Understanding consumer and community perspectives on End of Life Care

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Service Improvement

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Summary

Five focus groups were held with a total of 21 consumers who were either receiving services as they approached the end of life, or had cared for patients who had received End of Life Care (EOLC) on

the Sunshine Coast. Participants completed three main activities:

- Part 1: A story telling exercise where each participant took turns to share their story about EOLC on the Sunshine Coast.
- Part 2: Considering what they thought was a ‘good death’ and mapping the care network that supported them and the types of caring activities that took place in the network, such as domestic, emotional and health care.
- Part 3: A group exercise where participants identified perceived gaps in end of life care on the Sunshine Coast.

Key dates

Jul 2016

Jun 2017

Implementation sites

Sunshine Coast Hospital and Health Service

Key Contacts

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Aim

The goal of this project was to collect consumer stories, feedback and suggestions about their experience with end of life care to better understand consumer perceptions of care provided to patients at the end of life and how services could be improved.

Benefits

The benefits of this project include:
? First-hand feedback can be collected directly from consumers, their families and care partners.
? Demonstrating genuine consumer engagement and empowerment.
? Being able to acknowledge consumers as valuable participants in evaluation and planning, particularly as they may raise issues not known to the health service and provide suggestions for improvement that may not previously have been considered or prioritised.

Background

In 2015, Queensland Health released the statewide strategy for end-of-life care (The Strategy). Four service directions are outlined in The Strategy, with Service Direction 3 focusing on the way public health services “consistently responds to the needs of patients throughout their illnesses and meets established clinical safety and quality standards” (p.7). The Sunshine Coast Hospital and Health Service (SCHHS) End of Life Care Committee (EOLCC) is driving a continued program of work to embed the standards outlined in the Strategy into SCHHS core business.
The EOLCC is committed to ensuring consumer views and priorities are central to the work we do. Hospitals sit within communities and to provide a truly person-centred service, a greater understanding of how our services interface with the community itself is required. Professional service providers are a vital component of support networks but are not central. Evidence is emerging from sociological studies around naturally occurring social networks and the importance of social capital in enhancing those networks to provide support for everyday tasks such as shopping, transport, pet care or meal preparation. The absence of these supports is a common factor leading to ‘social admissions’ to an acute care facility, or reduced capability for managing a home death.

Solutions Implemented

This consumer focus group approach was found to be effective in eliciting feedback about consumer feedback, and this method will be used on an annual basis as a regular quality improvement activity. A detailed outcomes report is available on request.

Evaluation and Results

Participants’ stories were analysed to determine if there were consistent themes emerging. The five most prevalent themes were:

- Burden or impact on the patient of their family: participants spoke about the impact of illness on the person approaching the end of life, themselves, and family or carer.
- Support received: Participants described the professional and non-professional support received from their local community, friends, family and health care organisations.
- Illness trajectory and treatment: This included the impacts of the often-changing illness trajectory or sudden death of a loved one.
- Resilience and spirituality: How participants found meaning as they or their loved ones approached the end of life.
- Relationships: The relationships people built with staff, family members and members of their local community.

Positive influences on care were described, including when people received meals, practical support and donated goods.
Negative influences were cited as friends or family who did not acknowledge what was happening to the person who was approaching the end of life, or communication breakdown between doctors and consumers.

Lessons Learnt

This project was considered a valuable piece of work that will inform the EOLC Committee workplan for the coming years. It is planned that the focus groups will be conducted annually, albeit with fewer sessions. This will allow measurement of progress over time and to determine whether issues of importance to consumers are being adequately addressed. The following areas have been identified in particular:

1. Continuing to value and support our EOLC Committee Consumer representatives
2. Considering how the SCHHS can collaborate with other organisations in any further community development project opportunities that can support people at the end of life, their families and carers (eg local Council and Healthy Ageing network)
3. Supporting clinical teams to address areas of concern to patients, their families and carers, such as:

- Supporting people to have control over choices for treatment and care
- Supporting carers and families, by connecting them with other people and services within their existing communities
- Advance care planning
- End of life care guides and information, such as about services available and how to access them
- Improved communication between and within health services and health professionals
- Support for coordinating care plans, such as through a key contact

- Maintaining a person’s individuality through the end of life.

References

Jackson Foster, L. J., Deafenbaugh, L., & Miller, E. (2018). Group metaphor map making: Application to integrated arts-based focus groups. Qualitative Social Work, 17(2), 305-322. Horsfall, D., Noonan, K. & Leonard, R. (2012) Bringing our dying home: How caring for someone at end of life builds social capital and develops compassionate communities, Health Sociology Review, 21:4, 373-382, DOI: 10.5172/hesr.2012.21.4.373 Rosenberg, J.P., Horsfall, D., Leonard, R. & Noonan, K. (2015) Informal caring networks for people at end of life: Building social capital in Australian communities, Health Sociology Review, 24:1, 29-37, DOI: 10.1080/14461242.2014.999400 Queensland Health (2015). Statewide strategy for end-of-life care. Brisbane: Queensland Health.