Quality Training Program

Project Title: Aggressiveness of Cancer Care Near the end of Life

Presenter’s Name: Dra Cristina Caramés

Institution: Hospital Universitario Fundación Jiménez Díaz
Institutional Overview

General Hospital (Radiology, Nuclear Medicine, Radiotherapy...)

- 441,839 Patient volume
- 689 Hospitalization beds (25 oncology, 11 palliative care)
- 2 day hospital: General oncology (21 armchairs) and phase I (7 armchairs)
- 24 hours / 7 days a week oncologist on call
- 13 medical oncologist

2800 new oncology patients / year

All tumor types
Problem Statement

Aggressive management of cancer care near the end of life is harmful, associated with decreased quality of live and increases health costs needlessly. 55% of the patients at our hospital suffer at least one aggressiveness event at the last month of life. A substantial portion of these fact is avoidable.
## Team Members

<table>
<thead>
<tr>
<th>Team member</th>
<th>Name</th>
<th>Role</th>
<th>Discipline</th>
</tr>
</thead>
<tbody>
<tr>
<td>Team Leader</td>
<td>Jesús García-Foncillas</td>
<td>Head oncology department</td>
<td>Oncologist</td>
</tr>
<tr>
<td>Team Members</td>
<td>Ana León</td>
<td>Desing and implementation</td>
<td>Oncologist Oncologist</td>
</tr>
<tr>
<td></td>
<td>Cristina Caramés</td>
<td></td>
<td>Palliative care Palliative care</td>
</tr>
<tr>
<td></td>
<td>Álvaro Gándara</td>
<td></td>
<td>Pharmaceutical</td>
</tr>
<tr>
<td></td>
<td>Antonio Noguera</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Javier Bécares</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Project Sponsors</td>
<td>Ana Leal</td>
<td>Medical director</td>
<td>Doctor</td>
</tr>
<tr>
<td>Patient/ Family Members</td>
<td>Diego Villalón</td>
<td>Director “Fundación más que ideas”</td>
<td>Social worker</td>
</tr>
</tbody>
</table>
PATIENT and RELATIVES

- Unrealistic expectation
- Unknown of the prognosis
- Treatment demand until the end
- Emotional state
- Socio-cultural aspects
- Ethical and religious values
- Informed consents little individualized and truthful to the real situation

MEDICAL TEAM

- Overestimation of effectiveness and excessive reliance on new drugs
- Difficulty in predicting prognosis
- Lack of culture focused on shared decision-making between doctor and patient
- Lack of advance patient decision making
- Lack of communication skills
- Little and late communication with support/palliative teams

Team or system interaction (patient-oncologist-palliative services)

HIGH AMOUNT USE OF FUTILITY EVENTS
Process Map current state

Oncological patient with metastatic or locally advanced disease

Protocol prescription

- No: Another schedule
- Yes: Treatment administration
Aim Statement

Improve the number of aggressive events by halving each one:

- Chemotherapy on the last 15 days of life
- Starting a new treatment protocol at the last month of life
- Emergency room admission at the last month of life
- ICU admission at the last month of life
- Patients dying in an acute unit (including oncology hospitalization, all except hospice, home with support or palliative hospitalization)
- Patients not being follow by palliative units before dying
- Patients dying in a palliative care unit only 72 hours after being known for the palliative unit
<table>
<thead>
<tr>
<th>Diagnostic Data</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chemotherapy on the last 15 days of life (+10%)</td>
<td>3</td>
<td>15</td>
</tr>
<tr>
<td>Starting a new treatment protocol at the last month of life (+2%)</td>
<td>3</td>
<td>15</td>
</tr>
<tr>
<td>Emergency room admission at the last month of life (+4%)</td>
<td>11</td>
<td>55</td>
</tr>
<tr>
<td>ICU admission at the last month of life (+4%)</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Patients dying in an acute unit (including oncology hospitalitation, all except hospice, home with support or palliative hospitalitation) (+17%)</td>
<td>3</td>
<td>15</td>
</tr>
<tr>
<td>Patients referred to palliative in the last admission (no from outpatient clinic)</td>
<td>11</td>
<td>55%</td>
</tr>
<tr>
<td>Patients not being follow by palliative units before dying (-55%)</td>
<td>2</td>
<td>10</td>
</tr>
<tr>
<td>Patients dying in a palliative care unit only 72 hours after being known for the unit (+8%)</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td><strong>No advances directives</strong></td>
<td>20</td>
<td>100</td>
</tr>
</tbody>
</table>
Pareto chart
 Intervention 1: To **standardize referral criteria** to the palliative care unit

 Intervention 2: To **design and implement a methodology to encourage active participation of the patient in making health and therapeutic decisions**

 Intervention 3: **Promoting more psychological support**, which allows accompaniment and helps the patient adapt and face an end-of-life situation. Similarly, and with the same objective, propose to enable religious attention at the end of life. All this helps to acquire a more realistic view of the situation and make more optimal decisions with what the patient really wants and wants.

 Intervention 4: **Give greater visibility of the palliative care units**. They are very stigmatized and many people are afraid of the word "palliative". Therefore, making informative material close, without dramatises can be very useful. Explaining since the beginning what they contribute and how they work helps reduce the uncertainty. It is important to think that one of the main fears of death is related to fear of pain and suffering. Providing close information about the resources that exist for your control can be very useful.

 Intervention 5: More training related to **communication skills** to oncologists.

 Intervention 6: **Family-specific consultation**: It could be very useful to face of an end-of-life situation. The possibility of a consultation with the patient’s family whose purpose is to give information and guidelines, that help a best coordinated work and to respect the wishes of the patient. It could serve to resolve doubts, explain treatment and care issues, and provide some situation management guidelines. Maybe this consultation shouldn’t be given by a doctor, maybe nursing might be interesting. It would serve as an ideal channel of dialogue between family members and health workers.

 Intervention 7: Make written **material with information and recommendations addressed to families**. Any guidance is always welcome and if we accompany and resolve your doubts, less likely you will be to demand regarding treatments that are probably not going to help.
Prioritized List of Changes (Priority/Pay–Off Matrix)

<table>
<thead>
<tr>
<th>Impact</th>
<th>Easy</th>
<th>Difficult</th>
</tr>
</thead>
<tbody>
<tr>
<td>High</td>
<td>- Standardize referral criteria to the palliative care unit promoting an Early intervention</td>
<td>- Training related to communication skills</td>
</tr>
<tr>
<td></td>
<td>- Give greater visibility of the palliative care units. Facilitator diptych</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Active participation of the patient in making health and therapeutic decisions</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Material with information and recommendations addressed to families.</td>
<td></td>
</tr>
<tr>
<td>Low</td>
<td>- Family-specific consultation</td>
<td>change the way professionals think</td>
</tr>
<tr>
<td></td>
<td>- Promoting more psychological support</td>
<td></td>
</tr>
</tbody>
</table>
**Intervention 1**

**Standardize referral criteria to the palliative care unit promoting an early intervention**

Every time a new protocol is started in a metastatic patient → assessment criteria to identify risk situations for aggressive events

1. **NECESSARY**: In all cases the oncologist answers his/her self the **surprise question**. “Would I be surprised if the patient died over the course of next year?”

2. **Disease-related aspects**

   a. **Difficult-to-manage physical symptoms**: pain, dyspnoea, or other physical symptomatology that doesn't respond well to your oncologist's initial treatment or that is cause of **multiple incomes in recent months**

   b. **Difficulty with emotional adaptation of the patient or their families** that does not involve psychopathology: Patient suffers discouragement, loss of meaning, demoralization; Difficulty communicating, pact of silence in the family

   c. **Advanced constitutional syndrome** (pre-cachexia or tumor cachexia) that involves needing to have an essential conversation about possible progression of disease

   d. Severe functional impairment involving **aid for basic activities**

   e. **Cognitive impairment**

   f. Chronic use of oxygen

3. **Complexity of care**: Social complexity or Institutionalized or non-primary caregiver available

   **Meet one criteria → referral → first visit together (patient-oncologist-PCU)**
Process map future state

1. Oncological patient with metastatic or locally advanced disease
   - Protocol prescription
     - Yes
       - Assessment intervention criteria support team
         - Yes
           - The patient meets the criteria for intervention
             - Yes
               - Referral to support team to initiate early intervention
             - No
               - No referral to support team early intervention
         - No
           - Assessment criteria
   - No
     - Another schedule
Give greater visibility of the palliative care units. Facilitator diptych

1. Somos un equipo: enfocado en tu calidad de vida
   - Somos un equipo multidisciplinar
   - Somos expertos en control sintomático
   - Atendemos globalmente a la persona y consideramos sus diferentes dimensiones
   - Forman parte del equipo médicos, enfermeras y una psicóloga
   - Nos centramos en evaluar, prevenir y tratar el dolor y otros problemas
   - Iniciamos conversaciones como: "Estamos aquí para ayudar,..."

2. Importas tú: queremos conocerte
   - Queremos saber sobre tu experiencia con la enfermedad
   - Procuramos una relación terapéutica centrada en síntomas o preocupaciones
   - Trabajamos sin prisa con los pacientes
   - Nos interesa tu experiencia de enfermedad y cómo afecta a tu vida
   - Indagamos sobre las preferencias y aconsejamos en el proceso de toma de decisiones
   - Mantenemos una relación cercana y personal

3. La familia también importa: los más cercanos son importantes para nosotros
   - Queremos cuidar a los que cuidan
   - Queremos apoyar a los que cuidan
   - Escuchamos los puntos de vista de la familia
   - Colaboramos en organizar y coordinar la asistencia
   - Promovemos el autocuidado de quienes viven más de cerca la enfermedad
Active participation of the patient in making health and therapeutic decision

Disease knowledge exploration and patient values
1) want to know aspects related to the evolution or pronostic of your disease?
2) do you want to actively participate in decisions or do you prefer others to?
3) in the current situation, what's important? quality of life? is autonomy important?
4) do you have experitual or ideological beliefs that we should take into account?

Sharing treatment decisions and goals
1) treatments that try to control the progression of the disease, can cause significant side effects, what is the limit of side effects that you are willing to assume?
2) it is important that symptom control through "palliative care" is integrated as part of cancer treatment. Would you like to receive these cares?
3) if there was a serious, emergency situation, what do you want in terms of medical interventions?

end-of-life strategy
1) have you thought about how to consider care when the time comes when chemotherapy doesn't work?
2) have you thought about how to consider care when the time comes when chemotherapy doesn't work?
3) have you talked to your relatives about how to cope with the disease when it progresses and there are no options to stop it?
4) in case you can't express yourself, who is the person you want me to speak for you? have you spoken to that person?
5) where would you like to be careful if there comes a time when you are no longer independent? and in the last few days?
6) if symptom control could not be achieved with available treatments, would you prefer "palliative sedation"? Would you like to be asked this situation?
# PDSA Plan (Test of Change)

<table>
<thead>
<tr>
<th>Date of PDSA Cycle</th>
<th>Description of Intervention</th>
<th>Results</th>
<th>Action Steps</th>
</tr>
</thead>
<tbody>
<tr>
<td>1-2-2020 15-9-2020</td>
<td>Analysis of the causes responsible of agressive events</td>
<td><strong>Identification of main problems</strong></td>
<td>Redifine circuit, and created a cheklist that recognizes risk situations</td>
</tr>
<tr>
<td>1-9-2020 1-12-2020</td>
<td><strong>-Implementation of the cheklist that recognizes high risk situations in all oncology visitis</strong></td>
<td><strong>New process map done</strong></td>
<td>Periodic meetins and staff training</td>
</tr>
</tbody>
</table>
| Ongoing | **-Active participation of the patient in making health and therapeutic decisions**  
-Give greater visibility of the palliative care units.  
-Material with information and recommendations addressed to families. | **Indicators analysis** | Continous training |
informative diptych to give visibility to palliative care units

2. Somos expertos en control sintomático: nos centramos en evaluar, prevenir y tratar el dolor y otros problemas.
3. Estamos para disminuir el sufrimiento de la familia: escuchamos los puntos de vista de la familia y colaboramos en organizar y coordinar la asistencia.

structuring of the clinical interview for planning end-of-life care

1. Atendemos globalmente a la persona y consideramos sus diferentes dimensiones. Forman parte del equipo médicos, enfermeros y psicólogos.
2. Nos centramos en evaluar, prevenir y tratar el dolor y otros problemas.
3. Iniciamos conversaciones como: “Estamos aquí para ayudar…”

Material Developed (optional)
measuring results

Compare the number of aggressive events before and after the interventions

- Chemotherapy on the last 15 days of life
- Starting a new treatment protocol at the last month of life
- Emergency room admission at the last month of life
- ICU admission at the last month of life
- Patients dying in an acute unit
- Patients not being follow by palliative units before dying
- Patients dying in a palliative care unit only 72 hours after being known for the palliative unit

Measuring intervention impact in

QoL → PREMS and validated questionnaires of patient satisfaction

OS → with and without intervention
## Change Data

<table>
<thead>
<tr>
<th>Date</th>
<th>N first oncology dx</th>
<th>N early referral to PCU</th>
<th>% referrals</th>
</tr>
</thead>
<tbody>
<tr>
<td>1-9-2019/30-11-2019</td>
<td>418</td>
<td>70</td>
<td>16%</td>
</tr>
<tr>
<td>1-9-2020/30-11-2020</td>
<td>383</td>
<td>80</td>
<td>20%</td>
</tr>
</tbody>
</table>
Conclusions

Identifying risk situations for suffering aggressive events and providing patients and healthcare professionals with the resources to avoid them, will reduce aggressive events at the end of life.
Next Steps/Plan for Sustainability

- Consolidate the standardization of referrals to palliative care units

- Consolidate the structured clinical interview methodology for end-of-life care planning

- Results measurement and continuous improvement plan
Project Title: Aggressiveness of Cancer Care Near the end of Life

AIM: Improve the number of aggressive events by halving each one (list at presentation) in a period of 6 months

INTERVENTION:
- To standardize referral criteria to the palliative care unit promoting and early intervention
- To design and implement a methodology to encourage active participation of the patient in making health and therapeutic decisions at the end of life
- Give greater visibility of the palliative care units and facilitate material with information and recommendations addressed to families.

RESULTS:
Cause and effect diagram

CONCLUSIONS:
- Identifying risk situations for suffering aggressive events and providing patients and healthcare professionals with the resources to avoid them, will reduce aggressive events at the end of life.

NEXT STEPS:
- Consolidate the standardization of referrals to palliative care units
- Consolidate the structured clinical interview methodology for end-of-life care planning
- Results measurement and continuous improvement plan
Thank you