Introduction

Palliative medicine is a speciality for people living with a serious, often life limiting illness. It focuses on providing symptom management to patients and relief from the stress of their illness. Palliative care is an area of medicine that I'm particularly passionate about. I was inspired by the book *With the End in Mind* by Kathryn Mannix, a palliative care consultant. She says that life expectancy has increased, and people are gradually declining, rather than suddenly dying from an acute infection. People's experiences of illness have changed massively and now there is chance for cure of postponement of death, which was historically not possible. This has led to most ill people being rushed into hospital for treatment when that might not be the most appropriate option. This does enhance and save many lives, but for some people there comes a point of futility. The death rate of the population is 100% - I want to go into palliative care to have these conversations with families, to ensure that patients have a peaceful end, when the time is right. I want to be able to support patients and their family in their final days.

The aim of this project is to investigate what palliative care medicine does well and common areas for improvement. I want to know what patients believe that this sector is doing well and also not so well, so I can incorporate this learning into my practice as a medical student and, eventually, doctor. Learning from success is as important as learning from mistakes.

My own assumptions of what I'd find were: communication would be polarizing- people would write if it was terrible or excellent. I was expecting to see 'compassion' coming up positively.

Methods

To achieve my aims above, data from Care Opinion were analyzed. Care Opinion is an online platform on which patients and their family share their stories, positive and negative, to help elicit positive change in health and social care services. The platform has multiple visualization tools and a search engine that allows the user to specifically search for areas of medicine and healthcare providers. Stories are rated by criticality from 0 (positive)- 5 (less likely to be published due to the likelihood of a formal/ legal proceeding). Criticality is determined by the most negative part of the story- even if the majority is positive, it may still get a high rating. Each story has different 'tags' associated with it- key words that define positive or negative factors within it. 100 stories published between 01/03/2021 and 02/03/2022 on Care Opinion were analyzed, with the tag 'palliative care' . The time frame was chosen as Care Opinion don't accept stories from patients that are older than 3 years- this is due to the fact that services evolve so quickly, it is unfair to publish a story before this as it may not be representative of the current service. I chose 1 year rather than 3, to narrow down the search, allowing me to examine the stories more deeply.

Out of 100 stories, 0 had a criticality of 5, 2 had a criticality of 4, 6 had a criticality of 3, 5 had a criticality of 2, 1 had a criticality of 1 and 86 had a criticality of 0.

Using the 'sunbeam' visualization tool, it was possible to focus on stories of different criticalities and the different tags associated with them were analysed. I also searched 'criticality greater than zero' to look at critical stories and 'criticality equal to zero' to look at positive stories.
A report for stories tagged with 'palliative care' was undertaken.
Stories were separated into positive (criticality = 0) and critical (criticality ≥1) stories. The tag bubbles visualisation tool was used to examine the key aspects of the stories. Some stories were copy-edited for clarity.

Results

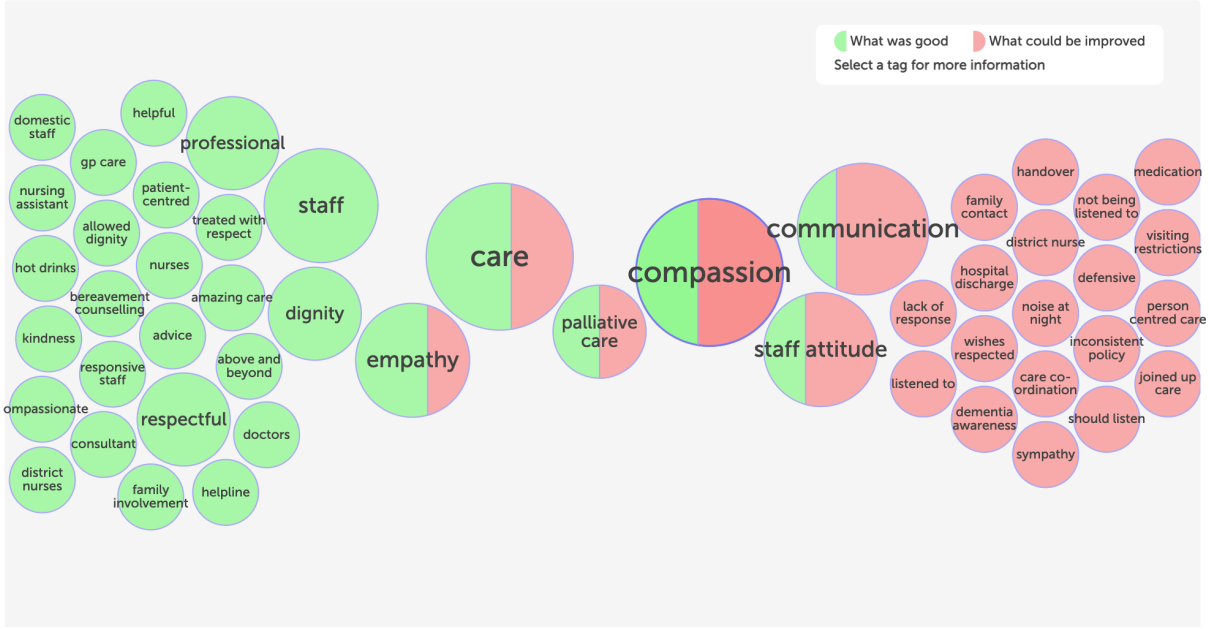

Figure 1- tag bubble visualization of 14 stories between 01/03/2021 and 02/03/2022 with a criticality greater than 1

In stories with a criticality greater than zero (figure 1) (14%), the common themes for improvement were: compassion(3% stories), communication (3% stories), staff attitude (2% of stories overall), care (2% stories).

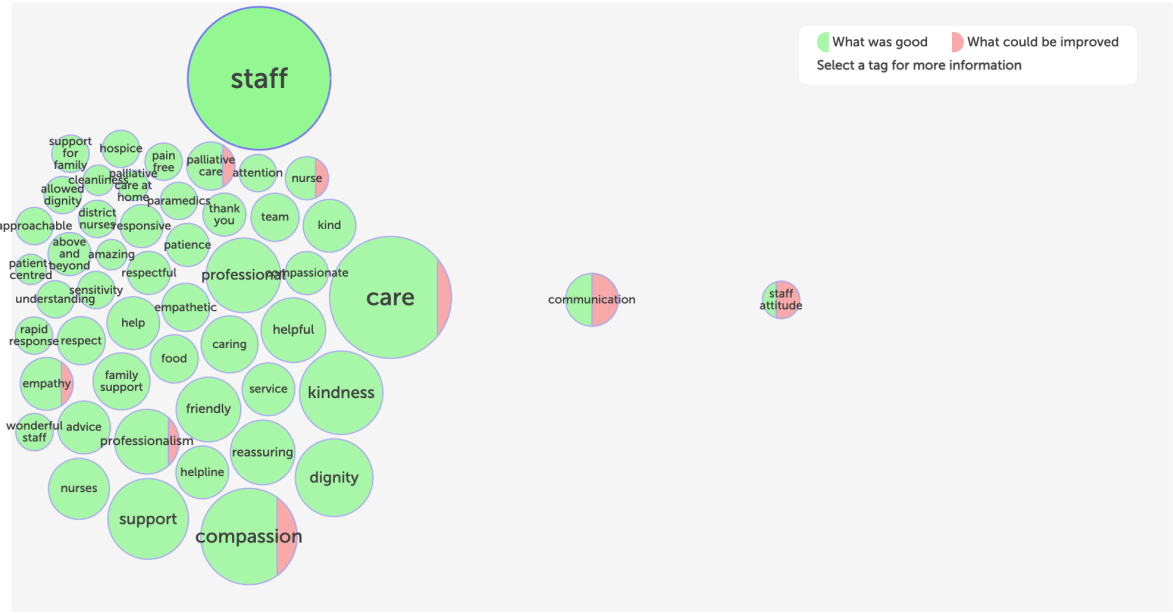

Figure 2- tag bubble visualization of 100 stories between 01/03/2021 and 02/03/2022 of all criticalities

In all the stories analysed, tags with 'staff' and 'care' were cited as the stories with the most positive tags associated with them (figure 2).

Figure 3- tag bubble visualization of 86 stories between 01/03/2021 and 02/03/2022 with a criticality equal to zero-

Discussion

Overall, 86% of stories written about palliative medicine were positive. There was huge variety in what people thought palliative care did well. In some cases, the same tag was written about both positively and negatively. An example of this would be communication.

Communication

Communication was mentioned positively in 3% of stories and negatively in 3% of stories. Communication is what is mentioned most often, negatively out of all the tags. Patients do not seem to notice it as much when it is good/ adequate. When it is written about negatively, the author seems to go into great detail. When it is positive, however, it is often a sentence. Some stories (e.g. 895631), have a positive communication tag but do not explicitly mention it.

'….The sensitive communication from the Doctors and Nurses allowed us to be involved in all aspects of the decision making care process, for this we are truly grateful….' [908666]

'…the communication from Kilbryde Hospice was superb….' [904673]

The following story is a pertinent example of when communication between staff and the family and also inter staff communication can be improved upon.

> *'In the early hours of the morning, our Dad was admitted to hospital whilst on holiday….He was diagnosed with lung and bone cancer in July ….and was awaiting radiotherapy and chemotherapy…….the next day my mum visited ……The day after, early morning my mum contacted MAU at around 845 and was informed that my Dad was really unwell and that she should come in straight away, along with my brother. A short time after this I received a phone call in Kent and was told that I should make the journey to Devon as Dad was not likely to make the end of the day…… Upon hearing this prognosis, my Dad decided that he just wanted to die……It was agreed to keep him on the fluids and antibiotics until I arrived that evening……Several Doctors visited during the day the next morning to check on Dad and the prognosis remained the same. ……At around 330pm that afternoon a nurse visited Dad and I - from the Palliative Care Team. She said dad looked so much better. Those meds she prescribed for him three days earlier had obviously worked. I was completely gobsmacked. This nurse informed us that she had diagnosed Dad with hypercalcemia on Friday and had immediately prescribed drugs. She informed us that these drugs take approximately 2 to 3 days to work. She recommended that we get Dad home asap to get his radiotherapy treatment.' [887947]*

It would be of interest to understand the full backstory- was there justification as to why the family was not told this? What was the staffing

like- do they rely on locum doctors and bank/ agency staff which would reduce the consistency of care? There was an response from the organization, in which the responder gave contact details for the author to discuss the matter further. Evidence of this or an online conversation of how the service works and what could have gone wrong would have been useful.

From my own experience, you can think you've had one conversation with a patient, to then clarify and realise that they have interpreted it in a completely different way. This is especially true when a person is stressed. In this case, how can misinterpretation be minimized in this setting. It could be suggested to have the conversation with the patient/ family member then ask how they will relay it another person to clarify understanding. The clinician could then write down all the main points of the conversation, for the person to look at later after they have absorbed the initial conversation.

Compassion

Stories with tags of 'compassion' (20%) (n=24) and 'compassionate' (4%) (n=4).

'My father was on end of life care, every time I visited him I was met with confusion and a lack of compassion from staff, appearing to be unknowledgeable in team coordination and how to speak to someone with dementia.' [844575]

'….we felt like we were treated with no compassion or empathy…. we were treated with rudeness by our local hospital but also by Rennie Groves Hospice at home who felt that a visit for a which chit chat every two weeks was enough when we were dealing with a terminally ill person…When I phoned up begging for help I found staff to be dismissive and then felt accused of not looking after her properly' [873477]

In instances where compassion was cited as negative, it is recommended to investigate further. For example, looking at staffing that day/ overall (the person could have been particularly stressed), the number of patients in, how many days that member of staff had been working for. There is also the possibility that staff members who were perceived as lacking compassion had personal stresses going on.

*'The outstanding care given to my dad over the last few weeks culminating in his admission to Kilbryde Hospice …. the team there treated him with compassion and respect so that he settled in quickly and begun to look forward to his weekly visits….the communication from Kilbryde Hospice was superb …. **always treating my dad as a unique individual and invariably making me feel that nothing was too much trouble**. My dad told me that "**the staff there seem to enjoy my company"…'** [904673]*

'A positive instance I would like to highlight involved a nursing assistant who truly went above and beyond his duty of care to offer my mum and I blankets,

comfortable seating, hot drinks and a friendly smile and a laugh. All of these things seem so minor but when you have been sat by a bedside for hours upon hours, they make a huge difference.' [902504]

Positive comments of compassion highlight the staff empathising with the needs of the patient and family e.g. 902504, the nursing assistant remembering to also look after the family present. Treating the person as an individual goes a long way too.

Conclusion

I was surprised at the fact that even in stories with a high criticality rating (4), the authors often still had a lot of positive things to say about the NHS and care that was delivered, despite what was often a traumatic experience

A major limitation with this data is that it only gives one side of the story and it is a perception of that in a time of great stress.

In the future, I'd like to get feedback on patient and families feedback about conversations regarding death. I appreciate this is a really sensitive subject and may be difficult to get engagement for it. I think it is important that feedback is received, to improve future practice of how difficult conversations are approached.

I'd also like to recommend future research about how communication between the family and healthcare service can be improved. Systems could be implemented to allow for staff to contact the family and minimize anxiety. Research could also be conducted into services that have positive communication tags associated with them and look at what they do differently.

I would also like suggest that the correlation between the criticality of the story is researched and how soon after the author chose to write about it.

I think there could be benefits in exploring compassion fatigue in the NHS and healthcare sector. Compassion fatigue is the the physical, emotional, and psychological impact of helping other- staff working in palliative care regularly dealing with pain, trauma, and the suffering they see by the nature of end-of-life care delivery (Cross, 2019). The NHS runs off the goodwill of the staff staying in extra hours to help out. Systems could be put in place to minimize the risk of burnout or compassion fatigue. This will likely have a huge positive impact on patients and their families as staff won't be 'pouring from an empty cup'.

I would also like to suggest more is done when a service is praised on certain aspects to tease out why they are good. As mentioned earlier, when communication is done well, it is either often not mentioned or a short comment is written, saying it was good. It is also recommended for Care Opinion to consider introducing the idea of 'core tags'- tags that appear regularly, across all areas of specialties and moderators can specifically ask

authors about these tags- there were two bubbles with 'compassion' and 'compassionate'- having key words that encompass these may help to group and analyze them more easily. It may be worth looking at the tags in Care Opinion that are positive and negative and write short questionnaires for authors to fill out if their story has that specific tag associated with it. These could be closed questions e.g.
'How often did the hospital communicate with you regarding your/ your family member's treatment?'
On a scale of 1-10, how much did you feel you were involved in your care?
Patient and family surveys could also be sent out to try and find out what is most important to them in regards to these tags.

Overall, 86% of the stories that were analyzed were positive. Especially in a pandemic, when staff, patients and their families were under extra pressure and visiting times were reduced, this is really impressive and shouldn't be negated. It's important to strive for improvement in healthcare but just as important to take a step back and celebrate the wins