Implementing Symptom Management Follow-up Using an Electronic Patient-Reported Outcome Platform in Outpatients With Advanced Cancer: Longitudinal Single-Center Prospective Study

Lili Tang¹*, MD; Yi He¹*, MD; Ying Pang¹, MSc; Zhongge Su¹, MSc; Jinjiang Li¹, MSc; Yening Zhang¹, MSc; Xu Wang², MBA; Xinkun Han¹, BSc; Yan Wang¹, MD; Zimeng Li¹, MD; Shuangzhi He¹, BSc; Lili Song¹, MD; Yuhe Zhou¹, MSc; Bingmei Wang¹, BSc; Xiumin Li¹, BSc

¹Key Laboratory of Carcinogenesis and Translational Research (Ministry of Education), Department of Psycho-oncology, Peking University Cancer Hospital & Institute, Beijing, China
²ePRO Vision, Health Technology Co, Ltd, Beijing, China
*these authors contributed equally

Corresponding Author:
Lili Tang, MD
Key Laboratory of Carcinogenesis and Translational Research (Ministry of Education)
Department of Psycho-oncology
Peking University Cancer Hospital & Institute
52 Fucheng Road
Beijing, 100142
China
Phone: 86 1088196648
Fax: 86 1088196648
Email: tanglili_epos@126.com

Related Article:
Comment in: https://formative.jmir.org/2023/1/e21453

Abstract

Background: Patients with cancer experience multiple symptoms related to cancer, cancer treatment, and the procedures involved in cancer care; however, many patients with pain, depression, and fatigue, especially those outside the hospital, receive inadequate treatment for their symptoms. Using an electronic patient-reported outcome (ePRO) platform to conduct symptom management follow-up in outpatients with advanced cancer could be a novel and potentially effective approach. However, empirical evidence describing in detail the preparation and implementation courses in a real setting is needed.

Objective: The purpose of this paper was to describe the implementation process and evaluation of an ePRO platform that facilitates symptom management for patients with cancer, share our experiences and the problems we encountered during the process of implementation, and share the solutions we identified for those problems. Moreover, we tested the feasibility, safety, and efficacy of the ePRO platform.

Methods: This was a real-world, ongoing, longitudinal, single-center, prospective study with a total of 7 follow-ups conducted within 4 weeks after the first visit to the symptom management clinic (on days 1, 3, 7, 10, 14, 21, and 28). Participants were encouraged to complete scales for physical symptoms (pain, fatigue, and shortness of breath), cognitive symptoms (memory problems and impaired concentration), and affective symptoms (especially depression and anxiety) during follow-up. The design and function of the ePRO-doctor client and ePRO-patient client, the patient-reported outcome (PRO) scales used in the study, and the strategies to promote symptom tracking have been described. Moreover, the training and evaluation for research assistants have been presented. The efficacy of the ePRO platform was assessed with a comparison of the baseline and 4-week outcomes on the MD Anderson Symptom Inventory.

Results: Using the ePRO platform for symptom management follow-ups in advanced cancer patients was associated with a high completion rate (72.7%-86.4%) and a low drop-off rate (23.6%). The ePRO platform sent 293 alert notifications to both patients and doctors, which promoted patient security. The short and sharp PRO tool selection, user-friendly interface, automatic reminder notifications and alerts, and multiple dimensional training were essential components for the preparation and
implementation of the ePRO system. The results showed significant improvements in the mean scores of pain, fatigue, and numbness from baseline to day 28 ($P=.02$, $P=.02$, and $P<.001$, respectively).

Conclusions: The use of an ePRO platform for symptom management follow-ups in advanced cancer patients is time-saving, energy-saving, and effective. PRO tool selection, platform design, and training of research assistants are important aspects for implementation. Future research should validate the ePRO platform in a larger randomized controlled study.

(JMIR Form Res 2022;6(5):e21458) doi: 10.2196/21458

KEYWORDS
electronic patient-reported outcome; symptom management; advanced cancer; outpatient; follow-up

Introduction

Patients with advanced or metastatic cancer usually have severe symptom burden, which is significantly higher than that in patients with no evidence of cancer metastasis [1]. Symptom burden has also been found to be correlated with treatment-related factors. About one-third of advanced cancer patients were found to have persistent severe symptom burden during chemotherapy [2], and high symptom burden was found to be negatively associated with patients’ psychological status, function, and quality of life [3,4].

However, research on symptom management has mainly focused on inpatients. Relevant research for outpatient symptom management has been limited. Traditional outpatient follow-up is usually via email or telephone, but a low response rate is a common problem in these 2 modes.

In China, since the average length of hospitalization has shortened dramatically, especially in some top cancer centers, much works on symptom management has been carried out in the outpatient department [5]. Symptom management in outpatients has some difficulties. First, outpatients only come to the clinic at a certain time point. Most of the time, they are outside of the hospital, and there is a lack of monitoring of their situations. Second, the means of communication between outpatients and doctors are limited. Many patients only come back to see their doctors when their symptoms become very serious. In some cases, patients cannot get timely and effective symptom management due to various factors, even though their symptoms are very serious. The poor situation of symptom management creates a burden for not only patients but also their families and caregivers, and it even introduces huge burdens of medical resources and costs. Unmet care needs may also decrease patient adherence to treatments [6]. A recent study [7] showed that a web-based app can improve symptom management and adherence for aromatase inhibitors in breast cancer patients.

Patient-reported outcomes (PROs) assess the problems a patient can report about his or her own experiences. These include symptoms, functioning, and mental health. However, a key barrier of using PRO data in clinical settings is the limitation of paper-based questionnaires, which cannot be transformed into instantly accessible information. Compared with traditional paper and pen testing, the electronic patient-reported outcome (ePRO) platform has the advantages of data collection standardization and quality management [8]. An effective ePRO platform can monitor the symptoms of patients outside the hospital better, give a timely alarm, and facilitate timely symptom management; therefore, the ePRO system can improve symptom management in outpatients. In recent years, many techniques of ePRO system design have been greatly developed, such as data transmission, storage, confidentiality, applicability, and convenience. Traditional electronic platforms are mainly based on an email system, while the new generation of ePRO platforms is mainly based on smartphones [9,10].

Most ePRO systems are treatment-centered and have been designed to serve a special kind of treatment [8,11,12]. In the selection of PRO tools, most involve treatment-related symptoms, and follow-up frequency and interval are set for the treatment. So far, an ePRO-based symptom management follow-up system for patients with advanced cancer generally is lacking. Nowadays, in China, the access rates of the internet and smartphones are very high. In 2018, an ePRO symptom management research project was launched in Peking University Cancer Hospital, which included a single-institute longitudinal study and a multi-center cross-sectional study. In the longitudinal study, we aimed to monitor the symptoms of outpatients with advanced cancer using an ePRO symptom management follow-up system based on a smartphone. The purpose of this paper was to describe the implementation process and results, present the advantages of the ePRO system, and share our experiences and the problems we encountered during the process of implementation, as well as the solutions we identified to solve the problems.

Methods

ePROhub, ePRO-Doctor Client, and ePRO-Patient Client

ePROhub

ePROhub provides the primary function of collecting data through PRO tools, as well as adapting and managing the data. Because of the connection with the hospital information system, the ePRO data are more convenient to be managed and analyzed together with other medical data. Intelligent operations include generating and managing the accounts of doctors and patients, collecting and checking patients’ information, sending follow-up reminders, and alerting automatically about serious symptom. This platform also has an electronic signature system that could be used for both subjects (sign informed consent) and research assistants (sign after each subject’s enrollment and follow-up to improve research quality management).
**ePRO-Doctor Client**

The doctor-client interface shows the important information of the program, such as the number of participants, the number of participants completed, the number of participants partly completed, and the number of drop-offs. The interface is updated in real-time to present the latest progress of the program for doctors and researchers. There is a list of people who need to be reminded to do the follow-up survey and another list of people who have symptoms over the alert level. In this study, according to the cut-off point of the MD Anderson Symptom Inventory (MDASI; ≥7), the platform sent an alarm to the ePRO-doctor client. Each doctor or researcher could view his/her own participants, and the management staff could view the entire enrollment situation (Figure 1).

**Figure 1.** Doctor’s interface for research management.

**ePRO-Patient Client**

The interface has been designed as a touch screen, which conforms to patients’ usage habits. Due to the limitation of the screen size of a mobile phone, the PRO scale has been designed to display in the horizontal direction, which is in line with the users’ experience to the maximum extent. There are only 1 or 2 questions on a page, making it easier to read, and the page could be enlarged, making it easier for patients to touch the screen to choose their answers (Figure 2). PRO data could be reported by patients anywhere through an applet based on the WeChat app, which is the most popular social app, without restrictions on the type of smartphone operating system. The ePRO system could identify how many times patients had fulfilled and matched the right scales. All the data were uploaded to a database established in Peking University Cancer Hospital. A strict encryption system was used to ensure data security.
PRO Scales
We used several validated instruments in the multi-dimensional ePRO system, which are presented below.

MDASI
The MDASI [13,14] is a widely used symptom inventory with 19 items (13 items for symptom severity and 6 items for life interference; 0=nothing to 10=most severe). A psychometric study has revealed that the Chinese version of the MDASI has good reliability and validity. Moreover, we added 5 more items for specific cancer sites in our study to capture the special characteristics (constipation was added for all cancers, hot flash and upper limb lymphedema were specific for breast cancer, cough was specific for lung cancer, and swallowing difficulty was specific for esophagus cancer). Compared to the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC-QLQ) [15], which needs at least 1 week between 2 follow-ups, we used the MDASI as our screening tool, which could be used every day, because we needed to monitor symptoms at a high frequency.

Insomnia Severity Index
There are a total of 7 items in the Insomnia Severity Index (ISI; 0-4 score for each item, with a sum score of 28). The ISI is a validated scale for measuring insomnia severity in the last 2 weeks. Scores of 0-7 indicate no insomnia, 8-14 indicate subclinical insomnia, 15-21 indicate moderate insomnia, and 22-28 indicate severe insomnia. The simplified Chinese version of the ISI has been validated by Lin et al [16].

Hospital Anxiety and Depression Scale
The Hospital Anxiety and Depression Scale (HADS) has 14 items with a score spectrum of 0-4 for each item, which is used to measure the anxiety and depression of patients in the past week. It is more commonly used for patients with somatic symptoms in general hospitals, with good reliability and validity, and is recommended for use in patients with advanced cancer or those receiving palliative care [17].

Patient Health Questionnaire-9 Items
The Patient Health Questionnaire-9 Items (PHQ-9) is used to evaluate depression in patients in the past 2 weeks. The score spectrum of symptom severity is from 0 (none at all) to 3 (almost every day), and the total score is from 0 to 27. Depression can be considered when the sum score is ≥10. The simplified Chinese version of the PHQ-9 has good validation [18].

EuroQol 5 Dimensions Questionnaire-5L Version
The EuroQol 5 Dimensions Questionnaire-5L Version (EQ-5D-5L) is a multidimensional measurement for health-related quality of life, which contains the following 5 domains to describe patients’ health: (1) mobility, (2) self-care, (3) usual activities, (4) pain/discomfort, and (5) anxiety/depression, with a scale from 0 (no difficulty) to 4 (extreme difficulty) [19,20]. The Functional Assessment of Cancer Therapy: General (FACT-G) [21] contains too many items, and some of them are easily avoided by patients. We used EQ-5D-5L to measure the quality of life because it has fewer items and has convenient access to get reliable results.

Distress Thermometer
Distress Thermometer is recommended by the National Comprehensive Cancer Network in the distress management guideline. It has only 1 item with a scale from 0 (no distress) to 10 (extreme distress). The problem list includes the following 5 domains: practical problem, communication problem, emotion problem, physical problem, and spirit and religion problem. It is recognized as the briefest tool for distress screening, especially in busy oncology clinical practice [22].

Symptom Tracking Promotion Strategies
Enrolled patients completed the baseline assessments and accepted ePRO standard operating procedure training when they first visited the symptom management clinic.
assessments included demographic and medical information, symptom situation, and medication situation. The ePRO system application training included instructions on how to log into the ePRO system, and how to report their symptoms and other medication situations. In order to improve follow-up compliance, the system sent a message automatically to remind patients at 8 AM on each follow-up day (1st, 3rd, 7th, 10th, 14th, 21st, and 28th day after the first clinic visit). If the follow-up self-report was not completed at 4 PM, the system automatically sent a message again. If there was still no response, research assistants would call them again the next day and record the reasons for noncompletion. If the patient was not connected after 2 calls, the data of this follow-up session were regarded as “lost.”

A time window of 24 hours before and after each follow-up was set, and the system recorded all the completion time points of the patients. Additionally, the system set the alert function. If the score of symptoms reported by the patients exceeded the cutoff value, the system reminded the patients to see a doctor in time.

Training and Evaluation for Research Assistants

Making a standardized operation process manual and an operation video for research assistants is convenient for them to study. The group training was organized for one time, while individual (one-to-one) training was carried out one-to-one. After the training, all research assistants were required to pass a test of practical operation to get started on their official work. There was a question and answer session to solve operation problems after enrollment of around 10 cases. In addition, the practical problems faced by research assistants were shared in the WeChat working group at any time.

Before application in clinical practice, some evaluations were carried out, including running the trial test for the ePRO system and its supporting system, testing the function of SMS text message notifications for patients, confirming the process of patients’ online follow-up, updating the layout of the doctor version of the ePRO system, and switching the testing system database to the formal project database.

Study Population, Eligibility Criteria, and Recruitment

All eligible patients who visited the symptom management clinic for the first time were invited to participate in the study by the doctors in the clinic. The inclusion criteria were as follows: (1) age over 18 years; (2) fluency in Chinese; and (3) confirmed diagnosis of advanced lung cancer, liver cancer, gastric cancer, esophageal cancer, colorectal cancer, or breast cancer. The exclusion criteria were as follows: (1) a history of major severe mental disorders (unable to cooperate with the investigator); (2) being in poor physical condition, as judged by the attending physician (not able to complete the whole study); and (3) being unable to use the ePRO platform.

Data Collection and Process

Completed data with both PROs and other information were collected at baseline (day 0, patient’s initial visit) and follow-ups conducted within 4 weeks after the first visit to the symptom management clinic (days 1, 3, 7, 10, 14, 21, and 28), using an ePRO platform system supported by the research team and ePRO Vision. The flow chart of the study is shown in Figure 3.
like SAS or SPSS, with a standard data format for the final data analysis. All data were deidentified and stored on the REDCap platform.

**Evaluation**

The completion rate was defined as the proportion of patients who completed the self-report using the ePRO system within the stipulated time. The drop-off rate was defined as the proportion of patients who refused to complete the self-report using the ePRO system or failed to complete the last follow-up at day 28.

**Ethics and Consent**

The original study was approved by the Institutional Review Board of Peking University Cancer Hospital on February 13, 2019 (study #2019YJZ07). All participants provided written informed consent.

**Statistical Analysis**

Baseline characteristics were summarized using mean and SD for continuous variables or number and percentage for categorical variables. Assessments for symptom (MDASI) characteristics were conducted for all patients, and a paired t test was used to determine whether there was a statistically significant change between the baseline and day 28 scores. SPSS software v26 (IBM Corp) was used to analyze the data. All P values were 2-sided, and $P<.05$ was considered statistically significant.

**Results**

**Recruitment**

Among 205 eligible patients with advanced cancer who were approached, 161 agreed to participate in the study and 153 completed the baseline assessment. Eligible patients refused to participate for various reasons, and the main reason was “I don’t want to be disturbed and it’s useless to improve my symptoms.” Patient characteristics are detailed in Table 1.

The completion rates were from 72.7% to 86.4% at each follow-up, and the highest completion rate was at follow-up 1 (day 1), while the lowest rate was at follow-up 6 (day 21) (Table 2).
Table 1. Disease and demographic characteristics of the participants (N=153).

| Variable                                           | Value         |
|----------------------------------------------------|---------------|
| Age (years), mean (SD)                             | 56.3 (11.0)   |
| Age range (years)                                 | 27-86         |
| **Gender, n (%)**                                  |               |
| Male                                               | 85 (55.6)     |
| Female                                             | 68 (44.4)     |
| **Ethnic group, n (%)**                            |               |
| Han                                                | 139 (90.8)    |
| Other                                              | 14 (9.2)      |
| **Education, n (%)**                               |               |
| Junior high school or below                       | 48 (31.4)     |
| High school/secondary school                       | 44 (28.8)     |
| Undergraduate/college                              | 56 (36.6)     |
| Master’s degree or above                           | 5 (3.3)       |
| **Cancer diagnosis, n (%)**                        |               |
| Breast                                             | 16 (10.5)     |
| Gastric                                            | 20 (13.1)     |
| Esophagus                                          | 10 (6.5)      |
| Liver                                              | 12 (7.8)      |
| Lung                                               | 48 (31.4)     |
| Colorectal                                         | 47 (30.7)     |
| **Disease status, n (%)**                          |               |
| Progressive                                        | 91 (59.5)     |
| Partial response                                   | 8 (5.2)       |
| Stable                                             | 38 (24.8)     |
| Unclear                                            | 16 (10.5)     |
| **Disease stage, n (%)**                           |               |
| Metastatic                                         | 142 (92.8)    |
| Locoregional                                       | 11 (7.2)      |
| **Eastern Cooperative Oncology Group score, n (%)**|               |
| 0                                                  | 39 (25.5)     |
| 1                                                  | 71 (46.4)     |
| 2                                                  | 28 (18.3)     |
| 3                                                  | 15 (9.8)      |
| **Current anticancer therapy, n (%)**              |               |
| No                                                 | 61 (39.9)     |
| Yes                                                | 90 (58.8)     |
Table 2. Completion rate and missing rate at each follow-up (N=153).

| Time point          | Completion, n (%) | Missing, n (%) |
|---------------------|-------------------|----------------|
| Baseline (day 0)    | 153 (100%)        | 0 (0%)         |
| Follow-up 1 (day 1)| 132 (86.3%)       | 21 (13.7%)     |
| Follow-up 2 (day 3)| 128 (83.7%)       | 25 (16.3%)     |
| Follow-up 3 (day 7)| 125 (81.7%)       | 28 (18.3%)     |
| Follow-up 4 (day 10)| 122 (79.7%)      | 31 (20.3%)     |
| Follow-up 5 (day 14)| 123 (80.4%)      | 30 (19.6%)     |
| Follow-up 6 (day 21)| 111 (72.5%)      | 42 (27.5%)     |
| Follow-up 7 (day 28)| 120 (78.4%)      | 33 (21.6%)     |

Feasibility

Overall, 43.5% (263/604) person-time follow-up assessments were completed by patients automatically before the notification was sent by the ePRO system, 42.6% (257/604) were completed within 8 hours after the first reminder message was sent, and 13.9% (84/604) were completed after the reminder phone call of a research assistant.

The drop-off rate was 23.6% (38/161) in the longitudinal study. Eighteen patients dropped off before the last follow-up (day 28), while 20 patients did not complete the last follow-up assessment. Among them, 14 patients rejected participation in the follow-ups continually, 19 patients could not be contacted, 3 patients died, 1 patient was considered not capable of participating in this study continually by a doctor, and 1 patient dropped off for an unknown reason.

Table 3. Symptom assessment scores between baseline and day 28.

| Assessment               | Baseline score, mean (SD) | Day 28 score, mean (SD) | P value |
|--------------------------|---------------------------|-------------------------|---------|
| Pain                     | 4.91 (3.3)                | 3.52 (2.7)              | .02     |
| Fatigue                  | 5.12 (2.8)                | 4.29 (2.8)              | .02     |
| Nausea                   | 2.52 (2.7)                | 2.29 (2.5)              | .32     |
| Disturbed sleep          | 5.32 (2.9)                | 3.94 (2.7)              | .50     |
| Distress                 | 4.42 (3.0)                | 3.28 (2.8)              | .31     |
| Shortness of breath      | 3.14 (2.7)                | 2.70 (2.7)              | .79     |
| Difficulty remembering   | 3.30 (2.6)                | 2.65 (2.4)              | .10     |
| Lack of appetite         | 4.32 (2.9)                | 3.31 (2.9)              | .89     |
| Drowsiness               | 3.69 (2.8)                | 3.08 (2.7)              | .38     |
| Dry mouth                | 3.78 (2.8)                | 2.92 (2.6)              | .19     |
| Sadness                  | 3.58 (3.1)                | 3.03 (2.9)              | .24     |
| Vomiting                 | 2.03 (2.7)                | 1.64 (2.4)              | .06     |
| Numbness                 | 3.74 (3.2)                | 3.14 (2.6)              | <.001   |

Discussion

Advantages of Using an ePRO System

Using an ePRO system for symptom management follow-up had a lot of advantages. First, compared with the paper-pencil test, the ePRO reporting interface is much more friendly to seniors with poor sight, and the size of the font could be enlarged to make reading easier. Second, the system could remind patients that there are items missing answers automatically and could improve data integrity. Third, the system’s automatic reminder for each follow-up was very effective, and over 40% of patients completed the follow-up assessments within 8 hours after the first automatic reminder was sent, which improved the completion rate greatly and saved the time of the research assistants when compared with traditional follow-up by telephone, mail, or email [23].

Studies showed that the real-time symptom severity alarm function has an important role in symptom management [24,25]. During the study period, nearly 300 alter notifications were
sent, so this function was very necessary for symptom management.

The ePRO system made research management easier. The researchers could see the real-time research progress of their clients. Researchers at different levels saw different kinds of reports, which not only made their research management easier but also protected the confidentiality of the research.

Experiences of Implementation

Consideration for ePRO Platform Design

Follow-up Times

Follow-up times should be determined according to the study purpose. Our platform was designed to complete high-frequency self-reports in a short period of time, with 7 follow-ups over 4 weeks. Several platforms have already been set up with their own follow-up time according to different aims such as a platform for posttreatment surveillance in head and neck cancer [26].

Flexibility

The electronic symptom management system applet was based on the most popular social app in China, WeChat, which can be used in any place with wireless internet or mobile network coverage, without the issue of different smartphone operating systems. This saves the cost of developing a new app and saves users the hassle of downloading one more app, and the app is convenient and totally free [27].

Alerts

For patients and medical researchers, alert information about symptoms can be sent in real-time, and the system can display reminders directly on the screen when the doctor logs into the platform. By contrast, other foreign ePRO platforms [28] send the medical staff an email notification as a reminder, which may delay the information.

Applicability for Interfacing With Other Systems

There is good interoperability with the REDCap system. For instance, the software company ESD (Evaluation Software Development) has been developing the CHES Platform (Computer-Based Health Evaluation System) [29], which is a specialized software dedicated to the assessment, storage, and processing of ePRO data.

Education

Education for patients is beneficial for better symptom management, like cancer-related pain [30], so we have added educational material and doctor’s advice into the applet, as well as referral tips. This could help patients and caregivers to learn the skills of symptom management.

Integration Capacity

Most previous platforms can be divided into the following 2 categories: (1) treatment center, which is a platform designed according to a certain treatment, such as a PRO platform in chemotherapy [31], and (2) patient center, which is a PRO platform designed for a certain patient population. This system is integrated with treatment-related (such as symptom management) and population-related (such as outpatients) aspects.

Experiences of Training Research Assistants

Multiple training methods were combined before the study implementation, including self-training, one-to-one training, and together with training, which makes the whole training process more time-saving and more effective. The training was not stopped after the evaluation, and the question and answer session at the beginning of the study was very helpful for research assistants to solve the problems they faced in practice.

Patient Adherence and Benefit

Several studies on patients who were followed up outside the hospital found that the traditional follow-up compliance was less than 50% [32,33]. In our study, the overall response rate of patients reached at least 70% in each follow-up, and there was an average response rate of 80.3% for all 8 out-of-hospital follow-ups in 2 months. Even in app-based studies, there has been a problem of a high dropout rate, and in intervention research, the dropout rate usually reached 60% [34,35]. It was suggested that we should pay attention to this problem in future intervention research.

Several studies found that integration of ePROs into routine cancer care was associated with increased survival compared with usual care [36,37]. This was an observational cohort study (no intervention), and it was found that patients had benefits for several symptoms. Symptom monitoring via ePROs following treatment for cancer was associated with increased benefits among patients.

Limitations

This study introduced the use of an ePRO platform. In the initial process, only patients who were referred to the symptom management clinic were enrolled in the study (not all patients treated in the oncology clinic). At the same time, only patients with advanced cancers at 6 sites were included. Our next goal is to integrate the platform with patient records, and future research should extend to all cancer patients.

Although the current ePRO platform had relatively high compliance, future studies should continue to explore ways to address dropout in populations at a high risk of dropout, especially in an intervention study.

In addition, the prospective nature of the study presented a limitation, and there was only 1 group of patients and no control group.

Conclusion

The use of an ePRO platform for symptom management follow-ups in advanced cancer patients is time-saving, energy-saving, and effective, which can improve the completion rate and decrease the drop-off rate. PRO tool selection, platform design, and training of research assistants are important aspects that require attention.
Authors' Contributions

LT, YH, and YP contributed to the study design. LT, YH, YP, JS, JL, Y Zhang, XW, XH, YW, ZL, SH, LS, Y Zhou, BW, and XL performed the study. YH, YP, JS, JL, Y Zhang, and XH drafted the initial manuscript. LT revised the draft. All authors have reviewed and approved the final manuscript.

Conflicts of Interest

None declared.

References

1. Cleeland CS, Zhao F, Chang VT, Sloan JA, O'Mara AM, Gilman PB, et al. The symptom burden of cancer: Evidence for a core set of cancer-related and treatment-related symptoms from the Eastern Cooperative Oncology Group Symptom Outcomes and Practice Patterns study. Cancer 2013 Dec 15;119(24):4333-4340 [FREE Full text] [doi: 10.1002/cncr.28376] [Medline: 24114037]

2. Cleeland CS, Mendoza TR, Wang XS, Woodruff JF, Palos GR, Richman SP, et al. Levels of Symptom Burden During Chemotherapy for Advanced Lung Cancer: Differences Between Public Hospitals and a Tertiary Cancer Center. JCO 2011 Jul 20;29(21):2859-2865 [doi: 10.1200/jco.2010.33.4425]

3. Tofthagen C, Donovan KA, Morgan MA, Shibata D, Yeh Y. Oxaliplatin-induced peripheral neuropathy’s effects on health-related quality of life of colorectal cancer survivors. Support Care Cancer 2013 Dec 1;21(12):3307-3313 [FREE Full text] [doi: 10.1007/s00520-013-1905-5] [Medline: 23903798]

4. Röhrle K, Guren MG, Astrup GL, Småstuen MC, Rustoen T. High symptom burden is associated with impaired quality of life in colorectal cancer patients during chemotherapy: A prospective longitudinal study. Eur J Oncol Nurs 2020 Mar;44:101679 [doi: 10.1016/j.ejonn.2019.101679] [Medline: 31751848]

5. Li Z, Li J, Tang L, Pang Y. Development of psychosocial oncology care in China: Consultation-liaison psychiatric service in a cancer center. Psychooncology 2019 Nov 16;28(11):2247-2249 [doi: 10.1002/po.5219] [Medline: 31525820]

6. Enting RH, Oldenmenger WH, Van Gool AR, Van der Rijt CC, Sillevis Smitt PA. The effects of analgesic prescription and patient adherence on pain in a dutch outpatient cancer population. J Pain Symptom Manage 2007 Nov;34(5):523-531 [FREE Full text] [doi: 10.1016/j.jpainsymman.2007.01.007] [Medline: 17664055]

7. Gaetz I, McKillop CN, Stepanski E, Vidal GA, Anderson JN, Schwartzberg LS. Use of a web-based app to improve breast cancer symptom management and adherence for aromatase inhibitors: a randomized controlled feasibility trial. J Cancer Surviv 2018 Aug 28;12(4):431-440 [FREE Full text] [doi: 10.1007/s11764-018-0682-z] [Medline: 29492753]

8. Jensen RE, Snyder CF, Abernethy AP, Basch E, Potosky AL, Roberts AC, et al. Review of Electronic Patient-Reported Outcomes Systems Used in Cancer Clinical Care. JOP 2014 Jul;10(4):215-e222 [doi: 10.1200/jop.2013.001067]

9. Furlong E, Darley A, Fox P, Buick A, Kotronoulas G, Miller M, et al. Adaptation and Implementation of a Mobile Phone-Based Remote Symptom Monitoring System for People With Cancer in Europe. JMI R Cancer 2019 Mar 14;5(1):e10813 [FREE Full text] [doi: 10.2196/10813] [Medline: 30869641]

10. Falchack AD, Tracton G, Stravers L, Fleming ME, Snavely AC, Noe JF, et al. Use of mobile device technology to continuously collect patient-reported symptoms during radiation therapy for head and neck cancer: A prospective feasibility study. Adv Radiat Oncol 2016 Apr;1(2):115-121 [FREE Full text] [doi: 10.1016/j.adro.2016.02.001] [Medline: 28740878]

11. Bennett AV, Jensen RE, Basch E. Electronic patient-reported outcome systems in oncology clinical practice. CA Cancer J Clin 2012 Jul 18;62(5):337-347 [FREE Full text] [doi: 10.3332/caac.21150] [Medline: 22811342]

12. Zbrozek A, Hebert J, Gogates G, Thorell R, Dell C, Molsen E, et al. Validation of electronic systems to collect patient-reported outcome (PRO) data-recommendations for clinical trial teams: report of the ISPOR ePRO systems validation good research practices task force. Value Health 2013 Jun;16(4):480-489 [doi: 10.1016/j.jval.2013.04.002] [Medline: 23796281]

13. Cleeland CS, Mendoza TR, Wang XS, Chou C, Harle MT, Morrissey M, et al. Assessing symptom distress in cancer patients. Cancer 2000 Oct 01;89(7):1634-1646 [doi: 10.1002/1097-0142(20001001)89:7<1634::aid-cncr29>3.0.co;2-x]

14. Wang XS, Wang Y, Guo H, Mendoza TR, Hao X, Cleeland CS. Chinese version of the M. D. Anderson Symptom Inventory: validation and application of symptom measurement in cancer patients. Cancer 2004 Oct 15;101(8):1890-1901 [FREE Full text] [doi: 10.1002/cncr.20448] [Medline: 15386315]

15. Zhao H, Kanda K. Translation and validation of the standard Chinese version of the EORTC QLQ-C30. Qual Life Res 2000 Mar;9(2):129-137 [doi: 10.1023/a:1008981502902] [Medline: 10983477]

16. Lin R, Xie S, Yan W, Yan Y. Factor structure and psychometric properties of the Insomnia Severity Index in Mainland China. soc behav pers 2018 Feb 02;46(2):209-218 [doi: 10.2244/sbp.6639]

17. Zhang GH, Xu MZ, Jin HY. Factorial structure of the hospital anxiety and depression scale in outpatients with somatic disease. Chin J Clin Psychol 2006;14:591-592

18. Chen S, Fang Y, Chiu H, Fan H, Jin T, Conwell Y. Validation of the nine-item Patient Health Questionnaire to screen for major depression in a Chinese primary care population. Asia Pac Psychiatry 2013 Jun 27;5(2):61-68 [doi: 10.1111/appy.12063] [Medline: 23857806]
19. Luo N, Liu G, Li M, Guan H, Jin X, Rand-Hendriksen K. Estimating an EQ-5D-5L Value Set for China. Value Health 2017 Apr;20(4):662-669 [FREE Full text] [doi: 10.1016/j.jval.2016.11.016] [Medline: 28408009]

20. Liu L, Li S, Wang M, Chen G. Comparison of EQ-5D-5L health state utilities using four country-specific tariffs on a breast cancer patient sample in mainland China. PPA 2017 Jun;Volume 11:1049-1056 [doi: 10.2147/ppa.s138028]

21. Yu CLM, Fielding R, Chan CLW, Tse VKC, Choi PHK, Lau WH, et al. Measuring quality of life of Chinese cancer patients. Cancer 2000 Apr 01;88(7):1715-1727 [doi: 10.1002/(sici)1097-0142(20000401)88:7<1715::aid-cncr28>3.0.co;2-k]

22. Tang L, Zhang Y, Pang Y, Zhang H, Song L. Validation and reliability of distress thermometer in Chinese cancer patients. Chin J Cancer Res 2011 Mar 12;23(1):54-58 [FREE Full text] [doi: 10.1016/j.jcsr.2010.09.007] [Medline: 23467708]

23. Schwartzenberger J, Presson A, Lyle A, O’Farrell A, Tyser AR. Remote Collection of Patient-Reported Outcomes Following Outpatient Hand Surgery: A Randomized Trial of Telephone, Mail, and E-Mail. J Hand Surg Am 2017 Sep;42(9):693-699 [doi: 10.1016/j.jhsa.2017.05.002] [Medline: 28600107]

24. Kyte D, Draper H, Calvert M. Management of Patient-Reported Outcome (PRO) Alerts in Clinical Trials: A Cross Sectional Survey. PLoS One 2016 Jan 19;11(1):e0144658 [FREE Full text] [doi: 10.1371/journal.pone.0144658] [Medline: 26785084]

25. Kyte D, Draper H, Calvert M. Patient-reported outcome alerts: ethical and logistical considerations in clinical trials. JAMA 2013 Sep 25;310(12):1229-1230 [doi: 10.1001/jama.2013.277222] [Medline: 24065005]

26. Manikantan K, Khode S, Dwiwedi RC, Palav R, Nutting CM, Rhys-Evans P, et al. Making sense of post-treatment surveillance in head and neck cancer: when and what of follow-up. Cancer Treat Rev 2009 Dec;35(8):744-753 [doi: 10.1016/j ctrv.2009.08.007] [Medline: 19744793]

27. Rincon E, Monteiro-Guerra F, Rivera-Romero O, Doronkorzo-Zubiete E, Sanchez-Bocanegra CL, Gabarron E. Mobile Phone Apps for Quality of Life and Well-Being Assessment in Breast and Prostate Cancer Patients: Systematic Review. JMIR Mhealth Uhealth 2017 Dec 04;5(12):e187 [FREE Full text] [doi: 2.12966/mhealth.8741] [Medline: 29203459]

28. Peltola MK, Lehikoinen JS, Sippola LT, Saarilahti K, Mäkitie AA. A Novel Digital Patient-Reported Outcome Platform for Head and Neck Oncology Patients—A Pilot Study. Clin Med Insights Ear Nose Throat 2016 Sep 27;9:CMENT.S40219 [doi: 10.4137/cment.s40219]

29. CHES Platform. URL: https://ches.pro/index.php/ches [accessed 2022-04-01]

30. Somers TJ, Abernethy AP, Edmond SN, Kelleher SA, Wren AA, Samsa GP, et al. A Pilot Study of a Mobile Health Pain Coping Skills Training Protocol for Patients With Persistent Cancer Pain. J Pain Symptom Manage 2015 Oct;50(4):553-558 [FREE Full text] [doi: 10.1016/j.jpainsymman.2015.04.013] [Medline: 26025279]

31. Mouillet G, Fritzsch J, Paget-Bailly S, Pozet A, EsSaad I, Meurisse A, et al. Health-related quality of life assessment for patients with advanced or metastatic renal cell carcinoma treated with a tyrosine kinase inhibitor using electronic patient-reported outcomes in daily clinical practice (QUANARIE trial): study protocol. Health Qual Life Outcomes 2019 Mar 04;17(1):25 [FREE Full text] [doi: 10.1186/s12955-019-1085-1] [Medline: 30717745]

32. Hirshberg A, Downes K, Srinivas S. Comparing standard office-based follow-up with text-based remote monitoring in the management of postpartum hypertension: a randomised clinical trial. BMJ Qual Saf 2018 Nov 27;27(11):871-877 [doi: 10.1136/bmjqs-2018-007837] [Medline: 29703800]

33. Agarwal P, Bhattacharyya O. Mobile technologies in healthcare: systematising the move from point solutions to broad strategies. BMJ Qual Saf 2018 Nov 29;27(11):865-867 [doi: 10.1136/bmjqs-2018-008200] [Medline: 30269058]

34. Brindal E, Hendrie GA, Freyne J, Noakes M. A Mobile Phone App Designed to Support Weight Loss Maintenance and Well-Being (MotiMate): Randomized Controlled Trial. JMIR Mhealth Uhealth 2019 Sep 04;7(9):e12882 [FREE Full text] [doi: 10.2196/mhealth.8728] [Medline: 31486407]

35. Landers MR, Ellis TD. A Mobile App Specifically Designed to Facilitate Exercise in Parkinson Disease: Single-Cohort Pilot Study on Feasibility, Safety, and Signal of Efficacy. JMIR Mhealth Uhealth 2020 Oct 05;8(10):e18985 [FREE Full text] [doi: 10.2196/18985] [Medline: 33016887]

36. Basch E, Deal AM, Dueck AC, Scher HI, Kris MG, Hudis C, et al. Overall Survival Results of a Trial Assessing Patient-Reported Outcomes for Symptom Monitoring During Routine Cancer Treatment. JAMA 2017 Jul 11;318(2):197-198 [FREE Full text] [doi: 10.1001/jama.2017.7156] [Medline: 28586821]

37. Denis F, Basch E, Septans A, Bennouna J, Urban T, Dueck AC, et al. Two-Year Survival Comparing Web-Based Symptom Monitoring vs Routine Surveillance Following Treatment for Lung Cancer. JAMA 2019 Jan 22;321(3):306-307 [FREE Full text] [doi: 10.1001/jama.2018.18085] [Medline: 30667494]

Abbreviations

- **ePRO**: electronic patient-reported outcome
- **EQ-5D-5L**: EuroQol 5 Dimensions Questionnaire-5L Version
- **HADS**: Hospital Anxiety and Depression Scale
- **ISI**: Insomnia Severity Index
- **MDASI**: MD Anderson Symptom Inventory
- **PHQ-9**: Patient Health Questionnaire-9 Items

https://formative.jmir.org/2022/5/e21458

JMIForm Res 2022 | vol. 6 | iss. 5 | e21458 | p. 11

(page number not for citation purposes)
PRO: patient-reported outcome