

Navigating the Metastatic Patient

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Defining Cancer Survivor

- The National Coalition for Cancer Survivorship states that survivorship begins at the diagnosis of cancer.
 - "The real challenge of cancer is to live as best as one can for as long as one can. The strength one must have to face the unknown every day; the courage one must muster each time they enter a doctor's office, wait for test results, or receive treatment; and the vulnerability they must endure throughout the cancer journey regardless of the outcome, defines the experience." (The NCCS Definition of a "Cancer Survivor", 2021)

"Survivor"

- Survivorship includes those with cancer, and this encompasses:
 - Post treatment and cancer free
 - Patients on active surveillance, not in treatment
 - Patients living with intermittent need for treatment
 - Patients with Metastatic Disease, our focus for today

Increased Survivorship of Metastatic Patients

- The American Cancer Society's 2020 cancer statistics report reports that cancer-related deaths are decreasing yearly.
- The 5-year relative survival rate for all cancers combined has increased substantially since the early 1960s, from 39% to 70% among whites and from 27% to 64% among blacks. Improvements in survival reflect advances in treatment, as well as earlier diagnosis for some cancers (Siegel et al., 2020).
- Improving treatment options, increased number of FDA therapies available, and targeted personal medicine means that metastatic patients are living longer and longer.
- The number of cancer survivors is projected to increase by 31.4%, to 22.2 million, by 2030.
- 26 Million cancer survivors in the US by year 2040, according to ACS statistics.
- This number includes those living with metastatic disease.

Navigating and Advocating for Patients with Metastatic Disease

- Defining Oncology Navigation
 - Per the Clinical Journal of Oncology Nursing - Oncology Navigation can be defined as individualized assistance offered to patients, families, and caregivers to help overcome healthcare system barriers and facilitate timely access to quality health and psychosocial care from prediagnosis through all phases of the cancer experience. (Petrillo et al., 2024)
 - Navigation wears many hats with patients.
 - Long term cancer survivors have not been well studied leading to gaps in the overall care of these patients.
 - Current ASCO and NCCN survivorship standards focus on patients that are treated with a curative intent.

Digging Deeper into the Concerns of the Metastatic Patient and the Role of the Navigator

- Prognostic Variability
- Coordination of Complex Care
- Symptom Management
- Psychosocial Concerns
- Financial Distress
- Caregiver Support
- Advanced Care Planning

Prognostic Variability

- Life expectancy has an important impact on healthcare, family, and personal lives. Those living with metastatic disease often think about treatment with life expectancy.
- No longer the fear of just recurrence but now the fear of progression of disease and fear of limited or no treatment options.
- Scan Anxiety "scanxiety"
- New treatment availability, clinical trials
- Fear of Statistics
- How can we as Navigators help?
 - What are the patient's life goals?
 - How can we help with achievable goals? How can we help with those goals that may need to be achieved but in alternative ways?
 - Navigators sort through the muck of cancer care and can reiterate education and move patients through available resources.

Coordination of Complex Care

- Multiple teams involved in care - such as medical oncology, radiation oncology, surgeons.
- Making sure patient is involved and established with their primary care provider (pcp).
 - If no pcp, help them find a resource to get one established. Many hospitals have clinics that will help establish patients with a pcp close to where they live.
- Navigation should help coordinate patient with resources such as social work, financial advocacy, dietician, chaplaincy.
- Reminding patients that if they are confused on who to call, it is never wrong to reach out to the navigator as we can help guide them to the correct office.
- Remembering the patient is the voice that needs heard among the large care teams.

Symptom Management

- Patients with increasing comorbidities and complex care teams – this can make sorting through symptoms difficult.
- Navigators play an important role by being able to help with Symptom Management
 - Adherence to treatment, having an established rapport with patient helps them feel comfortable with reporting symptoms. Unreported symptoms increase issues with compliance.
 - Education on use of medications, especially prn medications such as pain meds and nausea meds that have been prescribed. Navigation can help reiterate how to use these based on physician/app instructions.
 - Working with patients about keeping other physicians in the loop, such as current cardiologist etc.
 - Advocating for Palliative Care involvement
 - Getting Social Work, Dietician, PT/OT, and Chaplain needs as part of symptom management – looking at the full picture.
 - Long term goals need addressed - Knowing your patients and getting them to discuss what their long-term goals are will help with navigating patient during continuum.

Psychosocial Concerns

- Patients still express stigma with mental health help.
- Families experience burn out due to constant role of caregiver and struggle to take time off due to long term treatment.
 - Getting family involved with Social Work early to get resources such as transportation help, caregiver support groups, and help with FMLA paperwork that might benefit them.
- How can we improve on this?
 - Making sure that we report to the physician and advocate for the patient when further interventions are needed beyond our listening and reassuring words.
 - Addressing with patients that it is ok to not be ok.
 - Working with a collaborative team is essential in providing continuity in psychosocial care and addressing psychosocial needs.
 - Social Work, Chaplaincy, Financial Counselors, Support Groups
- Support group advocacy - Use trusted support groups such as Cancer Support Community, Local Oncology facilities, PANCAN, LLS, ect....educating patients on being weary of online support groups.

Financial Distress

- Metastatic or advanced cancer is a highly resource-intensive condition. Patients are often very sick and receive multiple treatment modalities, and generally, they spend more time in various care settings (inpatient care, long-term care, and hospice).
- Across cancer sites and stages, high financial burden has been linked to lower quality of life, higher emotional distress, treatment delay or discontinuation, and even increased mortality. (Rotter, J., Spencer, J. C., & Wheeler, S. B. 2019)
- Uninsured or self-pay individuals are typically responsible for the full cost of their care unless they have interventions such as charity care, manufacture assistance, and non-profit organization aid.
 - Even insured patients have large expenses due to cost of deductible, copayments, and large out of pocket maximum amounts.

Financial Distress continued

- What is the Navigator role in this?
- Making sure the patient has met with financial counseling.
 - Does the patient have insurance? Are they underinsured? Are they meeting income requirements for financial assistance?
- Making sure the patient is set up with Social Work to help with resources such as transportation needs, housing, food.
- Making sure patient knows community resources such as non-profit organizations that may be available to help.
- Be the squeaky wheel. If you have the opportunity to speak up about the costs of cancer care and the burden to the patients, please do.
- Have patients talk with financial counseling no matter their income. Patients tend to shy away from help financially when they feel they have coverage but their income may make them have further help.

Caregiver Support

- The cancer patient often needs support from their family and loved ones (caregivers) to help manage their complex disease and cancer related symptoms.
- Burden placed on caregivers can affect their ability to care for patients, which, in turn, may affect patients' health outcomes (Milbury, Badr, Fossella, Pisters, & Carmack, 2013)
- As Navigators, we need to assess home stressors. This will allow us to provide resources such as social work, palliative care, and support groups to the caregiver.

Advanced Care Planning

- The elephant in the room - but discussing goals of care in the beginning may help ease anxiety and open up the dialogue of advanced care planning and patient wishes.
- Patients with advanced disease, even in remission, need to discuss goals of care in the event they cannot make the decision for themselves.
- Knowing the patient wishes and exploring these in the presence of the caregivers may help ease the burden of decision making during any incapacitation.
- Discussing advanced care planning is not giving up. It is the opposite; this helps the patient with decisions they have control over.
- Understanding cultural considerations that may need to be acknowledged before these discussions can take place.

Navigation Impact Points

- Empower patients and caregivers to have a role in treatment planning and symptom management.
- Empower patient to feel free to ask questions and have dialogue with their healthcare team.
- Adherence is key, but symptom management needs to be part of the adherence planning
- Advocate for more research to be done on the psychological, social, spiritual, and financial impact of living for years with incurable cancer. This may yield more support opportunities, financial guidance, and impact care.
- Coordinate and involve palliative care, by helping to get rid of the misnomers that are associated with the word "palliative". Get them involved early if able.

Navigation Impact Points

- Get patients involved in support groups. Locally, there are groups like Cancer Support Community (cancersupportindy.org) they have over 170 locations across the world. They also have printable materials for patients.
- Educate the patients on reputable websites to get information from such as PANCAM, LLS, Susan B. Komen, ACS, etc..
- Make sure financial concerns are discussed as this is a huge burden for chronic cancer patients. Get patient connected with financial navigators at your institution.
- Advocate for an increase in us – We need more Navigators!!
- Bottom line - RESOURCES, RESOURCES, RESOURCES

SELF CARE

- To take care of others - you need to take care of yourself.
- Navigation is a hard job with high emotions.
- Find time to do something for yourself: read, swim, walk, sing in the car – just do something you enjoy daily.
- Take a time out - sometimes you need just 5 minutes to breath or focus on something other than the patient task.

Citations

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