Integrating Family Caregivers into Gynecologic Cancer Education & Support Services

Michelle Boisen, Grace Campbell, Heidi Donovan, Lauren Hand, Nora Lersch, & Barb Suchonic
Magee Women’s Hospital of UPMC

12/5/18
Institutional Overview

• Academic regional referral center - Pittsburgh, PA
• National Center of Excellence in Women’s Health
• NCI-designated Comprehensive Cancer Center
• 300 Inpatient beds
• Average of 10,800 clinic visits/year over past 3 years
• 10 GynOncs, 2 MedOncs, 7NPs & PAs
## Team Members

<table>
<thead>
<tr>
<th>Core Team Members: Dr. Michelle Boisen &amp; Dr. Lauren Hand (Team Leaders); Heidi Donovan, PhD, RN; Grace Campbell, PhD, MSW, RN (Facilitators); Barb Suchonic, Director of Operations; Nora Lersch, MSN, NP</th>
<th>EHR Medical Director: Glenn Updike, MD  UPMC Patient Reported Outcomes: Janel Hanmer, MD</th>
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<tbody>
<tr>
<td>Caregiver Advocate: Scott Harrison</td>
<td>Medical Assistants and Intake Staff: Alexis Morris; Kelsey Onufrey</td>
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<td>Palliative Care: Lisa Podgurski, MD; Lisa Griffiths, RN</td>
<td>Patient/family Navigator: Alex Ley, MSW, LSW</td>
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<td>Infusion Center: Annette Smith, RN  Collaborative Practice Nursing: Cathy Jackson, RN</td>
<td>Patient Care Coordinator: Robin Minich, RN</td>
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<td>Diversity &amp; Inclusion: Susan Baida  Director, UPMC Community Engagement:</td>
<td>QTP Improvement Coach: Stephanie Amport</td>
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### Project sponsors:
- Dr. Robert Edwards, Chair, OB/GYN
- Dr. Joseph Kelley, Division Director, GYN Oncology
- Troy Treanor, Program Administrator, Women’s Cancer Services
- Tami Minnier, RN, Chief Quality Officer, UPMC
- James Taylor, UPMC Diversity
Based on a medical record review of gyn onc patients receiving chemotherapy during a one-week period in July, 2018, only **19% of charts included any documentation of a family member and no (0%) charts included documentation of caregiver concerns or needs** (n=36).

Based on a needs assessment of family caregivers conducted between 9/17 and 12/17, **50% of caregivers report 9 or more distressing unmet needs** (n=56, score of ≥ 4 on 0-10 scale).

These data suggest that family caregivers are not receiving the support they need in the gynecologic cancer program to effectively care for themselves and their loved ones.
Patient/Caregiver Flow through Clinic

Check-In

- Patient + Caregiver Enter Office
- Check in
- Is Caregiver present?
  - No: What happens with CareGiver then?
  - Yes: 1st visit?
    - No: Review New Patient Packet and emergency contact documented
    - Yes: MA calls pt (+/-cg) and brings to room
  - Vitals taken
  - and/or MD
  - Patient seen by resident/PA/NP

Visit

- Treatment – Decisions; Need for ancillary services (including CARE Center)

Check-Out

- Check out
- New appt needed?
  - Yes: Scheduled for visit
  - No: Leave Office
- Problems between visits?
  - No: Leave Office
  - Yes: Patient/CG call or email office
- Patient needs to be seen?
Diagnostic Data - Caregiver Identification

Reasons for Lack of CG Identification/Documentation

- No designated field for CG in HER
- Lack of awareness of services...
- No staff designated to "own" CG...
- No protocol for communicating &...
- No accountability for ensuring CGs...
- CENTER GOALS set
- PATIENT PREFERENCES set
- LOGISTICS set
- Other staff pressures

ASCO Quality Training Program
By December 1, 2018:

- 85% of Magee Gynecologic Cancer Program patients will have an identified and documented primary caregiver within 2 clinic visits of receiving a confirmed diagnosis of gynecologic cancer, and
- 75% of caregivers will have distress level and sources of distress assessed within 2 weeks of caregiver identification.
Measures

Measure(s) & Calculation Methodology:

1. EPIC Query
   a. % Caregiver documentation

2. Survey (% = #positive response/#completing surveyx100)
   a. Did anyone in the clinic ask you about your needs as a caregiver today?
   b. Did provider give you education or support today?
   c. To what extent did info/support meet your needs? [0-4 Likert type scale; 0=not at all; 4=completely (Mean score)]
   d. Distress Thermometer - Level of distress over past week [Mean Score] [0-10 scale; 0=no distress - 10=as much distress as I can imagine]

- Patient population: All patients seen in gynecologic oncology clinic
Measures

- Data collection frequency:
  - 5 days/month; once on each day of the week
  - Pre & post implementation then annually
- Data quality (any limitations):
  - Not able to capture everyone in busy clinic
  - Caregiver reluctant to provide information on his/her distress when patient is not there
  - CGs consider any info provided to them and to patient as CG education/support education
Baseline Data n=166

1. 28% of Caregivers reported being asked about their needs as a family caregiver
2. 45% of Caregivers reported receiving information from a provider
3. Extent to which info met needs: 2.7 (range: 0-4)
4. Mean Caregiver Distress score: 2.9 (range: 0-10)
   • 38% of CGs scored >4 on distress thermometer
## Priority Matrix—Caregiver Identification

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<tr>
<th>Impact</th>
<th>High</th>
<th>Low</th>
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<td>1)</td>
<td>Printed materials (posters; flyers in new patient packets; pamphlets)</td>
<td>1) Implement wording of identification question/invitation: “Is anyone with you today? Please join us.”</td>
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<td>2)</td>
<td>Educate all levels of staff about services/program</td>
<td>1) Educate providers about value of including caregiver on care team</td>
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<td>3)</td>
<td>Staff meeting and division meeting agendas/minutes every 3 months (sustaining gain and visibility)</td>
<td>2) Monthly audits of identification and documentation to sustain the process</td>
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<td>4)</td>
<td>New staff orientation agendas</td>
<td>3) Develop caregiver data base for center to organize and search by caregiver, patient, service date, MD</td>
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<td>5)</td>
<td>Process for caregiver identification in clinic</td>
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<th>Ease of Implementation</th>
<th>Easy</th>
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### High Impact
- 1) Printed materials (posters; flyers in new patient packets; pamphlets)
- 2) Educate all levels of staff about services/program
- 3) Staff meeting and division meeting agendas/minutes every 3 months (sustaining gain and visibility)
- 4) New staff orientation agendas
- 5) Process for caregiver identification in clinic

### Low Impact
- 1) Implement wording of identification question/invitation: “Is anyone with you today? Please join us.”
- 1) Educate providers about value of including caregiver on care team
- 2) Monthly audits of identification and documentation to sustain the process
- 3) Develop caregiver data base for center to organize and search by caregiver, patient, service date, MD

### Ease of Implementation
- Easy
- Difficult
## Priority Matrix—Caregiver Assessment

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<th>Low Impact</th>
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<tr>
<td>1) Staff the center 5 days per week</td>
<td>1) Assess technical/medical ‘literacy’ of caregiver</td>
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<tr>
<td>2) Develop protocol for telephone education, counseling and referral</td>
<td>1) Assess technical/medical ‘literacy’ of caregiver</td>
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<td>3) Assess caregiver information needs</td>
<td>2) Assess what relationship caregiver is to patient and what kinds of support that person provides</td>
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<td>4) Targeted caregiver assessment w/in 2 weeks of identification (NCCN distress, emotional well-being, problem list, resources)</td>
<td>3) Ongoing assessment of metrics to demonstrate value</td>
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<td>4) Targeted caregiver assessment w/in 2 weeks of identification (NCCN distress, emotional well-being, problem list, resources)</td>
<td>4) Documentation template for caregiver assessment/notes in patient chart</td>
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<td>5) Ongoing feedback to clinicians re: caregiver follow up to show value</td>
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<td>1) Assess caregiver financial resources, insurance coverage</td>
<td>1) Develop protocol and decision points for referrals to behavioral medicine, crisis lines, etc.</td>
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<td>Description of Intervention</td>
<td>Results</td>
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<tr>
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<tr>
<td>Cycle 1: October 1-October 19</td>
<td>1) Define standard process for identifying caregiver 2) Identify/define standard location for documenting caregiver(s) in patient eRecord</td>
<td>1) Standard process and location identified and agreed upon by full project team.</td>
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## PDSA Plan (Test of Change)

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| Cycle 2: October 20- November 2 (cont’d) | 2) “Soft opening” two days prior to official center opening to educate staff about caregiver identification process, documentation location  
3) Daily promotional/’spirit’ activities (bagels; popcorn, lunch) during first week of clinic to increase staff awareness, investment, and buy-in | 2 & 3) Soft opening included 5 ‘spirit-building’ activities for staff (1 activity daily for first 5 days) to increase staff excitement and educate about Center. | |
## PDSA Plan (Test of Change) - ID

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| Cycle 3: November 9-November 23 | 1) Staff center 5 days/week  
2) Develop protocol for notifying center staff of caregivers to be assessed  
3) Develop protocol for completing phone assessment  
4) Implement targeted CG assessment (NCCN distress, emotional well being, problem list, resources | 1) Final CG identifications through 11/29 (with "mini PDSAs):  
• 174 CGs documented  
• 116 return pts  
• 49 new patients  
• 4 new recurrences  
• 5 no cancer | 1) Need to refocus our priorities on CGs of new patients or patients in transition; not bog down center staff. |
## PDSA Plan (Test of Change) - Assess

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| Cycle 3: November 9-November 23 | 1) Staff center 5 days/week  
2) Develop protocol for notifying center staff of caregivers to be assessed  
3) Develop protocol for completing phone assessment  
4) Implement targeted CG assessment (NCCN distress, emotional well being, problem list, resources | 2) Outreach initiated with 61 patients  
• 30 emails with info about center  
• 10 phone messages left  
• 21 phone conversations (cg &/or patient)  
• Only 4 full assessments done |
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| Cycle 4: November 26-December 2 | 1) Streamline Center’s CG data base  
2) Streamline/refine process for entering into Center data base  
3) Refine role/responsibility for each member of Center staff to ensure efficient, effective CG assessment | 1) Began working with IT to develop CARE Center documentation template in HER (work in progress)  
2) Role definitions begun and are ongoing | 1) Re-organize CG spreadsheet (“data base”) for easier tracking of priority follow ups  
2) Create new posters that define CG better  
3) Create a flyer for new patient packet that is both a form be completed AND information about the center. |
## PDSA Plan (Test of Change)

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<tr>
<td>Cycle 5 (planned): December 10-December 20</td>
<td>1) Increase education, marketing of center to: Providers/staff Patients Caregivers 2) Develop protocols for patient/caregiver case finding and outreach 3) Develop protocols for direct referrals to CARE Center from clinicians 4) Continue refining protocols for following up</td>
<td></td>
<td>1) Switch to active CG identification for new patients only</td>
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</table>
Date: _______  
My Name is: ____________________  
My closest support person, or “caregiver” (CG) is my ___________ (mother, sister, husband, partner, daughter, son, friend).  
CG Name: ______________________  
CG Phone: ______________________  
CG Email: ______________________

GynOnc CARE Center Guides  
Cancer Reaches Beyond the Patient; So Should Cancer Care  

Maintaining Your Emotional Health as a Family Caregiver

"Family Caregiver" means anyone (friend or family member) who provides day-to-day support for a woman with gynecologic cancer

Emotional health refers to your sense of well-being. People who provide support to a woman with gynecologic cancer face many of their own physical and emotional challenges as they deal with their loved one's illness. This is often a very overwhelming time.

Many caregivers feel unprepared for all the things they need to learn and manage. Even though
Change Data – Number of Caregivers Identified per Day

- Overall Median
- Median Since Implementation

- Launch
- ID Medical Assistant Champion
- Focus on CGs of New Patients
Change Data – Number of Caregivers Identified per Week

- **Week 1**: 10/22 – 10/26
- **Week 2**: 10/29 – 11/2
- **Week 3**: 11/5 – 11/9
- **Week 4**: 11/12 – 11/16
- **Week 5**: 11/19 – 11/23
- **Week 6**: 11/26 – 11/30

Launch (10/22 - 10/26)

Focus on CGs of New Patients (11/19 – 11/23)

ID Medical Assistant Champion (11/5 – 11/9)
Exemplar
Conclusions

• **Aim: Met/Not met??**

• Implementation process, outcomes data suggest positive benefits

• Distal quality indicators (e.g. ED visits; patient satisfaction) yet to be assessed

• Center adds value to patients, caregivers, clinicians (Exemplar)

• Labor-intensive for Center staff (QTP Team) but labor-saving for clinical staff
Next Steps/Plan for Sustainability

• Simplify and clarify Center processes
• Simplify measures; data collection
  – Optimize EHR documentation to streamline?
  – Continue improving tracking via data base for easier prioritization of follow up
• Finalize Center staff role descriptions
• Active referrals vs. case finding
• Integrate clinic screening and referrals into overall clinic work flow