REVIEW OF THE FACTORS THAT INFLUENCE A PATIENT'S DECISION

TO FOREGO CHEMOTHERAPY

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Abstract

Background/Objective: Cancer is the rapid, uncontrolled growth of cells. Cancer is the

second leading cause of death in the United States. Chemotherapy is a major course of

treatment used to cure and/or slow the growth of cancer. However, patients do not always

choose to undergo chemotherapy. The objective of this review is to identify major factors

that influence a patient's decision to forego chemotherapy treatment.

Method: This study was conducted by reviewing literature on the topic.

Result: Progression of the disease, quality of life, religious factors, cultural values,

financial ability, fertility, and physician recommendations were determined to be the main

factors that influence a patient's decision to forego chemotherapy.

Conclusion: Patients consider a variety of factors when deciding to either begin

chemotherapy or stop chemotherapy treatments. Patients and physicians may not share the

same priorities for treatment options, but the patient will ultimately determine the decision.

There are other treatment options or options for care when patients do not under

chemotherapy.

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INTRODUCTION:

Cancer has become a prevalent disease within the United States. Cancer is the second leading cause of death, and it is expected that cancer will surpass heart disease as the leading cause of death in the next few years (1). It is estimated that there will be 1,658,370 new cases of cancer in 2015, equivalent to 4,500 new diagnoses per day (1). Researchers also estimate that 589,430 Americans will die of cancer in 2015 (1). Males have a 43% chance of developing invasive cancer over a lifetime, and women have a 38% chance (1). African-Americans have the highest incidence rates, whereas Asian/Pacific Islander-Americans have the lowest incidence rates (1). However, from 2004-2010, there was a 68% rate of survival for five years in all races surveyed (1). Death rates increased throughout most of the 20th century, but they have steadily declined since 1991 (1). As healthcare expands, scientific knowledge increases, and the general public is more educated about cancer, the death rate is expected to continue to decline (1).

There are multiple treatment options available for cancer patients. Chemotherapy is a treatment that uses drugs to kill cancer cells by stopping or slowing the growth of cells (2). Radiation therapy uses high doses of radiation to kill cancerous cells and shrink tumors (2). Radiation can be used to manage pain from tumors, cure cancer, or slow cancer growth (2). Surgery can also be used to remove cancer from the body (2). Other types of treatment include immunotherapy, stem cell transplant, and hormone therapy (2). The American Cancer Society stated that while some patients will undergo one type of treatment, most will have a combination of treatments (2). Often, patients will have surgery and then

follow up with a different form of treatment to eradicate the cancer cells left behind (2). Treatment plans will be individualized based on a variety of factors.

Chemotherapy can offer a host of benefits. Oncologists prescribe chemotherapy in order to prolong life, manage and prevent more symptoms, and improve over all quality of life (3). Chemotherapy can shrink tumors, relieving pain and pressure (5). Some patients may undergo chemo to reduce the tumor size before surgery or radiation (5). Chemotherapy may also be used after surgery or radiation. When used after surgery or radiation, chemotherapy can help to manage any cancerous cells left behind (5). Chemotherapy can also eradicate all cancerous cells from the body (5). However, it should be noted that cancer can return; thus, physicians are hesitant to say that the cancer is cured (5).

With these potential benefits come several costs. A study that surveyed breast cancer patients reported that 22% of patients felt worse after chemotherapy (3). Only 26% of the patients surveyed reported feeling better after chemotherapy (3). Patients are also concerned with losing cognitive abilities, commonly called 'chemo brain" (4). Nervous system distress occurs in a majority of patients undergoing chemotherapy (7).

Chemotherapy can cause eating difficulties because it damages cells lining the mouth and intestines (2). One of the most common side effects reported is nausea (6). In one study, nausea and vomiting were the most commonly observed side effects (7). Diarrhea also affected half of the participants (7). Fatigue and loss of appetite are also frequently reported (6). Feelings of sadness are often experienced, with the potential of leading to depression (6). In fact nearly 50% of cancer patients meet the criteria for a psychiatric diagnosis of depression (10). Hair loss has been demonstrated to be a common side effect

(7). Other risks include infertility, kidney problems, and anemia (2, 4).

A patient's perspective is complex when making treatment decisions. Medical information can be difficult and overwhelming to attempt to understand (4). Patients are heavily influenced by their emotions and other experiences (8). Although most patients will defer to their doctor, they will be fielding various opinions from friends and family (9). Evidence suggests that patients will pursue the first treatment option they hear of, comparing other options to this first proposal (9). Moreover, it can be emotionally unsettling to deviate from the initial treatment plan (9). Age can also dictate patient perspective, as it encompasses experiences, culture, status quo, and individual priorities (10).

Physicians approach treatment decisions from a different context. It is natural that physicians will recommend treatments with which they have firsthand experience and know to be effective (8). Physicians will be limited in their experience with certain drugs and their respective outcomes (8). Physicians may be reluctant to try therapies with which they are unfamiliar versus options that they know well (8). Decisions made by physicians tend to involve less emotional factors than decisions made by patients, reducing cognitive biases (11). Physicians rely more on objective facts about treatments and associated benefits and risks (12). Quality of life may not weigh as heavily on a physician's decision if a treatment is likely to extend life or greatly reduce the cancer (13). Therefore, physician recommendations are formed within this context and are often limited to the unique perspective of the physician (11).

It is with these considerations that patients will decide to forego chemotherapy treatment. There are many factors that patients consider for themselves. Each individual

views the significance of the benefits and risks of chemotherapy differently (4). Because chemotherapy is not the only treatment option, patients must weigh the costs associated with chemotherapy against other therapies. Considerations of quality of life, financial ability, personal beliefs, and the influence of the physician can affect the decision (4). It is important for both the patient and the physician to consider what would suit the patient best (4). Patients must also think ahead and consider issues such as fertility and potential health consequences (4).

REVIEW OF FACTORS/DECISION

Chemotherapy can affect a patient's quality of life. The World Health Organization defines quality of life as, "An individual's perception of life, values, objectives, standards, and interests, in the framework of culture." (13) More specifically, health-related quality of life describes patient perception of his or her physical well being, psychological well-being, daily activities, social life, and disease symptoms (14). While chemotherapy helps to alleviate symptoms of the cancer, chemotherapy itself introduces a new host of side effects (17); these side effects associated with chemotherapy can negatively affect quality of life (17).

Quality of life encompasses many elements. The European Organization for Research and Treatment of Cancer produced a questionnaire referenced and used by many research teams to evaluate quality of life (14). The questionnaire evaluates physical, cognitive, emotional, role, and social functioning (14). Symptoms evaluated by the questionnaire include: fatigue, pain, dyspnea, insomnia, appetite loss, nausea, vomiting, constipation, diarrhea, and financial difficulties (14). Other symptoms such as hair loss, anemia, neuropathy, fever, and malaise are also included when evaluating quality of life

(16). Various other symptoms are evaluated with specificity to cancer types (14). It should be noted that quality of life does not differentiate the effects of cancer from the effects of

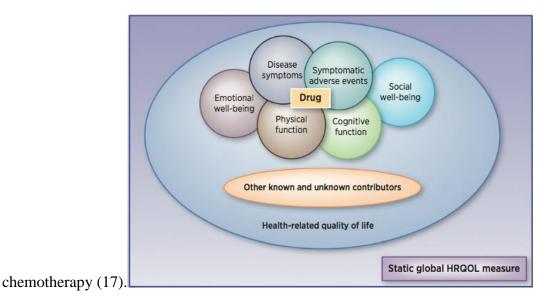


Figure 1: Key concepts that contribute to health-related quality of life in chemotherapy patients (50)

The effects of chemotherapy on quality of life are a major cause of concern for cancer patients. The effects of chemotherapy cause almost fifty percent of patients to consider cessation of their chemotherapy treatment (16). Side effects associated with chemotherapy are well known to the general public, and thus they elicit fear from patients (16). Patients anticipate that they will suffer from chemotherapy (16). On average, patients report experiencing twenty common side effects, specifically thirteen physical and seven psychological (17).

Physical Side Effects	Psychological Side Effects
Nausea	Concern about effect on family
Vomiting	Depression
Fatigue	Anxiety
Loss of taste/appetite	Fear/dread of treatment

Hair loss	Adverse effect on social life

Top 5 Reported Physical and Psychological Side Effects

Patients not only fear the physical side effects, but they dread how these effects will affect their social interactions and home life (15, 16). Patients also have great concern for how chemotherapy will affect their physical appearance as well as sexuality (15).

Chemotherapy induced alopecia is one of the most paramount physical and psychological influences on quality of life. The most feared side effect of chemotherapy reported by women is hair loss (16). According to one study, hair loss is the most devastating effect of chemotherapy, particularly in women (14). Hair loss affects a patient not only physically, but also mentally, emotionally, and socially as well (14). Patients feel uncomfortable with their hair loss, and many will limit running errands or other activities in public as a result (22). Because alopecia is a commonly recognized side effect of chemotherapy, patients fear that they will be recognized and viewed as cancer patients (22). Some patients may be unable to properly cope with their chemotherapy if they suffer from alopecia (22). Alopecia exacts such a great toll on patients that some will forego chemotherapy in order to avoid hair loss (22).

Difficulty in managing issues of quality of life may contribute to noncompliance. As a result of the onset of adverse side effects, patients may begin to be noncompliant with their treatment or cancer care in general (21). Noncompliance is generally caused by the inability to deal with severe symptoms and the interference of these symptoms with daily life (21). Symptoms such as chemotherapy-induced nausea and vomiting have caused patients to stop their chemotherapy regimens due to the severity of these side effects (19). Patients also become increasingly noncompliant with their clinic appointments as a result

of the difficulty of patients' side effects (21). Patients may skip chemotherapy appointments to avoid receiving the treatments that decrease their quality of life (21). Statistically significant correlations were found between avoidance of clinic appointments and difficulty of dealing with hair loss, nausea, and loss of appetite (21).

The direct financial costs of chemotherapy are another important factor for cancer patients. Direct costs are the financial compensations for services provided to the patient (20). These costs include the price of chemotherapy treatments, physician fees, and any other direct medical services (20). Monthly totals for chemotherapy alone can reach \$34,000 (20). Although health insurance offsets some dues, most health insurance companies will require some out-of-pocket payments for chemotherapy regimens (20). Patients are responsible to pay approximately 20% of the cost of care out-of-pocket if they have insurance; by the end of treatment, this could amount to tens of thousands of dollars paid out-of-pocket (20). Insurance also may not cover prescription medication or other treatment-related expenses (26). Uninsured patients will bear the full costs of treatment (20). Because of the costs associated with chemotherapy, close to 2 million people diagnosed with cancer will not seek the medical treatment they need (20). Because cancer costs are highest at the beginning of treatment, many people may not even begin chemotherapy regimens (20).

Indirect costs associated with chemotherapy are burdensome for cancer patients as well as loved ones. Financial losses incurred from lost time or productivity due to chemotherapy are indirect costs (20). Time spent at appointments can hinder a patient's ability to continue to earn the same income he or she had before chemotherapy (20). Many patients have to travel to and from medical centers in another city or state, resulting in time

off work and potential decrease in pay (20). The side effects of chemotherapy may also limit the time that a patient is able to work as well as the efficiency of his or her work (20). Chemotherapy may hinder employment opportunities for patients, affecting health insurance coverage (26). This can exacerbate the issues of direct costs (20). Caregivers and loved ones also suffer from indirect costs (20). Limited employment opportunities, time away from work, and decrease in pay due to care for a patient also cost caregivers (20). Other unforeseen expenses include transportation arrangements, hotel stays, and childcare (26). These factors can affect the care and assistance that required by patients, thus reducing patients' wills to receive and/or tolerate chemotherapy (20).

Cultural values can prevent patients from seeking chemotherapy. The values and beliefs of cultures may dictate how patients view cancer and chemotherapy (24). Because of cultural stigmas surrounding cancer, patients often refuse to disclose their illness to members of their family or those who identify with their culture (24). As a result, patients are less likely to agree to undergo chemotherapy (24). Also, patients who are raised within certain cultures may have limited knowledge about chemotherapy, and thus refuse to consider it because of cultural stigmas (24). Some patients may view cancer as a punishment for their actions, and they may not seek treatment because of this (25). Latino, African, and Asian Americans are shown to be more fatalistic about the preventability of cancer as opposed to Caucasian Americans (27). Some cultures that place great value on masculine identity may not be accepting of chemotherapy because it introduces weakness as well as physical changes to a man (25). Likewise, cultures with firmly defined roles for women may be unaccepting of chemotherapy because if women no longer function as the caretaker, she may feel shame (25). A woman's body may also be held sacred by cultures,

and any violations of it are unacceptable; this could include physical examinations by a healthcare provider or effects of chemotherapy (25). One study found that 23% of percent of Caribbean women, 50% of Indian women, 52% of Pakistani, and 63% of Bangladeshi women believe that cancer is fate (27).

Religious considerations may inhibit patients from choosing chemotherapy treatment. In one study of 257 participants, cancer patients were asked to complete a questionnaire that evaluated the importance of seven factors upon a patient's treatment decision (23). Faith ranks second in the list, just behind physician recommendation (23). Some religions stringently adhere to the belief that there is something greater controlling all things, including cancer (27). Religions vary on attitudes about illness and disease. Catholics have reported to refuse chemotherapy because suffering enriches their faith experience (28). Catholics also refuse chemotherapy because Catholicism dictates that pain can only be relieved in ways that do not hasten death or harm the individual (28). Those who practice Judaism accept chemotherapy, but they may stop their treatments or decline starting chemotherapy if they believe their disease is terminal (28). Muslims may refuse chemotherapy, accepting their disease as a test of faith (28). Many sects and various religions exist that will have different values related to sickness and healthcare, affecting an individual's decision to undergo chemotherapy.

Fertility and family planning can impact chemotherapy, causing patients to forego chemotherapy treatments. Fertility can be affected in both male and female patients (29). Because women are born with all of their reproductive oocytes, chemotherapy can compromise a woman's ability to reproduce (29). Chemotherapy can cause premature menopause (29). Chemotherapy may hurt a fetus if a woman gets pregnant during

chemotherapy, when it begins, or soon after chemotherapy treatments (29). For these reasons, women are advised to take birth control and other precautions to avoid pregnancy during or up to six months after chemotherapy (29). Males can also suffer from infertility as a result of chemotherapy (30). High doses of alkylating agents can cause a decrease in sperm in nearly 90% of male patients (29). Males may have to wait several years to regain sperm production, if it can be regained at all (30). Male and female children potentially lose fertility due to chemotherapy, even if they have not reached puberty (30).

Physicians may be reluctant to recommend chemotherapy for patients, dissuading patients from pursuing chemotherapy. The choice of treatment for patients is heavily influenced by the recommendations of the physician (31). Physicians consider a variety of factors, potentially from a different viewpoint than the patient (31). If a physician adopts the situation of the patient and would not go undergo chemotherapy his or herself, they are unlikely to recommend the treatment to a patient (31). Small gains made from chemotherapy that may sound enticing to a patient will not always be worth the costs from the perspective of the physician (31). Physicians also consider the ability of their patient to safely tolerate the chemo; if physicians believe chemotherapy would not be well tolerated, they may not pursue it (32). Oncologists are unlikely to recommend chemotherapy in patients of advanced age (32). Because patients with advanced age may have a progressed disease, a sense of a full and satisfying life, and a lower ability to tolerate harsh treatments, physicians are hesitant to move forward with chemotherapy (32). Physicians may also be less likely to pursue chemotherapy if they are unfamiliar with the disease and/or treatments (8).

Chemotherapy does not always succeed. Oncologists typically look for a 20% response rate in chemotherapy regimens to classify a treatment as useful (36). Response rates are important because they give the physician a good indication of the potential for a new chemotherapy regimen to improve survival (34). The American Society of Clinical Oncology suggests that physicians do not administer chemotherapy if the treatment is very toxic or very costly and only produces marginal benefits (34). In patients with terminal lung, pancreatic, and colon cancer, studies have shown that survival rates are longer by 39 days, 21 days, and 33 days respectively for patients who received hospice than patients who received chemotherapy (35).

Patients often decide to forego chemotherapy when their cancer is unresponsive to chemotherapy. Cancer may progress despite chemotherapy (34). When standard chemotherapy regimens have not succeeded in halting the cancer, patients are unlikely to respond well to other regimens of chemotherapy (35). Guidelines established by the National Comprehensive Cancer Center Network suggest that after two chemotherapy regimens have failed, physicians should recommend hospice or palliative care rather than another line of chemotherapy (35). Additional chemotherapy administered to patients with unresponsive cancer will produce adverse effects and hospitalizations with no measureable benefit (35). Because of this, patients will not continue chemotherapy when their cancer is unresponsive.

When curing the cancer is no longer an option, other short-term goals will become the priority. Although patients may still hope for a cure, they will change their treatment plan to meet other life or health goals (37).). These goals could be a wedding, a graduation, to create a will, or to spend their time with minimal adverse physical side

effects (37). When terminal cancer patients are asked what their end-of-life goals are, the top three responses include having meaningful experiences, connecting socially, and helping/supporting others; surprisingly, fighting cancer and being cured are ranked eight and eleventh, respectively (38). Because chemotherapy is likely to cause more hospital stays, increased doctor visits, and more prescriptions, chemotherapy may hinder patients from achieving their short-term goals (34, 37).

Although patients consider the advice of the physician, the decision to forego chemotherapy is ultimately in the power of the patient. It has not always been common for the patient to decide which treatment he or she will not undergo or if he or she will continue chemotherapy (8). With elevated risks of chemotherapy and the range of choices, ethics require that the patient be included in making treatment decisions (8). As patients become more educated about cancer and treatment options, they are more likely to assert their views and wills in the decision making process (39). In a study of advanced cancer patients, every patient reported that they wanted their physician to be involved in their treatment decision because of their knowledge and experience (39). However, only two patients wanted their physician to make treatment decisions without their input (39). The degree of patient involvement may vary with each doctor/patient relationship, but the American Society of Clinical Oncology strongly recommends that physicians actively involve patients in the decision making process so that patients may make the most educated decision (40).

OTHER OPTIONS:

Patients may pursue palliative care to assist in pain management throughout the course of their disease. the goal of palliative care is to provide a better quality of life for

patients and their loved ones by managing pain (44). A team of professionals, including physicians, nurses, social workers, chaplains, pharmacists, nutrionists, and ethicists work together to provide palliative care (41). Palliative care specialists will focus on treating physical side effects of chemotherapy as well as pain caused by the cancer itself (44). Specialists will also help with anxiety, depression, and/or confusion about any medical information (44). The American Society of Clinical Oncology suggests broader use of palliative care in order to manage quality of life for patients undergoing chemotherapy as well as those who do not undergo chemotherapy (42). Palliative care can be provided to patients prior to need of hospice, as palliative care can be provided at any stage of cancer, whereas hospice is specific to end-of-life care (41).

When cancer has become terminal, patients may choose hospice care. The National Hospice and Palliative Care states, "At the center of hospice and palliative care is the belief that each of us has the right to die pain-free and with dignity, and that our loved ones will receive the necessary support to do so." (41). As such, hospice is focused on end-of-life care to manage physical pain, control symptoms, and care for the psychological or spiritual needs of the patients and their families (42). The goal of hospice is to make patients and their families comfortable in the end of life, because hospice accepts that death is a natural part of life (42). On average, patients enter hospice care 55 days after the last dose of chemotherapy; this suggests cancer patients primarily use hospice when death seems imminent (43). Patients who receive a week or less of hospice care report the same quality of life as those who receive no hospice care (33). Longer levels of hospice care directly correlate to higher quality of life (33). Hospice care may become a more accessible option

for patients now as more health insurance companies are beginning to cover hospice care (37).

Patients and family members progress through several stages of acceptance of terminal cancer. Acceptance occurs both emotionally and cognitively (47). Elizabeth Kubler-Ross characterized a widely used model that describes how individuals progress to accept their death or the death of a loved one (45). Denial is the initial phase, followed by anger about cancer (45). Patients and family members move into a bargaining phase, in which they attempt to reverse the terminal cancer (45). When bargaining does not reverse the diagnosis, and the reality of terminal cancer sets in, patients and families may experience depression (45). If patients and loved ones progress through these stages, they will come to acceptance of terminal cancer (45). When families and patients have accepted cancer, they are able to make decisions regarding potential end of life care, wills, and specific health directives (48). Families will initially respond by unifying together to support the patient; however, family members may become increasingly stressed as the patient's health declines because more caregiving is needed (46).

Patients who wish to continue treating their cancer may participate in clinical trials. Clinical trials are conducted when newly developed treatments or treatment methods are believed to improve patient care (51). New treatments must successfully progress through the four phases of clinical trials before the Food and Drug Administration can allow treatments on the market (52).

Phase	Purpose of Phase
I	Emphasizes safety; evaluation of side effects and how the body responds (if
	drug, how is it metabolized/excreted); 20-80 patient volunteers
II	Emphasizes effectiveness; does the treatment work in specific diseases?
	Participants are usually compared to a placebo group; hundreds of volunteers

III	Further evaluation of safety and effectiveness amongst populations, with
	different doses, and in combination with other treatments; thousands of
	volunteers
IV	Monitoring the FDA-approved treatment for any side effects/outcomes not seen
	in clinical trials

Figure 2: Phases of clinical trials as established by the FDA (52).

Clinical trials are conducted with patients who volunteer to be part of the study (52).

Patients may elect to participate in clinical trials in order to access the newest therapies for their cancer (53). Other patients may enroll in clinical trials as a service to research; patient participation helps researchers to learn more about potential treatments, even if the treatments are not successful in clinical trials (53). Because there is little known about the treatments used in clinical trials, patients do risk unknown side effects or unpredicted adverse outcomes (53).

DISCUSSION:

Physicians, patients, and families view cancer care from their individual perspectives. Physicians approach treatment decisions from a more calculated perspective, because they draw upon their medical training (31). When presented with potential treatment options, physicians demand a higher success rate with lower risk than patients (11, 31). Patients are more willing to undergo treatments or therapies that promise little reward, even when they are fully aware of potential harm from the treatment (31). Families are often the most aggressive when making decisions about cancer care, because they do not want their loved one to stop treating the cancer (31). The limitations of the physician's, the patient's and the family's perspectives can lead to a lack of understanding in the patient/physician relationship.

Throughout the course of this research, I have concluded that there is an integral tension in the physician/patient relationship. Because patients and physicians approach the

cancer diagnosis and treatment plan(s) with differing perspectives, a fundamental tension is present within the patient/physician relationship. Physicians primarily consider objective facts by relying on their knowledge of cancer and potential treatments. Physicians present a calculated treatment plan with measurable and quantifiable goals. When chemotherapy no longer meets objective requirements, it is relatively easy for the physician to stop administering chemotherapy. On the contrary, patients process treatment decisions by considering not just medical facts, but they also drawn upon the influence of loved ones, emotions, and varying levels of education. Patients do not solely rely upon logic or rationale when they are battling cancer. Physicians may find the preferences or wishes of a patient to be irrational because the physician does not think like the patient. Patients, in turn, may find the physician to be insensitive to the concerns of the patient. Both the physician and the patient may voice their concerns and desires, but inherent differences in thought patterns could create barriers to productive communication. Tension in the physician/patient relationship can build if either or both parties see the other as an opposition to their views and does not affirm the validity of each person's needs or opinions. Conversations altogether may be avoided because of tension in this relationship.

There are valuable characteristics that optimize a physician's patient care. It is important for the physician to recognize that the patient is likely to make decisions that are founded on subjective emotions. Despite the potential irrationalities of emotions, physicians should not discount the patient's wishes or views. Patients respect the viewpoint of a physician, and many patients are looking for validation of the emotions they are experiencing. Physicians should clearly explain the status of a patient's cancer, being aware that patients have varying educational backgrounds. It may also be important for a

physician to reiterate to the patient that physicians do not always have the answers. It should always be a priority of the physician to have open and honest communication, even if conversations may be difficult. Although there are many obligations of a physician, I believe that the greatest patient care begins with the physician. Physicians are entrusted with extensive responsibility, but if a physician is a good steward of this responsibility, there is opportunity for great patient care.

In conclusion, I have learned imperative lessons that will prepare me for a career in medicine. It is imperative to maintain a health patient/physician relationship. I have learned the characteristics that optimize patient care, as well as characteristics that are detrimental to patient care. The power a physician holds when making treatment decisions should be recognized by the physician as an opportunity to protect the well being of a patient. I have also learned about the hardships inflicted by cancer on patients and their loved ones. Chemotherapy comes at a great cost, and no patient should feel forced to undergo chemotherapy treatment. Perhaps the greatest lesson I learned was that physicians possess great influence with patients and their families. Being a physician is not a responsibility to be taken lightly, and it demands special attention and care to ensure that patients receive the best treatment. I owe it to my future patients to utilize what I have learned and to maximize any opportunity to grow as a physician. I have been given a great privilege to be trained as physician, and I pledge to be a steward of this opportunity.

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