Completing the Circle: Grief Management for Families and Staff Through Development of a Unit-Based Bereavement Program

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• Project work occurred while as a Clinical Nurse Specialist for the Medical Intensive Care Units at Henry Ford Hospital In Detroit
“There Is No Such Thing As a Dragon”
Worlds Health Definition of Palliative Care

- Includes the offering of a support system to help the family’s ability to cope during the patient’s illness and during their bereavement
- Implies that palliative care does not cease with the death of the patient
Definitions

• Grief:
  • Psychological, behavioral, social and physical reaction to the loss of someone or something that is closely tied to a person’s identity

• Complicated grief
  • Persistent form of intense grief in which maladaptive thoughts and dysfunctional behaviors are present along with continued yearning, longing and sadness and/or preoccupation with thoughts and memories of the person who died.

• Mourning
  • Represents the process by which people adapt to loss

• Bereavement
  • Bereavement is the state of loss when someone close to you has died

Casarett D, et al. Annuals of Internal Medicine, 2001;134:208-215
What is a “Good” Death?

• Patients & families define a “good death” is based on;
  • Physical comfort
  • The quality of personal relationships
  • Finding meaning in their life in death
  • Feeling some sense of control in the situation
  • Active preparations for death

What Took Us So Long?

- The word bereavement didn’t appear in the Nursing Cumulative Index until 1988
- Up until 1997, most of the citations are from England
- The veterinary profession has been performing this service for a number of years
Review of the Literature
Impact of Bereavement

- Decline in health
- Inappropriate health service use
- Increase risk of depression
- Sleep disruption
- PTSD
- Increase economic burden
- Increased consumption of alcohol, tobacco and tranquilizers
- Increase suicide and death

Prigerson HG, et al. JAMA, 2001;286:1369-1376
End of Life and Beyond

- Bereavement care always ends up on the bottom of the list of things to do.
- Both cure and healing falls within the responsibility of the health care profession.
- Doctors and nurses offer the most powerful kind of healing possible when they really care about someone.
- Bereavement work is part of “finishing up” for us.

Penson RT, et al. The Oncologist; 2002; 7: 251-258
Unique Opportunity

• Nurses have the best opportunity to establish a relationship of trust
• A trusting relationship is necessary to optimize the experience for the patient, family and staff
• If nursing is truly moving towards a philosophy of patient/family centered care, then it follows that this care should not end when the life of the patient ends.
Challenges Facing Nurses

- Fast pace of the hospital allows little opportunity for caregivers to process their feelings before they are expected to provide high challenging care to other patients.
- If not addressed, the nurse may decompensate if they have been unsuccessful in completing their own grief work or develop positive coping strategies.
The Cost of Caring & Not Effectively Coping

- Anxiety
- Less able to have empathetic concern for patients
- Depersonalization
- ↑absenteeism/turnover
- Inappropriate behavior
- Compassion fatigue
- Moral Distress
- Burnout
- Work-related stress syndromes

Review of the Literature:
Benefits of a Structured Bereavement Program

• Assists in resolving grief, PTSD and combating the negative health consequences of bereavement for families
• Helps staff cope with difficult deaths & bereavement issues.

• Sharing the process with family validates nurses service role issues & personal role as caregiver
• Allows for healthy reinvestment in other patients & families.

Bereavement Programs in England

• Methodology
  • Survey to 179 ICU’s-113 responded
  • 78% return rate
• Results:
  • 81% bereavement folder present
  • 53% no training
  • 54% formal staff support groups (23% in 1995)
  • 47% formal policy
  • 27% lack of adequate facilities

Bereavement Programs In Australia (2005)

- Methodology
  - Survey to 117 adult ICU’s, 99 surveys returned
  - 84.6% return rate

- Results:
  - >50% no follow up
  - 33% some form of follow up
    - Cards, letters, & occasional calls
  - 10% established program
  - ½ interested in starting a bereavement program

<table>
<thead>
<tr>
<th>Element</th>
<th>Frequency n (%) (n=86)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Liaising with critically ill patients, family and friends</td>
<td>80 (93.0%)</td>
</tr>
<tr>
<td>Viewing of the deceased</td>
<td>79 (91.9%)</td>
</tr>
<tr>
<td>Debriefing of staff</td>
<td>67 (77.9%)</td>
</tr>
<tr>
<td>Communicating death and/or other events</td>
<td>66 (76.7%)</td>
</tr>
<tr>
<td>Brochure of community services</td>
<td>32 (37.2%)</td>
</tr>
<tr>
<td>Providing follow-up (sympathy card, telephone call)</td>
<td>26 (30.2%)</td>
</tr>
<tr>
<td>Other</td>
<td>16 (18.6%)</td>
</tr>
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</table>

Bereavement Service in the US

Methodology
- 1003 surveys-237 responded
- 24% response rate

Results
- ICU’s were diverse and from all geographical regions
- 67.1% bereavement service provided by another area
- 44% interested in starting a program
- 37.1% offered bereavement services
  - 50% reported staff nurses primarily responsible
  - 62.9% condolence cards
  - 43.8% brochures
  - 36% follow up telephone calls
  - 51.7% initiated contact within 1 month
### Bereavement Service in the US: Results

<table>
<thead>
<tr>
<th>Plans to expand bereavement follow-up services (n = 89)²</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
</tr>
<tr>
<td>Yes</td>
</tr>
<tr>
<td>Do not know</td>
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<tr>
<td>Other</td>
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<table>
<thead>
<tr>
<th>Money allocated for bereavement follow-up (n = 89)²</th>
</tr>
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<tbody>
<tr>
<td>No</td>
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<tr>
<td>Yes</td>
</tr>
<tr>
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<tr>
<td>Other</td>
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<table>
<thead>
<tr>
<th>Does the intensive care unit have an end-of-life or bereavement committee? (n = 89)²</th>
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<tbody>
<tr>
<td>No</td>
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<tr>
<td>Yes</td>
</tr>
<tr>
<td>Do not know</td>
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<table>
<thead>
<tr>
<th>Use of a bereavement risk assessment tool (n = 89)²</th>
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<tbody>
<tr>
<td>No</td>
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<tr>
<td>Yes</td>
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<tr>
<td>Do not know</td>
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<table>
<thead>
<tr>
<th>Evaluation of bereavement follow-up services (n = 89)²</th>
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<tr>
<td>Verbal family feedback</td>
</tr>
<tr>
<td>Staff feedback</td>
</tr>
<tr>
<td>Survey</td>
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<tr>
<td>No evaluation</td>
</tr>
<tr>
<td>Other</td>
</tr>
</tbody>
</table>

² Number may be greater than 89 because participants could choose more than 1 option.
Bereavement Service in the US: Results

Barriers

Lack of education
Not feeling qualified
No time
Lack of knowledge on bereavement
Lack of money
Bereavement Follow-up Study

- **Methodology:**
  - 26 relatives met criteria
  - 12 were studied
  - Descriptions of non-suitable subjects outlined

- **Results:** 7 Themes
  - Needs of relatives at time of death
  - Relatives reactions to follow-up service
  - Perceived social support
  - Concurrent problems
  - Disposal of belongings
  - Expressed emotions
  - Times of emotions

<table>
<thead>
<tr>
<th>Needs at time of Death</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Communication</td>
<td>83%</td>
</tr>
<tr>
<td>Opportunity to talk</td>
<td>8%</td>
</tr>
<tr>
<td>Permission to ask questions</td>
<td>58%</td>
</tr>
<tr>
<td>Assurance of patient’s comfort</td>
<td>8%</td>
</tr>
<tr>
<td>Need to say goodbye</td>
<td>16%</td>
</tr>
<tr>
<td>Need for a calm atmosphere</td>
<td>8%</td>
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# Needs at Time of Death

<table>
<thead>
<tr>
<th>Needs at time of Death</th>
<th>Percentage</th>
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</thead>
<tbody>
<tr>
<td>Rapport with professionals</td>
<td>67%</td>
</tr>
<tr>
<td>Permission to return</td>
<td>8%</td>
</tr>
<tr>
<td>Need to go home</td>
<td>8%</td>
</tr>
<tr>
<td>Need for privacy</td>
<td>58%</td>
</tr>
<tr>
<td>Ambience</td>
<td>25%</td>
</tr>
<tr>
<td>Facilities</td>
<td>42%</td>
</tr>
<tr>
<td>Reaction to follow up</td>
<td>Percentage</td>
</tr>
<tr>
<td>-----------------------------------------------------------</td>
<td>------------</td>
</tr>
<tr>
<td>Surprise (thought nurses to busy)</td>
<td>67%</td>
</tr>
<tr>
<td>Positive feelings</td>
<td>92%</td>
</tr>
<tr>
<td>Negative feelings (not sincere)</td>
<td>8%</td>
</tr>
<tr>
<td>Permission to ask questions</td>
<td>58%</td>
</tr>
<tr>
<td>No additional upset/contact not intrusive</td>
<td>34%</td>
</tr>
</tbody>
</table>

Reasons for Staff Not Wanting To Participate in Bereavement Program

• Concern centered on whether service would be intrusive
  • Once involved informal and formal feedback from staff & families change their opinion

• Uncomfortable with providing the service & uncomfortable about refusing to participate

• Lack of knowledge on how to deal with bereaved families
What is the Role of the Caregiver & Family in the Bereavement Process?
Caregivers Role

• Responsibility in preparing the family in advance for the death of their loved one
• Provide emotional support for the family at time of death… a presence
• Compassionate attention and validation of their loss, give them permission to grieve
• Assistance in accessing resources to help with the grieving process.
Preparing the Family for the Death of Their Loved One

- Assess spiritual needs/provide support through contacting of clergy/pastoral care
- Call in additional family members
- Assist in accessing resources to take care of any legal affairs
- Education on the grief process
- Reaffirming normal emotional responses
Assisting the Family at Time of Death

- Assist the family in meeting their spiritual needs/prayer at the bedside/facilitate non-judgmental cultural based grieving practices
- Make immediately available at the time of the loss of private quiet nicely furnished room as a place for family privacy
- Arrange, if desired by the survivors, the presence of a chaplain, Minister, Rabbi or priest
- Arrange for a time and place for private viewing of the body

Assisting the Family at Time of Death

- Create a bedside environment that is uncluttered, soothing with soft lighting to minimize the impact of the stark hospital decor
- Provide assistance in obtaining those belongings the deceased brought to the facility
- Assist with the processing of documents that need to be completed (standardize the process as much as possible)

Role of the Family in the Bereavement Process

- Informing the staff of any special wishes the dying patient may have requested or the families specific request
- Inform and call in other family members
So How Might a Staff/Unit Assist Patients and Families in the Grieving Process?
Idea Development
Driving Force for Involvement in the Project

- Past experience with caring for a high mortality patient population
- Personal experience
Committee Membership
Mission Statement for the Bereavement Committee

• To provide psychological comfort to our patients’ family members and significant others by showing our continued concern during the first year of bereavement after the loss of their loved one.

• To provide an outlet for grief and a sense of closure for our staff who are involved in the care of dying patients.
Guidelines for a Bereavement Program

- What families want
- Greeting and information delivery
- Witnessing resuscitation
- Time following deaths
- Religious and cultural considerations
- Care of self and staff
- Seeking further information
- Follow-up methodology and evaluation plan

The Bereavement Program: Format

- Collect information at time of death
- Sympathy card at 2 weeks
- Phone call to the family at 6 weeks
- A letter at 6 months and then again at a year
The Bereavement Data Collection Form
HENRY FORD HOSPITAL
BEREAVEMENT FOLLOW-UP FORM

PATIENT INFORMATION

Admission Date to MCC:  
Rm. #:  
MRN:  
Name:  
Age:  
Sex:  
Marital Status:  
Dependents/Children:  
Diagnosis:  
Date of Death:  
Cause of Death:  
Staff Physician:  
Physician present at time of death:  
Care Manager:  
Nurse present at time of death:  
Chaplain present at time of death:  
Nurse present at time of death:  
Chaplain present at time of death:  
Additional Information:  

FAMILY INFORMATION

Family present at time of death:  
Family reaction:  
Closest relative(s)/significant other for bereavement follow up:  
Name:  
Name:  
Address:  
Address:  
Phone #:  
Phone #:  
Form completed by:  
Date:  

BEREAVEMENT FOLLOW-UP CONTACTS

CONTINUED ON BACK
Within 2 weeks of death:  *EXPECTED DATE:____
Sympathy card sent to:__________________________________________
Actual date sent:___________  By:_____________________________

At 6 weeks:  *EXPECTED DATE:____
Phone call to:_________________________________________________
Actual date called:___________  By:_____________________________
Comments:___________________________________________________
Referrals:___________________________________________________

At 6 months:  *EXPECTED DATE:____
Note sent to:_______________________________________________
Address:___________________________________________________
Actual date sent:___________  By:_____________________________

At one(1) year:  *EXPECTED DATE:____
Note sent to:_______________________________________________
Address:___________________________________________________
Actual date sent:___________  By:_____________________________

Correspondence from family after death:
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
Bereavement Follow-up Process: Logging the Dates

- Patient’s name is placed on the calendar that corresponds to the dates of the various activities that need to be done.
- A calendar with the 4 activities is available for each month of the current year and the following year.
Henry Ford Hospital  
Department of Nursing

MICU Bereavement Committee

Activity for Month of February, 1998

<table>
<thead>
<tr>
<th>2 Week Sympathy Note</th>
<th>6 Week Call</th>
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<tr>
<th>6 Month Note</th>
<th>1 Year Note</th>
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<tbody>
<tr>
<td>NAME/DATE</td>
<td>NAME/DATE</td>
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• At the start of a new year, a blank calendar is posted for staff to sign up for a month. Usually each month is covered by 3 staff
• The member of the month goes to appropriate date in the calendar and completes the activities
• Responsible for logging in deaths for the current month
Do not stand at my grave and weep,
I am not there, I do not sleep.
I am a thousand winds that blow,
I am the diamond glints on snow,
I am the sunlight on ripened grain,
I am the gentle autumn’s rain,
When you awaken in the morning’s hush,
I am the swift, uplifting rush
of quiet birds in circled flight,
I am the soft stars that shine at night.
So do not stand at my grave and cry,
I am not there, I did not die.

“Author Unknown”

The staff of the Medical Critical Care Area wishes to express sincere sympathy during your time of loss.

May you be comforted in knowing that we care and share in your sorrow.
TELEPHONE GUIDELINES

1. Introduce yourself as one of the nurses in the MCC who is calling on behalf of the healthcare staff. Introductory statement: “We were wondering how you are doing since your loved one (mention name) passed away.”

2. Listen carefully. Know that people will want to talk about their loss. Encourage them to do this. The task of listening is to allow grief to reveal itself.

3. Respond with empathy. Some useful statements might include; How can I help? Tell me how you are feeling, It must be hard to accept, That must be very painful, It’s ok to be angry with God, I’m sorry.

4. Avoid using judgment and authoritarian statements. Avoid statements like; It’s God’s will, I know how you feel, Time heals all wounds, You will marry again, Your loved one is in heaven now.

5. Ask how they are eating, sleeping and performing ADL’s. Find out if they are spending a lot of time by themselves. Suggest that they try to keep busy and spend time with family and friends.

6. Suggest professional help if they feel severely depressed, express that they are using drugs or excessive alcohol or if they express suicidal thoughts. Many people experience some suicidal thoughts, however, these are usually temporary. Recommending grief support groups to the bereaved has proven to be highly beneficial. Refer them to the support group information in the bereavement folder.

7. All questions about autopsy, medical records, and financial information should be referred to the general hospital information number.

8. Remember this: “The first duty of love is to listen.”
BEREAVEMENT COMMITTEE
HENRY FORD HOSPITAL
MEDICAL CRITICAL CARE POD 1

The following is a form letter guideline to be utilized for the six-month follow up note. Please include any information that may be available to personalize the note.

Dear 

It has been several months since _______________’s passing, and on behalf of the Medical Critical Care POD 1 Bereavement Committee at Henry Ford Hospital, I want you and your family to know we are thinking of you and remembering your loss.

I hope this finds you dealing with daily life and moving toward emotional peace and comfort. If there is anything we can do to help you cope during this period of transition, please call on us.

Sincerely,

Your Name/Title
Educating the Staff

- Mailbox in-services
- Monthly meetings
- Marketing plan
Mailbox Inservice

Advantages

• Reaches a broader audience in a more timely fashion

• Relieves the creator of the stress of public presentations
The Market Plan Goal

- Create links with current things happening in the unit
- Get the staff as involved in the development process as possible
The Medical Critical Care Area is an innovative, caring environment dedicated to meeting the needs of the critically ill patient and family. Our primary focus is to promote the healing process through the linking of mind, body and spirit. We work as a multidisciplinary team providing researched-based care while striving to incorporate complimentary therapies and environmental design changes that foster humane care.
Program Development Time Line

October 1995

January 1996
Evaluation of the Bereavement Program

• Family survey
• Media response
• Cards & letters for families
• Staff survey
During the past year we, the staff from Henry Ford Hospital, Medical Intensive Care Unit, have made it a goal to stay connected with you after the death of your loved one on our unit. We are asking that you take a few moments to answer some questions about our contacts. We thank you in advance for your time and thoughts.

Please circle the best response. Comments are welcomed and will help us make this program better. Please feel free to use the back of this letter if necessary. A self-addressed, stamped envelope is enclosed to return the survey.

Have our phone calls and written contacts been helpful?  

YES  NO

COMMENTS: I am SO glad you called, and have not heard well for some time, that I appreciated your letter and thank you for remembering us! Mary L. Landrum

Have our calls or letters come at a bad time or have been a problem for you?

YES  NO

COMMENTS:

Did our calls and letters come at the right times to help you?

YES  NO

COMMENTS:

What ideas do you have to make our contacts more helpful for other families in the future?

YES

Thank you again for taking the time to help us improve our program. Please return this letter in the stamped envelope provided. Once again, we hope our contacts have been helpful.

Sincerely,

[Signature]
Henry Ford Hospital
Medical Intensive Care Unit
Bereavement Committee
Bereavement Program Survey Results 1998

77 surveys mailed
28 surveys returned
36% return rate

96.4% Overall Positive

3.57% Negative
Research Data on Bereavement Programs

- Condolence letters provide a feeling of support, humanization of medical system and sometime ambivalence of the benefit without further follow up
- 1 year anniversary is the most painful for families
- 92% of all patients surveyed stated a 1 year booklet was helpful
- Including information to help with grief support and showing you remember and care at the 1 year anniversary is important

Angelucci P. Nurs Manager 1994;25:80a-80b
Process Improvement

- Bereavement packet at time of death
- Restructuring of the MCC staff letter to families
- Voicemail guidelines
- 1 year anniversary booklet
- Support literature on loss of a child (independent of age)
Process Improvements

- Bereavement Packet at time of death
- Restructuring the MCC staff letter
- Answering machine guidelines
- 1 year anniversary booklet
- Support literature on loss of a child (independent of age)
Re-Evaluation of Bereavement Program Outcomes

- Family survey
- Staff survey
- Staff personal comments
## Survey Results 2001

<table>
<thead>
<tr>
<th>Surveys mailed to Families:</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>42 surveys mailed</td>
<td>100% Satisfaction</td>
</tr>
<tr>
<td>10 surveys returned</td>
<td></td>
</tr>
<tr>
<td>24% return rate</td>
<td></td>
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</tbody>
</table>
Family Survey Comments

- It was nice to know someone was thinking about you…Friends soon forget
- Your letter just accented your wonderful thoughtfulness & treatment in my wife’s last critical days but the nurses went way past the normal routine
- Your letters at 6 months and 1 year were timed just right. The pamphlet you sent was a big help
Thank-you for this very important and needed program

Your in my heart forever, I am not so sad. I was a mess before I thought no one cared

It’s wonderful to see that such a large hospital does care and tries to help

Thank-you for what you do
Staff Bereavement Program Survey

Bereavement Committee Survey
Medical Critical Care

The MCC Bereavement Committee is seeking your evaluation of the committee. Please take a few minutes and complete this survey by April 20, 2001. Thank you in advance for your time and feedback.

Part 1. Please estimate your answers to the following questions.

1. I have given the bereavement folders to my patient’s family member.
   - Never
   - 1-5
   - 6-10
   - 11-15
   - > 16 times

2. I have made a 6-week phone call to a family member.
   - Never
   - 1-5
   - 6-10
   - 11-15
   - > 16 times

3. I have written a letter to a family member.
   - Never
   - 1-5
   - 6-10
   - 11-15
   - > 16 times

Part 2. Respond to each item below in terms of your agreement or disagreement using the following rating scale.

<table>
<thead>
<tr>
<th>SA = Strongly Agree</th>
<th>A = Agree</th>
<th>SD = Strongly Disagree</th>
<th>D = Disagree</th>
</tr>
</thead>
</table>

4. I believe the Bereavement Committee is worthwhile.

5. The Bereavement Committee is beneficial to the family of a patient who has died.

6. The Bereavement Committee is beneficial to me.

7. I am comfortable making the 6-week phone call to a family member.

8. I am comfortable giving the bereavement folder to the family.

9. The Bereavement Committee has helped me cope with death in the unit.

10. I think I am imposing on the family at the time of death when I give them a bereavement folder.

11. Overall, the Bereavement Committee is a value added to the Medical Critical Care Area.

Please return the completed survey to the envelope on your unit. Thank you for your time.
Bereavement Committee: Demographics

- 60 staff surveyed
- Response rate 63%
- > 95% participate in handing out packets & collecting information at time of death
- 71% of staff make the 6 week phone calls
- 79% of staff have written letters
Bereavement Committee is Worthwhile
The Bereavement Committee is Beneficial to the Family
I think I am Imposing on the Family at the Time of Death When I Give Them a Bereavement Folder
I am Comfortable Making the 6-Week Phone Call
The Bereavement Committee has Helped Me Cope with Death in the Unit.
Personal Comments
Additional Strategies

- Biannual memorial services
- Staff support groups
- Debriefing sessions
- Providing a brochure on end of life, longer family conference and allow more time for family to talk showed statistically lower scores for PTSD and anxiety and depression scale 90 days post death (Lautrette A, et al. N Engl J Med, 2007;356:469-78)
Goal of the Healing Environment & Bereavement Program

Caring, Comfort and Safe Passage for Our Patients and Families While Minimizing Stress Within the Environment
Circle of Life

https://open.spotify.com/track/5vKkaZHPzuqQheytfKuXzp