INTRODUCTORY LECTURES

Opioids in Middle Eastern Populations

Michael Silbermann

Abstract

Morphine is one of the more ancient medicines known, yet the global access to this opioid is still severely limited. In spite of the fact that strong networks for national, regional and global care have been emerging, the overall situation of pain management, in general, and in cancer patients in specific, remains of great concern; when we examine the availability of pain relief drugs in Middle Eastern countries. The data presented in this abstract rely on the INCB annual reports. Consumption of Morphine. In the USA the consumption is on the rise and has reached over 76 mg/capita in the year 2007 (the global mean is 5.57 mg/capita). In Israel the consumption of morphine in 2007 is similar to that in 2004, a little above 3.0 mg/capita. In Cyprus during the year 2004-2007 the consumption was at about 2.8 mg/capita. In Jordan, morphine consumption has been on the rise since 2006 and is at about 2.0 mg/capita. In Lebanon, morphine consumption has been at a steady state (1.0 mg/capita) for the period 2004-2007. In Turkey, the consumption of morphine has been fluctuating at doses about 0.1 mg/capita fort the period 2004-2007. In Saudi Arabia, the consumption of morphine has been at very low doses of about 0.05 mg/capita for the same time period. In Egypt, the doss of consumption were fluctuating between 0.01-0.14 mg/capita during the years 2004-2007. When comparing the quantities of consumption in the various Middle Eastern countries with that in the United States (in year 2007), it became apparent that in the USA the consumption of morphine is: 10 times that in Israel; 27 times that in Cyprus; 38 times that in Jordan; 69 times that in Lebanon; 150 times that in Saudi Arabia; 447 times that in Turkey; 633 times that in Egypt. It is nowadays clear that the medial use of opioid drugs is indispensable for the relief of pain and suffering; and most developing countries use very small amounts of morphine.

Keywords: Palliative care - morphine use - Middle Eastern countries

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Introduction

Physical pain and the accompanying emotional suffering is not just a biological process, but is determined by people's emotions, behaviors, and social relationships. In treating cancer patients, these factors are often ignored or not defined as part of palliative care. However, pain management has a pivotal role in controlling disease progression, not to mention its impact on patients' ability to function and maintain a positive quality of life. Therefore, in order to accomplish reasonable quality of life, palliative care treatment has to combine both the physical along with the emotional problems. Today, every individual treated for cancer should expect to have his pains managed first prior to any additional treatments associated with his/her psychological and social needs. Opioids are today the leading drugs for the complex pain problems that individuals with cancer are experiencing.

Morphine is an ancient medicine, yet global access to opioids is severely limited. Therefore, in spite of the growing access to palliative dare worldwide, the situation remains of great concern when we examine the availability of pain relief to those in need.

Opioid Consumption in the Middle East

The various programs for cancer relief rely strongly on the availability of opioids. Reported opioid consumption figures have been used to give an approximation as to the availability of pain relief and palliative care in individual countries. The International Narcotics Control Board (INCB), the body responsible for monitoring narcotics, tracks availability of opioids and receives reports on national opioid consumption and estimates future needs.

The current report is based upon INCB annual reports for the United States and several Middle Eastern countries. In the USA: The consumption of morphine is on the rise and has reached over 76 mg/capita in year 2007, whereas the consumption of meperidine (pethidine, demerol) is clearly steadily declining (see Figure 1a and 1b). Fentanyl (80 times more potent than morphine) has been introduced into clinical practice and its consumption has apparently reached a plateau during the years 2005-2007 (see Figure 1 c). Consumption of Principal Narcotic Drugs in the USA (mg/capita) during the years 2004-2007 is illustrated in Figure 2.

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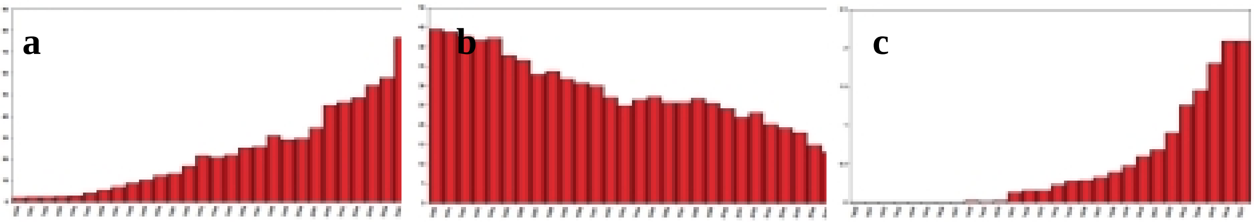

Figure 1. Consumption of Palliative Care Drugs in the USA, 1980-2007. a) Morphine; b) Pethidine; c) Fentanyl

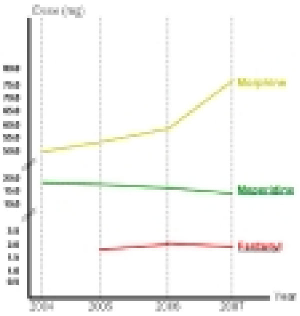

Figure 2. Consumption of Principal Narcotic Drugs in the USA (mg/capita) during years 2004-2007

In Israel: The consumption of morphine in 2007 is similar to that in 2004 (see Figure 3). The same is true for meperidine. There is a slight rise in the consumption of fentanyl in recent years. Consumption of Principal Narcotic Drugs in Israel (mg/capita) during years 2004-2007 is shown in Figure 4.

In Cyprus: Meperidine is the leading narcotic drug in use, followed by morphine and fentanyl (see Figure 5).Consumption of Principal Narcotic Drugs in Israel (mg/capita) during years 2004-2007 is shown in Figure 6.

In Jordan: Meperidine is the leading narcotic drug; while morphine follows and is on the rise (see Figure 7). Fentanyl has so far only limited use. Consumption of Principal Narcotic Drugs in Jordan (mg/capita) during the years 2004-2007 is illustrated in Figure 8.

In Lebanon: The consumption of all three narcotic drugs—meperidine, morphine and fentanyl — is steady for the years 2004-2007 (see Figure 9). As in all other Middle Eastern countries (except for Israel), meperidine is the leading drug followed by morphine and fentanyl. Consumption of Principal Narcotic Drugs in Lebanon (mg/capita) during the years 2004-2007 is illustrated in Figure 10.

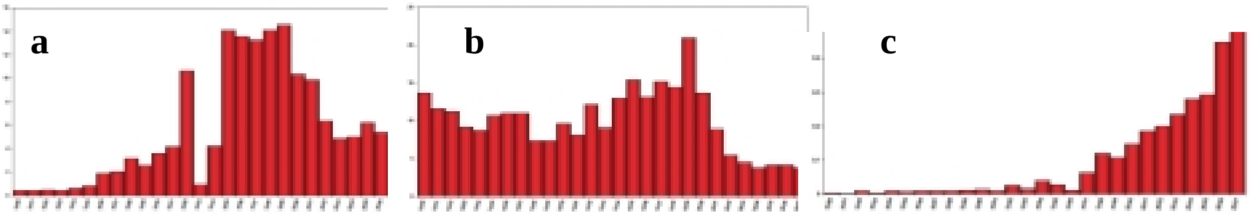

Figure 3. Consumption of Palliative Care Drugs in Israel, 1980-2007. a) Morphine; b) Pethidine; c) Fentanyl

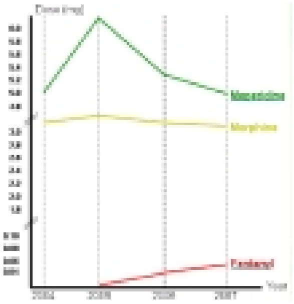

Figure 4. Consumption of Principal Narcotic Drugs in Israel (mg/capita) during years 2004-2007

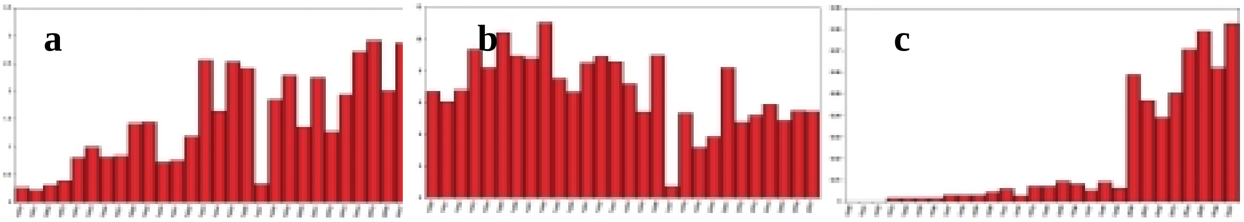

Figure 5. Consumption of Palliative Care Drugs in Cyprus, 1980-2007. a) Morphine; b) Pethidine; c) Fentanyl

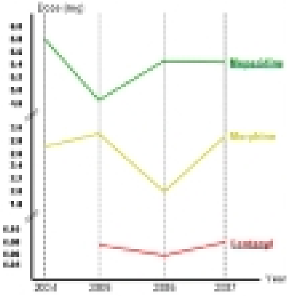

Figure 6. Consumption of Principal Narcotic Drugs in Cyprus (mg/capita) during years 2004-2007

In Turkey: As in other Middle Eastern countries, meperidine is by far the leading narcotic drug, followed by morphine and fentanyl (see Figure 11). Consumption of Principal Narcotic Drugs in Lebanon (mg/capita) during the years 2004-2007 is illustrated in Figure 12.

In Saudi Arabia: Meperidine is by far the leading narcotic drug before morphine and fentanyl (see Figure 13. Consumption of Principal Narcotic Drugs in Lebanon (mg/capita) during the years 2004-2007 is illustrated in Figure 14.

In Egypt: overall, the consumption of narcotic drugs

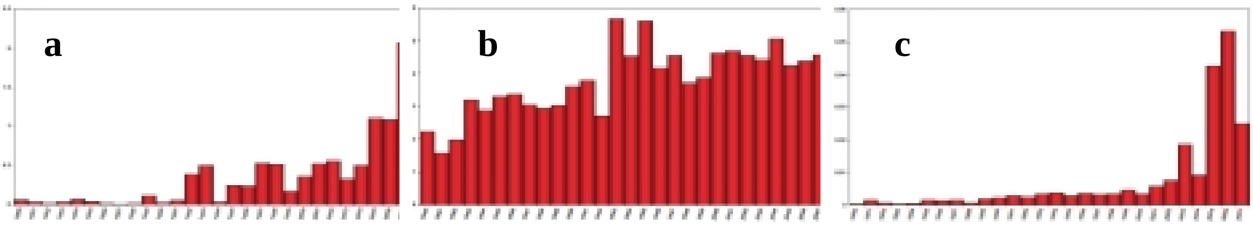

Figure 7. Consumption of Palliative Care Drugs in Jordan, 1980-2007. a) Morphine; b) Pethidine; c) Fentanyl

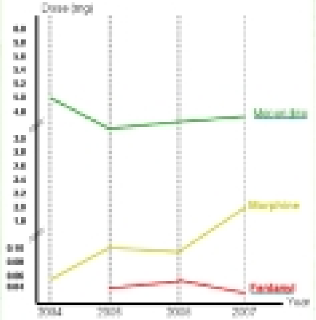

Figure 8. Consumption of Principal Narcotic Drugs in Jordan (mg/capita) during years 2004-2007

is very low. Meperidine is the number one narcotic in use, followed by morphine and fentanyl (see Figure 15). Consumption of Principal Narcotic Drugs in Egypt (mg/capita) during 2004-2007 is shown in Figure 16.

Consumption of Narcotic Drugs in the USA and the Middle East : A Comparative Survey

Morphine: In the United States, as in other North American and West European countries, the use of morphine is increasing, and this drug has become the drug of choice for the management of pain. In Israel its consumption is declining, whereas in Cyprus its consumption has shown fluctuations since 1999, but more recently is similar to what was used 10 years ago. In Jordan a rise was noticed in 2007. In all other countries the consumption is in a steady state through the period of 1999-2007.

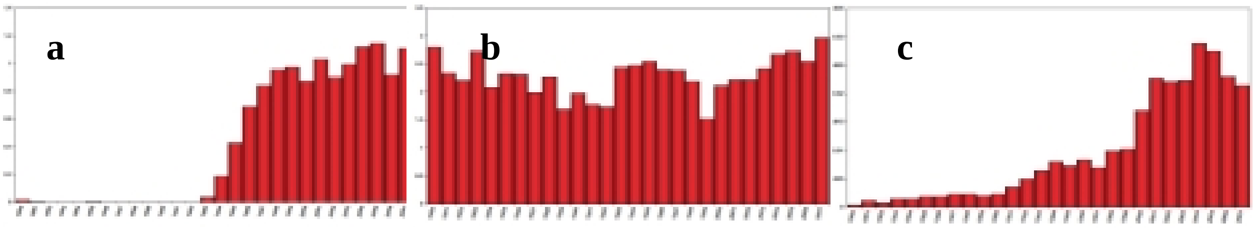

Figure 9. Consumption of Palliative Care Drugs in Lebanon, 1980-2007. a) Morphine; b) Pethidine; c) Fentanyl

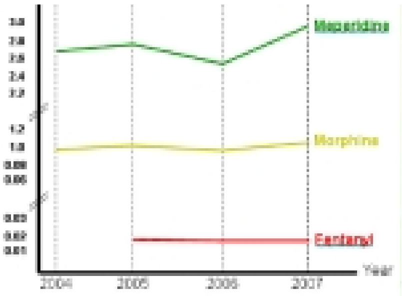

Figure 10. Consumption of Principal Narcotic Drugs in Lebanon (mg/capita) during years 2004-2007

Substantial differences were noted in the quantities used in the different countries: In the United States (as in other Western countries) the consumption of morphine is: 10 times that in Israel, 27 times that in Cyprus, 38 times that in Jordan, 69 times that in Lebanon, 150 times that in Saudi Arabia; 447 times that in Turkey and 633 times that in Egypt.

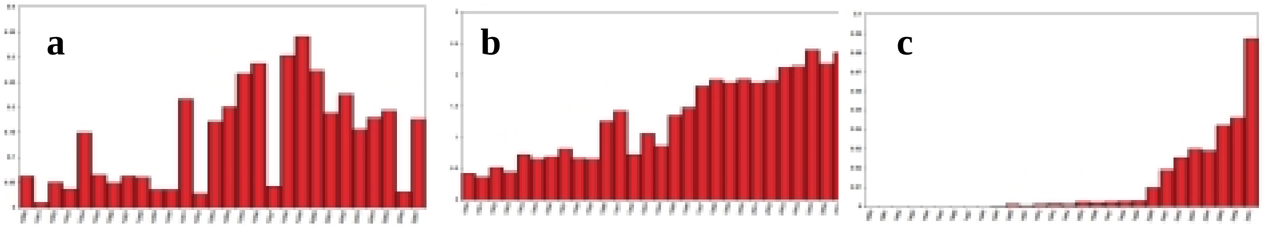

Figure 11. Consumption of Palliative Care Drugs in the Turkey, 1980-2007. a) Morphine; b) Pethidine; c) Fentanyl

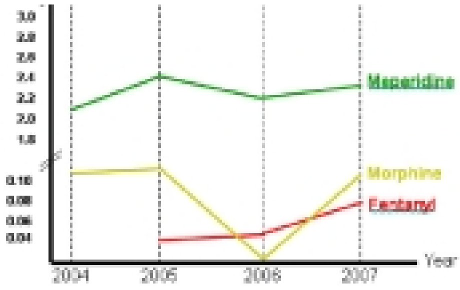

Figure 12. Consumption of Principal Narcotic Drugs in Turkey (mg/capita) during years 2004-2007

Meperidine (pethidine, demerol): The consumption of meperidine has been in a decline in the United States and Israel since 2007; and has been at a plateau ever since. In Cyprus, Jordan, Lebanon, Turkey and Saudi Arabia, a rise in the consumption was noted in year 2004. In Egypt the rate of consumption is unchanged from year 1999 to 2007.

In contrast to morphine, meperidine is still the most used narcotic drug in the Middle Eastern countries

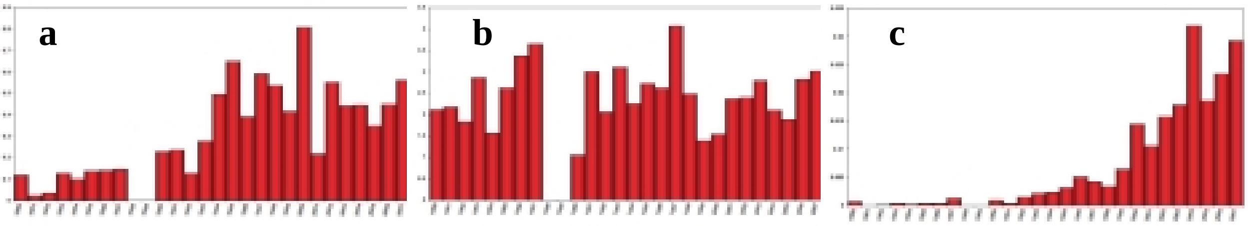

Figure 13. Consumption of Palliative Care Drugs in Saudi Arabia 1980-2007. a) Morphine; b) Pethidine; c) Fentanyl

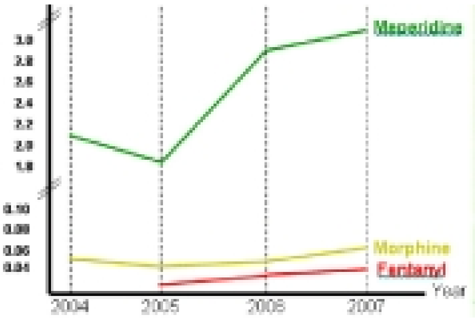

Figure 14. Consumption of Principal Narcotic Drugs in Saudi Arabia (mg/capita) during years 2004-2007

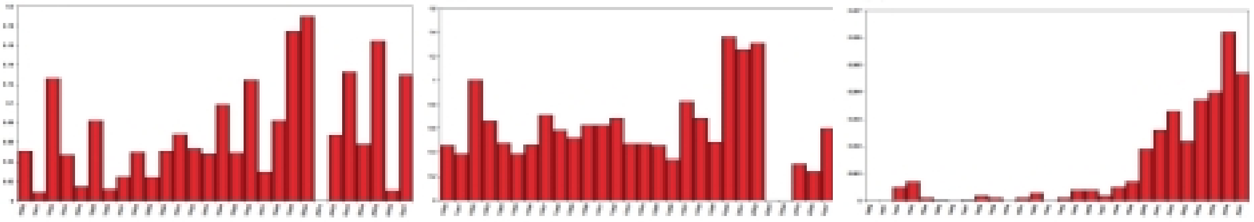

Figure 15. Consumption of Palliative Care Drugs in Egypt 1980-2007. a) Morphine; b) Pethidine; c) Fentanyl

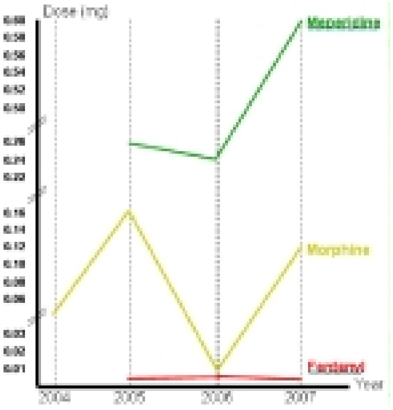

Figure 16. Consumption of Principal Narcotic Drugs in Egypt (mg/capita) during years 2004-2007

examined (except for Israel). By comparing the consumption of meperidine in the United States to that the Middle Eastern countries – the differences are significantly smaller: 2.5 times that in Cyprus, 3.0 times that in Israel and Jordan, 5.0 times that in Lebanon, 5.4 times that in Saudi Arabia. 6.3 times that in Turkey and 30.0 times that in Egypt .

Fentanyl. Overall, the consumption of fentanyl is steady in all countries except for Israel and Turkey which showed increases during the period of 2005-2007. The doses of fentanyl used in the United States are by far higher than those used in Middle Eastern countries: 5 times that in Israel, 28 times that in Cyprus and Turkey; 66 times that in Saudi Arabia; 100 times that in Jordan and Lebanon, and 400times that in Egypt.

Discussion

Table 1 illustrates a situation that reminds countries to enact palliative care and pain treatment policies. In order to promote these issues there is a need to develop a comprehensive strategy including community involvement. Oral morphine and other opioid-based medicines ought to be added to the list of essential medicines. This can be done, for example; Uganda's Ministry of Health and WHO developed national palliative are and cancer pain relief policies whereby nurses were authorized to prescribe oral morphine. The Ministry of Health in Vietnam developed a national palliative care program which included a package of training courses for practicing physicians.

One of the biggest obstacles to provision of good palliative and pain treatment services is a lack of training for health care workers. 82% of healthcare workers in Latin America and 71% in Asia had not received any instruction on pain or opioids in medical school.1 Even in the United States, many physicians are reported to fear unjustified persecution or sanctions for prescribing opioids for pain and, consequently, tend to underprescribe.

The developing world has 80% of the world's population and accounts for 6% of the global opioid consumption. Accordingly, it is clear that the need of

Table 1. Morphine Estimate, Mortality and Pain Treatment Need for Egypt*

Cancer deaths 2002 estimate	# of individuals expected to need pain treatment in 2009	Estimated total morphine need in 2009 (kgs)	Estimate of morphine need provided by country to INCB for 2009 (kgs)	# of individuals estimate is sufficient for	Percentage of those needing treatment covered %
62,299	49,840	303	10	1,646	3

*This table only calculates morphine estimates. Some countries also use methadone or pethidine for pain control.

patients for opioid analgesia is not being fully met. In the current survey it became clearly evident that the developing countries in the Middle East use small amounts of morphine The figures shown in this survey illustrate the consumption of Morphine, Meperidine and Fentanyl (mg/per capita), i.e., the total use in a country divided by the population. The difference and huge disparity between the United States and countries in the Middle East are clear. Morphine has been defined jointly by the WHO and the International Association for Hospice and Palliative Care (IAHPC) as an “essential drug”. Taking the current data into consideration, the Middle East Cancer Consortium (MECC) took upon itself the goal to encourage the respective governments, policymakers and healthcare providers to ensure availability of essential pain drugs and thereby support access to analgesia.

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INTRODUCTORY LECTURES

The Global Experience of Cancer Pain

Jeannine M Brant

Abstract

Pain is a significant problem in patients with cancer. Pain occurs in approximately 50% of patients at some point during the disease process and in up to 75% of patients with advanced cancer. Total pain impacts quality of life domains including physical, psychological, social, and spiritual realms. Unfortunately, pain is underappreciated and undermanaged throughout the world. Lack of knowledge among healthcare professionals, inadequate pain assessment, fears of addiction, and beliefs that pain is an inevitable component of cancer are common barriers. Education about comprehensive pain assessment and optimal management strategies and discussions about belief systems regarding pain can assist to bridge the gap between suffering and comfort. Self-report is the gold standard for pain assessment. Gathering information about the location(s), intensity, quality and temporal factors is essential. Intensity should be quantified on a rating scale to determine the amount of pain and the degree of relief from interventions. Quality can be used to diagnose the specific pain syndrome. Temporal factors provide input about how the pain is experienced over time and can offer input into the pain management plan of care. For patients who cannot self-report pain, non-verbal assessment tools are available to aid in assessment. The World Health Organization's Analgesic Ladder provides a template for the management of cancer pain. For step 1, pain can be managed with nonsteroidal anti-inflammatory drugs (NSAIDS) and other nonopioid analgesics. As pain persists or increases, step 2 involves managing pain with select opioids for mild to moderate pain along with NSAIDS and nonopioid analgesics. Step 3 of the ladder is applicable to many cancer pain syndromes, and includes opioids for moderate to severe pain in conjunction with NSAIDS and nonopioids. This 3 step approach can be 80-90% effective. This polypharmaceutical employed with behavioral complimentary techniques are often employed to interrupt pain along the physiological pathways during transduction, transmission, perception, and modulation. Severe cancer pain that is not managed with the Step 3 approach, deserves special attention and unique strategies for control. When pain control is inadequate or if side effects are intolerable, a change of opioid or a change in the route of administration is recommended. Intraspinal analgesics can be trialed in patients who have intractable pain or intolerable side effects with systemic opioids. This route is especially helpful in neuropathic pain syndromes located at the trunk level or below. Opioid doses in all patients with intractable pain should be titrated judiciously for optimal relief with a balance of toxicity management. Other strategies for intractable pain should be investigated including nerve blocks and neuroablation. The overall goal for patients is to attain comfort with minimal side effects and optimal quality of life.

Keywords: Cancer pain - QOL - World Health Organization's Analgesic Ladder - drug control

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Introduction

Over 10 million people around the world are diagnosed with cancer per year, and pain is a significant problem in patients with cancer. Approximately one-third of patients undergoing cancer treatment experience pain and up to two-thirds with advanced disease. In response to this serious problem, the International Society for the Study of Pain (IASP) recently launched a "Global Year Against Cancer Pain" campaign to focus on the pain and suffering experienced by people with cancer (IASP, 2010). The significance of uncontrolled pain cannot be underscored. Pain is often associated with depression (Turner et al, 2005), fatigue and sleep disturbance (Roscoe et al., 2007), and decreased quality of life (Thong et al., 2009). This manuscript will discuss the global experience of cancer pain including the concept of "total pain," pain barriers, pain assessment, and pain management modalities including the management of pain crises.

Total Pain

The concept of "total pain" was first introduced by Dame Cicely Saunders in the 1960s. Total or global pain involves the interplay of physical, psychological, social, and spiritual factors that constructs each patient's unique

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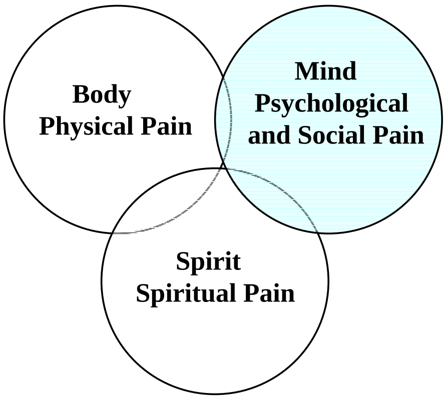

Figure 1. The Concept of Total or Global Pain

pain experience. Total pain reinforces the interconnectedness between mind, body, and spirit (Figure 1). Healthcare practitioners commonly focus on the physical pain; however pain is more than a physiologic process. Psychologically, pain can be described as dreadful, and reminds patients of the cancer and uncertainty of the future (Larsson & Wijk, 2007). Socially, patients may become isolated and even suppress pain to family members as a guard from family reactions (Larsson & Wijk, 2007). Spirituality can affect individual perception and intensity about pain, the significance of the meaning of the pain, and the acceptance of the medical treatment plan. If total pain involves physical, psychological, social, and spiritual domains, then management of pain should encompass all domains.

Barriers

International recommendations on the assessment and management of pain are remarkably consistent and provide a sound foundation for practitioners around the world (Curtiss, 2004). According to the International Association of Nurses in Cancer Care, 90% of pain could be adequately controlled with standard measures. Unfortunately, a chasm exists between recommendations and reality, and patients around the world continue to suffer. Barriers exist that avert optimal management of pain including lack of knowledge of practitioners, myths and misconceptions of patients and families, and inadequate healthcare systems. One global barrier involves fear of addiction and confusion with the terms “tolerance, physical dependence, and addiction” (Table 1). Efforts are being made around the world to overcome barriers through provision of education to healthcare practitioners (IASP, 2010), patients, and families. For example, a meta-analysis of 15 studies examined patient-based educational interventions on pain outcomes (Bennett et al., 2009). Education improved patient knowledge and attitudes, and decreased average and worst pain intensity scores. Overall, a collective voice is needed to improve pain assessment and management around the world.

Table 1. Definitions

Tolerance: Tolerance is a state of adaptation in which exposure to a drug induces changes that result in diminution of one or more of the drug’s effects over time

Physical Dependence: Physical dependence is a state of adaptation that is manifested by a drug class specific withdrawal syndrome that can be produced by abrupt cessation, rapid dose reduction, decreasing blood level of the drug, and/or administration of an antagonist

Addiction: Opioid addiction is a primary, chronic, neurobiological disease, with genetic, psychosocial, and environmental factors influencing its development and manifestations. It is characterized by behaviors that include one or more of the following: impaired control over drug use, compulsive use, continued use despite harm, and craving.

(American Academy of Pain Medicine, American Pain Society, & American Society of Addiction Medicine, 2001)

Table 2. Pain Assessment Domains

Domain	Pain Assessment	Components
Physical		
	Location(s)	o Body Diagram o Point and show area of pain
	Intensity	o “0 – 10” scale with “0” being no pain and “10” being the worst pain imagined o Mild, moderate, severe o Nonverbal pain scales
	Quality	o Descriptors about the pain: dull, sharp, shooting, radiating, numb
	Temporal factors	o Onset o Duration o Constant versus episodic o Breakthrough o Aggravating factors o Alleviating factors
	Impact of pain	o Activities of daily living o Function o Other domains below
Psychological		
	Psychological well-being	
	Prior psychopathology	
	Coping strategies (prayer, meditation, activities)	
	History of substance abuse	
Social		
	Social functioning	
	Degree of isolation	
	Social support system	
Spiritual/Existential		
	Cultural and/or religious beliefs related to pain and suffering	
	Spiritual practices used to manage or alleviate pain	
	Meaning of the cancer	
	Meaning of the pain	
	Spiritual support system	

Assessment of Pain

Adequate pain management begins with the assessment of the pain using a standardized assessment tool. Components of a pain assessment are included in Table 2 (American Pain Society, 2008; Middleton-Green, 2008). Psychological, social, and spiritual assessment tips are also included to reflect a “total pain” assessment. Practitioners should keep in mind that pain is a subjective experience; therefore, self-report is the gold standard. For the patient who cannot verbally report pain, nonverbal tools such as the Checklist for Nonverbal Indicators (CNPI) used in hospitalized adults and the Faces, Legs, Arms, Cry, Consolability (FLACC) tool used in children are available through the City of Hope Pain Resource Center (www.coh.org) and within other references in the literature (Herr et al., 2006).

Pathophysiological Pathways

The management of pain begins with an understanding of the pain pathway: transduction, transmission, perception, and modulation. Transduction initiates the pain response following a mechanical, thermal, or chemical injury. This initiates an inflammatory response resulting in the release of neuromediators such as prostaglandins, histamine, bradykinin, and substance P. Subsequently, an action potential occurs along the neuronal membrane. Transmission occurs as the action potential continues to the spinal cord and higher centers in the brain to the cortical level where perception of pain occurs. The brain then responds to the stimuli through modulation. Neurons release serotonin, norepinephrine, and endogenous opioid at the dorsal horn of the spinal cord in order to inhibit the transmission of pain impulses. Management of pain involves a polypharmaceutical and nonpharmacologic approach to interrupt the pain signal at all levels of the pathway and prevent pain input into the brain processing center.

Pharmacologic Management of Pain

The World Health Organization (WHO) Analgesic Ladder provides a framework for the pharmacologic management of cancer pain. When used appropriately, pain can be adequately managed 80-90% of the time. Oral nonopioid analgesics are used in step one to control mild pain. As pain persists or increases, step two includes opioids for mild to moderate pain in combination with nonopioids. As pain persists or increases and becomes severe, step three includes opioids for moderate to severe pain along with nonopioids. Adjuvant or coanalgesics are used as needed for each step of the ladder. Well-established evidence supports the three step ladder interventions. Nine systematic reviews and 24 intervention trials demonstrate strong evidence for the use of NSAIDS, opioids, radionuclides, and radiotherapy while there is less consistent evidence for the use of bisphosphonates for pain or a painful event such as fracture (Lorenz et al., 2008). The nonopioid, opioid, and adjuvant analgesics are described below.

Non-opioids: Acetaminophen, aspirin, and nonsteroidal anti-inflammatory drugs (NSAIDS) are nonopioids used for cancer pain. Acetaminophen is often used as a first line agent in treating mild pain. The maximum dose is 4 grams daily, which includes all opioid and acetaminophen combination products. NSAIDS are useful in the management of mild to moderate pain, post-operative pain, bone metastases, and inflammatory pain syndromes such as lymphedema. The mechanism of action is blocking the production of cyclooxygenase and subsequent prostaglandin synthesis. Benefits of NSAIDS should be carefully weighed with potential adverse effects including gastrointestinal irritation, inhibition of platelet aggregation, and renal toxicity (American Pain Society, 2008) .

Opioids: Opioids, the mainstay of cancer pain management, exert analgesic effects by binding to opioid receptors at the dorsal horn of the spinal cord. Opioid receptors increase in density 24-96 hours following dorsal root ganglia stimulation, caused by inflammation or trauma. Table 3 includes the most commonly used opioids for cancer pain management. The primary opioid side effects include respiratory depression, sedation, constipation, urinary retention, and nausea and vomiting. Prophylactic management of constipation includes the use of a stool softener and bowel stimulant. Methylnaltrexone, that reverses opioid receptors in the gut, can be used for refractory constipation (Chamberlain et al., 2009).

Opioid Dosing and Titration: Knowledge of pharmacokinetic properties of opioids is essential in dosing and titrating to analgesic efficacy. Opioids should be initiated using the least invasive route and at lowest dose to effectively treat the pain. Titration can occur after maximum serum concentration is reached and titrated by 25-50% for moderate pain and 50-100% for severe pain. Controlled release or long acting opioids are recommended for constant pain and prevent peak and trough blood levels, thereby preventing high peak levels associated with immediate release opioids and related side effects such as over sedation (Thomas & von Gunten, 2003). Breakthrough pain, a transient increase in pain over a background of constant pain is common in many cancer pain syndromes. It is characterized by a rapid onset with severe intensity and is managed with opioids at a percentage of the baseline dose. For oral opioids, the breakthrough dose should be 10-20% of the 24 hour dose. For IV infusions, the bolus dose should approximate 50-150% of the hourly infusion rate. High bolus doses are used with hard to manage episodic or incident pain. Dose titrations should be 25-50% for moderate pain and 50-100% for severe pain (Clary & Lawson, 2009). For uncontrolled pain or side effects with one opioid, rotation to an alternative opioid is an option. The dose should be reduced to account for the lack of complete cross tolerance (Clary & Lawson, 2009).

Opioid rotation to the parenteral or intraspinal route is another option for uncontrolled pain. The intravenous (IV) route provides a rapid maximum concentration, and subcutaneous route is an alternative to IV with equal efficacy. Advantages over the IV route include less expense, a lower rate of infection, and no need for IV access (Justad, 2009).

Adjuvants/Coanalgesics

Adjuvants or coanalgesics potentiate other analgesics, have independent pain relieving properties, or counteract side effects caused by the analgesic regimen. Adjuvants exert their effects through various mechanisms of action along the pain pathway. Some of the most commonly used adjuvants will be discussed. Corticosteroids are thought to block inflammatory mediators during transduction although their exact mechanism of action is unknown. They provide relief from visceral pain

Table 3 Opioids Used in Cancer Pain Management

Opioid	Preparations	Comments
Morphine	Oral Controlled release (CR) Immediate release (IR) Oral solution Rectal Parenteral Intravenous (IV) or subcutaneous (SC) Intraspinal Preservative free (PF)	Opioid for comparison of other opioids Variety of preparations useful when changing routes Metabolites that can accumulate with renal compromise: morphine-3-glucoronide (M3G) counteracts analgesic effect and may be responsible for side effects, morphine-6-glucoronide is a potent analgesic metabolite
Oxycodone	Oral CR IR Combination with acetaminophen / aspirin Oral solution	1.5 times more potent than morphine Parenteral preparation not available No known active metabolites CR has biphasal peak at 1 and 6 hours Metabolized by CYP450 but implications unclear
Oxymorphone	Oral CR IR Parenteral IV or SC Rectal	10 times stronger than IV morphine and 4 times stronger than oral morphine (Knotkova et al, 2009). Administer oral dose on an empty stomach; food increases the maximum concentration Do not administer with alcohol No CYP450 drug-drug interactions so consider in cases with polypharmacy issues. Contraindicated in moderate and severe hepatic impairment Initiate with a low oral dose (5 mg) in patients with a creatinine clearance < 50 mL/min, mild hepatic impairment
Fentanyl	Transmucosal Lollipop/Pastille/ Transdermal patch (TD) Parenteral IV or SC PF for intraspinal use	Pharmacokinetics vary depending upon route: oOral transmucosal fentanyl citrate (OTFC) an option for the mangement of breakthrough pain. Efficacy reported in 4 studies, 1 study reported that OTFC was superior to morphine (Zeppetella & Ribeiro, 2006) o TD – 12 hour onset, 24-48 hour peak o Parenteral – onset approximately 5 minutes IV, 10 minutes SC Lipophilic opioid which may assist in global distribution of drug Metabolized by p450 enzyme but clinical implications are not understood
Hydro-morphone	Oral IR CR Rectal Parenteral IV or SC PF for intraspinal use	5 to 7 times more potent than IV morphine; 4 times more potent than morphine (Knotkova et al, 2009) CR currently available Primary metabolite hydro-morphone-3-glucoronide (H3G) but little is known about its role May be an option in patients with polypharmacy issues due to lack of CYP450 interaction (Pergolizzi et al., 2008)
Methadone	Oral Sublingual (trials) Rectal Parenteral	High bioavailability Inexpensive Long-acting in all forms but not controlled-release Highly protein bound with long half-life allows for less frequent dosing but can cause potential for accumulation and toxicity Large inter-individual variation in dosing Metabolized by p450 with potential for drug-drug interactions High affinity for mu-receptors and delta-receptors; animal models demonstrate N-methyl-D-aspartate (NMDA) antagonism with potential to manage neuropathic pain syndromes and prevent tolerance Only skilled practioners should prescribe (Alford et al., 2006; Nicholson, 2007)

syndromes such as ascites, and from nerve entrapment such as brachial or lumbosacral plexopathies (American Pain Society, 2008).

Anticonvulsants such as gabapentin and pregabalin, inhibit transmission of pain through nerve stabilization and are indicated for neuropathic pain syndromes. Gabapentin can be titrated to 4800 mg per day, unless the patient has renal compromise: 600 mg twice daily if glomerular filtration rate (GFR) 30-59, 300 mg twice daily for GFR 15-29, and 300 mg daily for GFR less than 15 (Hanlon et al., 2009). Absorption is dependent on the gastrointestinal transport system. Pregabalin follows a simpler dosing schedule, starting at 150 mg/day and escalating to 150-300 mg twice daily (McDonald & Portenoy, 2006).

Antidepressants, specifically tricyclic (TCA) and serotonin and norepinephrine reuptake inhibitors (SNRI), are adjuvants, also used in the treatment of neuropathic pain. Tricyclic antidepressants can cause cardiovascular toxicity including orthostatic hypotension and heart block and should be used with caution, especially in the elderly. Less evidence exists for the use of SNRIs, but they may be favored because of their lower toxicity profile (McDonald & Portenoy, 2006; American Pain Society, 2008).

Bisphosphonates have become increasingly important in the management of pain from bone metastases. Over 30 randomized clinical trials report bisphosphonates

Table 4. Pain Management Tips

1. Conduct a global pain assessment on all patients.
2. If possible, determine the etiology of the pain so that strategies can focus on the source of pain.
3. Use a combination of nonopioids, opioids, and adjuvants as needed to control pain.
4. For elderly patients, start low and go slow, but efficiently for optimal comfort.
5. Use one opioid for both chronic pain and for breakthrough or acute episodes of pain.
6. Start with the simplest and most effective route of administration.
7. For long-acting opioids, titrate dosages by 25-50% for moderate pain and 50-100% for severe pain.
8. Keep breakthrough doses for oral medications at 10-20% of the 24 hour long-acting dose.
9. Use intravenous or alternative routes for pain crises.
10. For intravenous infusions, titrate hourly infusion rates by 25-50% for moderate pain and 50-100% for severe pain.
11. For bolus doses with intravenous infusions, keep bolus dose at least 50% of the hourly rate; higher bolus doses may be needed with severe incident pain.
12. Provide an adequate bowel regimen upon initiation of opioids that include a stool softener with a bowel stimulant.

Data from (American Pain Society, 2008; Ferrell et al., 2008).

provide some degree of pain relief in patients with bone metastases (Wong & Wiffen, 2009). There is a delayed effect; therefore, it is not a first-line therapy for pain.

Nonpharmacological Pain Management

Nonpharmacological treatment modalities reinforce the need to address the total pain experience. Massage and transcutaneous electrical nerve stimulation are complimentary measures that can modify transduction of pain. Distraction, relaxation, and music therapy are modalities that can alter pain perception. In addition, the perceptual centers include the brain cortex that integrates previous experiences of pain, cognition, interpretation of pain, and emotions (Middleton-Green, 2008). Guilt, fear, and unresolved psychosocial and spiritual issues may influence pain perception (Hemming & Maher, 2005; Ferrell et al., 2008). Therefore, the total pain plan of care should include discussion of psychological, social, and spiritual beliefs that contribute to suffering.

Intractable Pain Management

The majority of patients can be managed via the three step WHO ladder, but a subset of patients do not achieve ample relief of pain and require additional approaches. In addition, high opioid doses can lead to additional side effects such as tolerance, delirium, myoclonus, and hyperalgesia. Intraspinal analgesia using opioid and adjuvant combinations (e.g. bupivacaine, clonodine) or nerve blocks are options but are underutilized (American Pain Society, 2008; Jackson & Gaeta, 2008). One Scottish study showed that 8-20% of patients had pain indications that could potentially respond to anesthesiology approaches, but few patients were referred (Linklateret al., 2002). Clinicians should consider these options that can be more effective than traditional approaches alone.

Adjuvants such as N-methyl-D-aspartate (NMDA) antagonists can also be employed for intractable pain in attempt to decrease tolerance and address neuropathic pain challenges. Ketamine is an NMDA antagonist shown to alleviate pain in intractable and refractory situations. Administered at subanesthetic doses, it can be initiated at 0.1 mg/kg bolus doses and then converted to a subcutaneous or intravenous infusion. Opioids on board are usually dropped by 25-50% upon initiation of the ketamine and then titrated downward according to analgesic effect (Fine, 2005). Dextromethorphan is another NMDA antagonist although a trial that investigated the effect of morphine plus dextromethorphan found the combination not superior to morphine alone (Dudgeon et al., 2003). Lidocaine infusions can be used for intractable cancer pain, but efficacy, safety, and outcome studies are lacking (Fine, 2005).

Palliative sedation

Rarely, pain cannot be controlled using aggressive titration protocols, alternative routes of administration, and other procedures such as neurolytic blocks. In such cases, palliative sedation can be offered to patients who desire this option. Barbituates, neuroleptics, and benzodiazepines are options that can be employed, usually via SC or IV infusion (Fine, 2005). The goal is to achieve comfort without postponing or hastening death.

Summary

Around the world, pain is a deleterious symptom that is commonly associated with cancer. Uncontrolled pain can disrupt healing and can affect overall quality of life. Optimal management of pain requires a multifaceted approach. A comprehensive assessment should include not only physiological parameters but also “total pain” domains including psychological, social, and spiritual factors. A standardized assessment tool used at regular intervals facilitates the pain management plan that includes nonopioids, opioids, and adjuvant analgesics via the 3 step WHO analgesic ladder. Routes of administration should begin simple but may progress to parenteral and intraspinal routes as needed to control pain and minimize side effects. This step wise approach can optimize patient comfort and quality of life.

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INTRODUCTORY LECTURES

Using Leadership and Advocacy to Improve Cancer Pain Management - Based on a Presentation at the Cancer Pain, Suffering and Spirituality Course

Brenda Nevidjon

Abstract

Being a leader is not dependent on a title and, in fact, every oncology nurse is a clinical leader. Building on skills in caring for patients, oncology clinicians and nurses use their knowledge and skills to: advocate for patients; initiate performance improvement projects; develop new services for patients and families; ensure quality and safety of care; influence health policy. Because of oncology clinicians and nurses' closeness to patients and families in all settings, they know where the barriers to excellence are in organizations. This session will provide an overview of leadership skills and how nurses in particular can use their expertise as clinicians to improve the care delivery in their organizations and communities.

Keywords: Leadership - cancer pain and suffering - spirituality - care delivery

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Introduction

The management of cancer pain is not only a clinical challenge, but often is affected by cultural and governmental influences that cancer care providers must navigate. All cancer care providers have the opportunity not only to assess and treat the patient's pain, but can become leaders and advocates in the broader discussions of pain, suffering, and spirituality. Having the clinical knowledge of pain and its treatment is certainly necessary but so are the skills of leadership and advocacy. Some might argue that one is born a leader or that only people with administrative titles are leaders. (Sanborn, 2006) To the contrary, people can develop leadership skills and effectively advocate for programs and policies that support quality cancer pain management. They do not necessarily need to hold an administrative title but do need to know how to promote their ideas and proposals to administrators or policy makers. This paper will provide an overview of steps the clinician can take to enhance his or her leadership abilities and advocacy techniques.

Starting from Strength - Preparing to Lead Change

Leadership simply defined is positive influence. Leaders are not content with the status quo but continuously seek performance improvement and are willing take risks to achieve their goals (Maxwell, 1995). People will lead for different reasons usually because of their passion for the work or issue. Thus, leadership development begins with defining what one's goals are and whether he or she has the skills to meet those goals. In working with cancer patients, the clinician may identify barriers to providing the best pain management and decide to remedy the situation. The clinician has defined the goal – improved pain management for cancer patients. Further definition of the barriers and solutions for removing those barriers is the next step. The cancer care provider starts from clinical strength in this situation and will use leadership skills to accomplish the goal. Developing or enhancing leadership skills is not only possible but is necessary. The ability to lead and influence others will determine one's success. (Maxwell, 1993).

Kouzes and Posner (2007) have developed and used a framework for leadership development that furthers an individual's ability to guide others in getting extraordinary results. Through their research, they have identified five practices of exemplary leaders as seen in Table 1. Leadership is relational and cannot be developed without consideration of what others want and expect in a leader. Integrity is the foundation of leadership. Integrity builds trust and trust is the cornerstone to having followers.

Data from over two decades of surveys about the characteristics of admired leaders show that honesty, forward-looking, inspiring, and competent are consistently the highest rated characteristics. These are also the highest rated characteristics in several other countries. People expect consistency in what their leader says and does; seeing that words and actions are aligned. Thus, a lesson in leadership development is to do what you say you will do. Colleagues will follow the authentic

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Table 1. Five Practices of Exemplary Leaders – adapted from Kouzes and Posner, The Leadership Challenge, 2007

Practice	Description
Model the Way	Leaders must clarify their values and model the behavior they expect of others. People follow the person and then the plan.
Inspire a Shared Vision	Leaders see a future of possibility and are confident in their ability to make things happen. They engage others in sharing the vision through understanding their needs, interests, hopes, and goals.
Challenge the Process	Leaders are willing to take a risk, to innovate, to experiment. They expect to change the status quo.
Enable Others to Act	Leaders know that group collaboration and personal accountability lead to success. They build trust, share power, and strengthen others' abilities.
Encourage the Heart	Leaders show genuine caring, recognize everyone's contributions, and celebrate accomplishments.

leader. If the leader says that assessing the patient's goal for pain management is essential and incorporates the patient's goals in the plan of care, others will follow and results will be consistent. On the other hand, if the leader says that a policy change is needed and takes no action to promote change, some may or may not act and results will be inconsistent.

Gandhi said, "You must be the change you want to see in the world." (http://www.quotationspage.com/search.php3?homesearch=gandhi&page=3). Admired leaders have the ability and commitment to look inward and know their strengths and to identify areas that must be developed to bring success. Self-reflection is critical to developing as a leader. Table 2 is a list that can be used to assess one's leadership skills. Reviewing this list personally and asking others to indicate those skills that need enhancing. Another approach is in Table 3 which highlights some of the activities to create a personal leadership plan. Sometimes, circumstances will create a leader as has been seen during disasters. Many times, the individual sees a situation that is unacceptable and wants to change it. As Gandhi said, the person must start with self but then also must focus outward and define goals for change.

Planning and Managing Change

Once a gap is identified between a current practice or policy and the envisioned one, leaders want to make a change, to improve the situation. The process begins with describing the future, what the vision is for change. With a clear vision of change, not only is the direction set but others will be able to decide whether they want to join in the process. The role of the leader is to champion the project and to facilitate others success in accomplishing their assignments. An effective leader does not "do it all," but ensures that team members have the skills and resources they need.

There are many project frameworks but in general, to be successful in leading change, one must:

∑ Define the objectives and scope of the project. Explain the significance of the project.

∑ Conduct an analysis of the environment – organizational, regulatory, political (See Figure 1).

∑ Identify the stakeholders, who will have an interest in the outcome of the project, who needs to be engaged in the project, who might have to approve the change.

Table 2. Skills of Leadership: Review the List and Indicate whether you Possess this Skill or Need to Develop it

Skills to Possess for Needs Development
Defining and creating your goals and mission
Creating a vision and future-oriented thinking
Creating indicators for success
Finding financial resources for a project
Understanding the aspects of volunteerism
Building an effective team
Building relationships with stakeholders
Coaching/counseling/mentoring/mobilizing others
Creating, maintaining, and changing organizational culture
Critical thinking and decision-making
Dealing with difficult people
Dealing with the unknown
Delegating/communicating expectations/accountability
Developing a business plan
Developing a professional image
Developing power and influence
Giving constructive feedback/bad news
Influencing health policy in your country
Initiating and managing change
Making ethical choices
Managing a meeting/group
Managing a program/project
Managing conflict
Managing financial resources

From the Oncology Nursing Society's Starting from Strength: Leadership and Organizational Training for Building effective Nursing Groups 2010, supported by a grant from the ONS Foundation

Table 3 Developing a Personal Leadership Plan: Select One of the Options to Begin your Planning

1. Think of a leader you admire. List the qualities of that person and identify which are ones you possess. Identify ones you wish to develop.

2. Ask a trusted colleague, "Are there areas that I should focus in my leadership development?" or "What is it about me that may get in the way of being a successful leader?"

3. Ask yourself, "If I had it to over again, I would spend more time developing my XXX ability(ies)." Find resources such as books or classes that will assist you improve. Ask a person who has the skill you want to develop to support you.

4. List 3-5 areas in your life that lack discipline and prioritize them. Find resources such as books or classes that will assist you improve. Ask a person who has the skill you want to develop to support you.

5. Think about the messages you received encouraging or discouraging you from using leadership skills. Identify when you have felt comfortable and when you have felt uncomfortable as a leader. Determine if there are skills that you have not developed that will increase your comfort in being a leader. Find resources such as books or classes that will assist you improve. Ask a person who has the skill you want to develop to support you.

Strengths	**Weaknesses**
Threats	**Opportunities**

Figure 1. Assessing the Environment – List as many possibilities in each quadrant. This will give a comprehensive overview of the environment and help develop project objectives for improving or changing the situation.

∑ Identify and recruit team members to participate in the project.

∑ Outline the design of the project including resources, a timeline that shows the steps in the project, and a communication plan.

∑ Determine indicators to measure progress and evaluate impact.

Five essential factors for bringing about change are: vision, skills, incentives, resources, and an action plan. When all exist, change will occur, but if one factor is missing then change is not certain. If a clear vision is missing, then confusion will result because there is no direction. When people do not have the skills for the initiative, then anxiety can permeate the group. For example, if public speaking is not a skill that the leader has, speaking to an authority figure or a group may be avoided. When there are no incentives for change, there may be gradual change but it will not occur as desired as people will not feel an urgency or need to move deliberatively. Without resources, frustration will result as it will not be possible to implement change. Last, without an action plan, false starts are likely as there is nothing to guide activity.

Measuring Success

In every performance improvement, practice change, or policy revision initiative, indicators for success or measures of progress provide the feedback to the team. These indicators must be specific to the project and set at the time the objectives and project plan are developed. They will guide the leader and the team to make adjustments in their work if needed or compromise on their position to achieve their goal. Developing measures takes time and effort and should not be rushed. Measures include actual counting of a specific action to focus groups to achievement of the established goals. Broad communication about the measures and results engages others in providing feedback that enriches or focuses the initiative with new ideas. A comprehensive evaluation plan will also include how often the indicators are measured and to whom the results are communicated.

The Art of Advocacy

In leading change, there will be barriers to progress and people who resist the change. Thus, developing skills in advocacy, communication, persuasion, and negotiation are key in leadership development. Simply stated, advocacy is speaking out on an issue or cause that one cares about. This may be speaking up for one's self or for others and is leadership in action. In cancer care, this can include many issues from access to care or clinical trials to management of symptoms such as pain and from advocating for an individual to advocating for a national policy change. Although there may be a difference in the scope of the advocacy, the skills needed are similar. French, Gilkey, & Earp (2009 p. 114) state, "The role of a patient advocate calls on the skills of the diplomat, the inquisitiveness of the educator and the problem-solver, and the courage of the activist to speak up in difficult situations."

Oncology nurses demonstrate a type of advocacy as the liaison between the patient and others of the interprofessional team. Inpatient nurses have longer contact with patients and families than the other members of the team. They not only evaluate the patient's needs but also learn what the patient's wishes are and can educate their team members. Baldwin (2003) describes three essential attributes of patient advocacy: 1) Valuing: ensures the patients' freedom and self-determination in planning care, 2) Apprising: combines informing, advising, and educating the patient, 3) Interceding: helps patients to overcome barriers to meet their needs. Others, such as social workers and patient navigators (Fischer, Sauaia, Kutner, 2007), also take on the patient advocate role. Oncology nurses in some cultures may not recognize that they are advocates, or even clinical leaders, and may be intimidated to speak up for patients. However, once they do understand their role as a clinical leader and develop their leadership skills, advocating for a patient becomes customary. Additionally, the skills they use on behalf of patients are ones they will use when the cause is organizational, professional or legislative.

There are basic considerations when leading and advocating for a change. First and foremost is to be confident and not intimidated. If the issue or cause is one that inspires strong emotions, remaining calm when presenting information is critical. People can hear information best when the presenter is relaxed and assured. Combining statistics and patient anecdotes provides both quantitative rationale, "X% of our patients experience uncontrolled pain" and context for the change, "Mr. X suffered from pain because there were insufficient pain medication options due to government regulations." Particularly when advocating for policy change, such as access to opioids, anecdotes personalize the issue to policymakers and show how legislation directly affects their constituents. In all communication, written and verbal, conciseness and accuracy of information are expected and appreciated.

Advocacy is an ongoing process. Rarely does a policy or practice change with one encounter. Depending on the circumstances, change can take months or years and the leader's commitment to the process is essential.

Summary

Cancer pain is one of the many symptoms that patients in any country experience. With skills in leadership and advocacy, cancer care providers can impact the quality of life of individual patients and the broader society. Every cancer care provider is a clinical leader and can build on professional expertise by developing a leadership development plan. Integral to being a leader is managing change and using the tools of change management and advocacy to improve the care of patients.

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INTRODUCTORY LECTURES

Regulatory Barriers for Adequate Pain Control

Jerome W Yates, Rebecca Kirch

Abstract

In 1961 the "Single Convention on Narcotic Drugs" was adopted by the United Nations to explicitly address the need for narcotic drugs to curtail suffering and keep the distribution of these drugs in the control of health professionals. Fifty years later, neither goal has been reached for a variety of reasons. Governments have avoided putting in place systems to assure adequate supplies to relieve the suffering of those with severe pain, drug enforcement agencies maintain restrictive regulations and physicians are intimidated by threats of legal action if their prescribing patterns do not conform to arbitrary standards. There is a shortage of pain control consultants and the training for most health care providers is deficient when it comes to the management of chronic pain. Some of the regulatory barriers have been successfully addressed through advocacy efforts and the expertise deficiencies improved through targeted educational programs.

Keywords: Single Convention on Narcotic Drugs - regulatory barriers - international responsibility

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Regulatory Barriers to Adequate Pain Control

Prevalence of Pain

The prevalence of pain among adults with advanced cancer ranges between 75% in the outpatient clinic to 80% for people receiving end-of-life care. (McKegney 1981; Cleeland et al., 1994) Even under relatively ideal cancer management, approximately 40 to 50% of patients fail to achieve pain control and this is unacceptable considering our medical responsibility to provide adequate care.(Cherny and Portenoy, 1994) In the Netherlands, ineffective pain management was even seen with patients receiving curative cancer treatment and there was an increased association among those with a low education.(van den Beuken-van Everdingen et al., 2007a; 2007b) In developed countries patients receiving curative therapy and those with incurable cancer deserve better pain management. In other countries, with fewer resources available for cancer care, the proportion of the population destined to die of their disease who require pain management as part of end-of-life care is even greater. In another study, it was found that patients in an outpatient setting with a combination of cancer and non-cancer pain were at significant risk for under-treatment of their pain (Valeberg et al., 2008). A prevalence study of pain in older adults demonstrated how pain caused disability and reduced function, particularly in older women (Miro et al., 2007). In a pain prevalence study among hospitalized cancer patients in Norway, approximately 30% reported severe pain and were not receiving opioids or in some cases no analgesic therapy (Holtan et al., 2007). The presence of inadequately treated pain in countries with excellent medical resources and adequate supplies of opioid analgesics (often referred to as “narcotics”) underscores the problems imposed by educational deficiencies and regulatory barriers imposed on the healthcare system. WHO estimated that 80% of the World's population had no access to adequate treatment for severe pain (WHO 2007).

International responsibility

In 1961 the "*Single convention on narcotic drugs*" was adopted by member states confirming in its major thesis statement that narcotic drugs were critical for the relief of pain and adequate medicinal narcotic drugs should be made available (UN 1961). The WHO developed a pain relief guideline more than two decades ago and has continued to recognize the critical importance of morphine and other opioids for the treatment of severe pain (WHO 2000). To withhold, impede access to, or delay treatment for severe pain can be considered a form of passive torture that warrants appropriate corrective attention. Unfortunately there are economic, bureaucratic, educational, and drug supply barriers that require attention if there is any hope of achieving extensive application of these pain control guidelines.

These guidelines were developed to promote and improve the standard of care for severe pain. Many of those suffering severe pain are receiving end-of-life care and are therefore the most vulnerable; neither those patients nor their family caregivers are in a position to challenge their political leadership to solve the systems’ problems, namely: the shortage of available expertise, restrictive overregulation, inadequate drug supplies and widespread under-treatment of patients with severe pain.

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Successful programs have occurred internationally and both Uganda and Vietnam are examples of what can be done to overcome the dominant inertia working against these necessary improvements (Lohman et al., 2010).

Complex interactive Impediments for: sufferers, health care providers, legislators and regulators.

Pain and suffering have been part of the religious practices for man since the beginning of recorded history. The story of "Job" told in the Old Testament of the Bible, is a narration of an inexplicable painful test of faith. Self-flagellation and other self-inflicted pain as punishment for perceived unacceptable behavior or as a cleansing rite persist even today (Morris, 1994). From sensitivity to stoicism, there is a wide range of individual reactions to pain. Unless specifically queried about their pain, many patients will not reveal their pain experience and may even shield the attendant health care professionals from pain as one of their major problems. Others may overreact and be considered unreliable historians about the cause or severity of their pain. Misunderstanding about and fear of addiction, and concern about side effects [e.g. loss of control] may negatively influence the patient, supportive family members or even their health care providers (Ward et al., 1993). The ambiguity in the pain experienced by the patient and the quality of the communication with the provider can interfere with timely and effective pain assessment and management. In environments where the government interferes with access and supply of pain medications, the path of least resistance is often to accept the pain with a level of fatalism. The government is expected to facilitate an adequate supply of effective pain medications, but this is not always the outcome.

Prescriber burden in today's environment.

When prescribed responsibly, opioid analgesics are inexpensive, safe and highly effective medicines for relieving suffering (WHO, 2007). But these controlled substances also tend to trigger dueling policy challenges for health care professionals, who must consider the interface between providing safe, effective pain relief for their patients through responsible prescribing and curbing drug diversion, misuse and abuse (Woodcock, 2009). As a result, far too many patients are left to suffer because they and their health care professionals do not have access to morphine or other opioid analgesics needed to provide pain control. This is the case despite the fact that the UN drug conventions recognize that “the medical use of narcotic drugs continues to be indispensable for the relief of pain and suffering and that adequate provision must be made to ensure the availability of narcotic drugs for such purposes.”

Because of practice demands physicians may not have adequate time to assess the severity of each patient's pain, consider the potential interactions of analgesics with other medications, or educate the patient and family about effective pain management and the safe use of prescribed medicines. These drugs have a known narrow therapeutic index and their delayed metabolism may have cumulative adverse effects. Inadequate training in the management of severe pain, the lack of accessible consultative expertise and concerns about patient costs for expensive medications also contribute to the lack of optimal outpatient management of pain. Further impeding access, local pharmacies may be reluctant to carry inventories of opioid analgesics because of their fear of robbery, particularly in medically underserved neighborhoods. In some states in the US, duplicate or triplicate specialized prescription forms required for controlled substances make writing prescriptions for opioids onerous both in terms of time to write them, as well as a burdensome record keeping requirement. In the few states where these forms are still used, fewer opioid analgesic prescriptions are written because of the inconvenience, but with no correlative evidence demonstrating that these forms have made any impact on reducing drug abuse and diversion.

Therefore, the selection of less effective or inexpensive analgesics may result in the under-treatment of the patient's pain. In addition, some physicians reduce their pain prescribing because they are concerned that they may be subjected to regulatory oversight which could prove both time-consuming and a threat to their professional status (Fishman, 2007). Physicians must invest the amount of time necessary to assure that they know how to and do assess and treat pain in the most responsible and effective manner for every patient.

Substance Abuse in the United States.

While the dangers of prescription pain medications and their misuse often hit the news headlines, we hear far less often about the other side of the story – the individual patients who are suffering and need these medications to ease their cancer pain. Efforts to promote safe, responsible prescribing of controlled substances and prevent diversion and abuse of opioid analgesics are very important and necessary. But those efforts should not interfere with medical practice and patient care. Drug control policies must be balanced so they do not restrict medical decision-making and the availability of controlled substances for legitimate medical purposes. The roles of both health professionals and law enforcement personnel in maintaining this essential balance between patient care and diversion prevention are critical (Joranson and Gilson, 2006).

Unfortunately, the attendant publicity related to drug trafficking, morbidity and associated criminal behavior receives maximal attention from the news media. The overt suffering of individuals is unpleasant, resulting in the public as a whole not appreciating the magnitude of the problem. The abuse of prescriptive medications resulting in the deaths of celebrities such as Michael Jackson and violent crimes associated with illegal drug use, influences both the attitudes and beliefs of many members of the legislative bodies and the public. These attitudes are reinforced by law enforcement agencies resulting in more oppressive regulations in the name of crime control.

The problem of substance abuse among the young Americans is significant. Survey information tells us that about 47% of the high school graduates have tried an illicit drug (Johnston, 2008). Approximately half of those individuals have used an illegal drug other than marijuana. On the positive side, 57% of high school seniors have not ever tried marijuana. High school students have reported the ready availability of a variety of illicit drugs. Approximately 1/2 of all students state that cocaine is readily available and other illicit narcotics are available to approximately 1/3 of the students (see Table 1). For a comparable period of time the number of narcotics violation records for physicians in the United States remained constant until the appointment of a reactionary new attorney general of the United States (Bolin, 2006). This mixture of medicine with politics resulted in doubling the number of violation records over the subsequent four years. Conservative politicians interfered with the expected death of highly publicized unfortunate individuals such as Terry Schiavo, a lady with documented irreparable brain damage in a vegetative state. Political interventions have generated an atmosphere of fear among some physicians concerned about the inappropriate scrutiny of their controlled substance prescriptions by the US drug enforcement agency. This underscores the need to educate both the members of the executive branch of government as well as those responsible for promulgating the laws and regulations relevant to the availability of controlled substances.

There appear to be five major areas that contribute to the inadequate management of pain that could be remedied with the right programmatic approach (Gilson et al., 2005; Gilson, 2010).

Strategies for Improvement

1. Raise awareness about the importance of providing adequate pain management and improve understanding about the benefits and risks of pain control medications by adopting and communicating uniform, easily understood definitions of addiction, tolerance and dependence such as those developed and adopted by the Federation of State Medical Boards in the United States in its 2004 Model Policy for the Use of Controlled Substances for the Treatment of Pain.
2. Develop adequate drug supply systems by the government bodies responsible for controlling opioids. This appears to be a major problem in many countries whose leaders publicly endorse better pain control but are unable to provide the supply of drugs necessary to safely accomplish optimal pain control.
3. Examine and revise restrictive public policies relevant to pain management to ensure policies are balanced and do not interfere with safe pain prescribing and practice required to ease suffering.
4. Expand the pool of healthcare workers with pain management expertise through government facilitated programs.
5. Enact policies that recognize the importance of pain management and safe opioid prescribing as an essential component of quality care and limit the threat of unwarranted legal sanctions and the added administrative burden imposed on health professionals forced to defend appropriate cancer management. Selected patients may require large amounts of opioid analgesics or prolonged treatment with these medications to assure optimal pain control.

Table 1. A Depiction of the Illicit Drug Environment

Year	Cocaine	Other Narcotics	NPDB Reports
92	53	45	215
93	49	34	210
94	47	34	190
95	48	35	160
96	48	32	180
97	49	34	150
98	51	36	100
99	48	32	120
00	48	34	130
01	46	32	125
02	45	29	235
03	43	28	440
04	48	30	330

Based on the per cent of high school students who knew where to get illicit drugs (Johnston, 2008) and the number of narcotics reports filed in the National Practitioner's Data Bank (NPDB) There appeared to be an increase in which practicing physicians were reported during the tenure of two Attorney Generals of the US. (Bolin 2006)

Drug enforcement and pain control - the RIGHT balance

Effective drug management using agents with a narrow therapeutic index is a major responsibility for healthcare providers. In the United States there is widespread non-medical misuse of prescription pain relievers. An estimated 5.2 million people did so in one month alone in 2007 according to one report. (Woodcock 2009) Similarly, it is estimated that in 2006 there were approximately 57,000 emergency department visits in the US for the non-medical use of a variety of opioid analgesics, and 9179 children in a three-year period from 2003 were treated for the accidental exposure to prescriptive opioids. (Woodcock 2009) It is imperative that along with the ability to manage pain using the most potent and effective drugs, health care providers must also do so responsibly, essentially becoming “risk managers” when considering each prescription for opioids.

Developing benchmark indicators for the safe and adequate use of opioid analgesics for pain control is not easy, but looking at the UN data for a standardized mortality from cancer per hundred thousand people for a few selected European countries (a surrogate for need for

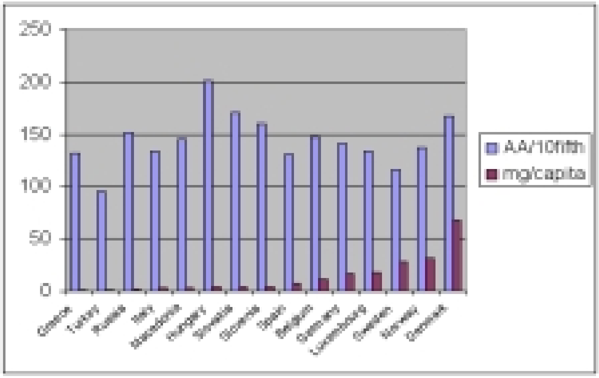

Figure 1. The Age-adjusted Cancer Mortality for Selected Countries. (Provided to show proportional demand for narcotics) and the per capita Consumption of morphine for the year 2000 (UN 2000)

pain management) along with the estimated milligrams per capita of opioids consumed, provides a confusing picture of disparities. (UN 2000). Ranking the countries based on opioid consumption suggests the Northern European Countries consume more opioids which may mean better pain control. Deficiencies for some of the countries have been and are being addressed. Information such as this stimulated Italy to address changes in their existing system using a work group appointed by the Ministry of Health (Blengini et al., 2003).

One of the well-documented major fears of patients with advanced cancer is a painful death. Balanced pain policies are critical to assure virtually all patients will not have to experience such terminal pain. Since 2000 policy statements have increased by 55% while there has been a minimal increase in the number of relevant laws and regulations (Gilson et al., 2007). The University of Wisconsin Pain and Policy Studies Group (PPSG) developed a state-by-state report card, which, similar to the Italian experience, resulted in positive policy changes. The process included the evaluation of all state laws and regulations for prescribing, dispensing and administering controlled substances as well as providing guidance to state medical and pharmacy licensing boards. These efforts were guided by the central principle of " balance". This is a long-standing national and international consensus statement : "efforts to control abuse and diversion of opioid analgesics should not interfere with relieving patients' pain and suffering and that regulatory policy should not contradict current medical and scientific knowledge." Balanced state policies should not impede appropriate patient pain management and should not sanction the use of controlled substances outside of the control of licensed healthcare professionals. The PPSG generated a 16 item policy evaluation criteria composed of a list of eight positive and eight negative items based on language found in existing state policies. States were then ranked based on a grading system. Following the publication of performance, strategic legislative advocacy resulted in 35 states making positive changes in their policies. Between 2006 and 2008 alone, 15 state policy grades improved (2008). Ongoing pain advocacy efforts will yield even more balanced policies in the future (Brawley et al., 2009).

Examination of government policies resulted in healthcare professional organizations pushing for positive changes: legal, financial, systems and other barriers. The use of outside consultants and educators experienced in developing the necessary local expertise to affect the political and clinical change necessary will add to the likelihood of success. It is critical to identify an executive or legislative champion prepared to gather a workgroup capable of addressing the existing policies in an unbiased manner. Using advocacy tools, such as those developed by the American Cancer Society Cancer Action Network, the advocacy affiliate of the American Cancer Society, have proved successful in various environments and could be adapted to save time and effort (Kirch, 2003). There are other organizations that have been successful in stimulating positive changes and they should be called upon for help whenever necessary.

We owe it to ourselves as potential sufferers of pain and all other patients in the future, to improve the existing situation, striving for the best pain management possible with our present medications, until the science of the future provides a superior option.

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INTRODUCTORY LECTURES

Advanced Care Planning - Empowering Patients for a Peaceful Death

Sloan B Karver, Jessalyn Berger

Abstract

In the early 1900's, Americans had a life expectancy of about 50 years. Childhood mortality was very high and an adult who lived into their sixties was considered to be doing pretty well. Prior to the advent of different types of antibiotics, people would die quickly of infectious disease or accidents and medicine only really focused on caring and comfort. Since then, there has been a shift in medicine's focus. New science, technology and communications have shifted the way Americans treat incurable diseases and have promoted the idea of aggressive fighting as well as to keep patients alive at any costs. The internet has allowed easy access for patients to do on-line research and to know the treatments for diseases and the availability of trials. This has promoted the idea that every disease or cancer is curable if the patient does exactly as the internet says. It has hindered the idea of compassionate care and dying with dignity so that a patient can stay alive at all costs, even in a vegetative state. In the last two decades, there has been a significant expansion of palliative and supportive care services in the United States. This has including the development of a specialty for palliative care medicine with a board certification in hospice and palliative medicine. A challenge to the field has been the reluctance of physicians to request palliative care consults in a very timely manner as well as relinquish care of their patients. A common occurrence in the United States, at many cancer centers, is the treatment of chemotherapy and radiation up until the day before a patient dies. At this point, the physician ends up throwing up his or her hands with nothing left to offer the patient or its family. However, what we have been finding is that presently there are now many oncologists who are willing to refer patients to palliative care for specific management of difficult pain control issues. At the Moffitt Cancer Center, we have a Palliative Care consulting service along with a Palliative Care Fellowship program where we work with cancer teams to provide resources to them when they are running into difficulties with their patients. Typically, we step in when first line treatments have failed, symptoms have shown no signs of decrease, or when the primary teams have exhausted their standard management options. Our hope is for the primary care teams to be able to manage basic symptoms themselves and only call on the Palliative Care team when they have surpassed their comfort zone. For example, the Palliative Care team would step in if a patient's dosage of medication was out of a primary team's spectrum. Other uses of the Palliative Care team include having the end of life discussion with the patients to find out what their expectations are of their treatment, what their concerns are and what their requests are. Normally treating primary teams are very uncomfortable in having this discussion with their patients due to the feeling that they are giving up hope or the fact that they are letting patients know that the end of the road is near. The Palliative Care team can then be called upon to come in and transfer the care from the primary team to the "death team". At Moffitt we have instituted a number of strategies to make this transition acceptable and more beneficial for the patients. One of the strategies that we used is an Advanced Care Plan. By having a consultation at the time when the patient is diagnosed, we are able to speak with them about what it is that they see in terms of what would be acceptable to them. We use the Project Grace Advance Care Plan which was developed by a physician and is very simple to understand. With this tool, we are able to bring up the discussion while trying to focus in on the patient's spirituality and the coping mechanism as the cancer patient. This allows the conversation of end of life treatment preferences and what the patient's typical desire is for life sustaining measures.

Keywords: Life expectancy - cancer not always curable - palliative care teams - Project Grace Advance Care Plan

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Introduction

In the early 1900's, Americans had a life expectancy of about 50 years. Childhood mortality was very high and an adult who lived into their sixties was considered to be in excellent health. Prior to the advent of different types of antibiotics, people would die quickly of infectious disease or accidents and medicine only really focused on caring and comfort. Since then, there has been a shift in medicine's focus. New science, technology and communications have shifted the way Americans treat incurable diseases and have promoted the idea of

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aggressive fighting to keep patients alive at any costs. The internet has allowed easy access for patients to do on-line research and to know the treatments for diseases and the availability of trials. This has promoted the idea that every disease or cancer is curable if the patient does exactly as the internet says. It has hindered the idea of compassionate care and dying with dignity, a patient can stay alive at all costs, even in a vegetative state. These new changes have influenced the dynamics of all medicine but especially pain and palliative care.

The idea of the family physician is dead. Due to changing times, patients in the United States jump from doctor to doctor, sometimes seeing a physician only once. This makes it difficult for a doctor to understand a patient's situation and history or really know their beliefs and wishes. Another problem we find is that many physicians have no formal training in delivering bad news or in having a conversation regarding end of life care. These issues can cause problems for doctors when they have to bring up that discussion. Part of our work is to advocate that patients have this discussion with their physicians at a time when they are healthy; however this does not typically happen because who wants to talk about death when it is ,in fact, the last thing on their minds? With the changing times, there has become a need for a separate doctor, different than the family doctor, who is trained in the "breaking of bad news" and able to offer the patient that comfort and ability to organize their wishes and get the results that are so important to them.

In the last two decades, there has been a significant expansion of palliative and supportive care services in the United States. This has included the development of a specialty for palliative care medicine with a board certification in hospice and palliative medicine. A challenge to the field has been the reluctance of physicians to request palliative care consults in a very timely manner as well as relinquish care of their patients.

Even though hospices have been operating in the U.S. for three decades, they remain widely misunderstood; however, they are the perfect example of quality end-of-life care (Gleckman, 2010). Many doctors are always uncomfortable in bringing up the idea of Hospice to their patients due to the fact that no one wants to rob a patient of their hope; by bringing up hospice care it is often felt to be a death sentence. In 2008, more than one-third of patients are enrolled in hospice for a week or less. In certain organizations, the numbers of short stays are increasing, perhaps because these requirements may be making already reluctant doctors even less willing to refer to hospice until their patients are actively dying (Gleckman, 2010). However, that should not be the case.

Hospice care is one way to deal with death in a compassionate way, but another common occurrence in the United States, at many cancer centers, is the treatment of patients with chemotherapy and radiation up until the day before a patient dies. At this point, the physician has nothing left to offer the patient or family. What we have been finding is that presently there are now more oncologists who are willing and able to refer patients to palliative care for specific management of difficult pain control issues, of complex pain syndromes, or for patients having atypical nerve pain of different complexities in their treatment strategies. We can co-manage these patients with these physicians to work towards a better outcome for the patient.

At the Moffitt Cancer Center, we have a Palliative Care consulting service along with a Palliative Care Fellowship program where we work with disease based cancer teams to provide resources to them when they have challenges with their patients. Typically, we step in when first line treatments have failed, symptoms have shown no signs of decrease, or when the primary teams have exhausted their standard management options. Our hope is for the primary care teams to be able to manage basic symptoms themselves and call on the Palliative Care team when they have surpassed their comfort zone.

The Palliative Care team typically is the team to have the end of life discussion with the patients and family to find out what their expectations are for their treatment, what their concerns are and what their requests are. Normally treating primary teams are very uncomfortable in having this discussion with their patients due to the feeling that they are giving up hope or the fact that they are letting patients know that the end of the road is near. One of the strategies that we use is an Advanced Care Plan. By having a consultation at the time when the patient is diagnosed, we are able to speak with the patient and family about what are their goals of treatment. We use the Project Grace Advance Care Plan which was developed by a physician and is very simple to understand. With this tool, we are able to bring up the discussion of the benefits and burdens of each treatment for the patient. We are also able to evaluate whether the benefits and burdens are compatible with the patients and their family's goals. This document provides a framework on which we can initiate the discussion with the patient. When counseling a patient it is important to determine first and foremost what their goals for healthcare are as they near end of life. As health care professionals, we must validate to the patient that these goals may change as the patient's illness progresses. Other times the family, as a unit, will be working on these goals. We have found that the proper management of symptoms in these patients may help them prioritize these goals. We stress to the patient that to honor these goals an effective mechanism needs to be in place such as the advance directive.

Unfortunately, there haven't been many studies to show the scientific benefit of using these documents. Teno et al (2003) examined 688 living wills as part of the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT) study. They found that 50% of the orders not to attempt cardiopulmonary resuscitation were not contained in the medical chart, rending it obsolete as the doctor had no idea that the order had been made. Furthermore, 87% of those living wills that do make it to the chart are written in vague medical language making it unclear as to what the patient actually wants. Only 13.3% go beyond general statements and 3.2% refer to current medical conditions.

Advance care planning with a community and organizational approach to advance care planning were studied in a project entitled the "La Crosse Advance

Directive Study" (LADS), which retrospectively reviewed all adult deaths in all local healthcare organizations for an 11-month period in 1995 and 1996. The objectives of the study were to determine the prevalence and type of end-of life planning and its correlation with treatment decisions. Data were collected from medical records, from death certificates, and from interviews with attending physicians and healthcare proxies. While other studies have documented low rates of advance directive completion, the LADS results stand in stark contrast.

Of the 540 deaths included in the study, the prevalence of written advance directives was 85%, with the most of these (95%) found in the medical record. Median time between the recording of the completed advance directive and death was 1.2 years, clear evidence of planning in advance of a medical crisis. And unlike other studies, which have found poor correlation between advance directive preferences and actual treatment decisions, we found that patient preferences to forgo life-sustaining treatment were honored by consistent medical orders reflecting these preferences.

While there are still lessons to be learned and improvements to be made, the results of the LADS provide strong evidence that certain strategies are likely to have a significant impact on the ability of healthcare systems to assist patients in choosing end-of-life preferences and the willingness of health professionals to respect them (Gundersen Lutheran Medical Foundation, 2007). Personally, I have had the opportunity to witness the benefits of having the Advance Directive done prior to a patient's demise. While treating patients in the palliative care setting, many family members are very relieved that they are very clear on what their loved one wanted and that they can follow those wishes because they are spelled out in a simple form. In my opinion, there is much less burden placed on the family member when this discussion is held.

The Pain and Palliative field is evolving at an extremely high- paced path. New methods for the comfort of patients are being put into place to make sure that a patient's last wishes are fulfilled as well as to ease the discomfort of family and friends and the relationship with the patient and his or her doctor. By utilizing, the advance care directives as well as the palliative care team, the overall dying process is made easier for those involved and takes the pressure off of oncologists and other physicians who may not feel comfortable with the idea of bringing up the topic of death or the idea of Hospice care. The main purpose of this new field and its treatments is to provide personalized and professional care as well as to bring back a certain dignity to dying.

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INTRODUCTORY LECTURES

Clinical Aspects of Pharmacogenetics of Pain and Co-Morbidities of Emotional Distress

Barton A Kamen

Abstract

The majority of patients treated for cancer will have pain at some point in their journey. It will be due to the disease (e.g. bone metastasis, fracture, organ invasion) or from iatrogenic causes (chemotherapy, surgery or radiation). A large number of patients will also have depression. Since pain and depression share common biological pathways and even neuro-transmitters it is not surprising that a comorbidity of pain is depression. It has already been reported that patients in severe pain are 4 times less likely to respond to therapy for depression. In recent years, especially in the era of molecular biology and post-genomic a wealth of data in the arena of pharmacogenetics/genomics has shed more light on cancer related symptoms such as pain and related them to the cytokine pathways, especially the interleukins and tumor necrosis factor (TNF). When we remember that the synonym for TNF is 'cachectin' it is no wonder patients feel awful when there is active disease and the body trying to mount a response. Neuroendocrine, immunomodulatory and inflammatory pathways are likely important in the pathophysiology of pain and depression. These realizations are in addition to a greater understanding of afferent pathways for pain perception, of the multiple opioid receptors, the effects of hormones and catechol metabolism and other transmitters. Moreover we already have a more complete under-standing of drug metabolism, especially of the opioids, the back bone of all pain treatment. There are a number of single nucleotide polymorphisms (SNPs) in the genes important for drug metabolism such as CYP2D6, a cytochrome responsible for about 25% of all drugs. There are about 90 variants already reported and rapid and slow metabolizers need very different doses of codeine or morphine. We are entering an era of having the capability to develop personalized treatment for our patients' nociceptive pain, neuropathic pain and depression. The convergence of new knowledge in the molecular biology and pharmacogenetic era should allow us to treat our patients' suffering with a resultant increased quality of life even while we strive to cure them of their malignancy.

Keywords: Cancer pain - co-morbidity - depression - drug metabolism - drug choice

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Introduction

There are multiple definitions for pain found on the internet. Two simple, brief notations are: *A) a symptom of some physical hurt or disorder* and B) *emotional distress; that is a fundamental feeling that people try to avoid* are crucial to realizing that pain and depression will often co-exist. Although most assume that somatic pain can cause depression, we also need to remember that depression (defined as sad feelings of gloom and inadequacy) will exist in the absence of pain. While it is argued that co-existence does not prove causation or interdependence, but simply an association (Laird et al., 2009), in the cancer literature and my own personal experience spanning three decades it would seem that pain is at least partially a causation of depression. The successful treatment of pain can decrease or even eliminate depression and in a recent study, pain was a strong predictor of depression and patients with severe pain were four times less likely to respond to depression treatment (Blair et al., 2004). This is important as the prevalence of depression and pain, especially in patients with advanced disease has been reported to be in the 50-80% range.

Maintaining a high quality of life with respect to somatic complaints is even more important when it is realized, that especially in the cancer literature, the pharmacological treatment of depression is difficult. As recently stated "*There is still a lack of pharmacological treatment algorithm for major depressive disorder in patients with advanced cancer…..There might be two ways to better understand the paradoxical lack of efficacy of anti-depressants in oncology. First cancer patients would not have same reactivity and sensitivity to pharmacological treatment…. and second…there might be overlap and confusion between somatic factors (pain and fatigue) inducing psychological distress….)* (Reich, 2008). In this regard and in retrospect, if I were to have broadened the scope of this brief discussion, I would have

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changed the title somewhat to be inclusive of fatigue, as a reminder that it is another major symptom in patients with cancer. In fact fatigue is one of the most common chief complaints in an oncology clinic whether it is caused by the underlying disease (see Reyes-Gibby et al., 2008 for general review) or, as we have previously discussed, that pain and general suffering (e.g. signs and symptoms including nausea, malaise, and anemia) are very often iatrogenic (Kamen and Saletsky, 2000).

There are numerous original reports and recent reviews discussing the co-morbidities of pain and depression.6 Point of fact is that simply searching "pain and depression and cancer" yields approximately 1,400 citations and only "pain and depression" yields more than 16,000. Bair et al (2003), Reich (2008), Reyes-Gibby et al (2008) and Laird et al (2009) are recent reviews that I found very informative in synthesizing this overview.

Acute pain perception (nociception) is often severe but limited and will usually respond to opioids. Neuropathic pain, often instigated by an injury may persist for a long time after the injury has healed. It remains chronic, responds less well to opioids and is more difficult to treat. While acute pain can serve as a warning to us that damage has been done and that we need to react (e.g. stepping on a nail) in a protective manner, neuropathic pain is more akin to a malfunctioning of the alarm system and as noted, more difficult to treat. In either case, since studies of both neuro-transmitters and imaging studies of the cerebral cortex show a commonality of pain and depression, it stands to reason that elimination of pain should often help to ameliorate severity of depression.

The somatic problems of pain, asthenia, general malaise/fatigue of cancer are at least in part due to the body's response (i.e. cytokines and hormones) as well as the tumor causing local and systemic reactions by releasing pro-inflammatory cytokines, and simply mass effects (e.g. brain and bone metastases). As we have accepted that depression can be associated with these somatic issues, it is logical to conclude that overall quality of life for our patients, both physically and psychologically can be improved through control of somatic issues, perhaps with anti-inflammatory agents capable of treating cause, not just blocking perception as the opioids do. Finally, a patient with advanced cancer, even having no somatic disease caused by the cancer may still have depressive problems simply knowing that their time is limited, but this issue will not be discussed here.

Below I will broadly discuss the pathophysiology-biochemistry of pain as caused by a tumor and/or the host response as well as noting some of the more well appreciated ADME (absorption, distribution, metabolism and excretion) phenomena of pharmacokinetics. These two issues are important as we think about treating our patients. Given the difficulty of isolating pure depression as well as the problem in treating it as noted above and space limitations, the emphasis here will be about pain and how when we look at cancer as a "state of being" or at least a complex tissue, that new alternatives for treating a patient's symptoms emerge. Reviews of the management depression are cited (Bair et al., 2003; Reich, 2008; Laird et al., 2009)

The Host (a euphemistic term for patient) - Tumor Relationship

is clearly a source of some cancer related symptoms. Cancer is a state in which a malignant cell usurps or bypasses the usual humoral or internal controls, that is the regulatory pathways governing proliferation. The end result is abnormal growth and metastatic spread. There are at least two critical issues here.

First, the body's own defense mechanisms that have evolved for defeating intruders such as infectious agents may react to the presence of a malignant cell. An appropriately intense inflammatory response or immune response may result in cancer control, indeed immunotherapy, whether active or passive remains a major area of clinical and basic research. Humoral responses by macrophages, dendritic cells and T-effector cells will often be mediated or initiated by the production of potent cytokines as immune and inflammatory modulators. The significance of a robust systemic reaction to a tumor may be analogous of the reaction to a bacteremia. If our defense mechanisms respond appropriately to a bacteria producing endotoxin we are cured, if the response is too exuberant, endotoxic shock or disseminated intravascular coagulation may occur. We only have to remember the side effects of exogenously administered interferons and interleukins or that tumor necrosis factor was initially identified and named cachectin because of its systemic effects to realize that somatic complaints can be related to the body's reaction to a tumor e.g. as in a patient with severe B symptoms such as fever, asthenia, pruritus with or without rash and night sweats.

Second, the malignant cell will take control/advantage of the local environment that will result in it evading the immune system and stimulating vascularization so that is may grow locally as well as spread systemically. Specifically, the cancer cell itself can elaborate immuno suppressive molecules such as transforming growth factor a and cytokines that block the normal defenses and other molecules that are pro-angiogenic. Cytokines are pleiotropic depending on location, concentration and other molecules in the environment. Over abundance of some such as IL 6 are associated with poor prognosis as well as pain as seen in auto-immune diseases like arthritis. There are a number of polymorphisms altering normal cytokine function that are associated with somatic disease and likely even psychological disturbances as very recently reviewed (Reyes-Gibby et al., 2008). The implications here relate to both the control of cancer related symptoms as well to potential control of the tumor. From a treatment view, recognition of an imbalance of cytokines and the robust inflammatory process allows the suggestion of using well tolerated drugs such as cyclooxygenase inhibitors or other drugs such as soluble receptors for TNF to eliminate somatic complaints or even control the tumor. Perhaps more specifically, an antibody against IL 6 is also being evaluated as noted by Reyes-Gibby et al (2008). Using more traditional anti-cancer drugs but scheduled in a more repetitive manner and dosed much lower than used in conventional regimens (i.e. metronomic chemotherapy) has also shown promise. Low dose, daily cyclophosphamide combined with daily celecoxib or methotrexate given twice a week have shown activity in prostate and breast cancer respectively (Glode et al., 2003; Wong et al., 2010). The drug doses are those that would be used in the setting of auto-immune disease or graft versus host, not the typical high dose therapy according to the usual paradigm of DLTs and MTDs (dose limiting toxicity and maximally tolerated doses). These lower doses are anti-inflammatory, anti-angiogenic and immune modulatory thus providing some control of tumor metastases and growth as well as providing a non-opioid treatment for cancer related symptoms! More studies need to be done, but if we can balance the control of the inflammatory process and cytokine production and properly sway the immune system towards effector cells, rather than self recognition we may achieve control of disease and symptoms. But we always need to be wary of tipping the balance in the wrong direction.

Pharmacokinetics and Dynamics of Treating Patients Pain

Opioids, natural, semisynthetic or synthetic remain the essential ingredient in the armamentarium for treating cancer related pain. Morphine remains the World Health Organization gold standard front line standard. Experienced cancer physicians have all used doses far above the standard dose for short term, post op or orthopedic pain seen in a non-cancer patient. Cancer pain, especially during hospice care can be chronic and unremitting and as discussed below, we know there is large inter-patient pharmacologic variability either at the opioid receptor or classically studied parameters of drug metabolism.

Govoni and colleagues (2008) provide a recent review of the known polymorphisms in the μ opioid receptor as well as of COMT (catechol-o-methyl transferase). There are already about 100 variants of the μ-receptor gene (OPRM1) and at least one important, functional variation in the COMT gene. It is clear that patients who are compound heterozygotes for these proteins need very different doses of morphine to attain analgesia. More over there are significant polymorphisms in the metabolism of and excretion of morphine based upon polymorphisms in the cytochrome P450 family of enzymes. This system is responsible for many of the drugs we use. CYP2D6 is important in about 25% of drug metabolism.

The ABC family of efflux pumps also has functional polymorphisms altering the kinetics of opioids and anti-neoplastics. The practical importance of knowing about these host (aka patient) characteristics is that as we prescribe pain medicine we are aware of the possibility that dosing can vary by 5-10 fold between patients and there are even some variants that result in the inability to activate/metabolize drugs such as codeine. Even with respect to morphine, the differences in the hepatic metabolism of morphine to morphine-3-glucuronide (M3G) and morphine-6-glucuronide (M6G) will affect therapy. M6G has analgesic properties and M3G, the main metabolite has antagonist activity and also be responsible for side effects (discussed in Govoni et al., 2008). A recent excellent review summarizes the rapidly expanding area of pharmacogenetics (Holmes et al., 2009).

With respect to other opioids, I would offer several brief comments: the synthetic opioids such as buprenorphine and fentanyl also have specific metabolic fates and their potency is dependent upon parent drug for the former and on free drug in the bloodstream for the latter respectively. There are additional narcotics such as oxycodone and μ receptor agonists such as tramadol that are not discussed here. From a practical point of view, I generally start with morphine and escalate the dose as needed. Switching to other agents is because of the rare allergy, side effects and toxicity and/or tolerance or patient preference for any reason. As a matter of practice, I personally do not use meperidine in pediatrics. The dosing is 10 times greater than morphine so I always remain concerned about prescribing an overdose if I start with it and then switch to morphine. Also normeperidine is a partial antagonist with a prolonged half life and can cause seizures. On the other hand despite cultural implications, at least in the United States, methadone, with a prolonged half life compared to morphine has provided much needed, facile oral dosing for some patients and may be under utilized compared to other longer acting agents in this class. The choice of opioid may vary by availability and custom but as long as the used correctly, effective analgesia can usually be attained.

The significance of noting just some of the pharmacokinetic issues here is not so that we routinely measure these compounds as we sometimes do with anti-epileptic medicines or follow kinetics of some anti-cancer drugs but to serve as a reminder that we need to be cognizant of the potential marked variability between patients and drug interactions so that in the real world, we are more comfortable treating patients with the amount of drug required to eliminate suffering without being overly concerned with the absolute dosing.

Conclusions

This very brief discussion of cancer related symptoms should serve to remind us that: A) somatic and psychological issues co-exist; B) that pain is very often associated with and likely exacerbates depression; C) the pain and fatigue of cancer are results of complex interactions of tumor and patient and biochemically caused by inflammatory and immunomodulatory molecules; and D) the treatment of a patient's symptoms may depend upon the polymorphisms for drug receptors, drug metabolism and other polymorphisms in the cytokine family. The ultimate treatment is removal of the cause, but for most patients with advance cancer (estimated to be about 10,000,000 world wide on an annual basis) this is not possible so that we are left with treatment of the symptom(s).

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TRADITION, HERITAGE AND SPIRITUALITY

Spiritual Pain and Suffering

George B Brunjes

Abstract

Spiritual pain/suffering is commonly experienced by persons with life-limiting illness and their families. Physical pain itself can be exacerbated by non-physical causes such as fear, anxiety, grief, unresolved guilt, depression and unmet spiritual meets. Likewise, the inability to manage physical pain well can be due to emotional and spiritual needs. This is why a holistic, interdisciplinary assessment of pain and suffering is required for each patient and family. The mind, body and spirit are understood in relationship to each other and, in those cases, in relationship to a deity or deities are important to understand. Cultural interpretations of pain and suffering may conflict with the goals of palliative care. Understanding the spiritual framework of the patient and family can help to assure that the physical and spiritual suffering of the patient can be eliminated to provide a peaceful death. Spiritual practices may help in the management of physical pain.

Keywords: Spiritual pain and suffering - physical pain - patients - treatment framework

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Introduction

Dame Cicely Saunders, founder of the modern hospice movement, describes the intense suffering by dying patients and their family members as "total pain" – including physical, social, psychological and spiritual pain – all interactive.

"Total pain – all interactive". So, whose responsibility it is to address it? In traditional medicine, the general practitioner was the one called up as the only doctor to see the patient and treat the total patient. With the compartmentalization of the medical field, it was relatively easy to decide whose role it was.

If the patient has pain, call the medical doctor.

If the pain is psychological in nature, call the psychiatrist.

If social and involves family and friends, call in the social worker

If spiritual in nature, call in the …

But wait a minute, if total pain is all interactive, does it become the responsibility of only one member of a team to deal with it? Does it require a team approach? How do we go about becoming comfortable with understanding the cause behind spiritual pain, let alone deciding who should be treating it? Spiritual pain is an on-going issue, not something that needs to be addressed only at the last moment by a chaplain.

My first employment in hospice was as the Director of Pastoral and Bereavement Care of the Visiting Nurse Service of New York. As a member of the interdisciplinary team, we cared for patients and their families in three New York City boroughs of Manhattan, Queens and the Bronx. At first, people wondered why they needed a full time chaplain to serve this wide area. Others asked about my role – would I be responsible for "death bed conversion?" Others indicated that they had worked in hospital where chaplains were available, but never quite knew their role expect to "pray with the patients when asked." Few, if any, in the beginning, had any concept of what spirituality was all about – or even "total pain" as define by Dame Saunders. It took a little to help them understand.

In my hospice career, I have always very carefully drawn a distinction between spiritual and religious. By definition, spiritual is to rise stand above and/or see beyond the material expression of the universe. It involves a personalized system of beliefs though which an individual understands the meaning and purpose of his/her life.

All people have spiritual dimensions. Taking the religious teaching of the three faiths represented in this room, Islam, Judaism and Christianity, we all share a similar creation story that emphasizes that dimension. The creation story tells how God ("the Transcendent Other" – or what ever name we wish to use) took a lump of clay (or several pieces of different colors of clay) and breathed into it "the breath of life." That breath – however you chose to understand or name it (soul, spirit, breath of life, energy, or essence) is the core of the individual – his/her spiritual dimension. It is the gift of life granted at birth which continues with the individual until the moment of death when it returned to the Source from which it came. It binds the individual with The Holy Other. While it is the same energy that animates the life of the individual, it is as different as DNA. Common elements might be involved, but there are differences that make it unique to the individual. Each individual builds his/ her own unique personal system of beliefs to answer the basic questions

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of life, such as

Who am I?
Is there purpose to my life?
What do I hope to accomplish with my life?
What do I value in life?
How do I live out my relationships with others?
And the ultimate meaning of life and death itself.

Take a moment to ask yourself – what gives meaning to your life? Friends, career, family, nature, art, animals, music, a higher Power? List five of them. There probably are as many answers to that question as there are people sitting in this room. Is one answer more appropriate than another? Is one answer more important than another? It is, only to the extent that it is YOUR answer and has meaning for you. While you might even have similar items on your list from those sitting around you, how you rank them in order of importance makes your list different and unique to your understanding of the meaning of your life.

While each of us has this spiritual dimension, its expression varies from individual to individual. Spirituality may be expressed in the form of a religion as a relationship with a deity. How one understands the concept of "deity" can vary from a personal relationship with God, Allah, Adonai, to a more general relationship with other concepts, such as nature, energy, force, belief in the good of all, believe in the importance of family and community. Whatever is made the center of one's understanding of the universe becomes the object around which everything else is given importance and value. Even atheists have a personal belief system that helps them manage, understand and relate to the world around them.

Spirituality is always searching for the answers to the questions of life. These answers are never constant, but are fluid as we grow and experience the world around us and the world around us changes. Who I understand myself to be today will change because of a new experience or relationship I form tomorrow and now needs to be incorporated into my world view. How I understand my purpose in life has grown from that of a young man to a man now in his 60's. But these answers become one's faith system which is unique to the individual, is based on the unseen and unknown, and gives meaning and order to life.

"Religion", on the other hand, is a more structured belief system that addresses the same universal questions. Coming from the Latin word religare it means "to bind together". It, too, provides a framework for making sense of the meaning of existence. In addition, it provides rules and ritual that can provide a concrete way of expressing spirituality. Corporate and group based by nature, it often requires general adherence to a particular body of beliefs (doctrines) regarding one's relationship with the Deity in order to participate and remain a member of the group.

Is being spiritual the same as being religious? Both spirituality and religion involve the search for meaning and attempt to answer the question of the purpose of life. They, however, do not always overlap. I have illustrated this by drawing to separate circles – each one complete and separate to it. For some people, those we consider holy people, these two circles almost always overlap. Their spirituality is a driving force in their lives and how they chose to express who they are as their live out their faith. For others, rules and rituals can be always obeyed and followed to the letter of the law. There is however, no spirit behind what is being done – just that it is being done because one has to do it. For the vast majority of people, the overlapping of these areas occurs in varies degree from large to very small.

Let me give you an example. I recently finished showering at the local health club and was proceeding to get dressed. My routine for doing so is "religiously' followed each day. Certain articles of clothes are put on first, then others, and the system never varies. A gentleman next to me commented about his ritual in putting on his socks and shoes. One sock first, followed by the shoe on that same foot, and then the other sock and shoe. He would never vary it from procedure, he said, putting both socks on first and then the shoes. While he did this he commented about a TV episode he had seen many years ago about a similar situation being the butt of a joke. If asked why he did it that way, probably he could not give an answer, just that it had always been so. So religiously he followed his tradition, without understanding or sensing why.

It is important to remember that even when there is a corporate identity of an individual to a religion, each individual still develops his/her own unique relationship with the Transcendent Other. One cannot simply conclude because the chart indicates Orthodox, Jewish, or Muslim that you will be able to know exactly what the individual believes or what is important to him/her. These things can be influenced not simply by his own spiritual growth or the religious teachings of the accepted religion, but by such factors as family traditions, community and culture. One's relationship to his/her Higher Power or God may be religious or philosophical, expressed or unexpressed. So we need to begin by asking the patient – what gives meaning to YOUR life?

Illness, especially life threatening illness, will always raise spiritual questions about forgiveness, afterlife, the value of life, etc. not normally asked in the course of daily living. "Why is God punishing me?" "What did I do to deserve this?" "Life isn't fair!" are all questions that indicate the presence of spiritual pain and suffering. Confronted with their own mortality, the individual faith system is tested.

For some, it is a source of strength and hope as they rely upon their understanding of the Transcendent Other to comfort and be with them this crisis into new life after death. For others, their religion can contribute to their spiritual pain and act against the very purpose of palliative medicine. Pain may be seen as a "payback" for a particular lifestyle they have led (i.e., disobedience to God's law, willful separation from God's command, sin, and alienation from the will of God.) If they see pain as "redemptive" they will welcome it and encourage more as a way of earning more points for "getting into heaven." For some, philosophically speaking, the request that nothing be done to take away the pain comes from a sense that "it tells me I am still alive." We need to always begin by asking the patient – “what gives meaning to your life?”

Loss of Identity

Spiritual aguish can be considered in terms of the past (painful memories, guilt), the present (isolation and anger) and the future (fear, hopelessness). As the basic assumptions of their personal belief system are being tested, the patient can experience the sense and reality of loss. The first and major loss is their sense of identity – who am I?

For many years in training hospice staff and volunteers, I used a simple tool that I referred to as “Ten Questions”. Giving them each a sheet of paper and a pencil, I would as a series of ten questions. “Who are you?” They would quickly write their answer and look up for the second question. “Who ARE you?” I would ask. “You already asked that question” some would respond, while others wrote. The same question a third time, a fourth time and so through question number 10. “Listen carefully, I would say: “why are you?” Inevitably, the answers were given in terms of nouns – telling me about their relationships with other people, or their professional life, but rarely would someone use a verb or adjective to describe themselves. When I lose a relationship, I lose my identity and need to go exploring to find out who I am.

As I worked with the dying, I saw again and again that such situations are not unique; they form a common part of the search for meaning. There are three basis questions that people ask when confronted with their mortality. They are the questions that are associated with the struggle to come to terms with the past as it was or could have been, the present as it is, and the future that stretches as yet unknown before them. I hear the dying ask the questions when they are told we have run out of treatment options. I hear the grieving ask them after their loved ones have died and they are left alone. The three questions are:

Who have I been?
Who am I now?
Who am I becoming?

“Who have I been?” is the question of the struggle associated with the past, as the dying person faces the loss and goes through the process called life review. It is usually the first question that appears after the shock and denial phase of being told the nature of the illness begins to wear off. It is also expressed in the angry “why me?” as people begin to review their lives and find nothing that they have done that could merit the state in which they find themselves.

This is especially true with the younger patient. They have not yet had the opportunity to live their lives and accomplish all the dreams that they saw for their future. For others, it is the lives filled with regrets and “if only’” as individuals wish they could go back and either undo that they had done, or do so much more. The opportunity presents itself to forgive and/or be forgiven as walls are taken down and bridges are built or rebuilt. It becomes the time to tend to unfinished business, to tie off all the loose ends that they have put off to some more convenient time in the future. For the living, who fail to do so, it often can produce fear at the time of their own death.

During several sessions with a 92 year old woman, she went back to do this life review. Like an onion, she unpeeled the layers of her life. Each layer was a little more risqué that the one before. Finally she turned to me, having tied off many loose strings into a nicely finished bow, she shared with me an incident she had carried as a burden for over 65 years and never told another human being. When he finished sharing her story, she said “Now, if you are Roman Catholic, you can give me absolution.” She herself was Episcopalian, and I am a Lutheran. I was still able to tell her God had forgiven her a long time ago and now was the time for her to forgive herself.

“Who am I now?” is the second question that people ask. It grows out of the struggle to find completion at this stage when life as they experience it might no longer continue to be. As they are deprived of the roles that they once played, and the responsibilities they once fulfilled, each loss further strips the patient of a sense of meaning and worth. The question becomes, not only “whom am I now, now that I am no longer who I was?” by equally as important “am I still loved now that I can no longer be or do what I once did?” and "am I still needed?”

Sometimes these roles and sources of meaning are taken from the patient by the progression of the disease. If the patient has always been an independent person and cherished a sense of independence and the ability to do for himself/herself, the value that that gave is taken away as he/she is confined to a wheelchair or bed. Now everything must be brought to them and done for them, and anger is the response to this sense of helplessness.

I recently had a mother and daughter come to see me. The parents had been married for over 60 years, and the husband had died. He had been the caregiver for his wife who had macular degeneration and was legally blind and unable to live alone and care for herself. The daughter lived in neighboring community and had moved in to care for her mother. Her mother was angry, not only about the death of her life long partner and love, but at the loss of her independence. She resented this lose of independence, and blamed her daughter for her condition and desired greatly to find a way to live alone at home She expressed that anger towards her daughter, who could not understand why this was happening since she had put her own live on hold to care for her mother. We talked about the mother’s feelings about the double loss she had suffered – the death of her lifelong partner and her independence, helped clarify the mother’s feelings, and looked for ways for the mother to gain a new sense of control over her life teaching her how to talk to her healthcare providers about living options she could consider for herself.

Sometimes the roles and sources of meaning are taken away by well meaning family members and health care professionals who only wish to ease the final moments of the patient and to protect them. This also increases the sense of loss, causing the patient to feel a deeper sense of isolation and loneliness.

“Who am I becoming?” grows out of the struggle to come to terms with a yet unknown future. It is the question that revolves around how well the patient has been able to deal with the first two questions. It is the question that brings with it either a great deal of hope and assurance, or fear and helplessness.

Fear/Dread

In Shakespeare's play "Hamlet" the author has the hero contemplate death and what occurs afterwards and concludes: "To sleep, perchance to dream; ay, there's the rub; for in that sleep of death what dreams may come when we have shuffled of this mortal coil, must give us pause: there's the respect that makes calamity of so long life."

Fear almost always relates to the imagined future rather than to the reality of the present. What is it like to actually die? If I have lived my whole life holding on, what will I experience when I finally let go? Will it hurt? Will I feel anything? What will actually happen to me? What will I experience when the spiritual aspect of my being separates from the material body?

There are no easy answers to these probing questions, but, nevertheless, the fear is real and needs to be expressed and explored with the patient. When this fear is especially strong, I have often encouraged a person to consider if there is a strong love attachment with some who is already dead, if that person could come and help them make the transition so that they will not have to do it alone. Strange things happen in hospice that I cannot fully understand myself. A social worker I hired early in my career worked for our program for 18 months before her husband died. At the funeral, she shared with me that her experience in hospice had prepared her for his death, but especially one event which occurred three days before he actually died. She looked out the living room window, she told me, and saw her father-in-law (who had died many years before) standing in the garden looking toward the house. She finally realized at that moment that Joe was going to die soon, and he did three days later.

"Where am I going?" is what they wonder. Our concepts of what happen to us after death are strongly influenced by our religious training. Has my life been worthy enough to be with The Transcendent Other, or do I wind up in the other place? And what if I don't like it there? Can I come back?

The nurse told me that a non-practicing Jewish patient wished to talk with me. I suggested I could find a rabbi to visit, but the nurse said she insisted on seeing me. When I arrived at the home, I sent an hour visiting with her. She had but one request – "tell me what heaven is like." I tried to draw out her own understanding of heaven, but she insisted on simply listening to me. I recited from the books of the Old Testament and my understanding of Jewish theology. After an hour she thanked me and I left. Three days later she continued her quest for knowledge by inviting a rabbi in and presented the same request. She either didn't like my response and she decided to gather more information before dying, but a week later, having gathered additional information she died with some idea of where she was going.

There is a third fear of dying that I have begun to discover among patients. This fears deals neither with what will I experience as I die nor where am I going, but deals with unresolved issues with those who have already died. How will they treat me, and/or what I will say to them once I see them introduces another dimension of fear. An elderly black women living in the south Bronx, dying of advanced lung cancer, sent word she would like me to visit. I did on a number of occasions. Each time she revealed a little more about her personal history, and the recurrent dream she was experiencing. She was one of seven children. Her father had his favorite three and her mother her favorite three – which quickly told me someone was left out. Her dream consisted of being in beautiful places, dressed in beautiful clothes which she knew did not belong to her. Other people were present in the same place, dressed in the same fancy clothes. She indicated she wanted to ask them if they owned their clothes, but never did. All she wanted to do was to find the exit to get out of there as quickly as she could before "anyone found her out I was there".

The "anyone" finally was acknowledged to be her mother. She had long ago reconciled with her father's lack of love, but being a mother herself, she could not understand her mother's behavior. She was afraid of what she would say to her mother, and rather than face situation, would run away and say nothing. We talked about writing her mother a letter which could be placed in the casket with her and her handing her the mother the letter when she arrived. This eased her fear, allowed her to express her feelings to her mother, and she died peacefully one week later, without a recurrence of the dream.

Anger

Anger is another indicator of spiritual pain, and something that is normally experienced in some form during the dying process. It is a common reaction in advance disease, both for the patient and their families. It occurs when they are threatened, frustrated, helpless or feeling rejected. Anger is also a common response to grief; many people are more comfortable with anger than with sadness.

That pain can be, and usually is directed both inward and outward. While the patient might not be fully aware of the true source of the anger, it commonly is projected or displaced on to situations, doctors, nurses, family members. We probably have all experienced such anger in the past. It is also directed toward God. There is a sense of betrayal and abandonment by God. "I have kept my side of the agreement to worship you, why are you letting this happen to me? Why have you forsaken me"? This for many is the "unforgiveable anger", and one that terrifies both patients and their families. They are often unwilling or unable to acknowledge this anger for fear of punishment from the One who they feel can truly help them the most. So anger is shared with and distributed with those who are present.

I have to often help family and friends understand this anger on the part of the patient. As death approaches, it is easier for the patient to separate from someone who is angry with them, than from those they love and still cling to keep them here. So they push away in anger to make it easier to separate and leave when their time comes.

When I visited with patients, I sometimes would image myself as a huge wastepaper basket. I would hold my arms out in front of me and allow the patient to discard all the feelings that they need to be rid of as they performed the process of life review. As they dealt with feelings they had carried with them for years, I would be willing to carry them away and discard those things they had dealt with and no longer need to spend energy on. I would never allow them to become part of me, but would empty the basket as soon as I left the patient's room.

Depression

Depression is another sign of spiritual pain and suffering. It is a normal part of the dying process, and one should not simply jump at the opportunity to deal with it with medications. At team meetings, the nurse would often announce that she wanted to order an antidepressant because the patient was depressed. I would always ask if she could identify the source of the depression – what the patient was depressed about. If the answer was no, I would ask if the social worker or chaplain had visited to speak with the patient. Again, if the answer was no, I would request such a visit to see if we could identify and deal with the cause of the depression rather than simply masking the symptoms with medications. It might be possible to "cure" the situation with more medication, but that might not always be the case. It might in itself be a cause of the depression – "I am beginning to feel like a medicine cabinet with all the pills that I am taking and no longer an individual."

People become depressed when they think about their approaching death and all that they are leaving behind and will never have an opportunity to experience – the wedding of a son or daughter, the first graduation of a grandchild from college. One patient I visited simply needed someone to sit with her and let her cry. She had been the steady rock in the family for her whole lifetime, and now needed the family to be strong for her so she could complete the anticipatory grief to prepare for her death. They were unable to allow her to cry, or cry in front of her. They needed her strong, especially her two sons. Needing to complete her own grief work, she was unable to fulfill that role for them and had become depressed. Sitting with her, I listened to her speak through her tears of her needs, her hopes for children and grandchildren's future, and then ways to she could write letter for important events in their lives to still be there for them even though she was dead and not physically present. Two days later the nurse announced she wasn't depressed any more.

Other Characteristics of Spiritual Pain

There are many other characteristics of spiritual pain which need to be considered by the team and acknowledged in the plan of care

Pain, constant and chronic that is not relieved with medication.

Withdrawal or isolation from their spiritual support system

Guilt/low self esteem

Feeling of failure in life

Lack of sense of humor

Sense of unforgiveness

Despair

It is important to realize that in dealing with spiritual pain, there may not be concrete answers to the questions that are being posed. It is not as important to try to answer the questions, as it is to allow their expression and for the patient to be allowed and encouraged to work through their own grief process.

Who on the team works meeting the need of the patient and family is not as important as it is that the work be encouraged and allowed. A social worker once came to me to express concern that he had "trampled on my territory." A woman shared with him a comparison of the dying process with an experience from her youth. She had grown up in the beaches of the state of South Carolina, and as a teenage had ridden dirt bikes on the sand dunes. The only light shone out from the single head light on the bike and there was blackness all around her. Her dying process brought her the same sense of fear and exhilaration. I shared with the social worker that exploring the experience with her was more important than with whom she shared it. We never know which member of the interdisciplinary team the patient and/or family will form bonds with during the process. Therefore, all need to be ready to listen and help in the process of dealing with spiritual pain.

Spiritual Healing

Spiritual healing, as well as psychological and emotional healing can happen even when physical cure is no longer possible. First, it can occur when the patient is helped to find new meaning for the remainder of his/her life. By helping the patient engage in the process of life review, he/she can remember the past and bring a new sense to the present. It can help them interpret the experience of illness in the context of his/her life as a whole. Finding release from the past will increase their confidence and their ability to cope with present difficulties, rather than having a sense of helplessness that may have overcome them.

Second, renewing hope is another avenue for spiritual healing to occur. Hope is a dynamic, fluid experience that flows through the person's life. It changes daily, based on what is happening to the patient. I learned early on to ask a patient "how are you feeling today?" knowing that each day will be different for each patient. The same is true with hope, which changes daily. "What are you hoping for today?" allows the caregiver to be emotionally and spiritual present to the patient in the face of suffering and despair. This will increase the bond of trust between patient, family and caregivers. Nothing is more hopeless than being told, in words and/or deeds, that "there is nothing more that we can do for you." Remember also, that individuals may take many more emotional and spiritual risks when facing their own deaths that they might not be willing to take otherwise.

Third, helping patients and their families express the emotions that accompany grief and loss on their way to final acceptance allows healing to occur. As persons are less able to engage in the activities of daily living due to functional limitations, they have time for spiritual reflection and spiritual practices. Because family members will not have another opportunity with their loved ones, helping them heal, reconnect and reconcile may bring peace and comfort to all.

Ira Byock, in his book The Last Things that Matter Most, A Book about Living, indicates that when the patient and family do not know what to talk about, we can suggest the following four topics. Each sentence alone can take hours to talk about and open communication that along has been bottled up:

Please forgive me. I forgive you.
Thank you I Love you.

I have included a fifth, which ultimately must be spoken by the patient and their loved ones when the time is right:

Good bye.

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TRADITION, HERITAGE AND SPIRITUALITY

Practical Approaches to Spiritual Pain

George B Brunjes

Abstract

Spiritual pain/suffering is commonly experienced by persons with life-limiting illness and their families. Physical pain itself can be exacerbated by non-physical causes such as fear, anxiety, grief, unresolved guilt, depression and unmet spiritual meets. Likewise, the inability to manage physical pain well can be due to emotional and spiritual needs. This is why a holistic, interdisciplinary assessment of pain and suffering is required for each patient and family. The mind, body and spirit are understood in relationship to each other and, in those cases, in relationship to a deity or deities are important to understand. Cultural interpretations of pain and suffering may conflict with the goals of palliative care. Understanding the spiritual framework of the patient and family can help to assure that the physical and spiritual suffering of the patient can be eliminated to provide a peaceful death. Spiritual practices may help in the management of physical pain.

Keywords: Spiritual pain - interdisciplinary assessment - cultural framework

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Introduction

Having made many presentations to clergy on the topic of working with the dying, I often heard the statement: “We can’t wait to hear what you have to say. You going to tell us exactly how to respond when a patient says …” I quickly learned that their expectations were greater than I could deliver, and needed to prepare the soil for planting. I would present three short situations to them and ask them to respond. I would ask you to do the same, by having a piece of paper and pencil handy to jot down the first answers that come into your mind in each situation.

First, you are in the hospital having talked with your doctor about surgery that is life threatening, and may not be successfully completed. There are all sorts of complications and risks involved, but you have decided to proceed with the hope that all will end well. After the doctor leaves, I, as your priest/rabbi/imam come to visit with you. What would be your expectations of me?

Second picture: You have cancer, and have been undergoing a series of treatments that have put the disease in remission several times, and prolonged your life. Your doctor has just visited to tell you that the cancer has reoccurred and there are no further procedures available at this time for you. If the disease runs it normal course, you have 3 months to live. After the doctor leaves, I, as your rabbi/imam/priest come to visit you. What would be your expectations of me?

Third picture: You are recently bereaved. Your life partner of 30/40/50 years has died. You have completed the prescribed period of mourning according to your religious tradition. Your family has returned home, and you find yourself home alone. I, as your imam/rabbi/ priest come to visit you. What would be your expectations of me in such a situation?

I have found that the usual expectations that people have of me in these situations do not involve religious ritual – at least not as top priority.

“Listen to me express my fears”
“Calm my anxiety”
“Reassure me about the future”
“Tell me you will look after my family”
“Sit with me and do not leave me alone”

These are among the most familiar requests that are made. There is always the request for prayer, and reading from Scripture. But these are never the first expectations that people express. Consider your own responses to these three situations that I presented to you. What were you looking for? What were your expectations? I share this with you as a reminder that what you need and hope to find in your spiritual counselor as you deal with serious illness and death is exactly what other people are looking for in us. Twenty minutes is not a long time to cover practical aspects of dealing with spiritual pain, but allow me to paint some broad bush strokes that may set you thinking about how you can do it, and how you might prepare yourself do be what your patients need,

Illness, especially life threatening illness, will always raise spiritual questions (about forgiveness, afterlife, the value of life, etc.) not normally asked in the course of daily living. Because the illness has taken away many daily activities, the patient has more time to consider spiritual issues. We, the professional caregivers, should be able to discern these questions both through their

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physical and verbal manifestations.

Physical signs of spiritual pain and suffering might include:

- Emotional:
  - Restlessness, agitation, anxiety
  - Denial of illness or of reality of prognosis
  - Powerlessness or loss of control
  - Depression/flat affect
  - Dreams or nightmares
- Behavioral:
  - Refusal to take medications
  - Refusal with help with activities of daily living
  - Power struggles with family members/care givers
  - Frantically seeking advise from everyone
  - Withdrawal/isolation
  - Statements about not wanting to be a burden
  - If active in religion, refusal to see religious leader or stops practices

Patients and the families might express their spiritual pain in such statements as:

- "Why me?" (unfairness)
- "I don't want to be a burden?" (unworthiness)
- "What's the point?" (hopelessness)
- "It's a punishment!" (guilt)
- "No one really understands" (Isolation)
- "I'm a coward" (vulnerability)
- "God doesn't care" (abandonment)
- "But I've led a good life" (punishment)
- "Why does God allow suffering?" (confusion)
- "My life's been wasted" (meaningless)

We need to be practical in our approach to dealing with this pain. I see that coming to play first in the actions WE can do to prepare ourselves, rather than something that the patient and family needs to do.

First, forget the "I". I know people are truly concerned for those who are facing life threatening illness and death. So many times, I have heard people worry and wonder about what they should say and do. "What if I say the wrong thing? What if I do the wrong thing?" So worried about saying or doing something wrong, they say and do nothing, and isolate both the patient and family through their lack of action.

This is not about you or me, but The One whom we represent. Learn to become the channel or instrument through whom your God can work. As soon as you begin to wonder and/or worry about what you are going to do and/or say in such a situation, you have place a hindrance in God's way. As an example, I was called one day by the bishop to visit with a local pastor whose wife has just committed suicide. I knew the couple well, and had been with them on many social occasions over several years. It was a 45 minutes drive to his house, and all the way there I kept thinking what do you say in a situation such as this. Finally, I turned it over to God and said "I don't know what to say or do. Work through me and don't let me get in the way". I spend over 4 hours with the pastor that day. For many months afterwards, he would tell people how I had helped him survive that experience by what we talked about. To this day, I can not remember a word of what I shared with him, but realize that it was not talk from me, but through me, that enabled him to survive his wife's suicide.

Do not worry about doing the right thing, or saying the right thing. The sense of abandonment the patient and family experiences is far worse that anything else. There is always something that can be done, even if it is no more than sitting there in silence and not leaving them alone.

Second, become comfortable with your own mortality. We are the dying, you and I. We all live with a terminal condition called "life." We are so used to seeing everything as a "life or death" situation, that we have failure to recognize that they are not opposites. Birth is the beginning of life, just as death will be its ending. Life is the period that stretches in between the two events. There is a mentality in the United States, and other parts of the world as well, that if I eat the right things, don't drink, don't smoke, get enough exercise, stay out of dangerous situations, get a physical examination from my doctor annually, etc, etc, etc, then I can live ____________. I'll let you fill in the word, but it usually is "forever".

The dying have not only taught me about my own mortality, they have also taught me to make the most of every day. People postpone to tomorrow what they would like to do in order to accomplish what they think they need to do today. Having sat with so many people who have long lists of "If only", I have learned to make today a combination of what I have to do, as well as what I want to do. Hopefully, I will live life more completely, and have less regrets when my death approaches.

Third, deal with your own spiritual/religious issues. If you are not comfort with your religious expression or relationship with God, you are not going to be able to assist someone else with theirs. Early in my hospice career, I found that the nurses wondered what my role would in visiting with "their" patients – would I go in to do "death bed conversions"? It was only after I began working with them, and helping them resolve with their own issues about God and religion, that they would entrust their patients to me.

If you have issues about God and your religious experience, you will not be able to sit with another person and help them deal with their spiritual pain.

Fourth, learn to listen with more than just your ears. We humans are involved in four kinds of language communication: reading, writing, speaking and listening. The act of listening is the core skill of all interpersonal relationship. We spend more time in listening than in any other communication activity. Unfortunately, people do not listen very well. In order to really listen, there must be a capacity to hear not only with the ears, but to penetrate the outer layer of the words spoken and understand what is being said beneath them.

There are six people involved in any two person conversation:

What I meant to say
What I actually said
What you heard me say
What you meant to say
What you actually said
What I heard you say

Can you understand why there is all this poor communication going on?

Active listening involves listening with openness, acceptance and positive interest – an interest so alive that judgment about what is being said is withheld. Active listening involves listening with involvement and understanding of the person's feelings – not just the words spoken. Active listening involves listening with care and concern – that the other person really matters.

To listen to another's person in a condition of disclosure and discovery may be almost the greatest service that any human being ever performs for another.

Fifth, be practical. Learn to be emotionally and spiritually "present" in the face of suffering and despair. Trust does not take hours, days or weeks to build. It can be established in minutes depending on what attitude you bring into the situation. I remember visiting with a woman I had never met. Her daughter greeted me at the door to the apartment and talked with me for a minute in the entranceway. All of a sudden I heard of squeal of delight from another room. "I like you" the patient cried out, and I had not even gone into the room to be introduced to her. What did she sense about me sight unseen, simply by hearing my voice?

Trust takes openness, sensitivity and a willingness to be yourself. It takes time to listen carefully to what is said by the patient and family. It is learning to check yourself at the door, and bring that openness into the patient and family and be a compassionate presence to them. That takes but minutes to do. Oh, and yes, remember to pick yourself up on your way out!

Sixth, respect the patient's belief system. There is a wide variation of beliefs and practices in all religions, even those with set doctrine that all believers are expected to confess about God. These variations are created by the individual as they develop their own personal relationship with their spiritual God. They are also shaped by family tradition, the communities in which the individual resides and the culture in which they live. While two individuals might share a common name to their relationship with God (Jewish, Muslin, Orthodox), the practices and expression of that faith may vary greatly.

Our roles are not to convert the patient to our understanding of God, or the meaning we have found in our world. It is to uncover and help them utilize their own system of belief to do the work necessary to help them deal with death. Even if a patient had drifted far from a formal religious life, they still return to an early faith system when confronted with their mortality. A spiritual counselor's role is to help the patient explore their own faith and use it to provide support in this final struggle of life. Ask the patient their individual preferences and needs regarding spiritual care at the end of life, and, when possible, help to see that their needs are met.

Lastly, there are varieties of spiritual practices that can help a patient manage physical pain:

Prayer
Chanting
Acts of atonement
Acupuncture
Relaxation techniques
Ritual cleansing
Herbal remedies

Spirituality is among the most important cultural factors that give structure and meaning to human values, behaviors and experiences. Use it to help you care fully and assist your patients completely. Dame Cicely Saunders known to have commented: "It is not the worst thing for patients to find out that they have lived and are now going to die; the worst thing is to find out that they haven't lived and are now going to die." Obviously, no end-of-life care can solve life's entire dilemma completely. However, appropriate spiritual counseling can help patients come to terms with missed opportunities.

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Spiritual Assessment Tools (FICA) are available on the internet.

TRADITION, HERITAGE AND SPIRITUALITY

Beyond Quality of Life: the Meaning of Death and Suffering in Palliative Care

Lodovico Balducci

Abstract

The majority of patients treated for cancer will have pain at some point in their journey. Suffering and death are common events in cancer patients. Palliative care has been very successful in reducing the discomfort caused by physical pain, but does not have the means to address the questions related to the meaning of suffering and death. The soothing of physical pain has helped highlighting other forms of pain, such as spiritual and existential pain, that uniformly accompany the terminal phase of the disease. Health care providers should be able to identify existential and spiritual pain for several reasons. First, because misdiagnosing these conditions may lead to inappropriate use of opioids and sedatives and may deprive both the patient and the patient's family of the experience of death as an essential and irreplaceable experience of life. Second, because spiritual and existential pain may be addressed by properly trained professionals that should be involved in the management of the patients when needed. Chaplains and spiritual directors have no lesser role in the management of a patient than a cardiologist, a surgeon or a psychiatrist. Third because clinical scientists cannot close their eyes in front of one of the most common human experiences falling under their domain. Lack of training and of full understanding is a lame excuse for skirting the suffering of a person dying under our eyes. Health care providers unwilling or unable to abandon their areas of comfort and to embrace new and risky experiences are a liability for themselves, for their patients, and for the society they serve. Both spiritual and existential pain address the basic questions of human consciousness: while are we alive? Why do we die? Spiritual pain is most commonly experienced by a person who has a religious or otherwise sense of transcendence and may be helped by a hospital care trained chaplain. Existential pain is more typical of a person uninterested in a transcendent context and may be more challenging to address in the health care context. Though both may produce emotional pain, neither is by itself a form of emotional pain and cannot be fully cared for by a counselor. The clinical definition of spiritual and existential pain is evolving and so is its treatment. Classical clinical trials have little to offer for these conditions. Qualitative research in its various forms, including open ended questions, content analysis and mainly personal narrative are the most promising forms of research to comprehend spiritual and existential pain.

Keywords: Cancer suffering - palliative care - existential pain - spiritual pain

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Introduction

The preservation of quality of life is seen as the main goal of patients receiving palliative care. The assessment of Health Related Quality of Life (HRQOL) has become usual in all forms of medical practices, including oncology. The acceptance of HRQOL assessment as a clinical tool should be credited with restituting to medicine the focus on the person (Granda-Cameron et al., 2008). One of the lasting consequences of this process has been the awareness that the whole personal experience cannot be circumscribed by questionnaires no matter how much detailed. Together with and beyond physical and emotional comfort, the person and especially the person affected by serious diseases needs to find the meaning of his/her suffering and his/her impending death. He or she needs to reconcile him/herself with a past populated by regrets, mistakes, guilt and rancor. In other words, physical and emotional comfort are interwoven with the existential experience of the person, with a form of existential distress that no drugs or soothing words can alleviate (Puchalski et al., 2009).

In this article we contend that one way to address existential distress in a terminal patient is to lead this patient to recognize and accept the meaning of personal suffering and death, and in the process we explore novel instruments to recognize and address existential distress.

This contention is based on the assumption that death is unavoidable. If death is the ultimate enemy, we all are doomed to failure as all of us are going to die. Rather than avoiding death, accepting death as part of life is a basic human need and a strategy to conquer death. The

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Biblical book of Qoleth had highlighted this simple truth 2500 years ago: " There is a time to be borne and a time to die…." This consideration is particularly relevant today, when one is able to manage his/her own death, and decide when the time has come to let death to take over. We suggest that the quest for personal meaning, rather than personal comfort is the compass guiding this decision. Human history is full of examples of individuals who have sacrificed their comfort, their wealth, and sometimes their very life to achieve a goal important to them. This may include becoming accomplished artists, athletes, professionals or missionaries. Thus, near death situations offer a unique opportunity to demonstrate how quality of life considerations should be complemented by considerations on the value and meaning of life, in medical decisions. We' ll start the presentation with a clinical case.

Clinical case

The young violinist. At 17 John was diagnosed with rhabdmiosarcoma of the leg. Despite surgery, radiotherapy and aggressive chemotherapy, by age 18 his cancer had recurred and had invaded both his lungs. After the failure of experimental treatment, we let him know that he would have died in the next few months. Both he and his mother who was a widow and had no other children appeared lost even more than depressed or desperate. I believe the holocaust victims must have felt that way when they were separated from their family and herded toward their ultimate fate over cattle trains. All of a sudden they were taken away from all familial surroundings and led toward the unknown in an uncomfortable and perilous journey, having lost all attributes that they had learned to identify as humans.

The hospital chaplain started paying daily visits to John. As John and his family were agnostic and had no church affiliation, he did not even try to mention the name of God. Instead, he asked the patient to think back to his brief personal history and to extract out of it the moments he considered more meaningful, the times he had felt best and worst about himself. John was a promising young violinist. For his fifteenth birthday his mother had bought him a very expensive instrument, that had allowed him to take part in regional performances, with remarkable success. Before his cancer recurred he had been scheduled to participate in a National competition for young musicians in Chicago. During his performances he had felt both distressed and fulfilled: distressed because he had not reached yet the flawlessness he aspired to, fulfilled because he had realized that perfection was within his reach. He was aware to have a unique gift that would have enriched the world, he had identified what he was good for. This sense of fulfillment was reinforced by his girl friend, a 19 year old freshman in college who had attended one of his performances and let him know she considered it a privilege to accompany and assist him in his journey to excellence. The awareness of a unique vocation and mission also gave meaning to the humiliation he had suffered during childhood and adolescence. In primary school his schoolmates had conjured against him: they considered him a nerd with weird tastes and joined him only to make fun of him. He had been regularly excluded from other children's game and from party invitations. Indeed, trying to overcome his isolation, his parents had invited fifteen kids to his tenth birthday party and only his two cousins showed up. The girl with whom he had his first sexual encounter at age 14 mocked him when he could not contain his orgasm and made fun with the coeds of his "lean dick." Close to death he had no problem to call back these painful memories he had suppressed for a long time. In the light of his accomplishment as a violinist, the rejection of his coeds appeared as a necessary consequence of being uniquely gifted. He realized that his deeper fulfillment derived from what he was able to give to the world rather than from what he was able to take from others.

The exploration of his life, led by the chaplain, operated a progressive change in the attitude of John and that of his mother. The daily visits to his room had become more prolonged and relaxed. Immediately after his cancer recurrence his eyes had avoided mine and his answers had consisted of barely hearable monosyllables. In the following days his countenance had changed to that of a proud host showcasing his home for his guest. He started questioning me about my family and my work and once commented that I looked tired and I should have taken some time off. Before he died surrounded by his mother, his girl friend and few like minded friends who had enjoyed his music, he made the following comment: " The last year of my life has been the most fulfilling and meaningful. Through dying I could appreciate my unique mission in this life and feel to a full extent the depth of love by which I have been surrounded; these discoveries have redeemed all the pain I had encountered in my life."

John's history underlines how meaningfulness and creativity supersede comfort and possessions when it comes to personal fulfillment. The case illustrates how personal riches consist of what one is able to give to the world rather than of what one is able to take from it. When he could revisit them at the light of his later accomplishments, the defeats of his earlier life appeared to John as a welcome price to pay to discover and develop his unique vocation; he did not begrudge them anymore. Pain becomes fully acceptable and welcome when one can understand its sense.

In addition, the proximity of death allowed John to enjoy his life fully, in his own words. Thanks to death he had been able to distillate out of life what really had mattered to him, like the few drops of rose essence extracted from thousand of Bulgarian roses that keeps alive the perfume of the flowers for years after they have gone. I like to compare John's journey toward death to that of a traveler who is allowed only 12 hours to visit Rome and decides to go to the top of the Gianicolo hill, from where he can get a global vision of the city and can select the monuments he really cares to see. In that way his visit can be unhurried and his impressions of the city lasting.

As a personal note, John's death was very consequential to me in two ways. First, he rekindled my own religious faith. I don't know whether John ever encountered God, but I gained a feeling of God and eternity in the progressive acceptance of his own death. The essence of his life involved two steps: the simultaneous acceptance of his sacredness and of its emotional toll. This twofold acceptance allowed him to die in peace, despite extreme discomfort from progressive air hunger. I could not help seeing the essence of John's life as lasting and imperishable, I could not help seeing in his death an encounter with eternity, that is with God.

Second, he and his girl friend overturned my perception of sexuality. Despite their inability to have intercourse during the last year of his life, by their own testimony they enjoyed intimacy more than ever, as they lay together in his hospital bed. I too had been the butt of my coeds' jokes, because of my sexual inexperience, and throughout my whole life I had felt haunted by the pressure to mount a satisfactory performance for my partner. Through John I finally understood what my loving spouse has tried to tell me since the beginning of our marriage: relax! This is not a context or a school test: let's enjoy each other as we are.

John's history shows how death and suffering may become an opportunity to find oneself. With the help of the chaplain he could isolate and enshrine the most consequential aspects of his life, those that made life worthy of living for him. His decaying quality of life that would have been scored very poorly by any of the instrument of common use, had not been an impediment to find lasting peace in contemplating the ultimate sense of his life.

Analysis of the Case of John

The year has been 1976. The hospice movement in the USA was in its infancy; most of the patients received terminal care in the hospital and we, the physicians knew very little about the management of pain and discomfort. John experienced both severe pain and dyspnea in the last couple of weeks of life. By any HRQOL instruments, his HRQOL must have been terrible. Yet he died in peace with himself and with the world, confident to have left a small but inerasable print of himself

What did the proximity of death do for John? First of all, death allowed him to appreciate his own life. The balance between his unique talents and the suffering and ostracism he endured because of them was highly positive. Not unlike a mountain climber enduring all types of deprivation to reach a summit, he recognized that the persecution he has suffered by his peers was the unavoidable price to assert himself, to leave a unique print on this world.

Second, death and suffering allowed him to taste the sweetness and to experience the power of human bondage. Those of us who have experienced the relief of a sip of iced water after running a marathon in the sun know what I am talking about. The devotion of his girl friend that lied by him and hold his hands when he started Chaine Stoking represented a more lasting and meaningful relief that that afforded by an aerosol of morphine administered by a foreign respiratory technician , fearful of looking into his eyes.

Third, John experienced the privilege of being cared for. The friendly competition of his mother and his girl friend at his bedside told him that his suffering was not in vain. Rather than a burden he was perceived as a unique opportunity to provide care by the women of his life. They discovered the gift of being caregivers, they let him know that they had discovered in themselves unexpected and untapped riches of caring, thanks to his suffering and his death.

Another way to express the same concept is that John, and through him his girlfriend and his mother discovered their own sacredness. Derived from the Latin sacer that means "reserved" for a special function that only that particular person can accomplish, sacredness implies that each and every life is consequential, because each life has been endowed with a unique mission and a unique vocation. The concept of sacredness is strictly linked to the concept of "sacrifice" from the Latin "sacrum facere" that means "to render sacred, reserved, unique." As an example, in a marriage a couple makes a "sacrifice" of their sex, that is "reserve" their sex to each other, and in that way they find a final, unique meaning to their sexual expression. The opportunity to make a sacrifice of one's own life is the opportunity to discover one's own sacredness. John found his own sacredness at the time he had to abandon his life: by dying he realized and accepted his life as a sacrifice of his talent to the world surrounding him. The last sacrifice of John was that of the pain and humiliation he had suffered for being "different" from the other kids. At the meantime, the people caring for him recognized their own sacredness as "caregivers" for John. Together they discovered the meaning of the world redemption. In ancient Judaism, the redeemer was the person who paid the debts of a family member to prevent him and his family from being sold into slavery. The humiliation of his early life had been redeemed by the emergence of his art; the suffering of his agony have been redeemed by the care of his girl friend and his mother. At his death, John has been able to say with the country priest of Bernanos, drowned from the blood hemorrhaging from his stomach cancer "qu'est ce que cela fait? Tout a grace!" "no matter what everything is grace (Bernanos)".

The case of John represents also an opportunity for health care providers to define their role in ministering to sick and terminal patients. A recent convention on medicine and spirituality, summarized in reference 2, recommended that all people involved in the medicine, from the physicians to the houskeeper be instructed on recognizing spiritual and existential distress, so that the patient may obtain a proper referral to a chaplain or a spiritual director experienced in the management of this condition. In the last part of this paper I will try to highlight what we know and what we need to know about spiritual and existential distress.

Health Care Provider Roles in the Management of Spiritual and Existential Distress

The case of John had a happy ending because the chief of oncology at the Center where I trained had invited the chaplain to make round with us, and because that particular chaplain had been trained in clinical and pastoral care.

Without he presence of the chaplain during the daily round none of us would have even thought of referring John to a chaplain, given his professed agnosticism. If he had not been trained in clinical pastoral care, that chaplain probably would have not been able to minister to John's need. He would have probably recused himself or made an unfruitful attempt to bring John back to his denomination of Christianity.

The case of John had a clear message for health care providers. The diseases, especially those that threaten one's life, elicit concerns that are beyond the physical and emotional domain. These concerns, if unresolved, represent a stumbling block to the achievement of healing, the condition of peace with oneself that is always possible, even when cure is out of reach (Byock, 2009). Contribution to a person's healing is a well established and cherished duty of every health care provider.

Clearly healing implies awareness of a spiritual/existential dimension (Puchalski et al., 2009). It is not clear at this point whether existential and spiritual discomfort are separate entity or two faces of the same. Spiritual distress may have close correlation with ethics and religion, while existential distress may originate by one's inability to define the meaning of life in rational and emotional terms. An example of spiritual distress is that of a woman who had an abortion when she was younger and feels that the disease is God's punishment, while an example of existential distress is that of a man or a woman that witness the faltering of their enterprises as a result of the disease and ask themselves whether all of their work was in vain. Irrespective of these nuances, it is clear that spiritual/existential distress may cause an emotional pain that cannot be soothed by medication or psychiatric intervention.

After diagnosing spiritual/existential distress, the next step involves the referral to the proper specialist, that ideally is a clinical-pastoral trained chaplain. If he or she feels comfortable in doing so, the practitioner may engage the patient in a discussion of his/her problems, aware of one's own limitations. Unlike a chaplain, a physician or a nurse have no authority in matter of religion and spirituality and may be wiser in providing understanding rather than recommendations. In my opinion understanding and compassion may extend to the point of participating in prayers or other religious activities upon the patient's request. In any case judgment should be avoided at all cost. I still remember with disgust a cigar smoking psychiatrist that walked in anger out of the room of an American Indian woman calling her a "religious fanatic" because she was distressed by her husband's vasectomy that was not congruent with her Roman Catholic faith. In the absence of a properly trained chaplain or spiritual director, the provider should acknowledge the problem and try to allow the patient to find his/her own answers.

The practitioner may be involved in the management of existential or spiritual distress in the case of a dying patient, if the patient or the family ask for the administration of the so called "terminal sedation (Quill et al., 2009a)." This practice involves either the relief of terminal suffering from physical symptoms, such as pain and air hunger, which is not controversial, or the induction of a condition of sleepiness with sedatives in a patient unable to face the incoming death. This second aspect of terminal sedation is highly controversial and in my opinion is rarely justified, and never justified without a previous attempt to address the patient's concern that are causing this terminal distress.

Clearly, the practitioner needs to be in touch with his/her own spirituality (Puchalski et alk., 2009) to be able to deal with spiritual and existential distress. While religious faith cannot be mandated, familiarity with different beliefs in a multi-ethnic society is essential for any medical person, the same way that it is important to learn how to communicate bad news with simultaneous truthfulness and compassion (Quill et al., 2009b). One cannot expect the patient and their families to treasure one's death if they are not properly prepared to it (Rio-Valle et al., 2009).

Finally it is important to ask what kind of instrument one can utilize to study existential and spiritual distress. Clearly questionnaires are inadequate for this purpose. Qualitative research and especially the patient's own narrative may represent the clue to appreciate this important and elusive aspect of medical care (Morton et al., 2010). With the description of John's case I tried to provide an example of how narrative may highlight the most compelling aspects of a medical history when it comes to existential/spiritual distress.

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TRADITION, HERITAGE AND SPIRITUALITY

Religion, Medicine and Spirituality: What We Know, What We Don't Know and What We Do

Christina Maria Puchalski

Abstract

Religion and spirituality have been linked to medicine and to healing for centuries. However, in the early 1900's the Flexner report noted that there was no place for religion in medicine; that medicine was strictly a scientific field, not a theological or philosophical one. In the mid to the latter 1900's there were several lay movements that started emphasized the importance of religion, spirituality and medicine. Lay religious movements found spiritual practices and beliefs to be important in how people cope with suffering and find inner healing even in the midst of incurable illness. The rise of Complementary and Alternative Medicine as well as the Hospice movements also influenced attention on the spiritual aspect of medicine. The Hospice movement, founded by Dr. Cecily Saunders, described the concept of "total pain"--- i.e. the biopsychosocial and spiritual aspects of pain and suffering. Since the 1960's there has been increased research done in the area of religion and health and spirituality and health. Most of the studies are association studies which demonstrate and association of religious or spiritual beliefs and practices and some healthcare outcomes. More recently, studies on meditation have demonstrated significant improvement in health care outcomes and suggest meditation as a therapeutic modality. There are also numerous surveys that demonstrate patient need for having spirituality integrated into their care. Finally, a recent study demonstrated that patients with advanced illness who have spiritual care have better quality of life, increased utilization of hospice and less aggressive care at the end of life. In spite of all these studies, we still do not have a biological evidence base for mechanisms of beliefs and practices. There is considerable controversy over whether spirituality and religion can or even should be measured as criteria for integration into clinical care. Many believe that healthcare professionals have an ethical obligation to attend to all dimensions of a person's suffering, including the psychosocial as well as the spiritual and that ethical obligation is sufficient to require integration of spirituality into clinical care. Over the last twenty years, there has been an increase in the number of required courses in spirituality and medicine in US medical schools giving rise to a new field of medicine. In February of 2009, a national consensus conference developed spiritual care guidelines for interprofessional clinical spiritual care. These guidelines as well as the educational advances, research and ethical principles have supported the newly developing field of spirituality and health.

Keywords: Prostate cancer - stigma - family - secrecy - disclosure - shame

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Introduction

Religion and spirituality have been linked to medicine and to healing for centuries. Healing was in the realm of shamans, witch doctors, as well as religious figures such as Christ and many saints. Healing was and is considered a gift. Healing has played a significant role in the development of humankind. In the neo-Paganism tradition there were a variety of healing methods via herbal, or folk remedies. Eastern traditions have focused on the changing of the body's energy fields; Native American and shamanic techniques were present in Western traditions. Within all major religions, people believed in the power of prayer as healing. The understanding of the body and spirit also impacted how healing was viewed. In ancient times there was no division between body, mind and spirit. Thus, healing was focused on all these domains as one.

Historically, spirituality was an integral part of the mission and practice of healthcare institutions and providers. The medical model of practice in healing prior to the 1900's was service-oriented compassionate care. Medical care was primarily supportive and palliative, with limited options for curing disease. Healers utilized a holistic approach of physical, psychological, social, and spiritual care.

The first hospitals in the United States were started by religious and service organizations whose service and calling were manifest in a focus of care on the whole person. Men and women choose careers in the health professions out of a calling to care for others, a desire to

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serve, and a commitment to make a difference in the well being of their patients(C. Puchalski & Lunsford, 2008). In the 1900's, with the development of science and technology, a biomedical model developed that focused on "cure" as the leading practice in the view of the western world. There was a shift away from spirituality with a resultant separation of body ad spirit and a focus on the more physical body as the target of healing practices. The philosophy of present medicine began with Rene Descartes, in the 19th century, who alleged that the world operated according to mechanical laws without mention to meaning and purpose. As a result of this, discussion of spirituality and religion has long been considered inappropriate in the study and practice of medicine(C. M. Puchalski, 2001). In the early 1900's the Flexner report noted that there was no place for religion in medicine; that medicine was strictly a scientific field, not a theological or philosophical one. The Flexner Report, written by Abraham Flexner and published by the Carnegie Foundation in 1910, was a study of medical education in the United States and Canada .The Report called on American medical schools to use higher admission and graduation standards, and to adhere strictly to the protocols of mainstream science in their teaching and research (Flexner, 1910). This report reinforced the separation of body and spirit, focusing on scientific evidence of physical health, disease and treatment. Suffering was largely looked upon as physical pain.

In the late 1900's there was resurgence in the interest in spirituality and holistic care with the advent of the religious healing practices, as well as mind-body and integrative practices. In the mid to the latter 1900's there were several lay movements that started emphasized the importance of religion, spirituality and medicine. Lay religious movements found spiritual practices and beliefs to be important in how people cope with suffering and find inner healing even in the midst of incurable illness. The rise of Complementary and Alternative Medicine as well as the Hospice movements also influenced attention on the spiritual aspect of medicine. The Hospice movement, founded by Dr. Cecily Saunders, described the concept of "total pain"--- i.e. the biopsychosocial and spiritual aspects of pain and suffering (Puchalski et al., 2009).

Definitions

In addressing the area of spirituality and health, it is important to note that one of the difficulties with studies and discussion in this area is the lack of a uniform definition. Are religion and spirituality synonymous? Does spirituality only refer to transcendence? Can an atheist be spiritual? The challenge in defining spirituality is that any definition does not give justice to the full complexity of the human spirit and of the transcendent, however people understand that. Consequently, it becomes difficult to study spirituality and to find reductionist methods for integrating spirituality into healthcare and for studying it. In two consensus conferences, one in 1999 and one in 2009, definitions were developed for the purposes of having a common unified definition for study and clinical work. In the first conference sponsored by the Association of American Medical Colleges, academic educators in medicine and clinicians developed a definition suitable for clinical care. The focus of this definition was on spirituality as the way people understand meaning and purpose in their life and that this understanding can be expressed in many ways, religious as well as non-religious. This definition also related spirituality to the way patients and clinicians understand health and illness and how they relate to one another in the clinical context. This definition is:

"Spirituality is recognized as a factor that contributes to health in many persons. The concept of spirituality is found in all cultures and societies. It is expressed in an individual's search for ultimate meaning through participation in religion and/or belief in God, family, naturalism, rationalism, humanism, and the arts. All of these factors can influence how patients and health care professionals perceive health and illness and how they interact with one another"(Association of American Medical Colleges, 1999).

In 2009, over forty US leaders in palliative care, as well as spirituality and theology convened to develop models and guidelines for interprofessional spiritual care (Puchalski et al., 2009). In this conference, the definition developed is:

Spirituality is the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred."

Again, meaning and purpose was considered an important element of spirituality but also how people experience their connectedness to others, to nature, the moment or how they define the significant or sacred. What both definitions emphasize is the necessity of an inclusive definition--- that all people are spiritual and the expression and understanding of that is broad.

Research in Spirituality and Health

Since the 1960's there has been increased research done in the area of religion and health and spirituality and health. Most of the studies are association studies which demonstrate and association of religious or spiritual beliefs and practices and some healthcare outcomes. In addition, there have been numerous theoretical papers written on the importance of spirituality in understanding and coping with suffering. Spirituality is often a central issue for patients at the end of life or those dealing with chronic illness (King & Bushwick, 1994, Ehman et al., 1999; Astrow et al, 2001; Puchalski et al., 2004). Every individual has to make a decision as to whether one's life has meaning and value that extends beyond self, life and death. Dealing with these existential questions focuses on a relationship with a transcendent being or concept (Sulmasy, 1999). Numerous surveys have indicated that people turn to spiritual and/or religious beliefs in times of stress and difficulty. Particularly when people are faced with a life-defining illness, such as cancer and AIDS, questions about meaning and purpose in the midst of suffering arise. It is not uncommon for people to question God, fairness, and life choices. People often undergo a life review where issues related to their life, relationships and self-worth might arise. Spiritual issues that people face include hopelessness, despair, guilt, shame, anger and abandonment by God or others.

Spiritual and religious beliefs have been shown to have an impact on how people cope with serious illness and life stresses. Spiritual practices can foster coping resources (Halstead & Fernsler, 1994; Baider et al., 1999; Roberts et al., 1997; Koenig et al,, 2001), promote health-related behavior (Koenig et al., 2001; Powell et al., 2003), enhance a sense of well being and improve quality of life (Cohen et al., 1996), provide social support (Levin et al., 1997; Burgener, 1999; Koenig et al., 2001) and generate feelings of love and forgiveness (Worthington, 2001; Puchalski, 2002). Spiritual beliefs can also impact healthcare decision-making (Roberts et al., 1997; Silvestri et al., 2003). Finally, a recent study demonstrated that patients with advanced illness who have spiritual care have better quality of life, increased utilization of hospice and less aggressive care at the end of life (Phelps et al., 2009).

Spiritual/religious beliefs however can also be harmful (Pargament, 2007). Pargament and colleagues (Pargament, 2007) have studied both positive and negative coping, and have found that religious experiences and practices, such as seeking God's help or having a vision of God, extends the individual's coping resources and is associated with improvement in health care outcomes. Patients showed less psychological distress if they sought control through a partnership with God or a higher power in a problem-solving way, if they asked God' s forgiveness or were able to forgive others, if they reported finding strength and comfort from their spiritual beliefs, and if they found support in a spiritual community. Patients had more depression, poorer quality of life and callousness towards others if they saw the crisis as a punishment from God, if they had excessive guilt, or if they had an absolute belief in prayer and cure and an inability to resolve their anger if cure did not occur. Pargament, et. al. has also noted that sometimes patients refuse medical treatment based on religious beliefs.

There are many stories and anecdotal evidence that some patients are able to understand their illness as an opportunity for growth and for seeing their life and their relationships in a new way which enables them to find a meaning in their life that is more profound and gratifying than what it was prior to their illness (Puchalski, 2006). Tsevat and his colleagues found from doing focus groups with patients with HIV/AIDS that many found their lives were better than before their diagnosis (Tsevat et al., 1999). The same authors also found in a previous, small study, that most patients with HIV/AIDS were at peace with God and the universe. Finally, in a recent study we have shown that spirituality and non-organized religious activity were associated with HIV/AIDS patients saying their lives were better after their diagnosis than before their diagnosis (Tsevat, 2006). These results raise the question of whether attention to spiritual and/or religious issues might be beneficial to patients with HIV/AIDS as well as others with chronic illness.

More recently, studies on meditation have demonstrated significant improvement in health care outcomes and suggest meditation as a therapeutic modality. The mind has tremendous potential to impact how a person perceives life, stress, illness, dying and the world around. There are a number of studies on meditation, as well as other spiritual and religious practices that demonstrate a positive physical response, especially in relation to levels of stress hormones and modulation of the stress response (Benson & Stuart, 1993). The data demonstrates an association between meditation and some spiritual or religious practices and certain physiological processes, including cardiovascular, neuroendocrine, and immune function. These studies show a significant role for mind body interventions in stress management but also as an adjunct to treatment of chronic illness as well as end of life symptoms. For example, pain and dyspnea may effectively be managed by meditation or the relaxation response.

Spiritual beliefs and mindfulness help people tap into their own inherent abilities to heal and cope, find meaning and purpose, hope, and do well with whatever life offers them. By focusing only on the physical aspects of care, healthcare professionals, and as a result, the systems in which they operate, often neglect the very areas that research is now beginning to find critical to care. Such approaches allow for the recognition of people's ability to transcend suffering and offer opportunities for healthcare professionals to treat the whole person—body and mind. It has been generally accepted that spiritual practices such as prayer, meditation, yoga, tai chi, and many others counteract chronic stress effects on the body rebalance autonomic nervous system and HPA axis (Schneider et al, 2004; Puchalski et al., 2006).

While the data on meditation and other mind body intervention are beginning to show a biological effect, we still do not have a biological evidence base for mechanisms of spiritual beliefs and practices. How is it that prayer helps patients heal, or belief in the sacred of significant results in increased coping? There is considerable controversy over whether spirituality and religion can or even should be measured as criteria for integration into clinical care.

Ethical Obligation

Many believe that healthcare professionals have an ethical obligation to attend to all dimensions of a person's suffering, including the psychosocial as well as the spiritual and that ethical obligation is sufficient to require integration of spirituality into clinical care. In a recent ACP consensus conference on end of life, it was concluded that physicians have the obligation to address all dimensions of suffering including the spiritual, religious and existential suffering and further developed guidelines for how to communicate with patients about spiritual and religious (Lo et al., 1999). JAHCO requires that spiritual care be available to patients in hospital settings.

Physicians, nurses, and other health care professionals commit themselves to caring for patients as whole persons. That is the basis of what is currently called patient-centered care. Illness and injury disrupt a patient's life in ways that extend beyond the physical, thus caring for whole persons must involve care of the spirit as well as the body. Physicians, nurses, and other health care professionals commit themselves, often by oath, to caring for patients as whole persons. Because illness and injury disrupt a patient's life in ways that extend beyond the body, encompassing families, communities, and a patient's religious commitments, a commitment to caring for whole persons must entail going beyond the care of the body. Human being is spiritual being. When injured or ill, human beings naturally ask transcendent questions about meaning, value, and relationship. Because health care professionals take an oath to provide compassionate holistic care, attending to the spiritual as well as the physical constitute a moral imperative. Attending to the spiritual needs of patients is justified because spirituality is intrinsic to nature of being sick and caring for the sick. This imperative is based on ethical precepts not dependent on evidence-based for improved health outcomes.

Patient-centered care enhances healing and the quality of care, as well as improves satisfaction of care (Epstein, 1999). The reason for this may be the attention to the spiritual aspects of people as well as the physical. But it also underscores the importance of the healing relationship between clinicians and patients. Building a relationship and the interaction inherent in the relationship are critical factors in spirituality in healthcare. Spirituality is seen as a basis for how healthcare professionals and patients interact (Association of American Medical Colleges, 1999). This interaction is intimate and transformational. It stems from the relational aspect of spirituality, where the physician or other healthcare professionals see the divine/sacred in their patients through the compassionate interactions with their patients. As noted by Kathe, "Our loving is a participation in the immensity of the love of the divine." This framework allows for the ultimate expression of compassion to patients, honoring their dignity as human and spiritual beings (Puchalski et al., 2009).

Medical Education

Based on this ethical mandate to attend to the whole person, there has been, over the last twenty years, an increase in the number of required courses in spirituality and medicine in US medical schools giving rise to a new field of medicine. The interest in spirituality in medicine among medical educators has been growing exponentially. Only one school had a formal course in spirituality and medicine in 1992. Now, over 100 medical schools are teaching such courses (Puchalski & Larson, 1998; Puchalski, 2006). A key element of these courses addresses listening to what is important to patients, respecting their spiritual beliefs, and being able to communicate effectively with them about these spiritual beliefs, as well about their preferences at the end of life.

In 1998, the Association of American Medical Colleges (AAMC), responding to concerns by the medical professional community that young doctors lacked these humanitarian skills, undertook a major initiative—The Medical School Objectives Project (MSOP)—to assist medical schools in their efforts to respond to these concerns. The report notes that "Physicians must be compassionate and empathetic in caring for patients . . . they must act with integrity, honesty, respect for patients' privacy and respect for the dignity of patients as persons. In all of their interactions with patients they must seek to understand the meaning of the patients' stories in the context of the patients', and family and cultural values"(Association of American Medical Colleges, 1999). In recognition of the importance of teaching students how to respect patients' beliefs, AAMC has supported the development of courses in spirituality and medicine.

In 1999, a consensus conference with AAMC was convened to determine learning objectives and methods of teaching courses on spirituality, cultural issues, and end-of-life care. The findings of the conference were published as Report III of the MSOP. The outcome goals stated in MSOP III are that students will:

∑ Be aware that spirituality, as well as cultural beliefs and practices, are important elements of the health and well-being of many patients

∑ Be aware of the need to incorporate awareness of spirituality, and cultural beliefs and practices, into the care of patients in a variety of clinical contexts

∑ Recognize that their own spirituality, and cultural beliefs and practices, might affect the ways they relate to, and provide care to, patients

∑ Be aware of the range of end-of-life care issues and when such issues have or should become a focus for the patient, the patient's family, and members of the health care team involved in the care of the patient

∑ Be aware of the need to respond not only to the physical needs that occur at the end of life, but also to the emotional, sociocultural, and spiritual needs that occur(Association of American Medical Colleges, 1999)

In 2009, The George Washington Institute for Spirituality and Health convened a group of medical educators to develop national competencies and standards in spirituality and health education. The report of this work will be forthcoming in 2011.

Clinical Model

In February of 2009, a national consensus conference developed spiritual care guidelines for interprofessional clinical spiritual care. These guidelines as well as the educational advances, research and ethical principles have supported the newly developing field of spirituality and health (Puchalski et al., 2009). A practical model of implementation of interprofessional spiritual care was developed by consensus. This model advocates that all clinicians address patient spirituality and integrate spirituality into the care of patients. The model is based on a generalist-specialist model, in which the board-certified chaplain is the expert in spiritual care. Thus, non-chaplain clinicians address spirituality as part of whole person care; they refer to the chaplains for treatment of spiritual distress and other spiritual issues that cannot be addressed by the clinician. This model addresses spiritual distress as equally important to any other type of distress, physical or psychological, that the patient presents with and in fact calls on spiritual distress to be a vital sign in patient assessment.

Conclusion

Spirituality is an essential element of the care of patients, grounded in the whole person and patient-centered model of care. There are ethical mandates for including spirituality in the care of patients. There is also research that indicated the role spirituality might have in healthcare outcomes. Standards for spiritual care have been developed through medical education as well as a recent National Consensus Conference, which developed a model for implementation of interprofessional spiritual care. This work has formed the basis for the field of Spirituality and Health.

What is not yet known are the exact mechanisms of how spiritual and religious beliefs and practices affect healthcare outcomes and why spiritual care increases patient satisfaction and quality of life and affects healthcare decision making such as increased hospice use for patients with advanced cancer. While a national model of spiritual care implementation has been developed we do not have specific outcomes of spiritual care, nor data on outcomes of this model. These are areas for future research and work.

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TRADITION, HERITAGE AND SPIRITUALITY

Formal and Informal Spiritual Assessment

Christina Maria Puchalski

Abstract

Spirituality is increasingly recognized as an essential element of health. A novel model of interprofessional spiritual care was developed by a national consensus conference of experts in spiritual care and palliative care. Integral to this model is a spiritual screening, history or assessment as part of the routine history of patients. Spiritual screening can be done by a clinician on an intake into a hospital setting. Clinicians who make diagnosis and assessments and plans, and make referrals to appropriate experts do spiritual histories. In spiritual care, board certified chaplains, spiritual directors and pastoral counselors are the typical spiritual care referrals. Board certified chaplain do a spiritual assessment that is a more detailed assessment of religious and spiritual beliefs and how those impact care or patient's healthcare decision-making. There are several screening and history tools. One history tool named FICA, was developed by a group of primary care physicians and recently validated at study at the City of Hope. This tool is widely used in a variety of clinical settings in the US and Canada. The spiritual history tools allow the clinician the opportunity to diagnose spiritual distress or identify patients' spiritual resources of strength and then integrate that information into the clinical treatment or care plan.

Keywords: Cancer death - spiritual care - palliative care - spiritual screening

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Introduction

Spirituality is increasingly recognized as an essential element of health. Spirituality speaks to what gives ultimate meaning and purpose in a person's life. It is that part of people that seeks healing and reconciliation with self or others (Foglio & Brody, 1988; Puchalski, 2002). Spirituality, broadly defined, is inclusive of the non-believers as well as the religious. Atheists, agnostics, spiritual but not religious, and religious patients all have an inner life that may be described in the overall understanding of spirituality. There is also institutional support for the inclusion of spirituality, broadly defined, into healthcare. JCAHO requires that when a hospitalized patient requests spiritual care, it should be provided (JCAHO, 1996).

Numerous surveys support patient requests for spiritual care from physicians and other healthcare professionals. Initial research suggests that between 41% and 94% of patients want their physicians to address these issues. In one survey, even half of the non-religious patients thought that physicians should inquire politely about patients' spiritual needs (Ehman et al., 1999). In these surveys, patients indicate their preference to have a more integrated approach to their care with their spiritual issues addressed by their healthcare professionals. In one study, 85% of patients noted that their trust in their physician increases if that physician addresses their spiritual concerns (Ehman et al., 1999). Ninety five percent of the patients who report that spirituality is important want their doctor to be sensitive to their spiritual needs and to integrate it in their treatment. In another study, McCord et al (McCord et al., 2004) reported that patients in a family practice setting felt that it was important for physicians and healthcare providers to address their spiritual issues and beliefs. In this study, 95% of patients wanted their spiritual beliefs addressed in the case of serious illness, 86% when admitted to a hospital and 60% during a routine history. These results are also corroborated by surveys regarding patients' desire for nursing attention to their spiritual concerns.

A novel model of interprofessional spiritual care was developed by a national consensus conference of experts in spiritual care and palliative care and co-sponsored by the City of Hope, the George Washington Institute for Spirituality and Health and the Archstone Foundation (Puchalski et al., 2009). Integral to this model is a spiritual screening, history or assessment as part of the routine history of patients. One goal of spiritual assessment is to diagnose spiritual distress as well as spiritual resources of strength of patients. Figure 1 below outlines a model of interprofessional spiritual care implementation developed at the National Consensus Conference which shows how spirituality is addressed with patients in an

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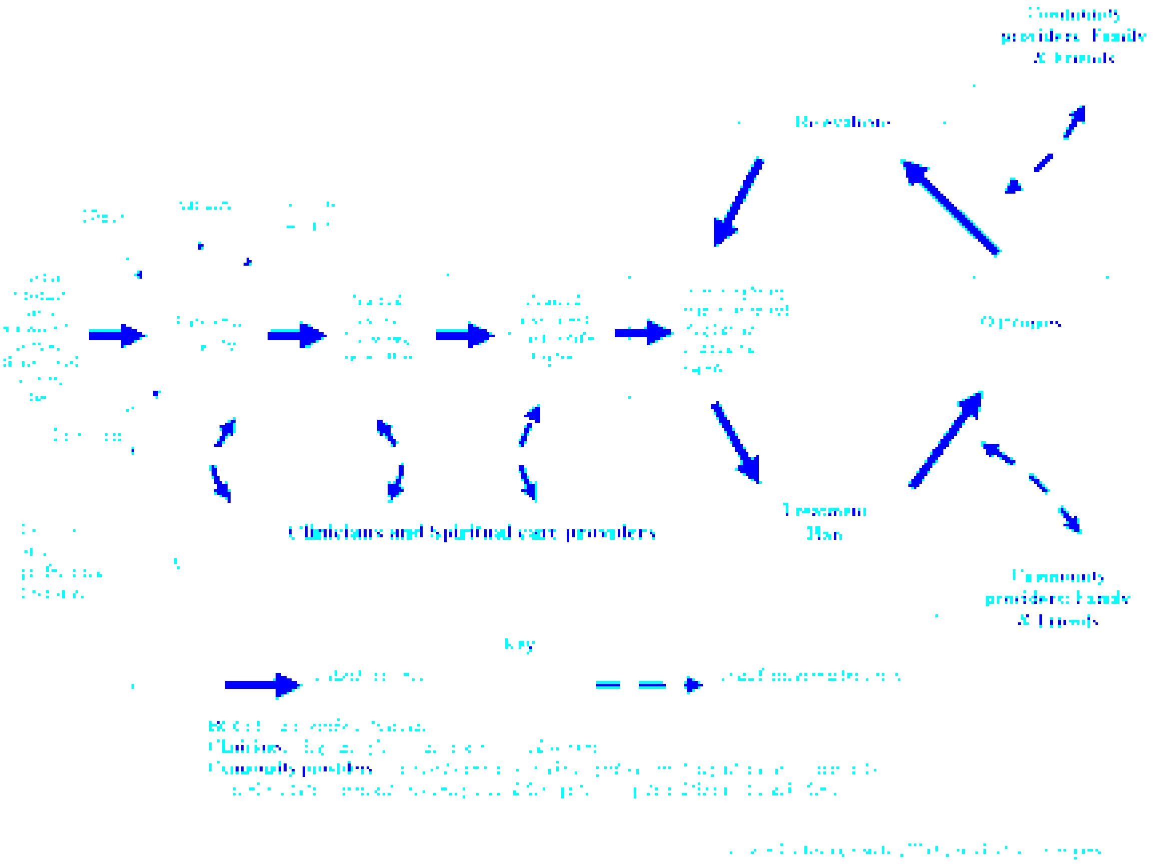

Figure 1. A Model of Interprofessional Spiritual Care Implementation Developed at the National Consensus Conference

in-patient setting, and how spiritual issues are integrated into a treatment plan. The model is based on a generalist-specialist model in which the Board Certified Chaplain is recognized as the spiritual care expert on the medical team. While all clinicians ask about spiritual issues of patients and do initial diagnosis and assessment, the chaplains are the experts that treat or counsel patients in spiritual care. Chaplains can also recommend appropriate interventions that non-chaplain clinicians can do (Puchalski et al., 2009).

Spiritual Distress

Spiritual distress can be manifested in many different ways. The inability to find meaning and purpose can lead to depression and anxiety. People find many sources of meaning and purpose throughout their lives that may be transient---jobs, relationships, accomplishments, and financial success. However, the challenge for all people is to find meaning and purpose even in the midst of failed jobs, relationships, accomplishment and unattained successes especially at the end of life. Ultimate meaning and purpose is meaning that sustains individuals in the emptiness of their external lives, or as people face their dying. Spiritual and religious beliefs play a significant role in how people transcend their suffering in order to find such ultimate meaning (Wong & Fry, 1998).

Hopelessness often arises in the midst of serious illness. Studies have indicated that people who are more hopeful do better with regard to depression and other health indicators (Synder et al., 1991; Breitbart, 2003). How people come to understand hope also varies. Initially, hope may be lodged in cure or recovery but when that is not possible, people may have a hard time tapping into resources of hope. In those times hope may be manifested as acceptance, completing important goals or activities, living life fully in the face of difficulty, finding meaning and eventually experiencing a good quality of life and death. Helping people restructure their thinking so that they can see hopefulness in the midst of despair is an essential part of therapy. Spiritual and religious beliefs offer people a language of hope. Religious and spiritual communities offer support in the quest to find hope and meaning.

Others spiritual issues include forgiveness and/or resentment. Illness can trigger many of the spiritual issues and therefore the clinical setting may be the first place where these spiritual issues arise. Religious issues can also cause distress in people's lives. Anger at God is common in the face of serious illness. Yet, it can lead to conflict, guilt and despair. It is important in the clinical setting to allow people to talk about that anger in a safe environment where they do not feel they will be judged. In their religious communities patients may be told that it is wrong to be angry at God, or that it reflects a weakening in one's faith to be angry at or feel abandoned by God. Yet, in the clinician's office, the patient may find a safe haven to explore these feelings in greater depth.

Many of the spiritual issues faced by patients are summarized in Table 1. This was developed as part of the National Consensus Conference on Interprofessional

Table 1. Diagnoses, Key Features and Examples of Statements by Patients (After Puchalski et al., 2009)

Feeling (Primary)	Key feature from history	Example Statements
Existential:	lack of meaning / questions meaning about one's own existence / concern about afterlife / questions the meaning of suffering / Seeks spiritual assistance	"My life is meaningless" "I feel useless"
Abandonment:	God or others lack of love, loneliness / not being remembered / no sense of relatedness	"God has abandoned me" "No one comes by anymore"
Anger:	at God or others/ displaces anger toward religious representatives / inability to forgive	"Why would God take my child away from me?"
Concerns about deity:	Closeness to God, deepening relationship	"I want to have a deeper relationship with God"
Conflicted or challenged belief systems	verbalizes inner conflicts or questions about beliefs or faith / conflicts between religious beliefs and recommended treatments / questions moral or ethical implications of therapeutic regimen / Express concern with life/death and/or belief system	"I am not sure if God is with me anymore"
Despair /Hopelessness:	hopelessness about future health, life despair as absolute hopelessness, no hope for value in life	"Life is being cut short" "There is nothing left to live for"
Grief/loss:	grief is the feeling and process associated with a loss of person, health, etc	"I miss my loved one so much" "I wish I could run again"
Guilt/shame:	guilt is feeling that the person has done something wrong or evil; shame is a feeling that the person is bad or evil	"I do not deserve to die pain-free" "I need to be forgiven for what I did"
Reconciliation:	need for forgiveness and/or reconciliation of self or others	"I would like my wife to forgive me"
Isolation:	from religious community or other	"Since moving to the assisted living I am not able to go to my church anymore"
Religion specific:	ritual needs / unable to practice usual religious practices	"I just can't pray anymore"
Religious/ Spiritual Struggle:	loss of faith and/or meaning / Religious or spiritual beliefs and/or community not helping with coping	"What if all that I believe is not true"

Spiritual Care. This table identifies these issues as spiritual distress diagnosis. It also gives examples as well as statements that patients might use in communicating about these issues with clinicians.

Spiritual Resources of Strength

Spirituality can also provide support for patients. Spiritual and religious beliefs and practices have been shown to have an impact in stress management, providing resiliency, as well as in coping with suffering (Boston et al., 2006). Spiritual groups such as faith based groups, yoga, or other types of spiritual groups can offer people social support. The ability to find hope in the midst of despair or meaning in suffering is examples of spiritual resources of strength. Having a purpose in one's life is immensely important for people.

Communication about Spiritual Issues

Communication with patients and families about spiritual issues ranges from identification of spiritual issues to formal assessment (Puchalski & Romer, 2000; Lo et al., 2002).

Thus there are four basic ways to approach communication about spiritual issues. The first three can be considered informal the forth is a formal part of the clinical encounter.

1. Recognition of spiritual themes, spiritual distress or suffering, and resources of strength.
2. Response to patients' statements about spiritual, religious or existential issues.
3. Response to patient's cues such as what they are wearing or reading.
4. Formal spiritual history, screening or assessment.

The first three approaches can be done by anyone on the care team. During the clinical encounter, one should listen for expressions of these themes and then follow up with an appropriate comment or question. For example, a patient may allude to a sense of hopelessness. The professional may elicit more conversation with the patient and identify appropriate treatment options. Patients may express spiritual or existential issues, for example, in asking "why is this happening to me?'. It is important to respond to these types of questions with open-ended questions, such as "Tell me more", or "Why do you think this is happening to you?" By trying to answer these often-unanswerable questions, the clinician could signal a lack of interest in hearing the patient's existential distress.

Patients may also voice explicit spiritual and/or religious beliefs. For example, a patient may make references to God or a higher power, or may mention helpful practices such as meditation or yoga. The clinician can follow up by asking more about these practices. Clinicians do not need to be experts in all spiritual or religious beliefs and practices; they can learn from their patients about what is important them.

Patients may wear religious or spiritual jewelry, or have religious or spiritual reading material at their bedside. Clinicians can acknowledge these objects and ask questions in reference to what the patient is wearing or reading.

Spiritual Screening, History, Assessment

A spiritual history, screening or assessment is a more formal part of the medical history in which the patient or family is asked about their spiritual and/or religious beliefs. In general, non-chaplain clinicians do a spiritual screening or a spiritual history; chaplains do a spiritual assessment. These are further defined below:

Spiritual Screening

Spiritual screening or triage is a quick determination of whether a person is experiencing a serious spiritual crisis and therefore needs an immediate referral to a professional chaplain. Spiritual screening helps identify which patients may benefit from an in-depth spiritual assessment by a professional chaplain. Good models of religious or spiritual screening employ a few, simple questions, which can be asked by any health care professional in the course of an overall screening. Examples of questions could be, “How important is religion and spirituality in your coping? and “How well are those resources working for you at this time?”

Spiritual History

Spiritual history taking is the process of interviewing a patient, asking them questions about their life, in order to come to a better understanding of their needs and resources. Compared to screening, history taking employs a broader set of questions to capture salient information about needs, hopes, and resources. The history questions are usually asked in the context of a comprehensive examination, by the clinician who is primarily responsible for providing direct care or referrals to specialists such as professional chaplains. The information from the history permits the clinician to understand how spiritual concerns could either complement or complicate the patient’s overall care. It also allows the clinician to incorporate spiritual care into the patient’s overall care plan. Unlike spiritual screening which requires virtually no training, those doing a spiritual history should have some training in and comfort with issues and how to engage patients comfortably in this discussion.

Spiritual Assessment

Spiritual assessment refers to a more extensive [in-depth, on-going] process of active listening to a patient’s story as it unfolds in a relationship with a professional chaplain and summarizing the needs and resources that emerge in that process. The summary includes a spiritual care plan with expected outcomes, which should be communicated, to the rest of the treatment team. Unlike history taking, the major models for assessment are not built on a set of questions that can be employed in an interview. Rather, the models are interpretive frameworks that are applied based on listening to the patient’s story as it unfolds in the clinical relationship. Because of the complex nature of these assessments and the special clinical training necessary to engage in them, only professional chaplains should do them.

When each of these inquiries occur depends on the setting as well as who is asking the question. In hospitals, long-term care sites or hospices, the nurse or social worker upon triage or admission does the spiritual screening. The purpose is to assess for spiritual emergencies that may require a chaplain immediately. Once the initial admission process is completed, then a spiritual history is taken as part of the intake or complete history after the initial triage. In outpatient settings, the spiritual screening might not occur. If the patient comes to the physician’s office and is in distress, a spiritual screening might be done as part of the initial conversation with the physician, nurse practitioner or physician-assistant.

Spiritual History Tools

For non-chaplains, there are clinical history tools that are used to collect and document clinical information. The spiritual history can be integrated into these tools; so for example, the spiritual history has been integrated into the social history section of the clinical database in many settings. A spiritual history is as important as any other part of the clinical history. When doing a clinical history, clinicians target specific areas. Simply listening to themes alone will not elicit all the information needed to provide good medical care. Thus, specific questions need to be asked to target areas of information regarding life events such as depression, social support, domestic violence, sexual preferences and practices. Patients may not volunteer information to a clinician unless they are invited to share in sensitive areas. This is particularly true of spirituality. While patients are interested in having spirituality integrated into their care, it is not yet a common practice to have physicians or others address spiritual issues; patients may need an invitation to share their experiences. A spiritual history is simply a set of targeted questions aimed at inviting patients to share their spiritual and/or religious beliefs if desired and to guide them to delve into the meaning of life events.

The goals of the spiritual history are to:

Invite the patient to share spiritual and religious beliefs if they chose.

Invite patients to define what spirituality is for them and what are their spiritual goals.

Learn about the patient’s beliefs and values.

Assess for spiritual distress (meaninglessness, hopelessness etc) as well as for spiritual resources of strength (hope, meaning and purpose, resiliency, spiritual community).

Provide an opportunity for compassionate care whereby the healthcare professional connects to the patient in a deep and profound way.

Empower the patient to find inner resources of healing and acceptance.

Identify patients’ spiritual and religious beliefs that

F.	"Do you consider yourself spiritual or religious?" - or - "Do you have spiritual beliefs that help you cope with stress (contextualize to the situation, for e.g. with what you are going through right now, with dying, with dealing with pain)?" If the patient responds "No" the physician might ask, "What gives your life meaning?"	Sometimes patients respond with answers such as family, career, or nature. Patients who respond "yes" to the spiritual question should also be asked about meaning.
I.	"What importance does your faith or belief have in your life? Have your beliefs influenced how you take care of yourself in this illness? What role do your beliefs play in regaining your health?"	These questions can help lead into questions about advance directives and proxies who can represent the patient's beliefs and values. One can also ask about spiritual practices and rituals that might be important to people.
C.	"Are you part of a spiritual or religious community? Is this of support to you and how? Is there a group of people you really love or who are important to you?	Communities such as churches, tamples, and mosques, or a group of like-minded friends can serve as strong support systems for some patients.
A.	"How would you like me, your health care provider, to address these issues in your health care?" Or ask the patient, "What action steps do you need to take in your spiritual journey?"	Often it is not necessary to ask this question but to think about what spiritual issues need to be addressed in the treatment plan. Examples include, referral to chaplains, pastoral counselors, spiritual directors, journaling, and music or art therapy. Sometimes the plan may be simply to listen and support the person in their journey.

Figure 2. FICI, A Spiritual History. F – Faith and Belief; I – Importance; C – Community; A – Address in Care or Action (Puchalski and Romer, 2000)

might impact healthcare decision-making.

Identify spiritual practices or rituals that might be helpful in the treatment or care plan.

There are several tools that have been developed for this purpose. These include FICA, (see Figure 2)(Puchalski & Romer, 2000; Puchalski, 2006) HOPE [see Figure 3] (Anandarajah & Hight, 2001) and SPIRIT [see Figure 4] (Maugans, 1996). Generally, these tools include objective data (religious affiliation, spiritual identification, community, spiritual practices) as well as provide an open ended part of the conversation to assess for spiritual aspects such as meaning, importance of belief and/or faith, beliefs in afterlife, sources of hope or distress. These tools are shown in the Figures 2-4. Of the three tools mentioned, the FICA tool is the only one that has been validated. In a study at City of Hope, FICA was correlated with the spiritual domain of the City of Hope Quality of Life questionnaire and demonstrated to assess for spiritual and religious issues in patients.

While these tools ask specific questions, they are not

H: Sources of hope, strength, comfort, meaning, peace, love and connection
O: The role of organized religion for the patient
P: Personal spirituality and practices
E: Effects on medical care and end-of-life decisions

Figure 3. HOPE- A Spiritual History – (Anandarajah & Hight, 2001)

S Spiritual belief system: Do you have a formal religious affiliation? Can you describe this? Do you have a spiritual life that is important to you? What is your clearest sense of the meaning of your life at this time?

P Personal spirituality: Describe the beliefs and practices of your religion that you personally accept. Describe those beliefs and practices that you do not accept or follow.In what ways is your spirituality/ religion important to you?How is your spirituality/ religion important to you in daily life?

I Integration with a spiritual community:Do you belong to any religious or spiritual groups or communities?How do you participate in this group / community? What is your role? What importance does this group have for you?In what ways is this group a source of support for you?What type of support and help does or could this group provide for you in dealing with health issues?

R Ritualized practices and restrictions: What specific practices do you carry out as part of your religious and spiritual life (e.g. prayer, meditation, service, etc.)What lifestyle activities or practices does your religion encourage, discourage, or forbid? What meaning do these practices and restrictions have for you? To what extent have you followed these guidelines?

I Implications for medical care: Are there specific elements of medical care that your religion discourages or forbids? To what extent have you followed these guidelines? What aspects of your religion / spirituality would you like to keep in mind as I care for you?What knowledge or understanding would strengthen our relationship as physician and patient? Are there barriers to our relationship based upon religious or spiritual issues?Would you like to discuss religious or spiritual implications of health care?

T Terminal events planning: Are there particular aspects of medical care that you wish to forgo or have withheld because of your religion / spirituality?Are there religious or spiritual practices or rituals that you would like to have available in the hospital or at home?Are there religious or spiritual practices that you wish to plan for at the time of death, or following death? From what source do you draw strength in order to cope with this illness?

Figure 4. SPIRIT- Taking a Spiritual History (Maugans, 1996)

meant to be used as checklist but rather as a guide to open the conversation with patients to deeper questions about a patient's inner life. The spiritual history should be done routinely during the social history section of the initial assessment or the annual history and physical exam. An example of a social history is in table 2 below taken from the curriculum at the George Washington University School of Medicine. However, one can ask a spiritual history in the context of a specific clinical issue. For example, if the patient is coming for a routine visit, one might address spirituality in the context of stress management or health. If the patient has just been told of a serious diagnosis, then the questions might be phrased differently. For example "Do you have spiritual beliefs that have helped you in difficult times before?" or "It must be hard to hear difficult news like this; do you have spiritual beliefs that might help you right now?"

The goal of all these tools is to obtain a comprehensive understanding of a patient's relationship to spirituality, what the patient's spiritual beliefs are, and what their goals are for spiritual health. These tools are not meant for use as a checklist but rather to give people the opportunity to share about their beliefs, hopes, fears and concerns. The spiritual history helps the clinician understand how the spirituality of the patient helps that patient understand their illness and health, cope with suffering and find meaning in the midst of what is happening to them.

Ethical Guidelines

In addressing spiritual issues with patients, it is important to recognize that the conversation is always patient centered and patient led. Proselytizing is not ethical in the clinical encounter nor is ridiculing patients for their beliefs. There is a power differential between patients and clinicians; clinicians should never abuse that power nor the trust patients place in them. A clinician that might want to share his or her beliefs with a patient might inadvertently encourage that patient to agree with or adopt the clinician's beliefs out of fear that the clinician will not treat the patient well if the patient does not agree with the clinician. Questions about spirituality should also be asked in a manner that conveys openness to all types of beliefs, humanistic, religious and non-theist alike. A spiritual history or assessment must be sensitive enough to identify concerns in all patients and ask general questions that invite all patients to share what is important to them and their care.

Integration into Treatment or Care Plans

Once spiritual issues are assessed clinicians can then integrate those issues into a treatment plan. Clinicians need to make the appropriate referrals to expert spiritual care professionals such as Board Certified Chaplains or Pastoral Counselors or Spiritual Directors. In table X below, an algorithm is described of how spiritual distress can be identified by clinicians that normally develop clinical assessment and plans and make referrals to experts depending on the issues. As noted in this figure there are complex spiritual issues that need an immediate referral to a chaplain. Simple issues may be able to be handled appropriately by the non-chaplain clinician with a variety of interventions such as compassionate presence, supporting a patients self described spiritual resources of strength such as meditation, hope, strong sense of meaning, referral for breath work, encouraging journaling or other reflective practices. Spiritual issues need to be assesses on an ongoing basis as with any other clinical issues and especially addressed if there is any change in clinical situation with the patient.

Two examples of the process is described below:

Case 1:"My life is meaningless"

Ms. Harper is a 75-year-old former advocate for the homeless, who recently suffered a stroke that left her with mild cognitive impairment and hemiparesis. The meaning in her life came from her work, and since the stroke she is unable to work and feels life has no meaning anymore.

Spiritual History

F: Atheist; meaning in social activism

I: Work is her life and her whole sense of who she is

C: Activist community

A: Interested in passing on her dreams to younger people who will carry on her work when she dies. Referral to pastoral counselor, find resources for patient to work with students, continued presence, journaling (patient may be interested in recording her narrative or history)

Interventions

The goal is to help Ms. Harper move beyond defining herself by what she did to a deeper intrinsic meaning and value of herself as a person. Cognitive-oriented therapy can help. One can ask questions such as:

What have been important events in your life?

What is the most important event in your life?

Have you loved?

The chaplain's spiritual assessment would explore Ms. Harper's sense of meaning and existential concerns more completely. The assumption should be that it is not the work per se that gives her meaning. If that were the case, any work would do. It is something about this particular work and what it produces or the good it brings to the world that has particular salience for her. Some of the questions might be:

Explore Ms Harper's sense of meaning and existential concerns more completely. Work per se may not give meaning—what is it about the work

What is it about social activism that is meaningful?

Why is it meaningful?

Why is she drawn to the homeless?

What events in her life made her who she is?

Ms. Harper has obviously already considered how she might pass on her passion and commitment to those who will follow her. The "how" of this process is fairly straightforward. The "what" is more complicated and should also be part of an assessment.

What ideas and beliefs does she have about the world and our duty to it that she wants to pass on?

On an existential level, why be an activist? (Example-Judaism calls all Jews to participate in the healing of the world.)

As always, this process is both an assessment and an intervention in that it gives the patient insight that can help her move on and find the same meaning through activities that she is still capable of. Sometimes people find meaning in their struggle, sometimes not. But as caregivers, we can support them in looking beyond the extrinsic and into an intrinsic sense of value in them and find some meaning for themselves in their struggle.Interventions by the non-chaplain clinicians on the team could include: Help patient create a dream list and facilitate passing onto others, ongoing compassionate presence and providing connection and listening to Ms Harper's life story.

The Assessment and Plan for this patient might be:
Ms. Harper: 75 yo s/ cva with hemiparesis and mild cognitive impairment
Physical: ongoing physical therapy, d/c to rehab when stable
Psychological: grief reaction over loss of previous state of functioning: supportive counseling and continued presence
Social: engage activist community in her care as much as possible, home health aid, and financial issues about long-term care
Spiritual: meaninglessness, consider referral to pastoral counselor or chaplain, connection with younger people at medical school interested in helping homeless, ongoing presence, provide connection, elicit life story.

Case 2:"Hopelessness"
Ronda is a 58-year old female with end stage ovarian cancer. Seven and one half years after multiple surgeries and chemotherapy with good outcomes, she is now faced with advanced disease for which there is no longer any treatment. Her hope has always been for a cure. Now she faces a deep sense of hopelessness.

Hope can be expressed in many ways. It may initially be for a cure, but when that is no longer possible, people may still find hope in finding important projects, making peace with others, and having a peaceful death.
Hope/hopelessness can also be related to other spiritual diagnoses. These would include feelings of abandonment by God and isolation from an important community, religious or otherwise. In general, hopelessness is often generated by a sense of abandonment or isolation- being abandoned by our communities, being abandoned by our higher power, or as in this case, being abandoned by our own bodies. Thus, the chaplain will always assess for all of the possible sources of the hopelessness.

Spiritual History
F: Raised Jewish culturally; meaning has always been in nature and not in religion
I: Spirituality is important and now that she is dying she would like to know how Judaism views dying and what rituals might help her
C: Friends are her spiritual support
A: Would like to see a Rabbi to discuss her spiritual questions with him. Referral to chaplain to help connect patient with Rabbi, dream list, explore sources of hope
While the spiritual history suggests that Rhonda's support to this point has come from friends, there are strong indications that she wants to explore her Jewish history as a source of spiritual support. Thus the chaplain's assessment questions would include:

What was her upbringing from a Jewish perspective? What is her experience with Jewish ritual?

If she did have some level of Jewish practice earlier in her life, why did she leave that?

What does it mean to her to be a "good Jew"?

What is her belief about an afterlife?

The interventions by the non chaplain clinicians on the team might include helping Ronda create a dream list, listening to her story and her relationships with people and with God, talking about her sources of hope in past times as well as current and helping her accomplish her dreams and wishes if possible.

Ronda's Assessment and Plan might be:
Ronda 52 yo with end stage ovarian ca .
Physical: pain is well controlled; continue with current medication regimen. Nausea; still has episodes of nausea and vomiting, likely secondary to partial small bowel obstruction (SBO). Add octreotide to current regimen
Psychological: grief reaction that "fight is over". Tearful, difficulty sleeping. Supportive counseling and continued presence.
Social: Ronda concerned about how to tell family she is dying; social worker to arrange for family meeting
Spiritual: hopelessness, main source of meaning in "winning the fight", active in ovarian cancer alliance and seen as inspiration. Not religious but now wants to learn how "Jewish Patients die?"
Dream List, legacy building, encourage talking with Ovarian Cancer Alliance, referral to chaplain and to Rabbi (choice of Rabbi might be impact by chaplain assessment above)

Conclusion

Spirituality is an essential element of the care of patients. A National Consensus Conference developed a model for interprofessional spiritual care where all members of the healthcare team address patients' spirituality and refer to the spiritual care professionals on the team, such as board certified chaplains, pastoral counselors and spiritual directors. There are formal and informal ways of communicating with patients about their spiritual issues. Formal ways include doing a spiritual screening, history and assessment. Spirituality should be integrated into the assessment and plan of patients' treatment and care plans and followed up as with any other clinical issue.

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TRADITION, HERITAGE AND SPIRITUALITY

My Illness, Myself: On the Secrecy of Shame

Lea Baider

Abstract

Research has shown that the experience of being diagnosed with cancer has a negative psychosocial impact on patients and their families, often resulting in distress, and numerous practical and relationship challenges. Men with prostate cancer and their partners face special challenges. A range of symptoms that result from monitoring patients and side effects of treatment may reverse the quality of life and intimate relations between patient and partner. However, patients often are reluctant to bring up their distress about the symptoms, leading to an underestimation and reduction in optimal symptom control. As a result of their illness, chronically-ill male patients often experience elevated levels of stress, daily activities are often limited, they are frustrated about the unpredictable course of the illness and its symptoms, and are immersed in fears about their present and future social identity. Most of them avoid disclosure about their illness – when and where possible - and place great importance on sustaining a normal life. Factors related to limiting disclosure include men's low perceived need for support, fear of stigmatization, the need to minimize the threat of illness to aid coping, practical necessities in the workplace, and the desire to avoid burdening others. This paper contributes to an understanding of the complex issues of disclosure related to prostate cancer patients and raises issues about how best to be helpful, within their cultural and social framework. It also deals with feelings of shame, guilt and inadequacy as the cause – or consequence – of concealing the illness. The oral presentation will use a clinical example of secrecy and the subsequent conflicts and quandaries of a religious person diagnosed with advanced prostate cancer. Dilemmas of shame, disclosure and guilt will be the focus of the discussion.

Keywords: Prostate cancer - stigma - family - secrecy - disclosure - shame

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Introduction

Cancer: a burdensome reality "*One person's truth is another's conundrum*." **P. Marshall**, 1994.

Cancer is a broad and complex subject interrelated with biological, sociological and cultural constructs. A number of studies involving patients diagnosed with cancer have been published that focused on qualitative and psychosocial aspects, thereby describing the patients' emotions, perceptions and functioning within the ecological system. Critical research has examined the reactions of patients - particularly of men diagnosed with prostate cancer- their perceived quality of life, and their family's responses. Nevertheless, there is less knowledge about patients' subjective appraisals and subsequent coping with the possible impact on their partners - specifically about the various side effects of cancer treatment (Boehmer and Clark, 2001; Spanish, 2004).

An understanding of coping strategies is particularly warranted in the case of advanced prostate cancer patients receiving hormonal therapy due to the unique nature and special severity of the psychosocial problems they may face (Terris and Rhee, 2005). The difficulties entailed in their disease are compounded by those stemming from its treatment, which is aimed at halting the tumor's growth via androgen deprivation.

Male patients are particularly vulnerable due to the age-related stressors and the uncertainties associated with the detection and treatment of prostate carcinoma (see Table 1 for statistical rates of incidence of prostate cancer in Israel). Profound effects occur on mood, with increased depression, irritability and anxiety. Side effects of treatment, such as hormonal therapy, steroids and pain medications, add to the reasons for high psychological distress, loss of libido, erectile dysfunction, gynecomastia, weight gain, female distribution of fat, loss of bodily hair, hot flashes and sweats, nausea, osteoporosis, decreased vitality and mood disturbances (Waldron, 2002).

The paper will describe the process that men diagnosed with prostate cancer go through in determining whether to disclose or conceal the illness from their family, friends and social network. There is perhaps a greater potential for stigma for these men than for men diagnosed with any other cancers. The association of prostate morbidity with symptoms such as sexual dysfunction, diminished testosterone and fatigue may be perceived by an outsider with disdain and negative judgments. While various studies have considered the impact of prostate

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Table 1. Prostate Cancer: Incidence Rates in Israel, 2000-2007 (Barchana and Lifschitz, 2007)

Diagnosis year	Jews		Arabs	
	Average	SD	Average	SD
2000	72.0	9.39	72.7	9.18
2001	72.4	9.34	70.5	10.32
2002	72.0	9.06	72.1	9.18
2003	71.5	9.40	72.3	10.05
2004	71.2	9.26	68.8	9.55
2005	71.0	9.56	70.8	10.57
2006	70.5	9.61	70.0	9.65
2007	69.6	9.38	70.2	10.15

∑ Prostate cancer is the most common cancer among Jewish men, and the rate of diagnosis has been affected mainly, since the end of the 1980s, by early detection through the use of PSA. More than 2100 men are diagnosed annually. The incidence rate increased steadily until 2004, at which point there began an apparent decrease in the incidence rate; even though it is not possible to predict if this trend will continue. ∑ A similar picture of increasing morbidity rate and somewhat of a decrease from 2004 was demonstrated among Arab men. This decrease can be real or a result of changes in the reporting and testing methods.

cancer on men and their spouses, only a handful have focused specifically on issues of stigmatization and disclosure (Gray et al., 2000).

Most research about disclosure is based primarily on stigma theory and, thus, is steeped in the assumption that ill or disabled persons are motivated to avoid being stigmatized by others by avoiding disclosure whenever possible (Okano, 1999). Although self-disclosure is an understudied area of investigation, especially with respect to cancer, the scarce research that has been done is suggestive of important implications for how men and their partners respond to illness. Especially concerning prostate cancer, with the double label of life-threatening illness and sexual dysfunction, relevance of disclosure and secrecy issues seems highly germane (Helgason et al., 2001).

The Circle of Life: Individual or Family Illness?

"Two voices is the minimum for life, the minimum for existence…" **M. Bakhtin**, 1984

It is becoming an accepted fact that models of stress and coping need to incorporate a relational perspective. Major life stressors affect not only individuals but the lives of their intimate partners, spouses, friends and others in their social-cultural networks. Systemic-transactional theory proposes that coping is a stress management process where partners either ignore or react to each other's stress signals to maintain a level of stability in the relationship on the individual and the dyadic levels (Bodenmann, 2005). Each partner's well-being mutually depends upon the other's well-being, as well as upon the couple's ability to use resources in the social environment during the stress process (Fekete et al., 2007).

Table 2. Relational Qualities (Kayser et al., 2007)

Characteristic: Definition

Relationship awareness: Thinking about one's relationship in context of the illness and the impact on the partner and the relationship
Authenticity: Not hiding feelings from partner
Mutuality: Empathic responding in a shared experience

Coping is typically thought of in terms of individual-level strategies, such as active coping, planning, positive reframing, acceptance and behavioral disengagement, but it also has fantasied or real dyadic-level implications. Relationship-focused coping strategies are designed to maintain, preserve and protect social relationships during times of stress. Studies on how couples face cancer center on how the strategies used by one partner affect the other partner's adjustment to the stress of the illness. Moreover, individuals' perceptions of their partners' emotional responsiveness may be more important in maintaining the relationship than their partners' actual behaviors (see Table 2).

Langer et al. (2009) emphasize a particular relationship-coping strategy of protective buffering (PB) as applied to cancer and defined as "hiding one's concerns, denying one's worries, concealing discouraging information, preventing the patient from thinking about the cancer, and yielding in order to avoid disagreement." A patient might be experiencing certain symptoms, but so as not to worry the partner or out of fear of the partner's reaction, hesitates to disclose any of these symptoms.

Patients in need of protecting their family may either pretend not to know the real meaning of the symptoms or forbid the physician to discuss their medical condition with family members. These façades can be distracting, debilitating and harmful. Sometimes, tragically, while the patient and family are attempting to protect the other by pretended or imposed denial, in reality both sides are desperate to escape from their self-imposed seclusion. Such denial obstructs both communication and the completion of the normal pattern of life's routines. The isolation may induce premature conflicts, depression and fear, and result in a more difficult interactional process for each family member (Vangelisti et al., 2004).

Cancer: Shadow of Secrecy and Shame

Family life is a dynamic, intricately patterned kaleidoscope of feelings and emotions, ranging from intense hues of anger, hate and love to the mildest shades of irritation, hurt and forgiveness. There are times when the family provides an emotional refuge, a "haven in a heartless world." At other times, the family is a crucible of dark emotions that may fracture and destroy family relationships (Caughlin et al., 2004).

The theory of family communication argues that people want to control private information by granting or denying access to confidential information. They feel they own it (and therefore have the right to control it) and because revealing the information has the potential to make them vulnerable and ostracized from social boundaries (Petronio, 2002). Secrecy is a metaphorical marker of who controls, regulates and shares ownership of private information (Petronio et al., 2003).

Data describing the deterioration of patients' relationships with their partners relate to the belief that they are no longer capable of fulfilling their role as

Table 3. Case History

General: The following clinical case describes a Rabbi who is defined not only by his religious commandments and responsibilities, but also by the socio-cultural environment and family system in which he lives and is expected to be a role model.

Sociodemographic data: David F. was born in France in 1956 and immigrated to Israel with his parents in 1958. Parents were born in Algeria. He grew up in a religious family and studied in a religious school. He graduated and became a teacher and rabbi. David has 6 brothers and 4 sisters, all religious and living in Israel. David is married to Yaffa, 39 years old, and they have 4 daughters: a married daughter of 18 and 3 aged 16, 12, and 7. Besides being a full-time homemaker, Yaffa runs a private day care group for babies in their home. She was born in Tunis and came to Israel as a child with her extended family.

Medical history; In March 2009, David was diagnosed with metastatic prostate cancer. Treated with radiation and hormone therapy (LHRH). Despite clear, persistent symptoms, patient refused to see a physician for more than one year. Because of intense pain and urinary difficulties, he finally consulted with his family doctor who sent him to the Institute of Oncology. There he received medical care from a senior oncologist.

Psychological referral: Patient was referred by the oncologist with symptomatology of high psychological distress. He thought that his wife could become pregnant again, if he discontinued all medical treatment. He refused to communicate with wife or any of his close family about the illness. Only his older brother knows about the present situation.

Problems that patient presented: Absolute privacy and confidentiality about disclosure; secrecy; shame of being ill; guilt that he cannot fulfill the commandment of giving his wife more children that she desires and expects; fear of being rejected socially and abandoned by his family.

husbands (see Table 3). Moreover, feelings of inferiority derive from the dual stigmatization of cancer and impotence, and the impairment of their psychological quality of life due to fatigue, low self-concept, anger and shame (Navon and Morag, 2008).

Whereas certain patients reportedly benefit from sharing their disease-related concerns with their spouses, others restrict communication to avoid upsetting conversations. Such concealment has also been found to be adopted for preventing social degradation (Gray et al., 2000; Jakobsson et al., 2000).

In Navon and Morag's study (2008), an initial analysis of the patients' psychosocial difficulties generated five topic areas related to their body image, sexual life, ties with spouses, social relationships and self-perception (see Table 4). As the statistical analysis progressed, only three topics emerged, because low self-concept and strained social interactions stemmed, in fact, from bodily feminization, sexual dysfunction and spousal tensions.

Patients live in constant tension between withholding personal anguish about their disease and sharing private struggles to sustain emotional closeness by hiding their asexuality (Okano, 1999).

Shame may be one of the most hidden human feelings. Patients are reluctant to talk about their own shameful experiences and often do not even want to admit having this feeling. It is the nature of shame that patients hide feelings of inadequacy or inferiority either from themselves or from others. Shame "generates concealment out of a fear of rendering the self unacceptable," in contrast to guilt which "invites confession and forgiveness." It is often experienced as the inner, critical voice that judges whatever we do as wrong, inferior or worthless. Shame and humiliation are closely connected to social exclusion, making the individual feel deviant and an outsider. They contribute to the understanding of the psychological and cultural aspects of being pegged as a cancer patient (Oravecz et al., 2005).

Heller (1996) points out the difference between the "physical manifestation of shame" –blushing - and "social shame" in cultures in which the intensity of the shame depends on the nature of the violated rule. In contemporary societies, the intensity is also determined by the social environment of the person who has violated the rule.

There are three different psychological aspects of shame:

A particular type of anxiety in a situation of threatened exposure or humiliation.

An emotion or a cognitive/emotional reaction.

A reactive formation (character trait).

Shame comes with consciousness - particularly self-consciousness – that is the awareness of our inadequacy and worthlessness. It comes with the sense of being cut off from an essential source of family support, community, God or other in the sense of splitting off or repressing the shameful part (Nathanson, 1992).

One source of shame is associated with the expression

Table 4. Coping Strategies (Navon and Morag, 2008)

Individual level	Feminized body	Extinguished sexuality	Constrained intimacy
Self-redefining	Self-perception with neither sex	Being asexual	Self-identifying as spouse's brother or friend
Self-distancing	Refraining from looking at oneself	Relegating sex to a past stage of life	Changing familial roles
Self-solacing	Reframing bodily changes		Changing intimacy
Interpersonal level	Feminized body	Extinguished sexuality	Constrained intimacy
Disguising	Camouflaging the bodily changes	Concealing the sexual losses	Masking the lack of libido
Diverting	Exhibiting masculine behavioral traits	Acting as if nothing happened	Emphasizing commitment to family and society
Avoiding	Refraining from public body exposure	Withdrawing from social events	Restricting any closeness

of impulsive emotions such as anger, fear, sadness and vulnerability. Often admonitions are internalized so that when we get in touch with any of these "shameful feelings," we will automatically feel shame and try to control or hide the feelings or, at the very least, to apologize profusely for not fulfilling what – under normal circumstances - is expected of us.

Shame may often be at the root of marital discord. If one member of the couple wants more intimacy, and/or communication than the other, both feel shame as a result. The one wanting more intimacy may feel rejected and shamed for wanting too much, and the other may feel shame for either not being comfortable with more closeness or for wanting more distance than the other. Shame is often bypassed and may produce coping styles by avoidance, withdrawal and isolation (Baider, 2008).

Quandary: Possible Resolution?

"*Man is only wise during the time that he searches for wisdom; when he imagines he has completely attained it, he is a fool*." **Solomon Ibn Gabirol**, circa 1040

What is shame and what is guilt, and when and how do these emotions occur and develop? Since the surrounding norms and conventions affect people's actions, thoughts and feelings, it is necessary to take a closer look at the specific society's cultural norms, family interactions and rules regarding private and public disclosure (Pattison, 2000).

It is the meaning patients attach to the experience of shame that is profoundly dependent on the socio-cultural and religious beliefs. Different meanings given to shame may reflect different behavioral secretiveness within each social group.

Adaptive individual and family functioning involves the open exchange of reactions, the frequent expression of positive and negative emotions and the ability to effectively regulate the range of these emotions concerning the fate of cancer. Psychosocially adaptive families may be those in which family members validate and embrace different notions of shame, guilt and secrecy within a culture that allows mutual acceptance, flexibility and compassionate regard for being different.

Patients may be able to learn the overt language of dialogue. Families may be able to readjust to their systems of beliefs and convert the silence of shame into a new language of trust, mutual care and spiritual hope.

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TRADITION, HERITAGE AND SPIRITUALITY

Beyond Pain – The Search for Hope in the Patient's Journey

Cathleen Fanslow-Brunjes

Abstract

Hope is the foundation of the cancer patients world and it is when the darkness is most profound that hope emerges as the true reality. Hope remains the patients inner strength, a dynamism that grows more powerful even as the physical body weakens. We humans are always hoping for something and The Hope System addresses all levels of the entire cancer experience: physical, emotional, psychological and spiritual. By systematically learning how to recognize and honor patients hopes, each of us can support him/her from first diagnosis to last breath in a way that is healing and positive for all. Utilizing this simple, powerful tool enables us to tap into the patient's ever changing reality, the role hope plays in one's life while confronting one's mortality, and be able to listen, hear and accompany them each step on their final life into death journey.

Keywords: Cancer experience - hope - Hope System - confronting mortality

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The Hope System

"*Hope is the thing with feathers that perches in the soul and sings the tune without the words and never stops at all…*" Emily Dickenson has captured in this poem the deep reality that is hope in the cancer patient's life today and beyond into the future. I describe Hope as an intrinsic inner dynamic reality. It moves and guides us through life and is the beacon we all follow as we move toward the transition we call Death. I wonder if puppy dogs and pussy cats have hope, but I know that we who are human live in hope. Actually, hope has directed us throughout our lives. It is always there moving and guiding us from birth to death and for those with cancer, from the moment of diagnosis to their last breath.

Disease and death are part of life. It's hard to accept that, but we have no choice. Yet, we do have a choice in how we live until we die and our hopes speak of these choices. In the face of terminal illness, hope comes to the fore to show itself in its full glory and we find it to be deeper than "wishing," more intense even than desire. We find that hope has been all for us, all along; the thing that sparked our motivation, energized us and gave us voice.

Just a glance at the dictionary gives you an idea of what a strong advocate hope can be:

Hope is "*the feeling that what is wanted can be had or that events will turn out for the best*".

The very act of "*hoping*" is to "*look forward*" to something "*with reasonable confidence*".

A "*hopeful*" person is someone "*who shows promise or aspires to success*".

"*Hope*" is actively connected and engaged with "*believing*" and "*trusting*".

One look at all the positive feeling states and powerful actions associated with hope in a plain old dictionary and you begin to understand how simply the act of hoping itself contains tremendous healing power, what I call the for-power of hope.

I will show hope's positive potential as an advocate and how, in supporting a patient's hope, helpers can do their part in meeting the three basic needs of the dying: the need not to feel abandoned, along with the need for self-expression and hope; especially the third basic need: the need to access their own Hope System, to connect with their hopes.

Over the years, I have become convinced that hope is our primary motivator; that fundamental life force that moves and directs us throughout life and disease. It certainly is the primary internal advocate in those confronting life's end, as the most current research and literature about death and dying has begun to confirm. Next, I would like to share the up-to-date science on the subject of hope as it pertains to long-term and end-of-life care, before exploring my own theory, which forms the foundation for The Hope System, developed during my 40 years of working with the dying.

Jerome Groopman, M.D., who wrote The Anatomy of Hope – How People Prevail in the Face of Illness, cites the science behind hope: "*Belief and expectation – the key elements of hope – can block pain by releasing the brain's endorphins and enkephalins, mimicking the effects on fundamental physiological processes like respiration, circulation and motor function.*"

Hope is such an integral part of our being that it changes and grows as we grow and change; in fact, hope is so intrinsic within us that it may be not only a person's first response to change but also the catalyst of change. This primary motivator is called by many names: life force, inner-self, higher-self, the spirit within. Regardless of what we call it, Hope remains as the cancer patient's

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inner strength, a dynamism that grows more powerful, even as the physical body weakens. Along with others in the healthcare profession, I have chosen to call this dynamic inner reality "*Hope*" , in order to avoid relegating it strictly to any category (such as religion or psychology) that might exclude anyone. Whatever mantel we lay upon it, hope is first of all universal to us all, as well as inclusive of any belief system a person might choose to attach to it.

Here I would like to make the distinction between what we call "*hope*" in our daily lives – a word that is often interchangeable with (head) "*goal*" or (emotion) "*wish*" and the powerful motivational state of (heart) "hoping," which expands and deepens as life's challenges intensify. It evolves from the simple hopes of childhood, continuing on as we mature to include the more esoteric hopes that forge our adult lives. For example, "*I hope to be able to ride my tricycle or two-wheeler*"; "*I hope to make the team*"; "*I hope to be asked to the prom*"; "*I hope to become a lawyer*"; or, the one we expect to hear from every beauty contestant, "*My hope is for world peace*". From the ridiculous to the sublime, hope is always demonstrating its unique ability to change. Hope moves, creates and recreates itself within the individual, in response to the many changes life brings us. This ever-changing quality is a reflection of the inner dynamism that defines hope at the core. This dynamism builds under duress, from hope's object as a notion (noun) to hope as an active vital force (verb).

At this time I would like to introduce the concept of the for-power of hope, the premise on which The Hope System was developed. The "*for*" emphasizes how much of an advocate within us hope truly is. This can't be emphasized enough, because traditionally, the concept of hope has been relegated to the sidelines, like an unreasonably avid, blindly optimistic fan. Too often, we use phrases such as "*hoping against hope*" or "*hopelessly unrealistic*" to describe a positive attitude that flies in the face of negative odds, whereas, in fact, for a person face-to-face with cancer, hope functions as the most realistic guide of all. In my experience observing and communicating with the dying, the role that hope serves in the transitional process could almost be described as like that of a second brain. Indeed, the most current research on hope is the biological sciences, as if hope were part of the human anatomy, possibly no less vital than another organ.

It is important to believe in thepower of Hope System as a guide with effective results, to observe the ways in which various hopes manifest themselves in the patients and be alert to it's messages. Then I show how hope has functioned as an interior force in my patients; usually as a conscious motivator, yet, sometimes at first unconsciously. You will see the way in which hope itself gives us a rationale for feeling hope when nothing else does. Even when circumstances seem to give us no grounds for hope, the act of hoping itself, establishes its own rationality – hoping is a reasonable act in and of itself, according to the dictionary again. Although a particular hope may appear to be irrational to others, humans are rational beings and we are hoping all the time; living and dying with hope intact.

It is important to recognize the for-power of hope for several reasons:

∑ In acknowledging hope as a positive force, caregivers strengthen the cancer patient's strongest inner advocate, which promotes healing. ∑ In listening without judgment, caregivers support fulfillment of the cancer patient's second basic need for self-expression. ∑ The patient's feeling that their hopes are respected and heard enables them to retain their identity as a person, not just a patient, fulfilling the first basic need, not to be abandoned by the living. ∑ From birth to death, hope enables us to shape and reshape our concept of self-identity so that we can thrive in alien territory and even against the seemingly insurmountable odds of a terminal illness. ∑ Hope is an integral part of the life-death process; it is the mechanism by which we gain access to the reservoir of our own (and in the universal) intrinsic life force. ∑ Since to be alive is to keep one's hope intact – in accepting the expressed hopes of the cancer patient, caregivers support quality of life for the patient, which often enables them to outlive their prognosis.

The Hope System within each of us either finds or actually is that place from which we draw the strength for life's challenges and struggles; the courage to face change, from birth to death, with equanimity. This is apparent throughout our lives, but is all-pervasive as we proceed on our journey toward death, the final stage of human growth.

I have cared for and observed countless numbers of cancer patients during my 40 year-career and I always felt from the beginning that there was something different about them, something we were missing, but I couldn't put my finger on it. Then I heard a patient named Jeff say it: "I hope this chemo works," and there it was, all the time, that little word that means so much to anyone with a life-threatening illness.

No matter how we define this somewhat mysterious and fascinating four-letter word, we probably agree that hope is not passive; it has an intrinsic energy within it that seems to direct, guide, move and change people through their life situations. Never is this dynamic force more apparent than when one is confronted with the reality that one's own life is limited and will, in a certain matter of time, come to an end, that moment when we face our own death.

All of us can live with the knowledge that we have an incurable disease, but none of us can live with the thought that we are hopeless. Let us examine this phrase that plays such a key role in describing what follows. The patient's acknowledgement of having an incurable disease occurs first on the intellectual level. Then, in time, this knowledge of possible incurability slowly filters through the mental, emotional, physical and spiritual levels and certainly has a deep effect. Faced with this devastating knowledge, this person can still live out and complete life. One knows it is possible to live, even with the slow progression of disease robbing vitality until death arrives. None us can exist in this world with the thought of hopelessness, for hope is an integral part of all levels and aspects of each individual. Could you live with the essential condemnation of you as a person, of your very essence, who you really are? Being labeled hopeless is like being declared a non-being, an object; not a human being, with all that entails – no history, no present, no future – truly a death sentence far more devastating and destructive than the disease that my be spreading unmercifully throughout your body.

We humans, when devoid of our hopes, feel robbed of the essence that defines us on all levels.

Surely none of us would want to be thought of as "*Room 308 – just a hopeless case*" . This type of insensitive statement demonstrates a somewhat prevalent attitude still among some health-care providers today: "*Since there is nothing I can do for the patients, since I am not able to cure them of their diseases, why stay involved with them at all?*" Thus, the abandonment of a cancer patient can subtly begin.

People need to die as they live, with their intrinsic life force, their individual hope system, in place. If we want to relate to the dying as human beings, we must not deal with them as hopeless cases, but rather direct our energies to accompanying them on their final journey. In order to do this, we must be willing to help them unearth their own hope systems.

Everyone's hope system can enable them to live each day until they die as the whole person they want to be, no matter what the depth or extent of the physical disease they are enduring. Despite all their suffering on a physical or emotional level, hope opens for them the possibility of realizing their full human potential. Indeed, the crisis of impending death can create tremendous opportunities for growth in many dimensions of who we are as humans. It is deep interior hopes that enable the dying to live each day in the face of incurable disease, until they are ready and able to let go and face death.

The Hope System approach to the cancer patient reaches into and relates to each person's intrinsic hopes, for we are what we hope. In order to understand the key concept for The Hope System, it is necessary to emphasize that hope, our interior life force, is merely changing. It is never destroyed. Hope is always present within each person experiencing the final life-into-death passage and it motivates each one to live through the dying process from the moment of the fatal disease or condition's diagnosis, until death.

I realized very clearly that we need to view the patient as a whole person, rather than as a disease or as being at a certain psychological stage in the dying process. Taking up where Elizabeth Kubler-Ross left off and with her blessing to take the next stop beyond her approach; I developed a unique framework for understanding the person with cancer and responding to what they are experiencing internally as a whole human being. My approach expands and deepens. Kubler-Ross' stages. It keeps the patient's family and the caregivers focused on the cancer patient as a whole person, fully present on all levels physical, emotional, mental and spiritual. When we relate to our patients in this way, we are being a fully-aware person ourselves.

I named my approach "*The Hope System*", which prompted Kubler-Ross to call me "*The Hope Lady*". My approach enables the caregiver and the family to understand that the patient's hopes are central to his/her wholeness and must be respected fully. Thus, The Hope System goes well beyond both Kulber-Ross' psychodynamic approach and the disease, medical model, by bringing back the concept of the whole person as the focus of how we think about and relate to the patient with cancer.

Table 1. The Four Stages of Hope

Hope for a Cure: "*I'm going to beat this thing!*".
Hope for Treatment: "*I hope I'm in the 29 percent that chemo helps!*".
Hope for Prolongation of Life: "*I hope to walk my daughter down the aisle at her wedding*".
Hope for a Peaceful Death: "*I hope I die pain-free and alert*".

The four stages of hope (see Table 1) alert the caregiver and the family to what is going on in the inner world of the dying person, as their hopes change in the face of life-threatening illness and impending death.

If we acknowledge that, at a core level, the patient himself is hope itself, we can see why hope is where we need to center our expectations, both as family members and professional caregivers. As the terminal illness progresses, hope actually comes closer to the surface than ever before. When a person is presented with a terminal diagnosis, hope begins to rise from the inner depths, on call now, on guard, our corporeal sentinel and guide. Spend one day with someone recently diagnosed with a terminal illness and you will understand the power of hope.

One may think that I get the hope thing, but how can I help the patient on her journey to find hope? Actually, it is quite simple for hope as we have discussed, is found within the cancer patient, not outside of them. So our role as professional caregiver is to help the patient with cancer to unearth her own Hope System by asking the simple, yet profound question, "What are you hoping for?" and listening for the answer.

In particular, one patient of mine illustrates how effective this question can be in facilitating understanding and communication between everyone involved: patient, family and professional caregivers alike.

Years ago, as part of my role as a clinical nurse specialist in oncology, I was asked by the staff of a medical oncology unit to see a man named John. They said that he seemed a bit down and maybe needed someone to talk to. A former policeman, he was a perfect example of the strong, silent type, but the staff had sensed sadness in him recently. In my visit with him, we got to know each other some. He spoke openly about his diagnosis and prognosis and lovingly about his wife of fifty years and his family. During our conversation I asked him, "*What are you hoping for?*" . He replied quickly, "*I hope the Mets win*". So we both smiled and exchanged baseball stories. After chatting a bit more, I told him I would return to see him again and then I left, understanding from his response that John did not want to explore anything more deeply with me at that time. This simple question drew John out of his medically-defined role of the compliant patient and gave him the opportunity to regain his sense of self as the full person he was before his diagnosis, not simply as a cancer patient. Several days later, as I was walking down the hall, I heard my name called and turned to see John walking toward me with his ever-present IV pole. He was accompanied by four men, each one taller and bigger than he. These were his four sons: two policemen, a fireman and a detective. "*Cathy, I want to talk to you*," John said. "*Remember the question you asked me the other day? I want you to ask me it again*". By this time, John and his giant sons had surrounded me—I felt like a small sapling, gazing up at giant redwoods—and I responded dutifully, "*I asked your father what he was hoping for*". Looking directly at me, John gave his real answer: "*I hope my sons will understand that I don't want any more chemotherapy. I want to go home and be with their mother and see my grandchildren, without vomiting my guts out, for as long as I have left to be with them*". The sons looked at him and then at me and I can assure you, there was not a dry eye among us.John went home that very day. He spent quality time with his wife, his children and his grandchildren, just as he hoped he would. And then he died peacefully at home, his wife and his sons beside him, assisted by a local hospice team.

One of the things I really love about the Hope System (see Table 2) is that it helps cut through what I call the patient's garbage and returns them to person-hood for themselves and their loved ones; it enables us to contact them where they are living at each moment of their journey toward healing or toward death. When we relate to our patients in this manner we are helping them unearth their own hope system. As I've learned from the journeys of my patients, very few move through the four stages of the Hope System in a predictable and orderly fashion from Stage 1 to Stage 4. During such an intense time, their hopes change in more of a back-and-forth zigzagging pattern than in a linear continuum. But the patient and their family may be experiencing different fluctuations and be out of sync with each other.

The most important lesson of all is that when you acknowledge whatever stage of hope the patient is currently going through, you are being there for then when it counts; you are serving as a listening presence.

By learning to track which stage of The Hope System the patient is going through over time—what their specific hopes are and how they are changing—you become able to engage with them on the deepest level, on a continuing and ongoing basis. In becoming aware of the changing hopes of the patient and resonating with these hopes, we avoid the trap of projecting our own hope system onto them. We actually hear what it is they are hoping for, instead of hearing what we imagine they are hoping for, or what we think they should be hoping for.

Making such a meaningful human connection—by asking the one simple question, "*What are you hoping for?*" –is healthy for all concerned. It is sure to foster clearer communication, a vital factor in ensuring appropriate medical treatment and patient-directed care from the moment of diagnosis all the way to the moment of death. That this approach should be as effective as I've found it to be with thousands of patients and their families isn't that difficult to understand: after all, we are what we hope—the dying, as well as the living. Our own humanity and wholeness are enlarged by asking this critical question and listening to the answer. By acknowledging their hopes at every stage, we are more in touch with our own hopes, both before and after our loved one or patient has died—and are more fully able, as survivors, to live our own lives without regret or guilt, knowing we helped them live or die as they hoped they would.

Table 2. Hope System for Care-Givers

Hope to be heard, to say the right thing.
Hope to be able to listen.
Hope not to hurt,
Hope to be able to help.
Hope to be present to those who need us.
Hope to always be able to respond.
Hope to be able to say "no" and mean it without feeling so guilty.
Hope to be able to survive the stresses.
Hope to be able to say "enough" when the time comes.
Hope to be able to leave with the thought of a job well done.
Hope to learn from the dying what life really means.
And live it to the fullest.
Hope to be remembered as someone who cared.
Hope (when all is said and done) to have made a difference.

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TRADITION, HERITAGE AND SPIRITUALITY

Bring about Benefit, Forestall Harm: What Communication Studies Say about Spirituality and Cancer Care

Jillian A Tullis

Abstract

Technological advances in medicine allow health care providers to diagnose diseases earlier, diminish suffering, and prolong life. These advances, although widely revered for changing the face of cancer care, come at a cost for patients, families, and even health care providers. One widely cited consequence of better diagnostics and improved treatment regiments is the sense that there is always one more test or therapy available to extend life. Such an approach to cancer care can prove detrimental to patients' healing. In addition, these new tests and treatments further focus attention on the body as the site of healing and cure while downplaying other aspects of health. The absence of psychological, social, and spiritual care from a patient's cancer care plan compromises healing and makes palliative and end of life care more complicated. In this essay, I discuss the tensions that exist between contemporary cancer care and spirituality and use Communication Studies scholarship to navigate the challenges of integrating a patient's religious or spiritual beliefs into their cancer treatment and care. In addition to discussing the challenges of communicating about sensitive topics such as illness, spirituality, and dying, this article uses narrative examples from a comprehensive cancer center and a hospice (both in the United States) to understand how people with cancer and other terminal illnesses communicate their spirituality and how these conversations influence health care choices and provide comfort. By understanding how patients communicate about topics such as the meaning of life, quality of life, dying and death, providers are better equipped to offer care that is consistent with a patient's beliefs and life goals. This approach maintains that communication is more than a means of transferring information, but is constitutive. By understanding that communication creates our lives and shapes our worlds, lay and professional caregivers can meet patients where they are spiritually, emotionally, and socially and offer effective care that is culturally situated. For many in Muslim societies, a cancer diagnosis is Divine fate. Understanding a cancer diagnosis as destiny offers comfort to some, yet cancer patients and their family members may experience isolation because of the stigmas associated with the disease. This double-bind can lead to spiritual or existential crises, which draws further attention to the need for effective spiritual care that ultimately fosters patient and family healing whether or not a cure is possible. Bringing together various approaches to communicating about diverse spiritual and religious ideas may allow for enhanced comprehensive cancer care.

Keywords: Narrative - illness - stigma - religion- healing to bring about benefit and forestall harm

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Introduction

A cancer diagnosis ruptures a person's existential and social well-being. To paraphrase cancer patient, Anatole Broyard (1990), for the physician, illness is a routine incident in their rounds, but for the patient, it is the crisis of their life. In such times of crisis, patients look to their physicians and other health care providers for guidance about how to heal the wounds caused by disease. Healing for such patients involves more than developing a plan for medical treatment, but also includes the need for compassion and solace. The need for empathetic care is universally important, but particularly necessary in societies where a conspiracy of silence around diseases, such as cancer, leads to isolation and suffering.

Increasing communication is a necessary step for improving cancer care in communities where the disease remains proscribed. Elizabeth Kübler-Ross (1969), a psychiatrist, made this observation about the proscription around dying and death in the United States more than 40 years ago. While communication that is more open can help counteract the stigma associated with diseases such as cancer, effective communication is essential if care is to improve and meet patients' needs. According to Yingling and Keeley (2007), many medical journals call for improving communication to advance health care, but few take seriously the scholarly study of communication and wrongly assume that more communication equals better communication. These studies rarely call upon the expertise of communication scholars (Yingling & Keeley

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2007). One reason for this oversight likely involves the perception that communication is simply a conduit for transferring information from a speaker to a receiver. Communication, in fact, is a complex process that profoundly shapes individuals' social worlds (Craig, 1999). By understanding the constitutive nature of communication, health care providers, especially those who focus on cancer care are better able to provide for patients in effective and holistic ways.

Around the world, advances in medical technology have significantly improved health care. In some cases, these advances result in longer life expectancies and can diminish physical suffering, but technology can simultaneously undermine a patient's emotional and spiritual well-being (Puchalski, 2006). Physicians, and sometimes their patients, focus more on seemingly objective conceptions of health, including scans and test results rather than peace of mind or quality of life (Balducci, 2008). I have observed patients, who with the support of their physicians, seek one more treatment, one more surgery, in hopes of extending their lives. An emphasis on treatment and cure takes attention away from caring for a person's spirit, her quality of life, and healing. As Puchalski (2006 p.x) notes, by focusing on spirituality, "we open ourselves up to a type of healing that, while not necessarily curative, does restore us to a wholeness that is perhaps more significant than the cure of a physical illness".

The separation of the spirit and spirituality from matters of health is a recent development (Parrott, 2004; Puchalski, 2006; Wills, 2007; 2009). Hippocrates, whose influence in Western medicine is far-reaching, believed in a connection between the physical body and the soul and instructed physicians to care for the entire person (DuPré, 2005). According to Farage (2008), in the Galeno-Islamic tradition, "to the trained physician's discriminating touch, the pulse sounded imbalances in both body and soul" (p. 23). Farage goes onto say that today the pulse is "mute, soulless, insensible and quantifiable" revealing the contemporary relationship between physician and patient (p. 28). Today, a patient's pulse is not listened to for its texture or quality, but measured in beats per minute (Farage, 2008) and a patient's story is reduced to a list of actionable symptoms (Browning, 1992; Eisenberg, 2008; Groopman, 2007; Tullis, 2009). A physician's touch now only comes in the form of palpating or navigating diagnostic probes.

The benefits of medical technological advances are immense and indisputable, yet they cannot supplant the healing power of touch or an empathetic listener. These developments do not eliminate the influence of religious or spiritual beliefs on understanding disease. In fact, Sachedina (2009) for example, argues for an extensive evaluation of Islamic moral values to guide contemporary medical professionals and care. Patients with access to the best, most advanced forms of treatment still seek compassionate care that attends to the body and the spirit (Tullis, 2009). Research demonstrated that spirituality and spiritual issues comprise a particularly important element of a person's life when the ill and their caregivers struggle to make sense of disease, dying and death (Kaut, 2002; Keeley, 2004; Puchalski, 2006; Keeley & Yingling, 2007; Wills, 2007; 2009). More and more studies document the benefits of spiritual care, and the relationship between a person's spiritual well-being and health (Balducci, 2008; McClain et al., 2003; Puchalski, 2006; Schenck & Roscoe, 2008; Wills, 2007; 2009). These studies note that systematic study of spirituality is difficult because conceptions of spirituality vary. Many scholars operationally define spirituality, drawing clear distinctions between spirituality and religion, associating spirituality with a search for meaning (Egbert et al., 2004; Hall, 1997; Hermsen & ten Have, 2004; Keeley, 2004; Wills, 2007), whereas organized structures and practices constitute religion and religiosity. Wills (2007) contends that spirituality is a private matter, while people enact religion collectively and in public settings. Religion and spirituality inform each other rather than subsisting apart from each other. In other words, according to Hermsen and ten Have (2004 pp. 354-355), "Religion usually expresses spirituality, but spirituality does not necessarily relate to religion". The distinctions between spirituality and religion acknowledge that while not everyone embraces a religion, all people are spiritual and can benefit from spiritual care. It is important to note, however, that scholarly distinctions between spirituality and religion may reflect contemporary American discourse and not necessarily mirror cultural or social practices that take place in health care settings . For some societies, including many of those informed by Islamic faith, religion is not separate from, but informed by Islamic teachings (Nasr, 1987).

Identifying and meeting individuals' spiritual needs presents several communication challenges for health care providers (Tullis, 2009). This esay offers descriptions of spiritual communication from a cancer center and a hospice in the United States to reveal the tensions that exist when providing spiritual care. These narrative vignettes serve as a foundation for understanding how seriously ill people talk about their spirituality. Analysis of these interactions illuminate strategies to assess spiritual needs and communicate about spirituality with patients and caregivers touched by cancer. In addition to offering stories from two health care settings, this article presents a definition of spirituality that is inclusive of many different belief systems.

The perspective adopted here maintains that spirituality is synonymous with a person's meaning of life and the beliefs and goals that comprise what gives a life meaning influences a person's approach to health. While not everyone would describe herself or himself as religious, or believe in an omniscient force that guides their life, this definition acknowledges that all people are spiritual. This definition also creates space for communicating many different types of spirituality and spiritual care and does not require that people label themselves spiritual. As this paper reveals, numerous spiritualities exist that include a variety of activities, behaviors, and ideas that reflect patients' conceptions of what gives their lives meaning. Experts note the relative ease of diagnosing and treating physical pain over other types of pain people experience at the end of life (Callanan

& Kelley, 1992; Puchalski, 2006); however, caregivers' ability to assess spiritual pain and suffering proves more difficult. According to Puchalski (2006 p.21), *Pain is multifactorial; physical, emotional, social, and spiritual. Anyone of these can exacerbate the total experience of pain*. Spiritual pain and suffering can include angst over unfinished business with family, fears of retribution in the afterlife, or guilt about past interpersonal conflicts. Health care providers may fall back on their bio-medical training and fail recognize the connections between a patient's suffering and spiritual pain. Spiritual pain is not necessarily invisible because as Kaut (2002 p226) notes, there is *evidence [that] spirituality is likely to be expressed in observable attitudes, beliefs, and behaviors*. People are capable of communicating their spiritual needs if prompted. A patient's spiritual self-awareness will influence a caregiver's ability to offer spiritual care because while some patients may not know, easily identify, or understand their spiritual needs, others may freely articulate their spiritual requirements. Spiritual or religious leaders (e.g., Chaplains, Imams, Pastors, Mullahs, Rabbis, and Priests) and other caregivers may have to identify patients' spiritual beliefs and needs by offering prayer, suggesting guided meditation, or asking patients about their beliefs related to the meaning of life, the purpose of illness or disease, or exploring what matters most to a patient on that day (Tullis, 2009).

Identifying and caring for a patient's spiritual needs does not necessitate special skills as much as it requires a willingness to be present with a patient and attend to their spiritual needs as they arise. The following section describes several examples of caregiver-patient interactions that highlight spiritual communication in two health care settings, a large not-for-profit hospice and a comprehensive cancer center both located in the Southeastern United States. The first vignette illuminates how one person's love of ballroom dancing constitutes what gave her life meaning – a marker of her spirituality – and influenced her health care choices. The second example describes how activities as mundane as household chores can hold spiritual significance. The following case comes from observations I conducted at a cancer center in 2005.

Spiritual Communication in the Field

"Hello Mrs. Crandall, " Dr. Basilio says, in a deep friendly Italian accent.

"Oh, Hi Dr. Basilio," Mrs. Crandall says, matching Dr. Basilio's friendliness. After receiving a kiss on the cheek from the doctor, Mrs. Crandall looks up at me and I smile self-consciously because of my new orthodontia.

"Hi," I say, as I extend my hand to Mrs. Crandall.

"Jillian is a professor of communication working with me," Dr. Basilio interjects.

"Pleasure to meet you," Mrs. Crandall replies, "This is my friend Helen. She's a retired RN," she continues, with a mildly perplexed look on her face. I convince myself Mrs. Crandall expression has more to do with the incongruent image of a professor wearing a white lab coat than my metal mouth. Dr. Basilio and I both greet Helen and I take my place near the exam table as the patient and her physician begin their visit at the cancer center's clinic. This clinic focuses on older adult patients.

"You look wonderful, Dr. Basilio says, "How are you feeling?"

"Not too good, doctor," she replies, with a slight accent indicative of some place in the Northeastern United States. As I try to commit the details of the scene to memory so I can record them in my field notes, Mrs. Crandall's resemblance to my 88 year-old great aunt captures my attention. Mrs. Crandall is in her 70s, a decade younger than my great aunt is, but Mrs. Crandall could easily be mistaken for a woman in her late 60s. She is wearing a striped sweater twin set, matching solid navy blue polyester pants with an elastic waist, and a strand of large white beads hangs heavily around her neck. She is very petite, which is probably why she reminds me of my great aunt.

Today, Mrs. Crandall's chief complaint is her painful distended abdomen. "My stomach is so big that my pants hardly fit anymore and it's so uncomfortable I can barely go dancing," Mrs. Crandall explains. I am surprised how quickly Mrs. Crandall's tone has turned from light and carefree to almost whiny.

"What type of pain? Is it dull or sharp?"

"It's dull, achy."

"Does it come and go or does it stay?"

"It's usually always there."

"Okay. Can I examine you?"

Mrs. Crandall rises in response to Dr. Basilio's request. As Mrs. Crandall stands, I can see that she is not very tall, maybe an inch or two above five feet. She does not remove any of her clothing and uses the small step stool to get on the exam table. Dr. Basilio pulls out the small shelf to support Mrs. Crandall's legs and gestures for Mrs. Crandall to lie down. Dr. Basilio lifts her shirt to reveal and palpate her abdomen. The skin across Mrs. Crandall's belly looks stretched and pulled taut. Although my medical training lost its currency long ago, I can see that this patient's body is a source of discomfort and pain.

After palpating all four quadrants of Mrs. Crandall's abdomen, Dr. Basilio tells Mrs. Crandall that the mass is probably her disease and recommends chemotherapy treatment. Dr. Basilio's delivery is matter of fact, neutral, but not cold. With only a few clinic observations under my belt to date, I think Dr. Basilio is telling Mrs. Crandall that her cancer is back. I expect Mrs. Crandall to look devastated and I glance in her direction to capture her reaction.

"Does that mean I'll lose my hair," Mrs. Crandall says, with reservation and anxiety in her voice. (Your hair? I can't believe Mrs. Crandall's primary concern is her hair!, I think to myself).

"Yes, that is a side effect of most types of chemotherapy," the doctor replies. Mrs. Crandall asks for an alternative treatment several times, she is practically begging for something other than chemotherapy. Mrs. Crandall even goes so far as to suggest a treatment that she did not tolerate well in the past.

"Can't I take that other thing? The stuff I took last time," Mrs. Crandall says, pleading.

"Mrs. Crandall do you remember the side effects the last time?"

"It was awful, it gave me dry heaves," she exclaims.

Confident there are few other treatment options, Dr. Basilio says, "I will look into a cooling cap for you. But I doubt they are available because they are not very effective at preventing hair loss."

Mrs. Crandall's friend, Helen interjects her opinion about the chemotherapy, "Just do it Diane. Your hair will grow back."

Dr. Basilio seconds Helen's comments and tells Mrs. Crandall that chemotherapy is the only way to stop the pain and arrest the cancer that is likely spreading throughout the lining of her stomach. "Okay Dr. Basilio. Whatever you say, I trust you," Mrs. Crandall says. "But I really wish there was some other way because I don't want to lose my hair."

"We'll schedule you an appointment at the infusion center and I'll call up there and ask about the cooling caps. We'll see you soon," Dr. Basilio says, as he leans over to give Mrs. Crandall a departing kiss. "It was pleasure to meet," he says to Mrs. Crandall's companion, Helen. "You are a good friend," he says, and walks out the door.

I shake Mrs. Crandall's and Helen's hands. "It was nice meeting both of you. Take care," I say, as I walk out the door.

Returning to the clinic work area, I learn, by listening to Dr. Basilio and his nurse Samantha that they probably do not have the cooling caps once used in an attempt to prevent alopecia, or hair loss caused by chemotherapy. "They don't work," Samantha says.

"I know, I just thought I would ask because Mrs. Crandall is worried about losing her hair. She probably has cancer all over her abdomen and she's worried about losing her hair," Dr. Basilio says. I am relieved to hear the doctor share my sentiments about Mrs. Crandall's imminent hair loss. I also learn that Mrs. Crandall is an avid ballroom dancer with a history of breast cancer and Dr. Basilio is concerned that the distended abdomen is a sign that she now has peritoneal cancer.

Analysis and Interpretations

This interaction between Dr. Basilio, Mrs. Crandall, and her friend Helen reveals several interesting insights about spiritual care, health, and communication. First, upon greeting Mrs. Crandall, Dr. Basilio greets his patient with a handshake and a kiss. People frequently underestimate the value of these types of nonverbal communication. A recent article in the New York Times reported findings from a study highlighting the benefits of touch, noting that brief contact can reduce serotonin levels (Carey, 2010). Second, Mrs. Crandall's reaction to chemotherapy is startling because it seems irrational to resist a potentially life-saving or life extending treatment to avoid hair loss. Mrs. Crandall's request for a form of treatment with detrimental side effects further emphasizes her commitment to keeping her hair. Mrs. Crandall's pleading is evidence (see Kaut, 2002) of her spirituality because ballroom dancing gives her life meaning and purpose. The tension of course is that Mrs. Crandall also needs the treatment if she ever expects to return to the activities that make her feel most alive. Third, this example illustrates that in some instances a person's spirituality rises to the surface during a conversation, however, one challenge remains, how do health care providers pursue appropriate medical care in light of spiritual beliefs and wishes? Hopefully, physician and patient can collaborate on a plan of care that meets the needs of the body and the soul. Mrs. Crandall easily acquiesced to the wisdom of her friend (a former RN) and her oncologist, and pursued treatment. Some patients, however, will refuse treatment in pursuit of life goals and quality of life (Balducci, 2008). The next time I saw Mrs. Crandall in the clinic, she was wearing a stylish wig, the distention in her abdomen subsided, and although she tired easily, Mrs. Crandall had returned to the dance floor.

Companions frequently accompany patients during visits to Dr. Basilio's clinic and it is common for that person to participate in the interaction (Eggly, et al., 2006). I have observed many levels of interactions during clinic and hospice visits from a silent spouse to an adult-daughter who takes copious notes and asks many questions. In families where cultural practices dictate protecting a patient from potentially devastating health information (Lipson & Meleis, 1983), identifying spiritual needs may prove more challenging. In addition, some family members, particularly those who are also caregivers, talk as though they are the patient, which is another type of communication prohibitive of addressing a patient's needs and determining her wishes. This was the case for Mrs. Robertson, a 73- year old patient with a history of breast cancer. During a clinic appointment, Mrs. Robertson's daughter accompanied her and was so involved that she commandeered the visit. Not only did Mrs. Robertson's daughter have a hand written list of seven questions, she often used the "we" pronoun when discussing test results and the patient's care plan. The daughter's involvement in the appointment became a concern when she insisted that her mother inquire about her diagnosis and treatment. "It's better to know," the daughter said, "so it [cancer] doesn't take you. Surgery [if needed] is just a stop along the way." Mrs. Robertson's daughter emphasizes fighting for life, no matter the circumstances. In hospice, a patient's family members (as designated by the patient) comprise the unit of care, but whether formally recognized or not, family and caregivers greatly influence communication in health care settings. Visibly upset and frustrated by her daughter's involvement, Mrs. Robertson acquiesced and agreed to aggressive treatment.

Mrs. Crandall and Mrs. Robertson brought one person to their clinic appointments, but it is not always realistic to expect just one or two people to join a patient during a visit. Family dynamics, culture, and timing all influence the number of people who might accompany a patient. I have observed clinic visits where a patient brings as many as five family members and in hospice settings the number of loved ones involved in a patient's care is sometimes greater. Family history and communication styles can constrain interactions prohibiting spiritual assessment and care. I have heard hospice team members report stories of patients who have abandoned their religious upbringings only to have family members and friends pressure the dying person to participate in rituals or insist on display religious idols or symbols. A health care provider's ability to identify and honor a patient's spiritual or religious wishes proves more difficult in such environments.

Spiritual needs for people who still have treatment options available to them are sometimes different from the needs of people who know the end of their life is near. In addition, according to Long (2001), spirituality and communication are interdependent and the two concepts are so enmeshed that it is difficult to know where one ends and the other begins. One patient I met while conducting hospice research illustrates this point. Mary was dying of chronic obstructive pulmonary disease, which prohibited her ability to clean houses, something she did for a living for years. She regularly mentioned her desire to clean house when her hospice social worker and I visited. On the surface, it seems that cleaning house is a superficial act easily given up when illness becomes prohibitive. Cleaning houses, however, gave Mary's life purpose, meaning, and a sense of order and control; thus cleaning was a spiritual act (Tullis, 2009). Kellehear (2000) called this type of spirituality, situational transcendence, which can arise out of such issues as the physical side-effect of symptoms, foreign environments, and the loss of familiar work and home surroundings. Although Mary recognized the limits the illness placed on her ability to carry out a central element of her life, her inability to do such meaningful work allowed the traumatic psychological dust to settle. Kübler-Ross (1969) argued that those of us not actively dying need to take the time to sit listen and share, but this process is a two-way street. By taking advantage of a captive audience, Mary supervised the cleaning of her spiritual house through storytelling or life review (Tullis, 2009).

Writing about spirituality in hospice care, Kellehear (2000) notes that people who are not religious have concerns about forgiveness and closure that are more synonymous with religious discourse than we might expect. The tendency is to assume that religious approaches are sufficient for resolving a patient's moral and ethical dilemmas as well as spiritual suffering, but this is not always the case. The observation makes clear the need for spiritual rather than religious interventions.

The examples above come from a predominately Judeo-Christian perspective in the United States. Yet, they are relevant to non-Christian societies and health care settings because they articulate the relative ease of identifying spiritual concerns when care providers move away from exclusively religious understandings of spirituality and spiritual pain. Although not often observed in the United States, there two factors that influence spiritual issues for cancer patients in the Middle East. According to Professor Michael Silbermann, Executive Director of the Middle Eastern Cancer Consortium, "Many Moslems [sic] believe in destiny, and accept the notion that getting cancer is a matter that is controlled by God-Allah and one has to accept it" (personal communication, January 30, 2010). The role of Islam in understanding a disease such as cancer influences patients in two important ways relevant to communication. First, ill people are more likely to accept God's role in disease, which may explain why cancer patients are less prone to openly complain about pain (personal communication, January 30, 2010). Having accepted illness as part of God's plan does not eliminate spiritual pain or suffering completely. According to Sachedina (2009 p.83), *Unmerited suffering is likely to make people doubt God's goodness, even if such suffering turns out to be the cause of some greater good…More critically, the problem of underserved physical evil generates a struggle between hope and despair – an inner conflict arises often in the face of the grim reality of inherited diseases like cancer*. As a result, patients may have fears that go unexpressed and unaddressed for fear of appearing less than righteous and unfaithful, whereas Americans may question God and seek answers to those questions from spiritual or religious leaders. In some Muslim societies (and some Christian traditions), understanding that good and evil both come from God still impede medical treatment because true believers would rely on God for healing (Sachedina, 2009). Second, for those who do seek medical care there is fear of stigma and isolation. For example, according to Silbermann, *women [may] hide the fact that they suffer from breast cancer, because of the fear that their daughters would have less of a chance to marry. Further, women hide the fact that they suffer from the disease since their husband has the right to get another wife without any difficulty* (personal communication). While serious illness can result in social isolation for people in the United States, public health campaigns, non-profit organizations, and patient demands for inclusion and compassion have changed how society once viewed many stigmatizing diseases. These approaches hold communication in common and recognize that talking about illness is a necessary step for promoting cultural and social change essential for individual spiritual and physical health. Organizations, such as the Middle East Cancer Consortium are making strides to influence attitudes and beliefs about cancer.

The ability to identify spiritual needs is challenging under social constraints and proscriptions. Yet, effectively communicating about spirituality in the context of potentially life limiting illness is possible if we consider what gives a person's life meaning and acknowledge that what makes life meaningful will guide health care choices. Despite research that supports the benefits of freely communicating about illness, dying, and death, people fail to talk (FitzSimmons, 1994-1995; Zhang & Siminoff, 2003). According to Zhang and Siminoff (2003), families avoid talking about illness and dying, hoping to maintain positive attitudes and to sustain the health of the ill family member. Miller and Knapp (1986) further observed that many people feel unprepared to communicate with people who have a terminal illness (see also, Ellis, 1995). Professional and lay caregivers avoid these conversations in part because they do not know what to say or for fear of saying the *wrong thing* . Simple questions can begin a dialogue or encourage storytelling locally and these conversations become the first step in affecting change globally (Frank, 1995). Miller and Knapp (1986) interviewed professional caregivers, specifically chaplains and hospice volunteers, about their experiences communicating with terminally ill people. Through

Table 1. Spiritual Conversation Starters

∑ What gives your life meaning/purpose?
∑ What activities or hobbies make you feel most alive?
∑ What is important to you today?
∑ Would you like prayer? Show me how you pray?
∑ Tell me about a time in your life when you were most happy?
∑ What are some things that you would like to do, but you can't because of your illness?

retrospective self-reports, these caregivers offered examples of what Miller and Knapp called wrong behaviors as well as advice for effective communication with the dying. Poor timing, offering false hope, platitudes and withholding feelings were some of the examples of wrong behavior. Advice included such suggestions as listening more and talking less, showing emotional commitment, and not worrying about saying the wrong thing. Based upon research with hospice, Table 1 lists several additional recommendations for spiritual conversation starters appropriate for health care settings that anyone willing to provide spiritual care can use (Tullis, 2009).

Using the phrase *wrong thing* draws attention to presumption that there is a *right* or *correct* thing to say to someone who is seriously ill.

Since *Islam does not divide the public space into spiritual and secular domains* (Sachedina, 2009) these suggestions for initiating spiritual conversations are respectful of a wide variety of cultural and social beliefs. The principle of *Maslaha*, forestalling harm and bringing about good requires that we treat all people with respectfully, but that we must act with the interests of the other in mind. In this essay, I have used examples from both a hospice and a cancer center in the United States to discuss the role of communication in providing spiritual care and illuminate effective ways to assess and offer spiritual care. Effective communication in cancer care should not focus on the amount of talk, but the quality of interactions. Recognizing that communication is constitutive (Craig, 1999), we can engage people with cancer and other life-limiting diseases in ways that fundamentally shape how they understand their lives and their illness. With good intentions in our hearts and minds, and a willingness to be present with people who are seriously ill, holistic care and healing is possible.

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TRADITION, HERITAGE AND SPIRITUALITY

Researching the Meaning of Life: Finding New Sources of Hope

Shirly Alon

Abstract

The purpose of the paper is to discuss means of assisting terminally ill patients in seeking for sources of meaning and hope, alongside the acknowledgment that their lifespan is short.Psycho-spiritual aspects make a substantial component patients suffering from incurable illness have to deal with. Evaluating and mapping the causes and expressions of psychological - spiritual suffering may assist in tailoring appropriate strategies of distress relief. Therefore, interventions should be given in accordance with their specific focus of difficulties, as well as with wishes and needs. Appropriate interventions in palliative psychotherapeutic rapport are inspired by identifying new sources for meaning in current life (sometimes, aided by past experiences or future visions). Reinforcing sources for meaning may attempt in providing patients amongst: - Equilibrium, between suffering and sorrow (which sometimes take over the patient's world), and on the other hand, new experiences, sense of satisfaction and fulfillment. Individual's acknowledgment that he is not completely withdrawn from the circle of life, and yet significance and fulfillment in life still exists. For a holistic meaning – centered intervention it is advisable to simultaneously integrate two central axes: the existential analysis, inspired by concepts driven from Frenkl's Logotherapy, such as freedom of choice, personal responsibility, inner truth, hope and transcendentalism; the operative axis, enhancing meaning and hope by assisting patient's wishes come true. Patients are aware, many times, that those wishes may be their last one, therefore perceive their fulfillment as crucial for their sense of meaning. Moreover, those wishes may elevate patient and family's spirit and reduce risk of demoralization. Whereas existential – spiritual interventions are recommended to be given by qualified professional therapists, the operation of fulfilling wishes is feasible by everyone, from family members to multi-disciplinary staff. Case illustrations for meaning - centered interventions will be discussed in the course of the paper. Cultural and traditional differences within the Israeli society, expressed in themes of work with patients, will lead to the conclusion, that there are many creative ways for researching meaning of life and sources for hope.

Keywords: Terminally ill patients - psychological intervention - existential and operative axes

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Introduction

Meaning, the focus of this discussion, raises many associations, such as choice, uniqueness, personal responsibility, hope, inner truth, empowerment and even more. These only demonstrate the abundance and complexity of the concept. Each and every individual may bound to at least one of the ideas above, while seeking for meaning, maybe even by using other terms. Describing meaning has a lot to do with age, cultural influence, individual's personality features and world outlook and perception;

Sara was a Jewish orthodox woman. She had allowed herself, for the first time in her life, to cast doubts in religion, right after being announced that her metastatic breast cancer was uncontrollable, she decided to no longer maintain her orthodox religious rituals. Her family and community tried to sympathize with her transformation by rationalizing her questions as a natural existential faith crisis, which is rather common in such cases, but her narrative was completely different: she decided, for the first time in her life, to take upon herself the freedom of choice. She felt she was born into facts, which automatized her and didn't allow her to really "feel" God from inside. She therefore decided to peel off religion and to start an idiosyncratic spiritual journey of her own. Interestingly enough, she kept insisting that her faith was well kept, however her behavior was considered drastic: it included lifestyle changes, many unasked questions and even provoking her religious community, which in other unfortunate cases could have ended in complete isolation and banishment. She started seeing a Rabbinic psychotherapist, with whom she searched for the connection between her true self and God. Revealing her true self and her personal connection to God had allowed Sara to find meaning in her doubts, regain inner strengths needed for coping with an imminent threat to her life and eventually, inner peace.

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How Can a Person Find any Meaning for Suffering?

It is well known, that in times of crisis, people try to use their difficulties as sources for inner growth or benefit finding. But how can people with incurable and advanced illness seek for such benefits, when all what they see is loss?

Indeed, people suffering from terminal illnesses are susceptible of experiencing continuing losses, sometimes occurring too fast to allow the any adjustment whatsoever. Patients are being forced to separate from beloved people, from previous roles, basic functions and also values, which can no longer be achieved (such as ambition). If so, the question of where (if at all) lies hope, is indeed very difficult to be answered. One horizon for receiving some answers may be by the search for meaning;

Logotherapy, originated from the Greek word LOGOS (meaning), is a psycho-philosophical approach, developed by Victor Frankl (1959). logotherapy was justified to be a tremendously powerful therapeutic tool for people suffering from terminal illnesses (Breitbart, 2001), since suffering is considered a major springboard, both to having a need for meaning and for finding it (Frankl, 1959). In logotherapy, the human spirit is referred to in several assumptions, but it should be noted that the use of the term spirit is not "spiritual" or "religious". In Frankl's view, the spirit is the will of the human being to search for meaning, and not necessarily God or supernatural being.

The basic principles of logotherapy claim the following: (1) The primary motivational force of human beings promotes seeking meaning in life. Whereas Sigmund Freud, in his psychosexual theory of development described impulses as primary motivational forces, Frenkl's logotherapy deals with much more supreme instincts. (2) Meaning exists and will always exist in life, under every circumstance. Hence, even under difficult, unchangeable conditions, the individual may find internal meanings for his own existence. (3) The individual has the freedom to find meaning, in each and every experience, occurrence or action of his. In other words, there are no rules rights or wrongs in finding meaning. Meaning is a subjective concept, a consequence of individual interpretation and may be translated into concrete actions or to internal insights. For this reason, the paper aims to discuss both paths as legitimate for identifying meaning towards hope.

Both research and practice (Breitbart, 2001) have proven logotherapy to be an effective and beneficial approach while treating people with a short lifespan. That is when existential questions appear and require some good answers (Yalom, 1980). Therefore, while stimulating different elements of the human essence, it is possible to assist the patient in regaining inner strengths, spiritual elevation and in due course, a conceptualization of hope.

Before describing the various aspects one may approach while searching for meaning, it is highly important to consider that some elementary conditions must exist beforehand. Like Abraham Maslow's hierarchy of needs (1943), here too, a person can not speak an existential language (i.e. dealing with meaning, self realization and fulfillment) without having basic psycho-socio-spiritual foundations. It is crucial, first and foremost, to confirm that the patient does not suffer from a significant level of depression and / or anxiety, which might obstruct the process of researching. If such psychopathology is diagnosed, it must be treated and well balanced first. Only then will it be possible to promote to the next steps.

The next conditions would be a somewhat adequate self esteem, meaning that under current circumstances, he still has a positive realistic evaluation of himself. Together with that, the patient should sense a satisfaction from life. Yet, even if at present he finds difficulty in identifying any satisfaction, interventions such as active - narrative reminiscence of satisfactory events or achievements from the past, may help in returning some level of satisfaction.

The third step that may assist in the process of searching for meaning is investigating goals and aspirations in life, either those which were left somewhere in the past, or those that still exist in the present. Assessing those will allow a specific direction for intervention.

Next comes the existential phase, which brings up aspects, such as freedom of choice (even if reduced due to illness), self revelation, and at last, meaning and sources of hope. It is important to emphasize, that even when "lower" levels are harmed due to demoralization or grief (such as self esteem etc.) it is still possible to climb towards the existential peak, but it will require a comprehensive work.

Meaning, however, does not necessarily have to do with optimism. Pessimist people are also able to find his meaning in life. For instance, by being well prepared for the worst case scenarios, they allow themselves to choose different coping routes, personal responsibility for consequences, empowering problem solving and so on.

Researching Individual Meaning via Different Dimensions

Meaning is a holistic concept. In many cases, the individual identifies some different dimensions composing the whole, and in others, humans are identified with one primary aspect. Therefore, in meaning centered intervention, it is the therapist's task to scan, along with the patient, the different dimensions and their relation to the latter, aiming to reveal the right transducer towards meaning.

Through the inter-personal dimension, people may look for meaning by preparing an organized farewell gatherings from significant others. Another way of interpersonal approach for meaning would be by leaving an inter-generation legacy, such as sharing individual history or experiences with the next generation, leaving a spiritual will and so on. End of life seems to be a good momentum for family gathering, getting together and closer to people with whom they feel comfortable. Calm close interaction with close people may alleviate patient's feeling of loneliness, a common side effect of end of life processes. Being together is also the right time for reminiscing shared history and experiences, analyzing them and re-living them together. Resolution of past conflicts, forgiveness and emotional expressions are common and may assist sense of satisfaction and positive self esteem, due to the positive relationships built in the course of life. Hence, it is frequent to hear patients and families report of achieving such an intimacy which never existed before.

The concrete dimension is very accessible for people with practical orientation. For those, completing missions may serve a satisfying means of acquiring meaning. Even by leaving instructions for the future after his own death, the patient is able to experience a tremendous sense of meaning, due to leaving behind an organized "future". Such living wills are common and have proven to assist both sides – the patient feels calm and carefree from worries about others, whereas his family feels satisfied to please his last wish.

The cognitive dimension is claimed to exist in almost every means of searching for meaning. Park & Folkman (1997) called the cognitive process of reevaluating events as positive as "meaning making". In other words, people's interpretations are those which create foundations for meaning. Those could be new explanations to events, new insights and most importantly, transforming dysfunctional / automatic thoughts into rational adaptive ones. Even the important steps of acceptance and completion with life coming to their end are at least partially based on cognitive analysis.

The emotional dimension brings meaning closer by experiencing intensive emotional expressions. Such emotions could be desire, interest, pleasure and joy – which are commonly translated by patients into experiences, such as "wholeness" or "completeness".

Those who view the world through their senses would seek for meaning by sensual means. They may describe meaning as enjoying the sunlight, smell of babies or favorite music.

And finally, the spiritual meaning, being perceived through transcendence.

People who search for meaning in the spiritual dimension will frequently look for answers in religion, faith or rituals. Today it is well known in the field of palliative care, that addressing spiritual distress is as important as alleviating other sufferings, therefore, the spiritual dimension is thought to be increasingly dominant among people suffering from terminal illnesses.

Wish Fulfillment as Meaning Making

Reviewing life towards their end may remind patient some of his missions, fantasies and goals, that were left behind, unfulfilled. Fulfilling last wishes is an effective tool for end of life interventions and most certainly can ease suffering and sorrow, both for the patient and family. Wish fulfillment is an operative opportunity for assisting patients to feel pleasure, satisfaction and self worth. By cooperating and assisting the patient to fulfill his wish, the family, too, may feel attentive and useful, as opposed to commonly reported feelings of helplessness.

Knowing that people with advanced illnesses tend to be frail and limited, it is not that simple just like that to achieve the unachieved. Without a doubt, fulfilling people's wishes in advanced stages require creativity. Due to unfortunate losses, many times there is a necessity to accommodate the original wish to current reality;

Nina was a 78 year old widow who survived the holocaust 65 years ago thanks to a catholic nun who hid her. Only a few months before being diagnosed with stage 4 ovarian cancer she succeeded in finding the nun's tracks in Poland. Due to a major surgery and radiation therapy she had to go through, her dream of reunion with the nun (who was already 90 years old) was delayed over and over again. Unfortunately, her cancer was aggressively spreading and she was suffering from physical distress. Her only son, Dan, who came to visit her in her nursing home on a daily basis, started noticing signs of disengagement and even depression. At first, he interpreted it as a reaction to the fact she was dying, however on one occasion, she mentioned something about the nun. He encouraged her to provide some more details, and from then on she told the whole story. Dan was astonished to hear the heroic story he has never heard before, and without any hesitation made an oath to his mother, that he himself will fly to Poland, to meet with her rescuer. Nina dictated a sentimental letter for the old Polish nun a month later passed away, not before Dan had promised her again, that soon enough he intends to go, in her name.

When a dream is under no circumstance possible to be fulfilled, it is highly important to be addressed as a grieving process the patient goes through and not to underestimate the pain and sorrow that lies within the acknowledgment, that the wish would never come true. However, even when wish is fulfilled, we should take into consideration, that once done, the patient might feel emotionally ambivalent, and sometimes even sense an increase in death anxiety. One of the reasons for such seemingly paradox is that once the wish is fulfilled, the patient might feel "ready to die", whereas he is never actually "ready" for that. Therefore, fulfilling wishes in not just a technical mission as it seems, but a very sensitive task, which should be executed in collaboration with psychological support.

Discussion

Researching the meaning of life is an ongoing process, which may be applicable either existentially, by finding sources for hope or by fulfilling last wishes. Meaning is a subjective concept, which could be very simple or practical for one individual, or philosophical to another. By identifying and perceiving meaning, the patient is likely to acknowledge, that life is worth living under almost any circumstance and by that increase his will to live. Also, finding meaning which connects past experiences with the present, may also lead to some sense of future. For example, if a patient's meaning in life is established on her maternal roles (past), she may observe her children growing with satisfaction (present) and believing, that once she is gone, they will successfully stand up for themselves (future). And finally, meaning may be an outstanding opportunity for the patient (and family) to feel "more".

The therapist may find himself deeply involved along with the patient, in the process of researching for meaning and hope. In meaning centered psychotherapy, especially towards the end of life, the therapist ought to take an active stand, and sometimes even stimulate the patient, who is many times afraid to get into unknown worlds all alone. It is the therapist's duty to be not only supportive, but to respect the patient's views and ways for making meaning, even if they seem odd .Only when the patient suffers from demoralization or stagnation, may the therapist assist in lighting up the way to one of the possible dimensions of meaning and hope.

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EXPERIENCES IN MIDDLE EASTERN POPULATIONS

Historical Perspectives and Trends in the Management of Pain for Cancer Patients in Oman

Salma Said Mahfudh

Abstract

Introduction. Sultanate of Oman is the second largest country in the Gulf, with a population of 2,867,428 (2008) of which 35.2% is under 15 years and only 3.7% above 65 years. Incidence of newly diagnosed cancers is also the second highest in the Gulf with 11%. Research conducted between 1997-2007 revealed that the most frequent cancers in males: stomach 10%, non-Hodgkins lymphoma 8.6% and prostate 7% while in females: breast 18.9%, thyroid 8.3% and cervix uteri 6.5%. A population-based registry was established in 1996 to compile an accurate database and monitor cancer trends. There is a rigorous follow up of reported cases. Unfortunately most patients report at the hospitals in advanced stages which complicate pain management. All treatment modalities of cancer are available in Oman at the two centers, Royal Hospital and SQUH. There is a continuous effort to develop national educational guidelines, protocols for cancer treatment, palliative care and pain management (PM). Historical Perspectives and Trends in the Management of Pain. In 1970s Omanis used traditional medicine, wassam (moxibustion), to treat pain. In 1988 severe pain was treated in hospitals with intramuscular opioid, whenever necessary (PRN). 1989 SQUH approved use of both parenteral and oral narcotics, received its first consignment, and started PM. The Ministry of Health (MOH) was concerned with possible misuse and for 8 years, thereafter, SQUH was the only hospital allowed to import, stock, prescribe and dispense oral narcotics. Legal requirement to obtain opioids in Oman involves MOH and World Health Organization (WHO) and there is a control as to who can prescribe for both inpatient and outpatient. The drugs available to control pain include non opioids, weak opioids, but the only strong opioids used for severe cancer pain are morphine and Fentanyl. This is complemented with adjuvant drugs. We use the "WHO Ladder" to guide us in the management of pain. Three different cases have been presented to see how PM of cancer patients has evolved from using only non-opioid in 1993, to using intramuscular pethidine in 1995, then to using morphine with adjuvants in 1999. Referral of patients to the PM Team has improved the pain control and at present even without referral, pain is controlled more effectively. Conclusion. There is no doubt that the Sultanate of Oman has progressed tremendously since 1970. The Government is working very hard and is taking major steps to improve cancer care in order to meet the International Bench Mark. Each 5 year plan focuses on actual needs. One of the important needs that have been addressed is the management of pain which has significantly improved. Factors that have improved PM in Oman include the introduction of the PM Teams, training of Nurses and Doctors, follow up of the PM services in the clinical areas, authorizing MOH hospitals to use oral opioids, opening of the National Oncology Centre with Radiation Therapy, inter institutional discussions and development of guidelines, implementation of WHO Guidelines on PM and audits, peer reviews and research.

Keywords: Cancer pain - management - Sultanate of Oman - WHO guidelines

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Background

Sultanate of Oman is located on the South East corner of the Arabian Peninsula. It is the 2nd largest country in the Gulf, with an area of approximately 309,500sq kilometers. The total coastline is around 1,700 kilometers. 82% of the total area is desert. The country has been divided into 10 health regions (Governates)(Sultanate of Oman MOH, 2008). In 2008 – the Population was 2,867,428 of which 1,967,180 were Omanis and 900,248 expatriates. 35.2% of the population is under 15 years and only 3.7% above 65 years of age (Oman Cancer Report of the MOH, 2008). Incidence of newly diagnosed cancers in Oman is the 2nd highest among the nationals of the 6 Gulf States:11%, the highest is Saudi Arabia-71.8% (GCC Research Centre report of 8yrs :1998-2005). The Oman Hospital Based Cancer Registry was established in 1985. A Population Based Registry covering the entire country was established in 1996 based on case notification. The objective is to compile an accurate database and monitor cancer trends. There is a rigorous onsite follow up of reported cases.

The research that was conducted between 1997-2007, revealed that the most frequent cancers by type and gender

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in Oman are in males: stomach 10%, Non Hodgkin Lymphoma 8.6% and prostate 7% while in females: breast 18.9%, thyroid 8.3% and cervix uteri 6.5%.Overall leukemia is very common as well. The head and neck cancer, marked separately as cancers of the larynx, mouth, oral cavity etc in the registry account to be around 65-70 each year making them the 4th-5th most common cancers. Unfortunately most patients report at the hospitals in advanced stages and this compounds and aggravates the issue related to pain management.

Cancer Control and Treatment

The main goal of Cancer control agencies in Oman is the development and implementation of cancer programmes that allow assessment of Cancer burden which in turn, set priorities and achievable targets. There are four major components of Cancer control programme which includes prevention, early detection, treatment and Palliative Care with control of pain and symptoms. The Ministry of Health in conjunction with Primary Health Services play a major role in promoting healthy lifestyle, developing and implementing tobacco control policies, conducting campaigns to increase awareness about cancer in general with special focus on breast and cervical cancers. A screening programme is being piloted in two regions.2 A non Governmental Organization (NGO), National Association for Cancer Awareness(NACA), was founded in 2004, by a cancer survivor. The aim was to educate, train the public and support cancer patients and research. As part of prevention and early detection initiative, the NACA has launched the 1st mobile mammography unit in November 2009, for women who do not have access to screening and education.5 The positive cases are referred to oncology centers and the Criteria for screening and referral have been established.

Oncology Centres

There are two centres treating cancers, the National Oncology Centre (NOC) at the Royal Hospital and the Oncology Units at the Sultan Qaboos University Hospital (SQUH). The Royal Hospital is a 700 bed capacity tertiary hospital which was opened in December 1987.The NOC was commissioned in December 2004. This centre has facilities of Medical Oncology, Radiation Oncology and Paediatric Oncology. Ministry of Health nurses and doctors, from other hospitals go to the Royal hospital for oncology training so that they can continue good care of the cancer patients in the regional hospitals. SQUH was commissioned in February 1990, It is a teaching hospital with a 550 bed capacity. It is involved in teaching nurses, undergraduate and postgraduate medical students, providing tertiary medical care.

At SQUH, patients with cancers are treated in one of the following 4 units: Medical Oncology unit of the Department of Medicine (all solid tumors and Lymphomas in adults; he Department of Haematology (Adult Leukemias); Section of Haematology in the Department of Child Health (Paediatric Leukemias); Section of Endocrinology of the Department of Medicine in conjunction with the section of Nuclear Medicine of the Department of Radiology (Thyroid Cancers).

SQUH is an ISO accredited hospital therefore pain control guidelines, protocols and standards are in place and regularly updated. Clinical audits and peer reviews are conducted.

All treatment modalities of cancer are available in Oman and offered in the above two Oncology Centres, the Royal Hospital and SQUH. Between the two facilities, state of the art medical oncology, Radiation Oncology, Bone Marrow Transplantation and Palliative Care Services are provided. Patients are managed according to disease stage, performance status by surgery, radiotherapy, chemotherapy, hormonal therapy, monoclonal antibodies, the recently introduced signal transduction inhibitors and immunotherapy or multi-modal approach. In addition there is a continuous effort to develop national educational guidelines for cancer treatment, pain management, and palliative care.

Pain Management Evolution Over the Years

Before 1970 Omanis were using traditional medicine, wassam (moxibustion), to treat pain. In 1988 severe cases of pain started to be treated in hospitals with intramuscular pethidine, whenever necessary. 1989 SQUH approved the use of both parentral and oral narcotics and received it's first consignment and started pain management during that year. The Ministry of Health was concerned with the possible misuse. SQUH reassured them of the patients' benefit. For eight years, until 2006, SQUH was the only hospital allowed to import, stock, prescribe and dispense oral narcotics. The SQUH opioids use was randomly monitored by the MOH and the police.

Legal Requirement

Institutions must submit opioid annual requirements to the Ministry of Health who in turn applies to WHO for import authorization. WHO monitors the country's consumption of narcotics and other psychotropic drugs. Senior House Officers are allowed to prescribe for inpatients but for discharged and ambulatory patients the prescription must come from a Registrar level doctor or above. A special prescription must be filled, signed, and stamped then submitted along with an electronic request.

Pain Management Drugs Available in Oman

Include non opioids such as Aspirin, Paracetamol, and NSAIDs, weak opioids Codeine and Tramadol, and strong opioids morphine and Fentanyl. The adjuvant drugs available include antidepressants, anticonvulsants, anxiolytics, steroids, hormones, laxatives, antispasmodics, local anaesthetics, and bisphosphonates. In Oman we use the " WHO Ladder" as a guide in the management of pain.

In SQUH, when we start oral morphine, we give it as syrup for example 10mg every 4 hourly regularly with rescue doses whenever necessary. We give this for two to three days then we calculate the dose needed in 24 hours. We divide into two and give as Morphine Slow Release tablets while maintaining rescue doses. We adjust the dose after 24 hours if pain is not 90% controlled. If the patient cannot take oral morphine, then it is given by other routes e.g. Continuous Intravenous Infusion.

Special Attributes of Omani patients

As Muslims, Omanis have strong faith. When something good or bad happens to them, they believe that it is a divine fate, they accept it better and they put all their trust in Allah. They tend to under report pain because they think it is part of the disease. Usually they wait until pain or symptoms are severe before reporting. They worry about addiction and therefore are reluctant to take opioids. They have excellent family and friend support and they find that reading Qur'an is very comforting. This helps them a lot in coping with pain.

Patient Education

At SQUH we educate our patients through educating our nurses. We conduct a Pain Management Course twice a year and we stress the importance of informing the patients about the cause of pain and symptoms, the importance of reporting pain when it starts and how to use a pain scale to report pain. The nurses also inform patients to take medication regularly and when to use a PRN (whenever necessary) prescription to control the pain. The nurses ask patients to report effectiveness and side effects of treatment and address their concerns on addiction, tolerance and physical dependence.

Case Reports on Evolution of Pain Management in SQUH 1993-2009

Case No. 1 in 1993

A 65 year old man with adenocarcinoma of the lung, pleural effusion, and involvement of ribs, was under the care of Pulmunologist. He complained of moderate to severe pain and in addition he had severe dyspnea, and depression. The initial treatment was Cysplatin intraplural and Mefenamic acid (Ponstan*) 500 mg three times a day (tid). This resulted in very poor pain relief. So the patient was referred to Pain Management Services which had just started at that time.

Pain Consultation: Neurolytic intercostal blocks were given with phenol and this improved the pain. Ponstan was continued 500 mg tid. Codeine eased dyspnea; a Laxative was started at the same time. Methylprednisolone Intravenously was started and Oral steroids followed. Amitriptyline was given at night. He died peacefully after one week.

Case No. 2 in 1995

A 37 year old lady was admitted with cancer of the left ovary and of the stomach with bone secondaries. She was under the care of Gynaecologist. She was operated one year earlier. She complained of severe abdominal pain, bone pain, anorexia and vomiting. Initially she was treated with Pethidine 75 mg intramuscular PRN with poor pain relief, so the patient was referred to the Pain Management Team.

Pain Consultation: Morphine syrup 10 mg (+Domperidol), was given 4 hourly with rescue doses, a Laxative was started on the same day. NSAIDs tid. and Amitriptyline 25mg at night. Nausea and vomiting resulted in inadequate pain relief. In addition, patient refused to take her medications. Loading dose of IV Infusion of Morphine was titrated until the patient was pain free then Patient Controlled Analgesia was started with Morphine, This controlled her pain. Anti-emetic was changed which controlled the nausea.

She died with dignity, pain and symptom free.

Case No. 3 in 2009

A 57year old lady with cancer of the breast, involvement of lymph nodes, metastasis in the bones with multiple destructive lesions of vertebral bones, pelvic bone, and left scapula. She had modified radical mastectomy 2 yrs earlier. She was admitted with generalized pain all over the body, severe headache, right sided weakness and pain causing difficulty in walking. MRI revealed cord compression and early stage of metastasis of the brain. She had stabbing pain in the rectum. It was later diagnosed that she had a second cancer in the uterus with metastasis in the rectum.

Pain Management Without Consultation: Oral Morphine 60mg titrated until it reached 500mg per day. Later it was changed to Intravenous Infusion 3 mg hourly. A Laxative was started on the 1st day morphine was given. NSAID was given tid, She had Radiotherapy daily for two weeks. Intravenous bolus Methyl prednisolone was started initially 1.5mg per kg./day, 2nd day 1mg per kg/day and then 0.5mg per kg/day; after that it was tapered to oral. Anticonvulsants-Gabapentin 300mg daily, then titrated to twice a day and then three times a day. Antidepressant was given at night. Psychosocial issues were addressed and sorted out. The family was giving her body massage, with warm oil, every night. She read Qur'an daily and listened to music and this gave her comfort and distracted her from pain. The muscle spasm in her back was relieved by Trans-electrical Nerve Stimulation (TENS).

Pain Management Consultation. Patient was referred to the PMT because even though the stabbing pain was better, it was disturbing the patient and the dose of opioid was high. The PMT performed a Lower chain sympathetic (Ganglion of Amper) block with phenol and Ketamin was added in the IVI of morphine. This together with sorting out of psychosocial issues helped to reduce the dose of opioid. At discharge most of her symptoms were controlled and she was taking Morphine orally 100mg twice a day only.

Comparison of the Three Cases:

As you might have noticed both the 1st two cases were initially treated by general physicians. In the first case, moderate to severe pain was treated with only a non opioid analgesic, leaving the patient to suffer from pain. This highlights the fear that most caregivers had about addiction. In the second case pain was treated with an opioid only. Pethidine, should not be used in cases of cancer, because of its metabolite "nor-pethidine" which has a half life of 18 hours and causes irritation to the central nervous system causing seizures. It is also short acting which means that the patient may have to be given several injections to relieve his pain. Pethidine was also prescribed PRN instead of regularly. This allowed the patient to be in pain before she was given pain relief. With referral to the Pain Management Team the first two patients' pain was effectively controlled and both these patients died pain free and in dignity. With the third case there was a definite improvement in it's initial management. The Oncologists who were looking after the patient have used the right opioid, complemented with a non opioid, and adjuvants, depending on the quality of pain. They had also allowed the patient to use non pharmacological pain relief such as TENS, hot oil massage and had addressed psychosocial issues. Towards the end it was necessary to refer the patient to the PMT and the Oncologists did. So, whenever necessary, patients are referred to the Pain Management Teams for nerve blocks or for the management of other types of pain which are difficult to control. This is how pain is treated now. Improper referrals have reduced and this is due to the knowledge and experience of the primary teams who are specialized oncologists.

Conclusion

There is no doubt that the Sultanate of Oman has progressed tremendously since 1970. The Government is working very hard and is taking major steps to improve cancer care in order to meet the International Bench Mark. Each 5 year plan focuses on the actual needs. One of the important needs that has been addressed is the management of pain which has significantly improved.

Factors that have Improved Pain Management in Oman include the return of doctors who have specialized in Oncology, training of Nurses and Doctors through courses, seminars, workshops and conferences, introduction of the PM Teams, follow up of the PM Services in the clinical areas, authorizing MOH hospitals to use oral opioids, opening of the National Oncology Centre with Radiation Therapy (prior to this all patients had to be sent abroad for radiation therapy), development of guidelines, protocols and standards, implementation of "WHO Analgesic Ladder" and Audits and Peer Reviews.

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EXPERIENCES IN MIDDLE EASTERN POPULATIONS

Pain Relief is a Human Right

Michel Daher

Abstract

For centuries, medical and surgical treatment has emphasized saving the life of the patient rather than ameliorating the patient's pain, particularly when there were few options for the latter. Today at the dawn of the 21st century, the best available evidence indicates a major gap between an increasingly understanding of the pathophysiology of pain and widespread inadequacy of its treatment. Epidemiologic evidence has proven that chronic pain is a widespread public health issue. Studies of cancer patients' pain control consistently reveal that up to half of patients receive inadequate analgesia and 30% do not receive appropriate drugs for their pain. Equally, for patients suffering HIV/AIDS, 60%-100% will experience pain at some stage in their illness. In the developed world, this gap has prompted a series of declarations and actions by national and international bodies advocating better pain control. One response to the worldwide undertreatment of pain has been to promote the concept that pain relief is a public health issue of such critical importance as to constitute an international imperative and fundamental human right. The importance of pain relief as the core of the medical ethic is clear. Pain clinicians promote the status of pain management beyond that of appropriate clinical practice or even an ethic of good medicine. They advocate a paradigm shift in the medical professions' perspective on pain management, from simply good practice to an imperative founded on patient rights. There is a need to promote policies which create conditions where human beings can bear even incurable illnesses and death in a dignified manner. This must help health professionals or lay groups to initiate a powerful agenda to reform local statutes. The essential components of such legislation are: 1. Reasonable pain management is a right. 2. Doctors have a duty to listen to and reasonably respond to a patient's report of pain. 3. Provision of necessary pain relief is immune from potential legal liability. 4. Doctors who are notable or willing to ensure adequate analgesia must refer to a colleague who has this expertise. 5. Pain management must be a compulsory component of continuing medical education. For too long, pain and its management have been prisoners of myth, irrationality, ignorance, and cultural bias. We are confident that the Pain Relief and Palliative Care Working Group under the auspices of the Lebanese Cancer Society is the main promoter of Palliative Care in Lebanon whose main goal is to relieve suffering and improve quality of life of the cancer patients, and advocate pain relief as a human right.

Keywords: Pain relief - human right - Lebanon

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Introduction

Epidemiologic evidence has proven that chronic pain is a widespread public health issue. Several studies showed that 15%-25% of adults suffer from chronic pain at any given time; a figure that increases to 50% in those older than 65 yr (Verhaak et al., 1998).Medical and surgical treatment, for several centuries, has emphasized saving the life of the patient rather than ameliorating the patient's pain. Today at the end of the first decade of the 21st century, the best available evidence indicates a major gap between an increasingly understanding of the pathophysiology of pain (leading to a variety of pain treatment), and widespread inadequacy of its treatment.

Studies of cancer patients' pain control consistently reveal that up to half of patients receive inadequate analgesia, and 30% do not receive appropriate drugs for their pain (Crombie et al., 1999). Equally, for patients suffering HIV/AIDS, 60%-100% will experience pain at some stage in their illness (Breitbart et al., 1996); therefore, insufficient pain management is a significant public health concern (European Federation of IASP Chapters, 2001). In the developed world, this gap has prompted a series of declarations and actions by national and international bodies advocating better pain control.

There is a need to promote policies which create conditions where human beings can bear even incurable illnesses and death in a dignified manner. Therefore, pain management is now being addressed across the disciplines of medicine and law. Their respective contributions are coalescing into a coherent position in which unreasonable failure to treat pain is poor medicine and unethical practice (Brennan et al., 2007).

Pain: Important Symptom in Cancer

There are 10 million new cases of cancer and 6 million deaths annually throughout the world. The World Health

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Table 1. Pain: Important Symptom in Cancer

- 20 – 40 % at diagnosis
- 40 – 70 % during treatment
- 70 – 90 % in advanced cancer and terminal care

Organization estimates that by 2020, that figure will double with approximately 70% occurring in developing countries reflecting better prevention strategies in the developed world (Selva, 1997).

Pain is prevalent among people who have cancer. Cancer patients may need pain relief at every stage of the disease. Estimates of the prevalence of cancer pain based on published studies range generally from 14% to 100% depending on the stage, severity, and site of cancer (Patrick et al., 2002; Gilson et al., 2007), (Table 1) making pain management a topic of continuing interest. More than two-thirds of patients with advanced cancer will experience pain, often severe (Burgess and Haworth, 1999). Moreover, pain experiences in patient with cancer are often influenced with psychological stress associated with the disease. An effective multidisciplinary approach to pain management and other symptoms is advocated where physicians need to work with other healthcare professionals (Burgess and Haworth, 1999; Thielking, 2003; Stearns et al., 2005; Gilson et al., 2007).

Inadequately Treated Pain and Consequences

Management of cancer pain has made significant progress in recent years, due to several guidelines suggested for cancer pain therapy (Zekry and Reddy, 1999). In spite of this progress, patients with advanced cancer described pain as moderate to severe in approximately 40%-50% and as very severe in 25%-30% (Von Roenn et al., 1993). Of terminal stage patients, 80% will have no analgesics they need.

In separate large studies of cancer patients in France (Larue et al., 1995), the United States (Cleeland et al., 1994), and China (Wang et al., 1999), the percentages of patients receiving inadequate analgesia were 51%, 42%, and 59%, respectively. Those at highest risk are listed in Table 2. Pain negatively affects the quality of life of patients with cancer (Gureje et al., 1998; Katz, 2002). Therefore pain management is crucial to reduce patients' distress and increase productivity and functioning (Blyth et al., 2001; Siddall and Cousins, 2004). A World Health Organization (WHO) study revealed that individuals who live with chronic pain are four times more likely to suffer from depression or anxiety than those without pain (Gureje et al., 1998).

Chronic pain is linked with physical, psychological and social consequences, and can be regarded as a disease entity per se (European Federation of IASP Chapters, 2001). Physically, these responses include reduced mobility with loss of strength, disturbed sleep, immune impairment and increased susceptibility to disease, dependence on medication, and codependence with caregivers (Siddall and Cousins, 2004). In addition, chronic pain incurs massive social and economic costs to society. Persons with chronic pain are more than twice as likely to have difficulty working (Gureje et al., 1998; Katz, 2002).A prevalence study in Australia revealed a strong association between chronic pain and being unemployed for health reasons and receiving disability benefits (Blyth et al., 2001).

Table 2. Patients Most at Risk for Undertreatment

- Children and elderly
- Cognitively impaired
- Patients who deny pain
- Different cultures
- History of substance abuse
- Uninsured and poor

Table 3. Barriers to Pain Relief

Professionals	o Poor assessment o Lack of knowledge
Health care systems	o Regulatory oversight
Patients	o Fear of addiction o Tolerance o Adverse effects

Barriers to Pain Management in Cancer

Several barriers to the adequate management of pain have been identified at different level: at the national policy level, in the provision of health care, and among patients themselves (Table 3). Barriers at the national policy level include restrictive laws and regulations limiting the medical use of narcotics, insufficient support for pain management programs by health authorities, and non recognition of pain management activities by financing authorities (Joranson, 1994).

Secondly, barriers in the provision of health services include insufficient education of healthcare professionals and physicians' knowledge and attitudes about opioids, the underassessment of patients' pain, divergent perceptions of patients' needs among health professionals, and physicians' reluctance to use potent analgesics, and overestimation of the effectiveness of prescribed treatments (Von Roenn et al., 1993; Larue et al., 1995).

Finally, patients themselves may be reluctant to report pain or to take analgesic medications, particularly morphine. Patients actually expect to experience pain in some medical situations or consider that pain management is not a priority with respect to other components of care. Furthermore, patients may report satisfaction with the management of their pain, even as they declare they are suffering from severe pain, and although their analgesic prescriptions seem to be inadequate (Ward and Gordon, 1994; Larue et al., 1999; Naccache et al., 2008). This has led pain advocates to seek legislative redress for this problem.

Pain Relief Is a Human Right

Pain is an international problem that requires an international solution. The Constitution of the WHO, as the supreme health agency of the UN, defines health as "*a state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity*." One response to the worldwide undertreatment of pain has been to promote the concept that pain relief is a public health issue of such critical importance as to constitute an international imperative and fundamental human right (Cousins et al., 2004; Fishman Scott, 2007).

The high watermark of this advocacy was the inaugural "*Global Day Against Pain*" cosponsored by the "*International Association for the Study of Pain*" (IASP), the "*European Federation of IASP Chapters*" and World Health Organisation. It took place in October 2004 in Geneva, Switzerland; the theme of the day was "*Pain Relief Should Be a Human Right*". It states that patients have a right to pain management, and they give content to that right. Such content includes the patient's right to be believed in the expression of pain, the right to appropriate assessment and management of pain, the right to be cared for by health professionals with training and experience in assessment and management of pain (Brennan et al., 2007).

The importance of pain relief as the core of the medical ethic is clear. Pain clinicians promote the status of pain management beyond that of appropriate clinical practice or even an ethic of good medicine. They advocate a paradigm shift in the medical professions' perspective on pain management, from simply good practice to an imperative founded on patient rights.

An example from the Australian Capital Territory, where the Medical Treatment Act of 1994 states "*a patient under the care of a health professional has a right to receive relief from pain and suffering to the maximum extent that is reasonable in the circumstances, and the health professional shall pay due regard to the patient's account of his or her level of pain and suffering*" (Medical Treatment Act 1994 (Australian Capital Territory), Section 23). Another example is a California statute that imposed three obligations. The first is a duty for doctors who refuse to prescribe opioids to a patient with severe chronic intractable pain to inform the patient that there are physicians who are specialize in the treatment of such pain. The second is a duty of all doctors to complete mandatory continuing education in pain management and the treatment of the terminally ill patients. The third is the requirement of the California Medical Board to develop a protocol for investigation of complaints concerning the undertreatment of pain.

These recent statutes in Australia and California are models for any future legislative activity, offering to professional or lay groups a powerful agenda to reform local statutes. The essential components of such legislation are (Brennan et al., 2007):

1. Reasonable pain management is a right.
2. Doctors have a duty to listen to and reasonably respond to a patient's report of pain.
3. Provision of necessary pain relief is immune from potential legal liability.
4. Doctors who are not able or willing to ensure adequate analgesia must refer to a colleague who has this expertise.
5. Pain management must be a compulsory component of continuing medical education.

Policy and Pain Management in Lebanon

In Lebanon, national health and political authorities should designate improving pain management as a key objective of public health policy. It is important that individuals experiencing pain receive the best possible care to relieve their suffering. It is imperative that organized efforts on the part of all pain care providers occur at the local and state level to improve our health care policy (Abu-Saad Huijer and Daher, 2005; Abu-Saad Huijer and Dimassi, 2007). Adoption of policies that make pain management an expectation for all physicians may make adequate relief more accessible to all people with pain.

This will occur only when there are no other barriers in the health care system that will obstruct patient access to these important medications, such as the knowledge and attitudes of healthcare providers or restrictive reimbursement policies. Positive policy, with no implementation of a professional training, has little chance of affecting healthcare practice (Davis et al., 1999; Manchikanti, 2006). So balanced state policy is insufficient by itself to enhance pain management, but it is a necessary component to achieve this important objective (American Pain Society and the American Academy of Pain Medicine, 1996).

Achieving the appropriate social and medical change that will make pain management a fundamental component of health care is the next great challenge in our country. Education is an important component of our medical system, but there is no systematic approach to teaching pain management at any level of training. The lack of appropriate integration of pain management into medical education should lead to recent legal and regulatory mandates to bring such education to medical students and physicians (Katz, 2002; Abu-Saad Huijer and Dimassi, 2007). Unfortunately, we should be aware that these external mandates, too often result in fragmented approaches to pain education, with each specialty offering its own approach without integrating the multidisciplinary complexity of pain and its treatment into a comprehensive curriculum. On the other hand, there is a need to update medical board members' knowledge about pain management and public policy (Daher et al., 2008).

Appropriate education of the public may reduce patients' reluctance to express pain and to increase their demand for adequate pain management. Information and education of the general public may help to influence policy makers and should incite health institutions and professionals to improve pain management practices. It seems likely that increased awareness of pain management choices among the public will generate increased demand on health professionals to provide precise information and adequate care to address to each patient's needs.

Healthcare professionals need to engage regulators in dialog to eliminate regulatory barriers that govern the prescribing and dispensing of opioids in our country. They have a professional responsibility as it is stated in the Code of Medical Ethics (Lebanon 1994) "Physicians have an obligation to relieve pain and suffering and to promote the dignity and autonomy of dying patients in their care.

This include providing effective palliative treatment even thought it may foreseeably hasten death". They have a professional obligation to understand the appropriate role of opioids in pain control and follow accepted guidelines when prescribing, administering, and dispensing these drugs. They also have a professional obligation to assist regulators and law enforcement personnel in identifying persons who may be involved in diverting opioids for non medical use.

Therefore, reform will require an integrated approach to address the problem of under-treated pain at all levels (Brennan et al., 2007):

1. Education for health undergraduates and graduates, including adult health professionals
2. Adoption of universal pain management standards by professional bodies
3. Promotion of legislative reform
4. Liberalization of national policies on opioid availability
5. Provision of affordable opioids
6. Promotion of pain control programs in all nations, irrespective of resources
7. Reimbursement issues for professional and facility services for pain care
8. Continuing collaboration with the foremost international pain relief organizations and the WHO.

Conclusion

For too long, pain and its management have been prisoners of myth, irrationality, ignorance, and cultural bias. The pain treatment gap is an international human rights crisis that needs to be addressed urgently both at the international and national level.

Therefore, the WHO recommends that countries developing public health programs in cancer pain relief and palliative care establish three process measures to monitor and evaluate programs. First, develop national policies to assure patients access to cancer pain and palliative care treatment. Second, establish educational programs for healthcare professionals and the public, such as medical and nursing curricula and media coverage about pain management. Finally, ensure analgesic drug availability, including recommendations to governments on ways to facilitate opioid availability for severe cancer pain (Scholten et al., 2007).

The evidence that effective pain management may be compromised by laws, regulations, and policies has led to systematic efforts to reform drug prescription laws, and state medical board policies and practices that impede effective use of opioids to relieve pain and suffering (Dahl, 2002; Joranson et al., 2002; Gilson et al., 2005). United Nations (UN) and regional human rights bodies should routinely remind countries of their obligation under human rights law to ensure adequate availability of pain medications. Human rights groups should include access to pain treatment and palliative care into their work, and submit shadow reports to UN treaty bodies.

Making real improvements in pain management will require the proactive efforts of many organizations, and we believe that education as well as discipline should be the cornerstone of efforts to improve pain management. We are confident that the Pain Relief and Palliative Care Working Group under the auspices of the Lebanese Cancer Society is the main promoter of Palliative Care in Lebanon whose main goal is to relieve suffering and improve quality of life of the cancer patients (Daher et al., 2008).

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EXPERIENCES IN MIDDLE EASTERN POPULATIONS

Pain Coping Behaviors of Saudi Patients Suffering from Advanced Cancer : A Revisited Experience

Amani A Babgi

Abstract

Background: Cancer is one of the major health problems thoughout the world. The number of cancer patients is increasing, out of the estimated nine million new cancer cases every year, more than half are in developing countries. The majority of these patients are incurable by the time their disease is diagnosed. Therefore, cancer mortality is expected to continue to rise in those regions of the world (WHO, 2002). In Saudi Arabia, the latest report from the Saudi Cancer Registry SCR for 2004 registered 9,381 new cases, of these cases 7,138 were Saudis. The crude incidence rate CIR of all cancers among Saudis was 41.9/100,000. The total number of adult cancer incidence cases reported was 8595, and for children were 713 cases (NCR, 2004). The most common feared symptom encountered in advanced cancer is pain. Through their perpetual encounter with pain, advanced cancer patients usually maintain different coping behaviors. Internationally speaking, there are limited researches and investigations that deal with cancer pain, and the importance of using adaptive coping behaviors to control it. In Saudi Arabia, specifically, pain coping behaviors has never been assessed or discussed before, so is the impact of cancer pain on the quality of life. The presence of any maladaptive coping behaviors with cancer pain will interfere with the patient's life style and their quality of life, and will affect the nurse's role in caring, planning, and implementing effective nursing interventions to reduce and control cancer patient's pain. Materials and Methods: A descriptive design was used for this study to assess the pain coping behavior Among Saudi patients suffering from advanced cancer. The study was conducted at the two tumor centers which deal with cancer patients in Jeddah City. A convenient sample of 132 patients with advanced cancer who were returning to the clinics, radiation therapy and medical oncology departments of the aforementioned tumor centers were included in the study. Data were collected by an interview schedule specially designed for this study, and the time ranged between 20-40 minutes. Tool's content validity and reliability were checked and established at 89% and 85%, respectively. Administrative approval from the two tumor centers in Jeddah City was obtained for study conduction. Different statistical methods were used for data analysis and interpretation to specify the value of correlation between study variables using SPSS v 10. Results: Patients age were almost equally distributed among thirties (22%), forties (24.2%), fifties (20.5%), and sixties (22.7%). Females (59.1%) were slightly more than males (40.9%). About one half (47%) of them were diagnosed since one - two years age, and slightly more than half (56.8%) of them were unaware of their diagnosis. The major adaptive and Active pain coping behaviors included: religious practices such as: praying (99.2%); and listening or reciting the Holy Qura'an (98.5%). Cognitive methods such as: thinking that one is more stronger than the pain (99.2%); thinking that one is still in a satisfactory health despite the pain (98.5%); distracting oneself from pain (93.9%); visualization of pleasant scenes (92.4%); thinking about pleasant things (90.9%). The major maladaptive and passive pain coping behaviors included: decreasing activities by: specified positioning (97.7%); protecting the painful area (90.9%); and remaining still and avoiding movement (78%). Expression of feelings by: seeking help from others (90.2%); and crying or moaning (80.3%). Suppression of feelings and tolerating pain as it is (97%). Conclusions: Most of the adaptive and active pain coping behaviors were coming from patient's belief in god & their faith and trust and holding and obeying Islamic commands. The informational support by the health care professionals was unprovidable in the study sample, which brings the attention to the importance of nursing interventions in this area by providing coordinated and directed programs.

Keywords: Pain coping behaviour - beliefs - coordinated programs - Saudi Arabia

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Assessment of Coping Behaviour

Cancer is one of the major health problems thought out the world. The number of cancer patients is increasing, out of the estimated nine million new cancer cases every year, more than half are in developing countries. The majority of these patients are incurable by the time their disease is diagnosed. Therefore, cancer mortality is

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expected to continue to rise in those regions of the world (WHO, 2002).

Cancer is defined as a disease of the cell in which the normal mechanisms of control of growth and proliferation are disturbed. This results in distinctive morphologic alterations of the cell and aberrations of tissue patterns. Advanced cancer is defined as the neoplastic process that have metastasised and/ or no longer fully controlled by antineoplastic treatment, and they produce increasing symptoms and dysfunctions. Palliation rather than cure becomes the focus of medical treatment at that stage (Carnevali & Reiner, 1990; & NCP, 2004). In Saudi Arabia, the latest report from the Saudi Cancer Registry SCR for 2004 registered 9381 new cases, of these cases 7138 were Saudis. The crude incidence rate CIR of all cancers among Saudis was 41.9/100,000. The total number of adult cancer incidence cases reported was 8595, and for children were 713 cases (NCR, 2004).

The most common feared symptom encountered in advanced cancer is pain (Bruera 1992; Fisher and Penson, 1995; WHO, 2002; NCP, 2004). In the U.S.A., the incidence of pain in the cancer population is one third of patients in active therapy, and 60% - 90 % of patients with advanced disease. The severity of pain ranges form moderate to severe, and it is chronic in nature (Grant & McCorkle, 1994; Ferrell et al., 2005). Chronic pain, in general, is caused by persistent or progressive disease. It is defined as an unpleasant sensory and emotional experience associated with actual or potential tissue damage that recurs or persists over an extended period of time and interferes with functioning (Burckhardt, 1990). Such pain can cause physical disability and psychological distress, which may have impact on patients' quality of life (Zimmerman et al., 1996). Much of the care provided to patients with advanced cancer-experiencing pain - occurs in the home environment. Increased length of patient survival and growing demands on already burdened health care resources have contributed to the increased use of the home as the primary setting for the advanced cancer patients care (Ferrell et al., 2005). Through their perpetual encounter with pain, advanced cancer patients usually maintain different coping behaviors.

Coping refers to the specific thoughts and behaviors people use to manage their pain or their emotional reactions to their pain. Patients employ a wide variety of behaviors for coping with their pain. Coping behaviors are classified as adaptive or maladaptive based on their relationship to pain indices. Patients may use active or adaptive pain coping behaviors when attempting to control or to function in spite of their pain. Alternatively, patients may use passive or maladaptive pain coping behaviors when relinquishing control of their pain to others, or when allowing other areas of their life to be adversely affected by pain (Brown & Nicassio, 1987). The presence of any maladaptive coping behaviors with cancer pain will interfere with the patient's life style and their quality of life, and will affect the nurse's role in caring, planning, and implementing effective nursing interventions to reduce and control cancer patient's pain (Arathuzik, 1994a). Internationally speaking, there are limited researches and investigations that deal with cancer pain, and the importance of using adaptive coping behaviors to control it. In Saudi Arabia, specifically, pain coping behaviors has never been assessed or discussed before, so is the impact of cancer pain on the quality of life.

The importance of promoting the quality of life of people with cancer through good palliative care is paramount. Community health nurses are part of the health care professionals who are most frequently and consistently in contact with people with cancer. So, it is expected from them to become more involved in the assessment and management of cancer pain at homes and in the hospitals. They can do much to validate with cancer patients what their illness means to them, support them as they grieve, aid them to adapt - as much as possible - to their altered state, and either enhance or modify their pain Coping behaviors (Grant and McCorkle, 1994). The present study was conducted to assess pain coping behavior among Saudi patients suffering from advanced cancer.

Materials and Methods

A descriptive design was used for this study to assess the Pain Coping behaviors Among Saudi Patients Suffering from advanced cancer. The study was conducted at the two tumor centers which deal with cancer patients in Jeddah City. A convenient sample of 132 patients with advanced cancer who were returning to the clinics, radiation therapy and medical oncology departments of the aforementioned tumor centers were included in the study. Patient's selection was based on the following criteria: (1) Patients should be Saudi; (2) Age 30 years and above; (3) Confirmed Medical diagnosis of advanced cancer; (4) Receiving prescribed pain treatment regimen on ambulatory basis; and (5) Welling to participate in the study.

Data Collection Tool

Data were collected by an interview schedule specially designed for this study. It entails 64 Questions divided into four parts: The first part is a specially designed assessment sheet to identify the: demographic data such as: age, sex, etc.; and the medical history such as diagnosis, its date, etc. This part consists of 11 Questions. The second part is a modified version of the Duke-UNC functional social support questionnaire -DUFSS (Broadhead & et al, 1988). It consists of the source and the types of social support. This part comprises 9 Questions. Thee third part is a modified version of Arathuzik's (1994b) pain inventory which contains items concerning pain intensity, location, duration, and patient's perception of pain effect on daily life. This part contains 17 questions. The last part is a modified version of: Vanderbilt's pain management inventory (Wallston, 1984; Brown & Nicassio, 1987); and Arathuzik's (1994b) Pain Coping Tool. It was used to assess the adaptive and maladaptive pain coping behaviors. This part entails 27 Questions. Approvals for using these tools was obtained from the authors prior to commencing the study.

Tool's content validity and reliability were checked and established at 89% and 85%, respectively. The tool was piloted on a sample of 15 patients with advanced cancer to test its feasibility. Little changes has been done to the tool after the pilot test to ensure good patients response at data collection time.

Data Collection Method:

Administrative approval from the two tumor centers in Jeddah City was obtained for study conduction. The data was collected through the structured interview method by meeting patients individually and reviewing patient's medical files for a period of 7 months divided between the two centers. Interview time ranged between 20-40 minutes.

Data Analysis:

Different statistical methods were used for data analysis and interpretation to specify the value of correlation between study variables. The SPSS v 10 computer program was used to analyze the data, and calculate the frequency distribution and correlation between Study variables and pain coping behaviors.

Results

Patients age were almost equally distributed among thirties (22%), forties (24.2%), fifties (20.5%), and sixties (22.7%). Females (59.1%) were slightly more than males (40.9%). Most of them (75%) were married, half of them (50.8%) were illiterate, and the majority (88.64%) were either not working or holding a non professional job. As substantial proportion (66.7%) of them have a monthly income less than 6000 Saudi Riyals.

Table 1. Cancer Morbidity by Gender and Mortality Rate

Male Cancer	%	Female Cancer	%
Colo-rectal	12.1	Breast	25.9
NHL	9.1	Thyroid	10.4
Lung &	7.6	Colo-rectal	9.4
Prostate	7.6	NHL	6.5
Liver	6.1	Corpus Uteri	4.0

Overall mortality 40,101 deaths, cancer mortality 5.4% related to neoplasms (MOH, 2006)

Table 2. Demographic Characteristics of Saudi Patients with Advanced Cancer

Demographic Characteristics		% (N=132)
Awareness of Diagnosis	No	56.8
Type of Cancer	Breast cancer	30.3
	Respiratory tract	20.5
	Different types of cancers	49.5
Treatment	Radiation therapy	57.6
	Symptomatic therapy	31.8
	Chemotherapy	6.8
	Chemo + radiation	3.8
Pain Management Regimen	NSAIDS	72.0
	Palliative radiation therapy	20.5
	Opioids therapy	3.0
	Combination >one type	3.0
	Adjuvant drugs	1.5

NSAIDS, Non steroidal anti inflammatory drugs

About one half (47%) of them were diagnosed since one - two years age, and slightly more than half (56.8%) of them were unaware of their diagnosis. The main diagnoses were (see Tables 1 and 2) breast cancer (30.3%), and cancer in the respiratory tract (20.5%). Patients were receiving radiation therapy (57.6%), or symptomatic therapy (31.8%), or chemotherapy (6.8%), or combination of chemotherapy and radiation therapy (3.8%). For pain management most of them (72%) were on non steroidal anti inflammatory drugs, 20.5% were on palliative radiation therapy, 3% were on palliative radiation therapy, 3% were on narcotics drugs, 3% were on combination of more than one type, and 1.5% were on adjuvant drugs.

Nearly a half (49.2%) of them were socially supported by their spouse, and 37.1 % by their children. All of them were receiving affective and emotional social support. Most of them were receiving instrumental and confident social support.

More than one half (53.8%) of them had been suffering from pain for < 6 months, and 24.2% since 6 - 12 months. Pain lasted for several minutes for 59.1%, for one hour for 13.6%, for several hours for 11.4%, for more than one day for 8.3%, and for < one minute for 7.6% of them. And pain was repeated several times during the day in 49.2% of the patients, and for the whole day in 48.5% of them.

The pain was either pricking in (51.5%), or squeezing in (18.2%), or burning in (8.3%), or throbbing in (6.1 %), or tearing in (1.5%). The pain was either severe in (18.2%), or moderate in (37.1 %), or mild in (44.4%); where as pain distress was either severe in (30.8%), or moderate in (40.8%), or mild in (28.4%).

The physiological adverse effect of pain was on performance of daily activities in (93.2%), sleeping patterns in (80.3%), and ability to concentrate in (34.1%). While its social effect was obvious in the social (75%) and family (43.2%) relationship and activities. However, the pain provoked the sense of challenge among about more than one half (57.6%) of the patients, yet it was also perceived as a threat for less than a half of them.

The adaptive and active pain coping behaviors included: religious practices such as: praying (99.2%); and listening or reciting the Holy Qura'an (98.5%). Cognitive methods such as: thinking that one is more stronger than the pain (99.2%); thinking that one is still in a satisfactory health despite the pain (98.5%); distracting oneself from pain (93.9%); visualization of pleasant scenes (92.4%); thinking about pleasant things (90.9%); relaxation of ones muscle 33.3%) and using previous successful experiences to handle pain (13.6%). Physical and local application methods such as: massage (81.8%); hot or cold compress (71.2%); and aromatic oils usage in massage or hot both (17.4%); ncreasing activities (87.1 %); acceptance of the situation by understanding the causes of pain (87.1%); use of pain killer medications (81.1 %).

The maladaptive and passive pain coping behaviors included: decreasing activities by: specified positioning (97.7%); protecting the painful area (90.9%); and remaining still and avoiding movement (78%). Expression of feelings by: seeking help from others (90.2%); and crying or moaning (80.3%); suppression of feelings and tolerating pain as it is (97%). Traditional methods such as: natural herbs (49.%); cauterization (6.1 %); cupping (3%); bathing with salt and water (0.8%); and restraining the painful area (0.8%).

Conclusions

This study was conducted to find out a baseline data on the experience of pain of Saudi patients suffering from advanced cancer and the behaviors they were utilizing to deal and control their pain whether was active (adaptive) or passive (maladaptive). The study findings presented the picture of how the patients coping with their chronic pain relying on their spiritual and cultural background affecting they way they deal and express the pain and also utilize different approaches to control it.

Most of the adaptive and active pain coping behaviors were coming from patient's believe in god & their faith and trust and holding and obeying Islamic commands. The informational support by the health care professionals was unprovidable in the study sample, which brings the attention to the importance of nursing interventions in this area by providing coordinated & directed programs. The correlation’s of adaptive and active pain coping behaviors & even the maladaptive & passive ones with most of the demographic characteristics, medical history, and social support of patient's were weak. However, on the other hand, the correlation's of adaptive and active pain coping behaviors and the maladaptive and passive ones with most of the pain experience elements, and psychological effect of pain on daily life were strong.

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EXPERIENCES IN MIDDLE EASTERN POPULATIONS

Ethical Dilemmas and the Dying Muslim Patient

Kassim Baddarni

Abstract

All health care providers may be confronted by a Muslim patient, but many health care professionals are lacking basic knowledge on the Muslim faith and medical ethics based on Islamic law (Shariah). One must endeavour to differentiate between ethnic customs and Islamic tradition. It is important for staff to have a general understanding of the principles of Islamic beliefs and actions to attain better cultural competency and improved patient care. Terminally ill cancer patients are vulnerable and require sensitive care of their physical, psycho-social, cultural and spiritual aspects and needs. Muslims believe that the purpose of life is a test from God with the objective of full obedience, the outcome being purification of the soul and the resultant judgment after life to be directed to heaven or hell. The Muslim goal is to live and die in accordance with God's will, as revealed in the Qur'an and practiced by the Prophet.

Keywords: Islam - medical ethics - spiritual care - terminal cancer illness - death

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Introduction

Islam faith encompasses approximately one-fifth of humanity, while its adherents reside in almost every country of the world. Over 90% of Arabs are Muslim but Arabs constitute only 25% of the Muslim population. Muslims constitute two major subgroups, Sunni majority (85%) and Shi'a minority (15%) with some similarities and differences in theological, legal and political interpretations of the Qur'an, and Tradition (Suneh). There are different Islamic sects and rulers, and some medical ethics issues are ruled differently and even oppose each other (Sachedina 2005). The Holy Qur'an was revealed from God through the archangel Gabriel. It consists of a cosmology, a theology and an elaborate eschatology. Over 19 million Muslim have made their homes in the West. These communities are heterogeneous in many aspects – in terms of dress, diet, language and ethnic origin (Sheikh 2007). Consequently, more doctors and nurses will administer to Muslim patients in the course of their work. This review of the Muslim life cycle, beliefs and needs of the Muslim patient will open the door to fruitful communication between Muslim patients and their health care professionals. The outcome will insure improvement of care and mutual respect, while preventing embarrassment and confrontation.

Religion controls many aspects of health and medicine through religious ruling (Fatwa) or the setting of laws on such as: contraception, fertility, cloning, medications, resuscitation (or DNR), brain death, organ donation, euthanasia, death and life after death. Thus, it is vital to be culturally competent if doctors are to improve the care (physically, mentally, socially and spiritually) of the Muslim patient. Poor communication and language barriers may lead many Muslim patients to avoid seeking medical attention until their diseases have reached an advanced stage and they are feeling less comfortable. Cultural competence of the Muslim spiritual and religious beliefs constitutes a critical component of total care.

Health and Sickness

The purpose of life is to pass the many tests that we must undergo during our sojourn here on this earth "*Who hath created life and death that He may try you, which of you is best in conduct*" Qur'an 67:2. If we pass these examinations or trials, then there will be eternal rewards, but woe to us if we should fail them. Among the many possible tests, one examination that tries us is wealth or poverty. While it surely is nice to have material wealth because of the ease and comfort it affords us, there is hidden deception in it, so it is actually one of the more difficult tests for us to bear. Wealth, by its very nature, has the potential to lead one astray far more easily than poverty ever could. Other tests include- "*Be sure We shall test you with something of fear and hunger, some loss in goods or lives or the fruits (of your toil), but give glad tidings to those who patiently persevere*" Qur'an 2:155. Between the human being and God are just two veils "*health and wealth*" all other veils come from these. Those who are healthy do not look for God and do not see Him, but as soon as pain afflicts them they cry out, "*O God! O God!*", calling out and surrendering to God. Therefore, health is their veil and God is hidden in their pain. As long as people have wealth, they gratify their desires and are preoccupied night and day with pleasures. The

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moment poverty appears, their spirits are weakened and they turn to God. Muhammad (pbuh) said: "*No fatigue, nor disease, nor sorrow, nor sadness, nor hurt, nor distress befalls a Muslim, even if it were the prick he receives from a thorn, but that Allah expiates some of his sins for that*."

Sickness awakens people from heedlessness, guides them to relinquish their sins, makes them think about the Hereafter, leads them to pious foundations, makes them more thankful to Allah, and teaches them the necessity of taking better care of their health and making better use of their life - something they didn't realize before. Sickness also teaches them to better understand other sick and pained people and feel sorry for them and help them, and this raises their ranks and degrees higher in the Hereafter.

Perceptions of Illness: The Islamic teaching encourages Muslims to seek treatment when they fall sick (Al-Shahri 2005), “Seek treatment, because Allah did not send down a sickness but has sent down a medication for it, except for death.” Muhammad (pbuh). The majority of traditional scholars view medical treatment as permissible in cases of chronic illness, and an obligation in cases of emergency in which loss of life would occur if an individual was not treated (Sheikh 2007).

If treatment has proven to be effective, Muslims are encouraged and in some cases obliged to seek such treatment. Several traditional beliefs regarding health and illness still prevail among many Muslims. One example is the phenomenon of the "*evil eye*", as one of several supernatural origins of disease and misfortune. Evil eye is suspected when any form of admiration is given from a blue-eyed person or by a woman without children (Leininger 2002) especially when a child is sick.

In terms of treatment options, Muslim patients resort to modern medicine, spiritual healing, and traditional healing practices. These spiritual healing practices include recitation of verses of the Noble Qur’an and specific Prophetic supplications, and the use of Zamzam water obtained from the well in the Holy Mosque located in Makkah, Saudi Arabia (Al-Shahri 2005).

Health staff should ensure that Muslim patients always have a copy of the Qur’an within reach and placed in such a way that it stands out from all other reading material. They should also be mindful of touching the Qur’an only with clean hands and should never put it on the floor (Mauk 2004).

During Illness:1. Muslims are expected to seek God's help with patience and prayer, increase the remembrance of God to obtain peace, ask for forgiveness, give more in charity, and read or listen to more of the Qur’an. 2. Muslim repeats the saying “To God we belong and to Him is our return” to ease the shock of death. Although Muslims may consider illness atonement for their sins, they do not consider illness a punishment from God. They believe that dying is part of living and entrance to the next life. 3. Atonement (tauba): this is done by experiencing a genuine sense of remorse for one's transgressions and a removal of the unhealthy effects of that state by turning to God and seeking divine grace through prayer, charity and a sincere resolution not to return to the destructive patterns of the past.

Muslim scholars have significant stature and are supposed to be central in the daily life of Muslim people, particularly in difficult conditions like end of life. Moreover, mosques are frequently used for health promotion in Islamic and even non-Muslim countries (Ghouri 2005).

Some patients not only want to be free from pain and suffering as they die, they also wish to have the opportunity to make peace with God, to resolve personal conflicts, and to make financial plans before death (Zahedi 2007).

Modesty: The hospital should provide a long-sleeved gown or allow a patient to wear his or her own clothes. Exposure of the patient’s body parts should be limited to the minimum necessary for treatment. Unnecessary touching between non-related people of the opposite sex should be avoided. The left hand is considered unclean, so it is preferred that the right hand be used for feeding or administering medications (Gulam 2003). Questions to a single, widowed or divorced patient regarding sexual habits should not be asked, as extramarital sex is absolutely forbidden.

A Muslim patient (male or female) should not be placed in a room with patients of the opposite sex. Staff should try to avoid eye contact not shake hands with female patients in order to prevent unnecessary embarrassment. Hospital staff needs to respect a patient's privacy by first knocking on a door before entering, announcing their arrival, and not touching while talking to the patient. Same gender care is an effective way to ensure female modesty. Muslim women may have language problems. Take time to explain tests, procedures and treatments to the patient. Women may prefer not to make decisions alone or to sign a consent form for an operation, without first discussing with a male member of the family.

A beard is considered a very important symbol to the Muslim male patient, and therefore permission is needed to shave any part of the beard, and should be done by a man (Gulam 2003).

Visiting the sick: strong emphasis is placed on the virtues of visiting the sick by relatives, neighbors and friends. These visits constitute a social caring obligation to the point that illness often becomes a social gathering, strengthening and renewing of social ties (Leininger 2002). Consequently, the Muslim patient is anticipated to have many visitors, and this should be recognized rather than criticized, as a cultural need. For the Muslim, visiting and assisting the indisposed person is a basic form of worship to bring one closer to God. The number of visitors can sometimes exceed what available space can accommodate, thus, healthcare practitioners are encouraged to express a high degree of sensitivity if it becomes necessary to interfere in such situations. The family feels responsibility to visit, particularly in the terminal stages of a patient's life, and not being able to provide this care is a stigma or a sin.

Cancer: considered to be the result of Divine Will or a spiritual trial (not a product of a carcinogen or risk behavior). Cancer is often referred to as “that disease” followed by “God keep it away”. Cancer is kept confidential, for instance, in a case of a daughter, due to the fear that it may affect her marriage.

Truth-telling: Telling lies is considered a great sin according to the Islamic faith. The Prophet (pbuh) said “*the signs of a hypocrite are three: whenever he speaks, he tells a lie; whenever he promises, he breaks it; and if you trust him, he proves to be dishonest*” (Al-Shahri 2005). Pain: the concept of pain, according to the Islamic philosophy of life, is a transcendental dimension to pain and suffering. According to a Muslim’s belief, pain is a form of test or trial, in order to confirm a believer’s spiritual station (Zahedi 2007). Suffering is considered a part of life, and forbearance of hardship is greatly rewarded in Islam. In particular, forbearance of an illness leads to expiation of sins in Islam (Hedayat 2006). The Qur’an tells us that those who claim to believe in Allah will not be left alone after proclamation of their belief, and asserts that believers will be put to the test in various ways. "*Be sure that we shall test you with something of fear and hunger, some loss in goods or lives or the fruits of your toil, but give glad tidings to those who patiently preserve*" Qur’an 2:155. Pain relief by analgesics to prevent suffering includes morphine, which is allowed and recommended, even if it hastens the death, actions judged by intention. Muslims believe that pain and suffering deletes sins. "*And bear in patience whatever (ill) maybe fall you: this, behold, is something to set one's heart upon*" Qur’an 31:17. The Prophet (pbuh) said "When the believer is afflicted with pain, even that of a prick of a thorn or more, God forgives his sins, and his wrongdoings are discarded as a tree sheds off its leaves”. This interpretation helps patients and families to cope with serious and life-limiting illnesses. Islamic teachings consider the relief of suffering of man and animal to be highly virtuous (Al-Shahri 2005).

The caring physician should keep the balance between alleviating the suffering while maintaining a level of consciousness that enables a patient to worship God till death.

For the irrational response: “*I can’t take this anymore*”, Muslim patients should believe: Islamic reframe “*no soul is burdened with more than it can bear*”. A Turkish study (Kuzu 2002) that examined the effect of colostomy verses sphincter-sacrificing surgery for rectal carcinoma on quality of life in Muslim patients found that: 1. Study: 178 Muslim patients completed an interview 3 years after colorectal carcinoma surgery; 2. Goal: to examine the effect of colostomy on prayer and fasting; 3. Findings: decrease in prayer ritual in mosques (social isolation) and private prayer (insufficient cleanliness) and fasting compared with colorectal carcinoma patients with sphincter-saving treatment; 4. Recommendation: preoperative counseling for patients having stoma surgery

Spiritual Comfort: The severely ill person, who might be distracted by his pain, greatly appreciates a companion who can read the Qur’an to him and remind him of God. A family member may wish to remain with the patient at all times, if medically appropriate.

In Islam, there is no distinction between religion and spirituality. Muslim patients understand that illness and suffering are part of life, while death is part of a journey to meet God. Muslims believe in divine predestination and attribute the occurrence of pleasure and suffering to the will of Allah (Al-Shahri 2005). Spirituality is often defined as the experience of meaning and purpose in our lives, and a sense of connectedness with people and things in the world around us. The terms “religiousness” and “spirituality” are often used interchangeably. Religiousness is adherence to the beliefs and practices of an organized place of worship or a religious institution. Spirituality provides a sense of coherence that offers meaning to one’s existence as a human being (Syed 2003).

Palliative care, and especially de-escalation of care, is seen as “giving up” or shirking one’s duty to heal. Furthermore, immigrant Muslims may feel that inferior care is being given because of the patient’s religion or ethnicity or level of insurance, or that the physician is lying to the family, exaggerating a poor prognosis to end care sooner and make way for other patients (Hedayat 2006). When death is inevitable, Islam directs that the patient be allowed to die without heroic measures. Muslims disapprove of any medical care that may hasten the death of a patient. Members of the immediate family will often stay by the bedside reciting from the Qur'an, and this assumes an even greater role in times of suffering and distress.

Terminally ill Muslim patients experience fear and loneliness during serious illness most of the time, which generates spiritual crisis requiring special care. Spiritual care can play an important role when cure is not possible. Terminally ill patients usually question the meaning of life, and the approach of death may stimulate serious spiritual questions that contribute to psychological symptoms such as anxiety, depression, hopelessness and despair. Spiritual care is not necessarily religious, but religious care, at its best, should always be spiritual (Asadi 2008).

Neither passive nor active euthanasia is allowed in Islam. The two ultimate causes of death are cessation of cardiorespiratory activity or brain death. Withdrawing care is permissible in only two circumstances, the first being when a diagnosis of brain death has been made, and the second when the current treatment, be it curative or palliative, is no longer curing or palliating suffering but merely prolonging a natural and inevitable death (Hedayat 2006).

The Prophet quoted saying "None of you should wish for death because of a calamity befalling him; but if he has to wish for death he should say: O Allah! Keep me alive as long as life is better for me and let me die if death is better for me". Most Muslims consider it important that when death approaches, the dying patient is helped to sit up or at least turn to face Mecca and to pronounce the Shahada. This little ritual is important for the parties present, the dying patient, and those witnessing the death. It will consolidate the dying person's expectation that death is not the end, and that he or she is now entering the world of the divine with the proper attitude. For the survivors, it means defying the certainty of death by taking a first step towards continuation (Parkes 2000).

When a Muslim is dying, several things may be comforting to the patient and the family: (a) turning the patient on his/her right side to face Mecca; (b) letting those visiting the patient recite the prayer of allegiance to Allah, encouraging the dying person to recite it also, if possible. If the patient is unable, another Muslim should recite it; (c) having the friends and loved ones pray that mercy, forgiveness, and the blessing of Allah be given to the deceased; (d) reading specific verses from the Qur'an; and (e) helping the dying person overcome the fear of death (Ott 2003).

Soul and Spirit: The relationship among the three is as follows: spirit (ruh) is like energy, which enters the light bulb of the body (jism). The light that is the product of this relationship is the soul (nafs). When the energy is cut off, the light dims and the bulb is no longer functional (Hedayat 2006). When suddenly faced with a serious illness and possible fatal outcome, a patient who otherwise is not so religious, sometimes turns to God to answer some difficult questions (why me?), and then finds support through his spiritual beliefs, even outside the context of an organized religion. Spirituality, as measured by inner peace and meaning of life, helps the terminally ill patient to avoid despair, avoid suicidal tendencies or wanting to die, as compared to similar patients without spirituality. Health care providers should incorporate psychological and spiritual elements into the palliative care of dying patients (McClain 2003).

Death: Death of a human signals the separation of the soul from the body and the termination of all bodily functions and activities. Death in Islam is an active process, a transition of the soul from the material world to a spiritual world of purgatory (Hedayat 2006). The earth is described as a resting place for the purpose of worshipping God and doing good deeds (Qur'an 2:20-21). Death is inevitable and occurs only with a command from God: "Every soul shall have a taste of death: in the end to Us shall you be brought back" Qur'an 29:57. It also states "Wherever you are, death will find you out, even if you are in towers built up strong and high" Qur'an 4:78.

When a Muslim obeys God during life he can be ready to meet him: "*When you were born, everyone was smiling, but you were crying. Live such a life that when you depart everyone is weeping, but you are smiling*" (Sa'di of Shiraz – died 1292). It is believed that at the moment of death the angel Izrael appears to the dying person to remove his or her soul. The appearance of Izrael is described as a devastating experience. Persons close to death are believed to suffer a burning thirst and the devil (shaitan) attempts to induce them to give up their faith in exchange for a sip of water (Dessing 2001). The Qur'an emphasizes that death is only a transition from one state of existence to the next future life. The Qur'an always affirms the unlimited mercy and forgiveness of God, but links future life to performance in the present life, from birth to death (Sarhill 2001).

The concept of death: the whole of life constitutes a trial and a test for the human being with respect to how his final destiny is determined. "*It is God who creates you and takes your souls at death*" Qur'an 16:70. The life to come is the eternal abode where one will reap the fruit of one's endeavors on earth. For Muslims, death is the return of the soul to its Creator, God, and the inevitability of death and the Hereafter is never far from his consciousness. This serves to keep all of his life and deeds in perspective as he tries to live in preparedness for what is to come. Death should not be resisted or fought against, but rather something to be accepted as part of the overall divine plan (Sheikh 1998).

When death approaches, the close family and friends try to support and comfort the dying person through supplication as well as remembrance of Allah and his will. Their attendance is to help the dying person to iterate his commitment to unity of God.

Origin and Purpose of Death:1. The origin of death: the original sin of Adam and Eve, and the punishment: "*In the earth you will live, and in it you will die*." Qur'an 7:24. Also stated: "*From it (the earth) did We create you, and into it shall We return you, and from it shall We make you appear once again*" Qur'an 20:55; 2. The will of God: God causes people to die. "*It is not possible for a soul to die except with the permission of God at a term set down on record*." Qur'an 3:139. The only guarantee that comes along with birth is death. "*To God we belong and to Him is our return*" Qur'an 2:156. Death is unpredictable and can happen at any time and as such Muslims should always be prepared for the inevitable and for what is about to occur; 3. Time of death: predetermined by God. "*When their time comes they cannot delay it for a single hour, nor can they bring it forward by a single hour*." Qur'an 16:61. It is but a gateway from this short but mortal existence to a life of immortality in the afterlife.

Death is seen as something predestined by God. It is only the beginning of eternal life. Death for the Muslim is a passage between two segments of a continuous life. Furthermore, this transition is portrayed by the Qur'an as a smooth and satisfying passage for faithful people and a difficult experience for the wicked because they did not believe in an afterlife. For them, the only life they practiced is ending, and it was spent carelessly and unwisely (Gatrad 1994).

Preparation for death: preparation for death is not to make prior funeral arrangements for this is viewed as interference in God's will. Muslims prefer to die at home if possible with the family providing comprehensive physical and spiritual support. The hospital environment restricts the gathering of the whole family, the recital of prayers aloud, and the family duty towards caring for a dying relative. The dying person should sit up or lie with their face towards Mecca. Ideally one should die with the declaration of Faith on the lips (Shahada). During the last days, many people come to forgive the dying for their sins and in return want to be given forgiveness; this ceremony "sulha" is extremely important in the life of family and community.

Procedure at death: eyes and mouth should be closed; all connected tubes and needles removed; all limbs flexed and the body straightened; lower jaw supported to avoid gaping, the large toes tied together and the head turned towards the right shoulder, in order to bury the body with the face turned to Mecca (Neuberger 2005). The body should not be washed at this time, but labelled and covered totally with a plain sheet. The body should be released as soon as possible, since Muslims prefer to bury the dead without unnecessary delay. The body must be handled with utmost respect and gently by a person of the same sex. Muslims believe that the soul remains close to the body until burial. Death is the decision by God to end a person's physical life on earth. It is a shift from one mode of life to another. Death is not regarded as permanent; the physical body decays, but the soul (nafs) moves on to a new plane. The Qur'an describes Heaven as a place of beauty where "*rivers flow*" (Qur'an 98:9), and describes Hell as "*a fire burning fiercely*" (Qur'an 85:5). Muslims believe that after death, which is seen as a transformation into a new phase of existence, Allah will judge their good and bad deeds, including their charitable giving, and their final utterance of the Shahada in the hope of mercy in the afterlife (Finegan 2007).

Burial and Funeral: Muslims believe that at birth and death, every human is equal; they come with nothing and leave with deeds. When death is announced: 1. Prompt issue of the death certificate will allow the burial to take place rapidly; 2. Washing: a same-sex member of the community ritually washes the body. The body is covered with a white unsown shroud (3 pieces for men and 5 for women) without knots, since these could obstruct the liberation of the soul. Camphor is often put in the armpits and in the orifices. Muslims are buried without a coffin, never cremated; 3. Muslims do not believe in reincarnation or soul transfer to other body (Al-Shahri & Fadul 2007). 4. Burying the body without a coffin should be as soon after death as possible. The body is buried on the right side, facing Mecca; 5. Women are not allowed to attend the funeral, while non-Muslim men may attend. Some men abhor women's reaction to their loss, and try to suppress any overtly-expressed emotion by keeping the women apart from men, or forbidding them to attend the funeral for fear of excessive crying or tumultuous senses (Parkes 2000); 6. The dead body should be treated with gentleness and respect (because it will be restored on the Day of Resurrection); 7. Announcement: in rural settlements the news of a death is made public in the morning, together with the call for prayer from the village minaret by a loud speaker announcing the name of the dead person and the time and location of the funeral; 8. Prayers over the dead (the four takbirs: proclamations of God's greatness). Family may recite the whole Qur'an if possible; 9. Mourning tent: the family establishes a tent large enough to host all guests and to recite the Qur'an, using amplifiers; 10. Children: they are not supposed to know anything about the deceased Muslim. They are sent to the neighbors almost immediately. They are not allowed to take part in the farewell ceremony or indeed to participate in the funeral procession (Parkes 2000); 11. Grief is normal and mourners are permitted to cry but should not be excessive, as this would disturb the dead and show lack of acceptance of God's will and purpose regarding death. Muhammad (pbuh) himself wept on the death of his son Ibrahim, pronouncing these words "Ibrahim, our eyes shed tears and our hearts are filled with grief, but we do not say anything except that by which Allah is pleased" (Atighetchi 2007).

Period of mourning is 3 days. A wife mourns her husband for 130 days. "*Those who die and leave wives, their widows shall wait four months and ten days*" Qur'an 2:234. She is not to remarry, leave her home, or wear decorative clothing. She may remarry after childbirth, if she was pregnant, and her child must bear the name of the deceased.

Family duties after their beloved deceased:

1. Payment of funeral expenses.
2. Payment of his/her debts.
3. Execution of his/her will if it exists.
4. Distribution of the remaining estate.

Life after Death: "*To Allah we belong, and to Him is our return*." Qur'an 2:156. Our souls sleep and do not awaken until a blast from an angel at God's command. The first blast signals the end of the world and kills any remaining souls on earth. It is followed by a second blast that causes all of the souls to be resurrected. Each soul is judged upon its beliefs and actions, which are weighed in the scales of divine justice. Muslims believe that body resurrection will be at the time of the coming of the Messiah, when no law will be necessary because truth will prevail everywhere (Neuberger 2005).

The Day of Judgment inaugurates the "*Afterlife*" in which God rewards and punishes, with respect to human obedience to His will. The concept of Life after Death (Afterlife) is one of the Major beliefs in Islam. Without belief in "*Afterlife*", Islam is an imperfect religion, as all the teachings and commandments of it rest on belief in Afterlife; so, if there is no "*life after death*" then no one could know other beliefs to be true respectively. Death is exactly like sleeping; complete with dreams. The period between death and resurrection passes like one night of sleep. The angel of death gathers those who are due to die, Qur'an 32.10/9-11. The body is buried and decays while the soul escapes the body and is, in a suspended state.

If the Muslim passes this first phase of the afterlife, the experience of the grave is pleasant, and he or she is given glimpses of the pleasures of paradise and the spirit will stay at Barzahk, (partition, barrier) a temporary stage of waiting, until the time of resurrection. If however, the deceased Muslim does not pass this phase, then the grave is the first stage of chastisement with a squeezing grave. After this, the soul sleeps and does not awake until a blast from an angel at God's command.

The Prophet Muhammad (pbuh) taught that three things continue to benefit a believing person, even after death:
1. Charity given during life which continues to help others;
2. Knowledge from which people continue to benefit, and;
3. Supplication on his behalf by a righteous child.

Conclusions

Health care professionals should adopt cultural competence and sensible awareness when caring for

Muslim patients and family. A holistic approach to care needs understanding of Islamic belief (internal and external), religious practice, spiritual beliefs, cultural mores and social background. With the 'open borders' strategy and the population shift from East to West, it is crucial that physicians and nurses be transcultural, with sensitivity to spiritual needs of their patients. Improving communication and mutual respect is the basis for achieving the best possible medical treatment with reduction of stress and conflict for the patient and family, and more satisfaction and reward for medical practitioners and care givers. Spiritual history and assessment are vital to implementing holistic care, preventing confrontations and embarrassment, and finally ensuring a better quality of life for both acute or terminally-ill Muslim patients and their families.

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EXPERIENCES IN MIDDLE EASTERN POPULATIONS

Psychiatric Aspects of Pain in Cancer Patients

Sedat Özkan

Abstract

The goal of this review is to discuss the psychiatric aspects of pain in cancer patients from a biopsychosocial approach. Pain in cancer patients is considered as a complex reaction causing severe suffering and involves many psychological aspects. It has many dimensions such as personality, affect, cognition and social relations. The pain experience may also be influenced by some psychological factors such as anxiety, depression and the meaning of pain. Therefore, a successful management of cancer pain requires a multidisciplinary approach. Since cancer pain is generally treated medically, the psychological impact of pain is often underestimated. However, cancer pain is usually related to high levels of psychological distress. Culture, as an important factor affecting cancer pain, will also be discussed during this review. It is crucial to understand cultural diversity in the treatment of cancer patients with pain. Research shows that a minority patients of various ethnicities have less control of their pain because of the miscommunication problem within the medical setting. By paying attention to patients' cultural diversities, problems such as miscommunication causing inadequate control of pain can be eliminated. In order to manage pain in cancer patients, cognitive-behavioral interventions may be integrated with pharmacotherapy. The main goal of these strategies is to provide a sense of control and better coping skills to deal with cancer. Patients' maladaptive thoughts or behaviors may cause physical and emotional stress. Main behavioral strategies include biofeedback, relaxation training, and hypnosis. Cognitive strategies include guided imagery, distraction, thought monitoring and problem solving. By discussing all of these aspects of cancer pain, the multidimensional characteristic of pain and the relation between cancer pain and psychiatric factors will be clarified.

Keywords: Cancer pain - psychiatric aspects - pain management - biopsychosocial approach

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Introduction

Pain is a symptom that points out the disturbance of biopsychosocial balance and adaptation. In a way, pain is a defence mechnism towards a negative stimulus. International Association for the Study of Pain described pain as "an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage." (Merskey & Bogduk, 1994). Besides biological factors, psychological needs and dynamics, cultural factors have an influence on pain. The perception and evaluation of the illness, ways of coping behaviours towards the illness all affect the pain. Three factors are important in the formation of emotional reaction towards a physical illness (Özkan, 1993). These are: 1-Characteristics of the illness; 2- Characteristics of the individual; and 3- the Psychosocial environment.

When evaluating the reactions towards an illness the interactions between physical pathology, psychological experience and psychosocial environment should be considered. The effects of psychological factors on pain symptoms, reactions and behaviour should be considered in three axes: 1-Psychophysiological mechanisms; 2-(Psycho) social factors (cultural, social and interactional) and learned socio-behavioral processess; and 3-Psychiatric disorders.

There are two types of pain: Acute pain is easily described. Agitation and excessive stimulation of sympathetic nervous system can be seen. The duration of chronic pain is generally six months. The pain stimulus at the beginning disappears or it is not enough strong to explain the pain. Chronic pain should be considered by psychological, psychosocial and biological components. It is usually the source of a serious pain and morbidity. In chronic pain, pain complaint is usually not related to somatic and physiopathologic disorders (Özkan, 1993).

Cancer pain is a complex, multidimensional phenomenon composed of sensory, affective, cognitive, and behavioral components. It is resulted from a complex interaction between physiological, cognitive, social, and other factors (Porcelli et al., 2007). The incidence of cancer pain is between 51%-70%. It is known that 40%-50% of pain is moderate to severe; while 20%-30% is very severe (Breitbart, 1989). Studies show that approximately 25% of cancer patients do not receive adequate pain relief (Portenoy and Foley, 1990).

Biomedical variables such as tumor sites and status of disease are closely related to the pain experience in

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cancer patients (Porcelli, et al. 2007). It is known that there is a strong association between advanced stage of cancer and pain. These patients are more likely to have complications like pain and depression (Nuhu et al, 2009). Data show that 70% of patients with advanced cancer have significant pain in the course of their illness. Especially in the presence of a terminal illness, pain may have a demoralizing effect and may create affective and behavioral changes in a patient (Portenoy and Foley, 1990).

Nonbiological aspects of social and emotional experience in cancer pain are also important besides the biomedical factors. Pain perception is closely linked to one's self representation, disease's characteristics, cognitive schemata, and coping mechanisms. Since patients vary in psychosocial and spiritual strengths and weaknesses, their ways of coping with pain are different (Porcelli et al., 2007).

Porcelli et al (2007) found that pain was predicted by several aspects of abnormal illness behavior and maladaptive coping. Patients with excessive observing and thinking about the physical symptoms, hopelessness, and cognitive problems in processing and identifying feelings have tendency to pain perception amplification. According to this study, cognitive difficulties in cancer patients in identifying feelings may experience higher pain intensity and they may describe sensations of pain sensations more severely. Therefore, besides the biomedical aspects of tumor site and status, alexithymia, maladjustment to cancer and health concerns of abnormal illness found to be associated with the cancer pain experience (Porcelli et al., 2007). In the enmeshment model of pain perception, Pincus and Morley (2001) also indicated that pain experience results from different overlaps of the three cognitive schemas of self, illness, and pain. Pain perception is also related to medical and biological variables in cancer patients and other pain-related clinical conditions (Pincus and Morley, 2001).

The related literature points out that cancer patients who are confident in coping and controlling the cancer pain experience less pain (Özkan and Armay, 2007). On the other hand, cancer patients who use catastrophizing coping skills and feeling helpless about their situation experience higher levels of pain and anxiety (Bishop and Warr, 2003). Patients with higher levels of mastery perceive themselves as having more control; therefore, they may appraise a situation as more managable than those with lower levels (Nuhu et al, 2009).

Theoretically, this model can be summarized as:

Nociception
Pain
Pain experience
Pain behavior

Nociception is a stimulus coming from a damaged tissue. In the perception of this pain, all emotional factors and psychological necessities have an important role. In some patients, especially in patients with chronic pain, the suffering dimension can be added. Suffering is a negative reaction to pain. Therefore, depression and anxiety are among frequently seen psychiatric disorders. The development of pain experience as a defective illness perception is related to patient's pain and environment's reaction to patient's perception of pain (Lipowski, 1976).

Cancer pain is often related to high levels of psychological distress, including higher levels of depression, anxiety, fear, and negative mood (Zaza and Baine, 2002). Both chronic and acute pain characteristics may be seen in cancer pain. Like acute pain, cancer pain is directly associated with tissue damage. When cancer pain persists, it may be considered as a sign of the progression of disease and a sense of hopelessness may arise since patients think that their lives are not worth continuing (Tavoli et al., 2008). Types of pain are also associated with different psychiatric symptoms. The onset of acute pain is associated with the affect of anxiety and signs of sympathetic nervous system hyperactivity. As the pain continues and becomes chronic, depression and vegetative signs, such as sleep disturbance, poor appetite, lassitude, poor concentration and diminished libido can be seen (Portenoy and Foley, 1990).

With the biopsychosocial approach to cancer treatment, the relationship of the cancer pain experience with psychological factors such as anxiety and depression become more important. Research shows that there exists a strong association between cancer pain and psychological functioning. Glover et al (1995) indicate that cancer patients suffering from pain report significantly higher levels of anxiety, depression, and anger. Another study conducted with hospitalized patients with advanced cancer shows that patients experiencing greater pain had much higher levels of worry about pain, fear of the future, and fear of pain progression (Strang, 1992).

Cancer patients who experience pain were found to be two and a half times more likely to be anxious than those who did not report pain (Glover et al., 1995). Uncontrolled pain may also cause anxiety in cancer patients. Anxiety symptoms may be a result of patients' fear of dying from the illness. With the presence of pain, this fear is augmenting since pain can be considered from patients as an evidence of progression of cancer. Patients' sleep problems may arise from a painful physical condition or indirectly from depression or anxiety which are found to be associated with pain (Nuhu et al., 2009).

Pain and depression are highly prevalent in cancer patients; however, although associations exist, there are no sufficient evidences to support an interdependent relationship between pain and depression. It is logical to conclude that specific characteristics of pain such as pain intensity or effect on enjoyment of life are related to depression (Laird et al., 2009). In their study, Heim and Oei (1993) examined patients with prostate cancer and showed that patients who experience pain were more depressed than those who were pain-free . There are also other studies showing that prevalence of depression is higher in patients with pain than those had not (Spiegel, 1994). Patients who reported that they have pain were more likely to have significant depressive symptoms, anxiety symptoms and suicidal ideation. Pain may be interpreted as a sign of illness severity and may therefore feel hopeless. They think that they can not escape from death. This way of thinking may cause hopelessness and helplessness in cancer patient (Nuhu et al., 2009). Another study compared patients with and without pain who were matched by site and progression of disease. Patients with pain scored higher on measures of depression as well as anxiety, hostility, and somatization (Ahles, 1983).

Cancer pain has a significant impact on the overall quality of a cancer patient's life by influencing physical, psychological, and spiritual aspects (Tavoli, et al. 2008). Patients' functional status and their quality of life may be affected by pain, as pain is the most distressing symptom experienced by approximately 50% of cancer patients (Porcelli et al., 2007). Pain is also associated with poor health satisfaction in cancer patients. Pain control plays a key role in determining health-related quality of life. Therefore, a better quality of life may be achieved by adequately controlling the pain. By this way, the associated psychological and physical symptoms can be prevented (Nuhu et al., 2009). If pain remains uncontrolled, it may have a detrimental, effect on many aspects of a patient's life. Anxiety and emotional distress can be seen; patient's well being is undermined, problems in functional capacity and in fulfilling familial, social, and professional relationships may arise. These effects would in turn diminish patients' quality of life. Patients who reported experiencing moderate or severe pain are found to have sleep problems, problems in daily activities, enjoyment of life, work ability and social problems (Yıldırım et al., 2005).

Pain is a multidimensional experience and it is closely related with patient's socio-cultural characteristics and belief system (Tavoli et al., 2008). Culture is an important factor that influences the dimensions of cancer experience for patients, family care givers and health professionals. The way pain is perceived, manifested and treated by patients and families is another area affected by culture (Juarez, et al., 1998). Since every culture is unique, the interpretation and meaning of pain is related to patient's cultural characteristics. Beliefs and values belonging to a specific culture also help to create an understanding for normalizing experiences of pain in some groups, whereas for other people they can be more problematic (Koffman, et al., 2008).

In some cultures, it is seen that cultural background, family beliefs and religion have a crucial role in how pain is managed and expressed by the patient and the care giver. In cultures where pain should be hiden or endured, pain is considered as a part of life and as God's will. Moreover, enduring pain may also reflect personal strength and pride especially for men (Juarez et al., 1998). A study which is conducted with Hispanic cancer patients reveals that these patients do not complain even though they were in pain, since they do not want to bother their family members (Ok and Guevara, 2007).

The oncology team should identify health related cultural beliefs and practices for each patient by listening carefully the patients' narratives, which include the meanings they attribute to pain (Koffman et al., 2008). In the assessment and treatment of cancer pain, consideration of cultural factors is important. In pain management, an individualized patient care is crucial in order to provide optimum care to the cancer patients (Juarez et al., 1998). Nonsteroidal anti-inflammatory drugs, opiods, and analgesics are among the most frequently used medications in the management of cancer pain (Lyne et al., 2002). However, since distress and pain can not be completely avoided by medication in these patients, it is also important to pay attention to nonpharmacologic treatment approaches in controlling pain (Tatrow and Montgomery, 2006). Thus, nonpharmacologic interventions are important adjuncts to treatment modalities. Since the medical treatment of cancer pain is essential, the impact of cancer pain on psychological distress is often underestimated by health professionals and the potential benefits of using psychological treatments to help manage cancer pain is rarely considered (IASP, 2009). Appreciation of the influences of psychological issues and appropriate interventions are important aspects in the treatment of pain. In this way, the suffering of the patient and family can be reduced. However, an insuffient pain control demoralizes both the family and the caregivers (Portenoy and Foley, 1990).

In the assessment of the patient, the general appearance of the patient, his perception and interpretation of the pain should be examined. When and how the pain begins, under which physical and psychosocial circumstances it increases and what is the potential effect of medical treatments are among the questions that should be asked. How the patient's life is affected from the disease should also be observed. It is also important to observe the patient's physical and psychological state and relationships in a patient's life, as well as psychosocial history. Pain's relation to the patient's daily life practices, compelling personal experiences, emotions and psychosocial events is questionned (Özkan and Armay, 2007).

It is crucial to inform and educate the patient and his/her family members about the physical, psychological and social dimensions of pain. Especially in chronic pain, the aim is to decrease the suffering while increasing the psychosocial adjustment and functionality of the patient (Özkan, 1993).

The components of psychomedical treatment are to encourage the expression of emotions about underlying hostility, depression and anxiety, as well as to change the point of view toward compelling life events and provide a successful life adjustment. Increasing the life objectives, helping to understand the underlying conflicts and motivations in the functional deficit, and the development of healthy coping skills is important for a successful pain management (Özkan and Armay, 2007).

Effective pain control is essential, but it may vary according to disease's stage. In the early stages of the disease, the goal of psychological treatment should focus on allowing the patient to function normally. However, for the terminally ill patient, comfort is more important. Providing sufficient relief and allowing patient to be free of pain should be primary goals of the pain treatment in this stage (Portenoy and Foley, 2000).

Cancer patients should be aware that during episodes of intense pain, changes in mood and emotion may be seen. Therefore, health professionals should pay attention to the symptoms of psychological distress in patients who are experiencing pain. A careful evaluation and treatment of psychological distress is indispensable for an efficient cancer pain management (IASP, 2009).

Pain beliefs help human beings in gaining a stable understanding of the events that they experience. The belief that pain is understandable is associated with better treatment compliance and adaptive coping strategies; however the belief that pain is strange is associated with the use of catastrophizing (Tavoli et al., 2008).

A way of helping cancer patients to adopt more adaptive coping skills with the disease may focus on identifying the source of their feelings. By using pain descriptors for their psychological maladjustment to disease, patients with alexithymic characteristics may misinterpret the negative affective dimension of pain (Porcelli et al., 2007). Understanding how each patient copes with pain and encouraging the patient in developing pain coping skills are crucial elements of the treatment. Educational and psychosocial treatments may be designed to improve pain coping skills in patients with particular difficulty dealing with cancer pain (IASP, 2009).

Distress and pain in cancer patients may be managed by a variety of psychological interventions. Especially, cognitive behavioral therapy (CBT) techniques are found to be important tools to reduce distress and pain in various cancer populations. The CBT approach includes; stress management and problem solving techniques, goal setting, pacing of activities, and assertiveness. Hypnosis, relaxation training, biofeedback, distraction, imagery and sensation redefinition can also be incorporated within CBT to increase the selfcontrol. Therapies such as relaxation techniques are used as adjuncts in cancer pain management and their utility make them important tools in managing pain (Tatrow and Montgomery, 2006). It is also known that significant muscle spasm responds well to relaxation techniques. Distraction, sensation redefinition and imagery are among other cognitive approaches that are applied in the treatment of cancer pain. These techniques are found to be effective in experimental and acute pain (Portenoy and Foley, 1990).

In psychotherapy, helping the patient for the emotional expression and, from the cognitive perspective, changing “the conditioned indifferenciation” to “learned productivity” is aimed. In cognitive therapy, firstly pain specific cognitions are described and changing them with more positive cognitions is the main goal. Besides, techniques such as coping with stress, assertiveness training, education about the origine of the pain may also be helpful. The aim is the perception of pain on behalf of the patient and changing his/her reaction (Özkan and Armay, 2007).

In summary, the most important aspect of pain treatment is the interdisciplinary approach. It is crucial to consider the psychological and psychiatric aspects of the patient in the management of cancer pain. The optimum treatment of cancer pain is reached by combining biological and psychiatric treatment approaches.

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EXPERIENCES IN MIDDLE EASTERN POPULATIONS

The Treatment Gap of Depression in Persons with Cancer

Itzhak Levav

Abstract

The epidemiology of depression showed that the rates are high. For example, the World Mental Health Survey, an epidemiologic community study conducted in 28 countries, found a life-time prevalence rate that ranged from 3.3 % in Nigeria to 21.4% % in the US. With regard to persons with cancer, 12.5% of a sample of over 17,000 respondents over the age of 50 of a US survey of community-dwelling adults found that people that reported they had cancer had higher risk of fatigue (OR =1.5 95% CI 1.3-1.6); depression (OR=1.2, 95% CI 1.1-1.4) and pain (OR =1.2, 95% CI 1.03-1.3.).The rate of depression seems to be differently associated with cancer site. For example: It is higher in pancreatic cancer (33%-50%) and lung (11%-44%), and it is lower in lymphoma (8%-19%) and colon (13% and 25%). For breast cancer –likely the most studied cancer site- the prevalence ranges from 1.5% to 46%. Ciaramelli and Poli (2001) found that depressed persons had more pain and metastasis than the non-depressed but no more lifetime depression that the non-depressed. In terminally patients, studies have found that the higher the level of disability the higher the rates of depression. Interestingly, while almost all studies of depression in the community found higher rates in women than in men - this is far from the rule among persons with cancer. Despite the marked burden and the existence of effective treatment, a very large proportion of the persons with depression remain untreated. The causes to be imputed for the treatment gap are of different nature. Some of these causes are related to the suffering person, to the social context and to the health system. Often, the treating physicians fail to identify depression and to treat it properly. For example, in one evaluation of 456 outpatients with solid tumors a minority (14%) of the depressed were identified as such. Why is it important to assess depression in persons with cancer? Untreated depression both enhances the risks to life and it lowers the quality of life. It may be associated to a reduced chance of survival in women with early stage breast cancer. One possible reason is limited adherence to the treatment plan. Timely identification and well prescribed and conducted treatment could make a substantial difference.

Keywords: Depression - cancer - site-dependence - treatment - non-treatment impact

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Introduction

A Case for Action

Unipolar depression ranks high in the global burden of disease, particularly in industrialized countries (World Health Organization, 2001). However, as the epidemiologic transition is setting in, developing countries may not be spared from such a burden. Almost in all countries where community-based epidemiologic studies have been conducted, depression was found to be common. For example, in the US, the life-term prevalence rate in the community was found to be about 20% (Kessler and Ustun, 2008). The World Mental Health Survey (WMHS), an epidemiologic study conducted in 28 countries that used the CIDI-Composite International Diagnostic Instrument to arrive at a psychiatric diagnosis, found that the life-term prevalence rate of any mood disorder, including unipolar depression, ranged from a low of 3.3 % (SE 0.3%), in Nigeria, to a high of 20.4% (SE 0.5%), in New Zealand. For Israel, the respective overall rate was 10.7% (SE 0.5). For Lebanon, another Middle Eastern country that participates in the WMHS, the life-term rates for any mood disorder was 12.6% (SE 0.9%) (Kessler and Ustun, 2008). The WMHS also estimated 12-month prevalence rates; these ranged from a low of 1.1% (SE 0.2), in Nigeria, to a high of 9.7% (SE 0.4%), in the US. In Israel, the 12-month rates among the Arab-Israelis and the Jewish-Israelis, estimated by the local component of the WMHS (Levav et al., 2007), were 8.2% (95% CI 6.2-11.0) and 5.9% (95% CI 5.1-6.8), respectively. The respective rate for Lebanon was 6.8% (SE 0.7%) (Kessler and Ustun, 2008).

Importantly, aside from being a frequent disorder in the community, depression causes much suffering and disability. In addition depression is co-morbid with other disorders and raises the risk for mortality (Kessler et al., 2003). The mental pain could be so intense that the person may contemplate suicide - and even carry it out.

Often, the rate of depression in persons with cancer is even higher than in "healthy populations". The reasons are varied, including biological, such as the effect of treatment, and psychological, resulting from losses such as the limitation of function in different areas of life (Massie, 2004). The epidemiologic studies on the

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comorbidity of depression and cancer have been conducted in different countries and in a majority of settings of the specialized services (e.g., inpatient services, outpatient clinics), and in the community.

Ciaramella and Poli, in Italy, studied 100 persons recruited from the Pain Therapy and Palliative Care Unit of a general hospital. They used a clinical instrument, the SCID, to investigate depression and another instrument to investigate pain based on the McGill Pain Questionnaire. The authors found that 49 persons had depression. This percentage decreased to 28, when physical symptoms were replaced by other – "psychological"- items. Importantly, the persons diagnosed with depression did not have a life-time mood disorder more frequently than the current depression- free group (Ciaramella and Poli, 2002).

A more recent study, conducted in Norway, on inpatient persons with cancer (N=225), used screening scales to ascertain the presence of depression and anxiety (both disorders are frequently associated). They found that 12% of the persons interviewed had anxiety; 12%, depression; and 44%, had both. Of clinical interest, the group that had neither, 32%, had less pain than any of the other three (Utne et al., 2010).

Those results, in which depression is higher among persons with cancer than in no-cancer respondents, have been replicated in the community. For example, in the US, the 2000 data from the Health and Retirement Study (N= 17210), a survey of community-dwelling adults over the age of 50, yielded the following results: 12.5% of the sample reported they had cancer. This group had higher risk of depression, measured by CESD (OR=1.2, 95% CI 1.1-1.4), had more fatigue (OR =1.5 95% CI 1.3-1.6) and pain (OR =1.2, 95% CI 1.03-1.3) (Reyes-Gibbi et al., 2006).

Reviewers, however, have noted that the studies have been affected by methodological limitations, for example, a majority of studies used a variety of depression scales (e.g. the HDS-Hamilton Depression Scale (Hamilton, 1960) or the CESD-Center for Epidemiologic Studies (Hann et al., 1999)) that are not truly diagnostic. Even when those scales are carefully calibrated and thus able to split apart persons with a disorder from those disorder-free they do not generate a psychiatric diagnosis. Indeed, studies that relied on more valid diagnostic methods, such as standard diagnostic instruments (e.g., the CIDI-Composite International Diagnostic Instrument, as applied in the WMHS) are a few (Kessler and Ustun, 2004). In turn, some of the latter, despite the methodological improvement, are affected by the inclusion of symptoms that are "physical" in nature and therefore they may result from cancer rather than being a "true" expression of the mood disorder. (Endicott modified a diagnostic instrument and submitted replacements for those ambiguous diagnostic items (Endicott, 1984).) Despite the limitations, there is an inescapable conclusion: the prevalence rate of depression is high in persons with cancer and the impact is considerable. The rates by selected sites are as follows: oro-pharyngeal, 22%-77%; pancreatic, 33%-50%; breast, 1.5%-46%; colon, 13%-25%; and gynaecological, 12%-23% (Massie, 2004). With regard to the impact of depression in persons with cancer McDaniel et al (1995) have noted that it is multiple and substantial, including reduction in the quality of life, reduced adherence to medical treatment and poorer outcome. Yet, "studies show that psychiatric disorder goes unrecognized and untreated" (Fallowfield et al., 2001).

The Treatment Gap

Despite the availability of rather efficacious means of intervention, such as antidepressant medications (Spijker and Nolen, 2010) and psychological methods, eg cognitive behavioral therapy (NICE, 2010), the treatment gap –the difference between the true and treated prevalence of depression (Kohn et al., 2004) - is frequent, while the treatment lag – the time from the onset of depression to the first contact –is considerable. With regard to the latter, the WMHS cited above found for all the participating countries that the median duration of delay in years among cases that subsequently made treatment contact ranged from a low of 1.1 (SE 0.3) to a high of 14.3 (SE 3.1). With regard to the treatment lag, a World Health Organization study found that world-wide at least 56% of the persons with a mood disorder are untreated (Kohn et al., 2004).

An analogous situation could be found among persons with cancer, including among those who undergo cancer care. Henceforth some selected facts: Hewitt and Rowland (2002) noted, in their community study (N=95615) conducted in the US, that individuals who reported that they had cancer (n=4878) used mental health services more often than those who were cancer-free. "Among individuals 18-44…14.0% of cancer survivors as compared with 6.5% of those without such a history reported having used a mental health service in the past year". But "a significantly higher proportion of cancer survivors as compared with those without such a history reported needing mental health services but not getting them because of cost …" The unmet needs were not randomly distributed: the younger respondents; those with lower educational attainment; the never or those previously married; those without health insurance; and those belonging to disadvantaged ethnic groups had higher unmet needs.

In another study conducted among low-income women with breast or gynecological cancer (N= 472) receiving care in a public hospital in the US, 24% reported moderate-severe depressive disorder. Of this group, only 12% of women received antidepressant medication while 5% reported seeing a counselor or participating in a support group (Eli et al., 2005). Obviously, many factors operate to determine the treatment gap.

In the general population those factors have been grouped as both objective and subjective (Kohn et al., 2004). With regard to the former (the three factors mentioned heretofore do not constitute an exhaustive list), the lack of availability or accessibility of the services are a formidable objective barrier to their use. Also, if services are not tailored to the specific population in need, such as in terms of gender or culture, the potential users or their families may stay away from them. Lastly, the untreated prevalence may not be reduced if the physician is unable to recognize or treat depression or holds a negative attitude towards psychological disorders. The subjective factors are of a diverse nature, such as stigma, that may prevent seeking care or cause aborting prematurely a course of treatment.

In the case of cancer all of those factors may operate, and even be further compounded by other (proximal and distant) causes. These factors are of a different nature according to the stage of the disorder and the setting of care, e.g., specialized services or primary care –at the stage of follow up or remission. The availability, knowledge and attitudes of the practitioners are markedly different in all those settings. Greenberg, in the US, grouped the barriers to care arising from both uncertainty and cost. For her, uncertainty reflects the difficulties in identifying and defining depression in the context of cancer, where sadness and distress could be understood as a natural reaction to a difficult predicament. This a priori assumption hinders both the ability of the treating physician to perceive the psychiatric disorder and of the person with cancer to ask for the appropriate care. Consequently, people with depression remain undiagnosed and not cared, with the ensuing risks (e.g., in the final stages of cancer, undiagnosed and untreated depression may result in earlier entry into a hospice (Christakis, 1994)).

Costs, notes Greenberg (2004), constitute an important barrier, particularly for countries where the health insurance coverage for mental health care is limited. Much less often mentioned in the relevant literature is that depression, with or without comorbid anxiety, may not only affect the person with cancer but the caretaker as well. Good practice calls for a double concern -patient and caretaker- and not for just one member of the dyad.

Recommendations

Obviously, recommendations purported to reduce both the treatment gap and lag depend on both the level of action that would assure to bring maximum change as well as on the feasibility of their implementation.

Two examples, both at the system and at the clinical levels illustrate the above. At the system level, if the barrier to care is caused by the limited or total lack of availability and accessibility of the mental health services, planning and administrative actions ought to be taking to dismantle those barriers. But, if the chief barrier is located at the clinical level then a routine procedure should be devised to both detect and treat those persons with depression. If rational decisions are adopted following a diagnosis, for example, of the location and type of the barriers, there is a good chance that the treatment gap and lag could be shortened to the benefit of the psychological status of the person with cancer and, hopefully, for the outcome of the medical care.

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EXPERIENCES IN MIDDLE EASTERN POPULATIONS

Selected Issues in Palliative Care among East Jerusalem Arab Residents

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Abstract

Understanding of cultural context is important when working with Palestinian patients, particularly in Israeli hospitals. Cultural competence includes individual assessment of communication needs and preferences. "This is God's will and one mustn't protest. A person who believes accepts all that God gives"(patient quote).

Keywords: Cancer patients - cultural competence - Arab culture - cultural stereotyping

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Introduction

The Oncology Institute of Shaare Zedek Hospital is located in Jerusalem and treats patients from all sectors of the Israeli society. Twenty four percent of Israel's population is Arab; 82% of which is Muslim. The majority of Arab patients receiving care at Shaare Zedek are East Jerusalem residents. There are 250,000 East Jerusalem Arabs in the city. They are 'permanent residents,' rather than citizens, a status which entitles them to many social rights, such as social security and health care.

Although the general Arab population in Israel is very diverse and is composed of a variety of groups such as Muslims, Christians, Druze, as well as sub-groups belonging to different geographical locations, it does share some common cultural features. Successful treatment of an Arab cancer patient requires a culturally sensitive professional intervention which addresses the significance of his or her cultural identity. In view of this, the Hospital's administration appointed an Arab social worker to assist the treatment of Arab patients in a targeted manner.

The East Jerusalem Arab population is distinguished from other Arabs in Israel in their legal status and insofar as they are less integrated into Israeli society. Their school curriculum is Palestinian or Jordanian rather than Israeli, many cannot speak Hebrew, and they reside in separate Arab neighborhoods. This chapter reflects experience derived from working with this population. By understanding and attending to the culture, beliefs and perceptions of the East Jerusalem Arab community, the social worker can better understand the Arab cancer patient and his family's preferred coping paths. Such insight is the first step toward adequate clinical intervention. Culturally sensitive intervention is the key concept here. A caregiver working with the Arab population needs to possess cultural knowledge, sensitivity and the ability to mediate between the majority culture (which is often Western) and Arab culture. This chapter focuses on the following central topics: the structure of the Arab society, cultural aspects shaping attitudes toward cancer (shame, secrecy), attitudes toward pain, women's status, dealing with death and preferences at life's end, patterns of caregiving and receiving.

The Structure of Arab Culture and Family

Haj-Yahia (1994) sees value-orientation as a structured, general framework which shapes a person's perception of time, nature, his place in nature, his desired and undesired qualities, and his inter-personal interactions. By being attuned to the value-orientation of the East Jerusalem Arab population, the social worker can better understand the coping mechanisms preferred by the Arab patient and his or her family, and can structure intervention accordingly.

Arab society is composed of the following central units; the hamula (a large kin network), the extended family and the nuclear family. The society is stable and strong emotional, social and economic ties exist between its members. Men hold the primary authority within each of these units. The father is the head of the family and has legitimate authority to make decisions regarding all aspects of family members' lives. The father is subordinate to the male head of the extended family, who is in turn subordinate to the head of the hamula. The status of women in the Arab family is usually lower than that of men. "*The Arab woman is expected to be dependent on her husband, to submit to his will and needs and to be a source of support for him and for his family*" (Haj-Yahia, 1994).

While modern, Western values and behavioral codes are widespread among the Jewish Israeli majority, the Arab Israeli population in general, and East Jerusalem Arabs in particular, still adhere to traditional customs and norms governing family life, gender roles, childrearing, and everyday conduct. The expression of conflict, whether internal or external, and the expression of negative feelings are not well accepted in the Arab culture.

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The anxious self-absorption that often accompanies a depressed mood is viewed negatively as "thinking too much," which is in turn viewed as a narcissistic preoccupation . Physical symptoms, however, are accepted as legitimate and morally acceptable expressions of pain (Al-Krenawi & Graham, 2000).

Attitudes Toward Cancer and Toward Expressions of Emotional Pain

Among the East Jerusalem Arab population, cancer is accompanied by a sense of shame and fear of genetic transmittance. Secrecy prevails as knowledge of the patient's sickness among the wider society might harm family members' marriage prospects. Keeping the secret is related to society's expectation of the individual to remain calm, suffer quietly, not show signs of weakness and protect the family's interests. Concealment makes it difficult for patients to seek and receive external help, especially through participation in support groups.

Many Muslim families believe that those who suffer more will receive a greater reward in the afterlife. Protesting one's fate is not accepted since fate is considered to be God's will. Patients are expected to accept their disease. Interventions which encourage the expression of emotions or to normalize feelings of anger or protest often elicit reactions such as "This is God's will and one mustn't protest. A person who believes accepts all that God gives." Faisal Azaiza and Miri Cohen in their study of Israeli Arab women's attitudes toward breast and cervical cancer also find that some still perceive cancer "as either a punishment or as a test devised by God." (Azaiza & Cohen, 2008 , p.34)

Patients perceive the expression of physical pain as more legitimate in comparison with emotional pain. This is illustrated in the following narrative:

Yusra, a 48 years old female patient with metastatic cancer, suffered from stomach aches every time she dined with her family. This symptom did not appear, however, when she dined with other people. One of the conclusions she reached as a result of counseling was that her expression of emotional pain was not acceptable in her family and that she found it difficult to meet her family's expectations to be strong and to continue functioning as usual within the family. As she developed skill in expressing her emotional distress, the stomach aches disappeared and she no longer needed to find alternative outlets for her emotional pain.

Coping with Death and End of Life

The main support networks of the Arab family are often informal ones including neighbors, friends and kin. Most Arab families see hospitalization at a hospice in end-of-life situations as disrespectful and believe that the family owes it to the patient to enable him or her to spend their last days at home. Many see the transfer of the patient to a hospice or to any other palliative framework as a failure. In everyday speech they refer to such institutions as "*death institutions*" and they do not regard them as places which might improve a patient's quality of life.

The following narrative illustrates the impact of these beliefs. In an attempt to admit Ahmad, a 54 years old terminal patient, to a hospice, his extended family became very angry with his wife, claiming that she was shirking her natural role as his caretaker and accusing her of being disrespectful. The wife was hospitalized that same day suffering from a nervous breakdown due to the stress generated by the reaction of the family. The family was not sympathetic to the wife's condition. In response, my professional intervention entailed gathering the family and explaining to them the complexity of the Ahmad's medical situation. I reached out to the head of the family and engaged the physicians on the medical team to add their authority to a discussion about the severity of Ahmad's condition. Following a difficult and painful conversation, he agreed to transfer Ahmad to a hospice in collaboration with Ahmad's wife.

In contrast, the society is more accepting of home care or home hospice, as it combines the tradition of caring for the patient at home and modern medicine. While home care might be the best way to maintain respect for family values and enhance patient care, it is not easily accessible for East Jerusalem Arabs. Today, home care is provided for people residing near the city center while physical and political conditions make East Jerusalem Arab neighborhoods less accessible to such arrangements.

Seeking Help

Haj Yahia (1994) argues that everyday behavioral orientation among Arabs imposes self -discipline and the notion that a person can attain complete self control, including control of the emotions and meeting one's responsibilities in various areas of life. The Arab individual is expected to be composed, patient, not to protest at times of distress, and to endure painful moments quietly. In many cases, Arab patients find it difficult to share personal problems and feelings with a person who is not a family member or a member of the community. A person who does share such issues with an outsider is perceived as weak and disloyal (Al-Krenawi & Graham, 2000).

Furthermore the special political and legal status of East Jerusalem Arabs makes it even more difficult for them to seek help from Israeli state institutions or their representatives. Meetings of Arab patients, their partners or companions, with the social worker are often very charged and characterized by substantial suspicion. Since many members of the Arab population see social workers as representatives of the establishment, they may not seek assistance. It is critical then, that the social worker explain their role and assert their readiness to work with the family, partner, or children as well as with the patient. Commonly, the social worker's outreach initiatives will be rebuffed until trust is developed, thus underscoring the importance of relationship building and perseverance.

Some patients and family members are apprehensive about the idea of emotional support and about discussing one's feelings, and others are apprehensive about receiving help from a professional external to the family system. The role of the social worker as part of the medical team is not self-evident to many Arab patients. This understanding starts to develop when the medical team uses the services of the Arabic speaking social worker as an interpreter since most patients do not speak Hebrew and the medical staff often does not speak Arabic. The sensitivity to cultural issues and familiarity of language helps establish trust between patients and the medical team.

Arab men tend to disclose and interact less with the psychosocial staff than do women. They often prefer to suffer quietly and focus on practical assistance. It is unclear if this is affected by the gender of the social worker or mental health clinician or due to the cultural requisite of being reserved. This is a question meriting further inquiry. To address the difficulty that East Jerusalem Arabs have in seeking formal help, we take the following steps:

∑ Raise awareness and educate about the role and work of the social worker

∑ Initiate referral of the patient, as part of the routine work of the medical staff, to the psychosocial staff, since a society which has much respect for authority tends to follow the recommendations of the medical staff

∑ Insist on transmitting information in the patient's native language.

Conclusion

The treatment of cancer patients, along the continuum of illness, requires attention to culture, values and traditions. The East Jerusalem Arab population has a special status and their unique needs must be addressed accordingly. Several issues require deeper attention. It is important to understand that cancer is still accompanied by a sense of social shame among the Arab population and causes some patients and their families to keep it secret, a practice that often leads to feelings of isolation and loneliness. There is still a lack of awareness and information about the disease in the Arab population and efforts must be made to disseminate knowledge about cancer, about treatment options and about attitudes toward those who suffer from cancer. The available support systems must be adjusted to address tradition and culture, especially the cultural inhibition which make it difficult to speak about painful feelings.

It is important to stress that this population suffers from limited access to medical and paramedical care, and that the home care staff that are trained to care for terminal patients cannot access East Jerusalem Arab neighborhoods due to physical and political conditions. This problem becomes even more acute in cases of immobile patients who cannot travel to receive medical care.

The value of accepting one's fate does not contradict the need to provide patients with emotional and medical palliative care. There is an urgent need for a system of home care teams to be established inside East Jerusalem Arab neighborhoods to accommodate the culturally mandated practice of spending one's last days at home. The challenge in treating Arab patients is in creating conditions in which Arab cultural reality and medical services would supplement, rather than contradict, each other. The skills of staff members attending to the Arab population should include, alongside conventional medical knowledge, awareness of and sensitivity to cultural issues, as well as an ability to mediate between the majority culture, which is often Western, and the minority Arab culture.

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