Love Your Liver

A Liver Transplant Support Group:
Working Together as an Interdisciplinary Team

Presenters

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Outline

• Introductions
• What We Did
• Why We Did It
• Where We Are Going
• Case Study
• Issues
• Results
• Questions
What We Did

Multi-disciplinary Model
- Chaplain
- LSW
- Advanced Practice Psychiatric Nurse

Multi-disciplinary Model
- Goal to bring together patients, families with others who had already gone through process
- Difficulty getting patients and families to attend
Multi-disciplinary Model

- Original disconnect between liver transplant team and the support group
  - Carla’s Role in breaching this gap
  - Past history – distrust by surgeons of interventions by non-liver team professionals in the care
  - Distrust of liver transplant team by floor nurses

Multi-disciplinary Model

- Long-suffering patients and families
  - Wait to be listed for transplant
  - Wait to receive liver transplant
  - Dramatic post-surgical course
    - Could be ill for months, even hospitalized for a year
    - Delirium
    - Seeing others get better or die

Multi-disciplinary Model

- Stigma
  - Alcoholism
  - Drug Abuse
  - Jaundiced, debilitated look
Multi-disciplinary Model

- Degree of illness was very frightening
  - Collaborating with nursing staff to bring very ill patients with tubes, drains, machines to meetings
  - Needing to both expose and reassure other patients, families to potential reality of post-surgical period

Multi-disciplinary Model

- Help from old group attendees
  - Kenny D as strong support for early group
- Change in focus from ongoing outpatient group to group focusing on inpatients

Multi-disciplinary Model

- Open to any liver transplant patient already listed for liver transplant, already received liver transplant, or was returning to hospital for liver or other health issues
Multi-disciplinary Model

- Very Diverse Presentations
  - Drug or ETOH in past
  - Older patients – refused elsewhere
  - People from lower socio-economic background
  - Transfers from Stroger Cook County Hospital
  - Highly successful professionals

Multi-disciplinary Model

- Program’s Reputation
  - Accept patients who were refused elsewhere
  - More minorities accepted here than all other programs in state combined

Multi-disciplinary Model

- Meetings Format
  - Picture of Liver
  - Introduction of attendees
  - Staff directed but attempt to make it more about peer support and education
  - Successful meeting when staff talked much less
Multi-disciplinary Model

• Group Stories
  – Severely ill patients and families still reaching out and helping other ill patients and families. Some survive well, some die, and some remain invalids.

Multi-disciplinary Model

• Group Stories
  – Liver recipient from hard background (very aggressive, resistant as surgery patient) who years later is so grateful for his care by physicians, nurses, etc. that he returns to groups to help others.

Multi-disciplinary Model

• Group Stories
  – Brother of recipient who first attends regularly but then falls back as patient becomes chronically hospitalized in SICU and never recovers
  – Young woman who loses two livers because of her non-compliance and eventually dies
Multi-disciplinary Model

- Group Stories
  - Alcoholic woman who stops drinking receives liver 4 years ago and then recently returns to care and support her alcoholic husband who is waiting for liver
  - This woman is major support to others!

Why We Did It

Why We Restarted the Liver Transplant Support Group

- Our experiences showed us there was a need
- The Liver Transplant Support Group had been successful for many years
- It had been extremely popular about 10 years ago
Examined the Success of Previous Support Group

- Group had a semi dedicated facilitator
- The support group was one of her main job responsibilities
- She spent all week recruiting patients on unit to attend

Examined the Success of Previous Support Group

- Most patients attended as in-patients
- Would return as outpatients
- The support group went on for many years

Why the Support Group Stopped

- Facilitator passed away
- Facilitator assignment changed
- Support group was then led by the liver transplant social worker
Why the Support Group Stopped

• Leading the group was one of the many job duties held by the social worker.
• Most of her work was not on the unit.
• She did not have the time to actively recruit patients for group during the week.

Why the Support Group Stopped

• There was not a bathroom or nurse’s station close to the group’s location.
• With only one leader, it was not safe to bring some of the sicker, less mobile patient’s to group.
• Lack of inpatient attendance lead to almost no outpatient attendance.

Where Are We Going
Where Are We Going

• Currently transplant program in transition
• Part of transition will add focus on pre-transplant education
  – Both for patients and their families

Where Are We Going

• Add New Requirement for Patients
  – Make attendance at least one group session a pre-transplant requirement
  –Expose pre-transplant patients/families to post-transplant patients/families
  –Give them the best insight/advice into the transplant process

Where Are We Going

• Would like to provide a quarterly pre-transplant class
  – Include our surgeons, hepatologists, RNs, pharmacists, chaplains, and social workers
  – Provide in-depth educational for patients and families
  –Make attendance a requirement for listing
Case Study

- DW is a young woman who received a liver transplant in 2006
- Cancer diagnosis
- Minor at the time of first transplant
- She was very ill

Case Study

- Family would not consent to the use of blood products during surgery
- Based on family’s religious beliefs
- Team thought the transplant possible without the use of blood products
- However, this was not the case.
Case Study

- Family continued to refuse to consent to the use of blood products
- Surgeon contacted DCFS
- Assume guardianship of the patient
- Transplant was successful
- Blood products were used

Case Study

- Recovery was essentially unremarkable
- Patient did very well for about 3 years
- Readmitted in 2009 in chronic rejection
- Needed a second liver transplant
- Original transplant hospital had declined to list patient.

Case Study

- Patient of legal age at this time
- Family again voiced disagreement with the use of blood products
- Patient and family met with:
  - Multiple members of the transplant team
  - Advanced Practice Nurse
  - Chaplain
Case Study

• Patient decided to allow blood products
• Second transplant was successful
• Recover was long and difficult
• Many crisis
• Several re-admissions
• Raised issues of religious freedom vs. societal responsibility for minors

Case Study

• Lessons
  – Each patient’s transplant experience is unique
  – Patient’s transplant experience can be complicated
  – Patient’s families/support systems play a critical role in the transplant experience
  – Patients, families, and their support systems need support throughout the transplant process

Ongoing Issues
Ongoing Issues

- Providing continuing support for patients and families
- Making support accessible
- Recruiting patients and families for support group
- Self Care
  - Families
  - Staff

Results

- Support group in its 4th year
- More consistent outpatient attendance
- Regular family attendance
- Based on feedback
  - Changed the date, time, and location
- Consistent positive feedback
  - Patients, families, staff