Future proofing palliative and end-of-life care for service users

Everybody dies though not everybody experiences a dignified and comfortable death. Palliative care emphasises caring, not curing, and focuses on psychosocial, spiritual, familial and wider quality-of-life issues (World Health Organisation, 2018). Recently, there has been a call for greater awareness of patient-centred care that actively listens to healthcare service users. Patient-centeredness takes a consumerist view of the quality of care, effectively shifting the traditional balance of power and viewing the patient as a healthcare consumer. However, many healthcare providers are still at loggerheads with regards to conceptualising, institutionalising and operationalising patient-centred care to its full potential. More worryingly, there are a plethora of quantitative systems that try to capture patient sentiment in a variety of guises but no systematic, robust way of capturing these experiences and no one system that encompasses all areas of service provision.

Therefore, over six years and via an impact case, we investigated patient experiences in end of life care. Our work has informed policy at Government level and impacted palliative care service provision across hospices, hospitals and patient’s homes, improving the ways services are designed, delivered, communicated and co-created with patients and their families.

We collected over 245 pathographies from patients (83), current caregivers (75), and bereaved caregivers (87). Drawing on services management tools and concepts, we developed a Trajectory Touchpoint Technique (TTT) (Sudbury-Riley et al., 2020), a new methodology to systematically uncover opportunities for palliative care services with an emphasis on capturing how users feel across the whole customer journey.

We also conducted 32 in-depth interviews with a variety of palliative care providers including specialist palliative care consultants, GPs, community nurses, hospital nurses who had administered palliative care in the previous 6 months, a hospital frailty consultant, and community care home managers. In addition, we administered a face-to-face survey comprising closed and open-ended questions to 100 hospital clinic outpatients who were waiting for diagnostic tests.

Key findings suggest that the TTT was superior to other available methodologies, leading to demand from several hospices (including chains such as Marie Curie, independent hospices and a children’s hospice) and palliative care providers (Macmillan, and an inpatient unit and outpatient services at two different NHS Hospital Trusts) to apply the technique to their services. Our research has led to the launch of a new Hospice@Home provision, which, during its first 6 months alone, prevented 50+ hospital admissions and enabled 102 people to die in their preferred place of death. These initiatives have benefitted patients and their families, palliative care staff, and other clinicians in the healthcare ecosystem. This includes service design (from Wi-Fi access to room layout); service delivery (including counselling and staff training); communication (e.g. debunking myths and patient-clinician communication); value co-creation (including continuing support and feedback); ecosystem modifications (how hospices connect with other healthcare providers); and home services (enabling people to attain their preferred place of death). Our research has also influenced significant operational and strategic changes in the ways in which palliative care services are delivered across all collaborating organisations.