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Using technology to manage long term conditions – patient perceptions

Long term conditions patients' attitudes and experiences of digital healthcare

Twenty-two people with long term conditions of fibromyalgia, myalgic encephalomyelitis (ME) and acquired brain injury were interviewed and asked to reflect on their experiences of receiving healthcare services and how they could see technology being used.

Participants were recruited through patient support groups and were in the age range 25 – 66 years (mean age 47), 3 males, 19 females.

Many of the patients reported one or more secondary long term conditions in addition to the primary one (hypermobility syndrome (4), chronic pain (12), arthritis (4), diabetes (3), irritable bowel syndrome (3), periodical depression (2), osteoporosis (2), spinal stenosis (1), chronic cough (2), sleep apnoea (1), Vitamin D deficiency (1), dystonia (1), pernicious anaemia (1), Barrett's oesophagus (1), Bipolar disorder (1)).

Attitudes to technology

- Most were active on Social Media and used the Internet for utility purposes, accessing information, networking and entertainment.
- Half of the participants reported using health apps and health monitoring devices, particularly medication reminders and pain diary apps.
- However, a few participants were unfamiliar with using any form of computer or mobile device.
- Of those that did use technology, some reported that they found it helpful for informally managing their condition, through friends and online patient communities.

"Helps me feel I'm not alone...helps with benefit claims, enables me to help others in similar situations..."

"Internet gives me the chance to participate in so many things, and contact people, which due to my condition I wouldn't be able to do without it"

Shared patient records

- Many patients reported difficulties in getting their condition satisfactorily diagnosed and frustrations at different professionals not having their full history to hand
- Some patients also noted that they would like to have access to their records so they could ensure key information is noted.

"If I could access my own records pre my GP appointment, I could read my consultant's letter and attend my GP appointment more prepared."

"I think it's about time, saves you trying to explain your condition/s over and over to each service provider."

"I would love to be able to access my medical notes and care in one package, where there are contact links for everyone dealing with my specific case/needs and be able to access from PC and mobile devices".

"This should already be in place. So many of our health records are not up to date, or the doctors don't read them."

Awareness of technology for self-management

- Patients were generally not aware of telehealth solutions for remote monitoring and had not been offered this as an option.
- Some patients indicated that they would like to monitor pain and other symptoms, but were unaware of apps or other products that could help with this.

Digital communications with medical professionals

Participants were asked to comment on preferences for face to face consultations and other means (telephone, email, video/Skype). Views were mixed.

- Several participants preferred face to face and felt that other forms of communication were a compromise.
- It was noted that face to face appointments are essential if a physical examination is required.
- Many participants, however, would welcome the convenience and saving a journey that could be uncomfortable, painful and tiring.
- Use of digital communications would also save considerable costs and time to patients, many of whom needed to use taxis or ask someone else to accompany them.
- There was some scepticism about remote appointments or the potential effectiveness of videoconferencing because participants felt that there would not be any flexibility on the side of their healthcare provider in accommodating appointments for them.

"I have never used Skype, but if it meant getting appointments or consultations quicker then I would give it a try."

"often when I have struggled to an appointment I am in a lot of pain and suffering cognitive problems which mean I cannot concentrate or express myself properly. If I could email, I could put things in writing in my own pace."

"I would be very pleased if I could email someone to clarify my understanding of what's happened in consultant appointments. Or just to get general answers about particular conditions."

"I am unable to know until the day whether or not I can attend as on average I am only well enough to leave the house a couple of days a week."

Conclusions

- Participant responses indicated a need for digital technologies amongst people with long term conditions in terms of:
 - Management of health condition
 - Maintenance of continuity of care, and
 - Enabling access to health care.
- Addressing the issues faced by people with long term conditions by integrating digital technologies into a variety of clinical and social settings may improve their quality of life.

