Symptom management at the touch of a button

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Side-effects of chemotherapy are nasty and can be dangerous. But soon patients may be able to log symptoms and receive prompt advice or, if necessary, medical attention, using nothing but a mobile phone... and a rather sophisticated computer programme.

An ambitious project based at the Cancer Care Research Centre, University of Stirling, Scotland, is setting out to help patients overcome the unwelcome effects of cancer chemotherapy through the use of mobile computer technology.

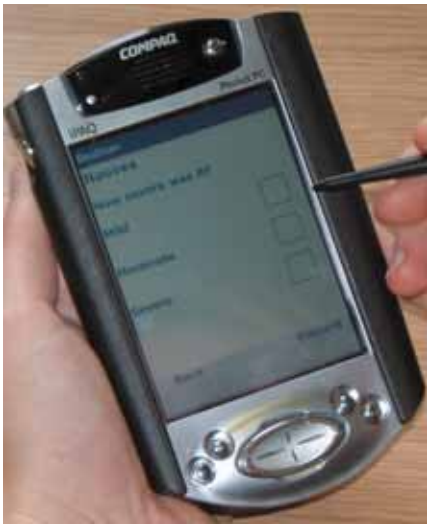
The idea is for patients undergoing chemotherapy to use hand-held computers and/or mobile phones to help them cope with their side-effects while at home. The technology gives patients information on self-management of certain reported symptoms and alerts medical staff to more serious problems that require immediate attention.

A research team led by Nora Kearney, professor of Cancer Care at Stirling University, recently completed a feasibility study which involved 18 patients using a hand-held computer. The team has also done early trials with mobile phones. The patients in the feasibility study, all of whom were undergoing chemotherapy, inputted data on their symptoms into the hand-held computer and sent it to a central server linked to their clinical centre. Here the data was automatically fed into an alert system devised to warn patients and staff of impending serious problems.

Early alert

"We want to be able to intervene early for someone who, for instance, is receiving chemotherapy for colorectal cancer and develops diarrhoea, which can be life-threatening," Kearney says. "Levels of alert have been built into the system based on what we know about the clinical symptoms from previous work. An 'amber' alert triggers a self-management protocol on the hand-held computer that will advise the patient on what steps to take, perhaps an antidiarrhoeal agent in the first instance. If three ambers are struck, a red alert is automatically triggered at the clinical centre with an immediate call-back to the patient from a nurse. Some defined symptoms, such as a high temperature, produce an immediate red alert."

The feasibility study builds on the work of the WISECARE initiative (Workflow Information Systems for European Nursing Care), which aimed to evaluate whether nursing care underpinned by practice guidelines and



Using this hand-held computer, patients can log their symptoms and send them to their treatment centre. Software at the centre will monitor the information, and grade it for levels of alert. At an amber alert, standard advice will be offered to the patient via their computer about steps they can take to relieve the symptoms. A red alert triggers an immediate call back from one of the nursing staff

information technology would improve patient outcomes. Patients in the WISECARE study (over 300 in number) listed their symptoms on a paper questionnaire that nurses then had to transfer to the electronic patient record when the patient visited the clinic, with interventions being based on the resultant scores. Kearney's project aims to cut out the paper-filling exercise and allow patients to enter data directly into the system. "Nurses involved in the WISECARE study told us that the process of data entry to the system was time-consuming, and patients said it would be better if they could get access to self-management information quicker," Kearney explains. "The new system addresses both problems and allows symptom assessment and management interventions to be completed in real time."

Patients were involved from the outset in designing the software and interface

Interventions in the feasibility study were based on protocols that members of the research team had built into the system following extensive reviews of the literature, analysis of patient data and testing with clinicians. Patients reported their symptoms using a modified version of the chemotherapy symptoms assessment scale (C-SAS), which asks whether the patient has the symptom, how bad it is, and how much it impacts on his or her functioning.

This generated a 'score' which corresponded with specified interventions within the protocol. General information about cancer and treatments was also available to patients through the technology.

Patients were offered a brief teaching session on the hand-held computers from one of Kearney's research team prior to entering the study. "Some of the patients, particularly older ones, worried that they would have problems, but none of them had difficulties. Indeed, most managed it with ease," Kearney says.

Keeping it simple

The key to making the system user-friendly was to keep it simple. Patients were involved from the outset in designing the software and interface, and this paid significant dividends. "We went into the clinics and worked with patients to find out what they wanted," Kearney explains. "They raised simple issues we might not have considered – like some patients thinking the instruction 'home' on the computer meant it should only be used in their own home. That made us think hard about the use of language and the value of graphics."

Kearney's experience of using hand-held computers in the feasibility study and mobile phones in other work is leading her to conclude that the latter might be the better option for the longer term. "Each has merits," she says. "The hand-held computer has a bigger screen and you can get lots of information on it, but mobile phones are easily available and people are more familiar with them."

While early results are encouraging, the challenges of devising and running a system such as this should not be underestimated, Kearney warns. Although the research team was determined that no patient would be excluded on grounds of age or diagnosis, the system will not be suitable for all patients, particularly those with severe cognitive or perceptual disabilities. And any project that involves technology is bound to raise suspicions about expense in the longer term.

In addition, the work involved in putting the protocols together is enormous. "Protocol building is complicated and has taken the best part of seven years to get to this stage," Kearney concedes. "A huge amount of work has been necessary in reviewing literature and analysing data received from WISECARE patients to identify their symptom profiles over time."

Scaling up

Kearney is nevertheless optimistic about future prospects. "The number of patients involved in the feasibility study was small, but they told us they felt their symptoms were managed better," she says. "Even though they weren't physically in the clinical area, they felt they could instantly send information about a problem to their clinicians."

Clinicians' initial scepticism also proved unfounded, Kearney claims. "When we interviewed clinicians post intervention, they told us they could see the benefits and that the system was enhancing their relationship with the patient, rather than replacing it," she says.

Kearney and her team are now putting together plans to launch a larger, multi-centre clinical trial in the UK to test the system's effectiveness.