

Patient attitudes towards improving their care by carrying their own medical information: a qualitative analysis

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Patient-held Health Records (PHRs)

- Paper based – diaries that both practitioners and patients write in
- Electronic – internet, organisation, workplace located – contributed to by both patients and providers

Our project

Patient-held Health File (PHF)

- Paper diary and electronic (USB) versions
- 4 year randomised controlled trial
- Patient and practitioner contributions
- Quality indicators

Our study - aims

- 1a) Investigate factors influencing effective use of patient-held portable health file by stakeholders in patient care delivery
- 1b) Understand the existing information resources and information use routines of stakeholders delivering collaborative care
- 2) Develop and trial a patient-held health record
- 3) Demonstrate the effectiveness, acceptability, and sustainability of a patient-held portable health file for improving health care delivery

Background

- Patient care – ageing population, numerous chronic conditions, multiple providers, geographically distributed sites
- Challenge - ensuring timely information exchange between providers
- Increasing the availability of clinical information leads to improvements in safety and quality of care delivery (Bates et al 1995, Kaelber and Bates 2007)
- Patients accessing information - internet based health records, health websites

This paper

- Aims

- 1a) Investigate factors influencing the effective use of a patient-held portable health file by stakeholders in patient care delivery
 - 1b) Understand the existing information resources and information use routines of stakeholders delivering collaborative care

- Results of interview data collected with inpatients and outpatients

- Preferences and perceptions of current information transfer

Methods

- Qualitative semi-structured interviews
- Six outpatients
- Four inpatients
- All aged 60 years or older
- All attended at least 2 specialists and one GP

Results

- Interview topics:
 - Information exchange between specialists and GPs about patients
 - Current record keeping about their own health
 - Health information given to them by health professionals
 - Carrying their own medical information

- Three themes:
 1. Interactions with doctors
 2. Maintenance of own records
 3. Opinions about a patient-held health file

1. Interactions with doctors

■ Active role:

"I just like to know. I mean I don't like this idea that the Doctor knows everything and he doesn't tell you – you know what I mean, I like to know and I like to try to understand as much as I can understand. I mean of course there's things that you know that I'm not trained as a Doctor and I won't understand fully but I like to try to understand my condition as much as possible and how its being treated and what the side effects might be because I just think its sensible." (Margaret)

■ Passive role:

"I haven't really [taken an active role] because most of the problems I had were a surprise to me you know so I sort of take their advice and I'm a very good patient, do what they tell me. I always do yes." (Pauline)

2. Maintenance of own records

- Two patients kept no records
- Seven kept some records
Medications, blood pressure, pathology results, doctors letters
- Seven sought information from external sources
Internet, health related books
- Two patients did not seek extra information:
“I try to just go along day by day. I don't worry about reading what's going to happen in the future...I mean Dr [name] explains so much. I'm happy with that. Somebody gave me a book in hospital one day and I was reading it through and it just went on and on until I said “no I can't take anymore”. I just shut the book and handed it back. I don't want to know all that.”
(Beryl)

3. Opinions about a patient-held health file

- Five patients positive about carrying their own health information

"In my case, I'm absolutely thrilled that I can take full responsibility and based using my background, my engineering background, I can understand the statistics and you can see trends." (Juan)

- Three patients negative

"If I had to I probably could but I would probably lose the lot of it you know on the way...I'm not a person that could accept full responsible of myself that's a fact ...Only unless I really had to... I could say "oh yes I'm sick" and that would be about the top of my information I could give...I've got a lot of faith in my doctors and I don't want to take the responsibility off them... they've studied hard to be a doctor so they know, I don't." (Steve)

■ Active patients (5)

- Active in decision making
- Read additional information
- Maintain own records
- Optimistic about PHF

■ Passive patients (4)

- Less involved in decision making
- Rarely read additional information
- Don't maintain own records
- Uncomfortable with carrying information, don't see need for PHF

■ Outlier (1)

- Maintain own records
- Seek additional information
- Positive about PHF
- Passive role in health care interactions

Implications

- Importance of gathering evidence with target population
- Divergence of current positions in relation to health information
- Likely to lead to variation in approaches to using PHF
- Success of PHF relies on practitioners' contributions
- Benefits likely for greater numbers including non-English speaking background, limited literacy

Future directions

- Continuing data collection
 - Interviews with further stakeholders
 - IT Industry
 - Health Management
 - Lawyers
- Randomised controlled trial of PHF
 - Paper diary
 - Electronic – software program on USBs

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