Listening to Families: Family Perspectives on the Value of a Complex Care Program

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BACKGROUND
- Children with medical complexity (CMC) have multiple chronic health conditions, functional limitations, substantial care needs, and high use of health services.
- Complex Care Programs (CCPs) help address challenges in caring for CMC.
- While studies have examined the benefit of CCP on CMC health service utilization, what families see as the value of CCPs is not known.

PURPOSE
- Elucidate family perspectives on the value of participation in a CCP

METHODS
- In 2018, CCP satisfaction surveys sent to 640 family caregivers of CMC in tertiary center CCP.
- Two open-ended questions explored perceived value to families.
- Five members of an interdisciplinary team individually reviewed verbatim responses and identified themes. The team developed coding categories and definitions from these themes. Individuals coded responses. Discrepant coding was discussed to achieve consensus.

RESULTS

1. Question 1: “What has improved for your family because of being in the CCP?” N=112.
2. Question 2: “What else would you like to see improve for your family because of being in the CCP?” N=77.

157 surveys were completed (24.5% response rate)
151 (96%) reported CCP had been valuable to their family.

What has improved for your family because of being in the CCP?

<table>
<thead>
<tr>
<th>Thematic Category</th>
<th>Representative Quotes</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Impact on Family</td>
<td>We can be our son's parents a little more. Worry a little less about coordinating care surrounding his condition.</td>
<td>45</td>
</tr>
<tr>
<td>Tasks of Care Coordination</td>
<td>We don't have to spend hours on the phone trying to coordinate doctor visits instead of driving 4 hours every week, we only need on trip per month</td>
<td>40</td>
</tr>
<tr>
<td>Addressing Medical Needs</td>
<td>Written POC, coordination between doctors, emergency plan, and accessibility during illness to answer questions.</td>
<td>40</td>
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<tr>
<td>Support and Care</td>
<td>It's a safe place I can talk about all of my concerns and get real help and solutions.</td>
<td>25</td>
</tr>
<tr>
<td>Availability</td>
<td>Having one person to contact instead of calling and dealing with all of the specialists myself.</td>
<td>24</td>
</tr>
<tr>
<td>Education and Information Sharing</td>
<td>They also have helped us prepare for what obstacles/hurdles we may encounter in the future.</td>
<td>10</td>
</tr>
<tr>
<td>Familiarity</td>
<td>It is nice having a team that is familiar with my child when we have problems in or out of the hospital.</td>
<td>9</td>
</tr>
<tr>
<td>Neutral or Negative Feedback</td>
<td>I didn't like losing our nurse, hard to start over, change is not easy.</td>
<td>4</td>
</tr>
</tbody>
</table>

Neutral or Negative Feedback

No Concerns or Positive Feedback
- Not sure there is anything else that could improve the complex Care team. They have made our very complicated life so much simpler to navigate. 48%

Community Resources
- Family mentors for new families. 18%

CCP Relationships and Interactions
- Better communication faster responses. 16%

Care Plan Development
- I would like to further discuss development and providers we need to see regarding his progress. 12%

Unmet Expectations, factors outside CCP
- Shorter time spend in ED (Most ED visits are very long). 12%

Transitions
- Smooth transition to adult care providers and assistance with appropriate timing for this. 8%

Unmet Expectations of CCP
- It would be great if the complex care program could follow into adulthood for those of us who are still in need of help. 8%

CONCLUSION
- The most commonly identified CCP impacts were intangible: peace of mind, support, and the ability to simply be parents.
- Will help CCP focus on services families value most.
- May direct future work to develop a tool to evaluate the impact of CCPs on CMC and their families.
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Background

Children with medical complexity (CMC) have multiple chronic health conditions, functional limitations, substantial care needs, and high use of health services. Complex Care Programs (CCP) help address challenges in caring for CMC. While studies have examined the benefit of CCP on CMC health service utilization, what families see as the value of CCPs is not known.

Purpose

Elucidate family perspectives on the value of participation in a CCP

Methods

Satisfaction surveys were sent to 640 family caregivers of CMC in a tertiary center CCP; 157 were returned (24.5%), and 151 (96%) reported the CCP had been valuable to their family. Two open-ended questions explored perceived value to families.

Five members of an interdisciplinary team individually reviewed verbatim responses and identified themes. The team developed coding categories and definitions from these themes. Individuals coded responses. Discrepant coding was discussed to achieve consensus.

Results

The first question asked, “What has improved for your family because of being in the CCP?” Among 112 responses, the most prevalent theme (in 45% of responses) was Impact on Parent and Family. This included peace of mind, feeling supported, decreased worry/stress, saving time, and ability to be parents. In the words of one parent, “We can be our son’s parents a little more... worry a little less about coordinating care surrounding his condition.” Additional prevalent themes (each in 40% of responses) were Tasks of Care Coordination (appointment scheduling and paperwork) and Addressing Medical Needs (using a big picture/long term approach, communication between subspecialists, decision making, and access to providers). One family stated, “Keeping us organized and on top of all of our appointments! Helping us get hold of different providers when we have concerns.”

Other themes were Relationship and Communication with Family (central point of contact, monthly check-in, familiar face in the hospital); Education and Information Sharing (new community/financial resources, explaining a diagnosis); and Negative/Neutral Feedback.

The second question asked, “What else would you like to see improve for your family because of being in the CCP?” The most prevalent theme (in 48% of 77 responses) was No Concerns/Positive Feedback. Other responses addressed Resources in the Community; Unmet Expectations for relationship and interaction, the hospital system, and general; Care Plan Development; and Transitions.

Conclusions

Some outcomes families identified illustrate the CCP missions of care coordination and medical co-management. Yet, the most commonly identified descriptions of CCP impact on parents were intangible: peace of mind, support, and the ability to simply be parents.
These findings will help the CCP focus on activities that are most valued by families. They may direct future work to develop a tool to evaluate the impact of CCPs on CMC and their families.

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