Exploring E-Health Ethics and Multi-Morbidity: A Qualitative Study of Patient and Clinician Views and Experiences of Using Digital Media for Health Purposes

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BACKGROUND E-health refers to a spectrum of digital health resources. The rapid explosion of health Internet use is viewed as transformational in accelerating the shift toward more informed, engaged and empowered patients as partners in healthcare.

OBJECTIVES To examine how people with arthritis and at least one other chronic condition use e-health in their daily lives and how clinicians use e-health in their practice; how e-health affects patient-health care provider communication; and explore the ethical and practical ramifications for patients, clinicians and health service delivery.

METHODS This qualitative study is generating data through focus groups and in-depth interviews. Fieldwork is ongoing. Results presented here are based on the focus groups we have conducted to date with patients and a range of health care professionals (HCP). Sessions were audiotaped, transcribed, and analyzed thematically, drawing on constant comparison, narrative, and grounded theory approaches. Building on our findings, we will conduct 24 in-depth interviews over 3 mos.

PARTICIPANTS We conducted 7 focus groups with a total of 32 participants: 4 patient groups, n=18, (16 women, 2 men) and 3 HCP groups, n=14, (11 women, 2 men). Groups averaged 4-5 participants. The age range across participants was 29-73 yrs.

Preliminary Findings

Trust

Not surprisingly, building trust in the patient-clinician relationship was key to successful information sharing in consultations (patients & HCPs);

Privacy concerns were expressed but were not as significant for patients as might be assumed.

"If there isn't that thread of trust binding you together… I think it's really crucially important … because you trust them (HCPs), you're taking it (Internet information) to them for the filtering right?" (Patient 2-FG1)

Responsibility

Strong agreement among patients of their responsibilities to be informed and equipped to ask pertinent questions in consultations;

Given multimorbidities, patients felt responsible to keep their health care team informed/couldn't rely on effective inter-professional communication.

" I work with a physiotherapist, an occupational therapist, social worker, my rheumatologist, my doctor, my infusion nurses… and other specialists… I am probably the centre of all that because I make sure that… I look at a test and see which of my doctors needs to see that" (Patient 2-FG4)

shifting roles transition tensions

Burdens

Working to find relevant, up-to-date and trustworthy information (patients & HCP);

Negotiating new roles in consultations e.g., sharing information (patients & HCP);

Burdens are amplified among patients with multimorbidity

"Researcher: What about when patients come in with information; how do you handle it?

HCP: Head on! Let's talk about. Where did you find it? What do you understand? And then take it from there."

(HCP-1-FG3)

Partnerships

Both patients and clinicians saw working together in a mutual partnership as a positive change;

This shift/change came with tensions such as potential challenges to clinician knowledge and patients not feeling equipped to be active e-patients.

"It's not the old medical hierarchy… you never asked a patient what they wanted… (now) we're negotiating. What have you read?... It's way more interactive because of the abundance of knowledge. Like the Internet is… huge (HCP-2-FG3)

IMPLICATIONS Patients with multiple chronic conditions have particular challenges in managing their health. As we track the transition toward engaged, empowered patients working with HCPs accelerated by e-health tools, it is critical to make the ethical issues visible.
We need to ask what do the shifting roles look like? What does transformation mean for patients, HCPs and the healthcare system?
How far does e-health impose new responsibilities on patients and amplify the considerable patient work that patients with chronic illness already do? [1-3]

LIMITATIONS Our study is ongoing. Ethical tensions are emerging as digital tools and e-health evolve. Change is rapid. As we continue our analysis we need to be cautious regarding any claims we make due to the unfolding nature of this area of study and practice. We recognise the need for flexibility as we develop a more rigorous understanding of how e-health will enhance or impede ethical health care delivery/services/experiences for patients and HCPs.

NEXT STEPS More in-depth constant comparative anaylsis, look for nuances, commonalities and range. Phase II: Conduct ~24 in-depth interviews with patients and HCPs to fully explore issues that emerged in focus groups; develop recommendations for practice and research on ethics in a digital world.

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