Digital pain diary brings relief to palliative home care patients

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Leili Lind, PhD, responsible for the study at Linköping University

In 2003, an academic study in Linköping, Sweden, tested the innovative use of Digital Pen and Paper technology in the care of terminally ill patients in their homes. The application developed by Anoto, gave palliative care patients the possibility to use a networked digital pen to keep a “pain diary” and register facts about their condition several times a day. This information was communicated to medical staff via mobile internet, leading to more precise and timely pain management.

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**Background**

As people come closer to death, their symptoms change rapidly and their need to communicate with their families, friends and health professionals also changes. Therefore pain assessment and control are crucial to the treatment of terminally ill cancer patients in palliative care. However, as compared to hospitalized patients, it is more difficult to assess home care patients’ pain and the degree to which they have responded to the pain therapy. All patients in the study were in a palliative state where no cure can be given.

The study was performed by the Department of Biomedical Engineering, Linköping University at the hospital-based home care clinic, Linköping University Hospital. It was co-financed by the Swedish Governmental Agency for

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**ANOTO CASE STORY**

**FACTS**

**Customer:** Leili Lind, PhD, Department of Biomedical Engineering, Linköping University; Sweden.

**Challenge:** To improve the pain control and overall care, of terminally ill patients in home-based palliative care in the Linköping area, and make possible for their professional caregivers to work with pain control in a more structured way.

**Solution:** The solution is based on Anoto functionality. Patients record information about their condition and their intake of pain relieving medicine with an Anoto Digital Pen in a special “pain diary”. Data is transferred via mobile internet to medical supervisors, who can act swiftly when the patient is registering increased pain.

**Benefits:**

- Patients get an increased sense of security and participation in their own care.
- The contact between patients and caregivers is improved.
- The pain assessment method is experienced as being effortless; digital pen and paper is familiar, light and easy to use, even for terminally ill patients with a limited capacity to manage technical equipment.

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Innovation Systems [VINNOVA], the Santa Anna IT Research Institute, Anoto and Vodafone. According to Leili Lind, PhD at Linköping University and responsible for the study, the participating patients responded very positively to the pain assessment method and all of them were able to use the digital pen.

**The chosen solution**
An IT-system was a prerequisite for sufficiently frequent pain assessments, as manual methods had been found unmanageable. The patients themselves used a digital pen to write in a pain diary with Anoto functionality. They assessed the intensity of their pain by marking a VAS scale (a 10 cm scale, often used for pain assessment) running from “No Pain” to “Severe Pain”. They also reported about extra doses of analgesics (pain relieving medicine) consumed to control their pain.

**How it works in practice**
- Patients assessed their pain three times a day at around 8 a.m., 1 p.m. and 8 p.m. They continued to do this until the pain stabilised below a certain level, which took a minimum of two days.
- Data was transferred immediately via mobile internet to medical supervisors, who could act swiftly to adjust medication when the patient was registering increased pain. The clinic’s secretaries checked the system for incoming assessments and printed the assessments during the daytime. In the evenings and at weekends, the assessments were examined, printed and signed by the responsible nurse.
- The caregivers gave the patients feedback on received assessments. Before the onset of the study, caregivers were instructed about the intervention in general and how to use the system and equipment.

**Conclusions of the study**
The digital pain assessment method was considered effortless by patients in spite of their state of health. It helped that the digital pen resembles an ordinary pen and is familiar and easy to use, even for fragile or elderly patients. “The results imply that Digital Pen and Paper technology is suitable for the assessment of symptoms by palliative patients, since these patients often have a limited capacity to handle technology, due to their state of health”, says Leili Lind.

Patients experienced an improvement in the contact with their caregivers and felt that they were participating more in their own care. The technology allowed patients to combine the comfort of being cared for in their own homes with real-time monitoring and control of their pain levels. “I cannot see any reason to why patients should not be given the possibility to use this technology. The positive effects achieved mean a lot for patients who are really suffering”, says Leili Lind.

Other future areas of usage for the technology are for example patients suffering from congestive heart failure, chronic respiratory diseases or diabetes.

**New study going on**
Five years have passed since the first study was performed and Leili Lind is currently conducting a follow-up study, for which a customized digital pen and paper solution has been developed in collaboration with Catrel.

The number of patients has increased and includes four Swedish counties. Whereas the first study gave qualitative results, the aim of the second study is to get quantitative data. The patients are divided into two equal groups, one using the digital pen and the other using regular pen and paper. In each group, the time taken from that an assessment is reported until the professional caregiver is informed about the assessment is measured. For patients using the digital pen, the information can reach the professional caregivers in a few seconds, whereas for patients in the control group it can take days.

**Anoto Digital Pen and Paper technology**
An Anoto Digital Pen looks and feels like a normal ballpoint pen. However, it contains an integrated digital camera, an advanced image microprocessor and a Bluetooth® transmitter. Any paper can be used with a digital pen, if the Anoto dot pattern is added to the layout before printing the paper. The Anoto dot pattern consists of numerous black dots that can be read by the digital pen, but are almost invisible to the naked eye. The pen reads the pattern and registers what and where the user writes.