

A model for decreasing patient distress, while ensuring your program's financial viability.

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ost supportive care interventions are not billable, which can impact a provider's decision to provide such care. Because many public and private payers do not reimburse for these services, many providers cannot justify funding to support needed psychosocial services.¹ On the other hand, there is universal agreement among providers that cancer patients should be treated holistically and that distress in cancer patients should be recognized and addressed.² Responding to recommendations in the 1999 Institute of Medicine report Ensuring Quality Cancer Care, the Commission on Cancer (CoC) of the American College of Surgeons (ACoS) requires a 2015 phase-in for new Continuance of Care standards.³ Subsequently, all CoC-accredited cancer programs must develop a patient navigation process and provide psychosocial distress screening. Both standards are critical components in efforts to provide adequate supportive cancer care. That being



said, supportive care programs should proactively identify and address potential issues related to the economics of a cancer diagnosis.

A recent Association of Oncology Social Work (AOSW) survey found that 56 percent of patients surveyed felt they were not at all prepared to handle the financial burden of a cancer diagnosis, and only 7 percent indicated that they were completely prepared.⁴ Increased medical expenditures and the potential of reduced earnings contribute to the financial hardships many patients face after a cancer diagnosis.⁵ Factor in that 62 percent of all U.S. bankruptcies are initiated because of medical debt and 75 percent of that number had health insurance.⁶ Accordingly, supportive care services at community cancer centers must provide support for both uninsured and underinsured populations. In addition, supportive programs should both help reduce existing or potential economic burdens

for the patient and address the financial health of the institution providing medical care. Finally, a structured supportive care process should address psychosocial distress and patient navigation.

Our Model

Akron General Medical Center (AGMC), McDowell Cancer Center, developed a unique patient navigation program, which reduced psychosocial distress, secured \$1.35 million in direct financial assistance to patients that would otherwise not have been available, and reduced institutional bad debt. Recognizing that patients with cancer should be treated holistically and distress should be identified and managed, we developed a structured distress management program as a component of patient navigation.

There is universal agreement among providers that cancer patients should be treated holistically and that distress in cancer patients should be recognized and addressed.

Our navigation model uses a two-person team composed of a resource counselor (an oncology social worker) and a reimbursement specialist who work together to meet the psychosocial and financial needs of our cancer patients. In brief, here's how our model works.

Our reimbursement specialist conducts a benefits investigation for all new patients receiving chemotherapy in the McDowell Cancer Center. This investigation is done prior to the start of therapy. All patients complete the National Comprehensive Cancer Network (NCCN) Distress Thermometer (DT).

Our resource counselor uses the data from the benefits investigation and distress thermometer to conduct a Brief Psychosocial Assessment (BPA) prior to initial therapy. The BPA includes a review of self-indicated stressors identified from the completed DT, the benefits investigation, and a brief assessment of emotional, practical, spiritual, financial, and medical concerns. The resource counselor then completes a comprehensive psychosocial assessment with those patients having more complex needs. Patients are assigned a case-complexity rating to help monitor those needing ongoing follow-up. The resource counselor enters data into a database and uses it to evaluate self-indicated stressors and to monitor the case-complexity rating of each patient. Our resource counselor then provides immediate and long-term interventions or makes referrals addressing the identified needs.

During their last scheduled chemotherapy sessions, patients complete the NCCN Distress Thermometer a second time. We use an ACCESS database to collect and monitor all demographic, distress, navigation, and financial data. This information is used for current and longitudinal research, to assist with program development, and for measuring program effectiveness.

For community cancer centers looking to implement a similar program, here is how we did it.

Our Experience

In 2011 McDowell Cancer Center requested and obtained a waiver of consent and approval for a study on distress screening from the AGMC Institutional Research Review Board. The title of the protocol was: Assessment of Distress Associated with Daily Life in Cancer Patients and Community Resources Available to Them. Study participants consisted of the first 106 patients who completed pre- and post-treatment distress thermometers at McDowell Cancer Center between June and November 2011. Patients completed DT One the day they started initial chemotherapy, and DT Two the day they finished their treatment regimen. We transferred all data from ACCESS to SPSS v 15 for analysis. We used an ACCESS database to monitor and track results of financial data. Study participants were:

- 1. Over 18 years old
- 2. Diagnosed with a cancer
- **3.** Able to read standard English (i.e., the screening instrument)
- Scheduled to receive chemotherapy at our outpatient treatment center.

As noted in Table 1 (page 43), initial DT results revealed that 25 patients starting chemotherapy were dealing with insurance and financial-related concerns and 39 percent of all patients self-indicated they were dealing with various practical problems. In the post DT screening, the number of patients indicating that they were experiencing insurance and financial concerns was significantly reduced from 25 to 13; all self-indicated practical problems were considerably reduced. However, as indicated under the Total Difference column, 6 new patients that were not experiencing insurance and financial concerns during their initial

CASE STUDY

A 34-year-old male non-citizen was admitted to the ER with no insurance, and citizenship requirements prevented him from qualifying for Medicaid. The patient then followed up with hematology oncology and was diagnosed with a blood disorder. The drug Soliris® was recommended. Our resource counselor referred the patient to our reimbursement specialist. The patient was then approved and enrolled in the Alexion patient assistance program and the drug was obtained free of charge.

It should be noted that we, as a provider, bill the drug Soliris out at \$104,000 per treatment with net cost to the hospital of around \$18,000. After further review by the resource counselor, the patient was also determined eligible and enrolled in the

Ohio High Risk Pool insurance. The patient had managed to pay the expensive \$600 a month premium, but experienced financial hardship trying to meet the additional out-of-pocket expenses required by the insurance. The patient was referred to our reimbursement specialist and was enrolled and approved for the diagnosis specific Patient Services Inc. (PSI) Foundation. Consequently, the foundation covered the entire \$1,500 deductible and \$3,000 maximum out-of-pocket. Because the patient would not have otherwise obtained medical coverage, all subsequent accounts are dollars generated for the hospital.

Table 1. Practical Problems (N=106)					
	DISTRESS THERMOMETER ONE		DISTRESS THERMOMETER TWO		
VARIABLE	TOTAL FREQUENCY	TOTAL PERCENT	COMPARABLE FREQUENCY	TOTAL FREQUENCY	TOTAL DIFFERENCE
Childcare	2.0	1.9	1.0	1.0	0.0
Housing	3.0	2.8	2.0	3.0	1.0
Insurance & Financial	25.0	23.6	13.0	19.0	6.0
Transportation	4.0	3.8	1.0	4.0	3.0
Work & School	7.0	6.6	1.0	7.0	6.0
Total	41.0	38.7	18.0 (17%)	34.0	(16)

Table 2. Practical Problems: Distress Mean (N=106)						
	DISTRESS THERMOMETER ONE			DISTRESS THERMOMETER TWO		
VARIABLE	M	N	SD	М	N	SD
"0" Practical Problems	2.83	75	2.708	1.88	78	2.363
"1" or more Practical Problems	5.77	31	2.918	3.96	28	2.687
All Patients	3.69	106	3.069	2.43	106	2.608 P<0.001

Table 3. Emotional Problems: Frequency & Distress Mean (N=106)						
	DISTRESS THERMOMETER ONE			DISTRESS THERMOMETER TWO		
EMOTIONAL PROBLEMS	FREQUENCY	%	М	FREQUENCY	%	М
0	30	28.3	1.87	53	50.0	1.15
1	22	20.8	3.41	17	17.0	2.65
2	15	14.2	4.80	11	10.4	2.64
3	15	14.2	3.07	9	8.5	3.44
4	5	4.7	5.60	6	5.7	5.67
5	11	10.4	6.45	6	5.7	5.50
6	8	7.5	5.38	4	3.8	6.25

DT screening now reported experiencing these problems at completion of therapy.

Table 2 (above) shows that patients with zero practical problems had a significantly lower (P<0.001) mean distress level than those with one or more practical problems. When comparing first and second DT data, mean scores from respondents checking at least one practical concern was reduced from 5.77 to 3.96.

DT data showed a significant decrease in mean distress scores when comparing DT One and Two. As noted in Table 2, mean distress scores decreased significantly from 3.69 to 2.43.

DT One results from Table 3 (above) show that 72 percent

of respondents self-indicated experiencing at least one emotional concern, as described by the NCCN DT checklist. Fifty-four people checked that they were experiencing more emotional problems when completing DT One. In comparison 18 respondents checked that they were experiencing emotional problems when completing DT Two—a significant reduction in self-indicated emotional problems (P<0.001).

Based on specific information from the BPA, 41 percent of cancer patients were assigned a Case-Complexity Rating of 3 or 4, thereby warranting immediate and ongoing intervention.

Table 4. Unmeasured Financial Data Variables That Can Potentially Generate Financial Hardship **IMPACT OF POTENTIAL HARDSHIP PATIENT PROVIDER** Federal & State Programs Direct Direct/Indirect Advocating and assisting with securing medical benefits or assistance programs, i.e., Medicaid (with or without a spend down), Medicare Savings Programs (QMB, SLMB, QI), Medicare Low-income Subsidy. **Potential Income Gaps** Direct Direct/Indirect Patient education may include advocating and assisting with Social Security Disability, employer short- and long-term disability, FMLA, life insurance policy, employment legal issues, estate planning. **Coordination of Benefits** Direct Direct/Indirect Providing unbiased medical coverage support and information regarding available medical coverage payer options. To include information about Medicare options, including Advantage and Supplement plan options. Explain information about private or group insurance plans. Explain insurance terminology such as deductibles, co-pays, and maximum out-of-pocket. Direct Direct/Indirect **Psychological** Connecting patients or family with counseling, education regarding role changes, support regarding family system changes, development of communication skills, and coping strategies.

The Economics of Cancer

and individual or family crisis support.

Practical

Medically speaking, to assure the best possible outcome, it is critical for a cancer patient to be diagnosed correctly and quickly. Further, to help avoid or mitigate a negative economic outcome from the cancer diagnosis and treatment, providers should offer cancer patients and their families education and assistance on many common but complex psychosocial, emotional, and financial issues.

Local and national resource utilization patient education may include assisting patients and families with transportation; skilled and unskilled home health needs; emotional or mental health support and referral; diagnosis-related individual and family counseling or support; communicating with family, friends, and physicians;

Table 4 (above) identifies unmeasured variables that can potentially increase financial burden and negatively affect a patient's ability to adequately manage numerous complicated issues. For example, if a cancer patient does not apply for Social Security Disability at the appropriate time, the patient may experience a significant reduction in monthly income. Depending on the circumstances, the patient may experience a substantial gap in which no income is received. Often cancer patients are required to pay a substantial amount for direct medical services and indirect nonmedical necessities. These additional expenses are often incurred at a time when patients have a reduced amount of financial revenue to pay for the additional costs.⁵

Bottom line: inadequate education and support may impact

the financial and emotional well-being of the patient and ultimately increase the financial vulnerability of the institution providing medical care. To help mitigate risk, providers should discuss these issues with patients and offer education on how to develop an economic game plan to reduce potential financial-related burden.⁷

Direct/Indirect

Direct

At McDowell Cancer Center, we use an ACCESS database to monitor and track:

- 1. The costs of drugs supplied by pharmaceutical manufacturers.
- Financial payment from co-pay or cost-sharing foundations providing financial payment of services directly to the medical provider.
- **3.** Financial payment directly to the patient from local or national foundations to assist with practical needs.
- 4. Financial payment directly to the medical provider from private insurance that without intervention would have otherwise not been obtainable. (Uninsured patients without resources or patients who did not qualify for private insurance because of a pre-existing condition or for safety-net programming, such as Medicaid, were enrolled in available insurance programs, such as the Ohio High Risk Pool. We

collect insurance payment data from these programs from the hospital billing system. These patient accounts would otherwise fall under the Hospital Care Assurance Program [HCAP] or other hospital financial assistance programming in which the hospital may receive pennies on the dollar for medical services provided.)

Table 5 (below) is financial data we collected in 2012. Here is how we track this financial data.

Local foundations. We use an ACCESS database to monitor data, which is then exported into an EXCEL spreadsheet to identify monthly trends. For example, if the cancer patient is behind on his or her mortgage payment and the resource counselor verifies potential financial hardship, the patient will be referred to one or more foundations that can assist with these practical needs. In turn, the resource counselor will communicate with these local foundations and enter the appropriate financial data in the database. If patients have access to financial resources to assist with practical needs, funds will then be available to pay for direct medical services and indirect expenses. In theory, this support reduces our program's financial vulnerability to nonpayment for services provided, thus having a positive financial impact on our program.

Cost-sharing foundations. Again, we track data in ACCESS and export it to EXCEL to monitor monthly trends. Patients must have insurance to qualify for these foundations. Our reimburse-

ment specialist completes a benefits investigation and determines if the patient has met the maximum out-of-pocket (OOP) required by the insurance provider. If not, the reimbursement specialist enrolls patients in diagnosis-specific foundations that can help cover some or all of the medical expenses until the required OOP limit is met. It should be noted that after a patient meets the maximum OOP, the insurance provider then pays for medical services at 100 percent.

Our reimbursement specialist tracks all financial assistance from these foundations. Further, our reimbursement specialist submits the patient's qualified medical expenses directly to the cost-sharing foundation. Basically, our reimbursement specialist serves as a proxy between the foundation and the patient.

We track all co-pay amounts approved, requested, and received. With funds distributed directly from the foundation to the provider, both providers and patients benefit.

Coordination of benefits. We track and monitor data in the same way, using ACCESS and EXCEL. Our resource counselor obtains relevant financial data directly from the insurance remit form located in the provider billing system. If an uninsured patient does not meet the requirements to qualify for state or federal medical coverage, the resource counselor will evaluate and enroll the patient in other available insurance programs. For example, if a patient is not eligible for Medicaid, the resource counselor may help the patient enroll in other medical coverage options, such as the Ohio High Risk Pool insurance. If patients are experiencing financial hardship and unable to pay their COBRA

Table 5. Measured Financial Data, 2012	
Variables That Can Potentially Impact Financial Hardship & Medical Provider Financial Vuln	erability

	PATIENT & PROVIDER FINANCIAL BENEFIT		AL BENEFIT
	PATIENT	PROVIDER	AMOUNT
Local Foundations Helps patients with concrete needs such as mortgage or rent payment, living expenses, insurance premium, utilities, transportation.	Yes	Indirect	\$119,405
Cost-Sharing Foundations Helps cover costs related to chemotherapy or other drugs— helps with medical coverage premium assistance.	Yes	Yes	\$148,403
Coordination of Benefits Helps patients with medical coverage: i.e., Ohio High Risk Pool, Private Insurance, Employer Options. Assisting patients with continuance of medical coverage, i.e., Private/State/ Federal Programs, COBRA, HIPPA—connect patients with premium assistance.	Yes	Yes	\$2,091,252
Pharmaceutical PAP Assists patients with non-coverage or high co-pay of drugs. These programs also help with reimbursement of drugs regarding insurance denial or off-label use.	Yes	Yes	\$1,040,101

Figure 1. Supportive Process Flowchart

Supportive Care Programming Process: Initial Diagnosis

Prior To Psychosocial Assessment				
Patient Completes NCCN Distress Thermometer (DT)	Reimbursement Specialist Completes Benefits Investigation			
Self-Indicated Distress Level 10= Extreme distress, 0= No distress	Insurance Verification Deductible, maximum out-of-pocket, lifetime maximum			
Self-Indicated Concerns Practical, family, insurance/financial, emotional, spiritual/religious, physical	medication pre-determination, prior-authorization, research protocol identify potential "red flags," possible foundation assistance			

Brief Psychosocial Assessment (BPA): Resource counselor uses distress tool & benefits investigation to help guide assessment.

Personal/Emotional

- Decision-making capacity
- Communication issues
- Psychological well-being
- Personal strengths evaluation

Medical

- Compliance-related concerns
- Doctor/patient relationship
- Functional capacity
- Diagnosis-specific special needs

Social

- Family systems review
- Literacy, language, culture
- Community resources
- Perceived stigma of malignancy

Practical

- Insurance coverage
- Employment issues
- Medical bills: ability to pay
- · Income gaps

Intervention/Navigation/Advocacy/Support

Personal/Emotional

- Counseling/support
- Psychiatric referral
- Healthcare system advocacy
- Communication support

Medical

- Patient/staff liaison
- Resolve compliance issues
- Patient satisfaction advocacy
- Complex adjustment needs

Social

- Family support system
- Resource utilization
- Patient education
- Role changes support

Practical

- Medical benefits investigation
- Financial assessment/ referrals
- Medical cost-sharing referral
- SSD/FMLA/medical coverage

Resource counselor assigns patient a "case complexity rating" 4 = Major ongoing support, 0 = Minimal support

Case complexity score used to monitor and manage support needs: Level 3 & 4 cases monitored and provided ongoing intervention/navigation/advocacy/support.

Patient completes post-treatment NCCN Distress Thermometer

Cancer patient completes second Distress Thermometer on last day of chemo or radiation therapy (data can be compared with initial distress tool).

premium, the resource counselor will connect them with hospital-based programs or foundation assistance to help cover the cost of the monthly premium.

Funds are sent directly to the provider to pay for services delivered. This arrangement benefits both patients and providers as otherwise the medical procedures would have been billed directly to the patient. These procedures are often expensive and often result in non-payment for medical services. Often the medical provider is forced to either use Ohio's HCAP (Hospital Care Assurance Program) or write-off the account.

Pharmaceutical patient assistance programs (PAPs). We monitor these data using web-based PaprxTracker software, which is then exported into EXCEL to identify monthly trends. The PAP software provides customized management of patient accounts, including reports to track demographic and financial data. This program reports drug value according to actual hospital billing, not average wholesale price (AWP). This information is important for the cancer program to determine the financial benefits of using PAPs.

Our reimbursement specialist enrolls patients in PAPs under three circumstances:

- 1. Uninsured, underinsured, or self-pay coordination
- 2. Coverage denial support
- 3. Off-label use of drug.

The reimbursement specialist and resource counselor work closely with Patient Financial Services and Pharmacy to assure that no payers are billed for drug(s) provided from a PAP. Again, both patients and providers benefit from the use of PAPs as the drug cost would have been billed directly to the patient, again resulting in a high potential of non-payment for medical services.

Our Process

Figure 1 (page 46) details our structured supportive care process, addressing both psychosocial distress and patient navigation as defined by CoC guidelines. Also outlined in the process are methods to help reduce the patient's existing or potential economic burden and the impending financial vulnerability of the medical provider. The resource counselor and the reimbursement specialist are necessary components needed to ensure program functionality.

Staff training & background. Our resource counselor training includes:

- MSW, LISW-S: Independent licensure with supervisor designation
- OSW-C: Certified Oncology Social Worker
- OSHIIP Certified: Ohio Department of Insurance.

Our resource counselor has expertise in 1) coordination of medical benefits issues, 2) local, state, and national resource utilization, and 3) program development and implementation.

Our reimbursement specialist has an Associate Degree in

Business Administration, with expertise in:

- Medical billing and coding
- Local, state, and national resource utilization
- Coordination of medical benefits issues.

Benefits investigation. A vital element of our supportive care process is the completion of a comprehensive benefits investigation for every patient beginning therapy. Without this investigation, it is impossible to calculate the actual out-of-pocket requirements as determined by the insurance provider. All relevant information is verified and used to identify potential red flags, such as prior-authorization needs or if it is possible for the patient to reach potential lifetime or annual maximums. This information is also used to determine if a patient would benefit from cost-sharing support.

A vital element of our supportive care process is the completion of a comprehensive benefits investigation for every patient beginning therapy.

Our team. Support provided to educate patients, physicians, and staff includes 1) coordination of benefits, 2) billing concerns, and 3) payment issues specific to each patient. The goal: to maximize patient access to therapy and decrease potential patient financial burden by reducing payer-related administrative burden. A team approach is used to provide these services.

Key staff or department contributors include:

- Resource counselor
- Psychosocial coordinator
- Reimbursement specialist
- Cancer center manager
- Outpatient pharmacy
- Patient financial services.

Key services provided include:

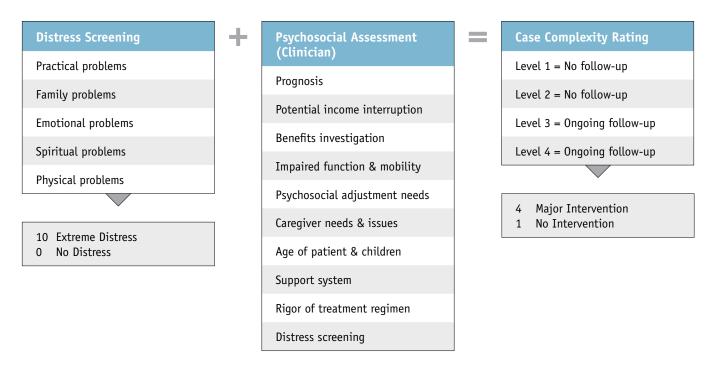
- Prior-authorization screening and tracking
- Coverage denial appeals support
- Off-label use support
- Compliance check for medical necessity on Medicare patients
- Manufacturer and foundation assistance as needed.

New CoC Standards

All CoC-accredited programs are required to phase in standards 3.1 (Patient Navigation) and 3.2 (Distress Management) by 2015. Our process (as identified in Figure 1) meets all identified requirements and criteria to meet compliance standards for CoC Continuance of Care Services.

Distress Management: CoC Standard 3.2 "requires accredited program to develop and implement a process to integrate and

Figure 2. Perceived/Actual Variables = Case Complexity Rating



monitor on-site psychosocial distress screening and referral for the provision of psychosocial care."³ Our process meets all CoC process requirements:

- **1.** Timing of screening
- 2. Method
- 3. Tools
- 4. Assessment and referral
- 5. Documentation.

Patient Navigation: CoC Standard 3.1 "requires each program to establish a patient navigation process, driven by a community needs assessment to address health care disparities and barriers to care for patients." It is important to recognize that this standard does not require each program to hire a patient navigator, but to provide a process by which patient navigation is taking place. The process must address specific barriers identified in the required community needs assessment. We conducted a community needs assessment in collaboration with three local hospitals. (Note: new healthcare reform guidelines also require every not-for-profit hospital to complete this same community health needs assessment.)

Our team addresses the healthcare disparities identified by this assessment during the brief psychosocial assessment that is scheduled with every new cancer patient. We use program data to evaluate the effectiveness of interventions that address self-indicated stressors. Additionally, the distress tool and benefits investigation data is used to assign each patient a case complexity rating (CCR), which is used to evaluate if additional ongoing support is needed. As noted in Figure 1, subsequent to the brief psychosocial assessment, the resource counselor assigns each patient a case complexity rating from 1-4 to help monitor and connect patients having more complex needs with ongoing assistance and supportive care.

Figure 2 (above) identifies the method used by the resource counselor to tally the case complexity rating. Each patient receiving a case complexity rating level 3 or 4 is scheduled for ongoing follow-up.

Discussion & Conclusion

In addition to increased emotional concerns, as noted in Table 2 on page 43, increased distress can also be associated with financial-related burden. Both the direct cost of resources consumed (medical and nonmedical) and the indirect costs of employment-related productivity lost as a result of the disease and treatment must be considered to fully appreciate a patient and family's economic vulnerability.⁸

Distress management and patient navigation are vital components of patient care, and our outcomes support those findings. Our model for conducting psychosocial and financial assessment:

- Minimizes the financial vulnerability of our cancer program as a result of bad debt, charity care, and write-offs
- Establishes a process for making mental health referrals to patients and families in need
- Allows staff the opportunity to connect patients and families to available financial and/or supportive resources

 Offers staff the opportunity to discuss existential issues related to their perceived "cancer experience" for the patient and family.

Patients diagnosed with cancer often deal with very complex issues. Accordingly, healthcare professionals should not assume that patients understand appropriate supportive resource utilization. Interventional programming and patient education addressing the concerns related to the "person in environment" is a critical component of providing care for the "whole" patient and caregiver. Our data confirm the economic and non-monetary value of addressing financial, emotional, physical, practical, and existential concerns on the front end of patient care. When psychosocial services address the patient, caregiver, and the medical provider, it is a win-win for all stakeholders. Certainly, it is worthwhile for medical providers to invest in supportive care staff. Such staff can help develop programs that address needs regarding a patient navigation process, psychosocial distress screening, potential financial burdens experienced by the patient, and the potential economic vulnerability of the institution providing medical care. OI

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