

NINR Precision Health: Smart Technologies, Smart Health Symposium Abstracts

1. Lindsey Ryan, PhD(c), MSN, BSN

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Application of Condition-based Maintenance in Health Care

Abstract

Background: In 2013, the National Institute of Nursing Research (NINR) charged a group of symptom science experts with identifying potential research questions that could be used to advance nursing science. Experts discussed the importance of identifying biological indicators, understanding the behaviors of symptoms, finding symptom precursors, and creating management algorithms. In addition, experts strongly recommended the leveraging of technologies to improve symptom management and change the chronic illness trajectory through innovative care delivery models. Application of equipment-related condition-based maintenance has been widely researched throughout various industries. However, use of condition-based maintenance has not been explored in relation to health maintenance among humans.

Hypothesis: Application of the condition-based maintenance model may prove to have relevance in reducing hospital readmissions as it relates to the monitoring, identification, and treatment of specific disease processes before an individual experiences a significant decline in health, warranting care.

Method: Eight-step method of concept analysis proposed by Walker and Avant. Literature was gathered using PubMed, Wiley Interscience Journals, and Emerald databases.

Results: Condition-based maintenance is defined as efficient, proactive support utilizing predictive methods to identify and repair precise problems, restoring and extending one's life. Four attributes were identified: predictive, proactive, precise and efficient. Antecedents include monitoring and analyzing of deterioration data as well as a loss in function. The consequences of condition-based maintenance include life extension, decreased burden and costs, and increased safety. A constructed model case, as well as borderline, related and contrary cases are presented. Empirical referents and concept uses are explored.

Discussion: Condition-based maintenance propels the NINR's focus on symptom science forward through the development of personalized strategies to treat and prevent the adverse symptoms of illness. It is anticipated that this concept analysis on condition-based maintenance will contribute to further identification of clinical signs of deterioration and accompanying interventions to prevent hospitalization and even unnecessary death.

Conclusion: Chronic illness burdens patients, providers, and health care organizations. Condition-based maintenance is a novel concept transposed from the engineering industry that holds great promise for alleviating unnecessary afflictions by enhancing current health care delivery methods.

2. SeonYoon Chung, PhD, RN

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FoodFoto™: Efficacy Testing of a System to Collect, Store and Analyze Longitudinal Diet Data

Abstract

Background: Diet has a profound effect on health regardless of the presence or absence of disease; therefore, it is essential to have tools to accurately measure diet. Currently the available tools to measure nutritional intake rely exclusively on memory-based recall, that is problematic because memory-based methods are inherently biased leading to inaccurate representation of diet.

Purpose: FoodFoto™, is a diet data collection, storage, and analysis system, designed to capture real-time longitudinal nutritional intake for a study examining the effect of diet on the vaginal microbiota and preterm birth (1R01NR014826). The findings reported here relate to efficacy testing conducted to evaluate use of the app for research purposes.

Research design/methods: FoodFoto™ is a cloud-based database linked to FileMakerGo on iPhones that resembles a mobile application while offering the functionality of a database. Users take food photos at the point of consumption and record audio or text annotations describing the meal, snack, dessert, or drink in more detail. Trained analysts translate the food images into food codes from Food and Nutrient Database for Dietary Studies (FNDDS). FNDDS are used to compute Healthy Eating Index (HEI-2010) scores that assess compliance with USDA Dietary Guidelines for Americans. Food images from a subset of 53 women enrolled in the parent study were analyzed to estimate diet quality among the cohort. Usage rates of the app were based on the number of images that the women submitted.

Results: Although not statistically significant, the findings showed that the increased use of FoodFoto was associated with higher diet quality scores.

Discussion: The efficacy testing was conducted to determine if use of the FoodFoto™ app was associated with differences in diet quality scores. Although not statistical significant the findings are highly suggestive. The lack of statistical significance was attributed to small sample size. Repeating the study with a larger sample is currently underway.

Conclusion: FoodFoto™ is a novel dietary intake application that offers an alternative method to traditional memory-based nutritional intake methods. The system effectively reduces participant data entry burden and accurately captures the dietary intake (Regan, et al., in review).

3. Sara B. Donevant, PhD, MSN, RN, CCRN

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Developing an Evidence-based mHealth Evaluation Tool for Healthcare Providers

Abstract

Background: Mobile health applications (mHealth apps) are one of the fastest growing areas of healthcare with 46% of Americans using a mHealth app. However, patient use depends on several factors including recommendations from healthcare providers. One barrier in identifying evidence-based mHealth apps is the excessive number of mHealth apps. Currently, over 325,000 mHealth apps are available with <10% including any evidence-based practice (EBP). Therefore, finding evidence-based mHealth apps is potentially a tedious and time-consuming process. One solution is an evaluation tool to assist healthcare providers in selecting evidence-based mHealth apps.

Current mHealth evaluation tools focus on information technology features with minimal attention to EBP. Additionally, all tools are in paper format and require the user to manually calculate the scores with no guidance on the interpretation.

Hypothesis: We hypothesized that an online, evidenced-based mHealth evaluation tool will assist providers in identifying effective mHealth apps.

Research Methods: The Obesity-Related Behavioral Intervention Trials model directed the development process. The aims included: 1) define a comprehensive pool of domains and features; 2) obtain feedback from healthcare providers on “essential”; “important”; and “nonessential” mHealth features; and 3) refine the comprehensive pool using feedback.

Results: A comprehensive pool was created by combining the features in the seven current evaluation tools and features identified in a recent mHealth research synthesis. The comprehensive pool included 6 domains with 79 features and served as the online survey in Research Electronic Data Capture.

The survey was e-mailed to 17,302 healthcare providers. A total of 347 healthcare providers responded, with 108 stating they recommended mHealth apps to patients. Frequency statistics identified 78 features as “Essential” or “Important”. Next, a factor analysis was conducted to prevent overlap between the mHealth features. The result was 32 mHealth feature statements organized in 6 domains, which created the mHealth evaluation tool.

Discussion: This is the first step in developing a mHealth evaluation tool for healthcare providers that includes mHealth evidence. The next step is proof-of-concept testing on the evaluation tool by healthcare providers.

Conclusion: To our knowledge, this is the first mHealth evaluation tool to use EBP and end-user feedback in the development process

4. Elizabeth Barnby DNP, ACNP-BC, FNP-BC

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A Metabolomics Approach Using NMR to Identify Neurological Modifying Metabolites in the Urine and Brain of a Mouse Model of Hereditary Tyrosinemia Type I (HT1)

Abstract

Background: Hereditary Tyrosinemia Type 1 (HT1) is an autosomal recessive inborn error of tyrosine metabolism caused by fumarylacetoacetate hydrolase (FAH) deficiency. Lack of FAH enzyme leads to accumulation of toxic metabolites, producing the HT1 phenotype in children. Present therapies are used to manage the disease, but children with HT1 eventually have cognitive decline and the etiology is unknown.

Hypothesis: To identify the biochemical pathway producing the cognitive changes in children with HT1 by studying the knockout mouse model for HT1.

Research design/methods: We analyzed mouse urine and brain extracts, to look for presence of potential neuromodulatory metabolites that are altered in HT1 mice. We used NMR to identify amino acids, neurotransmitters and other metabolites. Once measurement protocols are established and we have identified signature metabolites, produced at different levels between the groups of mice, we will have a therapeutic target to treat and address these issues, and re-evaluate the mice in the cognitive behavioral tests. Standard procedures will be adapted from protocols found at Metabolomics workbench (www.metabolomicsworkbench.org). Ethovision® software and mazes were used to study social cognition, learning, and memory in wildtype and HT1 mice.

Results: Maze studies showed altered social behavior in mice with HT1. Using NMR we have been successful in our proof-of-concept experiments and have identified a range of metabolites in the urine and brain extracts of mice using NMR. As expected, we have seen a several fold increase in tyrosine signals in urine and brain extracts from mice with HT1. We have been able to characterize several neurotransmitters and other metabolites of interest.

Discussion: The etiology of the cognitive decline in children with HT1 remains undetermined, but maze studies allowed us to compare wild-type mice to HT1 mice. These cognitive and behavior changes were strikingly similar to the phenotype in children. We have been successful in identifying >20 molecules in the urine and >6 molecules in the brain of mice with HT1 using NMR and metabolomic analyses.

Conclusion: Using NMR and metabolomics is a valid approach to identify biochemical differences and develop a treatment plan that will ameliorate the cognitive changes seen in children with HTI.

5. Mark E. Reynolds, DNP RN COI
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Implementation of Augmented Reality to Enhance Practice Outcomes in Senior Level Baccalaureate Nursing Students

Abstract

Background: Senior level baccalaureate nursing students at a local public university in the state of Alabama must satisfactorily complete 225 internship hours one-on-one with a Registered Nurse at an acute-care healthcare organization. In order to assess viability of the internship and overall preparedness of the student to implement nursing judgement, critical thinking, psychomotor skills, pressured time, and clinical reasoning augmented reality through three high-fidelity simulated scenarios were utilized. The High-fidelity simulated scenarios focused on real-life situations including a client with a kinked chest tube, a client with an infected gun-shot wound, and a non-verbal client with a chronic tracheostomy. The students moved from client to client with a partner to complete a head-to-toe assessment, any health care provider orders, and determine the priority needs of the client.

Hypothesis: To determine if the implementation of augmented reality scenarios will enhance practice outcomes in Senior Level Baccalaureate Nursing Students.

Research design/methods: Pre-simulation materials were provided to the students in order to adequately prepare for the augmented reality experience. Reflective journaling was implemented following the experience to allow the student to discuss the strengths, weaknesses, opportunities, and threats of their experience and to determine if the augmented experience would aid in real life.

Results: According to the reflective journaling by the students implementation of augmented reality experiences through high-fidelity simulations vastly improved the confidence, communication skills, and overall awareness of client care and nursing judgement. It was noted that 94% (n=56) of the students who participated provided positive feedback on the experience.

Discussion: Implementation of augmented reality through high-fidelity simulations is an active-learning methodology that can be used in schools and colleges of nursing across the nation. Increases in nursing student preparedness for the senior-level internship is evident

Conclusion: The implementation of the high-fidelity simulations was very successful at assessing learning and giving student's real-world opportunities to practice their skills in a pressured time situation. We will expand this project so that students can do additional time limited simulations next semester.

6. Ji-Young An, PhD, MPH
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The Effect of Pokémon GO on Physical Activity

Abstract

Background: Physical activity (PA) contributes to the prevention of obesity and chronic

diseases. Previous research has consistently reported that technology-based mobile interventions promote PA. Recently, serious games have been utilized to promote PA. Pokémon GO, an augmented reality game, is a mobile application, which uses a positioning system that motivates game users to walk around or travel to catch nearby Pokémon in the real-world setting.

Hypothesis: Does Pokémon GO increase PA and decrease sedentary behavior?

Research design/methods: A survey design with a structured questionnaire employing a convenient sample was used. A revised Godin Leisure-Time Exercise Questionnaire assessed days per week (0–7) and minutes per day (10-minute intervals from 0 to ≥ 60) spent in strenuous, moderate, and mild-intensity PA before and after beginning to play Pokémon GO. For the analysis, SPSS v. 24 was used.

Results: 676 responses (59.6% female; 43.0% White; 48.5% Asian; mean age = 27.1 [SD = 7.3] years; mean body mass index [BMI] = 24.2 [SD = 4.6] kg/m²; playing Pokémon GO an average of 24.0 [SD = 10.0] days) were analyzed for this study. The three PA indicators showed differences after using Pokémon GO with the largest change in the mild-intensity PA. There was no sex or race/ethnicity interaction but some indication that Pokémon GO may benefit the more-overweight participants. The BMI was positively related to the three indicators ($p < .01$); the number of days playing Pokémon GO was positively related to moderate and mild PA ($p < .05$); the total minutes of playing Pokémon GO was positively related to mild PA ($p < .05$).

Discussion: The potential of Pokémon GO was proved. Further research should be conducted to examine its long term effect on PA.

Conclusion: Pokémon GO increased PA and reduced sedentary behaviors. Therefore, augmented reality games can contribute to the prevention of obesity and chronic diseases caused by lack of PA.

7. Erica Schorr, PhD, RN

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Activity Tracker Increases Functional Capacity Post-Cardiac Rehabilitation Compared to Placebo Device

Abstract

Background: Despite improved levels of physical activity (PA) and functional capacity among patients immediately post-cardiac rehabilitation (CR), little is known about long-term changes in daily PA and functional capacity. Further, interventions to maintain recommended PA levels and functional capacity achieved during CR are lacking.

Hypothesis: Intervention participants wearing a Garmin vívofit for 15 weeks post-CR will exhibit increases in PA levels and functional capacity compared individuals wearing

a placebo device.

Research Design/Methods: Change in daily step count and 6-minute walk test (6MWT) were assessed over 15 weeks using the vívofit activity tracker in 35 patients (mean age 62±8 years; 83% male; 94% Caucasian) post-CR. Patients were randomized into the control or intervention group with control devices displaying a digital clock. PA goal was 10,000 steps per day for all participants. Vívofit step data were recorded continuously; the 6MWT was conducted at 0, 9, and 15 weeks. Comparisons between the 2 groups were made using test of proportion, t-test, and logistic and linear regression.

Results: Control and intervention groups were balanced with respect to age, gender, education, and body weight. Control group participants exhibited above average daily step counts (>8,000 steps) at 3, 6, 9, 12, and 15 weeks, and increased average daily steps and average daily active minutes over 15 weeks. However, intervention group participants exhibited average step counts above 10,000 steps per day at 3, 6, 9, 12, and 15 weeks. Further, intervention group participants (N=17) increased the distance covered during the 6MWT at 15 weeks by 106 meters (sd=130), compared to a 73 meter (sd=123) improvement among control group participants (p=0.558); although not statistically significant, but perhaps clinically relevant.

Discussion: These data provide preliminary support for using wrist-worn activity tracking devices to continuously monitor and maintain PA levels and functional capacity post-CR. There is a need for larger trials testing the effectiveness of these devices with a more diverse sample over a longer period of time.

Conclusion: Wrist-worn activity tracking devices should be coupled with other components known to support long-term behavior change (e.g., social support and text messaging) to develop effective interventions for secondary cardiovascular disease prevention.

8. Jasmine Nakayama, BSN

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Text Analysis of Nursing Progress Notes

Abstract

Background: Much nursing documentation, especially in nursing progress notes, is unstructured and difficult to analyze with traditional techniques. As they may provide valuable insight into patients' care and nursing activities, this study assessed the feasibility of using text analysis techniques with nursing progress notes.

Hypothesis: Text analysis is a feasible way to attain information about patients and nursing care.

Methods: A sample of 44,726 nursing progress notes was obtained from a database of 107,433 patients from a health care system. The R programming language and pre-programmed packages were used to determine term frequency and sentiment analysis. Words were combined into a single body of text and then organized according to the "tidy text" format, where each row of a table contains a single term. Term frequency was

analyzed for single words, 2 consecutive words, and 3 consecutive words. Then, words were classified according to 3 lexicons commonly used for sentiment analysis.

Results: Term frequency showed that nursing progress notes contained many abbreviations, frequent references to chart checks, and commonly used phrases such as "no acute distress." The most frequently used word was "pt," a common abbreviation for "patient." Nurses often noted the presence of a physician or family at bedside. The 3 different lexicons used for sentiment analysis associated words with emotions, positivity or negativity, or numeric scores. For example, "distress" was categorized as "fear" and "negative." However, some of the classifications were inappropriate for this context; for example, "patient" was categorized as "anticipation" and "positive."

Discussion: Term frequency revealed patterns of nursing documentation. Potential applications of this method include capturing nursing activities or identifying opportunities to improve documentation. Sentiment analysis techniques can be used to select words of a certain sentiment or to determine the overall sentiment of a body of text. However, using lexicons that are non-specific to health care warrants caution.

Conclusion: Overall, text analysis is feasible for nursing progress notes and provides opportunities for deeper insight. Specifically, term frequency revealed commonly used words and phrases in nursing progress notes, and popular lexicons classified words according to sentiment.

9. Gesulla Cavanaugh, Ph.D., MS, MPH

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Association Analyses Reveal Genomic, Epigenic, Environmental, and Therapeutic Networks in Autism Linked Pathways

Abstract

Background: Autism has very complex genetic and genomic etiologies along with phenotypic manifestations. While many genome-wide association studies (GWAS) greatly contribute to the identification of genes responsible for autism, other studies concentrate on the epigenetic or the environmental components alone. Likewise, drug and behavioral therapy research studies do not commonly include the genetic components and only focus on either the behavioral or pharmaceutical management of autistic symptoms.

Purpose: We studied the reported expressions and interactions of approximately 990 genes associated with autism. The focus was to create a model from currently available genetic, molecular, and environmental data involved in the onset, promising preventive, and active treatment of autism.

Hypothesis: We hypothesized that a group of chemicals with similar biological pathways as normal gene products can be modeled to compensate for gene disruption in autism.

Methods: We accessed the SFARI GENE database to examine 990 genes currently linked to autism. The comparative Toxicogenomics Database, the DrugMatrix, along with the GeneCards suite were explored to extrapolate pertinent information on the

associated genes. Protective chemicals, biological and environmental compounds were examined for their interactions with the investigated genes. We performed neural network and association rule analyses through the CARMA node using SPSS Modeler V.18.0. Highlighting hyper Markov laws, we constructed a decomposable graphical model from the generated epigenic and therapeutic models.

Results: The neural network results estimated a large epigenic network with relatively significant predictor variables with 90.3% accuracy for predicting whether or not a gene was syndromic. The association rule reveals 72% support and 39% confidence for different GO terminology and diseases shared among the autism linked genes and the investigated chemicals.

Discussion: We document pertinent suggestions for the need to conduct more in-depth autism related studies that analyze the genomic components through therapeutic treatments. If gene mutation is inevitable, a more robust model that mitigates the harmful consequences must be in place.

Conclusion: Researchers need to invest deeper in examining the protective factors for autism at all levels which may be able to mitigate the effects of gene mutation and environmental risk factors to autism.

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The Effect of a Culturally Tailored Web-based Physical Activity Promotion Program on Asian American Midlife Women's Sleep-related Menopausal Symptoms

Abstract

Background: Physical activity has been suggested as an effective strategy to reduce sleep-related menopausal symptoms among midlife women. However, the effect of a Web-based physical activity promotion program (WPAPP) on sleep-related symptoms has rarely been investigated, particularly among ethnic minority midlife women.

Hypothesis: The intervention group shows greater increases than the control group in 1) self-reported sleep-related symptoms (physical, psychological, psychosomatic, and total symptoms) and 2) self-reported physical activity (physical activity scores, attitudes toward physical activity, self-efficacy, perceived barriers, and social influences) from a pre-test (Time 0) to two follow-up time points (post 1 month [Time 1] and post 3 months [Time 2]).

Methods: This study adopted a randomized repeated measures pretest/posttest design among 26 Chinese and Korean American midlife women. The WPAPP provided the intervention group with culturally sensitive online educational modules and online

resources in English, Chinese, and Korean; group coaching via weekly online forums; and individual coaching by culturally matched nurse interventionists. Multiple instruments were used to assess background characteristics (e.g., sociodemographic and health status) as covariates and sleep-related symptoms and physical activity as outcome variables at Times 0 to 2. The data were analyzed using a modified intent-to-treat linear mixed-model growth curve analysis.

Results: Relative to the control group, the intervention group showed a higher rate of inclination only in active living habits over three months after adjusting for the covariates and random intercept ($p = 0.0161$ for treatment arm x time interaction). Both groups, however, did not present meaningful changes in the sleep-related symptoms over time.

Discussion: Low statistical power from the small sample size might have masked the actual positive changes in some outcomes (e.g., sleep-related psychological symptoms, attitudes, and self-efficacy of physical activity) among the intervention group. Potential response bias from underreporting needs consideration to interpret the results given Asians' reluctance to disclose personal matters even to family.

Conclusions: The effect of WPAPP on women's physical activity and sleep-related symptoms should be examined further with a larger sample in the long term.

11. Susana J. Calderon, Ph.D., RN

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Children Oral Symptoms: A Feasibility Study of the Beneficial Role of the Oral Microbiota and Oral Health Behaviors

Abstract

Background: United States children, ages 5 to 17 years old, are in distress because of poor oral health. Recently oral microbiota has been suggested to be associated with oral health and oral symptoms. Purpose of the study: The purpose of this feasibility study is to understand the relationship between oral microbiome and oral symptoms in children and the influence of toothbrushing and tooth flossing.

Subject: Convenience sample of approximately 20 children school age 7-12 years attending a community dental clinic, both genders and from different socioeconomic status.

Research Design: This study is an observational study.

Procedure: The recruitment site is a community dental clinic. Participants will be screened based on the eligibility criteria. Parental consent and child assent will be obtained. The parent will complete a demographic questionnaire, and the child will complete the other questionnaires. Child oral specimens and dental records will be collected by research team members.

Instrument: Three questionnaires will be used to collect information on demographics,

oral health behavior, and oral symptoms. Dental record and child oral swabs will be collected for oral health and oral microbiota information, respectively.

Data analysis: PCR amplification of 16SrRNA will be conducted to analyze oral microbiota information. Descriptive statistics will be used to characterize demographics and main variables. Pearson's correlations or Spearman's Rank order correlation, and general linear model or generalized linear model will be used to address research questions.

Findings: The findings will provide knowledge to develop oral health interventions targeting beneficial oral microbiota aimed at improving oral symptoms. Keywords: oral health, children, oral microbiome, oral microbiota, cavity

12. Hyochol Ahn, PhD, MSN, MS-ECE, MS-CTS, APRN, ANP-BC

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Transcranial Direct Current Stimulation and Laboratory-based Heat Pain Sensitivity in Adults with Knee Osteoarthritis Pain

Abstract

Background: Osteoarthritis (OA) is the most common arthritic condition and a leading cause of pain and disability in older adults. For this population, there is a growing interest in non-pharmacologic interventions targeting central nervous system pain processing, such as transcranial direct current stimulation (tDCS), owing to its neuromodulatory effects. tDCS involves the application of weak direct electric current to the head in a noninvasive and painless manner, leading to the modulation of the brain activity involved in pain processing. Previous studies have indicated that tDCS is effective in reducing clinical pain, but these studies did not focus on laboratory-based experimental pain sensitivity. Thus, we sought to assess the preliminary efficacy of tDCS on heat pain sensitivity in adults with knee OA pain.

Hypothesis: tDCS will reduce heat pain sensitivity in adults with knee OA pain.

Research design/methods: We conducted a double-blind, randomized, sham-controlled pilot clinical study in 40 community-dwelling participants with knee OA who were 50-70 years old. The participants were randomly assigned to receive either active or sham tDCS (1:1 for two groups). All thermal stimuli were delivered using a computer-controlled Medoc TSA-II neurosensory analyzer (Ramat Yishai, Israel) to measure heat pain threshold and heat pain tolerance at the knee using an ascending method of limits. Participants were instructed to press the button when the sensation "first becomes painful" to assess the heat pain threshold and when they "no longer feel able to tolerate the pain" to assess their heat pain tolerance.

Results: The increase in heat pain threshold (HPT_h) and tolerance (HPT_o) was higher in the active tDCS group than in the sham tDCS group (HPT_h: mean difference between group = 1.11 ± 0.75 , $t=1.46$, $df=38$; HPT_o: mean difference between group = 0.22 ± 0.46 , $t=0.48$, $df=38$).

Discussion/Conclusion: Although our primary results were nonsignificant, the

preliminary findings suggest that tDCS targeting the primary motor cortex may reduce laboratory-based experimental pain sensitivity in adults with knee OA. Additional stimulation sessions or stimulation durations are needed to refine this novel approach for pain neuromodulation.

13. Fay Wright RN, PhD, APRN-BC

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A Pilot Study Exploring Daily Morning and Evening Fatigue and Sleep Disturbance Variability in Women Newly Diagnosed with Breast Cancer During Their First Cycle of Chemotherapy

Abstract

Background: For women with breast cancer, morning and evening fatigue and sleep disturbance are prevalent and distressing symptoms experienced during chemotherapy (CTX). Higher more persistent levels of morning and evening fatigue limit patients' ability to tolerate treatments and participate in daily activities. A large amount of inter-individual variability in morning and evening fatigue and sleep disturbance has been identified at different points during CTX. No known studies have evaluated inter-individual variability in these symptoms during the first CTX cycle. Inflammation is a key underlying mechanism of morning and evening fatigue and sleep disturbance. Exploring the functional effect of genes on the inflammasome pathways (e.g., CARD6, IL1, NLRC4, NOD2) may generate hypothesis for future studies designed to differentiate the contributions of innate versus CTX-induced inflammation on inter-individual variability. Determining patterns of inter-individual variability between morning and evening fatigue and sleep disturbance will inform the timing of targeted interventions to prevent the development of morning and evening fatigue symptoms.

Aims: In a sample of in CTX-naïve women (N=12), diagnosed with infiltrating interductal carcinoma: 1) Explore the daily trajectories of morning and evening fatigue and sleep disturbances; 2) Explore the association of differentially associated genes on the inflammasome pathways with the daily trajectories of morning and evening fatigue and sleep disturbances; 3. Determine the feasibility of recruiting newly diagnosed women with breast cancer.

Methods: Using a prospective longitudinal repeated measures design, PROMIS® web-based assessments were administered twice-daily (morning fatigue and sleep disturbance within 30 minutes of awakening, evening fatigue at bedtime). Whole blood for RNA analysis was collected at the first and last day of the cycle. The PROMIS t-scores were graphically examined to characterize individual patterns. RT2 Profiler PCR Array determined changes in gene expression. Scatter plots visualized 2-fold changes in gene expression.

Results: Patients demonstrated unique patterns of morning and evening fatigue and

sleep disturbance scores. Higher levels of sleep disturbance were not consistently noted with higher levels of morning or evening fatigue. Differential expression in 20 genes was associated with inter-individual variability.

Conclusions: The complexity of morning and evening fatigue and sleep disturbance patterns warrants further study with a larger sample.

14. Jacqueline Vaughn BSN, RN, CHSE

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Advancing Symptom Science with Mobile Apps & Wearables for Pediatric Blood & Marrow Transplant Patients

Abstract

Background: Pediatric Blood & Marrow Transplant (PBMT) patients experience significant symptom distress. Mobile technologies can be leveraged to collect and monitor *patient generated health data*, improve our understanding of these symptoms and foster the development of precision health strategies. However, limited research exists integrating mHealth technology into PBMT symptom management.

Aim: Explore the feasibility, acceptability, and usability of using a PBMT specific mHealth application (app) to collect and monitor symptom data and wearable technology (Apple Watch) to measure objective data such as heart rate and activity.

Research Design/Methods: An exploratory mixed method design began in October 2017 to monitor PBMT symptoms for 20 patients using real-time data from: 1) a self-developed app specifically for PBMT to collect subjective symptom data; and 2) an Apple watch to collect physiologic measures such as heart rate and daily step count. Patient-Report Outcomes Measurement Information System (PROMIS) surveys are used to collect monthly symptom data. Acceptability and usability are assessed through satisfaction surveys and interviews at study completion.

Results: We have enrolled 9 patients to date with study completion expected in 2018. The overall mean number of hours participants wear watch is 8 hours per day and the overall average frequency of daily charting in the app is 52%. Most common symptoms recorded were fatigue and pain. Survey and interview data show participants find devices acceptable and usable.

Discussion: Preliminary findings suggest feasibility of using the mHealth devices is strongly correlated to the patient's post-transplant stage and is facilitated by caregiver participation with device management (reminders to wear watch and record in app). Patients reported satisfaction and ease of use with devices.

Conclusion: These findings indicate using mobile devices may be useful methods to collect patient generated health data. Data from these devices may improve our understanding of symptoms these patients experience. Precision health strategies based on these data may enhance symptom management for PBMT patients.

15. Ryan J Shaw PhD, RN, Jacqueline Vaughn BSN, RN, CHSE

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Advancing Diabetes Self-management with Mobile Technology and Data Visualizations

Abstract

Background: Diabetes is a chronic illness requiring daily monitoring and that poses significant self-management challenges. Because the vast majority of diabetes care occurs in outpatient settings, mobile health technologies have potential to improve care delivery and health outcomes. Mobile health technologies can be leveraged to collect and monitor real-time *patient generated health data* which may improve patients' self-management and foster the development of precision health strategies. However, limited research exists integrating this technology into diabetic self-management care.

Aim: Examine the feasibility and utility of having adults with Type 2 diabetes self-monitor multiple types of diabetes-related data (blood glucose, weight, physical activity, medication adherence) using mHealth technologies (wireless glucometer, wireless scale, accelerometer) over 6 months.

Research Design/Methods: An exploratory mixed method design began in March 2017 with 60 adults with type 2 diabetes using data from a: 1) wireless glucometer to collect blood glucose; 2) wrist-worn accelerometer to collect daily step count; 3) cellular scale to record daily weight; and 4) bi-weekly text message surveys to monitor medication adherence. Data were collected over 6 months. Acceptability and usability are assessed through one on one interviews at study completion. Additionally for the interviews, participants are provided data visualizations that present the trajectories of their own data over the 6 month time-frame.

Results: Mobile health data collection finished in 5/2018. We are currently conducting interviews with participants. The data visualizations facilitate discussion of the challenges participants face in diabetes self-management. Patients report satisfaction sharing these data with their providers.

Discussion: Preliminary findings suggest patients find the technologies feasible and usable. Importantly, patients report the technologies increased awareness of their diabetes and facilitated better self-management strategies.

Conclusion: These findings indicate using mHealth technologies may be useful methods to improve self-management and health outcomes for diabetic patients. And visualizing the data in a variety of ways can help facilitate self-management.

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Qualitative Coding and Analysis of Conversations in a Virtual Environment: Developing Methods to Gain Insight into Real-time Interaction and Support

Abstract

Background: Virtual environments (VEs) are uniquely positioned to capture and collect qualitative data from participants who interact to obtain real-time disease-specific knowledge and support. In VEs, participants interact with others via voice (e.g., they speak to others with a microphone), sound (e.g., they hear others), movement (e.g., they use their keyboard to navigate around the 3D space), and sight (e.g., they see others). Yet how participants engage in interactions in a VE, and to what extent the VE mediates these interactions, remains unknown.

Research design: We completed a secondary analysis of qualitative data collected from adults who interacted in a VE to obtain type 2 diabetes (T2D) education and support. Participants (n = 20) and diabetes educators (n = 4) interacted during twice weekly education and weekly support sessions for each participant's study enrollment period of 6 months.

Methods: Our analysis went beyond separately examining the interactional behaviors (e.g., turn-taking) and the content (e.g., topic of discussions) and included the influence of the VE in sequential interactions. Results We developed a new way of examining synchronous conversations in the VE using a combination of content, conversation, and discourse analysis to describe: what individuals discussed in an interaction, how individuals engaged in specific turn-taking behaviors, and to what extent the VE mediated the interaction. As social interaction is a multi-dimensional concept, we used our collective expertise about social interactions in face-to-face environments and human-computer interactions to develop a codebook that contained concepts from interdisciplinary and relational literature. Discussion We noted that conversations focused on living with T2D, engaging in T2D selfmanagement, and learning self-management techniques. The words participants used became an index for their experiences living with, and self-managing their T2D, in addition to providing information on their experience in the VE. Conclusion With the increase in Internet interventions that facilitate collection of real-time conversational data, we provide a methodology that facilitates the coding and analysis of these complex data. These synchronous interactions among individuals can be analyzed to examine how the participant's interactions change over time (conversation and discourse analysis) and how the content discussed changes (content analysis) over time.

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NIH Intramural Research Program

My STORI -- A Symptom Tracking and Reporting Instrument Mobile Application for Central Nervous System Cancer Patients

Abstract

Background: Managing symptom burden and its impact on the quality of life is an integral part of central nervous system (CNS) cancer patient care. However, keeping track of symptoms and their management is typically done through ad hoc means. Furthermore, reporting is often limited to completing survey instruments as part of the patient follow-up. While general-purpose mobile apps that track medical symptoms exist, they are not geared toward managing and recording the experience of patients with cancer. Cancer-specific apps are emerging but may not cover the entire range of symptoms in patients with CNS cancers.

Hypothesis: A mobile app can provide a novel and convenient way of recording, inspecting, and reporting key aspects of CNS cancer patients' experiences, and empower the patients and their caregivers to take an active role in their care.

Methods: We used two open source frameworks introduced by Apple to enable development of iOS operating system apps for medical research and personal care -- ResearchKit and CareKit -- to develop a mobile app framework for the CNS cancer context. Existing validated symptom reporting instruments, qualitative interviews, and evidence-based symptom management tools were used in the framework.

Results: We developed the My STORI mobile app to center on the experience of brain and spine cancer patients: patients and their family members can assess daily symptoms and impact and record any actions that were taken to mitigate them. Summaries of how these measures have evolved over time can be displayed in a series of plots and compiled into reports shareable with the care team. **Discussion:** The My STORI app is based on research instruments that reflect the knowledge accumulated through years of clinical research in neurooncology. The application possesses the potential to promote self-care, facilitate symptom management, as well as facilitate intuitive, frequent, and convenient collection of invaluable clinical-outcome research data.

Conclusion: The My STORI app is an innovation in patient care inspired and guided by years of outcomes research, and tells an important aspect of the story of brain and spine cancer patients.

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Adolescents with Epilepsy and their Families' Perceptions of using a Seizure Detection Device

Abstract

Background: Epilepsy is one of the most common neurological problems in adolescence. The nature of epilepsy, including the unpredictability and effects of seizures, impedes the normal developmental milestones of the adolescent with epilepsy (AWE). Anxiety about seizure safety contributes to poor quality of life (QOL) for AWE and their families. A seizure detection device called SmartWatch is a non-invasive

wristwatch that detects and evaluates movements and alerts caregivers about potential seizures.

Hypothesis: It was hypothesized that using a seizure detection device would improve QOL in AWE and their family.

Methods: This qualitative data was part of a mixed methods study where 10 AWE used the seizure detection watch for 6 months duration. At completion of the study, 9 of the AWE, and a family member, were interviewed using a semi-structured, phone interview to enquire about their experience with using the watch.

Results: Study participants ages ranged from 14-21 and each had a history of generalized, tonic-clonic seizures. Qualitative analysis of the transcribed interview data identified adolescent themes: *It's A Comfort Kind of Thing*, feeling increased safety and security when wearing the watch but using it mostly to reassure their caregivers; and *Not all That It's Cracked-up to Be*, feeling that wearing the watch was just another burden. Caregivers themes included: *This is the Answer*, describing relief when given the seizure detection device and how it allowed them to give their AWE more freedom; and *Great and Frustrating*, learning what the watch had to offer and bargaining with their AWE to wear it when most necessary. Both AWE and caregivers reported multiple technical difficulties with the overall *Watch Performance*.

Discussion: Despite the difficulties, AWE and their caregivers were receptive to using the seizure detection device. Seizure detection devices have the potential to greatly impact on the QOL for AWE and their families by decreasing anxiety about seizure safety and normalizing the typical adolescent developmental task of gaining independence from their families.

Conclusion: This is the first study of the impact on QOL of the SmartWatch seizure detection system. Improvements in the watch design and technology are needed to increase its effectiveness.

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Stakeholder Engagement Towards Development of a Novel Nurse-driven Continuous Predictive Analytics Monitoring Model in a Surgical-Trauma ICU

Abstract

Background: Continuous predictive analytics monitoring synthesizes data from a variety of inputs into a risk estimate that clinicians can visualize in a streaming environment. For continuous predictive analytics monitoring to be adopted in practice, developers of predictive algorithms must engage with users to develop and optimize models that can be used in real-life practice settings. Our overarching hypothesis is that the development of nurse-driven models can be routinely implemented to enhance adoption of continuous predictive analytics monitoring in clinical workflow. This abstract presents a proof of concept that stakeholder-driven design elements can be used to identify and develop novel predictive analytics monitoring models that are meaningful to end users.

Research design/methods: This study utilized immersive stakeholder engagement among point-of-care clinicians in a surgical trauma intensive care unit (ICU) unit where there was a streaming display of continuous predictive analytics modeled to detect early signs of clinical deterioration. This analysis employed a longitudinal qualitative descriptive design using both focus group and individual interviews as well as clinical observations. Data from the 14 individual interviews (n = 7 RNs) and five focus groups (n = 26) were included in the final analysis.

Results: While the original predictive analytics models based on prediction of clinical deterioration (i.e. emergent intubation, hemorrhage, sepsis) were utilized in the ICU, point of care clinicians requested additional models that could be adopted in routine practice. These suggestions included: models predicting extubation readiness, pain management, nurse-sensitive quality measures, and patient acuity for nurse staffing. Through iteration between the analytics team and nurses, it was decided that extubation readiness would be the first nurse-driven model of focus. An extubation readiness model was successfully developed (presented elsewhere) and is awaiting rollout and implementation.

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Leveraging Mhealth and Wireless Sensing to Empower Patients and Family Caregivers in the Safe and Effective Management of Cancer Pain

Abstract

Background: Poorly managed cancer pain has serious ramifications, negatively affecting sleep, adherence to treatment, mood and overall quality of life—for both patients and their caregivers. When patients with cancer are weakened by the effects of treatment or progression of disease, it is family caregivers who commonly assume primary responsibility for managing complex symptoms. Complicating cancer pain

management is the reality that opioids, a key class of medications used to control serious cancer pain, are also potentially drugs of misuse. A critical gap is leveraging wireless and mobile technology ('mHealth') to support family caregivers to safely and effectively manage distressing symptoms in the home environment. This research aims to optimize a home-based mHealth sensing system to understand pain as a dynamic phenomenon between patient and caregiver dyads in the home context.

Hypothesis: The Behavioral and Environmental Sensing and Intervention for Cancer (BESI-C) system is a package of tailored wireless and mobile sensing technologies set-up in a patient's home designed to unobtrusively and reliably collect behavioral, physiological, and contextual data. We hypothesize that BESI-C will be acceptable to patients and family caregivers and will reliably record desired variables related to cancer pain.

Research Design/Methods: This multi-phase pilot study utilizes a participatory approach. Phase I collects end-user design input via semi-structured interviews with patient and family caregiver dyads. Phase II involves BESI-C system optimization and deployment in dyad homes. Data collected during Phase II will be analyzed to validate the ability of the sensing modalities to infer/detect behavioral events and environmental contexts and to examine patterns, relationships, and concordance between actively and passively collected data.

Results: Preliminary results from Phase I reveal dyads are highly receptive to the components of BESI-C and have limited concerns regarding the system in their home.

Discussion: Dyads identify managing pain as a complex problem influenced by various environmental contextual factors and are eager for more home support.

Conclusion: Developing personalized models and tailored approaches to cancer pain management can reduce suffering and empower patients and family caregivers. Significant potential exists for BESI-C to support patients with advanced cancer, particularly those who live in un

Discussion and conclusion: For predictive analytics to be successful, developers must engage with nurses and other clinicians who are the key users of streaming visual surveillance models. Nurses readily identify model typologies that they deem relevant for their practice. More study is needed to determine how this approach impacts adoption.

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Informing SMaRTlyMotivate Design: Theory Foundation and Interdisciplinary Collaboration

Abstract

Background: Older adults with type 2 diabetic kidney disease (DKD) transition to self-management (SM) by adapting and adopting behaviors of inquiry and continued learning. DKD, a model of multiple chronic conditions including hypertension and heart

disease, requires intensive SM education and counseling for healthful lifestyle actions. Older adults often turn to the vast array of web information only to discover opinions and unclear evidence. Using technology to support query of expert reviewed websites and to access relevant SM tools (i.e. goal setting, diary, etc.) offers a solution to the dilemma of what to consider in self-management planning.

Hypothesis: A theoretically founded education and counseling activates self-management of a healthy lifestyle when the motivational interviewing (MI) component is delivered through mobile technology

Methods: The SMaRTlyMotivate app's focus is to provide self-management support for healthy eating and physical activity. At the onset the project team focused upon explicating the theory for a user friendly human–techno interface, SM behavior, and learning alongside the evidence for healthy eating and physical activity. Storyboard flowcharts were progressively modified to specify design features such as labels, branching logic, and additions. The MI statements developed in 4 sessions by undergraduate volunteers used the following criteria: (a) five kinds of change talk, (b) change talk strategies- desire, ability, reasons, need, commitment, and taking steps, and (c) ten change processes.

Results: Clarifying theory foundation and storyboarding led to a build using a cross platform application for use on notebooks, smartphones, and other devices.

Discussion: As developed to date, the SMaRTlyMotivate app serves as the base prototype. Mobile applications developed systematically through interdisciplinary collaboration catalyze future think by conceptualizing add-on functions and innovations.

Conclusion: Theory entailed application of engineering good technology design of simplicity, sameness, and conformity across all platforms, as well as theories from nursing, psychology and education, specifically self-management, health behavior change, learning, and transition perspectives. Interdisciplinary collaborative synergized a better build. Over 115 MI phrases were developed. A future study design entails evaluating the feasibility of the SMaRTlyMotivate application to promote SM in persons with Type 2 DKD.