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Truth-Telling: A Comparative Analysis of Cancer Diagnosis Disclosure Protocols in Western and Eastern Countries

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Abstract: **In Western countries, a cancer diagnosis is nearly always discussed directly and immediately with the patient, whereas in Eastern countries, a patient may or may not be told of their disease and prognosis. The aim of this study was to compare the current protocols in place for disclosing a cancer diagnosis (CDD) across a number of countries in different regions of the world to better understand the causes for different practices. A narrative review of the literature was conducted with thirty articles reviewed and discussed. The findings from the review show that cancer diagnosis disclosure is a constantly evolving science. *Truth-telling* is a complex concept that involves a patient's diagnosis, prognosis, treatment, side-effects, risks and benefits, quality of life and financial impact. This foundational perspective difference is what must be understood in order to make progress towards patient autonomy in cultures with strong family-centered values.**

Moreover, the study reveals that changing cultural stigmas about cancer through media education for the public as well as communication skills training for healthcare providers may help to bridge the gap.

Keywords: **Cancer diagnosis; Clinical practice; Culture attitude; Ethics, Family-centered; Patient wishes; Truth-telling.**

1. INTRODUCTION

No matter where in the world one resides, a cancer diagnosis would be unwelcome news. Depending on a patient's location, however, his or her experience during the disclosure process (if that even occurs directly to the patient) could vary greatly. In most Western countries, a cancer diagnosis is nearly always discussed directly and immediately with the patient, whereas in many Eastern countries, a patient may or may not be told of their disease and prognosis. A truthful disclosure process (truth-telling) may include the patient, family members and the patient's physician(s), making the interactions between these parties varied, and at times, difficult and complex.

Truth-telling is a complex concept that involves a patient's diagnosis, prognosis, treatment, side-effects, risks and benefits, quality of life, financial impact, etc (Xue, Wheeler and Abernethy, 2011). In multiple studies conducted across various regions of the world, truthful disclosure has been shown to have a significant impact on a patient's treatment decisions and cooperation (Rozveh, Amjad, Rozveh and Rasouli, 2016), trust in their physician and healthcare team and to positively influence their mental health because they feel they can discuss the emotions that accompany a terminal illness (Arabiat, Alqaissi and Hamdan-Mansour, 2011).

In 1977, Beauchamp and Childress released a field-altering book called *The Principles of Biomedical Ethics* which listed four crucial principles of medical ethics that are globally accepted in the medical field today. These principles are patient autonomy, beneficence, non-maleficence (do no harm) and justice (Murgic, Hébert, Sovic and Pavlekovic, 2015). While all of these principles are accepted as valuable in nearly every culture, Western healthcare systems tend to focus more on patient autonomy while many Eastern cultures find non-maleficence to be the most important. This foundational perspective-difference is what must be understood in order to know how one might increase patient autonomy in those cultures with strong family-centered relationships and values.

In theory, patient autonomy and non-maleficence do not conflict with one another, but reality seems to prove otherwise to an extent. In an attempt to prevent harm to a patient's psyche during a cancer disclosure, physicians may not reveal the full severity of a patient's illness, if they even choose to reveal it at all. Unfortunately, this can lead to a number of other issues emerging between the doctor, patient and even the patient's family members. There is strong evidence that, while an initial discussion of a cancer illness may be significantly challenging for a patient, the benefits of patient autonomy (i.e. full and honest discussion with a patient about an illness and treatment options) during disclosure typically outweigh potential harm. These documented benefits include greater trust between patient and physician, increased cooperation during treatment protocols, more realistic life expectancy amongst patients and statistically-significant prolonged survival (Su et al., 2020). Due to these proven benefits, a patient's autonomy has emerged as the most valuable of the four ethical principles. While this may be the reality today, patient autonomy was not always at the top of the list in Western healthcare cultures.

In the past, physicians in Western countries handled cancer diagnosis disclosure (CDD) similarly to the way those in most Eastern countries do today. This involved a paternalistic outlook on medicine, which meant that physicians would regularly avoid disclosing a cancer diagnosis to the patient, especially to those whose cancer was terminal, for a variety of reasons ranging from a desire to not lose their patient's business to genuinely attempting to prevent unnecessary harm to the patient's mental status. Several events that will be discussed further were pivotal to the socio-cultural changes that shifted Western physicians' paternalistic view to the current commitment to patient autonomy. Unlike many Western countries, Eastern cultures have relied heavily on family members as significant players in whether a patient knows or fully understands his or her cancer diagnosis and prognosis. Asian and Middle Eastern countries have strong family-centered cultures, whereas Western cultures tend to hold greater individual-focused perspectives (Al-Amoudi, 2013). Due to the increasing data revealing the desire for and benefits of patient autonomy, many Eastern countries are slowly making a shift towards placing greater value on patient autonomy. Society, culture, religion, government legislation and even technology all impact how and to whom a cancer diagnosis is revealed as well as how it is accepted and handled.

Recognizing that one culture's handling of CDD cannot be directly applied to another culture (Rozveh, Amjad, Rozveh and Rasouli, 2016), the aim of this research is to examine the current literature from numerous countries in varying regions of the world to better understand and compare the current CDD protocols in place, the reasoning behind current protocols, and to highlight any areas that may need further study. Specifically, this research is seeking to answer the following research question: what are the key distinguishing factors that facilitate or prevent the adoption of cancer diagnosis disclosure in Western and Eastern countries? The objectives of this review are to determine:

1) what are the implications of these countries' healthcare policies and practices for clinicians in cancer services;

2) what are patients' preferences for being told about their cancer and how do the patient's family members impact this dynamic; and

3) what are the implications of these policies for the patients and families involved.

This dissertation is divided into five chapters. The first briefly addresses the differing viewpoints of cancer diagnosis disclosure in the world today. The second chapter discusses the methodology used to determine which studies were reviewed and why they were chosen. The third chapter is the literature review which covers numerous countries from both Eastern and Western cultures. Policies and practices utilized by physicians as well as patient and family member perspectives during CDD are examined for each country presented. The fourth chapter presents a summary of the literature review, and the next chapter discusses the findings and their potential impacts on future policies for CDD. The fifth and final chapter provides limitations of the research, areas that need further research, and recommendations.

2. METHODOLOGY

2.1. Search strategies

The search engines utilized include PubMed, Science Direct, Google Scholar, Dove Press, BioMed Central and Wiley Online Library. These databases provide high-quality, easily accessible full-text articles. Only peer-reviewed articles in the English language that were published no earlier than 2010 were accepted. The only exception was an article that specified details relating to current protocols (i.e. information about the SPIKE protocol). This article was sought after the dissertation had begun and is believed to have been a valuable, applicable and necessary source of information. The keywords used for the searches were “cancer” AND “diagnosis” AND “disclosure” OR “truth-telling”. Boolean operators (OR and AND) have been used to merge search strings, and truncation has been used to ensure the recognition of search term when spelling word ends differ. Titles and abstracts were screened by the author, and full texts were retrieved for the most relevant articles.

2.2. Data collection and analysis

Full-text studies were thoroughly reviewed to determine relevance. They include some, but not all, countries from the North American, Middle Eastern, East Asian and European regions. Some papers contain empirical data studies and some are literature reviews of specific regions. Participant count in these studies ranges from n=20 to n=2,206. Those empirical studies with few subjects were still included in order to demonstrate the variety of views and beliefs that impact CDD protocols. Some studies focus only on patient point of view, some on physicians’ and other healthcare professionals’ points of view, some on both patients’ and family members’ of patients perspectives and some on all who are potentially involved in the disclosure process. It is important to examine all perspectives in order to gain the most complete understanding of the disclosure process in the different regions.

2.3. Inclusion criteria

Types of studies

Peer reviewed, English language narrative and systematic quantitative reviews, as well as primary studies including those that were cross-sectional, qualitative evaluations, case studies, controlled before-and-after, retrospective and prospective cohort studies, and randomized controlled trials were included.

Types of participants

All studies included only adult participants. Depending on the study, participants consisted of cancer patients, physicians, other healthcare workers, patient’s family members or a combination of some or all of these.

Countries

Research studies of countries that are located in the Western, East Asian, Middle Eastern and European regions of the world that met both the exclusion and inclusion criteria were included.

2.4. Exclusion criteria

Studies published prior to 2010, except for the one study mentioned previously due to its necessity and applicability were excluded, as were studies not specifically related to cancer diagnosis disclosure or truth-telling in medical practices.

Additionally, studies without full-text accessibility online were not included, as were countries not located in the Western, East Asian, Middle Eastern and European regions.

Figure 1: Filtering Flow Chart

Articles identified for possible inclusion following six databases searched= 9,351
Following exclusion of articles not in English= 9,271
Full text online only=4,873
Scholarly/Peer reviewed sources=2,570
No earlier than 2010=1,638

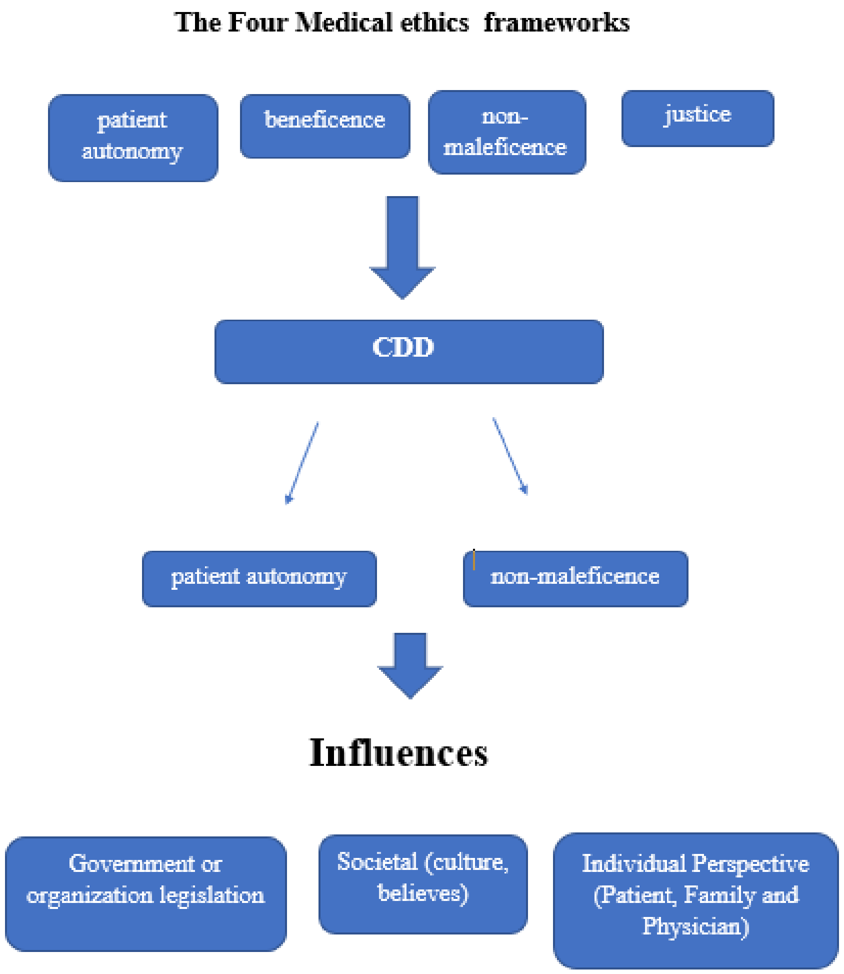
Following screening of titles, articles remaining=101
Abstracts read/articles removed=101/49
Full texts read for eligibility=52
Eligible and included articles=27
Additional articles included after snowballing=3
Total included=30

2.5. Theoretical Framework for analysis

A theoretical framework was developed for the purpose of analysis. This comprises four medical ethics principles: patient autonomy, beneficence, non-maleficence and justice (Childress and Beauchamp, 2001).

As a governing framework for analysis. However, because patient autonomy and non-maleficence are the most commonly used principles in cancer disclosure, and different conditions or perspectives influence CDD practices, factors such as patients and physician perspectives, societal and cultural beliefs and government legislation are also included. (See figure 2).

Figure 2: Theoretical Framework



2.6. Limitations

Only some countries had studies that qualified for review based on the exclusion and inclusion criteria. Within those studies, many offered only one perspective of CDD. These factors may limit a comprehensive understanding of CDD in each country's medical system. The limitations of the theoretical framework used in CDD are that findings could differ depending on the age of the patients and the extent to which information will be given that regards patient autonomy and regards non-maleficence who know the patients better, are their family or the physician, so who decided that in truth-telling will not do any harm to the patient

3. LITERATURE REVIEW

This literature review is quite detailed as there are a variety of countries with research studies that will be reviewed. It is organised by region (Western, Europe, Middle East and East Asia) and countries within those regions. Some regions only had one country reviewed while others discuss medical perspectives from numerous countries within that region. The number of countries discussed in each region varies due to the available studies that met the inclusion and exclusion criteria.

Background and context

3.1. Western

United States of America

To begin, it is helpful to provide the background and context to the significant change and catalysts of change in Western society regarding patient autonomy and non-maleficence. The perception of and importance placed on patient autonomy in the USA only came about as recently as the 1960s and 1970s (Sisk, Frankel, Kodish and Isaacson, 2016). In the 1800s, physicians often hid a patient's diagnosis, especially if it was terminal cancer, and made medical decisions based on what they (the physician) felt was in the best interest of the patient. This is known as paternalism: hiding the truth of a diagnosis from a patient and making medical decisions without consent specifically for an individual who could make their own decisions. In 1803, Thomas Percival coined the term "medical ethics" and wrote the first code of ethics for physicians in the Western world. In it, he discussed the need for physicians to be beacons of hope instead of bearers of bad news. He even went as far as to suggest that lying to a patient might be regarded as "praiseworthy" in certain circumstances. The American Medical Association, founded several years later, drew from Percival's code and stated in their own 1847 Code of Ethics that, essentially, doctors should never tell a patient about a diagnosis that would cause them distress and should instead, be a "*minister of hope and comfort to the sick*" (Sisk, Frankel, Kodish and Isaacson, 2016).

There were several reasons, both well-intentioned and self-serving, that this thought process became so popular. First, it was believed that if a person were to learn of a terminal diagnosis, it would have a severe and detrimental impact on the individual's mental health. Many physicians cared greatly for their patients and did not want them to suffer mentally as much as their bodies were suffering physically. They believed the best way to do this was to make decisions in favor of the patient without informing the patient. Unfortunately, there were also selfish motivations that inclined physicians towards dishonesty in their practices. During this time in the USA, the medical field did not have the rigorous training and oversight that it has today. Physicians were trained by apprenticeship, and some even began to "practice medicine" without any guidance. This resulted in a variety of methods for treating and interacting with patients as well as oversaturation in the field. Physicians felt that they needed to keep their patients "happy" so that they could keep their clientele. Not only did they believe their patients might leave their practice if they disclosed bad news, but physicians were also encouraged not to tell patients how to take care of non-threatening issues in order to maintain patients' reliance on the physician (Sisk, Frankel, Kodish and Isaacson, 2016).

Around the turn of the 20th century, the class divide between physicians and lay persons became more pronounced, resulting in the medical profession becoming a more respected occupation. This reality perpetuated paternalism in the medical field as physicians believed that their opinions of a patient's needs outweighed what a patient may have believed he or she needed. Physicians were trained to keep their patients, especially those with cancer diagnoses, ignorant of their illness for as long as possible. Again, the stated reason for this was to keep the patient from experiencing a severe and depressing mental “shock”. At this time, there was not a lot of vocal resistance from the majority of patients to know their diagnosis, so the status quo remained (Sisk, Frankel, Kodish and Isaacson, 2016).

In the mid-1900s, cultural attitudes and ideals began to shift in American culture, and consequently, in governmental legislation. Under President Kennedy in 1962, the Consumer Bill of Rights was passed allowing for patients to have “*the right to safety, the right to be informed, the right to choose and the right to be heard*.” In the following years, more ethics codes and laws would be published and implemented by the medical community. By 1973, “A Patient’s Bill of Rights” was created by the American Hospital Association officially acknowledging the patient’s right to obtain clear, reliable and understandable information from physicians and caregivers pertaining to the patient’s disease, treatment and prognosis. Ideals about informing patients, especially cancer patients, of their diagnosis shifted from *whether* to tell a patient to *how* to tell the patient. The dramatic shift in American socio-cultural norms occurred in less than twenty years and laid the foundation for the current patient-centered approach to medicine in most Western countries. The “Belmont Report”, published in 1979, specifically named the four founding principles of medicine today: autonomy, beneficence, non-maleficence and justice (Sisk, Frankel, Kodish and Isaacson, 2016).

Throughout the years, these principles have continued to be reestablished through updated laws and literature. There is no longer a question about whether to tell patients of their diagnosis. Instead, there is now an evolving focus on how to discuss it. The Institute of Medicine and National Cancer Institute have released a variety of documents and training regarding empathetic and tactful cancer care and end-of-life discussions with patients. The American Medical Association’s 1847 Code of Ethics has undergone revisions as well and currently reflects strong views on patient autonomy (Sisk, Frankel, Kodish and Isaacson, 2016).

Truth-telling Protocols

With the change in transparency, physicians now focus heavily on how to relay difficult information in the least harmful way. Training manuals, questionnaires, and various support systems have been developed and continue to be updated as the research continues to reveal areas that need improvement. Several protocols have been utilized to assist in CDD in Western countries. The main protocol taught and followed by physicians in Western countries was developed by Baile et al (2000) is SPIKES:

- **S**etting up the interview-- this involves the location, layout and comfort of the area designated for CDD as well as those who will be in attendance for the disclosure (i.e. family members);
- **P**erception--understanding the patient’s perception of his or her diagnosis, treatment and prognosis;
- **I**nvitation--obtaining the patient’s permission to discuss the details of the diagnosis and the extent to which the patient would like to know;
- **K**nowledge--giving knowledge and information to the patient;
- **E**motions--empathetically acknowledging and discussing the patient’s emotional needs after obtaining information; and
- **S**trategy and summary--discussing an actionable plan with the patient can help to quell fear of the unknown.

As is evident with this protocol, the process is patient-centred (Baile, et al. 2000)with a focus on making all involved, including the patient, family members and healthcare staff, as comfortable as possible, in order for the physician to ask questions, discuss information and plans together with the patient, for the patient to have the best possible experience when receiving their cancer diagnosis. It is also evident that the drastic change in mentality from paternalism to autonomy in the USA’s healthcare system has had a significant effect on other Western cultures as well, as many other countries have followed suit and implemented various truth-telling techniques.

Europe

In general, many European countries have either changed their perspective from a paternalistic one to an autonomous one or are slowly doing so. Several studies have been carried out to specifically identify the progression (if any) of paternalistic healthcare perspectives towards autonomous ones (Friedrichsen, Lindholm and Milberg, 2011; Murgic, Hébert, Sovic and Pavlekovic, 2015). The two following studies have been reviewed as examples of understanding patients' and physicians' general opinions on patient autonomy and the cancer disclosure process, and the progress made.

Sweden

One group of researchers (Friedrichsen, Lindholm and Milberg, 2011) studied Swedish patients (n=45) who were terminally ill and knew their diagnosis and prognosis. They varied in age, sex, cancer type, education, time since diagnosis and marital status. Patients were interviewed by members of their palliative care team regarding patients' experiences of diagnosis disclosure. This study revealed that all patients wanted to know the truth, but the degree of truth varied between absolute truth, partial truth and desirable truth. Absolute truth included all information pertaining to a realistic timeline, expectations, symptoms and treatment/management plans. Patients desiring absolute truth claimed they did not want to hide behind false hopes and wanted to know how to proceed with their lives moving forward. Those who preferred a partial truth preferred the facts of their disease mingled with positive information from which they could benefit. They did not want to discuss life expectancy or unmanageable symptoms. Ultimately, the goal was to hold on to some hope that there could be recovery or healing because the idea of death was too overwhelming. The patients who wanted to experience a desirable truth appeared to prefer not to be told the truth. They would receive the truth from their physician but always held onto an internal hope that something significant would change, i.e. their tumor would disappear; desirable truth relies heavily on a positive outlook and hope in order for the patient to avoid the severity of their disease. Each communication preference was chosen by the patient and communicated to the doctor prior to the actual cancer diagnosis discussion as a way to cope with the harsh reality of a terminal diagnosis, revealing the importance of a physician's understanding of the patient's personal preference when performing a CDD. This study reveals a substantial need for ongoing discussion between physicians and patients so that a physician, or any other healthcare members involved in a patient's diagnosis and treatment and the patient's family members may conduct a CDD in a way that is the most beneficial for the individual patient. This removes any perceived moral dilemma on the doctor regarding possible psychological harm to the patient.

Croatia

A qualitative study (Murgic, Hébert, Sovic and Pavlekovic, 2015) performed in Croatia gathered evidence of medical students' and professionals' perspectives and understanding of patient autonomy, specifically confidentiality, truth-telling and informed consent. The desire to understand the perspectives of patients and medical personnel arose because Croatian medicine is strongly paternalistic. Surprisingly, the paternalistic viewpoint seems to be stronger amongst patients, not healthcare workers.

Six focus groups were held over the course of a year and included first year medical students, final year medical students, physicians who practiced in one of the local hospitals, residents in family medicine and patients with chronic disease. The goal of the research was to better understand "how the participants viewed different situations regarding patient autonomy." Participants' answers during these focus groups revealed several perceived ethical problems including privacy issues for health information.

While privacy was a core concern, the most frustrating ethical problems arose in relation to truth-telling (what, when, how much to disclose) and a patient's right to know. All participants agreed that genuine truth should be told, but it also seems to be a flexible concept in the medical environment as doctors believe that there are situations that call for professional discretion. The close connections that many doctors feel with their patients can make a CDD conversation significantly more stressful because of the care they feel towards, and the relationship they have, with the patient. To ease this discussion, doctors in Croatia utilize either the "opt in" or "opt out" methods. The "opt in" method involves a doctor withholding information unless the patient specifically asks for more. The "opt out" method involves the opposite; a doctor continues to give information until the patient asks him or her to stop. The preference for which method a doctor uses and the specific terminology utilized is at the doctor's discretion based upon the relationship with the patient, the patient's age and the physician's understanding of the patient's cognitive abilities to handle the information.

The study found that patients typically prefer to know information regarding their diagnosis because, even though the information could be psychologically stressful or harmful, the benefits are believed to outweigh the risks. This study revealed that if a diagnosis was not discussed with the patient shortly after being discovered, the patients would equate that delay with poor prognosis. Oftentimes, the patient's family members will request that the doctor not reveal a terminal diagnosis to the patient. At these times, the physician is faced with a moral dilemma, but many have become proficient in dealing with these requests.

Many physicians in this study also claimed that the purpose of their paternalistic tendencies was to help protect those who could not protect themselves or the community (this relates more to the situation where someone had a communicable or psychiatric illness that could negatively impact others around them, not necessarily cancer). They believed that sharing a patient's medical information, with or without the patient's approval - thereby violating a person's privacy - was of greater importance. While "protecting the community" does not directly relate to a cancer diagnosis, the mentality in this study showed that the specific illness did not matter when it came to the idea of protecting a patient's privacy. Doctors who did this may have done so due to an ingrained mindset inculcated from a communist government that had just been toppled in Croatia. Interestingly, some practitioners who had more experience found that focusing on the community instead of the specific patient's issues often resulted in overlooking ways to help that patient heal, which would ultimately damage that patient's trust in their physician and the medical system. A greater emphasis is slowly being placed on patient autonomy in the Croatian medical system, but their attitudes towards this change requires further study, especially since Croatia is a recent post-communist country. The authors of the study recommend further investigation into the impact of specific types of governments on views of autonomy as this could lead to better understanding of the socio-cultural influences.

3.2. Middle East

Until recent years there had been little research done to understand the factors influencing Middle Eastern populations' perspectives on cancer diagnosis and disclosure. Currently, physicians in Middle Eastern regions generally follow a truth disclosure policy involving cancer disclosure to one family member and then tell the patient "*when possible*" (Li et al., 2018). Recently, however, studies have been conducted to help the medical community better understand cultural and religious attitudes and identify ways to address cancer conversations in a culturally-appropriate manner. One literature review completed in 2012 was conducted under the acknowledgement that not only was there widespread non-disclosure in Middle Eastern medical societies, but there is often intentional deceit in order to maintain a patient's high hopes (Khalil, 2012). Typically, cancer diagnoses are only discussed between a physician and a small number of the patient's family members. Interestingly, while Islamic beliefs advocate for an individual's right to know a medical diagnosis, physicians do not generally comply with these beliefs. This review examined publications from numerous countries in the Middle East, identifying similar and evolving perspectives. A subset of the countries from Khalil's review will be discussed in further detail.

Iran

Iran is one of the most studied countries in the Middle East with respect to CDD. According to Khalil's review, multiple studies and questionnaires over the past years revealed a strong inclination towards non-disclosure. Studies with varying numbers of participants show that there are opposing ideas when it comes to truth-telling. One small study (n=20) revealed that those physicians interviewed were in favor of disclosing a terminal diagnosis to family members instead of patients, despite another study (n=51) showing that over 85% of physicians and nurses in that study believe a cancer patient should be told the truth about their illness. Another survey revealed only 3% of physicians claimed to always tell the patient their diagnosis and only 28% usually told the patient, leaving an incredible 70% of physicians never or usually not telling their patients of their cancer diagnosis (Aghili, Yamrali, Akbari and Kazemian, 2016). Based on Khalil's observations, the prevailing attitude towards disclosure is for the physician to tell family members who then tend to conceal the truth from the patient.

Unfortunately, non-disclosure leads to the patient no longer making informed decisions about his or her treatment plan. Studies indicate that some family members believe that the patient is too frail mentally to be told of their diagnosis while others prefer that the patient be told in stages with therapy. Interestingly, healthcare workers claim that family members are the main obstacle to CDD involving the patient. It appears that even though non-disclosure has been the prevailing mentality, many physicians and nurses have positive attitudes towards diagnosis disclosure to the patient directly. In order for physicians to be able to act on their desire to include a patient in a CDD situation, change needs to take place in the minds of the family members. The issue can then focus on how to be sensitive and culturally appropriate when discussing a cancer diagnosis with a patient for the first time.

One reason it is believed that patients may experience psychological distress when told about their diagnosis by a physician is due to a lack of communication skills training and insufficient support systems. In 2017, Abazari et al. developed a "Breaking Bad News" protocol specifically for revealing cancer diagnosis to patients and their families in Iranian culture (Abazari et al., 2017). One of the major differences between this protocol and those used in Western cultures is that this one takes into account the cultural aspects of significant family-centered living as well as the prevailing attitude of "do no harm" during disclosure. It consists of six steps: assessment, planning, preparation, disclosure, support and conclusion. A team of healthcare workers are involved in this process and include, but are not limited to, an oncologist or surgeon, an oncology nurse and a clinical psychologist. Specifications regarding the CDD room are listed as well as questions specifically relating to the patient's preferred degree of disclosure. Based on the extent of the patient's desire to know information regarding his or her cancer, the disclosure team will proceed into the planning phase. The nurse will have prepared for one of three scenarios in this phase: 1) both the patient and closest family member want to be informed; 2) the patient wishes to learn the truth but the family member is reluctant to tell the truth (this is the most common situation in Middle Eastern countries); or 3) the patient does not want to know and prefers that the family members receive the information. The preparation phase will depend on the patient's preference in the planning phase and can include family preparation, environment preparation and patient preparation. Patient preparation is one of the most important phases and requires careful attention and discernment from doctors so that they can best determine the patient's current awareness of his or her disease and prepare the patient for the next step, disclosure. At this point, the physician will, empathetically and carefully, reveal an appropriate amount of information to the patient or family member, based on prior phases. Finally, the support phase is a crucial aspect of ensuring that those patients who chose to undergo full disclosure can experience and discuss all of the emotions they experience after receiving the information relating to their cancer diagnosis and prognosis.

While many of the steps in this protocol are similar to other CDD protocols, the cultural discussions and impact are unique. This protocol gives the patient priority in the truth-telling process while also allowing for the patient to opt out of the disclosure process in favor of a family member receiving the news. It also provides a support system for the patient so that the disclosing physician is not the only one assisting the patient and includes other important aspects of Iranian culture like religion (believing only God, not a physician, knows when someone will die) and using euphemisms to reveal a diagnosis (i.e. saying "tumor" or "malignancy" instead of "cancer"). Further studies are needed to verify the efficacy of this protocol in Iran, but it sets an optimistic tone for change, especially since many Iranian physicians already have a positive attitude towards changing their disclosure practices (Aghili, Yamrali, Akbari and Kazemian, 2016).

Qatar

One study published in 2012 by Del Pozo et al. sought to understand and document current CDD practices in Qatar. Their study consisted of n=131 physicians from nine local hospitals and outpatient centers. The survey discovered that over 88% of respondents regularly implemented a transparent truth-telling policy, but a majority (over 66%) also stated that they would make exceptions to that policy when it was deemed necessary. A third of respondents stated that their disclosure policy had changed in favor of transparency over the years, and about half agreed that their policies would most likely evolve. Physicians would determine a patient's ability to handle full disclosure based on their emotional stability, age and perceived intelligence. Doctors sometimes felt that a patient's sex and/or religion could impact their ability to handle disclosure as well, but that may have been based on personal stigmas regarding sex and religion. Many physicians who completed this survey claimed to be religious (90.7% were Muslim) and nearly 20% completed their medical training in a non-Arab country. This is important because it was noted that only Arab *and* Muslim doctors who completed their training in Qatar had a non-disclosure policy. A large majority of doctors (70.2%) felt that if more research were released in favor of full disclosure, they might improve or change their current policy regarding truth-telling (Del Pozo et al., 2012).

Lebanon

Similarly, to other Middle Eastern cultures, Lebanese physicians elevate the principle of non-maleficence to a higher degree than patient autonomy. Their typical discussion pattern is slightly different than other countries surrounding it.

When a patient's cancer is confirmed, the oncologist will inform the patient's family practitioner who will then discuss the prognosis and treatment options with the family. Once the family is informed, they will determine whether or not to tell the patient, and the physician typically accepts their decision resulting in a low 19.1% of physicians informing their patients of a cancer diagnosis (Doumit and Abu-Saad, 2014). In a study conducted to understand the attitudes of current cancer patients in palliative care towards truth-telling, findings revealed that all patients felt it was necessary to learn of and discuss their cancer diagnosis. In fact, the majority of those patients felt they needed to hide their emotional turmoil from their families because of family members' lack of desire to discuss the diagnosis. Family members felt that they did not want to cause psychological distress to the patients, but this study indicated that not discussing the diagnosis and prognosis led to a different and lonelier emotional stress for the cancer patients. From both perspectives, the goal was peace, but intentionally refusing to discuss the diagnosis ultimately led to greater stress in the patient. While this study may not be easily generalized, it revealed an overarching desire in cancer patients to have the current truth-telling mentality shift towards a more communicative and autonomous one.

Saudi Arabia

In Saudi Arabia, the cultural shift from paternalism to autonomy is slowly following Western trends. It was noted in 2010 that a combination of political, social and religious factors have created hurdles to overcome before the common perception of cancer diagnosis truth-telling in Saudi Arabia will be the same as in Western cultures. It is important to note, however, that the slow progression may not benefit the country as greatly as needed because incidences of cancer are expected to increase by 350% between 2013 and 2025. This could greatly increase the country's health burden (Al-Amoudi, 2013).

Currently, society's view of an individual is that they are an extension of the family. When it comes to decisions, especially regarding cancer patients, family members become very involved in the support process. Saudi Arabian families believe it is necessary to support cancer patients in every way during their cancer journey, oftentimes to the point of exhaustion. Typically, patients will accept this view and follow the advice and decisions of the dominating family members. In Saudi Arabia specifically, there appears to be a lack of CDD procedures so physicians are less inclined to discuss a diagnosis with a patient, despite one survey revealing that 113 out of 114 cancer patients interviewed would want to know all of the information, both positive and negative, pertaining to their disease. The cultural perspective tends towards non-disclosure or partial disclosure while patients clearly prefer full disclosure. According to Aljubran, one of the best models that could assist a cultural shift in the medical community comes from an article written by James Hallenbeck and Robert Arnold entitled "A Request for Nondisclosure: *Don't Tell Mother*" (Hallenback and Arnold, 2007, cited in Aljubran, 2010). It fits well with socio-cultural perspectives and beliefs and may be a good starting point for changing the perspective on truth-telling while being sensitive to those beliefs.

Hallenback and Arnold specifically discuss how to handle a request for nondisclosure of a serious diagnosis or prognosis by a family member. They call on the doctor and healthcare team's abilities to remain calm and navigate understandably emotional situations in a beneficial manner. The steps involved are appropriate for any difficult conversation regarding a patient's illness and can be used cross-culturally. They are as follows: do not overreact; attempt to understand the family's viewpoint; be flexible; respond empathetically to the family's distress; talk to the family about what the patient would want; state your views as your views; propose a negotiated approach; and ask for the patient's views and wishes regarding their desired understanding of the medical situation. This protocol could greatly reduce stressful situations for all involved in CDD in medical cultures similar to Saudi Arabia's.

Similar to other studies, a survey conducted amongst medical students and non-medical staff at a Breast Cancer Center at King Abdulaziz University in 2012 discovered an overwhelming desire for transparent truth-telling. This study also showed that healthcare workers and non-medical staff felt that it was the right of the patient to not only know their own diagnosis, but to hide their diagnosis from family members (depending on the sex of the respondent). Medical students typically agreed that patients should tell their family members, and some agreed that family members also had the right to know the patient's diagnosis. This study is yet another that opens the door for greater exploration into whether or not there is a significant difference between a healthcare worker's gender and any form of paternalistic tendencies.

In 2018, a large study (n=581) involving cancer patients and their family members sought to understand the personal and familial perspectives and attitudes after CDD, as well as the influencing factors of these attitudes (Alzahrani et al., 2018).

As expected, patients were more inclined to desire that they be told about the diagnosis before family members, and they were also more likely to believe they should be told prior to the first treatment protocol. Patients were also more likely to believe they could recover from cancer than their family members. The greatest reason that family members stated for preferring nondisclosure was to protect the psychological well-being of the cancer patient. Three reasons emerged by both patients and family members in favor of full disclosure: better cooperation during and involvement in patient's treatment, organizing their lives, and avoiding living under false pretenses. The study also noted important factors that helped patients and family members better accept a cancer diagnosis: religion, relationship between doctor and patient and support from family and friends. Despite these helps, "fear" was listed as the number one reaction to a negative cancer diagnosis. "Acceptance" was found to be the greatest positive reaction.

As in other Eastern countries, a majority of patients prefer to know their diagnosis and experience disclosure in a beneficial and empathetic way, so determining appropriate protocols is necessary moving forward. While it is important to focus on implementing change that is in favor of disclosure, there must also be support for the physicians and healthcare workers as well. Physicians in Saudi Arabia have stated family opposition, fear of being unable to control the emotional reactions of a patient after disclosure, fear of harming the patient with cancer disclosure, concern over the fact that disclosure is not an acceptable option according to professional culture, lack of proper and effective communication training, current workload and lack of legislation have all been listed as difficulties to overcome if full-disclosure protocols are going to be widely accepted and implemented (Ehsani, Taleghani, Hematti and Abazari, 2016). Issues from the perspectives of all involved in cancer disclosure should be considered.

Jordan

In the case of a child's diagnosis with a terminal illness, one interesting study revealed that mothers of children with cancer had similar responses to the family members of adult cancer patients. They either wanted their child to know all of the facts, only know some of the facts that did not include the grim reality of the illness (often through the use of euphemism or even lying about the what the child actually had) or they attempted to completely shield the child from the knowledge of their disease (Arabiat, Alqaissi and Hamdan-Mansour, 2011). Many factors may play a role in a parent deciding which option is best for their child including the child's age and maturity level, dynamic relationships in the family, the severity of treatment options, etc. In a way, a parent's desire to protect their child is similar to a doctor's desire to protect a patient with the main difference being that the parent has the most experience with the child. Because the parent knows the child better than a physician, the parent's input is extremely valuable; this perspective should be the same when it comes to an adult patient. An adult patient's input regarding CDD and any potential treatment plans should be viewed as essential to the process.

3.3. East Asia

Like Middle Eastern cultures, East Asian cultures focus heavily on the "do no harm" principle of medical ethics. With a strong familial culture, East Asian countries that are shifting towards an autonomous point of view have several barriers to surpass, especially depending on the specific country. Due to its pervasive influence, the following Chinese study provided insight into barriers that must be overcome during this shift.

China

Varying perspectives of truth-telling have been studied in Chinese culture. Attitudes from nurses, practitioners, family members and patients themselves have all been examined. A study in 2013 focused on family members of cancer patients (n=186) in an attempt to analyze their attitudes towards disclosure and the factors affecting those attitudes. It was discovered that 44.1% believed cancer patients should be given full-disclosure while 55.9% were emphatically in favor of nondisclosure (Wang, Peng, Guo and Su, 2012). Another study (n=124) confirmed similar findings that patients preferred full disclosure while family members did not. It also showed that, despite their desire to know their diagnosis, the majority of patients were unaware of their diagnosis prior to the start of chemotherapy. Factors that influenced the likelihood of a patient being told about their diagnosis included education level and economic status (Liu et al., 2018). A very recent survey of oncology nurses (n=25) showed that they are increasingly in favor of CDD and would like to experience communication skills training in order to communicate more efficiently with patients' family members and physicians (Liu et al., 2019). A large-scale study (n=2,206) that included cancer patients, physicians, patient family members and members of the public with no personal or familial connection to cancer, revealed an unexpected result. In contrast to Gan et al.'s hypothesis, physicians were the least likely to be in favor of full disclosure. There were multiple influencing factors for this, but the main one was to avoid doctor-patient conflict or violence (Gan et al., 2017). In China, legislation can cause a major conflict because while physicians are supposed to disclose a diagnosis, the burden is also on them to do no harm to the patient's psychological state. In addition to this stressful expectation, physicians often have to worry about their own personal safety due to family members' reactions as some doctors have been physically harmed or even killed after a disclosure session (Ni and Alræk, 2016).

Japan and Taiwan

Other countries, including Japan and Taiwan, have similar situations. There is a progression towards patient autonomy, but busy schedules (doctors often spending 15 minutes or less with a patient) make it difficult to have an empathetic conversation during a CDD (Tang, Fang, Fang and Fujimori, 2012). Japanese physicians created a family-centered CDD protocol called SHARE that is intended to be a guide for practitioners to convey the most important cancer diagnosis information in about 10-15 minutes while still allowing for a gentle and beneficial tone (Tang et al., 2013). SHARE emphasizes four dimensions of truth-telling: supportive environment, how to deliver bad news, additional information and reassurance and emotional support. A 2014 study showed that, when adopted by Taiwanese practitioners, the SHARE model had a positive impact on physician's preference for truth-telling because it empowered them in their communicative abilities (Tang et al., 2013).

Summary

Thirty studies consisting of qualitative, quantitative studies and literature reviews addressing Western, European, Middle Eastern and East Asian countries were reviewed and discussed. Numerous studies have shown the importance and benefits of patient autonomy. Western countries have adopted a patient-centered practice regarding cancer diagnosis disclosure and many Eastern cultures are doing the same. The research overwhelmingly shows that the majority of cancer patients, no matter where they are located, desire to know the details related to their illness (Shahidi, 2010). In Western society, the question is no longer whether to tell a patient about their diagnosis, but how to go about doing so. Some Eastern societies are implementing and actively pursuing the development of culturally appropriate procedures. So far, these procedures seem to be increasing physician's abilities to communicate skillfully and effectively.

4. DISCUSSION

As discussed, cancer diagnosis disclosure is a complicated and complex process. The ultimate goal is to confer relevant, clear information that will provide a balance between helping the patient to understand the reality of the illness while also providing a safe and supportive environment for patients to experience the emotions that typically arise after a cancer diagnosis, especially if it is terminal. CDD involves a plethora of elements surrounding a person's cancer diagnosis including severity, prognosis, treatment protocols, emotional support, financial burden, etc. The disclosure process also involves several persons including the physician and patient and oftentimes, a support group either consisting of family members, other professionals (nurses, home care teams, psychologists, etc) or both. A deep understanding of the desires of all involved in CDD is necessary to develop and implement best practices in each culture. In this chapter the individual's perspective including (patient, family, physician and nurses), the societal (culture and believes) and government or organization legislation which all could have influences on the CDD will be discussed.

4.1. Individual Perspectives

As mentioned, in nearly all cultures, there is an expressed desire from cancer patients to know the information relating to their diagnosis. The way in which patients prefer to be told can vary. Some prefer complete and absolute knowledge. This includes all pertinent information relating to their diagnosis including severity, treatment options, risks and benefits, possible side effects, the reality of expected symptoms and life expectancy. Patients choosing this method of disclosure want to face their illness in the most prepared way possible. Some cancer patients prefer a partial knowledge which would include many details about their cancer, but would withhold certain negatives like possible unmanageable symptoms and a life expectancy timeline. They believe that holding on to some hope in the face of a difficult prognosis is the best way to cope. Others still prefer to know that they have cancer, but also want to hold firmly to an unlikely positive hope (like finding out that their cancer has suddenly disappeared). Each of these preferences is the individual's way of coping with distressing news.

The similarities between children and adults who were not told of their illness are apparent. Many individuals discover, or are at least suspicious of their diagnosis. While the goal of keeping a patient, no matter their age, ignorant of their disease is to attempt to keep psychological distress at bay, several studies have shown that this can lead to greater stress because frequently, the patient ultimately learns of his or her disease on their own which can leave them feeling like they have no one with whom to discuss their illness (Arabiat, Alqaissi and Hamdan-Mansour, 2011).

Physicians also play a significant role in CDD. Whether the physician is informing a patient or the family is determined by the specific culture. Doctors in Western cultures have a significant focus on how to best reveal a cancer diagnosis to a patient directly while many Eastern cultures are focused on which individual should be told about a diagnosis, the patient or family members. In Eastern countries, there are mixed emotions from physicians about paternalistic versus autonomic views. Some physicians are supportive of full disclosure while other physicians prefer nondisclosure for various reasons. The literature shows that some doctors tend to determine how much information a patient should be given based on numerous factors like their cognitive abilities, emotional stability, age, religion, gender (to a lesser extent). This can be a significant source of stress on a doctor which is an area that may need more research when understanding physician decisions regarding CDD.

Finally, the perspective from family members cannot be ignored. This is not particularly an issue in Western society, but in Eastern cultures, where the social norm holds a family-centered perspective, family members' opinions and desires can hold a lot of influence. Understanding and relating to patients' family members while acknowledging and supporting an increasing trend towards patient autonomy requires balance and tactfulness. A powerful portion of the SHARE model for families who do not want the patient to know the diagnosis when the patient has made it clear that they do wish to know involves helping the family understand the practical and emotional benefits of the patient being included in the disclosure. This part of the model validates the family's concerns and efforts while tactfully and sensitively educating them about what may be best for the patient in the long-term. Other countries with family-centered cultures who wish to make further progress towards patient autonomy during CDD would benefit from establishing a system or protocol that includes this type of discussion.

4.2. Influencing Factors

As important as understanding the individuals' influences in CDD, is understanding the potential influencing factors behind why cancer diagnosis disclosures happen the way they do; this is now systemically examined.

In Western societies, the word "cancer" is not feared or automatically equated with death. Many individuals know at least one person, if not more, who has experienced and survived cancer. Cancer patients often feel empowered when facing their diagnosis because they have been given all of the pertinent information and have been given the "plan of attack" regarding treatment (Sisk, Frankel, Kodish and Isaacson, 2016).

Many Eastern cultures do not want to discuss "cancer" specifically, but prefer to use euphemisms like "tumor" or "malignancy". The word "cancer" carries a cultural stigma leading individuals to assume that any cancer brings with it an inevitable death sentence

In the United States, print media tends to discuss aggressive treatments and survival more than death and poor outcomes (Fishman, Ten Have and Casarett, 2010). This strategy could be used to change the prevailing mentality in Eastern cultures. It would be important, however, not to give false expectations in marketing about cancer. Interestingly, a study published in 2018 (Chen, Wang and Tang, 2018) found that while gender was not a significant predictor in Taiwanese patients involving preference for knowledge of disease and decision making, there was a significant difference found between men and women regarding family support, scope of information and survival time. The study found that most males did not want family support during CDD while women preferred to be accompanied by family members or friends; men only wanted the main points regarding their disease while women sought detailed explanations; and most men were not interested in hearing about a "survival timeline", whereas women preferred to be given a range of life expectancy. Understanding how gender plays a role in CDD can assist in developing appropriate training materials for physicians who prefer patient autonomy.

Religion is influential when it comes to which medical principle is held in higher regard during cancer diagnosis. Studies show that those with strong faith connections, whether Christianity, Islam, etc., tend to handle terminal diagnoses better (Salsman et al., 2015). They often have a great hope of healing and find comfort in believing that their life events are controlled or influenced by a higher power. Some studies have even discussed "prayer" as a way to reduce stress associated with illness. The mechanisms behind this may shed light on how to best support those with terminal illness during and after the initial diagnosis discussion.

A physician's medical training can also have a heavy influence on initial cancer diagnosis disclosure. A practitioner's area of expertise, location of medical training (Western versus Eastern universities) and degree of communication skills training can impact the disclosing physician's confidence in their ability to meet the needs of the patient or family members during CDD. For countries that are beginning to hold patient autonomy as a higher principle than non-maleficence, understanding how to direct the CDD conversation in a beneficial and culturally-sensitive way is crucial to a successful disclosure.

Governmental legislation also plays a critical role in how CDD conversations occur. In America, since the 1960s and 1970s, legislation has established and protected the patient's right to know about their illness and everything involved with that illness. Informed consent is regarded highly, to the point that it is illegal and considered unethical (in most cases) to perform procedures and treatments without informed consent. Even though this is the case, doctors cannot have legal action taken against them unless they clearly violate these laws. This is in stark contrast to Chinese legislation where, even though doctors are expected to disclose disease information to the patients themselves, the legal burden also falls on the doctor to do no harm to the patient. This is a very fine line to walk since many CDD conversations will inevitably cause some sort of emotional or mental trauma or stress to the patient. Sadly, situations where Chinese doctors were physically harmed or killed by family members of cancer patients who felt that the physician caused emotional harm to the patient have occurred often enough that physicians would rather subtly defy the law in one area (disclosing cancer diagnosis to a patient directly) than risk the potential wrath of family members for "violating" the law in another area ("do no harm" to the patient). If doctors are going to be empowered to confidently pursue patient autonomy as a high standard, then legislation needs to be written in such a way that supports both the physician and the patient.

4.3. Truth-telling Protocols

Truth-telling protocols are part of influences factor of CDD which fall under the government and organization legislation. As previously discussed, culturally-sensitive protocols need to be in place to empower physicians and other healthcare workers during CDD conversations so that they can garner confidence and trust in their relationship with the patient and the patient's family. While the following list is not a comprehensive list of truth-telling protocols, they are ones that have been implemented with success in various cultures.

SPIKES is a model that was established in 2000, is intended to be completed in approximately 60 minutes and has been verified in numerous countries as a successful communication skills protocol to follow. It covers all aspects of a CDD discussion from the setting of the room to analyzing the patient's cognitive state to emotional support following disclosure. Despite its creation for Western cultures, Japanese physicians have had success using this for their CDD with their patients as well.

Even with successful use of the SPIKES model, Japanese physicians felt it necessary to develop a different protocol called SHARE. SHARE provides greater efficiency for physicians who have large patient loads and can only spend 10-15 minutes with each patient, but who want to remain sensitive to the patient's needs during disclosure. This model is more in line with Eastern cultural preferences when it comes to CDD and is regularly used in Japanese, Taiwanese, Chinese and Korean cities. Developed with Taiwanese physicians' hectic schedules in mind, researchers created a 1-day or 2-day intensive communication skills training program. Doctors were taught how to use the SHARE method and then given the opportunity to practice this method. Both the 1- and 2-day workshops improved the attendees' skills and abilities, but the 2-day training revealed even greater improvement (Tang et al., 2013).

Iran's "breaking bad news" model is an excellently developed protocol. It allows for a comprehensive healthcare team to provide support in every area for the patient and family members during the disclosure session. There are six steps that begin with discovering the patient's and family members' preferences in regards to the disclosure process and conclude with the doctor, nurse oncologist and clinical psychiatrist providing emotional support. With its unique approach to patient autonomy and emotional support in a family-centered culture, this protocol may be one that becomes suitable for numerous cultures. Further research should be done to determine this protocol's success in Iran as well as in other countries.

The final protocol is one that could be used independently of or alongside Iran's truth-telling process. Hallenbeck's and Arnold's protocol, discussed previously, allows for physicians from any background to develop the skills necessary to communicate with family members who are specifically requesting nondisclosure of a cancer diagnosis. If done properly, it can relieve a lot of the stress on all parties involved by providing a compromise that could benefit everyone. More studies involving this protocol should be conducted to determine its effectiveness across a variety of cultures.

5. CONCLUSION AND RECOMMENDATION

This research shows that cancer diagnosis disclosure is a constantly evolving science. Physicians and other healthcare workers typically enter the medical field because they want to be part of changing lives and helping others heal. No matter a health practitioner's cultural background, managing the four principles of health (autonomy, non-maleficence, beneficence and justice) requires grace and tactfulness. As the literature continues to reveal the overwhelming benefits of patient autonomy during CDD and involvement after, cultures that rely heavily upon the principle of "do no harm" to the patient are seeking to reexamine and learn how to balance a patient's right to know with emotional and psychological support. In these situations, family members are often the barrier that keeps a physician from directly informing a patient. Changing cultural stigmas about cancer through media education for the public as well as communication skills training for healthcare providers may help to bridge the gap. Not only may this be necessary for those seeking treatment in their own cultures, cross-cultural training may also be crucial for physicians and patients alike who are seeking to provide and receive successful treatments in a culture different from their own.

We know that cancer does not always equal death so removing this stigma may be one of the first steps towards helping family-centered cultures overcome their gripping fear of even a discussion involving the word. The goal should be to help the general public recognize that there are ways to effectively fight cancer and support cancer patients, thus empowering the patient (and even the family members) through their knowledge of options and reduced stigma

The creation of new protocols and evaluations of current CDD models are necessary to move forward for the greatest chance of success for all involved in these discussions. Incorporating all of the understanding that has been gained through research studies about the pros and cons of impressing greater importance on one health principle over another, ideally, a CDD communication model would be developed that could translate across multiple cultures. This would be a challenging task to undertake and would need to involve physicians and researchers from various cultures. Unless and until that happens, local medical training centers should empower their healthcare providers through regular, culturally-relevant communication skills training opportunities as well as providing a foundational understanding of other cultural perspectives of cancer diagnosis disclosure. Abilities and confidence in this area are a direct result of repeated and updated training in communication skills which is why it is important for the conversation in Eastern cultures to change from *whether* to tell the patient to *how* to tell the patient.

Some limiting factors of this narrative review include only some countries from each region were examined. Also, for some countries, only one CDD perspective was studied, and other studies involved relevant, but small sample sizes which can limit generalisability. These limitations may restrict a comprehensive picture of that culture's experiences with CDD.

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