Title: Leveraging mobile health technology and research methodology to optimize patient education and self-management support for advanced cancer pain

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Abstract

Purpose: Patient education is critical for management of advanced cancer pain, yet the benefits of psychoeducational interventions have been modest. We used mobile health (mHealth) technology to better meet patients' needs.

Methods: Using the Agile and mHealth Development and Evaluation Frameworks, a multidisciplinary team of clinicians, researchers, patients, and design specialists followed a four-phase iterative process to develop comprehensive, tailored, multimedia cancer pain education for a patient-facing smartphone application. The target population reviewed the content and provided feedback.

Results: The resulting application provides comprehensive cancer pain education spanning pharmacologic and behavioral aspects of self-management. Custom graphics, animated videos, quizzes, and audio-recorded meditations complemented written content. Computable algorithms based upon daily symptom surveys were used to deliver brief, tailored motivational messages that linked to more comprehensive teaching. Patients found the combination of pharmacologic and behavioral support to be engaging and helpful.

Conclusion: Digital technology can be used to provide cancer pain education that is engaging, and tailored to individual needs. A replicable interdisciplinary and patient-centered approach to intervention development was advantageous. MHealth interventions may be a scalable approach to improve cancer pain. Frameworks that merge software and research methodology can be useful in developing interventions.

Keywords: mHealth, pain, cancer, technology, opioid, education, graphic design, symptom management

Declarations

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Ethics Approval: This study was approved by the institutional review board of the DFCI as exempt.

Consent to Participate: Informed consent was obtained from all individual participants included in the study.

Consent for Publication: Not applicable

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Introduction

Pain affects 75-90% of patients with advanced incurable cancer,[1, 2] and has a major impact on quality of life. Opioids are considered the standard treatment for moderate to severe cancer pain;[3] however, many patients experience poorly controlled pain despite having access to opioids.[4, 5]

Patients frequently lack the knowledge, self-management skills, and support needed to utilize opioids and manage their pain effectively.[6] To meet these needs, psychoeducational interventions have been extensively evaluated for cancer pain.[7, 8] Unfortunately, meta-analyses suggest that psychoeducational cancer pain interventions have yielded only small improvements in pain severity and functional wellbeing.[7–9] This limited efficacy may relate to shortcomings in existing interventions, many of which have delivered static cancer pain education (e.g. booklets, videos). Such tools have minimal opportunities for active learning, they are generally not tailored to patients' specific needs, and they are unable to provide longitudinal support that addresses the dynamic nature of the cancer pain experience.[6, 10–13] Moreover, few educational interventions include content reviewing the underlying psychological and behavioral processes that influence pain self-management, such as motivation, stress management, self-efficacy, and addiction fears – which are particularly important in light of the current opioid epidemic.[4, 5, 10, 11, 14, 15]

Mobile health (mHealth) technology is a promising yet underutilized strategy to tailor and deliver cancer pain psycho-education to patients in their home, and to harmonize education with support for other critical aspects of self-management such as medication organization, supporting care team communication, and real-time symptom management advice. Most mHealth apps developed for cancer pain facilitate pain reporting without tailored psychoeducation.[13, 16, 17] Others have taught behavioral pain management strategies via pre-recorded lessons or video chat with a therapist, but have had limited support for the medical aspects of self-management.[12, 18, 19] Existing mHealth symptom support interventions have not fully capitalized upon the technology to personalize symptom education and support (i.e. using computable algorithms, or patient-facing clinical decision support).[12, 19] There has also been little emphasis on exploiting creative, user-centered design possibilities to enhance the impact of the education itself.[13, 20]

A critical barrier to realizing the full potential of mHealth for symptom education interventions is the dearth of literature describing reproducible intervention development methodologies. While mHealth possesses unique possibilities for presenting and delivering educational content, this comes with unique challenges. Research

teams must find ways to bridge the perspectives of content, programming, and graphic design experts, and target users (i.e. patients). Detailed descriptions of these processes, and particularly methods to integrate patient perspectives are currently lacking in the literature.[12, 21–23] The Smartphone Technology to Alleviate Malignant Pain (STAMP) study aims to optimize opioid management for advanced cancer pain through mHealth technology. Here we describe a rigorous, reproducible methodology to develop comprehensive cancer pain psycho-education for delivery via an mHealth application – while integrating patient perspectives throughout. Our objective was to develop comprehensive cancer pain education materials formatted for mHealth, and to leverage the unique potential of technological solutions to deliver education to patients in a way that is responsive to their personalized and unique pain management needs in the moment they need it.

Methods

Procedures for development

We drew from both the Agile[24] and mHealth Development and Evaluation Framework[21] models to develop our application. Both are well-established, highly iterative software development frameworks built upon real-time, interdisciplinary collaborations with feedback from target users during each phase.[21, 24, 25] These methodologies emphasize being guided by the existing literature and building upon theoretical models that align with anticipated mechanisms of action.[26–28] These models also emphasize the importance of interdisciplinary collaborations that include content experts, technologic and design experts, and target users. Modeled after the mHealth Development and Evaluation Framework,[25] our content and application development was carried out in four, pragmatic phases including: 1) Defining the theoretical and conceptual basis, 2) Refining concepts through formative research, 3) Developing and optimizing content, and 4) Refining intervention content. Borrowing from the Agile framework,[21] STAMP development involved the target population and key stakeholders (researchers, software and design partnerships, patients, and clinicians) to employ rapid cycles of content review and feedback that drive iterative, responsive-to-change development procedures within and between each phase. See Figure 1 and Table S1 This study was approved by the Dana-Farber Cancer Institute (DFCI) Institutional Review Board (#18-504).

PHASE 1: Defining the theoretical and conceptual basis of STAMP

Theoretical basis

Grounded in Wagner's Chronic Care Model (CCM),[29] the underlying goal of STAMP is to use mHealth to support both advanced cancer patients and a paired clinician portal to connect care teams for the management of cancer pain in the outpatient setting. CCM emphasizes redesign of reactive, acute-episode-oriented approach to care delivery, in favor of proactive interactions between activated/informed patients, and prepared/proactive care teams.

Establishing a primary study team, scoping and refining intervention priorities

The **Primary Study Team** included content experts in oncology, palliative care, pain psychology, and nursing – many have expertise in health information technology and cancer care delivery research. At the outset of the project, the primary team met several times to refine the overarching project goals and to map these goals onto application features. We then had a series of meetings with a digital media consultant and software programmers to scope the application. We modified and eliminated aspects that were too complex, costly, or deemed less relevant by our stakeholder panels.

PHASE 2: Refining concepts through formative research

Engagement of patient and professional stakeholders

To further guide development of the application, we recruited members for a **Patient Advisory Panel** by partnering with the Patient Family Advisory Council of a large academic cancer center, and by clinician referrals. Patients were invited if they had personal experience with cancer pain and had used opioids. We also formed a **Clinician Advisory Panel** by recruiting a diverse group of clinicians and researchers with expertise in cancer pain management. [See Table S2].

Stakeholder engagement processes

Clinician and patient advisors were oriented to the project goals during separate kick-off meetings at the initial stages of the project. Thereafter, the clinician advisory panel met in biweekly working meetings dedicated to defining priority content, brainstorming, reviewing and revising draft materials, and providing feedback on issues of formatting and visual design. The patient advisory panel met with the primary research team quarterly to provide input on priority content areas, and to provide feedback on draft content to ensure that it met the needs of our target population.

Determination of priority content areas

The study team reviewed publicly available, patient-facing cancer pain education materials from leading oncology organizations [Table S3],[30–34] and published descriptions of content from cancer pain psychoeducational interventions.[8] The team then created a spreadsheet of potential topics for inclusion, indexing examples from existing materials, identifying topics to eliminate or add, and suggesting areas that were important to refine. Patient advisors also reviewed the priority content areas, highlighting information they "wished they knew earlier on."

PHASE 3: Developing and optimizing content

Identifying mHealth formats to enhance usability and patient engagement

The primary study team, graphic designers, and advisory panels discussed formatting options for the educational content. A matrix was created to decide which format(s) content areas would be presented with the most important content presented through multiple formats. (Table 1).

Development of educational content

The study team and a digital media consultant met regularly to draft and refine written content. The team prioritized a conversational and empathic tone,[35] and integrated analogies, metaphors, and visuals to enhance clarity. Drawing from clinical experience and standard pharmacologic databases (e.g. Micromedex), the team also developed novel comprehensive teaching materials for commonly used opioid/non-opioid analgesics and laxatives keeping with the patient-centered, conversational writing style. Concepts and scripts for animated educational videos were developed through a group writing process. The pain psychologist on the study team (D.R.A.) developed scripts for relaxation exercises.

Production of educational content

Written materials were developed using best practices,[36] including targeting a 6^{th}-8^{th} grade reading level, using headers and bulleted lists, defining medical terms, and creating content summaries and action steps. We used a web-based content-management system to create a user-friendly smartphone display with color-coded headers, accordion graphical control elements (i.e. collapsible/expandable lists), paired visuals, and hyperlinks to cross-reference related materials.

Prioritizing strong visuals and creative information display, we collaborated with a digital media consultant and artists to develop animated characters to be featured within the application and 2-D animated videos. Characters

were designed to be warm and relatable, without specific gender or racial hallmarks, yet still registering as human. After our media specialist mocked-up storyboards, the scripts were recorded by a professional voice actor and ultimately animated into 2D films. Graphic designers then integrated visual design features into the application. See Figure 2.

Stakeholder review, quality assurance, and iterative content refinement

Each production process involved iterative rounds of feedback from the study team and advisory panels to ensure that they were clear, accurate, useful, and actionable for patients.[36] Once the content was in close to final form, the clinician advisory panel systematically rated them using the 24-item *Patient Education Materials Assessment Tool-Printable materials (PEMAT-P)*[37, 38] to provide understandability (range 0-116) and actionability scores (range 0–38, higher scores are better). We used the *"Health Literacy Advisor"* software program assigned a Fry-based grade level.[39]

PHASE 4: Refining intervention content

Patient Feedback and Revisions

Following phases 1-3, we conducted individual, in-depth interviews with our target population to obtain feedback on the educational content, design and wireframes. Eligible patients were adults with an advanced cancer who had used opioids for cancer-related pain. Following consent, trained interviewers (D.A. and D.K.) conducted in-person, semi-structured individual interviews using standard cognitive interviewing techniques (e.g. think aloud, rephrasing) to assess the acceptability of the content, supplemented by questions to solicit suggestions for improvements. Once the content was refined, a separate cohort of participants reviewed and provided feedback on wireframes, design concepts, and audiovisual content. Interviews were audio-recorded and notes were then reviewed to inform content revisions.

Finally, once a clickable prototype of the intervention had been developed, we enrolled participants and conducted user acceptability testing with our target population (identical eligibility criteria). User-acceptability was measured using the 5-item Acceptability E-scale for web-based patient reported outcomes in cancer care, using a 5-point Likert scale.[40]

Results

Patient and Professional Stakeholders

In addition to our primary study team, we formed a multidisciplinary clinician advisory panel that included 11 specialists (Table S2). Six patient advisors joined the patient advisory panel.

Scoping and refining intervention priorities

Discussing priorities with our advisory panels, software programmers, and design experts (section 2.2.2), we agreed upon the following set of core application features: 1) a resource library with comprehensive multi-media symptom education, 2) a virtual "medicine cabinet" to organize and provide specific teaching for patients' analgesics and, 3) daily symptom and medication reporting, 4) delivery of tailored educational messages driven by patients' reported symptoms, 5) patient-facing clinical decision support to provide specific advice for managing laxatives, and 6) a web-based clinician portal to facilitate patient monitoring, proactive outreach and communication. Several potential features (e.g. a system of "on demand" pain reporting, clinician-facing decision support tools) were eliminated because they were too costly from a programming perspective, or they were considered to be less useful by our patient stakeholders.

Review of publicly available cancer pain education and determination of priority content areas

We found that most patient-facing cancer pain educational materials, explained types of cancer pain, treatment options, opioid formulations, opioid side effects, and communicating pain with their care team (See Table S3). Available resources were text-heavy with few visuals, and most focused on how clinicians assess and treat cancer pain – rather than providing self-management advice.[8] Attention to psychological/behavioral contributors to pain was lacking, and behavioral pain management strategies were generally limited to bulleted lists of techniques without any information on how to access or learn them.[8]

There was a strong consensus from the advisory panels that the application should differ from publicly available materials by focusing primarily on self-management support, and that it should integrate education on pharmacologic, psychological, and behavioral self-management approaches. (See Table 1). It was considered important to provide specific and actionable advice that addresses common practical challenges; for example, instead of simply describing what opioid medications are often prescribed, providing specific suggestions for what a patient should do if they miss a dose of their scheduled opioid. Patient stakeholders wanted its content to validate the difficulty of their experience with cancer pain, to mitigate stigma associated with opioid use, and to encourage self-care and accepting help.

Final Educational Content

Through our iterative process of prioritizing educational content areas, matching content to specific formats, drafting and revising the content – we ultimately developed 3 animated videos, 22 long-form texts with supportive visuals, 12 quizzes to highlight common self-management challenges (paired with visuals), 108 brief educational and/or motivational messages, comprehensive teaching for 34 distinct medications, and 11 audio-recorded relaxation exercises. Broadly speaking, the content spanned pharmacologic and non-pharmacologic approaches of pain self-management including five primary topics (Table 1): 1) using medications effectively; 2) constipation management; 3) pain psychology principles; 4) health behaviors and pain; and 5) skills training. See Stable S4 for PEMAT scoring.

The three videos ranged from 1:29 to 2:36 minutes, and used animated characters developed specifically for the project (See Figure 2).[41, 42] The first video explained how opioids can help cancer pain, invited patients to identify their pain management goals, acknowledged common worries and ambivalence regarding opioid-use, and encouraged patient-provider communication to address concerns. The second video explained short and long-acting opioids utilizing a metaphor, and the third video reviewed activity pacing, a behavioral technique to achieve meaningful physical activity goals.

The characters were used to generate visuals that supported longer-form text-based education regarding major topics. From each long-form text, we identified several core principles which were reformatted into short teaching "pearls" of motivational messages that could be "pushed" to patients [Table S5]. To create active learning opportunities, we created quizzes surrounding common self-management challenges. Comprehensive drug teaching for opioid/non-opioid analgesics and laxatives were developed by identifying patients' core information needs (e.g. "how long will it take to work?"), extracting information from pharmacologic databases, and using this to draft novel, patient-friendly explanations. Because opioid-induced constipation was considered particularly challenging for patients to self-manage, the team not only developed constipation and laxatives teaching materials, but also developed stepwise instructions for titrating over-the-counter laxatives.

Mechanisms to deliver and tailor educational content to patients' symptoms

We developed several strategies to present the educational content, and to tailor its delivery to patients' needs. First, all long-form content, videos, and relaxation recordings were available within a browsable resource library. Second, a virtual "Medicine Cabinet" organized the patients' specific medications into as-needed pain

medications, scheduled pain medications, a daily laxative plan and a constipation "rescue plan." Each medication linked to novel, in-depth medication teaching. Finally, we developed mechanisms to deliver brief educational messages and self-management advice tailored to patients' symptoms on a given day.

Following completion of daily symptom reports (Section 3.2), patients received a survey summary with tailored advice for pain, constipation, and opioid side effects. Regarding pain, computable algorithms based upon 3 survey items classified patients' pain control as being "good," "suboptimal," or "poor" (Figure 3). This triggered the delivery of a brief, tailored message *randomly* selected from a message-bank spanning topics of pharmacologic education, insight-building, motivating toward pain-management goals, pain psychology, and relaxation exercises [Table S5]. Each message began with an empathic statement ["Sorry to hear your pain isn't doing well today"], was paired with the image of an animated character expressing an emotional reaction paralleling their level of pain control, and linked to more comprehensive education. Regarding constipation, clinical decision support algorithms generated specific advice on laxative dosing options and when to contact care teams for severe symptoms.

Assessment of Content, Patient Testing, and Revisions

After content revisions, we enrolled patients who were not previously oriented to the app to review wireframes of the content and its delivery (n=14), and UAT of the application (n=7). The primary study team completed content thematic analysis of patients' feedback on the educational content and related app features. Primary themes included 1) clarity, 2) visual appeal, 3) usefulness, and 4) engagement. Clarity was most commonly mentioned, with the majority of participants describing the content as "clear," "simple," and "easy to understand." Visual appeal was referenced by many; Participants were particularly receptive to how the visuals balanced the amount of text presented on wireframes. One patient explained,

> "I like the amount of verbiage you have on here…It's informative… I like having the separate pages and smaller pieces to read, than I would a larger document. So, user-friendliness is great."

Engagement was often mentioned in conjunction with visual appeal. Participants described the videos as being "helpful" and "a great reminder;" however, a few participants indicated they would not be interested in being entertained during pain episodes. Usefulness was commonly mentioned during both wireframe and UAT testing. The majority emphasized the content and the methods of delivery as useful, describing the materials as being "informative" with "relatable" examples, and that the information provided "answers to [patients'] questions" and "an action plan" for their pain. Most participants expressed that they had learned valuable information from the

materials, and several asked if they could take copies home, serving as further evidence to the content's usefulness. During UAT, patients responded to the intervention saying,

> "It's a fantastic idea. As one who was living in constant pain, I was not one to call the doctor. If I had this resource available, things maybe would have changed for me a lot faster than they did,"
>
> and,
>
> "I like that it's inter-generational. My 90 year-old mother could navigate through this app, as well as my 30 year-old son."

Mean acceptability ratings (range 1-5) of the app were high scores for all domains assessed: overall satisfaction(m=4.7), enjoyability(m=4.9), time required(m=5), ease of use(m=4.6), and understandability(m=4.6) on a 5-point Likert scale.

Discussion

We combined elements of the Agile[24] model and the mHealth Development and Evaluation Framework[21] to create a novel mHealth app for cancer pain. This theory-driven approach[29] enabled us to build upon existing evidence and integrate multiple perspectives in an efficient and reproduceable manner. Most importantly, patients with cancer pain (our target users) were at the center of the development process and helped to prioritize content, refine this content, and optimize the user experience. We created extensive educational content about cancer pain, spanning pharmacological, psychological, and behavioral strategies, and we presented all content in several multimedia formats that were integrated with patients' daily symptom reports. Informed by our patient, clinician, mHealth, and design partners, the mHealth app was designed to be inviting, empathetic, conversational, and informative to promote patient engagement.[13, 20]

Digital technology enabled us to optimize cancer pain education and self-management support in several unique ways. First, we were able to present key materials in multiple formats including animated videos, audio-recorded relaxations, educational text with supportive visuals, quizzes, and brief motivational messages. Second, using a web-based content management system allowed us to make the educational materials more interactive through features including collapsible/expandable lists and embedded links to complementary content. Third, we were able to match the education to patients' specific needs, for example, by delivering tailored motivational

messages and self-management advice based upon patients' symptom reports. In user acceptability testing, patients found the educational content to be enjoyable, engaging, relevant to their concerns and easy to navigate.

Although mHealth is increasingly popular, processes and frameworks to guide mHealth intervention development are lacking.[21, 22] mHealth development requires collaboration between software programmers, graphic design specialists, behavioral scientists, content experts and patients – who often have different approaches to work. Projects can easily fail because of the inherent challenges of these trans-disciplinary collaborations, and because of the difficulty balancing theoretical, clinical, and technical needs.[24] Our development approach integrated ongoing multidisciplinary collaboration with opportunities for rapid cycle feedback – which enabled us to create an evidence-based, patient-centered, and user-friendly product. These reproduceable methods may allow other teams of investigators to create technologic patient educational interventions that are evidence-based, grounded in theory, patient-centered, and hopefully effective.

While our study has many strengths, it also has limitations. First, this developmental study occurred largely at a single academic medical center; perspectives on mHealth for cancer pain may differ amongst providers and patients in other settings. Second - although 81% of adults in the United States now own a smartphone,[43] some cancer patients may prefer not to receive education and symptom support through this mechanism. Third, patients had highly favorable opinions of the educational content and a prototype of the application; however, the feasibility and efficacy of the intervention needs to be tested. We are currently conducting a pilot feasibility study of STAMP, and are planning a randomized study, to test its ability to improve patients' pain outcomes (pain intensity, pain interference) and secondarily opioid use, psychological wellbeing, physical function, and care team engagement.

The development and production methodology of STAMP presented in this manuscript can serve as a successful example of joint scientific research, clinical, patient, and technological collaborations to create a novel technological intervention geared to treating a complex medical symptom – advanced cancer pain.

Table 1. Review of education topics and multi-media delivery formats throughout MPP

Topic	Educational Materials	Subtopics	Long-form texts w/ visuals	Bite-sized tips	Videos	Scenarios / Quizzes	Med Specific	Relaxation scripts
Opioids	Opioid basics	- What are opioids and how do they work?	X	X	X	X		
	Understanding Short- and Long-Acting Opioids	- When to expect relief and how long they last - How to use short-acting opioids - Reading a prescription bottle	X	X	X	X	X	
	Putting it all together: Short- and Long-Acting Opioids	- Common question - Typical opioid schedules	X	X	X	X		
	Opioid safety	- Using opioids safely	X	X		X		
	Addiction and Tolerance	- Clarifying the differences - When to get help	X					
	Opioid side-effects	- Side effects and tips for management	X	X				
	What is Naloxone?	- Explanation and directions for use	X					
	Medication Education:	- Education specific to each short and long acting opioid					X	
Non-opioid pain medications	Medication Education: non-opioid pain medications	- Education commonly used non-opioid pain medications					X	
Constipation	Medication Education: Laxatives	- Laxative education - Tips for use	X	X		X	X	
	Constipation	- Defining constipation/being proactive	X			X		
	Laxatives	- Describing how laxatives work	X			X		
	Daily Constipation Plan	- Step by step guide for managing constipation	X					
Pain / Mind-Body	Understanding pain and self-management	- Pain physiology - Sensation and perception principles	X	X				X
	Emotions & Pain	- How emotions impact pain and tips	X	X				X
	Stress & Pain	- How emotions impact pain and tips	X	X				X
	Goals & Pain	- Identifying patient-centered goals	X	X				
	Pain and symptom reporting	- How pain and symptoms reporting can improve pain management	X					
	Biopsychosocial Model of Pain	- What factors impact pain	X	X				

	Activity pacing	- Tools and example for pacing activity	X	X	X			
Health Behaviors	Sleep	- Sleep Hygiene	X	X				
	Coping Skills for Pain	- Adaptive coping skills	X	X				
Commun-ication	How to talk to your doctor about cancer pain	- Identifying words to resemble your pain - What your doctor needs to know	X	X				
TOTAL			**22**	**108**	**3**	**11**	**34**	**11**

Figure Captions:

Figure 1. Agile & mHealth Development and Evaluation Framework for the STAMP app

Figure 2. Screen shots of excerpts from education content in the STAMP app and screenshots from 2D animated videos

Figure 3: Pain score (average and worst pain) and acceptance algorithms and categories for personalized educational content and feedback.

Supplementary Information:
Tables S1-S5. See attached

References

1. van den Beuken-van Everdingen MHJ, de Rijke JM, Kessels AG, et al (2007) High prevalence of pain in patients with cancer in a large population-based study in The Netherlands. Pain 132:312–320. https://doi.org/10.1016/j.pain.2007.08.022
2. Van Den Beuken-Van Everdingen MHJ, Hochstenbach LMJ, Joosten EAJ, et al (2016) Update on Prevalence of Pain in Patients with Cancer: Systematic Review and Meta-Analysis. J Pain Symptom Manage 51:1070-1090.e9. https://doi.org/10.1016/j.jpainsymman.2015.12.340
3. World Health Organization (2018) WHO guidelines for the pharmacological and radiotherapeutic management of cancer pain in adults and adolescents
4. Kwon JH (2014) Overcoming barriers in cancer pain management. J Clin Oncol 32:1727–1733
5. Jacobsen R, Møldrup C, Christrup L, Sjøgren P (2009) Patient-related barriers to cancer pain management: A systematic exploratory review. Scand J Caring Sci 23:190–208. https://doi.org/10.1111/j.1471-6712.2008.00601.x
6. Dalal S, Tanco KC, Bruera E (2013) State of art of managing pain in patients with cancer. Cancer J 19:379–89
7. Bennett MI, Bagnall AM, José Closs S (2009) How effective are patient-based educational interventions in the management of cancer pain? Systematic review and meta-analysis. Pain 143:192–199. https://doi.org/10.1016/j.pain.2009.01.016
8. Adam R, Bond C, Murchie P (2015) Educational interventions for cancer pain. A systematic review of systematic reviews with nested narrative review of randomized controlled trials. Patient Educ Couns 98:269–282. https://doi.org/10.1016/j.pec.2014.11.003
9. Dworkin RH, Turk DC, Farrar JT, et al (2005) Core outcome measures for chronic pain clinical trials: IMMPACT recommendations. Pain 113:9–19. https://doi.org/10.1016/j.pain.2004.09.012
10. Wright EM, El-Jawahri A, Temel JS, et al (2019) Patient patterns and perspectives on using opioid regimens for chronic cancer pain. J Pain Symptom Manage. https://doi.org/10.1016/j.jpainsymman.2019.02.023
11. Zheng C, Chen X, Weng L, et al (2020) Benefits of mobile apps for cancer pain management: Systematic review. JMIR mHealth uHealth 8:1–10. https://doi.org/10.2196/17055
12. Somers TJ, Kelleher SA, Dorfman CS, et al (2018) An mHealth pain coping skills training intervention for hematopoietic stem cell transplantation patients: Development and pilot randomized controlled trial. J Med Internet Res 20:1–16. https://doi.org/10.2196/mhealth.8565
13. Jibb LA, Cafazzo JA, Nathan PC, et al (2017) Development of a mHealth Real-Time Pain Self-Management App for Adolescents With Cancer: An Iterative Usability Testing Study. J Pediatr Oncol Nurs 34:283–294. https://doi.org/10.1177/1043454217697022
14. Potter VT, Wiseman CE, Dunn SM, Boyle FM (2003) Patient barriers to optimal cancer pain control. Psychooncology 12:153–160. https://doi.org/10.1002/pon.627
15. Gunnarsdottir S, Donovan HS, Serlin RC, et al (2002) Patient- related barriers to pain management: the Barriers Questionnaire II (BQ-II). Pain 99:385–396
16. Allsop MJ, Johnson O, Taylor S, et al (2019) Multidisciplinary Software Design for the

Routine Monitoring and Assessment of Pain in Palliative Care Services: The Development of PainCheck. JCO Clin Cancer Informatics 1–17. https://doi.org/10.1200/cci.18.00120
17. Agboola S, Kamdar M, Flanagan C, et al (2014) Pain Management in Cancer Patients Using a Mobile App: Study Design of a Randomized Controlled Trial. JMIR Res Protoc 3:e76. https://doi.org/10.2196/resprot.3957
18. Somers TJ, Abernethy AP, Edmond SN, et al (2015) A Pilot Study of a Mobile Health Pain Coping Skills Training Protocol for Patients with Persistent Cancer Pain. J Pain Symptom Manage 50:553–558. https://doi.org/10.1016/j.jpainsymman.2015.04.013
19. Somers TJ, Kelleher SA, Westbrook KW, et al (2016) A Small Randomized Controlled Pilot Trial Comparing Mobile and Traditional Pain Coping Skills Training Protocols for Cancer Patients with Pain. Pain Res Treat 2016:. https://doi.org/10.1155/2016/2473629
20. Wildenbos GA, Peute LW, Jaspers MWM (2015) A framework for evaluating mHealth tools for Older Patients on Usability. Stud Health Technol Inform 210:783–787. https://doi.org/10.3233/978-1-61499-512-8-783
21. Jacobs MA, Graham AL (2016) Iterative development and evaluation methods of mHealth behavior change interventions. Curr Opin Psychol 9:33–37. https://doi.org/10.1016/j.copsyc.2015.09.001
22. Allsop MJ, Taylor S, Mulvey MR, et al (2015) Information and communication technology for managing pain in palliative care: A review of the literature. BMJ Support Palliat Care 5:481–489. https://doi.org/10.1136/bmjspcare-2013-000625
23. Dorfman CS, Kelleher SA, Winger JG, et al (2019) Development and pilot testing of an mHealth behavioral cancer pain protocol for medically underserved communities. J Psychosoc Oncol 37:335–349
24. Cockburn A, Highsmith J (2001) Agile software development: The people factor. Computer (Long Beach Calif) 34:131–133. https://doi.org/10.1109/2.963450
25. Whittaker R, Merry S, Dorey E, Maddison R (2012) A development and evaluation process for mhealth interventions: Examples from New Zealand. J Health Commun 17:11–21. https://doi.org/10.1080/10810730.2011.649103
26. Michie S, Yardley L, West R, et al (2017) Developing and Evaluating Digital Interventions to Promote Behavior Change in Health and Health Care: Recommendations Resulting From an International Workshop. J Med Internet Res 19:e232. https://doi.org/10.2196/jmir.7126
27. Venkatesh V, Davis FD, Venkatesh V, Davis FD (2000) A Theoretical Extension of the Technology Acceptance Model : Four Longitudinal Field Studies. Manage Sci 46:186–204
28. Carman KL, Dardess P, Maurer M, et al (2013) Patient and Family Engagement: A Framework For Understanding The Elements And Developing Interventions And Policies. Health Aff 32:223–231. https://doi.org/10.1097/nna.0000000000000317
29. McCorkle R, Ercolano E, Lazenby M, et al (2011) Self-management: Enabling and empowering patients living with cancer as a chronic illness. CA Cancer J Clin 61:50–62
30. PDQ Supportive and Palliative Care Editorial Board T (2019) Cancer Pain (PDQ®)–Patient Version. In: Natl. Cancer Inst. https://www.cancer.gov/about-cancer/treatment/side-effects/pain/pain-pdq
31. The cancer.net Editorial Board T (2019) Managing Cancer-Related Pain. In: Conquer Cancer ASCO Found.
32. Cancer Care Ontario T (2016) How to Manage Your Pain. In: Cancer Care Ontario Patient

Guid. http://ocp.cancercare.on.ca/common/pages/UserFile.aspx?fileId=357477
33. The American Cancer Society medical and editorial content (2019) Facts About Cancer Pain. In: Am. Cancer Soc. Treat. Support
34. (2018) Cancer and Pain Control. In: Cancer Res. UK. https://www.cancerresearchuk.org/about-cancer/coping/physically/cancer-and-pain-control/about-cancer-pain
35. Maghnati F, Ling KC (2013) Exploring the Relationship between Experiential Value and Usage Attitude towards Mobile Apps among the Smartphone Users. Int J Bus Manag 8:1–9. https://doi.org/10.5539/ijbm.v8n4p1
36. Agency for Healthcare Research and Quality (2015) Assess, Select, and Create Easy-to-Understand Materials
37. Shoemaker SJ, Wolf MS, Brach C (2014) Development of the Patient Education Materials Assessment Tool (PEMAT): A new measure of understandability and actionability for print and audiovisual patient information. Patient Educ Couns 96:395–403. https://doi.org/10.1002/cncr.27633.Percutaneous
38. And QA for HR (2013) PEMAT for Printable Materials (PEMAT-P) Agency for Healthcare Research and Quality. https://www.ahrq.gov/professionals/prevention-chronic-care/improve/self-mgmt/pemat/pemat-p.html. Accessed 8 Jun 2019
39. Health Literacy Innovations (2019) Health Litearcy Innovations. Newsletter, Volume 1, Issue 1. Available at: http://www.healthliteracyinnovations.com/newsletter/. Accessed 24 Jun 2019
40. Tariman JD, Berry DL, Halpenny B, et al (2011) Validation and testing of the Acceptability E-scale for Web- based patient-reported outcomes in cancer care. Appl Nurs Res 24:1–10. https://doi.org/10.1016/j.apnr.2009.04.003.Validation
41. Menezes P, Quayle J, Garcia Claro H, et al (2019) Use of a Mobile Phone App to Treat Depression Comorbid With Hypertension or Diabetes: A Pilot Study in Brazil and Peru. JMIR Ment Heal 6:e11698. https://doi.org/10.2196/11698
42. Michie S, Abraham C, Whittington C, et al (2009) Effective Techniques in Healthy Eating and Physical Activity Interventions: A Meta-Regression. Heal Psychol 28:690–701. https://doi.org/10.1037/a0016136
43. Pew Research Center IT (2020) Mobile Fact Sheet. In: Pew Res. Cent. Internet Technol.