Patient and Provider Experiences using e-Health Tools for Self-Management in Long Term Conditions

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Background

- Rapid development of and increased access to online information, mobile health apps, and digital tools is accelerating change in health care delivery and chronic illness self-management

→ *engaged & empowered e-patients*

- Yet little research has systematically focused on ethical or practical ramifications for patients and health care providers

Relational Ethics Lens

- Extends bioethical principles (e.g., autonomy, beneficence, justice) to “everyday ethics”
- Emphasizes context, interpersonal relationships, interdependence
- Well-suited to examining characteristics of the patient-provider relationship, e.g., mutual respect

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Sounds like client-centred practice

Study Objectives

To examine…

- how people with multiple morbidity (arthritis plus $\geq$ 1 other chronic condition) use e-health in their daily lives,
- how health care professionals use e-health in their practice,
- how e-health affects patient-provider relationships, and
- the ethical and practical implications of e-health for both parties in the context of supporting self-management of chronic conditions

Design: Narrative Approach

- To hear storied accounts and gain ‘insider’ perspectives of health-related actions arising from e-health use

Stories from two perspectives:

- Patients with multiple chronic conditions b/c they deal with complex self-management and care plans, sometimes receiving contradictory advice
- Health Care Professionals (HCP) from any discipline providing direct care

Data Gathering in Two Phases

- Focus groups (2 – 2.5 hours) explored range of experiences with e-health tools and resources
- Separate groups for Patients and HCPs
- Findings broadly described ehealth use; informed an interview guide

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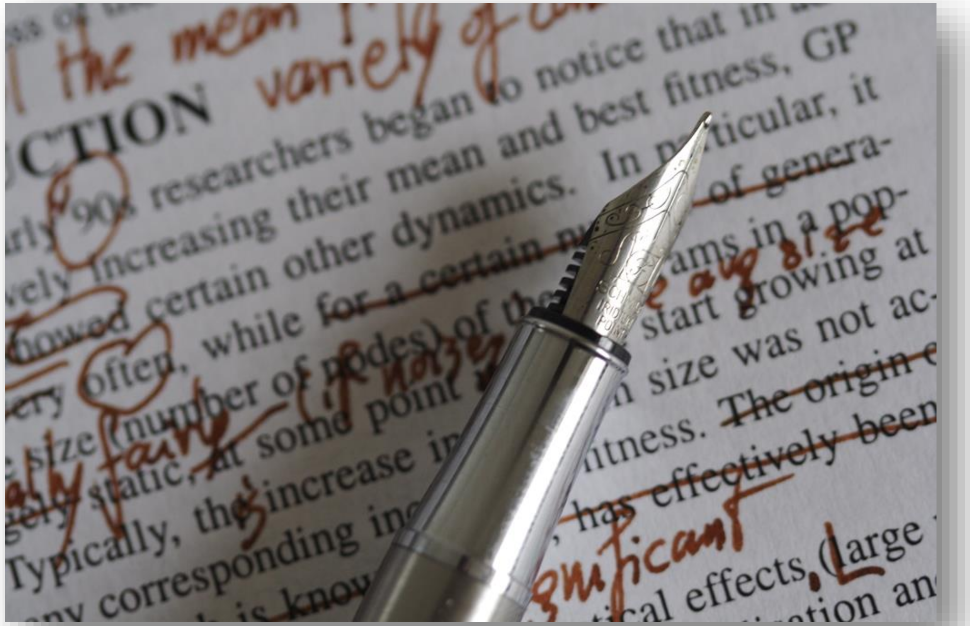
- Findings broadly described ehealth use; informed an interview guide
- Individual interviews with additional Patients and HCPs to gain more in-depth understanding and examples of evolving relationships
- One face-to-face interview (40-90 minutes) plus telephone follow up interview (15-30 minutes)

Data Analysis

Iterative, thematic analysis drew on elements from both narrative and grounded theory traditions

- focus groups first
- then interviews
- then all data + literature



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65 Participants

35 Patients

n = 18 in 4 focus groups

n = 17 in-depth interviews

85% women

Age: 20s to 70s

60% reported 2 to 5 conditions

40% reported ≥ 6 conditions

OA, RA, depression, irritable bowel, diabetes, kidney disease, cancer…

30 Health Care Professionals

n = 18 in 3 focus groups or converse

n = 12 in-depth interviews

64% women

Age: 30s to 60s

Experience: 1-29 years in practice

Physicians (fellows, GPs, specialists), Nurses, Occupational Therapists, Physiotherapists, Lab Tech

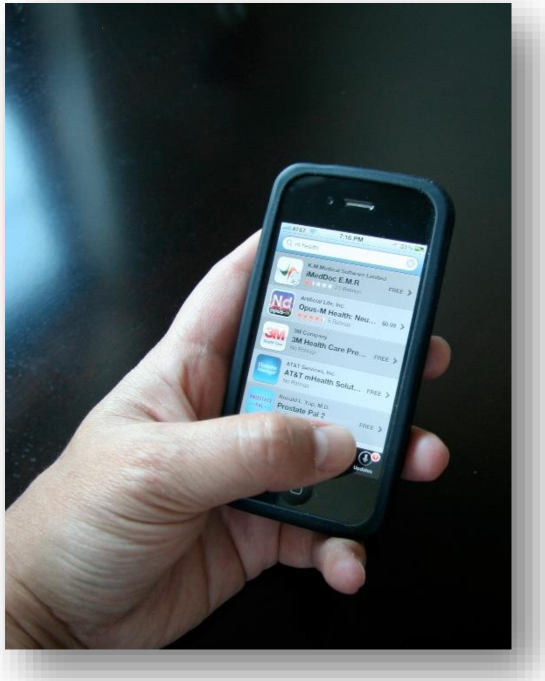
Patients talked about using…

- Internet sites for health information
- Social media, e.g., blogs, Facebook (closed groups), Twitter
- Monitoring devices (mobile apps, wearables), e.g., to track blood sugar or blood pressure, diet, physical activity
- Patient portals, e.g., download test results
- E-mail & video consultations with HCPs

Experiences on what was helpful or not, cautions, frustrations, hopes for future

HCPs talked about using…

- Internet sites to stay current, including professional development subscriptions like UpToDate
- Internet sites to print patient handouts, like RheumInfo
- Electronic health records and pharmacare database
- Diagnostic tools and calculators (apps or online)
- Test results or monitoring devices patients brought to the office/clinic visit



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Recurring ethical or moral topics

Respectful Relationships
Empowerment/Shifting Power

Credibility & Skepticism
Balancing Burden & Benefits
Efficiency

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→ specific to implications of e-health on practice

Online Health Information

- Patients and HCPs reported similar strengths and concerns
- HCPs uniformly guided patients to specific sites
- Patients pointed out that HCPs were “only human”

Online Health Information

- Patients and HCPs reported similar strengths and concerns
    - defined trustworthy sites & search strategies
    - shared cautionary tales
- HCPs uniformly guided patients to specific sites

- Patients pointed out that HCPs were “only human

Online Health Information

- Patients and HCPs reported similar strengths and concerns

- HCPs uniformly guided patients to specific sites
  - several thought online info was increasing health literacy
  - but patients bringing too much info to consultations = problematic
- Patients pointed out that HCPs were “only human”

Online Health Information

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  appreciated HCPs who said “I don’t know” and
  engaged in respectful dialogue vs being dismissive

I think it (e-health) ***makes consultations more collaborative****. It also helps to sort of level the playing field of knowledge. I, those patients becoming experts in the disease, we may have more of the expertise on the latest updates and stuff and the patient becomes more of an expert in their own experience of the disease and monitoring it. Then it comes together and they really navigate and get better health outcomes. Teamwork… you're working together toward the end goal. [MD]*

Respectful relationships; shifting power

> *…****it’s really exciting because we can actually do more****. The person is coming in already thinking about things, forming questions and so I think* ***it really helps us to perform health literacy in a much more meaningful and deeper way****. And I think there are patients that really value that. [MD]*

Respectful relationships; shifting power

*I think part of that is being overwhelmed. You know, because **the internet is incredibly overwhelming**. I mean, how many hundreds of thousands of hits do you get from just searching on Methotrexate for example. [RN]*

*…on the first visit (I want them to) recognize that what’s on the internet, there’s quite a bit of variability and anyone can publish there. So they **recognize that danger about just believing everything you read**. Some people are misled by the internet. Sometimes it can cause a lot of anxiety. [MD]*

Balancing burdens & benefits; Credibility & scepticism

> *I go on them to look up medications, side effects, symptoms, and other natural ways to combat.* ***And I always look for hopeful stories****… And you know what else? I also look up a lot of, like, inspirational stuff like it might sound corny. But things like affirmations…*
>
> *They say something like your disease can really depend 90% on your mind and 10% of your physical, right. So that's really huge for me. I'm trying to get there. … I'm trying to identify, trying to find people that kind of are sort of in the same boat as me.*
>
> [Patient Focus Group 2; Participant 1.]

Balancing burdens & benefits

*It's **empowering**…well, there's just more information accessible at your fingertips so you don't have to wait to ask a doctor. You can just look something up. It allows you to be proactive rather than waiting for an expert. **You can almost become your own expert**. [Patient: Claire]*

Monitoring Tools: “know your numbers”

- Patients & HCPs relayed benefits from tools that tracked patient progress, e.g., being able to “look at the numbers” augmented the quality and efficiency of the consultation

  But:

- HCPs interpreted this as a way to enhance adherence while
- Patients saw this as support for shared decision-making and, in some instances, liked to monitor numbers for general interest not behavior change

I was interested in the monitoring because I like to think that I walk enough and I exercise enough. ***I'd like to monitor things but I'm lazy. So if it doesn't work or it takes too much energy to track then I won't do it****…*

But what I'd be interested in, I know that they're coming out with really fancy sensors you know, that will sync to your phone and do that kind of thing. If I had the money to get that then I probably would because I think it would be quite interesting. [Patient: Claire]

Balancing benefits & burdens

Which brings up another e-health I forgot to mention and that’s lab data.

…(the lab) has a portal that patients can log into and look at their own results. I think that’s really useful. Patients used to come to my office or phone my receptionist, and we’re getting a lot less of those calls now. Sometimes they call, they want some explanation, but generally less. In fact, I tell pretty much everybody to start looking at their own results because I don’t want to be the guardian of their results. ***I expect people to be partners in their health and I want them to know what their numbers are****. I want them to know how to read and interpret them. It saves me time and I think it’s better for the patient to be educated. …that’s been a really good thing. [MD]*

Shifting power; efficiency

E-mail: uses and abuses

Patients appreciated the efficiency of e-mail when available and looked forward to a future with online bookings, confirmations, and document exchange

HCPs were divided over benefits and drawbacks to e-mail

Most HCPs believed e-mail couldn’t be adequately controlled, re: best use of their time plus liability and privacy concerns.

I have this stellar client who e-mails me questions in advance, which kind of gets me prepared, she's prepared.

Much of it's empowering patients via education. So them coming and having done their pre-reading ***gives you more time to focus*** *on what you're going to assess, treat, and actually impact. [AHP]*

Efficiency; Shifting Power; Balancing benefits & burdens

*With email, it's hard to track it and document it; if you missed one, there would be **a lot of risk**. If you went away on vacation, for example, and somebody emailed you something really important and you weren't there, I think it can cause some **medical legal issues**. [MD]*

Balancing benefits & burdens

Social Media

Patients were divided over benefits and harms of social media

Most reported it a source of social support, immediate empathy or nurturing when needed, or genuinely helpful for learning about events and resources

Those who found it helpful knew how to use it and guard privacy.

Others believed it would be a waste of time or overwhelming.

> *Like, I sort of am following this one girl who is a tri-athlete who has RA and she's now off medication. She's on remission now and training to go for the triathlon or whatever. That's exciting for me. I don't think I'll get that far but I mean it's just about getting back on my snowboard and back on my mountain bike. So finding stuff like that…* ***a sense of hope and inspiration and, like, motivation*** *because there's a lot of days that I'm not very motivated. And it's hard to, I don't know how you feel but, like, when I'm in pain I just don't, it's kind of depressing [laughter].*
>
> [Patient Focus Group 2; Participant 1]

Balancing burdens & benefits

A lot of support groups will have links where they'll have stories… I think those are great because you just kind of get a different perspective… ***to me that's the real thing that gets you kind of a kick in the pants to say it's time to move on.*** *You know, get over feeling sorry for yourself and get out and enjoy life.*

[Patient: Kevin]

Electronic Health Records & Patient Portals

Patients and HCPs anticipated a future where digital data was linked and accessible, enhancing communication, making visits more efficient, and leading to better health outcomes

*I think it **would be great if patients had copies of their health records** on some app, had copies of their imaging. I think that would be very useful. If we had a centralized system, that would be useful. Like having St. Paul’s, VGH, and Royal Columbian on different systems is ludicrous.*

*Having blood work available to all, **we wouldn’t have to repeat so much blood work**. **We wouldn’t have to repeat imaging**. [MD]*

Efficiency

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e-Health Tools, Behaviour Change, & Patient-Provider Conversation

- Tools by themselves will not change health behaviours and habits

Well I have the blood pressure app… And so what I do is I go down to the pharmacy and I take my blood pressure and then I can put it in the app. And it gives me a rating and …tells me how I'm doing from week to week. I usually go once a week…and it tells me what kind of level I'm at. You know, am I spiking here or there or staying normal or is it going up or down. You can put in your height and your weight and whether you're sitting or standing, left arm, right arm. And then it also has some other stuff in there as well that you can look up. It has a bunch of things as well but mostly I just use that part.

Well every once in a while I'll look back and I'll see how it's doing because I take two kinds of blood pressure medicines; my blood pressure is higher because my kidney is damaged…and I'm also overweight. But I'm not super duper heavy overweight but I'm overweight like everybody else in North America.

And so I kind of try and watch that and I want to see how it does. But then I go to my specialist and he always asks how is it? So now when I go there, I can show him, which I couldn't do before because it actually graphs it.

Which would have been perfect but my phone just updated and it dumped everything I had so that didn't help. But the idea is there…oh yeah that's what happened. I lost a whole bunch of other stuff that I had, which was really annoying.

Interviewer: So if you take …that tracking in, is that your rheumatologist you take them in to? [yes] *What would they do with that then? Do you have a conversation?*

Well he'll usually say, 'Well how is it doing?' And I'll say, 'Well, you know, it's stable' or 'It hasn't changed much' or 'it's gone down a bit.' And then he'll usually say, 'Well why do you think it's gone down?' And then I'll tell him, 'Well I'm exercising more' or 'I've lost ten pounds.' And then he usually makes me weigh myself and tells me I haven't lost anything at all. So we discuss that and he says, 'Well if you lost some weight that would help. And if you exercise more that would help.' You know, he tells me what to do, which I go home and promptly don't do. But yeah, that's usually what we talk about.

Interviewer: Does that help you in any way, you know, does it actually influence the exercise you take or the food you eat or would you just want it to and it doesn't?

I think it does influence it because I think more about it. … But trying to get away from those habits is difficult. But I think it helps because if it started spiking and going up, I'd be, oh man, you know, I'm going to have to watch even more carefully. I think it's handy for that… I'm sure there's probably more [apps] that I could do if I really put my mind to it. But I don't even know how I ended up with that one on there to tell you the truth. I think I saw it somewhere and thought, oh I'm going to try that.

Yeah, there’s no end to it (email) really. That’s the problem. The patient will ask a question. I’ll reply. Then they’ll reply. You know when it’s an office visit, I feel like there’s a finite amount of time for the consultation. And then both the patient and I say, ‘okay, times up for this appointment. If you want to talk some more, come again.’ But that doesn’t happen with email. With email it just goes on and on. [MD:Michael]