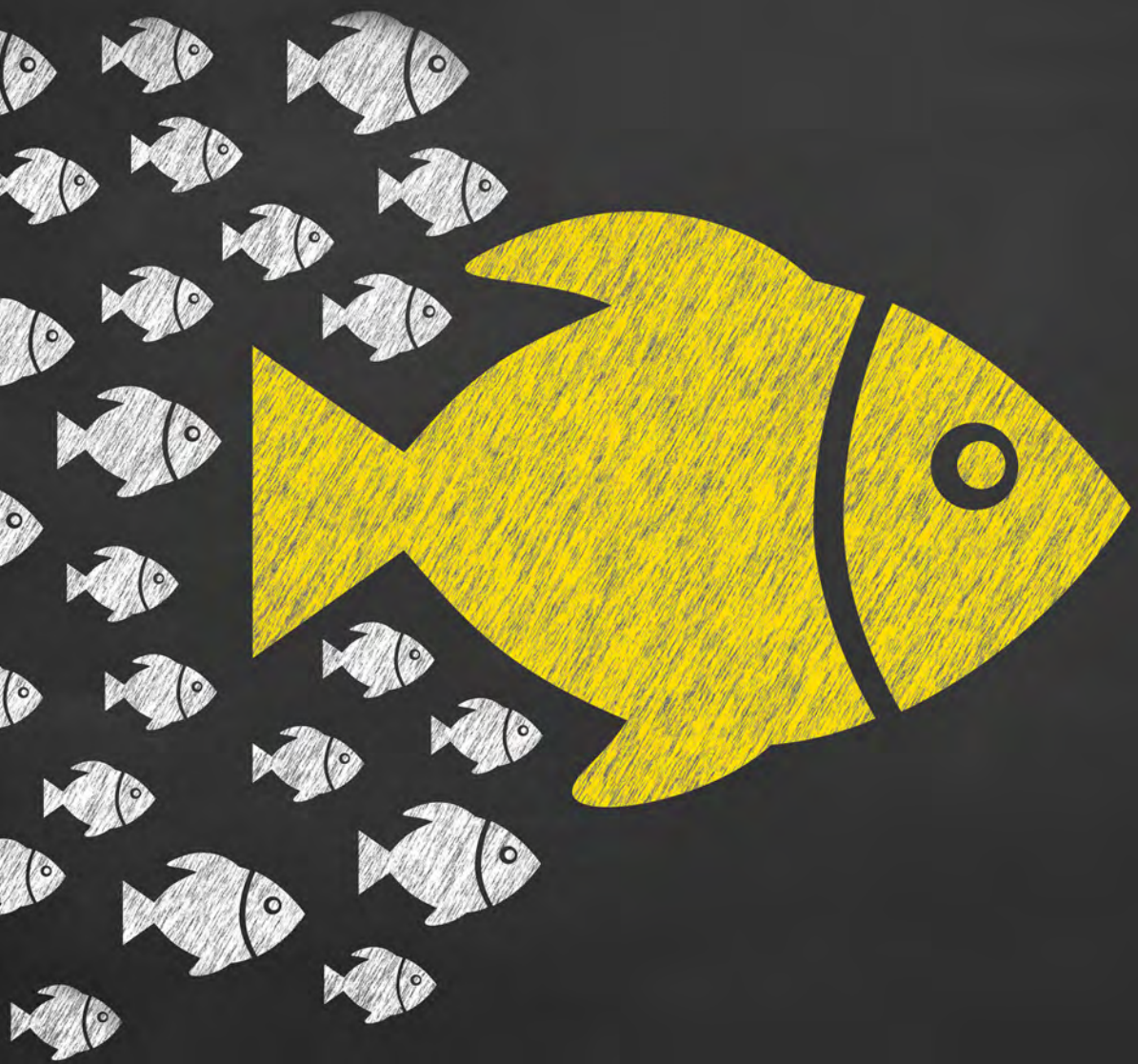
Guided Patient Support



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Helping patients navigate the clinical, psychosocial, and financial aspects of cancer care

At Northwestern Medicine McHenry Hospital Cancer Center, McHenry, Ill., the Guided Patient Support (GPS) Program is helping patients navigate life and care after their cancer diagnosis. This innovative program provides coordinated whole-person care, ensuring that patients receive the support they need through psychosocial counseling, social support, rehabilitation services, financial counseling, nurse navigation, nutritional intervention, transportation assistance, physical therapy, tertiary care referrals, and medication assistance. The GPS approach helps the cancer care team proactively identify patient needs and prepare patients for treatment. Patients who have participated in the program say that they feel more connected to their cancer team and experience better quality of life throughout the cancer care continuum.

Making the Case for Coordinated Care

In the 1990s, Northwestern Medicine McHenry Cancer Center (formerly Centegra Sage Cancer Center) expanded its cancer service line and began providing adjunct services to patients receiving medical, radiation, and surgical oncology care. The hospital subsequently added staff through the years, building a team of experienced professionals, including:

The GPS Program begins with a single appointment in which patients and their caregivers meet with all members of the team and learn about the specialized services they offer throughout the cancer care continuum.

- Oncology dietitian
- Licensed clinical social support counselor and chaplain
- Social worker
- Financial counselor
- Physical, speech, and occupational therapists
- Genetic counselor
- Oncology nurse navigator
- Support services administrative coordinator.

At first, referrals to these support services were largely based on recommendations from physicians and other clinicians who were part of the patient care team. So, for example, if patients told their medical oncologists that their appetites had decreased during their treatments, physicians would refer them to the oncology dietitian. Patients who seemed to struggle with the emotional burden of cancer care were referred to social support/counseling. Although patients could receive multiple referrals, these referrals were not coordinated, meaning that patients were not always aware of the full range of services available to them. As a result, at times different members of the supportive care staff found themselves making multiple calls to the same patient on the same day. Further, support team members were spread out in different locations throughout the cancer center, making care coordination challenging.

Developing the GPS Program

To streamline care, in 2018 Northwestern Medicine McHenry Hospital Cancer Center consolidated its support services into a dedicated office suite called the Cancer Resource Center. This resource center was made possible through a generous grant from the Northwestern Medicine Foundation. The resource center is designed to give patients a centralized location for cancer support services, increasing staff efficiency and more effectively connecting patients with the supportive care providers they need.

That same year the Cancer Resource Center team developed the GPS Program for newly diagnosed patients and their families. Using the GPS Program, the team created a roadmap for the support resources available throughout the cancer center. The GPS Program begins with a single appointment in which patients and their caregivers meet with all members of the team and learn about the specialized services they offer throughout the cancer care continuum. Ideally, patients attend this initial GPS session shortly after their diagnosis, as their plan of care is being developed. (To allow patients and their families time to process information received at their initial medical consultation, this first GPS appointment is scheduled on a different day.) Referring patients to the GPS Program—rather than to individual services—has resulted in a more coordinated, comprehensive approach to supportive care. Patients may be referred to the GPS program in several ways, depending on the type of oncology services they require:

- **Physician referral.** A medical oncologist or surgeon may refer patients to the GPS Program to ensure that their care is comprehensive and coordinated.
- **Breast center referral.** The breast health navigator often refers patients to the GPS Program after diagnosis or after initial surgery so that patients can immediately receive education about the wide range of support services available.
- **Radiation Oncology.** Patients who present for a radiation therapy consult receive a visit from a support staff team member, who invites them to the GPS Program and schedules visits.

Patients may also be referred by independent physicians, clinicians, and community members who know about the GPS Program.

Currently, Northwestern Medicine patients who are diagnosed at our breast center, all patients receiving radiation consults, and all new patients to our infusion center are contacted by our support services administrative coordinator, who introduces the GPS program and schedules the appointments. Appointments are made at that time for a future GPS session. Patients who are not ready to decide are encouraged to reach out to the coordinator when they are ready for support. Patients do not have to go through GPS to access supportive care services; they may be referred directly to any members of the support team individually before, during, or after treatment.

The Initial GPS Session

The supportive care team designates three hours every Wednesday morning for initial (first-time) GPS patient sessions. During these sessions, patients meet with each member of the multidisciplinary care team for 20 minutes. Our nurse navigator, dietitian, rehabilitation specialist, financial counselor, and social support/counseling specialist each conduct a screening or assessment of each patient's needs and describe the services they provide. Follow-up appointments are scheduled as appropriate, and patients are assured that even if services are not currently needed, they are available at any time in the future. Patients are also educated about additional services, including support groups and programming, genetic counseling, American Cancer Society programs, transportation options, and tobacco cessation support (see Table 1, right). These initial GPS sessions have been successful because each member of the supportive care team contributes to the care of the whole patient.

The Oncology Nurse Navigator:

- Teaches patients about how she participates in their care at different points in the continuum.
- Educates patients about their diagnoses and treatment options.
- Reviews comorbidities and hospitalizations.
- Begins to assess the patients and family's need for support (see Figure 1, page 46).
- Uses an evidence-based tool (modeled after the Billings Clinic's patient navigation acuity scale) to determine a patient's navigation acuity score. Based on the results, she is able to prioritize patient care and can make community referrals regarding transportation needs, psychosocial support, insurance options, and second opinions (see Figure 2, page 47).
- Prioritizes the level of follow-up needed as well as the timing of a follow-up call or appointment, as patients with advanced disease, such as head and neck cancer, require more coordination and support as they adjust to their cancer diagnoses.
- Sets a timeline for future discussion about the patient's survivorship care plan.

The Oncology Dietitian:

- Reviews the patient's plan of care and conducts a malnutrition screening (Figure 3, page 48), which helps determine whether nutrition intervention is necessary.
- Reviews the patient's appetite, hydration, weight changes, and potential side effects of treatment.
- Teaches about diet modification, substitutions, and supplements.
- Schedules follow-up appointments with patients to help them gain a deeper understanding of how to eat nutrient-dense meals that are essential during treatment and recovery.
- Educates patients about enteral feeding, if indicated.

The Rehabilitation Specialist (depending on the patient's treatment plan):

- Helps patients get the most out of daily living by maximizing their cognitive, physical, and social functioning.
- Assesses the need for patients to receive speech and swallow therapy and lymphedema management.
- Helps patients understand how cancer and its treatments affect activities of daily living.
- Identifies immediate needs and educate patients about potential treatment side effects that could signal a need for additional therapy support.

The Physical Assessment Screening Tool can be found on page 49 (Figure 4).

The Financial Counselor:

- Helps patients understand their financial responsibilities.
- Reviews a patient's insurance coverage, explains out-of-pocket expenses, and identifies the potential for financial distress or financial toxicity.
- Educates patients about resources that may be available to help them, offering information about programs for which the patient may be eligible to relieve the financial burden of care.

The Social Support Counselor:

- Discusses with patients and their families how cancer and its treatment affect not only the physical body but also the emotional, mental, spiritual, and social aspects of life.
- Asks patients to complete an evidence-based distress self-assessment adapted from the American Cancer Society (see Figure 5, page 50) that addresses issues including:
  - Symptoms of anxiety and depression
  - Changes in sleeping habits, focus, and appetite
  - Cancer's interference with daily family, social, and sex life
  - Pain, discomfort, and physical limitations
  - Physical, emotional, spiritual, and/or financial hardship caused by cancer
  - Body image concerns
  - Coping
  - Overall quality of life.

Table 1. Additional Supportive Care Services and Resources

- Support groups
- Home care and nursing home resources
- Educational programs
- Pharmaceutical program assistance
- Transportation assistance
- Grief counseling and "Living with Grief" program
- Palliative care and hospice referrals
- Massage therapy
- WellBridge
- Tobacco cessation program
- American Cancer Society program referrals
- Wig Boutique
- Survivorship programming.

If the self-assessment indicates a moderate to high level of distress, the counselor encourages patients to participate in individual counseling, support groups, and other programming opportunities. The counselor also educates patients about emotional distress that may develop over time. Patients and family members are often surprised to learn that distress can increase after treatment ends, when they have time to reflect on the ways in which their lives have been altered by cancer.

Information from GPS Program visits is integrated into the medical record through scheduling, charting, and scanning. Each visit is scheduled and captured in the patient's medical record as well as charted in progress notes. Any written screening tools used are scanned into the patient's medical record. This information is available to the clinical team.

Ongoing Support

The Cancer Resource Center offers supportive care services long after treatment has ended. The support team helps develop each patient's survivorship care plan, which includes information about overall health maintenance and future cancer prevention measures, the importance of adhering to follow-up appointments and testing an established timetable, and instruction about exercise, nutrition, and ongoing emotional and medical management.

We teach patients and their families how to identify future issues that could benefit from the help of our supportive care team post-treatment. Patients are encouraged to contact support team members any time after their treatment has concluded. Support services are free of charge and considered part of a patient's care at the Northwestern Medicine McHenry Cancer Center.

(continued on page 51)

Figure 1. Patient Navigation Intake Form

Name: _____ **Age:** _____ **DOB:** _____

Contact number: _____

Emergency contact person/number: _____

Okay to leave messages: _____

Primary insurance: _____

Secondary insurance: _____

Policy #: _____ **Phone #:** _____

1. How was the patient referred to the navigation program? _____
2. What has your doctor told you so far? _____
3. Biopsy date/result: _____
4. Primary doctor: _____
5. Med Onc: _____
6. Rad Onc: _____
7. Surgeon: _____
8. Specialist (dental and urologist): _____
9. Family history: _____
10. Surgery: _____
11. Chemo: _____

Navigation Acuity Score

Health decision making
1. Difficulty with decision making
2. Wants second opinion
3. Language or disability barrier

Home Life
1. Childcare issues
2. Housing issues
3. Transportation needs
4. Food needs

Physical
1. Activities of daily living
2. Falls
3. Fertility issues

Emotional
1. Distress tool
2. Support

Lifestyle
1. Smoking
2. Alcohol
3. Drug

Financial/Health Insurance
1. Prescription coverage
2. Difficulty paying bills
3. Financial assistance

Referral/order form completed: Yes / No

Education materials given: Yes / No

Contact numbers provided: Yes / No

Situation: _____

_____

Background: _____

_____

Assessment: _____

_____

Recommendation: Plan of care and follow-up (MD appointments, port placement, scans, dental forms or peg tubes, referrals for coverage): _____

_____

_____

Figure 2. Oncology Nurse Navigation Acuity Tool

The acuity scale will be applied at initial contact. Initial contact could include at consult, chart review prior to start of care, initial start of treatment, initial navigation contact, or at the first doctor day. This number can be adjusted per the clinician's discretion throughout treatment. This number is assigned during active treatment.

Acuity Level 0

(Guidelines and Considerations)

- In survivorship and stable
- Active treatment has ended
- Cancer *in situ*
- Distress scale 0-2

(**Care Coordination Focus)**

- Meet with patient initially and assure distress screen is completed
- Navigation intake documentation completed and plan reviewed with the patient
- Provide initial education/clinical coordination/referrals and support
- Follow-up only if requested by patient or provider

Acuity Level 1

(Guidelines and Considerations)

- Stage 1
- Single-agent chemo or radiation only
- Starting surveillance/observation
- Performance Eastern Cooperative Oncology Group (ECOG) = 0-1
- Distress scale less than 3

(**Care Coordination Focus)**

- Meet with the patient initially and ensure that distress screen is completed
- Navigation intake documentation completed and plan reviewed with the patient
- Provide initial and ongoing education/clinical coordination/referrals and support
- Monitor every month for any new needs and document a follow up note during treatment

Acuity Level 2

(Guidelines and Considerations)

- New cancer diagnosis
- Stage 2
- Multi-agent chemotherapy and/or radiation therapy
- Oral chemotherapy
- Performance ECOG = 1-2
- Distress scale 4-5

(**Care Coordination Focus)**

- Meet with the patient initially and ensure that distress screen is completed
- Navigation intake documentation completed and plan reviewed with the patient
- Provide initial and ongoing education/clinical coordination/referrals and support
- Monitor closely every three weeks or as needed for any new needs and document follow-up note

Acuity Level 3

(Guidelines and Considerations)

- Hospitalized in the past 60 days
- Receiving multiple treatment modalities (chemo/rad/surgery)
- Serious comorbidities
- Head/neck/gastrointestinal cancer diagnosis
- Colostomy/ileostomy
- Non-compliant with treatment
- Performance ECOG = 2-3
- Distress scale 6-7
- Stage 3 disease
- Little or no family support

(**Care Coordination Focus)**

- Meet with patient initially
- Navigation intake documentation completed and plan reviewed with the patient
- Provide initial and ongoing education/clinical coordination/referrals and support
- Monitor closely every two weeks or as needed for any new needs and document a follow-up note
- Maintain phone contact with the patient as needed in between visits and document under notes
- Assist with care coordination during transitions of care (hospital, home health, etc.)

Acuity Level 4

(Guidelines and Considerations)

- Stage 4 disease
- Feeding tube
- Tracheostomy
- Frequent hospitalizations
- Unstable and/or end-stage disease
- Performance ECOG = 3-4
- Distress scale of 8-10

(**Care Coordination Focus)**

- Meet with patient initially
- Navigation intake documentation completed and plan reviewed with the patient
- Provide initial and ongoing education/clinical coordination/referrals and support
- Monitor closely every week or as needed for any new needs and document a follow-up note
- Maintain phone contact with the patient as needed in between visits and document in notes
- Assist with care coordination during transitions of care (hospital, home health, etc.)
- Provide end-of-life support to patient/family/caregivers as needed

Resources

American Cancer Society. Tools to help measure distress. Available online at: https://www.cancer.org/treatment/treatments-and-side-effects/emotional-side-effects/distress/tools-to-measure-distress.html. Last accessed June 8, 2015.

Baldwin D, Jones M. Developing an acuity tool to optimize nurse navigation caseloads. *Oncol Issues.* 2018;33(2):17-25.

Blaseg K, Daugherty P, Gamblin K, eds. *Oncology Nurse Navigation: Delivering Patient-Centered Care Across the Continuum*. Pittsburgh, PA: Oncology Nursing Society; 2014.

Figure 3. Nutrition Screening Tool

Patient Name: _____

DOB: _____

Phone Number: _____

Date: _____

Check if form filled out by patient listed above: _____

Nutrition Screening Score: _____

Weight Changes

Weight:_____ pounds
Height:_____ inches
Weight 6 months ago: _____pounds
Weight 1 month ago:_____ pounds
During the past 2 weeks, my weight has:
- Decreased (1) _____
- Not changed (0) _____
- Increased (0) _____

Food Intake

During the past 2 weeks, I have eaten:
- My usual amount—no problem eating (0) _____
- More than usual (0) _____
- Less than usual (1)_____

If less, I am now taking:
- Normal food but less than normal amount (1) _____
- Little solid food (2) _____
- Only liquids (3) _____
- Only nutritional supplement drinks (3) _____
- Very little of anything (4) _____

I have (or will have) a feeding tube (4) _____
- I receive IV feedings (4) _____

Activity Level

Over the past month, I would rate my activity level as:
- Normal, with no limitations (0) _____
- Not my normal self, but able to be up and about most of the time with fairly normal activities (1) _____
- Not feeling up to most things but in bed or chair less than half the day (2) _____
- Able to do little activity and spend most of the day in bed or a chair (3) _____
- Pretty much bedridden, rarely out of bed (3) _____

Symptoms

I currently have the following symptoms:
- No problems eating (0) _____
- No appetite, do not feel like eating (3) _____
- Nausea (1) _____
- Vomiting (3) _____
- Feel full quickly (1) _____
- Problems with chewing or swallowing (2) _____
- Depression (1) _____
- Dry mouth (1) _____
- Mouth sores (2) _____
- Smells bother me (1) _____
- Constipation (1) _____
- Diarrhea (3) _____
- Things taste funny or have no taste (1) _____
- Pain (3) _____

Figure 4. Physical Assessment Screening Tool: Oncology Rehab and Support Services

Completing this form will help us partner together in your care. You may be asked to complete this assessment tool more than once during your cancer experience.

Patient Name:_____DOB:_____

Phone Number: _____Date: _____

		No	Yes, and I would like to address this	Yes, but this has already been addressed. I don't need to discuss it
1	**Are you having any joint or muscle pain? *If yes, where?***			
2	**Do your hands and/or feet feel numb or tingle? *If yes, where?***			
3	**Does any part of your body feel swollen? *If yes, where?***			
4	**Are you feeling weak or having trouble moving around?**			
5	**Are you experiencing excessive tiredness/fatigue?**			
6	**Are you having trouble concentrating or remembering things?**			
7	**Are you having trouble with your balance?**			
8	**Are you having trouble swallowing?**			
9	**Are you having trouble taking care of yourself (bathing, dressing or grooming)?**			
10	**Are you having trouble with daily tasks like chores or shopping?**			
11	**Are you having trouble driving?**			
12	**Are you having trouble completing your tasks at work?**			

Please choose only one response for each question.

A	**Do you exercise? Please circle: Yes or No** **If you answered yes, how many days a week?**
B	**If yes, please specify what your exercise program consist of (i.e., strength training, cardio, etc.):**
C	**If no, are you interested in more information about the programs that can help you get started with an exercise regimen?** **Please circle: Yes or No**

Please list what you are concerned about the most and that you would like to address immediately:

This box is for internal use only.

This form was reviewed by (please print): _____

Date:_____

Figure 5. Evidence-Based Distress Self-Assessment*

Name: _____

Date: _____

Support Recommended to Address Distress—Patient Self-Assessment

I have felt anxious or worried about cancer and the treatment I am receiving.

Not at all 1 2 3 4 5 All the time

I have felt depressed or discouraged.

Not at all 1 2 3 4 5 All the time

I have been irritable or unusually angry and I have not controlled it well.

Not at all 1 2 3 4 5 All the time

My sleeping habits have changed.

Not at all 1 2 3 4 5 All the time

I have noticed a change in my appetite.

Not at all 1 2 3 4 5 All the time

I have had trouble focusing at work or at home or on routine things such as reading the newspaper or watching television.

Not at all 1 2 3 4 5 All the time

Cancer and its treatment have interfered with my daily activities.

Not at all 1 2 3 4 5 All the time

Cancer and its treatment have interfered with my family or social life.

Not at all 1 2 3 4 5 All the time

Cancer and its treatment have interfered with my sex life.

Not at all 1 2 3 4 5 All the time

Pain and discomfort have caused me to limit my activities.

Not at all 1 2 3 4 5 All the time

Cancer has caused physical, emotional, spiritual, and/or financial hardship for me.

Not at all 1 2 3 4 5 All the time

Cancer and its treatment have caused changes in how I look, and this concerns me.

Not at all 1 2 3 4 5 All the time

I have had trouble coping with the distress I have been having.

Not at all 1 2 3 4 5 All the time

My quality of life during the past 2 weeks has been:

Excellent 1 2 3 4 5 Very poor

If many of your answers are 4s or 5s, you may be having significant distress and it is recommended that you consider talking with a counselor or other mental health professional.

*Adapted from the American Cancer Society. Tools to help measure distress. Available online at: https://www.cancer.org/treatment/treatments-and-side-effects/emotional-side-effects/distress/tools-to-measure-distress.html. Last accessed June 8, 2015.

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Our Results

During implementation of the GPS Program, our supportive care team met weekly to address real-time issues as they arose. Today, the team meets biweekly to review the program and make adjustments as needed. Fourteen months after the program's launch, our team continues to make improvements to enhance efficiency and improve the patient experience. Our evaluation indicates:

- ***Number of patients offered GPS*:** 458 patients were offered information on the GPS Program from October 2018 through December 2019.
- ***Patient acceptance rate*:** 54 percent of patients accepted the offer to attend the program.

Though all patients said that the GPS Program was beneficial, one message was particularly consistent: patients felt more closely connected to members of our team and were more likely to use our services after they participated in the GPS Program.

Patient acceptance rates of the GPS Program—measured by whether patients attend the initial session—are not where the team hoped they would be. Some of the reasons patients have given for refusing a GPS appointment include concern about having multiple appointments, uncertainty about their plan of care, the belief that they already have enough support, concern about lack of time, and the belief that they "don't need it." The team has found that patients are often so focused on their medical treatment plans that they are unable to absorb much more information early on. Many times, it is someone close to the patient who recognizes the need for supportive care, whether it is for the patient or for him- or herself as a caregiver.

While not every patient accepts the referral to the GPS Program, many who do attend say that they did not know they needed the team's services until they met the specialists who provide supportive care. Based on the low acceptance rate, we have changed the scripting of how the GPS Program is presented to patients. It is now described as an integral part of care rather than optional. In the next year we have a robust list of additional areas we are addressing. We increased our time from three hours a day to six hours on Wednesdays, noting a need for afternoon options and time to see more patients. We will add reminder calls prior to scheduled appointments to increase attendance rate. Our reach will now include Northwestern Medicine medical oncology offices opening in 2020, adding a social worker to our support team, and including new screening tools. We are looking to conduct a participant survey to identify barriers to care or gaps in resources provided, and gather feedback to help analyze our program and identify areas for improvement. Upcoming enhancements to the electronic medical record will allow for standardized templates, decreasing the team's time spent charting and scanning.

Initial Outcomes

From the launch of the GPS Program, it has been important to the team to monitor how and whether the program is impacting patients' use of supportive care and services in ways that improve the quality of patients' overall cancer experience. Early outcomes for the program indicate that patients' needs are being more efficiently and effectively served as care and services are being offered to and used by more patients and families affected by cancer. Supportive care services are also being offered to people earlier in their cancer treatment. These earlier, proactive interventions are reducing the severity and length of challenges that patients face in cancer management. For example, patients who are less worried about finances, appointments, and transportation have more time and energy to devote toward their physical and emotional health and wellness. Patients have even verbally expressed decreased anxiety with just knowing who—and when—to contact if, and when, a need arises. Below are some of the findings and outcomes data we have seen after implementation of our GPS Program:

- Nutrition screening scores during GPS showed 84 percent low risk, 14 percent moderate risk, and 1 percent high risk for malnutrition. Typically patients receive nutrition counseling after initial cancer treatment. Therefore, nutrition screening during GPS provides the opportunity for early nutrition intervention and discussion of side effect management or initiation of enteral nutrition support.
- GPS has allowed us to identify patients who need transportation prior to the start of treatment, ensuring availability of the bus service and avoiding a delay in the start of treatment.
- Thirty patients and/or family members received supportive counseling as a direct result of connecting with the counselor through the GPS Program.
- Fewer individual referrals resulted in fewer phone calls to patients, improving continuity of care.
- The financial counselor assisted 40 patients in applying for various programs, including 11 patients who applied for financial assistance, 7 patients who signed up for Medicaid, 9 patients who applied to foundations grants/co-pay programs, 4 patients who were found eligible to receive supplements from Medicare, 4 patients who were enrolled in medication replacement programs, and 13 patients who received help with co-pays, deductibles, and/or out-of-pocket costs. (Note: Some patients were eligible and signed up for more than one program.)
- Twenty-four percent of patients seen by the nurse navigator were assigned with an acuity level 4, which is the highest level of acuity. The GPS Program allowed for early face-to-face contact with high-acuity patients and their families. The meeting time has allowed for reinforcement (and continued

By referring patients to the GPS Program—rather than to individual services and staff—patients have benefited from a more coordinated, comprehensive approach to their care. Patients have also gained an increased knowledge and more comprehensive understanding of the suite of services offered by the cancer center team.

education) of the treatment plan and time to discuss pertinent follow-up that is needed, improving care coordination and identification of gaps in care.

Patient Feedback

Follow-up interviews between the cancer center's manager of patient care and GPS patients reflected the need for the wide range of services the team offers. Though all patients said that the GPS Program was beneficial, one message was particularly consistent: patients felt more closely connected to members of our team and were more likely to use our services after they participated in the GPS Program. During the interviews, patients shared:

- "*Having cancer is scary—this comprehensive team made it amazing. I am cared for.*"
- "*I did very well all throughout treatment, but it was good to know that if I did need anything there was a team to help me.*"
- "*I felt like meeting with the whole team at once was really beneficial and made me much calmer. I knew what to expect.*"
- "*I didn't feel like I needed it, but if I had then I see how it would have been helpful.*"
- "*This made me more comfortable. I thought the experience was very helpful in letting me know what I needed.*"

Early in the program, it became evident that our initial follow-up method—gathering feedback through telephone calls from the team's manager—was not working due to time constraints. We are now using a post-GPS survey card (Figure 6, right) in the hope that it will gather more feedback for the team about the value of the program.

Patient Case Study 1

A young patient and spouse attended an initial GPS session. The patient—who presented with neoplasm of the tonsil—and spouse seemed anxious about the cancer diagnosis, yet ready to handle upcoming treatments and procedures.

The dietitian counseling session led to an assessment that the patient was at mild risk for nutritional issues due to reported pain, dysphagia, and taste changes. The patient had already lost weight prior to the start of treatment, and the dietitian provided counseling about the reasons a feeding tube was indicated. She explained how the tube would be inserted and described feeding schedules to proactively educate the patient.

The nurse navigator's discussion ensured that the couple was prepared for the upcoming treatments, and they seemed organized and informed about the care that was planned. The navigator reviewed upcoming clinical appointments with the couple, which included the percutaneous endoscopic gastrostomy port, dental clearance, medical imaging, fertility visits, a swallow study, and medical oncology visits. At the time, there were no home life, physical, or lifestyle issues identified.

The physical therapy evaluation included education about post-treatment lymphedema therapy, and the therapist provided the patient a referral to a swallow evaluation.

During their meeting with the social support counselor, the patient and spouse each acknowledged a history of anxiety and depression and described the ways in which they had dealt with and continued to address their individual mental health concerns. The couple agreed that future counseling specifically related to the challenges of living with and beyond cancer and treatment could be helpful, but they did not immediately schedule services because they had so many other clinical appointments scheduled already.

During the financial counseling session, our counselor explained that the patient had an outstanding balance in excess of $1,200 and the patient paid the balance in full.

As this patient's treatment progressed, the true benefit of the GPS Program was revealed. The patient began to experience increased distress in response to the growing emotional and physical demands and side effects of treatment. The couple experienced more conflict as the patient's mood became increasingly variable, with depressive symptoms growing more significant and exacerbated by the use of alcohol.

Because of the initial GPS session, the patient's spouse was already familiar with the cancer center's staff and knew who to reach out to for assistance. The couple began regular counseling to address the distress they were experiencing and received multiple interventions, including adjustments in medication to regulate and stabilize mood, adjustments in tube feeding practice, and a rehabilitation program.

The coordinated team effort resulted in the patient and spouse being connected to the services and support they needed to successfully complete treatment and achieve their goals of care and treatment.

Patient Case Study 2

A patient with breast cancer was enthusiastic about her introduction to the GPS Program, which was scheduled shortly after her oncology surgery. During her initial GPS session, the patient demonstrated low distress levels and seemed capable of navigating

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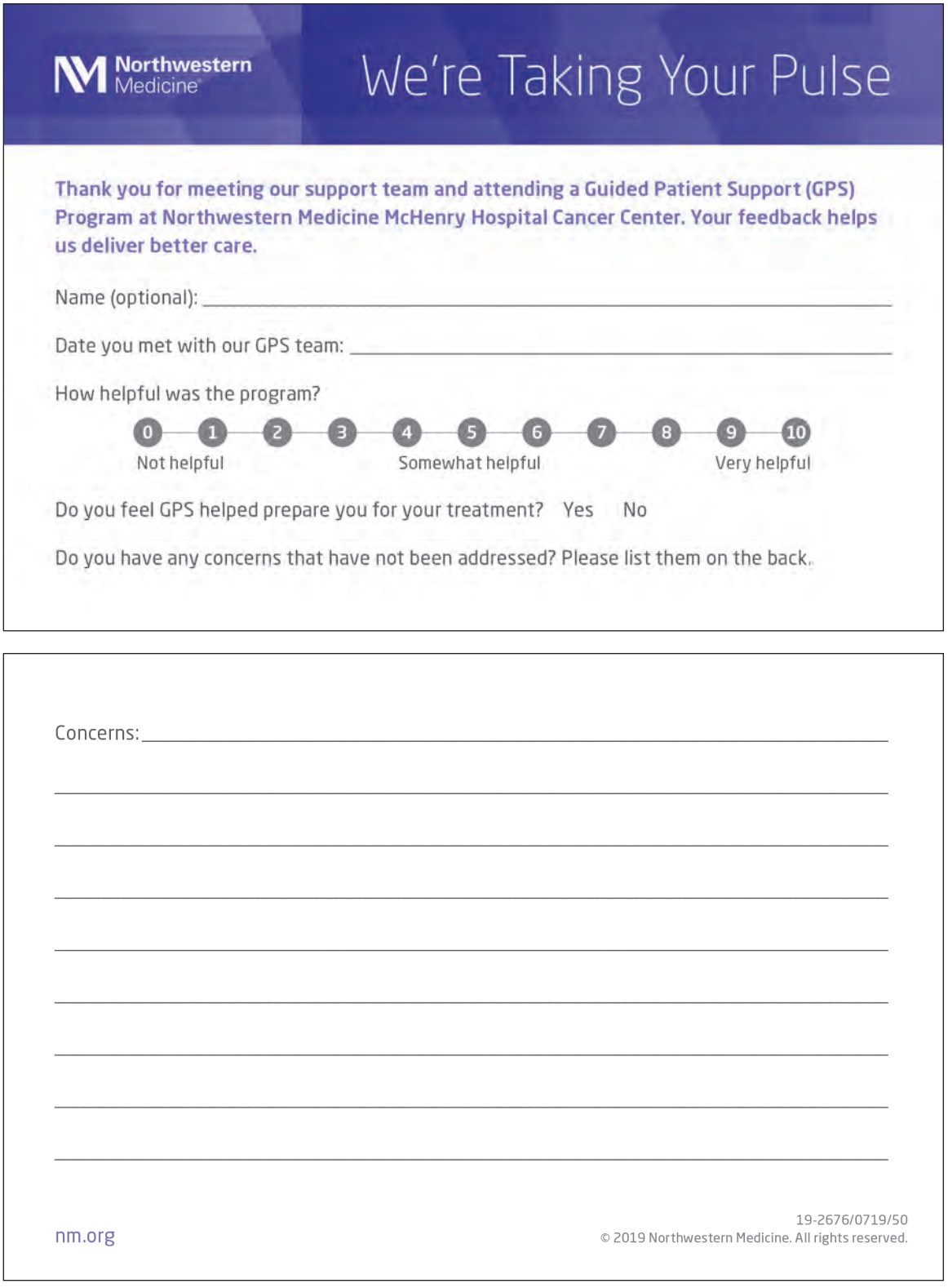
Figure 6. GPS Program Feedback Card



Northwestern Medicine

We're Taking Your Pulse

Thank you for meeting our support team and attending a Guided Patient Support (GPS) Program at Northwestern Medicine McHenry Hospital Cancer Center. Your feedback helps us deliver better care.

Name (optional): _____

Date you met with our GPS team: _____

How helpful was the program?

0 1 2 3 4 5 6 7 8 9 10

Not helpful — Somewhat helpful — Very helpful

Do you feel GPS helped prepare you for your treatment? Yes No

Do you have any concerns that have not been addressed? Please list them on the back.

Concerns: _____

nm.org

19-2676/0719/50

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her care. The patient had previously met with a physical therapist, and her related needs were already being addressed.

Although some of the patient's risk levels were determined to be low, team members identified the patient's need for additional education regarding her diet and finances. The patient was at low risk for cancer-related dietary issues, but she demonstrated a lack of knowledge about how nutrition could affect her diabetes. Because of her own concerns about diabetes and her husband's high cholesterol and blood pressure, our dietitian identified an opportunity to provide more information about nutrition to improve their overall health.

During the financial counseling session, the patient shared her concerns about the financial burden of her cancer care. The counselor described ways in which she could help the patient obtain co-pay benefits and work with her insurance providers. Together, they created a follow-up plan.

In the following months, the patient received dietary counseling and financial counseling and contacted the team for psychosocial support for needs that arose after the initial GPS session. Each of the patient's needs was addressed during the radiation therapy treatment period. Without the GPS Program, it is possible the patient may not have discussed her concerns about her diabetes and financial questions; she had not understood how those concerns related to her radiation therapy.

After treatment, the patient met with the social support counselor to address her distress related to managing her life and fear beyond treatment. Through this contact, the patient has become more involved in supportive care through groups and programming, which are improving her emotional health and overall quality of life.

Future Direction

Going forward, we hope to make a number of improvements and enhancements to our GPS Program, including:

- Enhancing the scheduling process, which currently takes more time than is desired.
- Creating new ways to track and report: (1) when patients are coming to the Cancer Resource Center; (2) referrals to the GPS Program; (3) follow-up calls, scheduling, reminders, and rescheduling; and (4) services scheduled, completed, and referred at GPS visits.
- Evaluating new opportunities to generate revenue for appointments that are scheduled through the GPS Program. The cancer program currently offers support services as a community benefit, and psychosocial and nutrition counseling are potentially billable services. Although the nurse navigator position is currently filled by a master's degree-level nurse, an advance practice nurse could fill the position and charge for follow-up survivorship care plan appointments.
- Educating patients who have lung and colon cancers about the GPS Program earlier in their cancer journeys. The team is expanding partnerships with thoracic surgeons and gastrointestinal specialists to promote earlier referrals to the program.
- Updating scripting to communicate to patients that GPS is part of a patient's care plan rather than an optional appointment.

By referring patients to the GPS Program—rather than to individual services and staff—patients have benefited from a more coordinated, comprehensive approach to their care. Patients have also gained an increased knowledge and more comprehensive understanding of the suite of services offered by the cancer center team (see Figure 7, right). Bringing the support team together to one centralized location has also enabled increased collaboration and more effective, timely communication among staff members. Members of the once-fragmented team have noted that their new configuration has made them a more cohesive unit, allowing them to better collaborate and provide timely services to patients. This strong team environment acts as a support mechanism for staff members, who help one another improve their performance and enhance their professional development. Building these professional bonds and being able to rely on one another is extremely important when serving patients with cancer. OI

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Figure 7. GPS Program Brochure