Liver Space
A facebook health application to strengthen online communities

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Importance of Early Diagnosis in BA

- Early diagnosis is associated with better outcomes
- One of the only clues to aid in early diagnosis is a baby’s pale stools
- Stool cards programs have been shown to shorten diagnosis time, improve survival and decrease rates of transplantation

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Infant Stool Color Card

No. of Booklet: __________

Abnormal

1

2

3

It is essential to observe your baby's stool color continuously after discharge from a nursery. If the stool color resembles the numbers 1~3 (white, clay-colored, or light yellowish), the possibility on your baby suffering from biliary atresia is higher. Please take this card and your baby to consult a doctor as quickly as possible. Regardless of what the stool color is, please bring this card to your doctor at 30 days of age for health check. If the baby cannot go back for health check, please fill in the number of the color resembling your baby's stool, along with the following blanks, and mail this card to our registry center.

Normal

4

5

6

The baby’s stool color is most like No. __________ Date of this kind of stool __________

Name of the baby ________ Birthday __________

Name of the mother ________ Tel. __________

Address __________

The hospital or clinic where the baby was born __________

If the number is No.1~3, please inform us by fax immediately. We will provide the related information and help you out.

Fax: 02-2388-1798 ; Tel: 02-2382-0886

Infant Stool Color Card Registry Center

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*Lien TH, Hepatology, 2011
PoopMD

- Increasing role for mobile health applications
- Greater functionality compared to cards
- Preliminary data suggests PoopMD is over 90% accurate in identifying pale stools
- Advanced analytics
- Version 3: Integrated with Apple Researchkit
Changing Health Landscape

- More data sources collected remotely
- The quantified self more accurate?

(Steinshubl SR et al., Science Translational Medicine, April, 2015)
Changing Health Landscape

over 8000 downloads for Parkinson’s and asthma app
• 1.65 billion users
• 90% of 18-24 years olds would use social media to engage in health activities and trust info, and 80% would share info
• 56% of 45-64 year olds would use social media to engage in health activities and trust info, and 45% would share info

(pwchealth.com)
Social Media and Liver Disease: What’s out there?

- *both initiatives developed by Johns Hopkins and Dr. Andrew Cameron*

on facebook:
- declare organ donor status

- reach out to potential living donors
Social Media and Liver Disease: What’s out there?
Social Media and Liver Disease
What’s out there?

Entered the following search terms (May, 2016):

biliary, Alagille, alpha-1, Wilson, autoimmune hepatitis, hepatitis, primary sclerosing, fatty liver, liver transplant, and NAFLD:

• 26 groups with over 1000 members
• 9 groups with over 2000 members
• The largest groups were centered around (N): pediatric liver transplant (7828), fatty liver (5146), viral hepatitis (4822; 4271; 3025; 2638), biliary atresia (4063) and alpha-1-antitrypsin deficiency (2192)
Limitations of the facebook Environment

Difficult to search

- facebook is about scrolling (i.e., only recent posts)
- facebook is **not** about searching for older content

Structured forums and threads would be better suited for searching old information

- lacks structure
- can’t find misspelled medical jargon
Liver Space 1.0: a mobile app

A hub for those with liver disease or caring for others with liver disease

- Update patient profile, lab results, weight, and medications
- Participate in clinical research studies to better understand pediatric liver disease
- Find out more about liver disease, medication, nutrition, and hot topics
- Ask questions and get answers from peers and experts

Download on the App Store
Download on Google Play
Liver Space 2.0: a facebook health app

• built with the facebook application programming interface
• seamlessly integrated into the facebook experience
  • individuals who sign up for Liver Space are logged into the app whenever they are logged into facebook
  • when patients receive updates to their Liver Space account, the notifications (red dot 🔄 are posted to their main facebook account
• expand on the building blocks of facebook (i.e., people, platform), and provide new functions to enhance the existing community
• leverage facebook’s advertising mechanism to engage the thousands of liver group members to download Liver Space
Liver Space 2.0

An information hub for children living with liver disease, and for the people who care for them.

track
Update patient profile, lab results, weight, and medications.

research
Participate in clinical research studies to better understand your disease.

learn
Find out more about your liver disease, and receive the latest news related to your disease.

q&a
Ask questions and get answers from peers and experts.
Liver Space 2.0: Create a Profile
Liver Space 2.0: Administrative Dashboard

dashboard allows administrator(s) to monitor user profiles and distribute content to appropriate users
Liver Space 2.0: Research

receive questionnaires that are tailored to the user’s interest
Liver Space Research: Initial Questions

• better understand cultural barriers to living donor liver transplantation

• evaluate patient satisfaction in young adults transitioning care from pediatric to adult hepatologists

• assess knowledge about nutrition among adolescent liver transplant recipients

• determine proof of understanding following informed consent in mHealth vs face-to-face

• use of the Liver Transplant Quality of Life survey

• prevention of community-acquired infections in transplant recipients
Liver Space 2.0: Hot Topics

receive the latest news that’s tailored to the user’s interest
Liver Space 2.0: Forums

create threads and easily search content
Liver Space 2.0: a facebook health app

current functions

• develop profiles based on disease, age, transplant status
• tailored hot topics and research
• q&a: forums/threads
• ask an expert
• basic info on diseases, meds, nutrition, and blood tests
• track: labs, weight

proposed functions

• identify people who live nearby in order to organize play groups
Liver Space 2.0: User Dashboard

one place for updates to:
- forum responses
- ask an expert responses
- hot topics
- research invitations
Value Proposition for Liver Space
Consumers

Enhance community *between* patients/caregivers

- forums and threads
- find people with similar diseases that live nearby (future)

Enhance community by *creating a bridge* to healthcare providers

- receive the latest news
- obtain basic, accurate info about drugs, nutrition, etc.
- ask an expert

Tools to improve care: lab and weight tracking
Value Proposition for Liver Space Researchers

• creation of a database with users that are highly engaged in social media and corresponding liver communities

• distribution of surveys to conduct patient-centered research

• expansion of the sampling frame for research beyond (elite) academic centers
Value Proposition for Liver Space
Johns Hopkins University

- potential to increase referrals

Is this the first Facebook health app that is centered around existing groups, and designed to enhance community, and promote research?

- opportunity for Hopkins to be a leader in a new model for community engagement and research in patient-reported outcomes
What Do Members of Liver Groups Think?

277 respondents (>18 years), 88% female
median 10 hours per week on facebook

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<th>Table: Interest in potential Liver Space functions</th>
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<tr>
<td>Source:</td>
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Timeline

• Funding: grant from The Gilead Foundation (May, 2015)

• Phase 1: development of mobile app → lots of problems

• Phase 2: work with Johns Hopkins Technology Innovation Center to create a facebook integrated app for desktop and mobile

LAUNCH AUGUST 1st

• Phase 3: work with family advisory council to expand functions (e.g., local support groups) and research
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<td>• advertise posts from Liver Space forums to users primary facebook page</td>
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