

REGISTRAR PIP

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Treatment Options vs Treatment Refusal

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We're all familiar with a "treatment plan," that necessary part of the patient's cancer story that includes treatment options prescribed, when the decided-upon regime was started, and the doses, frequencies and procedures that they underwent in order to best treat their cancer. Most of the time, this information is straightforward and easy enough to code. (Well, maybe coding all the radiation treatment detail will continue to be a challenge for a while!)

Interpreting the documentation associated with treatment plans can be a little confusing sometimes. Patients are often presented with a number of options to choose from, and it can be difficult to distinguish between whether a patient is choosing one treatment (or no treatment) over another option offered to the patient to consider, and when the patient is refusing a treatment option(s) recommended by their medical team.

This article will attempt to clear up some of the confusion by going over the criteria to:

- Determine which treatment modalities are actually considered to be recommended
- Help us identify whether the patient chose one recommended treatment plan with specified modalities over another potential treatment plan with different modalities outlined
- Identify whether one or more treatment modalities should be coded as refused because they were ultimately considered part of the final recommended treatment plan.

First, let's go over what qualifies as first course of therapy. The SEER Program Coding and Staging Manual 2018 (SPCSM) describes first course of therapy as "All treatments administered to the patient after the original diagnosis of cancer in an attempt to destroy or modify the cancer tissue." Antineoplastic treatment includes surgery, radiation therapy, chemotherapy, immunotherapy, hormone therapy and so-called 'other treatment,' which are all outlined in Section VII of the SPCSM. When unsure which category a specific drug falls into, or whether it should be considered antineoplastic at all, we can use the SEER*Rx Database as a coding reference.

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Standard of Care References

In situations where a treatment plan is not documented, nationally accepted treatment standards can be used in its place. Two helpful references that provide treatment typically offered for a specified reportable tumor given the presenting site, histology and stage can be found on the following websites:

PDQ National Cancer Institute's (NCI) **Physician Data Query (PDQ)** cancer information summaries website: <https://www.ncbi.nlm.nih.gov/books/NBK82221/>

NCCN National Comprehensive Cancer Network's (NCCN) **Guidelines for Treatment of Cancer by Site** website: https://www.nccn.org/professionals/physician_gls/default.aspx

Factors Impacting Treatment Options Offered

The purpose of documenting a treatment plan is to identify what the medical team ultimately **recommended** the patient do. The operative word in that last statement is **recommended**, not suggested, not discussed, but **recommended**. Cancer treatment is personalized. It is tailored to the patient and their circumstances. While there may be treatment standards suggested given a patient's presenting disease status (i.e., site, histology and stage at diagnosis), these standards are often modified by such factors as a patient's:

- Understanding of the risks and benefits of various proposed treatment options
- Overall health status after taking into consideration the existence and severity of physical comorbidities (e.g., diabetes, cardiovascular disease, infectious diseases, dementia, etc.) and mental comorbidities (e.g., anxiety disorders, substance abuse, etc.)
- Age
- Perception of how cancer treatment might impact one's physical health, emotional health and lifestyle.

"Either/Or" Choices vs Refusal

For many patients, there is more than one option available to treat their cancer, and patients often choose from multiple recommended options which ones they would like to pursue. If the physician's recommendations are documented, then determining whether the patient is opting for another choice or refusing the recommended treatment is simple.

For example, a physician may recommend that a patient receive chemo for her lung cancer. The patient refuses the chemotherapy for whatever reason and the refusal is noted in the patient's chart. This situation is coded as a refusal of chemotherapy, the recommended treatment.

Now let's say a physician recommends radiation or chemotherapy for a patient's lung cancer. The patient chooses radiation rather than chemotherapy. In this situation, the chemotherapy is not being refused because it was one of the treatment options recommended by the physician. In these either/or type situations, choosing one option over another is just that: a choice. This doesn't mean the patient is refusing

chemotherapy; they are simply opting for one of the treatment alternatives suggested by the physician as a way to treat their disease.

It is also helpful when the physician notes a patient's refusal in the medical record, and also documents that it goes against their prescribed recommendation. For example, should a lymphoma patient decide he would rather undergo serial imaging every six months to monitor the disease rather than start chemotherapy recommended by the physician, if the physician notes in the medical record that she feels strongly the patient should initiate chemotherapy immediately, the patient is considered to be refusing this treatment modality recommended. These situations are straightforward, and coding refusal is simple for such cases.

Situations that aren't as clear-cut involve patients who refuse standard treatment in favor of other unconfirmed remedies (like acupuncture or herbal medicines, for example) in order to treat their disease. The argument can be made, of course, that these treatments could very well be antineoplastic and therefore fit into our description of a treatment plan. When a patient opts instead to pursue a drug regimen that is not listed in the SEER*Rx database and it is not an accepted treatment standard, this is considered a refusal of standard treatment if it was recommended.

Unconventional and/or alternative medicine options may be coded as Other Therapy following the instructions in the SEER Manual, Section VII, Other Therapy when standard treatments are not offered or given. Keep in mind that a referral to a surgeon, oncologist or radiation oncologist is considered equivalent to a recommendation for that specified treatment option per the SPCSM. But more than that, it is actually an indication an additional medical record review is needed to learn the results of those consultations and more accurately code treatment fields. For example, a patient may be referred to radiation oncology, where she subsequently decides that radiation is not worth the risks to her health given the potential benefits outlined by the radiation therapist. Her physician agrees. In this situation, the radiation referral recommendation is nullified by the physician's final decision not to treat the patient with this modality. The patient is not refusing radiation because, upon review, the medical team decided the patient opting not to receive radiation is one treatment alternative from which the patient could choose.

The SPCSM instructs us to code standard treatment options for a given site/histology to 'refused' when the patient makes a blanket statement refusing all treatment. For example, a seventy-eight year old patient is diagnosed with Stage III pancreatic cancer. Before the medical team can present treatment options the patient states he wants no treatment whatsoever and he just wants to go home. The physicians agree this is a reasonable choice and discharge the patient. In this case, code refusal for chemotherapy and radiation because these are the standard treatment options for this disease at this stage.

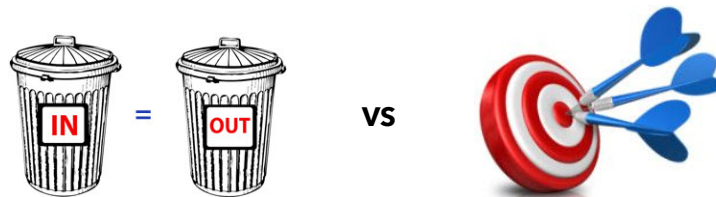
Conclusion

As new information regarding the biology of cancer is learned, more treatment options will be developed and modified to increase the effectiveness, precision, survivability, and quality of life for the patient. Physicians have a responsibility to identify and relay information regarding all reasonable treatment options to a patient for consideration. When multiple treatment options are still under consideration by the patient, a final treatment plan has yet to be determined.

Reading an expanded list of options presented to the patient can make it challenging for us to figure out what represents a:

- Treatment choice when multiple options for cancer care are being considered
- Refusal of care vs the option of “no treatment” being a reasonable alternative given a patient’s current medical condition

When we do locate documentation regarding treatment discussions between physicians and patients in medical records, oftentimes we think we can only find a list of options offered and no final, formal treatment plan ever being recorded. To improve our ability to accurately code treatment refusal, we need to improve our understanding of the standard treatment options offered for various types of cancer, how those options might be modified given the presenting unique patient characteristics and how those factors might actually be reflected in the physician documentation available.



When doing treatment data collection, it is important to avoid having the database become a “garbage in, garbage out” warehouse. To do that, we have to continually improve our understanding of various cancer treatment options and expand the detail of the data we collect. We need to know the expected standard treatment and anticipate any modifications that might need to occur for a specific patient in order to improve our ability to determine what, if anything, should be coded as a refusal of treatment. Researchers analyzing large sets of accurately collected treatment data will be able to spot correlations and hidden patterns in the data to gain insight and be able to predict better treatment options for individual patients in the future.