Hospice of the future: partnering with the next generation



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Background

Co-designing services is increasingly recognised as an important means of ensuring the development of people-centred services. Whilst young people have been consulted when designing children's services, they are rarely involved in the design of adult services.

Aims:

1. To engage with young people

2. To explore their attitudes towards Hospice and hospice care

Methods

Results

- "Listening Events" were held in three secondary schools on the Isle of Man (IOM) as part of the Physical, Social and Health Education (PSHE) curriculum.
- Following question 1, Hospice clinicians and researchers delivered a short educational presentation on Hospice IOM and hospice care more broadly. This helped students answer questions 2 and 3.
- Students discussed questions among peers, then summarised their thoughts on Post-it Notes[®], which were analysed using Braun and Clarke's¹ description of thematic analysis.

Three questions posed to students

- 1. What do you know about Hospice?
- 2. If you or a member of your family became seriously unwell and needed Hospice's services, what would be most important to you?
- 3. Thinking about the future, what could we do to make Hospice a better service?

203 students 105 male (52%) 98 female (48%) Aged 11 to 16 10 PSHE classes

- Students gave vague to detailed descriptions of Hospice's identity. Language surrounding "helping" and "caring" was used.
- Some recognised that Hospice "helps people who are terminally ill", whilst others referred to "illness" in more general terms.
- Many students knew nothing about Hospice.

"A hospice is where people with a serious illness go so they can look after them. And if they pass away, they don't have to pass away in a hospital."

"Gives people a better life when they are ill."

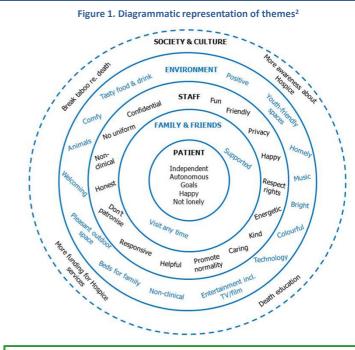
"I'll be honest, I've never heard about it."

- Students wanted to be "treated like a normal person", which includes respecting their rights and independence, offering distractions from illness, and supporting them to fulfil goals in a youth-friendly environment.
- Person-centred support for friends and family was important to young people. This includes access to Hospice and respite.
- Students wanted kind and caring staff to provide comfort and alleviate physical and psychological symptoms.
- If patients were unable to stay at home, the Hospice should be a comforting, home-like environment.
- "I wouldn't want anything to be intimidating or scary and I wouldn't want a constant reminder that something was wrong with me."
- * * To feel supported but for the nurses to be realistic and not act like

everything's ok."

"To be able to do things that they want to do before they die."

"That once I die my family are looked after."



- Students suggested increasing awareness and understanding of Hospice by engaging with local communities and schools.
- Many students recommended expanding the workforce and services provided, including respite and in-patient beds.

"Make people more aware of it as I didn't really know much about it and now I do know I would feel better going into Hospice knowing I will be looked after."

"More beds so more people can be seen/looked after without a worry to get one of the limited beds."

Conclusions

- Young people provided many valuable and thoughtful suggestions that were used to inform Hospice strategy and service design.
- Community engagement programmes may strengthen relationships between Hospice and the Island's next generation.

References

¹Braun V, Clarke V. Using thematic analysis in psychology. *Qualitative Research in Psychology*. 2006;3(2):77-101. ² Diagram drawn from: Bronfenbrenner U. *The ecology of human development: Experiments by nature and design*. Cambridge, MA: Harvard University Press; 1979.

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