Too Soon

You both went away too soon
Unexpectedly, up there on the clouds
I'm down here now
Crushed, weight on my chest
There's relief, knowing that you're at rest

Christie, I love you, I miss you
I know you're in a better place
Pretty blue sky, fluffy clouds
My dad, right there, smiles on your faces
Looking down on me, I know they're proud
As I shine out loud, I shine out loud

Courage and confidence
They taught me to fight for life
Here I am, I'm here for you
And your memories, they pull me through

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Meeting of the Minds:

Compassionate care of a parent with mental illness during her child's palliative care experience

Cortney J. Taylor, Ph.D.
Suzanne Holm, Ph.D.
Aisha Jones, LCSW
Saraben Turner, CCLS
Pam Krinock, Chaplain
Olive Eckstein, M.D.

Baylor College of Medicine
Texas Children's Hospital

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Objectives

- Identify key elements of supporting a parent with severe mental illness through their child's palliative experience.
- Understand the process of supporting a child through the palliative care and dying process when their parent has severe mental illness.
- Recognize the importance of an interdisciplinary team approach to managing the effect of parental mental illness during a child's palliative care trajectory.

July 2012

- 15 year old female diagnosed with metastatic alveolar Rhabdomyosarcoma, treated on protocol TAT ARST0531 Regimen A (VCR/Irinotecan/Temodar, XRT)
- Lived with mother and 19-year-old brother several hours away from hospital
- Father deceased; two half-sisters
- Maternal paranoid schizophrenia, diagnosed 1991, history of nonadherence to medication, symptomatic
- Security involved during initial inpatient stay

Parent-Child Relationship

- Mother and patient have a strong, but strained relationship
- Parentification of patient due to mother's mental illness – long history of frustration, resentment, and embarrassment
- Reported history of intense family conflict, domestic violence, and drug use in the home – previous CPS and police involvement
- Patient took charge and competently organized her own health care and when patient was ill, mother had difficulty managing without her guidance

Medical Power of Attorney

- Patient's mother has schizophrenia and has a 20-year history of being noncompliant with her medication. She has full legal custody of the patient. Many people have expressed significant concerns about mother's ability to care for the patient's needs. How would you proceed?

1. Request that CPS evaluate the potential for medical neglect and explore foster care placement for patient.
2. Request that mother relinquish medical power of attorney for the patient to another family member.
3. Attempt to involve other family members to assist with management of mother's illness.
4. Do nothing at this time; observe and modify the plan as needed as treatment progresses.

August – December 2012

- Proceeded through treatment with minimal difficulty

- Psychosocial interventions
  - managing parent-child relationship, which continued to be close but strained
  - parental self-care
  - patient coping with hair loss, sadness, isolation
  - patient coping with the death of a friend, which brought up feelings about father's death
  - preparation for radiation therapy
  - initiation of memory making

January 2013

- Discovery of relapse
- Increase in pain
- Mother with increasing difficulty managing patient's medical needs, high distress
- Patient's primary concerns:
  - Mother's emotional health and ability to handle relapse and prognosis
  - Increasing frustration with mother's illness and side effects of medication
  - Her own coping – possibility she will develop depression

Parent Suicidality

- According to medical team report, patient's mother made suicidal statements while patient was receiving treatment on the inpatient unit. Given her mental health history and current stressors, how would you manage these concerns?

1. Provide mother with referrals to community mental health providers and assist her in making an initial appointment.
2. Contact security and have mother removed from the inpatient unit until she can get a formal psychiatric evaluation and renew discussion of issue of medical power of attorney.
3. Ignore suicidal statements as they are likely a product of her mental illness and therefore are of no consequence and she has been doing fine.
4. After evaluating mother for safety, create a step by step emergency plan to be implemented by the medical team.

February 2013

- Increased psychosocial interventions:
  - Crisis planning regarding mother, more parent focused support
  - Patient began working on Legacy of Love, other expressive activities
  - More interventions focused on mother and patient together
  - Pain management
- Mother increasingly agitated due to patient's pain, increase in observable symptoms of schizophrenia, increase in patient's frustration with mother; parent child conflict noted by both

February 2013

- Patient in and out of the hospital, primarily due to pain crises
- Concern for seizures/AMS – related code/crisis support needed for both patient and mother
- Family meeting with medical team to discuss palliative nature of care, not curative
- Strong positive communication between patient and mother observed and reported by patient – she described mother's support at comforting
- Spread of pain, concern for exaggerated pain due to anxiety, Lexapro

Hospice

- After being told there were no more treatment options, both the patient and her mother expressed their desire to go home. The patient was very happy about this option and the mother believed she could manage it. With the family history in mind, how would you respond to this request?

1. Indicate this is not a viable option due to the uncertainty of level of care and support available at home.
2. Openly communicate concerns regarding adequate support at home and create as much a homelike environment in the hospital as possible.
3. Approve the request and quickly transition patient to Hospice care confident in the knowledge that they will be able to provide adequate care of the needs of both the patient and mother.
4. Approve the request on the condition other family members, such as the brother and/or uncle also remain in the home.

March 2013

- Multiple interdisciplinary meetings to discuss continued progression of disease and active dying process
- Acute increase in mother's distress, subsequent increase in symptoms of illness and treatment effects, which leads to more parent-child conflict
- Placement of Pain Pump
- Family focused on getting home, mother expressed being unsure if she can cope with being in the hospital any longer or watching patient suffer
- Medication in pump increased, patient more sedated, mother more calm

Parent-Child Relationship

- Psychosocial interventions shifted to facilitation of communication and story telling between mother and patient and then family focused end of life planning
- Eventually little intervention was needed as the family focused on supporting each other
- Patient awoke during sedated state to tell her mother “I love you” the day she passed (March 21, 2013)

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Thank you!

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