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Background Paper

Involving patients in patient safety programmes: A scoping review and consensus procedure by the LINNEAUS collaboration on patient safety in primary care

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KEY MESSAGE:

- The evidence about the effectiveness of involving patients in patient safety initiatives is weak.
- Involvement of patients in their safety should be integrated in the educational curricula and promoted by the professionals at individual and organizational level.
- A checklist for promoting patient involvement is now available for routine use in general practice.

ABSTRACT

Background: Patient involvement has only recently received attention as a potentially useful approach to patient safety in primary care.

Objective: To summarize work conducted on a scoping review of interventions focussing on patient involvement for patient safety; to develop consensus-based recommendations in this area.

Methods: Scoping review of the literature 2006–2011 about methods and effects of involving patients in patient safety in primary care identified evidence for previous experiences of patient involvement in patient safety. This information was fed back to an expert panel for the development of recommendations for healthcare professionals and policy makers.

Results: The scoping review identified only weak evidence in support of the effectiveness of patient involvement. Identified barriers included a number of patient factors but also the healthcare workers' attitudes, abilities and lack of training. The expert panel recommended the integration of patient safety in the educational curricula for healthcare professionals, and expected a commitment from professionals to act as first movers by inviting and encouraging the patients to take an active role. The panel proposed a checklist to be used by primary care clinicians at the point of care for promoting patient involvement.

Conclusion: There is only weak evidence on the effectiveness of patient involvement in patient safety. The recommendations of the panel can inform future policy and practice on patient involvement in safety in primary care.

Keywords: Patient-participation, patient-centred care, medical errors, patient safety, primary care, LINNEAUS collaboration

INTRODUCTION

The involvement of patients in quality improvement initiatives has raised long-term interest and has resulted in a large body of work (1,2). Interest on how this approach can be best used for improving patient safety, however, is much more recent (3), and has been triggered by the awareness that the patient is an important and mostly untapped resource for quality development in the care, as demonstrated by the London Declaration, endorsed by the World Health Organization World Alliance for Patient Safety (4).

The concept of patient involvement remains defined inconsistently despite abundant literature. Various terms such as patient collaboration, patient participation, patient engagement, partnership, patient empowerment, or patient-centred care are used interchangeably.

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Furthermore, patient involvement itself can relate to aspects of health care as diverse as decision-making, self-medication, self-monitoring, patient education, goal setting, and development of practice guidelines, planning or management of healthcare services (3).

A recent qualitative study by the EU, based on in-depth interviews with 225 patients and health practitioners across 15 EU member states concluded, that

> *... the term "patient involvement" was not clearly understood by either patients or practitioners and often meant different things to different people. For many patients, the term was a nebulous concept revolving around healthy living and being responsible for one's own health. For both practitioners and patients it was often simply equated with medical compliance and following doctors' orders.*

According to the study, the more concrete benefits of involvement in healthcare process are not clearly focused (5).

Studies on patient involvement in patient safety have predominantly included secondary healthcare settings (6). For general practitioners (GPs) and other primary care professionals, it is crucial that methods and tools for the purpose of involving patients increasingly in their care and safety are developed on the basis of studies carried out in general practice, taking into consideration the distinct nature of the long-term relations between patient and practitioner in this setting.

This paper summarizes two reports prepared as part of the EURO-PC LINNEAUS project, which has aimed at exploring how to integrate patient perspectives in the improvement of patient safety in primary care. The work has focused on two objectives:

(a) To identify best practices of patient involvement in patient safety in European countries.

(b) To propose recommendations aimed at primary care professionals, their organizations, researchers and other interested parties on how to endorse patient involvement in patient safety in practice.

METHODS

To achieve these aims, we have built mainly on two resources:

1. A scoping review of the literature on patient involvement in patient safety in European primary care;
2. An expert panel meeting aiming at formulating a statement with recommendations for clinicians, researchers, professional organizations, policy makers and healthcare organizations.

Scoping review

The review focused on the following questions: Which safety risks in primary care can be minimized through patient involvement according to health professionals, patients and their relatives? Which methods of patient involvement are used for this purpose? What are the strengths and weaknesses of these methods?

The review spanned across the years 2006–2011 and included both indexed literature in Medline, Cochrane Library and other databases and grey literature (7). The limited span of years was chosen because of an a priori expectation that the large majority of papers focusing on patient safety in primary care were published after 2005. Search terms are summarized in Box 1. A report summarizing the review was then used to inform recommendations by a panel, as described below.

Expert panel meeting

On 23 May 2012, an international panel convened in Copenhagen to articulate specific recommendations for

Box 1. Search and selection strategy for a scoping review of the literature on patient involvement in patient safety in European primary care.

Searching the literature

The indexed literature was retrieved in a systematic electronic search including scholarly articles focusing on Europe and published in the English and the Nordic languages between 2006 and 2011 (7). The MESH search terms used included the combination of patient participation/ consumer participation/patient-centred care and medical errors/safety/safety management/risk management AND primary health care/community health services/general practice/family practice/general practitioners/physicians, primary care/pharmaceutical services/community pharmacy services/nursing homes/intermediate care facilities/dental care (7). The search for grey literature was not limited to Europe and was carried out on the websites, i.e. publication lists, bibliographies and databases, of 13 large international organizations concerned with patient safety (7). A free text search was carried out in Google, and reference lists of all included articles were hand-searched (7).

Selecting relevant articles

The librarian and the authors of the study (7) carried out the selection process in three stages (titles, abstracts and full text). The abstracts of the identified articles were reviewed and selected based on four thematic criteria of relevance: The articles had to be relevant for patient involvement in patient safety in primary care in Europe. The grey literature included reports from organizations from all Western countries. Given the very limited number of relevant publications, not methodological appraisal was performed and all eligible publications that fulfilled the criteria were included.

policy makers and professional organizations across the EU. The panel participants were selected by the LINNEAUS partners, who were asked to identify experts and/or stakeholders in the field. In total, there were ten participants from six different countries: Denmark, UK, Greece, Spain, Poland and The Netherlands. The profiles covered by the participants were: three health services and quality development researchers, three safety and quality managers, two GPs, one pharmacist, and one patient. The task of the panel was to develop consensus recommendations that could be applied across the EU, supporting the development of patient involvement in patient safety organizations. The panel was familiar with the literature study (7), which was distributed to the participants before the event and summarized at the beginning of the meeting. The panel discussed the current knowledge and what recommendations could be made based on the existing evidence.

RESULTS

Scoping review

Thirteen articles and nine reports were included in the study (Figure 1).

Five of the articles and five of the reports focused specifically on primary care, the remaining 12 including both primary and secondary care (Appendix 1). Five articles focusing exclusively on primary care included two descriptive cross-European interview studies, one of them conducted as part of the LINNEAUS collaboration (8,9). The main findings of the review on patients' perspectives, barriers and enablers for participation and potentially successful strategies are summarized here.

Patient perspectives. Main areas of concern for patients were medication, diagnosis, communication, treatment and care, technology and equipment, organization and administration, and environment, with several patient groups being mentioned as particularly vulnerable, the elderly being the most significant group.

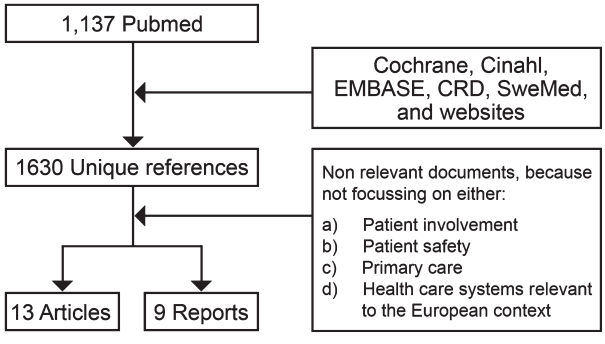

Figure 1. Flowchart for a scoping review of the literature on patient involvement in patient safety in European primary care (7).

Facilitators and barriers for patient involvement. The review also identified a number of factors that influence the ability and willingness of patients to be involved in patient safety. Enabling factors include vulnerability to safety issues, younger age female sex and higher educational level. Engagement is intensified by prior experience of illness or safety incidents and inhibited by impact of illness/symptoms. Patients also experience less difficulty participating with a GP than in hospitals. Participation is easier for patients in tasks that do not require medical knowledge and do not confront professionals. Other relevant variables include healthcare workers' attitudes and abilities, acceptance of new patient role, confidence in own capacities and type of decision making required.

Specific barriers related to patient characteristics are old age, lack of education, non-Western background while professional's training and specialization pose barriers centred around the health professional. Health workers' attitudes are emphasized as crucial for patients' willingness to be involved and to speak up if they have safety concerns.

Patients' strategies for patient involvement. A number of potential strategies for patient involvement were mentioned. In general, most of these strategies are about 'speaking up' in the case of safety concerns, awareness and knowledge of safety risks, close observation of medication and treatment, coordination of care, contributing to hygienic practices, self-management and compliance. Evidence of some effect on patient safety is found in self-management of medication (oral anticoagulants), in simplifying dosing regimens and educating healthcare workers in patient involvement. Several studies mention patient involvement in the hand hygiene practices but the evidence of its effect on safety is unclear. The little and weak evidence on the effectiveness of patient involvement in patient safety in primary care does not provide a base for establishing best practices.

Panel statement

Key issues. The key issues addressed by the panel statement can be accessed in full elsewhere (10). The panel noted that clinicians are often hesitant to recognize the extent to which patients wish to be involved in understanding their health problems, expressing their concerns, knowing their options, and making decisions on account of their personal preferences. Furthermore, patients find it difficult to take an active part in patient safety, because they lack confidence to question health professionals (e.g. because they are reliant on the professional), have limited understanding of patient safety, health and its determinants, and have difficulties accessing clear, trustworthy and understandable information.

Patients and their relatives remain a largely untapped resource for developing a safe, high-quality healthcare.

The panel found that there is a deficit in activity related to patient safety in primary care and the primary care/secondary care interface in Europe. This deficit relates to research, sharing of information, and to collaborative learning from both negative and positive events.

The panel recognized that there is widely differing legislation and engagement with this issue across Europe, and that recommendations should include support for developing patient involvement in patient safety organizations.

Recommendations for professional organizations, clinicians and researchers. These were:

- To secure more qualified evidence through further research on the effect of interventions aiming at patient safety in primary care.
- To integrate patient involvement and safety in the health professional curricula at both undergraduate and postgraduate level, with specific attention to the patient's perspective, health care professional/patient relations and cultural diversity in different parts of the EU.
- To act as first movers, as they have the duty to take the initiative to ask, encourage, invite and welcome the patients to be involved, both at an organizational and individual level.
- To endorse the development of a common checklist for patients and professionals to be used as part of the agenda of the meeting/consultation process.
- To encourage patients to give feedback on safety incidents, near misses and safety concerns—together with positive feedback.
- To establish ways of communicating with patients (phone, mail, etc.) to solve their questions or concerns about treatment, care or safety issues as soon as possible.

Checklist for primary care professionals. The panel suggested a common checklist to be used by primary care professionals in relation to clinical encounters, addressing questions about the patient's need, concerns and resources (Box 2).

Recommendations to policymakers and health care authorities. The panel also made the following recommendations to policymakers and health care authorities, urging them:

- To ensure that legislation supports the rights for patients (and their relatives) to engage in issues relevant for their safety, with special emphasis on the right to access their health record as a sound basis for their informed consent to treatment.
- To support patient-led voluntary associations' work in order to contribute to the development of tools, policy, etc. in collaboration with policymakers and professionals.
- To make it possible for patients and their relatives to report safety incidents, promoting an organization that is set to facilitate and focus on learning and thus differing from organizations handling complaints.
- To encourage IT solutions that ensure patient data are compiled in databases accessible to professionals (with secure access) from all healthcare sectors.
- To secure access for patients to high quality, intelligible information on diseases, treatment options and patient safety issues in user-friendly language and format.
- To launch campaigns that enhances public attention to the need for and benefits from strengthened involvement of patients and their relatives in patient safety in primary care.

DISCUSSION

Main findings

The literature study failed to identify a set of best practices for involving patients in patient safety, but pointed to several factors that enhance the extent and character of patient involvement. These include positive attitudes

Box 2. Patient involvement checklist for primary care clinicians: Have the patient's or companion's needs, concerns and resources been taken adequately into account at the time of contact? The checklist is aimed at managing patient safety issues at each consultation or contact. It can be used by the clinician together with the patient for confirming that reasonable steps have been taken to ensure the safety of both the consultation and future steps.

1. Is there an agreement between the patient and me concerning the purpose of the contact?
2. Is the patient sufficiently informed about his/her condition?
3. Have any problems concerning communication issues, including the option for involving a relative, a companion or a caregiver been addressed?
4. Have the patient's options and choices for management of the condition been sufficiently described?
5. Has the patient expressed specific concerns, and have they been adequately addressed?
6. Has the patient been informed about next step and appointments (time, date, location, name of)?
7. Does the patient have an updated list of medicines?
8. Has the patient been informed of precautions and actions to take if the condition develops in an unanticipated direction?

among the health professionals towards encouraging the patients to take an active role.

Based on the current knowledge, the expert panel called attention to the need for more research on the effect of interventions and the importance of integrating patient involvement and safety in the healthcare professionals' curricula. The panel recommended that clinicians, researchers and their organizations should act as first movers by inviting the patients to be engaged in their safety.

Strengths and limitations

Some limitations of this work need to be acknowledged. The literature review focused on recent literature for pragmatic reasons. Although we screened all references in the relevant papers, our strategy may have omitted previously published relevant work that had not been picked up by subsequent publications. It is important, however, to note that given the changing nature of health services, this approach allowed us to concentrate on those interventions most likely to be relevant to current delivery models. The search strategy aimed at maximizing efficiency using established MESH search term, but more extensive use of free terms may have potentially resulted in the identification of an increased number of relevant studies.

The recommendations made by the panel are important because they provide for the first time a roadmap for patients' safety specific for in primary care in Europe. However, its validity and generalizability may be limited due to the small number of participants, the selection of countries and the range of expertise represented. In addition, the limitations in the evidence retrieved inherently pose limits to the validity and generalizability of the recommendations. The compromise between the broad scope of the panel questions and the necessity of formulating the recommendations, with consideration for their implementation in many different EU member states may have promoted more generic rather than specific recommendations.

Implications and perspectives

Given the scanty conclusions derived from the literature, it is very important to conduct further studies. Research must include clarification of concepts and well-defined interventions including rigorously defined outcome measures.

When taking the panel recommendations into account, it is important to note the evidence retrieved in relation to the barriers to and limitations of an approach based on patient involvement. Although general practitioners may have a positive view of patient involvement, they do not necessarily consider patient involvement methods as instrumental for improving patient safety. In addition, potentially negative effects of involving the patients must be considered. The EU interview survey identified two main concerns: The resourcing requirements needed (for example, additional time and staffing) and the negative impact it might have on the patient/doctor relationship (5). In addition, patients may dislike that the responsibility for their safety will be forced upon them (11). Patients do not want to be responsible for decision making, but they want to be able to ask questions and to understand how decisions are made (5). It must be said, though, that in this area there is a shortage of evidence to support or reject the raised concerns.

One of the answers to this challenge may be to make use of methods like shared decision making and tools like patient decision aids largely through the continuum of consultations. These concepts, both aiming at enhancing inclusion of the patient's preferences and individualizing the course of treatment, are described in detail elsewhere (2,12,13).

Patients are able to identify and report safety incidents in a reporting system (6). They are also willing to speak up when they are concerned about their safety. However, their willingness depends heavily on the relation and interaction between patient and practitioner (14). Considering the nature of the patient–practitioner-relationship in general practice, this setting should provide in principle an optimal environment for empowering patients to speak up. The most important condition must be that the health personnel openly encourage the patients to speak up about their concern. A 'question prompt' given to the patient before the consultation may be helpful in improving patient satisfaction and reducing anxiety (15). An example of a question prompt for patients is available at the Danish Society for Patient Safety homepage (16).

The concept of patient involvement in patient safety must be regarded in a broader context, including the nature of the patient–clinician relationship, which is crucial for empowering the patients to get involved in their safety. Patient oriented instruments, such as question prompts, may support the process, but invitation and encouragement from the clinician is considered pivotal. A number of tools and methods for practitioners to use for enhancing patient involvement are available, including shared decision making, patient decision aids and, presented in this article, a simple checklist to be used in the clinic. Further research is needed to establish the effectiveness and safety of these interventions.

CONCLUSION

The literature study did not identify efficient methods or a set of best practices for involving the patients in patient safety in primary care. Based on the available knowledge, a LINNEAUS expert panel:

- identified the need for more research about the effect of interventions;
- emphasized the importance of the commitment of the clinicians to actively encourage their patients to get involved in their safety; and
- underscored the necessity of integrating knowledge about the significance of involving patients in their safety in the educational curricula in healthcare that was studied.

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Supplementary material available online

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