



Usability of an online application for reporting the burden of side effects in cancer patients

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Abstract

Purpose In the Netherlands, online patient reporting of side effects is a new phenomenon. The aim of this study was to gain insight into patients' user experiences and the benefits of the web application BijKanker ('AlongsideCancer').

Methods Patients in seven hospitals were asked to make entries in BijKanker at least once a week. On logging in to the application for the first time (T1), patients were asked to complete a questionnaire on information needs and Internet use. Four months after starting their treatment (T2), they were asked to complete a second questionnaire on their experiences with BijKanker and its four functions: information; reporting side effects; communication with oncology nurses and clinicians; and data feedback.

Results Ninety-nine patients logged in to BijKanker, 60 patients (61%) had completed the first questionnaire (T1) and 40 (40%) had also completed the second questionnaire (T2). In total, 1661 side effects were reported. Generally, patients experienced BijKanker as user-friendly and patients appreciated the attention given to their side effects.

Conclusions The user-centred design gives ample insight into user experiences and usability. The results provide useful starting points for improvements to the online application. We recommend to put much effort into supporting oncology nurses in the implementation of the application.

Keywords Cancer · Side effects · Online application · Patient-reported outcomes · Chemotherapy

Abbreviations

CTCAE	Common Terminology Criteria for Adverse Events
HRQoL	Health-related quality of life
IKNL	The Netherlands Comprehensive Cancer Organisation
NPA	Nurse Problem Analysis

P R O -	Patient-Reported Outcomes Common
CTCAE	Terminology Criteria for Adverse Events
RCT	Randomised clinical trial

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Introduction

Chemotherapy often induces severe side effects which reduce cancer patients' health-related quality of life (HRQoL) in the short term and probably also in the long term [1, 2]. (Note that in the remainder of this paper, for greater readability, symptoms/toxicity/side effects are referred to simply as 'side effects'.) Side effects are the main reason that patients choose dose reduction, are not compliant with treatment or even choose early termination of treatment, all of which are associated with decreased survival [3, 4]. Also, some patients may refrain from reporting mild-to-moderate side effects, which can be a great burden if they occur concurrently [5]. However, despite severe side effects, most patients continue with chemotherapy. Some of these effects could be prevented if patients and oncologists had a complete overview of all side effects over time, as early

anticipation accompanied by dose reduction or co-medication can prevent symptoms from worsening.

Because side effects are mainly measured in clearly defined patient groups in clinical trials, there is an insufficient insight into their incidence, pattern and severity in daily life [6]. In daily life, the burden of side effects on patients is likely to be greater than in clinical trials [5, 6] as well as the variety and magnitude of interventions after the occurrence of side effects.

Other studies have examined the effects of patients reporting their side effects, mostly in randomised clinical trials (RCTs) [7–11]. An RCT conducted by Basch et al. showed that patients in the intervention group reported a lower decrease in mean HRQoL, presented less frequently to the emergency room or were hospitalised less; they remained on chemotherapy for longer, and one-year survival was higher [8]. A comparable RCT conducted by Denis et al. used a web application for feedback from high-risk lung cancer patients in follow-up. Denis et al. reported a median overall survival of 19 months in the intervention group versus 11.8 months in the control group ($p = 0.0014$). In the supervised follow-up, better performance status at relapse, earlier supportive care and reduction of routine imaging were also reported [11, 12].

Generally, patients seem to be willing to report their side effects online [8, 13–15], although not always over the long term [16, 17]. Being able to communicate with oncology nurses and clinicians through an online system positively affects patients' motivation to use such an application [18, 19]. However, patients and oncology nurses must be instructed how to use the system properly [20, 21].

Online patient reporting of patterns and outcomes of side effects can have dual advantages: firstly, clinicians are informed of side effects in a timely fashion and secondly, patient-centred symptom management can be improved. This is especially important in those side effects in which prevention is key (such as peripheral neuropathy) as no treatment is available for them [22].

In the Netherlands, online patient-monitoring of side effects is a new phenomenon, for which a web application known as BijKanker ('AlongsideCancer') has been designed and built. The aim of this study was to gain insight into patients' user experiences and to assess the added benefit of the application in the communication between patient and oncology nurse and clinician. The results will be used to improve the application by making it suitable for daily use by a larger group of patients and oncology nurses.

Methods

BijKanker application

BijKanker provides (1) access for patients to information on possible side effects, (2) the opportunity for patients to report

the burden of side effects caused by systemic treatment in a digital diary, (3) patient communication with oncology nurses and (4) feedback of data to patients, oncology nurses and clinicians in the form of a personalised graph showing the course of their side effects (see Fig. 1).

During the BijKanker usability study, patients were able to report 12 commonly occurring side effects, i.e. constipation, diarrhoea, dyspnoea, fever, haemoptysis, hair loss, headache, nausea, oral mucositis, pain, peripheral neuropathy and vomiting. These side effects were retrieved from the only validated tool available at that time for the Netherlands, the so-called Nurse Problem Analysis (NPA). In the digital diary, the patients scored the experienced burden of these side effects on a scale of 0 (no burden) to 10 (extremely high burden) and answered some questions. If the answers exceeded the pre-defined threshold level—as determined per side effect in the NPA—a certain behaviour was automatically advised, for example: 'Ensure that you drink sufficient water'. If they indicated that they were suffering from a certain side effect (≥ 1), further questions were automatically asked to determine its severity (i.e. health risk). An example of the NPA questions for diarrhoea are as follows: How often do you suffer from diarrhoea per 24 h? Do you vomit? no/yes How often per 24 h? How many glasses of liquid do you drink per 24 h? Do you urinate less often than usual? no/yes. Is the urine dark in colour? no/yes Is your faeces slimy/sticky colour: black or blood? The cut-off scores for all side effects conformed with the Common Terminology Criteria for Adverse Events (CTCAE) (version 4.02) [23].

The communication option (e-consult) enabled patients to send a message to their oncology nurse. However, the patients knew that their messages would only be answered during office hours. During the consultation before they started systemic treatment, patients were instructed to call the hospital immediately if they developed severe side effects such as fever.

Setting and participants

At the start of this small-scale usability study with a human-computer interface design method [24], a workflow was outlined for the health professionals and a telephone helpdesk was organised for patients. The researchers in collaboration with patients designed a digital questionnaire on their information needs and Internet use. We have used these questionnaires before to evaluate other Internet applications and Internet use [25].

The nurses at the seven participating hospitals were instructed on how to use the application BijKanker. Also, a paper-based instruction was provided for the nurses and an information leaflet for the patients. The nurses invited patients to use BijKanker. After the invitation was accepted, patient characteristics and the type of systemic treatment were entered

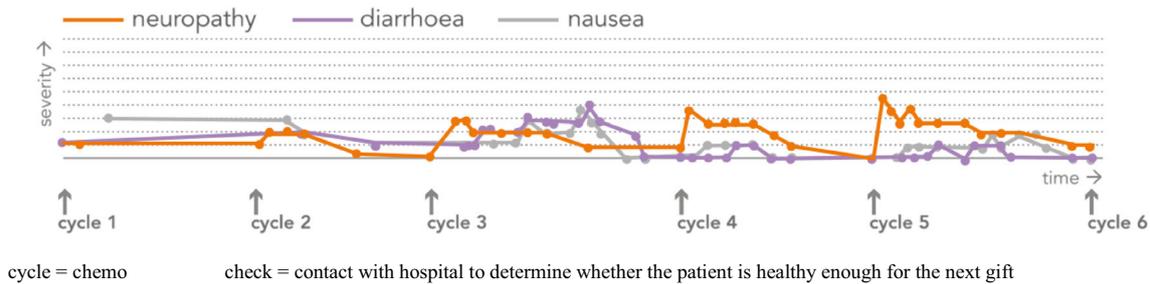


Fig. 1 Data feedback of patient X: course of side effects following six chemotherapy treatments. Cycle, chemo; check, contact with hospital to determine whether the patient is healthy enough for the next gift

into the application. The patient was then able to log in and received information about that specific systemic treatment, including the treatment schedule, the possible side effects and advice on how to deal with them. In terms of patient characteristics, there were no criteria (e.g. tumour type, treatment phase or types of systemic treatment) that restricted patients from participating in this study. A declaration of no objection was granted by the Medical Ethics Review Committee Midden-Brabant (NW2015-17). All participants provided informed consent online.

Data collection

Participating patients were asked to make entries in their BijKanker digital diary at least once a week, or more often if they were experiencing side effects, from the start to the end of their treatment. On logging in to the application for the first time (T1), patients were asked to complete a digital questionnaire and 4 months after starting their treatment (T2), they were asked to complete a second digital questionnaire on their experiences with the BijKanker application. The questions concerned use of the application and its four functions (i.e. access to information, reporting of the burden side effects, communication with their nurses and data feedback). The patients had the option of making additional comments about the application in the questionnaires, including suggesting improvements.

Results

Socio-demographic characteristics

In total, 99 patients logged in to the BijKanker application, 60 patients (61%) completed the first questionnaire (T1) and 40 (40%) also completed the second questionnaire (T2) (Table 1). Only one patient with a low educational level completed the second questionnaire. Of the total number of patients, 93% (T1) and 100% (T2) had mobile Internet access and 83% used the Internet every day. In the period immediately after being diagnosed with cancer, while waiting for their treatment to

begin and during the treatment period, 60% of patients had searched the Internet at least weekly for information about their illness and treatment.

Reported side effects

The actual use of the BijKanker application varied greatly among patients. In total, 1661 side effects were reported (Table 2). Most of the patients reported incidental or prevalent side effects approximately 10 times. Eight patients reported on their side effects more than 50 times. Peripheral neuropathy was reported most frequently (20%), followed by nausea (15%) and diarrhoea (13%).

General user experiences

Generally, patients experienced the application as user-friendly and appreciated the attention paid to their side effects (Fig. 2). They found the information easy to understand, objective and complete, and 84% of them did not encounter

Table 1 Socio-demographic characteristics of patients at T1 ($n = 60$)

	T1: N (%)	T2: N (%)
Sex: male/female	20/40 (33/66)	11/29 (28/72)
Mean age (range)	59 (33–76)	58 (34–76)
Partner	57 (95)	36 (90)
Educational level ^a		
Low	16 (27)	1 (3)
Medium	28 (47)	25 (63)
High	14 (23)	11 (28)
Not stated	2 (3)	3 (8)
In employment		
Yes	32 (53)	23 (58)
No	28 (47)	17 (43)
Internet use		
Mobile Internet access	56 (93)	40 (100)
Daily Internet user	50 (83)	33 (83)

^a Educational level: low (no schooling or primary school only); medium (lower general secondary education or vocational training); high (higher vocational training or university)

Table 2 Reported side effects (score $\geq 1^*$) among 60 patients

Side effects	No. of reports	%
Peripheral neuropathy	328	20
Nausea	254	15
Diarrhoea	217	13
Oral mucositis	192	12
Constipation	176	11
Pain	130	8
Vomiting	128	8
Haemoptysis	120	7
Hair loss	50	3
Fever	33	2
Headache	32	2
Dyspnoea	1	0
Total	1661	

* ≥ 1 : presence of a side effect, grades 1–10

difficulties making digital diary entries on their side effects, although 29% did find this to be tiring. In addition to their general experiences, at T2, they frequently pointed out three drawbacks: (1) practical Internet problems (IT skills), (2) the large number of additional questions for each side effect and (3) that they were only able to score 12 side effects instead of all side effects.

User experiences of the four BijKanker functions

Patients were asked how they got the information about how to use BijKanker. Eighty-five percent said they had been told about it by nurses during consultations at the hospital and 15% had been informed by email. Most patients (79%) reported that the information was very extensive.

At T2, patients ($n = 40$) indicated that they were positive about the four functions of the BijKanker application (see

Fig. 2 General user experiences of the BijKanker application ($n = 40$)

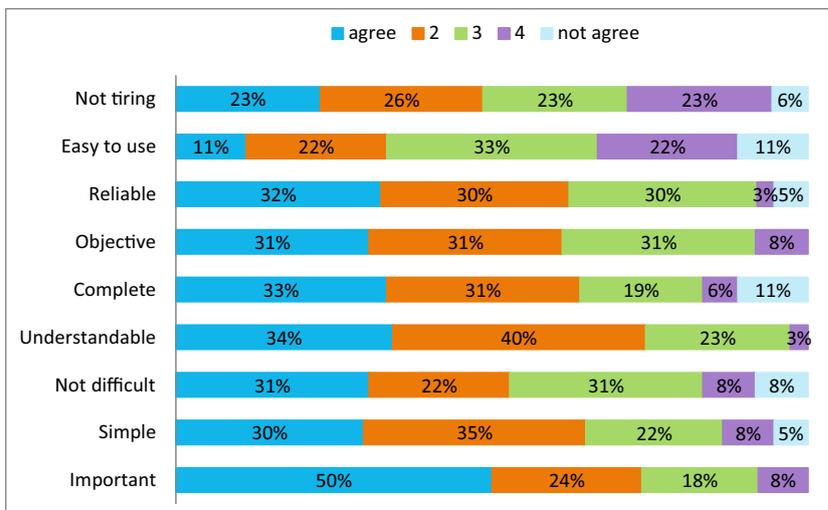


Fig. 3). The majority of the group were positive about information provision (68%), communication with oncology nurses and clinicians (60%) and data feedback (57%). Reporting of side effects was the function that was found to be least important (47%).

The satisfied users greatly outnumbered the dissatisfied users (see Fig. 3). After the study had ended, 50% of the patients stated that they would recommend using the BijKanker application to other patients, whereas approximately one third of them indicated that they were not motivated to continue using it (mean 5.5/SD 2.5, on a scale from 1 to 10).

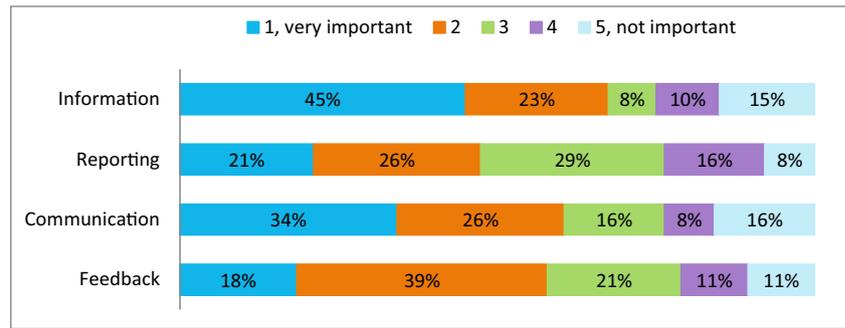
Information provision

At T2, 40 patients reported that they had been informed about possible side effects, either verbally (88%) and/or by means of a brochure (43%) and/or through BijKanker itself (53%) and/or in some other way (19%). The vast majority (95%) of the patients were satisfied or extremely satisfied with the information provided. However, 20% of the patients indicated that they would have preferred to receive more information. None of the patients complained that they had received too much information.

Among 40 respondents, the mean rating for the amount of information accessed through the BijKanker application was 7.0 (on a scale from 1 to 10), whereas the mean rating for the experienced effect of that information was 6.7 (Table 3).

Reporting of side effects burden

At T2, 34 of 40 respondents (85%) found it useful to report side effects and they were moderately positive about the function of regularly reporting their side effects burden (mean 6.2/SD 2.4, on a scale from 1 to 10). However, they thought that using the application did not greatly influence their decision to

Fig. 3 Importance of BijKanker functions (n = 40)

either persevere with or abandon chemotherapy treatment (mean 4.3 /SD 2.7, on a scale from 1 to 10).

Communication with nurses and clinicians

At T2, 31 of 40 respondents (78%) were satisfied with the response from the oncology nurse and clinicians, and 4 (10%) were dissatisfied. Most (75%) of the patients used this for communication, although they only experienced its contribution to the communication between them and the nurse as limited (score = 4.9, on a scale from 1 to 10).

Data feedback

Patients ($n = 40/78%$) were positive about the way in which the feedback was presented (Fig. 1). Oncology nurses preferred the insight at a glance into the reported side effects over a long period of time as presented in Fig. 1, instead of only checking those cross-sectionally during a consultation, as in current regular care.

Discussion

The main result of this study into an online application is that respondents appreciated being able to report the burden of side effects they experienced during systemic treatment. Just over half the patients stated that they would like to continue using the

application in the future. Most patients were generally positive about their experience of using the BijKanker application, and many of them made suggestions for improvements. Patients experienced the support functions of information provision, the communication with oncology nurses and clinicians and the data feedback as being of either great or moderate benefit. Reporting the burden side effects function was regarded as too laborious in its present form; however, it is the basis for communication and feedback. The most important advantage of such reporting is that it can lead to early intervention in order to reduce side effects in the short term and hopefully also have long-term positive consequences [26, 27].

User experiences

In a review, Li et al. (2013) show that numerous factors influence the acceptance of an Internet application, including characteristics of healthcare professionals and perceived usefulness and needs [28]. If the patients are familiar with digital media, find an application useful and can actively use it in their treatment process, then it will have a positive effect on their motivation to regularly report side effects and to discuss these with oncology nurses [28, 29]. During this study, the verbal responses to the help desk from our respondents indicated that our application had motivated them to report their side effects, if outcomes had been discussed during consultations with their nurse and if they had responded to automated alerts if values had exceeded a cut-off score.

Table 3 Perceived effect of using and motivation to continue using; the BijKanker application ($n = 40$)

	Mean ^a	SD
1. How do you rate the information that can be accessed through BijKanker.nl?	7.0	1.5
2. To what extent do you think the information that can be accessed through BijKanker.nl has had a positive effect?	6.7	2.3
3. How do you rate the function of regularly reporting which side effects were a burden to you?	6.2	2.4
4. To what extent do you think that completing short questionnaires in BijKanker.nl has had a positive effect on your decision to persevere with or abandon the treatment?	4.3	2.7
5. To what extent has BijKanker.nl positively contributed to the communication between you and the healthcare professional?	4.9	3.0
6. How satisfied are you in general about using BijKanker.nl?	6.1	2.2
7. How motivated are you to use/continue using BijKanker.nl in the future?	5.5	2.5

^a The higher the score, the greater the experienced effect of using BijKanker, scores ranging from 1 (extremely dissatisfied) to 10 (extremely satisfied)

Information provision

The vast majority of the patients in this study (95%) were satisfied with the information provided, whether through the BijKanker application or by some other means. Similar studies have reported that 50–70% of patients were satisfied with the information provided [30–32]. Fletcher et al. reported in their review ‘the most frequently identified needs were side effects of treatments, severity of side effects, and when to report side effects (24.6%)’ [33]. A possible explanation for this difference is that in our study, information on side effects was always accessible through the BijKanker application via the Internet. Only four of the 104 papers included in the review of Fletcher et al. [33] make an explicit connection with information on the Internet.

Reporting of side effects burden and resulting data feedback

Two thirds of the respondents ($n = 40$) (see Fig. 2) reported that they had found BijKanker easy to use for reporting their side effects. The literature shows that such reporting by patients leads to greater care and insight among healthcare professionals regarding side effects [18]. Besides, it changes the severity of clinician-reported side effects towards a more realistic level [8, 34]. Patients also reported that they expected few positive effects of reporting their side effects burden in terms of therapy compliance and/or communication with the oncology nurse and clinician. It is questionable whether individual patients who used the application would be able to estimate what the consequences of reporting side effects would be. For example, oncology nurses reported the benefit of the data feedback on the reported burden of side effects, an example of which is shown in Fig. 1. Clearly, patient X’s neuropathy worsened after each dose of chemotherapy. However, at certain points in time during the regular treatment schedule when the oncology nurse checked if the patient felt fit enough to receive the next dose, his/her reported level of neuropathy was relatively low. In this patient’s case, following dose no. 6, the dosage was reduced to prevent chronic neuropathy. Without the use of the BijKanker application, this observation of worsening over time and dosage adjustment would most probably not have been made. Neither would the patient have been aware of the risk.

Reporting side effects, an important function of the BijKanker application, seemed the least important for patients. We assume that not every healthcare provider explained and discussed the impact of the patient’s reports with patients. If this application will be used during treatment, then it will have a positive effect on patient’s motivation to regularly report side effects and to discuss these with the oncology nurse [28, 29]. It is also possible to collect information on the severity of the symptoms by means of the BijKanker application. Both

patients and nurses knew the severity, but these data were not collected for our study. At this point of the development process, we wanted to know patients’ user experiences.

Our study shows that different factors influence the experiences of patients with an eHealth application. The focus was on the usability of the application, but it also appears that personal characteristics of the patient, such as gender, age and education, influence usage. The attitude of the healthcare provider influences to what extent an application will be used by patients. This was confirmed by statements from patients to the study helpdesk.

Recommendations for BijKanker 2.0

In order to be able to compare the burden and risk of side effects, it is necessary to attune patients’ reporting of burdens and clinicians’ reporting of health risks to each other by means of unified definitions (i.e. standardised terminology). This requires the development of a national or, preferably, international standard of side effects. Involved researchers in the Netherlands have recently started working towards this goal for oncology.

The upcoming version of the BijKanker application will use an international standard, i.e. the Patient-Reported Outcomes Common Terminology Criteria for Adverse Events (PRO-CTCAE) score [35]. This will enable patients to report all their side effects, which is expected to increase patient satisfaction with the application and patient perseverance with the task of reporting [35–39]. Based on their review, Atkinson et al. [40] expect patient care to improve if healthcare professionals use PRO-CTCAEs in combination with Common Terminology Criteria for Adverse Events (CTCAE) ratings. This combination of registrations could give insight into the real incidence and severity of side effects [40–43].

Limitations

The main limitation of this study is that only a small number of patients participated. More patients ($n = 99$) logged in to the app than answered questionnaires 1 and 2 (respectively 60 and 40). Table 1 shows that it was mainly people with a lower level of education ($n = 15$) who stopped participating in this study between T1 and T2. It is not known how many patients were eligible for participation or to what extent the oncology nurses consciously or unconsciously selected the patients for participation. Respondents who had access to BijKanker might be a selected group of more highly educated and employed patients (see Table 1).

Considerable differences are apparent in this study, not only between the numbers of patients included per hospital but more importantly, in the number of side effect entries per

patient. These differences may have negatively influenced the representativeness of data.

For patients' reporting of side effects during this study, we used a Dutch nursing protocol that is more limited than the National Cancer Institute's PRO-CTCAE list [35] as this protocol was not yet available in the Dutch language.

Conclusions and recommendations

On the basis of this study, it can be concluded that evaluating an application for online reporting of side effects in cancer patients undergoing systemic treatment is possible and resulted in important improvements. Patients who report their side effects in this way prefer to report all of the unpleasant symptoms that they experience. However, they also prefer not to have to answer too many questions about each side effect.

Patient motivation to use such an online application during chemotherapy increases if the oncology nurses also proactively use the application while supervising their patients during treatment and at consultations and if they respond in a timely fashion to the patients' messages concerning side effects, their treatment needs and requests.

Involving patients in the evaluation and further development of such an online application (i.e. user-centred design) gives ample insight into user experiences and usability. Such insight can be fed back into the application itself and enhance it by refining questions for purposes of further research into side effects.

The results of this study provide several useful starting points for improvements to online applications such as BijKanker and usability study designs. In the context of its future, broader implementation, we recommend that there should be more focus on instructing and coaching oncology nurses in the optimal use of the possibilities offered by online reporting by patients. Further research is necessary to determine if the BijKanker application can make a real difference in healthcare.

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Compliance with ethical standards

A declaration of no objection was granted by the Medical Ethics Review Committee Midden-Brabant (NW2015-17). All participants provided informed consent online.

Conflict of interest The authors declare that they have no conflict of interest.

Disclosures All the authors have approved the contents of this manuscript. This manuscript is not being considered for publication elsewhere and its findings have not been previously published.

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