

Faculty/Presenter Disclosure

- **Faculty: Katherine Whitehead**
- **Relationships with commercial interests:**
 - **None whatsoever!**

Optimizing End of Life Care for People With Severe Mental Illness:

OVERCOMING BARRIERS WITH SHARED CARE AND INNOVATION



Enough about you...



Attending Physician Inpatient Palliative Care Ward

Recovering Emergency Physician

Expert in Conflict

Mediator

Mother

...Ok Let's Hear About Who You Are



- Who is in the room?



Possible Learning Points for the Session:



- 1. To identify characteristics of patients with severe mental illness that may affect how they access, respond to, and engage in care at the end of life.
- 2. To identify barriers and motivators in care team members when working with people with a severe mental illness at the end of life.
- 3. To reflect on strategies to improve care through shared expertise and resource sharing between care team providers, patients, and families.

Consider...



- Mental illness affects 1 in 5 Canadians
- 1 in 17 have SPMI (Severe Persistent Mental Illness)
- 100% of people will die



T.B.



- 64 y/o man with advanced malignant melanoma
- History of Bipolar Disorder, CAD, ETOH abuse
- Main symptomatic issues: chest and flank pain
- Refuses to be examined and offers minimal history on admission
- Poor eye contact. Seems very anxious. “I don’t want to talk right now.”

J.W.



- 39 year old man
- Diagnosed with Schizo-affective disorder and depression. Has not seen a mental health professional in 10 years. No psychiatric medications.
- 20 year alcoholic
- Unemployed and living in his parent's attic.
- Occasional paranoid ideation that his immediate family is trying to kill him.
- Generally avoids his family and does most of his ADL's at night when they are sleeping.

J.W.



- Un-characteristically seeks out his father to complain of “sore throat”
- Presents with his father to walk in clinic. Refuses to be examined. Diagnosed with strep throat. 7 days of Pennicillin.
- Same complaints monthly for 5 months. 5 visits to walk in clinic. 3 courses of antibiotics.
- Presents himself to emergency at 3am (having hitchhiked there) on month 7 for throat pain.
- Diagnosed in Emergency with probable oropharyngeal tumor (grossly visible on exam)

J.W.



- Attends PMH for radiation therapy for Grade 4 oropharyngeal cancer with support from his parents
- Expresses a desire to “get healthy” and enters an alcohol cessation program
- Becomes more interactive with his family and begins spending time downstairs during the daytime
- Cancer is ultimately progressive despite treatment
- Re-commences heavy consumption of alcohol.
- Starts becoming suspicious that his family is poisoning him
- Stops tolerating PO and is encouraged by his family and oncologist to get a G tube
- Refuses G tube. Tells family “I’ve had enough”

C.H.



- 55 year old man with metastatic SCC lung
- Admitted to PCU for respite from group home due to maintenance ongoing at group home.
- Long history of Schizophrenia. Has never been employed or lived independently
- Followed by SMH outreach team.
- Brother is his POA.
- Chest pain controlled on prn dilaudid.
- Long history of incontinence.
- Often refuses basic care (ie showering, changing soiled clothes).
- Group home fears his pain is under-treated as he frequently refuses medications.

Severe Persistent Mental Illness



- Prolonged and/or recurrent mental illness causing some impairment of IADL/ADL's requiring long term treatment.
- Common examples: Schizophrenia, Major Depression, Bipolar Disorder, Anxiety, PTSD...

Palliative Care



WHO Definition:

...an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Palliative Care



Often in last months of life but don't need to be

Common issues encountered:

Pain control

Dyspnea

Delerium

Decreased intake

Weakness

Insomnia

Constipation

Thoughts/fears about end of life

Issues of worth

Issues of identity

Spiritual questions

Death Planning (wills, funerals, family matters)

No Presentation is complete without some statistics:



- VERY LIMITED RESEARCH but....
- People with SPMI:
 - Have shorter life expectancies (10 years less for people with schizophrenia)
 - At least 2x the risk of dying from natural causes at any given age
 - 35% have undetected significant medical conditions
 - Medical co-morbidity is associated with more serious psychiatric symptoms.
 - Later presentations, less aggressive interventions.

Symptomatic Care: What is unique about people with SPMI?



2/3 of people with SPMI have a substance abuse issue

Many drugs used in both disciplines have interactions

- risk/benefit at the end of life

- shared experience with common side effects

Monitoring parameters are different at the end of life

Need for security on medical ward

Symptomatic Care: What is unique about people with SPMI?



- **Mental illness itself may lead to atypical and late presentations**
 - Deterioration in mental status and psychological health can be a manifestation of increased physical symptoms
- **Mental illness may alter pain perception/expression**
 - Anxiety/Depression have variable effects
 - Some patients with schizophrenia do not willingly verbalize pain and are more tolerant to pain
 - ✦ ?negative symptom related
 - ✦ ?Incorporate pain or presumed source in to delusional system
 - ✦ Analgesic properties of antipsychotics

Access to Care



- What are some barriers to end of life care care for patients with SPMI?
- How do they access the system differently than the general population?

Access to Care



- “I don’t want to talk about that pain. Don’t touch me.” C.H.
- “If I take that medication I won’t feel it when you try to hurt me” J.W.
- “Sent to resp clinic for SOB. Sent to ER for CXR. Did not get Xray and went home. 2 month history of hemoptysis and weight loss. Back to resp clinic on Form 1. Went with case worker for Xray. Opacity L lung.” Chart of C.H.
- “I’m having a difficult time. My room mate has too many visitors. He wants to talk. I don’t. I have a lot to think about” T.B.

Access to Care



- **Barriers/access?**
 - Vulnerability
 - Fear of humiliation
 - Fear of institutions
 - Mistrust of health care system
 - Less likely to be screened
 - Less likely to be examined
 - Imposed routines
 - Invasiveness
 - Lack of control
 - “atypical” presentations
 - “difficult” histories/decline to be interviewed

Enablers



- What are enablers to care?

Enablers



- “Discussed hygiene and not going outside wet from incontinence...patient refuses care...patient asks if staff can get Tim Horton’s coffee for him...Staff was able to get Tim Horton’s coffee...Pt very happy...Pt accepted wash at bedside” Chart of C.H.
- “ I like my oncologist. It’s nice to have someone tell me things. Also it’s an activity that I have to get to. It gets me going, you know? Also Dad has to take me, which is also nice.” J.W.
- “ Went back multiple times to to encourage him to take his pain meds. Sat with him for 40 minutes when he agreed to take them. We talked ++ about his life, family, struggles....” Chart of T.B.
- “Accompanied pt to quiet space (chapel) on first floor...he expressed he would like to go back there again to enjoy the solitude.”

Enablers



- Trust
- Flexibility
- Promotion of Autonomy
- Non-abandonment
- Multi-disciplinary teams
- Variability in venues/schedule

Health Care Providers: Barriers and Enablers



- What do you find difficult about providing care to people with SPMI and life limiting disease?
- What are some strategies that have improved care in your setting?

Health Care Providers: Barriers and Enablers



- **What do you find difficult about providing care to people with SPMI and life limiting disease?**
 - Symptoms outside of my scope of care
 - Behavioural issues
 - Inability to deliver the standard of care
- **What are some strategies that have improved care in your setting?**
 - Shared expertise (between disciplines, specialties, institutions)
 - Alternate venues of care
 - Utilization of trusted persons/clinicians
 - Graded patient directed care

What makes mental health clinical care teams unique?



What makes Palliative Care clinical teams unique?



- Person centred
- Open minded
- Non conventional
- Collaborative
- Compassionate
- Holistic
- Respect for autonomy and choice
- Concern for quality of life
- Focus on family as unit of care
- Multidisciplinary team focus
- Priority given to dignity
- Focus on psychosocial care

Unique skills of Palliative Care Nurses



Nurses experienced in Palliative Care switch from “doing” to “being”

Johnston and Smith 2006 – Patients and Nurses agreed that the most essential skills of expert Palliative Care nurses were:

- Interpersonal skills (ie focused listening, connectedness)
- Caring skills (kindness, warmth, compassion, realness)

Perceived Knowledge of Health Care providers



- Polled mental health workers generally report little or no knowledge of Palliative Care
- Palliative Care providers list “behavioural issues” and “psychiatric issues” in patients as a significant source of work-related stress

Existing Integrated Care Programs



- **Cross Training:**
 - Work of Foti et al in Massachusetts : 47k patients, 58 cities/towns, cross training of PC and MH professionals.
 - San Diego Hospice (1000 patients) 1 week to year long electives in PC Psychiatry. PC psych referrals increased from almost none to 3000/year in just 4 years
- **Incorporating Mental Health Professionals in to PC teams:**
 - US DVA requires psychologist or MH professional as part of PC team. Requires at least .25 FTE per team
- **Ottawa Inner City Health Project**
- **Increased published literature and educational materials:**
 - www.promotingexcellence.org/mentalillness

End of Life Planning



- Can and should people with SPMI participate in advanced care planning?

End of Life Planning



- “Pt wants to arrange POA with brother. T is ok to have brother consulted but emphasizes that he, T, wants to be involved in all discussions” (Chart of T.B.)
- “ I have rights. I don’t want to be here. This is a convalescent home. I want to go to MY home” ...pt states that he is not happy anywhere but he wants to go back to his group home... “it’s not good but it’s my home”. (Chart of C.H.)
- “If you put one of your sh*t tubes in me I will tear it out and f**king strangle you with it.” (J.W.)

End of Life Planning



- **End of Life discussions in people with SPMI :**
 - Often do not happen
 - Why?

End of Life Planning



- **End of Life discussions in people with SPMI :**
 - Presumption of incapacity
 - Fear of emotional/psychological destabilization
 - Who are the SDM's?

Types of Advance Directives



- **Instructional:** Detailed written instructions of treatment preferences in specific situations.
- **Proxy:** appointing another person to act as a SDM
- **Hybrid:** Combine both elements

Advance Directives in Ontario



- Only proxy directives are officially recognized.
- “Power of Attorney for Personal Care”.
- Some include instructions to guide SDMs.
- Can be used in Consent and Capacity Board situations.

Psychiatric Advanced Directives



An Instructional AD

A variation of a concept originally used for end of life care

Used in the event of mental incapacity

Advantages?

Drawbacks?

Psychiatric Advanced Directives



Improves autonomy

Increases involvement in medical decision making

Almost never used to refuse all care

Most common use is to list specific medications that are not desired or to refuse ECT

76% of people with mental illness prefer instructional to proxy directives (what does that tell us?)

End of Life Planning



- **4 abilities for decision making (MacCAT-CR tool) :**
 - To understand the relevant information
 - To appreciate the information
 - To use recognizable reason and logic
 - To express a stable choice

- No “perfect test”

End of Life Planning



- Greater capacity needed for a more complicated choice?
- Decision making capacity is specific to a particular decision or task (not to a diagnosis) .
- Life experience has been different and so too may be end of life choices.
- People who are competent have the right to make “bad decisions” .

Ambrosini et al, 2012



- Use of facilitated interviews to create PADs
- 10% vs 70% completion rate without/with interview
- Decisions are possible but more investment is needed for the mentally ill.

Foti et al, 2006



- Use of a structured interview
- Majority of people with SPMI are comfortable discussing end of life topics
- Only 4% reported a great amount of stress with interview
- 77% participated in follow up interview
- 71% understood questions without clarification
- 70% interested in designating a health care proxy (comparable to GP)
- Good reliability between self and hypothetical person choices
- Overall preferences are for more intervention and display less trust in health care
- Similar to other populations marginalized by healthcare.

End of Life Planning



- **Concerns of people with SPMI at the end of life:**
 - Financial burden on family or loved ones
 - Emotional burden on loved ones
 - Being in pain/suffering
 - Interpersonal issues (i.e. leaving loved ones)
 - Funeral arrangements/disposition of body
 - Spiritual Concerns

Supporting Families, Friends, and Patients.



- End of life is often a time of interpersonal reconnection.
- Mental illness leads to increased incidence of estrangement from family/loved ones.
- SDMs struggle with their role (pt decision making when “well”, guilt, impaired connection, estrangement) .
- Patients can struggle with asking people for help.
- Encouraging early dialogue does no harm and often provides a superior result for all.

Provision of Care



- “Optimal care” may need to be re-defined
- Management decisions which maintain relationship
- “Am I making this decision because something is difficult for me or because it’s what’s best?”
- Advocate for the individual. Work as a team.
- Periods of lucidity are great times to make decisions and provide care
- Active listening
- Use of familiar/trusted care-givers and friends
- Facilitating self reported importance
- Flexibility on location and timing of care
- Non-abandonment is key