

Physical Death, Digital Life, and Post-Self: That Dragon, Cancer as a Digital Memorial

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ABSTRACT

That Dragon, Cancer represents one of the first notable biographical documentary games to address terminal illness and personal loss. This article highlights how the actionable properties of games are repeatedly reversed to generate a thoughtful reflection on the impact of medical jurisdiction over the dying and its regulation over the end of life. Liberating the medium's reliance on certain commonplace and overused design principles, *That Dragon, Cancer* seeks to foster empathy, and urge care, hesitation and preservation rather than progression, advancement and winning states. The resultant game is a poignant digital commemoration of the game creator's son, Joel, whose life was affected and curtailed by cancer. In addition to being a document of parental grief and loss that offers an emotionally resonant and candid articulation of the effect of disease on the trajectory of life and biography of a child, this article also reasons that the game comprises Joel's constructed post-self, allowing his life to be extended post-mortem.

INTRODUCTION

This paper introduces *That Dragon, Cancer* (Numinous Games, 2016) as a noteworthy game text for the manner in which it both stimulates compassion and sympathy for an expiring (digital) life and shares the emotional burden of contending with an approaching death, whilst confined by medicalized procedures and settings. In straying from industry preoccupation with entertainment, which has made the medium such a “driving economic force” (Spiegel, 2009, p. vii), *That Dragon, Cancer* instead seeks to capture the debilitating effect of, and weariness caused by, the control exerted by the medical profession over the end of a life once a medical diagnosis is affirmed. *That Dragon, Cancer* constitutes a personal experience game in which players accompany the Green family as they experience the hold that both cancer and medical processes occupy over their life, and the (contracting) life of their five-year-old son Joel. The game voices the ruminations of Joel’s parents, Ryan and Amy Green, in coping with the experience of being removed from their domestic life and placed in a transitory clinical space that incites feelings of isolation and loss of control.

Structurally, *That Dragon, Cancer* is comprised of a series of gameplay vignettes in which the player participates in an assortment of family moments characterized by diverging sentiments (articulations of love, hope, joy, despair). The player inhabits a curtailed world comprised of medical treatment, consultation, and patient rooms in which they adopt different roles and perspectives (harbinger, comforter, sitter, or witness) that play a part in the Green family experience of treating Joel’s cancer. Across the game’s 14 chapters, the player forms a relationship with Joel (Bread on the Water), is present at his medical procedures (On Hospital Time), given access to intimate and devastating medical consultations (Sorry Guys, It’s Not ...), experiences exasperation attempting to comfort Joel (Dehydration), shares Ryan and Amy’s hope (End of Treatment, Waking Up), despair (Drowning), and confronts Joel’s passing (The Temple of God). Penetrating the more sober moments of the experience are flashes of abandon and play. Play is best used to describe the Mario Kart-style wagon ride through the hospital corridors (that simultaneously recounts the volume, range, and cost of prescription drugs used for Joel’s treatment) and

the medieval platform mini-game that pits Joel the knight vs. (that) dragon, for player progression never hinges on success or winning such contests. Indeed, *That Dragon, Cancer* repeatedly embraces the processes of play converging on player's acquiring attitude and constructive desire to unravel and resolve setbacks and hindrances, only to deny the player agency and control over the final outcome.

In enabling players to share the thoughts, feelings, and experiences of a family contending with death and dying whilst institutionally subjugated by medical professionals, *That Dragon, Cancer* provides an everyday account of the experience of dying in the present day. The game highlights the impact of a set of procedures and practices that have otherwise served to hide and remove the dying from everyday life, thus contributing to perceptions of the West as a death-denying culture (McManus, 2013; Walter, 1994). This existing state of affairs commenced in the 17th century when the medical profession first extended its jurisdiction over the body to include end of life care (Vanderpool, 2015), and in doing so, fundamentally altering the nature and human experience of dying. As Ivan Illich (1975) argued,

We have seen death turn from God's call into a 'natural' event ... Death had paled into a metaphorical figure, and killer diseases had taken his place. The general force of nature that had been celebrated as 'death' had turned into a host of specific causations of clinical demise (p. 139).

As doctors replaced priests in presiding over the end of a life, the final stages of life also lengthened with individuals now accustomed to living with the prognosis of death while its symptoms are suppressed. Although the medical profession has grown adept at reading the body for causes of malfunction, disease, and decline, it is not always necessarily able to prevent or halt its advancement.

As a brief aside, further control over the body ensued with the establishment of the funeral industry in the mid 19th century, which gave rise to death care professionals who undertook the role of caring for and preparing the dead for interment or cremation. This had the effect of displacing roles otherwise performed by family or members of the local community (Kelly, 2015). As a result of the professionalization of dying and death, and its now customary physical removal from everyday life

(O’Gorman, 1998; Walter, 1994), individuals in the West today are typically characterized as estranged from, and consequently fearful of, death (McManus, 2013).

ENVIRONMENTAL STORYTELLING

Players of *That Dragon, Cancer* gain an insight into the way a life-threatening disease can trigger the surrender of regular life to the schedules and processes of medical care and treatment, including confinement to medical spaces that trigger feelings of isolation and helplessness. In an interview, *That Dragon, Cancer* creator (and Joel’s father) Ryan Green described the experience of Joel’s hospitalization as being, “alone with 500 families” (Schott, 2017). As Gibbs et al. (2015) also note, “the dying are typically removed from daily life ... [while] the dead are removed to funeral parlours and cemeteries” (p. 257). Maddrell and Sidway’s (2010) edited collection, entitled *Deathscapes*, reflects on the spaces allotted to death and associated states of dying. Yet, within this significant volume, only a small selection of work is devoted to consideration of the spaces in which dying occurs, underrepresenting the private and public tensions that exist between life and death spaces (Grant-Smith, 2012). The stark realism of the Green family’s sequestration from regular life is ably rendered in *That Dragon, Cancer* through their confinement and the lack of freedom proscribed by a medium based on rule systems. The game opts to confine them, and the player, so that they linger in a range of emotionally provoking hospital-based scenes that reflect hope, setback, grief, and loss. The Green family remains largely submissive to the choices and decision making of medical specialists throughout the game experience.

While space typically affords freedom and movement, the dynamics of place serve to communicate a space with a particular meaning. While Joel and his family initially enter medical settings seeking what O’Connor (2004) refers to as a transition in status from illness to wellness. During the game emphasis shifts from restoration of health to pain management (i.e., palliative care). The player learns, with the family, that the disease has given Joel a time-defined life (Small, 2009), in which he will remain in a sanatorium setting dominated by clinical intrusions. Ryan Green signalled his recognition of the spatial affordances of games when he stated that,

unlike any other mediums, [games] allow you to linger in spaces ... looking back at the time we spent with Joel it wasn't what he said or it wasn't the event that we remember but those spaces between ... I think videogames [sic] allow you to rest in that space better than anything else (Green quoted in Schott, 2017, pp. 6-7).

Indeed, one of the core ways in which the game serves to invert the medium is the way it inflicts inactivity and immobility within an otherwise interactive medium. This adequately serves to emphasize the way hospitals are places where autonomy is relinquished, illness is often a barrier to activity, and where the physical environment is designed for confinement, holding, or waiting.

Typical portrayals of death in games as temporary suspension only serves to make light of its irremediable nature and the associated grief felt by those who suffer loss. *That Dragon, Cancer* avoids reducing death to a gameplay mechanic, something that can be repeatedly experienced, avoided, or defeated. Representations of health and death as damage points, energy bars, or infinite respawns are therefore discarded. Instead, death is reinstated to a definitive event as the core theme of the game, a portentous presence to be resisted and approached with trepidation. Myers (2009) stated that, "human experiences are accessible only as they are represented and valued by the video game mechanics" (p. 52). As a game about dying, and the unwelcome attendance of death, *That Dragon, Cancer* firmly rejects the medium's over-reliance on screen death to tutor players, induce suspense, or punish failure. Temporary death that allows life to be restored, is also highly player-centric. The intent of *That Dragon, Cancer* is not to modify or reverse events, but as Ryan Green has stated: "We wanted to ... invite other people to mourn with us" (Biggs, 2016). As Oliver and Bartsch (2010) noted, the largely insignificant nature of death in games to-date has done little to encourage "the perception of deeper meaning, the feeling of being moved, and the motivation to elaborate on thoughts and feelings inspired by the experience" (p. 76).

A PARENT'S ANGUISH

The access *That Dragon, Cancer* grants to what was unquestionably the most distressing and devastating news for a parent to receive was not the

initial intent of the game. The Greens began game production in November 2012 when Joel was approaching four years of age. At that point, Joel and his family were becoming accustomed to life with cancer, as Joel had been diagnosed shortly after his first birthday (Tanz, 2016). *That Dragon, Cancer* evolved into a game that captured the distress and grief associated with the inescapability of losing a child to cancer. To this effect, the progression of Joel's illness during development highlights the documentary nature of the project. Also, because *That Dragon, Cancer* tells the story of a five-year-old impaired by a rare form of brain cancer (that had already left him partially blind and inhibited his speech development), the game heavily relies on the anguished articulations, thoughts, and dilemmas of his parents through their journey, articulated via letters, voiced thoughts, everyday phone messages to deep truth-seeking discussions.

Woodgate (2006) describes the death of a child as, "living in a world without closure" (p. 78). Compassion for the Greens is hard-wired into the game as it never offers a satisfactory gametic resolution for the player, or capacity to liberate Joel and his family from his disease. As Ryan Green has stated, "so much of life isn't so much about the answers, but about walking with each other in the midst of not knowing the answers" (Schott, 2017, p. 8). Indeed, Green has traced the impulse to make *That Dragon, Cancer* to a definitive moment during Joel's illness that is also recreated in the final game. In a *Wired* feature article on the game Green describes, "a process you develop as a parent to keep your child from crying, and that night I couldn't calm Joel" (Tanz, 2016). Green likened this experience to, "a game where the mechanics are subverted and don't work" (Tanz, 2016). This describes the nature of the game he went on to produce.

During the course of the game, Ryan is portrayed surrendering to the bleakness of losing his child by allowing himself to sink in a deep body of water. While the player is able to command Ryan to resist the urge to succumb to the hopelessness by swimming, the impact of a button command is short lived and quickly diminishes, resulting in Ryan descending towards the bottom. Recurrent action and persistence are required by the player to eventually help Ryan return to the surface. In this way, player instinct is exploited repeatedly in *That Dragon, Cancer* to generate effort and action from the player. The player is repeatedly

deceived into thinking that the causal nature of player input leading to achievable outcomes remains applicable in this game. In another scene, the player is required to guide a soaring Joel, elevated by party balloons, through a hovering mass of black spiky cancer cells. This is one of several discrete game play scenarios that evade the representativeness of the hospital setting, transporting play into a surreal domain. The scene successfully triggers the gamer instinct, leading players to attempt to dodge the spikes and keep Joel afloat. The task given to the player, like that performed by the medical professionals or sought by Joel's parents, is ultimately unattainable and Joel eventually falls regardless of the player's best efforts. Unlike failure, in which a player is typically sent back to repeat until completed, the experiences offered by *That Dragon, Cancer* draw more on early coin-operated arcade games which involves sustaining life and keeping the moment alive for as long as possible.

The game induces a mindful approach to play as it deviates from the known formulas employed in other game experiences. The player is often ill-prepared for what each new scene or chapter will disclose and the requirements and demands that will be placed on them (as is evident in narrated playthroughs posted online). To this extent, *That Dragon, Cancer* echoes the different forms of uncertainty attached to the medical outcome and the confounding experience of submitting to medical processes and practices. Jose Zagal (2011) cites the director of *Heavy Rain* (Quantic Dream, 2010), David Cage, in highlighting the industry's pre-disposition toward formula, "when you look at most games you see today, they are based on patterns, on loops: you always do the same thing, whether you shoot, drive, or jump on platforms," (p. 58). In *That Dragon, Cancer*, ambiguity of the player's role is amplified by being present in and around the situation but never fully adopting a defined role. The player adopts various perspectives throughout the game, beginning the game as a duck that is being fed by Joel (allowing the player to overhear Ryan and Amy explaining the association between Joel's illness and his developmental delays to his siblings), then as doctors, Joel's parents, or an unspecified person (most likely a medical professional) available to offer Ryan some respite from caring for Joel, play with Joel, or simply on hand to listen to Ryan and Amy and bear witness to their experiences. The game's unfamiliar states create

an uncertainty that somehow mirrors and communicates the broader unease and apprehension germane to the context.

PRESENCE AND COMPANIONSHIP

Prevented from changing the course of events, the *That Dragon, Cancer* player is instead present throughout, sometimes as a silent witness or observer, and also is available to provide relief and support to the family or act as a playmate and companion to Joel while his parents are engaged with medical professionals. In accepting the award for Games for Impact at the 2016 Game Awards, Ryan Green declared,

You let us tell the story of my son Joel. In the end, it was not the story that we wanted to tell. But you chose to love us by being willing to stop and to listen and to not turn away. To let my son Joel's life change you because you chose to see him and to experience how we loved him.

A good example of the way players are encouraged to simply be in the company of the family in *That Dragon, Cancer* is found in the chapter entitled, "Waking Up." In this chapter, the player simply is with Amy as she cradles Joel as he slowly arouses post-treatment. In this scenario, the player may be occupying the form of a nurse, physician, or consultant at work in the "everyday spaces of terminal illness" (Watts, 2010). Being in Amy's presence, it is possible to overhear her telling Joel that one day in the future, cancer will only constitute a small chapter in his life. She claims hopefully that, "cancer will be such a small part of all you could grow to be. You will tire of hearing about it. You won't want to see the cards and notes I saved. I'll hold the memories of this hard day. You, just leave it behind." At that moment, the player's attention is drawn to the cards and handprints that fill the room. Should the player inspect the handprints or pick up and read the cards they discover that each one is a eulogy to other individuals that have battled cancer. As Ryan pronounces later in the game (within the arcade-style knight mini-game), "Joel isn't the only one to ever fight that Dragon." The handprints and cards serve to acknowledge how "so many people have gone before Joel and too many more will follow after" (Green, 2015). Indeed, the eulogies and memorials included in the game represent the stories of the game's Kickstarter backers, providing a mode of digital memorial.

Belman and Flanagan (2010) recognize the power of games to “affirm human values” (p. 5) and the feasibility of empathetic play, which elicits both cognitive empathy (in which the player understands the thoughts and feelings of another) and emotional empathy (an emotional response to the situation). In addition to the subject matter and the manner in which the player is absorbed within a family drama, the structure of *That Dragon, Cancer* also is a likely contributor to an empathetic response. As Lankoski (2011) argues, players “experience positive affects when moving forward, or reaching a goal” (p. 298), conditions *That Dragon, Cancer* does not afford. Remaining with the family throughout their experience, the player develops an attachment to Joel. To this effect, *That Dragon, Cancer* provokes affective empathy (Stotland et al., 1978) as the player endures the moments in which strong emotions are experienced and expressed by the Greens and play is performed with the knowledge and anticipation of an approaching loss. Commenting on the physiology of sadness, Russell and Lemay (2000) note that the emotion is characterized by motor inactivity. Distinct from entertainment, *That Dragon, Cancer* addresses a cognitively effortful subject (Cole et al., 2015) providing an atypical articulation of interactive sadness that challenges the notion that sadness is “an avoidant or unnecessary emotion” (Zagalo et al., 2006, p. 48). Morbid design (Kera, 2013) accepts the impermanence of life.

As *That Dragon, Cancer* progresses beyond the punishing realities of treating cancer in its early chapters, both the family and players are forced to reflect on the shadow of death in terms of what it means for a defenseless dependant to leave the family and pass over and depart the world. In the chapter “Sorry Guys, It’s Not ...”, Amy and Ryan receive the news that Joel’s treatment options have been exhausted. A surreal flooding of the consultation room ensues, effectively conveying the weight and uncontrollability of the news presented. As the hospital consultation room fills with water, the scene transitions to Joel alone, separated from his family, adrift on open water in a rowboat. While Joel is safe, he is nevertheless alone. Bearing witness to these scenes again serves to invert the otherwise customary desire and pleasure of progression by instilling in players a disinclination to advance or hasten the game and deliver this vision.

DIGITAL REMEMBRANCE

While the medicalization and professionalization of death and dying redefined the borders between life and death, so too has digital technology. In contrast to the way dying and death has been eschewed, hidden, and made private, today the separate states of life and death intersect more now than ever before thanks to the considerable number of ways our self is saturated (Gergen, 1991), extended, and dispersed via our networked and digital presence and the creation of digital assets that constitute online footprints that eventually form a digital legacy. We exist in the age of the post-self, in which Walter Benjamin's (1936) oft-cited assertion that, "dying has been pushed further and further out of the perceptual world of the living" (p. 93) has now been realized. Shneidman (1973) first posited the concept of post-self to acknowledge human concern with how others will see us and continue to think of us after we have gone. Such considerations typically relate to "the concerns of the living individual" (Schneidman, 1973, p. 45), thus reflecting future-oriented thinking and conscious thought, effort, and planning. In the case of *That Dragon, Cancer*, Joel was a young child oblivious to adult concerns that typically drive the construction of a post-self. However, the game stands as a testament to his experience and permits Joel to continue to affect the lives of others. Joel's public post-self is contained within and conducted via the game in which the occasion of his life is captured and survives via a dematerialized, re-embodied version (Belk, 2013). While players are granted access to what is undoubtedly a tragic moment in the Green's family history through a digital artifact, it is intimate in its preservation of the memory and representation of their son and the period in which they fought hardest to hold on to him.

Society has grown accustomed to the digital representation of a life prior to its physical arrival. Expectant parents associate digital ultrasound images with the concealed activity of a new life growing inside the body. Moncur (2016) states that when such images are then shared with family, friends, and/or acquaintances it will "kick-start the baby's social life, creating a social presence for it before physical birth" (p. 109). At the opposite end of life, when an adult's social life reaches its end, digital death is often much harder to conclude, for there is "no universal off-switch for digital death" (Mancur, 2016, p. 109). Given that dying commonly is more gradual and

protracted, death in the modern era is now typically more anticipated (Carr, 2012), triggering a greater level of participation in a digital perpetuation of the self. For digitally connected individuals who routinely participate in an online “reputation economy” (Zimmer and Hoffman, 2011) the construction of a digital after-life has become inexorable. Faure (2009) has commented that, “As people spend more time at keyboards, there’s less being stored away in dusty attics for family and friends to hang on to.” Goffman’s (1959) dramaturgical metaphor that acknowledged the way people are performers that attempt to convey and manage a certain impression, has become heightened with social media. So much so, that digital adjuncts to a life also are planned and supported by online services. LegacyOrganiser will curate a life online, mygoodbyemessage.com can schedule communications and messages to loved ones and friends “after you are no longer able to,” and Eterni.me is able to create a virtual self, powered by artificial intelligence, that offers an enduring digital presence for those with a fear-of-missing-out and “desire to stay continually connected with what others are doing” (Przybylski et al., 2013, p. 1841).

Even prior to a digitally distributed self, a typical response to a prognosis that foregrounded the end-of-life for an individual also would trigger actions to preserve a personal identity (Fulton, 1965). Marshall (1980) states that impending death often will increase self-reflection and the “conscious construction of a coherent personal history” (Carr, 2012, p. 188). Such actions serve as an attempt to transgress looming rituals of separation (Murray, 2010), in which committal of the body often is presented as a final farewell and subtraction of the individual from everyday life. Relative to being remembered and the universal desire to leave a mark on the world, being forgotten can generate significant fear and psychological impact (Ray et al., 2019). In *Death: A history of man’s obsessions and fears*, Wilkins (1996) claims: “Fear of being forgotten after death is one of man’s deep-rooted anxieties” (p. 14). Today the decoupling of body from data (Graham et al., 2013) is no longer a barrier to a digital post-self, digital persistence and presence combats physical removal from daily life.

David Joselit (2000) distinguishes two models of identity: “one in which subjectivity is immanent to the body, and one in which the architecture of

selfhood is imposed from without” (p. 27). Indeed, symbolic interactionist George Herbert Mead (1934) assigned the term *generalized others* to describe a social reference group whose presence and conjectured opinions serve to shape an individual’s sense of self and reputation. With the intensification of self-presentation online, Russell Belk (2015) argues that the self is now more actively co-constructed. No longer simply the consequence of reflection and presumption, the digital self can be initiated by others via everyday acts such as posting and tagging an image of another person on social media that remains present and viewable online and can illicit reaction and response from others. In this way, there is a distinction to be made between individual desire for symbolic immortality and an externally executed post-self that is directed by others actions.

Germane to the responsibility others assume for effecting post-self, Moncur and Kirk (2014) discuss modes of digital memorialization, following an “ubiquitous human practice which is increasingly intersecting with our digital lives” (p. 1). They stress how, today, “memorial is bound up with cultural modes of practice” (Moncur & Kirk, 2014, p. 1) permitting a growing range of artefacts to be applied in the memorialization process. Contemporary modes of memorial typically find charming means of accessing digital residua that exploits digital activity and the assets created. Walker (2011) attempted to illustrate the extent of our collective digital productivity as:

five billion images and counting on Flickr; hundreds of thousands of YouTube videos uploaded every day; oceans of content from 20 million bloggers and 500 million Facebook members; two billion tweets a month. Sites and services warehouse our musical and visual creations, personal data, shared opinions and taste declarations in the form of reviews and lists and ratings, even virtual scrapbook pages. Avatars left behind in World of Warcraft or Second Life can have financial or intellectual-property holdings in those alternate realities. We pile up digital possessions and expressions, and we tend to leave them piled up, like virtual hoarders.

Moncur and Kirk (2014) highlight the example of Hadas Arnon’s Digital Cemetery, which replaced gravestones with USB-sticks containing personal data of the deceased. Such actions transform and imbue everyday material objects and actions with dedicatory significance and meaning (Walter, 2010). Gibbs et al. (2015) have remarked on how little scholarly attention

has been given to the way everyday media platforms currently intersect with traditional mourning practices. Just like a post-mortem social media presence, a roadside memorial, or a diamond created from the remains of a loved one, the production of *That Dragon, Cancer* serves to reposition the deceased “back within the flow of everyday life” (Gibbs et al., 2015, p. 257). *That Dragon, Cancer* permits, what is an otherwise personal loss, to be communicated within the formal system structures and contemporary aesthetic of what Gibbs et al. classify as the platform vernacular of a prevalent medium. That is, in its expression of grief, loss and memorialization, it exploits the structuring force of a common platform. In the case of *That Dragon, Cancer*, it has exploited game rule systems and the particular practices of its users to communicate a parent’s love and the weight of grief. This has permitted Joel’s life experiences to continue to make an impression after death via a post-self that engages individuals beyond his lifetime capable of “new circulations, repetitions, and recontextualizations to variously constituted publics” (Graham et al., 2013, p. 133).

CONCLUSION

This paper has examined how *That Dragon, Cancer* offers a courageous and confronting depiction of ordinary death and dying as a medicalized process. *That Dragon Cancer* highlights the frequent inadequate handling of death in games as a solemn subject worthy of sincere consideration. Cultural preoccupation with dramatic violent depictions of death are misleading and do little to further our experiential knowledge and acceptance of a universal life experience. The subject matter of *That Dragon, Cancer* is thus, on the one hand, unremarkable as the nature of the death portrayed is all-too-common and routine, but made remarkable on the other hand, for the way the player is invited into a family experience and the intimacy it permits. The game offers an authentic statement and experience of coping with death and dying that functions to challenge what has been termed the emotional invigilation (Walter et al., 1995) of death referring to its re-appropriation as a non-serious entertainment form. It instead serves to represent medicine as a “social institution intrinsically involved in social control” (McManus, 2013, p. 46). The story of Joel’s treatment is an account of the loss of control over “bodies, over illness

and pain, over emotions, over the passage of time, and ultimately over life itself" (Sourkes, 2007, p. 39).

The confronting nature of the subject matter of *That Dragon, Cancer* is attributable to the way that the game deals with one of the hardest categories of deaths to comprehend and transition through and beyond: child death. This is a form of loss for which the frame of expected response and behavior is narrower than loss of a loved one at more advanced points in the lifespan (Prigerson et al., 1999). The death of a child defies the *expected* order of life events. The perceived unnatural, untimely (Wheeler, 2001) and therefore socially unanticipated nature of child death also is reflected in the level of knowledge on the subject. It brings with it the loss of an assumptive world, in that the generalized sense of predictability and stability of the world is challenged (Emmons, Colby & Kaiser, 1998). As Green (2015) has similarly stated, "Joel didn't have the chance to make an impact." In this way Joel's post-self exists "to show the world how important Joel was to us. Loving him and losing him was the richest part of our life so far."

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