Chronic Disease Management

Structured review

Patient Involvement and Collaboration in Shared Decision-making: a Structured Review to inform Chronic Disease Management

National Centre for Health Outcomes Development, University of Oxford
Patient-reported Health Instruments Group
Report to the UK Department of Health, March 2005

Executive Summary

Background
Focus of the review
Methods
Key findings
  Collaborative care interventions
  Outcome measures
  Study results
Conclusion and recommendation

Description of intervention methods studied, and summary of study results
  Descriptions and examples of patient-targeted intervention methods
  Descriptions and examples of provider-targeted intervention methods
  Summary study results

Related Publications

User Groups

Executive Summary

Background
A high and rising proportion of health services is devoted to chronic disease, reflecting the shift from acute to chronic illness as the major cause of health problems in the UK. In response, new models of chronic disease management have emerged that share a central theme of patient involvement in the health-care process. These programmes strive to utilize patient expertise and to support patients to manage their conditions optimally by using a combination of collaborative care, or care in which patients are seen as experts in their own lives and are encouraged to identify their problems and define goals, and self-management education, or education that provides patients with problem-solving and management skills for self-care of a chronic condition.

Focus of the review
This review evaluates the effectiveness of the collaborative care element of chronic disease management, defined for the purposes of this review as ‘an interaction or series of interactions between a patient and the health-care system in which the patient is active in providing information to aid diagnosis and problem-solving; sharing his or
her preferences and priorities for treatment or management; asking questions; and/or identifying management approaches that best meet his or her needs, preferences, and priorities.

**Methods**
Medline, accessed through Webspirs Silverplatter, was searched for the years 1977-2004. The main search was designed to return intervention studies seeking to enhance patient collaboration in the health-care process. This search cast a wide net that allowed initial identification of a typology of interventions. Identification of this typology then allowed focused searches and/or reference to recent systematic reviews to retrieve additional studies within each intervention category.

Data were extracted related to study design, sample, intervention characteristics, and study results.

**Key findings**

**Collaborative care interventions**
Five distinct types of intervention that met the criteria for being collaboration-focused were identified:

1. Patient-reported outcome measures/other questionnaires that increase the provision of information from the patient to the provider regarding problems or preferences;
2. Communication interventions (including written checklists, educational materials, and one-to-one coaching for patients, or communication skills training for providers) that encourage patient expression of problems, priorities, or preferences;
3. Patient-held records that allow patients to contribute to the information in their medical records;
4. Patient goal-setting for behaviour change or self-management;
5. Patient values-clarification exercises, generally for identification of treatment or management approaches that best meet identified preferences and priorities.

Patient-reported outcome measures were the most commonly studied intervention.

**Outcome measures**
The wide range of reported outcome measures were grouped into the following seven broad outcome domains:

- patient-provider communication
- decision satisfaction (patient involvement in decision-making, patient-provider agreement, decisional conflict/regret)
- patient attitudes and behaviors (self-efficacy, adherence, behavior change)
- provider attitudes and behaviors (diagnosis and management of patient conditions)
- patient satisfaction
- patient health status
- health-care resource use

Outcome measures were also defined as being:

- short-term - within a week after the intervention
- intermediate - two to eight weeks post-intervention
- long-term - three or more months post-intervention
**Study results**
Communication, decision satisfaction, and provider behaviors benefited most from collaborative care interventions, with positive results reported in more than 50% of cases. The interventions appeared to have less impact on patient attitudes and behaviors, satisfaction, health status, and resource use. Interventions had the most positive effect in the short term and tended to be reduced in the intermediate and long term. Whether the intervention was targeted at the provider or patient appeared to have little impact on the effectiveness of the intervention.

Conclusions about which intervention method is most beneficial for a given outcome are hindered by studies’ limited focus on a few outcomes and on the short term. For example, the impact of the use of patient-reported outcome measures (PROMs) on patient-provider communication, patient decision satisfaction, and patient attitudes and behaviors has been neglected and most studies do not assess continued use of PROMs over the long term, leaving the true benefit of PROMs interventions unknown.

**Conclusion and recommendation**
Innovations in chronic disease management have focused on increasing patient collaboration in the health-care process. This review provides encouraging evidence that increasing patient collaboration may have a positive impact on a variety of patient and provider outcomes. Based on such evidence, the use of the interventions outlined in this review should be seriously considered as an important means of improving care for chronically ill people.

Tables with descriptions and examples of intervention methods studied, and summary results, follow below.

**Further information regarding characteristics of the studies reviewed, intervention characteristics, outcome measures, and study results can be found by referring to a full copy of the report, available in PDF format on the PHI Group website.**

---

3
### Description of intervention methods studied, and summary of study results

#### Descriptions and examples of patient-targeted intervention methods

*(Table 5a of the report)*

<table>
<thead>
<tr>
<th>Method</th>
<th>Description</th>
<th>Example</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Checklist</strong></td>
<td>A list of frequently asked questions; provides patients with the opportunity to make note of questions they wish to ask during the consultation</td>
<td>Butow et al (1994) provided patients with a worksheet consisting of example questions and space for patients to write five questions they wished to ask</td>
</tr>
<tr>
<td><strong>Coaching</strong></td>
<td>One-to-one interaction between a research assistant and patient stressing the importance of patient participation; frequently includes role-playing</td>
<td>In a study by McGee et al (1998), a health educator met with each patient to discuss patient’s goals for the consultation, encourage patients to ask questions, and assist with wording and writing of questions</td>
</tr>
<tr>
<td><strong>Educational Materials</strong></td>
<td>Written materials provided to patients addressing the importance of communication in the consultation and encouraging patients to clarify the questions they have and the reasons for their visit</td>
<td>Frederikson et al (1995) included in their intervention a leaflet encouraging patients to think about the reasons for their visit, the concerns they have, and what they’d like their provider to do</td>
</tr>
<tr>
<td><strong>Goal-Setting</strong></td>
<td>Patients identify the goals they would like to reach with regards to self-management or lifestyle change</td>
<td>In a study by Gagne and colleagues (2003), patients were provided with a notebook in which to record self-defined goals and progress toward them; providers regularly engaged patients in discussion about their goals</td>
</tr>
<tr>
<td><strong>Group Education</strong></td>
<td>Education provided to groups of patients, generally focusing on increasing patient participation in the health-care consultation</td>
<td>Dow et al (1991) presented the Medical Communication Skills Program (‘MedCom’) to patients, with an emphasis on asking medication-related questions and providing information</td>
</tr>
<tr>
<td><strong>Patient-held Record</strong></td>
<td>Patients have access to their medical records and are able to contribute to the information contained in them</td>
<td>Williams et al (2001) provided patients with a booklet containing their past medical records plus space for entries by patients and professionals; patients were encouraged to write questions and comments in their record</td>
</tr>
<tr>
<td><strong>Patient-reported Outcome Measures</strong></td>
<td>Patients are asked to fill out questionnaires that elicit information about health status or quality of life issues; patient responses are then fed back to providers</td>
<td>Velikova et al (2004) reported patient responses to the EORTC QLQ-C30 to the patients’ providers, giving providers additional information on patient quality of life</td>
</tr>
<tr>
<td><strong>Questionnaires (other)</strong></td>
<td>Patients are asked to fill out questionnaires that don’t fall into the traditional category of PROMs. Patient responses are fed back to their providers</td>
<td>Feuerstein et al (1989) asked patients to fill out the Weight Loss Profile, which identifies problem areas in weight loss. Providers were then apprised of patient problem areas</td>
</tr>
<tr>
<td><strong>Values Clarification</strong></td>
<td>Patients work through an exercise that helps them to identify their priorities and preferences regarding a medical decision</td>
<td>O’Connor et al (1999) provided menopausal patients with a decision aid for hormone replacement therapy (HRT). As part of the decision aid, patients were asked to rate each benefit and risk of HRT in terms of its importance to them</td>
</tr>
</tbody>
</table>
**Descriptions and examples of provider-targeted intervention methods**  
*(Table 5b of the report)*

<table>
<thead>
<tr>
<th>Method</th>
<th>Description</th>
<th>Example</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Provider</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Educational</strong></td>
<td>Written information on problems in health care communication and/or ways to improve communication</td>
<td>Evans et al (1987) gave clinicians materials describing techniques to address common communication problems</td>
</tr>
<tr>
<td><strong>Materials</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Prompt list</strong></td>
<td>List of items designed to prompt the provider to take certain actions during the consultation</td>
<td>McLean et al (2004) used a prompt sheet of example questions to encourage providers to ask questions eliciting patient concerns</td>
</tr>
<tr>
<td><strong>Training</strong></td>
<td>Communication skills training for providers emphasising eliciting patient information about problems, priorities for the visit, and/or preferences for treatment or management</td>
<td>Pill et al (1998) trained providers in communication skills meant to allow patients to air their concerns, select discussion topics, and set targets for themselves</td>
</tr>
</tbody>
</table>

**Summary study results**  
*(Table 10 of the report)*

<table>
<thead>
<tr>
<th>Outcome Domain</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Short-Term*</td>
</tr>
<tr>
<td></td>
<td>N</td>
</tr>
<tr>
<td><strong>Communication</strong></td>
<td>53</td>
</tr>
<tr>
<td><strong>Decision Satisfaction</strong></td>
<td>17</td>
</tr>
<tr>
<td><strong>Provider Attitudes &amp; Behaviours</strong></td>
<td>31</td>
</tr>
<tr>
<td><strong>Patient Attitudes &amp; Behaviours</strong></td>
<td>10</td>
</tr>
<tr>
<td><strong>Satisfaction</strong></td>
<td>44</td>
</tr>
<tr>
<td><strong>Health Status</strong></td>
<td>11</td>
</tr>
<tr>
<td><strong>Resource Use</strong></td>
<td>10</td>
</tr>
</tbody>
</table>

*For the purposes of this review, ‘short-term’ applies to results measured immediately after the intervention up to one week post-intervention, ‘intermediate’ means two to 8 weeks post-intervention, and ‘long-term’ refers to those results measured 3 months or more after the intervention was completed.

† Study results were reported as ‘positive’ (+) if a statistically significant (p < 0.05) difference between intervention and control groups was reported by the authors and the difference was in the expected direction.
Related Publications


User Groups

Work in progress

These pages are under constant review.
We welcome constructive feedback and suggestions for appropriate links, user groups etc.

AM
17 July 2006