Standard procedures, protocols and good organization in hospitals and medical centers ensure that arriving patients receive the best possible care for their ailments. But for many patients, their disease progression, problems, symptoms and concerns are beyond the traditional disease and treatment-oriented perspective. These are questions Carl Johan Fürst, professor of palliative medicine at Oncology and Pathology (Medicon Village) and Principal Investigator at the Institute for Palliative Care, wants to find the answer to with his research in the field of palliative care. In his current projects, Carl Johan Fürst is looking to improve the palliative care for cancer patients with a progressive disease by establishing a more organized approach to receive, evaluate and provide the best care possible for these patients. Swedish palliative care is fairly well established. However, much of the knowledge in the field of palliative care is not based on scientific knowledge but is gained through successful empirical clinical experience. So, there is great need for research.

Carl Johan Fürst has established courses in communication skills training in which physicians learn how to approach cancer patients and other patients with a critical illness and to talk about their condition, from diagnosis - the “breaking of bad news” - until death. He is currently running a project (in collaboration with Harvard School of Public Health, Boston, USA) in Växjö Hospital where, for example, cancer patients with a limited prognosis are offered the opportunity to have an invited dialogue around the disease prognosis, wishes and concerns with their attending physician who has undergone a communication skills training program. These conversations are necessary to support a process of shared decision making and establish common goals of care.

“It shouldn’t be a coincidence but standard procedure for a patient to meet a doctor with good communication skills who empathically brings up issues on prognosis and individual concerns. Especially for patients that might have a limited time left to live”, says Carl Johan Fürst.

To help medical staff face these dialogues, Carl Johan Fürst and his team is working on establishing advanced courses also for nurse and other health care staff. Medical doctors and nurses practice with simulated patients. The actors can adapt their behavior depending on what type of patients (quiet, angry, sad) the medical doctors and nurses have difficulties approaching. These courses help prepare the medical staff to better deal with the patients' feelings and thoughts.

These courses also include how to approach the relatives of a dying cancer patient. A group that require extra attention is teenage children who phase the worst trauma of their lives in losing a parent. The teenagers need adequate information and a chance to express themselves about the situation to medical staff. If not given that chance the mental and emotional distress these teenagers experience can take a toll that is lifelong. Communication is a prioritized area of research including two PhD students. Carl Johan Fürst states that medical personnel should provide both patient and family the chance to express their concerns and feelings, even more so prior to and after the passing of a family member.

In addition to improving the communicative skills of the medical personnel, Carl Johan Fürst also wants to improve the evaluation process of when a cancer patient is entering the last part of their
life and the transition to palliative care. Here, Carl Johan Fürst is running several projects, some of which utilizes the Swedish Palliative Registry, a national quality register of deceased cancer patients. One such study explores when in time patients are informed about the transition to palliative care at the end of life, another study the prevalence of severe pain in patients with cancer during the last week of life. The conversations about end-of-life care is suspected to occur too late, and in some instances far too close to death. Carl Johan Fürst is hoping that these studies will raise awareness of the needs of patients at the end of life.

A long-term goal that Carl Johan Fürst wishes to see is the hospital where communication skills and a palliative care approach is integrated to all relevant services – particularly for patients with cancer even if this is very important also for many other patients.

“I think most fellow medical doctors and researchers would agree with me when I say that every patient should be offered the option of good palliative care when the time is right, and provided a chance to have an open dialogue and express their concerns to doctors and other staff who is trained to meet them with knowledge and empathy”, says Carl Johan Fürst.

-Joakim Hising