

Chapter 3.4f **Patient-direct and patient-mediated KT interventions**

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Key learning points

Patient-direct KT interventions

- Aim to actively engage patients to enhance their knowledge, experience, service use, health behavior, and health outcomes.
- Focus on health literacy, clinical decision making, self-care, and patient safety.
- Improve patients' knowledge and can have positive effects on their experience, service use, health behavior, and health outcomes.

Patient-mediated KT interventions

- Are targeted at patients but aim to change health professionals' behaviors through patient-provider interaction.
- Have not been evaluated adequately to determine their impact on changing health care practitioners' behavior.

Knowledge translation (KT) interventions should be tailored for the target audiences; one of which is patients. For patients, these interventions can be grouped into interventions designed to: (1) directly influence patient outcomes, here termed “patient-direct”; and (2) or interventions provided to patients but aimed at mediating health professionals' behaviors, here termed “patient-mediated” (see Figure 3.4f.1). Similarly, interventions

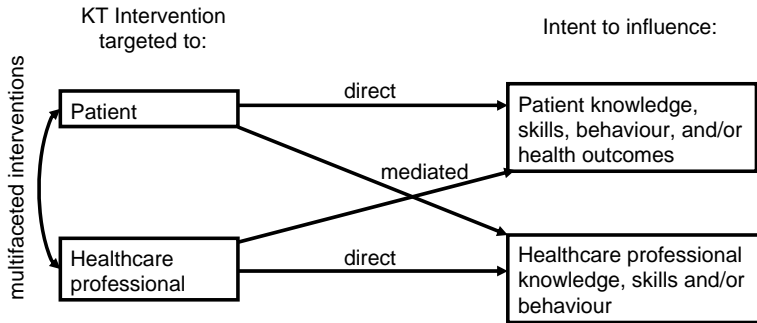


Figure 3.4f.1 Direct versus mediated KT interventions for patients and health care professionals.

targeting health professionals may influence their attitudes, knowledge, skills, and behavior directly and may also mediate patients' behaviors (see Chapter 3.4b). All of these interventions are used to increase uptake of evidence in clinical practice and self-care.

Interventions provided to patients for reducing the knowledge to care gap are premised on having an informed and activated patient [1, 2]. This chapter summarizes the state of the knowledge and research gaps regarding patient-direct and patient-mediated interventions used to enhance KT.

Patient-direct interventions

Patient-direct interventions aim to promote patients' involvement in implementing appropriate, safe, effective, and responsive self-care and health care (see examples in Table 3.4f.1). The framework of Coulter and Ellins [1, 3] is used to classify these strategies into four broad categories according to their intent to improve health literacy, clinical decision making, self-care, and patient safety.

A person who is *health literate* is able to access, understand, evaluate, and communicate information as a way to promote, maintain, and improve health in a variety of settings across the life-course [4]. Examples include written health information materials, alternative format information resources (e.g. video), targeted approaches for disadvantaged groups with lower health literacy (e.g. using non-written media such as pictograms, videos, interactive computer systems), and mass media campaigns to promote

Table 3.4f.1 Examples of patient-direct and patient-mediated interventions for KT

Patient-direct interventions	Patient-mediated interventions
<ul style="list-style-type: none"> ● health information materials ● mass media campaigns ● question prompts ● patient decision aids ● self monitoring/self-administration ● self-help groups, peer support ● tele-care ● enhancing adherence to treatment ● patient reporting adverse events 	<ul style="list-style-type: none"> ● question cards to prompt asking questions of practitioners ● coaching in preparation for consultation with health professionals ● patient decision aids ● patients providing reports to health professionals ● communication skills training to patients and to professionals ● patients reporting their results to the health professional (e.g. blood pressure readings, depression scores, blood glucose readings)

specific health behaviors or service use (e.g. television, radio, newspapers, posters, brochures).

Interventions focused on supporting patient involvement in *clinical decision making* includes patient decision aids (see Chapter 2.2), question prompts, health coaching, and training clinicians in communication skills [1, 3]. Health coaching is used to develop patients' skills in preparing for a consultation, deliberating about options, and implementing behavior change [5].

Self-care and self-management interventions aim to improve people's practices in maintaining health and managing disease. Examples include: self-management education to develop skills to cope with the condition and manage daily problems; self-monitoring and self-administered treatment; self-help groups and peer support; patient access to personal medical information; and patient centered tele-care. Many self-management education programs used the Lorig model which aims to help patients develop the skills needed to manage their chronic health condition [6, 7]. The Lorig model for self-management is a generic, lay-led, community-based course provided in six weekly sessions and includes cognitive skills, symptom management, healthy lifestyle, communication skills, managing medication, planning for the future and taking action, problem solving, making informed decisions, and working in partnership with the health care team. Patients exposed to this self-management program had short-term improvements in health behaviors, self-efficacy, and use of health services.

Patient-direct interventions whose aim is to improve *patient safety* include information about choosing safe providers, patient involvement in infection control, adherence to treatment, checking records and care processes, and patient reported adverse events.

Do patient-direct interventions work?

Coulter and Ellins [1, 3], identified 129 reviews of patient-direct interventions. Drawing on their findings, we report patient outcomes for knowledge, experiences, health service use and costs, and health behavior and health outcomes (see Table 3.4f.2 for specific outcomes in these categories).

Table 3.4f.2 Outcomes for patient-targeted interventions

Categories of outcomes	Outcome description
Knowledge, comprehension and recall of information	<ul style="list-style-type: none"> ○ knowledge of <ul style="list-style-type: none"> ○ the health condition ○ long term complications of the health condition ○ self care options ○ treatment options
Experience	<ul style="list-style-type: none"> ● patient satisfaction ● satisfaction with doctor-patient communication ● quality of life ● psychological well-being ● self-efficacy ● involvement with health care decision making and self care ● empowerment
Use of health services and costs	<ul style="list-style-type: none"> ● hospital admissions ● length of hospital stay ● number of visits to health professionals ● costs ● costs to patients ● days lost from work or school
Health behavior	<ul style="list-style-type: none"> ● health related lifestyles ● self-care activities ● treatment adherence
Health outcomes	<ul style="list-style-type: none"> ● severity of disease or symptoms ● physical and mental functioning ● clinical indicators

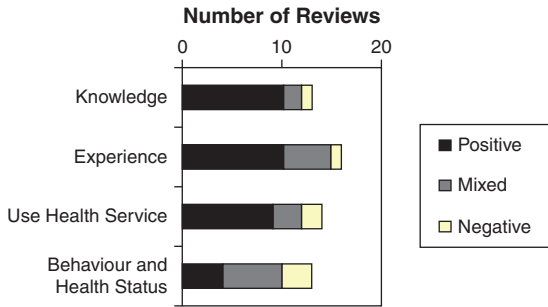


Figure 3.4f.2 Reviews of health literacy interventions (n = 25).

Patient-direct interventions to improve *health literacy* were the focus of 25 reviews [1, 3]. These interventions have the most consistent positive effects on knowledge and to a lesser extent on patients' experience and use of health services (see Figure 3.4f.2). Health literacy interventions alone do not have consistent positive effects on behavior and health outcomes. Written materials improve knowledge and recall particularly if personalized. Combined written and oral information can improve patient experience and sometimes use of health services. Other formats, such as websites, improve user satisfaction and some studies report positive effects on self-efficacy and health behavior. Although information adapted for disadvantaged populations who lack health literacy skills has shown positive effects on knowledge and behavior, fewer studies have examined effects on reducing inequities in health outcomes. Targeted mass media campaigns increase awareness often within 3 to 4 months, improve use of services (drugs, medical or surgical procedures, diagnostic tests), but have less effect on health behavior. Only two studies showed that mass media influenced smoking behavior among young people [8, 9].

There were 22 reviews on interventions to improve *clinical decision making* [1, 3]. The most consistent positive effect is on knowledge followed by use of health services (see Figure 3.4f.3). The reviews that examined question prompts and coaching found that these interventions have positive effects on patients' knowledge, information recall, and participation in decision making. Their effects on satisfaction and treatment outcomes were inconsistent. The reviews of patient decision aids indicated that they improve patients' participation, increase knowledge of their treatment options and outcome probabilities, and improve agreement between patients' values and subsequent treatment decisions. For example in one meta-analysis of 11 trials, the use of discretionary surgery decreased by 20% without apparent adverse effects on health outcomes [10].

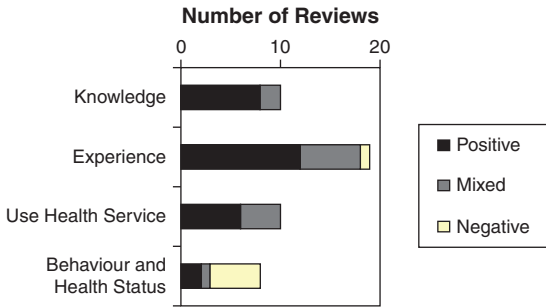


Figure 3.4f.3 Reviews of clinical decision making interventions (n = 22).

Coulter and Ellins [1, 3] synthesized 67 reviews of *self-care or self-management* interventions (see Figure 3.4f.4). Overall, findings revealed improved knowledge, patient experience, health behavior, and health outcomes. Although there were mixed effects across reviews, self-management programs improved knowledge, coping behavior, adherence, self-efficacy, and symptom management. Programs which included skill development were more effective than those which provided information alone. Health services use and cost sometimes were reduced and quality of life enhanced. There were beneficial effects on health behavior and health outcomes within 3 to 6 months, which tended to lessen over time. Quality-of-life effects tended to be sustained beyond the intervention period. For example, more multi-faceted programs (self-management program, regular health professional consultation, patient action plans) that targeted asthma improved service use. Specifically, there were fewer hospitalizations

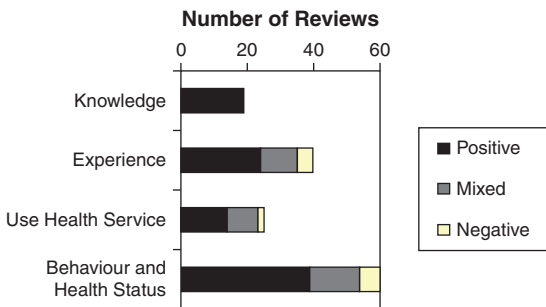


Figure 3.4f.4 Reviews of self-care and chronic disease self management interventions (n = 67).

(Relative Risk (RR) 0.64, Confidence Interval (CI) 0.56, 0.82), unscheduled visits (RR 0.68, CI 0.56, 0.81), quality of life (Standardized Mean Difference 0.29, CI 0.11, 0.47) and self efficacy (0.36, CI 0.15, 0.57). Children and adolescents also had moderate improvements in lung function measured with spirometry. In contrast, the effects of arthritis self-management education on pain (effect size range 0.12–0.22) and function (effect size range 0.07–0.27) have been small and short-lived. When diabetes self-management education was combined with other disease management strategies, blood glucose control was improved and diabetic complications were reduced. For patients with Type 2 diabetes, group education improved blood glucose and blood pressure. In summary, larger effect sizes were associated with self-management programs that focused on specific topics, used participative teaching methods, had multiple components including regular review by health professionals, involved family or other informal caregivers, and lasted at least 12 weeks.

There are fewer reviews of self-monitoring ($n = 8$), peer support groups ($n = 3$), patient-held medical records ($n = 4$), and patient centered tele-care ($n = 4$). Blood glucose self-monitoring in patients with diabetes has not been shown to be effective [11, 12]. In contrast, self-monitoring of blood pressure and anticoagulant therapy had similar outcomes to those of professionally managed care. In the case of hypertension, self-monitoring was cost neutral; for anticoagulation therapy, it was cost-saving. Self-help and support groups were viewed positively by participants in terms of sharing information, experiences, and problem solving. In the case of caregiver support groups, they improved confidence, coping, family function, and perceived burden of care. Patients found patient-held records useful and increased their sense of control. Recording consultations improves patients' recall, understanding, and uptake of information. Patient-centered tele-care in the home reduces patients' perceived isolation and improves self-efficacy, quality of life, patient empowerment, and psychological outcomes such as depression. Cost savings were evident when routine care was replaced by "virtual visits." Self-help, support groups, patient held medical records, and recording consultations did not affect health behavior or health outcomes.

Most of the 18 reviews by Coulter and Ellins [1, 3] focused on *improving safety* through better treatment adherence (see Figure 3.4.f.5). Overall safety KT interventions are effective in improving knowledge and patients' experience and to a lesser extent use of services, health behavior and health outcomes. The most effective strategy to optimize patients' treatment adherence is to simplify dosing regimens (8 to 19.6% improvement in 7 of 9 trials). Education and information provision was necessary but not sufficient to improve adherence. Little is known about the long-term effects of

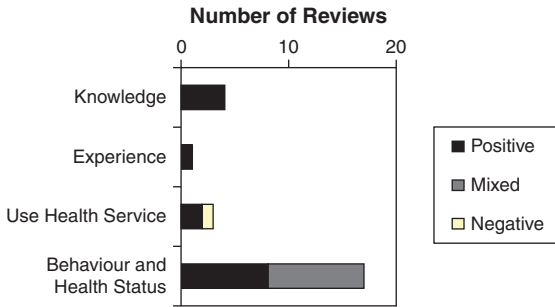


Figure 3.4.f.5 Reviews of safety interventions (n = 18).

treatment adherence interventions. One review of patient-oriented hospital infection control campaigns concluded that it increased compliance to hand hygiene when hand washing facilities were provided along with patient encouragement to ask health workers if they have washed their hands. Coulter and Ellins [1, 3] report that there have been no systematic reviews of patient reporting of adverse drug events. In individual studies, the evidence is mixed on the role of patient safety information in preventing adverse events. The effect of direct patient reporting into adverse event monitoring systems is unknown. The only review on equipping patients for safer health care reported one trial that provided patients with detailed information about their medications and another trial of a self-medication program. Both significantly reduced medical errors. There were some beneficial effects on patients' knowledge and confidence from an educational video. Personalized information on drugs had no effect on patients' experience of care. The effects from personalized information on error rates and adverse events were mixed so no conclusion can be made. Considering the surgical context, there are no reviews of asking patients to mark the site where their surgery will take place; however, single studies indicated that patients do not always follow through with requests to mark the correct surgical site.

Patient-mediated interventions

Patient-mediated interventions are targeted at patients but aim to change health professionals' behaviors through patient-provider interaction. According to the Cochrane Effective Practice and Organization of Care Review Group [13], patient mediated interventions are defined as new clinical information collected directly from patients and given to the provider

such as depression scores from an instrument (see Table 3.4f.1). We have expanded this definition to include any intervention targeting patients that aims to influence uptake of evidence by health care professionals. To scope out other potential interventions, we adopted the framework for organizing reviews used within the Cochrane Consumers and Communication Review Group. First, the framework organizes interventions by main direction of communication, in recognition of the multidirectional nature of communication and the central role of consumers to effective interactions and health care [14, 15]. Second, an intervention for communication and participation is defined as a “purposeful, planned and formalized strategy associated with a diverse range of intentions or aims. These interventions aim to inform, educate, communicate with, support, skill, change behavior, engage, or seek participation of people in all spheres of health – from individual to collective contexts [15].” While this therefore encompasses a wider range of interventions than are discussed here, the definition alerts us to the multiplicity of purposes of communication, including the indirect series of effects anticipated by interventions for consumers in changing the behaviors of professionals. According to this framework, other potential patient-mediated interventions include: (a) interventions for communication exchange between health care professionals and consumers (e.g. patient decision aids, communication skills training for consumers); or (b) interventions from the consumer (e.g. provider education by patient or family care representatives or civic participation interventions such as consumer involvement in developing health care policy, research, and clinical practice guidelines) [16].

Do patient-mediated interventions work?

Four systematic reviews evaluated the effect of interventions on communication exchange between health care professionals and consumers [10, 17–19]. In one review of 86 trials of patient decision aids, 11 trials measured patients’ participation in decision making and 4 measured the effect on patient–health professional communication (see Table 3.4f.3) [10]. This review found a reduced proportion of decisions being made by the health professional alone (RR 0.61; 95% CI 0.49 to 0.77) and more communication about the decision occurring between the patient and their health professional when patients were exposed to decision aids compared to usual care. Two systematic reviews evaluated the effect of interventions on enhancing shared decision making in clinical practice [17, 18]. From a patient reported perspective, one review of 21 trials found that all 3 trials that improved shared decision making included a patient-mediated

Table 3.4f.3 Evidence for patient-mediated interventions (n = 4 systematic reviews)

Systematic review focus	Trials (n)	Summary of findings
Patient decision aids (86 trials) [10]	11 trials [26–36]	↑ Patient participation in decision making ↓ Practitioner controlled decision making
	4 trials [37–40]	↑ patient-health professional communication about the decision
Patient reported shared decision making (21 trials) [18]	3 trials [41–43]	↑ shared decision making (when decision aid given with training of health professionals)
Third party reported shared decision making (5 trials) [17]	2 trials [44, 45]	↑ shared decision making (when decision aid used in consultation and/or used with training of health professionals)
Shared decision making in mental health (2 trials) [19]	1 trials [41]	↑ shared decision making (when used a patient decision aid)

intervention (e.g. patient decision aid) combined with an educational session about shared decision making for health professionals [18]. From a third party observer perspective, a review of five trials found that the two positive trials improved shared decision making and both used patient-mediated interventions [17]. One trial compared a patient decision aid used within the consultation to a patient decision aid used in preparation for the consultation. The other trial compared usual care to an intervention that included patient decision aid, educational session on shared decision making and performance feedback. The fourth systematic review of interventions to enhance shared decision making in people with mental health conditions identified two trials; both of which used patient decision aids and both trials were included in reviews reported above [19].

Other patient-directed interventions such as question prompts, which use question cards to prompt patients to ask the practitioner questions, or coaching in preparation for the consultation, both have the potential to be patient-mediated interventions. However, reviews of these interventions have not discussed their effect on health professionals' behaviour [20, 21].

For interventions from the consumer, one systematic review evaluated the effect of methods of consumer involvement in developing health care policy and research, clinical practice guidelines, and patient information material [22]. However, this review did not identify any studies that evaluated the effect of patient-mediated interventions on health care professionals'

behavior. A narrative overview of systematic reviews of communication skills training directed to consumers identified that apart from consultation length, no health professional outcomes were reported [23]. Improvements for consumers included outcomes associated with participating in the consultation. Interventions directed to both professionals and patients had mixed results including improvements in physicians' communication styles.

Although other systematic reviews report including patient mediated interventions, it was difficult to identify their effect on outcomes because: (a) patient-direct interventions were used alongside patient-mediated interventions; (b) studies evaluated patient-mediated interventions as part of a multi-faceted intervention; (c) studies didn't report their impact on health professionals' behaviors; or (d) patient-mediated interventions were inadequately described. For example, patients remotely submitting their home glucose records to their health care team may have combined it with a patient education intervention and study outcomes focused on glycemic control [24]. Similar issues were identified in a synthesis of systematic reviews focused on interventions to enhance medication prescribing that included patient-mediated interventions [25].

Future research

Research gaps regarding patient-targeted interventions occur at the fundamental and implementation levels. There are fundamental questions about the underlying theoretical frameworks of the interventions, essential effective elements, required duration, and adaptation for disadvantaged groups. More focus is needed on cost, long-term outcomes, and impact on narrowing health inequities. In the case of interventions with established efficacy (e.g. patient decision aids), research on optimal strategies to address implementation barriers is needed. Finally, studies of patient-targeted interventions that have the potential to be patient-mediated interventions need to consider measuring the effect on health professionals' behavior.

Summary

In view of the findings from systematic reviews, patient-direct and patient-mediated interventions may improve uptake of evidence to change behaviors of patients and health professionals respectively. Patient-direct interventions that actively engage patients improve their knowledge and can have positive effects on their experience, service use, health behavior, and health outcomes. To change other outcomes, additional strategies are required such as increasing the specificity and personalization of information, combining interventions with professional or other social support and

extending the duration of the intervention when long term behavior change is required. Patient-mediated interventions such as patient decision aids have been shown to change health professional behavior; however, there is a need to provide some link between the patient and the health professional either by using the decision aid within the consultation or by training health professionals in shared decision making. Important in the development of high-quality patient-direct and -mediated interventions is the systematic synthesis of the evidence used to inform them and the iterative process of ensuring they are relevant to the targeted user.

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