Interventions for improving older patients’ involvement in primary care episodes (Review)

Wetzels R, Harmsen M, Van Weel C, Grol R, Wensing M

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<table>
<thead>
<tr>
<th>TABLE OF CONTENTS</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>HEADER</td>
<td>1</td>
</tr>
<tr>
<td>ABSTRACT</td>
<td>1</td>
</tr>
<tr>
<td>PLAIN LANGUAGE SUMMARY</td>
<td>2</td>
</tr>
<tr>
<td>BACKGROUND</td>
<td>2</td>
</tr>
<tr>
<td>OBJECTIVES</td>
<td>4</td>
</tr>
<tr>
<td>METHODS</td>
<td>4</td>
</tr>
<tr>
<td>RESULTS</td>
<td>6</td>
</tr>
<tr>
<td>DISCUSSION</td>
<td>9</td>
</tr>
<tr>
<td>AUTHORS' CONCLUSIONS</td>
<td>11</td>
</tr>
<tr>
<td>ACKNOWLEDGEMENTS</td>
<td>12</td>
</tr>
<tr>
<td>REFERENCES</td>
<td>12</td>
</tr>
<tr>
<td>CHARACTERISTICS OF STUDIES</td>
<td>17</td>
</tr>
<tr>
<td>DATA AND ANALYSES</td>
<td>26</td>
</tr>
<tr>
<td>WHAT'S NEW</td>
<td>26</td>
</tr>
<tr>
<td>HISTORY</td>
<td>26</td>
</tr>
<tr>
<td>CONTRIBUTIONS OF AUTHORS</td>
<td>26</td>
</tr>
<tr>
<td>DECLARATIONS OF INTEREST</td>
<td>27</td>
</tr>
<tr>
<td>SOURCES OF SUPPORT</td>
<td>27</td>
</tr>
<tr>
<td>INDEX TERMS</td>
<td>27</td>
</tr>
</tbody>
</table>
Interventions for improving older patients’ involvement in primary care episodes

Raymond Wetzels¹, Mirjam Harmsen¹, Chris Van Weel², Richard Grol¹, Michel Wensing¹

¹Centre for Quality of Care Research (WOK), Radboud University Nijmegen Medical Centre, Nijmegen, Netherlands. ²Department of General Practice, Radboud University Nijmegen Medical Centre, Nijmegen, Netherlands

Contact address: Raymond Wetzels, Centre for Quality of Care Research (WOK), Radboud University Nijmegen Medical Centre, (117 KWAZO), PO Box 9101, Nijmegen, 6500 HB, Netherlands. r.wetzels@kwazo.umcn.nl.

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ABSTRACT

Background

There is a growing expectation among patients that they should be involved in the delivery of medical care. Accumulating evidence from empirical studies shows that patients of average age who are encouraged to participate more actively in treatment decisions have more favourable health outcomes, in terms of both physiological and functional status, than those who do not. Interventions to encourage more active participation may be focused on different stages, including: the use of health care; preparation for contact with a care provider; contact with the care provider; or feedback about care. However, it is unclear whether the benefits of these interventions apply to the elderly as well.

Objectives

To assess the effects of interventions in primary medical care that improve the involvement of older patients (>=65 years) in their health care.

Search methods

We searched: the Cochrane Consumers and Communication Review Group Specialised Register (May 2003); the Cochrane Central Register of Controlled Trials (CENTRAL), The Cochrane Library issue 1, 2004; MEDLINE (Ovid) (1966 to June 2004); EMBASE (1988 to June 2004); PsycINFO (1872 to June 2004); DARE, The Cochrane Library issue 1, 2004; ERIC (1966 to June 2004); CINAHL (1982 to June 2004); Sociological Abstracts (1963 to June 2004); Dissertation Abstracts International (1861 to June 2004); and reference lists of articles.

Selection criteria

Randomised controlled trials or quasi-randomised trials of interventions to improve the involvement of older patients (>= 65 years) in single consultations or episodes of primary medical care.

Data collection and analysis

Two review authors independently assessed trial quality and extracted data. Results are presented narratively as meta-analysis was not possible.
Main results

We identified three studies involving 433 patients. Overall, the quality of studies was not high, and there was moderate to high risk of bias. Interventions of a pre-visit booklet and a pre-visit session (either combined or pre-visit session alone) led to more questioning behaviour and more self-reported active behaviour in the intervention group (3 studies). One study (booklet and pre-visit session) showed no difference in consultation length and time engaged in talk between the intervention and control groups. The booklet and pre-visit session in one study was associated with more satisfaction with interpersonal aspects of care for the intervention group although no difference in overall satisfaction between intervention and control. There was no long-term follow up to see if effects were sustained.

No studies measured outcomes relating to the use of health care, health status and wellbeing, or health behaviour.

Authors’ conclusions

Overall this review shows some positive effects of specific methods to improve the involvement of older people in primary care episodes. Because the evidence is limited, however, we cannot recommend the use of the reviewed interventions in daily practice. There should be a balance between respecting patients’ autonomy and stimulating their active participation in health care. Face-to-face coaching sessions, whether or not complemented with written materials, may be the way forward. As this is impractical for the whole population, it could be worthwhile to identify a subgroup of older patients who might benefit most from enhanced involvement, i.e. those who want to be involved, but lack the necessary skills. This group could be coached either individually or, more practically, in group sessions.

Plain language summary

Ways of improving older patients’ involvement in their primary care

Stimulating the involvement of older patients in their primary care may enhance their health. Therefore we reviewed studies of interventions to improve older people’s involvement in their care. There has been little research in this area involving older people as the main target of the research. Only three trials were identified. These evaluated the effects of written or face-to-face preparation for consultations with doctors. Interventions of a pre-visit booklet and a pre-visit session (either combined or pre-visit session alone) led to more questioning behaviour by older people and more self-reported active behaviour. Overall, there is sparse evidence about the effects of interventions for improving older patients’ involvement in their primary care.

Background

Over the past quarter of a century, societal support has grown for patient involvement in the delivery of health care (HMSO 1983; Weiss 1986; Williams 1994). The case for patient involvement is based on evidence that patients’ active participation during the medical interview is associated with better health outcomes (Kaplan 1989; Kaplan 1996) and increased involvement improves aspects of medical care (Atkin 1998; Liaw 1996). On the other hand, lack of involvement may have adverse consequences such as non-adherence to treatment, possibly with negative outcomes (Bibowski 2001). Besides this, the fundamental importance of patient dignity and autonomy has increasingly been recognised (Lothian 2001), and there is a growing expectation among patients that they should be involved (Verhoeef 1999). Accumulating empirical studies show that patients of doctors who encourage them to participate more actively in treatment decisions have more favourable health outcomes, in terms of both physiological and functional status, than those whose doctors do not (Kaplan 1995).

Involvement

Involvement may be at different levels: 1) involving patients/consumers in the development of medical care and 2) involving patients in their own medical care (Wensing 2003). For this review we focused on the latter and defined patient involvement as enabling patients to take an active role in deciding about and planning their own primary medical care. This means supporting patients in deciding about using health care, facilitating the role of patients as their own health advocates and encouraging patients to share responsibility for their own health. Also the intention is to assist the patient in making as informed a choice as possible about the diagnosis and treatment (taking benefits and risks into...
Interventions

Interventions to improve the involvement of patients in their own health care may focus on patients, healthcare providers and/or the healthcare system itself. The amount of physician time allocated to a visit obviously has some effect on the nature of the interaction (Haug 1987); this also applies to waiting lists and the accessibility of the care providers' office. Although we are aware of their importance, in this review we excluded interventions focused on these items and interventions focused on the healthcare system. We also excluded interventions like self-help groups.

We included patient-focused interventions; these can take place before, during or after the patient/healthcare provider consultation. We used a categorisation of interventions based on patients' views on health care described by Wensing and Grol (Wensing 2000), as follows:

- interventions focused on the use of health care (giving information on appropriate use of health care, giving information to choose a care provider);
- interventions focused on the preparation for contact with a care provider (supplying patient data, preparation for active participation);
- interventions focused on contact with the care provider (providing patient tailored information; stimulating the communication strategy of shared decision-making); and
- interventions focused on feedback about care (patients' evaluations of care and procedures used for complaints and comments).

Older patients

The participants in this review were older patients. Most developed countries have accepted the chronological age of 65 years and above as a definition of 'elderly' or older person. While this definition is somewhat arbitrary, it is often associated with the age at which one can begin to receive pension benefits (WHO 2003). For this review we defined an older patient as a patient 65 years of age or older. We used the term older patient, although there are a lot of other terms in use for older patients, like older consumer, older person, senior and so on.

In 2000 almost 7% of the world's population was aged 65 years or older. It is expected that this proportion will have more than doubled by 2050 (United Nations 2002). In addition to this population ageing, more attention has to be paid to the problems and needs of older patients. Older patients often have multiple health problems. In previous studies figures vary, but it seems that at least 80% of people older than 65 have one chronic condition or more, and 65% have multiple chronic conditions (Wolff 2002). Communication with some older patients is made more difficult by age-related physiological changes as well as disruptions in the social and physical environment. Impaired hearing and vision can impede communication, while deficits in mobility can lead to physician impatience with the length of interaction. Environmental changes can include loss of spouse and friends, new living arrangements, and unfamiliar healthcare settings (Haug 1987). Besides this, some older people view the process of ageing as one that is inevitably linked with health problems, and therefore they may not contact the doctor with conditions which are treatable, such as breathlessness (Morgan 1997). Another difficulty might be the lack of contact with doctors older people may have had in their earlier years. A lifetime of reliance
on self-care, possible language barriers, lack of experience in dealing with possibly higher socio-economic class, and usually white, practitioners (Haug 1986), and potentially a lower educational level (Haug 1987) might all contribute to older people’s reluctance to seek help for their complaints (Foster 2001) and to their lower level of participation in consultations than other patient groups (Kaplan 1995; Cassileth 1980). In a study by Cassileth and colleagues (Cassileth 1980), patients’ qualitative additions to questionnaire responses illustrated their points of view. “The layman is not qualified to make decisions,” was the older person’s typical reason for rejecting participation in medical decisions. Older patients similarly justified their preference for minimal information by explaining: “I’m not qualified”; “I need as little to worry about as possible”; “It’s the doctor’s job, he’ll take care of the details”. Although this may now only be applicable to the older old, no recent references contradict these findings.

Doctors, as well as patients, belong to specific age cohorts which may affect their attitudes toward older people. There are some signs that age stereotypes may affect the medical care provided to older patients. Doctors may view older patients as less desirable patients, spend less time with them and respond less to their psychosocial concerns (Giles 1990). In response, older patients may become more unwilling to seek or continue needed treatment. In contrast, a recent international qualitative study (Wetzels 2003) showed that GPs were positive about involving older patients in their own general practice care. GPs in this study mentioned their own lack of time, and sometimes the cognitive and physical impairments of older patients, as barriers to involvement.

In conclusion, there may be gaps in communication between older patients and doctors that potentially reduce the effectiveness of medical care by, for example, failing to address symptoms of treatable conditions that impact upon functional status and quality of life. Promoting the involvement of older patients may improve the effectiveness of medical care by, for example, enhancing their satisfaction with health care, and health status (Rodin 1986), and improving their adherence to prescribed medication and the advice provided (Roter 1998). This review evaluated the effects of interventions aimed at improving older patients’ involvement in their own medical care. A secondary purpose of the review was to identify the range of interventions that have been assessed by randomised trials or quasi-randomised trials.

**OBJECTIVES**

To assess the effects of interventions in primary medical care that improve the involvement of older patients (≥65 years) in their health care.

**METHODS**

Criteria for considering studies for this review

**Types of studies**

- Randomised controlled trials (RCTs).
- Quasi-randomised trials (for those with inadequate randomisation methods).

**Types of participants**

Older patients (all study participants to be ≥65 years). Interventions may include a role for patients’ caregivers/family members and/or their GP in primary medical care, as long as the intention of the intervention was to improve the patient’s involvement. Interventions focussed wholly or mainly on carers’ participation were therefore not included. We excluded interventions involving dentists, pharmacists, hospital nurses, community nurses, nurse practitioners and practice nurses.

**Types of interventions**

Interventions had to have the intention of increasing patients’ involvement in the primary medical care consultation, and needed to meet the following criteria:

- Set in primary medical care, related to doctors or their practice; and
- Undertaken in relation to (single) consultations (either before, during or after the consultation), or in relation to the use of health care in episodes of care.

We included patient-focused interventions; these can take place before, during or after the patient/healthcare provider consultation. We used a categorisation of interventions based on patients’ views on health care described by Wensing and Grol (Wensing 2000), as follows:

- Interventions focused on the use of health care (giving information on appropriate use of health care, giving information to choose a care provider);
- Interventions focused on the preparation for contact with a care provider (supplying patient data, preparation for active participation);
- Interventions focused on contact with the care provider (providing patient tailored information; stimulating the communication strategy of shared decision-making); and
- Interventions focused on feedback about care (patients’ evaluations of care and procedures used for complaints and comments).

We excluded:

- Self-help groups;
- Interventions focusing on structural aspects of care, for example the management of waiting times or waiting lists, appointment times, or length of consultation;
• Disease-specific interventions (such as decision aids);
• Activities that were about prevention or health promotion rather than involvement.

Types of outcome measures
A number of processes and outcomes might be affected by interventions that aim to improve older patients’ involvement in the primary care consultation. We extracted all reported outcomes and categorised them as follows:
• Use of health care ((appropriate) use of health care, information access and use, knowledge acquisition);
• Preparation for contact with a care provider (supplying patient data, preparation for active participation);
• Contact with the care provider (use of communication aids, communication enhancement, providing patient tailored information; stimulating the communication strategy of shared decision-making; stimulating patient adherence);
• Feedback of care (patients’ evaluations of care and procedures used for complaints and comments; retention of information/ability to recall information, patient satisfaction);
• Health status and wellbeing (physical health of patient, psychological health of patient, psychosocial outcomes);
• Health behaviour (attitudes, adherence to shared decision, use of interventions or services (associated with assessment of recommended practice from clinical guidelines or their equivalent));
• Treatment outcomes (physiological measures);
• Outcomes related to health professionals (eg. knowledge, attitudes, skills, behaviour); and
• Health system outcomes (eg. length of consultation).

Data collection and analysis

Selection of trials
Two review authors independently inspected the titles and/or abstracts of the studies identified by the search to determine whether the articles were likely to be relevant. In case of disagreement between the two authors or when it appeared likely from the abstract that a study may be relevant, the full article was obtained for independent assessment by two review authors. We categorised these articles into three groups: 1) background literature, 2) possibly included studies, and 3) excluded studies. To be included, studies had to meet the criteria specified above. We also required that the articles described the content and process of the intervention. We used a standardised data extraction form.

Assessment of methodological quality
The methodological quality of potentially-included studies was assessed independently by the same two review authors who selected the studies. We assessed whether the method of randomisation was adequate and subsequently whether an adequate method for concealment of allocation was used. We used the criteria described in the Cochrane Handbook (Clarke 2002), which are based on the evidence of a strong relationship between the potential for bias in the results and the allocation concealment, and are defined as:
A. Adequate concealment of treatment allocation (low risk of bias);
B. Some doubt about the concealment of treatment allocation or unclear (moderate risk of bias);
C. Inadequate concealment of the treatment allocation: eg. ‘open methods’ (high risk of bias);
D. Concealment of allocation was not used.

Search methods for identification of studies
We used the strategy presented at Appendix 1 to search MEDLINE (Ovid), 1966 to June 2004. We used appropriate variations of that strategy to search the following electronic databases:
• Cochrane Consumers and Communication Review Group Specialised Register (May 2003);
• Cochrane Central Register of Controlled Trials (CENTRAL), The Cochrane Library issue 1, 2004;
• EMBASE (1988 to June 2004);
• PsycINFO (1872 to June 2004);
• DARE, The Cochrane Library issue 1, 2004;
• ERIC (1966 to June 2004);
• CINAHL (1982 to June 2004);
• Sociological Abstracts (1963 to June 2004);
• Dissertation Abstracts International (1861 to June 2004).

Other search strategies
We sought additional studies by searching the reference lists of relevant trials and reviews identified. Finally we examined our personal literature collections to identify relevant studies.
• Outcomes (timing of outcome assessment, outcomes);
• Notes (power calculation); and
• Allocation concealment.

Disagreements were discussed between the review authors. One review author entered data into RevMan software. An editor and staff member of the Cochrane Consumers & Communication Review Group checked the entered data against original study reports. Whenever details of methodology were not available we did not attempt to contact the authors of included studies for additional information.

Data analysis
We considered combining the studies quantitatively once we had completed the search. However, the diversity of interventions and outcome measures used in the studies made this impossible. We therefore undertook a structured review of the studies. Throughout the review process review authors were not blinded to trials.

RESULTS

Description of studies
See: Characteristics of included studies; Characteristics of excluded studies.
In this section we describe the studies included in the review; including the characteristics of the interventions; the characteristics of the participants; and the types of outcomes measured.
Electronic searching identified 9716 titles and abstracts (databases searched to 1 June 2004). In total, we judged that 88 of these potentially met the inclusion criteria, and we retrieved the full articles for further detailed assessment. Three studies met all inclusion criteria (Cegala 2001; Kimberlin 2001; Tennstedt 2000). These studies were all published in English and conducted in the USA.

Characteristics of the interventions
There was a limited range of interventions in the studies. Two studies combined a pre-visit booklet and a pre-visit session (Cegala 2001; Tennstedt 2000), and we have categorised these interventions as falling into the categories of focusing on the preparation for contact with a provider, and focusing on contact with a provider. One study (Kimberlin 2001) used a pre-visit interview, which we categorised as focusing on contact with the care provider.
We found no studies assessing interventions focused on the use of health care, or studies assessing interventions focused on feedback of care.

We outline below the three included studies, in terms of the content and timing of the interventions, and the outcomes measured. Cegala 2001 was set in a family practice center in Ohio, involving 33 patients and 9 physicians. Fifty per cent of the patients in the sample were randomly selected from appointment records and were randomly assigned to intervention or control group, before being telephoned and invited to participate. The other half of the sample was recruited as follows: patients for the control group were recruited in the waiting room, whereas patients for the intervention group were randomly selected from a list of all available patients. Selected patients were telephoned, and overall 84% of those telephoned agreed to participate. The intervention group finally consisted of 16 patients, and the control group of 17 patients.

In the control group, patients had to sign a consent form and were asked to fill in a brief pre- and post-visit questionnaire. Interviews between patient and physician were audiotaped. The intervention group followed the same procedure as for the control group, with the addition of 1) a training booklet mailed to the patient approximately 3 days before their appointment and 2) a 30-minute face-to-face session with a researcher before the physician visit. The training booklet concerned patient communication skills and was divided into three sections, addressing information provision, information seeking, and information verifying. The booklet posed sample questions and had room to list patients’ own questions and concerns. The face-to-face session involved discussion about notes the patient had written in the booklet, verification of patients’ intentions (when patients had not written anything) and making sure all details were included. Sessions were guided by the booklet, with the researcher verifying the patient’s intentions and helping to organise the patient’s approach to the physician visit. Patients in both groups were paid to participate. Physicians completed post-interview questionnaires, typically at the end of the day. Physicians did not know the precise nature of the intervention and were blinded to patients’ group assignment. Researchers unitized and then coded interview transcripts, to assess participants’ information exchange.

The study by Kimberlin and colleagues (Kimberlin 2001) was set in a family practice outpatient center in Florida, involving 45 patients and 20 physicians. Patients were recruited when they came for an appointment in the family practice clinic. When patients gave consent, they were alternately assigned to intervention or control group, after a coin toss determined each day’s first patient assignment. Fifty-four patients were asked to participate, and 45 consented and completed the study. The intervention group consisted of 22 patients, the control group of 23 patients.

The intervention consisted of an interview before the physician visit to assist patients in identifying questions about their current treatment. The interview was performed by a medical student, who was under supervision of a clinical pharmacist, one of the investigators. The student used several interview prompts to generate patient questions. The student wrote the questions down,
and gave a copy to the patient to take into their visit with the physician. The control group was not described. In both groups consultations with the physician were tape-recorded. Patient questions were counted and type of questions were categorised. Coders and physicians were blind to group assignment.

**Tennstedt 2000** took place at an unspecified number of community sites, which were either senior housing or senior centers. A total of 355 patients were recruited to participate in this study. Sites were pair-matched, with one site of the pair randomly assigned to the intervention group and the other to the control group. The intervention group consisted of 155 patients and the control group of 200 patients. The objective of the intervention in this study was to "empower older patients to take an active role as partners with their physicians to improve their health care and to provide realistic examples of partnership behaviors and communication techniques to improve older patients' satisfaction with health care encounters" (p. 65). The intervention consisted of three elements: 1) a 2-hour group program which included modeling of "undesirable (ineffective) and desirable patient behaviors" (p. 65) and opportunities to practice these behaviours in role-playing exercises, with discussion about participants' interaction style and its consequences; 2) cue cards listing active behaviours; and 3) a preparation booklet in which patients could record and prioritise reasons for their visit, their current medications, and questions for the doctor. The intervention was conducted up to three months prior to the physician visit. The primary outcome was patient-reported active participation in the physician visit, assessed by a series of closed- and open-ended questions in a post-visit telephone interview. These interviews were tape-recorded to analyse open-ended questions. No baseline measurement was performed, in order not to sensitise patients.

**Participants**

The three studies included older patients visiting doctors working in primary medical care. Cegala and colleagues provided detailed data about patient demographics. The mean age in both groups was around 72 years, with males comprising 56% of the trained (intervention) group and 29% of the untrained (control) group (Cegala 2001). The authors present additional information on the ethnicity, education and household of participants; no significant differences were found between the two groups. Cegala also provided information about whether participants were alone or accompanied by a spouse or other relative. Kimberlin 2001 added additional inclusion criteria for study participation, namely that patients had to be taking medication for a chronic condition, and caring for themselves. The patients in this study were over the age of 64, but the authors did not describe their mean age. In both intervention and control groups approximately three quarters of participants were female. The authors present information on the number of prescribed medications patients were taking. Participants in Tennstedt 2000 were mainly women (83%), with an average age of 77.4 years and an average 11.4 years of education. Twenty-six per cent of participants were from minority groups. Most participants had been treated by the same physician for several years (average: 4.7 years). In conclusion, not all studies specified demographics of the different groups, and no additional information such as diagnosis was given (although Cegala records mean scores of patient and physician-assessed medical status).

**Outcome measures**

Two studies measured questioning behaviour of patients as their primary outcome (Cegala 2001; Kimberlin 2001). One study had self-reported active behaviour as its primary outcome measure (Tennstedt 2000). As secondary outcome measures Cegala reported on appointment length and Tennstedt reported on satisfaction with visit (using items from RAND Patient Satisfaction Questionnaire). Most of the outcomes were assessed using qualitative analysis with an internal validation procedure. No outcomes were assessed over a longer time period (ie. beyond the main consultation between doctor and patient). Other information about the studies is given in the Characteristics of included studies table.

**Risk of bias in included studies**

**Study design**

Two of the studies (Kimberlin 2001; Tennstedt 2000) were randomised trials and the third (Cegala 2001) was a quasi-randomised trial. Two studies mentioned that patients had to sign a consent form (Cegala 2001; Kimberlin 2001), one study gave no information on this (Tennstedt 2000). No information on ethical clearance was given, although Cegala noted that patients were asked to sign an Institutional Review Board consent form, implying that IRB clearance has been obtained.

**Method of allocation, and allocation concealment**

In Cegala 2001 a partly open method of allocation was used. For about 50% of the sample, researchers randomly selected patients from appointment lists of participating physicians and randomly assigned them to intervention or control groups. These patients were telephoned and invited to participate. For the remainder of the sample, researchers selected control patients from the waiting room and randomly selected intervention group patients to be telephoned from a list of available patients. In Kimberlin 2001 the randomisation consisted of an alternate assignment to one of two groups, after a coin toss determined each day's first assignment; the allocation was open to the researcher. Tennstedt 2000 gave no information on the allocation procedure. An unspecified number of community sites were pair-matched
by type of setting and percent minority, with one site of the pair randomly assigned to the intervention group and the other to the control group. It is not clear whether the allocation of community sites to each group was concealed. Participants from a community site were all allocated to the same group to avoid contamination; again, the authors give no further information about this procedure.

Blinding
In Cegala 2001 and Kimberlin 2001, outcome assessors and physicians were blinded to the intervention condition. In Tennstedt 2000 blinding was not described. This study's intervention condition had aspects that cannot be easily blinded (cue cards, preparation booklet).

Use of intention-to-treat analysis
Tennstedt 2000 performed an intention-to-treat analysis, as well as a sensitivity analysis. Cegala 2001 and Kimberlin 2001 did not describe the type of analysis they performed. The number of analysed participants was respectively: 33 (16 intervention and 17 control) (Cegala 2001); 45 (22 intervention and 23 control) (Kimberlin 2001); and 355 (155 intervention and 200 control) (Tennstedt 2000).

Baseline measurement
Cegala 2001 gave patients from both groups a brief pre-interview questionnaire as a baseline measurement. Neither Kimberlin 2001 nor Tennstedt 2000 included a baseline measurement. In summary, the included studies are at risk of potential bias, primarily due to inadequate allocation concealment procedures. Randomisation was adequate; allocation concealment was not; blinding was adequate where possible; baseline comparability was adequate; measurement tools used were not validated; coding procedures seem to have been undertaken with care.

Effects of interventions
In this section we report on the results of the included studies. We discuss results of interventions first by study and then by category. Two studies gained their data through observation (Cegala 2001; Kimberlin 2001), and one study through patients’ self-report (Tennstedt 2000).

In Cegala 2001 trained patients asked more questions about medically-related topics than did control patients (mean = 6.41 (SD 3.86) versus 2.28 (SD 2.02)). Trained patients elicited more information than did untrained patients (mean = 21.62 (SD 15.73) versus 6.94 (SD 6.06)). Trained patients obtained more information per questions asked than did untrained patients (mean = 2.30 (SD 1.25) versus 1.29 (SD 0.86)). Trained patients provided more information than did untrained patients (mean = 38.69 (SD 28.26) versus 18.47 (SD 16.37)). Trained patients did not engage in more information verifying than did control patients (mean = 2.31 (SD 1.82) versus 1.29 (SD 1.50)). There was no difference in overall appointment length (mean = 18.81 versus 22.59 minutes; P = 0.46) nor in time in which the patient and physician were engaged in talk (16.25 versus 14.41 minutes; P = 0.68).

In Kimberlin 2001 half of patients in the intervention group (11/22) generated questions about medication they were currently taking. These 11 participants generated 35 questions before the medical visit. Of the remaining 11 intervention patients who had no questions about therapy prior to their visit, 4 asked at least 1 question about their therapy during their medical visit. In the intervention group 14 out of 22 subjects asked at least 1 question, versus 8 out of 23 in the control group. Qualitative analysis showed that in contrast to the intervention patients, control patients did not ask about purpose, proper use, monitoring of effectiveness, side effects perceived, or what to do if a dose was missed, with regard to current prescribed therapy. Tennstedt 2000 found that older patients are generally not involved in their physician visit. The following data account for the whole sample: over half (54%) had not identified specific issues to discuss before the visit; and 77% had done nothing to prepare for the visit. More than 80% did not bring a list of questions, problems, or medications to the visit, ask questions about their illness or condition, or ask questions about tests or procedures. Twenty six per cent reported they had asked questions, and 30% stated their preference about treatment or tests. However, only 21% stated that the physician dominated the encounter. Seventy six per cent of participants were satisfied with the medical visit. In terms of the effects of the intervention in Tennstedt 2000, the intention-to-treat analysis (155 intervention patients and 200 control patients) showed a trend (P < 0.08) for reporting of more targeted behaviours by those in the intervention group, i.e. more self-reported active behaviours. Similarly, they were more likely than control participants to report bringing a list of problems to the visit. Intervention patients were more satisfied with interpersonal aspects of the visit (P < 0.05), however, no differences in overall satisfaction were found. When the 114 intervention patients who actually did attend the intervention group program were compared with the 200 control patients the results changed slightly. Program attendance was associated with a greater number of self-reported active behaviours during the physician visit (P < 0.05) when controlled for relevant characteristics. Other significant correlates of active behaviours included younger age (P < 0.001) and female gender (P < 0.01).

Study authors did not report confidence intervals and rarely reported effect sizes for their results.

In terms of the different outcome categories, we report as follows:
• Use of health care: no outcome data found.
• Preparation for contact with a care provider: In Kimberlin
Tennstedt 2000, 54% of all patients had not identified specific issues to discuss before the visit; and 77% had done nothing to prepare for the visit.

- Contact with the care provider: In Cegala 2001 it appeared that trained (intervention group) patients asked more questions about medically-related topics, elicited more information, obtained more information per questions asked and provided more information than did control patients. Trained patients did not engage in more information verifying behaviour than did control patients. In Kimberlin 2001 a greater proportion of participants in the intervention group (64%) asked at least one question, compared to participants in the control group (35%) \((P < 0.001)\). Patients from intervention group asked different questions, as qualitative analysis showed that in contrast to the intervention patients, control patients did not ask about purpose, proper use, monitoring of effectiveness, side effects perceived, or what to do if a dose was missed with regard to current prescribed therapy. In Tennstedt 2000 26% reported they had asked questions, and 30% stated their preference about treatment or tests. However, only 21% stated that the physician dominated the encounter. In the intention-to-treat analysis there was a trend \((P < 0.08)\) for reporting of more targeted behaviours by those in the intervention group. Similarly, they were more likely than control participants to report bringing a list of problems to the visit. A sub-analysis showed that program attendance was associated with greater numbers of self-reported active behaviours during the physician visit \((P < 0.05)\) when controlled for relevant characteristics. Other significant correlates of active behaviours included younger age \((P < 0.001)\) and female gender \((P < 0.01)\).

- Feedback of care: In Tennstedt 2000 intervention patients were more satisfied with interpersonal aspects, side effects perceived, or what to do if a dose was missed with regard to current prescribed therapy. In Kimberlin 2001 a greater proportion of participants in the intervention group (64%) asked at least one question, compared to participants in the control group (35%) \((P < 0.001)\). Patients from intervention group asked different questions, as qualitative analysis showed that in contrast to the intervention patients, control patients did not ask about purpose, proper use, monitoring of effectiveness, side effects perceived, or what to do if a dose was missed with regard to current prescribed therapy. In Tennstedt 2000 26% reported they had asked questions, and 30% stated their preference about treatment or tests. However, only 21% stated that the physician dominated the encounter. In the intention-to-treat analysis there was a trend \((P < 0.08)\) for reporting of more targeted behaviours by those in the intervention group. Similarly, they were more likely than control participants to report bringing a list of problems to the visit. A sub-analysis showed that program attendance was associated with greater numbers of self-reported active behaviours during the physician visit \((P < 0.05)\) when controlled for relevant characteristics. Other significant correlates of active behaviours included younger age \((P < 0.001)\) and female gender \((P < 0.01)\).

- Outcomes related to health professionals: no outcome data found.

- Health system outcomes: In Cegala 2001 there was no difference in overall appointment length \((\text{mean} = 18.81 \text{ versus} 22.59 \text{ minutes}; P = 0.46)\), nor in time in which the patient and physician were engaged in talk \((\text{mean} = 16.25 \text{ versus} 14.41 \text{ minutes}; P = 0.68)\) between intervention and control group.

Additional study

One excluded study is described in more detail here, as it came very close to our inclusion criteria for this review and had an interesting intervention. The reason for exclusion was its study population: the mean age was approximately 60 years. The study was about the evaluation of a patient educational appointment guidebook (Wilkinson 2002). Two hundred and seventy eight patients were recruited from schedules of primary care team visits at a facility of the Veterans Affairs Health Care System in Tucson (southern Arizona, USA). In total 93% of study participants were male, and the average age of the sampled population was approximately 60 years. Participants were mailed the appointment guidebook prior to their scheduled routine visit. The guidebook included suggestions for getting ready for the appointment, and for completing the visit, and sample phrases to assist in discussing issues with the care provider. No baseline measurement was performed. Post-appointment patients received a visit evaluation questionnaire, assessing patient perceptions related to preparedness, self-effectiveness, and visit effectiveness. Response rates (for sending in post-appointment visit evaluation questionnaires) were low (intervention group 31% \((n = 43)\); control group 54% \((n = 73)\)). No differences in experience of primary care visit effectiveness were detected between intervention and control groups. Twenty-three out of 39 patients who received the guidebook prior to their visit were able to use the guidebook during the appointment. The majority (77.6%) of all patients did not leave the appointment with unresolved issues, 88.8% stated that the provider listened to what they had to say and 76.7% stated that they were involved in making decisions about their care and treatment during the appointment.

DISCUSSION

This review identified three studies that evaluated interventions to improve older patients’ involvement in their episodes of care. Due to a lack of eligible studies, this review is unable to assess the whole range of possible interventions to improve the involvement of older patients in their primary care. The results of the three studies show positive effects on the involvement of older patients, but conclusions have to be made with care, as two of the studies were small, the overall quality of the included studies was less than ideal, and there was no longer term follow up of outcomes to see if effects were sustained.

Low number of studies

Although we performed a highly sensitive search in order not to overlook interventions, the low number of relevant studies we found was striking. We found that there is very little evidence about interventions for improving the involvement of older patients in general practice care. Despite abundant literature on involvement, there are few trials focussed solely on older populations. This seems strange, as older peoples’ needs and morbidity make them large consumers of health care (Fryer 2003), in contrast to the younger age group, for which there is some evidence about involvement. Is involving older patients merely ideology, or is our review too
restricted, for example are the selection criteria we chose too narrow? We excluded many studies on the basis of the intervention content. Many studies evaluated health assessment, reminder or preventative interventions, which we did not consider to be about patient involvement. The range of interventions we identified was narrow. As shown in the table Characteristics of excluded studies, we excluded no intervention studies on the basis of their methodology alone. We excluded fifteen studies solely on the basis of the age criterion (Berakis 1991; Billault 1995; Cegala 2000a; Cegala 2000b; Combielet 2002; Davison 1999; Hornberger 1997; Liaw 1997; Little 2001; Little 2004; Malý 1999; McCann 1996; Post 2001; Roter 1977; Savage 1990); we excluded other studies on the basis of a selected group of patients (for example, non primary medical care), or a combination of the reasons previously mentioned. If we had lowered our age criterion to 50 years of age, we might have included only another three studies (Billault 1995; Davison 1999; Wilkinson 2002). Therefore, we find that our inclusion criteria were not too narrow. Rather, there is simply little evidence about involving older patients in their primary medical care.

Types of interventions

In this review we found two main types of interventions: 1) face-to-face sessions to coach patients in question-asking and participating in consultations, either immediately pre-appointment on an individual basis, or longer before an appointment on a group basis; and 2) written interventions, in a booklet or checklist form. This conforms with a recent review about improving patients’ communication with doctors (Harrington 2004). Harrington and colleagues did not find other types of interventions compared to our review, although they reported a variation on a face-to-face session, namely the use of video in modeling effective communication. In a review about interventions to alter the interaction between patients and practitioners (Griffin 2004) some other interventions are included, such as training practitioners in communication skills, including listening and eliciting patients’ views or employing a completely different consultation style. Information about disease or treatment, and discussion of behaviour change were other interventions included in Griffin’s review. However, usually these interventions included booklets or letters, either alone or in combination with training sessions. Types of interventions that were not mentioned were: interventions focused on the use of health care, on feedback of care, and on evaluations of care.

Effectiveness of interventions

If we look at relevant reviews which are not specifically about the elderly, we must consider their conclusions about the effects of interventions on the process of consultations, and whether these conclusions could be valid for older people as well. For example, Harrington and colleagues showed that the interventions they assessed had the effect of encouraging patients to be more active in their consultations (Harrington 2004). Ten out of sixteen studies reported a significant increase in variables related to patient participation. When considered according to type of intervention, face-to-face or video interventions were more effective (five out of six face-to-face interventions and three out of three video interventions showing a significant increase in overall participation) compared to written interventions (two of ten interventions showing a significant increase in participation). Harrington 2004 also showed that the range of question asking was low (across both intervention and control groups). Griffins’ review shows that in three quarters of studies (22/30) the process of consultation significantly improved in the intervention group (Griffin 2004). Although in two studies a part of the consultation process significantly deteriorated according to patients, Griffin noted that in one of these two studies other process measures significantly favoured the intervention. When considering the effects on patient outcomes, Griffin found that in 18/35 studies at least one health-related outcome significantly favored the intervention group. Could these results be valid for the old age group as well? Our results are broadly similar to the reviews by Griffin and Harrington when the influence of interventions on the process of consultations is considered. At least there seems to be no contradiction in the results.

Outcome measures

When we look at patient outcomes, it is clear from our review that the interventions result in patients asking more questions, and also different questions. We might cautiously conclude that patients become more active due to pre-visit preparation. The outcome measures employed in the included studies were based on observations (tape-recordings) of physician visits, except for one study (Tennstedt 2000) which used subjective, self-/patient-reported outcomes. However, no study measured health status or well-being as outcomes. The effects of people becoming more involved on these outcomes remains unclear. The studies included by Griffin and into a lesser extent also by Harrington were able to assess other health outcomes of practical importance, besides subjective, perceived health outcomes and satisfaction, although only in a minority of included studies. For example, in three studies Harrington identified measurements of attendance, which improved; in one study a measurement of disease control, which improved; and in one study a measurement of adherence to medication and behavioural treatment, which also improved (Harrington 2004). Griffin was also able to include disease processes (eg. HbA1c, blood pressure, mortality) in almost one-sixth of the included studies (Griffin 2004).
We did not identify many relevant studies, nor did we find a wide range of interventions, yet the three studies we did find show some positive results, although studies are at risk of bias. These results correspond to two recent reviews about the same subject, although with a different perspective and included population. This review does not justify a recommendation to implement these interventions in current clinical practice. Yet it seems that, based on the results of studies included in this review, face-to-face interventions (whether or not complemented with written materials) are the way forward to enable older patients to become more involved in their general practice consultations. However, interventions that involve pre-visit interviews or coaching may be impractical, and studies did not show who would be the ideal person to undertake the sessions. In addition, costs are unknown. In our opinion, therefore, there should always be a balance between stimulating the active participation of patients, and respecting their autonomy.

Strengths and weaknesses of this review

Our review has a number of limitations. Two of three included studies had low patient numbers, which makes it difficult to generalise conclusions. Allocation concealment procedures were not optimal, possibly introducing bias into the results. Comparing and summarising the results of the studies is difficult, as they are heterogeneous in terms of intervention type, procedures, sampling procedures and outcome measures. Another issue introducing bias into the results is the participating physicians’ awareness of the study and its topics. Although some protective measures were taken, patients entering the doctor’s office with a booklet, cue card or question list may have been identified by the doctor as belonging to the intervention group, which may have influenced the doctor’s attitude. This may, therefore, have introduced bias into the results. In Tennenstod 2000 the period between the intervention and the doctor’s visit was up to three months, which may be too long to measure results. Outcome measures largely did not consist of validated tools, although in two studies it seems that the analysis of tape-recordings of the visits was careful and adequate. These were observations; one study only recorded self-reported patient data (Tennenstod 2000). None of the studies reported on harms or anxiety. Finally, no study was described in sufficient detail to reproduce it, which made assessment difficult.

This review also has notable strengths. It was a thorough search of all literature (not limited by date or language). We used clear selection criteria which were published prior to undertaking the review, and followed standardised Cochrane review methods for selecting studies and assessing study quality. Our review shows the lack of research in this field, yet it also shows three studies with positive results. Therefore it is able to give direction to future studies on involvement of the elderly in their health care.

Implications for practice

Overall, this review shows some positive effects of specific methods to improve the involvement of older people in episodes of health care. Nevertheless, due to a lack of data, we cannot recommend the use of the examined interventions in clinical practice. It is not clear why evidence in the field of involvement of older patients is sparse; perhaps one thinks that older patients do not need a different approach to improving involvement in their medical care compared to younger patients. In our introduction, however, we tried to make clear that older patients should be approached differently. The results of our review do not contradict the results of two recent reviews which include younger people. It is possible that their conclusions are valid for our population as well. As there is limited evidence, it is difficult to make recommendations for practice. We think that there should be a balance between respecting patients’ autonomy and stimulating their active participation in their health care. Face-to-face coaching sessions, whether or not complemented by written materials, may be the way forward. As this is impractical for the whole population, it could be worthwhile to identify a subgroup of older patients who may benefit the most from enhanced involvement, that is those who want to be involved, but lack the necessary skills. This group could be coached either individually or, more practically, in group sessions.

Implications for research

Although the evidence is sparse, there are some positive effects of these interventions which means they should not be ignored. In order to draw conclusions about the effects of these interventions, further research is needed. This research may focus on pre-visit interventions including a face-to-face session supported with a written element, as this package seems one of the most promising methods of involving older patients in their care. Future trialists should consider who ought to deliver the intervention, when, and to whom, for example to a subgroup of older patients, such as those who want to be involved more but lack the requisite skills. The studies should be randomised controlled trials with adequate allocation concealment methods, use an appropriate number of older patients and preferably should include objective health outcomes as well as a valid measure for involvement. This measure for involvement may be, in addition to the outcomes mentioned in this review, a combination of patients’ self-reported behaviour and patients’ self-reported evaluation, complemented with an objective observation of patients’ involvement. As patients’ preferences for involvement may vary, it may be important to collect this data, in order to be able to correct results for these preferences. Outcomes should preferably be measured over a longer period to see if apparent effects of interventions are maintained over time. We also note the lack of interventions focusing on the use of health care and on patients’ evaluations of care; these are deserving of clinical practice?

Authors’ conclusions

Interventions for improving older patients’ involvement in primary care episodes (Review)

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further research.

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Oermann 2003b [published data only]

Oermann 2003c [published data only]

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Wolff 2002

WONCA 2002

* Indicates the major publication for the study
### Characteristics of studies [ordered by study ID]

#### Cegala 2001

| **Methods** | - Study design: quasi-randomised trial.  
- Randomisation procedure: half of the patients were randomly selected from appointment records, and randomly assigned to intervention or control group, before being telephoned and invited to participate. The other half of the sample was recruited as follows: patients for the control group were recruited in the waiting room, whereas patients for the intervention group were randomly selected from a list of available patients before being telephoned and invited to participate.  
- Intention-to-treat analysis: not stated.  
- Physicians were blinded to participants' group assignment.  
- Baseline measurement: patients from both groups were given a brief pre-interview questionnaire |
| **Participants** | - Inclusion criteria: age >= 65 years.  
- Setting: Family Practice Center, Ohio, USA.  
Information about participants:  
- Intervention group: 16 participants; control group: 17 participants. Nine physicians also participated.  
- Mean age 72 years (intervention group) versus 71.94 years (control group).  
- Medical status: patient judgement: 5.56 (intervention) versus 5.23 (control) and physician judgement: 4.00 (intervention) versus 3.62 (control)  
The following demographic information pertains across both intervention and control groups:  
- Gender: 14 men, 19 women.  
- Ethnicity: 17 white, 15 black, 1 Asian.  
- Education: 5 grammar school; 22 high school; 2 college; 4 graduate degree.  
- Participants: 27 alone; 5 with spouse; 1 with relative |
| **Interventions** | Trained (intervention) group: (n=16).  
- Training booklet sent by mail, approximately 3 days before appointment. The booklet was divided into three sections, addressing information provision, information seeking and information verifying, with space for patients to list their own questions and concerns.  
- Face-to-face session with researcher, 30 minutes in duration, just before physician visit  
Untrained (control) group: (n=17).  
- brief pre-visit questionnaire. |
| **Outcomes** | Questioning behaviour (assessed by recording, transcribing and coding the patient-doctor interview), appointment length |
| **Notes** | Patients in both groups were paid to participate in the study |

### Risk of bias

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<th>Item</th>
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<td>No</td>
<td>C - Inadequate</td>
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Kimberlin 2001

**Methods**
- Study design: randomised controlled trial.
- Randomisation procedure: Patients were alternately assigned to intervention or control group after a coin toss determined each day's first patient assignment.
- Intention-to-treat analysis: not stated.
- Physicians were blinded to participants' group assignment.
- Outcome assessors were blinded to participants' group assignment.
- Baseline measurement: none.

**Participants**
- Inclusion criteria: age >= 65 years, taking medication to treat chronic conditions, and caring for themselves.
- Setting: Ambulatory care family practice outpatient center affiliated with a hospital, Florida, USA
- Information about participants:
  - Intervention group: 22 participants; control group: 23 participants. Twenty physicians also participated.
  - Number of prescribed medications currently taken: 6.5 (intervention group) versus 5.3 (control group).
  - Gender: 11 men, 34 women across both groups.

**Interventions**
- Intervention group: (n=22).
  - Pre-visit interview with researcher (a medical student) to help to formulate questions about current therapy, questions were written down, with a copy given to the patient to take into their visit with their physician.
- Control group: (n=23).
  - No details provided.

**Outcomes**
Questioning behaviour (assessed by recording, transcribing and coding the patient-doctor interview)

**Notes**

**Risk of bias**

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Tennstedt 2000

**Methods**
- Study design: randomised controlled trial.
- Randomisation procedure: randomisation occurred at the site level. Sites were pair-matched, with one site of the pair randomly assigned to the intervention group and the other to the control group.
- Intention-to-treat analysis: yes.
- Blinding: unclear.
- Baseline measurement: none.

**Participants**
- Inclusion criteria: not stated.
- Setting: community sites (senior housing, senior centers) - number of sites not specified. Within each site, participants were recruited with the assistance of site staff.
- Information about participants:
  - Intervention group: 155 participants; control group: 200 participants.
  - Average age: 77.4 years.
- Women 83%.
- Average years of education: 11.4.
- From minority groups: 26%.
- Average time treated by same physician: 4.7 years.

### Interventions

**Intervention condition:** (n=155).
- A 2-hour group program (up to 3 months before visit to doctor) about patient behaviour styles, including modeling of “undesirable (ineffective) and desirable patient behaviors” and opportunities to practice these behaviours in role-playing exercises, with discussion about participants’ interaction style and its consequences. During this program, participants were given cue cards with a list of “desirable active behaviours” and a preparation booklet, to record and prioritize reasons for the visit to the doctor, a list of current medications, and questions for the doctor.
  
**Control condition:** (n=200).
- No group program (usual care).

### Outcomes

Patient-reported active participation during the visit to the doctor, patient satisfaction with the visit (selected items from the RAND Patient Satisfaction Questionnaire)

### Notes

**Risk of bias**

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### Characteristics of excluded studies [ordered by study ID]

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<td>Setting not met: Psychiatric outpatient clinic</td>
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<tr>
<td>Banks 1998</td>
<td>Patient criteria not met: women 15-80</td>
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<tr>
<td></td>
<td>Intervention criteria not met: health education intervention</td>
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<td>Beck 1997</td>
<td>Intervention criteria not met: not focused on episodes of care; not focused on improvement of involvement</td>
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<tr>
<td>Begley 1997</td>
<td>Intervention criteria not met: pharmacy based intervention</td>
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<td>Bernabei 1998</td>
<td>Intervention criteria not met: case management programme</td>
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<td>Bernsten 2001</td>
<td>Intervention criteria not met: pharmacy based intervention</td>
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<td>Bertakis 1991</td>
<td>Patient criteria not met: Participants all ages</td>
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<td>Study</td>
<td>Criteria Not Met</td>
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<td>Billault 1995</td>
<td>Patient criteria not met: Participants mean age 51-55</td>
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<td>Billip 2001</td>
<td>Intervention criteria not met: Intervention focused at improving self-esteem and reducing depression by interactive use of computer terminals</td>
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<tr>
<td>Boston 2001</td>
<td>Intervention criteria not met: Intervention not focused on improving involvement</td>
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<td></td>
<td>Design not met: prospective non-randomized comparative study</td>
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<td>Cegala 2000a</td>
<td>Patient criteria not met: Participants mean age 43-46</td>
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<td>Cegala 2000b</td>
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<td>Cornbleet 2002</td>
<td>Patient criteria not met: Participants 18+</td>
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<td>Davison 1999</td>
<td>Patient criteria not met: Participants age 50-79</td>
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<td>Demiris 2003</td>
<td>Design not met: No trial</td>
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<td>Intervention criteria not met: virtual visits for chronic patients</td>
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<tr>
<td>Dietrich 1989</td>
<td>Intervention criteria not met: Intervention consisted of reminders</td>
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<td>Drury 2000</td>
<td>Patient criteria not met: Participants aged 16+, selected patients: radiotherapy outpatients</td>
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<tr>
<td>Dubbert 2002</td>
<td>Patient criteria not met: Participants &gt; 60</td>
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<td>Intervention criteria not met: Intervention was not focused on enhancing involvement</td>
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<td>Edworthy 1999</td>
<td>Patient criteria not met: Participants 50+</td>
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<td></td>
<td>Intervention criteria not met: computer assisted educational intervention to facilitate appropriate utilization of an antiinflammatory medication</td>
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<tr>
<td>Ersek 2003</td>
<td>Intervention focused on self-management of pain</td>
</tr>
<tr>
<td>Gabbay 2003</td>
<td>Patient criteria not met: age range 18-79; selected subjects: depression</td>
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<td></td>
<td>Design not met: part of a trial, intervention not aimed at improving involvement</td>
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<tr>
<td>Gagnon 1999</td>
<td>Patient criteria not met: Selected group of participants</td>
</tr>
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<td></td>
<td>Intervention criteria not met: nurse case management intervention</td>
</tr>
<tr>
<td>Greenberger 2003</td>
<td>Design not met: cross-sectional study</td>
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<tr>
<td></td>
<td>Intervention criteria not met: no intervention</td>
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<tr>
<td>Groessl 2000</td>
<td>Patient criteria not met: Participants &gt; 60; selected group of patients: osteoarthritis</td>
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<td>Intervention not met: intervention focused on improvement of living with OA</td>
</tr>
<tr>
<td>Hainsworth 2003</td>
<td>Patient criteria not met: selected group of patients: arthritis</td>
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<td></td>
<td>Design not met: no control group</td>
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<tr>
<td>Study</td>
<td>Outcome 1</td>
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<tr>
<td>------------------</td>
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<tr>
<td>Hall 1992</td>
<td>Intervention criteria not met: Intervention that supplies extra care</td>
</tr>
<tr>
<td>Hershey 2002</td>
<td>Patient criteria not met: Participants mean age 41-52</td>
</tr>
<tr>
<td>Hickson 2003</td>
<td>Patient criteria not met: Participants age 56-93</td>
</tr>
<tr>
<td>Holland 2003</td>
<td>Design not met: no trial</td>
</tr>
<tr>
<td>Hornberger 1997</td>
<td>Patient criteria not met: 18 years and older</td>
</tr>
<tr>
<td>Kerse 1999</td>
<td>Intervention criteria not met: health promotion intervention focused on GPs</td>
</tr>
<tr>
<td>Kidd 2004</td>
<td>Patient criteria not met: all patients attending diabetic clinic at a hospital</td>
</tr>
<tr>
<td>King 2002</td>
<td>Patient criteria not met: selected participants (only women, aged 49-82 year)</td>
</tr>
<tr>
<td>Kobb 2003</td>
<td>Design criteria not met: no trial</td>
</tr>
<tr>
<td>Kralik 2004</td>
<td>Design not met: no trial; exploration concept self-management among chronic patients</td>
</tr>
<tr>
<td>Krishna 1997</td>
<td>Design not met: Review of trials</td>
</tr>
<tr>
<td>Lecouturier 2002</td>
<td>Patient criteria not met: selected group of patients (colon/lung cancer; all ages)</td>
</tr>
<tr>
<td>Lets 2003</td>
<td>Design not met: no trial</td>
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<td>Liaw 1997</td>
<td>Patient criteria not met: all ages</td>
</tr>
<tr>
<td>Little 2001</td>
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<td>Patient criteria not met: all ages</td>
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<td>Lorig 2001</td>
<td>Patient criteria not met: participants 40+ with certain chronic diseases</td>
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<td>Lorig 2003</td>
<td>Patient criteria not met: selected group of patients, Hispanics with chronic diseases (heart, lung disease of type 2 diabetes)</td>
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<td>Maly 1999</td>
<td>Patient criteria not met: Participants aged 19-75 years</td>
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<tr>
<td>Matuska 2003</td>
<td>Design not met: no trial; intervention focused at participation in occupations not in healthcare</td>
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<td>Study</td>
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<td>--------------</td>
<td>--------------------------</td>
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<td>McCann 1996</td>
<td>ages 16-74</td>
</tr>
<tr>
<td>McGilton 2003</td>
<td>residents of nursing home units</td>
</tr>
<tr>
<td>McKinstry 2000</td>
<td>no intervention</td>
</tr>
<tr>
<td></td>
<td>all ages</td>
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<td>Miaskowski 2004</td>
<td>intervention focused at pain control</td>
</tr>
<tr>
<td>Mundinger 2000</td>
<td>comparison nurse practitioner and physician</td>
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<tr>
<td>Murray 2001a</td>
<td>selected subjects, women (mean age 50)</td>
</tr>
<tr>
<td>Murray 2001b</td>
<td>selected subjects, men (mean age 63)</td>
</tr>
<tr>
<td>Newbury 2001</td>
<td>Health assessment programme</td>
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<tr>
<td>Oermann 2003a</td>
<td>focused on health-promotion teaching instead of involvement.</td>
</tr>
<tr>
<td>Oermann 2003b</td>
<td>not focused on involvement</td>
</tr>
<tr>
<td>Oermann 2003c</td>
<td>not focused on involvement</td>
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<td>Parry 2003</td>
<td>interdisciplinary team intervention</td>
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<tr>
<td>Penner 1991</td>
<td>reminder study</td>
</tr>
<tr>
<td>Post 2001</td>
<td>Participants mean age 42-47</td>
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<tr>
<td>Pugh 1999</td>
<td>in-hospital patients, selected patients (CHF)</td>
</tr>
<tr>
<td>Radecki 1999</td>
<td>Participants 18 or older</td>
</tr>
<tr>
<td>Reed 2004</td>
<td>review, about partnership in research</td>
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<td>Reuben 1999</td>
<td>Comprehensive assessment study</td>
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*Interventions for improving older patients' involvement in primary care episodes (Review)*

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<tr>
<th>Reference</th>
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<tr>
<td>Roter 1977</td>
<td>Participants median age 50 years</td>
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<td>Rubenstein 1994</td>
<td>Ineligible study design: Baseline measurement of a CGA</td>
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<tr>
<td>Sahar 2003</td>
<td>Intervention criteria not met: not focused on involvement</td>
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<td>Saunders 2003</td>
<td>Intervention criteria not met: health promotion study</td>
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<td>Savage 1990</td>
<td>Patient criteria not met: Participants aged 16-75</td>
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<td>Schraeder 2001</td>
<td>Intervention criteria not met: Intervention was not focused on enhancing involvement</td>
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<tr>
<td>Sidani 2003</td>
<td>Design not met.</td>
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<tr>
<td>Sommers 2000</td>
<td>Intervention criteria not met: Multidisciplinary team intervention</td>
</tr>
<tr>
<td>Sorby 1991</td>
<td>Patient criteria not met: Participants 18+; selected group of patients (with anxiety disorder)</td>
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<td>Stump 1995</td>
<td>Patient criteria not met: Participants 50+; mean age 67 Design not met: no trial, no intervention.</td>
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<td>Sturgess 2003</td>
<td>Intervention criteria not met: pharmacy based intervention</td>
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<td>Patient criteria not met: Participants all adult patients Intervention not focused on involvement, but on trust</td>
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<td>Patient criteria not met: Participants mean age 47 Intervention not focused on involvement, but on trust</td>
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<td>Toseland 1992</td>
<td>Patient criteria not met: Participants &gt; 59 Intervention not focused on involvement, but on support of spouses</td>
</tr>
<tr>
<td>Tsay 2004</td>
<td>Patient criteria not met: selected group of patients (end-stage renal disease); all ages</td>
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<td>Von Korff 1998</td>
<td>Patient criteria not met: subjects aged 25-70 Intervention criteria not met: Intervention disease specific</td>
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<td>Wasson 1984</td>
<td>Patient criteria not met: Participants 55+ Intervention criteria not met: provider continuity; not focused on involvement</td>
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<td>Wasson 1999</td>
<td>Intervention criteria not met: more assessment study than focused on involvement</td>
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<td>Waxman 2003</td>
<td>Patient criteria not met: 60+ Intervention not focused on involvement: self-management foot care program</td>
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<td>Whatley 2002</td>
<td>Intervention criteria not met: Study was about presenting information</td>
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<th>Study</th>
<th>Patient criteria not met</th>
<th>Intervention not focused on involvement, but on preventive health care</th>
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<tbody>
<tr>
<td>Wilkinson 2002</td>
<td>mean age 60</td>
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<td>Williams 1998</td>
<td>all patients</td>
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<tr>
<td>Williams 2001</td>
<td>Participants 18+; selected group: patients with cancer</td>
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DATA AND ANALYSES

This review has no analyses.

WHAT'S NEW

Last assessed as up-to-date: 28 June 2004.

<table>
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<th>Event</th>
<th>Description</th>
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| 10 July 2008 | Amended   | Converted to new review format.  

HISTORY

Review first published: Issue 1, 2007

CONTRIBUTIONS OF AUTHORS

Raymond Wetzels:
- protocol drafting and revising
- searching for trials
- abstract assessment for eligibility
- quality assessment of trials
- data extraction
- review drafting and revising

Mirjarm Harmsen:
- protocol drafting and revising
- searching for trials
- abstract assessment for eligibility
- quality assessment of trials
- data extraction
- review revising

Chris van Weel:
- protocol revising
- review revising

Richard Grol:
- protocol revising
- review revising
Michel Wensing:
- protocol drafting and revising
- abstract assessment for eligibility
- quality assessment of trials
- data extraction
- review revising

All authors gave final approval of this version to be published.

DE CLARATIONS OF INTEREST

None known.

SOURCE S OF SUPPORT

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- Cochrane Consumers and Communication Review Group, La Trobe University, Australia.

External sources
- The European Union; Quality of life and management of living resources programme (1998-2002); The ageing population and disabilities, QLRT-1999-02035, Not specified.
- Netherlands Organisation for Health Research and Development (ZONMW 920-03-252), Netherlands.

INDEX TERMS

Medical Subject Headings (MeSH)
*Patient Participation; *Primary Health Care; *Self Care; Treatment Outcome

MeSH check words
Aged; Humans