Patient perceptions that limit a community-based intervention to promote participation

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Abstract

A workshop designed to teach seniors to communicate more effectively with their physicians and enhance patient participation in the consultation was held in a community centre. A grounded theory analysis of follow-up telephone interviews provided examples of effectiveness but also revealed six categories of barriers to changing the pattern of established communication, particularly over the short term.

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1. Introduction

Shared decision-making requires good communication between doctor and patient and active patient participation. Most work has focussed on improving communication skills of doctors. However, sole reliance on the physician for the quality of communication in the consultation tends to perpetuate a paternalistic ‘doctor knows best’ approach to the relationship. Skills practice and modelling interventions to promote patient participation have been effective when associated with a specific visit to the doctor’s office [1–3]. They have not been reported outside the research context. Community-based interventions have the potential for greater dissemination, lower cost and are consistent with the patient empowerment movement. In partnership with a seniors’ interest group in North Vancouver, Canada, we explored the possibilities of enhancing patient participation through a community-based intervention. Seniors were the selected target because they make frequent visits to the doctor, are large consumers of health care and readily have the time to go to workshops.

2. Method

We put on workshops for seniors at a community centre in conjunction with a regular weekly ‘keep well’ programme. The seniors in this group came from a relatively affluent urban community and had a high socio-economic status (>60% with post secondary education). Participants were volunteer responders to posters advertising the workshops titled: “Talking with your doctor”. The workshops were about 2 h in duration, interactive and used a tested framework and booklet [4,5] with modelling by simulated doctors and patients. The objective was to promote active participation of patients in the consultation through planning, asking questions, checking understanding and expressing concerns. Nine attendees consented to follow-up audiotaped telephone interviews approximately 2 months after attending the workshop. Interviews were semi-structured and 10–15 min in length. Interview questions were about experience of the workshop and communications with physicians. Transcripts of the interviews were subjected to grounded theory analysis. Two researchers developed codes for each of the ideas in the interviews and subsequently coded the transcripts independently. The codes were then grouped into frameworks with characteristic illustrative examples.

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3. Results

The participants’ major reasons for attending the workshop were categorized as: to improve communication generally; reassurance about existing communication; and help for specific problems. The physician relationships they had with general practitioners were well established. Their experience of decision-making with their physician covered the spectrum of patient led, doctor-led and shared decision-making.

The participants’ examples of what was learned from the workshop fell into the following categories: need to prepare; present information effectively; communicate expectations; express concerns, ask questions. They gave examples of how they had used or were intending to use the information in the workshop. For example:

I might not have told him how I was feeling without that workshop.
The specialist—I had some questions that I wanted to know, so I thought about them before going.
Well I might tell him to sit down. Sit down before you fall down! Yeah, I think I will.
I’ll ask him more [about the referral], as to why I’m going and what it entails.

Participants reported high levels of satisfaction with current relationships. Typical comments were:

I have a very understanding doctor, so it wasn’t as if we miscommunicated in any way.
We can just discuss things in an amicable fashion.

However, at the same time they reported a variety of communication difficulties. These difficulties fell into six categories:

Anxiety (e.g. feeling intimidated): “Well you’re already in an inferior position … with you sitting down below and they’re standing up, looking down at you. You know, that’s well, intimidating.”

Futility (e.g. inability to make a difference in the relationship): “I’m afraid that I feel that I can’t do much about fostering a good relationship between the doctor and me because I think that’s something they don’t teach in university and [doctors] don’t learn it in medical school.”

Time (e.g. doctor always busy): “Most of the time I felt that I was intruding on their time … I felt that they wanted it to be over in the 4 min and 59 s.”

Reluctance to bother the doctor (e.g. perception of health care system under great strain): “You’re always feeling that you shouldn’t bother them too much. In fact, they have a sign on the door ‘only one problem per visit’.”

Language (e.g. medical jargon): “I think the doctors maybe feel that the patient wouldn’t understand anyway if they tried to explain it to them in little words.”

Memory (e.g. forgets intent to talk about something): “Usually I forget something or the other I wanted to talk about.”

Maintenance of a good rapport with the doctor was perceived to be important to get the best possible health care.

Well I try to stay on good terms with my doctor and that seems to work … You know, we’re on first name terms, we talk about fishing and stuff like that and that keeps the relationship good … Good relationship—you give them half a shot at it, when you have a problem they will look after you.

4. Conclusions

The workshop was acceptable and resulted in some specific examples of behavioural change. It appeared to be limited in effectiveness by: (1) expressed satisfaction with existing relationships (low drive to change); (2) most barriers to communications, with the exception of the category of ‘memory’, were attributed to the doctor (outside of patient’s control); (3) importance of maintaining good rapport (any attempt by the patient to make a change may be perceived to put this at risk); and (4) the difficulty of changing an established pattern of communication, especially in the short term (patients have no tactics to change the existing relationship). In the face of these barriers to change, it seems that a community-based intervention will also require a follow-up/support component and needs to be sanctioned or endorsed by physicians.

4.1. Practice implications

- Changing an established pattern of communication is slow and difficult and needs support and reinforcement.
- If interventions are to be sustained over the long term they need to be embedded in existing community programs and run by trained local facilitators.
- If patients perceive that rapport may be put at risk if they change their communication behaviour, the intervention may require endorsement by physicians.
- To counter their dis-empowerment, patients need ‘evidence’ (role models, testimonials) of what is possible to demonstrate that it can be done and that they can put these skills into practice.

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