Leveraging Technology to Enhance Equitable Access to Pain Management

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Questions…

Why was this so difficult? Even for a family with a nurse?

How can we do better? Especially for vulnerable patients and families?

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Technology Enhanced Cancer Care (TECC) Lab

- **Mission:** to conduct innovative and rigorous research that leverages technology to improve cancer care – for patients, family caregivers, and healthcare providers – in both domestic and international settings
  - Emphasis on cancer pain management

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BESI-C
Behavioral and Environmental Sensing and Intervention for Cancer

www.besic.org

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Background and Significance:

- Pain (especially breakthrough pain) is a serious problem for patients with cancer
- Most cancer symptom management occurs in the home setting
- Family caregivers play a big role, but often have little support
- Opioids are key treatment, but increased scrutiny can negatively impact pain control
- Interventions in context of advanced cancer need to be low-burden

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The Challenge

Too often, pain management is a reactive, one-size-fits-all approach

We hope to shift to more pro-active, personalized interventions

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The Questions

Can we more fully understand the multitude of factors that may increase cancer pain and distress?

And if so, could we then *predict* when pain and distress may escalate and *intervene earlier*, in real-time, more effectively?

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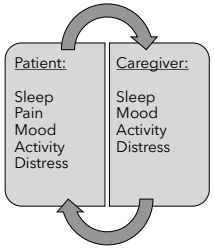
The Big Picture

Explore the dyadic effect and how to support both partners

Increase self-efficacy and empowerment related to symptom management

Keep patients out of the hospital / Emergency Department

Improve access to care those geographically isolated; support the healthcare providers who care for them



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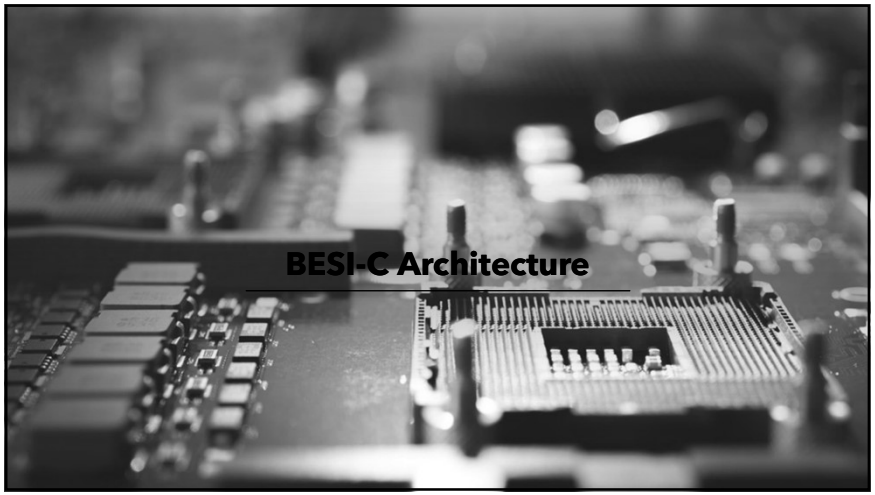

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What is BESI-C?

BESI-C
Behavioral and Environmental Sensing and Intervention for Cancer

- End-to-end sensing system + data analytics
- **Understand the home (environmental sensors)**
  - Ambient noise; barometric pressure; humidity; light; temperature
- **Understand the person (wearable sensors, smart watches)**
  - Heartrate; pedometer; accelerometer; location
  - Brief surveys (Ecological Momentary Assessments, EMAs)

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The "BESI-Box"

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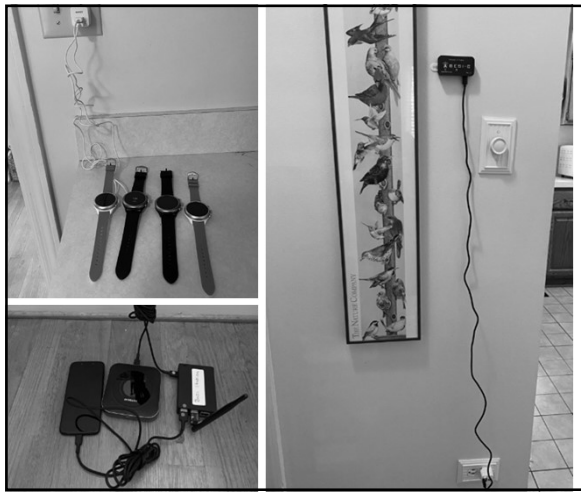

What is BESI-C?

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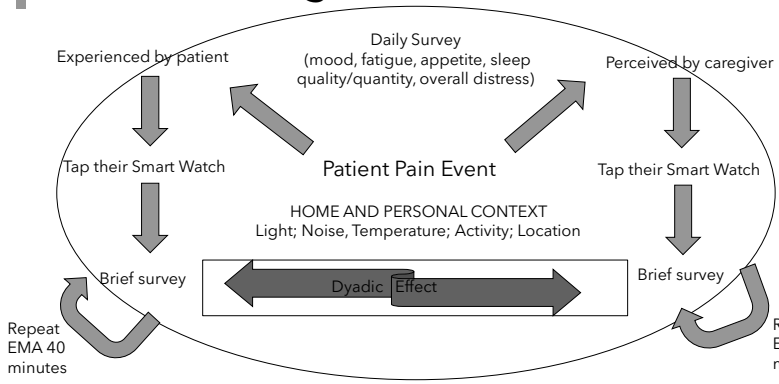
Understanding Pain Events in Context



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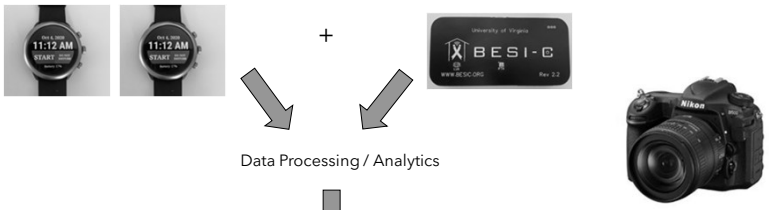
Putting It All Together



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Phase I: End-User Design Input

- Structured interviews with cancer patient-caregiver dyads (n=10); recruited from the UVA Palliative Care Clinic
  - Experience of cancer pain at home
  - Variables to measure
  - Design input regarding BESI-C components

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Cancer Pain at Home – Patient

It hits me so bad sometimes it brings tears to my eyes…When I'm in really, really bad pain it gets me down. I get depressed and it's like, 'God, is this ever gonna quit? - Pt 10

Most difficult? Taking my medicine. Sometimes I'll take more than I should if I'm really in a lot of pain, and I know I'm not supposed to but it's hard not to. - Pt 2

I pretty much became a hermit since this happened. I try to stay away from everybody so I don't have to talk very much. I stay in the bedroom,, and watch TV most the time so I don't have to talk to people. - Pt 1

That's one thing about the cancer pain, is that you never know what you're going experience…I think he [her CG] kind of puts on a show of handling it better than he does. - Pt 5

I worry about the medications and if I'm gonna have enough or God forbid if I lose some or whatever. - Pt 10

Just be secluded...When I'm really, really in pain, if I'm alone it seems to soothe it…nothing there to irritate me to make it worse. - Pt 11

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Cancer Pain at Home – Caregiver

I find it a little difficult…like she appears to be in pain, definitely lethargic and I think between the pain and feeling tired that definitely affects her mental health…so it's just kind of all blurred together. - CG 5

It's really pulled her down. You know, we went from being outside every day and doing things to, you know, pretty much watch watching her lay on the couch. - CG 9

Keeping up with the medications and as they change. - CG 5

I can see when you need it [pain medicine] but I don't just automatically give it to you…you've got to ask for it too. - CG 6

The experience to me, he gives me a headache.
- CG 1

Well, I know it hurts. Some days it looks worse than others. - CG 2

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Phase I:

Key Themes/ Findings

- Cancer pain is unpredictable, stressful and impacts daily life, especially sleep and social interactions
- Keeping track of medications and balancing side effects with pain relief can be challenging; fears of running out of pain medication
- Patients and caregivers validated the proposed variables to measure by BESI-C; very open to testing the system
- Primary concerns related to privacy and burden

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Phase II – Pilot Testing of BESI-C

Feasibility

- Logistic barriers related to in-home deployments
- Fidelity of data capture

Acceptability

- Dyad perceptions and receptivity to BESI-C
  - Likert survey
  - Semi-structured interviews

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Study Details

Sample & Inclusion Criteria

- Patients with locally advanced or metastatic cancer + family caregiver;
- Pain ≥ 6/10 NRS/PROMIS Pain interference scale;
- Taking short-acting opioids for cancer-related pain;
- Ability to interact with smart watch

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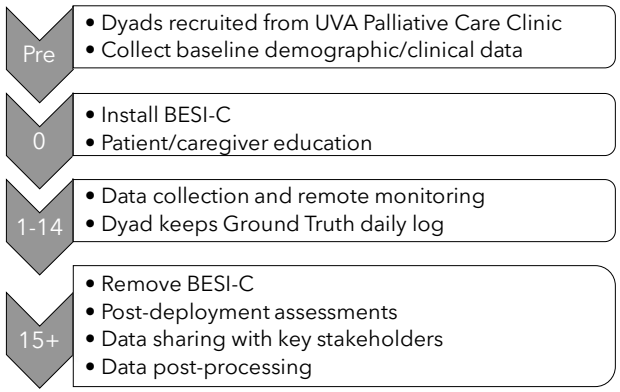

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Ensuring Privacy

- Does not record raw audio; only pre-processed features related to ambient noise characteristics that do not enable reconstruction of conversation content
- No cameras
- Sensors are only deployed in approved rooms and never in highly personal areas, e.g. bathrooms
- All data streams are de-identified, contain no patient identifiers
- Participants can turn off sensors at any time; stop wearing smart watch or put watch in a 'do not disturb' mode

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What do we know so far?

People *will* mark pain events and answer brief surveys on the smart watch

They find the system low-burden and easy

Increases communication and awareness between partners

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Phase II: Preliminary Results

5 dyads completed deployments
- 80% of dyads (n=4) were rural; 40% of dyads (n=2) African American; 3 patients (n=3; 60%) with head and neck cancer

283 total pain events (198 patient; 85 caregiver)
- Average severity score 5.4/10 for patients; 4.6/10 reported by caregivers
- Over 70% of responses indicated that the patient took an opioid for the pain
- Most frequent reason for not taking an opioid was 'not time yet.'

52 follow-up pain events (18%; 42 patient; 10 caregiver)
- Reported patient still in pain 30 minutes after taking an opioid
- Average severity score of 4.7/10 patients; 3.7/10 caregivers

- Caregivers reported > self-distress and pain interference levels than patients
- Patients rated caregiver distress > than caregivers rated patient distress

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Exemplar Quotes from Semi-Structured Interviews, Overall Impression of BESI-C (n=5 dyads)

It was easy, took little time out of my day…I paid more attention to the small things; it raised awareness about pain management and how she [my partner] looks and acts. (^D3C3)

She [my wife] asked me more specific questions about my pain. (D4P4)

Made me pay attention to what I was feeling and how my caregiver felt. (D3P3)

I think it can help a lot of people out there who cannot get to a doctor when they're really hurting and sick. This is a good way to communicate…I think you have a great invention here! (D5C5)

Before the BESI-C system I wouldn't always communicate my pain with my caregiver in trying to prevent him from worrying. The system made me aware by not communicating I was doing the opposite. (D5P5)

^D=deployment #; p=patient; c=caregiver

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Selected Likert Survey Results and EMA Metrics (n=5 dyads)

Likert Survey Question *(1=strongly disagree; 5=strongly agree)*	Patient	Caregiver
BESI-C can collect helpful information to better manage cancer pain	4.6	4.6
Remembering to mark pain events in the moment was easy	4.6	4.2
It was easy to answer questions on the Smart Watch	4.6	4.0
BESI-C made me concerned about privacy	2.0	1.8
BESI-C was a burden for me	1.4	1.6
EMA Metric	**Patient**	**Caregiver**
Average time to complete initial pain EMAs	0:38	1:21
Average time to complete follow-up EMAs	0:38	0:57
Average time to complete daily EMAs	1:19	2:00
Percentage of completed follow up EMAs	63-83%	44-80%
Percentage of completed daily EMAs	42-80%	33-57%
Average # initial pain events/day	3.63	1.78

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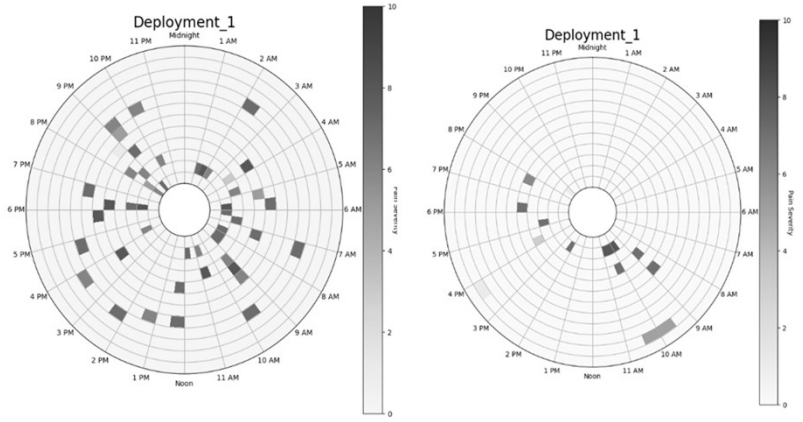

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Phase II: Other Key Take-Aways

- The most common reason for not taking an opioid *even if a patient indicated they were still in pain was 'not time yet'*
  - Suggests prescribing patterns or education re: dosing may be needed so pain doesn't escalate
- CGs feel more distressed and report their partner's pain impacts them > compared to patients' perception of the impact
  - CG burden is real
  - Underscores critical importance of understanding the dyadic effect and how the CG experience and patient experience influence each other

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Future Directions

- Recruit larger sample
  - UVA PC clinic/Hospice of the Piedmont
    - What differences/similarities will we see with these pain profiles?
- *Characterizing the Complexity of Advanced Cancer Pain in the Home Context*
  - NIH R01, National Institute of Nursing Research
- Aims: 1) Characterize digital phenotype of advanced cancer pain; 2) Build predictive models; 3) Enhance data sharing capabilities

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The Vision and the Path Forward

- **Potential to be paradigm shift in how we manage symptoms at home**
- **Applies** to many symptoms and illnesses (non-cancer pain? post-op pain?)
- **Leverages Complex Data** to deliver personalized care in real-time
- **Empowers patients and caregivers** in safe, effective symptom management
- **Supports remote care delivery** and honoring goals of care

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The Team

BESI-C
Behavioral and Environmental Sensing and Intervention for Cancer

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Thank you!
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