What Matters Most for End of Life Care? *Perspectives from Palliative Care Providers*

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BACKGROUND

Some research has documented what matters most in end-of-life (EOL) care from the perspective of seriously ill patients and their family members; one study reported the most commonly cited value being trust and confidence in the care team, while other studies have identified that pain management matters the most. In many of these studies, quality EOL is defined through the perspectives of patients and families, who each have only one experience with EOL care. Palliative care providers are involved in EOL care everyday and may have a different perspectives.

STUDY OBJECTIVES

The purpose of this study was to define quality EOL care from the perspective of palliative care providers including nurses, physicians, allied health professionals, and service managers, who have daily encounters with death and dying.

METHODS

Palliative care teams were selected from 15 regions across Ontario; these teams were exemplars of palliative care innovation or newly evolving

Brockville and District Hospice Palliative Care Service/ South East LHIN
Cambridge Palliative Care Team
Central LHIN Palliative Care Team
Central West LHIN
Guelph Palliative Care Team
Hamilton Central (HNHB LHIN)
Kitchener-Waterloo Palliative Care Team
Mississauga Halton LHIN

Niagara North Palliative Care Team
Niagara West Palliative Care Team
Pain and Symptom Management Consultation Service (PPSMCS), Champlain LHIN
Stedman Palliative Care Outreach Team, Brantford ON
Temmy Latner Centre for Palliative Care (TLCPC) Team, Toronto ON
Toronto Central LHIN
Upper Grand Wellington Palliative Care Team

Semi-structured, in person interviews were conducted from February - August 2013, with 107 front-line, managerial, and administrative staff involved in EOL care. Palliative care providers were asked the following question:

"What Matters Most for End of Life Care?"

Written and verbal responses were documented

ANALYSIS

Qualitative data were transcribed and responses were analyzed using thematic coding and a grounded theory approach. 40 unique themes defining quality end-of-life care emerged from the data. These themes were then grouped into 9 major themes to better assist in interpreting all the data.

RESULTS

Study Sample:

Provider Type/Years in Current Role	Physicians	Nurses	Other – with patient interaction	Other – limited patient interaction	Total
0-5 Years	6	19	10	10	**45**
6-10 Years	2	13	4	1	**20**
11-15 Years	1	5	2	1	**9**
16-20 Years	2	5	3	-	**10**
21-30 Years	4	2	2	-	**8**
Unknown	5	3	3	4	**15**
Total	**20**	**47**	**24**	**16**	**107**

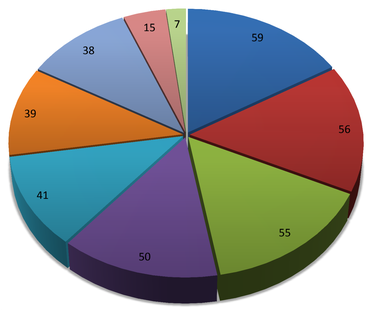
Other – with patient interaction includes: allied health professionals, personal support workers (PSWs), etc.
Other – limited patient interaction includes: service administrators, managers and directors

Top 10 of 40 unique themes that emerged from the data:

- Patient Wishes are Fulfilled
- Pain & Symptom Management
- Family Needs are Supported
- Providing Holistic Care (physical, emotional and spiritual)
- Patient is comfortable
- Health care team assists in emotionally preparing the patient for death
- Patient is supported
- Death in place of choice
- Health care team is accessible and provides timely care
- Patient is treated with respect

9 Major Themes (Grouped):

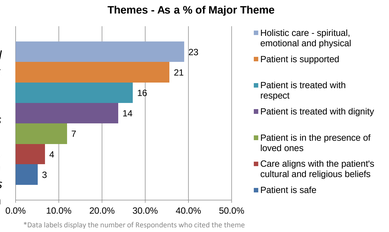
- Addressing the Non-Physical Needs
- Healthcare Team's Nature of Palliative Care Delivery
- Patient Wishes are Honoured Throughout the Care Journey
- Addressing the Physical Needs
- Preparing for and Accepting Death
- Communication and Relationship Development
- Involving and Supporting the Family
- Understanding the Patient and Family Experience
- Society & the Health System Have a Culture of Supporting Palliative Care



N = number of unique Respondents who cited the major theme

Major Theme #1: Addressing the Non-Physical Needs

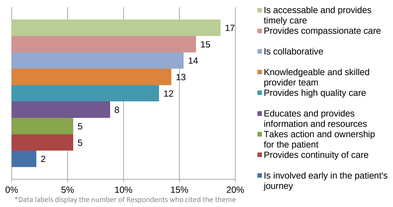
"*Its management of all of these issues, it's not just pain, it's not just nausea, it's not just shortness of breath it's this management of psycho-social struggle, the psycho-social pain and suffering that goes with dying*" – Stedman



*Data labels display the number of Respondents who cited the theme

Major Theme #2: Healthcare Teams Nature of Palliative Care Delivery

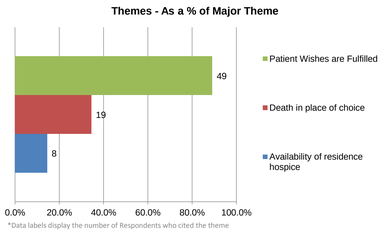
"you need to have somebody that's knowledgeable in that, you need to have a team that's talking to each other, that's cohesive and that has all the same information that like I said isn't going to repeated by fourteen different people" - Central



*Data labels display the number of Respondents who cited the theme

Major Theme #3: Patient Wishes are Honored Throughout the Care Journey

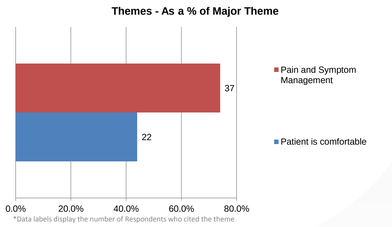
"I think it's really trying to have a successful end to life that is comfortable, and in accordance to whatever the individual preferences are, with minimal stress and burden on their loved ones." – Mississauga Halton



*Data labels display the number of Respondents who cited the theme

Major Theme #4: Addressing the Physical Needs

"symptom management, that's vital, there is nothing worse than dying in pain." – Waterloo Wellington



*Data labels display the number of Respondents who cited the theme

KEY FINDINGS & FUTURE RESEARCH

Key Findings:

- Four of the top five themes were also among the top 4 major themes. There were no differences in the relative importance of major themes by provider types
- Quality end of life was described as a multifactorial approach that addresses needs across a variety of care domains (pain management, patient control, family care, peace, etc.)
- Fulfilling patient wishes was the most dominant theme cited in this study
- Addressing the Non-Physical Needs was cited more than Addressing the Physical Needs

Future Research & Considerations:

Results from this study will help to denote areas for future research. It is important to consider:

- Whether our healthcare system currently delivers palliative care that aligns with what matters most in EOL care
- Whether our healthcare system is equipped to provide quality EOL care that's patient centered and customized
- The extent to which provider's perceptions of what matters at EOL are similar to those of patients and caregivers

STUDY LIMITATIONS

This study includes perspectives from community-based providers only and from providers who worked in existing interdisciplinary community-based teams.

CONCLUSIONS

This study was conducted to capture the definition of quality EOL care from palliative care providers.

We learned that:

- Quality EOL care extends beyond managing the physical pain, but includes a holistic perspective of care, patient control, and a healthcare team dedicated to the palliative journey.
- Tailoring the provision of care to consider these important elements plays a critical role in supporting a positive EOL experience for patients and families

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