

Sandra E. Kurtin, PhDc, AOCN[®], ANP-C

Assistant Professor of Clinical Medicine
Adjunct Clinical Assistant Professor of Nursing
The University of Arizona Cancer Center
Tucson, Arizona

Mobile Applications to Support Health Self-Management

Welcome to Managing MDS. My name is Sandra Kurtin. I am a nurse practitioner and researcher at the University of Arizona Cancer Center. I am also a member of the Board of Directors for the MDS Foundation. This is an international organization devoted to supporting and educating both providers and patients with MDS, and doing research with the intent to try to find a cure for this currently incurable disease. My research interests include health self-management, communicative health literacy, and health technology as tools to empower cancer patients and their caregivers in managing their own disease. We know that active involvement of the patient and their caregivers in managing their disease can result in extended survival, and this data was again supported by an [ASCO presentation](#) just recently. We also know that engagement of patients and their caregivers in expressing their wishes, including advanced directives and discussion of end of life needs, is mandated by many of the regulatory agencies today.

I am going to focus more on mobile health applications, which provide the capability for an interactive, dynamic, and untethered technology to support health self-management. Electronic and mobile health technology can be used to gain knowledge and skills needed for this self-management. However, we really are lacking in the education and support for these technologies in an organized way. A recent survey of currently available mobile health applications shows that there are roughly 400,000 mobile health apps focused on health. Most of these are either never downloaded or, if downloaded, are used for less than 30 days, which really does not do much to have a person manage their health. My focus is how we can look at innovative strategies to improve this communication and empower the patient and their caregivers.

My dissertation is focused on the usability and feasibility of a mobile health application to enhance self-management in older adult cancer survivors. We know there are going to be roughly 20 million cancer survivors in the year 2020, and the majority of these will be over the age of 65. MDS is a perfect disease to study this because this bone marrow disorder, which is characterized by progressive cytopenias and a variable risk of leukemic transformation, has a mean onset of age 73. We know that these patients and their caregivers are expected to understand very complex information, adhere to prescribed treatment plans, and perform technical skills. The majority of this care is provided in an outpatient setting, and so we expect a lot of the patient and their caregivers in managing their adverse events, reporting these adverse events in a timely manner, and being able to access the health care system effectively. Yet they have little or no formal training, so there is definitely a gap.

MDS Manager which is the mobile health app that I have created with colleagues at the MDS Foundation and others, is a newly developed health application designed for smartphones and

tablets. It includes a variety of features to assist the patient and their caregiver in managing their care, tracking their response to treatment, and allowing them to access resources.

The first thing we did was conduct an online survey through the MDS Foundation to learn more about technology use in the MDS population. We had 137 responses in the online survey, and the median age of the patients was 67. Most of these were females, 54%, and the median age for the caregivers was 60. 86% of the caregivers were female. 78% reported at least one comorbidity and an average of four prescriptions, so we know that comorbidities are also a challenge for both the patients and providers in effectively managing not only the primary disease but the other illnesses. These respondents accessed information through foundations, they looked to their physician for information, and they did go online (Google, or “Dr. Google” as we call it, and WebMD are the two most common), and used applications like Facebook, Youtube, and FaceTime for other resources. 78% of this population used a smartphone either “daily” or “often,” with the use of tablets being a little less common, with 47% indicating use “daily” or “often”. 73% of them use patient portals, so this is another way to integrate health technology in managing illness, and these are connected to the electronic health records.

With that information, we found that they were using technology. We moved forward with *MDS Manager*, and the purpose of the pilot study was really to look at feasibility and usability of this technology in this MDS population. Both the results of the study I just mentioned and this pilot study were presents at the 14th International Symposium on Myelodysplastic Syndromes held in Valencia, Spain in May of 2017. We had a convenience sample of 15 patients and 12 caregivers, and the age range was 56 to 89, so we had some older adults, and they were recruited through the MDS Foundation. They participated in two consecutive 4-week pilot sessions between August and October of 2016. Each group completed weekly tasks, and these were aimed at testing the functionality of the *MDS Manager* app. We also conducted weekly telephone calls to gain more information from the user looking at things like font size and color and functionality. Then they also answered questionnaires at the end of each week using 5-point Likert scale SurveyMonkey questionnaires. 73% of these participants had an existing Google account which is required for access to the app (it is API interface through Google which is HIPAA compliant) and an additional 10% registered at the time of the study. We know there is a certain level of technology proficiency in this older adult population. They found access to resources through the app including clinical trials information to be “very easy to access,” 83% of the participants indicated this, and they found it “effective” or “very effective” 68% of the time, emphasizing the ability to potentially improve clinical trial participation. 84% of the participants rated *MDS Manager* as “very effective” or “somewhat effective” in this pilot study, so that was good news.

What we basically found was that *MDS Manager* as a mobile health application provided a useful tool for MDS patients and caregivers. It has the capability to improve access to clinical trials. It has bidirectional functionality with the ability to send a push notification in the event that a clinical trial is newly opened or might be available to that particular user, based on the MDS profile that they have input into the device. We did note that some areas for data entry, particularly the very complex cytogenetic profile, were a little bit more challenging for some users. We know that there is likely a need for collaboration with healthcare providers to help input this information so that the patient can maintain that data in the app. We noted that user input in design and optimization is very critical to improving functionality and usability. The app has now been further modified, and that modified application was actually launched at the

meeting in Valencia. Moving forward, *MDS Manager* will now be used in ongoing research that basically creates a research platform. The data from the app are streamed to a database, so people who opt in after reading a disclaimer will have their data streamed in real time to a database, which allows us as researchers to view this data either as individual data or aggregate data. We have the ability to push out resources based on symptoms that are entered into the device to help guide that user to tools and information on managing individual symptoms. We know from the data at ASCO that being able to access information readily for symptom management can improve patient outcomes. We are hopeful to expand on this feature of the device, and so this really creates this research platform, and we hope to use the app in conducting additional clinical trials. So, I want to thank you for viewing this activity and Managing MDS.



MDS Manager™ is available for iOS and Android devices

iTunes App Store <https://itunes.apple.com/us/app/mds-manager/id1140404422?mt=8>

Google Play <https://play.google.com/store/apps/details?id=com.mymdsmanager&hl=en>