An Exploratory Analysis of Pediatric Hospice and Palliative Care Dialogue on Social Media

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Agenda

- Overview
- Team of Researchers
- Opening a line of research inquiry – the 1st study
- Future research
- Future collaborations
Overview

- Area of research interest in pediatric hospice/palliative care.
- Research to date has focused on hospice organizations and questions about access to and cost of care for terminally-ill children and their families.
- This study is our initial inquiry to a new line of research exploring mobile health (mHealth) and social media in pediatric hospice/palliative care
The Team

- Dr. Lisa C. Lindley, PhD, RN (UT - Nursing)
- Dr. Wenjun Zhou, PhD (UT - Business)
- Dr. Jennifer Mack, MD (Harvard - Medicine)
- Dr. Xueping Li, PhD (UT – Engineering)
- Warren De Wit (Research Assistant)

- Health Information Technology & Simulation Laboratory (HITS)
Background

- On any given day in the US as few as 6 terminally-ill children access hospice and palliative care, even though there are over 50,000 pediatric deaths annually.
- One of the barriers to pediatric hospice and palliative care is a lack of understanding of and experience with pediatric hospice and palliative care by pediatric clinicians.
- Social media has emerged in recent years as a means of interactions among people in which they create, share, exchange and comment on content among themselves in virtual communities and networks, even in hospice care.
- Despite the benefits, little is known about the dialogue that providers and clinicians are engaged in about pediatric hospice and palliative care.
The purpose of this study is to explore pediatric hospice and palliative care dialogue using social media.
Methods

- **Design**: Prospective, descriptive qualitative design
- **Data Source**: DiscoverText (http://discovertext.com/)
- **Sample**: 200 pediatric hospices and hospitals
- **Statistical Analysis**: Descriptive statistics and data mining techniques
Results

- We anticipate that there will variation in the type and volume of pediatric hospice and palliative care messages.

- It is expected that most messages from pediatric hospices and hospitals will be with pediatric clinicians and the content of the messages will be information-seeking exchanges about pediatric hospice and palliative care.
Conclusions

The findings for this study will provide important insight into the need for educational and referral information by pediatric clinicians caring for terminally ill children about a critical end-of-life care service.
Future Research

Needs Analysis
- CA Hospice & Hospitals
- Blog
- Twitter

Intervention
- Review of literature
- Pilot
- Focus group

Evaluation
- Outcomes study
- Survey
Future Research

Blog & Twitter

http://www.pallimed.org
Future Research

Intervention: Mobile App
Future Research

Intervention: Pilot & Focus Group

- Review of the literature
- Pilot: CA pediatric clinicians - Referring to CA pediatric hospices
- Pilot & Focus Group: Pallimed.org
Evaluate: Outcomes & Survey

- Outcomes: CA hospice data to assess impact on pediatric hospice use over time
- Survey: Use mobile app to survey clinician on effectiveness and efficiency of mobile app in improving understanding and use of pediatric hospice/palliative care
Future Collaborations

- Computer science
- Engineering
- Geography
- Sociology
- Social Work
- Medicine
- Information science


