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The 3rd International Conference on Current and Future Trends of Information and
Communication Technologies in Healthcare (ICTH-2013)

Proceed with Caution: Transition from Paper to Computerized Pain Body Maps

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Abstract

Patients with advanced-stage cancer often have a high symptom burden and reduced functional status, implying that
the patients themselves should be involved in development and testing of interactive assessment tools. This paper
reports on an assessment of use of a pain tool, which led to changes in both medium and program in order to adapt to
the patients' needs and abilities. Our study shows how a change in medium for pain assessment from paper via laptop
to iPad affects the interaction with the tool on important aspects of use. We also show how changes of medium affect
the readability of the output for health care workers. We achieved better results with an iPad-based pain assessment
tool developed through user-centered design compared to both a paper-based and conventional laptop-based tool.

Keywords: Pain, Palliative, Cancer, Assessment, User-centered design

1. Introduction

Pain is experienced by about 80 % of patients with incurable cancer [1], and one of the symptoms most feared
by cancer patients [2]. Insufficient pain control is associated with reduced quality of life, and both pain and pain
medication have negative effects on cognitive function in experimental tests [3]. Patients' ability to perform self
assessment is limited by (among other factors) their cognitive functioning, especially in the later phases of the patient
trajectory [4]. Reduced cognitive capacity could lead to a vicious cycle of reduced ability to perform pain assessment
and thereby reduced quality of pain management. This is why cognitive function must be considered before assessing
the patient, but this has to be done in an easy and valid way. So far there is no consensus on how this should be done.

The assessment has to include all important dimensions of the pain. A central feature is where the pain is located.
This aspect of pain has traditionally been assessed by a pain body map (PBM); an illustration of the human body on
which patients mark the location of their pain (Figure 1). Paper-and-pencil PBMs have proved to be highly useful
in pain assessments [5, 6, 7]. However, sharing and processing of paper data are time-consuming, cumbersome and

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dependent on human resources. Even though pain management has been a focus for several years, pain prevalence is still high in this group of patients. Cancer pain is a complex symptom to assess, but by using computers, data can be processed in order to recognise patterns and provide decision support for clinicians dealing with pain.

Earlier HCI-related studies addressing the effect of paper-based versus digital tools in clinical situations show that changing the medium may have a strong impact on the usability of the information and communication systems, and on the context of use [8, 9]. Understanding how to take advantage of the interactive possibilities offered by a digital medium, and at the same time avoiding introducing or minimizing potential negative side effects, is therefore crucial when designing computerized tools that replace paper-based ones. For some patients a progressing cognitive impairment occurs along the disease trajectory, and without a thorough assessment it is hard to determine each patient's ability to perform self-assessment of pain. In the aspect of doing a user-centered development, we need to include patients with symptoms that are typical for all phases of the patient trajectory. This might also include patients within the last 6-3 months of their lives, whom previous studies have identified as having problems related to reduced ability to do self assessment [4]. The common cognitive test battery is quite time-consuming and far too extensive for this group of patients, which makes a thorough testing unethical and close to impossible. Mini-Mental Status Examination (MMSE) and Trail-Making-Test (TMT) are two short screening tests for cognitive impairment [10, 11]; the MMSE measures global cognitive functioning, and TMT measures (among other things) executive functioning. We want to explore how we can design mobile computerized PBMs that accommodate the specific needs of palliative care cancer patients. Designing for persons with chronic pain and other symptoms associated with cancer represents a relatively unexplored area in Human-Computer Interaction. In order to form a qualitative understanding of aspects that need to be taken into consideration when designing for advanced cancer patients, we have conducted an iterative user-centered process in which PBM prototypes have been assessed in realistic clinical contexts of use. The main contribution of this paper is the design lessons learned from this process.

2. Methods

In this study we have compared three different media used for PBMs: the original paper-based, the first attempt at a Computer-based PBM (CPBM) on a laptop [12] and different versions of an iPad-based CPBM (which were interactively developed as part of this study), in five different experiments. Thus, each test not only supplied results to a general analysis of the media used, but also fed into the next development cycle of the iPad-based PBM.

2.1. Experimental design

Evaluations of mobile systems benefit from being done in a realistic environment [13, 14]. As our main area of interest is how patients interacted with each medium in the context of clinical care, the tests were conducted in two locations: either at the patient's bed in the hospital ward or in a room designated for research in the out-patient clinic.

Each patient experiment consists of three steps: The first step was to inform patients about the procedure and ask demographic questions including age, Karnofsky performance status (KPS), MMSE or TMT and a pre-test interview [15, 10]. KPS is a standard measure of performance, range from 0=dead to 100= normal, no complaints and used for prognostic evaluation of the patient. The next step was the experiment itself, and the final step was a post-trial interview to elicit the user's opinions about and satisfaction with the tool. Different clinicians were included as test-persons or gave feedback on the test results. Patients were observed in each experiment. In all experiments except two, audio was recorded and interaction was captured through screen capturing software installed. No recordings were made in the first experiment. In the third, only audio was recorded.

2.2. Test participants

The primary test participants were advanced-stage cancer patients. These patients were recruited from the Palliative Medicine Unit and outpatient clinic at St. Olavs Hospital, Trondheim University Hospital. Patients were identified by the research team in cooperation with the responsible care team on the ward. The patients who were able to give written informed consent and confirmed that they were experiencing pain were eligible.

In addition to the patients, physicians involved in the daily treatment of such patients were also recruited as domain experts to evaluate the quality and clarity of the pain body maps. Finally, to supply general interaction expertise, HCI experts were recruited among PhD students and post docs in the field working at the university.

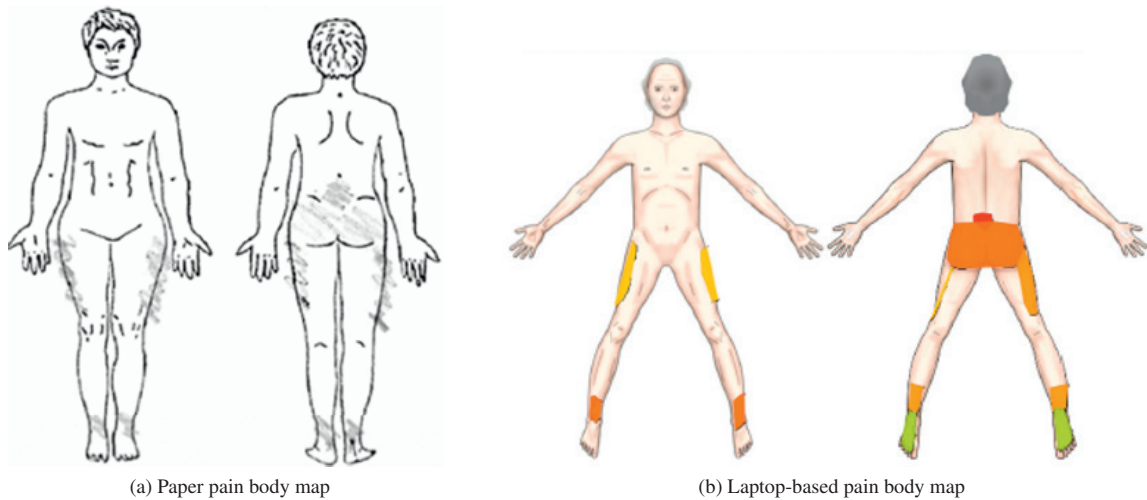(a) Paper pain body map (b) Laptop-based pain body map

Figure 1: Comparing paper-based and computerized pain body map

2.3. Test Scenarios

Two scenarios were used for testing the different platforms. The first scenario was about using the PBM in bed at the ward where the patients were admitted (the *bed scenario*). This test scenario was tested on patients whith low KPS. The second scenario simulated any situation where the patient might use the PBM outside of bed, and/or the hospital; that is at a table (the *table scenario*). The patients tested in this scenario had higher KPS. The focus was on how patients interacted with the PBM with regard to usability in general, and in relation to correcting errors if they were made. The objective for the physicians was to evaluate how they interpreted the result of the patients' PBMs, and in case of corrections, how these were perceived.

3. Results

All in all, five different experiments were carried out. The initial experiment compared the result of patients filling in both the paper-based PBM and the initial laptop-based prototype, in both scenarios. The second experiment further investigated usability issues of the laptop-based CPBM. The third experiment was carried out on the first paper mock-up of the envisioned iPad interface for a CPBM. The fourth and fifth experiments dealt with specific implementation issues of the iPad-based application.

3.1. Comparing paper-based and computerized pain body map

92 patients were included in this experiment. A nurse presented the patients with both a paper PBM and a CPBM (see Figure 1) to fill in. The patients were also subject to several other questionnaires, including an MMSE [12, 16]. The two body maps were presented in a preassigned random order with at least 20 minutes between the two tasks [12, 16]. The paper-based PBM was marked with a pencil. The CPBM was marked with a stylus on the laptop touch screen (HP Compaq TC4200 tablet PC). When the patients had marked a painful area, a color box prompted them to specify the pain intensity of the area. Errors could be corrected by pressing a remove button placed in the dialog box.

We compared the map pairs with respect to the number of areas and the anatomical locations marked (pain location). Patients were to a large extent (75 %) able to mark the two maps in the same way. The study design did not elicit detailed information about how patients interacted with paper assessment or computerized assessment, but observations of patients filling in the two body maps gave us some information.

In the *bed scenario* patients with low KPS were tested. These patients were not able or willing to sit due to advanced disease. In general, both media did not work very well in the *bed scenario*. The paper version was too thin and flexible to be useful in bed. Without underlying support, it was very difficult to draw on the paper. The laptop, on

the other hand, was too heavy and cumbersome, and the screen was difficult to view from certain angles. In particular, this was a problem for patients with very advanced disease who were not always able to sit up while doing the pain assessment. For the *table scenario* the laptop still suffered from being too cumbersome. It was too thick, and proper arm support was difficult to achieve. Paper, on the other hand, was for most patients quite easy to use. Some patients, who were too weak and frail, did not have enough strength to make good and visible markings.

Some of the patients inevitably made errors when using both maps. Correcting errors on the paper was a problem for some; the weakest patients had problems using an eraser, some simply used a new piece of paper instead. Most of the patients using the laptop did not use the correction button. Whether this was due to not making conscious errors, not being properly instructed in its use, or not being able to detect or correct errors, was unclear. We also compared variables like age, education, experience with computers, KPS and the MMSE score of the patients who managed to mark the two maps the same way with the average score of the patients who did not. Table 1 shows the average score in each test. Due to low number of participants p-values are not calculated, but no large deviation between mean results in these groups of patients was detected. The completed paper PBM and CPBM were inspected and judged by two physicians who without any doubt preferred the results from the CPBM over the paper PBM. Markings were easier to see on the CPBM. On the paper version, the quality of the pencils heavily affected the readability; and when errors had been corrected, the eraser made it difficult to decide which markings were intended and which were erased. The fact that the CPBM reported both the location and intensity on the same place was also rated favorably.

3.2. Usability test of the laptop-based pain body map

The main purpose of this experiment was to explore the usability issues uncovered in the previous experiment. For this trial, nine advanced cancer patients were recruited. For the experiments a researcher instructed the patients in the use of the CPBM. Patients were subject to a pre-test and post-test interview which included an MMSE. The laptop also included Camtasia Studio, which recorded audio and visual interaction with the system by the patients. The patients were also observed by three usability experts.

As seen in the previous test, all of the patients were able to use the program. We also confirmed the findings related to the *bed scenario* and the *table scenario*. Two patients needed less guidance in order to use the program than the rest of the patients. These two patients were both in their fifties and were daily computer users. The difficulties were not always reported by the patients but observed or recorded on the videos. The patients who seemed to struggle the most were the ones with some degree of functional or cognitive impairment. The patients' age did not seem to play similar importance.

The first window of the CPBM contained a question about the pain right now. Several of the patients were uncertain about the time frame for the question. When the actual body map appeared on the screen, several were in doubt about how to mark their painful areas, as no specific instructions were provided. The nine patients marked their pain in many different ways, and not all were accepted by the program. There were instructions on how to mark intensity of pain, but we observed that it took many of the patients a long time to read these.

All but two of the patients had difficulties with the stylus and the screen. Either the screen did not react when the stylus was applied to it, or the marking was vague and small. There also seemed to be a delay between the marking on the screen and the response from the computer. In other cases the computer reacted too fast, and changed screen before the patients had finished marking the area. When the dialog box disappeared, the patients were uncertain if the color represented the intensity they had intended to mark. Some wanted to mark their pain just as a point. This was possible, but when doing so, the pain intensity (color) was not visible. One patient in her sixties reasoned that if she kept tapping on the dialog box, she would obtain a higher intensity score (like a volume button).

The instructions for correcting errors were hidden underneath instructions for marking pain intensity and the radio buttons with the scale. This information and input were presented as a pop-up box. Some patients did not even notice that the pop-up box appeared or disappeared. Patients did not seem to search for an error correcting option.

The two physicians pointed out that they were confused by the unclear markings on the CPBM. They thought that the unclear markings either were errors made by patients or errors in the program. The program allowed patients to mark all over the screen and not just on the body. The test also revealed that in order to give the correct intensity, the patients had to hit exactly in each scale button. Every time the patient clicked outside the button, this made the marked area turn grey. In the same manner, if the patients did not notice the pop-up box, the previously marked area would also turn grey. Grey did not represent a number on the pain intensity scale. It was for this reason not possible to determine if a grey area was an error made by the patient or by the program.

(a) First version of iPad screen   (b) Second version of iPad screen
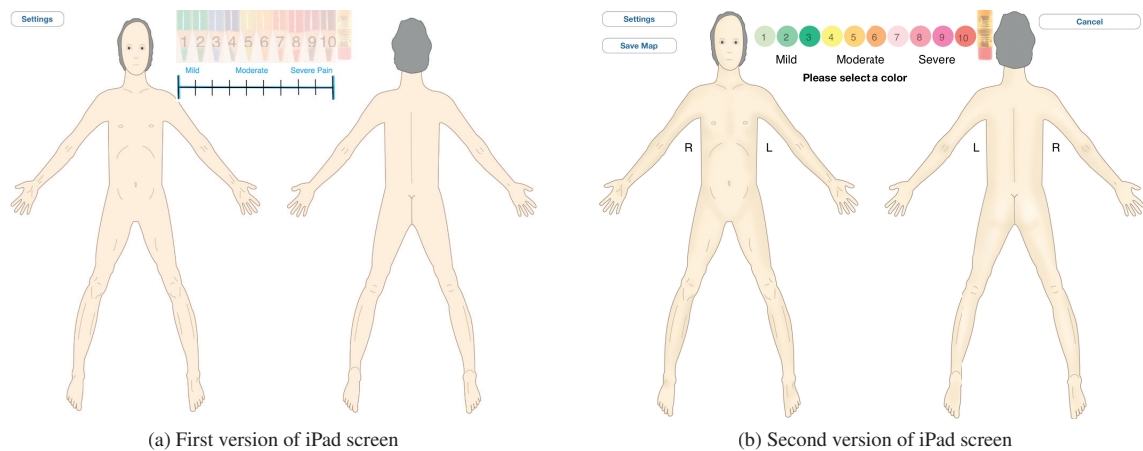
Figure 2: The two versions of the iPad-based pain assessment tool

The three usability experts had a somewhat different focus than the patients. They gave more feedback directly related to the system; e.g., pointing out that the size of the body did not fill the screen. They suggested that for patients with visual impairment, a larger body drawing and clearer boundaries between the background and the body would be helpful. The system should confirm the patients' selections or actions through feedback, and the pain intensity number should appear on the marked area. In addition, the experts agreed that the dialog box appeared and disappeared too quickly. They suggested that the patients should be asked to confirm their choice by pressing OK before the box disappeared. The experts found the gender neutral body disturbing, however, this was not an issue for the patients.

3.3. Paper mock-up of iPad-based pain body map

Ten patients were recruited, and informed about the purpose of the study: to develop a CPBM where the functions and features of the program would be created on the basis of patients' feedback. Each patient was given oral instructions on use of the paper mock-up: Mark the mock-up-PBM in a way that would make their physician understand where they had pain, and its intensity. They were presented a paper with a drawing of a human body. The upper part of the drawing also included a colored set of radio buttons with numbers from 1-10. Behind the paper ten coloring pencils were set up. Each pencil was numbered from 1-10, and colors and numbers corresponded with the radio buttons. The paper was attached to a piece of cardboard with 4 paper clips.

In general, the patients interacted quite well with the mock-up when marking painful areas and choosing intensity of the pain, despite some mechanical problems with setting up the coloring pencils in the *bed scenario*. The system was quite cumbersome to set up, consisted of several small parts which easily came out of place (e.g. coloring pencils in a box), making it somewhat challenging for both the health care personnel and patients.

The implementation of pain intensity combined with pain location on a paper PBM (mock-up) worked very well. Patients immediately understood the purpose and what they were supposed to do without further instructions. This system worked better in this group of patients compared to the CPBM used on a laptop. The problems correcting errors and the necessity of many small parts made this system more cumbersome. For health care workers, the area and location of pain were more visible than on the commonly used paper PBM, but the lack of a good error correction system made paper as medium unreliable.

3.4. First iPad-based pain body map

The first iPad version of the CPBM was based on the paper mock-up. It consisted of a drawing of the human body (front and back views) with a picture of coloring pencils numbered from 1 to 10. A description of pain levels (mild, moderate and severe) and a scale were presented below the coloring pencils (see Figure 2 a)).

Ten patients with advanced cancer were presented with the iPad CPBM. The patients were instructed to mark the area of pain in a way such that the physician would understand where they had pain and the intensity of the pain.

Before marking on the CPBM, all patients were asked to do a TMT. Time was recorded for each patient doing the test. Patients were instructed to choose an intensity of the pain by first selecting the image of the corresponding numbered coloring pencil. Three of the ten patients had no problem using the iPad and were able to figure out themselves how to choose the intensity first and then mark the painful area. Out of the seven patients, five were able to mark intensity and area with some more guidance. These patients got very confused by the scale placed underneath the radio buttons (for dividing the pain intensities into mild, medium and severe pain). One also suggested that he was confused by the marked area, since the number he had pressed was not displayed on the screen next to or on the marked area. These patients were bedridden and had more problems related to the touch screen than the patients who were sitting at a table. The reason why these patients were tested in bed was partly because they were in so much pain that sitting was no option, or they were too tired or frail. Out of the last two patients one was judged, before testing, by the staff nurses to be cognitively intact, but as we sat down and talked, the patient was able to communicate about the study but not able to follow instructions. The other patient was able to discuss and give his evaluation of what he was seeing but he was too frail to manage to give input. These two patients were never able to give any input on the iPad. Both of these patients used 88 seconds on the TMT, compared to between 28 and 41 seconds for the others.

Patients in the *bed scenario* had no problems with the view of the screen and could identify all the contents of the screen. The iPad was light and most patients were able to hold the iPad whilst drawing. The problem arose when the patients were marking on the screen. Insufficient support for the arm made patients rest part of their hand on the iPad screen, which made further marking difficult or impossible. By putting a cover around the iPad where patients could find support for their hand, we achieved some improvement. A majority of the patients did not understand that they had to avoid resting their hand on to the iPad surface in order for the program to work.

When using the iPad in the *table scenario* patients filling in the CPBM on iPad had no major difficulties in relation to arm support or view of the screen. Most patients were able to use the program. A few tried to mark on the iPad with their finger instead of the stylus but found the finger to cover too much of the area they wanted to mark. Some found the stylus to have a too wide and round tip and wished the tip to be more pointed.

Interviews with the physicians showed that the output was clear and gave good information. Correction of errors was somewhat confusing since some patients did not take time to remove all of the marking, although it was obvious that there had been an attempt to remove it. We discovered that the eraser function was set too narrow and made erasing too cumbersome.

3.5. Second iPad-based pain body map

The second iPad version consisted of the same body drawing (see Figure 2 b)) but the coloring pencils and scale were replaced with radio buttons numbered from 1 to 10 and an image of an eraser placed next to the radio buttons. We also set the eraser function to erase in a wider line. The experimental setup was identical to the first iPad-based pain body map experiment above, including performing a TMT. Another seven patients and three health care workers from the Palliative Care Unit were recruited. The change from coloring pencils to radio buttons worked well, as eight of the patients had no problems related to choosing intensity of the pain and marking the painful area. Nevertheless two patients were not able to fill in at all due to drowsiness/sleepiness and due to problems following instructions.

In both the *bed scenario* and *table scenario*, one or two of the patients wondered about the eraser function or tried to hit the button in order to see what happened. One asked for help to remove markings and was shown to press the erase button and use the stylus as an eraser. One patient was not able to follow instructions for the CPBM and he was not able/willing to do the TMT. He was able to show on his body where he had pain.

4. Discussion

Our work demonstrates that the patient population in palliative care is a challenging group for user centered development, but nevertheless very important. Development of a CPBM is performed in the intersection between healthcare and technology, where clinical measures can provide valuable information for the development process. In this study patients with low KPS (represented by the *bed scenario*) have demonstrated how performance status can inform choice of platform in a development process. We suggest a tablet (iPad) as the best platform for a CPBM in this patient population when compared to paper and a laptop. We have also demonstrated that paper and iPad worked better for patients with high KPS (represented by the *table scenario*). Irrespective of scenario, we have demonstrated how a cognitive measure such as TMT can be used as indicator for which patients can interact well with the CPBM.

		Multicenter		Usability	Mock-up	iPad v1	iPad v2
		Different	Alike				
	Gender (M/F)	14/9	45/23	5/4	5/4	7/3	4/4
	KPS	67 (40-90)	67 (40-100)	60-70	64 (50-100)	78 (40-100)	84 (40-90)
	MMSE*/TMT†	28 (24-30)*	28 (16-30)*	30 (26-30)*	-	48(28-88)†	33(18-58)†
	Age	68 (46-83)	65 (20-88)	60 (47-75)	77 (40-92)	59 (42-82)	63 (46-83)
Computer experience	Not given	3	8	0	9	2	0
	None	6	14	2		0	3
	A little (monthly)	7	8	3		0	0
	Some (weekly)	6	20	1		1	0
	A lot (daily)	1	16	3		7	5
Education	Not given	0	0	0	9	0	1
	≤ 9 years	9	12	1		0	0
	10-12 years	8	24	5		7	2
	College ≤ 4 years	3	13	2		2	3
	College > 4 years	3	10	1		1	2

Table 1: Data from experiments

This knowledge could not have been obtained without involving end users. We have also shown a discrepancy between what might work well for patients, and what is optimal for health care workers. This study showed that we managed to implement the desired functionality in the iPad program in a way so that most patients were able to use it.

A proper cognitive assessment includes a whole battery of tests, including TMT and MMSE, which give detailed information on cognitive functioning. We were not interested in each patient's exact level of cognition, but were looking for a simple test where we could immediately relate test results to the ability to use the CPBM. We found that the patients' performance when taking the TMT was comparable to their degree of success with using the CPBM; we observed a large variation of measured TMT time among the patients, also matched with a similar variation related to successful interaction with the CPBM. The different sub-tests in the MMSE did not provide any immediate transferable value related to the observed performance when using the CPBM. The MMSE scores did not show a wide distribution, even though we observed a great variation in the degree of success the patients had when interacting with the computer program. This indicated that the TMT was a better measure for cognitive impairment in this study.

Even though pain is highly prevalent in advanced cancer, reports show that a considerable number of patients experience inadequate pain management [17, 18]. This may be due to several factors, of which lack of systematic assessment has been recognized in several studies. A review of pain assessment tools for self-reporting concluded that intensity, location, and time of occurrence are the most important aspects to include in a comprehensive assessment, as they may give the physician important clues for the pain diagnosis and treatment [19, 20].

Pain body maps have been available for around 60 years. At the time the first PBM was developed and validated, there were no alternative platforms available [21, 22, 7, 23]. Today we have several options, but the different platforms provide different opportunities and challenges which need to be addressed. The first part of the study consisted of two different methods of evaluating a laptop version of the CPBM. Even though the first test showed that the program worked fairly well in a large patient population, defined by comparison of two pain assessment methods, it was obviously not working well when we looked closer by performing a usability test. It was also obvious that when striving for inclusion of the patients who were burdened by their disease, the platform represented a larger obstacle than expected. From testing the frailest and sickest patients we have seen that none of the platforms were without problems. Working with paper assessment tools have taught us that due to cognitive restrictions, patient compliance is drastically reduced in the last few months of the patient's life [4]. There is also evidence that (possibly fluctuating) states of confusion are more frequent in late stages of advanced cancer. [24] We do not know if three of our patients were suffering from a light delirious condition or if there were other causes of lack of ability to execute instructions, but our study has demonstrated the great importance of keeping a program simple and easy.

Paper as platform is for many patients easy to use, but as demonstrated in this study, in order to provide more information into a regular paper PBM we were dependent on using colouring pencils. The system was not optimized for

the sickest and frailest patients, and quite cumbersome for the health care workers. Information on pain management in this group of patients is often shared between GPs, pharmacists and palliative consultants, which a paper format does not support in a convenient manner, and paper does not lend itself to automatic processing.

By providing these patients with a medium they can interact with, pain assessment might be made easier, thus increasing the potential for better symptom management for advanced-stage cancer patients. Technology is continuously improving, and tailoring tools to a specific purpose is now much easier than it was just a decade ago. Usability testing of the different platforms showed that the least favorable option compared to paper was a laptop. This was partly due to the software, but even with flawless software we would have met the same problems related to the unreliable response, the poor view of the screen, and the bulkiness and weight of the equipment.

5. Conclusion

This study showed assessment of pain location and intensity is easier for advanced-stage cancer patients, and gives a more reliable and robust output for health care personnel when using an iPad and a program developed specifically for this group of patients. This study shows how important clinical measures can be used to inform a software development process. Our study suggests selection of platform for CPBM can be based on testing of platform compared with registration of KPS. Patients with higher performance status had no problem using paper or iPad while patients with low performance status had better interaction with iPad. Program interaction worked well for patients with TMT less than 41 seconds, and patients who used more than 88 seconds were not able to interact with the program. These results need to be confirmed in further studies.

Acknowledgment

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