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Case Report

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Abstract

Objectives. The COVID-19 pandemic presented many challenges for patients with palliative care needs and their care providers. During the early days of the pandemic, visitors were restricted on our palliative care units. These restrictions separated patients from their families and caregivers and led to considerable suffering for patients, families, and health-care providers. Using clinical vignettes that illustrate the suffering caused by visiting restrictions during the pandemic, the introduction of a new concept to help predict when health-care providers might be moved to advocate for their patients is introduced.

Methods. We report 3 cases of patients admitted to a palliative care unit during the COVID-19 pandemic and discuss the visiting restrictions placed on their families. In reviewing the cases, we coined a new concept, the “Suffering Quotient” (SQ), to help understand why clinical staff might be motivated to advocate for an exemption to the visiting restrictions in one situation and not another.

Results. This paper uses 3 cases to illustrate a new concept that we have coined the Suffering Quotient. The Suffering Quotient (SQ) = Perceived Individual (or small group) Suffering/Perceived Population Suffering. This paper also explores factors that influence perceived individual suffering (the numerator) and perceived population suffering (the denominator) from the perspective of the health-care provider.

Significance of results. The SQ provides a means of weighing perceived patient and family suffering against perceived contextual population suffering. It reflects the threshold beyond which health-care providers, or other outside observers, are moved to advocate for the patient and ultimately how far they might be prepared to go. The SQ offers a potential means of predicting observer responses when they are exposed to multiple suffering scenarios, such as those that occurred during the COVID-19 pandemic.

Introduction

The COVID-19 pandemic was a challenging time for palliative care providers. It was particularly challenging at the start of the pandemic when vaccination was not available, personal protective equipment was in short supply, and early reports raised concerns that health-care systems would struggle to meet patient and staffing needs.

Our regional hospitals adopted visitor restriction guidelines meant to strike a balance between the potential benefits of visiting at the end of life and the potential for harm to patients and staff. The enforcement of the visitor restriction guidelines and potential exceptions to the restrictions were left up to the frontline health-care providers and individual health-care team managers. Often these decisions were made by individual health-care providers who were themselves dealing with burnout and compassion fatigue.

This paper introduces a concept coined the “Suffering Quotient” (SQ), which offers a way to help appreciate how the relationship between the individual/small group and ambient environmental suffering impacted decision-making for exceptions to the visitor restrictions at the end of life.

To illustrate this concept, we present 3 clinical vignettes of patients admitted to a palliative care unit during the early days of the COVID-19 pandemic.

Case reports

Case 1

This case involved a 40-year-old man with a wife and 2 children, ages 7 and 9. The patient was imminently dying from cholangiocarcinoma, and his prognosis was expected to only be hours or, at most, a short number of days. At this time, only 2 visitors were allowed, and

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the patient's wife arrived at the door of the hospital with her 2 children and no other adult to help as a caregiver. She was forced to leave the older of the 2 children to sit on the grass alone outside the hospital, which left all the family in tears. Rather than risking having to ask hospital administration to make an exception to the visiting rule and potentially have the request denied, the palliative care staff snuck the child onto the ward to be with her family.

Case 2

This case was of a 65-year-old woman dying from breast cancer with a prognosis of about 1 week. The visitor restriction only allowed 2 visitors, but the patient had a husband and 2 adult children who all wished to visit. The family requested an exception to the visiting restriction to the hospital administrators, but no exception was made. The palliative care staff did not take further action on their own. One of the adult children contacted the media, and the family's story about their visiting restriction was aired on the local evening news.

Case 3

A 73-year-old man with pancreatic cancer and a prognosis of short weeks was seen by the palliative care consult service at a tertiary care hospital. He was the only patient on a surgical ward to be followed by palliative care, and perceived as dying, on that unit. The surgical ward authorized an exemption to the visiting restrictions and the patient was allowed 6 family visitors for a week, before he was transferred to the palliative care unit. Once he arrived at the palliative care unit, the visiting restriction of only 2 visitors was enforced. This was very distressing for the patient and family, who consequently requested to go back to the surgical ward. Their request was not granted.

Discussion

The SQ

These cases illustrate a concept we have coined, the SQ. The SQ can be thought of as a ratio describing the relationship between perceived individual (or small group) suffering and the overall ambient suffering of the contextual population.

The Suffering Quotient (SQ) = Perceived Individual
(or small group) Suffering/Perceived Population Suffering

Suffering is complex. Cassell (1991) described it as "the distress brought about by the actual or perceived impending threat to the integrity or continued existence of the whole person." Others have described it as having a component defined by relationships with others (Daneault et al. 2022) and as having an objective component that can be perceived by others (Tate and Pearlman 2019; Van Hooft 1998). It was this perceived distress, which was objectively observed and labeled as suffering by the palliative care staff, that led to the concept of the SQ.

Application of the SQ

In the first 2 cases, the patients were on the same palliative care ward. Hence, the contextual suffering of this population at the end of life, the denominator, was the same. However, in the first case,

the suffering of a 9-year-old child left alone outside a hospital while her father was dying inside was perceived to be untenable to staff, i.e., the numerator was inordinately high.

In Case 3, the patient was the only dying patient on a surgical ward. His situation and the magnitude of his suffering were perceived as unique enough to grant an exception to the restrictions. However, when he moved to the palliative care unit, while his individual clinical circumstances remained the same, the degree of suffering within the baseline population he was being compared to – the denominator – expanded. His suffering was not perceived as unique or inordinate relative to other patients on the palliative care unit, and this lowered the SQ.

Suffering cannot be described in terms of absolute values for the numerator, denominator, or SQ. However, the higher the SQ, the more likely health-care providers and others are moved to act. In contrast, for individuals and families, suffering is perceived within the realm of their own experience, and as such, their suffering is substantive, intolerable, and independent of the experience of others. Hence, SQ is only relevant from the perspective of the observer, not the observed.

The SQ, compassion fatigue, and observer variables

Despite acknowledging public health risks and accommodating visitation restrictions with virtual communication, families reported bedside presence was irreplaceable during the pandemic (Mercadante et al. 2020). Prohibiting visitation interfered with connectedness and tasks associated with anticipatory grief. This was difficult for our frontline palliative care providers, who define the unit of care as patients and their families (Guo et al. 2022; World Health Organization 2020). This led to multiple instances of moral distress, injury, and compassion fatigue (Mewborn et al. 2023; Rushton et al. 2022) within our staff. The high and increasing rate of burnout we observed in our staff was similar to what has been previously reported in the literature (Baqeas et al. 2021; Boland et al. 2023; Lluch et al. 2022; Wang et al. 2020).

Fernando and Consedine (2014) described a transactional model of compassion fatigue, indicating that a physician behaving compassionately toward a patient reflects the dynamic influences of physician, patient, and clinical and institutional factors. In a pandemic, decision-making is set by various regional and institutional authorities and is very complex and often changing. It requires multiple health-care providers (not just physicians) to make very challenging decisions. These decisions are based on compassion for the patient and family but are also weighed against the consideration of risk for other health-care professionals, their own families, the health-care system, and societal well-being. While the transactional model is very useful, it does not gauge the influence of these various relationships. However, the SQ offers a possible formulaic prediction of observer response, reflecting the threshold beyond which the care provider is moved to advocate for the patient, and ultimately how far they might be prepared to go.

As the SQ is to be interpreted from the perspective of the observer, factors that can potentially influence the numerator become important considerations. It is difficult to ascertain exactly how an observer intuitively measures the perceived suffering of another person. However, implicit bias, seeing themselves in the suffering of others, the culture of clinical advocacy, the risk of institutional discipline or criticism, and other individual characteristics all play a role in the perception of, and the decision to respond to, suffering (Davoodvand et al. 2016; Thacker 2008).

In a set of social experiments by Callan et al. (2012), participants perceived the suffering of older persons as less unfair, and this reduced participant willingness to help older persons in need. Indeed, age-based discrimination has been well described in palliative care, with older patients generally having less access to specialist palliative care services and less adequate symptom management (Dobson 2005; Kotzé and Roos 2022; Lloyd et al. 2016; Rostoft et al. 2022). The numerator may also have been higher in Case 1, as the young age of the patient and his family may have resonated more intensely with the clinical staff, who could envision themselves as being the young patient or his spouse. This is consistent with the work of Davoodvand et al. (2016), who described empathy, and envisioning themselves in the patient's shoes, with increased patient advocacy from nursing staff.

Slovic (2020) described a concept of psychic numbing to explain how people deal with mass atrocities (Resnick 2017). He described psychic numbing as a paradox that occurs because people are unable to process large-scale suffering. In his work, he noticed that, as the number of individuals affected by tragedy increases, our willingness to help reliably decreases (Resnick 2017). This is consistent with the essence of SQ, where observers are less likely to be moved in the setting of a high denominator. The literature also describes the use of individual stories to help the public to really appreciate the suffering of a single person and aid with fundraising (Bhatia et al. 2021; Slovic 2020).

Predicting observer response and increasing advocacy

It is not possible to know for certain how health-care workers might act in future situations when faced with patient suffering, and further study is certainly needed. However, the SQ may be thought of as a tool to help predict potential observer responses and improve advocacy. For example, in situations where immense suffering blunts the compassionate response, the SQ suggests there may be 2 conditions in which observers might be compelled to help relieve the suffering for individual patients: by the patient having a uniquely distressing story of suffering, or by the patient receiving care in an area where ambient suffering is less. In daily practice, we should consider both conditions when we advocate for our patients by presenting their stories, and when we determine the best place for their care.

Conclusion

The SQ concept came out of our experience interacting with many dying patients, and the health-care workers tasked with deciding the number of visitors they were allowed to have. In situations where background suffering cannot be altered, such as during a pandemic, patient advocacy can potentially be increased by presenting individual stories that resonate with decision-makers to increase the awareness and perception of patient suffering. We hope that introducing the SQ construct helps policymakers and individual caregivers recognize the impact that widespread suffering can have on caring and decision-making. Ultimately, the aim of introducing SQ is to heighten the awareness of what shapes our perception of suffering and to provide fair, high-quality palliative care to all patients and their families.

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