

Emergence of a Cancer Identity in Emerging Adults: Weblogs as Illness Narratives

by

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ABSTRACT

The focus of this research is on the specific relational and particular circumstances that result in an emerging cancer identity expressed through the daily lived-experiences of emerging adults via personal weblogs. Identity, a complex term in its own right, is discussed here under the rubric of social identity as processual, therefore it is expected that an emerging cancer identity will develop as the participants begin to narrativize their daily experiences with cancer on their weblogs. By critically engaging with notions of emerging adulthood theories with theories on the sociology of death and dying and illness narratives, this research seeks to understand the specific psychosocial changes that occur as the participants engage with their illness on their weblogs, which arguably contributes to an emerging cancer identity.

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Chapter 1 ~Introduction~

Emerging adults with terminal cancer pose an existential problem for Western societies: reconciling youth and imminent death. Improvements over the past centuries in medical interventions and the increasing confinement of mortality to the elderly contribute to the pervasiveness of the taken-for-granted assumption that death does not happen to young people. For emerging adults with cancer this creates marginality within the scholarship on youth. Emerging adults who are in the prime of their lives, peak of their beauty, strength and virility, simply should not get seriously sick. According to Young Adults Cancer Canada's research, young adults with cancer have not benefitted from the same increase in cancer survival rate as is found in other age groups in the past four decades¹. Bleyer (2002) argues that the unique physical, emotional and social challenges posed by cancer in emerging adulthood are specific to this life stage, and would benefit from such recognition. Emerging adults with cancer are faced with unique psychosocial and medical needs, and like pediatric and geriatric patients, require recognition as a distinct age group (Bleyer, 2002). In 2011, a workshop was held in Toronto that was entitled "Opportunities and Challenges of Establishing a Nationwide Strategy for Adolescents and Young Adults in Canada with Cancer". The aim of this conference was to bring together various stakeholders to address the issues of care specifically for emerging adults. This conference demonstrates the growing recognition of the

¹ Retrieved from the Young Adults Cancer Canada website May 15, 2012
<http://www.youngadultcancer.ca/organization/p/background/>

unique challenges a cancer diagnosis elicits for emerging adults. In the words of Robison (2011) the death of a young adult is particularly tragic.

The lack of recognition of emerging adults with cancer causes a sense of marginalization amongst the population. Marginalization results from the expectation that this age group should not be seriously ill and this expectation is emitted through culturally available models in television, radio, advertisement and marketing. Emerging adults with cancer are unable to live up to these expectations due to their terminal cancer diagnosis. Youthfulness is promoted as guaranteed continued health, beauty and employment and those who became ill or decrepit would be left behind by an industrial society (Addison, 2006). In the 1910s and 1920s, while Hollywood was becoming established, a preoccupation of youth was becoming more evident in advertisement. Hollywood took up the cult of youth by creating, along with the Industrial Age, a youth-oriented consumer culture (Addison, 2006: 6). The legacy of Hollywood's emphasis on the youth market and the pervasive ageism that continues to persist today is well documented in scholarly research (Carrigan and Szmigin, 1998, 1999; Reid, 1997; Rampton, 1998; Kay, 1998; Marrin, 1998; Treguer, 1998; Thomas and Wolfe, 1995; Lee, 1997; Corlett, 1998; Long, 1998). According to Carrigan and Szmigin (2000) advertisers and marketers are "particular offenders" of ageism, and in turn generate a cult of youth. Addison argued that the Industrial Age, coupled with the emerging consumer culture, "devalued maturity and experience and exalted young adulthood" (2006: 5). Consequently the exaltation of youth served simultaneously as a basis and as a

target for eliciting consumer desire, which young adults were easily persuaded to consume.

Youth has become a lifestyle to be achieved by members of society, and the pervasive attitude through popular culture makes the desirability of youth apparent and something to be fulfilled. Members of society that fail to remain in the “youth market”, such as the elderly and individuals with illnesses, do not conform to the acceptable standards within a youth-centred society, and thus are marginalized. Emerging adults who have cancer face isolation and marginalization resulting from their inability to embody the typified and attractive lifestyle of our youth-centred society as exhibited in the media. Thus, the societal expectation anticipates that emerging adults should be in good health, which has been demonstrated in the work of Chasteen and Madey (2004). Furthermore, Chasteen and Madey (2003: 321) found that the death of a younger person was believed to be more unjust and wasteful than the death of an older person. The dissonance caused by a terminal illness diagnosis during the emerging adulthood life stage confronts societal norms and expectations for their age group, and places emerging adults, who are already straddling the gap between adolescence and adulthood, into further ambiguity. From this, it can be extrapolated that emerging adults with cancer are an anomaly within our society, and because of this schism between what is to be expected of individuals who should embody youthfulness with the reality that their illness imposes on their bodies and their potentialities, are pushed to the margins of society.

The societal perception of the idealized healthy and vibrant lifestyle associated with emerging adulthood has been demonstrated in the works of psychologists Madey & Chasteen (2004), Hummert (1990) and Gekoski & Know (1990). In their work, they demonstrate the existence of stereotypes of younger adults as being in good health. This impacts emerging adults who are ill, or in the case of this research, have cancer: the expectation of their stage in the lifespan includes being in good health. As Eisenstadt articulated “cultural definition of an age span is always a broad definition of human potentialities, limitations, and obligations at a given stage of life” (1965, 30), and the expectations have been repeatedly demonstrated that emerging adulthoods be in good health. Hummert demonstrated that stereotypes of young adults focus on healthy components, but stereotypes of older adults include both healthy and unhealthy components. Thus, expectations of physically unhealthy components of emerging adulthood are not widespread. The focus of this research is on the specific relational and particular circumstances that result in an emerging cancer identity expressed through the daily lived-experiences of emerging adults via personal weblogs.

Many emerging adults are turning to forms of social media, such as weblogs, to share their experiences with cancer and the ensuing marginalization that results from the neglect of the medical research community. Weblogs have become prominent in online culture where new ways of creating communities and constructing the self has manifested in late-modern times (Hookway 2008). The aim of this research is to analyse weblogs written by these young men and women with cancer, using an illness narrative approach to analyse their lived experience with

cancer. A sense of marginalization by emerging adults with cancer is expected as it manifests from the reflexive and interactive nature of social interaction; it is through interaction that identities are constructed. During social interaction important meanings, symbols, values, and mores are communicated to members and these symbolically establish normative or non-normative identities that are either appropriated by individuals for themselves or imposed on them by others. Therefore, a cancer identity evolves from this interaction and is conveyed and processed by emerging adults through narrativity. Through analysing their weblogs a better understanding of how emerging adults engage with their new identity to include their experience with cancer will be explored.

Chapter 2 ~Literature Review~

Emerging Adulthood

In recent years, there has been a focus on the psychosocial effect of cancer on Adolescent and Young Adults (AYA) from a clinical perspective (Evans & Zeltzer, 2006; Thomas, Albritton & Ferrari, 2010; Treadgold & Kuperberg, 2010; Zebrack & Isaacson, 2012; Anazodo & Chard, 2013). Generally, the accepted age range for the AYA group is from 15 years to 40 years of age, and the research of this age group with cancer emphasizes developmental and biomedical issues of AYAs. However, the literature would be more meaningful if it considered the separation of adolescents from young adults. While they may face similar biomedical challenges, the age range is too broad and the challenges faced by adolescents and young adults are vastly different across the age group. The literature presented on AYA with cancer is flawed in that it does not critically engage with

the psychosocial issues of both adolescents and young adults, which are arguably different, and in some cases, not applicable to the entire AYA cohort.

In clinical oncology research the delineated age range of AYA appears to be motivated by biomedical issues, which is problematic due to the specific psychosocial aspects that cannot be captured at the biological level. Young adults face unique obstacles when dealing with cancer, including financial challenges, potentially truncated career opportunities or growth, and shifting dependency on family and friends, which are not typically shared with a 15 year old adolescent. There is too much breadth in social experience and interaction between a 15 year old and a 40 year old that their issues become diluted and generalized to the point where analysis loses meaning. Too much emphasis is placed on the biomedical commonality of this age group for a proper psychosocial analysis of cancer, and this research would benefit from employing different life span approaches that places more emphasis on psychosocial aspects rather than biomedical commonalities.

Objectively, emerging adulthood is bounded by Arnett's (2000) ascription that emerging adulthood encompasses the period between the late teens to early twenties; however, those who may be older than the top boundary proposed by Arnett may subjectively consider themselves emerging adults and may not exhibit the external markers that are commonly ascribed to indicate attainment of adulthood. Emerging adults who are outside of Arnett's bounded demographic may still be considered emerging adults as Arnett himself acknowledges that the subjective sense of being an adult has validity, and thus, the age restriction should not be strictly adhered to. Responsibility for oneself, gradual development of

autonomy, and independent decision-making are external, yet subjective, indicators of adulthood (Fadjukoff, Kokko & Pulkkinen, 2007; Sneed, Johnson, et al., 2006; Kagitçibasi, 1996). The subjective sense of adulthood, and the tenuous status of each, illustrates the “in-between” feeling many emerging adults feel as their internal criteria for adulthood shifts in the face of a loss of independence due to financial or health related reasons. The very nature of a subjective sense of adulthood is difficult to quantify and to assess without input from the individual. Narratives allow for individuals to voice their own lived-experience, and their feeling of “in-between” is better demonstrated and conveyed through narrative.

In the case of individuals from 18 years old to 30 years old, Jeffrey Jensen Arnett’s “Emerging Adulthood”, or EA, would be more beneficial as it “... is a critical juncture in life span development when the relationship between the individual and society takes on a new meaning” (Tanner, 2005: p. 22). Tanner (2005) states that the period of EA represents the era of people’s lives where the most significant life events typically occur (Tanner 2005). The research of AYA with cancer is beneficial in that it focuses attention on this age group; however, its value is somewhat diluted as it cannot capture the issues facing individuals of different ages. For Treadgold and Kuperberg (2010), their research focuses on individuals from mid-teens to 40 year olds, who, although have little in common in terms of lifestyle, is united by the rarity of their situation. The rarity of their situation is not sufficient in finding common ground with the challenges and the psychosocial consequences that cancer imparts on AYAs. Emerging adulthood,

encompassing the 18-30 year old age range is more capable in acknowledging the challenges and obstacles specific to this group.

Thomas, Albritton and Ferrari (2010: p. 4781) capture the irony of using the blanket term of AYA in clinical oncology as the artificial divide between pediatric and adult medicine, where young people are usually placed. Emerging adulthood identified by Jeffrey Jensen Arnett in the early 2000s as an emerging life span between adolescence and adulthood resulting from the specific demographic features of industrialized society. According to emerging adulthood theory, the attainment of adulthood is pushed back as young people are delaying entry into marriage, parenthood, and the job market, which are the transitions that have traditionally marked the attainment of adulthood. Arnett (2006) argues that the theory of emerging adulthood is a way to conceptualize the development of young people, and is characterized as the age of identity exploration; the age of instability; the most self-focused age of life; the age of feeling in-between; and, the age of possibilities (Arnett 2006). Arnett states that this new phase in the life span is not “young adulthood” as it implies that adulthood has been achieved as most young people would disagree that they have reached adulthood (2000; 477). Eighteen, according to Arnett, is a good age marker for the end of adolescence as it correlates with the end of secondary school and the attainment of legal age of adult status. However for Tanner (2005: 26-7) an understated characteristic ascribed to adult status is the processual transformation of the relationship between emerging adults and their parents from dependent to independent, which underlies the importance of the subjective sense of adulthood.

For young adults in the United States, cancer is the leading cause of disease-related deaths and affects eight times more individuals between 15 and 40 years of age than those younger than 15 years of age (Thomas, Albritton & Ferrari, 2010: p. 4781). However, the age group has not seen the same amount of medical scholarship and focus as other demographics. Unfortunately, the cancers affecting young people are typically leukemia, brain tumors, epithelial cancers and sarcomas, which generally have worse outcomes and are considered rare in their occurrences across the lifespan (Thomas, Albritton & Ferrari, 2010). Emerging adulthood, theoretically and empirically, is gaining traction in sociology and psychology as evidence by the recent introduction of the *Emerging Adulthood* journal that will be launched in 2013.

Sociology of Death and Dying

The fear of death is different for individuals along the life span continuum, and as Kellehear (1984) argues, it is through socialization that young children are taught to fear death. In the same vein, Howarth (2007) states that the particular form that death takes in different societies provide individuals with an acceptable range of responses to it. Elderly people fear notions of dependency and disability more so than they fear their own mortality and impending death. Adults could fear death more, given the fact that they have more to lose. Kellehear notes that it is perhaps prudent to separate fear of death from fear of dying, or fear of loss of consciousness. It could be a fear of dying, and the specific connotations of loss of control, dying of a certain type of death or averting it completely that is feared instead of the actual notion of death. The dying are second class citizens and are deprived of their

economic and social status (Kellehear, 1984; 717), which arguably leads to a sense of fear. Thus, denial of death is too simplistic and reductionist, instead the societal response to death is about transformation, as a result of the medicalization process, of the dying role into low status (Kellehear, 1984).

The notion of society as ultimately “death denying” originates from the works of Gorer (1965) and Ariès (1974) and has often been cited to explain the “taboo” nature of death and dying. However, the notion of a “death denying” society has arguably lost its legitimacy and instead, a fear of death has taken its place. Kellehear (1984) disagrees with the rhetoric of a “denial of death”, which does not adequately address the fear of death. The medicalization of death has given new meaning to the idea of a public death and as a result “age” has become the new measure of our dying (Kellehear, 1984). Thus, the expectations related to death correlate to age in that the medicalization of death has confined dying to the realm of old age. In Walter’s (1991) research, he explores the societal response to death as a taboo and the constant proclamation, however ironically, of this argument.

Walter (1991) and Howarth (2007) reject the notion of a death-denial thesis by pointing to the public presence of death. Walter, focusing on the research on death in the UK notes the scarce research done on the topic except under the rubric of medical sociology. Walter’s (1991) thesis that modern death is hidden, rather than forbidden, has legitimacy when considering the treatment of emerging adults with cancer in modern and industrialized societies. The perception, which is inferred by Walter’s thesis, of “good” and “bad” death can explain why death, especially the death of an emerging adult, is hidden. The death of a young person is seen as

wasteful, or “bad”, and the death of an elderly person, at the end of a fulfilled life, is seen as “good”. As death in old age becomes normalized, the more unprepared and the more tragic death becomes for those who died before “their time” (Howarth, 2007). Thus, there is a sense that the death of a young person is unjust, which was found in the research done by Chasteen and Madey (2003) on the perceived injustice of dying young versus dying old. Ultimately our experience with dying, death and bereavement is embedded within social and cultural worlds, and Howarth argues that death is an ever present force within our society.

Death, in modern societies, have been “sequestered”, or it has been removed from the public realm and placed firmly within the private sphere of the family and the individual, thus removing death from an overtly public or social context (Howarth, 2007; Giddens, 1991; Mellor, 1993; Mellor & Shilling, 1993; Shilling, 1993) Thus, we are not so much a death denying society, as Gorer and Ariès argue, but rather one where it is pushed to the margins of society into acceptable medical and private spheres outside of mainstream culture (Howarth, 2007). The absence of death from public space has been mistaken for a taboo or for a “death-denying” society. Walter’s introduction of an alternative argument of death as being hidden rings true for emerging adults with cancer, as their death is thought to be incongruous and tragic. As Howarth has argued, the response to death is implicit in society, and Treagold and Kuperberg (2010) have demonstrated that adolescents and young adults find the subject of death to be taboo with their parents and may feel pressure not to raise the subject so to avoid upsetting them. The “good” death is one where death occurs in old age, a “bad” death is the untimely or premature end. For

Treadgold and Kuperberg, the consequence of the death of a young person brings up discussions on the tragedy of the “waste of human life” and the need to lay blame on someone (2010: 23).

“Sequestration of death is said to occur because death poses problems of meaning for the lives of individuals in complex, postmodern societies. Thus death is argued to be publicly absent but privately present.”

Thus, the death of an emerging adult is sequestered from public life, and their death is not widely seen, unlike the elderly where death is expected as a natural part of their life stage. The death of a young person, a rare event in modern societies, falls outside the realm of expectation for their age group as their death is seen as “tragic”, “wasteful” or that they died “before their time”. However, the Internet has become a platform from which individuals can become embedded in networked communities and where they can engage in interactions with others with whom they can relate to. Emerging adults have found a way to process their illness and mortality through their weblogs, and have found online communities based around cancer.

The individual experience of death is not widely researched in the social sciences, especially the death of an emerging adulthood. They have been pushed to the margins, not due to malicious intent, but due to societal ignorance on the occurrence of terminal illness and death in emerging adults, combined with taken-for-granted notions of health and youthfulness results in the medical and social marginalization of emerging adults with cancer. It is in the margins that some emerging adults have found a place, on the Internet, to explore and share with others.

Weblogs - Social Identities and Social Media

The Internet presents opportunities for emerging adults to overcome the marginalization that results from a cancer diagnosis by linking young people (Treadgold & Kuperburg, 2010; Thomas, et al., 2010), and there is evidence to suggest that weblogs could be used to fulfill social and interpersonal goals that are not available in the “real world” (Stefanone. & Jang, 2008). Treadgold and Kuperburg posit that cancer can potentially limit social relations and networks for young people, however, the opportunities of using social media, such a weblogs, to build social networks is apparent through the pervasive use of weblogs by young people. Weblogs, or blogs, create an individualistic outlet for intimate forms of self-expression and self-empowerment (Herring, Scheidt, Wright & Bonus, 2005; Blood, 2002a). Blogs have, unsurprisingly, become widely adopted for interpersonal ends as seen in its use as a personal diary, or journal, with additional participatory functionality (Stefanon & Jang, 2008; Herring, Scheidt, Bonus & Wright, 2004, 2005; Lenhart & Fox, 2006; Schiano, Nardi, Gumbrecht, & Swartz, 2004; Viégas, 2005). Thus, the use of blogs in research is invaluable for collecting subjective experiences and day-to-day life experiences otherwise difficult to obtain in traditional forms of data collection techniques. Blogs are hailed by Herring, Scheidt, Wright & Bonus as fundamentally different than diaries as they have the capacity to be socially transformative as blogs, intimate in nature, can be shared through space and time among a wide audience, which personal diaries are unlikely to replicate, with exceptions².

² The Diary of a Young Girl by Anne Frank, 1947

The little technical knowledge required in maintaining a blog and the number of hosting sites available to individuals have enabled a wide audience with Internet access to create their own blog. These “computer-mediated communication” or CMC are tools that facilitate relationships and allow individuals to pursue their social goals easily (Stefanone & Jang, 2008). In 2004, Herring, Scheidt, Wright and Bonus found that 70% of blogs were classified as personal diaries, and this finding has stirred up discussion on their effect on social relationships; rather than promoting isolation, the traditional view of blogs, they are functioning as a tool to enhance existing relationships (Hampton & Wellman, 2000; Katz & Aspden, 1997; Stoll, 1995). Arguably, for emerging adults with cancer the creation of new social relationships is made possible through their blogging activity and through their activity we can gain an understanding of their particular experiences with day-to-day life as a “cancer patient”. Palfrey and Gasser (2008) have considered the unique affect the “Internet age” has imparted on the social identities of “Digital Natives”, which can be expanded to include emerging adults who participate in blogging.

The net effect of the digital age has decreased an individual’s ability to control their social identity and the perceptions others have on them (Palfrey & Gasser 2008). As will be seen in the Theory chapter, this notion fits in to the arguments Claude Dubar (2000) has put forth regarding “identités pour soi” and “identités pour autrui”, which is the dialectically relationship between ascribed identities and appropriated identities. However, Palfrey and Gasser argue that the Internet age has paradoxically allowed for greater experimentation with identities

online, while being bound to a “unitary identity” (2008: 20) and the identities that individuals convey online have been shown to be consistent with their identities in “real space”. From this argument, it can be extrapolated that emerging adults with cancer, who are engaged in social media, are expressing their identity as they would in “real space”. Furthermore, it is conceivable that the identity conveyed by emerging adults online could be an emerging cancer identity. The information consciously put forth by individuals using social media represents their identity. Many of the weblogs written by individuals, including emerging adults, with cancer is cancer-centric, in that the impetus for writing their blog was precipitated by their cancer diagnosis. Thus, the information emerging adults with cancer consciously put forth on their blog is conveying something about their identity and their need to engage with the meanings surrounding their terminal illness.

Palfrey and Gasser state that networked public spaces are crucial socialization environments and aid in the process of identity development, which could point to the tendency of emerging adults with cancer to express their day-to-day experiences with cancer through blogs. Blogging and the networked community of the blogosphere, allows emerging adults to develop their emerging cancer identity, and to get involved in socialization. Individuals participating in online networked public spaces do not necessarily distinguish between their “online” and “offline” identities, but instead their real-space self and online expressions of self are synthesized (Palfrey & Gasser, 2000: 36).

Chapter 3 ~Theoretical Framework~

Introduction

The concept of identity is one that has its roots in multiple disciplines, each discipline imparting its own particular perspective and assumptions that contribute to the often-conflicting definition of identity. For the purpose of this research, it will suffice to engage with literature concerned with the social aspect of identity. Identity is not some inner state that is waiting to be revealed; it is constructed within the socio-historical network of relations we find ourselves ensconced. Social relations are primary to our lives, and these relations gives us our sense of self: our identity. Calhoun (1994) argues that identity is always constructed, even if it feels like a discovery, amid a flow of contending cultural discourses. For Weigert, Teitge & Teitge (1986) the concept of identity is the era's answer to the seminal question: "What is a human being that we are mindful of ourselves and of one another?" This notion of the self³ and of others is one taken up by Claude Dubar in his book *Les Crise des Identités*, in which he explores the dual nature of identity as both "identités pour soi" and "identités pour autrui"⁴. Thus identity is, in itself, a social product that is fragmented with a multitude of identities; there are as many selves as there are social relations (Burkitt, 2008).

Since the 1960s there has been a "mutation" in the configuration of available identities, and Dubar (2000) believes the changes in economic, political and symbolic social relations has given rise to new forms of identities, which results in

³ Self, here, denotes the unit of individuality; that which distinguishes the person from the collective.

⁴ Roughly translated as 'identity for self' and 'identity for others'

the emergence of new forms of individuality. Thus, it is through social processes, social change and cultural transformations that we see the emergence of available identities that can be appropriated by individuals, or be imposed on individuals by society. Identity is about becoming; not being (Burkitt, 2008).

Identity as a Social Process

Identities, while appropriated from culturally available forms, are also unique. Dubar argues that two aspects of identity, differentiation and generalization, give identity its paradoxical nature: “ce qu’il y a d’unique est ce qui est partagé” (2000: 3). Similar to Dubar, Weigert, Teitge & Teitge view human identity as a “special meaningful object” that is both social and uniquely personal, and “results from the varying degrees of appropriation by the self and/or bestowal by others” (1986: 31). Therefore, as demonstrated by Dubar (2000) and Weigert, Teitge & Teitge (1986) identities result from processes of identification that are historic and that are at once collective and individual:

Il existe un mouvement historique, à la fois très ancien et très incertain, de passage d’un certain mode d’identification à un autre. Il s’agit, plus précisément de processus historique, à la fois collectif et individuels, qui modifient la configuration des formes identitaires définies comme modalités d’identification.

- Claude Dubar (2000: 4)

Here Dubar assumes the existence of an underlying relationship between claimed identities (*identités pour soi*) and assigned identities (*identités pour autrui*), which are processes of appropriation that are, according to him, the foundation of

identities⁵. The process of appropriation of “identités pour soi” and “identités pour autrui”, where the identities appropriated are not bestowed, and those identities that the self does not want appropriated, are involved in an endless process of negotiation (Weigert, Teitge & Teitge, 1986: 31). This negotiation occurs as we construct our identities within a given socio-historical network of relations, and the notion of “social selves”, although seemingly paradoxically due to the intuition of a self as a singular unit within our modern, individualistic and capitalist societies, represents this negotiation. Here, the argument by Dubar of two processes of identification resonates in that it denotes both processes of identification as fundamentally social. Furthermore, Burkitt highlights the importance of social activity in the discovery of our own self, even though it may seem like an intensely internal process of discovery. The notion of a pre-given identity waiting to be revealed does not exist. For Burkitt (2008) and Dubar (2000) identity is made in interaction with others, and is not an internal essence that exists prior to social relations.

Constructionist versus Essentialist notions of identity

Identity is said to be a process, whereby it is constructed through social interaction. Many sociologists frame this perspective on identity, namely constructionism, against the essentialist perspective (Dubar, 2001; Calhoun, 2004; Weigert, Teitge & Teitge, 1986; Shakespeare, 1996). Constructionism, as introduced by Berger and Luckmann in their book *The Social Construction of*

⁵ See *La Crise des Identités* (2000) page 4: “C’est la relation entre ces deux processus d’identification qui est au fondement de la notion de formes identitaires.”

Reality, argue that social interaction is the basis of all knowledge, including the taken-for-granted assumptions of everyday reality. On the other hand, the essentialist approach considers identity as harmonious, singular and wholly unproblematic (Calhoun, 1994). The essentialism approach to identity considers its nature as immutable, temporally constant, and existing a priori to social interaction. The arguments against essentialism challenges our notion that identity is given naturally given and that it emanates from acts of individual will (Calhoun, 1994). Dubar engages in this debate between “essentialiste” and “nominaliste”⁶ theories of identity, and firmly argues that identities are not fixed in essentialist terms; identity is not that which remains the same, but is based upon contingent identities of “différenciation” and “généralisation” (2000: 3). Identity is an established sense of uniqueness immersed in the shroud of commonality.

The economic, political and social upheavals have caused a “mutation”, alluded to above, in available identities and has changed the configuration of familial, professional, religious and political, and institutional relations (Dubar, 2000). Here, we see how Dubar thinks of identity as not something that is “naturally given”, but that which results from socio-historical circumstances. For Weigert, Teitge & Teitge, identity is “a typified self at a stage in the life course situated in a context of organized social relationships” (1986: 53). Conversely identity, in the essentialist tradition, is immutable, permanent through time, and has reality unto itself (Dubar, 2000). Burkitt attempts to de-centre the self by eschewing the Christian notion of an inner soul or substance in favour of the argument that “the

⁶ ‘Nominaliste’ is understood as ‘constructionism’ (Castel & Haroche, 2001)

self is understood as created in society and is contingent on accidental amalgamation of the different aspects of the influences that have in-formed us, literally making us who we are” (2008; 26). Thus, Dubar’s notions of “identités pour soi” and “identités pour autrui” opposes the essentialist view of identity as immutable, as his conception demonstrates the fragmentary, fleeting and temporal, characteristic of identity. However, as Burkitt (2008) cautions, social constructionism can, ironically, fall into the trappings of deterministic thinking.

As argued by Shakespeare (1996), constructionism has a tendency to be rigid and deterministic. Calhoun reasons that as constructionism denies or minimizes personal and political agency by stressing the ubiquitous “diffuse social pressures as the alternative to biological causation” (1994: 16) constructionism takes on similar deterministic characteristics as essentialism. Cancer, as an identity, is itself an essential category that can be appropriated by or imposed on an individual with cancer. A cancer identity becomes an essentialist category due to the biological conditions that precipitated the categorization of the emerging adult as a “cancer patient”. Calhoun, erring on the side of social constructivism, recognizes that “we cannot really stop thinking at least partially in categories”, and “therefore in at least something rather like an essentialist manner” (Calhoun, 1994: 19). Thus, a “cancer identity” is a social construct, and develops through social interaction. However, it also includes a biological reality, or an essentialist categorization, and as Gitlin observes “anatomy once again becomes destiny” (1994, 153).

Narrative Constitution of Identity

Narratives, or stories, are not merely representational nor are they purely the embodiment of reality; narratives create meaning (Somers, 1994; Jackson, 2002). Jackson (2002) seeks to move away from the notion of “stories as isomorphic with lives” and instead focuses on the social process of storytelling, and the process of identity as constituted by narrative (Somers, 1994; Mathieson & Stam, 1995; Jackson, 2002). Somers reconfigures identity by including both social epistemology and social ontology into this process, and by doing so this provides understanding of the social world. It is through narratives that we are able to constitute our social identities, and as Somers articulates “everything we know, from making families, to coping with illness, etc. is at least in part the result of numerous cross-cutting relational story-lines in which social actors find or locate themselves” (1994: 607). The ability of narrative identity to provide tools for dealing with illness is key in this research and will be used to understand how emerging adults constitute their cancer identity through narrative activity by constituting it within the context of relationality.

Reframed narrativity, according to Somers, is one where we consider the ontological dimensions of narrativity while eschewing representational notions, and by including expressions of social being and identity. Jackson also prefers to focus not on the product of narrative, but on the process itself. The fallacy of narrative is the assumption that it has a beginning, middle and end; narratives as told by individuals do not have an ending, unless contrived. Stories usually end abruptly without the typical tying up of loose ends, and it excludes “sense-making of a

singular isolated phenomenon” (Somers, 1994: 616). Narrative, Somers continues, gives us understanding and meaning of events within the context of temporal and spatial relationships linked to other events. Thus, understanding a cancer diagnosis event is usually embedded in the relating to and ordering of other events that precipitated and resulted in the diagnosis event. Narratives are temporally and spatially embedded within a web of intersubjectivity and, according to Somers, are constituted by causal employment. Thus narratives that are shared by emerging adults with cancer include features illustrated above; the initial diagnosis and the subsequent experiences of cancer must be linked to other events as temporally ordered by the narrator.

How to avoid the essentialist categorization of “cancer patient”? Here we consider the identity as claimed by the emerging adults who readily narrates their experience, thereby constituting a cancer identity. The experience of cancer has a strong discursive tradition due to the breadth of personal and indirect experience with cancer and the exposure of cancer in Western society. For Somers, to counter the tendency to conflate identities with fixed “essentialist” singular categories is to “incorporate into its core conception of identity the categorically destabilizing dimensions of time, space, and relationality” (1994: 606). While this research remains focused on cancer identity formation through the act of narratives, the reality of differing experience and cancer identity is not a totalizing, or essential experience. However, its disruptive nature and the storytelling of emerging adults warrants a focus on the way emerging adults attempt to understand their experience and how they create meaning through narrative identity.

Identity as emerging through narratives and storytelling

Why is it that we narrate? Why do we story the events of our lives? And what plots, storylines, or relationships become the major focus of certain narratives, while others in comparison are not as prominent? In Michael Jackson's book *The Politics of Storytelling* he emphasizes storytelling over stories – he wants to focus on the process rather than the product of narrative activity (2002: 18). He argues that storytelling is a strategy for transforming private into public meaning. For Jackson storytelling is vital for humans in maintaining agency in the face of disempowering circumstances or situations. Disempowerment can come in the form of political subjugation, violence, illness, and so on. Stories help us to symbolically restructure events and to transform how we experience those events, as he says “storytelling gives us a sense that though we do not exactly determine the course of our lives we at least have a hand in defining its meaning” (Jackson, 2002; 16). Thus emerging adults who recount their daily lived-experience with cancer, which is its own form of disempowerment, draw meaning from story-ing their lives. He argues that changes in our relationship with others and/or society precipitates storytelling when that change entails loss of recognition, truncated autonomy, and inability to act; it gives us the ability to rework reality to make it bearable. The loss of recognition, truncated autonomy and inability to act are all triggered by a cancer diagnosis for emerging adults; the antidote, Jackson argues, is the act of storytelling.

By narrating our experience, humans attempt to, but for a moment, temper the variableness and randomness of human existence. Furthermore, narrative offers individuals a way to give meaning to their experience and to draw understanding

from seemingly unrelated or disjointed events. However, it is too simple to state that stories give meaning to our lives; it symbolically restructures events, and thus transforms our experience (Jackson, 2002: 15). Through research of weblogs of emerging adults with cancer, it became apparent their intention was to share, through storytelling, their experience with cancer:

*“But most of all, I wanted to journal my fight against cancer, so that when I am a survivor I can look back and remember the pain, fear, support, love, and courage I went through to become a better, stronger person!”*⁷

*“I hope to use this blog to provide a way for friends and family to know what I am going through both mentally and physically,”*⁸

*“I wrote this blog cause I know a lot of people want me to keep them up to date what is going on and this is an easy way to share my story.”*⁹

Many of the emerging adults who share their story through weblogs prefaced by emphasizing their desire to share with family and friends their experience. Narratives allow people to constitute their experience through storytelling, and it allows them to make sense of what happened and what is happening by assimilating stories into cohesive narratives. Finally, the available social, public and cultural narratives that are deemed appropriate guide people to act in certain ways (Somers 1994). Through narrativizing their experience with cancer, a cancer identity emerges. For Somers (1994) narrativity is the mode through which we form and make sense of the social world, and it is how we constitute our social identities.

⁷ <http://aliciasboobblog.blogspot.ca/>

⁸ From <http://thestolencolon.blogspot.ca/>

⁹ From http://nick-raitt.blogspot.ca/2007_05_01_archive.html

Conclusion

My argument is that young adults with cancer articulate a cancer identity through the use of online diaries, or weblogs. They seek out these digitized and networked spaces because the very nature of their disease alienates them from the social expectation of their age group, which is the assumption that emerging adults do not get seriously sick. The trappings of youth, beauty and vitality, are social products resulting from this assumption and they are propagated by popular culture. Emerging adulthood is ambiguously perched “in-between” adolescence and adulthood. While they may be in the proper age category, the circumstances surrounding their particular lifestyle is markedly different and/or they may not identify as having attained “full” adult status. The additional hurdle they face is the pervasive societal stereotype that they be in good health, which results in feelings of isolation. This prompts them to find a community, or to share their experience using personal weblogs.

Chapter 4 ~Methodology~

Part I: Methodology

Content analysis

“Content analysis is potentially one of the most important research techniques in the social sciences. The content analyst views data not as physical events but as texts, images, and expressions that are created to be seen, read, interpreted, and acted on for their meanings, and must therefore be analyzed with such uses in mind. Analyzing texts in the contexts of their uses distinguishes content analysis from other methods of inquiry”

- Klaus Krippendorff (2012: xii)

Introduction

This research is focused on analyzing weblogs of emerging adults with cancer to explore how they express their illness, and whether a cancer identity (ies) emerges through the illness narrative process. A qualitative content analysis is arguably the most appropriate technique for extracting data in support of this research, as it is well suited to the type of data, mainly illness narratives, made available by weblogs. Weblogs, or simply blogs, provide a readily available source of data within the public domain and blogs present a convenient and fruitful source of information as authors express considerable information about their “real life” on their personal blogs (Herring, Scheidt, Wright & Bonus, 2004). Blogs, which document the day-to-day lives of the author, are similar to traditional personal diaries, except that blogs can have a number of followers, are in the public domain, and the author’s identity can remain anonymous.

Content analysis, the method for analyzing data in this research, is “... a research technique for making replicable and valid inferences from texts to the contexts of their use” (Krippendorff, 2004: 18). It involves a specialized procedure that is separate from the personal authority of the researcher and does not obstruct the phenomenon to be studied. This technique yields new insight into the phenomenon, and thus increases the researcher’s knowledge of the topic at hand. Weber (1990) argues that content analysis, in addition to providing a method for systematically analyzing texts, has inherent advantages over other data-gathering and analysis techniques in that it directly operates on a text, which can exist over time. The content analysis approach can, thus, be beneficial when applied to

research of a sensitive nature, as it allows for the unobtrusive measure of data collection, as the originator of the text at the time of creating the text, does not know that it will be analyzed. It characteristically allows for a process of data collection that is nonreactive, unaffected by researcher bias, and provides valuable, unself-conscious insights from the text-creator. Finally, content analysis is especially beneficial for research into illness narratives of emerging adults with cancer as it enables the researcher to obtain insight that would, potentially, be impossible to gather from traditional social science research techniques, such as interviews and questionnaires.

Qualitative vs. Quantitative Methodology

Quantitative content analysis is unable to, by its nature, capture through counting the nuances and complexity of human language. On the other hand, qualitative content analysis intensely examines language in order to classify, not through counting, large amounts of texts into categories (Weber, 1990; Hsieh & Shannon, 2005). By creating the dimensions of a coding scheme, which is then applied to the data, researchers can systematically, through careful analysis, organize large sets of data into smaller themes or categories. In this way, the data is reduced into manageable categories based upon similarities outlined in the coding scheme, for analysis. However, Berelson (1952) argues that content analysis is “objective, systematic, and quantitative”, while Silverman (1993) and Morgan (1993) dismisses content analysis altogether, believing it to be wholly outside the realm of qualitative data analysis. While many argue for the quantitative nature of content analysis, a consideration of its limitations in terms of its applicability to

research of a qualitative kind is valid; the failing of this implementation in qualitative data is the potential for loss of meaning by the exclusion of texts that are not numerical (Hsieh & Shannon, 2005). Krippendorff (2012: xii) cautions the adoption of a “natural scientific methods of inquiry” as it prevents researchers from focusing on those things that matter most in everyday social life: human communication and how individuals coordinate their lives. Thus, this research is employing a qualitative content analysis of blogs, which underlies those things that Krippendorff argues is of utmost importance to social life: communication.

Qualitative Content Analysis

Qualitative content analysis makes valid inferences of text, about the sender of the message, the message itself or by the audience, through a set of procedures (Weber, 1990). Weber argues that the methodology around content analysis is never dogmatic as there is no one right way to conduct content analysis, and as Krippendorff argues, seldom does content analysis seek to render a literal description of communications content. Content analysis, from a qualitative slant, seeks to perform in-depth analysis of text as oppose to measurement. The process of qualitative content analysis data is categorized using inductively generated codes, and is generally applied to the data through close reading (Forman, J., & Damschroder, L., 2008; Morgan, 1993). The goal of qualitative inquiry is not to make generalized statements of the population based on statistical inferences of a study sample; its goal is to understand a given phenomenon (Forman & Damschroder, 2008).

Two problems are present in content analysis: validity and reliability. By using a qualitative analysis software program, issues with reliability are decreased. However, the problem with validity is not so easily managed as a given code is only valid to the degree it measures the construct intended by the researcher (Weber, 1990: 15). Thus, to address issues with validity and reliability designing and implementing a coding scheme is a desirable activity for content analysis methodology.

Coding

Content analysis is a systematic and replicable technique for organizing words of text into content categories based on explicit rules of coding (Stemler, 2001; Berelson, 1952; Krippendorff, 1980; Weber, 1990). Generally, coding is the process of combing through data to explore themes and categories, and to examine and compare codes to find patterns; codes provide the classification system for the analysis of qualitative data (Forman & Damschroder, 2008: 48). The categories derived from the process of coding a text express patterns or themes from the analysis of the text and the relationships between categories. According to Coffey and Atkinson (1996) qualitative coding encompasses detecting relevant phenomena, collecting instances of those phenomena and, finally, analyzing those phenomena to uncover patterns, commonalities and structures. Part of content analysis is determining whether to focus on latent content, the interpretation of the underlying meaning of the text (Babbie, 1992; Catanzo, 1988; Holsti, 1969), or manifest content, the surface or superficial content. For the purpose of this research the approach to coding will be heavily focused on the analysis of the latent content, as

this approach will provide greater insights into the research problem identified, as opposed to focusing on the manifest content, which is better suited to quantitative research.

Forman and Damschroder argue that the study design begins and is initiated by the research questions(s), which will also indicate the unit(s) of analysis. Selecting the unit of analysis is one of the most basic decisions when using content analysis and Graneheim and Lundman (2004) suggest that entire interviews may be considered as a unit of analysis as long as they are large enough to be considered a whole, but not so large that the meaning is lost during the process of analysis. For this specific research, the object of analysis will be the individual blogs that have been selected for this research.

Codes are given meaningful names that represent the idea or concept underlying the theme or category, and this process involves reading the text in order to identify themes. If a new code is identified and does not belong to any preexisting themes, a new code is created (Krippendorff, 2012). The approach to coding in this research is an a priori coding, which is coding that is based upon previous research or theory, and techniques such as the frequency of words and key-words-in-contexts will be applied to explore potential new codes (Weber, 1990). However, as new codes are created during the coding process, all codes need to be applied to the whole data set. As new codes are created, they will be reviewed by checking the units of data coded previously to the newly created code(s). The process of coding data gives the researcher the opportunity to engage with the data by reorganizing it into analytically meaningful categories (Forman and Damschroder, 2008)

The Internet as an emerging data source for social science research

Weblogs as data source

Digital technologies, according to Palfrey and Gasser (2008), have drastically changed the way people relate to one another and, in addition, have created a networked space for individuals to connect with each other. For emerging adults with cancer digital technologies, especially weblogs, present the opportunity for them to connect with individuals with whom they can relate. It helps them to overcome a sense of isolation that a cancer diagnosis imposes on them. The following quote succinctly expresses the desire of young people to connect with others who also have cancer.

I'm Alicia. I was diagnosed with invasive breast cancer 10 days after my 27th birthday... After researching online and not finding anything that pertained to my age (very young) I decided to start a blog. My hope is that other very young breast cancer patients can have a resource, a place for comfort, to know they are not alone during the scariest and most confusing fight of their life¹⁰

What is poignant about the quote above is how Alicia mentions her age of 27 as “very young” in relation to her cancer diagnosis, which exemplifies the marginalization felt by young adults with cancer. The significance of the emphasis she places on the fact that her age is “very young” reflects a larger societal discourse on the accepted expectations for her age group, which include being in good health. Her motivation behind creating her blog validates the underlying argument that cancer incites a need to connect with others in similar circumstances, which is not satisfied in ‘real’ life as the resources to support young people with

10 From <http://aliciasboobblog.blogspot.ca/>

cancer is sparse. Instead, a community of individuals in similar circumstances is sought in networked spaces, such as blogs.

A weblog, or colloquially a “blog”, is a website containing frequently updated, reverse chronologically ordered posts, usually written by a single individual (Hookway, 2008; Bar-Ilan, 2005; Herring et al., 2005; Serfaty, 2004). Blogs are typically housed by software programs that enable users of low technical competence to present attractive and regularly updated online material (Thelwall and Wouters, 2005). Blogs present a rich source of data for social science research that has, up until this point, been mostly ignored. For the purpose of this research, nine blogs were selected for analysis using a chain referral sampling approach based upon links from blogs to other blogs. The number of blogs encountered during the chain referral sampling indicates a prevalence of blogging by individuals with cancer, including emerging adults. The blogs written by emerging adults with cancer share the same motivation: the need to connect with others and share their experiences. There is a striking similarity in the presentation of the experience with cancer, which include details about their treatment and the impact cancer has on their lives. Blogs characteristically take the form of online diaries, or self-narratives, which bloggers use as a medium to post personal content in a linear and chronological manner, with no ending.

Blogs offer far more opportunities than their offline counterpart, the personal diary, for qualitative research. Hookway (2008) states that blogs provide a low-cost, an accessible and an instantaneous technique for collecting substantial amounts of data. The anonymity afforded by blogs allows for relatively

unselfconscious writing on the part of the blogger. Blogs are a popular medium for expression due to their accessibility and their low technical and financial barriers (Zhu, Mo, and Lu, 2010), which enhances their appeal and popularity. According to Scheidt (2006), 92.4% of weblogs were produced by authors less than 30 years of age, which provides this research with the ideal resource for gathering data on emerging adults. Blogs are attractive as a data source for qualitative research because it allows the researcher to collect information unobtrusively, which is advantageous in studies on potentially sensitive topics, such as cancer. Additionally, blogs allow access to populations that would normally be removed from the researcher due to geographical or social circumstances (Hessler et al., 2003; Mann & Stewart, 2000). This is especially salient for research on emerging adults with cancer given their relatively low numbers and geographically disbursement. Weblogs have become prominent in online culture, where new ways of creating communities and constructing the self has manifested in late-modern times (Hookway, 2008).

Searching and selecting blogs was difficult, as previously alluded to, given the difficulty in finding blogs through conventional search engine queries. Additionally, the nebulous nature of blogs and the accessibility for users of all competencies to create blogs is at once advantageous for social science research, while also presenting challenges, such as the number of abandoned blogs. The second difficulty in searching and selecting blogs was the demographic requirements of the individuals based upon criteria from Jeffrey Jensen Arnett's theory of emerging adult. Individuals were selected between the ages of 18 and 39

years old, were unmarried and were childless, which highlights the last difficulty encountered while selecting blogs; the inability to wholly confirm the identity of the author. Due to this inability to confirm the “true” identity of the blogger, the focus of the research is not to confirm whether their experiences are indeed true, but to focus on the experiences conveyed. Weblogs, as a data source, offer qualitative research with practical means of analyzing social processes and everyday-life across space and time (Hookway, 2008).

Ethics of Employing Weblogs in Social Science Research

As a data source, blogs present an unobtrusive source for collecting data on a variety of qualitative research topics, and is especially conducive to research on controversial or sensitive topics. Blogs overcome issues associated with finding and accessing unsolicited personal diaries and are left uncontaminated by researchers’ interests (Hookway, 2008). However, the opportunities of using blogs for research does present new and challenging ethical dilemmas and controversies, especially as they related to the right to privacy of the blog authors (Bowker and Tuffing, 2004; King, 1996; Sixsmith and Murray, 2001; Walther, 2002; Waskul and Douglas, 1996). Weblogs are arguably within the public domain and constitutes a public act of writing for an implicit audience. The exception proves the rule: blogs that are interpreted by bloggers’ as “private” are made for “friends only”, and weblog software allows for this distinction and privacy for the user. Blogs are part of the public domain, and thus approval from the author is not necessary for inclusion in social science research. According to Hevern (2004) the act of blogging is a social act of position that invites the reader to encounter some aspect of the blogger’s self,

represented through posted items. As Hookway argues, blogs are inherently public as a result of their accessibility and their definition by the user. Notwithstanding the above, every attempt was made to contact participants in order to notify them of the use of their blogs in this research. Requests for removal of their weblogs from the research were honored as they were made.

Part II: Methods

Doing Qualitative Content Analysis

The work of Forman and Damschroder (2008) provides an in-depth and comprehensive approach to qualitative content analysis that will be followed for the purpose of this research, especially their description of the data immersion, reduction and interpretation phases of research. Content analysis is an innately iterative process, and by breaking up the content into three phases, immersion, reduction and interpretation, allows for the efficient analysis of the data. As Forman and Damschroder state, the process of content analysis requires that each case be examined as a whole, after which, the data is broken up and reorganized to systematically examine individual cases, and to compare and contrast the data across cases (2008: 46-47). The first phase of the analysis of data is immersion where the researcher engages with the data to obtain a feeling of the information before rearranging the data into units of analysis (Forman and Damschroder, 2008). An essential part of this phase is memo-ing. Memos are documents that contain just about anything that helps to make sense of the data and it is written by the researcher as they inspect the data. The role of the memo is to serve as an audit trail

of the analytical process of the researcher, and adds credibility to the final analysis and conclusion (Forman and Damschroder; 2008: 47).

The next phase in the analysis is the reduction phase. This phase allows the researcher to approach the data in a systematic way, and according to Forman and Damschroder, is the heart of the content analysis process. Three goals of this phase include reducing the amount of raw data to be reviewed against the research question(s), rearranging the data into more manageable themes, and finally, strategically reorganizing data into categories that address the research question(s) (Forman and Damschroder, 2008: 48). Within this phase comes the development of the coding scheme, and the development of the codebook is an iterative process, beginning with a process of preliminary coding. The usefulness of the codebook is that it contains a list of codes, definitions and example quotes for each (Forman and Damschroder, 2008), which helps to ensure that codes are used reliably throughout the coding process. Once the coding scheme has been created the interpretation phase begins. Not only are code reports, which are generated from the coding process of the text, included in the data to be interpreted but so are memos. The data is gathered and is further analyzed, interpreted and synthesized as a means of formulating results (Forman and Damschroder, 2008: 56). The process of interpretation allows the researcher to identify patterns and to formulate initial conclusions that fit within the theoretical framework. There are many legitimate ways of interpreting data, they note that most interpretive activities will include re-organizing data, writing descriptive and interpretive summaries, presenting results,

and confirming and delineating conclusions (Miles and Huberman, 1994; Forman and Damschroder, 2008).

Presentation of Categories and Codes

An initial list of codes was created by drawing from the literature review and the theories presented in previous chapters. Initially five categories, containing fifteen unique codes were applied to a test sample, with the expectation that the initial coding scheme would be modified based on the data being analyzed. A brief description of the categories and the codes included within each will be provided. As expected, the final coding scheme was modified and can be found in Appendix II with additional details.

Coping Strategies

This category was created to explore and analyze the coping strategies that emerging adults employ to process and deal with their cancer diagnosis and mortality. Many of these coping strategies are socially communicated to us, however, the rarity of occurrences of terminal illness in emerging adults does not provide examples of how to deal with this specific situation. The codes used to analyze this category included “Coping Mechanisms” and “Depression – Anxiety”.

Emerging Adulthood

This category explores the unique obstacles that emerging adults with cancer experience as it relates to their stage in the life span. This category was heavily influenced by the theories of emerging adulthood by Arnett, and they including the following codes: Dependency on family, fertility, health care – insurance, involvement of family / SO / friends, relationships, sexuality and work / education.

Cancer Timeline

This category was formulated to account for the framing of the cancer narrative from the initial health problems that eventually lead to a diagnosis, followed by the treatment narrative. This way the timeline can be categorized as a whole. It includes the “Diagnosis Event” code, the “Experience with Symptoms / Side Effects” code, “Leading Up to Diagnosis” code, “Feelings about Cancer” code, and “Treatment Description” code.

Future Orientation

This category was created to explore how emerging adults process their future in the wake of their illness, and how they talk about projecting themselves in the future. Codes included in the Future Orientation category include “Disruption”, “Mortality” and “Uncertainty”.

Isolation

This category is meant to capture the depression, sadness, the perceived marginalization, or inability to participate in activities that emerging adults were engaged in before their diagnosis. It includes the following codes: “Loss of control”, “medical marginalization”, “sense of injustice”, and “social marginalization”.

Connecting / Communicating

This category was created to explore the motivations of bloggers to share their experience with others and how they speak of or describe their weblog. It includes “Relating to Others” and “Talking about Blogging” codes.

Selection of Participants

For this research, the selection of participants was based on the demographics of the author, and the content of the blog. The demographic criteria for participants was selected based on the emerging adulthood theory by Jeffrey Jensen Arnett, which he argues is a new stage in the life course and is deserving of recognition as its own demographic group. Arnett's theory of emerging adulthood aided in determining whether the participants fit within this life stage, which is the demographic the research is intending to study. Of specific interest to this research was the specific demographic criterion Arnett describes for individuals in this life stage, mainly their marital status as single and that they be childless. While the criteria are quite rigid, I hope to explore nuances in emerging adulthood, given the traits of feeling in-between, and how this sense of not wholly being an adult while not conforming to adolescence, is impacted with a cancer diagnosis. The second criterion for selecting blogs was the content, or rather the intent of the blog by the author. For obvious reasons, the focus of the blog search was on emerging adults with cancer who shared their experience with their illness through their blog. Based on these two major criteria, nine bloggers were selected [refer to Appendix I].

Chain Referral Sampling

The chain referral sampling method yields a sample of respondents through a series of referrals from people who have insider knowledge and who share or who know others with similar desired research characteristics (Biernacki and Waldorf, 1981). The method is particularly applicable when the focus of the study is on a sensitive subject that would render problematic the task of identifying those with the

desired characteristic. Noy (2008) argues that this sampling method has two features, social knowledge and power relations. The idea of ‘power relations’ is interesting, given that the internet has altered the landscape of power, which for many is a matter of access to resources desired by others. However, the power of relations in the case of networked space is diluted and disbursed given the mass accessibility of the Internet, and in particular, blogs. Requiring extensive social knowledge is also diluted given the traditional barriers associated with social relations in the ‘real’ world, mainly geography, is no longer an issue due to the advancement of digital technologies. Noy argues that chain referral sampling illustrates the essential social nature of this method using and activating existing social networks (2008: 332). There are several problems when applying the referral technique, including finding respondents and starting the referral of chains, verifying eligibility of potential respondents, or in the case of this research bloggers, controlling the types of chains and number of cases in any chain (Bernacki & Waldorf, 1981). The relatively low visibility of emerging adults presented some challenges in locating adequate blogs. In place of using search engine queries, focus was placed on links found on the Young Adult Cancer Canada’s website, which proved effective in enabling the locating of other blogs through such links.

The chain referral sampling method was used for searching blogs for analysis in this research. Chain referral sampling method, also known as snowball sampling, is applicable for studies focusing on sensitive subjects, requiring the knowledge of search terms that are not available to “outsiders” in order to locate people for research. The low visibility of the population of emerging adults with

cancer coupled with the sensitivity of the topic requires this kind of sampling methodology for locating participants for analysis. The use of the Internet and search engine queries creatively employs the prerequisite of having knowledge of “insiders”. An initial search of weblogs was done through conventional search engine queries using key words such as “cancer blog”, “young adults with cancer”, and “ cancer+youth”. From this initial query, a website Young Adults Cancer Canada was found that is dedicated to advocating for young adults with cancer. The links contained in this website included blogs written by young adults with cancer. From this initial query, several blogs were found through sampling links and thus these links were akin to a chain referral. The referrals of links to other blogs of emerging adults with cancer who share their experience with their illness and meeting the requirements based upon Arnett’s (2000) external markers of emerging adulthood made up the list of participants for analysis.

Qualitative Analysis Tool - Nvivo 10

The intensive analysis and coding demanded by content analysis requires the use of a qualitative analysis tool. For this research, Nvivo 10 was chosen given the software’s ability to collect, organize and analyze content from web pages, among conventional sources. This ability to use weblogs as a source of data is essential for this specific research on emerging adults with cancer and Nvivo 10 allows for data collection of weblogs through special features included in their software. Nvivo 10 is a qualitative data analysis computer software package and is aimed at researchers using multimedia and rich text-based information and it allows for the deep analysis of the data on small and large volumes of data (“What Is Qualitative Research”,

2013). This software will provide the ability to classify, sort and arrange the unstructured data from weblogs.

Chapter 5 ~Data Analysis~

Presentation of Participants and Weblogs

The participants for this research are composed of five men and four women. They ranged in age, with the youngest, Jamie, being 19 years old at the time of his blog and Naomi, at 28 years old at the time of her blog. The bloggers were mostly from Canada, the United States, and the United Kingdom. Many of the bloggers were either employed or attending school during their diagnosis. For example, Adrian was working for a newspaper at the time of his diagnosis, and his blog was hosted by the newspaper's website. Suleika, after diagnosis, began blogging about her experience, and similar to Adrian, her blog was hosted by the New York Times.

The Participants

Adrian

Adrian was 25 years old at the time of his diagnosis of leukemia and throughout his illness he became an outspoken promoter for bone marrow donation. He spoke candidly of his day-to-day life and experiences with cancer, and sought to share as much as he could on his own experience in order to help others with similar experiences. He leveraged his position at a newspaper in the United Kingdom to blog and share his experiences. After his diagnosis, Adrian became engaged to his long-term girlfriend, Poppy; however, after the terminal prognosis, their engagement was broken. Adrian did not have children, but spoke often of the difficulty he had in accepting his inability to have children as a result of his

chemotherapy. In the end, Adrian chose to stop treatment knowing it would end his life. Afterwards, the foundation he was involved with continued to grow and his friend would, at times, update his blog.

Nic

No stranger to cancer, Nic had previously been treated for leukemia before writing his blog. Nic drew strength from his spiritual beliefs, which he spent considerable energy writing about on his blog. He described himself as a fighter, was honest about the side effects of cancer, and spoke of sexuality in the context of cancer – something that was uncommon among the participants selected for this research. Nic did not have a significant other, nor did he have any children. Nic was from Toronto, Ontario, and it is uncertain whether he was attending school, or whether he was working during the course of his treatment.

Laura

Laura, also no stranger to cancer, had been diagnosed a total of five times in less than five years. She provided insight on the impact cancer had her beauty, her fertility, and weight. She was a devoted vegan, and was inspired to become a holistic nutritionist, specializing in cancer patients, after her recovery. At the time of diagnosis, Laura did not have children; however, she did speak of her inability to have children due to her treatment, and the sadness she felt over her infertility. She had a boyfriend who supported her through her cancer, and they lived together in Toronto, Ontario, and later moving to British Columbia.

Naomi

Naomi, from the United States, was diagnosed with brain cancer at the age of 28 years old. Her blog illustrates not only the immediate effect cancer has on her physically and emotionally, but also the long range implications that her brain tumor poses on her body. At the time of her diagnosis, she was working for a non-governmental organization, and she had a significant other who was supportive of her.

Paul

A gay DJ from the United Kingdom wrote poignantly of his experience with colon cancer and with dying. Initially, Paul was single without children, but after his diagnosis he began dating his boyfriend, who he eventually moved in with, and who took care of him during the end stages of his life.

Becca

Becca was from the United States and did not have access to health insurance, thus she incurred a large amount of medical debt. She wrote of her lack of financial support, which caused tremendous stress on her. Many times Becca had to choose between going to work to make money to afford her treatments or going to treatment and missing work. She was single and without children, and she eventually died from cancer. Her mother began posting on her blog after her death, and shared some passages from her diary and from private Facebook messages.

Jonathan

At 23 years old, Jonathan was diagnosed with a tumor on his shoulder. His experience with treatment in the pediatric oncology was significant for him as he was not given the proper care and attention he deserved. Jonathan spoke of his

fiancée, Laci, and how she made him believe he could have a normal life, including a wife, a job and children, and sought to get his real estate license for New York. Before and in the beginning of his cancer treatment, he was in a band that was on the verge of launching in mainstream markets; however, Jonathan had to leave his band as his cancer worsened. He and Laci moved in together, and she took care of him until his death. She began her own blog and continued writing about Jonathan after his death.

Suleika

Suleika writes for the New York Times as a young adult with cancer. Her blog focuses on the fact that she is a young adult, in-between adolescence and adulthood, having to pause her life while being treated for cancer while her peers continue living their life. Suleika had recently entered a relationship prior to her diagnosis, and wrote of the problems she faced with talking about her possible infertility with her new boyfriend, Seamus.

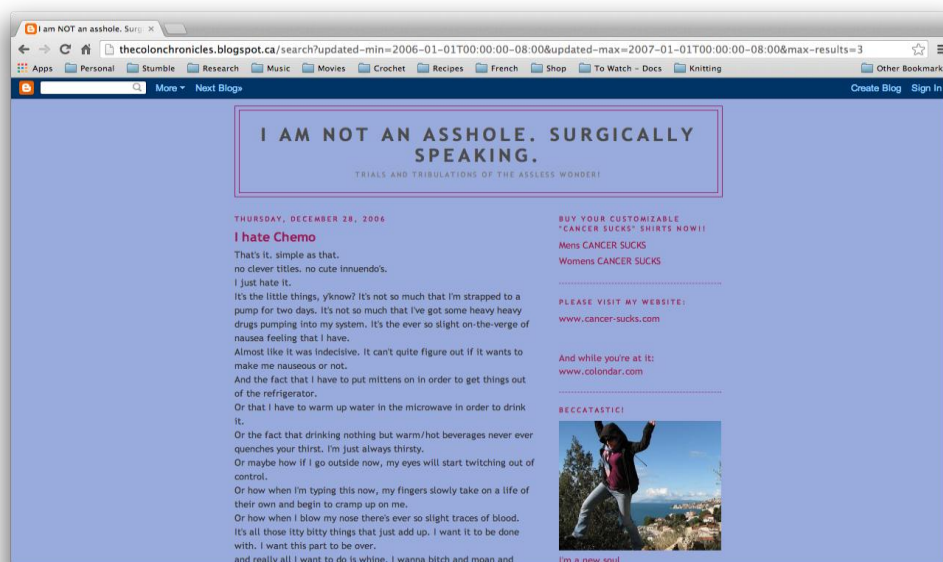
Jamie

At 19 years old, Jamie was diagnosed with testicular cancer and provides humorous insight into his experience with cancer. While he wrote comically of his cancer, he had sobering moments when it came to the side-effects of chemotherapy, which for each of the participants, were extreme on its physical effect on their bodies. Jamie was single, and had no children at the time of his treatment. He wrote about his possible infertility due to the chemotherapy, and expressed concern on how to bring this issue up with future significant others.

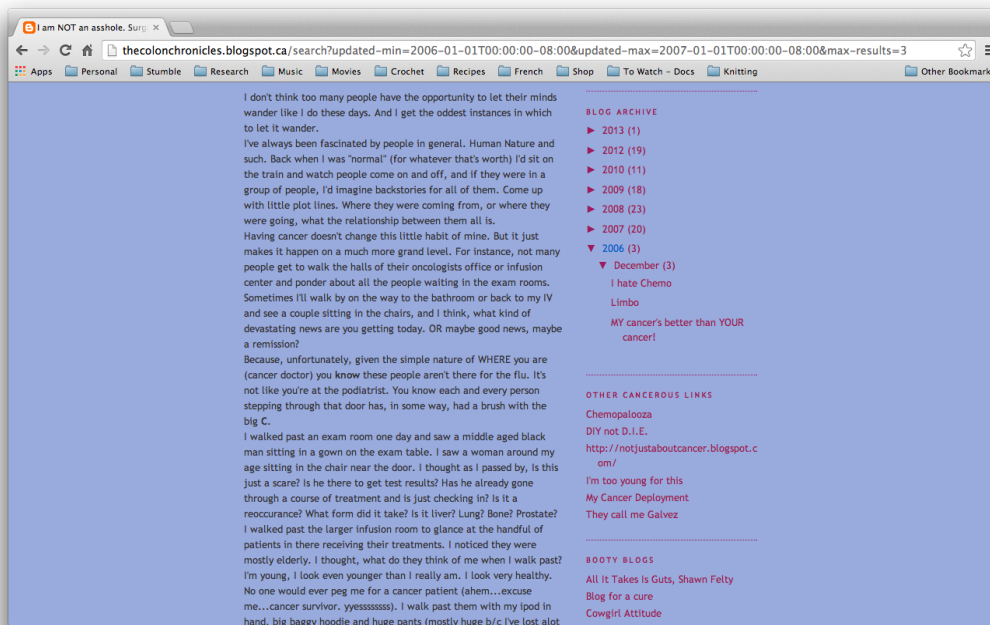
The Blogs

Aside from Adrian and Suleika, who wrote their blogs as journalist for newspapers, the blogs were generally hosted on free blog hosting platforms, such as Blogger or Wordpress. The posts were in reverse chronological order, with the most recent blog posts on the main page of the blog. The blogs include a title; many of them include the words cancer or chemotherapy, or related to a characteristic associated with their cancer, e.g. “Baldy’s Blog” as many cancer patients characteristically become bald due to chemotherapy treatment. Becca’s blog was cleverly titled “I am not an asshole, surgically speaking” as a witty reference to her colon cancer and related surgery to remove part of her colon.

Using Becca to illustrate the particularities of weblogs, as her blog includes different characteristics that are found in most of the blogs of the other participants. In terms of design and layout, the screenshot below show the top portion of the blog, the archival method and blog roll, and finally, the comment section.



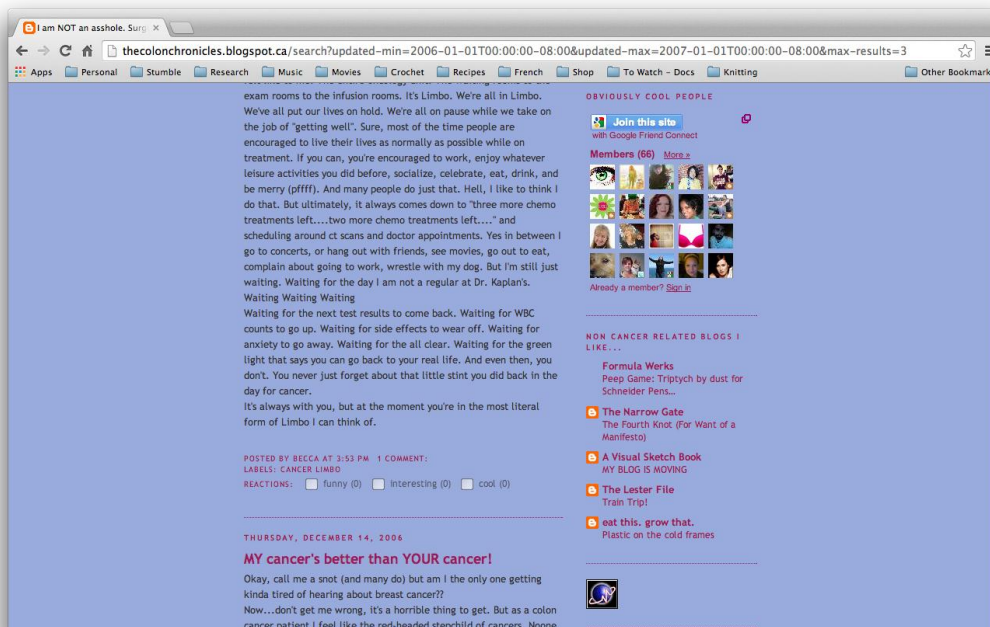
The layout of the blog includes self-portraits and photos taken by others. Some bloggers allow others to add comments to their blogs, which for Suleika and Adrian (who gained notice for their activism for young adults with cancer) signal high traffic on their weblogs. While the other blogs did not have the same layout or all the features as Becca's blog, her blog incorporates many of the features that other participants' blogs included.



In the screenshot above taken from Becca's blog, we see, to the left, her blog is archived by year. There is also a section for links to other cancer blogs. Many of the other bloggers included links to friend's blog or to similar cancer themed blogs. In the image below Becca included a link for members that were following her blog. It is interesting to note that, in addition to allowing for comments on her posts, her readers could provide feedback on a given post as "funny", "interesting" or "cool".

In this way, her blog was an interactive networked space where people could respond to her posts, and also provide feedback on the content of her blog.

Becca's blog was selected for analysis because of the many characteristics, such as the link section, her archival method, the layout, the comment section, and photos that is representative of the other blogs that were included in this research for analysis. While it is interesting to note the various features of her blog, the main portion of analysis was the content of the written posts by the participants.



Analysis

Section I Physical Changes

The physical toll cancer, and its treatment, has on the participants of this research is captured in their writing. Every one of them experience some aspect of this impact, whether it is through hair loss, weight gain or weight loss, the sense of loss of beauty, and finally, the separation of mind and body. While these

experiences are intensely personal they provide insight on the manifestation of societal expectations of youth, beauty and health attributed to emerging adults.

1.1. Weight

My nursing team insist that me putting on weight is a good sign, but they're hardly going to prod me in the stomach and dance around in a circle singing 'podgy podgy cancer face' are they? Having said that, I don't actually see any reason why they should weigh me other than the desire to put me through yet another mildly humiliating saga - I have cancer, not bulimia. On many occasions I've considered screaming 'Fuck off! I'm comfortable in my own skin!' and then running off in tears, much like Rik Waller did on Fat Club. (Jamie)

The emotional reaction to Jamie's regular weigh-ins is a source of shame, or as he puts it "yet another mildly humiliating saga". His nursing team told him that putting on weight is good, as some cancer patients experience weight loss as a side effect to treatment, but Jamie considers the weigh-in unnecessary. The issue for Jamie is not



Figure 1 Photo of Nic near the end of his life

the weigh-ins themselves, but the fact that he has put on weight.

Well fuck, I am too weak to open this little package of cereal and I just busted the plastic knife they gave me. Oh and it just went everywhere. Great. You know whats fucked up? I am 6'3 and I weigh 120 lbs. Fully muscled and fattened I am easily 200 lbs. I am a god damn bag of bones. Whatever, lying in bed all day is too fun. (Nic)

Nic has experienced severe weight loss due to his treatment, which has also rendered him physically weak. In the above passage we see how he associates himself as a "bag of bones", drawing a comparison

between his weight before cancer and his physical self now. The description of his previous weight is indicative of a sense that there is essentially an old Nic and a new Nic.



Figure 2 Becca in a wheelchair at an event.

While the experiences of Jamie and Nic are different, as the former has gained weight and the latter has lost weight, the common pattern here is their struggles with changing bodies that are out of their control.

I dropped down to 98 pounds. But in the midst of all this, I had planned to attend the "Colon Cancer is a Big Dam Problem Walkathon" in Little Rock AR. I got the ok from my doc to go, probably mostly because my mom was going with, and two friends. so I had mom there to be my nurse. I wasn't even able to walk i was so weak, thin, and lethargic, so pretty much the whole road trip, i was in a wheelchair. But I was determined to go. It was great fun. And even though I barely look like i'm having a good time, I truly enjoyed meeting so many new awesome folk, specially all those newbie colondar models from the upcoming 2010 issue. However, seeing photos showing up from that weekend on facebook, I was a bit horrified at how I looked. I know its trivial to talk about physical effects, but you all have to understand, I freak out when something odd happens to me physically because it just serves as an obvious visual reminder of the cancer I try to avoid for little bits of a time. (Becca)

Becca's weight loss is a constant reminder of the cancer that she tries to "avoid for little bits of a time", however, she is bound by her body. She wrote that she was horrified when she saw the photo of herself in the wheelchair. Horrified is a strong word for Becca to use to describe her experience of seeing herself and the physical toll her colon cancer has inflicted on her body.

1.2. Beauty

I don't have the self confidence I once had. It upsets me if I catch a glimpse of my body in the mirror. The last time I properly saw myself I cried. It had been a long time since I'd looked before that time. So the difference was huge in what I last saw of myself. I have never had body issues, not saying I had a high opinion of myself, but I have always been happy and content with how I looked and my physique. (Paul)

The body that Paul once had, his physique, has been altered by cancer to such an extent that Paul no longer has self-confidence. His reflection in the mirror causes grief over his old body. Paul wrote of the physical effects of his cancer on his body throughout his blog, and grieved for the body he once had. Paul wrote that he was happy and content with how he looked before and with his body, but now when he sees himself in the mirror, he feels upset. He explains that the last time he saw himself properly he cried because of how he looked.

I have heard and repeated to myself such things as “cancer cannot take away your beauty” many times... I have been tempted to write it on my bathroom mirror in bright, red lipstick. I want to believe it. But most times, it is hard to think that it is true. It's rather difficult to feel “beautiful” much less “feminine” through chemotherapy. Sure; nothing can take away one's inner beauty -- I'd agree with that -- but it's almost impossible to admire the image in the mirror when you hardly recognise it. I avoid mirrors at all costs. I have not been clothes shopping in ages. And it's hard now for me to care much about acting -- an at times superficial industry so dependent upon appearance. (Laura)

Laura's experience with the effects cancer has on her body, and by extension, her beauty is that both are being extinguished by the side-effects of chemotherapy. Laura writes “it's almost impossible to admire the image in the mirror when you hardly recognise it”. She refers to her reflection in the mirror objectively as “it”. The “it” she is referring to is her external beauty, which she cannot recognize as it no longer aligns with her expectations; it is an object that is separate from her. Her physical beauty is a consumable object, but it has changed and has become

unrecognizable. She does not relate to the image in the mirror, nor does Paul who expresses the experience of seeing his body in the mirror as upsetting.

I was quite disappointed when I realized recently that my eyebrows had disappeared. They had given me the impression that they might hold on through this ordeal, but apparently they just didn't have the longevity I thought they had. The hairs on top of my head were gone almost instantly, so good riddance to them, but I thought my eyebrows were different. As it turns out, they were as fickle as the rest of them. The reality is that whenever I look in the mirror, I anticipate my eyebrows being there, and it takes me a moment every time to acknowledge and accept their absence. (Jonathan)

Jonathan's experience with the side-effects of chemotherapy on his physical appearance is focused on the loss of his eyebrows; a surprising event that was unexpected and has fundamentally changed the way that Jonathan relates to his reflection in the mirror. The expectation of seeing his eyebrows is dashed as the and his expectation of his physical appearance can no longer be taken for granted.

One interested commonality among Jonathan, Laura and Paul is they have each referenced seeing their reflection in the mirror which precipitated strong emotional reactions to their physical reflection. This is deeply symbolic as they have an idea in their mind's eye of what they look like, or what they expect to look like, which is then shattered when they see their reflection. The reflection that they see in the mirror is difficult to relate too, and for Laura, is unrecognizable.

1.3. Hair Loss

I'm not bald, but I do look very much like a Barbie doll that a toddler has maniacally attacked with a pair of scissors. I'm now put in a position where I need to decide whether I should bother to keep the hair that I have or just get rid of it. The problem is that a bald head is to a cancer patient what the yellow Star of David was to Jews in Nazi Germany. (Jamie)

Hair loss is a common experience among cancer patients. It can be an emotionally charged experience when hair loss begins. Jamie writes that a bald head is an instant identifier for cancer patients. He draws a comparison of what it means to have a bald head for a cancer patient, interestingly, to the Star of David for Jewish people in Nazi Germany as a marker used for easy identification and thus persecution. The bald head for a cancer patient sets them apart, and marks them as someone with cancer. His choice of comparison is interesting as the Star of David was used during Nazi Germany to persecute Jewish people; however, Jamie uses this comparison as a marker of death, which is arguably true for Jewish people. Therefore, the persecution that Jamie is referring to in reference to his cancer is not social, but it is the physical threat of cancer on his mortality. The hair loss symbolizes the threat of death and a bald head has become the equivalent of the meaning of the Star of David to a Jewish person. This instant identifier is particularly painful for female cancer patients, for whom hair is associated with beauty and femininity (see any shampoo commercial).

Losing all of your hair, especially for women, can be a very upsetting experience. I chose to shave my head before chemotherapy because I couldn't deal with the idea of long wisps of wavy brown hair coming out by the handful. (Suleika)

Suleika decided to preemptively shave her head before she had to endure losing her hair. For Suleika, this was a matter of control over the course of her physical appearance that was not going to be decided entirely by the effects of chemotherapy. The photo Suleika posted to her blog is symbolic of the power she is

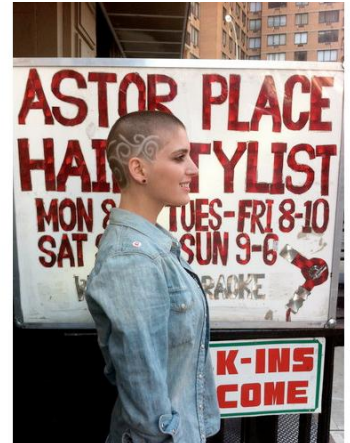


Figure 3 Suleika with a design in her shaved head

trying to regain in the face of losing her hair due to chemotherapy. Not only did she choose to have her head shaved, but she expressed her identity by having an intricate design shaved into her fuzz. The background of her photo, a sign for a hairstylist, asserts that she still adheres to the rituals of hair grooming, which is to have it done at a stylists. Becca also describes how she decided to shave her hair once Erbitux¹¹ caused her hair to thin.

*But it just kept coming out. My hair was limp, thinned, and lifeless. It's not a very common side effect of Erbitux. So I don't understand why after not comign out with the multitude of chemo drugs, it was doing so now. I started by cutting it pretty short. (depicted here by the "many faces of me" heh). So I knew the inevitable was coming. *gulp*. I was going to have to baldly go...where few women ever have to go (Becca)*

While both Becca and Suleika preemptively shaved their heads to stave off the inevitably of hair loss due to side-effects of chemotherapy and other cancer-related drugs, it was not entirely their choice. Their choice was prompted by the reality of their treatment; however, they were able to regain some measure of control through deciding when and how they would go bald.

1.4. Separation of Mind and Body

I have to continue living in a body and a mind that I don't fully recognize, continuing to wonder when I might once again feel like myself (Jonathan)

Jonathan wrote how far reaching the affects of his cancer had on his mind and body. He felt so transformed by the side-effects of cancer and of his chemotherapy treatment to the point that he no longer recognizes his body or his mind. He hopes that he can go back to feeling like himself, he wants to go back to the person he

¹¹ Erbitux or Cetuximab is an epidermal growth factor receptor (EGFR) inhibitor used for the treatment of metastatic colorectal cancer and head and neck cancer.

recognizes, to the person he was, both in body and mind, before cancer. For Becca, she describes her experience as “freakish”.

Did you know how freakish it can be when your own body parts take on a life of their own and move without you trying or wanting them to? (Becca)

Becca’s narration is striking in that her body is totally separated from her mind, in that her body parts have taken on a life of their own and, without prompting from her mind, are moving of their own volition. Thus, she is describing a total lack of control over her own body, which has become unrecognizable to her mind. Adrian also uses similar language to Becca’s, except that Adrian’s mind is willing to do “things any 26-year-old can do - but I can’t”.

Don’t have enough energy to up and leave and just do something completely different... My mind still wants to do all the things any 26-year-old can do - but I can’t. (Adrian)

Here, it is not the body that is working discreetly from the mind, but rather, the mind is attempting to have the body act, to no avail. The difference between Adrian and Becca’s description is the point of view that each has taken; one where the body is freakishly acting on its own volition and, the other, where the body is not acting as it should through promptings from the mind.

I feel so divorced from my body. I feel like this body is not mine. It is weak and tired. It catches infection after infection. It is fragile. It doesn't feel very feminine anymore. It can't go on the subway, or to the movies, or sit on a plane. It doesn't want to go for a run or even a long walk. It naps as often as a two-year-old. It currently cannot stomach vegetables. It needs so many damn pills all the time. But I am unable to break down or cry about it anymore. I feel very "formal." As though I am watching this happen to someone else. (Laura)

Laura’s experience with this separation between mind and body has caused her to refer to her body as a separate entity from her mind. The body has become an ‘it’, divorced, as she describes, from her own sense of identity. It does what it wants and

avoids the things it does not want to do. It has failings, such as not being to walk, and not being very feminine. It has become a thing completely separate from her; it has taken on a life of its own.

This week's terror has, however, shaken my confidence enough for me to treat every single thing about my person with the utmost suspicion. A spot is now a face tumour, and a cough is one of my lungs falling off. Plus, I'm not getting fat, my man breasts are just two massive growths. I can safely say that it's nothing to do with the two kilogram bucket of jellybeans that my podgy sausage fingers are nestled into right now which my Dad bought for me. A gift, considering the form of a jellybean, that would have taken on a cruel irony if I had heard there was something terribly wrong with my testicle. (Jamie)

For Jamie, he describes how he can no longer trust his body. Every anomaly on his body is cause for concern, and as he says, is treated with the “utmost suspicion”. Not only are things on his body treated with the utmost suspicion, but also Jamie believes them to be caused by extreme occurrences, e.g. a cough attributed to his “lungs falling off”. Jamie’s body has now become a separate thing from his mind that threatens his existence, and cannot be trusted. His body has betrayed him, and Jamie feels as though his body will continue to betray him. Each of the passages above details the anxiety of being divorced from one’s body. The body has become a stranger to the mind, not behaving as it should or behaving on its own without consent from the mind. I argue that this description of a separation between mind and body is the betrayal that the participants feel as a result of their illness.

1.5. Looking Ill

I am paranoid that I am starting to look ill. I don't want this at all or people lye to me about it. I just don't want people to know I am sick or mistake me for the common Glasgow “junky” look.



Figure 4 A photo of Paul and his "freak" look

funny how my vanity still rears its head when I am dying of cancer or I am really worried is how I look. Well I loved how I looked before and yet another thing this disease stripped me of. (Paul)

Paul acknowledges that while dying, his vanity remains intact. In the photo he posted to his blog, his piercings, including a plug in his ear to stretch his piercing, his tattoos, and the multiple colors in his hair represents his “freak” aesthetic. However, Paul is worried that the physical toll of cancer on his body, and his tattoos and piercings will have him mistaken for a “Glasgow Junky”, addicted to heroin and thus malnourished and thus a low status and undesirable member of society. Neither does Paul want to appear sick as he is afraid of people knowing he has cancer, and thus, he does not want people to feel sorry for him. Paul’s freak aesthetic makes him stand out, as his tattoos and piercings are very visible; however he wants his physical appearance to be defined by his aesthetic and not by the physical effects of his cancer and chemotherapy treatments.

Section II Emotional Changes

Cancer is an emotionally tumultuous time for emerging adults, and brings up feelings of fear, loneliness, indignity, anger, alienation, and it causes them to question “why me?”

2.1. Helpless

I guess that means more chemo for me. What a fucking shit way to end such a short and shit life. Cancer, chemo, cancer, chemo, cancer - chemo not working, done. Is that any way for any one to die? I feel so miserable, I feel so helpless, I feel so fucked. (Nic).

While many of the bloggers usually wrote with an underlying sense of hope, especially in Nic’s case, who always tried to remain positive against insurmountable odds, there was usually an expression of helplessness brought on by bad news. In

Nic's passage above, you can feel the weight of all his experience with cancer, and the sense of helplessness and suffering that spills forth in his blog post. The passage is a powerful piece of writing, and conveys a great depth of feelings he has in facing death. For Nic, there is no way out of his predicament. The yearning for a healthier body, the injustice of dying at a young age, and the card he's been dealt with in terms of his cancer diagnosis is palpable. Adrian, similar to Nic, wrote with positivity, hoping to help others in similar situations as he. However, with the weight of his diagnosis, his experience with Graft versus Host Disease¹², the break-up of his engagement, and the inability to continue pursuing his career, all come down to one decision to take his own life, unsuccessfully. His honesty, his willingness to share the helplessness that he endures belies courage even in the face of his own mortality and suffering.

Just over a week ago I nearly took my own life. I had drunk a generous glass of whiskey and was lying on my bed. I am sorry to say it now but I have never felt so worthless and empty. Despite everything I have been through there just seemed no point in carrying on. There was no hope at all. An overdose seemed the most logical option. I had even worked out the order in which I was going to consume the copious amounts of tablets stuffed in a bag by my bedside. (Adrian)

Adrian wrote how feeling worthless and empty, and having lost all hope made him attempt suicide. Enduring cancer and chemotherapy was difficult for Adrian as it radically changed his life and took many things from him: his career prospects and his fiancée. For him, the logical option and his only recourse from his empty and worthless existence was to end his own life. While he did not see his suicide

¹² Or GVHD is a common complication following a stem cell or bone marrow transplant where the immune cells in the tissue, the graft, deem the recipient, or host, as foreign and thus begin to attack the host's body cells.

attempt through, his passage is telling in the relationship between hope and projecting himself into his future.

2.2. Frustration

I'm frustrated that I've lost control of so many aspects of my life. I can't eat what I want because it's been in the refrigerator too long. I can't go out because I might get sick. I go in for chemo when they tell me my blood levels are okay, and I go home when they tell me I can go home. I eat what they bring me in a plastic container, I pee in another plastic container, and the mechanical bed on which I get to sleep decides all by itself when and how to change shape. Nurses find excuses to wake me up every twenty minutes (or so it seems) when all I want to do is be left alone to sleep through the night. Even at home, I have to wake up every morning at 6am to take meds for the pain and nausea, even though I know that I'm going to be nauseous whenever I wake up. (Jonathan)

This citation illustrates the loss of control over one's everyday life. For Jonathan, that loss of control has manifested itself in numerous ways. Deciding what to eat, a generally trivial decision is now decided based on the needs of Jonathan's new reality as a cancer patient. In his passage above, he not only describes the limitations placed on his body from the chemotherapy and cancer, but also from the sheer fact that he no longer has full autonomy over the course of his life. Simple day-to-day decisions are no longer straightforward, and are no longer up to him. For Nic, his frustration is based on the pandering he perceives from his medical team on the success of his treatment.

When it comes to support on one side I have the medical personnel who really don't help much. They are all really excellent and nice people but all their faith is in the medicine that is slowly but surely failing. They say "don't give up" but then tell you how the latest chemo doesn't work anymore. (Nic)

The frustration lies in being told to hope where no grounds for hope exists. Laura also experiences frustration with her medical team, but it relates to her lifestyle

decision of being a vegan. Her doctors attributed her lifestyle as the cause for her weight loss, instead of her chemotherapy.

Feeling very frustrated. They think I have an eating disorder. I get why: I have dropped a few pounds off my already small frame... They seem to be mistaking what chemo is doing to my body for a body image complex. I want to scream. It's not my fault that I feel nauseated to eat half the time, and the rest of the time, I have mouth ulcers that make it difficult to chew or swallow... What's more, they are poopooing all over my vegan diet. They're doing everything to convince me to let eggs and dairy back into my world. I told the dietitian that I am quite lactose intolerant, so she was willing to drop the dairy pushing, but is still on the egg train. I said I would consider it. This is discrimination! (Laura)

For all three of these bloggers, the frustration is specifically focused on the power over them exerted by medical personnel and the broader issue of loss of autonomy and self-determination.

2.3. Loss of Dignity

Loss of dignity occurs as individuals are shuffled through medical examinations, and doctor's visits. They are seen for the disease, with which their body is inflicted, as it is the source of, and the reason for, their interaction with medical professionals.

After a load of filthy talk about injecting eggs with sperm, they tell me that, "if I desire", I can get another sample tested after my treatment ends. This choice of words places me in a terribly awkward situation. Why have they given me the option of whether I want to go or not? Surely I now can't return without looking like a deranged fetishist who loves nothing more than romancing himself in a hospital? As you may imagine, it's an awkward enough social situation even when you have a very good reason to be there. I've never experienced such shame than when handing over my sample, avoiding all eye contact with the nurse. But when you add the extra dimension of it being a personal choice to be there I don't think I could ever look at myself in the mirror again without feeling pure contempt and disgust for myself. (Jamie)

As Jamie was diagnosed with testicular cancer, part of his treatment plan included the freezing of his sperm in the event his treatment rendered him infertile. He

describes the shame and embarrassment involved in masturbating into a cup and handing the sample over to a technician in the hospital. For Jamie, the sperm preparation for freezing involves self-blame and self-contempt due to his perception that the production of the sperm sample is undignified.

2.4. Loss of Affection

The loss of affection is physical but is experienced as something emotional. As a result of the varying consequences of chemotherapy, this has affected Jonathan and Paul in different ways. Jonathan laments the fact that he is unable to come into physical contact with people for fear of contracting germs.

I can't shake hands or give hugs when anyone comes to see me, the dog can't sleep on my bed. (Jonathan)

His compromised immune system prevents him from embracing others, and from allowing his dog to sleep on his bed. While for Paul, his sex drive has suffered from chemotherapy as he experiences excruciating pain, resulting from his chemotherapy treatment, when touched.

Hopefully these [Gabapentin¹³] will help with my sex life as recently it has been suffering quite bad. I am lucky I have a very open relationship with Chris and can talk to him about anything. He is very understanding about this. I cant bare to be touched in the areas I used to love as pain shoots from legs up into my abdomen which is very strange. (Paul)

The loss of affection for Jonathan and Paul is troubling, as they can no longer enjoy the physical touch from their significant other, as is the case for Paul, or be embraced by friends, as is the case for Jonathan. Not only has the cancer caused physical pain, but it has also isolated Jonathan and Paul from others.

¹³ Gabapentin is a pharmaceutical drug that is used to treat neuropathic pain.

2.5. Alienation

For some of the participants in this research, a feeling of alienation was present, as Laura described being ignored in the “corporate cancer world”.

Being part of a demographic (15-39) that accounts for little-to-no attention in the corporate cancer world as well as in the realm of clinical trials -- a demographic that has not seen its survival rate improve by even 1% throughout the past thirty years -- is alienating and frightening. And it sure is freaking lonely in those patient waiting rooms, where I am often the youngest person there by at least thirty years. (Laura)

Here Laura describes being ignored by the institutions that surround cancer. She expresses feelings of loneliness resulting from being much younger than all of the others in the cancer ward. For others, the alienation is more internal to their sense of identity. For Paul, he is alienated from his former sense of self. He is trying to assemble parts of himself scattered by the experience of cancer and the treatment.

I feel like I am on a bit of a journey to myself to show that even tho I am sick I am still me. I do have to change a hell of a lot. But if little bits of me can still come out then i think i will be ok. (Paul)

However, for Paul, this alienation is not entirely negative, as he understands that the change he is undergoing is a processual part of having to deal with a terminal illness. For Adrian, his alienation manifests as loneliness as he does not know who to turn to his is turmoil.

Sometimes I'm not sure who to turn to. What should I say and how do I expect this person to reply? It's clearly not all going to be all right. (Adrian)

There is no one to tell Adrian that everything is going to be okay. The expectation that the people in his life know what to say, and know how to comfort him the way he needs, is not entirely certain. Adrian is alienated as his cancer causes him to require a level of comfort that the people in his life are unable to provide him, as they cannot fully relate to the trials and fears he has as he tries to navigate his

illness. For Nic, his alienation results from feelings of abandonment from Doctor Minden, his oncologist.

The beast still lingers but we have a time of peace now. I don't really know what Minden wants to do now, infact I havn't heard from him at all in the past few hospital visits. I feel abandoned :(but I mean...maybe it really is being left up to me to see if I can find a way to make peace with this disease. (Nic)

Here, Nic's alienation is focused on one person, Doctor Minden. He quickly attempts to dismiss the feeling of abandonment by placing the onus on himself to find a way to come to terms with his illness. While he attempts to deflect his feelings, it remains obvious by his passage that he is deeply unsettled at the lack of contact with Doctor Minden.

I've heard it claimed in the past that 'cancer is a gift' - it isn't. A big lovely cake, that's a gift. A tiny, fluffy, huggable kitten, that's a gift. Catching a disease which could quite easily kill you when you're nineteen or, at the very least, make you relentlessly vomit for six months is not a gift. Let's just be grateful that the people who claim this haven't applied for the post of Father Christmas at your local shopping centre. (Jamie)

The alienation that Jamie describes in his post relates to the inability of individuals to properly interact and deal with a person with an illness such as cancer. Jamie describes how painful platitudes can be when delivered thoughtlessly. While some have offered philosophical takes on being afflicted with cancer and recommended that he find the up-side, Jamie feels the sting of the insensitivity of this type of comment. Therefore, the effect of this interaction results in a sense of alienation from "normal" people, who do not understand the day-to-day experiences of people with cancer.

2.6. Loneliness

Feeling alone is a common theme among the bloggers participating in this study. Adrian's treatments compromised his immune system to the point where he was placed in a medical isolation room for several weeks to avoid contracting infections. His experience was scarring, as he describes in the passage below.

Unfortunately my time in isolation has fundamentally scarred me. I can no longer bear being on my own for long periods of time. I really need company and the comfort of other human beings. No one's going to marry me now so I somehow need to address the fact that I'm never going to have a family or children of my own. (Adrian)

The loneliness is extended to the recent break-up of his engagement from his long-time girlfriend, Poppy. Not only does he crave and need human companionship more than before, he links this need to the idea that he will never get married nor have children. Not only have the experiences with medical isolation heightened his feelings of loneliness, but also as Laura also describes, cancer creates the conditions for loneliness and isolation.

And I know that I might be in "Spiritual Retreat" -default to zen message 50% of the time, but I'm not sure anymore that isolating myself is the healthiest idea. Having cancer is isolating enough. I don't have much in common with the eighty-year-old man with prostate cancer sitting beside me in the onco room reading Reader's Digest. (Laura)

Jonathan also feels alone most of the time. While family and friends can be around to ease the sense of loneliness, he understands that there is a layer of experience that he must face alone, and that cannot be assuaged by family and friends.

Being alone at the time, I realized how often I am by myself, and it hit me, how easy it is to feel alone when you're sick like this. The support I've received from my friends and family has been great, but it's just inevitable that sometimes I feel like I'm all alone. (Jonathan)

Paul too feels this loneliness. While his friends and family are busy with their own lives, he feels alone.

My mood is a bit up as have had a couple of nice days with Chris and he always makes me forget. I miss it when he's not here, I am always stuck on my own, I wish people would come visit me, I know people are busy and sometimes I can't be bothered But my days consist of being in a bubble. (Paul)

Paul refers to his daily experience as metaphorically being in a bubble, one that is fully occupied with being a terminally ill person. The bubble forms part of Paul's daily experience of being alone due to his cancer and his chemotherapy treatment.

2.7. Fear

The fear that is expressed by the participants of this research are layered and complex. Jonathan wrote of his experience with cancer as a nightmare.

*I could tell I was taking it out on other people, but I just couldn't make myself care. **I'm trapped in this nightmare** and I can't run or take a break or get away from it because right now it defines me. (Jonathan)*

The feeling of being trapped for Jonathan is a real fear. There is no way out of his predicament. However, in another passage he discusses what it means to once again live a "normal" life, a life that is beyond the cancer.

For so long, I eagerly awaited my chance to resume normal life; to loosen the reins that had become so suffocating. I ignored the impending responsibility and demands that accompany "real life," and all of a sudden I'm more afraid of going out and living than I am of the persistent uncertainty that I'll be around to do it. (Jonathan)

Jonathan's fear in the second passage is telling in that he has become accustomed to his new life with cancer. The cancer is so all-encompassing that he cannot fathom a life outside of it. Jonathan conveys a fear of the uncertainty related to a life that exists separate from cancer and from treatment. Jonathan is expressing how his

ability to relate and to function in “real life” is fundamentally altered by his illness, and thus, this added dimension to his personhood causes uncertainty in how to act as a cancer patient in “real life”. For Adrian, the fear he expresses is also attributed to uncertainty.

Lying in bed, not knowing if you are going to get better, or what exactly is causing you to feel sick, is scary. (Adrian)

The fear of not knowing the reason why one is sick, and the uncertainty of a recovery, is cause for concern. Nic describes his fear as though it is a giant entity that lingers above him.

It feels as if I am being crushed...but then it is gone. There is a giant body of fear lingering, hovering, waiting above me, waiting for the right moments to apply pressure. It comes and goes but I feel as if its ultimate purpose here is to stamp out my existence here on this earth. It would have me believe this, but I know better. (Nic)

For Nic, his fear has a physical presence hovering above his head. Alternatively, the fear that Jamie expresses is somewhat different than the fear that is expressed by Nic, Jonathan and Adrian. Jamie has stated on occasion his testicular cancer is “one of the best cancers to have” given its low mortality rate. However, his perception of his situation changed with the threat that the cancer could spread to his vital organs.

The best pun ever written aside though, it was the first time that all of this has actually scared me. It can attack my lymph nodes all it wants, I don't even know what they do, but it would cease to be at all funny if it started to pick on my organs. Particularly if those organs were Excalibur or, as I thought this week, the Knights of the Round Table. I'm reliably informed, however, that this is practically impossible during my treatment as they know that it's working well. I'm shunning migrant cancer cells seeking asylum in the safe haven of my body like an insane nationalist. (Jamie)

Jamie describes a literal battle against cancer cells. Paul is afraid of dying and feels uncertain about the process. The consequences of his illness and his lack of appetite will strongly determine his life expectancy. He is terrified of his lack of appetite and

its significance, but he understands the reality of his situation and attempts to accept it while also facing the fear of death

The reason I am really scared just now, is because it's a gradual descent. Your appetite decreases and so does your energy and it gets less and less. I don't have an appetite really at all just now and can't eat much. I also just want to sleep all the time. I have been putting it down to any factor I can, and there is a few reasons that could be causing it, but right now I am scared it is because of the cancer. If I don't regain my appetite and get a bit more lively in the next month then I know for sure that I am fading out. It's so terrifying to know you only have a month to know if your as close to death as you fear. It's on my mind constantly, dying, It's not that I have given in, or that I really believe I am, but I have to be honest with myself and know it's going to happen a lot sooner than later. (Paul)

2.8. Why Me?

The respondents each attempted to understand why they were diagnosed with cancer, and attempted to justify it somehow. Laura could not rectify her lifestyle, of being healthy and adhering to a vegetarian diet, with the fact that she was diagnosed with cancer for the fifth time in less than five years.

In spite of my devotion to healthy living, twelve years of vegetarianism followed by a strictly organic vegan diet, a very active lifestyle, a lifetime of not smoking, and a family history that does not include cancer ... I have cancer for the fifth time. (Laura)

Adrian, similarly to Laura, frames his attempt to understand his illness within the context of his healthy lifestyle. Both participants state that they do not smoke and that there is a lack of cancer in their family history.

On reflection the early days were overwhelming. I was a fit and healthy 25 year-old, who doesn't smoke, has no history of cancer in the family and has a job I like. It was hard to understand why all of this was happening and to comprehend the difficult times ahead. (Adrian)

Nic, on the other hand, has outwardly asked “WHY ME”, instead of attempting to understand his illness within the context of his health or his age.

The day was soon after I had just found out I had cancer again. I was so sad. So depressed. I have never been an angry person but try as I might I would feebly try to piece together WHY ME- why was this happening AGAIN.(Nic)

Speaking in jest, Jamie explains how after diagnosis the question of why it has happened to him, and not to the “millions of worse people in the world” became his focus in understanding his diagnosis. Jamie’s statement underlies a sense of injustice that it has happened to him.

When you’re diagnosed, you do wonder why this has happened to you when there are clearly millions of worse people in the world. (Jamie)

Jonathan not only feels the injustice of his illness by asking whether he has done something to deserve his illness, but also attempts to understand his illness within the context of his healthy lifestyle.

Did I do something wrong to deserve this? I must have, right? How else can you explain it? I’ve always taken good care of myself. I eat healthy, hell, I was a college basketball player just over a year ago, for crying out loud. I was a good friend, a good brother and son, I worked hard. Then, all of a sudden I wake up in the middle of the night with a tumor that has about 40 cases a year and about a 20% survival rate. Where’s the logic? What’s the explanation? It doesn’t seem fair. (Jonathan)

What is really interesting about Jonathan’s statement is that he queries the logic of his cancer. It speaks to his sense that there is a ‘natural ordering’ of age-related events and he feels a sense of injustice for being young and in all likelihood terminally ill.

2.9. Anger

Just thinking about it for a second makes me so angry; I can’t work, can’t attend school, bars, theatres, none of that for 2 to 3 years. (Nic)

Anger was a common emotion that the respondents experienced throughout their cancer treatment. Nic expresses his anger over his inability to participate in

everyday activities, such as going to bars and attending school. The activities that Nic can no longer participate in are central activities for all of his peers. Adrian also expresses anger over the impact that the cancer has on his potential future as a father (a *right*) – his fertility has been compromised due to the effects of the chemotherapy:

I get angry that my natural right to have children has been ripped away from me. (Adrian)

Similar to Adrian and Nic, Paul is angry that his illness is preventing him from participating in club scenes and furthering his DJ'ing career. The uncertainty of his health and the physical toll of the disease prevents Paul from engaging in an activity that could bring him a lot of success:

But, I have decided to stop DJ'ing for a while, I can't guarantee my health from one date to the next, and for now I need as little pressure on me as possible. Makes me sad knowing I will have to give it up, but I also want to end on a high rather than getting to the stage I don't get to say goodbye to my once promising career. I keep getting annoyed that I had to quit and go home but I cant describe to you the pain I was in. I thought I was going pass out and collapse. And that wouldn't have been a good way to en the night. God I am so angry that the illness managed to get in the way on MY night. (Paul)

These young men are mourning endings: the anger that Paul, Adrian and Nic express is one that is rooted in their inability to engage in activities due to their illness. The toll the cancer, and the chemotherapy treatment, has on their bodies hinders their engagement in pursuits that are socially expected for their age group. For Adrian, as for the others, the end of something that is usually a given at his age, in his case fertility, adds layers of anger and resentment to the cancer diagnosis and treatment.

Section III Social Changes

Common among the participants of this research is the impact of their cancer on their social lives. For these emerging adults, they expressed the social consequences related to their disease, including stigma from their peers, a loss of social autonomy as they must adhere to the demands placed on them by medical professionals, the feeling of being stuck in time while being in treatment, and an inability to project themselves into the future.

3.1. The gaze of others

Jamie shares an experience of being at his doctor's office for an ultrasound appointment that he expressed as embarrassing. His attempt to conceal, partly, the purpose of his medical appointments and treatments with a "swagger", and his attempt to avoid the risk that a room full of strangers would know why he was there, turned into a "demoralizing ordeal" when the truth came out. He felt all eyes in the room turn toward him:

The tell-tale signs that it was going to be a demoralising ordeal struck me right in the face from the very beginning. Swaggering into the busy reception area thinking I was the cat's pyjamas, I shook out my headphones which were playing some loud rock and roll music and approached the attractive young receptionist to tell her that I had an appointment at 2.10pm. "Jamie Ross...a testicular ultrasound isn't it?" - a deafening silence immediately fell upon the waiting room. At this exact point about twenty people shared a moment of looking at me out of the corner of their eye and, to a man, thought 'I wonder what's wrong with his balls?'. Having been firmly put in my place, I quietly nodded and sat down to read Bella Magazine in a desperate attempt to avoid the gaze of every single person in the room. (Jamie)

Being outted publicly for the source of his illness, his testicles, feels shameful for Jamie. Becca, on the other hand, has a positive experience with public knowledge of her disease:

There were so many people I crossed paths with that made the experience just a bit more bearable, and helped me continue to feel like a person rather than a number or a disease. (Becca)

Compared to:

Yesterday was probably the day that the proportion of medical professionals in Perthshire who have seen my testicles finally exceeded the proportion of those who haven't. These days, it's a rare occasion when I leave the house and return without having been paraded around a doctor's clinic wearing nothing but a weary grimace. (Jamie)

This account is both poignant and painful to read as Jamie's experience of "being paraded" around doctors and having them see his genitalia; the most intimate and physically private parts about James are exposed degradingly to doctors.

3.2. Social Consequences

It's surely enough of a stigma being a full three years older than the majority of the people who will be staying there [dormitory], I'll more likely be excluded from all sorts of youthful high-jinks and I'll only be approached when some young roister-doister is in need of banking advice. (Jamie)

Jamie decided to go to the University once he went into remission. In his blog, he expresses uncertainty of being able to integrate into the University culture. He is worried that he will be excluded from the social life of his peers, as he is a full three years older than his peers in the dormitory.

That doesn't necessarily mean my illness is directly to blame but it changed how I look, stopped me being able to travel like we used to, stopped me becoming who I wanted to be professionally. (Adrian)

For Adrian, the consequences of his illness has made him look different, but on a social level, it has prevented him from becoming who he wanted to be professionally, and it has stopped him from being able to travel. Like Jamie, Adrian feels excluded from participating in activities that his peers are engaged in.

I've felt preposterously ill, all the while waking up to people's Facebook status updates about how terribly rough they were feeling because they

threw caution to the wind and had an extra Apple Sourz the previous night. I would have crawled through a tunnel woven together from shards of glass, out-turned salt and vinegar crisp packets and pig faeces to have experienced just five minutes of a glorious hangover this week. You people don't know you're born. (Jamie)

Jamie describes his desire to have the same experience his friends' share via their Facebook statuses. Jamie compares his feelings of being ill, caused by his chemotherapy treatment, to the hangovers his friends experience. He describes the lengths he would go to experience five minutes of the hangover his friends have, in place of feeling the kind of ill he does as a result of his treatment. Here Jamie is drawing a contrast between the choices his friends are making regarding drinking, and its resultant hangovers, and his feelings of being ill attributed to his treatment.

3.3. Relating to Others

You as in, the rest of our normal world. I don't belong there anymore, as I am not normal. I am in another class now. And not the "cool kids" or the "theater dorks" or the "jocks" class. I am now a member of a society of people, I believe, who cannot help but acknowledge that what we once were is no longer, and what we now are is a completely bizarro twilight-zone reality that most can ever even fathom. (Becca)

Becca describes how she no longer feels like she belongs in “normal life”. She now belongs to another class that others cannot relate to or understand. Becca draws a comparison between her old self, which was normal, to her new self, which belongs in a “bizarro twilight-zone reality that most can ever even fathom”. Becca does not feel as though others, who do not belong to this new class, can understand her.

Also, do I mention it to my new flatmates and risk becoming known as 'you know, Jamie, the cancer one'? (Jamie)

For Jamie, he is worried that he will not fit in and will be known as “Jamie, the cancer one”. The distinction between Jamie’s sense of no longer being normal, and Becca’s, is that Becca has marked herself as being different because of her cancer.

On the other hand, Jamie is concerned that he will be marked as different by his peers because of his cancer.

3.4. Unknown Future

*It's so difficult sometimes living your life from week to week, never knowing what lurks around the corner and being unable to make any firm plans.
(Adrian)*

Part of the difficulty for Adrian with his diagnosis is not being able to make plans. His ability to project himself into the future has been hampered by his terminal illness, and his existence, which was a fact, is now uncertain. Even Paul acknowledges that he does not know how much time he has left.

*I don't know how long I will have but even a month without being controlled by appointments, chemo, planning when I feel good to do something, which is usually spur of the moment as I can't say on this day I will feel like this.
(Paul)*

His cancer, appointments, and chemotherapy rule Paul's entire existence and his day-to-day life. His involvement with activities is based on how he feels that day, which for him is uncertain. He describes how he cannot be certain of how he will feel on a given day, which is one more thing about his own self that has become estranged from Paul. Suleika describes her experience as being stuck in place.

Almost four weeks into my hospitalization, I reached the height of my despair, frustration, and anger. I couldn't help but see the world in the binary: everyone out there is moving forward, and I'm in here, in an oncology ward, stuck in place. (Suleika)

She contrasts her life as being stuck in place as she sees people around her living normal lives and engaging in normal activities. Her passage evokes a boundary, where people around Suleika are moving along, while she is stuck in the oncology ward. On the other hand, Naomi imagines herself living a normal life, and then, all of the sudden; she dies or loses motor or cognitive functioning.

take yesterday, for example, when i was blow-drying my hair and picturing my life in a few years — done with chemo, healthy, happy, vibrant, impassioned. and then...BAM. i die. just like that. or maybe it's not quite so sudden. maybe i lose more motor function and end up in a wheelchair. maybe i lose my ability to speak, my cognitive reasoning, my memory. (Naomi)

Here, we see Naomi wrestle with the uncertainty of death or of the deterioration of her health because of her brain tumor. For Becca, she sees the life that she cannot have as a result of her cancer as her treatment has rendered her infertile and it has taken away her ability, to determine for herself, decisions around becoming a mother.

I ask that simply because, the more I think about all the time I spend getting treated for cancer, all I can see is all the things that get taken away from me because of it. And it's all cancers fault. I drive down the street and see a young 20-something mother pushing her stroller down the street and I think "nope. never will be me. (Becca)

Reconfigured Physical, Emotional and Social reality

Youth and health are supposed to be synonymous. If only I could sue my body for breach of contract with the natural order of things. (Suleika)

Cancer's deeply disruptive nature, causing people to reconsider who they are at fundamental levels (Bury, 1982), is illustrated in the weblogs of the respondents as they tried to justify their cancer diagnosis and as they struggled between the separation of their body and their mind. It shatters expectations and plans held by individuals, and it forces a dramatic reconstitution of their own sense of future and of the future imposed on them by society. In addition to the absolute upheaval experienced by individuals as a result of cancer, social interactions are profoundly impacted as shared meanings of what it is to be young break down as expectations of youth and health are shattered. The respondents deviate from the socially

expected launch phase – perhaps into post-secondary education and graduation, into employment, and committed relationships - “usually” occurring at this stage of the “normal” life course, historically established by age-based criteria. Their treatment schedules, enforced isolation due to their compromised immune system, and loss of autonomy, etc., have claimed their old identities and in its place a new reconfigured sense of identity has taken shape.

Theories of the life course begin with the assumption that lives are socially constructed, with a series of age-based transitions. Broadly, life in most western societies is divided into an education and training segment, followed by a continuous working segment, and finally a leisure and retirement segment (Settersten, 2003). As Eisenstadt (1965) states, cultural definitions of age are significant to the structuring of the self as age provides a grid for assigning cultural and social goals through the lifecourse. He emphasizes the relationship of age - the framework for allocating roles - with the division of labour and with shared meanings and symbols. This helps to shape the expected base to frame the acceptable life course and characteristics of certain age groups. The age-related expectations for emerging adults are to gain skills so they may enter the workforce, relationships, and parenthood; however, the onset of cancer disrupts this process as demonstrated by the respondents in this research. In addition, the cultural definition for young people does not include serious illness, as expectations for young people presume robust health (Madey and Chasteen, 2004). Illness disrupts the temporal continuity of the lifecourse, as it diverges dramatically from earlier events (Bury,

1982). It also affects the fundamental aspect of life: its extension in time (Hydén, 1997).

Emerging adulthood is characterized by a period of instability, as described by Arnett (2006), and the consequential feeling of “in-between” is an outcome of the attainment of particular external markers for adulthood while still entrenched in patterns traditionally associated with adolescence. Here we expect to find emerging adults moving inbetween adolescence and adulthood and exploring their sense of identity; however, the respondents illustrate a new engagement with their identities that occurs as they attempt to reorient themselves as their illness imposes a reconfiguration of their social, physical and emotional reality.

Conclusion

Arnett (2006) describes emerging adulthood as the age of possibilities; an age where young adults can strike out on their own, obtain degrees and gain meaningful employment, fall in love and have children, travel, and plan their future. For Adrian, Becca, Nic, Laura, Jonathan, Naomie, Paul, Jamie and Suleika the age of possibilities and the autonomy to make their own decisions and chose the path their lives will take was curtailed and restricted by cancer. The pain of losing the potentialities promised to them is palpable through their writing and is well represented in the passages included in this chapter. All their plans had gone awry and attempts to regain a measure of control over their lives was reigned in by the demands cancer posed on their lives. Cancer is deeply disruptive causing people to reconsider who they at fundamental levels (Bury, 1982), and this was exhibited

through the writings of the respondents as they tried to justify their cancer diagnosis and as they struggled between the separation of their body and their mind.

The disruptive nature of cancer on emerging adults has devastating effects on their sense of identity and on their ability to orient themselves toward the future. In effect, cancer displaces others and becomes the dominant frame of reference for identity. A fissioning between “before cancer” and “after cancer”, and a re-definition of identity thus occurs. The loss of potentialities for the respondents is particular difficult to cope with, as their time of life is supposed to be a time of discovery, of independence, and of new beginnings. The concept of emerging, as in emerging into adulthood, is filled with hope and promise, akin to the butterfly emerging from the chrysalis, to broaden their experience. Instead of emerging, the respondents are shrinking; becoming less. They are defined by what they have lost. They have become less healthy, less attractive and less energetic; the antithesis to the social definition of youth. Instead of becoming “more”, as socially expected, they are becoming “less” due to the fissioning caused by their cancer diagnosis. Instead of reaching their potential, they become ill, and for some, die. Dying is the ultimate betrayal, both on a personal and on a social level, for individuals of this age group. Dying, and ultimately death, is not suppose to occur for these respondents and is paramount to the loss that they have suffered.

Chapter 6 ~Appendix~

Appendix I - Blogger Demographics

Name	Emerging Adult	Sex	Marital Status	Web URL	Deceased
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Name	Emerging Adult	Sex	Marital Status	Web URL	Deceased
Adrian	25-29	Male	Single	http://baldyblog.freshblogs.co.uk/	Yes
Nic	Yes	Male	Single	http://sirnic1001.blogspot.ca/	Yes
Jamie	18-24	Male	Single	http://cancerouscapers.blogspot.ca/	No
Laura	Yes	Female	Single	http://cancerployment.blogspot.ca/	?
Jonathan	18-24	Male	Single	http://chemonotherapy.blogspot.ca/	Yes
naomie	25-29	Female	Single	http://iamnaomishrain.com/	?
Becca	25-29	Female	Single	http://thecolonchronicles.blogspot.ca/	Yes
Suleika	18-24	Female	Single	http://well.blogs.nytimes.com/category/voices-2/life/	No
Paul	25-29	Male	Single	http://musicisdisease.blogspot.ca/	Yes

Appendix II - Coding Scheme

Code	Description	Category
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Code	Description	Category
Coping Mechanisms	This accounts for the mechanisms used by EAs to cope with their cancer experience.	Coping Strategies
Dependency on Family	A key feature of Emerging Adulthood, according to Arnett, is a feeling of "in-between", or not feeling like an adult nor like an adolescent. The consequence of this feeling places EAs in a precarious position of independence both financially and emotionally. This is exacerbated with the onset of cancer, and causes shifts in dependence on family for emotional and financial support	Emerging Adulthood
Depression - Anxiety	The expressed depression or sadness that is felt as a result of their cancer.	Coping Strategies
Diagnosis Event	Important event that creates a form of schism, whereby the individuals see their lives as before and after cancer.	Cancer Timeline
Disruption	Will be useful to explore the disruption on the lives of EA with cancer that their diagnosis and illness has had an impact on their lives.	Future Orientation
Experience with Symptoms / Side Effects	Content regarding the experience, both physical and emotional, of the symptoms and side effects of the illness and the treatment.	Cancer Timeline
Feelings About Cancer	How the bloggers respond emotionally to the cancer and treatment side-effects	Cancer Timeline
Fertility	Exploring the issues around Fertility is an important aspect for EAs, as many of them have yet to enter parenthood. Thus infertility caused by treatment raises questions and issues around mitigating infertility.	Emerging Adulthood
Health Care - Insurance	created to account for the instances that blogger's discuss the cost of health care or insurance.	Emerging Adulthood

Code	Description	Category
Involvement of Family, SO & Friends	Involvement from significant others, family, or friends is an important aspect to explore, especially given the stage of the life course EAs are in, which is quite unstable.	Emerging Adulthood
Leading up to Diagnosis	Content relating to the initial portion of the Cancer Timeline, the discussion around what lead them to seeing their doctor and getting a prognosis.	Cancer Timeline
Loss of Control	The expressed loss of control as a result of the illness and its effect on the individual	Isolation
Medical Marginalization	Expressed sense of marginalization from within the medical field, medical academia, etc...	Isolation
Mortality	How to EAs with cancer speak of their own deaths? This node will give us a glimpse into their coping skills and how they come to terms (or not) with their own death.	Future Orientation
Relating to Others	The connections EAs express with others in similar positions. This is useful to explore in how EAs with cancer relate to others, as this is an indication of how they see themselves.	Connecting - Communication
Relationships	The impact of cancer on the romantic, platonic and familial relationships of EAs.	Emerging Adulthood
Sense of Injustice	The injustice experienced from the illness and the side effects.	Isolation
Sexuality	Content relating to the sexuality of the bloggers. Meant to capture how they speak of sexuality after their cancer diagnosis.	Emerging Adulthood
Social Marginalization	Expressed sense of marginalization caused directly or indirectly by their cancer diagnosis, preventing them from participating in social activities.	Isolation

Code	Description	Category
Talking about Blogging	Exploring the reasons why EAs with cancer blog, and how they talk about their blog. This could potential underlie the importance of connecting through weblogging with others who can relate to their experiences.	Connecting - Communication
Treatment Description	Content regarding the treatment of cancer experienced by Eas.	Cancer Timeline
Uncertainty	This node was created to account for the expressed uncertainty of EAs. This will provide insight into the specific obstacles that may be faced by EAs that are not captured elsewhere, such as in the Emerging Adulthood category.	Future Orientation
Work / Education	This node was created to account for the way careers and/or education of EAs are impacting with the onset of cancer. Work and Education represent the two most salient identities for Emerging Adults, so their impact can potentially be important in terms of the way they express the assumed impact.	Emerging Adulthood

Chapter 7 ~Bibliography~

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