mHealth For Fatigue, Pain, & Depression: A Tailored Symptom Self-Management System In Underserved Populations Living With HIV/AIDS

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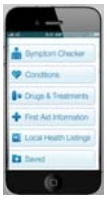
WHAT WE ARE DOING?

- Grant submission for the development and testing of a mHealth-based text, audio, and graphical application.
- Delivering a symptom management intervention for persons living with HIV that integrates text, audio, and graphic animation impages as part of a targeted and tailored message delivery process - The MASS System.
- The MASS is designed as a reinforcement tool to promote symptom self management for people living with HIV.

WHAT ARE WE DOING?



WHY WE ARE DOING THIS?

- Targeted and tailored interventions for primary and secondary HIV infection symptom prevention/amelioration are needed – message differentiation
- Racial and ethnic disparities
  - In NYC and Northern NJ, more Hispanics and Black - non-Hispanics are likely to have an AIDS diagnosis in less than 12 months after being diagnosed HIV, at 42% and 38% respectively. (2006 HIV surveillance)
  - 53% of AIDS related deaths were among Black - non-Hispanics, 28% among non-Hispanic-Whites. (2006 HIV surveillance)
- Substance abuse
  - Individuals with co-occurring substance abuse problems are often report experiences of increased antiretroviral therapy toxicities and side effects of medications.

WHY WE ARE DOING THIS?

- PLHIV continue to experience multiple physical and psychosocial symptoms, either from the disease itself or from its treatment and side effects and has a detrimental effect on HRQoL. (Hudson, Kirksey, et al, 2001)
- Recent studies state that pain and other physical and psychological symptoms such as a lack of energy, numbness, worry and felling sad *continue to be commonly reported* among ambulatory people living with HIV (Merlin, Cen, Praestgaard et al, 2012; Wantland, Mullan, Holzemer, Portillo, et al. 2011) .
- Even those who have not experienced opportunistic infections or progressed to AIDS may experience a variety of symptoms (Willard, Holzemer, Wantland, 2008).
- Health care providers (physicians and nurses) are not necessarily good judges of patients' symptoms (Reilly et al, 1999).
- The patient is the gold standard for understanding the symptom experience (Holzemer, 2002).

WHY ARE WE DOING THIS?

- ***Still*** few successes in sustaining long-term behavior change interventions in Web/Computer – based Interventions. (Wantland et al, 2004; Ramadas, Quek et al 2012)
- Targeted & tailored strategies may help to sustain use of the system and improve patient symptom status. (Kreuter, 2000)
- Sustaining self management behaviors – ability to self-manage the symptoms of HIV-related illness decreases symptom severity (Holzemer et al, 2001) , improves social support,(Gustaffson et al, 2001), improves quality of life (Cunningham, 2002), and improves engagement with health care. (Bakken et al , 2000; Ruland et al, 2006)
- Need for improved articulation of the type and frequency of self care strategies used and effect on symptom change. (Wantland et al, 2010)

The Symptom Experience

- Multiple, often simultaneously occurring symptoms
  - Illness related and/or
  - antiretroviral medications related
- Often transitory,
- Have individually moderating influences that affect an individual's perception of intensity, impact, and degree of bother.
- Symptoms may restrict a person's ability to perform their daily living tasks.

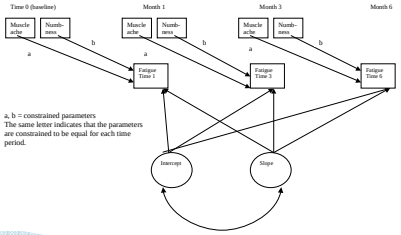
- People living with adverse HIV-related and treatment-related symptoms seek care from their providers when one or more symptoms become too intense for self management.

  In the meantime –

- Many patients cope with adverse symptoms – struggling to find self-care solutions that ameliorate the frequency and intensity of the symptoms.

Longitudinal Lagged and Concurrent Relationships Between Fatigue, Lower Extremity Neuropathy, and Muscle Aches in Individuals With HIV/AIDS (Wantland, Mullan, Portillo, Holzemer, McGhee, Slaughter, J. Pain & Symptom management, 2011)

- Managing multiple symptoms and maintaining optimal quality of life have, become the major daily tasks for people living with HIV/AIDS.
- 6 month repeated measures study, N=243
- Multilevel, logistic regression growth models revealed significant relationships between muscle aches and fatigue over six-months (OR=1.8, $p \leq 0.05$).
- Significant relationships between numbness and fatigue were also noted over 6 months (OR=2.7, $p \leq 0.05$).
- Combined model with both muscle aches and numbness on fatigue showed no significant relationship with fatigue (OR=1.21, $p > 0.05$)
- A temporal relationship between numbness and fatigue in this sample over 6-months (OR=2.48, $p \leq 0.05$).
- A depression diagnosis was significantly associated increased report of fatigue (OR=3.60, $p \leq 0.05$).



HIV Self Care Symptom Management

Grounded in Rigorous and Iterative Research

A MANUAL FOR SELF CARE SYMPTOM MANAGEMENT STRATEGIES

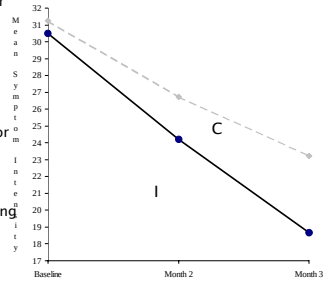
- Conceived and developed by pre and post doc graduate students at the UCSF School of Nursing in 1999.
- Help vest patients and their families with some degree of responsibility and control with their illness.
- Empowers those living with and closest to the disease to make decisions that enhance their well-being.
- Free and available in eight languages (English, Afrikaan, Sesotho, Siswati, Zulu, Spanish, Russian, and Chinese)

USE & VALIDATION OF THE SCSM STRATEGIES & MANUAL

- Numerous cross-sectional and descriptive studies and dissemination on strategies used for fatigue, neuropathy, anxiety, fat redistribution changes, depression, prayer as a self care strategy, among many others
- Three month, Longitudinal RCT – 2006-2007

USE AND VALIDATION OF THE SCSM MANUAL

- Compared symptom management manual with self care strategies for 21 common symptoms to a basic nutrition manual.
- Evaluating symptom frequency change over time
- 775 person, repeated measures study, 2006 – 2007.
- The effects of symptom-specific strategies were statistically superior to general nutrition
- Significant predictors for higher symptom intensity were protease inhibitor-based therapy, comorbid illness, and being Hispanic receiving care in the US.
- Comorbid illness & Hispanic were significant predictors for steeper decreases in symptom status over time.
- The symptom manual had a significantly higher helpfulness rating and used more frequently compared to the nutrition manual.



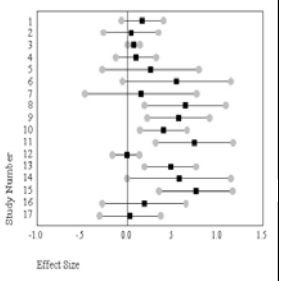
(Wantland, Holzemer, Moezzi et al, 2008)

Are Face to Face and Web Based Interventions Comparable?

Evidence

- Evidence supports that Web-based interventions improve behavioral change outcomes.
- Generally small to moderate effect sizes (0.2 to 0.6)
- Interventions directing participants to relevant, individually tailored materials reported longer Web site sessions per visit and increased visits.
- Sites incorporating a chat room demonstrated increased social support scores.

Study #, Primary Author, Study Focus-Effect Variable	ES
1. Andersson, et al. Pre-post-follow up tinnitus reaction questionnaire	.16
2. Celio, et al. Change in Body Shape Questionnaire	.04
3. Christensen, et al. Goldberg Depression Scale-Mean Module 1 scores, gender combined	.07
4. Clarke, et al. Depression (CES-D) score change	.09
5. Flatley-Brennan, HIV Use of ComputerLink networking -Slower health decline	.25
6. Gustafson, et al. CHESS-HIV Change in participation in healthcare	.54
7. Harvey-Berino, et al. Weight Loss Maintenance – pounds lost	.15
8. Harvey-Berino, et al. 18-month weight loss maintenance	.64
9. Horner, et al. Change in knowledge of asthma-treatment	.57
10. Krishna, et al. Change in asthma knowledge scores in children	.40
11. Lange, et al. Change in impact of event intrusion and avoidance combined score	.75
12. Marshall, et al. Change in physical activity	-.01
13. Oenema, et al. Tailored Nutrition Education – Intention to change diet	.47
14. Ritterband, et al. Pediatric encopresis behavior change in bowel habit accidents	.57
15. Southard, et al. Minutes of exercise	.74
16. Strom, et al. Change in Headache Disability Inventory	.19
17. Winzelberg, et al. Reducing risk factors for eating disorders - change in body shape questionnaire scores	.03



Web-Based Intervention

- Study designs included one time web participant to usual care health outcome studies, self-paced interventions, and repeated measure interventions
- Repeated measures studies ranged from 3 to 78 weeks.
- An average loss of about one quarter of the participants over time in both intervention and control groups.
- Methods to ascertain the use of a web site included count of visits to various pages, paths to tracing links and usage patterns of the user.
- Average session time was 21.6 minutes
- Time spent per session/per person ranged from 4.5 to 45 minutes
- Session logons per person per week ranged from 2.6 over 32 weeks to 1008 logins per person over 36 weeks

Benefits of Interactivity

- Web-based information sharing can improve patient safety and knowledge sharing for both the patient and provider.
- Evidence of greater disclosure of sensitive behaviors such as alcohol and drug use and sexual risk behaviors when assessed by computer than when assessed by a face-to-face interview. (Gerbert et al, 1999)
- Participants in a computer-administered interview may perceive a web-based survey as more neutral and private than either face-to-face interview or paper-based survey, potentially increasing patients' willingness to disclose medication nonadherence.(Bangsberg et al, 2002)

Personal Health Records

Linking Patient Portal Access with Self care symptom management

Personal Health records (PHR) access via a portal

Save time – and paperwork for HCP and Social Work for Client needs

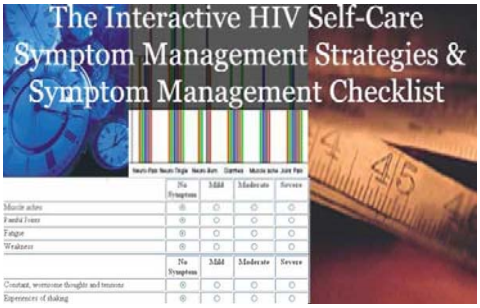
Improve the quality of your care
- more complete history
- Connects others involved in your care

Manage dependents' care and caregivers management of patients care (as necessary)

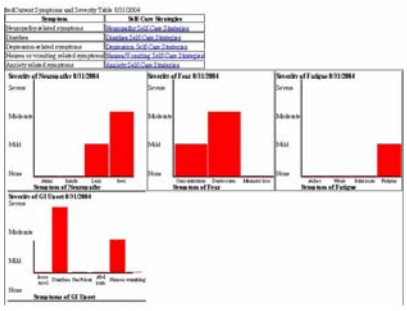
Meaningful Use Incentive program – Stage II includes a PHR use provision – will lend to increased consumer use.

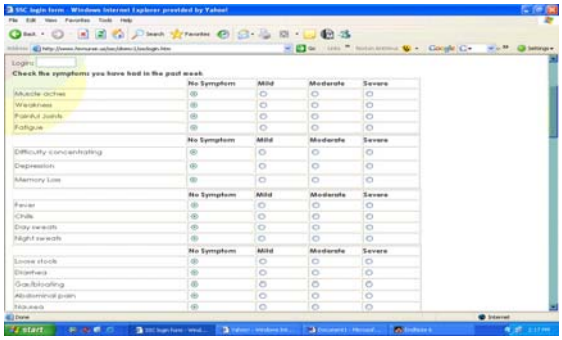
Testing Interactive Web-based And Mobile HIV Symptom Self-care Applications

The development, testing, and feasibility research funded by:
P30NR 010677 03S1SC2 (Wantland, PI 2010-11)
and
P30 NR010677(Bakken)



- Self-monitored symptom checklist that graphically and tabularly tracks and trends symptoms over one or more time periods





Symptom Self-management Strategies

Caring for your HIV-related problem: **Neuropathy**

PROBLEM: Pain, tingling, burning or numbness in your hands, arms, feet or legs (peripheral neuropathy).

This problem may be due to HIV infection, HIV medications, drugs, or other health problems.

TREATMENT: There are many ways to treat this problem. The first step is to contact your physician or nurse. By working together, a treatment plan can be developed for you. This plan may include prescription or non-prescription medications, counseling, or other treatments.

SELF CARE: Here are some strategies you may try to help you feel better.

- Wear loose fitting, comfortable shoes with well-padded soles.
- Avoid long periods of standing or walking.
- Consider soaking your feet or hands in ice water until you feel better or for no more than ten minutes.
- Consider wearing white, cotton socks to reduce wetness.
- Try stress-reducing activities (e.g., meditation, massage, etc).

Guidelines for the symptoms of

Anxiety	Depression	Diarrhea	Fatigue	Fever
Forgetfulness	Insomnia	Lipodystrophy	Nausea	Neuropathy
Night Sweats	Shortness of Breath	Skin Rash/Dermatitis	Unplanned Weight Loss	Vaginal Problems

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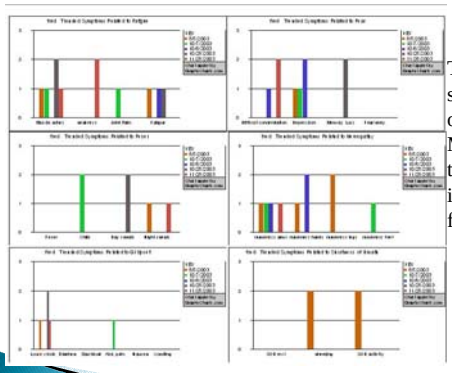
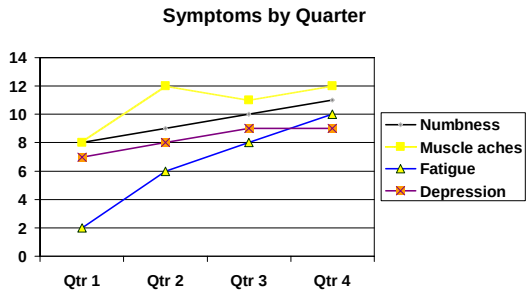
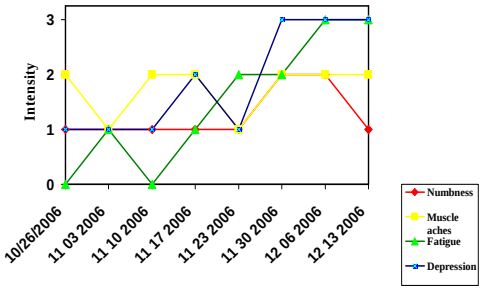


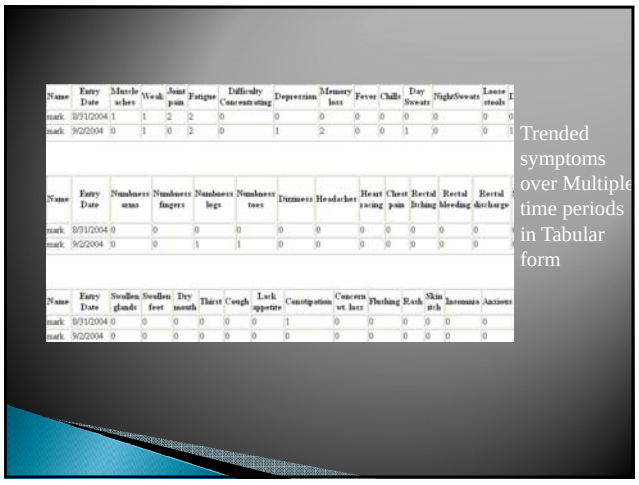
Trended symptoms over Multiple time periods in Graphic form

Symptom Trend by Quarter



Symptom Trend by Week





Name	Entry Date	Muscle aches	Weak	Joint pain	Fatigue	Difficulty Concentrating	Depression	Memory loss	Fever	Chills	Day Sweats	NightSweats	Loose stools
mark	8/31/2004	1	1	2	2	0	0	0	0	0	0	0	0
mark	9/2/2004	0	1	0	2	0	1	2	0	0	1	0	0

Name	Entry Date	Numbness arms	Numbness fingers	Numbness legs	Numbness toes	Dizziness	Headaches	Heart racing	Chest pain	Rectal Itching	Rectal bleeding	Rectal discharge
mark	8/31/2004	0	0	0	0	0	0	0	0	0	0	0
mark	9/2/2004	0	0	1	1	0	0	0	0	0	0	0

Name	Entry Date	Swollen glands	Swollen feet	Dry mouth	Thirst	Cough	Lack appetite	Constipation	Concern wt. loss	Flushing	Rash	Skin itch	Insomnia	Anxious
mark	8/31/2004	0	0	0	0	0	0	1	0	0	0	0	0	0
mark	9/2/2004	0	0	0	0	0	0	0	0	0	0	0	0	0

Trended symptoms over Multiple time periods in Tabular form

Content and Functional Assessment of a HIV/AIDS Symptom Self Management Tool

(Wantland, 2009. Studies in Health, Technology & Informatics)

- How to define the symptom (agreement on definition) (4)
  - i.e. What is fatigue?
  - Diarrhea vs. loose stools
  - Order of the symptom on the list
- "We tell them what symptoms they have, they don't tell us" (1)
- Strategies are helpful (5)
- Are they validated? (3)
- Results useful for patient to bring in at time of visit (7)
- Strategies useful as discussion tool with patient (8)
- Use data base as a minimum data set for multiple sites
  - Identify patients uniquely by sites
  - Opportunity to specialize data set for unique data needs
- Most frequently accessed strategies in beta sample
  - Fatigue (8); Neuropathy (7); Depression (7); Anxiety (4)

Perceived Benefits of the Web Applications

- Potential to provide empirical symptom change data on a monthly, weekly, daily or intra-day basis.
- Improved HCP and patient interaction quality
- Symptom amelioration
- Information may be useful for return-to-work assessments – time of day trending or nausea occurs after meals or taking medications.
- Applications may help individuals starting a new medication regimen, when medication side effects are most likely to occur.
- Seeing a trend may help providers allay the concerns of the patients or take further action as needed.

The Digital Divide and mHealth Applications

- Study attrition rates are lower in those who maintain access than those who ceased access.
- Include individuals who have little or no access to other sources for their health care and thus may benefit most from e-Health applications.
- Crucial that methods continue to be refined and validated in order to accurately determine the efficacy of eHealth in the populations it has the potential to reach.
- The digital divide adds to the disease disparities in various communities as the empowerment associated with Internet access (including messaging communication) potentially increases patient-clinician interactions.
- The Internet & mHealth can be used to help educate and inform patients and improve their understanding and their motivation to make changes that would improve their healthcare.

Security and Information Confidentiality

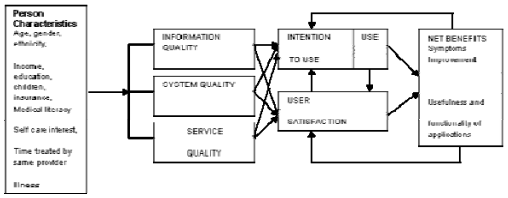
- Security maintained using a session cookie,
  - identifies the client upon entry of his/her study ID and self deletes when the user leaves the system (a session).
- Active server pages can be designed to delete any reserved memory (cache) needed for the operation of the web based data entry pages upon logout.
- Prevents any Internet tracker from tracing user history to these secure web sites.
- Further security can be obtained by using encryption technology during online periods, which prevents a tracker from reading data in transfer

The ViP System

Video Podcasting

- Developed and tested a Web-based video application
- Delivering a symptom management intervention for persons living with HIV that integrates video podcasting as part of a targeted and tailored message delivery process - The ViP System.
- The ViP is designed as a reinforcement tool to promote symptom self management for people living with HIV.

FRAMEWORK



The Information System Success Model (Delone & McLean)

DEVELOPMENT (based on Kreuter, 2000)

Designing feedback:

- Feedback is designed by the research team based upon our sources of evidence.
- 28 commonly reported symptoms that cluster into six frequently reported symptom clusters
- Symptom Clustering – muscle aches, weakness, joint pain, fatigue, unable to concentrate ⇒ Fatigue (Corless et al, 2002; Voss et al, 2008, Wantland, 2011)
- Numbness/tingling of arms, hands/fingers, legs, feet/toes ⇒ Neuropathy (Nicholas et al, 2006, 2010)

DEVELOPMENT

Writing tailored messages:

Scripts vary based on the initial symptom entry and a consecutive increase in symptom intensity, decrease in the symptom intensity, a severe report of a symptom, reporting use of street drugs, alcohol, marijuana, cigarettes.

DEVELOPMENT

Automating the tailoring process

- Now using HTML-5 ASP.net for database entry and page reporting from the mobile device.
- Windows sql Server and Standard Query Language are used for database manipulation.
- The pre-recorded text, audio and graphical messages reside in a separate database from data and play upon feed request.

HEURISTIC, & USABILITY TESTING

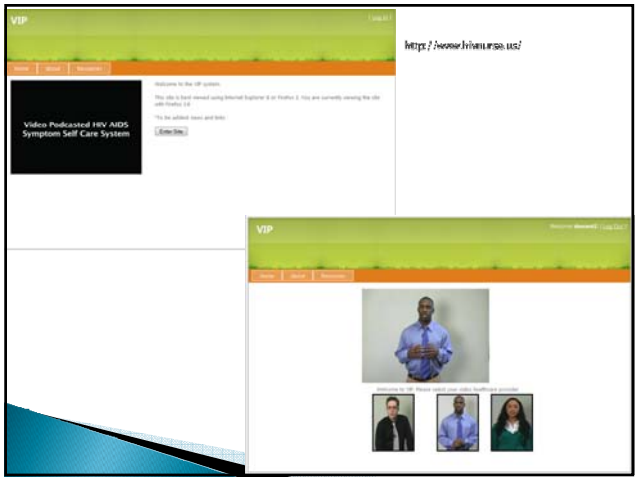
- ViP prototype was designed as a stand alone system
- Iterative refinement the ViP Symptom Self-Management prototype based on usability results. Usability experts' perceptions of the usability of the ViP Symptom Self-Management prototype.
  - PLWH's perceptions of the usability of the ViP Symptom Self-Management prototype.
  - PLWH's ratings of information quality, system quality, and behavioral intention to use the ViP Symptom Self-Management prototype.

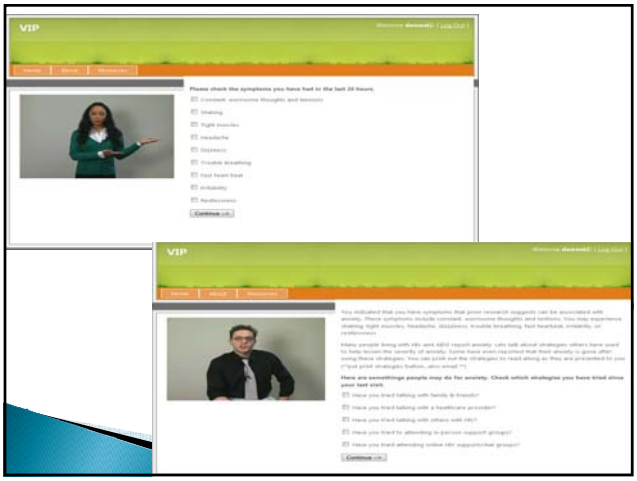
Testing the Applications to Realize the Benefits

Video demonstration

Three Scenarios:

1. Initial visit
2. Return visit – symptom(s) worsening
3. Return visit – symptom(s) improving





FEASIBILITY TESTING

- Conduct of a three-month repeated-measures randomized controlled feasibility study to obtain effect size estimates between the Intervention and Control groups for:
- Dependent variables of symptom frequency and intensity, perceptions of healthcare provider engagement, and QoL change over time. Independent variables include patient demographic and illness characteristics.
- Information system success factors (measured at the final assessment period)

Formally represent patient symptom terms and self-management strategy terms using standardized terms and codes from the Unified Medical Language System (UMLS) and integrate into the ViP Symptom Self-Management prototype.

What proportion of patient symptom terms can be represented by UMLS terms and codes? What proportion of self-management strategy terms can be represented by UMLS terms and codes?	Descriptive, nurse expert sample (n=5 & n=3); sample of symptom and self-management terms (n=about 200 for cancer and HIV)	% match between symptom terms and standardized terms from UMLS, % match between self-management strategy terms and standardized terms from UMLS	Descriptive statistics, inter-rater agreement (Kappa, ICC)

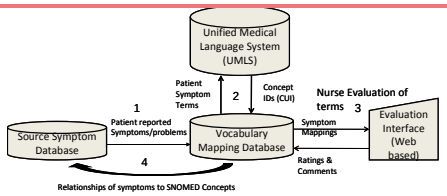
Representation of Patient Terms for Symptoms and Health-Related Problems Using SNOMED CT. Wantland DJ, Ruland C, Nordberg SJ, Bakken S. (2010) Medinfo. Capetown, South Africa .

Rationale:
Differences in patient and professional terminologies for symptoms and health-related problems can result in miscommunication and misunderstanding.

Source terminology comprised patient terms for symptoms and health-related problems that were collected from a support system for cancer patients. The target terminology was Systematized Nomenclature of Medicine – Clinical Terms – (SNOMED-CT), a concept-oriented health care terminology containing more than 310,000 unique concepts and more than 1.3 million links or relationships between them.

7 oncology nurses evaluated 107 patient self- reported symptoms or problems term.
3 HIV Nurses evaluated 72 patient self reported symptom or signs of HIV-related illness

The Vocabulary Mapping Process



1). Importing the symptoms and synonyms from the source symptom database using XML export functionality; 2). Matching the concepts in the UMLS using multiple searching methods; 3). Nurses evaluation of the mappings through the Web application; and 4). The storage of the evaluated concept mappings into the source symptom database.

Single Concept Patient Term CUI Match (n=240)

Patient Symptom Description	Concept term (CUI) Number	Concept description	Mean rater CUI match score
General body pain	0281856	Generalized aches and pains	7
Headache	0018681	Headache	7
Fever	0015967	Fever	7
Chills	0085593	Chills	7
Grief	0018235	Grief reaction	7
Weight gain	0043094	Weight gain	7
Painful urination	0013428	Dysuria	7
Stomach pain	1278920	Entire stomach	4

Ambiguous/Non-represented CUI Match (n=23)

Patient Symptom Description	Concept term (CUI) Number	Concept description	Mean rater CUI match score
Gas/bloating	1541907	Beta-hemolytic Streptococcus, group A	2
Difficulty finding meaning in things I do	0444504	Mean	2
Worried I won't get well	0205170	Good	2
Difficulty feeling inner peace	0205102	Intrinsic	2
Difficulty finding meaning in things I do	0263541	Equine laminitis	1
Difficult getting enough support from family/friends	0004002	Aspartate transaminase	1
Bathing/grooming/ Dressing/dressed	0004002	Aspartate transaminase	1
Not able to participate in conversation	0439836	Conversions	1
Having questions about my financial situation	No SNOMED Match Found		

Multi-Concept *CUI Match (n=70 representing 267 CUI matches)*

Patient Symptom Description	Concept term (CUI) Number	Concept description	Mean rater CUI match score
Worried about my relationship with my partner	0682323	Partner in relationship	7
Sweats/ night sweats/hot flashes	0028081	Night sweats	5
Sweats/ night sweats/hot flashes	0020040	Menopausal hot flushes	5
Trouble breathing/out of breath	0004048	Inspiration, Inhaling	5
Uncertain whether I am getting the best possible treatment	0087111	Therapeutic procedure	4
Uncertain whether I am getting the best possible treatment	0332272	Better	4
Afraid of becoming sterile	0015726	Fright	3
Difficult looking after my children the way I would like to	0332218	Difficult	3
Arm/leg pain	0023222	Pain in lower limb	3

RESULTS

- Single terms often present only a partial representation of a patient symptom/problem.
- Data support the understanding that a group of concepts are often necessary to more clearly define one patient reported symptom or health related problem.
- The use of interface terminologies to combine reference terms stored in the EHR are developed for the purpose of linking multiple CUI concepts to represent the patient experience more completely.

Personal Health Records

Linking Patient Portal Access with Self care symptom management

Personal Health records (PHR) access via a portal

Save time – and paperwork for HCP and Social Work for Client needs

Improve the quality of your care
- more complete history
- Connects others involved in your care

Manage dependents' care and caregivers management of patients care (as necessary)

Meaningful Use Incentive program – Stage II includes a PHR use provision – will lend to increased consumer use.

FUTURE STATE

- Future migration as part of an updated and sharable clinical care document for both the patient and provider
- Availability in a mobile format


Gracias
Merci
THANK YOU!
Kob Khun
Vielen Dank
QUESTIONS?