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**We Don’t Know What We Don’t Know! Knowledge and Communication Barriers Still Prevalent Among Palliative Care Patients and Families.**

Content:

Background

There is a struggle to meet the demands of adequate, let alone high-quality, palliative care, with one in four UK families unable to access the expert palliative care they need. This research uncovered difficulties experienced in accessing palliative care along with insights into why others have not accessed these services at all.

Methods

This research is part of a larger ongoing study into palliative care. Data collection began in 2015. To date we have collected almost 2 million words of data from in-depth interviews with palliative care patients and their families (n=223) and healthcare professionals including GPS, Community Nurses and Hospital Staff (n=22). We also surveyed (n=100) non-users.

Results

We find that many of the long-recognised barriers, such as patient and family misconceptions (“the Death House”) and lack of knowledge (“I didn’t know what a palliative care nurse was”; “I thought it was just for cancer patients) are just as prevalent as they have always been. There is an acute lack of awareness of wider palliative care offerings (e.g., non-pain physical, psychological, spiritual). Many people believe hospice care is solely for patients with cancer, or just for inpatients, or is private and has to be paid for. Confusion and lack of confidence among healthcare providers are also widespread, particularly when dealing with non-cancer patients. We also found poor integration of healthcare services in the wider ecosystem, often confounded by technological barriers and a lack of effective collaboration between service providers.

Conclusions

Palliative and hospice care needs to be rebranded and better communicated to the wider public. Better training is needed to educate and equip healthcare professionals with the knowledge and confidence they desperately need. Champions are needed to improve collaboration and integration among healthcare professionals and their systems.