

Intimate Strangers

Social Work Palliative Care with Older Adults

A Homecare Perspective

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Intimate Strangers - Social Work and Social Service Work in Palliative Care

Intimate

- Marked by close acquaintance, association, or familiarity.
- Relating to or indicative of one's deepest nature

Stranger

- One who is neither a friend nor an acquaintance.
- A visitor or guest.

<http://www.thefreedictionary.com/intimate>

What is palliative care?

Palliative care is a special kind of health care for individuals and families who are living with a life-threatening illness usually at an advanced stage.

(Health Canada: Division of Aging and Seniors)

Palliative Care is the physical, emotional, social and spiritual care given to a dying individual and his or her loved ones where active treatment is no longer the goal.

(Five Hills Health Region, Saskatchewan)

Canadian social work competencies – task force discussion

- Historically the role and functions of social workers Hospice Palliative Care and not been clearly defined
- A national task force of educators and practitioners were brought together to help identify competencies necessary for practice
- 9 people came together from across Canada and the production was supported by a financial contribution from the Secretariat of Palliative and End of Life Care, Health Canada.
- 11 competencies were identified
- These competencies are meant to be used as a framework that are relevant in any setting.
- The direct application of these competencies may vary across setting and by different practitioners depending on experience and education.

(Canadian Social Work Competencies for Hospice Palliative Care: A Framework to Guide Education and Practice at the Generalist and Specialist Levels, 2008)

Competencies as outlined by the task force

- Advocacy
- Assessment
- Care delivery
- Care Planning
- Community Capacity Building
- Evaluation
- Decision making
- Education and Research
- Information Sharing
- Interdisciplinary Team
- Self reflective Practice

Each competency has attached to it descriptions involving Attitudes and Values; Knowledge and Skills.

A Homecare experience : Practice with clients

- ❖ Referrals come through the Palliative Care team at the Community Care Access Centre
- ❖ Scope of intervention varies depending on needs of the client and where they are in their journey
- ❖ Interdisciplinary team involved including: Pain and Symptom management physician, nurse practitioners, nurses, PSW's, Occupational Therapists, Social Workers, Physiotherapists, Speech Language Pathologists, Dieticians, depending on the needs of the client
- ❖ Social Workers will support family until death of the client dependent on if client is subsequently hospitalized or not
- ❖ Clients may choose to die at home or opt to go to Hospice when they are EOL
- ❖ Work involves the client as well as the family.

Common issues that arise include but are not limited to:

- A. Adjustment Reaction to Diagnosis/Prognosis
- B. POA/Substitute Decision Maker Discussion
- C. Advanced Directives
- D. Caregiver Support
- E. Financial Guidance
- F. Spiritual and Emotional Support

Adjustment Reaction to Diagnosis/Prognosis

- ❖ Assessment of client and family is critical at this point.
- ❖ Important to start where the client and family are at
- ❖ Reactions to diagnosis/prognosis are as diverse as every individual client
- ❖ Discussion with client/family is often dependent on how far the illness has progressed
- ❖ Determine what plans and wishes of client and family are
- ❖ Often times the referral is made when client is EOL and Social Workers role is short in time
- ❖ Therapeutic intervention dependent on client's and families unique views on death and dying

POA/Substitute Decision Maker Discussion

- Involves discussion with client and family about who will make the decisions involving care if client is no longer able to speak for themselves
- Encourage clients and families to speak to a lawyer
- May need to educate clients and families about the difference between Power of Attorney for Personal Care, Continuing Power of Attorney for Property and Substitute Decision Makers.
- According to a 2004 poll by Ipsos-Reid, 47% of Canadians had not designated a Substitute Decision Maker to make health care decisions for them and less than 44% had discussed end of life care with a family member
- Seniors over 80 represent the fastest growing age group with 1 in 5 of them dying in hospital, although many of them would prefer to die at home, confirming the necessity of these very important discussions and decisions

Advanced Care Planning and Advanced Directives

- Voluntary process
- Involves planning for a time when you may not be able to make decisions about your own health care
- It does not include consent to treatment. This must be provided by client or POA/SDM
- It is a way of making last wishes known, which the POA or SDM must carry out
- It's best to have the advanced care plan written out or be communicated with the family member that is trusted to act on behalf of the client
- Social Workers and Social Service workers can assist in facilitating the discussion if the client is capable.
- Interdisciplinary collaboration is often required to ensure these wishes are met.
- Social Work may be required to have discussion about Advanced Directives i.e.. DNR or Full Code. This discussion should be in collaboration with Medical professional.

Caregiver Support

- Social Workers work with family members to assist them in their needs
- Advocate for respite care in the home, emotional support
- Families react to death and dying in diverse ways
- Important to use active listening skills to determine how best to assist caregivers
- Work with anticipatory grief along the projectory of the client's illness
- Assist in finding resources for caregivers, which could include support groups and practical community supports to assist with caregiving
- Again..important to start where the caregivers are at, respecting the diversity of reactions to end of life concerns.

Financial Guidance

- Can include working together with interdisciplinary team to determine what financial resources are available to clients and their families
- Connect clients and families to legal resources if necessary to discuss financial issues
- Advocate for income support

Spiritual and Emotional Support

- Must be able to discuss issues and concerns about end of life with sensitivity and a good sense of self awareness and comfort
- Must be open to dialogue despite personal beliefs and respect clients and families belief systems
- Connect clients and families with faith communities if they are not connected and if that is what they wish
- Follow client's and families lead. They may want to discuss their concerns separately
- Must be able to be empathetic, in the moment with the client and their families but not over involved or over emotional

Client Scenario

Mrs. White

Has been diagnosed with a terminal lung cancer with bone mets and wishes to die at home. She lives with her partner of 16 years however, she is still legally married to someone else. Her adult children are not involved as there has been much conflict. John, her partner, has agreed to care for her as she progresses through her illness. John has support from the interdisciplinary hospice team and is managing well with Mrs. White's care. Through your discussions with the couple you learn that they are confused with the difference between Wills and POA/SDM. There is no POA in place. The adult children become involved after finding out their mother is terminally ill and demand to take over her care, wishing to place her in Hospice care. They argue and fight with Mrs. White's partner. Mrs. White has made her wishes to die at home known to the Palliative Care Team. Mrs. White, frustrated with the fighting, asks you to call Hospice to determine if this is a bed. She is clearly torn and still capable of making her own decisions. Where do you go from here?

Things to remember from the field – Words from a Homecare Social Worker

- Some people are afraid to talk about death, some aren't. Be prepared for both. Use your clients language to talk about their experience. Help your dying client to express their wishes to their family members and care team
- Don't tell someone they are dying. That's not your job. If they tell you they are, then talk about it. Consult with team to determine what the client knows or accepts.
- Remember that you are someone outside the family to talk to. They don't want to worry how their words impact you. Let your clients know by your words and actions that you can "hear whatever they have to say to you"
- The best thing that caregivers do for themselves is to eat health and get sleep. Encourage it and discuss with them.
- Whether your client is dying or caring for someone who is dying they need to let their tears flow. However, if they can't stop crying they may need to talk to a doctor.
- Working in HPC often reminds us of our own mortality
- Sometimes clients who have been classified as palliative don't die. Help them to adjust to their new reality
- As a social worker, social service worker, cry as little or as much as you need to. Try not to cry in front of your client. A tear or two makes you human. Sobbing suggests that you are identifying with your client and not maintaining professional boundaries. If you are struggling as a professional see supervision and talk to your colleagues.

Challenges

- Referrals are made when the client is actively dying and all advanced directives, SDM are in place. Social work support is sometimes short in duration
- When a dying client goes to Hospice care the community social worker role often ends abruptly.
- WWCCAC homecare allows one bereavement visit amongst all professionals on the team. Given the intimate nature of the relationships with clients and their families this can often add to the feelings of loss.
- Challenging clients and families may find themselves with limited resources i.e. shelter and housing
- When client's and families views and wishes do not come together.
- Lack of hospice beds.

Reflection

- Important to get involved with HPC network in your professional community to stay current with trends and best practices
- Self care is very important
- Communication among interdisciplinary team is vital for care planning and client and caregiver support
- Must have a high level of self awareness with regards to own beliefs on death and dying.
- Each client and each family member is unique. Although there is a framework to help guide palliative care work, there are no scripts to follow. Most important to begin where the client is at.
- Bereavement support must extend beyond death. There is much work to be done to acknowledge the importance of the therapeutic relationship. Social Workers and Social Service workers working in HPC must advocate for a continuum of service that encompasses caregivers after the client has died.



“Death is not the opposite of life, but a part of it.”

— Haruki Murakami, *Blind Willow, Sleeping Woman: 24 Stories* (Japanese writer)

Questions?