

Rapid Synthesis

Supporting Parents in Making Informed Decisions
in Relation to their Children's Health Needs

4 October 2018



EVIDENCE >> INSIGHT >> ACTION

**Rapid Synthesis:
Supporting Parents in Making Informed-Decisions in Relation to their
Children's Health Needs
10-day response**

4 October 2018

McMaster Health Forum

The McMaster Health Forum's goal is to generate action on the pressing health-system issues of our time, based on the best available research evidence and systematically elicited citizen values and stakeholder insights. We aim to strengthen health systems – locally, nationally, and internationally – and get the right programs, services and drugs to the people who need them.

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Timeline

Rapid syntheses can be requested in a three-, 10-, 30-, 60- or 90-business-day timeframe. This synthesis was prepared over a 10-business-day timeframe. An overview of what can be provided and what cannot be provided in each of the different timelines is provided on McMaster Health Forum's Rapid Response program webpage (www.mcmasterforum.org/find-evidence/rapid-response).

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Conflict of interest

The authors declare that they have no professional or commercial interests relevant to the rapid synthesis. The funder played no role in the identification, selection, assessment, synthesis or presentation of the research evidence profiled in the rapid synthesis.

Merit review

The rapid synthesis was reviewed by a small number of policymakers, stakeholders and researchers in order to ensure its scientific rigour and system relevance.

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KEY MESSAGES

Questions

- What are the most effective approaches for supporting parents in making informed decisions related to their children's health needs?
- What can be done to support the implementation of effective approaches for supporting parents in making informed decisions related to their children's health needs?

Why the issue is important

- Prevention or treatment decisions in healthcare are optimized when they take into consideration patient preferences, research evidence, and clinical expertise.
- For pediatric patients, however, the decision-making process is more challenging, requiring clinicians to inform, obtain consent, and consider the values of both the child (depending on the age) and the parent or caregiver.
- Several systematic reviews and primary studies have shown that involving parents/guardians in the decision-making process has many benefits, including: reducing decisional conflict among parents/guardians; improving patient and family experience; improving treatment adherence; and more effective use of health resources.
- Given this potential, it is timely to consider the evidence about what approaches can be used to support parents and caregivers in making informed decisions related to their children's health needs and how these can be effectively implemented in the health system.

What we found

- We found 17 relevant documents, including 10 systematic reviews and seven primary studies that addressed the two questions.
- For the first question, the literature focused on the effectiveness of three approaches: 1) shared decision-making among parents, children and health professionals; 2) education and information provision to parents; and 3) patient (parental) decision aids.
- In general, the literature found that these approaches reduced decisional conflict, enhanced knowledge and confidence in decision-making, and improved the congruence between decisions made by parents and their children, but had mixed effects on parent satisfaction with care and may be challenging to establish consistent use among health professionals.
- For the second question, we found six systematic reviews and four primary studies that focused on parent preferences for how information about their child's condition should be presented, as well as factors that affect parent participation in decision-making.
- Parental preferences for the sharing of information and involvement in treatment decisions related to the content (e.g., up-to-date; evidence-based; relating to treatment options and their relative effectiveness), source (e.g., from many different types of resources but mediated through a trusted health professional), timing (e.g., layered information rather than all at once) and setting of information (e.g., in private with a spouse or family member present).
- Factors identified from the literature that affect parent participation in decision-making included professional attitudes and culture about the involvement of parents, organizational attributes (e.g., availability of treatment options), specific features of the child's condition, and parental characteristics such as their personality, values, beliefs and prior knowledge and experience.
- The literature also found that providing training that builds the skills needed for shared decision-making and fostering a culture that values patient and parent engagement (e.g., where professionals offer to answer any questions parents have, where expressing concerns and preferences is actively encouraged, and where shared decision-making is a routine part of the care process) could help to inform parents about their children's care as well as increase participation in treatment decisions.

QUESTIONS

Two questions are addressed in this rapid synthesis:

- 1) What are the most effective approaches for supporting parents in making informed decisions related to their children's health needs?
- 2) What can be done to support the implementation of effective approaches for supporting parents in making informed decisions related to their children's health needs?

WHY THE ISSUE IS IMPORTANT

Momentum for patient and caregiver engagement in health and social care is growing across Ontario.(1) This is evidenced by a number of recently released strategies and frameworks highlighting the importance of involving Ontarians in their own care as informed consumers of health and social services. One such notable example was the *Patients First Act 2016*, for which a key pillar was informing and educating patients to make informed decisions about their health in efforts to improve their experiences and health outcomes.(2)

Prevention or treatment decisions in healthcare have been found to be optimized when each of research evidence, patient preferences and clinical expertise are considered.(3) For pediatric patients, however, the decision-making process is more challenging as it requires clinicians to inform, obtain consent, and consider the values of the parent or caregivers as well as the child (depending on developmental maturity).(4) Further, depending on the condition and severity, parents and caregivers may experience a significant amount of decisional conflict, stress and concern when making treatment decisions for their children that can lead to undesired outcomes, such as delaying the decision, regret about the decision or blaming health providers.(5)

To promote informed decision-making among parents and caregivers, various interventions have been developed, such as patient (parental) decision aids, shared decision-making models (e.g., where clinicians and patients share the best available evidence and where patients are supported to consider options to achieve informed preferences) and family-centred educational programs.(6-8) However, data from recent surveys conducted in Ontario show that there remains room for improvement with regards to increasing parents' capacity to make informed decisions. Specifically, in a survey of parents seeking care for their child in a pediatric tertiary care hospital in Ottawa, 48% of parents reported not being offered more than one treatment option to consider and 23% recalled experiencing decisional conflict (e.g., being unsure about the best choice) when offered several different clinical choices.(5)

Several systematic reviews and primary studies have shown that involving parents/guardians in the decision-making process has many benefits, including:

Box 1: Background to the rapid synthesis

This rapid synthesis mobilizes both global and local research evidence about a question submitted to the McMaster Health Forum's Rapid Response program. Whenever possible, the rapid synthesis summarizes research evidence drawn from systematic reviews of the research literature and occasionally from single research studies. A systematic review is a summary of studies addressing a clearly formulated question that uses systematic and explicit methods to identify, select and appraise research studies, and to synthesize data from the included studies. The rapid synthesis does not contain recommendations, which would have required the authors to make judgments based on their personal values and preferences.

Rapid syntheses can be requested in a three-, 10-, 30-, 60- or 90-business-day timeframe. An overview of what can be provided and what cannot be provided in each of these timelines is provided on the McMaster Health Forum's Rapid Response program webpage (www.mcmasterforum.org/find-evidence/rapid-response)

This rapid synthesis was prepared over a 10-business-day timeframe and involved four steps:

- 1) submission of a question from a policymaker or stakeholder (in this case, Health Nexus);
- 2) identifying, selecting, appraising and synthesizing relevant research evidence about the question;
- 3) drafting the rapid synthesis in such a way as to present concisely and in accessible language the research evidence; and
- 4) finalizing the rapid synthesis based on the input of at least two merit reviewers.

- reducing decisional conflict among parents/guardians;
- improving patient and family experience;
- improving treatment adherence; and
- more effective use of health resources.(5; 6; 9)

Given this potential, it is timely to consider the evidence about what approaches can be used to support parents and caregivers in making informed decisions related to their child's health needs, and how these can be effectively implemented in the health system.

WHAT WE FOUND

We found 17 relevant documents, including 10 systematic reviews (two recent and one older high quality, and three recent and three older medium quality) and seven primary studies that addressed the two questions.(6-22) We review our findings from these documents for each of the questions below. Additional details for each of the systematic reviews and primary studies are provided in Appendix 1 and 2, respectively.

Question 1: What are the most effective approaches for supporting parents in making informed decisions related to their children's health needs?

We found five systematic reviews and three primary studies that addressed the first question.(6-8; 11-13; 20; 21) The literature we found focused on the effectiveness of three approaches: shared decision-making amongst parents, children and health professionals; education and information provision to parents; and parental decision aids.

Two recent and one older high-quality reviews examined the use of shared decision-making.(7; 11;13)) The first high-quality review found this approach led to a significant reduction in decisional conflict among parents and significant increase in knowledge, but found no significant effect was reported for satisfaction.(7) The second review reported an improvement in patient and parent satisfaction with the performance of pediatricians who engaged in shared decision-making.(11) However, it should be noted that the findings from the second high-quality review are based on one randomized controlled trial.(11) Finally, the third review was unable to identify any studies that met the inclusion criteria for shared decision-making for parents of children with cancer.(13)

One recent medium-quality review reported that providing parents with written information supplemented by additional resources such as video or slide presentations, home visits, consultations with health professionals or structured educational programs reduced the number of consultations, improved parental knowledge and confidence when making decisions, but found mixed effects on parent satisfaction.(8) Similarly, an older medium-quality review examined the effectiveness of coaching and educational approaches compared to no intervention. The review found that coaching improved the congruence between decisions made by parents

Box 2: Identification, selection and synthesis of research evidence

We identified research evidence (systematic reviews and primary studies) by searching (in September 2018) Health Systems Evidence (www.healthsystemsevidence.org) and PubMed. In Health Systems Evidence, we used the following key word search (parent* OR caregiver), combined with the following filters: under implementation strategy the filter for communication and decision-making facilitation. and under document type, filters for overviews of systematic reviews; systematic reviews of effects; and systematic reviews addressing other questions. In PubMed we used the following key word search: (inform* decision*making) AND (parent* OR caregiver) AND (Canada) [limited to the last five years].

The results from the searches were assessed by one reviewer for inclusion. A document was included if it fit within the scope of the questions posed for the rapid synthesis.

For each systematic review we included in the synthesis, we documented the focus of the review, key findings, last year the literature was searched (as an indicator of how recently it was conducted), methodological quality using the AMSTAR quality appraisal tool (see the Appendix for more detail), and the proportion of the included studies that were conducted in Canada. For primary research (if included), we documented the focus of the study, methods used, a description of the sample, the jurisdiction(s) studied, key features of the intervention, and key findings. We then used this extracted information to develop a synthesis of the key findings from the included reviews and primary studies.

and their children, while education improved the quality of decisions. No significant results were reported for coaching approaches delivered alongside educational interventions.(12) However, the findings from this review were based off of a limited number of studies that varied in methodological quality.(12)

Three primary studies reported on patient (parental) decision aids. The first study reported high levels of satisfaction from parents facing extremely premature births (23 to 24 weeks gestation) who were presented with a patient (parental) decision aid and decision coaching. The study reported a reduction in decisional conflict from parents, and that the combined use of decision aids and coaching supported shared decision-making.(20) The second primary study examined the use of medication choice cards to support parent decision-making.(21) The study found that clinicians using the cards reported positive experiences, but that reliable implementation and use of the decision aids was difficult, having only been implemented in 35% of visits where starting or switching medication was discussed.(21) The final study described the process of developing a decision aid for parents of children with sleep disordered breathing and found the need for three key pieces of any decision aid: description of the condition; information on treatment options including potential harms and benefits; and a section eliciting parental values.(6) These three pieces are also required criteria for being defined as a patient decision aid by the International Patient Decision Aids Standards Collaboration.

Question 2: What can be done to support the implementation of effective approaches for supporting parents in making informed decisions related to their children's health needs?

We found six systematic reviews and four primary studies that addressed the second question.(9; 10; 14-19; 22) The literature we found focused on parent preferences for how information about their child's condition should be presented and the mediating factors that affect parent participation in decision-making.

Three recent and one older medium-quality reviews examined how information about children's conditions should be presented to maximize parent engagement in treatment decisions.(10; 14; 15; 18) The reviews focused their findings on four categories of information needs: content, source, timing and setting. With regards to content, reviews found that parents wanted information about their child's condition that:

- is up-to-date;
- is evidence-based;
- is focused on treatment options and their relative effectiveness;
- is tailored to their needs and reading level;
- provides information on assessing severity of symptoms and when to seek help from health professionals; and
- provides examples of families with similar diagnoses.(14; 15)

Systematic reviews reported that parents expressed wanting information from a variety of trusted sources (e.g., videos, presentations, pamphlets, websites) that is mediated by a trusted health professional with whom parents had a prior relationship.(10; 15) With regards to timing, the reviews found that parents expressed wanting time to digest the information before attending an appointment, valued receiving layers of information rather than a large quantity at once, and appreciated the opportunity to ask their health professional any relevant questions.(14; 15) Finally, with regards to the setting, the reviews found that parents wanted discussions to occur in a private setting and in the presence of their spouse or another family member. In particular, one of the recent medium-quality reviews found that informational interventions were least effective when provided in the emergency room, potentially due to the stress and anxiety experienced by parents.

One older medium-quality review, one older low-quality review and three primary studies examined mediating factors that affect the extent to which parents or guardians participate in decisions about their child's care.(9;

17-19; 22) The review found that professional's attitudes towards the involvement of parents played a significant role in determining whether or not the parent was actively engaged in decision-making. Other factors that limited the extent to which parents or guardians participated in decision-making included available resources (e.g., short hospital stays, limited availability of treatment options), culture of patient engagement within the healthcare organization, and parent knowledge of their child's condition).(9; 19)

The older medium-quality review and one primary study found that providing training that builds the skills needed for shared decision-making and fostering a culture that values patient and parent engagement (e.g., where professionals offer to speak with parents to answer any questions; where expressing concerns and preferences is actively encouraged; and where shared decision-making is a routine part of the care process) could help to inform parents about their child's care as well as increase participation in treatment decisions.(9; 18) Additionally, the lower-quality systematic review and primary study highlighted that parent characteristics such as prior healthcare experiences, personality, values, beliefs, familial and emotional factors, and amount of prior knowledge influenced their decision-making, as did the age, gender, cognition and maturity of their children, particularly when making difficult decisions such as children's genome sequencing or disclosing positive results from parental BRCA1/2 screens to their child.(17; 18; 22)

One lower-quality systematic review also found that parents needed direction about when and how to engage their children in decision-making.(22)

Finally, one primary study focused on the implementation of a shared decision-making approach and identified the need for four key roles:

- 1) a leader who facilitates shared decision-making and assumes responsibility for implementing the decisions;
- 2) professional experts who provide information and insight into the health condition;
- 3) someone who takes lead for the synthesis of information; and
- 4) parents acting as surrogate decision-maker.(16)

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APPENDICES

The following tables provide detailed information about the systematic reviews and primary studies identified in the rapid synthesis. The ensuing information was extracted from the following sources:

- systematic reviews - the focus of the review, key findings, last year the literature was searched, and the proportion of studies conducted in Canada; and
- primary studies (in this case, economic evaluations and costing studies) - the focus of the study, methods used, study sample, jurisdiction studied, key features of the intervention and the study findings (based on the outcomes reported in the study).

For the appendix table providing details about the systematic reviews, the fourth column presents a rating of the overall quality of each review. The quality of each review has been assessed using AMSTAR (A MeaSurement Tool to Assess Reviews), which rates overall quality on a scale of 0 to 11, where 11/11 represents a review of the highest quality. It is important to note that the AMSTAR tool was developed to assess reviews focused on clinical interventions, so not all criteria apply to systematic reviews pertaining to delivery, financial or governance arrangements within health systems. Where the denominator is not 11, an aspect of the tool was considered not relevant by the raters. In comparing ratings, it is therefore important to keep both parts of the score (i.e., the numerator and denominator) in mind. For example, a review that scores 8/8 is generally of comparable quality to a review scoring 11/11; both ratings are considered “high scores.” A high score signals that readers of the review can have a high level of confidence in its findings. A low score, on the other hand, does not mean that the review should be discarded, merely that less confidence can be placed in its findings and that the review needs to be examined closely to identify its limitations. (Lewin S, Oxman AD, Lavis JN, Fretheim A. SUPPORT Tools for evidence-informed health Policymaking (STP): 8. Deciding how much confidence to place in a systematic review. *Health Research Policy and Systems* 2009; 7 (Suppl1):S8).

All of the information provided in the appendix tables was taken into account by the authors in describing the findings in the rapid synthesis.

Appendix 1: Summary of findings from systematic reviews about supporting parents to make informed decisions in relation to their children’s health needs

| Type of review | Focus of systematic review | Key findings | Year of last search/ publication date | AMSTAR (quality) rating | Proportion of studies that were conducted in Canada |
|-------------------|---|--|--|---|---|
| Systematic review | To report on the efficacy of shared decision-making interventions in pediatrics on patient-centred outcomes (7) | <p>Shared decision-making in pediatrics aims to engage patients, parents/guardians and clinicians in a collaborative partnership to make medical decisions that are supported by evidence and aligned with the patient’s and the family’s values, preferences and treatment goals.</p> <p>This review of 61 studies aimed to summarize the effects of pediatric shared decision-making interventions on patient-centred outcomes. Interventions were implemented in various formats, including electronic only, paper-based, live sessions, or a combination of the aforementioned formats. The most frequently reported outcome measured of patients and parents included satisfaction, followed by decisional conflict and knowledge.</p> <p>Of the 13 studies that included patient and parent satisfaction as an outcome measure, six studies reported this outcome in sufficient detail for inclusion in meta-analysis. The results demonstrated a non-significant trend toward increased satisfaction with shared decision-making interventions.</p> <p>Ten studies included decisional conflict as an outcome measure; however, only nine of these studies reported decisional conflict in sufficient detail for inclusion in meta-analysis. The results of the meta-analysis showed a significant reduction in decisional conflict with shared decision-making interventions.</p> <p>Of the seven studies reporting knowledge as an outcome measure, six studies were included in the meta-analysis. The results showed significant increase of knowledge with shared decision-making interventions.</p> <p>The findings from the meta-analysis revealed that shared decision-making interventions significantly improved parent knowledge and decreased decisional conflict. The effect of shared decision-making interventions on patient and parent satisfaction levels tended to be favourable, though not statistically significant. However, the methodological limitations of this review, including the lack of a control group in many of the included studies, warrant further research to improve the practice of shared decision-making in pediatrics.</p> | 2013 | 10/11 (AMSTAR rating from McMaster Health Forum) | Not reported |
| Systematic review | To summarize parents’ and informal caregivers’ views and experiences regarding communication about | This review included 38 studies that focused on the perspectives of parents and informal caregivers regarding information about vaccinations for | 2016 | 7/9 (AMSTAR rating from | 3/37 |

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| Type of review | Focus of systematic review | Key findings | Year of last search/ publication date | AMSTAR (quality) rating | Proportion of studies that were conducted in Canada |
|-------------------|--|--|--|--|---|
| | childhood vaccinations, as well as the influence that this communication has on their decisions regarding childhood vaccination (10) | <p>children aged up to six years, and the influence of communication strategies on parents' and caregivers' decisions about childhood vaccination.</p> <p>The results of the thematic analysis show that parents and caregivers perceived information and communication about childhood vaccination to be important. They wanted to receive relevant information in advance of each vaccination appointment. Parents and caregivers also wanted information about vaccination to be available at a variety of different locations, as well as help and guidance from trained health workers in identifying important information.</p> <p>In general, parents and caregivers viewed the amount of information they received to be insufficient. Many parents and caregivers reported experiencing difficulty with locating trustworthy vaccination information sources. They also found it difficult to retrieve information that they felt was unbiased. As such, parents wanted to receive succinct, impartial information about both the benefits and harms of vaccination. They also wanted information to be presented through a variety of mediums, including through mobile health interventions.</p> <p>Many parents and caregivers, regardless of their attitudes towards vaccination, felt that their decision to vaccinate had not been adequately supported by reliable information. This may elicit feelings of worry and regret about their vaccination decisions.</p> <p>The findings of this review range from very low to high confidence, with the most commonly identified methodological limitations being poor reporting of context, sampling or methods, as well as lack of researcher reflexivity. Thus, the results of this synthesis should be interpreted with caution.</p> | | McMaster Health Forum) | |
| Systematic review | To assess the benefits and potential harms of shared decision-making for children and adults with asthma (11) | <p>This review included four studies that examined the effects of shared decision-making on asthma-related quality of life, patient satisfaction with care, medication adherence, exacerbations of asthma, asthma control, and unwanted effects.</p> <p>Three studies reported asthma-related quality of life as an outcome. One study involving adults with poorly controlled asthma reported improved quality of life for the shared decision-making group in comparison to the control group. However, the two other trials that examined quality of life did not identify an improvement.</p> | 2016 | 10/10 (AMSTAR rating from McMaster Health Forum) | 0/4 |

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| Type of review | Focus of systematic review | Key findings | Year of last search/ publication date | AMSTAR (quality) rating | Proportion of studies that were conducted in Canada |
|-------------------|--|--|--|--|---|
| | | <p>In one trial involving children, patient/parent satisfaction with the performance of pediatricians was greater in the shared decision-making group as compared to the control group.</p> <p>Medication adherence was higher in the shared decision-making group in two studies – one involving adults and one involving children.</p> <p>Three studies assessed exacerbations of asthma as an outcome. Of these three, one study found that asthma-related visit rates were lower in the shared decision-making group than in the usual care group. However, the other studies did not report any clear between-group differences among those receiving shared decision-making and those receiving usual care.</p> <p>Three studies examined asthma control as an outcome. One study reported better odds of experiencing no asthma problems in the shared decision-making group as compared to the usual care group. However, two other studies reporting asthma control did not find a benefit with shared decision-making.</p> <p>None of the included studies reported any information on adverse events.</p> <p>Although some evidence suggests that shared decision-making might benefit individuals with asthma, the authors noted that meaningful overall conclusions cannot be provided owing to methodological limitations and study heterogeneity.</p> | | | |
| Systematic review | To describe and synthesize research on parents' perceptions of their participation in decision-making in child healthcare services (9) | <p>This review of 18 studies sought to synthesize research on parents' perceptions of their participation in decision-making, as well as the challenges they face in navigating healthcare services for children. Three main themes emerged from the synthesis related to decision-making: relational factors and interdependence; personal factors and attitudes; and organizational factors.</p> <p>The findings suggest that parents participated in decision-making about their child's healthcare to varying extents, and that they wanted to participate more than they were able to. However, it was evident that the relationship between parents and health professionals was asymmetric, whereby health professionals played a dominant role in decision-making processes. Parents' level of confidence and participation in decision-making was affected by the quality of communication with professionals. Furthermore, professionals who acknowledged parents' preferences and needs had a positive impact parents' participation in decision-making.</p> | 2011 | 5/10 (AMSTAR rating from McMaster Health Forum) | 3/18 |

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|-------------------|---|--|--|---|---|
| | | <p>The results show that parents' participation in decision-making was influenced by professionals' interpretations of parents' role in healthcare. Some professionals struggled to include parents in decision-making. Personal factors such as demographic characteristics, life circumstances, attitudes and competence also influenced parents' participation in decision-making. Parents' degree of knowledge of their child's health condition also affected their involvement, with increased knowledge and experience leading to higher participation levels in decision-making processes.</p> <p>Organizational shortcomings in healthcare services were perceived to affect professionals' ability to support parent participation. Parents' degree of participation was influenced by available resources. For example, short hospital stays and lack of routines for including parents in decision-making hindered parents' level of participation.</p> <p>The findings of this review highlight the critical role of health professionals in involving parents in decision-making processes related to their child's care. However, methodological limitations, including researcher bias during the synthesis process, may limit the possibilities for generalization.</p> | | | |
| Systematic review | To examine the effectiveness of information resources to support parental decision-making on when to seek medical care for an acutely ill child under five years of age (8) | <p>This review included 22 studies that assessed existing informational interventions in helping parents know when to seek help for their acutely sick child. The factors influencing intervention effectiveness were also assessed. The majority of the interventions comprised written information. Written information was supplemented by video/slide presentations, home visits, reinforcement within consultations, or was integrated into a structured educational program. Three different studies reported on the same 'Baby Check' intervention (an information booklet designed to support parental assessment of ill babies) in different settings/populations. The most commonly employed measures of effectiveness were: consultation frequency; knowledge; anxiety/reassurance; satisfaction; confidence; and antibiotic prescription.</p> <p>Fifteen studies measured consultation frequency as an outcome. Of these 15, six studies showed a significant reduction in either actual consultation rates, or intention to consult in the future. One study found a reduction in home visits, but an increase in out-of-hours visits. The remaining eight studies showed no difference on consultation rates with the intervention group.</p> | 2014 | 7/9 (AMSTAR rating from McMaster Health Forum) | 2/22 |

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| Type of review | Focus of systematic review | Key findings | Year of last search/ publication date | AMSTAR (quality) rating | Proportion of studies that were conducted in Canada |
|----------------|----------------------------|---|--|-------------------------|---|
| | | <p>Nine studies examined the effect of information-provision interventions on parental knowledge of childhood illnesses (e.g., fever, upper respiratory infections, febrile convulsion and otitis media). Eight studies identified a significant increase in parental knowledge post-intervention. However, one high-quality study showed reduction in knowledge post-intervention.</p> <p>Of the seven studies that reported anxiety/reassurance as an outcome, only one study identified significantly reduced parental concern in comparison to the control group following intervention.</p> <p>Four studies assessed parents' satisfaction with their communication with health professionals, and with the information received, as an outcome. Two studies did not report significantly increased satisfaction in control and intervention groups, while another study demonstrated significantly increased satisfaction for intervention groups compared to controls. The fourth study revealed that a web-based self-triage tool might elicit parental satisfaction.</p> <p>Two of four studies that included parents' confidence in managing childhood illness at home as an outcome did not show an increase in confidence levels. The remaining two studies found positive effects of interventions on parents' confidence levels.</p> <p>Four studies examined antibiotic prescription as an outcome. Of these, one study found a significant reduction in antibiotic prescriptions given by clinicians in the intervention group, while another study found a reduction in the number of parents who sought antibiotics and over-the-counter medications inappropriately. The remaining two studies found no significant effects on antibiotic prescribing.</p> <p>This review also identified several factors that influence the effectiveness of an intervention. The provision of information on multiple childhood illnesses as opposed to interventions addressing single symptoms appeared to be more effective. Moreover, educational material which addressed the assessment of illness severity and the management of minor illness appeared to be more effective in supporting parents to care for their children and seek help when needed. Finally, interventions implemented in emergency departments were found to be the least effective, which may be attributed to the negative impact of stress and anxiety on the learning potential of parents.</p> <p>Findings reveal that information needs to be relevant and comprehensive to support parents in managing an episode of childhood illness. However, the</p> | | | |

Supporting Parents in Making Informed Decisions in Relation to their Children's Health Needs

| Type of review | Focus of systematic review | Key findings | Year of last search/ publication date | AMSTAR (quality) rating | Proportion of studies that were conducted in Canada |
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| | | authors noted that the inclusion of low-quality studies warrants the conduct of further confirmatory research. | | | |
| Systematic review | To review characteristics and effectiveness of interventions that support health decision-making of children (12) | <p>This review included five studies that explored the characteristics and effectiveness of interventions that support the decision-making needs of children who are considering a health-related decision. Three types of interventions were assessed: decision coaching alone versus attention placebo/no intervention; coaching plus educational aid versus attention placebo/no intervention; and education alone versus attention placebo/no intervention. The primary outcomes assessed were those that improved decision quality. Secondary outcomes were those that improved the decision-making process. Other decision-making outcomes included: congruence of treatment preferences between child and parent, participation in decision-making process, decisional conflict, and communication.</p> <p>Two studies compared coaching with an attention placebo or no intervention. Of these two, one study reported improved congruence between parent and child. In terms of decision-making process outcomes, one study found that children were more satisfied with the decision-making process, while another reported no difference. None of the two studies found any between-group differences in decisional conflict scores, the quality of child-decision coach communication, and the child's level of participation in health decision-making.</p> <p>Two studies examined coaching plus educational aid in comparison with an attention placebo/no intervention group. In terms of decision quality outcomes, coaching supplemented with an educational co-intervention had no effect on congruence between participants' values and their chosen behaviour when compared to an attention placebo in one study. The second study, which assessed the overall quality of decision-making, found no between-group differences.</p> <p>One study assessed an education-alone intervention versus attention placebo/no intervention. The intervention decision-making quality scores improved over a 12-month study period.</p> <p>Overall, only two studies produced statistically significant findings: coaching alone increased congruence between parent and child values, as well as child satisfaction with the decision-making process, and education alone improved overall decision-making quality. However, there are several limitations that</p> | 2012 | 7/10 (AMSTAR rating from McMaster Health Forum) | 0/5 |

McMaster Health Forum

| Type of review | Focus of systematic review | Key findings | Year of last search/ publication date | AMSTAR (quality) rating | Proportion of studies that were conducted in Canada |
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| | | should be noted when interpreting the results of this review, including the variable methodological quality of the included studies. | | | |
| Systematic review | To summarize literature on communication preferences of parents at the time of their child’s cancer diagnosis (14) | <p>Pediatric oncology providers must provide parents/caregivers with adequate information to help them make medical decisions. The role of communication is crucial in this context, as families need to understand complex information prior to making an informed choice. This review of 16 studies aimed to summarize the communication preferences of parents at the time of their child’s diagnosis of cancer. Four themes were identified from the review. The communication style theme comprised ideal personal attributes of a healthcare provider during the delivery of the child’s cancer diagnosis. The content theme encompassed examples of topics parents wanted to discuss during the diagnosis meeting. The logistics theme outlined parental preferences for the timing, location and participants during the diagnosis meeting. The healthcare-team theme highlighted communication challenges between families and the healthcare system as a whole.</p> <p>The communication style theme revealed that parents had communication needs particular to the provider, to the message delivered, and to the language used during the cancer diagnosis consultation. In terms of provider style, parents appreciated having a healthcare provider who was sensitive, patient and empathetic. With respect to message style, parents preferred messages that offered hope while maintaining honesty. Lastly, parents perceived the use of diagnostic jargon by providers as an insensitive communication method.</p> <p>The content theme addressed topic suggestions parents may prefer in addition to the standard diagnostic consultation topics. The most frequently suggested content items from parents included: information on treatment choices; treatment efficacy; information on how to talk to kids and family about the diagnosis and stories of children with similar diagnoses; nutrition for the child during therapy; and an estimate of the cost of therapeutic services.</p> <p>Under the logistics theme, parents highlighted the importance of holding the meeting in a private, quiet location, with a spouse or a family member present for additional support, as well as providers who offered families advance notice and set aside ample meeting time.</p> <p>Under the healthcare team, three important core ideas emerged: the role of nurses as health navigators; the importance of consistent messages; and the need for availability and continuity of providers. Across studies, parents</p> | 2016 | 4/9 (AMSTAR rating from McMaster Health Forum) | 3/16 |

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| Type of review | Focus of systematic review | Key findings | Year of last search/ publication date | AMSTAR (quality) rating | Proportion of studies that were conducted in Canada |
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| | | <p>characterized nurses as providers who helped them understand physician-provided information. In terms of core idea, the value of message consistency became apparent when parents expressed frustration that resulted from their inability to make sense of incorrect or contradictory messages. Finally, the lack of continuity and availability with respect to the parent-provider relationship rendered parents uneasy about their child's safety.</p> <p>This review presents an overview of the complex communication needs of parents at the time of their child's diagnosis of cancer. However, methodological limitations, such as a small number of included studies with heterogeneous data, highlight the need for higher-quality studies in this field.</p> | | | |
| Systematic review | To identify the decision-support needs of parents attempting to make an informed health decision on behalf of a child (15) | <p>This review included 149 studies that sought to identify parents' decision-support needs when attempting to make an informed decision for their child. Three key themes emerged from the thematic analysis: information, including suggestions about the content, delivery, source and timing; talking to others, including concerns about pressure from others; and feeling a sense of control over the process that could be influenced by emotionally charged decisions, the consultation process, and structural or service barriers.</p> <p>A consistent theme to emerge was the critical role that information plays when attempting to make an informed decision. The four descriptive categories relating to information involved the content, mode of delivery, source and dimensions of timing. In terms of content, parents wanted information that is consistent, up-to-date, comprehensive, evidence-based, value free and tailored to their needs and reading level. Furthermore, parents also wanted information delivery to be tailored to individual needs, available in a variety of formats, and languages appropriate to the client group. With respect to information sources, the evidence suggests that parents typically rely on a variety of information sources, including family, friends, health professionals, the media, and the internet. Finally, many parents expressed that they would like to have sufficient time to process and discuss information both during and outside the consultation.</p> <p>The second theme, talking to others, reflects the idea that parents value the opportunity to talk to other parents in similar situations to share insights. However, the issue of pressure from others to make particular choices also emerged as a sub-category within this theme.</p> | 2008 | 5/9 (AMSTAR rating from McMaster Health Forum) | Not reported |

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| Type of review | Focus of systematic review | Key findings | Year of last search/ publication date | AMSTAR (quality) rating | Proportion of studies that were conducted in Canada |
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| | | <p>Control over the process emerged as a theme because parents wanted to be in control over the process of making a decision for their child. Three sub-categories were identified under this theme: emotionally charged decisions; the consultation process; and structural/service barriers. In terms of addressing parents' emotionally charged decisions, parents preferred when health professionals acknowledged these emotions and discussed them within the consultation. Furthermore, having trust in, and maintaining an open line of communication with the health professional are essential to the process of informed decision-making. Lastly, structural/service barriers, such as inaccessible clinic opening times and locations, may render it difficult for the parent to maintain control over the decision-making process.</p> <p>The review findings suggest that the three overarching themes described above are often inadequately addressed by service providers.</p> | | | |
| Systematic review | To review the current research on parent decision-making about pediatric treatments, and highlight areas in need of further investigation (22) | <p>This review of 55 papers sought to summarize the current research on parent decision-making about pediatric treatments and identify knowledge gaps in this area. Four key themes emerged through review of the literature: parents' role in decision-making; influences on parents' decision-making; parents' perspectives on the physician's role; and parent and child decision-making interactions.</p> <p>Several studies provided insight into parents' roles in decision-making. Most parents preferred having an active role in decision-making about their children's treatment. However, parents were more interested in collaborative decision-making processes than either an independent or a paternalistic approach.</p> <p>The second theme, influences on parents' decision-making, outlines the idea that a diverse range of factors can have an impact on parents' decision-making. For example, prior healthcare experiences can have variable influences on parents' decision-making, with one study finding that parents who had fewer visits in the previous year were more active in the decision-making process. Other influential factors identified in this review include: experience with similar situations, such as with other family members; provider recommendations; a child's preferences; and familial and emotional factors, which may play a larger role than physician recommendations.</p> <p>The third theme, parents' perspectives on the physician's role, highlighted that many parents preferred some variation of shared decision-making (i.e., the physician as a partner in decision-making). From the parental perspective, a key role for healthcare providers is offering parents the</p> | 2011 | 3/8 (AMSTAR rating from McMaster Health Forum) | 6/55 |

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| Type of review | Focus of systematic review | Key findings | Year of last search/ publication date | AMSTAR (quality) rating | Proportion of studies that were conducted in Canada |
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| | | <p>information and education needed to make an informed decision. Parents appreciated physician-provided information and the opportunity to partner with care providers in establishing treatment goals for their child.</p> <p>With respect to parent and child decision-making interactions, this review showed that parents may require support in determining when and how to involve children in decision-making processes.</p> <p>This review presented a diversity of factors that influence parental decision-making processes and preferences. However, further research is needed to identify effective means of supporting parents through the difficult treatment decisions.</p> | | | |

Appendix 2: Summary of findings from primary studies about supporting parents to make informed decisions in relation to their children’s health needs

| Focus of study | Study characteristics | Sample description | Key features of the intervention(s) | Key findings |
|---|--|---|---|---|
| <p>Exploring the nature of an Interprofessional Approach to Shared Decision-Making Model in a neonatal intensive-care unit (16)</p> | <p><i>Publication date:</i> 2018 <i>Jurisdiction studied:</i> Canada <i>Methods used:</i> Exploratory qualitative approach</p> | <p>The sample included healthcare professionals such as registered nurses, physicians, respiratory therapists, and other health professionals working in a tertiary care neonatal intensive care unit in Canada. Twenty-two members of an interprofessional team participated in the study.</p> | <p>In the Interprofessional Approach to Shared Decision-Making Model assessed in this study, different professionals collaborate together to identify best options, and support the patient or family to be involved in decision-making about those options for preference-sensitive decisions. The patient and family, shared decision-making facilitator, the trained decision coach and healthcare professionals involved in the patient’s treatment are key players within the Interprofessional Approach to Shared Decision-Making framework. As part of this model’s process, these players exchange information about the harms and benefits of the available options and glean the patient’s/family’s perspectives.</p> | <p>Participants reported several features of the Interprofessional Approach to Shared Decision-Making in the neonatal intensive-care unit. Themes that emerged included: key participants and roles; components of the Interprofessional Approach to Shared Decision-Making process; and outcomes of the Interprofessional Approach to Shared Decision-Making.</p> <p>In terms of key participants and roles, participants noted that the following roles were important to the Interprofessional Approach to Shared Decision-Making: a leader who facilitates shared decision-making and assumes responsibility for the decision; professional experts who provide information and insight into the case; someone who takes lead on the synthesis of information; and parents acting as surrogate decision-makers.</p> <p>The main sub-themes that emerged from the data related to the Interprofessional Approach to Shared Decision-Making process include collaboration, sharing, weighing and building consensus. Participants from all the interviewed professional groups agreed that an Interprofessional Approach to Shared Decision-Making occurs through a collaborative process of identifying the options to make a high-quality decisions. In terms of the sharing sub-theme, participants highlighted the importance of exchanging information as an integral part of the Interprofessional Approach to Shared Decision-Making process. Furthermore, another key aspect of the approach involves weighing the pros and cons of various options, weighing the evidence, and weighing the reliability of an opinion. Finally, consensus was cited as the most common method of collaborative decision-making.</p> <p>The participants reported that the main outcome of an Interprofessional Approach to Shared Decision-Making was making a well-informed decision. A secondary outcome of the approach frequently reported by participants was that team members felt valued as active participants in the decision-making process.</p> <p>Findings from this study suggest that the perspectives of healthcare professionals are important contributors to the quality of decisions made in intensive care.</p> |
| <p>Examining parents’ perceptions of their decisional needs when considering genome-wide sequencing (17)</p> | <p><i>Publication date:</i> 2016 <i>Jurisdiction studied:</i> Canada</p> | <p>Fifteen parents aged 20 to 49 were recruited from a local children’s hospital in British Columbia through</p> | <p>Genome-wide sequencing enables geneticists to test the entire genome at once, and can provide fairly</p> | <p>The following themes emerged from the focus groups and individual interviews: parents’ decisional context; informational needs; psychosocial needs; and supporting strategies identified by parents.</p> |

| Focus of study | Study characteristics | Sample description | Key features of the intervention(s) | Key findings |
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| | <p><i>Methods used:</i> Interpretive description qualitative methodological approach</p> | <p>convenience sampling. Parents who had experienced the decision-making process and had agreed to genome-wide sequencing for at least one child were targeted. Parents had children with a range of potentially genetic health conditions.</p> | <p>accurate diagnoses. Focus group or individual interviews were conducted to explore parents' perceptions of their decisional needs when considering genome-wide sequencing for their child.</p> | <p>In terms of parents' decisional context, the data showed the context-dependent nature of decision-making for genome-wide sequencing. Participants' diverse contexts and other characteristics such as personality, values, beliefs and amount of prior knowledge influenced their decision-making, and was perceived by many participants to be a factor in the amount and type of information they needed.</p> <p>With respect to informational needs, participants raised more concerns related to the process of receiving information than the content of information itself. For example, many participants felt that a large volume of information given at one point in time was not helpful.</p> <p>Participants' psychosocial needs was another identified theme, as participants commonly discussed the relational and psychosocial aspects of their decision-making process. Most participants described the importance of the healthcare professional-parent relationship during decision-making about genome-wide sequencing. Participants also valued the instances when healthcare professionals recognized and exhibited sensitivity towards their well-being as parents in a stressful situation.</p> <p>Participants offered suggestions about best supportive strategies during the decision-making process for genome-wide sequencing. These strategies include: brief and understandable summaries; tailored approaches to information delivery using different media; provide layers of information rather than a large quantity of information at one point in time; and credible sources of information.</p> <p>Findings from this study reveal that healthcare professionals who provide genome-wide sequencing for children should assess parents' values, priorities, and informational needs. and modify information delivery strategies accordingly.</p> |
| <p>Describing the development process of a decision aid prototype for parents considering adenotonsillectomy for their children with sleep disordered breathing (6)</p> | <p><i>Publication date:</i> 2016</p> <p><i>Jurisdiction studied:</i> Canada</p> <p><i>Methods used:</i> Decision-aid prototype was developed using the framework proposed by the International Patient Decision Aids Standards Collaboration</p> | <p>Several parents and providers contributed to the initial phases of decision-aid prototype development (e.g., pediatric otolaryngologists, otolaryngology clinic nurses, parents of children who had undergone otolaryngology</p> | <p>This paper outlines the preliminary phases of decision-aid prototype development including establishing a steering committee, conducting a needs assessment, designing the decision aid prototype, and assessing the comprehensibility, feasibility and acceptability of the</p> | <p>The steering committee included one pediatric otolaryngologist, one child health psychologist, one cognitive psychologist with expertise in shared decision-making, two parents of children who previously had elective pediatric otolaryngology procedures, one nurse with expertise in patient-provider communication and shared decision-making, and one nurse research coordinator. The committee met nine times throughout the project as a group, and subsets of the committee met 15 additional times to evaluate results and organize next steps.</p> <p>The next phase of decision-aid prototype development was a needs assessment, involving 41 parents. The needs assessment revealed that many parents faced decisional conflict, and that strategies to increase shared-decision making, such</p> |

| Focus of study | Study characteristics | Sample description | Key features of the intervention(s) | Key findings |
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| | | procedures and child health psychologists). | decision-aid prototype, and tailoring it accordingly. | <p>as decision-support tools, are required for parents considering pediatric otolaryngology surgeries.</p> <p>The decision-aid prototype was developed and tailored based on semi-structured qualitative interviews and a scoping literature review. The decision-aid prototype comprised the following three main sections: a description of pediatric obstructive sleep apnea and the main management options; information on these options including potential harms and benefits; and a section on values clarification.</p> <p>The final phase involved three cycles of accessibility, feasibility and comprehensibility testing. Based on these three cycles, the decision-aid prototype seemed feasible, acceptable and comprehensible. The findings described in this paper suggest that the decision-aid prototype may function as an effective means of improving shared decision-making. However, the authors noted several limitations within this study, including the limited generalizability of the tool.</p> |
| Gaining insight into parental decision-making regarding the disclosure or nondisclosure of a mutation-positive BRCA1/2 test result to minors (18) | <p><i>Publication date:</i> 2016</p> <p><i>Jurisdiction studied:</i> Canada</p> <p><i>Methods used:</i> Demographic questionnaires, semi-structured interviews, and conversation summaries were employed as data collection methods; van Manen’s selective approach was used to thematically analyze data</p> | Fifteen female mutation-positive BRCA1/2 carriers who had at least one child aged 6-18 were recruited at a western Canadian hereditary breast and ovarian cancer clinic. | No intervention. | <p>The themes that emerged from the semi-structured interviews included: 1) influential factors; 2) parental decision-making; 3) supportive resources; 4) the inner circle; 5) knowledge deficit; and 6) parental recommendations.</p> <p>Many parents reported that age, gender, cognition, emotional readiness and maturity of children were factors that influenced parental decision-making. A deferral in disclosure was viewed as affording appropriate time for parental planning and time for maturity to develop. A commitment to maintaining honest relationships with children, other family members, and the community served as a decision-making factor for disclosing parents.</p> <p>Parental decision-making, the second theme, captured parents’ perceptions of their decision-making process. Many participants reported that dialogue occurred between parents regarding their decision to disclose.</p> <p>In terms of supportive resources, parents believed that members of the genetics team offered important mutation-positive BRCA1/2 risk information.</p> <p>The fourth theme, the inner circle, explored disclosing parents’ reflections on the parent-child disclosure conversations. Conversations were generally characterized as unscheduled, non-structured, casual, and delivered in a positive manner.</p> <p>Knowledge deficit emerged as a theme because some parents lacked knowledge regarding specific BRCA1/2 information. Parental knowledge deficit warrants the implementation of additional parental education and supplemental resources.</p> |

| Focus of study | Study characteristics | Sample description | Key features of the intervention(s) | Key findings |
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| | | | | <p>The final theme, parental recommendations, captures the nature of the requests that many parents made during the interviews. The majority of parents requested clinicians' guidance with disclosure context, referrals to allied healthcare professionals, a list of reliable internet sites, and a helpline for children.</p> <p>Participants generally highlighted the need for additional support pertaining to the decision-making process. However, several study limitations, including the relatively small sample size, warrant acknowledgment.</p> |
| <p>Exploring the views of clinicians on the barriers and facilitators to shared decision-making in child and youth mental health using the Theoretical Domains Framework (19)</p> | <p><i>Publication date:</i> 2018</p> <p><i>Jurisdiction studied:</i> England</p> <p><i>Methods used:</i> Qualitative semi-structured interviews and focus groups</p> | <p>Fifteen clinicians were recruited from two English National Health Service Trusts. In terms of their professional roles, there were five clinical psychologists, three trainee psychologists, two psychiatrists, four mental health nurses, and one therapist.</p> | <p>The Theoretical Domains Framework is an amalgamation of 33 behaviour-change theories and explores barriers and facilitators across 14 unique domains.</p> | <p>Twenty-one barriers and facilitators for shared decision-making in child and youth mental health were identified across 10 domains of the Theoretical Domains Framework. These barriers and facilitators spanned three specific areas related to capability, opportunity and motivation.</p> <p>Under capability, barriers and facilitators were identified for knowledge, cognitive and interpersonal skills, memory/attention/decision-making processes, and behavioural regulation. A lack of knowledge regarding care and treatment options served as a barrier for clinicians. Furthermore, training in the skills needed for shared decision-making was identified as a facilitator to shared decision-making. In terms of memory/attention/decision-making processes, clinicians reported that the availability of options within their service may limit the options they choose to present to their clients. This was perceived as a barrier to shared decision-making. For behavioural regulation, a lack of clarity around whether there are guidelines for shared decision-making, as well as reviewing treatment progress and goals on a sporadic basis, served as barriers to shared decision-making.</p> <p>Under opportunity, barriers and facilitators were identified for environmental context, and resources and social influences. Within these Framework domains, the following barriers to shared decision-making were noted: 1) built facilities that are not conducive to shared decision-making; 2) limited or a lack of psychological interventions for shared decision-making; 3) administration and time constraints that inhibit shared decision-making; 4) procedural influences, such as best practice pathways, that prevent shared decision-making; and 5) social influences, such as treatment team members' negatively influencing decisions.</p> <p>Finally, under motivation, barriers and facilitators were found for professional role and identity, beliefs about consequences, beliefs about capabilities, and emotions. Within the domain of professional role and identity, the fact that shared decision-making is something clinicians already 'do' was reported as a facilitator, while overruling a young person's wishes due to professional</p> |

| Focus of study | Study characteristics | Sample description | Key features of the intervention(s) | Key findings |
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| | | | | <p>standards were at odds with shared decision-making. In terms of beliefs about consequences, the belief that shared decision-making empowers young people and families was cited as a facilitator. In regards to beliefs about capabilities, feeling confident in engaging in shared decision-making was perceived as a facilitator, whereas feeling less confident due to a lack of knowledge around options was reported as a barrier. Lastly, within the domain of emotions, feeling overwhelmed served as a barrier to engaging properly in shared decision-making.</p> <p>This paper identified several clinician-reported barriers and facilitators to engaging in shared decision-making with young people facing mental health challenges, and their parents. Such findings could help inform future interventions to improve the experience of shared decision-making in the 'real world.'</p> |
| <p>Evaluating and modifying an existing decision aid and field-test decision coaching with the adapted aid during consultations with parents facing potential delivery at 23 to 24 weeks of gestation (20)</p> | <p><i>Publication date:</i> 2017</p> <p><i>Jurisdiction studied:</i> Canada</p> <p><i>Methods used:</i> Assessment of the existing patient decision aid using the International Patient Decision Aid Standards instrument</p> | <p>Decision coaching with the modified patient decision aid by one of the four trained neonatologists was offered to pregnant women (n=12) and their partners (n=8) if the women were at risk of delivery at 23 to 24 weeks of gestation.</p> | <p>Patient decision aids can facilitate shared decision-making in clinical settings. Decision coaching, where trained professionals offer patients individualized guidance and support, is often used in conjunction with patient decision aids. This study used the International Patient Decision Aids Standards instrument to evaluate an existing patient decision aid. Furthermore, shortcomings from the evaluation, coupled with feedback from stakeholders external to the working group and research team, guided content and format adaptations to the existing patient decision aid. The modified patient decision aid was then alpha- and field-tested.</p> | <p>The assessment of the existing patient decision aid did not meet all the criteria required to be considered a decision aid at the study sites (The Ottawa Hospital, General Campus, and the Children's Hospital of Eastern Ontario). The following reasons were cited as the key contributors to the low scores: the lack of a palliative care card to illustrate the main options for the decision (qualifying criteria); data that were not based on recent results specific to the study sites; and the lack of information in some factors identified by the survey. In addition, the survey revealed the following seven, commonly high-ranked health-related factors for inclusion in the patient decision aid: survival rates; severe and moderate neurodevelopmental disability of the survivors; quality of life of both the parents and survivors; and maternal risk of mortality and long-term morbidity.</p> <p>The existing patient decision aid underwent three key modifications before alpha-testing. First, the authors designed a palliative care card. Second, the existing survival and neurodevelopmental disability cards integrated national survival data and up-to-date neurodevelopmental disability data. Finally, the addition of several new cards addressed the other four health-related factors identified by the survey. After implementing feedback from various stakeholders, the International Patient Decision Aids Standards instrument assessment showed that all criteria were fulfilled.</p> <p>Twenty subjects participated in field-testing. Participants reported high levels of satisfaction with the patient decision aid and decision coaching. The majority of participants would definitely recommend this form of consultation to other parents facing a similar decision. In terms of decisional outcomes, the total decisional conflict score decreased significantly.</p> <p>This study showed that consultations using the aid with decision coaching were feasible, decreased decisional conflict, and may support shared decision-making.</p> |

| Focus of study | Study characteristics | Sample description | Key features of the intervention(s) | Key findings |
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| <p>Developing and implementing a decision aid for treatment of children with juvenile idiopathic arthritis (21)</p> | <p><i>Publication date:</i> 2017</p> <p><i>Jurisdiction studied:</i> Canada, U.S.</p> <p><i>Methods used:</i> Parents surveys were collected to assess decision-aid outcomes</p> | <p>Four Pediatric Rheumatology Care and Outcome Improvement Network sites implemented the medication choice cards intervention. Collectively, the sites collected 223 parent surveys over 18 weeks of data collection to assess outcomes.</p> | <p>To develop juvenile idiopathic arthritis medication choice cards, the research team partnered with a graphic design student from the University of Cincinnati, and patients, parents, and clinicians from the Pediatric Rheumatology Care and Outcome Improvement Network. Six medication choice cards were created to allow clinicians and patients/parents to discuss medications that are practical options in a given clinical situation. Using plain language and pictorial depictions, each card presented a key issue on which potential medications differ. The issues addressed by the cards were: 1) how often each potential medication must be taken; 2) how soon the medications take effect; 3) side effects; 4) cost; 5) how long each medication must be taken; and 6) other factors to consider prior to starting or while taking each medication.</p> | <p>However, the authors noted several study limitations, such as a study design that precluded determining the effect of the different healthcare professionals' communication styles on the parents' response to the consultation.</p> <p>Following 18 rounds of testing and refining, stakeholders approved the decision-aid design for regular use.</p> <p>Qualitative feedback from clinicians using the decision aid was generally positive. Frequently reported facilitators of successful use of issue cards was buy-in from clinicians on the value of shared decision-making, training in use of issue cards, and reminders and prompts for card use and accessibility at time of discussion of medication choice.</p> <p>During the implementation phase of the project, the decision aid was used in a median of 35% of visits where starting or switching medication was discussed. Clinicians used the decision aid as intended (parent was asked to pick the first card to discuss) in a median of 68% of visits where cards were employed. The vast majority of surveyed parents reported high levels of shared decision-making following visits with and without use of the issue cards. Furthermore, the vast majority of parents reported no uncertainty after visits with and without use of the decision aid.</p> <p>Although user acceptability of the decision aid was high, reliable implementation of shared decision-making with decision aids proved difficult. This is evidenced by the survey results, which did not signify differences in levels of shared decision-making and parental certainty with and without use of the aid. Such findings signal a need for innovative approaches to facilitate implementation of decision aids and assessment of outcomes.</p> |
| <p>Exploring multiple stakeholders' perceived barriers to</p> | <p><i>Publication date:</i> 2016</p> | <p>Fifty-seven individuals representing four key stakeholder groups in a</p> | <p>Shared decision-making in a pediatric context involves partnerships</p> | <p>Six main barrier and facilitator themes emerged from focus groups and stakeholder interviews.</p> |

| Focus of study | Study characteristics | Sample description | Key features of the intervention(s) | Key findings |
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| <p>and facilitators of implementing shared decision-making and decision support in a tertiary pediatric hospital (23)</p> | <p><i>Jurisdiction studied:</i> Canada</p> <p><i>Methods used:</i> Interpretive descriptive qualitative study was conducted using focus groups and interviews with various stakeholder groups</p> | <p>tertiary academic pediatric hospital participated in this study. Five focus groups were conducted with the following stakeholder groups: social workers (n=13); nurses (n=5); multidisciplinary clinical unit including physicians, nurses and a social worker (n=13), parents (n=15), and youth aged 12 to 18 years (n=7). In addition, four interviews were held with senior hospital administrators (n=3) and a physician (n=1).</p> | <p>among the clinicians, parents and the child. However, implementation of shared decision-making interventions in pediatric healthcare is limited. To promote shared decision-making in pediatric healthcare settings, the authors implemented a hospital-wide decision-support program for families and clinicians. Decision support is a type of clinical counselling to address decisional needs using evidence-based tools and strategies, such as patient decision aids. The authors' proposed decision-support program aimed to make pediatric-relevant patient decision aids accessible to the public, train clinicians to use decision-support strategies, and offer decision-coaching support to patients and families.</p> | <p>The most frequently reported barrier was inadequate shared decision-making and decision-support knowledge. Although participants were familiar with the idea of patient and family engagement in health decision-making, stakeholder groups reported limited knowledge of specific shared decision-making strategies or decisional aids.</p> <p>All stakeholder groups perceived alignment between shared decision-making and decision-support concepts with the hospital's organizational culture, values and practice ideals as a facilitator to program implementation.</p> <p>Stakeholder attitudes and motivation for shared decision-making and decision support served as a facilitator for senior administrators, clinicians and parents, but as a barrier for young people. While senior administrators, care providers and parents endorsed the decision-support program, several young people did not deem the program as a necessary service.</p> <p>Applicability of the decision-support program for different clinical scenarios was cited as both a barrier and facilitator across stakeholder groups. While senior administrators identified specific clinical situations that may be well-situated for decision-support strategies (i.e., complex conditions), clinicians stated that decision support may be difficult to implement when urgent medical care is needed. Youth reported that decision support may be useful for complex decisions, but may not be necessary for simpler decisions.</p> <p>Finally, the impact of the decision support program on the clinical process could act as both a barrier and facilitator, depending on the context. For example, several senior administrators and clinicians suggested that additional appointments or wait times to visit a decision coach may disrupt clinical processes and further strain healthcare resources. However, some clinicians believed that shared decision-making and decision support would decrease repeat visits if patients and families were more informed.</p> <p>This study suggests that specific knowledge-translation strategies that improve shared decision-making knowledge and address the barriers identified by the stakeholder groups may be required to support shared decision-making and decision-support implementation in the authors' pediatric hospital. However, the authors noted several study limitations, including the purposeful sampling of many participants who also held patient advocacy roles that potentially biased their perspectives.</p> |



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