

Informatics for Advanced Cancer: Addressing Palliative, End of Life and Bereavement Care

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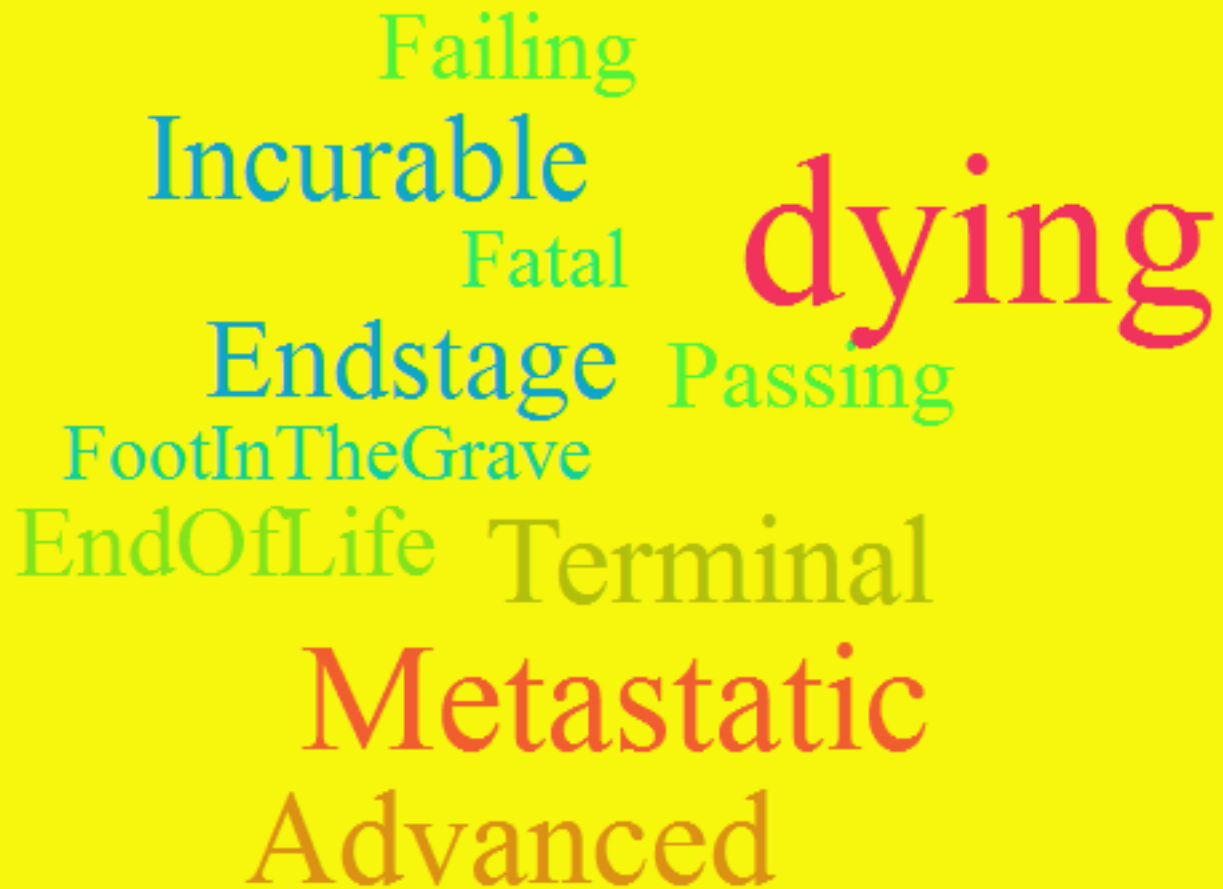
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Today I'm going to talk
about...

Today I'm going to talk
about...

dying

Today I'm going to talk
about...



A word cloud on a yellow rectangular background. The words are arranged in a somewhat circular pattern. The words include: 'Failing' (green, top), 'Incurable' (blue, top-left), 'Fatal' (green, top-center), 'dying' (pink, top-right), 'Endstage' (blue, center), 'Passing' (green, center-right), 'FootInTheGrave' (teal, bottom-left), 'EndOfLife' (green, bottom-left), 'Terminal' (green, bottom-center), 'Metastatic' (red, bottom-right), and 'Advanced' (brown, bottom-right).

Failing
Incurable
Fatal
dying
Endstage
Passing
FootInTheGrave
EndOfLife
Terminal
Metastatic
Advanced

To adequately address cancer suffering, we need to:

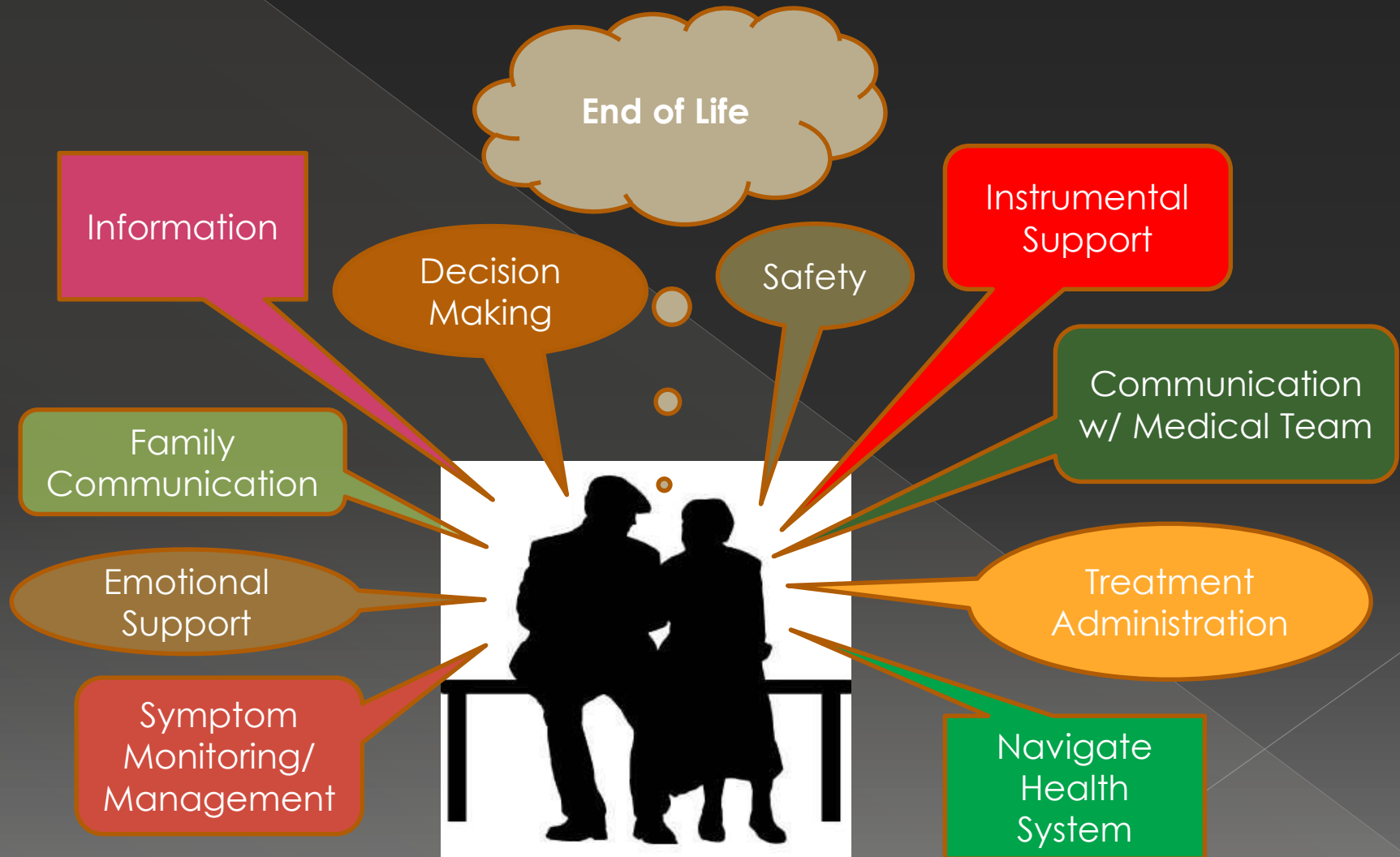
- Address the entire spectrum of the illness trajectory, including advanced illness and end of life
- Address the social system in which the patient belongs

A Caregiver's Perspective...

“I was with my husband on a daily basis and could see the decline in his health, physical abilities, and emotional state, but when I tried to relay this to the [clinical team] it was seemingly ignored. They chose to focus on tests, scans, and bloodwork... they only saw him for a very short time and he always wanted to put his best foot forward. When he was at home he would cry in my arms... When I could no longer “rah-rah-rah” I shut down and went through his last few months feeling unsupported.”

-Bereaved spouse caregiver

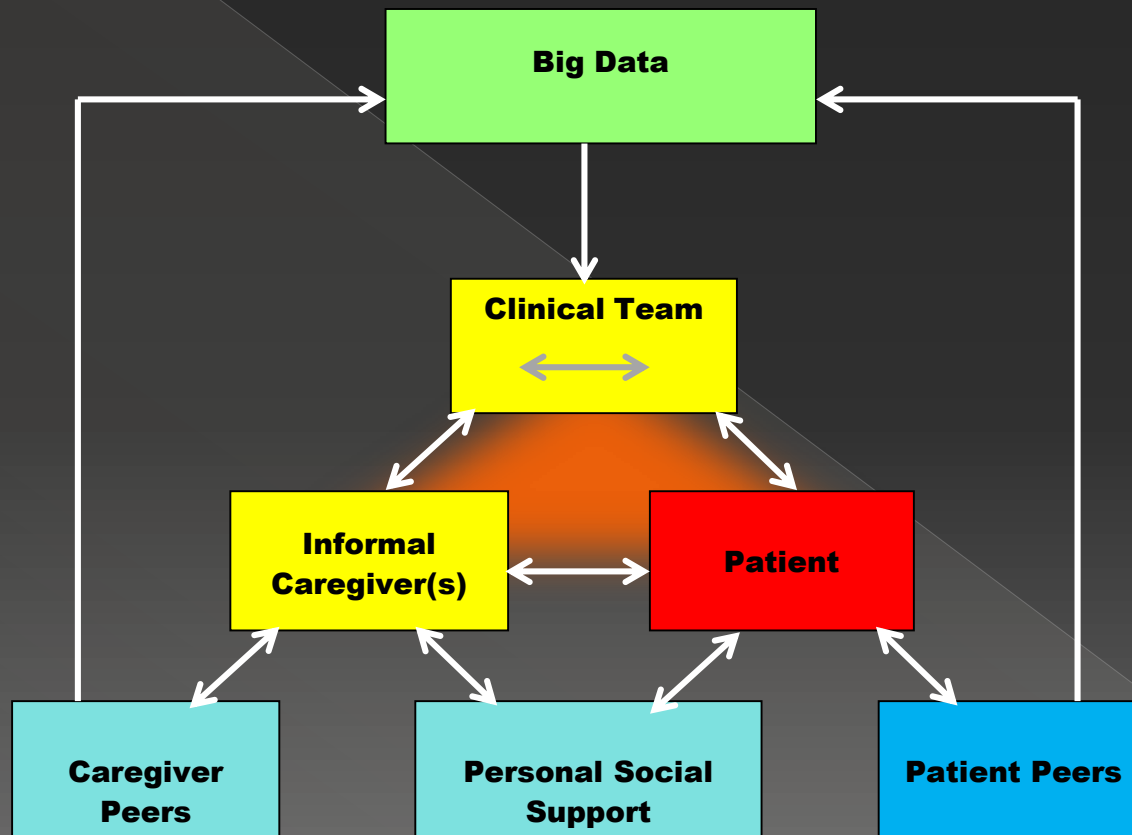
What do Patients & Caregivers Face?



Critical areas of Focus

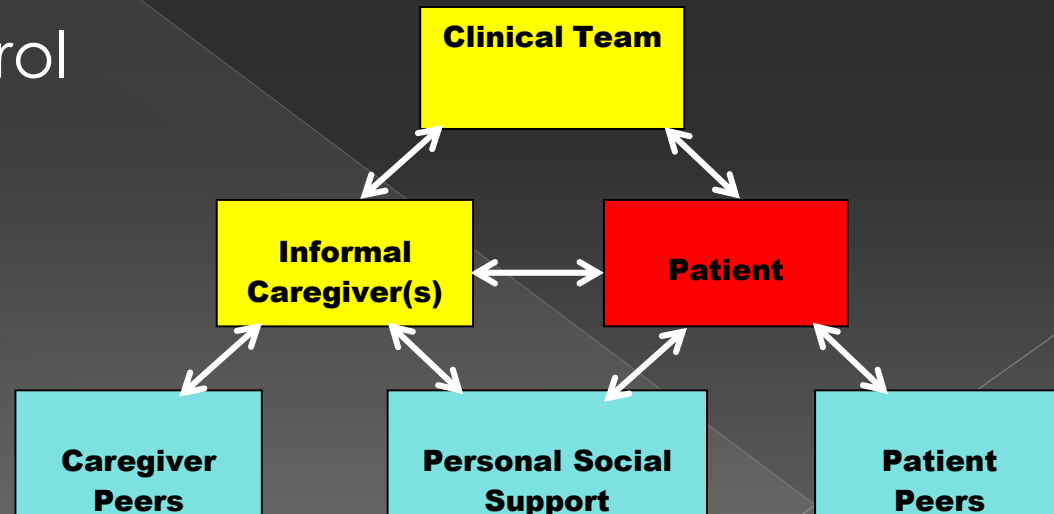
- Symptom management
- Decision Making
- Caregiving *thru* Bereavement

Channels of communication offering opportunities for informatics



Example: UW's CHESS*

- Comprehensive Health Enhancement Support System
 - > Web-based resource offering Information, Communication, Interactive Tools
- Advanced stage cancer caregivers and patients
- RCT vs Internet control

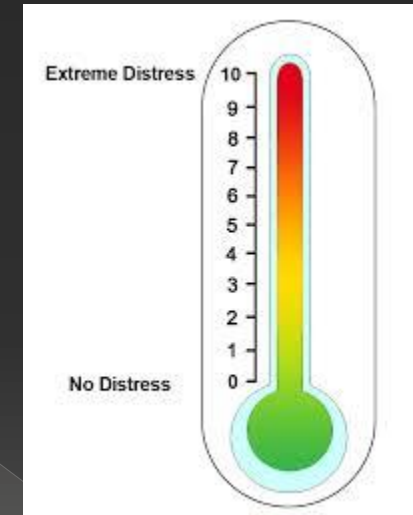


*PI: David Gustafson, PhD, Director, Center for Health Enhancement Systems Studies, University of Wisconsin -Madison

Informatics Opportunities: Symptom management

Assessment (anytime, anywhere)

Reporting of distress

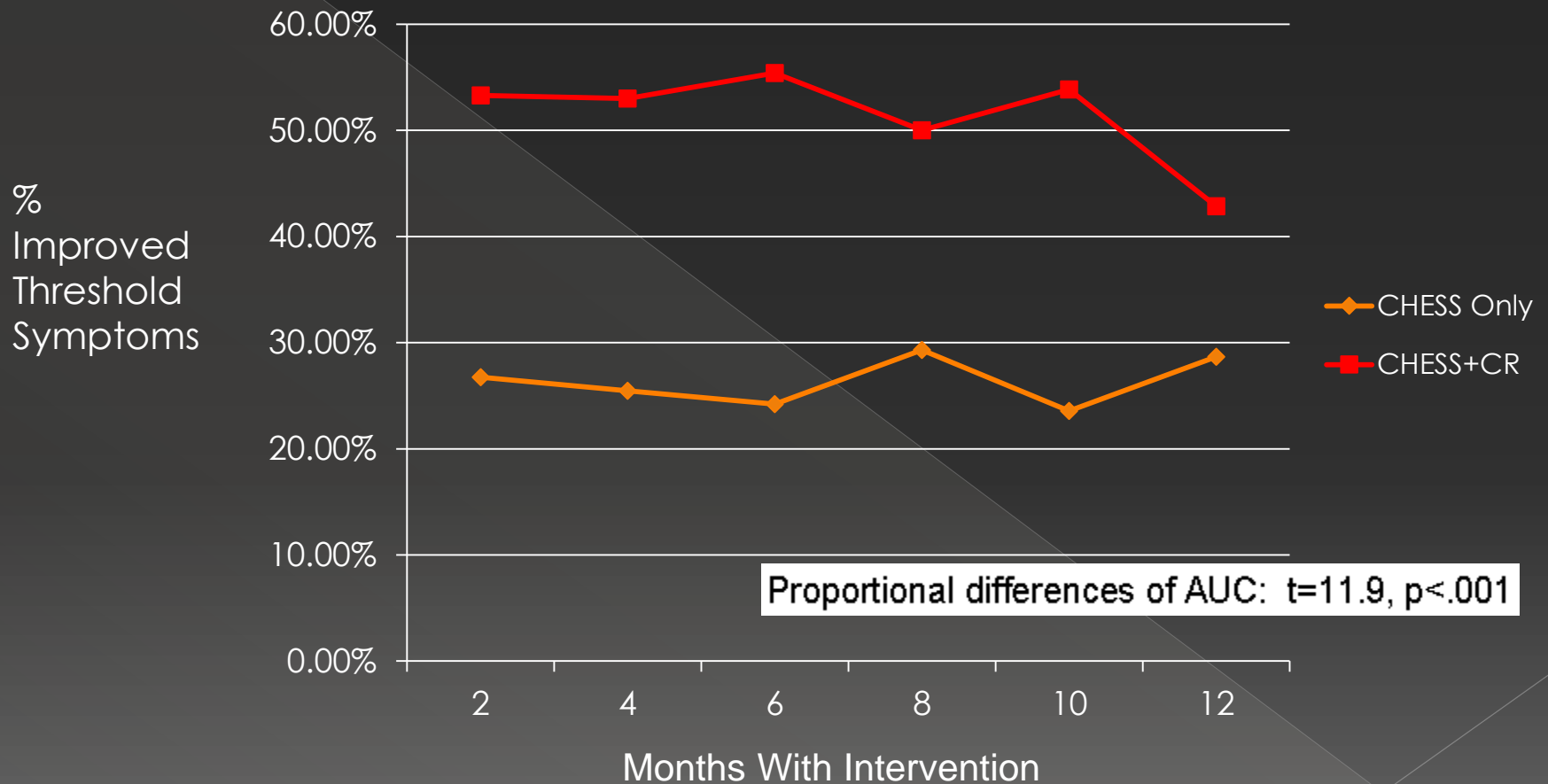


Direct integration in medical record

Electronic Symptom Reporting

- Examine impact of CHES's Clinician Report feature on caregiver's rating of patient symptom distress (ESAS)
- Clinician Report
 - > **Email alert to clinician if symptom level 7 or higher (0-10)**
- 217 advanced lung, breast, & prostate cancer caregivers randomized to:
 - > CHES (N=107) vs. CHES+CR (N=110)
- All completed Health Status Check-In
 - > Automatic Check-In with first login after 7 days
 - > ESAS symptoms distress
- Examined whether symptoms reported at 7+ were rated as improved at subsequent Check-In

Symptom Improvement



Informatics Opportunities: Decision Making

◉ Decision Aides

- Ability to facilitate decisions across broad base of options
- Inclusion of family and facilitate resolution of decision conflict
- Decision is not end point – need to guide successful implementation of choice

◉ Machine learning and predictive analytics

- Power of “Big Data” modeling to offer likely scenarios of end life outcomes

Informatics Opportunities: Caregiving through Bereavement

- Prepare caregivers to meet patient's care needs (information, training, evaluation)
- Connect them with other caregivers
- Foster communication with clinical team
- Guide caregivers in meeting their own needs



Example: UW's CHESS*

- Lung cancer caregivers
- Research Findings:
 - > Lower caregiver negative affect, burden
 - > Lower bereaved depressed mood, anger

*PI: David Gustafson, PhD

So, what's the right technology?

- Technology evolves faster than our ability to collect evidence base for any device.
- Answer : it's not about the technology.
- Innovation for innovation's sake is not helping.
- MUST meet the user where THEY are.



Hi-tech

High Touch

Hesse 2011 Cancer
van Vliet & Epstein 2014 J Clin Onc