Evaluation of Oncology Patient Experiences and Preferences for Shared Decision Making and Patient-Centered Care

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Research Hypothesis

We hypothesize that patients will rank interventions and activities associated with increased participation in Shared Decision Making (SDM) and patient-centered care planning highly on a scale of importance.

Aim Statement

Over an eight week period, survey at least 50 oncology patients regarding their preferences and experiences with SDM, patient-centered care activities, and treatment of interests (e.g. quality of life, survival, financial impact of treatment, decisional conflict, etc.).

Research Study Dates

June 16, 2017 – August 11, 2017 (8 weeks)

Background

Shared Decision Making (SDM) is defined as a collaborative process where patients and members of their clinical team work together to make healthcare decisions informed by scientific evidence as well as patients’ own values and preferences. Essential elements of SDM include: defining the problem, discussing available treatment options; discussing risks and benefits of options; understanding patient values and preferences; discussing the patient’s clinical condition and making a recommendation; checking patient understanding using “teach-back,” and providing an opportunity to defer the decision. Evidence suggests that SDM is positively associated with improved patient satisfaction, reduced decisional conflict and improved behavioral and physical health outcomes; among other things.

The treatment of cancer is a crucial field for the study of decision making; the stakes for treatment are often life and death, and even when there are multiple treatment options to consider, the importance of SDM is elevated that much more. Research has identified numerous obstacles to SDM in practice, including variable and often suboptimal communication (between the patient and healthcare provider) that may not be culturally or personally appropriate, and information overload for the patient and family without appropriate written documentation of treatment plans, options, and expectations that the patient and family might refer to after a visit.

The stress of a potentially life threatening cancer diagnosis impacts both learning and memory. Patients in a stress state are less likely to understand information presented, remember risks and/or guidelines for treatment, advocate for their personal preferences, take an active role in treatment planning, and adhere to treatment decisions. Consequently, patients experience increased distress and are more likely to feel a “doctor knows best” type attitude, relying on their healthcare providers to inform treatment decisions rather than being an active part of the planning process. Patients who are not able to advocate for their personal needs and preferences are left vulnerable to an impersonal healthcare system.

Research Design

We asked patients to tell us what were some of their greatest sources of stress during the cancer journey:

- “As a patient, I feel that there have been too many instances where all my physicians failed to keep one another up to date with my treatment.”
- “Initially fear. Then stress from several side effects and depression and anxiety. Finance worries are also a problem too.”
- “Lots of anxiety, sometimes depressed and stressed.”
- “Emotional factors – burden on my family”
- “The first thing I thought of was how am I going to pay for all of this. My family came to mind and especially thinking I am going to die. It was something very difficult for me and my family.”

Facets of Stress and Stress-Management Support: Survey participants were asked questions regarding stress and communication and stress management support.

Disclosures and References

The study protocol and survey instrument was submitted to the ethics (institutional review boards) at Methodist Dallas Medical Center (MDMC) and Parkland Health and Hospital System and also to CancerCare, a national program that offers free counseling and support services for cancer patients and their families.

Results (N=76) – As the SDM survey was conducted at different cancer centers, we pool all responses for analysis.

Facets of SDM: Survey participants were asked 10 questions about how important elements of shared decision making were to them.

<table>
<thead>
<tr>
<th>Facet</th>
<th>Male</th>
<th>Female</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>My physician clearly explained my cancer, such as my chance of cure, helps, and general</td>
<td>87.5%</td>
<td>6.9%</td>
<td>4.2%</td>
</tr>
<tr>
<td>My physician made me aware of my preferences for treatment</td>
<td>66.1%</td>
<td>25.5%</td>
<td>5.6%</td>
</tr>
<tr>
<td>I made treatment decisions that had my values and preferences</td>
<td>62.3%</td>
<td>27.5%</td>
<td>7.2%</td>
</tr>
<tr>
<td>I was informed about treatment options (including the option of doing nothing)</td>
<td>62.8%</td>
<td>27.5%</td>
<td>7.2%</td>
</tr>
<tr>
<td>I felt confident in my treatment choice</td>
<td>77.8%</td>
<td>19.4%</td>
<td>2.8%</td>
</tr>
<tr>
<td>I felt my treatment support met my needs and wishes</td>
<td>70.8%</td>
<td>20.8%</td>
<td>4.2%</td>
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</tbody>
</table>

Experiences and Preferences for SDM: Survey participants were asked about their preferences for SDM in treatment choice as well as their experiences with SDM in treatment choice.

<table>
<thead>
<tr>
<th>Experience/Preference</th>
<th>Male</th>
<th>Female</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>My physician asked me about my preferences for treatment</td>
<td>88.5%</td>
<td>31.5%</td>
<td>60.0%</td>
</tr>
<tr>
<td>I was presented with treatment options (including the option of doing nothing)</td>
<td>85.0%</td>
<td>25.0%</td>
<td>50.0%</td>
</tr>
<tr>
<td>My physician clearly explained my cancer, such as my chance of cure, helps, and general</td>
<td>88.5%</td>
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</tbody>
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Conclusions

A large percentage (>85%) of patients ranked 8/9 essential elements of SDM as important or very important. However, preferences for clinical trial information varied across the scales. Oncology patients’ preferences for SDM largely and positively aligned with their experiences with SDM (rhom = .05, p<.0001).

Many patients feel stress impacts communication with their healthcare provider and that the healthcare system should offer stress-management support. However, only 17% of respondents reported receiving stress management resources.

Next Steps

- Understanding stress affects communication on the part of providers and patients; we will conduct a survey of nurses and physicians on sources of stress and factors that impact stress regulation (i.e. mindfulness, self-regulation, and self-care).

Limitations

- The results represent a majority of patients coming from Texas Oncology clinics.

Special Thanks

Texas Oncology Methodist Dallas: Cheryl Sampson, Tracy Messing, Deb Jimerson, Julie Smith, Stacie Harris, and Clinic Staff

Liver Institute Methodist Dallas: Jennifer McRae, Ricole Brooks, Doris Spearmon

Methodology

The survey instrument was translated to Turkish to test for patient discrimination.

Disclosures and References

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