Slide 1: Web-based Cancer Communication and Decision-making Systems:
Connecting Patients, Caregivers and Clinicians for Improved Health Outcomes

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Slide 2: Acknowledgements

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Slide 3: Introduction

- Interactive Health Communication Systems (IHCS) provide information, communication and coaching tools
- Comprehensive Health Enhancement Support System (CHESS) as model
- Induction of "Coping with Lung Cancer: A Network of Support"
    - o Development
    - o Implementation

Slide 4: Impact of Cancer

- Physical, emotional, spiritual challenges
- Treatment regimen
- Navigating health care system
- Coordinating care
- Dependence on family caregiver
    - o Monitor symptoms, side effects
    - o Instrumental/emotional support
    - o Information gathering/treatment decision-making

Slide 5: Cancer Decision-making

- Multiple options w/ no "right" answer
- Shift from paternalism to consumerism model
- Need for patients/caregivers to be fully engaged in care decisions
    - o Increased personal responsibility

  o Actively pursuit own QOL

Slide 6: Decision Process

- Information: options available
- Deliberation
- Decision
- Implementation
- Evaluation

Slide 7: Patient-Caregiver-Clinician Partnership

- Ongoing communication critical
  - o Clinicians informed of patient status
  - o Patient/caregiver need information/support to meet challenges
- Facilitating information exchange is critical

Slide 8: Interactive Health Communication Systems (IHCS)

- Conduit for information/communication/coaching
- Variety of technologies available
- Facilitate:
  - o Understanding
  - o Coping
  - o Partnership with health team
  - o Community support
  - o Decision-making

Slide 9: IHCS Advantages

- Wide spread dissemination/low cost
- Timely, tailored resources on demand
- User-preferred location, speed, depth, privacy
- Facilitate multidisciplinary team care

Slide 10: Comprehensive Health Enhancement Support System: CHESS

- Non-commercial
- Internet-based
- User driven
- Integrated suite of resources

- o Information
- o Communication
- o Coaching
- Facilitate coping and decision-making

Slide 11: New Directions for CHESS

- Lung Cancer
- Advanced-stage disease
- Caregiver involvement
- Clinician reporting system

Slide 12: Model of CHESS Services and Communication Lines
A model illustrating information, communications (peer, expert, colinicain, and social network) and coaching for patients and caregivers

Slide 13: CHESS Services
Image of a page from the CHESS Web site.

Slide 14: CHESS Support for Decision-Making

- Decision Aids
- Overall facilitates patient/caregiver engagement
- Knowledge regarding options
- Understanding potential outcomes from professional and experiential sources
- CHESS continues support beyond decision – Expands to implementation and evaluation

Slide 15: CHESS Benefits for Caregivers

- Decreased caregiver burden (vs. Internet control)
- Decreased negative mood (vs. Internet control)

Slide 16: CHESS Benefits for Patients

- Potential survival benefit for lung cancer
- Secondary analysis:
  - o Lung, breast and prostate cancer caregivers
  - o CHESS vs. CHESS+Clinician Report (CR)
- Greater rates of improvement for symptoms reported as high for CR

- o Earlier alert and intervention
- o Enhanced patient-caregiver-clinician communication

Slide 17: IHCS Development

- Needs Assessment
  - o Critical Incident Interviews
  - o Survey Instruments
- Key considerations:
  - o Appropriate sampling
    - Timing, demographics, experience w/ proposed technology
  - o Sample bias may exclude those w/ greatest need

Slide 18: IHCS Development (cont.)

- System Prototyping
  - o Paper-prototyping
  - o "Live" review of system by clinicians, target audience, development team
    - Comprehensiveness
    - Clarity
    - Appropriateness
    - Usability

Slide 19: IHCS Implementation

- Critical to match intervention to need
- Technology as barrier:
  - o Lack experience, and health crisis not time to learn
  - o Already have resources they need
- IHCS needs to be user-friendly and appeal to preferred format

Slide 20: IHCS Implementation (Cont.)

- Timing: Individual preference
  - o Too early – overwhelmed
  - o Too late – needed info. at diagnosis for decision-making
- Addressing spectrum of illness allows user to jump in when ready and find relevance

Slide 21: IHCS Implementation (Cont.)

- Clinical Team
    - Central role connecting patient to clinical care system
    - IHCS that make their work more efficient more readily accepted
    - Fit within existing practice guidelines in clinic setting

Slide 22: IHCS Implementation (Cont.)

- Training
    - Leads to greater levels of CHESS use
    - Greater use and certain kinds of use yield greater benefits
    - Training users increases likelihood of such benefits
- How does training impact use?
    - Exposure
    - Competence
    - Connection to system and staff

Slide 23: Conclusion

- CHESS model IHCS demonstrating potential for benefits to patients, caregivers and clinical setting
- IHCS hold potential to navigate cancer crisis
    - Single place for trusted information, supportive communication, coaching across disease trajectory
    - Need comprehensive approach to both development of system as well as content within system
    - Thoughtful application of technology
    - Strategic implementation