

International exchange

Older patients' involvement in their health care: can paper-based tools help? A feasibility study in 11 European countries

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ABSTRACT

Three paper-based tools to enhance older patients' involvement in general practice care have been used and evaluated by 63 general practitioners (GPs) and 351 patients in 10 European countries and Israel within the IMPROVE project. In all countries the tested tools were helpful for some patients, by encouraging them to ask questions, address important issues and offer their own opinions. In none of the participating countries were the tools suitable to be used universally with all older patients, and sometimes they even hindered patient involvement.

In everyday practice, tools may be used from time to time, in order to remind and motivate older patients and their GPs to pay more attention to the patient's view. GPs should tailor the choice and the use of any instrument to the individual patient, and it should be the patient's choice whether to use a specific tool or not.

Keywords: doctor–patient communication, general practice, older patients, paper-based tools, patient involvement

Introduction

Patient involvement may be defined as 'enabling patients to take an active role in deciding about and planning their care'.¹ Many countries have policies to promote inclusion of patients' voices and patients' perspectives in healthcare planning, quality improvement and clinical decision making. For example, patients' representatives participate in political decision processes as well as in the development

of clinical guidelines and disease management programmes. Patients get informed more and more about their rights – and duties – in health care, and they are asked for their experiences and opinions by means of patient surveys and patient groups.² Moreover, it is increasingly recognised that active involvement of the patient in his or her consultation with a health professional has positive effects on health outcomes,

adherence to treatment and satisfaction with care.^{3–9} However, it does not always take place in practice.^{10,11} Also, the desire of patients to be involved varies. Older patients often prefer a directive style of their doctor, so it may be difficult to involve them more actively in their health care.^{12–14} In some situations a directive style is appropriate, for example if the patient feels unsure and needs the doctor to take responsibility and to tell him or her what to do. Still, to motivate and give the opportunity to older people to take a more active role, if they are able to do so and want so, might help to improve health care for this group. This study explored the value of specific tools to achieve this aim.

In an international study with 11 countries, called the ‘IMPROVE project’, we aimed to test tools for enhancing patient involvement in general practice care for older people. The study was performed in Austria, Belgium, Denmark, France, Germany, Israel, The Netherlands, Portugal, Slovenia, Switzerland and the UK. In the first part of the project, the ‘barriers study’, general practitioners (GPs) and patients in each of the 11 countries were interviewed about their views on the facilitators of and barriers to patient involvement.¹⁵ We found that for older patients ‘patient involvement’ meant that their doctor, in addition to being available and having enough time in the consultation, is interested in them as a whole person and in their life situation, and includes this knowledge in decisions. In general they seemed to prefer their doctor to make the decisions about their health care. We concluded that tools for elderly patients should enable them to talk with their doctor about aspects that are important to them, to ask questions and to offer their opinion. With the second part of the project, the ‘feasibility study’ reported here, we aimed to explore the acceptance and perceived value of selected tools for enhancing patient involvement for older patients and GPs in different countries.

Methods

Selection of tools

A collection of candidate tools was gathered by extensive literature searches, including internet searches and consultation with experts in different countries at international meetings. Medline was searched first for literature reviews and literature analysis, then for single studies. Keywords used were ‘general practice’, ‘family medicine’ and ‘primary health care’ in combination with many different keywords connected to our issue like ‘patient involvement’, ‘patient participation’, ‘doctor–patient communication’, ‘shared decision making’, ‘patient information’ etc. Additionally,

these words were combined with ‘elderly’, ‘old’, ‘aged’, ‘geriatric’ and ‘gerontology’. We identified 440 articles relevant for our purpose, and made a selection of tools, using the criteria outlined in Box 1. In an international consensus discussion, three paper-based tools were chosen, which had been used successfully in previous studies, either as a tool for patient involvement,^{16,17} or as a means for assessment of functional status of patients,^{18,19} but not specifically with older patients. Two tools (QS and PAC, see below) were tested in a pre-pilot study by 18 GPs and 78 patients in five countries (2–4 GPs per country) and amended slightly based on the experiences of this test phase, before they were used in the main study.

Box 1 Selection criteria for tools

The tools should be:

- used by patients rather than by GPs and increase patients’ control over their health care
- multipurpose rather than disease specific
- simple and implementable
- suitable for older patients
- feasible for an international study
- supported by some research evidence or, as a minimum, by some practical experience.

The following tools were chosen:

- the ‘question sheet’ (QS): A single sheet leaflet in A5 size with a single open question (‘What I want to talk about with my doctor ...’) invited the patient to ‘please write down anything you want to ask your doctor or talk about’. The QS was handed to the patient at the end of the consultation. The GP explained its purpose and asked the patient to fill it in at home and use it at the next consultation. The patient could choose to use it as a memory aid or hand it over to the doctor. The wording of the original tool ‘I forgot to ask ...’¹⁶ was changed because in the pre-pilot study in several countries patients felt offended as they thought this meant that their doctor was telling them that they were forgetful now because of their age
- the ‘patient agenda checklist’ (PAC) was a single sheet leaflet in A4 size titled ‘How to make the most of your time with the doctor?’. The PAC had three open and four closed questions, to be filled in by the patient at home, in preparation for the next consultation. The open questions were: ‘Which points do I want to raise with the doctor?’; ‘What thoughts/ideas do I have about these points?’; ‘What questions do I want to ask the doctor?’. The following four questions could be ticked ‘yes’ or ‘no’: ‘What do I want the doctor to do: investigate, explain causes/diseases, prescribe medication, give advice

on what I can do myself?'. There was space left to add other issues. The wording of the original tool was slightly changed,¹⁷ according to the experience of the pre-pilot study. The PAC was used in the same way as the QS

- the 'health diary' (HD): A booklet based on seven COOP charts which comprise standardised questions to be answered on a five-point scale;^{18,19} each step on the scale is illustrated by a picture. The patients were asked about their physical fitness, their feelings/emotional problems, difficulties with daily activities, limitation of social activities by physical and emotional health problems, bodily pain, overall health and change in overall health. All questions referred to the last two weeks. There was additional space for patients to add their own notes on each aspect. The patients were asked to fill in this diary once within a two-week period (four times per booklet over an eight-week period) at home, and discuss it with their GP at the next consultation.

Study population

We aimed to recruit a heterogeneous study population of older patients and GPs, which covered a diversity of sex, age and region (see later).²⁰ GPs were recruited by researchers in each country. Each GP was asked to test one specific tool. In each country two GPs were recruited for each tool (for exceptions see later).

Each of 63 participating GPs received either 30 Qs or 30 PACs or 15 HDs. They were asked to hand out and use as many tools as possible within 12 weeks. The GPs were asked to offer the tool consecutively to all patients of 70 years or older who consulted them. The exclusion criteria were cognitive restrictions of the patient, as decided by the GP.

Evaluation instruments

Three evaluation methods were used. First the GPs were asked to use prepared checklists to record the age and sex of patients who received a tool, and of patients who used it. They were asked to note comments, for example if the patients said anything positive or negative about the tool, or, if patients refused to use the tool, why they did so. Secondly, a short evaluation questionnaire was given, by the GP, to the patients who had used a tool, at the end of the consultation in which the tool had been used. Thirdly, at the end of the study the GPs were interviewed by telephone about their views concerning the usefulness of the tools.

Results

Participating GPs and patients

A total of 63 GPs from 11 countries participated in the study. In most countries six GPs took part to test three tools (two GPs per tool; exceptions: in France only one GP used the QS, in the UK only one GP used the HD, and in Portugal the HD was not used at all). Altogether, the QS and the PAC each were used by 22 GPs and the HD by 19 GPs.

The mean age of the participating GPs was 47 years (range 26–61 years), and 46% were female. Over all countries, 37% of the GPs' practices were situated in a rural area, 25% were urban and 38% were in a city; 38% of the GPs worked in a single-handed practice, 25% in a two-partner practice and 37% in a group practice.

Table 1 shows the number of patients who received a tool and patients who used it. A total of 351 patients returned a questionnaire; 63% of them were female. Their mean age was 77 years (77 years for the QS and the HD, 76 years for the PAC; 70–94 years range overall).

Table 1 Number of participating patients

Tool	Number of countries	Number of GPs who delivered data	Number of patients who received the tool	Number (%) of patients who used the tool	Number of evaluation questionnaires sent back	Number of questionnaires per country mean (SD)	Response rate of questionnaires %
QS	11	19	354	193 (55)	120 ^a	13 (12)	62
PAC	11	18	386	211 (55)	147	13 (11)	70
HD	10	19	134	107 (80)	84	8 (8)	79
sum		56	874	511 (59)	351		69

^aEvaluation questionnaires for the QS were sent back only from nine countries.
SD: standard deviation.

Results from standardised questions: general attitudes of patients and GPs towards the tools

Because the number of patient questionnaires varied widely between countries (from 3 to 112), we present the means of the results from the single countries in Table 2. The majority of patients who sent back a questionnaire were positive about the tool they used, and for all tools more than 75% of the responding patients were of the opinion that their GP should use it more often in future.

The results regarding the GPs' attitudes are shown in Table 3. The majority of GPs found that the tool was

rated 'good' or 'very good' by their patients. However, only between 31% and 41% of the participating GPs said they would use the tested tool in future. Some GPs stated that they would use it, if some changes were made concerning the design or the way to use it (see later).

Results from open questions

Barriers to using the tools

GPs reported the reasons why some patients did not want to take the tool or did not use it after they received it. These patients said that they did not need the tool, did not understand how or why to use it, did not want to

Table 2 Patients' general evaluation of the tools

	% answers yes/partly yes (means (SD) of the results from <i>n</i> countries)	Number of countries (<i>n</i>) ^a	Number of patients
Do you think this tool is a good idea?			
QS	97 (5)	8	112
PAC	87 (16)	10	134
HD	93 (10)	8	74
Was it helpful for you?			
QS	89 (12)	8	104
PAC	66 (22)	10	119
HD	81 (25)	8	67
Do you think this tool should be used by your GP more often?			
QS	89 (12)	8	102
PAC	76 (16)	10	114
HD	81 (23)	8	71

^aCountries with fewer than four patient questionnaires per tool were excluded for statistical reasons.

Table 3 GPs' general evaluation of the tools

	% answers 'good' and 'very good' (<i>n</i>)		
	PAC	QS	HD
How well did your patients accept this tool?	78 (18)	55 (20)	69 (16)
From your point of view, how helpful was this tool – when it was used?	28 (18)	35 (17)	31 (16)
	% answers 'yes' (<i>n</i>)		
Would you use this tool in your practice in future?	33 (15)	41 (17)	31 (16)

take part in a study, or had problems with reading and writing. Problems with using a tool because of illiteracy of patients were reported especially from Portugal, Israel and Slovenia. Sometimes patients forgot to bring the tool to the next consultation or they did not come back for a further consultation within the 12-week study period.

Advantages and disadvantages of the tools and proposals for improvements

THE TOOLS IN GENERAL

A general advantage that was mentioned for all tools by patients and GPs was the fact that the patients received more attention from their GPs. By offering a tool the GPs showed interest in the patient's problems and questions. Also, for all tools it was reported from GPs that by using them they received important information previously unknown. Some GPs proposed to offer the tools in the waiting room for any patients who want to use them. For the PAC and the HD other GPs proposed to offer them only to selected patients.

Some GPs stated that the tool was helpful, but that they did not have the time to use it with many patients. On the other hand it was mentioned by some GPs that it did not take much more time to use the tool, and that in the long run it might help to save time, as it helps the doctor to find out what are the most important questions and problems from the patient's point of view. A generally perceived disadvantage was that the tool sometimes made it even more complicated for patients to address their issues, and patients sometimes saw it as a duty to use the tool, even if they did not find it helpful.

Specific tools

QUESTION SHEET (QS) AND PATIENT AGENDA CHECKLIST (PAC)

For both the QS and the PAC, GPs and patients reported that they:

- were helpful as a memory aid for the patient
- motivated patients to prepare for the consultation and reflect over their expectations
- encouraged them to ask questions
- helped patients to focus on important points in the consultation.

Disadvantages reported by GPs and patients for both the QS and the PAC, were that:

- they sometimes made the communication artificial by splitting it into single questions
- it was not suitable to use these sheets with patients when they had problems with reading and writing
- some patients felt under pressure as they considered the QS or the PAC as a means to save time for the doctor

- some patients found the tools patronising or intrusive
- the tools might be an obstacle for patient involvement if the patient's problems were not suited to being written on a sheet.

Patients for example stated:

- 'If a person is really ill, he finds it hard to write' (QS)
- 'It's far easier for a patient to explain verbally' (PAC)
- 'It is very complicated. I feel very confused with it' (PAC)
- '[It's] 'a warning, that there are more people who need the doctor's help' (QS).

Some GPs and patients reported that the QS was not very different from a sheet that some patients had used previously. On the other hand patients found that by offering them the QS their doctor showed more interest in their questions and problems and were motivated to write down their concerns, which they had not done previously.

Especially for the PAC, several examples were given by GPs from different countries of how it had been very useful: one GP from Slovenia found out that a patient who had a bypass operation three years ago did not know what a bypass was nor why he received it. Also, more patients than she expected were interested in the cause of their disease, although the disease had been present for a long period of time. She had expected that they would be more interested in how to live with the disease. Another GP from Switzerland reported that by using PAC a woman suddenly began to speak about her depression. He had not realised that she was depressed. In Belgium a woman with many health problems was able to formulate a clear question, and a patient from the UK found that it 'helps to know why these things happen and if there is anything I can do'. In France it allowed one woman to express resentment against her doctor, which she could not do before, and that relieved a situation that had lasted for three years.

Some GPs made proposals for a slightly different use of the PAC: one doctor would prefer to ask patients more for their feelings (for example their fears) than for their thoughts, as the PAC does. Another doctor proposed to use it just as a help for speaking with patients who did not want, or were not able, to write down their concerns.

HEALTH DIARY (HD)

In general, patients saw the HD either as a means to promote doctor-patient communication – which was the intention within this study – or as an instrument to monitor and 'control' their health.

They reported:

- 'I like that I can tell my everyday feelings'
- [it is] 'good for describing situations'
- [it] 'helps GP to understand problems'
- [it] 'encourages discussion with your GP on health problems. May bring to light ailments/problems not previously mentioned'
- 'one thinks more about one's own health and its development'
- 'I can monitor myself, how my condition changes'
- 'self-control'.

The aspect of monitoring and reflecting on one's own health too much was also considered as a possible disadvantage of the HD by some patients and GPs (see later).

Positive aspects of the HD from the GPs' point of view were, that it:

- encouraged discussion of psychological and social matters
- was helpful if a patient was not very communicative
- was useful as a memory aid for patients
- had a stabilising effect on the doctor–patient relationship.

They stated:

- [one thing that is] 'positive about it is that you look at a patient in a more qualitative manner'
- 'the social dimension is very important for older people'
- 'it's a good idea to examine the state of health for a longer period of time. In the consultation patients forget a lot. Also, we have a look at how they feel at home'
- 'writing the diary was something for handling loneliness better. They felt safer and better connected with their doctor'.

Disadvantages that were reported from patients and GPs were that:

- for some patients the health diary was too difficult to use
- it sometimes was too time consuming to explain and discuss it
- it sometimes made patients concentrate too much on their illnesses
- it was not always suitable to fill in the diary once in a two-week time period.

Patients complained:

- [it is] 'too complicated'
- 'self diagnosis may cause concern to some patients'
- 'you have to choose "good" or "bad" for a longer period of time, both can occur in that time'.

GPs reported:

- 'I prefer to ask those questions in direct contact with my patients'
- 'patients might go searching for something that can be wrong with them'
- 'it costs too much time and energy for patient and GP'.

Some study participants presented ideas how to use the HD in a more suitable way: some patients proposed to use the HD more flexibly than once over a two-week period, for example to fill it in when there are certain problems, rather than on a certain date. One GP proposed to use it in single consultations, not as a diary. Another doctor had the idea to simplify it by using only 2–3 questions.

The health diary proved to be the tool that was most complicated and therefore only useful for some patients, but in these cases it obviously was very helpful. One GP from Slovenia reported that during the research while using the HD the patients were more open and there was better contact with the doctor. They had important discussions about how to make the best use of the patients' time when they are lonely, how to remain active, how to separate from the family and go to the old people's home. In Austria one woman motivated by the HD 'poured out her heart' to the doctor, and in the Netherlands the HD gave the GP an opening to talk again about a mental problem of a patient, which was appreciated by the patient very much. One GP from Denmark stated that the HD was 'especially useful with patients you don't know, but you can also be surprised when you use it with patients you think you know well'. A GP from France reported that 'it takes you out of beaten tracks'.

Discussion and conclusions

The three paper-based tools to enhance patient involvement were accepted and valued by older patients and their GPs on some occasions in all participating countries. In several cases the tested tools obviously helped patients to explore their ideas, fears and expectations, which is an important part of patient-centred care and shared decision making.²¹ For all tools more than 75% of the responding patients were of the opinion that their GP should use it more often in future.

However, the tools were not seen as something to be used universally with older patients in any of the countries. For some patients the tools had the opposite effect to that intended. These patients felt under pressure to save the doctor's time, felt that the questions they were asked with the tool were intrusive, or

found that using the tool made it even more difficult for them to address their concerns. Probably, besides the patient's individual characteristics and preferences, the attitude of the GP and how he/she presented, explained and used a tool had an influence on whether it was helpful for patient involvement or not. We conclude that it is important that the idea of patient involvement is understood and accepted by GPs who use a tool. Therefore clear information about a tool's aim should be presented to the doctors, and care should be taken that a tool is not used in a way that is hindering the patient from taking a more active role. It always should be the choice of the patient whether to use a tool or not. GPs should tailor the choice and the use of any instrument to the individual patient, and GPs and patients may need some time to learn how to use the tools in a helpful way. If a tool proves to be helpful for the patient, it may become a 'natural component' of the consultation.

This study aimed to explore a range of views among older patients and their GPs in different countries. It has limitations in representativeness. The numbers of GPs and patients per country were too low to allow valid comparisons between countries. Qualitative analysis indicates that the tested tools were helpful in all countries in some situations, but that there were more difficulties in using them in countries where older patients are less educated (e.g. Portugal, Slovenia, Israel). Particularly in these countries, but also in other countries, the tools might be used in a slightly different way with patients who are illiterate or have problems with reading and writing, as proposed by patients and GPs in this study: the doctor and patient might go through the instruments verbally. The HD might be simplified by choosing 2–3 questions fitting best to the individual situation of the patient, and/or it might be used in single consultations, not as a diary. The qualitative results of this study indicated that there is much variation between older patients *within* countries concerning their individual situation, health status, educational background, wishes and needs. Therefore, certain tools or ways to use them probably cannot be recommended specifically for certain countries. Patients – particularly older patients – need different ways of involvement, adapted to them individually.

Our study confirms previous work, showing that patients often have unvoiced agendas, and that it is important to motivate them to address these agendas, in order to prevent major misunderstandings.^{22,23} The feasibility and value of the paper-based tools should be considered in relation to other methods of involving older patients more actively in their health care, such as communication skills training of practitioners, screening questionnaires for health needs, or feedback based on surveys of patients' experiences in health care.²⁴ The paper-based tools that were tested in our study can be used flexibly in everyday practice by GPs and

patients, and they have proven to be helpful for some patients. Moreover, using the tools from time to time may promote the idea of patient involvement among patients and GPs, even if they are not used very often.

Results of the IMPROVE project as well as the tested tools in the languages of all participating countries were summarised in an international booklet.²⁵ Additionally, for each of the participating countries national brochures were created, which offer the tools with some explanation to GPs and patients to use them in daily practice.²⁶

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CONFLICTS OF INTEREST

None.

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