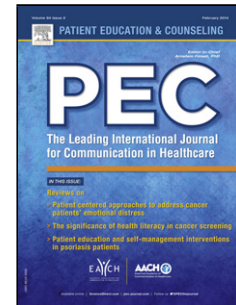


Accepted Manuscript

Title: Improving Shared Health Decision Making for Children and Adolescents with Chronic Illness: A Narrative Literature Review

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PII: S0738-3991(18)30411-7
DOI: <https://doi.org/10.1016/j.pec.2018.11.017>
Reference: PEC 6131

To appear in: *Patient Education and Counseling*

Received date: 25 July 2018
Revised date: 9 November 2018
Accepted date: 19 November 2018

Please cite this article as: Krockow EM, Riviere E, Frosch CA, Improving Shared Health Decision Making for Children and Adolescents with Chronic Illness: A Narrative Literature Review, *Patient Education and Counseling* (2018), <https://doi.org/10.1016/j.pec.2018.11.017>

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Improving Shared Health Decision Making for Children and Adolescents with Chronic Illness: A Narrative Literature Review

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We are grateful to the Leicester Judgment and Decision Making Endowment Fund (Grant RM43G0176) for support in the preparation of this article.

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Highlights

- Shared decision-making helps treatment adherence and satisfaction of adult patients
- Increased shared decision-making could improve care of paediatric chronic patients
- High risk-taking, reward-seeking and impulsiveness impair children's health choices
- Social influences and peer pressure can also interfere with children's decision making

- Shared decision-making needs to be adapted to needs of paediatric chronic patients

Abstract

Objective. This review aims to increase understanding of health decision-making by children and adolescents with chronic illnesses and offer suggestions for improving shared decision-making with healthcare professionals.

Methods. Using cross-disciplinary publication databases, we surveyed literature on children's and adolescents' health decision-making from psychology, health sciences, and neuroscience.

Results. Several factors influencing health decision-making were identified. Considering neurobiological aspects, children lack functionality in the frontal lobe resulting in lesser cognitive control and higher risk-taking compared to adults. Additionally, adolescents' generally higher arousal of socioemotional systems demonstrates neurological underpinnings for reward-seeking behaviours. Psychological investigations of children's health decision-making indicate important age-dependent differences in risk-taking, locus of control, affect and cognitive biases. Furthermore, social influences, particularly from peers, have a large, often negative, effect on individual decision-making due to desire for peer acceptance.

Conclusion. Acknowledging these factors is necessary for optimising the process of shared decision-making to support minors with chronic illnesses during healthcare consultations.

Practice Implications. Doctors and other healthcare professionals may need to counteract some adolescents' risk-taking behaviours which are often spurred by peer pressure. This can be achieved

by highlighting the patient's control over health outcomes, emphasising short-term benefits and long-term consequences of risky behaviours, and recommending peer support networks.

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Keywords: Children; Adolescents; Risk-taking; Shared Decision-making; Chronic illness

1. Introduction

Children and adolescents suffering from chronic illnesses such as diabetes face a multitude of complex health decisions every day. For example, they have to judge the likelihood of a common headache being caused by hypoglycaemia, and decide on the course of action, such as whether to alert a parent, test their blood sugar or eat something [1]. Chronic illnesses, referring to conditions of at least three months that impair normal activities and require extensive medical care [2,3], affect between 7% and 18% of children [4], i.e., persons under the age of 18 years [5]. Common chronic conditions in children include asthma, type 1 diabetes, cystic fibrosis and gastrointestinal conditions such as ulcerative colitis [6-8].

To improve patients' management of illness, current healthcare approaches promote a shared decision-making (SDM) model, with patients and healthcare professionals working together to reach a shared treatment decision [9,10]. This improves patient confidence in health decisions and treatment adherence [11,12], and is associated with higher levels of patients' happiness [9]. SDM and the promotion of healthcare autonomy [13] and agency [14] may be particularly important for paediatric patients with chronic illnesses, who are presented with an ongoing series of health-related judgements and decisions and often develop psychological and social problems [8,15-19]. However, SDM fails to be consistently applied to paediatric healthcare [20,21]. Studies report that many doctors doubt obtaining a child's approval for treatment is important [22], even though research suggests that children want to be actively involved in the medical decision process [23,24]. Furthermore, only little research has investigated interventions to improve communication between doctors and paediatric patients [19]. Given the advantages of

SDM, especially for patients with chronic illnesses, barriers to paediatric patients' involvement need to be better understood. A necessary focus must be children's capacity for, and factors influencing decision-making. For example, increases in risk-taking when children with chronic illnesses enter puberty are associated with drops in treatment adherence [1,9,25,26], which can increase morbidity and medical complications [27].

This article will review the processes involved in health decision-making of children and adolescents with chronic illnesses, summarising and evaluating research pertaining to their direct decisions concerning chronic illness, as well as decision-making in everyday life, which may influence their condition. There are different general approaches to improving health decision-making, including the development of decision aids for specific illnesses [28-30]. However, previous literature questions the comprehensiveness of such aids and re-affirms the continued need of traditional healthcare consultations with an emphasis on SDM to achieve best outcomes for the patients [31]. Hence, this review will make recommendations on how to successfully engaging children in health decision-making within the existing model of SDM. Additionally, we will propose avenues for future research, which may result in new, effective interventions and communication techniques designed to improve the quality of life and future health outcomes of children affected by chronic illness. This article presents a narrative literature review with the intention to provide a broad overview of the topic and bring different strands of research together. It does not intend to provide a comprehensive review of the entire literature in this field.

Previous literature suggests different stages of childhood [32,33]. While Piaget famously suggested abstract stages of cognitive development, more recent literature categorizes children by their educational stage (e.g. pre-schoolers, primary school children, high school children) [34]. There appears to be a lot of fluidity around these age categories, and the exact boundaries of

different developmental stages are debatable. For each study discussed in the review, we adopted the age categorisations and labels used by the respective author. To add more transparency, we also included the participants' exact ages throughout the entire manuscript. It is important to note that findings might be limited to the specific age group investigated in the respective study.

Due to the limited literature in this field, this review will include literature on all age groups. However, given a certain minimum of cognitive development necessary for decision-making and health-related decision-making in particular, the review inevitably has a stronger focus on older children, most notably adolescents.

2. Method

2.1. Inclusion criteria

Following initial surveying of relevant literature in overlapping fields of psychology, health sciences, and neuroscience, we identified key research studies and influential theories for this review based on a subjective process of evaluating overall impact and number of citations. A crucial emphasis was put on literature about children's and adolescents' decision-making. The included research discusses children of all age groups, but under the age of 18. Another focus was chronic disease decision-making, but the lack of research in this field meant that articles describing child health decision-making in general were also included. The article covers empirical and theoretical work, as well as qualitative and quantitative studies. Only publications in English were considered.

2.2. Information sources and search The literature search was conducted in a non-systematic way. We set out by reading general texts on health psychology, screening the recommended literature, and checking the literature's reference lists. Using the cross-disciplinary publication databases Web of Science and PubMed, we then searched for publications from 1980

to present day (2017). Search terms included “chronic illness”, “health decision-making”, “judgement”, “child”, “adolescent” as well as the synonyms “judgment”, “children”, “adolescents” and “adolescence”. A title sift removed articles examining decision-making *about* children rather than decision-making *by* children. Additionally, relevant publications were identified from citations in core articles.

3. Results

Three major factors are relevant to understanding children’s health decisions: neurobiological, psychological and social influences. Given the paucity of research specifically on children with chronic illnesses, articles describing child health decision-making in general were also included.

3.1. Neurobiological considerations

Neurological underpinnings and developing brain structures provide a biological framework for health decision-making of children and adolescents. Lesion and neuroimaging studies have found that the ventromedial prefrontal cortex and related structures play key roles in judgement and decision-making [35].

3.1.1. Cognitive control system. An important aspect of decision-making are executive functions, i.e., cognitive processes that control behaviours aimed at goal attainment [36]. The frontal cortical networks, specifically the prefrontal cortex, is known to be a key structure responsible for executive functions [37]. Since the entire frontal lobe undergoes significant development during adolescence, the implications for decision-making are important to explore [38].

A meta-analysis of studies involving neuropsychological tests reports age-related increases in frontal lobe executive functioning [39]. Development began in early childhood (5-8 years) with maturation of frontal lobe functioning. By the age of 12, children typically mastered the inhibition of attention to irrelevant stimuli. Development continues—albeit at a lower rate—into early adulthood [40].

Furthermore, certain neurological processes involving changes in brain structure were found to facilitate improvements in self-regulation. Such changes include synaptic pruning and myelination of prefrontal brain regions after puberty [41], which are associated with improvements in executive functioning (e.g., response inhibition) [42].

The relationship between executive functioning and risky decision-making was explored in an experiment with 112 children and adolescents aged 8-19, who completed the Game of Dice Task (GDT) used to assess risky decision-making [43]. Participants also performed the Modified Card Sorting Test (MCST) to investigate executive function and the Ravens Progressive Matrices to assess reasoning. The results showed that risk-taking in the GDT decreased with increasing age. Furthermore, performance on the MCST indicated that weak executive functioning was associated with very risky decision-making. Similarly, another study showed that increased prefrontal activity during risky decision-making is correlated with less risk-taking in both adults (20-40 years) and adolescents (9-17 years)[44]. Adults displayed greater prefrontal activity overall than adolescents during risky choices. Therefore, the cognitive control that prefrontal activity exerts, appears to decrease risk-taking and this is evidenced to be greater in adults than in adolescents.

3.1.2.Socioemotional system. Socioemotional responses, which refer to affect and emotional responses to human interaction, are controlled by limbic and para-limbic areas of the brain (e.g., amygdala, orbitofrontal cortex, medial prefrontal cortex, nucleus accumbens) [42].

Human functional magnetic resonance imaging (fMRI) studies have found that dopaminergic activity is increased in the amygdala and nucleus accumbens when making risky choices and processing emotional information [45-47]. This activation is exaggerated in adolescents (aged 10 or older), relative to younger children or adults [45,48]. The heightened activity of limbic systems and reliance on the amygdala rather than prefrontal regions compared to adults suggests that risk-taking behaviour seen in adolescents may be a result of high levels of emotional arousal, reactive decision-making and reward-seeking [49].

Furthermore, another study showed that nucleus accumbens activity in response to rewards was highly correlated with self-reported likelihood of engaging in risky behaviours in adolescents (13-17 years) and adults (23-29 years) but not in children (7-11 years)[50]. This suggests the affective system's involvement in decision-making. The authors found an age-related decrease in self-reported impulsivity which corresponds to the development of cognitive control systems [50], and Steinberg [42] reported similar results in a study of 10-30 year olds that used both self-report and cognitive behavioural indicator measures. The findings confirm that reward-seeking and impulsivity develop along different trajectories. Reward-seeking peaks in mid-adolescence (age 14-15), whereas impulse-control increases steadily from the age of 10.

3.1.3.Intertemporal choice structures. Intertemporal choice refers to the way in which current decisions affect future outcomes. For example, by refraining from enjoying something immediately, enjoyment levels may improve significantly in the future, also referred to as delayed gratification [51,52]. Future-oriented thinking is a term used to describe a similar principle, referring to the ability to weigh up short and long term consequences [53]. Intertemporal choice is highly relevant to decision-making about chronic health issues, with more future-orientated patients being more likely to follow treatment recommendations despite unpleasant immediate side

effects. [54] In a temporal discounting task [54], young adolescents (aged 10-15) consistently demonstrated a weaker orientation to the future than individuals aged 16 and older.

Another study [55] measured developmental changes in future-oriented decision-making of school-aged children and adolescents, using an adapted gambling task. Results showed that only 16-18 year olds were better at anticipating outcomes and learned to make advantageous choices during the course of the task, but this group still did not make as many advantageous choices as adults [27,56].

3.2.Psychological factors

This section will examine relevant psychological factors including risk-taking, locus of control, affect, and cognitive biases.

3.2.1.Risk-taking. As outlined above, risk assessment is a crucial element of health-related decision-making, and high risk-taking may leave patients vulnerable to poorer outcomes regarding general lifestyle [38] or treatment plans. Furthermore, risky behaviour in adolescence was found to be a powerful predictor of other behavioural problems in later life [57].

The results outlined in the previous section clearly demonstrate that risk-taking increases from childhood through to adolescence. A common misconception is that young people's risk-seeking is a result of a limited cognitive ability to weigh up probabilities compared to adults [38]. If avoiding risky behaviour was due to matured cognitive ability then a decrease in risk-taking would be seen from childhood through to adolescence. As this is not the case, other factors are likely to be involved [58].

Another commonly held misbelief is that adolescents see themselves as invulnerable to risk [38]. Quadrel, Fischhoff and Davis [59] found adolescents and adults rated themselves as similarly

vulnerable to potential negative outcomes. Some evidence even suggested that adolescents may overestimate their personal vulnerability [40].

Most studies reviewed examined risk-taking under confined experimental conditions but real-life risk evaluation and decisions regarding chronic illness are likely to be influenced by a number of additional factors. Hence, future investigations need to investigate risk-taking outside the laboratory.

3.2.2.Locus of Control. Individuals differ in the extent to which they perceive events as being controllable. Rotter [60] coined this concept locus of control, differentiating between internal and external loci of control. While individuals with internal loci may view their actions as key to achieving certain health outcomes, individuals with external loci are likely to perceive health as a result of external factors beyond personal control [61]. For example, a study of diabetic youths (16-25 years) found that an internal locus was associated with adhering to a self-care regimen while a belief in the influence of ‘powerful others’ was associated with decreased risk perceptions related to the disease [62].

In a cross-sectional 3-year longitudinal study of children aged 8-13, Sherman [63] found that an internal locus of control developed steadily with increasing age. However, an internal locus of control may also depend on life experiences. Steinhausen [61] compared the locus of control in chronically ill children with healthy controls. The internal locus was significantly higher in the patient group. This could be due to patients having learned that their own actions will likely affect personal health outcomes as a result of their experience in managing the symptoms of the condition. It thus appears that the mere experience of living with a severe chronic illness may increase the internal locus of control. Given that high internal loci are generally associated with positive health

outcomes and greater abstinence from poor health behaviours such as smoking and drinking [64], the above longitudinal results are reassuring.

However, locus of control might differ depending on the type of chronic illness involved. A study [65] evaluated locus of control in adolescents (aged 12-18) with chronic fatigue syndrome (CFS) and same-aged healthy adolescents and their respective parents. Results indicated that families with adolescent CFS patients experienced reduced levels of internal control compared to healthy control families. A possible explanation for this difference may be that CFS is of unknown aetiology, which may lead to individuals feeling uncertain and ill-equipped to manage the condition [65]. This explanation highlights a potential area to address in the management of chronic conditions.

3.2.3.Affect. Evidence shows that adolescents (aged 10-16) with chronic illnesses are more likely to suffer emotional disturbances compared to healthy adolescents [66]. The emotional consequences of receiving a diagnosis and hospital stays are among an extensive list of contributors to a child's stress [7]. Moreover, childhood and adolescence are periods of significant emotional change even in healthy individuals [49]. Consequently, this section will evaluate the influence of affect (i.e., the experience of feelings or emotions, [67]).

Naturally, most individuals seek positive affective states. These may be achieved through excitement and thrills, which are often a consequence of risky behaviours. Risk-seeking behaviours motivated by achieving such intense experiences have been termed "sensation-seeking" [68]. It is well evidenced that sensation-seeking rises dramatically during adolescence peaking at age 16 for girls and at 19 for boys [68,69]. This is closely related to reward-seeking behaviours which were discussed from a neurobiological perspective in the previous section. In the context of sensation-seeking behaviours, the excitement created acts as a reinforcement which increases the

likelihood of future engagement in sensation-seeking activities [70,71]. With regard to chronic illness, this may mean that adolescents are driven to make risky choices in order to enhance a positive experience associated with that choice; such as a diabetes patient choosing to indulge in a high-sugar meal rather than controlling their diet.

Caffray and Schneider [72] studied the role of “affective motivators” in adolescents’ (mean age: 16-17) risk-taking, differentiating motivators that worked by (1) encouraging pleasant affective states, (2) by reducing or avoiding negative affective states, and (3) by avoiding anticipated regret. The study assessed participants’ previous levels of engagement in risky behaviours (e.g. smoking) and their subsequent desire to engage in these behaviours again. Results revealed that less experienced adolescents were more focussed on reducing negative affective states associated with negative outcomes. However, adolescents with greater experience in risky behaviours held stronger beliefs that participation in the behaviour could both enhance positive and reduce negative affective states. These findings imply that the motivational strength of different affective states varies in adolescents, depending on their previous experience of risky behaviour.

When applied to adolescents suffering from chronic illness, those with limited previous experience, such as the newly diagnosed may respond better to interventions focussed on highlighting the negative outcomes of engaging in risky health behaviours. Conversely, interventions focussed on developing a better understanding of the limitations of enhanced positive affective states associated with risky behaviour may be better suited to more experienced patients.

3.2.4. Heuristics and cognitive biases. Decision makers frequently engage in quick, intuitive thought processes to save time and cognitive effort [73]. It might be this type of reasoning which is most commonly affected by biases in judgement, and the use of inappropriate heuristics

[40]. Heuristics refer to mental shortcuts for easing complex decision tasks [74,75]. Although heuristics generally improve efficiency in judgement processes, they can result in systematic errors, so-called “cognitive biases” [73]. One example relevant to health decisions are framing effects.

Framing effects explain how people’s preference shifts between identical choices depending on how the options are presented or “framed” [76]. This was illustrated by Tversky and Kahneman [77] who asked participants to select between two different treatment options in a hypothetical scenario involving a lethal disease. The results showed that more participants chose a treatment presented with positive framing (“saves 200 lives”) compared to the same choice presented with negative framing (“400 people will die”) [77](also see [78]).

Reyna and Ellis [79] examined framing effects in children aged 4-11, presenting outcomes of a ball game either as wins or as losses. Overall, children were far more consistent across frames than adults [80]. The results showed that younger children did not exhibit framing effects, focussing on quantitative differences whereas older children were increasingly more likely to assimilate quantitative differences and, thus, demonstrate framing effects. This developmental difference could be a result of an increase in qualitative reasoning with age [38].

A relevant theory pertaining to heuristic decision-making is Fuzzy-trace theory (FTT), which differentiates between gist-based and verbatim reasoning [84]. According to FTT, the creation of simple, gist-like mental representations of different options is a sign of advanced decision-making. Being able to form meaningful “fuzzy” memory traces as opposed to detailed quantitative representations of information was described as a useful skill that simplifies complex decision situations and enables individuals to make efficient choices [85,86].

The previously discussed evidence that younger children (aged 10 or younger) exhibit less susceptibility to the effects of framing is in line with FTT, because they tend to focus on

quantitative information and so are less vulnerable to framing effects [58]. Overall, the findings suggest that younger children may need support in being able to abstract a choice situation, contextualise it, and create simple choice representations [84].

3.3 Social influence

Decision-making rarely occurs in isolation. Social influences on children's affective and cognitive processes have been well documented [58,87,88]. Children's decisions may be influenced by parents, siblings, peers, teachers, doctors and others. The purpose of this section is to explore the impact of social influence on children and adolescents with chronic illness.

While younger children rely heavily on parental advice, [89,90], school-aged children (above age 6) tend to spend more time with their peers [91], who may encourage risky behaviours or even provide social pressure. Accordingly, we will mainly focus on peer influences.

Some literature has proposed an argument for the positive influence of peer interaction in adolescent decision-making [92]. For example, Moshman and Geil [93] found that interactions with peers when trying to solve a problem led to dramatic improvement in older adolescent (aged 18) reasoning. They suggest this improvement is the result of increased reflection, reconstruction and justification of ideas.

In contrast, an experiment on age differences regarding the effect of peer context on risky decision-making demonstrated that the mere presence of peers may lead to increased risk-taking [94]. The researchers asked adolescents (13-16 years), youths (18-22 years) and adults (>24) to perform a computer driving task which contained life-like, risky decisions of whether to continue through yellow traffic lights. Participants either carried out the task individually or with two same-aged peers. When carrying out the task alone, the three age groups engaged similar amounts of risk-taking. However, adolescents took twice as many risks when completing the task in the

presence of peers compared to when completing it alone. Youths were approximately 20% more risk-seeking and the adults demonstrated no differences in risk-taking depending on the presence of peers.

Moreover, developmental neuroimaging studies suggest that adolescents have heightened neural activation in response to a variety of social stimuli, such as facial expressions and social feedback compared to younger children and adults [95]. These findings indicate that adolescents are hypersensitive to social stimuli, which may increase their vulnerability to peer influences [96].

Furthermore, a large scale study [97] investigated risk perception in different everyday scenarios including cycling without a helmet or crossing a street while texting. They sampled a large group of participants aged 8-56. After scoring their risk perceptions, participants were informed about the average ratings of different social groups. Subsequently, they were invited to rate their risk perception again. Results indicated that younger participants were more strongly influenced by other people's ratings than adults. Interestingly, children aged 8-11 were more influenced by the ratings of fellow teenage groups than by adults. The authors [97] explained this with reference to a desire for peer acceptance.

Children and adolescents may be particularly sensitive to peer rejection [98,99], and conforming to peer influence could be a reward-seeking behaviour. Applying these findings to a health context, it may help to explain to paediatric patients that peers may hold different views because of different experiences, and to caution against allowing this to influence their decisions. This is particularly the case if peers mostly consist of children without chronic illnesses.

4. Discussion and Conclusion

This final section will provide an evaluative discussion and make recommendations for supporting chronically ill children with health decision-making.

4.1.Discussion

Our review demonstrated that children and adolescents are generally capable of decision-making, but specific aspects of their cognitive and emotional development may need to be taken into consideration during consultations. To identify areas requiring additional decision support, we will outline the most important differences in decision-making between adults and children. Neurobiological considerations suggest that children lack functionality in the frontal lobe, resulting in less cognitive control and higher propensity to risk-taking compared to adults [44]. Additionally, adolescents' socioemotional systems (limbic systems and amygdala) show higher levels of arousal than in adults, suggesting that a desire for reward-seeking may increase risk-taking (e.g., [45]). Finally, due to differences in intertemporal choice structures, children and adolescents are less future-orientated and therefore more prone to spontaneous decisions with negative long-term consequences than adults (e.g., [54]).

In the context of psychological factors, individual differences in risk-taking, locus of control, affect and cognitive biases play an important role. Risk-taking increases in older adolescents despite accurate perceptions of risk vulnerability and more mature brain structures at that age. This suggests the existence of additional factors that influence risk-taking [38]. Steinhausen [61] suggests that an external locus of control may have negative consequences for following treatment recommendations. While individuals typically develop more internal loci of control when growing up, paediatric patients suffering from chronic conditions with unclear aetiology or treatment may be at greater risk of developing more external loci. Furthermore, research suggests the importance of affect on decision-making, with adolescents engaging in risky,

sensation-seeking behaviours to seek excitement and positive arousal [68,69]. Finally, children become more prone to cognitive biases as they age. This may be linked to younger children's difficulties with encoding detailed information as simplified gist representations. While this makes them more resistant to framing effects, it means that they struggle to abstract information and make efficient choices in complex decision situations [84,85].

Lastly, we investigated the importance of social influences in children's and adolescents' health decision-making. Social groups of similar ages have a disproportionately large effect on individual decision-making due to a desire for peer acceptance, which often results in increased risk-taking [98,99].

4.2.Practice implications

The research reviewed and summarised above has important implications for cases of shared medical decision-making involving paediatric patients with chronic illnesses. Previous literature on SDM demonstrates a variety of different understandings of the term [100], but a popular process model by Elwyn et al [12] proposes three key steps. These include (1) the healthcare professional's introduction of the health choice, (2) their detailed description of the choices available, and (3) their support during the patient's process of decision-making [12]. This article's recommendations for SDM all aim to challenge the traditional power imbalance in paediatric healthcare consultations [21], and will be presented in the order of the three steps identified above. We illustrate our recommendations in Figure 1, which extends Elwyn et al.'s [12] shared decision-making model with concrete suggestions on how to approach the young patient.

4.2.1 Choice talk. During this initial step of SDM, the healthcare professional's key responsibility is to inform patients that different treatment options exist. They need to emphasise a decision based on the patient's preferences, outlining uncertain treatment outcomes [12]. Given

the evidence for a lower internal locus of control in younger children, it might be necessary to establish a greater sense of control. This may involve emphasising the patient's responsibility for their future health and outlining the link between present health choices and long-term quality of life. Based on the low levels of perceived control found in certain chronic health conditions such as CFS, healthcare professionals need to pay particular attention to patients suffering from these illnesses. One possibility might be to reiterate that despite a lack of medical knowledge on the aetiology or optimal treatment, certain health choices may invariably yield better outcomes than others.

4.2.2 Option talk. To initiate the decision talk of SDM, Elwyn et al. [12] emphasize the importance of checking existing knowledge relevant to the medical condition. While this is important in adult patients, it may be crucial in paediatric patients who are likely to differ greatly in their understanding of illnesses. Any explanations of treatment options need to be worded carefully, with age-appropriate terminology and simple analogies. Younger children will need additional support to simplify detailed information and reduce it to 'gists' that enable more efficient decision-making. Rather than overwhelming them with detailed data, healthcare professionals should reduce the information to simpler messages, which are contextualised within a "bigger picture". They also need to be aware of possible cognitive biases and barriers to information processing, which are likely to affect older adolescents [79,80]. To avoid framing effects, all information needs to be presented as objectively as possible.

4.2.3 Decision talk. When trying to reach a decision, Elwyn et al. [12] state the need for support to identify the patient's personal interests. In this context, paediatric patients may require more help than adults. Potential barriers to optimal decision making include high-risk decisions with immediate pleasurable outcomes while neglecting future-oriented options with more long-

term benefits. During the decision talk, healthcare professionals may need to ask their patients to actively contrast short-term benefits of unhealthy behaviours (e.g., consuming large quantities of sugary dishes as a diabetic) with long-term benefits through resisting (e.g., healthy blood sugar levels; fewer side effects). To increase tangibility of future health outcomes, healthcare staff should give concrete examples, possibly drawing on individual patient cases or highlighting concrete future incentives such as being able to drive cars. Alternatively, they might help to establish short-term reward-systems for certain health achievements or treatment adherence. Such reward systems could include regular parental praise or small material rewards, which would guard against the temptations of immediate gratification.

To counteract negative peer influences, healthcare professionals need to draw attention to social diversity and outline that healthy peers typically face lower risks than patients suffering from chronic illness. Additionally, it may be helpful to establish peer support networks of informed youths with similar health conditions, who could reinforce healthy behaviours and provide a more similar reference group for social comparison.

4.2.4 Limitations. The practice implications of this review are limited due to the narrow focus on bilateral relationships between doctors or other healthcare professionals and patients, even though most paediatric healthcare consultations typically also include a parent. Extensive literature points to the important triadic relationship of paediatric patients, their parents and the doctor [30,31]. As the cognitive skills of children mature, they are more likely to form health opinions different from their parents, which can be a potential cause of conflict. An in-depth consideration of this complicating relationship is beyond the scope of this review, which focused on the decision-making skills of children and adolescents, but it could be fruitfully examined in future research.

4.3. Conclusion and future research directions Despite high numbers of children and adolescents suffering from chronic diseases, little research has focused directly on the processes affecting their health choices. Large-scale longitudinal studies are necessary to increase understanding of barriers to optimal decision-making and identify areas of decision support through healthcare professionals and caregivers. Furthermore, the complicated relationship triad of paediatric patients, parents and doctors requires more research to optimize the SDM process. Some research demonstrates that chronic health conditions differ in the decision processes involved (e.g., CFS is not perceived to be controllable). Thus, future research will need to identify particular challenges associated with different illnesses.

Declarations of interest: none.

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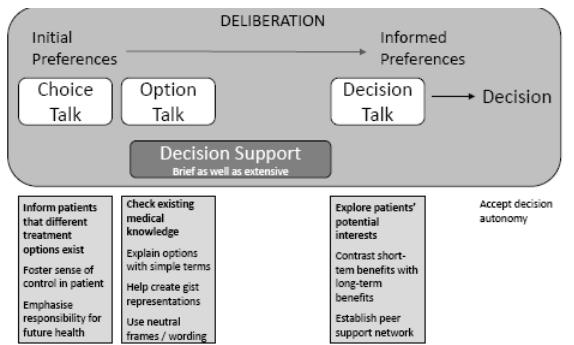


Figure 1. Extended diagram of Elwyn et al.'s [12] three-talk model of shared decision-making:

This extended version includes concrete suggestions on the doctor's approach during consultations with children and adolescents suffering from chronic illnesses