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Using a community advisory board to develop a serious game for older adults undergoing treatment for cancer

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Abstract

Introduction—Older adults undergoing treatment for cancer are at risk for serious complications such as chemotherapy-induced nausea and vomiting (CINV). Older adults are often overwhelmed by information and under-manage cancer treatment-related side effects. New educational strategies such as serious gaming may help teach or reinforce key symptom self-management strategies. This paper describes how a community advisory board of older adults, their caregivers, and oncology nurses were consulted to develop a serious game for CINV.

Methods—A formative evaluation process using a community advisory board (CAB) and a series of three focus groups were used to develop this serious game about managing CINV at home.

Results—The formative evaluation process and involvement of the CAB allowed researchers to learn about the experience of having CINV from an older adult perspective. Common themes related to CINV onset, severity and self-management formed the basis for the serious games' script and scenarios. Themes were validated and CAB members provided feedback on a game prototype. Feedback from CAB members indicated that the serious game was realistic and reflective of their CINV experience

Conclusion—Including older adults in the development of a serious game was instrumental in creating a relevant educational opportunity. Serious gaming should be considered as a way to add to the educational experiences of older adults as generic teaching methods may not address the needs of all age groups. Exploring for new ways to emphasize key points related to symptom management and prioritize learning may impact outcomes for older adults.

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Keywords

Cancer; older adults; nausea; serious game; ehealth; intervention development

Introduction

Older adults comprise the largest group diagnosed with cancer with over 50% of people age 65 years of age and older (Smith, Smith, Hurria, Hortobagyi, & Buchholz, 2009) and are at high risk for cancer-related side effects (Balducci & Stanta, 2000). Aging and limitations in organ systems (renal, gastrointestinal, liver) often cause prolonged plasma levels of chemotherapeutic agents that can increase risk for treatment-related toxicity and poor outcomes in older adults (Balducci, Colloca, Cesari, & Gambassi, 2010; Jakobsen & Herrstedt, 2009; Sawhney, Sehl, & Naeim, 2005; Sehl, Sawhney, & Naeim, 2005). One symptom that can be particularly troublesome is chemotherapy-induced nausea and vomiting (CINV). This symptom impacts over 64% of people being treated for cancer (Cohen, de Moor, Eisenberg, Ming, & Hu, 2007) and occurs in over 80% of older adults undergoing chemotherapy treatment (Massa et al., 2009). It is also one of the top 5 reasons why patients call their doctor while receiving treatment for cancer (Flannery, McAndrews, & Stein, 2013) and it has been shown to lead to an increase in unplanned emergency department or hospital admissions (Geddie, Loerzel, & Norris, 2016). Practice guidelines for managing CINV include pharmacologic and non-pharmacologic strategies (National Comprehensive Cancer Network, 2017), however recommendations are not specific to older adults.

Typically, people newly diagnosed with cancer are inundated with a large amount of written materials as they are only just beginning to process their diagnosis and treatment plan. Some information given may not be relevant immediately, but given “for later” or “just in case”, without tailored instruction to the most likely side effects they will experience. The amount and complexity of information can be overwhelming and confusing to older adults (Portz & Johnston, 2014) who often need material reduced to “must know” information (Zurakowski, Taylor, & Bradway, 2006). Older adults receive the same information as younger adults despite recognized differences in learning needs and styles (Knowles, 1990).

Complicating successful management of cancer treatment-related symptoms is how older adults experience their symptoms within the context of alterations in perception that occur with aging. Some researchers suggest that older adults are less responsive to symptoms than younger adults (Leventhal, Brissette, & Leventhal, 2003; Prohaska, Keller, Leventhal, & Leventhal, 1987). Some symptoms like fatigue, sleep disturbances, bowel changes and pain may already be present at diagnosis due to other chronic illnesses making changes or worsening of those symptoms difficult to discern. Studies have shown that older adults minimize the impact of symptoms from cancer illness and treatment on health (V. W. Loerzel & Aroian, 2012; Ryan & Zerwic, 2003). Some older adults normalize symptoms (Kessler, Lloyd, Lewis, & Gray, 1999) or assume symptoms are a part of aging (Leventhal et al., 2003; Prohaska et al., 1987) which can lead to delays seeking treatment. In addition, recent research indicates that some older adults do not believe their actions will impact the severity of the symptom (V. Loerzel, 2016) despite being educated about numerous

strategies to manage it. Because of older adult's unique learning needs and perceptions of their symptoms, new educational strategies need to be developed to address these.

The purpose of the project described in this paper was to develop a relevant, age appropriate, tailored intervention for older adults to teach and reinforce how to self-manage CINV better at home. Given that older adults receive plenty of generic written materials about managing CINV, the researchers chose to use a formative evaluation process and a community advisory board to create an educational "serious game" that would capitalize on learning strategies for older adults that included practicing new skills (Fenter, 2002; Zurakowski et al., 2006) and changing patterns of behavior (Fenter, 2002) to introduce new and reinforce previous information and learning. The use of storytelling by either using the patient's own experiences as a learning tool, or introducing new stories is also an effective means of promoting learning in elders (Sorrell, 2008).

Methods

This study was funded by the National Institute of Nursing Research and approved by the University of Central Florida Institutional Review Board. A formative evaluation process using a community advisory board (CAB) and a series of focus groups was used to develop this serious game about managing CINV at home. The overall goal was to create a scenario for the game using evidence-based strategies for managing CINV and the real life experience of older adults (age 65 and older), family members and oncology nurses who have managed CINV. Participants for the focus groups were recruited from a local cancer center. Nurses were recruited from the outpatient infusion treatment center staff. Patient and family members were screened for age and personal experience with CINV and approached about participating during a cancer treatment appointment. The final sample included older adults under treatment for cancer (n=5), caregivers (n=3), and oncology nurses (n=4) with experience managing CINV. Semi-structured interviews were used. The original intent was to conduct traditional focus groups at each phase of game development, however potential participants approached about the study did not want to commit to the study on a day they did not have treatment. Therefore, for ease of participation, the focus groups became dyad or one-on-one interviews. Patients and family members participated during a chemotherapy infusion appointment, oncology nurses participated at the end of the work day. For the purposes of this paper, the interviews will be referred to as focus groups.

During focus group 1, participants were asked to describe their personal or professional experiences with CINV. Interviews were designed to allow participants to tell their stories about CINV using semi-structures questions guiding them to describe the severity of their CINV, how they self-managed it, and what they perceived to be the consequences of managed and unmanaged CINV. In focus group 2, participants were asked to validate themes from the first focus group and provide feedback related to the emerging game scenario, character development, reality of the setting and scripts, self-management choices, and outcomes of those choices. Focus group 3 had participants provide feedback on game consistency, usefulness, engagement, entertainment factor and the "dose" of the future intervention.

Data from each focus group were audio-recorded and transcribed. Classic content analysis (Hsieh & Shannon, 2005) was used to analyze data from the focus groups. Transcripts were read and coded using language similar to that used by participants. These codes were grouped by similarity and used to summarize feedback about game development. Themes were developed from the codes. Data were not intended for generalization, but to answer specific questions to support game development.

Results

Learning the Story: Experience of participants with chemotherapy-induced nausea and vomiting

Results from the first set of focus groups indicated that the experience of CINV was different for everyone. Some patients managed CINV on their own, others stated they could not have managed without the help of their spouse or other caregiver. There was tremendous variability as to when nausea began after treatment, how long it lasted, how it impacted their daily life, and what participants did at home to self-manage CINV. Nausea came in many different levels of severity from mild to severe resulting hospitalizations. The role and value of the spouse/caregiver in helping patients manage CINV was also varied. One common thread was that patients had to be proactive when managing CINV because once it starts, it is too late to control. Many did not use anti-nausea medications as their first defense against nausea and waited too late to take it. Another commonality was that education received for cancer and its treatment was overwhelming and CINV was not the only side effect from treatment experienced.

The most valuable piece of information from the nurses was verification that a new strategy for educating older adults was needed. Nurses described older adult being overwhelmed by the information they are given about cancer side effects, their reluctance to take anti-nausea medications, their lack of communication with the clinic in between treatment visits when they have side effects at home, and the need to reinforce education and present it in different formats-including visually. Nurses also believed that family members needed to get involved in helping to manage older adults and their side effects from treatment due to the increasing complexity of some anti-nausea regimens and the fact that older adults often feel overwhelmed.

Using the story: Validating themes and providing feedback on game prototype

Results from focus group 2 helped to clarify particular aspects of managing CINV in order to inform the emerging scenario to give the game authenticity. Participants provided more information about what they ate and drank when nauseated, how they treated themselves when feeling good, what they did to manage CINV besides taking medication, and what life events and activities they missed out on when nauseated. We asked them to describe what phrases such as “small frequent meals” and “drink fluids” meant to them. This contributed to the reality of the self-management choices and scenes as we developed the script for the game.

The initial prototype of the game was a scenario that involved an ongoing conversation between a patient and caregiver about how the patient was feeling over time. Many participants felt that this interaction was too much and one became annoyed with the scenario due to constant questions from the caregiver about how the patient was feeling. There was much discussion as to how involved a caregiver should be. Another polarizing aspect of the prototype were the characters which were supposed to reflect a typical older adult receiving cancer treatment. The patients and family members felt the characters, especially the male character, looked “old” and gravely ill. Nurses commented that the characters were very representative of their patient population. Despite this, most participants thought the characters looked real and better than they had imagined they would look.

Specifically related to game play, we discussed the best way to portray nausea and feeling nauseated for the games characters. Ideas ranged from having a nausea indicator on the side of the screen to changing the characters posture and facial expression based on the level of nausea. Dose of the game was also discussed. Patients and family members believed that more exposure to the game was better and recommended it be played several times over several appointments.

Finally, participants were asked about what changes they wanted to see in the game. Many felt that a “backstory” for the characters was needed to set the scene and make the characters more “real”. Others commented on the size of the print and instructions for the player on how to play the game. Some felt the game was too generic, however the goal was to create a scenario that the majority of the players could relate to. One player did not think we should call it a “game” because it was not “fun” or entertaining.

Finalizing the story: Final thoughts and play testing

Overall, the serious game was very well received by participants. They were excited to see how their experiences and their suggestions were incorporated into the game. Several participants acknowledged how the script was realistic and almost exactly the same as conversations they had with their caregiver at home. They appreciated it when they saw a specific self-management choice for CINV that they used when they had nausea. However, some participants were disappointed with some of the game’s self-management and meal choices because they were not specific to their individual preferences for food and drink.

Technical glitches were also identified. Problems with the scenario algorithm which caused the character feel nauseated or well was “off balance” or not reflective of reality. This was fixed by asking nurses which self-management choices were most important to help older adults minimize the impact of CINV. The need for a tutorial on how to play the game also became apparent. Several participants did not know what choices they could select to manage nausea for the character and others did not know they could select more than one choice.

Discussion

Managing cancer-related symptoms at home can be a challenge for older adults. Barriers include their being overwhelmed with traditional education and not believing their self-management actions can impact symptom severity. This paper describes the process of using a community advisory board comprising older adults, their caregivers, and oncology nurses to describe their personal experiences with CINV to serve as the foundation for the development and initial testing of a serious game about managing CINV at home. This educational intervention directly addresses identified barriers and uses different educational strategies such as demonstration and practice for patient learning. Initial feedback on the intervention is promising.

The integration of the different perspectives of CAB members was accomplished using a formative evaluation process. The CAB gave insight into practical and actual strategies used by older adults to manage CINV at home. While everyone's experience was different, this process helped us to identify similarities that were then used to create scenarios for the serious game. The final product was acceptable to all participants.

Intervention self-management strategies used in the serious game were based on common evidence-based self-management strategies found in the patient education materials at the cancer center and on patient experience and interpretation. However, the CAB and the formative evaluation process allowed us to further investigate how older adults interpreted and used these strategies at home. It helped us prioritize strategies to be used in the intervention and discard others that this population did not value or identify with in their experiences. This format of using the CAB and formative evaluation process helped ensure that the game was perceived as relevant.

The process described in this article had several limitations. All participants of the CAB experienced or managed CINV as either a patient, caregiver or nurse. This factor brings inherent biases to the experience. At times, participants became too focused on their own experiences and became insistent on certain aspects of their experience being included as a learning tool for others. The nurses also had a difficult time distinguishing behaviors and patterns of older adults with CINV verses everyone else. A final limitation is that the CAB lacked diversity even though nurse's identified populations with a great learning need (e.g. Spanish speakers). The next versions of this intervention will need to be linguistically and culturally relevant to other groups.

Conclusions

As our population continues to age, nurses and other healthcare professionals are encouraged to tailor cancer education to specific populations and their beliefs about symptoms and symptom management. Generic teaching and learning methods may not address the concerns and needs of all people. Serious gaming for older adults should be consider as an option. In addition, getting the input of the target population will lead to developing a relevant experience based on their own needs. Exploring new ways to

emphasize key points related to symptom management and prioritize learning may impact outcomes for older adults.

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