PATIENTS USE OF, ATTITUDES TO, AND BELIEFS ABOUT WEB-BASED CARE PLANNING

(GPMPS, TCAS AND SUBSEQUENT REVIEWS)

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The introduction of Chronic Disease Management (CDM) Medicare items and use of information technology (IT) has had an impact on GPs, patients and health professionals. As e-health initiatives are implemented, concerns have been noted about patients' variability in computer and mobile phone ownership, skills and use.

The aim of this research was to investigate patients' use of, attitudes to and beliefs about web-based care planning, using a combination of questionnaire and interviews.

Similar levels of computer and mobile phone ownership were reported. Although two-thirds of the cohort of 99 participants used the Internet, hardly any (1%) used the Internet to upload their glucose readings and very few (0.05%) 'often' used their mobile phones to receive and/or send SMS messages.

Conclusion: the reluctance by patients to become directly involved in web-based health records might be due in part to their limited use of the Internet and mobile phones, although other factors also need to be explored.

INTRODUCTION

Chronic disease management (CDM) Enhanced Primary Care (EPC) Medicare items and funds for computers introduced by the Australian Government during the 1990's assisted endeavours to achieve better outcomes for patients (McInnes et al. 2006; Australian Government 2010a; Australian Government 2010b). More recently, support has been provided through the use of revised Medicare item numbers including General Practice Management Plans (GPMPs), Team Care Arrangements (TCAs) and subsequent reviews (Inner East Primary Care Partnership 2007; Shortus et al. 2007; Zwar et al. 2007; Hartigan et al. 2009), as well as continuing developments in information technology and e-health (Adaji et al. 2008; Khambati et al. 2008; HealthConnect SA 2009; Wikipedia 2010). Although the physical presence of computers has increased significantly in GPs' clinics over the past decade, some GPs are still reluctant to fully embrace this technology (Henderson et al. 2006). This may be due to medico legal concerns (Nash et al. 2009) or difficulties in making changes to current practice to adopt a more systematic approach to care (Saunders et al. 2008).

Nonetheless, when patients are diagnosed with a chronic illness, there is a need to ensure they can access GPs and allied health professionals to develop an ongoing, trusting relationship and consistent care (Martin et al. 2009). Efficient practice systems are also important to assist the GP to make the right clinical decisions, make links with community resources and services (Centre for Primary Health Care and Equity 2006) and provide patient education (Brooks 2008). As multidisciplinary teams are effective in improving chronic disease outcomes and adherence to guidelines, developing multidisciplinary team care is an important component in the optimal management of chronic conditions (Australian Primary Health Care Research Institute (APHCRI) 2006). Additionally, electronic support assists the care team and patients to enhance communication and patient outcomes (Piette 2007).

For some time in Australia, some patients have been active in finding health information on the Internet and taking it to their GPs, and have also made a major contribution to the understanding of e-health advancements and the subsequent benefits (Infante et al. 2004; Consumers' Health Forum of Australia 2005; Consumers' Health Forum of Australia 2007). Nonetheless, concerns have been noted about the lack of access of many patients to computers, inconsistencies in privacy legislation and subsequent tensions as e-health initiatives are implemented (Consumers' Health Forum of Australia 2006; Australian Health Ministers' Advisory Council 2009; California HealthCare Foundation. 2010). One study conducted in England about the introduction of centrally stored medical records where people can view their summary care record (SCR) and can use a personal health organiser (known as HealthSpace), which is accessible through the Internet, reported patients' views about potential benefits and negative aspects about a range of issues. Issues included the impact of this type of record on those with a stigmatising illness; access to health care; the quality and efficiency of care; more objective care or further entrenched prejudice; patient empowerment; clinician-patient trust; and issues about security and/or exploitation of individuals' records (Robertson et al. 2010). Overall patients did not see this Internet program as useful, nor was it easy to use, and in terms of interest, anecdotally, patients rarely seek access to either paper or electronic health records (Greenhalgh et al. 2010).

The Chronic Disease Management Network (CDM-Net) project, led by Precedence Health Care (PHC), was undertaken in 2008-2009 by a collaboration of twelve Australian and international organisations. There were two parts to this project: one was to develop and test a broadband-based network of health services known as the Chronic Disease Management Service (CDMS) to facilitate the use of GPMPs, TCAs and subsequent reviews electronically and to improve communication between GPs and other health professionals. Type 2 diabetes (T2DM) was used as the demonstrator disease to evaluate CDMS. The second part was to evaluate the impact of the introduction of CDMS.

The aim of this component of the evaluation is to explore the patients' use of, attitudes to and beliefs about web-based care planning, including GPMPs, TCAs and subsequent reviews.

METHODOLOGY

Methods: Mixed; questionnaire (1) and semi-structured face-to-face interviews (2).

DATA COLLECTION

1. Questionnaire

A questionnaire was purposively developed for the CDM-Net project comprising 10 sections with a total of 102 questions using a range response options. Questionnaire sections were variously administered to the 99 participating patient cohort at three time points during the intervention period: Time 1 (T1) soon after the commencement of the intervention, Time 2 (T2) approximately half way between T1 and T3, and Time 3 (T3) close to the conclusion of the intervention period.

Patient participants' attitudes and beliefs were recorded in four sections of the questionnaire:

1. communication (collected at T1; multiple choice questions),
2. self reported allied health service utilisation (collected at T1, T2, T3; yes/no response),
3. beliefs and attitudes about and satisfaction with CDMS (collected at T3; Likert scale),

4. sharing of health information electronically and privacy (collected at T3; Likert scale).

2. Face to face interviews:

A semi-structured schedule was purposively developed and interviews were conducted with ten patient participants between March and October 2009. The ten participants, five females and five males with an age range from 54 years to 82 years, were purposively selected in an endeavour to reflect a representative sample of the project cohort. Patients were invited to participate by their GP, and when patients indicated their agreement and provided written informed consent, their contact details were forwarded to one member of the research team who contacted the patient, made arrangements and conducted the interviews. Seven interviews were conducted in GPs' practices and three in participants' homes. The interviews were approximately 30 to 45 minutes duration, tape recorded and transcribed verbatim.

DATA ANALYSIS PROCESSES

1. Questionnaire – data were analysed using descriptive analysis.

2. Semi-structured interviews – data were analysed using thematic analysis and verified independently by two investigators. When there was a difference of opinion, discussion was held until agreement was reached (Telford et al. 2002; Liamputtong and Ezzy 2005; Reid et al. 2010).

Findings are reported and discussed under the four sub-headings used in the interviews.

ETHICS

Ethics approval for this project was obtained from Barwon Health Research Ethics Advisory Committee (REAC 08/09) and Monash University Standing Committee on Ethics in Research Involving Humans (SCERH 2008/0262), and noted by the Deakin University Human Research Ethics Committee (HREC).

FINDINGS

1. QUESTIONNAIRE

Of the 99 patient participants, all completed the questionnaire at T1, 93 at T2, and 80 at T3. The cohort comprised 61 males and 38 females; 48 were <65 years and 51 were 65 years or over. Analysis conducted for differences in gender and age revealed, overall, that there was a small trend towards males and/or those <65 years owning and using Internet and mobiles.

1.1 Communication (collected at T1 n=99)

Approximately two-thirds 63/99 (67%) indicated they have Internet – either a broadband Internet (57%) or a dialup (10%) connection in their home (Consumers' Health Forum of Australia. 2006). Approximately twice as many males than females indicated they had an Internet connection, with more than half being <65 years (Table 1).

Table 1 - Access to the Internet (Collected at T1 n=99 – multiple choice questions)

Question	All N=99	All (%)	Male	Female	Age <65	Age 65+
No Internet connection	32	32.32	18	14	8	24
Yes, broadband	57	57.58	36	21	32	25
Yes, dial-up connection	9	9.09	7	2	8	1
Use Internet sometimes	66	66.67	42	24	33	33
Use Internet weekly	40	40.00	25	15	22	18
Use Internet daily	33	33.33	25	8	18	15

Of the 67% who had an Internet connection, while all indicated they used the Internet sometimes, only 33% indicated they used the Internet daily. Men and/or those <65 were more likely to have and use the Internet. Approximately half (51%) of the cohort used the Internet for email or Internet searching, and 20% used the Internet for banking, paying bills and/or making purchases. Few used the Internet for social networking (7%), Voice over IP (5%) or other reasons (4%), including health purposes. Of importance to this study, only 1% uploaded their glucose readings on the Internet (male 65+). In other words, using the Internet for health purposes was significantly lower given the number of participants who had an Internet connection (Table 1).

Mobile phones were owned by 75/99 (75%), and of those, 42 (56%) primarily used the mobile to make phone calls, with 25 (33%) 'sometimes' sending and receiving SMS. Of importance, both generally and to this study, very few, 4 (0.05%) 'often' received and sent SMS. Men were more likely to own and use a mobile phone than women, and those 65+ who used a mobile phone, were less likely to send/receive SMS text. Similarly, while mobile phone ownership was reasonably high, the use of the SMS facility was low (Table 2).

Table 2 - Mobile phone use (Data collected at T1 n=99)

Question	All	All (%)	Male	Female	Age <65	Age 65+
No Response	7	7.07	4	3	2	5
Don't have a mobile phone	17	17.17	9	8	2	15
Yes – primarily to make phone calls	42	42.42	27	15	19	23
Yes - phone calls and sometimes receiving SMS text	17	17.17	13	4	13	4
Yes - phone calls and sometimes sending SMS text	8	8.08	5	3	6	2
Yes - phone calls and often receiving SMS text	3	3.03	2	1	3	0
Yes - phone calls and often sending SMS text	1	1.01	1	0	1	0
Other	4	4.04	0	4	2	2
Totals:	99	100.0	61	38	48	51

1.2 Self reported allied health services utilisation (Collected at T1 n-99, T2 n= 93, T3 n=80)

Reported at all three data collection points, attendance at the five categories of health professionals tended to increase during the study (Table 3).

Table 3 - Patients' attendance at five health professionals (data collected at T1, T2, T3)

	Patients who attended (%)		
Health Professional	Time 1 (n=99)	Time 2 (n=93)	Time 3(n-80)
Pharmacist	90 (91%)	74 (80%)	76 (95%)
Podiatrist	39 (39%)	51 (55%)	42 (53%)
Optometrist	34 (34%)	28 (30%)	30 (38%)
Diabetes Educator	18 (18%)	31 (33%)	17 (21%)
Dietitian	9 (9%)	26 (28%)	23 (29%)

1.3 Beliefs and attitudes about, and satisfaction with CDMS (Collected at T3 n=80)

Generally, participants 68/80 (85%) felt the GP adequately explained what CDMS was and its purpose, and 72/80 (90%) indicated the GP adequately explained what the GPMP entailed (Inner East Primary Care Partnership 2007; Shortus et al. 2007; Australian Government 2009). However, fewer 52/80 (65%) liked the GP using computers to help manage their diabetes (Infante et al. 2004; Consumers' Health Forum of Australia 2007).

Regarding CDMS, 49/80 (61%) agreed that the GPMP developed through the CDMS improved their control of diabetes, and 50/80 (62%) felt that the CDMS helped them comply with their GPMP. Fewer, 23/80 (29%) indicated that the CDMS call centre (provided by Diabetes Australia – Victoria) was helpful, but around half 41/80 (51%) were unsure about the call centre. This low response could reflect the reported low use of the Internet and mobile phones, or the low contact between patients and the call centre (Consumers' Health Forum of Australia 2006; Consumers' Health Forum of Australia 2007).

While 50/80 (62%) indicated they understood that one of the benefits of a TCA was that it enabled patients to access Medicare Rebates for allied health professional services, of importance is that 10/80 (12%) neither agreed nor disagreed with that statement, suggesting these patients may not be aware of the availability of rebates or may not need the rebates to manage their diabetes (Australian Government 2010a).

Similarly, only 31/80 (39%) finding reminders and alerts helpful, and 6/80 (8%) felt there were too many reminders. These figures need to take into account the reported low use of the Internet and mobile phones by this cohort.

Of the 80, 58 (73%) indicated they understood the purpose of the GPMP and TCA, but few 8/80 (10%) indicated that viewing their GPMP, TCA and health information on the Internet was helpful (California HealthCare Foundation 2010). This again suggests that lack of use of the Internet may have a significant impact, particularly when 13/80 (16%) indicated they found using the technology difficult (Consumers' Health Forum of Australia 2007; Greenhalgh et al. 2010). Nonetheless, 53/80 (66%) of respondents agreed they would recommend that CDMS be made available to others with diabetes.

Of importance for future research, the majority of participants in this cohort 68/80(85%) indicated they did not mind answering the questionnaire that was used for evaluating the project and could be contacted for further involvement in this or other research.

1.4 Sharing of health information electronically and privacy (collected at T3 n=80)

Collected at T3 only, of the 80 participants, the majority 66/80 (84%) indicated they were comfortable with who had access to their health information, felt fully informed, were comfortable with the nature and extent of information sharing that takes place, understood how their privacy and personal information would be protected within CDMS and were confident their personal information would stay private. But from a privacy perspective, fewer 56/80 (69%) indicated they would be willing to participate in projects that involved sharing information (Consumers' Health Forum of Australia 2005; Consumers' Health Forum of Australia 2006; Australian Health Ministers' Advisory Council 2009; Nash et al. 2009; Robertson et al. 2010). Overall, males were more likely to agree/strongly agree, as were those 65+.

Table 4 - Sharing of health information electronically and privacy (collected at T3)

Question	Agree Strongly Agree	Male	Female	Age <65	Age 65+
I was comfortable that all HPs could see their health information on the computer	66 (82.5%)	42	24	28	38
I was fully informed as to the range of health professionals and others who have access to my information.	68 (85%)	41	16	26	42
I am comfortable with the nature and extent of information sharing that takes place to develop a care plan for me.	66 (82%)	42	24	28	38
I understand how privacy of my personal information will be protected within the Chronic Disease Management Service.	69 (86.25%)	39	30	26	43
I am confident that my personal information will stay private	68 (85%)	40	28	28	40
Based on the way my privacy was managed by the CDMS, I would be willing to participate in other projects that involve sharing of my info	56 (80%)	34	22	25	31

2. SEMI-STRUCTURED INTERVIEWS (N=10)

2.1. Communication

All ten participants reported they were informed by their GP, with the majority indicating the information was ‘brief’ and “…*it was a study to see how people coped with diabetes and to become more familiar with some of the solutions (Pt1)”.* Nine indicated the purpose and requirements were explained clearly and the tenth explained the GP had misplaced the documents; *“...but when found, were completed and forwarded to the research team (Pt10)”.* Nine felt they were involved in the development of their GPMP, the tenth explaining; *‘... it wasn’t explained to me that I was supposed to make the appointments (Pt10)”.* The majority (8/10) felt the GPMP was developed specifically to meet their diabetes management needs, *‘...because there are different people you can see and* [the GP] *thought it would be best to see certain people like the diabetic educator and the podiatrist and the optometrist (Pt1)”*, and “*... he asked me about it and I responded. I think I felt a part of it, yeah (Pt7)”.*

The majority felt that having a care plan didn’t help them communicate with their GP because they already had a good relationship with their GP. One patient felt the plan assisted with communication with the diabetes educator; *“... but then I know her (Pt10)”.* Another mentioned the pharmacist; *“... yes it’s certainly helped with the pharmacist (Pt2)”* (Robertson et al. 2010).

2.2. Self reported allied health service utilisation

Opinion was divided regarding whether sharing information electronically helped participants access other health professionals; some felt; *"... yes it helped manage Diabetes Educators and increase allied health professional's communication among each other (Pt6)"*, but others thought *"... no , I was seeing those other people before he* [GP] *had the care plan (Pt7)".*

2.3. Beliefs and attitudes about and satisfaction with CDMS

The majority felt there was benefit from having their diabetes and health information shared electronically with other professionals, *"... so that when I go to see the podiatrist or the diabetic educator or whatever they've got access to it all, I'm quite happy about that (Pt2)".* The majority indicated they felt that sharing health information electronically had no impact on what information they disclosed when they visited the doctor (Infante et al. 2004; Adaji et al. 2008), *"...No I just like to feel that the information they've got is correct that's all (Pt8)".* Others felt there was a positive impact, "*... yes, because having it in a system like this, I think there's more likelihood of your GP keeping track that you are seeing these other health providers and reminding you that you need to… (Pt2)".* Generally participants did not agree that sharing information electronically had an impact on their diabetes care, but three did because; *"... I think a lot of it is a very personal matter and obviously the whole self-discipline is just paramount (Pt2)".* For another, *"... it helps remind you to keep on the ball" (Pt4),* and for the third *"... it's easy for health professionals to confer, especially the pharmacist (Pt5)"* (Australian Health Ministers' Advisory Council 2009).

Less than half agreed that sharing health information in this way meant they did not have to repeat information every time a referral was made by health professionals; as one patient commented; *"... I still keep repeating it (Pt9)"* (Robertson et al. 2010). Similarly, less than half felt that having a care plan improved the way the GP managed their diabetes care because; *"... any assistance is helpful (Pt6)",* but the majority either saying 'no' or were ambivalent; *"... it should, I couldn't tell you whether it does or not but it should (Pt9)".* Nonetheless the majority felt that having a care plan improved their understanding of their role in managing their diabetes; *"...it makes me aware of certain foods that I had questions about, which was good (Pt1)".* Some were unsure; *"... as yet I'd say it hasn't changed the way, but I'm willing to change if there's any suggestions (Pt8)".* Regardless, the majority had a good understanding about the purpose of care plans, *"... to help and guide me, especially people who live alone (Pt6).* One participant had *"no idea"* but felt it was about; *".... accountability I would imagine (Pt9)".*

Half had a home medicines review (HMR) as part of their management plan; "… I'm on nine different medications so our chemist has recommended strongly that I get a review to see the interactions (Pt 1)". The reasons varied for why patients hadn't had an HMR. Some felt it was unnecessary because; "… I know how to manage my medications already (Pt7)". Others had tried but "… but it hasn't worked out. I think the last time [the pharmacist] was scheduled to come I had the stroke and was gone [to hospital] (Pt9)".

Of those who indicated they had a computer in their home, half had not looked up their care plan; *"... I didn't know I could, should I look it up? (Pt3)",* and two had; *"... yes once and had challenges with the passwords (Pt10)".* After the password challenges were dealt with; *"... the system was easy to navigate, but there was a load of rubbish in there (Pt10)".* This suggests patients may perceive using Internet programs as difficult, the program is not useful, or they may lack interest in seeking and/or accessing their personal health information (Greenhalgh et al. 2010).

Only two patients had received an SMS and one a telephone call. For one patient; "*initially the SMS's were occasional, but there has been a lot in the last few weeks* (*Pt10")*. There were problems with the time of the message; "*…which came about 1.15pm for a 10am appointment ... there needs to be a set time to send out emails because I don't turn on my computer every day and there weren't emails for weeks (Pt 10)".* When the messages were received; *"... the content was OK (Pt10)".*

2.4 Electronically sharing health information and privacy

While the majority felt sharing information electronically did not make a difference to their sense of privacy, two were less certain; "... *I assumed it was on kind of an anonymous (Pt 7)*, and *"... well I think it would (Pt 9)"*. Another felt that the system; *"... some people mightn't like the privacy aspect of it (Pt2")* (Consumers' Health Forum of Australia 2006; Australian Health Ministers' Advisory Council 2009).

DISCUSSION AND CONCLUSION

One clear message from the data was that the use of CDMS as a communication tool to help manage patient health may not be optimal because of patients' limited use of the Internet and mobile phone for managing their health issues throughout the intervention period and/or patients not having an interest in using electronic health records (Greenhalgh et al. 2010). This suggests the uptake of the use of electronic equipment by patients may impede the introduction of programs such as CDMS for managing health (Consumers' Health Forum of Australia 2005; Centre for Primary Health Care and Equity 2006; Consumers' Health Forum of Australia 2006; Greenhalgh et al. 2008; Australian Health Ministers' Advisory Council 2009; Martin et al. 2009).

Nonetheless, it is important to note that the responses to the questionnaire and the semi-structured interviews were similar, particularly around important matters such as patients having the process explained to them adequately (Consumers' Health Forum of Australia 2006; Inner East Primary Care Partnership 2007; Shortus et al. 2007; Australian Government 2009; Australian Health Ministers' Advisory Council 2009), feeling that there were improvements to the management of their diabetes as a consequence of using CDMS, particularly around being able to access Medicare item numbers (Australian Government 2010a). While participants indicated support for the concept of electronic transfer of medical information (Adaji et al. 2008; Khambati et al. 2008; HealthConnect SA 2009; Wikipedia 2010) and the subsequent benefits such as improved control of their diabetes (Infante et al. 2004; Consumers' Health Forum of Australia 2006; Consumers' Health Forum of Australia 2007), some reported they still had to repeat personal and health information to health professionals. Of importance was the patients maintaining their trusting relationship with their GP and other health professionals involved in their management and care (Australian Primary Health Care Research Institute (APHCRI) 2006; Martin et al. 2009), because, for some, sharing health information electronically impacted on what information they disclosed when they visited the doctor (Infante et al. 2004; Adaji et al. 2008). While opinion on sharing of health information electronically was generally positive, some expressed concern about their privacy and the security of their health information (Consumers' Health Forum of Australia 2005; Consumers' Health Forum of Australia 2006; Australian Health Ministers' Advisory Council 2009; Nash et al. 2009).

Notwithstanding the challenges, the patients generally reported their experience with CDMS was positive.

CONFLICT OF INTEREST

Nil for all authors.

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