

What patients want to know about their medications

Focus group study of patient and clinician perspectives

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ABSTRACT

OBJECTIVE To describe what patients want to know about their medications and how they currently access information. To describe how physicians and pharmacists respond to patients' information needs. To use patients', physicians', and pharmacists' feedback to develop evidence-based treatment information sheets.

DESIGN Qualitative study using focus groups and a grounded-theory approach.

SETTING Three regions of Canada (British Columbia, Nova Scotia, and Ontario).

PARTICIPANTS Eighty-eight patients, 27 physicians, and 35 pharmacists each took part in one of 19 focus groups.

METHOD Purposeful and convenience sampling was used. A trained facilitator used a semistructured interview guide to conduct the focus groups. Analysis was completed by at least two research-team members.

MAIN FINDINGS Patients wanted both general and specific information when considering medication treatments. They wanted basic information about the medical condition being treated and specific information about side effects, duration of treatment, and range of available treatment options. Physicians and pharmacists questioned the amount of side-effect and safety information patients wanted and thought that too much information might deter patients from taking their medications. Patients, physicians, and pharmacists supported the use of evidence-based treatment information sheets.

CONCLUSION Patients and clinicians each appear to have a different understanding of what and how much information patients should receive about medications. Feedback from patients can be used to develop patient-oriented treatment information.

RÉSUMÉ

OBJECTIF Décrire ce que les patients veulent savoir à propos de leurs médicaments et comment ils accèdent actuellement à ces renseignements. Décrire la réaction des médecins et des pharmaciens aux besoins d'information des patients. Se servir de la rétroaction des patients, des médecins et des pharmaciens pour élaborer des fiches d'information thérapeutique fondées sur des données probantes.

CONCEPTION Une étude qualitative à l'aide de groupes témoins et une approche à base empirique.

CONTEXTE Trois régions au Canada (la Colombie-Britannique, la Nouvelle-Écosse et l'Ontario).

PARTICIPANTS Au total, 88 patients, 27 médecins et 35 pharmaciens ont participé à l'un des 19 groupes témoins.

MÉTHODOLOGIE On a eu recours à des échantillons de commodité sur une base volontaire. Un animateur formé à cet égard se servait d'un guide d'entrevue semi-directive pour diriger les discussions des groupes témoins. L'analyse a été réalisée par au moins deux membres de l'équipe de recherche.

PRINCIPALES CONCLUSIONS Les patients souhaitaient à la fois des renseignements généraux et spécifiques lorsqu'ils envisageaient suivre une pharmacothérapie. Ils voulaient de l'information de base sur l'état de santé traité et des renseignements précis sur les effets secondaires, la durée du traitement et l'éventail des options thérapeutiques. Les médecins et les pharmaciens remettaient en question la quantité d'information que voulaient les patients sur les effets secondaires et l'innocuité, et ils étaient d'avis que trop de renseignements pourraient décourager les patients de suivre la pharmacothérapie. Les patients, les médecins et les pharmaciens appuyaient tous le recours à des fiches de renseignements thérapeutiques fondés sur des données probantes.

CONCLUSION Les patients et les cliniciens semblent ne pas avoir la même opinion sur la nature et la quantité de l'information que devraient recevoir les patients sur les pharmacothérapies. La rétroaction reçue des patients pourrait servir dans l'élaboration de renseignements thérapeutiques à leur intention.

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Cet article a fait l'objet d'une évaluation externe.

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One of the most noticeable changes in health care over the last few decades has been the increased involvement of patients in their treatment decisions. Patients want and are seeking more information about drug and non-drug treatment options. While a great deal of patient information about medications, treatments, and diseases exists, much of it contains conflicting, inaccurate, poorly written, or non-evidence-based information.¹⁻³ For example, direct-to-consumer advertising by pharmaceutical companies typically promotes a particular product as opposed to providing patients with an assessment of a range of therapeutic options.⁴

Medication counseling programs are often developed without input from patients, and accordingly, sometimes do not provide the information patients want.⁵ The United States Food and Drug Administration had set a goal of having 75% of patients receive written information about medications by the year 2000, but it appears this goal has still not been met.³ A 1994 cross-sectional national telephone survey demonstrated that only 15% of patients at physician offices and 59% of patients at pharmacies had received written information about medications.⁶ The need for balanced, accessible patient information still exists.

The Canada Drug Guide study was established to develop and test evidence-based patient information sheets. The focus group study described here was the first phase of this study. The objectives of phase 1 were to describe what patients want to know about medication treatment options and how patients currently access information, to describe physicians' and pharmacists' responses to patients' information needs, and to incorporate patients', physicians', and pharmacists' feedback into the development of information sheets.

METHODS

Design

This qualitative study used a grounded-theory approach.⁷ Focus groups were held with patients, physicians, and

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pharmacists between January and March 1999 in three regions of Canada (Ontario, Nova Scotia, and British Columbia). Facilitation of the focus groups followed accepted methods.^{8,9} This study received ethics approval from the St Joseph's Healthcare Research Ethics Board in Hamilton, Ont, the Dalhousie University Faculty of Medicine Research Ethics Community in Halifax, NS, and the University of British Columbia Ethics Committee in Vancouver, BC.

Study sample

We used a combination of purposeful and convenience sampling. Purposeful sampling involves consciously seeking out participants who can contribute to the subject area.^{7,10} In this study, it was important that participants reflect the cultural and demographic reality of the cities targeted by the study. Once stratification of potential participants was devised, convenience sampling was then used to recruit patients.⁷ Through contact with community organizations, naturally occurring groups were recruited for the focus groups.

Anyone older than 18 years who had taken at least one medication was eligible to participate in the patient focus groups. Pharmacists and physicians who had practised in a clinical capacity for at least 1 year were invited to participate in the study. Sample size was estimated in consultation with a qualitative research expert. Focus groups were conducted until theoretical saturation (repetition of themes) was reached.⁷

Focus group format

Focus groups were chosen because they provided the opportunity for different groups of people to share their thoughts and ideas. Patient focus groups were conducted using an interview guide consisting of 17 open-ended questions that asked about patients' general medication information needs and for their opinions about the draft information sheets. The information sheets addressed treatment options for three conditions that each represented a broader disease classification: sore throat (acute symptomatic), gastroesophageal reflux disease (chronic symptomatic), and osteoporosis (chronic asymptomatic). Physicians and pharmacists were asked for their opinions about the themes emerging from the patient focus groups.

The interview guide was pilot-tested to ensure clarity in the order, timing, and wording of questions. The guide was modified as themes emerged. All groups were audiotaped. At least two research team members were present for each group; one member facilitated the group, the other took detailed handwritten notes. After each group interview, the researchers held a

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debriefing that included their perceptions of the group and any format and process issues that arose. All tapes were transcribed and cleaned before data analysis.

Data analysis

Verbatim statements from the audiotapes and debriefing notes were coded to identify common themes. Each transcript was coded independently by at least two research team members using an operational code book. A qualitative data retrieval computer program, QSR NUD*IST (version 4.0)¹¹ was used to help organize the data.

Themes were continually developed and explored during data analysis. This iterative analysis strategy meant that further analysis was conducted as new themes emerged. Summaries of each theme were completed by at least two research team members. Transcripts and summaries were reviewed to elicit both confirming and nonconfirming data for the themes being generated. Following completion of the theme summaries, three researchers discussed the findings to ensure there was consensus for the report.⁷ A model was then developed to describe the relationships between the key variables generated.¹⁰ This theoretical model sought to provide contextual information about the factors that influence how patients access and evaluate treatment information.

RESULTS

Eighty-eight patients, 27 physicians, and 35 pharmacists took part in one of 19 focus groups. Focus groups were held in British Columbia (five), Nova Scotia (five), and Ontario (nine). At least two patient focus groups had one of the following as a dominant characteristic: rural residents, similar ethnic background (one Asian group, one Italian group), advanced age, low income, and chronic medical conditions. Each focus group had between three and 12 participants.

The mean age of patients was 54 years (standard deviation [SD] ± 19); 75% were women, 29% were working, and 41% were retired. Participants were taking a mean of 2.1 (SD 2.2) medications. Mean number of visits to their family physicians in a year was 5.5 (SD 6.6) and to their pharmacies was 6.4 (SD 7.2).

Of the 27 physicians participating in the focus groups, 74% were men, and 93% were family physicians. Of the 35 pharmacists, 43% were men, and 97% were community-based.

Patients discussed wanting general information about the condition under consideration before they made informed decisions about treatment. Many

patients thought they did not have a strong grasp of their diagnoses; when evaluating written information, they looked for enough description of the condition so that they could be certain the information pertained to them. Patients also identified five specific areas they wanted information on: side effects and risks, range of treatment options, how long to take medications, cost of medications, and whether the medication was right for them.

Side-effect and risk information

The need for side-effect and risk information was mentioned in all 11 patient focus groups. This category included statements about interactions and contraindications. In most groups, this was the first mention of what patients wanted to know about medication. Patients expressed frustration about not getting as much information about side effects and risks as they would like. One patient in a group of young professionals noted,

I find that unless I ask the questions to my doctor, that she doesn't always come out and tell me... and after, there had been some side effects that I would have thought she would have automatically told me about...

Patients generally believed that full disclosure of side-effect information would help them make more informed treatment decisions.

Range of treatment options

In almost every group, participants mentioned wanting to know about the range of treatment options available, including nonpharmacologic and alternative remedies. As one patient said, "Most doctors don't give you options, they just say this is what you are taking." Patients were also interested in learning about self-care strategies they could begin before seeing a health care professional (eg, how to manage a sore throat). In general, patients thought they had not usually received this information from their physicians or pharmacists and so they used other resources to meet their needs.

How long to take medication

Some patients expressed concern about the lack of information regarding the length of time they should take a medication. In some cases, they were confused about whether the suggested medication would need to be taken "forever." Patients also wanted to know the typical follow-up process when receiving a medication prescription, "One thing I was wondering about

is the length of time you're supposed to take it... I've been taking it for quite some time, and the doctor hasn't arranged for me to see the doctor who prescribed it." For these patients, knowing how long they would need to take the medication was important information for decision making.

Cost of medication

Cost of medication was cited as important in many groups. Patients wanted to know whether a medication was covered by their drug plans and whether there were more cost-effective alternatives available.

[T]here's many brands of the same kind of medication, and often the doctor will prescribe one that comes to the centre front of his mind just because maybe he's seen it or read about it... and sometimes we don't think to ask, "well, can I get the same kind of medication but in a different brand name that would almost cut the cost by a third..."

Is this medication right for me?

Patients were also interested in knowing whether the medication prescribed for them was the most appropriate for them *personally* rather than a medication that could have been prescribed to anyone with that condition. For these patients, it was important to know that the treatment under consideration reflected their individual health situations.

Sources of information

Patients sought information from a variety of sources. Access was the main factor in determining from whom or where information was sought. Overwhelmingly, patients thought that pharmacists were the most accessible source of information because they were typically available when patients needed information, "[A]t the pharmacy you can always walk right in [at] any time... you're not disturbing a doctor whose time is fairly important;... it's handier that way than a doctor's office." Pharmacists and the medication printouts or pill labels they dispense were patients' most frequently mentioned current source of drug information. Patients wanted to ask their doctors about treatment but often found doctors were difficult to access or did not have the time to discuss what patients wanted to know. Other sources of information included those that patients could access on their own time, such as television, newspapers, libraries, the Internet, family, and friends.

Clinicians' response to patients' information needs

Participating physicians and pharmacists demonstrated a general understanding of patients' information needs.

They expressed concern about the amount of information on side effects and other safety issues they should provide to patients. They thought that extra information on drugs should be given only if it did not contribute to information overload, confusion, or noncompliance. Clinicians also acknowledged that information about treatment options and alternatives was important to patients.

Participating clinicians all seemed to be unaware that patients wanted treatment information that was explicitly personalized for their own unique health situations. They also did not recognize that patients want to know why a particular medication or treatment was suggested for them. Pharmacists in all regions raised concerns particular to their profession; they thought they were at a disadvantage when providing information to patients because they often lacked access to the diagnosis that engendered a prescription. Both physicians and pharmacists acknowledged the importance of written information in affirming oral discussions.

Using feedback to develop evidence-based information sheets

The information sheets were initially developed by the research team and reflected what the team perceived to be the information patients wanted. As the focus groups progressed, changes were made to the information sheets to incorporate patients' preferences. Three major changes were made: placing basic information about the medical condition at the beginning of the sheet, simplifying how numbers and statistical information were presented, and including self-care strategies. The three sheets can be seen at www.ti.ubc.ca/canadadrugguide.

Development of a theoretical model

Figure 1 depicts the model developed to help explain how patients seek information. The impetus to seek information about a medication comes either from having a medical condition diagnosed or being prescribed a treatment. Several contextual and intervening factors can affect whether a patient actively seeks information. Finding information might help patients to be more informed or to have more useful discussions with their physicians and pharmacists. If information is not sought, patients cannot be better off and might even be worse off in ways that are as yet unknown.

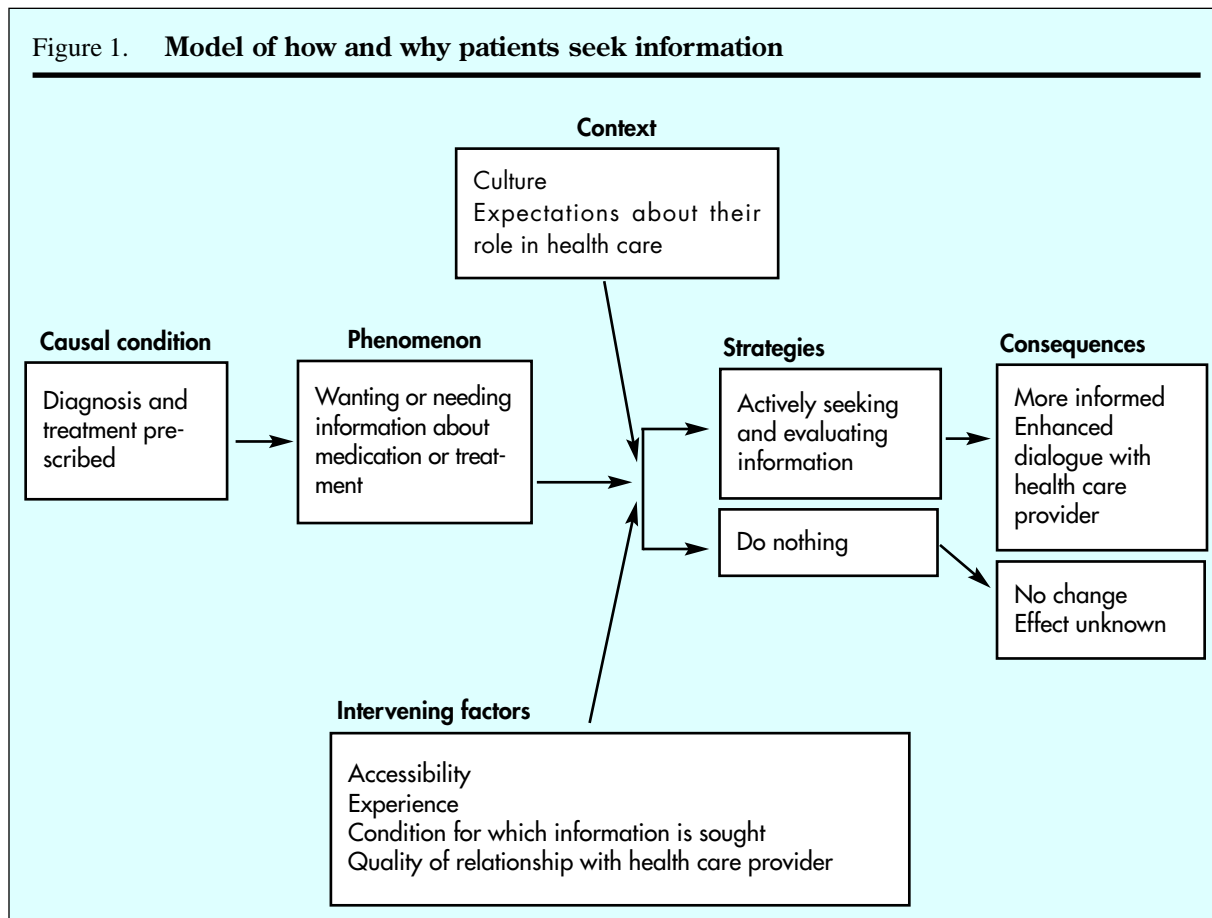
DISCUSSION

This study demonstrates that patients want a range of information about treatment options. Patients often

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Figure 1. Model of how and why patients seek information



thought they did not receive enough information about cost, duration of treatment, and what the treatment was for. Patients were also consistent in stating their need for detailed, comprehensive information about the side effects and safety of medications. While physicians and pharmacists were generally cognizant of the kinds of information patients wanted, they consistently said that too much information could be detrimental to patients.

Participating clinicians thought they should be able to use their own judgment as to what and how much information to pass on to patients. They uniformly recognized, however, that lack of time was their biggest barrier to providing information. It could be that clinicians' bias against providing detailed information is a defence against ever more demands on their time; this hypothesis is strengthened by clinicians' support of providing both oral and written information simultaneously. They thought written documents could provide more complete information when there is little time for discussion.

Most patients access information from the sources most convenient for them. Although physicians remain the preferred source of information, other more easily

accessible sources, such as pharmacists, are consulted if physicians are unavailable. To supplement information provided by pharmacists and physicians, patients access a variety of human, print, and electronic sources. Given that some of these sources provide misinformation, it is important that patients and health care professionals discuss medications fully before making decisions.

Existing research supports our finding that patients have unmet information needs. One qualitative study found that the information patients obtained about medications was one factor that influenced adherence.¹² Another study involving gastroenterology patients found that 92% wanted more information about medications.¹³ A recent study investigating how much information about adverse effects patients want found that 76.2% of 2500 respondents wanted full disclosure of all possible adverse effects.¹⁴ Current literature provides conflicting perspectives on whether information about side effects leads to poorer compliance or more reported side effects. Several studies have found no statistically significant differences between groups

when information about side effects was presented.¹⁵⁻¹⁷ The “adverse effects of talking about adverse effects” need to be studied further to determine whether providing information about medication risks has a negative effect on health outcomes.

Strengths

This study has several strengths. Many focus groups were conducted with a diverse patient sample, which facilitated the analysis process to reach saturation. Two suggested qualitative verification procedures were carried out⁷: negative case analysis and investigator triangulation. Negative case analysis, the examination of data to find contradictory evidence in an effort to acknowledge the breadth of possible responses,⁷ is an important mechanism to ensure that bias does not unduly affect analysis. Investigator triangulation was also used to diminish bias and to affirm consistency of findings by having more than one person conduct the analysis.⁷

Limitations

Despite the rigour of data collection and analysis, this study has limitations. First, while the study was large enough to identify strong consistencies across groups, it was not large enough to allow saturation for identification of subtle differences between subgroups (eg, urban vs rural). Second, the use of volunteer participants likely resulted in overrepresentation of those more interested in patient information needs. Finally, most participants in these groups were older women. Although this is partly due to specific sampling of seniors and women to comment on the osteoporosis guide, our findings likely reflect the preferences of this particular group. Further research with men and younger people will help to ascertain whether these preferences and needs are uniform among different groups.

Conclusion

Both patients and clinicians acknowledge that patients need information to make informed decisions about treatments. Patients seem to want more information about adverse effects than clinicians think they should provide. Patients, physicians, and pharmacists supported the use of evidence-based treatment information sheets as a means of reinforcing oral advice. ❖

Acknowledgment

We thank the patients, physicians, and pharmacists who participated in the focus groups. Their open and honest sharing of their needs, experiences, and expectations helped us better understand patients' medication information needs.

Editor's key points

- Patients want information about the medications they are prescribed, particularly about side effects, other therapeutic options, and the length and cost of treatment.
- Patients want to know that proposed medications are right for them personally. Most patients think pharmacists are the most accessible source of information.
- Physicians and pharmacists realize that patients want information about their medications, but are reluctant to discuss side effects in case it leads to noncompliance. Clinicians were unaware that patients were concerned about medications being right for them personally.
- Results of this study were used to help develop patient information sheets compatible with patients' information needs.

Points de repère du rédacteur

- Cette étude qualitative décrit les besoins d'information des patients face aux médicaments et les sources d'information qu'ils utilisent. Ceux-ci veulent avoir des renseignements sur les risques et les effets secondaires, les différentes options thérapeutiques, la durée et le coût du traitement.
- Ils veulent également savoir si la médication proposée est appropriée compte tenu de leur état de santé personnel. La grande majorité des patients estiment que le pharmacien est la source d'information la plus accessible.
- Les médecins et les pharmaciens participants sont généralement conscients des besoins d'information exprimés par les patients. Ils sont toutefois réticents à fournir une trop grande quantité d'information sur les risques et les effets secondaires, ce qui pourrait affecter la fidélité au traitement. Les cliniciens ne sont pas conscients que les patients désirent discuter du choix d'une médication en fonction de leur état de santé personnel.
- Les résultats de cette étude ont servi à développer des feuillets d'information tenant compte des besoins et des préférences des patients

Author contributions

Dr Dolovich, Dr McCormack, Dr Levine, Dr Gray, and Dr Mann made a substantial contribution to the concept and design of the study. **Ms Nair, Mr Cassels, and Ms Burns** were involved in acquisition of the data and, with **Dr Dolovich**, contributed to the analysis and interpretation of data. All authors

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were involved in preparing and revising the manuscript and approving the final version for publication.

Competing interests

None declared

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References

1. Thomas LG, Corwin EJ. The readability of printed education materials regarding hormone replacement therapy. *J Am Acad Nurse Pract* 1998;10:447-52.
2. Davis TC, Michielutte R, Askov EN, Williams MV, Weiss BD. Practical assessment of adult literacy in health care. *Health Educ Behav* 1998;25:613-24.
3. Buck ML. Providing patients with written medication information. *Ann Pharmacother* 1998;32:962-9.
4. Wilkes MS, Bell RA, Kravitz RL. Direct-to-consumer prescription drug advertising: trends, impact, and implications. *Health Aff (Millwood)* 2000;19:110-28.
5. Connelly MT, Ferrari N, Hagen N, Inui TS. Patient-identified needs for hormone replacement therapy counseling: a qualitative study. *Ann Intern Med* 1999;131:265-8.
6. Morris LA, Tabak ER, Gondek K. Counseling patients about prescribed medication: 12-year trends. *Med Care* 1997;35:996-1007.
7. Creswell J. *Qualitative inquiry and research design: choosing among five traditions*. Thousand Oaks, Calif: Sage; 1998.
8. Kitinger J. Introducing focus groups. *BMJ* 1995;311:299-302.
9. Ashbury J. Overview of focus group research. *Qual Health Res* 1999;5:414-20.
10. Miles M, Huberman A. *Qualitative data analysis: an expanded sourcebook*. Thousand Oaks, Calif: Sage; 1994.
11. Qualitative Solutions and Research. *QSR NUD*IST (4.0)*. Melbourne, Aust: Qualitative Solutions and Research Pty Ltd; 1997.
12. Dowell J, Hudson H. A qualitative study of medication-taking behavior in primary care. *Fam Pract* 1997;14:369-75.
13. Eaden JA, Ward B, Smith H, Mayberry JF. Are we telling patients enough? A pilot study to assess patient information needs in a gastroenterology outpatient department. *Eur J Gastroenterol Hepatol* 1998;10:63-7.
14. Ziegler DK, Mosier MC, Buenaver M, Okuyemi K. How much information about adverse effects of medications do patients want from physicians? *Arch Intern Med* 2001;161:706-13.
15. Lamb GC, Green SS, Heron J. Can physicians warn patients of potential side effects without fear of causing these side effects? *Arch Intern Med* 1994;154:2753-6.
16. Myers E, Calvert E. The effect of forewarning on the occurrence of side-effects and discontinuance of medication in patients on amitriptyline. *Br J Psychiatry* 1973;122:461-4.
17. Howland J, Baker M, Poe T. Does patient education cause side effects? A controlled trial. *J Fam Pract* 1990;31:62-4.