TECHNOLOGIES FOR CAREGIVING AND AGING IN PLACE: RISKS AND ETHICAL CONSIDERATIONS

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April 25, 2024

1

TELEHEALTH & REMOTE PATIENT MONITORING

SHARED CARE PLANNING & COORDINATION

SMART LIVING & HOME CARE

MEDICATION MANAGEMENT

HEALTH ASSESSMENTS

Source: HealthXL Platform (Note: The companies listed above are meant to be representative, not exhaustive. Visit HealthXL.co for more detailed company information including partners, funding, and publications).

CrunchBase and Digital Health Report HealthXL & AARP: Enabling connected and independent living through new care models

2

"...gathering data at every second to observe each elderly person through their daily activities. To identify and chart their individual behavior patterns to spot any significant deviation."

24/7 Notifications for Staff Efficiency

Caspar provides 24/7 notifications and automated check-ins. The real-time dashboard allows staff to provide care to residents more effectively.

Even with 1 less FTE, staff provides better care to residents.

Clara Berridge | University of Washington School of Social Work

The Triple Win
of the aging-and-innovation discourse

L Neven, A Peine. (2017). From triple win to triple sin: How a problematic future discourse is shaping the way people age with technology. *Societies*

Technologies of focus

Direct to consumer devices

- Digital health-related technology
- Ambient assisted living
- Smart tech
- Internet of things
- Remote monitoring/passive monitoring

- Social robots/virtual companions

The problem

- Ethics conversation on gerontechnology was slow to get started

- We are now aware of numerous risks and value tensions (Mortenson, Sixsmith, Woolrych 2015; Novitsky et al., 2015, Ienca et al., 2019; Ho, 2020; Lariviere et al., 2021; Higgs 2022, etc.).

- There is a pressing need to be attentive to older adults' preferences for control and privacy in design, implementation, and policy (Berridge et al., 2022).

"...if AAL [ambient assisted living] technologies are a success at the expense of the individual's privacy then to what extent is the AAL really empowering or improving the well-being of the elderly?"

McNeill, 2017:101

Online cohort survey: Research via Internet of Technology and Experience (RITE cohort)

Analytic sample = 825

Age range: 25-88, mean=64 (496 participants were 65+)

We conceptualized control as a form of ongoing agency in which an individual can decide if and what information is collected about them and with whom it is shared.

Berridge, C., Zhou, Y. Lazar, A. et al. (2022). Control matters in elder care technology: Evidence and direction for designing it in. In Designing Interactive Systems Conference (DIS '22), ACM

11

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n=825 members of the online RITE cohort

	Not at all important	Very Un-important	Somewhat unimportant	Somewhat important	**Very Important**	**Extremely important**
To be reminded every now and then about what information a technology collects about you	1%	2%	5%	16%	35%	41%
To have your primary support person check in with you now and then about whether you've changed your mind about using the technology	3%	2%	8%	20%	41%	26%
To have the ability to pause a technology in your home when you want privacy	1%	1%	1%	3%	20%	74%

Berridge, C., Zhou, Y. Lazar, A. et al. (2022). Control matters in elder care technology: Evidence and direction for designing it in. In Designing Interactive Systems Conference (DIS '22), ACM

12

Technology control options: participants with mild AD (n=29)

Option	No	Unsure	Yes
I want to **know if** a technology is being used to monitor me (1 missing)	1	0	27
I want to be **asked again** about these technologies to see if my feelings change	5	3	21
I want to **stop using** a technology if I become uncomfortable with it.	1	2	26
I want **to be able to pause** a technology in my home when I want privacy.	0	4	25

Turner, N., Berridge, C. (2023). How I want technology used in my care and why: Learning from documented choices of people living with dementia using a dyadic advance care planning tool. *Informatics for Health and Social Care*

13

Older adults and people living with dementia are among the most targeted groups for technological intervention in the name of risk assessment and management (Higgs & Gilleard, 2021; Sue & Woo, 2021)

The availability of technologies to support dementia care at home is outpacing our understanding of how to help people think about if and how to use them.

14

Involvement of the person living with dementia to the extent possible supports <u>ethical use</u> (Alzheimer Europe, 2010; Meilland, 2017; Novitzky et al., 2015).

Technology <u>preferences are diverse</u> and relationally embedded.

15

Uninformed decision making is a stressful burden for caregivers (Reamy et al, 2011; Menne et al., 2008).

Feeling prepared reduces stress (Miller, Whitlatch, Lyons, 2016).

Awareness of what a person living with dementia wants in their care benefits CGs personally (Menne et al, 2008; Berridge et al., 2023).

16

Movable barriers to shared decision making about technology use

1. Caregivers often assume that a person cannot understand the basic functions of care technologies well enough to be involved in decision making.

2. Caregivers often underestimate their desire or ability to participate in care decisions (Hirschman et al., 2005; Reamy et al., 2011).

> People at a mild-to-moderate stage of dementia are able to express their preferences and generally prefer to be more involved in decision making than they are (Whitlatch et al., 2005; de Boer et al., 2007; Harman & Clare, 2006; Miller et al., 2016).

Movable barriers to shared decision making about technology use

3. Caregivers underestimate the risks of technology use because they are not informed of them, leaving them unprepared to negotiate tradeoffs.

> These include privacy invasion, loss of control, data inaccuracy, unnecessary restrictions, and reduced autonomy and human interaction

4. Caregivers are disinclined to involve people living with dementia because it is a difficult conversation, especially if they are not in agreement.

> "I would love it and my mom would hate it."

Potential for conflicting views

Divergent assessments of location tracking, home motion sensors, web-cameras

—In every case of incongruence, the adult child held the favorable view

—All adult children underestimated parents' ability to comprehend basic functions of the technologies

Berridge, C. & Wetle, T.F. (2019). Why older adults and their children disagree about in-home surveillance technology, sensors, and tracking. *The Gerontologist*

Families are left to navigate this space alone

• Persuade
• Pressure
• Bypass
• Override
• Issue ultimatums
• Moralize
• Conceal use
• Miss out on technology tools that could be beneficial

Berridge, C. (2017). Selling passive monitoring to manage risk in independent living: Frontline workers in a bind. In S. Adams, N. Purtova, & R. Leenes (Eds.), Under Observation: The Interplay Between eHealth and Surveillance. Springer.

This digital divide can't be bridged by technological advances in dementia care if families are left to navigate this complex technological landscape alone.

Adult Protective Services

—Informal survey, Sept 2021

—42 Adult Protective Services investigators in Washington State

Q1. Devices I've observed or believe are in use in homes or facilities (select all that apply):

Web-camera (in any form – hidden or in plain view)	95% (40)
Sensors on a door or windows	88% (37)
Other sensors that detect motion and indicate where someone is in a home or what they are doing	57% (24)
Location tracking of the individual by another person (such as through a smart phone, wearable, etc.)	17% (7)
Audio recording without visual	12% (5)

23

Q2. Concerns I've had (select all that apply):

My visits may not be private (suspect covert recording or I observe a camera/other recording device).	87.80% (36)
I don't know what to recommend if an individual lacks capacity to consent to a monitoring device.	75.61% (31)
I don't know if an individual gave consent or was consulted about a monitoring device in their living space.	60.98% (25)
The monitoring may be used for nefarious purposes (over-surveillance, for control over individual, etc.).	29.27% (12)
A family member or guardian covers up or thwarts use of a surveilling device.	17.07% (7)
An individual expressed that they aren't comfortable with or don't want a device that's present.	2.44 % (1)

24

State Medicaid analysis of home and community-based services

"There's a consent factor there, and understanding if the person knows they're being monitored, and if their representative is solely safety-driven and doesn't include evaluation of dignity at risk. So there are a lot of factors. How informed is the person?"

-State Medicaid waiver manager

Berridge, C. (2018). Medicaid becomes the first third-party payer to cover passive remote monitoring for home care: Policy analysis. *JMIR, 20*(2) e66.

25

What's at stake for people living with dementia in decisions about how technologies are used in their care?

Lariviere, M. et al. (2021). Placing assistive technology and telecare in everyday practices of people with dementia and their caregivers: findings from an embedded ethnography of a national dementia trial. BMC Geriatrics

26

Aims of the technology for dementia care expert study

- identify technologies expected to be prevalent in 5 years

- identify those most likely to cause value tensions

- **understand the potential benefits and risks of each**

- **identify options to mitigate those risks**

Berridge, C., Demiris, G. & Kaye, J. (2021). Domain Experts on Dementia-Care Technologies: Mitigating Risk in Design and Implementation. *Science & Engineering Ethics*

Those most likely to cause value tensions

- Recording audio in a person's home to respond to emergencies, monitor socialization, detect cognitive change

- Video conferencing allowing a caregiver to turn the webcam on and "enter" the room visually for social connection and visual assessment

- Location tracking outside the home

- Location tracking inside the home to monitor safety and social activity, variation in activity

- Using an AI virtual agent or socially assistive robot for non-human companionship to ease loneliness or prompt engagement

- Remotely monitoring physiological variables for frequent assessment to predict and manage health risks

Common risks (1/4)

— privacy invasion for individual and visitors

— feeling uncomfortable/bugged/no place to hide

— infantilize or lead to feeling "baby sat"

— compromise one's dignity

Berridge, C., Demiris, G. & Kaye, J. (2021). Domain Experts on Dementia-Care Technologies: Mitigating Risk in Design and Implementation. *Science & Engineering Ethics*

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There is some level of privacy that's taken away, and depending on the person, it could affect how they lead their lives or how they feel like they can lead their life. Your life is open and exposed in a way that it wasn't.

The more and more one feels one's privacy is being invaded, the more and more degraded some can feel.

-62-year-old son of a Meals on Wheels client

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Privacy framework (McNeill et al., 2017)

Functions of privacy:

- Self-protection
- Autonomy
- Emotional release
- Confiding ("control over the extent of information disclosed and to whom it is disclosed")
- Social identity
- Self-concept
- Protecting others

McNeill, A., Briggs, P., Pywell, J. Coventry, L. (2017). Functional privacy concerns of older adults about pervasive health-monitoring systems. International Conference on PErvasive Technologies Related to Assistive Environments (PETRA '17), 96–102.

Common risks (2/4)

—caregiver stress from ambiguous data/alert overload

—false sense of security, reducing proactive help

—reduction of visits or calls, leading to loneliness

Berridge, C., Demiris, G. & Kaye, J. (2021). Domain Experts on Dementia-Care Technologies: Mitigating Risk in Design and Implementation. *Science & Engineering Ethics*

Common risks (3/4)

— tension caused by caregiver paternalism in form of intrusive or harassing questioning

— caregiver limits freedom, using data to rebuke, restrict, or micromanage

— behavior change to conform w/ expectations

Berridge, C., Demiris, G. & Kaye, J. (2021). Domain Experts on Dementia-Care Technologies: Mitigating Risk in Design and Implementation. *Science & Engineering Ethics*

Common risks (4/4)

— data lead to knowledge of non-adherence or high risk activities that lead to increased premiums or denial of coverage

— data security risk & nefarious use

— unknown or unsanctioned third party use

Berridge, C., Demiris, G. & Kaye, J. (2021). Domain Experts on Dementia-Care Technologies: Mitigating Risk in Design and Implementation. *Science & Engineering Ethics*

Ways to mitigate risks in dementia care tech (categories)

- intervene during design

- make specific technical choices

- build in choice and control

- enable informed consent

- proactively educate users

- place restrictions on data use and ensure security

- require data transparency

Berridge, C., Demiris, G. & Kaye, J. (2021). Domain Experts on Dementia-Care Technologies: Mitigating Risk in Design and Implementation. *Science & Engineering Ethics*

35

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Berridge, C., Zhou, Y. Lazar, A. et al. (2022). Control matters in elder care technology: Evidence and direction for designing it in. In Designing Interactive Systems Conference (DIS '22), ACM

36

67% of dementia care technologies have been developed without explicit consideration of any ethical principles.

Ienca, M., et al. (2018). Ethical design of intelligent assistive technologies for dementia: A descriptive review. *Science and Engineering Ethics*

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Let's Talk Tech
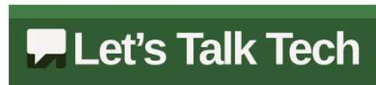
38

Enable informed consent

- Counsel about the risks and benefits associated with monitoring, use of data, by whom

- Establish informed consent as a process

- Repetitive opportunities to try it out and decline

- Provide alternatives to enable actual choice about use

- Advanced directives for technologies that monitor/use AI

Berridge, C., Demiris, G. & Kaye, J. (2021). Domain Experts on Dementia-Care Technologies: Mitigating Risk in Design and Implementation. *Science & Engineering Ethics*

What Matters to people in relation to their data?

An aspect of understanding goals of care is understanding preferences regarding the extent to which one wants more intensive personal data monitoring outside of the clinic.

Build in choice and control

- Enable ability for individual to pause system/data collection

- Enable data deletion and approval by individual

- Employ end-user defined function metrics

- Allow individual to stop or not use

- Provide alternative options to enable actual choice about use

Berridge, C., Demiris, G. & Kaye, J. (2021). Domain Experts on Dementia-Care Technologies: Mitigating Risk in Design and Implementation. *Science & Engineering Ethics*

Let's Tech Tech -helping dyads understand technology options and implications to negotiate use they can feel good about

It facilitates:

1. research-based education about data-diverse technologies:
   - location tracking
   - in-home activity sensing
   - in-home web cameras
   - virtual (AI) companions

2. dyadic communication about technologies

3. documentation of the PLWD's preferences in a collaborative process

Let's Talk Tech — for clinical use
≡ Menu

Welcome to Let's Talk Tech

Why talk about technology now?
Naturally, people feel differently about using technologies to support their care. Having conversations about technology choices can help you think about what you want and don't want. Communicating your choices now is useful for when you might need help in the future.

Sign in to your account

Sign in

Theory of Dyadic Illness Management

Care dyads with shared appraisals and more collaborative illness management will have better health outcomes.

Lyons KS, Lee CS. The Theory of Dyadic Illness Management. *J Fam Nurs*. 2018;24(1):8-28.

43

Intervention hypotheses

—Care partners will demonstrate improved **knowledge of the PLWD's preferences**

—Care partners will feel more **prepared** to make decisions about technology use

—Both groups will report improved **understanding** of each of the technologies

—Care partners will **perceive improved understanding by PLWD**

—Both groups will report greater **mutual understanding** of their partner's feelings about the technologies

44

Pilot findings

n= 29 dyads of people living with mild AD and their care partner (58 individuals)

Age of CPs: 55-83, M=68
person living with AD: 59-82, M=70

100% completion (8/493 total questions skipped)

Most reported that LTT has the right amount of information (>84%), presented in a balanced way (>90%)

It facilitated documentation of the PLWD's preferences.

Berridge C, Turner NR, et al. (2022). Advance planning for technology use in dementia care: Development, design and feasibility of a novel self-administered decision-making tool. *JMIR Aging*

Preliminary efficacy

Care partners demonstrated improved **knowledge of the PLWD's preferences** (+30.5% accuracy)

Care partners felt more **prepared** to make decisions about tech use

Care partners reported improved **understanding** of each and PLWD improved understanding of 2 of 4 categories

Care partners **perceived improved understanding by PLWD**

Care partners reported greater feelings of alignment and mutual understanding

Berridge C, Turner N, Liu L, Fredriksen-Goldsen K, Lyons K, Demiris G, Kaye J, Lober WB. (2023). Preliminary efficacy of Let's Talk Tech: Technology use planning for dementia care dyads. *Innovation in Aging*

THEME: **Provided the structure and direction for hard conversations that may not have otherwise happened**

Exemplary excerpts
CP: You read all these articles that says we need to discuss all these things. And yeah, you know that. But it was like okay because of this we're going to talk about this.
CP: It gave us the direction to talk about it just out front.
PLWD: **I think this could be a good thing to have because it gives you a chance to sort of codify.**

47

THEME: **Raised awareness of technology and its possible applications to their lives**

Exemplary excerpt
CP: I'm 79, and it's kind of like whoa there's a whole lot of new possibilities that we wouldn't even know existed, so I think it's important to really evaluate it and say, would this be helpful or not, you know? **PLWD: Yes, and that's very helpful to know what your options are.**

48

THEME: Sharing perspectives on values and areas of importance

Exemplary excerpt
PLWD: It gives us an opportunity to look at how do we feel about these technological things. CP: Add our input. Get to the heart of our core values and feelings about this stuff.

THEME: Prompted negotiation around possible technology use

Exemplary excerpts
PLWD: It's for clarification. I mean no two people think exactly the same thing, no matter how long they've been together
CP: Every single question we discussed. Yeah we did. Every single one. And also some feelings, you know there again like we talked about if we couldn't trust you at the house alone for safety reasons, you know what-- **PLWD: Yeah and we ironed that out. You know it's been really helpful.**

THEME: Enabled consideration of partner's perspective in planning for the future

Exemplary excerpts
PLWD: I'm sure I'm probably going to be getting worse. So if I could get these things sorted out because I don't want him to always have to do everything. I don't want to be like that. I just don't want to be lagging on this.
CP: It made me feel happy to think he would like a medical alert bracelet. And he would be totally comfortable with a location tracker. So knowing that he's got that comfort with that makes it easier to proceed with pursuing something like that.

THEME: Desire to share preferences beyond the dyad with larger care network

Exemplary excerpts
CP: It was a great impetus for having that kind of conversation because I always want to make sure that I'm on board with what [PLWD] wants primarily because he's got 3 kids who are not my kids and I'm smart enough to realize even as close as we are, when push comes to shove there could be issues....families get rather dysfunctional in these situations.
CP: [this discussion] really needs to be a big family issue, not just the spouse.

Berridge C, Turner N, Liu L, Fredriksen-Goldsen K, Lyons K, Demiris G, Kaye J, Lober WB. (2023). Preliminary efficacy of Let's Talk Tech: Technology use planning for dementia care dyads. *Innovation in Aging*

Implications

People living with mild AD were able to formulate and express their preferences for technology use.

Comprehension and communication barriers to informed, shared decision making are movable.

Berridge C, Turner N, Liu L, Fredriksen-Goldsen K, Lyons K, Demiris G, Kaye J, Lober WB. (2023). Preliminary efficacy of Let's Talk Tech: Technology use planning for dementia care dyads. *Innovation in Aging*

Dyad ID	Tech 1	Tech 2a	Tech 2b	Tech 2c	Tech 2d	Tech 3	Tech 4
1	N	N	N	N	N	N	N
2	Y	N	N	N	N	N	N
3	U	N	N	N	N	N	N
4	Y	N	Y	N	N	U	Y
5	Y	U	N	N	N	U	U
6	Y	Y	Y	Y	Y	Y	U
7	Y	U	Y	Y	U	U	Y
8	Y	N	Y	N	Y	U	U
9	U	N	N	N	N	N	N
10	Y	Y	N	N	Y	Y	Y
11	Y	N	N	N	N	N	N
12	Y	U	Y	Y	U	Y	U
13	U	U	N	N	N	U	N
14	Y	N	Y	U	Y	U	U
15	U	U	N	Y	Y	N	N
16	Y	N	N	N	N	U	N

Implications

Tailoring to the person

- Adds to the evidence that individual needs and preferences vary (Meiland et al., 2017; IBM, 2016; Reeder, et al., 2013; Coughlin et al., 2007; Percival & Hanson, 2006).

- Personalized, tailored solutions are needed for person-centered use decisions (Niemeijer et al., 2015; Meiland et al., 2017).

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Berridge, C., Demiris, G., Kaye, J. (2021). Domain experts on dementia-care technologies: mitigating risk in design and implementation. *Science and Engineering Ethics*

Limited data protections in the U.S.

Data sharing practices matter to people but are inadequately communicated to them (Berridge, 2023).

Example: most health apps focused on dementia require explicit entry of personal information (Ye et al., 2023) –and most lack a privacy policy and admit to possible data sharing with outside parties (Rosenfeld et al., 2017).

Survey section on AI virtual companions and data sharing

- Virtual companions that employ AI (table-top robots)

- Data collection and sharing preferences for:
    - Audio (conversations in the home)
    - Facial expressions for the purpose of inferring emotional state

Berridge, C., Zhou, Y., Robillard, J., Kaye, J. (2023) AI companion robot data sharing: comfort and preferences of an online cohort with policy implications. *Journal of Elder Policy*

"Overall I like the idea of an AI companion or device to check-in on a family member. Particularly to alert medical services and family if an emergency arises. However, I have concerns about how that data is being stored and used by third party companies. Far too often that data is not being stored securely and being sold to third party companies for data aggregation."

-survey participant

Berridge, C., Zhou, Y., Robillard, J., Kaye, J. (2023) AI companion robot data sharing: comfort and preferences of an online cohort with policy implications. *Journal of Elder Policy*

"Would these systems be encrypted? Who would have access to the data? Will it be secured in a robust manner? The opportunity for companies to use this data would enable them to exploit someone with diminished capacities."

"I use a lot of technology. I worry about infringement of personal information. Dementia would affect my ability to monitor abuse of information."

Berridge, C., Zhou, Y., Robillard, J., Kaye, J. (2023) AI companion robot data sharing: comfort and preferences of an online cohort with policy implications. *Journal of Elder Policy*

"My mood is not a piece of data like my temperature or blood pressure. Yet, people tend to accept as information things which are stated with authority. There is huge opportunity for intrusion into privacy and for action taken in reliance on mechanical intelligence against the wishes of the patient."

Berridge, C., Zhou, Y., Robillard, J., Kaye, J. (2023) AI companion robot data sharing: comfort and preferences of an online cohort with policy implications. *Journal of Elder Policy*

61

"Policy + best practices need to keep both [privacy and personal agency] under consideration while exploring these options."

"Any of these devices would be OK if I had full control of when they're on and off...I would want full control of any device like this."

Berridge, C., Zhou, Y., Robillard, J., Kaye, J. (2023) AI companion robot data sharing: comfort and preferences of an online cohort with policy implications. *Journal of Elder Policy*

62

Limited data protections in the U.S.

There is no requirement that developers provide privacy policy statements in the U.S., or make them widely comprehendible (Ho, 2023; Lupton & Jutel, 2015).

"Notice and consent" leaves burden on the user/consumer

Under HIPAA regulations, companies making direct-to-consumer devices are not covered entities, despite the use of health information (Ho, 2023).

63

STAT — Reporting from the frontiers of health and medicine

HEALTH TECH

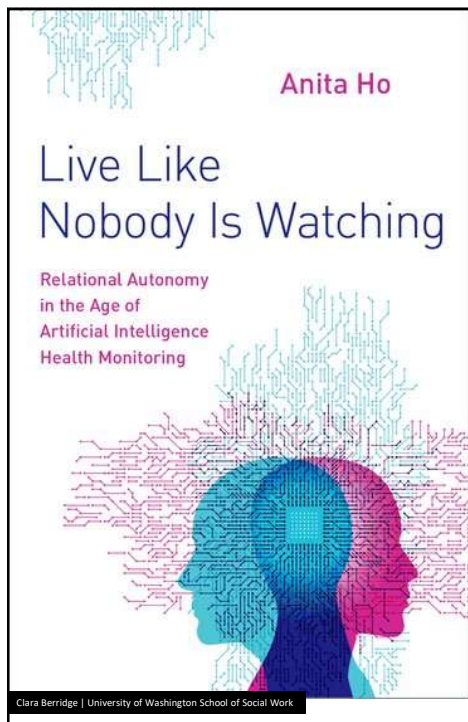**Hospitals pledge to protect patient privacy. Almost all their websites leak visitor data like a sieve**

A STAT INVESTIGATION

'Out of control': Dozens of telehealth startups sent sensitive health information to big tech companies

By Katie Palmer — STAT and Todd Feathers and Simon Fondrie-Teitler — The Markup Dec. 13, 2022

64

Anita Ho (2023). Live Like Nobody is Watching: Relational Autonomy in the Age of Artificial Intelligence Health Monitoring. Oxford University Press

Key Questions

- With interdependence in view, how do we support decision making in which peoples' preferences and values are considered?

- How do we ensure people have opportunities to manage their own boundaries?

- How should information and data technologies be presented to enable meaningful engagement?

- How do we ensure that older adults' diverse interests are represented in data privacy regulation and AI governance?

Collaborators and funding

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67

67

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Thank you
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68