Perspectives of patients and professionals on the use of patient-reported outcome measures (PROMs) in primary care: a systematic review of qualitative studies

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Background/Aims

• Although the use of Patient-Reported Outcome Measures (PROMs) in healthcare settings has increased substantially over recent years, there is potential for them to play a greater role in primary care.

• The underlying goals of this study were to review and summarise studies on patients and healthcare professionals’ perspectives about the use of PROMs in primary care, to identify barriers and enablers to their use.
Methods

• A qualitative systematic review was conducted in Medline, Embase, PsychInfo and CINAHL from inception until 2016, and further relevant references were retrieved through snowballing.

• Five reviewers screened all the references for eligibility.

• Studies conducted in primary care settings using qualitative methods exploring patients and/or healthcare professional’s perspectives on the clinical utility of using PROMs in clinical practice.

• Thematic synthesis identified common themes across studies.
Flowchart of study selection

Total records identified through database searching (n=11618)

Duplicates removed (n=2540)

Number of records after duplicates removed (n=9078)

Number of titles & abstracts excluded (n=8957)

Full-text articles assessed for eligibility (n=121)

Number of full texts excluded (n=100)

Studies included in review (n=21)
Summary of studies

• 21 studies met the inclusion criteria (6 after 2012): UK (12), Canada (2), Netherlands (2), Sweden (2), USA (2), Germany (1), Norway (1).

• Studies reported on the views of only professionals (8), only patients (5), and both professionals and patients (5).

• Majority of studies (12) focused on mood disorders, and the PROMs most commonly reported on were the Edinburgh Postnatal Depression Scale (EPDS), Beck Depression Inventory (BDI), Patient Health Questionnaire (PHQ-9) and the Hospital Anxiety and Depression Scale (HADS).

• Recent studies have focused on electronic Patient-Reported Outcomes (ePROs).
Patient results

Diagnosis and management

• Some patients considered the questionnaires to be useful in assisting the general practitioner in diagnosing and managing depression. (10, 12)

• Other patients thought that the questionnaire would distract the doctor from their “real” job of diagnosing and treating the physical complaint of the patient. (12)
Impact on relationship with health professionals

• Using PROM an opportunity to discuss how they felt. For some, ticking boxes seemed easier than broaching sensitive topics verbally. (8, 12)
• Also concerns that lack of dialogue could result from using a pen and paper assessment. (9, 12, 14)
• Some patients reported feeling isolated using mobile device (ePRO), and worried that the tool could become a replacement for in person consultation. (18)
Awareness

- Some patients felt that completing surveys increased their self-awareness their health [both how well and how poorly they could be doing]. Reflecting on progress and achieving goals. For some self-affirming, for others a “wake-up call.” (9, 10, 16, 18)

- QoL feedback could be seen as negative, highlighting things people couldn’t do anything about. (16)
Stigma

• Some patients concerned that questionnaires were stigmatising and would have the effect of categorising or negative labelling. Especially in relation to mental health. (10, 12, 14)

• However, better understanding of QoL seen as challenging stereotypes practitioners may hold about groups (e.g. older people), enabling them to be treated as individuals. (16)
Barriers to implementation (cont.)

Confusing scales
• Patients expected a rating of 10 to be good; however, scales were based on tools designed for providers, who tend to see high values (i.e., spikes) as a negative health outcome. Additionally, some of the scales were flipped. (20)

Time/resources/burden
• Some patients were critical of the abundance of paper-work. Impractical for busy doctors. (12)

Confidentiality
• Some individuals stated that they would feel uncomfortable completing such a questionnaire in the surgery in close proximity to other patients. (13)
Barriers to implementation (cont.)

Lack of feedback
• Some patients not provided with feedback and felt this unsatisfactory. If GP fails to discuss the [PROM] results and what they may mean for the patient, this may jeopardise usefulness and even make the patient feel worse (13, 14, 15)

IT issues (ePROs)
• Impersonal. Insufficient ease of use: step learning curve and insufficient training and tutorials. Patients experienced technical errors and difficulty in reviewing previously entered open-text data. Questions often did not appear at the correct times or days. Too much time investment and lack of security. (18, 19)
Professional results

Diagnosis and management

• GPs (both experienced and less experienced) acknowledged PROMs could identify more depression and highlighted management options. Questionnaires increased confidence in decision-making, confirming that they were not “just doing whatever came up.” (6)

• Could be used to persuade patients they were not depressed, although some GPs felt that the patient’s confidence in the doctor would be jeopardized. (2, 17)

• GPs noted a benefit in terms of better understanding the longitudinal life of patients, seeing what specific issues their patients had been facing and then targeting discussions. (9, 20)
Impact on relationship with patients

• GPs felt that use of PROMs leads to a more bureaucratic work style. A distraction, hampering the ability of the GP to be an active and engaged listener, jeopardising the “human” element of consultations. (5, 10, 17)

• ePROs considered impersonal. (19)

• However, some professional felt that PROMs facilitated patients “opening up” on sensitive topics. Facilitating structured, focused and meaningful communication, encouraging goal setting. Providing physicians with a more complete picture. (2, 6, 7, 8, 11, 17, 21)
Impact on clinical judgement

• GPs accepted the scores as part of the clinical assessment, but more as a confirmation of their own findings. (10)

• Professionals did not always trust PROMs score and sometimes valued their subjective assessment of the client as more important, thus relying on their own clinical judgment as the “gold standard”. (2, 5, 6, 10, 17)
Barriers to implementation

Burden: Time and resources
• Time to complete questionnaires, record and interpret data takes too long. Longer consultations needed. (1, 3, 11, 18)

IT barriers
• A lack of integration of computerised PROMs within existing systems perceived as important barrier. Technical issues, not aligned with current programs and practices. (18, 19)
Barriers to implementation (cont.)

Knowledge

• Lack of awareness about up to date information. More training needed to interpret and feedback PROMs. Wariness about probing patient responses due to lack of knowledge. (3, 11)

Lack of motivation/scepticism

• Professional inertia, lack of motivation or interest. Some GPs sceptical about using PROMs at individual patient level. Belief that some tools “overused and open to manipulation.” Scepticism about the motives behind the introduction of tools, seeing them as “academically” oriented or supported by a government wishing to save money. (3, 2, 9, 10, 11, 19)
Conclusions

• Patients and professionals highlighted a number of benefits of using PROMs, particularly in terms of supporting decision making, patient awareness and management/self-management options.

• Notable contrasts: both sides worried about PROMs undermining human contact, yet an acknowledgement they can open up sensitive topics. Potential to open up and restrict conversations.

• ePROs criticised on both sides – patients because they are cumbersome, professionals because they are not aligned to their processes and systems.

• Negative feedback loop. Patients frustrated by lack of PROMs feedback, clinicians don’t feedback because of frustrations:
  – Time, resources, burden
  – Lack of knowledge/motivation
  – Clinical judgement still the “gold standard”

• These constitutes major barriers that need to be addressed in the future implementation of PROMs in primary care.
Thank you

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