Better quality of life and cancer patients' satisfaction with a coordinating nurse
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Investing in the continuity of care for lung cancer patients can bring tremendous benefits in terms of patient satisfaction and quality of life. In Quebec, Canada, this investment has taken the form of a dedicated role on the medical team: The Pivot Nurse in Oncology (PNO). A study presented at ELCC 2018 (European Lung Cancer Congress) in Geneva has produced new evidence of the different ways in which this service improves patients' lives during treatment.

"Introduced to oncology clinics in 2001, the position of the pivot nurse was enshrined by the Ministry of Health and Social Services of Quebec in 2005 as part of its Fight Against Cancer campaign," said study author Elie Kassouf, haematologist and medical oncologist at Centre Hospitalier de Lanaudière (CHDL) in Saint-Charles-Borromée, Canada. "In over 15 years of existence, however, very little data has been collected about its impact on patients' lives. Our study's main goal was therefore to determine whether the continuity of nursing care has tangible benefits to patients treated for lung cancer, as compared to the usual standard of care without a coordinating nurse."

Lung cancer is the number one cause of cancer-related deaths in both men and women. Although progress has been made with treatment, according to Kassouf, increased cure rates and survival have come at the cost of higher toxicity. The multidisciplinary teams required to administer combination therapy have also led to greater complexity in the care process. Quality of life during treatment has deteriorated as a result, and healthcare institutions are increasingly confronted with discontent about delays, service fragmentation or even misinformation - all of which are thought to lead to confusion, distress and compliance issues among patients.

"At the CHUM, patients who enjoy continuity of care have a treating pivot nurse in addition to their treating physician. Each pivot nurse cares for 50 to 60 patients, who all have his or her direct phone number," Kassouf explained. "The PNO has the patients' files and can take care of scheduling follow-up appointments with their physician as soon as they receive new test results. If a patient calls to report worrying symptoms, the nurse will also speak directly to their doctor, who may then see that person on short notice without the latter having to go through the regular emergency system."

To study the efficacy of this service, Kassouf recruited 65 patients with advanced lung cancer at Notre Dame University Hospital in Montreal three months after the start of their treatment. The patients were divided into two cohorts: 82% were assigned to the continuous care (CC) arm, and the 12 individuals who had not had access to a pivot nurse during their treatment constituted the usual care (UC) control group. Patients in both cohorts answered validated patient satisfaction and quality-of-life questionnaires, as well as questions to assess their understanding of their health status. The CC group additionally filled out a specific survey on the role of their pivot nurse.

"The size difference between the two cohorts is because the PNO program has been around for 15 years, and the vast majority of patients in Quebec today have access to a pivot nurse," Kassouf explained. "The reasons why the study participants in the control group had not used this service three months into their treatment constituted the usual care (UC) control group. Patienst in both cohorts answered validated patient satisfaction and quality-of-life questionnaires, as well as questions to assess their understanding of their health status. The CC group additionally filled out a specific survey on the role of their pivot nurse."

"The Princess Margaret Hospital Patient Satisfaction with Doctor Questionnaire (PMH/PSQ-D) that we used in the study covers four dimensions of a patient's relationship with his physician: interpersonal skills, empathy, information exchange and quality of time," said Kassouf. "The score difference we saw between the two cohorts"
was huge across the board: not because the usual care group scored poorly - their results were similar to those found in other studies based on the same questionnaire - but because the continuous care cohort produced exceptionally high scores."

In the so-called FACT-L scale, which is a validated questionnaire for evaluating lung cancer patients' quality of life in Canada, the results also favoured the CC cohort in all categories - including physical, emotional and functional wellbeing - although the difference between the two groups was less marked. "This can be attributed to the fact that, contrary to their level of satisfaction with care, patients' quality of life is heavily influenced by the disease itself," said Kassouf.

"A previous study of the PNO system had shown no difference in patients' quality of life, but most of the nurses in its usual care arm had specialised oncology certifications and over 10 years of experience, which was not necessarily the case of the pivot nurses at the time," he added. "With the generalisation of the PNO program, this asymmetry had disappeared when we conducted our study, so the results are a useful addition to the literature on the subject."

In their assessment of the PNO service, a large majority of patients stated that they had a better understanding of the course of their disease and treatment side-effects, and that the presence of their pivot nurse gave them more strength in their fight against cancer. "The only concerns that many people felt were not sufficiently addressed by their PNO were those pertaining to intimacy," said Kassouf.

Due to its small sample size and confinement to a single hospital, it is difficult to generalise the results of this study. "Earlier data suggests, however, that lung cancer is the malignancy associated with the highest levels of psychological distress compared to other forms of cancer. Presenting more unmet psychosocial needs, these patients could thus be particularly susceptible to the benefits of continuous follow-up and medical scrutiny," Kassouf remarked. "Our results certainly show that it is an avenue worth exploring."

Anja Kröner, a PhD-prepared nurse in oncology and member of the management team at the Comprehensive Cancer Centre in Zurich, Switzerland, commented: "Despite the small number of patients involved, which means we must be cautious with the results, this work shows a clear tendency of continuity of care improving when there is an established role similar to that of the pivot nurse on a patient's medical team," she said. "In Europe, too, we have seen promising signals: several clinics in Germany, for example, found it was beneficial to assign a case manager to cancer patients."

Kröner further underlined that the growing complexity of cancer treatment - from surgery to oral therapy and radiation - creates many breaks in the care process. "Parallel to this, we see patients with financial or social burdens who are at particular risk for low adherence to treatment," she said. "In oral therapy, for example, they have pills to take on their own at home that cause severe side-effects: The routine care process is not very good at detecting individuals who stop taking their medication without telling their doctor about it. That is where pivot nurses can make a real difference."

According to Kröner, however, cancer patients should not only be satisfied with their doctor, but rather with the entire care setting. "It would be interesting to take the research further by framing patient satisfaction more broadly, as well as considering other outcomes alongside quality of life, such as patients' ability to carry their own weight, or to work, throughout the process," she added. "In light of the financial pressure faced by many healthcare systems today, it would also be worth exploring whether pivot nurses can reduce the cost of cancer, as another study (6) has already suggested."
