

7th International Conference on Information and Communication Technologies for Ageing Well and e-Health (ICT4AWE 2021) April 24-26, 2021

Aging, eHealth, and COVID-19

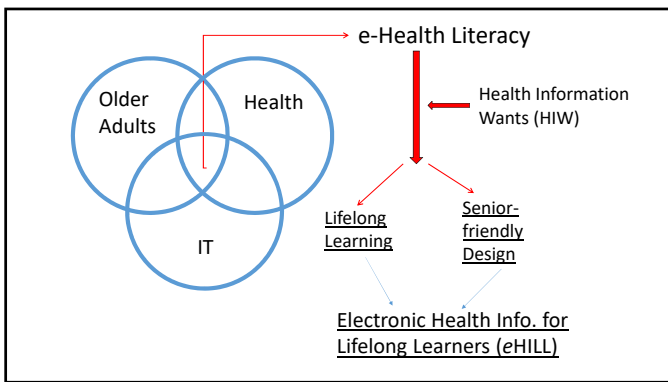
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Outline


- Self-introduction
- *Electronic Health Information for Lifelong Learners (eHILL)*
- Aging during the COVID-19 pandemic
- *Health Information Wants (HIW)* → family caregivers of persons with Alzheimer's disease and its related dementias (ADRD)
- Interdisciplinary collaboration

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Electronic Health Information for Lifelong learners (eHILL)

- R01AG041284; PI: Bo Xie



- eHILL – Collaborative & Cognitive (eHILL-C²)
R21AG052060; PIs: Bo Xie; Julie Bugg

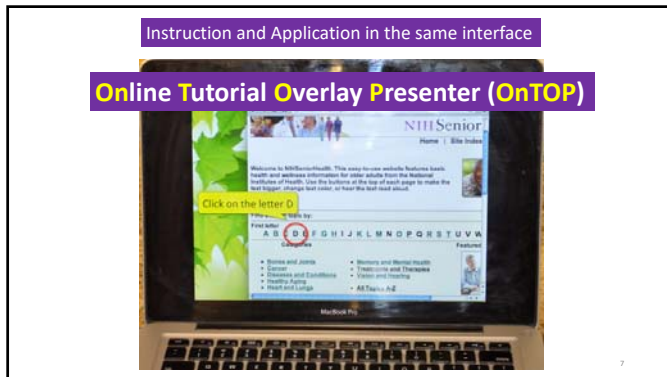
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eHILL: Combining Lifelong Learning and Senior-friendly Design:

Online Tutorial Overlay Presenter (OnTOP)
(R21AG052761; PI: Bo Xie; Sub-PI: Tom Yeh)

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Older adults are in triple jeopardy during COVID-19

1. Develop serious conditions;
2. Social isolation;
3. Less access to digital information or services.

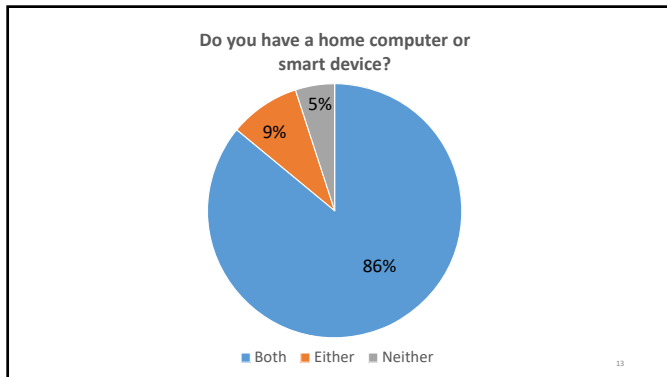
Xie, B., Charness, N., Fingerman, K., Kaye, J., Kim, M., & Khurshid, A. (2020). When going digital becomes a necessity: ensuring older adults' needs for information, services, and social inclusion during COVID-19. *Journal of Aging & Social Policy*, 32(4-5): 460-470. <https://doi.org/10.1080/08959420.2020.1771237>

Age-appropriate technology—and accompanying training and support

- High-speed Internet access as a basic human right
- The diversity of the older population
- The importance of community partnerships

Pilot Study: Older Adults' Needs for Information, Services, and Social Interaction During COVID-19

- A first step of our larger study—to develop educational interventions to meet older adults' needs
- Data collection took place via the phone during summer 2020
- $N = 200$; age range: 65-92 years; *Mean*: 73.6; *SD*: 6.33



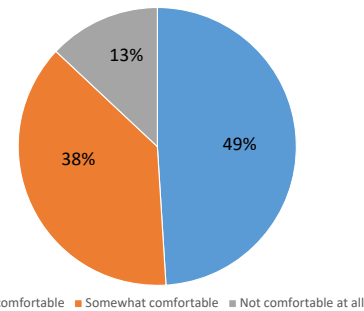
Challenges related to technology access

- “I don't have a computer. I have a very old, old smart phone... It's not holding charge. I can't get online, because I don't have [internet] service.”
 - “My phone connection is lousy, so if I drop you [on the call] I didn't intend to.”
 - “I have a computer but I don't have internet coming in.”
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Challenges related to technology literacy

- “I don't know how smart it [smartphone] is. It all depends on the person using it.”
 - “What is a smart phone? [explained] It's smarter than me, at times it feels like.”
 - “I got this phone. Don't know if it's a smart phone.” [There's someone coming to teach her how to use it.]
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How comfortable are you using video chat services?



NSF RAPID: Trust in Public Health Information among Older and Younger Americans During COVID-19

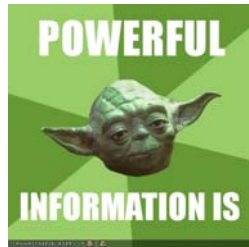
- Mixed-Methods Data Collection
 - Survey
 - Interviews
 - Experiments
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CDC: Precision health: Improving health for each of us and all of us

- “Your **genes**, **behaviors** (such as exercise and eating habits), and **environment** are all factors that affect your health. The goal of precision health is to protect your health by **measuring** these factors and **acting** on them. Interventions can be **tailored** to you, rather than using the same approach for everyone. ...precision health approaches can better **predict**, **prevent**, **treat**, and **manage** disease for you and your family” (https://www.cdc.gov/genomics/about/precision_med.htm)
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Information is power

Technology—a key gateway to information and opportunities



<http://contactdb.files.wordpress.com/2012/06/yoda21.jpg>

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Technology-introduced new opportunities



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The Health Information Wants Questionnaire (HIWQ)

Subscale	Information	Decision-making
Diagnosis	X	X
Treatment	X	X
Lab test	X	X
Self-care	X	X
Psychosocial	X	X
CAM	X	X
Health care provider	X	X

Xie, B., Wang, M., Feldman, R., & Zhou L. (2014). Exploring older and younger adults' preferences for health information and participation in decision-making using the Health Information Wants Questionnaire (HIWQ). *Health Expectations*. 17(6):795-808.

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Table 1. The HIW-ADRD 3.0 framework

Type of information	Sample keywords
Treatment/Medication/Prevention	Drug; oriental; acupuncture; vitamins
Characteristics of/Experience with the health condition/Diagnostic procedures	Diagnosis; complication; cause; prognosis; process; symptom; memory loss; lab test; MRI; PET; blood
Daily care for a patient at home/Care for a caregiver (practical strategies or tips, not psychosocial)	Wandering; bath; hygiene; sleep; eat; driving
Care transition and coordination/End-of-life care (practical, not psychosocial)	Adult day care; rehab; hospital; memory care; nursing home; hospice
Psychosocial aspects	Stress; lonely; heartbreaking; overwhelmed; venting
Resources/Advocacy/Scientific updates/Research participation	Lobby; fundraising; clinical trial; news; article; scientist
Legal/Financial/Insurance	Power of attorney; POA; living will; Medicare; Medicaid

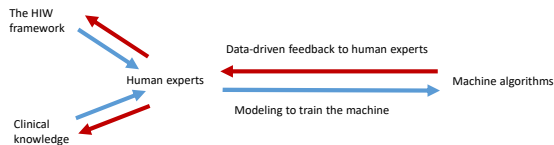
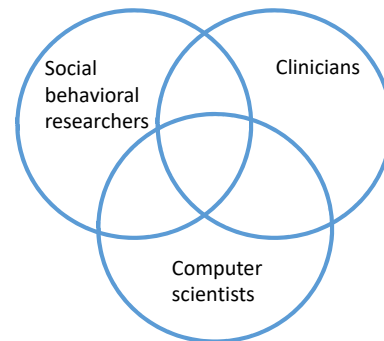


Fig. 1. The Expert-Machine Co-development (EMC) Process

Wang, Z., Zou, N., Xie, B., He, D., Luo, Z., Hilsabeck, R. C., & Aguirre, A. (2021). Characterizing dementia caregivers' information exchange on social media: exploring an expert-machine co-development. In *Proceedings of the 2021 Conference* (to be published in Springer's *Lecture Notes in Computer Science*). 21 pages.



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Interdisciplinary collaboration is key!

..... BUT be patient and be prepared for the initial "cultural shock"!



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Interdisciplinary thinking and collaboration: my own experience

Health Sciences

- "Patient education"
- Community-based participatory research (CBPR)
- Specific "diseases" or "health conditions"

Information Science

- "Information behavior"
- Participatory design
- Informatics tools can be used with most if not all diseases or health conditions

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Developing technology-based interventions for ADRD caregivers—where are we?

- Using AI to assist in ADL, targeting a limited number of specific activities
- Exploratory—qualitative, small sample, atheoretical
- Lacking empirical data from human subjects (technical specifics or system architecture for designing AI systems)
- Missing key pieces of information for PRISMA extraction, e.g., demographics, research settings, sites
- Mixed results
- Little overlap between the health sciences and CS/engineering databases
- Research is still in the stage of tech development, far from ripe for clinical evaluation—more opportunities for interdisciplinary collaboration!

Xie, B., Tao, C., Li, J., Hilsabeck, R., Aguirre, A. (2020). Artificial intelligence for caregivers of persons with Alzheimer's disease and related dementias: systematic literature review. *JMIR Medical Informatics*. 8(8). <https://medinform.jmir.org/2020/8/e18189/>

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Will the generational digital divide disappear on its own?

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Thank you! Questions?

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