# To Improve Supportive Care for Patients Taking Oral Anticancer Agents

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## Abstract

*Oral anticancer agents (OAA) are increasingly prescribed to treat cancer because they are flexible and convenient to use. However, managing complex OAA regimens and life-threatening toxicities at home can be challenging for patients and their caregivers. It is urgent to better understand the supportive care needs for OAA and develop novel approaches to facilitating self-management and communicating about OAA. Guided by the chronic care model (CCM), we conducted a grounded theory-based study to analyze OAA-related online discussions and potential mHealth interventions. We found that patients and caregivers commonly used the online community to share personal experiences and concerns, exchange emotional and informational support, identify relevant resources, and obtain benefits of peer coaching. The findings deepen the understanding of the needs for OAA self-management and mHealth interventions, contributing to the development of mHealth models to enhance supportive care and improve communication among peer patients and between patients and providers.*

## Keywords:

Oral Antineoplastic Agents, Social Media, mHealth

## Introduction

Cancer is one of the most common chronic conditions in the world [12]. Surviving cancer is challenging to patients and caregivers as cancer significantly affects their physical and emotional well-being, and requires stringent management of medication use and associated side effects. Patients with cancer are increasingly prescribed oral anticancer agents (OAA) because of their evidential benefits toward expected health outcomes, i.e. increased survival for several types of cancer [9]. Although convenient and flexible for cancer treatment in home settings, OAA are characterized by complex regimens and often associated with a variety of toxicities. About 25-50% of patients require dose modification or discontinuation of OAA therapy due to severe side effects [14].

While patients taking OAA at home and their caregivers need to assume the responsibilities of self-management of the OAA use and the associated toxicities, little is known about these patients' and caregivers' experiences of OAA use and their supportive care needs. However, the challenges of patients taking OAA may be similar to those taking medication for long terms when managing other chronic conditions (e.g., hypertension, diabetes). For example, medication adherence is a challenge because of the need to diligently take medication following the prescribed dosage, timing, frequency, and duration [3]. Patients with other chronic conditions may also experience side effects (e.g., statins used to lower blood lipids can cause muscle pain and abnormal liver function [13]). Therefore, understanding the experiences of patients using OAA, and comparing the similarities and differences of these experiences with those of medication use for other chronic conditions, can help develop management strategies for the cancer patients and their caregivers to use.

Because of the potential similarities in their experiences of managing OAA use and medications for managing other chronic illnesses, research that helps to understand patients' and caregivers' experiences with OAA use and their supportive care needs may benefit from the use of the Chronic Care Model (CCM) that has been widely used to understand the experiences of patients with chronic illnesses and their families and to empower them to engage in self-management [4]. The CCM highlights productive interactions between informed, activated patients and a well-prepared, proactive practice health care team to improve outcomes; informed and activated patients can provide meaningful feedback on their experiences and perceptions of safety. While CCM has guided interventions that are designed to support patient self-management of many chronic conditions, OAA may pose unique challenges that are not addressed by CCM. First, compared to other chronic conditions and medications for treating these diseases, OAA regimens for cancer treatment can be more complicated often with an individualized intermittent schedule [8]. Second, the interactions between OAA and other medications or food are more common and often lead to toxic effects that may have more severe symptoms than those caused by other medications [18]. Patients often feel it difficult to tolerate these side effects of OAA, leading to reduced or interrupted dosages. Third, compared to patients with other chronic conditions, cancer patients generally experience more severe emotional disturbances and stress [8]. Fourth, patients taking OAA are usually diagnosed with metastatic cancer, and thus, the treatment goal may be focused on the improvement of symptoms and quality of life [8, 18]. Therefore, compared to self-management of medication use for chronic conditions, innovative approaches are needed to help patients who use OAA to be compliant with their stringent medication regimens and administration, as well as managing OAA-related side effects.

Mobile health (mHealth), the use of mobile and wireless information and communication technologies to deliver medical or health care services, has been increasingly used in chronic illness management [10]. mHealth can provide patients with chronic illnesses and their caregivers with self-management support whenever and wherever they need it at a

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low cost. mHealth delivery mode includes text messaging, mobile apps, interactive voice response, smart bracelets, and other mobile devices [10]. Despite its widespread use to support patient self-management of chronic conditions such as hypertension and diabetes [2; 5], to the best of our knowledge, mHealth is yet to be fully used to support OAA self-management [16].

Online health communities (OHC) have been widely used by patients and caregivers for sharing their experiences and seeking support [21]. Previous research has utilized OHC posts to understand patient-reported outcomes [20], informational and emotional needs during their cancer survivorship [19], and implications for designing consumer-facing technologies to better support patients' self-management [2]. The discussions on OHCs afford great potential to understand patients' and caregivers' experiences and concerns when taking OAA, which may offer insights into what current consumer health technologies such as mHealth should be designed in supporting self-management of patients taking OAA.

Therefore, this study aimed to conduct an in-depth qualitative analysis of OAA-related discussions in an OHC to unveil the information, emotional, and other supportive care needs of the patients and their caregivers, as well as their needs for self-management while taking OAA. Leveraging our findings and the characteristics of OAA use in cancer care, we made recommendations and applied a model based on CCM to guide the design and development of mHealth intervention to improve supportive care for patients taking OAA.

## Methods and Material

### Data Collection and Processing

We collected data from one of the most popular online communities, Reddit, which includes OHC sections and has been used in previous studies for understanding patients' and caregivers' perspectives [7]. We used the Python package PSAW to crawl posts and their associated comments using common OAA names informed by medical experts [11]. The search was performed in March 2021, and the search keywords of OAA are listed in Table 1.

*Table 1- Search Keywords*

| Xeloda,Nexavar,Tarceva,Temodar,Xtandi,Zytiga,Afinitor,Nexavar,Sutent,Iressa,Tykerb,Ibrance,Votrient,Revlimid |
| --- |

### Data Analysis

Following a grounded theory approach [17], we first conducted qualitative open coding of the filtered data to identify the common topics discussed by patients and caregivers related to OAA. Then, two coders each qualitatively coded 100 posts, discussed their initial codes such as side effects and efficacy, and resolved disagreements. The codes were applied to the rest of the data and new codes were extracted when appropriate. Through this iterative process, we reached thematic saturation at around 120 posts and merged the codes into several major themes. Then, the identified themes were summarized to understand the supportive care needs of OAA self-management. For each post, we first screened whether it contained OAA-related information, then we applied the major themes and subthemes. Finally, we coded whether the post was authored by patients or caregivers.

To help theory development, we used an innovative intervention mapping approach based on the OHC findings to help define mHealth interventions for the supportive care needs of patients taking OAA [6]. This approach requests a solid theoretical foundation to propose assessment and intervention

for health problems. Therefore, we mapped the themes of patients' needs with mHealth intervention techniques, and mHealth functions based on the CCM elements to address the challenges of self-management of mHealth and made recommendations on the design and development of mHealth intervention to support self-management of OAA. We integrated the findings and discussed the essentiality of using a modified model to design mHealth functions in supporting OAA self-management.

## Results

### Descriptive Statistics of Online Discussions

In total, we collected 2,197 posts and 3,213 comments posted between 7/7/2007 and 3/9/2021. We removed 821 posts that were deleted or archived by moderators, or contained only links and images but no textual content, leaving 4,588 posts and comments in the dataset. The number of posts related to OAA on Reddit has increased over time, with a sharp increase in 2019, as shown in Figure 1. We note that the big drop in discussion volume in 2021 may be related to the fact that only three months' data were collected in 2021.
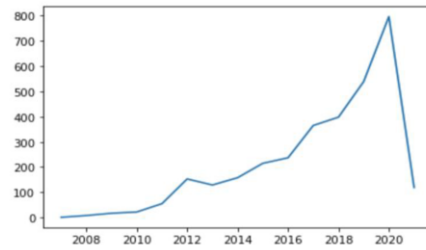


*Figure 1 - Temporal trend of online discussion volume*

Among the 4,588 posts and comments left, 100 posts and 200 comments were coded using the finalized codebook. Within the sample we coded, 64 were authored by caregivers, 100 by patients, and 44 by users whose roles could not be determined. The rest 92 were related to news and advertisements of OAA, thus not relevant to our study purpose.

### Commonly Discussed Topics in OAA Forums

We identified four major themes that represent the discussions related to a wide range of informational and emotional needs related to OAA use (See Table 2). We summarized the themes and included examples of the quotes of each theme that are paraphrased to protect user privacy.

*Table 2 - Major themes of OAA discussion in OHC*

| Major themes | Description | Subthemes |
| --- | --- | --- |
| Sharing personal experiences of OAA use | Sharing patients' and caregivers' personal experience with OAA use during patients' cancer journeys | Side effects |
| | | Efficacy |
| | | Personal health conditions |
| | | Cost and reimbursement |
| Sharing information and resources related to OAA | Sharing information based on personal experiences, external information on OAA use, and resources related to OAA | Mechanism of OAA |
| | | Extra OAA for redistribution |
| | | Opportunities (clinical trials, financial programs) |
| Peer emotional support | Seeking and offering emotional support to each other | Encouragement |
| | | Praying and comforting |
| Coaching | Seeking and providing practical | Coping with side effects |

| | and actionable tips to support OAA use | Patient-provider communication |
|---|---|---|

### Sharing personal experiences of OAA use

Patients and caregivers exchanged their personal experiences of using OAA to treat cancer, including their overall impression of OAA, OAA side effects, and the efficacy of OAA. Patients who are about to take OAA sought others' personal experiences of side effects: "*I will be starting Xeloda soon. Can anyone advise me when the side effects kick in? Is it the day you take it? A week later? I'm worried about the diarrhea.*" Users who are more experienced with OAA described the severity of the OAA side effects: "*My mom was on Xeloda pills (6 per day) and they completely fatigued her and flared up her existing colitis which led to nausea and no appetite and rapid weight loss.*" A patient described the side effects of OAA on mental conditions: "*Velcade, Revlimid, and Darzalex have mental side effects too but, as bad as they are, they are nothing compared to the Dex.*" While reports of side effects were common, some also shared their experiences with OAA efficacy: "*My husband did four cycles of DRd (daratumumab/revlimid/dex). That brought his light chains to normal in just one cycle. In retrospect, we're very, very glad.*"

Experiences with managing the cost and reimbursement issues with OAA also appeared in our data. Some shared the prices they need to pay under certain insurance plans, e.g., "*My mom will hopefully get a SCT and then likely will continue to take revlimid. Her Medicare broker is saying she'll pay about 12k a year for revlimid.*" When sharing their experiences of OAA use, patients and caregivers often provided their specific cancer types, stages, and previous treatments to contextualize their experience. For example, one patient described: "*Stage 4, HR+ HER2-, bone mets here. Can't tolerate Verzenio or Ibrance. On Kisqali/Exemestane now.*"

### Sharing information and resources related to OAA

Patients and caregivers shared a wide array of OAA-related information and resources that they believed will benefit those in need. They obtained those information and resources from their providers, their social circles, insurance companies, and other internet sources. For example, one patient shared opportunities from pharmaceutical companies to help financially disadvantaged patients: "*The thing is that vast majority of the pharmaceutical manufacturers offer 'patient assistance programs'. If someone has no health insurance or is underinsured and can't afford the drug, they help these patients access drugs for little or no cost if you ask them. This is the link to the PAP of Revlimid; the drug which mentioned in the article URL.*" Another user shared clinical trials and their requirements: "*Most clinical trials require that the patient had gone through standard of care first. National Cancer Institute is a good place to start: URL. They currently have two listed, one for newly diagnosed. URL.*" A caregiver posted on the OAA that they had long needed and wished to redistribute them to others: "*My mom who passed away recently has about 3 months of Ibrance leftover. Does anyone know of any resources of legal ways to get this to people in need?*" Users also shared information about the mechanisms of OAA to help others understand how they work: "*Xeloda is systemic and kind of acts like a cleanup crew to mop up any straggling cancer cells that might still be around somewhere.*"

### Peer emotional support

Patients and caregivers often sought and provided emotional support on the online forum. For example, one patient encouraged another by stating that OAA worked for his/her case: "*Tumor. That was 6 years ago. After a good resection, radiation, and Temodar I still have no signs of regrowth. You can do this. I know it sucks and it's scary. But, you just have to do it one day, one thing at a time. You just have to do what you can around your treatment and you'll be amazed how quickly it begins to pass by.*" Caregivers also received prayers and comforts when their patient family members were going through pain or passed away: "*Don't feel bad for wanting to carry on your own life plans after he's dead. It's tragic, but life goes on.*"

### Coaching

Patients and caregivers, especially those who are more experienced with OAA, tend to offer practical tips to coach those who plan to or recently begin taking OAA. Caregivers asked for tips to help their family members accept OAA use: "*He is being offered Temodar and radiation 30 days concurrent followed by monthly 5-day Temodar treatment. He is supposed to start treatment Wednesday this week. But he has declined rapidly in the last few weeks. Is there any point to putting him through this treatment?*" Patients shared tips on how to cope with OAA side effects. For example, one patient recommended "*Very -extremely - important to take Xeloda with sufficient food. If the food is too little, you will feel it. (unfortunately, overeating puts weight on you) hopefully you escape the side effects.*" Some suggested to other patients what OAA they should ask for: "*Ask about Gemcitabine+5FU and maybe Tarceva, if they have it.*" Users also shared tips on how to communicate with providers about OAA. For example, patients and caregivers recommended asking for specific types of OAA: "*Ask about Gemcitabine+5FU and maybe Tarceva, if they have it.*" Some also suggested asking for lab tests from their providers: "*There is a blood test for capecitabine sensitivity, ask your doctor about that. It tells you if you will have severe side effects or not.*" The tips are generally well received by other users, e.g., "*I will ask the oncologist about Temodar, we didn't get to the specifics of which chemo drugs yet but I will write down all of these questions and revisit it with her care team.*"

### Mapping the themes for mHealth interventions

As shown in Table 2, the self-management needs identified from the OHC discussion are mapped with intervention techniques and mHealth functions based on CCM.

For the self-management of OAA, mHealth can provide patients with low-threshold (i.e., anytime anywhere) access to health assessment and healthcare assistance. The health assessment includes built-in questionnaire surveys to conduct self-assessment of the side effects of the medications used and the patient's psychological condition. Patients can share the assessment results and their experiences with doctors or peers via online chat. This can improve patients' real-time awareness of their health conditions and inform healthcare providers to provide patients with assistance such as symptom management strategies and medication adjustment suggestions. Moreover, mHealth can provide patients with various forms of educational/motivational materials such as text, videos, web links, and other online resources. These resources can not only be implanted in mHealth applications as functional modules but also can be automatically sent to patients in the form of push messages. The assistance can enhance patients' awareness and ability to self-management of OAA use, thereby promoting their compliance with medication. Particularly, when patients have doubts about the efficacy of the medications under the torture of their side effects, the information provided by mHealth may help them understand the characteristics and treatment mechanisms of OAA, and activate patients' confidence to perform self-management behaviors of OAA use

## Discussion

### Exploring Online Discussions of OAA

The increasing volume of OAA discussions on Reddit suggests that online communities are increasingly adopted by cancer patients and caregivers to discuss OAA use. The OHC analysis revealed a wide array of topics that patients and caregivers discuss on online forums. They share personal experiences of using OAA such as efficacy and side effects, information and resources that they derived based on personal experiences or came across online, emotional support to encourage others, and practical tips. To our best knowledge, our study is the first to investigate online discussion on OAA to inform mHealth design, and therefore offers rich insights into the concerns of patients and their caregivers and needs to support OAA use. These findings serve as the foundation to design patient-facing technologies and derive underlying theoretical models that support the unique needs of OAA use.

*Table 3 - Mapping results of OAA themes for mHealth interventions*

| Patients' needs in OAA use | CCM elements | Intervention techniques | Recommended functions | Goals of supportive care |
|---|---|---|---|---|
| Sharing personal experiences of OAA use | • The community - resources<br>• Self-management support<br>• Clinical information systems<br>• Delivery system design | • Mobilize community resources to meet patient needs<br>• Empower and prepare patients to self-manage their OAA use<br>• Organize patient experience to facilitate efficient and effective care<br>• Assure effective, efficient care and self-management support | • Online questionnaire surveys<br>• Online chat | • Improve patients' illness perceptions<br>• Enhance patients' interaction with peers |
| Sharing information & resources related to OAA | The community – resources & policies | • Mobilize community resources to meet patient needs | • Resources, health tips, videos | • Improve patients' symptoms management capability |
| Peer emotional support | The community - peer-peer communication | • Mobilize community resources to provide emotional support | • Automatic push messages | • Lessen patients' depression, anxiety, and distress |
| Coaching | Delivery system design | • Assure effective, efficient care and self-management support | • Health tips, videos | • Improve patient health/ medication beliefs and self- management capability |

The active discussions in the OHC forum reflect patients' urgent needs for guidance and support in the process of taking OAA from peers, which may not be adequately supported by their providers or formal educational materials. For example, concerns about side effects and uncertainties around OAA efficacy are prevalent in the OHC discussions. Although mHealth has demonstrated its value in chronic condition management such as hypertension and diabetes [2; 5], mHealth for OAA primarily focused on self-management and adherence improvement, without recognizing the wider spectrum of concerns and challenges that patients face. The challenges we identified through the OHC analysis open up new spaces for future mHealth design to support OAA use.

**Peer-peer Communication and Coaching**

Patients may be skeptical of its treatment effects when suffering from long-term side effects of OAA during or after the treatment. mHealth provides a platform for patients and caregivers to exchange information with doctors or peers anytime, anywhere, to help them eliminate these doubts and receive corresponding assistance. As our OHC analysis shows, patients and caregivers accumulated practical tips throughout their journeys using OAA, which they shared with those who are new to OAA on the online forum. Peer coaching and mutual support help consolidate patients' health beliefs to achieve optimal outcomes. By providing educational materials, mHealth also helps patients to form a more systematic and scientific understanding of OAA characteristics, mechanism, and usage and enable them to better manage side effects, thereby improving their compliance with OAA use.

**mHealth Design Model for OAA Self-management**

mHealth interventions may support patient self-management of common chronic conditions based on medication therapy and improve adherence to medication [1; 5; 22]. For example, mHealth applications provide patients with hypertension and diabetes with functions including mobile diary, reminders, interactive prompts, assessment of vital signs, action plan to improve their medication adherence, self-management behaviors, and blood pressure and glucose control [5]. The commonalities of self-managing chronic conditions should be used to inform further innovative design in OAA self-management. Nonetheless, the toxicities and side effects of OAA have posited inevitable challenges, causing some patients intermittently to follow a specific schedule of OAA intake due to intolerable symptoms, and emotional disturbances, and stress [8; 18]. Despite the wide adoption of CCM in primary care settings, patients taking OAA in transition to home strongly indicate the needs via the OHC discussions and should be supported by innovative digital solutions such as mHealth.

Based on CCM elements, the mHealth intervention we designed using the intervention mapping approach conforms to a newly developed 6A model, which specifically explains the mechanism of using mHealth to manage chronic illness [15]. This model explains that with the portability of mobile devices and digitization of information, mHealth provides patients with a unique opportunity to access health assessment and healthcare assistance anytime and anywhere, which improves their self-management awareness and ability, thereby activating their self-management behaviors.

The use of mHealth provides patients using OAA with *access* to communication and interaction with healthcare providers and peers. Online questionnaires help patients systematically conduct self-assessment of symptoms of side effects and mental states of using OAA, enhancing their *awareness* of their conditions. The educational materials and information provided by mHealth can also *assist* patients in enhancing their *awareness* and *ability* to use OAA scientifically. Through the encouragement messages and OAA use reminders sent automatically by mHealth, the self-management behaviors of taking OAA are *activated* intrinsically and extrinsically, thereby improving their medication adherence.

According to CCM, patients should be informed and activated and are expected to interact with a prepared and proactive healthcare team. Therefore, it should be a unique opportunity of using mHealth to support patient self-management of OAA use. For example, compared to other online discussions on chronic health, OAA discussions contain a high proportion of posts that relate to side effects and toxicity. Taking into account the toxicity of OAA, the strong side effects impact the well-

being of patients and they must take the OAA intermittently according to individual prescriptions.

This may lead to a critical challenge in the management of other chronic conditions, i.e. patients' adherence to their medication as prescribed. Although mHealth holds potential in mitigating this problem by pushing real-time, automatic messages to remind patients to take medication, it is worth noting that the results of the OHC discussion do not directly reflect this challenge. The possible reason is that forgetfulness does not always happen or is not the priority of patients in the supportive needs of taking OAA. This is different from other chronic condition management, such as hypertension and diabetes. Our results indicate that mHealth interventions targeting OAA self-management should pay more attention to improving communications between patients and their healthcare providers or peers and the provision of coaching to improve their health literacy and medication beliefs.

### Limitations and Future Directions

The OHC data was collected from one single social media site where OAA topics are scattered over various cancer types, and may not represent the characteristics of users on other social media sites. The results are subject to continuous surveillance on the site. More personalized needs should be collected through surveys or interviews and the effectiveness of the mHealth solution needs to be evaluated preferably through randomized clinical trials. Besides, further empirical research that uses focus groups and interviews is suggested to validate and expand our findings.

## Conclusions

Patients taking OAA face challenges in self-management that are not adequately supported by current mHealth technologies nor other sources. Existing theoretical models for chronic care such as CCM do not take into account the unique challenges of patients taking OAA, such as coping with toxicity and side effects and managing intermittent OAA regimes. To inform future mHealth design that supports the unique challenges of OAA, we qualitatively analyzed patients' and caregivers' online discussion related to their OAA use. The analysis revealed challenges that they face, such as managing side effects, emotional and information needs, and financial concerns. Our results from the empirical OHC discussion analysis and theoretical mapping to the CCM lay the foundation for future mHealth design to support OAA use and self-management.

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