Evaluation of the Use of Digital Pens for Pain Assessment in Palliative Home Healthcare

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Abstract. An information system supporting pain assessment in palliative home healthcare was implemented at the hospital-based home care clinic of University Hospital in Linköping, Sweden. Using digital pens and pain diaries, pain assessments were sent from the patients’ home to the professional caregiver. A total of 12 patients participated in the study. Patients, spouses and professional caregivers were interviewed. Qualitative content analyses were performed on the study material. All patients managed to use the pain assessment method, they experienced an improved contact with the caregivers and had a sense of increased security. After an initial cautious outlook the caregivers experienced positive outcomes for themselves and their patients. The medical records showed that the method had had impact on treatment. In conclusion, the home healthcare solution provided an effortless method for pain assessment with a high degree of user acceptance for palliative patients and had positive influences on the care.

Keywords. Telehealth, patient monitoring, Home care services; hospital-based

Introduction

Adequate symptom control is one of the most important components of delivering effective palliative care [1-2], whether care is given in a hospital or at home. As people come closer to death their symptoms change rapidly and their need to communicate with their families, friends and health professionals also changes [3]. For cancer patients in a palliative state a systematic assessment of pain is crucial [2, 4], and the American Cancer Society, ACS, [5] has established policies that support palliative care, with particular focus on pain and symptom management. Stone et al. has stated the need for frequent assessment of patients’ momentary pain to capture pain variations around-the-clock and allow the caregivers to describe the pain pattern over time [6].

Telecommunication and IT can be used to support the patients in assessing and reporting their pain, and such technologies can also support the professional caregivers to work with pain control in a more structured way. Studies where patients have assessed and reported their pain using paper-based and/or electronic pain diaries have been performed earlier [7-9]. Electronic, handheld pain diaries have been found useful
and to provide a high degree of patient satisfaction in studies with patients suffering from chronic pain [8-10]. For an older patient group, pain assessment can be complicated by sensory and cognitive impairment, and motor loss [11]. Older users of handheld computers, such as PDAs and cell phones, often find the screen brightness insufficient and the screen fonts too small to read clearly [12].

In our study, where palliative home care patients suffering from end-stage cancer assessed their pain and reported intake of extra doses of pain relieving medicine by use of a pain diary, we applied digital pen technology from Anoto™ 1. Various digital pen technologies have been tried in studies for clinicians’ use [13-15], but to our knowledge there were no earlier reported experiences from patients’ use of digital pen technology in palliative home healthcare.

The aim of this study was to explore and describe palliative home care patients’ experiences of assessing their pain by using paper pain diaries together with digital pen and mobile Internet technology, and furthermore, to explore and describe the professional caregivers’ experiences of the system and of their patients’ use of this pain assessment method.

1. Material and Methods

The main requirements for the system and study, together with a description of the system, can be found in Lind & Karlsson [16]. Results from the patient/spouse part of the study can be found in Lind et al. [17].

The Anoto Technology is based on digital pen and paper. The digital paper is printed with a dot pattern that is almost invisible to the eye. The digital pen used in our study, a Chatpen™, looks and feels like an ordinary ballpoint pen and is used in the same way. The internal part consists of a camera, an image processing unit and a communication unit. The pen knows its exact position in the whole pattern space by using the dots’ displacements in the pattern, and the strokes made by the pen are recorded and can be transferred via wireless Internet technology to a server.

Traditionally, patients receiving care from the HBHC clinic had frequent contact with their professional caregivers, either via a telephone or home visits, during which they conveyed their pain and other symptoms. The reporting of pain could be accomplished in a non-structured way through an informal talk about the pain with the visiting nurse/physician or on the phone. Occasionally pain assessment could be performed using a VAS instrument carried by the nurse/physician.

The Regional Ethical Review Board in Linköping gave permission to carry out the study which was conducted at the hospital-based home care (HBHC) clinic, Linköping University Hospital. In-depth face-to-face interviews were performed with patients, spouses and professional caregivers. The study material further consisted of an ease-of-use questionnaire [16], medical records, and the system log.

- In the patient-spouse part a descriptive and explorative case study design with a cross-case content analysis was performed, including interviews with patients and spouses, an ease-of-use questionnaire, medical records and the system log.

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1 Anoto (http://www.anoto.com)
In the professional caregiver part a qualitative descriptive and explorative design with a content analysis approach was performed, including interviews with professional caregivers, the system log and the participating patients’ medical records.

2. Results

Evaluation of the pain assessment system aimed at exploring and describing patients’ and professional caregivers’ experiences of the system. For an overview of socio-demographic and clinical data from the study patients, see Lind et al [17].

Six sub-categories showing patients’ experiences of using a pain diary and digital pen technology for frequent pain assessment were identified and described in the two categories Effortless method for pain assessment and Positive influences on the care. The professional caregivers’ experiences of the patients’ use of the pain assessment method resulted in the categories Shifting outlook towards the pain assessment method and Positive patient influences, emerging from seven sub-categories.

One selected original quotation, translated into English, from each category is presented to illuminate the experiences of the patients and the professional caregivers.

a) Effortless method for pain assessment. The pain assessment method was regarded as being effortless in spite of the patients’ state of health. The patients made it clear that they could handle the digital pen, which was looked upon and used as an ordinary pen, and they could easily interpret all parts of the pain diary. They did not need help from their next-of-kin in writing with the digital pen. The spouses did not help with writing but could help with other things, such as reminding the patient to perform the assessment. It was furthermore revealed that understanding of the technology and pain assessment system was limited but the motivation to use the method was not decreased by technology problems.

“No, I was never too bad to use the pen.” (Patient 4)

b) Positive influences on the care. The patients perceived an increased and improved contact with their professional caregivers. Using the digital pen and pain diary was described as superior to using the phone for reporting the pain, since the former was seen as a less intrusive way. The method also made it possible to report improvements in pain in an easy way. The patients took a greater part in their own care. By keeping the original pain diaries the patients could go back and see for themselves how the pain had varied over time and this led to a wish to continue with the pain assessment after the period using the digital pen. What the patients appreciated above all with the pain assessment method was that it resulted in a sense of increased security.

“Well I must say it’s absolutely clear that it is positive … and only has advantages, for it is considerably faster. I can reach them [the caregivers] easier and that means a feeling of greater peace for me, which is the main thing.” (Patient 12)

c) Shifting outlook towards the pain assessment method. The professional caregivers’ outlook was initially cautious due to low expectations concerning the patients’ abilities and due to uncertainty about how to use the system. Contemporary organisational changes put the caregivers under stress and the pain
assessment system was described as increasing their workload. Although they were reluctant to use the system and change their way-of-working, the caregivers experienced positive outcomes. They found it valuable to receive information on the patients’ pain situations and they learned to be more aware of and focus on the patients’ pain. The improvement suggestions for future use comprised assessment of all pain locations and assessment of more symptoms.

"Somehow we use the VAS in a little more objective way than we did before … I don’t say in words that the patient is in more or less pain, instead I say that ‘The patient assesses pain VAS six’. Later on in the afternoon he perhaps assesses VAS three … then it is not my subjective judgment of what he tells me, but his objective.” (Nurse 1)

d) Positive patient influences. This category comprised the professional caregivers’ perception of the participating patients’ experiences. The caregivers saw that the patients had benefited from the pain assessment method by means of increased participation in their care, increased security and by improved responses to pain fluctuations in terms of changes in treatment. According to the caregivers, patients sometimes seemed to be somewhat amused by using the pain assessment method, which led to continued pain assessment after the period.

"I believe that some patients have received much quicker help than if we had handled this in routine care.” (Physician 2)

3. Discussion

Digital pen technology was found suitable in regard to the fact that the HBHC clinic used paper-based medical records. Of the interviewed patients only one was a woman while of the interviewed spouses all four were women, which can be seen as a limitation to the study. However, palliative patients at their end-of-life constitute a very frail group, which means that it is not always possible to create similar and complete cases [18]. The qualitative descriptive and explorative design for evaluation comprising a content analysis was used in order to capture patients’ and professional caregivers’ experiences of the pain assessment method. Qualitative content analysis was deemed suitable due to the fact that it focuses on the subject and context, and it points out differences and similarities between and within categories. Furthermore, it preserves the core of the original analysis material [19].

During the study the participating patients assessed their momentary pain three times per day at regular times. The advantages of letting patients assess their momentary pain several times per day, instead of asking the patients to recall and summarize their pain over a period of time (e.g. one day), have been shown by, for example, Stone et al. [20] and Lefebvre and Keefe [21].

The success of home telehealth depends on both patients’ and professional caregivers’ acceptances. Home telehealth interventions change the caregivers’ practice patterns and have an impact on their way-of-working. Also, the level of patient acceptability is influenced by the way in which patients understand the technology and intervention [22]. In a Canadian home telehealth project, involving palliative patients using video visits, the caregivers were concerned by the impact of the new technology on their usual work patterns; time and effort needed for the technology were seen as a
large investment, whereas the benefits were less obvious [23]. The professional caregivers in our study reported reactions which showed initial similarity with the Canadian study; the caregivers at HBHC showed an initial cautious outlook due to their own reluctance to use the system and change their way-of-working. Contemporary organisational changes put the HBHC caregivers under stress and the pain assessment system was described as contributing to an increase in the workload, since they had to use the computer-based system and handle both the equipment and all pain assessments on paper. Due to low expectations of the patients’ abilities to use the pain assessment method certain patients, especially older women, were never asked to participate. This can be coupled to the professional caregivers’ own feelings of uncertainty towards the technology which were transferred to the patients. To compensate for possible caregiver reluctance towards the technology, individual positive experiences of technology usage were important. Such positive experiences were described and contributed to a shifting outlook towards the pain assessment method. Another positive experience expressed was the fact that they had become more aware of the patients’ pain and that also the patients had become more aware, which could make pain assessment and reporting easier since they “spoke the same language” by using VAS as an instrument.

The patients in the Canadian study [23] showed quite similar reactions to the patients in our study; the Canadian patients had positive reactions towards the technology though they were not familiar with it, also, they seemed “reader” than their caregivers to use the monitoring equipment. The patients in our study found the pain assessment method as being effortless in spite of severe illness and limited understanding of the technology and system intervention, and they did not need help from their next-of-kin in performing the assessments. Furthermore, the patients expressed that they took a greater part in their own care during the pain assessment period. Their motivation was that it felt good to co-operate with the professional caregivers and to see one’s own pain variations and have control over consumed extra doses of analgesics.

The professional caregivers experienced several positive patient influences from the pain assessment method, which were in accordance with the results from patients'/spouses’ interviews and patients’ ease-of-use questionnaire and which contributed to the shifting outlook, namely that the patients took a greater part in their own care and that they experienced an improved contact with their caregivers, which in turn led to a sense of increased security. There was also a quick response to variations in the patients’ health status by means of changes in medical treatment, as shown in the medical records.

For palliative patients in advanced home healthcare there is a need for ease-of-use interfaces in handling technology. Therefore digital pen technology is suitable for the assessment of symptoms since these patients often have a limited capacity to handle technology due to their state of health. By using pain diary forms on digital paper in combination with digital pen and wireless Internet technologies, our system combines many of the good parts from systems using electronic diaries and systems using traditional pen and paper-based diaries.
4. References


