Sharing Health Information on Facebook: Practices, Preferences, and Risk Perceptions of North American Users

Sadegh Torabi & Konstantin Beznosov
health information (HI) on the Internet

• Shared online since the 1990s [Pew Research Center]

More recently,

• 80% of internet users looked online for different health topics

• Increasing number of users who share/seek HI on social networking sites (SNSs):
  - 26% followed friends’ health experiences
  - 16% looked for others with similar health concern
  - 11% posted comments, queries, or information about health
to share HI on SNSs or not?

• **Expectation of benefits**
  - Social support, learning from shared experience, and self-management education
  - The benefits are **two-way**

• **Perceptions of risks**
  - HI is **personal** information
  - Privacy invasion, unintended information disclosure, shared information misuse

• **Other factors** (e.g., health status, privacy attitudes)
why, how, and with whom people share their HI on FB?

investigate

- the main factors that influence users’ motivation to share
- features that enable effective and safe sharing
methodology

1. Exploratory study (1 hour interviews)
   - Guided by grounded theory (sampling, data collection, and analysis)
   - Interviewed SNS users with chronic health condition(s)
   - Explored HI sharing practices, risk perceptions, and motivation to share HI on FB

2. Confirmatory study (online survey)
   - Recruited a more representative sample of FB users
   - Validated and extended our findings
results: interview study

- recruited through Spinal Cord Injury BC, Craigslist, kijiji
- 21 FB users with different chronic health conditions

**Gender**
- Female: 7
- Male: 14

**Age**
- 19-30: 1
- 31-40: 4
- 41-50: 3
- 50+: 1

**Health conditions**
- Mental: 3
- Physical & mental: 4
- Physical: 14
results: qualitative data analysis

- Open coding (line-by-line coding): 90 unique codes after analyzing 8 interviews
- Axial coding (interrelated codes/categories): 10 categories
- Selective coding (core category): *Motivation to share HI on FB*

### prior HI sharing experiences
- Shared HI before?

### perceived benefits
- learning from the shared experiences
- initiating conversations
- reaching out to others who had similar health conditions
- engaging in social support

### recipients of the shared HI
- Close friends/family
- Friends/family with mutual health experiences or medical expertise
- Strangers with similar health conditions or medical expertise

### health status
- Perceived good health
- Manageable condition
- Health conditions and stigma (e.g., mental)
- Anonymity and online identities (e.g., physically unreachable)
- SNS vulnerabilities and HI misuse (e.g., misuse by insurance companies)

### privacy concerns
confirmatory study: online survey

- Close- and open-ended questions about HI sharing practices, preferences, and motivation
- Recruited 492 Facebook users through Amazon MTurk (95% approval rate, $1 compensation)

<table>
<thead>
<tr>
<th>Gender</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>Female</td>
<td>49.9%</td>
</tr>
<tr>
<td>Male</td>
<td>50.1%</td>
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<table>
<thead>
<tr>
<th>Age</th>
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<tr>
<td>19-30</td>
<td>46%</td>
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<tr>
<td>31-40</td>
<td>29%</td>
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<tr>
<td>41-50</td>
<td>13%</td>
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<tr>
<td>50+</td>
<td>12%</td>
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<table>
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<th>Completed education</th>
<th>Percentage</th>
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<td>Undergraduate</td>
<td>43%</td>
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<tr>
<td>Diploma</td>
<td>7%</td>
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<tr>
<td>High school</td>
<td>10%</td>
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<tr>
<td>Graduate</td>
<td>12%</td>
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<tr>
<td>Some courses</td>
<td>28%</td>
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<table>
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<th>participant characteristics</th>
<th>%</th>
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<tr>
<td>Had degree or experience related to IT/Computer</td>
<td>20</td>
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<tr>
<td>Spent 2 hours or more on the internet every day</td>
<td>91</td>
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<td>Checked Facebook on daily basis</td>
<td>85</td>
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<td>Were on Facebook for at least 4 years</td>
<td>97</td>
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motivation to share HI on SNSs

- 51% shared the HI on SNSs
- Sig. difference between both groups
- experience with HI sharing

- positive experiences correlated with benefits
  Sig. difference between Positive & other groups

- number of health conditions
- health status

Health categories
- Healthy 73
- Manageable 253
- Unhealthy 66

Sig. difference between Healthy & Unhealthy groups
Sig. difference among all groups

between-subjects comparison using Kruskal-Wallis and Mann-Whitney U test
preferred recipients of the shared HI

“I would consider sharing my HI with the following FB users.”

- **Friends/family** members were preferred over other users

- **Sharing HI with strangers**
  - Unhealthy vs. Healthy

- **Willingness to search for different users**
  - with mutual health experiences vs. medical expertise
other preferences

- **Anonymous** online identity (e.g., hide last name, location info)
- Trusted SNS **provider** (e.g., governmental health authority)
anonymous online identity

“Suppose you want to create an anonymous identity in order to share your health information with strangers on Facebook. How likely would you ‘hide’ each of the following personal information?”

- 36% were likely to use anonymous identity for sharing HI with strangers
- Explored willingness to hide different information items
  - Identified correlated items using principle component analysis (PCA)
- Users were significantly less likely to hide Demographic information
- Hiding of health condition(s) was correlated with hiding of demographic information
Trusting SNSs based on recommendation made by others?

- recommended by their doctor(s) vs. friends and/or family members
design implications

FB can **motivate** HI sharing by:

1. Facilitating finding others with mutual health experiences (e.g., automatic recommendations?)

2. Providing an option for creating anonymous online identities in order to share HI with strangers (e.g., hide contact, location, and identity information)

3. Motivating users’ through their doctors (e.g., incentify doctors to recommend FB)
contributions

• **Explore** HI sharing practices on FB

• Provide a better **understanding** of users’ motivation to share

• Identify the main **factors** that influence users’ motivation

• Shed light on **features** that could facilitate sharing
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