Supporting patients and families affected by cancer through the COVID-19 pandemic

In April 2020, at the start of the Covid-19 pandemic, cancer support services in the North East sector sought to reach out to all local cancer patients during a time of worry and uncertainty. It began as an informative letter drafted and sent out to every patient who had been diagnosed at one of our hospitals within the last five years. The letters generated immediate and ongoing engagement from local patients and led on to further service improvement work as well as a greater understanding of the needs and concerns of cancer patients during a pandemic.

Aims:
- To ensure local cancer patients felt supported and had questions and concerns addressed.
- To ensure local cancer patients had appropriate contacts to discuss worries and raise any concerns about impact on their care.
- To communicate key messages and information around cancer and Covid-19.
- To understand the needs of local cancer patients during a pandemic.

Context
The project started as a way to communicate with cancer patients in the North East Sector during the pandemic. It was recognised early on by the NCA Cancer Services Team that there would be a significant impact on cancer patients and their families, both in terms of their diagnostic pathways and treatments that either had to be stopped, postponed or adjusted and their follow up plans changed as well as an increased anxiety for patients.

Method and involvement
The project was collaborative with involvement from professionals across cancer services, clinical administration and Business Intelligence. An informative letter was drafted by the Macmillan Information and Support Service with input from clinical teams. It contained key messages, as well as information about what to expect from hospital services in terms of changes to appointments and procedures and encouraged patients to make contact to discuss concerns and access support. The Business Intelligence Team identified 10,426 appropriate patients who had received a cancer diagnosis in the last 5 years and volunteers from cancer services and clinical administration worked together to send the first batch out. The letter was also included in new patient packs for all patients receiving a new cancer diagnosis. Within days of going out, patient calls were received with requests ranging from treatment and appointment queries to concerning symptoms to a simple listening ear. The calls were fielded by the Macmillan Information and Support Service and the Macmillan Acute Oncology Service. All calls were logged on a shared database and actions were tracked. The database was discussed on a weekly basis to identify themes allowing us to adapt and implement service improvement. Since the initial batch, two further batches of letters have been sent to patients diagnosed in subsequent months allowing us to continue to support patients and adapt the letters with up to date messages and in line with what we have learned about patient concerns.

Calls
146 calls have been received by the Macmillan Information and Support Service and Macmillan Acute Oncology Service since the first distribution of letters.

Themes
The majority of calls related to concerns around procedure or treatment delays/cancellations or how they would take place. Another common theme was concerns around how follow-up would be impacted by the pandemic. There were also worries about shielding, attending the hospital and MDT outcome communication (which had begun to take place remotely for the first time).

Incidents and risks
The calls have highlighted several areas that require improvement and work began immediately to address these issues. A number of more serious incidents were also identified, allowing important investigations to take place and learning for future improvements.

Case study (*pseudonym used to protect patient identity)
Julie* had a diagnosis of breast cancer and had been treated with radiotherapy 3 months previous. She had started with a cough whilst on radiotherapy which had still not resolved. Julie had not reached out for support as she was anxious about attending the hospital during the pandemic. On receiving the letter, she contacted the Acute Oncology team for advice. Acute Oncology liaised with the CNS and she was reviewed via telephone by the consultant with assessment for metastatic disease. The consultant advised further assessment from GP and formal referral back to the hospital. This was all completed within 48 hours of patient call.

Phone calls gave the opportunity to reduce confusion and anxiety in patients.
- It allowed us to access valuable insight into patient experience during the pandemic, collecting information that would not otherwise be collected.
- Communication channels were created with patients who were struggling.
- Positive patient feedback was received; patients had the opportunity to talk and feel informed and supported during uncertain times.
- We were able to reassure patients when procedures and treatments were delayed or cancelled and information was given on how and when they would take place.
- Discussions gave worried patients the confidence to self-manage through the pandemic.
- It gave us an understanding of the importance of timely and appropriate communication of MDT outcomes during a pandemic.
- Cancer services were able to track delayed and/or cancelled procedures or treatment.
- Urgent appointments were arranged.
- Detailed pathway mapping was undertaken by a Cancer Services working group which allowed teams to address and implement improved systems for tracking patient pathways as well as resolving issues that would not have otherwise been identified.

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