Information*

Interview	Pseudonym	Ill/Deceased Parent (Mother or Father)	Illness Diagnosis	Approximate Number of Years Since Illness Diagnosis	Status of the Illness
1	Andrew	Father	Multiple Myeloma	Four	Remission
2	Lisa	Father	Multiple Myeloma	Four	Parent is Deceased
3	Jacob	Mother	Multiple Sclerosis	Less than a year	Progressing

### **Research Site**

Research was conducted at a large, public, research university in the Midwest. This study will refer to the institution as MRU to protect the identity of the university and its students. MRU is a Predominately White Institution (PWI) and has a residential campus. In Fall 2013, MRU self-reported a total enrollment of 24,445, with 19,376 of those students identified as undergraduates. It is unknown how many undergraduate

students have a parent with a significant illness, as this is a self-report item not collected by the institution.

### **Institutional Review Board (IRB) Approval**

I completed the Consortium for IRB Training Initiative (CITI) training prior to submitting the research proposal to IRB. This training ensured I was knowledgeable of how to conduct research ethically on human subjects. Upon conception of this study, I, with advisement from my faculty advisor, submitted the research questions, protocol, and related documents to IRB for approval. The initial request was for an exempt review, approved by IRB if there is no more than what they term “minimal risk” to participants. IRB instead chose to conduct an expedited review, as they found a potential for “minimal risk” to participants. The risk was identified as the potential for triggering participants. Given this risk, I reminded students prior to the interviews that they might elect to discontinue participation at any time. In addition, prior to and after interviews, I identified the institution’s counseling and psychological services as a resource.

The informed consent document was given to participants via email after confirmation of each student’s desire to participate. Therefore, informed consent was signed prior to participation in the interview. All participants provided written consent to their interviews being audio recorded. Interview transcripts and participants’ personal information was stored online under password protection and on a computer in my possession. This method of collection ensured participant confidentiality. Participants were given pseudonyms to protect their identity and these pseudonyms were utilized in the transcription process. The participants’ true identity was also stored in the online, password-protected database.

## **Methods of Data Collection**

According to Maxwell (2005), qualitative research necessarily involves a relationship between the researcher and participant, as both are stakeholders in creating new knowledge and finding ways to make that knowledge useful. Political, ethical, and philosophical issues inherently impact research and this relationship. Researchers must negotiate and reconcile their research intent and impact in order to illuminate authentic knowledge; this negotiation and reconciliation occurs in a variety of ways, as different research projects involve necessarily different contexts (Maxwell, 2005). Mertens (2010) identified the risks associated with establishing the relationship between the researcher and participants. The role of the researcher as either a friend or stranger is a complicated dichotomy that can enhance rapport and comfort or potentially bias the dialogue.

Researchers must be conscious of the relationship they hope to establish by engaging in self-reflection and recognizing that they are, in some respects, an “instrument for collecting data” (Mertens, 2010, p. 249). Researchers’ values influence data collection methods. In this research study, given the researcher’s commitment to hearing the stories of the impact of parental illness on the traditionally-aged college student experience, a semi-structured interview approach was utilized. According to Esterberg (2002), “although the researcher typically begins with some basic ideas about what the interview will cover, the interviewee’s responses shape the order and structure of the interview” (p. 87). Given the notion that “research questions cannot be definitively established before the study begins,” this approach provided some structure while allowing participants’ experiences to shape the conversation and production of knowledge (Mertens, 2010, p. 20).

All participants engaged in two one-on-one interviews with me. During the initial interview, participants discussed the context surrounding the development of their parent's illness, their role in the family, and their initial feelings and concerns. The initial interview questions were designed to illuminate context and to help me establish rapport with the interviewee. Since the study had minimal risk because of its potential for triggering participants, I was concerned with creating a nonthreatening space during both interviews, but especially during the first, for the participant to share their experiences. During the second interview, participants discussed how the development of their parent's significant illness impacted their collegiate experience and the ways in which they sought and received support within and outside the institution.

Two interviews not only provided an opportunity for participants to "explore a topic more openly and...express their opinions and ideas in their own words," but also an opportunity to establish a rapport that provided comfort and support as the participants shared the more personal details and reflections captured in the second interview (Esterberg, 2002, p. 87). According to Esterberg (2002), developing rapport, or trust, between the primary researcher and the participants is very important. She claimed, "even if participants do agree to an interview, they may not be willing to talk honestly or discuss intimate details about their personal lives if they do not feel some level of trust" (Esterberg, 2002, p. 91).

Another way in which rapport was established was through allowing participants to have control over multiple aspects of data collection. Interviews were conducted in a quiet, private space at the convenience of the participant. These locations included a private conference room in the main campus library, a semi-private area within a library

on campus, and a private conference room in my workplace. In addition, the semi-structured interview protocol empowered participants to control areas of elaboration or direct their story in ways I did not anticipate. I attempted to clarify interpretations regularly to ensure participants' voices were being accurately represented. In self-disclosing my experience with parental illness and supporting students in sharing their story, I believe I built a strong foundation to collect authentic stories and identify areas of support that should be bolstered for this unique and hidden population.

### **Data Analysis**

I utilized a combination of open coding and narrative analysis in order to develop both categorizing and connecting strategies. According to Maxwell (2005), coding is the primary categorizing strategy utilized in qualitative research. Coding often involves, "an initial phase involving naming each word, line, or segment of data," and a focused stage, which "uses the most significant or frequent initial codes to sort, synthesize, integrate, and organize large amounts of data" (Charmaz, 2006, p. 46). Connecting strategies involve an attempt to utilize various methods designed to illuminate the relationships between aspects of the data (Coffey & Anderson, 1996). Narrative analysis is one such connecting strategy and was employed to "identify how people tell stories the way that they do: how they give the events they recount shape; how they make a point; how they 'package' the narrated events and their reactions to them, and how they articulate their narratives with the audience or audiences that hear them" (Coffey & Anderson, 1996, p. 58).

These two strategies were used purposefully to capture the unique aspects of the impact of parental illness on the college student experience and participants' meaning-

making of the challenges associated with this experience, and simultaneously attend to components salient across all participants' experiences. The connecting strategy of narrative analysis was used primarily when analyzing data from the first sets of interviews with participants. The first interview focused on the development of the participants' parents' illness and allowed the participants to articulate their experiences. Therefore, it is important to consider that "individual narratives are situated with particular interactions and within specific social, cultural, and institutional discourses" (Coffey & Anderson, 1996, p. 62). Coding these experiences could have been reductive, as the participants' voices might have been manipulated into themes that would not necessarily accurately reflect the nuances of their experiences.

According to Coffey and Anderson (1996):

Analytically, recognition that social actors organize their biographies narratively provides a potentially rich source of data. How social actors retell their life experiences as stories can provide insight into the characters, events, and happenings central to those experiences. How the chronicle is told and how it is structured can also provide information about the perspectives of the individual in relation to the wider social grouping or cultural setting to which that individual belongs. (p. 68)

This approach allowed me to maintain the integrity of the participants' individual stories and also develop an understanding of broader implications.

The categorizing strategy of coding was primarily used to analyze data from the second interview, an exploration of the concerns of and resources for these students. During the initial coding phase, I utilized Charmaz's (2006) recommendations:

- Remain open
- Stay close to the data
- Keep your codes simple and precise
- Construct short codes
- Preserve actions
- Compare data with data
- Move quickly through the data (p. 49)

During focused coding, I attended to the codes that appeared most frequently and seemed most significant. Then, I determined broader themes to incorporate the categories of data (Charmaz, 2006).

The data analysis process began prior to the third participant's second, and final, interview. I coded in order to identify preliminary findings for a conference presentation on my thesis topic. During this process, I reflected constantly on my own position as the researcher and as an individual who identifies with the population being explored. I reviewed the transcriptions multiple times and used colored highlighters to identify categories. My two peer reviewers read the introduction, literature, and methodology sections, providing feedback and suggestions, prior to reading the full thesis. Member checks were conducted to allow participants the opportunity to question or support my understanding and interpretation of their experiences. After participants completed their second interview, they were sent transcriptions of our conversations and encouraged to provide clarification and suggest minor adjustments. As a final precaution, I sent participants my chapter four to examine my findings. None of the participants responded with any suggestions or concerns after they received the transcriptions and chapter four.

In these ways, I utilized various strategies to ensure my findings were legitimate and meaningful.

### **Researcher Reflexivity**

Reflexivity is an important consideration for any researcher involved in qualitative research. According to Rossman (2003):

We, the community of qualitative researchers, can no longer assume that we write up our research in an antiseptic, distanced way. Reflexivity has become central to the qualitative project, demanding that we examine the complex interplay of our own personal biography, power and status, interactions with participants, and written word. (p. 93)

All aspects of my research, from the topic I chose to the way in which I interpreted the collected data, were necessarily influenced by both the innate and developed aspects of my overall identity. My innate qualities include being White, ethnically/culturally Jewish, female, the daughter of a man battling a degenerative disease, and a member of a low-income family. Identities I have developed include being religiously Jewish, a graduate from a small private university in the Midwest, and a current graduate student at a large public research institution in the Midwest. The ways in which these various identities affected my research were anticipated only to a certain extent.

I have experienced the impact of parental illness my entire life. My dad has Parkinson's Disease, a degenerative, progressive neurological disease that affects the nervous system and is caused by a continual decrease in dopamine levels. At many times during the past 10 years, I have served as a caregiver for him. After going to college and graduate school out-of-state, I grappled with the guilt of not providing this support for my

dad, as well as my mom and brother. A year and a half ago, we transitioned my dad to a nursing home.

The support I received during my time as an undergraduate and graduate student played a large role in how I have developed my own identity and successful coping mechanisms. At the same time, I sometimes felt the support systems I sought were ill-equipped to assist me. While my dad did not develop a significant illness while I was in college, I see many parallels between my experience and the experiences of my participants. My own experiences are inextricably linked to my interest in traditionally-aged students who have a parent develop a significant illness while they are in college.

I acknowledge that I have opinions and thoughts about how institutions of higher education serve this student population. At the same time, I think my knowledge surrounding some of the issues of this population allowed me to situate my questions and manners of collecting data in a way that reflect what I hope produced new insights and understandings for student affairs professionals. I believe my own experiences allowed me to develop a strong rapport with participants, which provided an opportunity for them to share their authentic and meaningful stories.

My biases about research, in general, are also important to note. I acknowledge that the ways in which research is situated and funded is often politicized in ways that favor populations perceived by the majority to be underrepresented. My own research for this project does not simply reflect a conscious desire to enlighten the community about a population of particular interest. Instead, my topic also represents an area of personal interest. Overall, I acknowledge that these biases influenced my decisions about the research process, my interactions with participants, and my way of presenting and

reflecting upon my findings. This reflection does, however, situate my study and provide important areas of consideration when examining the value of my research.

### **Trustworthiness and Goodness of Research**

Trustworthiness and goodness of research are important components in any research study, but particularly in qualitative research because of the interpretative nature and unavoidable connection between the researcher and participant. According to Merriam (2009), “credibility, transferability, dependability and confirmability, substitutes for internal validity, external validity, reliability, and objectivity have become widely adopted in qualitative research” (p. 211). Creswell (2013) suggested qualitative validity is utilized to ensure findings are accurate within the confines of the researcher’s description and interpretation. As previously mentioned, multiple reflective measures were taken, both in establishing and conducting the research study.

I utilized two specific efforts to establish qualitative validity: peer review and member checking. Peer review and debriefing were used to establish a space in which outside perspectives could challenge or support my interpretations. Two peer reviewers were involved in this study. One was a student affairs professional familiar with my background and experiences with parental illness. Another was a fellow graduate student who had not completed a thesis project and was therefore removed from the expectations and processes. Another strategy I utilized was member checking, “which involves taking data, analyses, interpretations, and conclusions back to the participants so that they can judge the accuracy and credibility of the account” (Creswell, 2013, p. 252). As previously mentioned, each participant was given an opportunity to provide feedback on

my interpretations in an effort to ensure their experiences were conveyed accurately and appropriately.

Therefore, measures were taken not only to appropriately bracket personal opinion and reactions, but also to validate participants' contributions and my interpretations. I found this approach necessary and helpful in maintaining trustworthiness and the goodness of research expected within qualitative research. In addition, this comprehensive approach was particularly important in that my thesis addressed students concerns that have largely gone unexplored. Since there is little else established on this topic, I needed to rely on internal validity and reliability.

### **Limitations**

My participant pool was limited to a sampling of three students dealing with the impact of parental illness on the college experience at one public research university in the Midwest. As previously mentioned, all participants identified as White/Caucasian and two of the three participants identified as men. These aspects of identity were not foci of the study and no questions were asked to identify how these factors played a role in their experience. While the number of participants in this study can be perceived as a limitation, I actively recruited participants through multiple avenues. Recruitment emails were sent through the Academic Advising listserv, to the Director of Residential Life, to fraternity and sorority house directors and advisors, and to a student organization that serves families with cancer.

This student population was coping with a challenging circumstance that is often hidden. Therefore, it was challenging to find students willing to share their experience. Two individuals who did not meet the criteria for the study volunteered to participate.

One's parent developed a significant illness multiple years prior to them entering the collegiate setting. Another was not yet 19. The purpose of the research was to gain a deeper understanding of how participants experienced parental illness during a time of significant transition and independence. Therefore, it was important to set parameters for the time frame of the development of the illness.

Another limitation of the study was that all three participants' ill parents suffer(ed) from common, significant physical illnesses. Therefore, the voices of students coping with a parent suffering from a more obscure physical illness or a mental illness were not captured. In addition, all three participants transitioned to MRU from other areas of Nebraska. Therefore, the experiences of students with an ill parent in a different state were not identified. There is still a significant deficit in the research on this student population. Participants' experiences and recommendations were not prescriptive, but rather provided key insight into some challenges related to the impact of parental illness on the college student experience.

As previously identified, I have a vested interest in this student population. It is possible that this interest, and my own experiences, impacted the research in unanticipated ways. Participants may have altered their responses or focused descriptions of their experiences in different ways based on what they perceived to be my expectation of them. Although I continually checked in with students to ensure I understood what they intended to say, they may have been swayed by my interpretations.

Time was another significant limitation. I was required to complete this study in order to graduate. Therefore, the study, including participant interviews, had to be conducted and defended within one academic year. I could have solicited additional

voices or conducted a longitudinal study to produce a more robust narrative and understanding of this student population at MRU if time constraints were not present.

Overall, only certain aspects of my findings are generalizable. The voices and stories were unique, yet they enhanced knowledge and understanding surrounding the impact of parental illness on the college student experience. Their challenges provide important justification for future research on this hidden population and suggest institutions have the capacity to provide more support.

## **Chapter 4**

### **Findings**

#### **Introduction**

The purpose of this research was to gain a greater understanding of the impact of parental illness on the traditionally-aged college student experience. Since little is known regarding the size or experiences of this population on MRU's campus, or any campus, this research provides valuable insight into this student population. I utilized specific participant criteria to ensure the data would reflect how individuals experience this challenge within a higher education environment. The following sub-questions were developed from the grand tour question - what is the impact of parental illness on the traditionally-aged college student experience at a public, four-year institution? - to explore students' unique experiences:

- What are traditionally-aged college students' initial feelings and concerns when they learn of their parent's significant illness given their role in the family and the context surrounding the development of the illness?
- How has the development of their parent's significant illness impacted their collegiate experience?
- In what ways have they sought and received support within and outside of the institution?
- What can institutions do to support these students' unique needs?

Several themes emerged regarding the impact of parental illness on the college student experience from the data gathered from the three participants. These themes provide

insights regarding academic and social challenges and implications for how higher education can better serve these students.

### **Introduction to Participants**

The three participants were at least 19 years of age or older and were all enrolled full-time in an undergraduate program at MRU. The participants were interviewed in a variety of locations on campus. Two of the interview spaces were completely private. The third interview space utilized was chosen by the participant because of its quiet and semi-private nature and his familiarity with the space. As previously mentioned, all three participants' ill parents suffer/suffered from a significant physical illness. Two of the participants' dads have/had multiple myeloma, a cancer caused by malignant plasma cells. The third participant's mom has multiple sclerosis, a disease impacting the central nervous system and the immune system.

The participants all have experienced the impact of parental illness within the context of higher education. There are some similarities between their experiences of their parent's diagnosis. For all participants, their ill parent was diagnosed within eight months of their transition to college. Additionally, all participants identified their home, where their ill parent resides/resided, as being no more than two hours away from the MRU campus. The following are primary themes found in the research that further highlight parallels between the participants' experiences. First, a description is provided of the participants' family and how they first came to learn about their parents' illness. Then key themes and salient aspects of the participants' experiences are identified.

**Andrew.** Andrew was the first participant who volunteered, and met the criteria, for the study. He was excited to participate and began sharing his experience

immediately when we sat down – before I had a chance to ask him what I anticipated to be my opening question. Throughout the interview, Andrew shared his experience in a very calm manner. He was soft-spoken and demonstrated deep reflection of both his own and his family members' experiences with his dad's illness.

Andrew is a junior anthropology major who is also fulfilling the requirements to pursue medical school. He is a member of a first-generation, low-income learning community that has academic requirements and co-curricular opportunities. He is involved with a non-profit student organization designed to assist local cancer patients both emotionally and financially, as well as a student-run summer camp for children with cancer or children who had a parent with cancer.

Andrew described his immediate family as including his father, his older brother, and his twin sister. Andrew first learned of his dad's diagnosis of multiple myeloma – a tumor in his hip, instances of cancer in his ribs, and a tumor in his skull – three years ago, during the second semester of his senior year in high school. Andrew's dad had been in remission for almost a year – since the summer after his sophomore year – when the interviews were conducted.

**Lisa.** Lisa is a sophomore student at MRU, studying pre-secondary education. Her area of emphasis is social science. She, too, is involved on campus. She is a member of both of the organizations in which Andrew participates. Additionally, she serves as a volunteer Peer Mentor through a scholarship program that serves to recruit and retain top students. As a Peer Mentor, she assists students as they transition from high school and promotes academic resources on campus. She is also a member of a selective state council designed to organize opportunities to educate youth on farming.

Lisa expressed, throughout both interviews, her interest in helping others who experience the impact of parental illness. She talked animatedly and quickly, providing a lot of context about her experience. Overall, she maintained composure when sharing, but did tear up once during each interview. While some aspects of Lisa's experience match Andrew's, her experience with parental illness is vastly different than the experiences of the other two participants. Lisa's immediate family during high school included her mom, dad, and younger sister. Her dad was diagnosed with multiple myeloma her sophomore year of high school, around four years ago.

Lisa's dad pursued treatment for approximately six months before entering what doctors referred to as remission – in which the cancer was suppressed enough where he did not need to receive regular treatment – for around two years. Right before Lisa left for MRU, her dad was in and out of the hospital and was not feeling well. He was re-diagnosed with multiple myeloma during Lisa's first semester of her freshman year – the first Monday of classes. Her dad continued treatment, including an aloe transplant of stem cells, throughout her first year at MRU and through the summer before her sophomore year. In late September, early October – prior to participation in this study – Lisa's dad started kidney dialysis. The doctors anticipated kidney dialysis would be a continual process for the rest of his life. Lisa's dad decided in early November that he did not want to continue the dialysis process. Shortly before November of her sophomore year, he passed away. Lisa shared the following regarding this experience:

Um I was staying at home and I had planned on staying at home the rest of the week. Um I told...um I knew that night was different than any other night in that it probably was gonna be soon because my mom, when I had stayed at home the

other nights, she had never said, “if, if it gets too bad, do you want us to wake you up?” And she’d never said that and she said that that night. And I can remember her uh coming halfway up the stairs and telling h- me and my sister to get out of bed. Um. We came downstairs. Um. You knew it was the end um. I got to say goodbye so that was. Lots of people don’t get to do that in things like car accidents and heart attacks and even cancer. And I got to say goodbye, which I never – which I absolutely love. And we held his hand all the way through.

Lisa began to tear up when sharing this part of her experience. Given the fact that her dad passed away a little over two months before we met for our first interview, this experience was particularly salient and raw for her. She emphasized not only her appreciation for saying goodbye, but also her support for his decision to end treatment, “I’m super happy it was his decision and the medical community and my mom or me and my sister didn’t force that upon him.”

After her dad passed away, Lisa had six weeks left in the semester. While Lisa had experienced parental illness prior to college, she transitioned back into this experience during her collegiate experience. Her story is also unique, compared to the two other participants, in that her experience of parental illness transitioned into death.

**Jacob.** Jacob was the third participant I interviewed. He was very excited to participate in the study. Jacob is a member of a high-ability, high-achieving cohort of students within the business school on MRU’s campus. He began the interview by sharing his membership in this group and the fact that he considers himself to be “kinda a nerd.” Jacob is also member of a social fraternity. Additionally, he is involved with a group whose aim is to promote attendance and school spirit for MRU’s athletic programs.

He was able to more quickly remember his immediate concerns and feelings, but sometimes struggled to answer questions that required reflection regarding what the institution could do to better help students navigate this challenging experience. A few times, he expressed uncertainty about answering “correctly” and saying what I “wanted to hear.”

Jacob had experienced parental illness for the shortest amount of time compared to the other participants. Jacob’s mom was diagnosed with multiple sclerosis about two weeks before he started his freshman year. As a second-semester freshman, Jacob has had little time to adjust to this drastic change prior to leaving for MRU.

**Overview.** While the three participants have some similarities in their backgrounds and their experiences with parental illness, their experiences also have significant differences. Their backgrounds helped shape and inform the themes that emerged.

### **Overview of Themes**

Four themes emerged from the participants’ stories regarding the impact of parental illness on their experience as a college student. The first theme (I) was initial feelings and concerns, which developed when participants first learned of the diagnosis of their parent’s significant illness. The second theme (II), how the collegiate experience was impacted, explores, primarily, how students negotiated their familial and personal concerns while simultaneously attending to their role as a student. The third theme (III) identifies support utilized by the students. This theme attends to both support utilized within and outside of the institution. The fourth, and final, theme (IV) identifies advice for institutional support to clarify what students believe institutions can do to support

their unique needs. These themes relate to and answer the research question and sub-questions of the study. The themes and subthemes are summarized in Table 3.

Table 3. Research Themes and Subthemes

<b><i>Theme I: Initial Feelings and Concerns</i></b>
<p><b>Factors Attributed to Feelings and Concerns:</b></p> <ul style="list-style-type: none"> <li>• Nature of the illness</li> <li>• Relationship with the ill parent</li> <li>• The family dynamic</li> <li>• The college decision process</li> <li>• Financial concerns</li> </ul>
<b><i>Theme II: How the Collegiate Experience Was Impacted</i></b>
<p><b>Impacted Aspects:</b></p> <ul style="list-style-type: none"> <li>• Academics and career aspirations</li> <li>• Social experiences</li> <li>• Involvement</li> </ul>
<b><i>Theme III: Support Utilized By the Students</i></b>
<p><b>Types of Support:</b></p> <ul style="list-style-type: none"> <li>• Familial support</li> <li>• Peer support</li> <li>• Institutional support</li> </ul>
<b><i>Theme IV: Advice for Institutional Support</i></b>
<p><b>Factors for Consideration:</b></p> <ul style="list-style-type: none"> <li>• Intake self-disclosure</li> <li>• Training for advisors, counselors, and professors</li> </ul>

**Theme I: Initial feelings and concerns.** The first major theme that emerged from the data relates to the first research sub-question of what initial feelings and concerns developed when students learned of their parent's significant illness. Specifically, participants reflected on their role in the family and the context surrounding the diagnosis of the illness. Five factors, *nature of the illness, relationship with the ill parent, the family dynamic, college decision process, and financial concerns*, appeared, from the data, to be present in participants' initial feelings and concerns. These five factors are explored below.

*Nature of the illness.* Participants explained the nature of their parent's illness when sharing about their family unit and their ill parent, as well as when they identified the context surrounding how they found out about the illness. All three of the participants were somewhat unfamiliar with their parent's illness upon initial diagnosis.

Andrew's dad disclosed his illness during a family meeting with Andrew and his sister, as his older brother was in college at the time. Although his dad admitted he was concerned about what would happen, he shared his plan for getting scans done, such as an MRI, and speaking with an oncologist to monitor the progression of the disease. Andrew described a retrospective account of his initial reaction:

It was a bit surreal and it was a bit...sort of um...black humor. Like, congratulations, you got a new car and then it gets totaled three days later. It's sort of like, wow, graduating, moving on with your life, becoming a real person, uh you know blah blah blah accomplishing major life goals and then oh, by the way, your dad's really sick...

Here, Andrew suggests his dad's diagnosis caused a sense of dissonance. Andrew was about to celebrate an accomplishment – that of graduating from high school – and was preparing to enter a period of transition typically accompanied by some level of independence, or, what Andrew describes as “becoming a real person.” This excitement, which he likened to getting a new car, was overshadowed by the concern for his dad.

Andrew described his initial feelings regarding the nature of his dad's illness of multiple myeloma as influenced by the way society has portrayed and come to view cancer: “It was really scary um at first having the experience of like you know your dad has cancer ‘cause whenever people hear cancer in their family, they get really scared.” Even though Andrew had this visceral response, he also described feelings of uncertainty. His dad reminded him of the uncertainty of the disease.

He just explained it really straight-forward and you know after we were sort of worried about his health and what was going on. And he said directly, “you know, I’m not sure what’s happening and I will tell you if something’s happening” and so it was sort of like kinda bitter and kind of like uhh it’s just great, wonderful...but it was more sort of an ambiguous thing because he said it could be something really serious or it could be nothing really serious so don’t, you know, make the leap that dad’s gonna get cancer and he’s gonna be dead in a year ‘cause we don’t know that, the doctors don’t know that.

This type of uncertainty, which the other two participants experienced as well, can complicate a student's ability to adequately prepare for either situation. Andrew could have either prepared for the worst in anticipating whether “something really serious” would happen, thereby experiencing continual concern – in which case the progression of

the illness could manifest as serious or non-serious – or, Andrew could try to avoid concern about the progression and either experience another shock if the progression did become serious, or continue to remain in limbo. His dad decided to make a proactive plan for the worst: “He – he kind of also made it clear um after we talked about him getting cancer that he – this is how he was gonna plan stuff out...in case things went wrong.” In doing so, his dad set the stage for how the family would proceed. Since his dad anticipated and was planning for the disease to progress significantly, Andrew didn’t necessarily have an opportunity to try to avoid concern.

Lisa’s parents also utilized a family meeting to disclose her dad’s illness. Between track practice and a band concert, they sat her and her sister down and told them he had cancer:

They – we knew they were at the doctor earlier that day. And the day before and it was just something that’d kinda become normal. That he um was sick and they didn’t really know what was going on. Uh they sat us down and told us uh he had cancer. They really don’t know – they still don’t know exactly how it happened.

As was the case for Andrew, there was initial uncertainty regarding what was going on and what was going to happen. Even though Lisa and her sister had just received news of their dad’s cancer, her family still continued with their plans – they went to the band concert; her sister went to their cousin’s house:

Um my sister still went and stayed the night at a friends’ – uh my cousin’s house. Um I later that night I remember sitting at the top of our stairs having my mom and my dad tell some of our best – uh their – our really close family friends um what had happened...And I just remember sitting there crying. I really didn’t

know what was going on. I knew can – like cancer and but it was all just kinda like whoosh.

Despite the fact that the family continued their activities, Lisa was still emotionally impacted by her dad's diagnosis. Lisa knew her dad was going to the doctor and that something was wrong, but the diagnosis made this experience more real. She, too, focused on how she latched on to the concept of cancer without knowing the nuances of her dad's form of cancer: multiple myeloma. Both Andrew and Lisa described their dads as being ill and not feeling well prior to their diagnosis, however neither of them described this as an indicator of a significant illness.

Jacob, however, was with his mom when she experienced an unanticipated and unusual medical complication. Approximately eight months ago, Jacob, his younger brother, his mom, and his dad were at the lake when his mom started experiencing double vision. As an optometrist, she had one of her partners check her out. Further tests confirmed she had developed multiple sclerosis and that she had advancing lesions on her brain and spinal cord. Jacob described a feeling of shock, which although not directly articulated by the other participants, appeared to be a common element of their reaction:

Um so it was kind of a shock having – being my mom diagnosed with this just because it was I guess kind of a rift in my, I don't wanna say perfect, life. But I mean just like normal life, nothing ever happen to us. I mean we didn't do much and now that kinda changed a little bit.

Jacob's initial feelings and concerns were then put on hold: "Um we ended up going to Costa Rica the next week. Um we had planned that for months. So we went to Costa Rica, she kinda just forgot about it. We kinda just let it go."

The way Jacob described the diagnosis suggests that in some respects, the family attempted to delay their initial feelings and concerns, and, instead, focused on spending time together. In some ways, this mirrors the way in which Lisa's family proceeded after the news. There was only about a week between when Jacob's family returned from Costa Rica and when he transitioned to MRU. Therefore, some of his initial feelings and concerns about the diagnosis developed after he had physically separated from his family:

I think being away and knowing if anything ever happened like if something got dramatically different and she was – I mean something in my family – I mean there's always the possibility that she could end up in a wheelchair pretty much any day. I mean her lesions in both her...brain and spinal cord...could act up and cause something to happen. Um so I guess that fear, especially at the beginning of not being at home and not being close, not being able to help if something happens um was definitely weighing on me personally.

Again, Jacob – like the other participants – expressed concern regarding how the disease would progress. In addition, Jacob was scared that something would become “dramatically different” and he wouldn't be around to assist.

I think realizing that oh she could be in a wheelchair as of or worse within the next month or within 20 years or never. So I mean I think the idea of not knowing but also seeing what her classmates have gone through has been frightening for us and that's probably been the biggest thing for all of us is knowing what could happen and not knowing when it could happen has been probably the worst part of it all so.

The uncertainty really seemed to weigh on Jacob, especially since he was privy to the struggles and progression of MS experienced by a number of his mom's high school classmates.

Overall, the nature of the illness impacted the participants' initial feelings and concerns. Andrew and Lisa had initial reactions based on their understanding of the disease prior to their parent's diagnosis. For Andrew, this initial reaction was re-negotiated because his dad was up front about what he knew and the futility of worrying. Jacob described an initial feeling of shock, which was then mediated by his family vacation. All three participants had an intense emotional reaction to the experience of learning one of their parents was ill.

***Relationship with the ill parent.*** Participants' relationships with their ill parent also impacted their initial feelings and concerns. Andrew shared that his dad was: "Kind of down and out and really sick and tired and kind of you know...your personality changes when you're sick and...you know, my view of him as a person kind of shifted 'cause his identity changed." Typically, college students are the ones in the family whose identity or personality changes. To experience this shift as a college student complicates an environment of stability that typically balances the experience of transitioning to school. He elaborated more on this feeling:

It's – it was sort of like a – a realization that like the person you spend all of your life with has fundamentally had a change you know. It's sort of like realizing like not all policemen or politicians are like... have the best intentions. It's sort of like looking at my dad in a very different light.

The policemen and politicians metaphor insinuates that Andrew held his dad to a high esteem and saw him as having a reputation of authority. After the diagnosis, Andrew saw his dad as vulnerable. Andrew went on to share more regarding his relationship with his dad:

I don't think my relationship really changed with him. Um I think I see him more as a – a human being you know rather than a dad. With his own hopes and wants and desires but I'm not sure if that's because he got sick or it's because I'm becoming older and more savvy to how things go.

Even though Andrew was uncertain about whether he could attribute his shift in perspective to the illness, his level of maturity is atypical for a student transitioning to college. Some students might be aware of their parents as human beings, but typically are more concerned with understanding their own identity. He wanted to help his dad, but his dad discouraged him from having this concern:

I kind of really wished that I was like able to go out and help and do everything that I could but he said like I – there's nothing for you to do. I'm – I'm gonna feel bad and I'm gonna have really good days and I'm gonna have really bad days and I'm gonna be tired and I'm gonna be irritable but there's nothing you can do about it because it's not like it's an infectious disease where you keep taking the medicine and gradually get better. It's sort of a – a more ambiguous sort of thing where the medicine you get makes you sicker and how sick you feel that day depends on how much you've had to eat, um you know whether you got enough sleep, and then the alignment of the stars and the sun, you know.

The concept of not being able to do anything resonated for all three participants and invoked a feeling of helplessness.

Lisa didn't directly comment on how her relationship with her dad changed in relation to her initial feelings and concerns. She did, however, identify ways in which her role in the family changed, which is explored in the next subtheme.

Jacob's relationship with his mom shifted very quickly after the diagnosis. The illness began rapidly impacting her functioning, and Jacob was the only one in the family who didn't, at that point, have other priorities:

I mean it was a difficult situation for me um I mean she couldn't drive at that point and she had to go to the hospital multiple times I mean a week if not every day. Couldn't drive so I drove her 'cause I had nothing else to do.

Even though Jacob "had nothing else to do," it was a difficult situation for him because of the shift in his role as son to a caretaker:

I've been especially close with my mom, so I think it's been especially hard on us. Um I think it's been difficult with her and her treatments. I mean it makes her tired, makes her more worn out. She used to be very patient. Not that she's not now, but I can tell it's taken a toll on her I mean sometimes we'll argue over things we would normally never argue over. And it's been difficult um. It's been – it's been hard on us um she's trying to take care of me but at the same time I'm trying to take care of her. So it's been a different – different interaction between us.

Jacob saw, fairly immediately, the toll the disease was taking on his mom. Due to their close relationship, he noticed a change in their interactions. While they had previously

had a close, but traditional mother-son relationship, he was now acting in a role traditionally reserved for a parent: that of serving as a caregiver. Although Jacob left to go to MRU, their close relationship continued:

I talk to my mom all the time...my mom and I text pretty much every day. Just asks me how I'm doing or asks how something went. Um. We don't usually talk about it really, um, talk about how she's doing. She'll – if she'll tell me if she has treatment or somethin' coming up. Um we kinda just try to leave it out of our con- or at least she tries to keep it out of our conversation I think because she doesn't want me to worry about it.

Once a physical distance was established, their relationship shifted back into somewhat of a traditional mother-son dynamic. The physical distance allowed his mom to reclaim a role of authority and gain control over the illness. Jacob still was, and is, often worried despite his mom's attempt to alleviate his concerns.

For both Andrew and Jacob, the diagnosis of their parent's illness altered their relationship. In Andrew's experience, this alteration manifested itself in an indirect way. Andrew did not believe the relationship itself changed, but he developed a fundamentally different view of his dad in which his role as a human superseded his role as a parent. Jacob's relationship with his mom went through a number of changes. At first, he absorbed the role of the caretaker. His mom reclaimed this role when he went to MRU by controlling the conversation to attempt to ensure he did not worry.

*The family dynamic.* The participants all discussed how the diagnosis impacted the family unit, and, for Andrew and Jacob, the extended family. These familial relationships affected the participants' initial feelings and concerns.

At the time of the development of Andrew's dad's multiple myeloma, Andrew's sister had already decided she was going to community college and that she was going to live at home. Andrew believes "it had an impact that [he] was not a primary caregiver":

So she was the one who was mainly around him most of the time and so she helped him out and so um dealt with him being sick and so helped him out when she could. And so my main concern was um I think initially I shifted to like okay how can I get as much stuff you know done as I can in the shortest amount of time and get on my track to do what I need to do so I can get that done and, you know, if I need to help take care of my dad.

Andrew experienced an intensified drive to quickly earn his degree and saw his transition as a means to an end, rather than as an opportunity for social or personal development.

This is explored later, in another subtheme.

Andrew described his sister as a "homebody." He also shared that his sister has cerebral palsy and that his family felt the public education system had not really supported her in pursuing a four-year institution. She planned to complete her prerequisites and "get a better basis for like a four-year college." Andrew's brother was, at the time, a sophomore at MRU. Andrew shared the following regarding his brother:

I'm not sure how um my dad's diagnosis affected him...I think he was a bit more um insulated from it because he had his own apartment [at MRU] and he um had, you know, sort of a social system built [at MRU] and wanted to stay...and do classes and do other stuff.

Andrew's brother had, perhaps, a different experience, which suggests the impact of parental illness can be mediated by where students are at in their collegiate trajectory.

A year ago, Andrew's brother moved back to their home upon his graduation.

Andrew described his interpretation of this transition:

[He] became a bit more intimate with my dad um being sick and my sister and that sort of stuff and I think it was a bit hard for him coming back and, you know, seeing an authority figure you know you love and care about become sick and sort of weak and needing help. And going from being relatively independent in a city where there's things to do to [a city of around 58,000 people], which is um not as big – there's not as many social events and then mainly staying at home and you know missing friends and you know friends graduating and doing other things so yeah I think that impacted him as well.

This anecdote provides one example of what a college student coping with parental illness might experience upon re-entering the family unit – either during breaks or after they have left the collegiate environment. Andrew believes his brother's experience was complicated by trying to reconcile his former MRU life – social events and friendships – with being back in the family unit. Andrew's brother is now in medical school, and once again is not physically included in the family unit.

Andrew and his sister experienced the diagnosis of their dad's illness differently than their brother due to their brother's physical and emotional separation from the family unit. Since Andrew's sister lived at home, she was the child primarily responsible for helping him and interacting with him while he was sick. Andrew explained that their dad encouraged and wanted his sister to prioritize her academic commitment. Andrew and his siblings had some conversations about their dad's cancer:

I don't think that she was angry that she was there helping out um I think she was more worried about um how my dad was progressing and how he was feeling but um and we talked a little bit about – my sister and my brother we talked about it a little bit...I think that when I visited my sister was really happy I was there 'cause she could have somebody else to talk to and somebody else to help out and was just really happy that I could be present and I think my dad appreciated it as well um but my sister never said to me like I just feel like I'm being taken advantage of.

Andrew had support to pursue his agree away from the familial unit. This is important to acknowledge because not all students experiencing the impact of parental illness have someone who can and are willing to absorb caregiving responsibilities. Both Andrew's brother and sister expressed concern about their dad:

I talked with my brother a little bit about it and he – he kinda said that um he was concerned about my dad... And I think [it] was affecting my sister a little bit because um she was you know physically seeing him that way but um yeah.

While they all had concerns about their dad, they all played different roles in the family dynamic. Andrew and his brother were typically physically distant from their dad and expressed more general concern. They were able to focus their attention on expanding their career aspirations – a concept that is explored further. Their sister saw more of the progression and interacted with their dad on a daily basis. While she continued to pursue her degree, Andrew shared that she questioned whether “it's worth it” to continue her education. While this is likely an aspect impacted by a variety of circumstances, it is possible her concerns related to her role as the primary caregiver.

Other family members Andrew identified as involved in the diagnosis and treatment included his uncle. His uncle saw some of the initial medical records and created a sense of alarm when he estimated Andrew's dad had five years to live. Additionally, Andrew expressed frustration that various, well-intentioned, family members would give advice about what they needed to do and how they needed to handle the illness. Andrew's dad's doctor was able to assure all family members that the particular form of multiple myeloma Andrew's dad had had typically responded well to treatment.

Lisa, like Andrew, shared how she engaged with her sibling. While Lisa described her family as very close, she and her sister developed a stronger bond during this period in time.

I kinda joke with my sister and my mom that I was kinda mom 2.0. I would make sure that she had her homework and that she got to practice on time that we went to bed and ate dinner. Not that – not saying that my parents weren't there and weren't doing those things. It's just – especially in the beginning and it was a lot of...we don't know really and so my mom was just trying to learn all of this information. She was still going to work and she was working as much as she could and just. It was a lot of stress all of a sudden. Um so I took care of my sister a lot. We – I would say we took care of each other more than I took care of her.

Lisa's relationship with her sister was complicated by the uncertainty of how the disease was progressing and what needed to be done. In one way, Lisa stepped into a parent role

in making sure she and her sister were fed and prepared for school. In another way, they experienced a close sibling bond and provided support to one another.

When Lisa's dad was re-diagnosed, after she had transitioned to college, this relationship shifted:

Um my sister spent a lot more time alone. Um she had to kind of self-motivate herself to make sure she got to school on time and got her assignments done and um she spent a lot of time by herself. Um whether that was at home just because she – we don't have school on Monday's so she would spend all day Monday either by herself if my dad had a doctor's appointment or she would get to spend all day with my dad.

While Lisa did not describe this as her sister taking on a caregiving role – as Andrew's sister did – the family dynamic still shifted. Lisa's physical separation from the family unit also altered how she experienced the illness:

Um it was harder in the sense that I didn't get to see him and I didn't know exactly um how he was doing on a daily basis. 'Cause when you live at home you can see well like today was a good day, today was a bad day sort of thing. But it was easier in that sense as well is I didn't have the constant up and down roller coaster. It was – but my mom called or I knew there was a doctor's appointment I'd call and ask. And if it was good then you know – it was still a roller coaster but it wasn't quite as a day to day up and down. It was kind of a every three days or every week or it was – it was still emotionally tolling um but it wasn't as like every day was something – was a new like – was a whole new emotional...seeing something so that made it way easier.

Lisa suggests it might have been more difficult to cope with her dad's illness if she saw the progression of the disease every day. Still, physical separation did not alleviate her concerns; instead, it complicated her emotions and preoccupations. Even though she was living at MRU, she would see family often:

My dad did treatments and all of that stuff [an hour away from MRU]. My mom and my sister came to [MRU] on Sundays and we would go to church and shop and hang out. And my dad has a cousin [near MRU] so that made it easier. My great uh my great – one set of grandparents lives um really close nearby. The other set lives an hour the other direction.

From the interviews, it seemed Lisa spent more time with her immediate and extended family while at MRU compared to the other participants.

Jacob, as previously mentioned, helped his mom during the brief time period between the diagnosis of the illness and when he moved to MRU. His brother and dad had competing priorities:

Uh my brother had started school um so he's a – as of right now he's a junior [in high school]. Um so my dad was working full time, she couldn't work but she had – I had to drive her around, my brother was at school so I mean it was a very hard transition for us. I mean I acted as – kind of took care of everyone um so going into college was very difficult for me um having to leave my family, having to let them deal with it and kind of let my brother step up and actually have to help around the house more than he normally had to. Not that we didn't help beforehand but just doing other things that we normally didn't have to do.

Jacob adopted not only the role of caregiver for his mom, but also for his brother and dad. The transition to college disrupted his transition into this role, as he quickly had to shift caregiving responsibilities back to his brother.

Jacob has had to reconcile his roles as a son, brother, and student:

It's been interesting for me not being home seeing it every day but being I guess being away from it and having it all in the back of my mind like oh I should be home helping but having to just put it aside and at the same time just enjoy my life but get a phone call like oh I'm doing this um – doing this treatment or doing – having some infusion but it's been interesting getting used to that so um.

Like Lisa, Jacob suggested his parent's illness is a constant consideration, despite physical separation. Not only does he have to balance his internal thoughts and concerns, but the external reminders of the illness also impact him. At the same time, he doesn't think his mom's diagnosis has changed the closeness of his family:

I don't think it's really changed. I mean, we've always been close. I mean, I've always been close with my family more than most people my age are I mean, heck I tell my parents everything. I mean, never really got in trouble growing up. Um we talked a lot more than most kids my age did. I mean, they know a lot about my life – I mean, I wouldn't say this event actually brought us closer. I mean, maybe strengthened our relationship as a family, but I mean, honestly before that we've always been close. I mean, my brother and I have always been close, always been close with my parents.

Jacob believes he already had a stronger relationship with his family than others his age. “Family’s always been the number one priority,” Jacob shared. In fact, this closeness led to his initial hesitation about leaving home for MRU:

I think it crossed my mind like it personally without ever telling them that I didn’t really want – I didn’t want to leave them. I wanted to – thought about staying home and getting a job and trying to help them out but it never – never came up... Yeah she had MS, but I need to – we need to go on with life as normal as possible and I was gonna go to school.

In these ways, Jacob’s experience mirrors Andrew’s experience. Jacob, too, was concerned with trying to help the family. Andrew’s initial reaction was to channel his energy and commitment toward figuring out his path in college, whereas Jacob’s initial reaction was to consider staying home to support his family. Part of the reason for these differences stem from the fact that no one in Jacob’s family had adopted a caregiver role, as Andrew’s sister did.

I think it was hard not being able to help contribute and help my family on a daily basis like with my brother being a 3, 4 sport athlete, um my dad working full-time, I mean working 7 in the morning 'til 6 at night and my mom dealing with this and trying to still have her job. I think it was – it was hard for me not to be home just to help clean the house, help do the dishes, help make dinner I mean just small things like that it was like I should be ho – I mean personally I was thinking I should be home.

It was hard for Jacob to transition to MRU because he knew his family would have difficulty taking on some of the responsibilities Jacob absorbed between the diagnosis of MS and when he left for school.

Jacob also acknowledged his concerns about the future of their family:

We're pretty active, I mean my mom played sports through high school, so did my dad. Um my brother and I have always played sports um mom loves to ski and I mean just being a very active family has been difficult.

Jacob was the only participant who shared how he thought his entire family dynamic would change.

The family dynamic played a significant role in the participants' initial feelings and concerns. Lisa and Jacob adopted caregiver roles, which were complicated when they transitioned to MRU. Andrew had concerns about his extended family's involvement in the diagnosis, as it caused him additional anxiety. All three participants inherently shifted roles in the family by transitioning to MRU because of the physical separation between themselves and their family. These experiences altered their concerns – sometimes re-directing them toward their collegiate experience and sometimes exacerbating their concerns.

*The college decision process.* At the time of his dad's diagnosis, Andrew had plans to attend MRU. His dad reassured him that this should be a priority by saying, "I don't want you kids to worry about um not getting an education." In particular, Andrew wanted to go to MRU because he felt it "offered good programs" and he liked the campus. Additionally, Andrew's father, uncle, and brother went to MRU:

We kind of had a – a family history of people going here and knowing where things are and it's – um it was farther than [the local state school] which is – it was sort of described as a commuter school and I can see that because it wouldn't be that hard for me to go from [that school] back to home, [that school] to home, and not really getting uh my identity as an individual. And so by coming to [MRU] there was enough stuff to keep me occupied and do things and I thought [the city where the local state school was located] would have been a bit too big of a step to go from [my hometown].

Here, Andrew shares common concerns and considerations typically experienced by traditional students transitioning to college.

When Lisa's dad was first diagnosed with multiple myeloma, she had not yet decided where she was going to college, but she knew she wanted to go to MRU.

When my dad got sick, it kinda reaffirmed the fact that I wanted to go to [MRU]. It was close to home, I could go home whenever I wanted to but at the same time I was at a Big 10 University. I was [going to get] a great education.

Proximity became a deciding factor for Lisa. Lisa's dad, like Andrew's dad, was insistent that she go to college:

Uh that was something my dad always wanted me to do um it was kind of this unspoken thing that you will go to college, you will get a four-year univer- uh four-year degree. Um I don't care what in, and I'll support you in whatever you decide to do, but you will go to college. That was something that he was very adamant about.

Lisa had support to attend college, which impacted her feelings and concerns regarding navigating her roles as a daughter and as a student. Lisa's college decision process, and therefore feelings and concerns, was complicated by her dad's re-diagnosis. She shared the conversation she had with her mom over the phone when Lisa's dad was re-diagnosed with multiple myeloma:

“Your dad has been re-diagnosed with cancer.” I was walking along 16<sup>th</sup> Street, actually. Um uh told me what had happened. I cried, obviously, um and she...asked me if I wanted to stay [at MRU]. And I told her yes, so that was – that's something um and they started treatment again.

Despite her dad's re-diagnosis, Lisa wanted to remain at MRU. This might be attributed to her dad's insistence and support for pursuing a degree.

Jacob's parents were also supportive of and insistent that he still go to MRU.

I mean my parents made sure, made it clear that I was still going to school, that nothing had changed... I mean it was always I was gonna to go to [MRU], I was gonna go to school, I was gonna go to college and enjoy my life.

Both of Jacob's parents went to MRU, and he was raised as a MRU sports fan. Despite this, MRU was initially Jacob's last choice. Jacob was the only participant who had officially committed to and planned to attend MRU prior to his parent's illness. His commitment and excitement about MRU stemmed from his admittance into the honors program described in the participant profiles.

Andrew, Lisa, and Jacob all had initial concerns and feelings related to their college decision. Although Andrew anticipated going to MRU, he also wanted to help at home. Lisa decided on MRU around the time that her dad entered remission. She was

asked to reconsider MRU when her dad was re-diagnosed. Jacob was the most concerned about leaving his mom, which is perhaps a function of the short time frame between the diagnosis and when he had to go to MRU.

***Financial concerns.*** While only one of the participants, Jacob, experienced financial concerns following the diagnosis of their ill parent, all three participants mentioned the finances in relation to their feelings and concerns.

Andrew had access to two financial resources – a scholarship and a Pell Grant:

Um I had a scholarship to help me with tuition, and we had Pell Grants that helped with tuition and a few loans so I wasn't stressed financially. If it was sort of like something where there was um like a major financial issue I think I would – my personality would be different. But there was enough stuff set up for things to go well.

Not only was Andrew unconcerned about finances, but also his dad was able to continue working full-time for much of the time he was battling multiple myeloma. Lisa's family had saved for her college experience, so she didn't experience any financial concerns either:

Financially it wasn't – my parents had saved um my mom um my mom and my dad knew they – going to college and getting a four year degree, they knew saving for college and not – not having necessarily always having the nicest clothes or like not always going on or going out with to do things or um. It – we – financially it was not a concern. Even now it's still...I probably don't have to take out loans until my senior year of college and even then I might not even have

to so. Um I'm very grateful that my parents saved the way they did and were prepared for pretty much anything.

Even though Lisa's parents didn't plan for her dad's diagnosis, they did plan for, and make an early commitment to, her education.

Jacob, however, identified that, financially wise, it was a difficult transition. His mom was not able to work, so their family transitioned from dual income to single income. Jacob became worried about their situation:

Um I think financially was I mean yeah financially was a big thing um just worrying about that um and how I was going to pay for school... um yeah I don't think – I think it definitely impacted being in a [Greek] house, um financially a little bit. Just dealing with costs for some things I mean just having to pay for random shirts for whatever, Homecoming, or stuff like that. Um paying dues and stuff was difficult.

While many students have financial concerns, Jacob's concerns were triggered by the diagnosis of his mom's illness and were compounded by other, aforementioned, concerns related to her illness. Jacob felt compelled to consider his own responsibility for his financial situation:

I had to start looking for a job. Um which I've never – didn't – wasn't planning on doing 'til at least this semester if not this summer. So it kinda sped up events that I didn't think were gonna happen, created events such as trying to find a job.

Here, Jacob suggests the development of his mom's illness created new concerns and caused him to become more independent more quickly than he anticipated.

While the other two participants did not share the same financial concerns as Jacob, it is important to acknowledge that they understood financial concerns to be a potential consequence of parental illness.

**Theme II: How the collegiate experience was impacted.** The second major theme that emerged from the data relates to the second research sub-question of how the development of the participants' parent's significant illness impacted their time as college student. Specifically, participants reflected on a variety of curricular and co-curricular components of their experience. Three factors, *academics and career aspirations, social experiences, and involvement* appeared, from the data, to be areas impacted by the salience of their experience with parental illness. These three factors are explored below.

*Academics and career aspirations.* All three participants described how their academics were impacted by parental illness. For two of the participants, Andrew and Lisa, academic experiences also tied into and supported their career aspirations. The previous theme alluded to the ways in which Andrew's experience with his dad's illness impacted his plan for his time at MRU.

Andrew expressed commitment to ensuring he made the most of his time in school:

And so I kinda ran through like the idea of like okay what can I do that would take you know at the very least like 5 years and so there was a program called clinical lab science and I have like a lot of the classes I need to take it. And after doing clinical lab science you just get a degree and then you can go to [a medical center] or other health colleges and it's a year program and then done and then you can work anywhere in the country and it's a pretty decent paying job. And it was sort of like oh, you know, I can do something and I can sort of take care of it

if things really go south. Which was different from my main, and still my main goal now, which is uh medical school.

Sometimes, parents influence and/or establish their student's career aspirations.

Andrew's experience is slightly different in that he created two different plans: one that would allow him to work immediately within his field of interest to help support his family if need be, and one to pursue more schooling. He described his plan as an internally driven attempt to be prepared for his dad's illness to either progress or stabilize. He elaborated on his interest in the clinical lab science program:

The clinical lab science was less of an end-goal and more of a an alternative path and so I wasn't stuck with um no real flexible career where I can move around and go where I needed to and make um a pretty decent living and um be you know financially supporting my dad if I needed to.

His main goal of pursuing medicine stemmed from seeing his dad battle multiple myeloma:

I've been shadowing [my dad's doctor] and seeing people who have cancer and you know how do they live and how do they act and how do family act and like what their life is sort of like. And so I've been getting more interested in like dealing with like people who have chronic illnesses...And then I think it really kinda solidified my ideas of going into a healthcare related field...I think it would help me become a better either a better patient advocate or a doctor or anybody involved with health care and you know not push for a – a certain treatment method because it –it'd look for the university but it's sort of like I've been in the same situation so I'm gonna be a bit more sensitive to their concerns.

Not only did Andrew develop an interest in healthcare, but he also was able to articulate a relationship between this interest and his knowledge and expertise gained from being close to someone experiencing illness. In this way, his dad's experience sparked his interest and developed his confidence in effectively working in this field.

Andrew further identified his dad's illness as enhancing his academic performance:

Um I think I have a little bit more of a drive to do well. In part because of the illness, you know, because it sort of um kind of hits home why I'm here and what I'm doing and like you know. I wasn't all that inclined to kind of goof around in the first place. But I think like oh you know having a parent who is sick or something is sort of like oh you know I kind of really need to make sure that my time here counts.

Andrew shared that although he anticipates that he would have been internally motivated to take his academic experience seriously, his dad's illness made him feel even more compelled to succeed and ensure his commitment to receiving his degree was unwavering.

While Lisa attributes her career aspirations to her relationship with her dad and her dad's illness, she believes her academic experiences were negatively impacted. Lisa discussed how her dad's illness was related to her exploration of food science and pharmacy as majors:

Um. In the beginning um I wanted to do – I was a food science major to being with in college um. Very quickly I realized I didn't want to work that hard um [laughs]. Um but I was really intrigued with um helping people who – 'cause his taste buds had changed. He was always saying things had too much salt in it

when they didn't. Or just things like that and I – I felt like in that industry I would be able to kind of help people who were going through things and needed like – and food didn't taste good so just making something that was like healthy enough for them to eat and that like tried to get to taste well and that – that's that it did impact me, his illness, that way.

Lisa had to navigate a desire to pursue a career/academic trajectory that she saw as having a positive influence on her dad and others suffering from similar challenges with the reality of what such a commitment would require in terms of effort and ability.

Umm especially my first semester here I think it definitely impacted how I did um. I wasn't – I wasn't transitioned well enough I don't feel like and I don't think I had completely. I don't think I was ready to deal with it but I did anyway. And I did okay – I could have done probably better than I did but I think I took on a little bit more heavy coursework or just like not a lot of hours just a lot of the courses I took were very uh intensive and I wasn't in the state of mind to be studying all the time and being completely focused on school so.

Although Lisa shared that the coursework for food science was challenging, her preoccupation with her dad's illness and re-diagnosis also made her transition more difficult. She was forced to cope with the challenges of parental illness while also coping with the challenges of a new academic environment. Before changing to education, she considered another major: "I considered pharmacy school at the time and just being around the amount of pharmaceuticals that I had been, I was, I felt like that would be a way to help people like him or help him in general." Again, her interest in this area stemmed from her desire to help others. At the same time, it also incorporated something

she was knowledgeable about related to his illness: medication. Ultimately, her current major stemmed from her dad's interests and from her lack of support in high school:

We would go to museums when we were younger and my dad would always be the one to read almost every single word on those boards and he kind of had fostered a love for the past and for learning about the people that lived there and that you can learn so much from other people like that you – so you don't make those same mistakes and - and so I was always interested in history. I loved history it was something I – from like that I feel like I've gotten from my dad um and education was just a way that I knew I'd get a job...also I wanted to teach because of what happened like my dad got sick in high school and teachers don't know what to do. And as much as they say "oh anytime we'll talk to you" or counselors like "if you ever need the chance to talk like we're always here." And I want to be the person that can actually say, "no, seriously, if you need to talk I have gone through not the same thing but I've gone through something similar."

Lisa's teachers weren't able to engage in productive conversations with her regarding her feelings and emotions in coping with her dad's illness. She sees herself as an effective advocate and support system and feels she can contribute to a void in the educational environment.

Lisa's dad also influenced her commitment to school:

Even after he got sick and even um when I went to college and he was re-diagnosed...At – almost a year ago um he was still very adamant that you will not be skipping class, that even if you are – even when literally he was – he had decided that he was gonna be sick. He was like - I had a quiz on a Friday. He's

like, “are you – you better be going back and taking that quiz. Like you better make sure” and so that’s something like he was very – wanted me to do.

Overall, she feels she “didn’t struggle a lot academically, but [she] definitely...felt like it kind of hurt [her] a little.” Lisa’s academic experience was also impacted when her dad passed away:

It was hard to pay attention as – before when I knew he was sick, um it was easier. It was a thing like if like in discussions things had been – come up or if you’d hear conversations from people, like you would think about it but it was easy enough to focus on the material and like let what was going on kind of take a back seat. But that’s when it kind of was full frontal and...SO hard pay attention. [I] didn’t even attempt to write down notes or anything at all like so right away when it – when it was coming to the end it was – it was definitely really really hard to pay attention.

One key difference she describes here is that when she was coping with parental illness, she had managed to find a balance between her focus on academics and her focus on her dad. When her dad had stopped treatment and she anticipated he was going to pass away, she felt completely incapable of focusing on academics. A shift in the seriousness of the progression of the disease challenged the mechanisms she had in place, suggesting students are constantly renegotiating their concerns and attention.

Jacob, too, expressed that his mom’s illness negatively impacted his grades:

And I feel like it definitely think it did impact my grades, as much as I like to tell myself I don’t like finding excuses. I mean [sigh] I mean I wanted to do my own thing I wanted – I should have just gotten my grades...I think my grades weren’t

nearly as good as they could have been. Um having I guess that distraction at home – not so...I mean at the time I called it a distraction just to make myself feel better. It was definitely a concern of mine that I mean day by day I didn't know what was gonna happen. Especially back in August, September, I was nervous of what to expect and what could happen.

The concern and uncertainty regarding how the disease was progressing was a preoccupation. Jacob appeared to still be working through what he attributed to the illness and what he wanted to claim as personal responsibility to succeed in spite of challenges external to the collegiate environment.

Later, Jacob shared mixed feelings about whether his mom's illness actually impacted his academics.

I think my grades were definitely not where I wanted them to be um I definitely struggled. I don't know if I can account that to my mom's illness, but I think it definitely had a – it definitely played a part um. While it's still hard to adjust to school in general I think it was hard adjusting with that as well and my mind was not completely on my schoolwork as much as it should have been. Not only did – I mean I had my mind on involvement, mind on just friends, social life, et cetera. But it def- my mom's illness was definitely something that impacted me, impacted the way I went about my life and when it came to academics, there was probably times where I should have stayed and studied and probably should have done homework and stuff differently and I didn't. And I went home sometimes or was on the phone for a couple hours with just parents or just family members talking about that when I probably should have been doing other things. And I

think while it affected my grades I don't think it affected them dramatically. It definitely affected them, though, more than I actually thought they would um. Coming in and like we talked about how I wasn't gonna let it affect me at all. It was gonna be fine. And it's hard not to – it's hard not to let it seep in. And it's hard not to have something extra on your mind. And even if it's not something that's really bothering you that day, it's still another thing to add on. It's just something at the back of your mind. It's just something else. Especially when you're extremely stressed and you have two exams the next morning, you have six hours of homework to study that night, and you have a million other things going on and you have just one more thing. And it's just – it definitely affected my grades. Not positively. Um so yeah. They – my grades were not where I wanted them to be and not that I did horribly – I could have done much much worse but at the same time, it definitely could have gone differently and it definitely could have – I feel like it would have been easier if she – if I hadn't had that news right before school. If I didn't have that one extra thing on my mind, would my grades still have been where they are? I mean maybe but I feel like it definitely influenced it and – and in a negative way.

Jacob thinks the general adjustment to college could have played in a role in his academic performance. At the same time, he knows he was distracted by his mom's illness, as well as his co-curricular involvement. He doesn't think his grades were dramatically impacted, which mirrors Lisa's sentiments. He and his family discussed not letting his mom's illness affect his grades, but he found it difficult to actually ensure this happened.

Right now, Jacob said his biggest academic concern is his specialized accounting class:

Um just being in the [honors program], our classes are way harder than most. Um I think that's been my biggest issue. Time management, um has definitely been harder. Um I have many more – I have pretty much a whole 'nother class this semester 'cause I only had 13 last semester and I have 16...14 last semester...I had 14 or 13 last semester and now I'm at 16 and like while it's only basically one more class, it's still a lot more work and different involvement. I've become more and more involved um it's definitely tough finding that balance and not even with my mom's illness but it's been difficult finding a way to handle everything – juggle everything and keep my grades up to the standards that I have to. Now that I'm realizing how I have to have this GPA at the end of the semester to get through the [honors program], it's tough and I think right now just grades are the hardest thing on my mind.

What Jacob has shared about his academic experiences is reflective of what many students experience as they try to navigate college. He has more classes this semester and increased involvement on campus. Finding a balance between these commitments has been difficult. He has increased pressure to maintain a certain GPA due to his involvement in the MRU honors program.

While Jacob expressed his own concerns about his grades, he also shared that he feels his parents are disappointed by his academic performance:

[I'm also concerned about] letting my family down 'cause I don't want to...I know what my parents expect of me and what I got last semester is not where I

want it to be. Not even what they want me to be at. But just I just didn't feel comfortable with where I was and this semester trying hard and still struggling as much as I am is definitely hard [especially] coming from high school and not trying very hard and getting good grades and then coming here and being challenged as much as I am. Um. I think with having their own issues and knowing what my paren- my family's dealing with right now.

Jacob brings up another salient point for many college students: that of navigating the transition of not having to put in very much effort in high school and still performing well academically. Still, this traditional experience is complicated by concerns about his mom's illness.

Andrew, Lisa, and Jacob primarily engaged in critical self-reflection regarding this topic during the second interview. While Jacob didn't discuss his career aspirations, his voice adds to the experiences of Andrew and Lisa regarding academic performance. The participants acknowledged the role of their parent's illness in affecting their GPA, yet they all identified additional factors that they contribute to their performance.

*Social experiences.* Only one participant, Lisa said her social experiences were impacted by her dad's illness. Andrew and Jacob still commented on their social experiences at MRU. Social experiences are an important component of the collegiate experience, especially since the participants all live on the MRU campus or in the surrounding community.

Although Andrew doesn't identify as the most social person, he shared how he thinks his dad's illness relates to his social experiences:

I don't think it really changed how I associated with people um but then again I wouldn't know how it would be any different but I feel like I'm a bit more – like a bit more to the point and a bit more sort of like not really willing to deal with people who are who have like really sort of like reckless behavior like people who binge drink all the time or people who um just seem kinda self-destructive because it's – it's sort of like well I don't – I don't have time to like deal with this. I don't want to deal with somebody who's – doesn't care about their health and is setting themselves up for something really bad to happen in the future. So you know I'm not gonna just be around them...so I feel like I've been a bit more withdrawn, but not overly withdrawn you know, just sort of like I'm kinda fine being by myself and um being aware of what's going on.

Here, Andrew acknowledges a nuanced challenge. At MRU, he encounters students who make poor choices regarding their health. There appears to be no immediate or perceived consequence for these decisions, yet Andrew is acutely aware of the large impact health can make on one's life and family.

Andrew later elaborated on his social experiences:

And then I think I've gotten a bit more sympathy for um people who have family with cancer or other sort of diseases or family members who have gotten sick...so it really kind of makes you think about like what's important and what sort of behavior you think you know would be worth doing and stuff that you don't think is worth doing and like people who tend to freak out about stuff that doesn't really matter.

Again, Andrew's social experiences appear influenced by the impact of his dad's illness. He and his family have had to cope with significant challenges, making it hard for him to sympathize with or understand others who perceive their problems – which are insignificant compared to his concerns – as important.

Lisa's description of her social experiences is unique in that she discussed her experiences when her dad was sick and also after her dad passed away. In relation to social experiences when her dad was ill, Lisa shared:

I made friends, I have talked to people um. I didn't really discuss my dad being sick with anyone other than my friends from high school that knew he was ill until about October/November um of my freshman year. Um. People were understanding, but at the same time um they don't know how to react.

Lisa illuminates a challenge students face when disclosing parental illness: peers can sympathize, but they are typically unable to empathize or engage in conversation because it is usually a foreign experience. She elaborated on what it was like to share her experience with others:

People, not that they shun you, but they don't really. Lots of – especially 17, 18 year olds life is pretty shiny and perfect and seeing that there's a 17 to 18 year old whose life isn't shiny and perfect and who was – whose life was shiny and perfect and from the outside looks like it should be shiny and perfect and seeing that it really messes with – like it – it really shakes people's understanding of the world and that bad things do happen. But I'm only 18 so bad things shouldn't happen to me sort of thing and seeing that in someone else scares them. And so that's really I feel difficult to then meet new people and make friends and try to – I'm a

normal person other than that my dad had cancer...Like I'm just like anyone else.

So. That's hard for them – that's hard for people to see so.

Lisa has had to reconcile her competing feelings. On one hand, she considers herself a normal college student because she has a traditional experience of living on campus and being a full-time, traditionally-aged student. On the other hand, she acknowledges that her experience is not normal, especially for a young adult, because her peers have not yet had significant challenges.

Jacob, like Andrew, didn't really feel as though his social experiences were impacted:

I don't think it's really impacted me much. Um at least by making friends um I think there's been days that I've had a hard time and they – if something's been going on and I've been stressed – they've noticed and like we've talked about it. And we've brought it up a little bit. I mean, I'm a pretty sociable person. I mean I'm involved, I have friends in a lot of different areas of just my life. So I feel like overall it really hasn't affected me as socially as much as it could have. Um I feel like it could have affected me more if I'd been a lot more focused on it and not tried to focus more on school and tried to focus on – I think being in a fraternity actually helped in a way um just having so much going on, having 40 guys there constantly in my pledge class who knew generally what I was doing but kinda just kept my mind off it and we had so much going on that it was just something that never came up. And it was something that was definitely kept me not having the – it kept me away from having any social issues I feel like. So I really honestly don't think it's affected me socially as much as it could have.

Jacob seems to suggest that his mom's illness typically only infiltrates his social experiences when he is noticeably upset or stressed. Otherwise, his social experiences appear to mediate his familial concerns.

The particular ways in which the participants' social experiences served as a support system are explored in more depth in the next theme. Again, it is important to acknowledge that all the participants learned of their parent's illness prior to starting at MRU. Therefore, it's possible that they will not be able to fully reflect or understand the role it has played until after they have graduated.

***Involvement.*** Lisa and Jacob discussed how their parent's illness impacted their involvement. For Lisa, her dad's illness influenced what she chose to be involved with at MRU. Jacob did not choose his involvement based on his mom's illness, but involvement is a salient aspect of his experience because he has used involvement as a coping strategy. Andrew's involvement was shared in the participant profile. He didn't share, through the interview process, how his dad's illness impacted his involvement. There does appear to be a connection in that the two groups he spoke about being involved with are related to cancer.

Lisa shared first about her involvement in the MRU student-run summer camp for children with cancer or children who had a parent with cancer: "Most of the counselors are people who have somehow been impacted by someone with cancer or some sort of terminal illness uh so that definitely impacted a group I decided to get involved with." Lisa sought an experience that would allow her to be surrounded by others who would understand, to some extent, her feelings and concerns. This also influenced her decision

to be in the non-profit student organization designed to assist local cancer patients both emotionally and financially:

Again, cancer was a big part of my life for my – it – it was and it always will be um. It will be a big part of my life for the majority of my life so it's – it's definitely impacted the people and the groups of people I choose to talk to and hang out with.

Her membership in the selective state council was important to her because of her dad's reaction to her invitation to participate:

When I got accepted the first time my dad was really proud of me um It's kind of a prestigious thing. Not a lot of people know about it, but the people that do know about it – it's a big deal. Um and he was really proud of me when I got on that so in a way it kind of is connected to him so.

In contrast to Lisa, Jacob shared: "I don't think it really – I don't think it really affected anything. I mean I knew what I wanted to do. Knew that I wanted to be involved. I don't think it really stopped me at all." Jacob went on to share about two groups he is involved with:

I mean [MRU Athlete Team] has been a way for me to go to sporting events and get my mind off life and not have to think about anything for a while. A [Greek] house has given me an outlet just of a 105 brothers who I just have that are always there for me...

Jacob did not seem concerned with participating in activities to connect with others who have experienced familial or parental illness. The participants didn't speak extensively

about their involvement on campus, but it was a component of their collegiate experience impacted by parental illness.

**Theme III: Support utilized by the students.** The third major theme that emerged from the data relates to the third research sub-question of how the participants sought and received support within and outside of the institution. Three factors, *familial support*, *peer support*, and *institutional support* appeared, from the data, to be areas impacted by the salience of their experience with parental illness. These three factors are explored below.

***Familial support.*** All three participants discussed their immediate family as a source of support as they coped with their parent's illness. This type of support is unique compared to peer support and institutional support, as other members of the family unit were coping with the same experience.

For Andrew, who only disclosed his experience to one peer, familial support was particularly important:

I mainly spoke to my brother or my sister or my dad for support. So I didn't really mention it to friends 'cause I just didn't particularly want to. Um reaching out to my brother or my dad or my sister um it was essentially just um emailing or calling or talking because um we try to do this thing where we call like once every other week or once a week or something just to check in and see how we're doing and if there's something we feel like talking about and that's when we usually do it.

The ways in which Lisa sought support from her family was illuminated in the discussion of Theme I. She saw her sister and mother weekly and was close to extended

family members, such as her grandparents. In addition, her dad received treatment about an hour away from the MRU campus. She did not elaborate on how often they communicated or saw each other. She shared that although her sister has been a support system, she “still doesn’t completely have the same experience... ‘cause she’s at home all the time and with peers that she’s known for a long time.” Because Lisa’s sister has not transitioned to college, she has not had to develop new support systems.

The ways in which Jacob utilized his family for support was also explored in the discussion of Theme I. In the second interview, Jacob discussed the ways in which he has struggled to continue using them as a support system. As previously identified, Jacob and his mom are especially close. He shared how this relationship has shifted as he has learned to cope with her illness:

I think I’ve definitely tried to not ask as many questions almost in a way – not ask as many questions about how she’s doing, not detailed questions more just general how are you doing or how are you doing this week and kind of just going off that and if she says, “good,” it’s fine and kinda just take that for what it is and not look far into it, not try and find anything wrong and take her saying she’s okay as just she’s okay, it’s fine, focus on your own thing. And trying to – I’ve tried to distance myself in a way. I mean just making it so we had a normal father – er not father – normal mother, son relationship and just normal conversations and I think that definitely has helped, helped my stress level um while it’s still not perfect, um, I think – and I haven’t thought about it a whole lot. I guess I’ve kinda just done it instinctively and I’m just kinda trying to do that. Um I think it’s definitely helped.

Here, he discusses how he has strategically changed the way in which he engages with her to regain a “normal mother, son relationship.” This implies parental illness can skew a typical parent-child relationship.

Not only did Jacob identify the ways in which he has reframed what he hears from his mom, he has also felt conflict with what he feels comfortable sharing:

I also struggle knowing what to talk about with them – about my personal struggles and giving them another thing to worry about. It’s been kinda hard just knowing like well I need – like if I need a day I just need to talk to them about something I will. But if it’s a normal just everyday little issue that I’m stressed out about and I’d like to talk to someone about but I know I really don’t need to. It’s something I just need to suck up and deal with. It’s – it’s a struggle deciding what I need to worry them with and what I don’t and that’s been the biggest thing I think.

Prior to the diagnosis of his mom’s illness, he would approach his parents with his concerns and stress. Now, he feels like he should cope with these challenges on his own. In this way, Jacob has developed more independence. While familial support was the most important and most utilized form of support for Andrew, other support systems, such as peers and institutional resources, have been integral to the ways in which Lisa and Jacob have coped with parental illness.

***Peer support.*** The participants illuminated conflicting feelings regarding peers as support systems. Jacob described his peer support network as overwhelmingly positive and effective. Lisa shared appreciation of her peer support network, but was also

frustrated that none of her peers have shared the same experience as her. As previously mentioned, Andrew only disclosed to one peer:

I mentioned it to one friend but um it was more of a kind of just spur of the moment and I was just kinda really tired and I was like oh you know this kinda sucks. And she was like yeah I can sympathize, it does kinda suck and that was the only really time I kind of reached out [to a peer].

Andrew suggests he did not intentionally reach out to this peer, but merely disclosed because he was in a vulnerable position. In fact, in some ways, Andrew avoided using a peer support network:

It kinda takes people aback and I feel like um personally if I kept telling people about how sick my dad was I'd become more of like a – a victim and so you know use that to garner sympathy so I could feel better and I just didn't really want to do that. It just seemed kind of disingenuous and you could say I was kind of reluctant to talk about it you know with just friends around the street or just random conversation.

Instead of feeling like peers provided support, Andrew felt peers – because of their surprise and lack of experience – exacerbated his self-awareness about the challenges of his experience coping with parental illness. Lisa also expressed hesitancy at disclosing to her peers:

They don't really know how to talk to you I feel like...I was – I am more adult than more – most – 20 year olds are so that was – that's really – that was and that is very hard to kind of connect with people.

Compared to her peers, Lisa felt like an adult; her challenges associated with parental illness forced her to grow up quickly and established concerns not typically experienced by most traditionally-aged college students.

Lisa went on to discuss how she has two types of friend groups:

I found people that I can talk to about it and have gone through not similar – not necessarily cancer – but have gone through either their own sort of emotional roller coasters or things and it was easier to talk to those people and those um were kind of the friends that I really talk to about this.

While she sees her friend groups as sources of support, it's important to acknowledge that they cannot completely relate to her experiences as a traditionally-aged student coping with parental illness. Her second friend group encompasses a lot of her friends:

They know my dad was sick and they know he's not here but they don't know all of the details. They don't know – they see the front that I put on. The – like the face where you're happy all the time but they don't get to see the times when you're curled up in a ball in the corner. Those are kind of – I separate two different groups of friends. Where those friends that see me in the corner also see me happy. I'm not saying that I strictly have like depressional friends – like I have friends that we just like cry all the time.

Lisa is able to control how she engages with others. She is able to be vulnerable, but she also feels compelled to hide her true feelings and concerns with certain friends. She went on to elaborate why she is often hesitant to disclose:

Um it's hard to relate to students a lot of the times uh especially because they have both parents or um even if they didn't grow up having both parents in the

house, both of them are still alive, free to contact them if they want to. If they don't like they do have that option and I don't really have that anymore which definitely makes it hard to relate to kids um. It's kinda...it's something that just uh like it doesn't weigh on my mind all the time, but like if things come up in conversation or I'm watching something on TV or listening to music or reading or anything really like there'll just be a moment where I just can't like hold it together anymore and that like kinda is like well a lot of the times people just like stare at you if you're in public or they'll be like okay there's some – she's weird or they don't really...And you don't want to like explain it to every single person so it kinda like creates distance between you and people and just like everyday like conversation and life.

Lisa highlights the fact that most students don't have experience with parental illness or parental death. While this isn't always something she considers, she does have experiences that trigger reflection and emotionality. Lisa explained that it's difficult to experience these triggers because she feels simultaneously compelled to explain what others consider to be odd behavior and annoyed that she has to justify her actions.

One positive peer support network she has is her group with the selective state council:

“They uh knew about my situation so that was. They're a close – there's some close friends I have on there so that was really nice.” Lisa did not share whether this group knew of her dad's illness prior to her time at MRU, when she was in high school, or if she disclosed while at MRU.

Jacob described a very strong peer support network:

I think my friends have definitely been very supportive um they're probably – there's a few – there's probably three of my closest friends are the ones I come to the most and they've always been very supportive of just listen to me and also giving advice.

Jacob's friends provide a sounding board for him to share his concerns and they are able to provide him with suggestions. He elaborated on this strong peer group and other peers he's connected with on campus:

Two of them are new friends I've met. One has been my best friend from high school so he knew my family situation coming in 'cause he's practically like my brother at this point. So I mean he – he's one that I've always talked to no matter what, so he's kinda invalid. Um he's um – no so he's one I had coming in and then my other two I've just met um actually probably last October and they've become two of my closest friends I mean...had nothing to do with my mom or any of my situation. They've just been people – and they're just great people and they're just good friends and I've gotten to know them very and they've gotten to know me very well and in that process they've just been two people I've been able to talk to and they've been able to talk to me so it's just been a good fit. And there's been other – I mean there's other friends that I talk to on a pretty regular basis – not as in-depth about things but they're still – I still have lots from the [honors program], and the house, and in my dorm that I've been able to talk to and become friends with so.

Jacob really lit up when he talked about the connections he has made at MRU. Both Jacob and Lisa have at least one friend who is also at MRU and is aware of their parent's illness.

The participants had a wide range of experiences with their peers. None of the participants disclosed their experience to every friend. However, all of the participants had at least one friend to whom they disclosed. Peers provided support, and, at times, exacerbated participants' feelings of alienation.

*Institutional support.* While all participants utilized institutional support, only Lisa and Jacob utilized this support to help them cope with their parent's illness. Andrew shared that he has developed close relationships with professors and student affairs professionals on campus, but did not feel the need to disclose his experience to them. In addition, he did not feel he needed to visit the counseling center on campus:

I – I knew there were the services for [counseling] um but I – again and maybe it was a perceived thing, but I didn't think I was terrible. And I think it was mainly because that my dad was still working and he was still up and about and still doing things. He was just kinda – kinda down and there was only one period of time where it was kind of bad because he had the hip surgery so he couldn't walk around. But um I think I've been very lucky in terms of um my dad and his illness and that he's still up and able and that my brother's doing pretty well and my sister's doing pretty well as well so and I'm doing well you know and if there was a you know if um my dad was sick and then if my brother or my sister got sick I think it'd be kind of a different experience you know.

Andrew felt he was not in an emotional place where he needed counseling. This feeling of luck is something Andrew referenced throughout the two interviews. He was very clear to acknowledge that he feels his experience with parental illness is very different from others because his dad was able to continue working, entered remission, and did not have a degenerative disease. It is unclear whether he felt his experience was different and optimistic from the beginning, or whether the time his dad has been in remission has given him the opportunity to reflect on his experience in a way that helped him see his experience in a positive way.

Lisa utilized the MRU counseling center as well as the office through which the Peer Mentor program is run. Lisa described her experience with the counseling center as very positive:

I used [the counseling center] um last semester or last spring semester so a year ago. Um I felt like I was having a lot of trouble like understanding why everything was happening and I had never for myself talked about it – it was is my mom okay, is my sister okay. Like with everything I never talked and made sure I was okay myself. And at that point I felt like I needed to so um I used that which was really nice. I only went the three free times but um I felt like she was really good and she listened to what I had to say and um she was really helpful and like the things we talked about and making sure like that my parents under – that I made sure that my parents understood how I was feeling ‘cause some – ‘cause sometimes like I felt like I wasn’t really explaining to them exactly like how things made me feel um.

Lisa's counseling experience suggests students experiencing parental illness need support throughout their process of coping – not just when the diagnosis occurs. In addition, it is important to acknowledge that Lisa sought this support system when she was ready. She might have had a different experience if she utilized counseling services at the recommendation of someone else. Lisa elaborated on her experience at the counseling center:

[At the counseling center], I liked how it was um private and not even like my parents were gonna find out what I was saying. Not that I said anything bad about them or anything but like I just – the privacy of it made me feel really comfortable um...It made me gain and insight on how I was feeling about it. Which I kind of repressed for the last three years. Um I definitely – and before I had gone I had a negative image of mental health professionals and mental health like in general. I thought it was like crazy people went and all of that. But like I def – after going I definitely see the benefit in talking about things, esp- and talking about it with another person who can then – doesn't know your situation and doesn't know what's going on but then can have a conversation with you and really cares about how you feel about things and not necessarily what your parents, your family, your friends' opinion about things like they honestly care about what you think and that was really – I thought was really good especially for me when I had kind of hadn't cared about myself before that and the whole situation and so...

Even though Lisa had previously identified that she does not like always having to disclose her experience to others, she liked entering the counseling space without the counselor having this knowledge.

Lisa also reached out to the advisor for the selective state council, who she said she was very supportive, and to the Peer Mentor program advisors:

I felt like in their job position this is like a sort of thing they were supposed to kind of deal with or help students find resources or help students through that so I felt more comfortable talking to them about it so... than I would professors or other students and friends.

Lisa viewed these advisors as being prepared to help her through this experience.

Perhaps this is a function of the fact that these advisors work in a program that promotes institutional resources and encourages students at MRU to utilize institutional support systems.

Even though she sought support, she was still hesitant to use MRU's resources:

I didn't feel comfortable telling a lot of people like or people in the University. I felt like they would think of it like as an excuse to why I got a bad grade on the test or homework or things like that. I didn't want it to be like an excuse and even when um he was – he had decided to stop treatment and was – liked passed away. I still felt like...I told my professors probably at the last second um because I didn't want them to feel like it was an excuse for me being gone or I didn't want it to be a reason I wasn't showing up to class. Which, it was – like I showed up to class I just it shouldn't have been a reason for my poor academic performance.

Here, Lisa brings up a point made by Jacob when he discussed his academic experiences: the concept of using parental illness as an excuse. This fear kept her from reaching out for help.

Jacob feels his connection with his academic advisor, Clara, who also serves as the Associate Director of the honors program he is involved with, has been immensely helpful. She was the first person Jacob disclosed to MRU and he continues to seek her support: “I felt she needed to know just where I was coming from. And she’s been the probably the biggest person on campus that has actually helped me. I mean she’s been there through everything.” Jacob initially disclosed to Clara because he was concerned about the impact of his mom’s illness on his performance in the honors program. She quickly developed into a key resource. Jacob expressed why he did not and has not used other resources:

I’m aware – I mean I could have gone – I could have talked to people. I could have gone to the health center, stuff like that. Um to be honest I don’t think it ever really crossed my mind to use those resources because I’m pretty independent, never really felt I needed to. Were there days I probably could have? Yes. Would I have gone? No, because I didn’t – I viewed it as I have enough on my plate – I don’t have time to go out of my day to do this. And I need to just suck it up, get it done, do my work. I’ll deal with my emotions later.

Here, Jacob identifies that he is able to choose when he deals with his emotions and that his emotions are a secondary concern compared to the work he must get done. In addition, Jacob suggests he felt counseling would be an additional burden and responsibility to juggle with his other concerns, rather than a resource for coping with his other concerns.

Jacob shared a lot about Clara's impact on him, which also clarifies why he felt he did not/does not need other institutional support systems. Below are a few aspects he touched upon:

She's been extremely supportive. Um she's almost acted as a second mother in a way 'cause she's very motherly. Um given the support that I needed um given me a hug when I'm really down. Also at the same time, she knows me well enough that she's also been challenging in a way that if I need...if I'm having a day where like I have no motivation and I just need to – I need to find some motivation, she challenges me to push myself and to pick myself up and move on. And she's been that person that she's always been there for me to talk to no matter. Um no matter how busy she is and she's always been able to talk things out with me. Asks questions, but not too in-depth that it brought up more emotions but at the same time was a very active listener as in I could just talk and say whatever I needed to get out and she'd listen. At the same time, she would compare my life at home with my life at school and how it's affecting me in school and was able to reassure me when I was worried about how it's affecting my grades and how I'm doing in a single class or do I need to go home this weekend. And she's said, she's given me options where you could go home this weekend, see your family, come back, do this and she's just been someone that has given me the options and almost a path to go on just to being a freshman and not knowing what I'm doing most of the time...not knowing 95% of the time.

Clara helps Jacob see options for negotiating his role as a student and a son in order to cope with parental illness. Despite not being able to identify with Jacob's experience, her

active listening and ability to both challenge and support him through this experience was seen as an immense source of support. Jacob continually referenced Clara's role in his life throughout the two interviews.

In addition:

She's been that person saying don't worry about the future, you have no control over it. Focus on today and it's – she's just been very understanding and just so supportive in a way that, hell I don't even know how to explain that. Just...just someone who's been able to not even tell me that – I mean she's told me she's always there for me but in a way she's just – emanated that persona that she is always there no matter what. I can text her anytime and she's just always someone no matter what happens in school, no matter what happens with my friends, no matter what happens to my family. She will be there just for me to talk to and just an open resource that has as much communication as I need to as possible. And that's been the biggest thing.

Clara has been accessible to Jacob outside of the institution and serves as a support system as he navigates new friendships and his academic experiences. Jacob's relationship with Clara has been transformational to his experience. He almost teared up on multiple occasions when expressing his deepest gratitude for her support.

The participants had complicated experiences with various support systems. Andrew felt most comfortable using his family as a support system. Lisa, on the other hand, seemed to find peer support groups and institutional resources more helpful. Jacob appeared to have strong experiences with all three components.

**Theme IV: Advice for institutional support.** The fourth major theme that emerged from the data relates to the fourth research sub-question of what can institutions do to support these students' unique needs. Two factors, *intake self-disclosure and training for advisors, counselors, and professors* appeared, from the data, to be areas impacted by the salience of their experience with parental illness. These two factors are explored below.

*Intake self-disclosure.* The participants identified the benefit of intake self-disclosure, or the opportunity for students to disclose their parent's illness to the institution.

I think that'd be actually very helpful like get a sense of like what your family background is. 'Cause they ask for race and your nationality and they get socioeconomic data but it might be interesting... But it's sort of something to look at and maybe they could add like something else to it like about um like the – the time of like a diagnosis, you know sort of like oh you know my so and so – my relative – that I'm close with had this disease but it was two years ago so it's mainly under control versus people who are like oh um I'm just starting college and my mom or my dad just got into a major car accident and so we're kinda worried about that you know. – Andrew

I feel like it could definitely be manageable to say...when you register for school that you have a parent with a – mother or father with MS or any other disease and I feel that that's something to put on...an application...I feel like you'd almost have to have more background information on...the family history of that to really judge if that person wants to be talked to. I mean if it's someone that's had a parent – parent's had that disease for 8 to 10 years or something like that, they

probably don't need as much help. Um in my case, someone who got diagnosed about two weeks before I left, yeah that's probably something that depending on what it is – if it's cancer or if it's MS or Alzheimer's or something yeah – Jacob Both Andrew and Jacob suggest there are mediating components to parental illness that can impact what resources students need. Andrew brings up an important consideration – that institutions have decided what components of family background are relevant to the college experience. In leaving parental illness out, institutions are, in some ways, dismissing the impact of parental illness on the college student experience.

*Targeted outreach.* Andrew and Jacob elaborated on the usefulness of intake self-disclosure. They feel it would be most beneficial if students are able to disclose and then receive individualized outreach based on their situation.

I feel like definitely someone that reach – would at least reach out and not be overbearing about it but just like hey this is open if you need to talk about anything...Someone that – just to reach out enough that they – the person knows they're there. If they never use that – utilize that resource, I guess that's gonna happen. I mean there's people that are not gonna wanna use it. However, I bet you would find students who might need it...but, I think it's definitely something you'd have to have background information coming in...And I mean – it would just be nice I think if you had that person reach out to you. Not – not a million times and some of the emails you get from certain offices on campus are ridiculous and you get one every day if not twice a day. You don't need that – just once maybe the first – maybe once in the first few weeks of school. You'll more than likely forget it as a freshman 'cause you're – you get so many emails

and so many things thrown at you immediately that you'd probably forget you'd even got it. Maybe again October/November. Um I think it would definitely be useful. Like just not to be overbearing about it but just enough of a presence for the student to know that you're there. – Jacob

...so they could look at like oh this person has a – a brother whose ill and they've been missing classes. Oh you know I wonder what's going on there – it could be they're you know doing more family stuff, it could be that they're you know skipping classes to skip class. – Andrew

Jacob suggests the experience of parental illness might be mediated by the initial concerns and preoccupations students have when they first transition to college. Students might not be ready to attend to their concerns about their parent until they feel more settled. Some students might need this type of outreach right away, indicating, again, that the concerns of this population of students is diverse. Andrew's quote suggests there can be warning signs indicating students are struggling to cope with their dual roles.

*Support groups.* Lisa and Andrew believe intake self-disclosure could provide an opportunity for the institution to develop and promote support groups for students experiencing the impact of parental illness. They both shared a desire to engage with this type of group.

I kinda wish that in a way that um I knew people that were going through the same thing at the time I was. That was one thing I wish I still could have and like wish I had at the time 'cause...there are people that have gone through it but not like – so they understand but when it's going on as you're trying to take classes and as you're trying to meet new people and you're trying to like figure out who

you are...it – it was a lot to take like – like it’s a lot to deal with and I wish like, I still do – I still feel like the – ‘cause I know there are people walking around me and sitting in class that are probably going through the same thing I am or something super similar and I wish like there was a way that we could all like be there for each other because I know it’s really hard and no one really understands.  
– Lisa

Not like a formal [student organization] or anything but just like something where people can go and talk and – and I don’t know if people would actually show up but like for me it would have been nice to know like how many other people that are going through the same sort of thing. And I bet every single one – every single person on campus that’s going through something like I am probably will say similarly so. – Lisa

I kinda like um the fact that uh well there’s an idea and it’d be kinda nice if it could happen but I’m not sure how likely it is but to get students whose parents have been ill and sort of like have them kinda meet together because it’s sort of like oh you know I know what it’s like to have a parent who’s ill so it’s sort of like one less thing you have to be subconsciously on your toes about you know with other people and you can say oh you know I went to the hospital and the hospital smells really bad. – Andrew

Lisa and Andrew believe this support group would not have to be formal, but they would like the opportunity to engage with others students on campus who are coping with similar experiences. Since this student population is hidden, it is very difficult for students to establish their own support groups.

*Training for advisors, counselors, and professors.* All three students commented on the importance of training advisors, counselors, and professors.

*Advisors.*

Jacob had two suggestions for advisors:

Just be trained to read students in a way that they'll know. I mean – that they can if something's wrong with a student kind of pick up on that and maybe start asking questions and just making sure that person's okay. I think with the system we have now though I don't think there's really any way that students would talk to an advisor. Um at least a generic advisor about problems at home. And yeah, people are gonna open up if they really need that and depending on the situation, yeah they might. In general, though, no I don't think – I don't know how you'd just change the system right now to have just advisors know how to handle that. Um. I really think you'd have to change the system of how advisors work and giving specialized advisors to certain people but...maybe in a way I guess you should go off the application and you have people say they have illness and you put them in a certain college if they're all business majors maybe put them with one advisor...I mean, have other people with that advisor but give that small group to one advisor who really is trained in that area and knows how to handle them.

Just push – encourage the student to have a life and to be involved and not let it define them as a person I think that's been the hardest thing. Is don't let your background and your life at home define you as a person at school when people don't see you as that person. Even though you might think you are.

His first suggestion calls for advisors to receive training on how to read students. Earlier in the interview, Jacob mentioned that he would probably not have disclosed to a general academic advisor, as they are typically seen as resources only for academics. Although he is not entirely sure how it could work, he expressed interest in the idea of providing a specialized advisor to students who identify as having a parent with a significant illness. At one point in the second interview, he shared concern about forcing students to only meet with an assigned advisor. His second suggestion encourages advisors to recommend that students take advantage of involvement and try to establish an identity beyond that of a child of a significantly ill parent.

Lisa provided another suggestion for advisors:

For anyone I think just being open-minded and being willing and um to talk to students and being – and being able to open yourself up and show – ‘cause a lot of – a lot of the times, not necessarily for myself but I know a lot of people like my sister, she wouldn’t have talked to anyone until they’d shown like that they were vulnerable so. That’s one thing especially like...makes like – when you get those groups of kids together make sure that like you give like that your life wasn’t always perfect ‘cause that’s sometimes people are afraid to talk about the hard things because they see everyone else as being perfect. And if you let them know that you didn’t always have it peachy and happy go-lucky then I think they would be a little more willing to express how they’re doing a lot of the times ‘cause I feel that if they do see them as having everything be perfect then they don’t think that they’ll understand which most of the times people will understand in a way that they – in some way or another.

For some advisors, expressing vulnerability undermines what they perceive as their role. Whether they are an academic advisor, or an advisor for a particular program, these individuals often have immediate concerns to follow up on whether a student is on track to graduate or whether a student has completed their responsibilities for an event. A power dynamic is inherently established. Lisa suggests that for student coping with parental illness, a deeper relationship can be formed.

Andrew adds another perspective:

With student affairs I think it might be a good idea um if they kinda mentioned the counseling a little bit more so like hey this is sort of when it's open and the people who can help and here are other people who can help out and here is some stuff so that you know that you're not alone; there are other people who are talking with you and they are willing to help.

Andrew shared that he heard about counseling services when he first started at MRU, but didn't really continue to receive these messages as he progressed through his sophomore and junior years.

#### *Counselors.*

Jacob shared a suggestion for members of the counseling center:

Have them kinda...maybe even have pamphlets of like just...kind of background within the disease that that person's parent may have. And go off that and kind of just give them – especially if like the person doesn't really know any background behind it, it might be good to know what to maybe expect in a way, but at the same time have someone in the institution who...I mean basically just a counselor I guess to look at a person's grades, look at their involvement, look at how they're

doing and then say well how do you think this is – I mean how do you feel like your life at school has been affected by your life at home and vice versa and basically just talk someone through know – like if they know the disease the person’s parent has like with mine – MS is completely random and you have no idea what to expect and there’s no warning symptoms – and so different in each person that there’s really no way to prepare for that. Basically just talk about you have no control over life, I mean you have no control over the future. Here’s how you need to do in school, this is what you need to focus on at school, this is what you need to focus on at home and you need to separate – I mean just someone – a counselor just in the institution that not needs to know every dis – like needs to have background on every disease – but at least have the resources to learn about that and teach someone about that and kind of just provide that leadership I guess to that person – to that student who has no idea what they’re doing. Especially freshmen, I think is the biggest thing. ‘Cause if you have a junior who’s parent get diagnosed, yeah they’re gonna have a hard time, but I feel like they won’t have as hard a time like I mean first semester those first few weeks for me like everything’s brand new, you have no idea where you’re going, you’re scared to get to class on time ‘cause you don’t know if your professor’s gonna yell at you.

Jacob addresses a number of concerns this population might have. First, he suggests it would be helpful for the counseling center to develop pamphlets that identify key aspects of various illnesses so students can learn more if their parent becomes significantly ill. Next, he suggests counselors should be the ones responsible for the targeted outreach identified earlier in the theme. Jacob believes counselors should help students negotiate

their roles as a student and as the child of an ill parent. Freshmen, in particular, he feels would benefit from this type of support.

*Professors.*

Andrew suggests that professors can also be resources for students experiencing parental illness:

I think most professors are pretty um pretty understanding and pretty open. Um the one thing again would be saying you know there are these counseling services and then um maybe occasionally be willing to just like have the students sit and vent and then talk about – talk about their life because they don't have to you know be a counselor or play counselor but it's just having somebody you trust, especially a mentor figure, can be really really sort of cathartic and nice and sort of a safe place to let it out 'cause not everybody wants to go to therapy and talk with a therapist.

Andrew believes professors can choose to engage with students on a personal level.

Students might experience hesitation in utilizing resources that carry a stigma, such as a therapist or counselor. Professors, therefore, can be a nonthreatening resource.

**Conclusion**

The four central themes – initial feelings and concerns, how the collegiate experience was impacted, support utilized by the students, and advice for institutional support – gathered from the interviews with three students at MRU experiencing the impact of parental illness illuminate various challenges and opportunities for support for this population. These themes provide glimpses into common experiences among the participants and also offer different perspectives regarding how students cope with this challenge. Chapter five explores the implications of this study, connecting the research

findings to the literature related to this population. I then suggest potential best practices for effectively supporting the invisible group of students who have a significantly ill parent and make recommendations regarding how future research should proceed.

## **Chapter 5**

### **Discussion**

#### **Introduction**

The number of traditionally-aged students who have a parent develop a significant illness while they are in college is currently unknown. Institutions have not developed specialized resources to support these students, though it is clear they have unique challenges that should be addressed. As resources for hidden student populations continue to grow, it is imperative that institutions prioritize this population. There are a number of factors that influence how students cope with the challenges of parental illness, making it difficult to identify solutions ideal for everyone. Since little research exists, more should be done to better understand this population and develop practical strategies for support.

#### **Summary of Findings**

The following research sub-questions were designed to explore the experiences of three traditionally-aged undergraduate students experiencing parental illness:

- What are traditionally-aged college students' initial feelings and concerns when they learn of their parent's significant illness given their role in the family and the context surrounding the development of the illness?
- How has the development of their parent's significant illness impacted their collegiate experience?
- In what ways have they sought and received support within and outside of the institution?
- What can institutions do to support these students' unique needs?

Two interviews, utilizing a semi-structured protocol, were conducted with each participant to allow them to share their unique experiences. As the primary researcher, I felt both hesitant and hopeful that a few current students at MRU would be incentivized by the idea of a potential gift card and the opportunity to illuminate a hidden experience. Five students volunteered to participate – three who met the study criteria and two who did not. The first student who could not participate, per the parameters of the research study, had a parent who had developed a significant mental illness many years prior to them entering college. The second participant who could not participate, per the parameters of the research study, was not yet 19. While there was not an influx of responses, the three participants who volunteered and met the criteria were excited to share their story in the hopes of building awareness. Their stories are powerful and reflect hardship, grit, and resilience. The willingness of these students to share their stories might be indicative of their ability to successfully navigate the experience. This study was unable to include voices of students who could not persist or who are silently struggling.

In this concluding chapter, the four themes illuminated through the research are summarized. In addition, these themes are connected to the aforementioned literature. I will then outline the implications of the study and offer recommendations for future research.

### **Summary of Themes**

Four primary themes were established from the research questions and the subsequent data. Subthemes were developed to identify factors affecting students' initial feelings and concerns, how the collegiate experience was impacted, support utilized by

the students, and advice for institutional support. The factors related to initial feelings and concerns include five subthemes: *nature of the illness, relationship with the ill parent, the family dynamic, the college decision process, and financial concerns*. The impacted aspects of the collegiate experience include: *academics and career aspirations, social experiences, and involvement*. Three types of support utilized by the students were identified: *familial support, peer support, and institutional support*. The final theme suggested two factors for consideration: *intake self-disclosure and training for advisors, counselors, and professors*. The main ideas from the findings are summarized below:

- Students who experience the impact of parental illness have a number of initial feelings and concerns related to their role as a child and role as a student. Negotiating these two relationships requires an understanding of the illness, the prior functioning of the family unit, shifts in the family unit after the diagnosis, and an understanding of the student's experience on campus.
- The collegiate experience is impacted when a student has a parent develop a significant illness. It is important to explore how academic and co-curricular experiences are mediated, as well as how students engage socially on campus.
- While the students all had familial support to continue to pursue their degree at MRU, other forms of support were not accessible until the student felt comfortable disclosing their experience and challenges.
- The students were able to articulate a desire for intake self-disclosure, support groups for the population, and enhanced training for institutional personnel, suggesting more can be done to support this population.

### **Connections to Literature**

As discussed in Chapter 2, there has been very limited research conducted on the impact of parental illness on the traditionally-aged college student experience. This study contributes immensely to the qualitative literature, which is even more underrepresented than the quantitative research related to this topic. The four themes stemming from the research questions and data will now be connected to the previous literature.

**Initial feelings and concerns.** There is little research that explores the initial feelings and concerns of traditionally-aged undergraduate students who experience their parent developing a significant illness during their collegiate experience. What research does exist and relates will be explored within each subtheme.

*Nature of the illness.* All three participants have/had parents with incurable illnesses. The two illnesses represented were multiple myeloma and multiple sclerosis. Schmidt and Welsh (2010) provided research on the adjustment of university students facing chronic or terminal illnesses of a family member. Their research is relevant to this subtheme in that they suggested when the crisis of illness occurs, adjustment to college can be negatively impacted. Lisa was the only participant who had more than a year to adjust to her dad's diagnosis; even given this, her adjustment was complicated by the fact that her dad was re-diagnosed right as she began college. Andrew and Jacob had much less time to adjust. Schmidt and Welsh (2010) suggested students with prepared coping mechanisms can mediate perception of crisis. Arguably, the three participants had to simultaneously develop coping mechanisms and adjust to the college environment.

*Relationship with the ill parent & The family dynamic.* The adolescent-parent relationship was a salient aspect of this subtheme. Andrew, Lisa, and Jacob all

expressed they were close with their parent who became ill, indicating they were securely attached. The diagnosis of the illness disrupted this attachment: Andrew had to cope with the uncertainty of how his dad's illness would progress; Lisa became "parentified" (Stoeckel et al., 2014) and helped take care of her sister; Jacob also became "parentified" (Stoeckel et al., 2014) as he supported his mom and allowed his dad and brother to maintain their activities and priorities. Schultheiss & Blustein (1994) suggested secure attachment to parents can help students transition more effectively to college. For Andrew, Lisa, and Jacob, secure attachment seems to have exacerbated the impact of the illness and complicated their ability to adjust to the new situation of transitioning to college. None of the participants had conflictual independence (Schultheiss & Blustein, 1994) because there was guilt and anxiety involved in the new relationship established by the development of the illness. Lapsley and Edgerton (2002) also explored conflictual independence, supporting the notion that students will likely have more difficulty adjusting when they have emotional dependency.

Wei et al. (2003) identified a relationship between coping strategies and attachment. The initial feelings and concerns of all three participants primarily stemmed from their fear and uncertainty. These feelings increased their need for parental attachment and, according to Wei et al. (2003), negatively impacted their coping abilities. While Andrew, Lisa, and Jacob coped effectively enough to transition to MRU, they did face additional challenges as they tried to reconcile their familial relationships and collegiate experience. Skowron et al.'s (2004) research is also relevant to this study's findings. They explored differentiation of self, which, as previously mentioned, was complicated by the development of the participants' parents' illnesses.

Hiester et al. (2009) discussed how students' relationships are renegotiated when students transition to college. They suggested more autonomy exists for students, however, the participants all identified feeling preoccupied, at times, with what was happening at home and how their parent's illness was progressing. Hiester et al. (2009) also explored gender differences among students as it relates to parental attachment. It is unclear how this aspect of their research relates to the findings, as the sample for this study was too small to guess at potential generalizations.

***The college decision process.*** Lapsley and Edgerton (2002) found that physical separation between college students and parents helps students more independently make decisions regarding their future. For Andrew, Lisa, and Jacob, their family largely impacted their college decision process. Andrew and Jacob's parents both attended MRU and Lisa made her decision regarding MRU based on her dad's support. While Jacob had already decided to attend MRU prior to his mom's diagnosis, Andrew and Lisa did not make their college decision independently. Their new familial situation played a role in their decision-making process.

***Financial concerns.*** Financial concerns for students experiencing the impact of parental illness were not discussed in the literature explored for this study. Since this was an aspect of parental illness identified by the participants as impacting or being able to impact their college experience, more research should be done in this area.

#### **How the collegiate experience was impacted.**

***Academics and career aspirations.*** Servaty-Seib (as cited in Neubert, 2012) identified a common experience shared by the participants of trying to focus on academics. This research illuminated the difficulty in simultaneously focusing on

academic requirements and the development of the illness. There is often a disconnect because parents encourage their students not to worry and request that they remain in school. Andrew, Lisa, and Jacob all expressed that these requests do not actually mollify their concerns.

***Social experiences.*** Rosenberger (2011) discussed self-discovery and the developmental desire to socialize and engage with others. While the participants were able to form new friendships, Rosenberger's (2011) research assumed parents are not present. For Andrew, Lisa, and Jacob, their parents were not physically present but present in that they were constant considerations when these participants were engaging on campus.

***Involvement.*** The research did not address how involvement mediates the college experience. Since this was an aspect of parental illness identified by the participants as impacting their college experience, more research should be done in this area.

***Support utilized by the students.*** Maunu and Stein (2010) are the only researchers explored in this study who identified a specific type of support that mediated the experience of parental illness. Religion and spirituality were not salient experiences identified by any of the participants in this study. Kinsella and Anderson (1996) identified coping skills utilized by individuals coping with mentally ill parents. Overall, the participants expressed healthy methods of coping: utilizing familial support, peer support, and institutional support. While some elements of self-isolation were present in Andrew and Lisa's stories, it appeared that interacting with peers who were unable to

understand such a challenging experience contributed to what Kinsella and Anderson (1996) considered an unhealthy method of coping.

*Familial support & Peer support.* While the literature touches on the concepts of attachment and identities/relationships, it does not really attend to the ways in which families and peers can serve as support systems. Instead, as previously mentioned, the focus is on how familial and peer relationships are complicated.

*Institutional support.* The literature does not attend to institutional support, as the majority of the research is not on undergraduate students experiencing parental illness. Students discussed the impact of forming significant relationships with staff members, which is largely unexplored.

#### **Advice for institutional support.**

*Intake self-disclosure.* It is clear that students are beginning to take matters into their own hands. The development of and existence of chapters of Students of Ailing Mothers & Fathers Support Network on college campuses provides the type of support group the participants identified as wanting (Students of AMF, 2015). Other than this connection, the suggestions identified by Andrew, Lisa, and Jacob are not discussed in the literature.

*Training for advisors, counselors, and professors.* Again, it is important to recognize that the literature is severely lacking in providing a basic insight into this student population. Therefore, recommendations for institutions have not been considered.

#### **Implications for Future Practice**

This study explored the impact of parental illness on three traditionally-aged college students at a large, public, research institution. Participants shared their voices to illuminate their experiences and recommendations for support. The following are the two major implications for future practice at Midwest Regional University and similar public research universities:

- The institution is strongly recommended to create a system through which students can self-report having had a parent develop a significant illness while they are in, or right before they transition to, college. This population faces significant concerns related to transition, especially when re-locating to the institution. More specifically, this system should allow students to provide background information that can illuminate their unique concerns. Creating such a system will create the means for institutions to track the existence of this population on their campuses and establish support systems accordingly.
- Students shared that student affairs professionals and faculty members provide significant and meaningful support as they navigate this challenging experience. Therefore, developing consciousness of how they can practice vulnerability and “read” students can help encourage students to disclose. Additionally, developing an understanding of the ways in which parental illness mediates academic and social experiences can be useful so students feel validated in their complicated transition. Perhaps students who self-identify as having this experience could be matched with a student affairs “mentor” who has experience connecting with students who have hidden challenges.

Since this research only includes a few voices in regard to this experience, it is important to understand that the implications are grounded in what this study has illuminated. This research study identifies far more recommendations for future research than future practice.

### **Recommendations for Future Research**

As previously mentioned, research on the impact of parental illness on the traditionally-aged undergraduate student is extremely limited. While there is research on coping, attachment, and identities/relationships that can be used as a framework for understanding the unique needs of this population, more can be done to integrate these components in a direct exploration of this student population. Additionally, it is incredibly important for the research to utilize qualitative methodologies in order to truly capture these students' experiences. This study suggests there are students willing to share their experiences, who feel invisible on the college campus. The following are the major implications for future practice:

- Future research should seek to incorporate a variety of perspectives on parental illness. This study was only able to illuminate experiences of students who have/had a parent with an incurable disease. While more needs to be done in this area, it will be important to include voices of students who have a mentally ill parent.
- Future research should seek to explore the ways in which other identities mediate this experience. The participants in this study were all white, cisgender, and able-bodied. Focusing on aspects of identity, such as race, ethnicity, gender, nationality, military status, and sexual orientation would

provide more insight regarding the intersectionality between marginalized identities and how this influences students' experiences coping with parental illness.

- Future research should include the voices of students who are not close with their parent or their immediate family unit. All three of the participants in this study identified as being close with their ill parent and their immediate family members. Research should attend to how the experience of parental illness is complicated by different types of parent-child relationships.
- Future research should explore the differences between students' experiences when their parent is diagnosed right before or immediately during the college experience compared to students whose parent develops an illness during sophomore year or beyond.
- Future research should include participants who choose not to persist through college or who transfer to a different institution. All of the participants in this study intend to complete their degrees at MRU. It would be important to identify what factors related to this experience impact retention.

## **Conclusion**

This study was designed to provide an understanding of the impact of parental illness on the traditionally-aged college student experience. Three students experiencing the impact of a parent's incurable illness reflected on their initial feelings and concerns, how their collegiate experience was impacted, the support they utilized, and their advice

for institutional support. The students' stories are powerful and contribute significantly to our understanding of this population's unique needs. Andrew continues to consider himself lucky that his dad has remained in remission. Lisa continues to mourn the loss of her dad. Jacob continues to navigate what he often sees as competing priorities: his role as a son and his role as a student. Their obstacles and challenges, while heartbreaking, provide important implications for institutions that are continually seeking to support new populations of students. The findings provide some practical implications, and several research implications, that should guide universities in better serving and validating this population's challenges.

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**Appendix A**  
**Informed Consent Form**

## Informed Consent Letter

IRB Approval#:

20141214818 EP

**Title:** The Impact of Parental Illness on the College Student Experience

**Purpose:**

The purpose of this study is to examine the impact of parental illness on the traditionally-aged college student experience at a public, four-year institution. You are invited to participate in this study because you are an undergraduate student between the ages of 19-22 and have had a parent develop a significant illness during your collegiate experience.

**Procedures:**

Participation in this study will require approximately two hours of your time. You will be asked to participate in two interviews. The first will be to discuss the context surrounding the development of your parent's significant illness, your role in the family, and your initial feelings and concerns. The second interview, approximately four weeks after the first interview, will be to discuss how the development of your parent's significant illness has impacted your collegiate experience and the ways in which you have sought and received support within and outside of the institution. Both interviews will be audio recorded and conducted in a quiet, private space at your convenience.

**Benefits:**

This study will give you an opportunity to reflect on your unique experiences as a traditionally-aged college student who has had a parent develop a significant illness and how that has impacted your time at [REDACTED]. This may allow you to make greater meaning of your experience and to share your experience with others anonymously for the benefit of the institutions and other students who encounter this same challenge. You will have an opportunity to discuss an aspect of your collegiate experience that is often invisible to peers, faculty, and staff.

**Compensation:**

Participants will each be entered into a drawing to receive a \$25 gift card to a local restaurant. The winner of the gift card will be selected at random and notified by March 1, 2015, following the completion of both sets of interviews. If participants only participate in one interview, they will not be entered into the drawing. Odds of winning will depend on the number of participants who complete both interviews.

**Risks and/or Discomforts:**

If either of the two interviews elicits difficult feelings or memories, you can contact the [REDACTED] Counseling and Psychological Services office. All registered students are eligible for services, with students enrolled for 7 or more credit hours eligible for subsidized rates. Students enrolled in less than 7 credit hours may elect to pay University Health Center (UHC) facility fees to become eligible for subsidized rates. Counseling/psychotherapy sessions one, two, and three are available for no charge. There is a charge for the fourth and subsequent counseling/psychotherapy sessions. Subsidized rates for the fourth and subsequent counseling/psychotherapy sessions will be received if the UHC facility fees for the current semester/session are paid. Costs for psychiatric visits begin with the first session and the UHC facility fees for the current semester/session must be paid to receive the subsidized rates. Participants will be responsible for all CAPS services costs. Please note that you can elect to discontinue participation at any time.

**Confidentiality:**

Any information obtained during this study which could identify you will be kept confidential. The data will be stored in a password protected computer, in the possession of the primary researcher, and in a password protected storage database. The data will only be seen by the principal investigators during the study, and will be discarded immediately after the study report is finalized in May 2015. The information

obtained in this study may be published in scientific journals or presented at professional conferences, but the data will be unidentifiable.

**Opportunity to Ask Questions:**

You may ask any questions concerning this research by contacting one of the investigator(s) listed below. If you would like to speak to someone else, please contact Research Compliance Services Office at [REDACTED] or [REDACTED].

**Freedom to Withdraw:**

Participation in this study is voluntary. You can refuse to participate or withdraw at any time without harming your relationship with the researchers or the [REDACTED], or in any other way receive a penalty or loss of benefits to which you are otherwise entitled.

**Consent, Right to Receive a Copy:**

You are voluntarily making a decision whether or not to participate in this research study. Your signature certifies that you have decided to participate having read and understood the information presented. You will be given a copy of this consent form to keep.

**Signature of Participant:**

\_\_\_\_\_  
Signature of Research Participant

\_\_\_\_\_  
Date

By checking this box, I agree to have my interviews with the researcher be audio recorded.

**Name and Phone number of investigator(s)**

Molly Wilensky, Graduate Assistant, Principal. [REDACTED] or [REDACTED]

Deb Mullen, Ph.D. Associate Dean of Education and Human Sciences and Research Advisor.

[REDACTED] or [REDACTED]

**Appendix B**

**Recruitment Email to Academic Advisors**

Dear Academic Advisors:

I am an Associate Dean in the College of Education and Human Sciences. In order to earn a masters' degree in Higher Education, our graduate students are required to do original research and prepare a thesis. My advisee, Molly Wilensky, is conducting a research study that explores the impact of parental illness on the traditionally-aged college student experience. Participation in this study will entail two individual interviews and will take approximately two hours of participating students' time in total. For their time, participants will each be entered into a drawing to receive a \$25 gift certificate to the local restaurant of their choice with 1 in 6 odds of winning. If you have met with any students who identify with this experience and might be interested in participation, please provide them with my email address and encourage them to reach out to either Molly or myself by January 6<sup>th</sup>, 2015.

Further instructions will be provided to interested students. The two interviews may illicit difficult feelings or memories, but students will be provided with information about resources such as [REDACTED]'s Counseling and Psychological Services office.

If you have any questions, please feel free to contact either Molly or myself.

Molly Wilensky, Graduate Assistant, Principal Investigator

[REDACTED] or [REDACTED]

Deb Mullen, Ph.D., Associate Dean of Education and Human Sciences and Research Advisor

[REDACTED] or [REDACTED]

Regards,

Debra Mullen, Ph.D

**Appendix C**

**Recruitment Email to Known Student**

Dear [REDACTED]:

In order to earn a masters' degree in Higher Education, graduate students are required to do original research and prepare a thesis. I will be conducting a research study that explores the impact of parental illness on the traditionally-aged (19-22) college student experience. Participation in this study will entail two individual interviews and will take approximately two hours of participating students' time in total. For their time, participants will each be entered into a drawing to receive a \$25 gift card to a local restaurant. The winner of the gift card will be selected at random and notified by March 1, 2015, following the completion of both sets of interviews. If participants only participate in one interview, they will not be entered into the drawing. Odds of winning will depend on the number of participants who complete both interviews.

I wanted to reach out to see if you might be interested in participating in this study, as you have previously disclosed having this experience. Whether or not you wish to participate, I was hoping you could pass along information regarding this study to others you may know who have also had this experience. If they would like to participate, please provide them with my email address, as they will need to reach out to me by January 26<sup>th</sup>, 2015. Further instructions will be provided to interested students.

The two interviews may illicit difficult feelings or memories, but students will be provided with information about resources such as [REDACTED]'s Counseling and Psychological Services office.

If you have any questions, please feel free to contact Dr. Deb Mullen or me.

Molly Wilensky, Graduate Assistant, Principal Investigator

[REDACTED] or [REDACTED]

Deb Mullen, Ph.D., Associate Dean of Education and Human Sciences and Research Advisor

[REDACTED] or [REDACTED]

Regards,

Molly Wilensky

**Appendix D**

**Study Overview and Semi-Structured Interview Protocol**

## **The Impact of Parental Illness on the College Student Experience Study Overview and Interview Protocol**

The purpose of this study is to examine the impact of parental illness on the traditionally-aged college student experience at a public, four-year institution. Many studies examine the experience of children or adults who have a parent develop a significant illness, and many studies explore attachment theory, coping, and identity/relationships, but very little research has identified how this experience impacts the collegiate experience for traditionally-aged students. The researcher wants to explore this atypical stressful event to illuminate an experience that is typically invisible.

### **Primary Research Question(s):**

- What are traditionally-aged college students' initial feelings and concerns when they learn of their parent's significant illness given their role in the family and the context surrounding the development of the illness?
- How has the development of their parent's significant illness impacted their collegiate experience? In what ways have they sought and received support within and outside of the institution?

### **Secondary Research Question:**

- What can institutions do to support these students' unique needs?

### **First Interview Questions:**

- 1) Tell me about yourself.
- 2) Tell me about your family and your parent who has developed a significant illness.
- 3) How did you find out about this development and what were your first feelings and concerns?
- 4) Tell me about your role in the family prior to this development and after this development.
- 5) Tell me about your college experience prior to this development.

### **Second Interview Questions:**

- 1) Tell me about your college experience after your parent's illness developed.
- 2) How were your academic experiences impacted?
- 3) How were your social experiences impacted?
- 4) In what ways did you seek support within the institution?
- 5) In what ways did you seek support outside of the institution?
- 6) In what ways did resources within and outside of the institution help you?
- 7) What needs were not addressed within or outside of the institution?
- 8) What is your biggest struggle now?
- 9) Is there anything else related to your experience that you feel I should know? Please describe.