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ADDICTION AT THE END OF LIFE
'TOTAL PAIN' AND THE PASSIONS

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Abstract

Addiction in its multiple forms represents a major health problem and source of suffering worldwide. When addiction is combined with terminal illness, the burden of suffering can be particularly challenging to address. Palliative care is the health care discipline committed to the holistic relief of suffering in persons with advanced or life-limiting illnesses. The concept of suffering as 'Total Pain' embracing four dimensions: physical, psychological, social, and spiritual is particularly useful in understanding the complex multifaceted distress that afflicts addicted persons at the end of life. The spiritual tradition of Eastern Christianity provides a rich source for understanding addiction as one of the passions. A holistic approach to addressing all aspects of the 'Total Pain' of a Christian's terminal illness that is complicated by a history of addiction creates the possibility for a small but real victory in the spiritual warfare even at the 11th hour of life.

Keywords: addiction, passions, end of life, palliative care, total pain

1. Introduction

The worldwide impact of addictions on the health of individuals and society in general, especially in terms of lost productivity and disrupted relationships is enormous. World Health Organization statistics highlight the cost to humanity due to substance abuse: "The harmful use of alcohol results in 2.5 million deaths each year worldwide. 320,000 young people between the age of 15 and 29 die from alcohol-related causes, resulting in 9% of all deaths in that age group. At least 15.3 million persons have drug use disorders. Injecting drug use has been reported in 148 countries, of which 120 report HIV [Human Immunodeficiency Virus] infection among this population." [http://www.who.int/substance_abuse/facts/en/, accessed on 13 November 2012]

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Thus, substance abuse and addictions produce a significant and in many ways unique burden of suffering. This burden becomes particularly challenging when the addicted person is faced with a terminal illness. Recent decades have witnessed the rapid growth and development of the specialty of palliative medicine within health care which is focused on the relief of suffering, especially in persons with advanced or terminal illnesses. Palliative care attempts to address this suffering in a holistic manner whether it be in the form of physical or psychological symptoms, disruption in relationships, spiritual or existential anguish. Within the spiritual tradition of the Eastern Church there is a rich understanding of human nature based on empirical knowledge acquired over many centuries by monastics and lay persons in their experience of the spiritual warfare, the daily struggle with temptation and sin. This essay will review the specific challenges posed by addiction in caring for the terminally ill and how insights drawn from the traditional Christian understanding of the passions might inform a more holistic approach to relief of the suffering experienced by addicted individuals at the end of life.

2. Suffering and 'total pain'

Suffering has been defined as: "…the state of severe distress associated with events that threaten the intactness of the person" [1]. However, suffering is not only experienced on a personal level but also in the context of relationships. The founder of the modern hospice movement, Dame Cicely Saunders, coined the term, 'Total Pain' to embrace the complex and multifaceted nature of human suffering [2]. Pain in its totality can be experienced in at least four dimensions: physical, psychological, social, and spiritual. When pain or significant distress of any kind is experienced in this larger context of 'Total Pain' it more closely approximates suffering. The great value of the 'Total Pain' concept lies in the emphasis placed on the different domains as discrete and yet closely interconnected loci in which suffering may develop and be expressed. For those concerned with identifying and relieving suffering, it has become a powerful reminder of the various ways in which persons experience suffering. It also highlights the need to explore and understand suffering in the fullest context possible. Persons, who have struggled with addictions, often have experienced significant disruptions in relationships such as failed marriages, job loss, and other forms of conflict during their lives. Even prior to diagnosis of a terminal illness, they have already been intimately acquainted with 'Total Pain' especially the dimension of social pain but also psychological and spiritual pain. Frequently, addictive behaviour is a manifestation of psychiatric co-morbidity or so-called 'dual diagnosis' in which addicted persons may seek to self-medicate with substances, licit or illicit, to relieve suffering in the psychological dimension. This may be true for many persons suffering with major psychiatric illnesses such as schizophrenia, bipolar illness, and post-traumatic stress disorder (PTSD).What starts as escape from psychological suffering can escalate into compounded suffering from the sequelae of substance abuse and addiction.

Spiritual pain is experienced when there is a loss of meaning or may also be a reflection of remorse on the part of the addicted individual for past injuries to loved ones or regret over lost opportunities. Thus, addicted individuals bring a significant and often long history of suffering with them as they encounter their final illness.

3. The suffering of the addict and the passions

Traditional Christianity can offer powerful insights and help to addicted persons and their caregivers who together encounter suffering. The Eastern Church has always expressed an understanding of the human person that is grounded in the full integration of soul and body. "…Christianity was located in the body because the body, in the most literal sense, was what God had fashioned in the beginning and where God had chosen to find us in our fallenness. This was why God acted through the incarnation." [3] The early fathers of the Church clearly emphasized the full integration of the spiritual and corporeal aspects of the human person. In the early second century, Ignatius of Antioch stated the relationship in this way: "But even what you do according to the flesh is spiritual, for you do all things in Jesus Christ" [4]. John Climacus, the sixth century abbot of the Monastery of Saint Catherine at Mount Sinai, used poignant language to describe the pain associated with the dissolution of the intimate relationship between body and soul at death: "How can I hate him when my nature disposes me to love him? How can I break away from him when I am bound to him forever? How can I escape from him when he is going to rise with me?" [5]

Recent advances in the neurobiology of addiction have identified major aspects of the anatomic and biochemical pathways of addiction [6, 7]. Anatomic changes, even at the sub-cellular level, associated with memories generated within those portions of the brain involved in perceiving rewards and pleasure play an important role in the phenomenon of relapse in which addictive behaviours may recur even after long intervals of abstinence. The powerful connection identified between physical changes in the central nervous system of addicted persons and the phenomenon of relapse underscores the traditional Christian view of the close integration of the physical and spiritual aspects of the human person. Interestingly, when one considers the original Greek word for suffering, *pathos*, its secondary meaning is passion, examples of which are anger, lust, and envy [8]. Thus, suffering is very closely, even linguistically, connected to the concept of the passions. From the perspective of traditional Christianity, human suffering takes on various forms and patterns in the context of the passions. Each passion has its opposite virtue, for example, pride versus humility, which is to be cultivated within the spiritual life of the Christian. In the Christian context, addictions are types of passions.

God did not create the passions. They are distortions of gifts human beings were given as creatures. "God neither caused nor created evil and, therefore, those who assert that certain passions come naturally to the soul are

quite wrong. What they fail to realize is that we have taken natural attributes of our own and turned them into passions…Nature has provided us with anger as something to be turned against the serpent, but we have used it against our neighbor." [5, p. 251] The particular passions that trouble each person define the specific character or quality of one's suffering and can intensify it. For example, anger in response to stress may weaken the recovering addict's determination to remain abstinent, especially if substances had been misused in the past as a means of relieving anxiety and anger related to stress. As we consider the challenges associated with providing care and support to terminally ill persons who have struggled with addictions, it is very helpful to remember the passions and their impact on a person's response to pain and other forms of distress in the context of 'Total Pain'. If one struggles with anger, regardless of a history of addiction, it may be all the more difficult for one to control one's anger when in severe pain during suffering. This could make the suffering worse by wounding loved ones with uncontrolled anger and, in turn, increase social isolation (pain in the social dimension of 'Total Pain').

4. The challenges of caring for addicted persons at the end of life

Within the physical dimension of 'Total Pain' a history of addiction creates some unique problems. Frequently, persons with a history of addiction may have significant medical co-morbidities, often compounded through self-neglect, and may be quite ill at the time they present with a terminal diagnosis. This may be reflected by an increased prevalence of chronic lung and liver disease in smokers and alcoholics. They may have a much greater tolerance to opioid pain medications which will necessitate the use of higher starting doses when the medications are being titrated to relieve pain or breathlessness in advanced cancer. Some with prior histories of addiction to opioids may also have difficulty differentiating pain relief from the euphoric sensation they had sought from the same types of medications in the past. This can be particularly dangerous during rapid dose escalation of an opioid medication to relieve uncontrolled pain. If the person in pain is expecting an emotional 'high' from the medication they may risk taking higher doses that may be associated with the potential for serious side effects such as sedation, confusion, or respiratory depression.

It has been estimated that in the U.S. approximately 6-15% of the general population have some type of substance-use disorder. There is no reason to assume that the prevalence of substance-use disorders would be less in persons with advanced illnesses. Indeed, it would likely be higher for those with certain advanced illnesses including some cancers and liver disease [9]. For patients admitted to a specialized palliative care unit for poorly controlled symptoms in advanced cancer, 27-28% of them were found to be alcoholics by careful screening using Diagnostic and Statistical Manual (DSM) III-R criteria [10]. In a review of nearly 600 consecutive cancer patients attending a palliative care clinic who were screened for alcohol misuse, 17% were found to be misusing

alcohol [11]. Patients who screened positive for problems with alcohol use were younger, male, often had head and neck cancer, and tended to be referred earlier to the palliative care clinic. At presentation, cancer patients screening positive for alcohol misuse had significantly worse symptom burdens including more pain, sleep disturbance, dyspnoea (shortness of breath), and lower sense of well-being. They were more frequently receiving opioid pain medications at the time of presentation. The authors of the study reported that it was possible with careful management to relieve these patients' pain and other symptoms without the need for subsequent escalation of opioid dosing at a follow up visit [11]. However, in another study the same investigators showed that patients screening positive for alcohol misuse were more likely to have a history or actively engage in smoking and illegal recreational drug use. This raised the concern that these patients may have an increased risk for inappropriate opioid escalation and abuse during treatment of their cancer pain [12]. Active alcoholism and alcohol-related health problems (e.g., pancreatitis, liver disease, history of delirium tremens) have been found to be independent predictors of mortality and poor prognosis in patients with head and neck cancers [13]. Alcohol withdrawal may be a contributing factor in some cases of terminal restlessness or agitated delirium at the end of life [14]. Taken together, these observations underscore the many challenges within the physical dimension of 'Total Pain' that contribute to the difficult journey addicted persons must take as they approach death.

Within the psychological dimension of 'Total Pain' addicted persons facing a terminal diagnosis may not have the emotional or cognitive resources to seize their last opportunity for personal growth. The addictive personality type may instead tend to seek the 'quick fix' driven by a desire to feel better immediately. This type of response may significantly limit the addict's ability to cope with the long and arduous nature of many cancer treatment protocols and contribute to the poor compliance with treatment that can be encountered in this patient population. Patients with 'dual diagnoses' of serious mental illness complicated by substance abuse/addiction may have an especially difficult experience trying to cope with advanced cancer or other terminal diagnoses. They are at high risk for poorly controlled pain and other distressing physical symptoms which may present in an atypical manner such as worsening psychiatric symptoms. Such patients will likely need to receive palliative care with close psychiatric support in stable inpatient settings earlier in the course of their progressive illness, whenever feasible.

Within the social dimension of 'Total Pain' addicted individuals have already 'burned many bridges' in terms of relationships within and outside their families. As a result they often face a terminal illness, alone and isolated. Not infrequently, they may also be homeless or at least have severely constrained financial resources which add to their sense of insecurity and fear at the end of life. Another facet of addicted individuals' behaviour may come into play in an inpatient setting of care. Although there may be great tension and strain demonstrated in their relationship with close family members when these relationships still exist, nursing and other health care staff may be confused by

the charming and at times manipulative patterns of behaviour exhibited toward them by the addicted patient with an advanced illness [15]. Such patients may appear to be more focused on winning concessions over relatively trivial issues than addressing the major existential questions or other 'unfinished business' of the dying such as reconciliation and forgiveness. Old habits and behaviours die hard; they may feel more secure in returning to familiar and comfortable patterns of charming and manipulating acquaintances rather than facing real change.

Within the spiritual dimension of 'Total Pain' addicts have usually experienced growing degrees of isolation from their major sources of meaning, including religious faith. This may be a result of the central role that the addiction has played for so long in their lives. Its distracting influence may have effectively prevented them from developing any form of inner life including meaningful self-reflection and prayer. They may also experience feelings of guilt or regret for self-inflicted injuries to their health, especially if their terminal diagnosis is linked to their addictive behaviour. Persistent or residual effects of spiritual or religious conflicts from their youth which may have even started them on the path to addiction may still be operative, compounding a sense of hopelessness and despair which can produce a real inertia antagonistic to spiritual growth and change.

Many addicted persons presenting with advanced cancer or other life-threatening illnesses may not have the benefit of real participation in a recovery program like alcoholics anonymous. What are realistic goals for such patients and what would constitute 'healing' for these suffering ones who present at the 11^{th} hour when they are dying? It would be highly desirable to achieve some sense of wholeness for these persons, even though they may not be able to demonstrate 'mastery' over their addiction(s) through some period of active recovery due to their very limited prognosis from the advanced illness.

5. Impact of addiction on care at the end of life

Persons struggling with addiction present an often challenging dimension to end-of-life care. Their suffering, which can be very great, should be addressed with the same compassion as that offered to anyone in significant distress. Management of their pain and other symptoms with medications, especially the use of opioids for symptom relief must be monitored closely and carefully, not only for reasons of safety but also to assure that they are effective. In addicts it may be advisable to plan for more frequent follow up visits either in the home or clinic. Smaller amounts of opioid medications and other medications that might be abused should be provided at each visit and ideally left for safekeeping with trustworthy family members. No matter how good their intentions, it may still be tempting for individuals with a recent history of addiction issues to misuse their prescribed medications. They may also 'supplement' their pain medications with alcohol or other substances which could endanger them. As noted above, it may be difficult for some patients to differentiate expected euphoria associated with an opioid analgesic from actual pain relief, leading to over medication. At times,

palliative care providers may be tempted to avoid addressing addiction and chemical dependency issues in terminally ill patients, rationalizing that patients should not be deprived of sources of pleasure as they are dying. However, there are major consequences when uncontrolled chemical dependency persists during the terminal illness of an addicted person. They include: masking symptoms without their actual relief, poor compliance with medication regimens, increased stress for family members and other caregivers, and ultimately increased patient suffering and poor quality of life [16] (and death). Although strict abstinence may not be a realistic goal, controlled use of alcohol on a limited and scheduled basis can restore order to a chaotic situation and help achieve some level of dignity in the last days and weeks of an addicted person's life. This approach to managing the physical dimension of pain more effectively creates a small window for spiritual growth, a shift in focus away from altering one's current mood state by being intoxicated to living with good symptom control and hopefully allowing for a growing awareness of one's mortality. Restoring order at this most basic of levels will thus impact all four dimensions of 'Total Pain' in the addict who is dying. In the psychological dimension it will reduce denial which is so strongly aided by escape into intoxication. To the degree that the use of firm and consistent rules enforced by the palliative care team has shifted the focus away from manipulative behaviours, there is one last opportunity for healing in relationships and reduction of suffering in the social dimension.

Two clinical case examples may help illustrate the importance of different aspects of 'Total Pain' in the lives of terminally ill persons with histories of addiction:

A 51 year old divorced father of a 15 year old daughter presented with advanced cancer at the junction between the oesophagus and stomach which impaired his ability to eat. He was considered the 'black sheep' of his highly successful family because of his chronic alcoholism which led to the failure of his marriage. When his terminal diagnosis became known, his ex-wife voluntarily returned to care for him during his last few months of life bringing healing to their broken family.

A 56 year old man with a long history of alcoholism was diagnosed with locally advanced hepatocellular carcinoma (liver cancer). He also had a longstanding mood disorder which was stabilized with medication. For the first time in his life, his confrontation with his mortality helped him achieve sobriety and spiritual growth. When he was briefly considered for a liver transplant as potential curative treatment for his cancer he expressed great anxiety about the possibility of cure, worrying that longer term survival might threaten his new found sobriety.

These two case examples illustrate the very real, albeit time-limited, opportunities that some patients with addictions are able to seize when confronted with their mortality. Helping them maintain excellent symptom control while also remaining sober were very important elements supporting the healing they experienced at the end of life.

6. Conclusion – addressing the passions and 'Total Pain' in addicted persons at the end of life

In summary, it is crucial for the caregivers of those who suffer to recognize that each person has his or her own unique set of passions that not only affect the individual's experience of suffering but also may create specific challenges in providing the care needed by that person. This is especially true for persons with addictions who are confronted with their mortality in the form of a terminal illness. For terminally ill Christians who have been struggling with lifelong addictions, it may be very helpful to reframe their struggle in spiritual terms, both with regard to their addictions and terminal illness. The palliative care provider's responsibility from a Christian perspective is first, to be empathic and not judge, and second, to use one's skills to relieve those aspects of the patient's 'Total Pain' that interact with the passions to harm the soul. Since within the traditional Christian perspective both soul and body are fully integrated and indivisible as a living person, helping the terminally ill addict be free of pain and other physical distress while also maintaining the dignity of sobriety is of fundamental spiritual significance. It represents a small but very real victory in the spiritual warfare, even if it comes at the 11th hour. John Climacus had some very encouraging words for those who struggle and suffer with the passions which may be especially heartening for the addict who is dying: "An active soul is a provocation to the demons, yet the greater our conflicts the greater our rewards. There will be no crown for the man who has never been under attack, and the man who perseveres in spite of any failures will be glorified as a champion by the angels." [5, p. 251]

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