HELPeR: A Novel Digital-Health Librarian Supporting Ovarian Cancer Patients and Caregivers Through Tailored Health Information

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Introduction

- Ovarian cancer (OvCa) poses complex physical, emotional, and informational challenges for both patients and caregivers.
- These challenges are intensified by limited disease knowledge, inconsistent information quality, and the complexity of treatment decisions.[1,2]
- **HELPeR (Health E-Librarian with Personalized Recommendations) (**R01 LM013038) is **a digital health platform** designed to empower OvCa patients and caregivers.
- Provides tailored, evidence-based health information to support informed decision-making and proactive disease management.
- **Customizes recommendations** according to each individual's: disease stage and trajectory, information needs and literacy level, personal preferences and goals

Objective

To examine user characteristics, online information-seeking behaviors, and perceptions of the recommended information.

Methods

- **Design**: 12-week longitudinal study with surveys administered at baseline, week 6, and week 12.
- **Participants**:
  - Recruited in person and online.
  - Eligibility: Confirmed OvCa diagnosis (patients) or identified as a caregiver for someone with OvCa.
  - Must have internet access for participation.
- **Procedure**:
  - Participants received a guided tablet-based demonstration of HELPeR, highlighting: Personal Library, User Profile, Recommended Articles, and Feedback Tool
  - Participants were encouraged to use HELPeR freely in daily life throughout the study period.
- **Data Collection**: Surveys captured engagement patterns, usability, and changes in information access and confidence over time.

Characteristic	Patients (n = 7)	Caregivers (n = 13)
Age (years), median (range, IQR)	66 (30, 26)	52.5 (46, 23.25)
Female, n (%)	7 (100%)	7 (53.8%)
Hispanic, n (%)	7 (100%)	12 (92.3%)
Married, n (%)	3 (42.9%)	10 (76.9%)
College degree or higher, n (%)	6 (85.7%)	9 (69.2%)
Employment status, n (%)		
Employed	3 (42.9%)	7 (53.8%)
Retired	3 (42.9%)	4 (30.8%)
Adequate health literacy, n (%)	5 (71.4%)	8 (61.5%)
Self-rated OvCa knowledge, median (0 = Not at all – 10 = Expert)	7.5	5.5

Table 1. Participant Characteristics

Results

- A total of 20 participants were recruited; participant characteristics are described in Table 1.
- **Online Information Use**:
  - Search engines (e.g., Google, Bing) were frequently used and perceived as helpful by: 71.5% of patients (n = 5), 69.3% of caregivers (n = 9)
  - Experience with online recommendation systems (e.g., Netflix): Patients: 85.7% (n = 6), Caregivers: 84.6% (n = 11)
    - However, fewer found them helpful: Patients: 42.9% (n = 3), Caregivers: 53.8% (n = 7)
- **HELPeR Usage Patterns**:
  - Patients: Accessed 29 articles, bookmarked 11, submitted 19 feedback responses.
  - Caregivers: Accessed 13 articles, bookmarked 2, submitted 19 feedback responses.
  - Both groups rated **recommended articles highly for relevance and ease of understanding**.
  - Most frequently accessed topics: Symptom management and treatment information (Table 2).

Overall Top Accessed Topics (n)	Caregivers' Top Accessed Topics (n)	Patients' Top Accessed Topics (n)
Symptom/Treatment (n = 51)	Symptom/Treatment (n = 32)	Symptom/Treatment (n = 20)
Treatment (n = 24)	Caregiving (n = 12)	General Information (n = 18)
General Information (n = 21)	Treatment (n = 8)	Treatment (n = 15)

Table 2. Frequently Accessed Topics

Discussion/Conclusion

- **Active Information Seeking**: Both patients and caregivers actively search for online health information, underscoring the need for personalized, evidence-based tools like HELPeR.
- **Promise of HELPeR**: High engagement and positive feedback indicate HELPeR's potential to bridge informational gaps and improve access to trustworthy cancer-related resources.
- **Engagement Differences**: Patients engaged more frequently than caregivers, likely reflecting greater perceived information needs or caregivers' limited time and competing demands.
- **Limitation**: The sample largely consisted of individuals with higher education and digital literacy, which may limit generalizability to broader populations.
- **Future Directions**:
  - Explore barriers and strategies to enhance caregiver engagement.
  - Evaluate HELPeR's long-term impact on health outcomes.
  - Assess variations in use by gender, role, and demographics.
  - Expand recruitment to improve diversity and representativeness.
- **Overall Impact**: Digital platforms like HELPeR hold strong potential to enhance information access, support informed decision-making, and improve the care experience for both patients and caregivers.

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Citations

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