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Decision-making with children, young people, and parents

Chapter: Decision-making with children, young people, and parents

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Introduction



The origin and importance of support in decision-making in paediatric palliative care (PPC) is rooted in its primary goal: to reduce suffering and maintain and even improve the quality of life of seriously ill children and their families. Decisions take place throughout the trajectory of a child's illness and many are straight forward and barely noticed. However, often at pivotal points such as changes in treatment plans and the focus of care, the outcomes of the decisions assume much more importance and how they are made becomes a significant task for the family and clinicians involved.

Decision-making



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The two essential components of decision-making, from almost any perspective, are firstly defining the problem and secondly identifying goals and preferences. The clinician plays a crucial role in both of these tasks and as a result, the way in which the clinician goes about these is pivotal. Importantly, that role is more than passing on information about the patient's condition and what the options are for treatment. It involves the clinician's own assessment of the situation and their perception of what is to be accomplished by pursuing a particular line of care and treatment. This engages the clinician's own values and goals as a palliative care practitioner.

Defining the problem

All decision-making, including medical decision making, begins by defining the problem about which a decision must be taken. In the care and treatment of seriously ill children such problems are defined and redefined throughout the course of the child's illness, from diagnosis through relapses, exacerbations, acute episodes, and onset of deterioration or decline. This process involves not only reviewing the child's history, investigations, and current condition but also formulating the steps that can be taken and what might result if any of these actions is chosen, assessing the parent's understanding of these options and responding to their questions and concerns.

There is no single right way to do this. As Binmore, speaking in the context of economic decision-making, remarks:

Decision problems aren't somehow built into the structure of the universe. [The decision maker] must decide how to formulate her decision problems for herself. There will often be many formulations available, some of which satisfy the basic assumptions of whatever decision theory she plans to apply—others which don't (1, p. 6).

This process of identifying the problem itself has consequences and these can be far reaching. Feudtner, speaking from clinical experience, writes, '*Any treatment decision is framed by the initial detection and subsequent assessment of a problem In clinical practice, purported disagreements about medical decisions often turn out to be differences of what problems the various individuals are focused on*' (2, p. 855).

In medical decision-making there is a unique dynamic between the participants involved. One party is an expert who possesses the information needed to formulate the problem, and which also has what the others lack, the competencies needed to fully understand that information. Yet, proper medical decision-making requires that the patient or the patient's family be given enough information so that they too develop an adequate understanding of the problem and the options available for responding to it.

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This passing on of information, essential to the definition of the problem is challenging. The individual to whom the information is being passed is not simply receiving it, as something poured into an empty vessel. The clinician formulates the problem in a particular way and the family is also actively interpreting that information. In practice this means clinicians must be asking themselves: 'How is my message coming through to the patient and family? How is my message being heard and interpreted?'

We need to apply what is known about how people respond to the presentation of information and what issues might arise in their using it to formulate and work out problems for themselves, to help decide how we should best proceed.

Framing

The clinician can formulate their message in different ways. One dimension of such differences of presenting a message is captured in the idea of framing. Framing has been extensively studied in adults but only a small amount of work has been done in paediatrics (3).

An example of framing is that a choice of treatment options can be framed in terms of either survival or mortality statistics. In a well-known example, the outcomes of surgery alone versus radiotherapy alone were presented to a variety of subjects in two different ways. One was in terms of post-procedure: 1-year, and 5-year survival. The other was in terms of mortality at the same time points. Post-procedure and 1-year survival was better for radiotherapy, but long-term survival was better for surgery. In experiments in which the options of radiotherapy or surgery were presented using these two different frames, even experienced physicians made different choices which depended on the frame, not the content. Framing thus has an impact on the way in which the same basic message or information may be taken up, interpreted, and responded to by the patient and family (4).

Another way in which the presentation of a message influences people's responses relies on the finding that people behave differently depending on whether the proposed action is perceived as a gain or as a loss. Generally, people show an aversion to losing something which they already have. Given a choice between a certain gain—a guaranteed £50, for example, and a 50/50 chance of winning £100—most individuals prefer to take the smaller sum and avoid a possible loss rather than take a risk for a gain (5).

Tversky and Kahneman also found that whether an outcome is regarded as a gain or a loss depends upon factors related to individual experience (4, 5). There is no universal scale shared by everyone with an agreed zero point. Individuals set their own reference point, on a decision by decision basis. Factors such as previous experience and social norms will affect where their reference point is set (4).

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These ideas are relevant to the decisions faced in the care of children with life-limiting conditions and life-threatening illnesses. A decision to limit treatment, for example, can be framed in different ways as in the following clinical example.

Suppose experimental therapy is being considered for a child whose condition is deteriorating. The chance of response is real but low. The associated symptom burden is significant. In framing the choice the clinician could dwell upon the family's concern with a response that will be lost if treatment is not taken, or they could frame the decision in terms of the gain which the child and family will experience as a result of the child living for a period of time with a better quality of life. The child and family's past experience will also affect how aspects of each choice are seen as a loss or gain. If the child has, in the past, responded to treatment when expectations were low, forgoing the experimental therapy now might seem more as losing an opportunity. In contrast, if management of symptoms has been difficult, the possibility of a period of better quality of life may appear a significant gain. If the choice were to involve withholding life-sustaining treatment, values might also come into play in setting the reference point. The family's beliefs about the sanctity of life, for example, and what that entails could affect how they see withholding therapy. Some families might as a consequence of their values establish basic survival as a reference point. Other families may set that point as survival with a certain quality of life manifested in the patient's experiences and abilities.

Another type of framing very relevant to decisions involving palliative care is that a decision about electing a particular therapy with curative intent might be framed, at least by parents, simply as a decision whether to continue treatment. Such framings are often promoted by news reports of cases and court decisions that say that the request by parents for further treatment was rejected and that the hospital was directed to provide (only) palliative care. Clinicians need to correct such misleading framings by explaining the care and treatment which palliative care provides can include further pharmacologic and even surgical intervention for reversible conditions or to ease symptoms when appropriate.

The patient and family may add their own layer of interpretation to what the clinician presents. Ubel suggests that decision makers can add an affective or interpretive layer to statistical information (6). Given a statistic, what does one make of it? Is it good or bad? What does a parent who is given a very low estimate of long-term survival for their child make of that number? Their interpretation can be based on prior expectations.

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If they were expecting to be told that their child has no chance of cure, a 5% chance can be taken as a positive thing and the resulting positive perception may carry over and affect their assessment of treatments. It is these sorts of interpretations which clinicians need to seek out in order to understand how their message is being taken up.

Studies of adult patients suggest that discovering and uncovering framing effects and informing the patient of the effect can sometimes lead people to change their decisions. Returning to the earlier example of a mortality versus a survival framework, if the impact of this framing is explained to those decision makers and they see that the weight that they placed on radiotherapy's low initial mortality, whilst neglecting the longer overall survival following surgery, they may change their minds. But this is not always the case.

Changes in preference in response to different framings do not necessarily indicate a fault in a decision maker's thinking. The differences which a decision maker experiences in looking at the problem in different ways are real and may be difficult to resolve. For example, the belief that not electing to give further disease-directed therapy (including a clinical trial) or intervention (including what to the clinician is palliative chemotherapy) is giving up on the child has to be genuinely weighed against the belief that limiting disease-focused treatment might be better for the child's quality of life. Tversky and Kahneman themselves note that the way in which the decision is framed can not only affect how we weigh different choices but also the way in which we experience those decisions and their consequences as we move forward (4). This is an important point for clinicians in that framing not only affects outcomes for the patient but can also affect outcomes for parents who will live with their decisions and may be doing so in bereavement.

Emotions and decisions

Any clinician who has been involved in important decisions with and about seriously ill children knows that the context is emotional. This leads us to also ask whether emotions are incompatible with sound decisions or essential to them. Both sides have been argued (7). *'The interesting bioethical question is whether and how we should factor those powerful emotions into the process of decision-making'* (8, p. 803). At the moment there is relatively little research available to address this issue. We do know that parents report that receipt of a serious diagnosis such as cancer can be initially overwhelming and make it difficult to take on and process information (9). Emotions still may be part of sound decision making but we lack a reliable understanding about how precisely emotions might contribute. Decision making is a relational and interactive process and emotional displays need to be sensitively accepted in difficult clinical consultations.

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Individual preferences and information

Parents and children and young people (CYP) generally want information about their illness and its treatment, but individual preferences vary in detail from individual to individual and by situation for a specific individual. Just as it has been found with adults that informational preferences vary substantially from person to person and are influenced by a number of factors—personality (10, 11), type of disease (12), and stage of disease (13)—similar findings apply to CYP as well (14, 15). Those presenting information also need to take into account the variation in preference in relation to the amount and type of information desired and whether it is statistical or descriptive.

Identifying goals and preferences: A joint enterprise

The second of the two critical processes in decision-making is often described as ‘eliciting preferences’, usually from parents and from patients themselves when appropriate. In the context of PPC the terms ‘preferences’, ‘values’, and ‘goals’ are often used interchangeably. Dealing with preferences marks a second, typically overlapping, step in decision-making. The clinician is not only using his or her expertise to explain the child’s disease and physical condition to the child and her parent, he or she is also working to help the patient and family fashion a response to this situation. In a clinical consultation, families often move back and forth between understanding and defining the problem and the task of articulating goals and preferences.

Although the clinicians will be familiar with the medical system, that terrain is initially completely foreign for families (16, 17). The options with which families are confronted can be unlike anything else about which they have ever had to make a choice. It therefore takes work to find and express a preference or goal.

When faced with unfamiliar, complex, and emotionally charged situations such as those facing seriously ill children and their parents this is often not a straightforward task. *‘It is increasingly recognized that patients don’t have clear, stable, and strong preferences that they can simply declare when given information about treatment options and that can then be relied upon to ensure good decision-making’* (18, p. 9).

Indeed, the term ‘eliciting’ may not be an ideal choice of terminology. It may misrepresent both what preferences are and also how families, and clinicians, arrive at them. Emanuel and Emanuel suggest patient preferences and values are not necessarily fully formed or fixed. The goals relevant to medical decisions are not like straightforward desires but are more complex and evolve in response to specific situations. They describe the work of exploring and expressing preferences as a search into the patient’s aspirations, commitments, and character. They suggest that the clinician may even have to ‘conceive the patient’s life as a narrative whole’ and from this tease out the patient’s values and

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priorities. By linking preferences to commitments and character Emanuel and Emanuel are suggesting that they have a moral dimension and are rooted in the patient's, parents', and family's ethos. The clinician also bring his or her own preferences, goals, and values, forged consciously or subconsciously, both within and outside the medical system.

Given that goals and preferences emerge in response to the complex situation which patient and family are facing they will tend to be specific to the situation. They may not be able to be converted into general principles which will apply to future decisions. *'Even when a person's values are constant, how they get expressed in specific preferences regarding diagnostic and therapeutic options may vary over time'* (19, p. 54). Once articulated, families can revise and re-evaluate goals when they no longer seem to be achieving what is wanted. This is different from being unsure about one's goals. Emanuel and Emanuel take the position that revisability of goals or preferences is basic to personal autonomy and clinicians need to keep this in mind. Also, a number of goals and preferences may be held at any one time and can sometimes conflict. Satisfying one of the goals does not necessarily offset the neglect of another goal. Indeed, conflicting goals may arise in part from the very nature of the parental role.

The role of parents



The role of parents and the nature of their participation in decision-making for and with their children is unique. Parents' own goals and preferences do not feature in the decision process in the same way that they would for someone making a decision for themselves alone. There are two perspectives from which we can view this unique parental situation, from a social/interactive perspective and from an ethical/legal perspective.

Advocate and protector

Research has found that parents' behaviour in caring for their seriously ill children is powerfully guided by their understanding of their role (20). This perspective has also been confirmed by research which found that parents of ill children strive to conform to their understanding of what it is to be a good parent (21). This role is defined by two aspects. One task parents undertake is to be advocates for their children. When a child becomes unwell this aspect of role is engaged and marks the beginning of journey to find a cause, diagnosis, and appropriate management. Parents' persistent advocacy drives what can be a frustrating pursuit. A second dimension of their role is that of protector of their child. Parents' ability to fulfil this aspect of their role is challenged by the threat, which serious illness and its treatment bring to the child and to the family.

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Law and ethics

Law and ethics see the parents' role from a different perspective. In these contexts, parents are often referred to as surrogate decision makers. In healthcare a surrogate is usually deemed to be someone who stands in place of another to represent their views and opinions. However, in the case of children, this is only possible when they are at a point of understanding their illness, so that their views could be given weight. Many seriously ill children are too young for this to happen and some ill children will, because of their disease and its treatment, never achieve this ability. To deal with these circumstances, the term surrogate is given a second interpretation according to which a surrogate is someone who acts in the best interests of another person.

This principle is not merely a guide for parents in making decisions about their children, it is also a standard to which their decisions can be held and, on the basis of which, be challenged by others. It is a standard widely employed throughout North America, the UK, and Europe, supported there by article 3 of the Convention on the Rights of the Child (CRC) (22). The way this standard applied can vary substantially.

Parents' understanding of their role is consistent with making choices in the child's best interests. Opportunities which benefit their child must be sought; they do not always simply appear. Throughout the world, parents cannot simply rely upon a system to respond accurately and promptly to their child's healthcare needs even when the situation is acute. One characterization of parents in carrying out this role of advocate is that they work under the obligation to leave no stone unturned (23). At the same time, adversity—pain and symptoms—must be identified and avoided, in their role as protectors.

The understanding of the parent as a literal surrogate who is there to represent the views of the child moves in a direction different from either the parents' own basic understanding of their role and from the fundamental test by which their decisions are assessed by the courts when that occurs. Recent empirical studies discussed in the following sections, which show how CYP and parents can work together in decision-making also suggest a more complex relation than that of surrogacy.

On any of the previously mentioned understandings of parents' role in decision-making it is clear that their preferences occupy a different position in the process from patients who are choosing for themselves. Decisions are not about what parents prefer in an ordinary sense. The goals which parents set and the options which they find preferable are mediated by their duties and obligations, imposed by both themselves and society.

The complex role of parent and how parents both understand and execute their role has consequences for the way in which the clinician should go about eliciting goals and preferences. With decisions for children it is not

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finding what the parent, as an individual, wants so much as what is best for the child. Parents should not make decisions on the basis of what pleases them alone. They must and they generally do make choices for their children which they deem right and best for the child (and possibly their other children). In making these decisions parents consider many factors including emotions, family values, personal moral values, community ethos, religious precepts, and cultural norms.

The complexity is reflected in the way different cultures and different legal and healthcare systems give different weight to the views of parents. For example, in both the USA and UK, there is a presumption that parents are best placed to know the best interests of their child. However, the strength of this presumption varies substantially. In the USA, typically (law on these matters is determined by individual states, not the central government) parental behaviour would have to approach being criminal—physical abuse or abject neglect—before being overridden in court (24). In the UK, clinical opinion of the best interests of the child is accorded more weight and can, in a court, be endorsed over the parents' assessment of best interests. Clinicians in both systems are not obligated to provide treatment outside standards of best practise, treatment which they believe is not in the child's best interests.

Participation of CYP in decision-making



Today, in large parts of the world, the principle that the views of CYP should participate appropriately in decisions about their care and treatment has been endorsed (25, 26, 27). The widespread ratification of the CRC is one example of this. The CRC states that children should be able to express their views about matters concerning them and that these views be given due weight. Professional guidance for physicians in many countries also advocates the involvement of CYP in their healthcare decisions. The CRC does not specify the ways in which weight and respect for children's views should be demonstrated. It does relate the weight given to a child's views to the child's capabilities and maturity.

Bioethics has also been an active advocate for the inclusion of CYP in discussions and decisions about their care and treatment. The core principle from which the ethical requirement to give adults control over the treatment they receive through consent is respect for autonomy. As competence is associated with autonomy, bioethicists argue that CYP should be given an appropriate role in decision-making as their understanding and judgment develops.

Both the child rights approach and the bioethical approach are attempts to map out a role for CYP in decisions about their care by building on principles. However, in the last decade and especially the last 5 years, empirical research on how parents and CYP make decisions and on their preferences about the process has been carried out in depth, providing a different approach to CYP involvement in decisions. Recent research with CYP offers the opportunity to explore more deeply ideas of being

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informed, being involved, participating, having one's voice heard, and having an impact on a decision, in a way which is not simply a priori, but which is informed by an understanding of patients' and families' experience of illness and treatment. We believe that empirical studies of both children and adults show that a relational approach to autonomy and decision-making is what is actually practised and preferred. This contrasts with the individualistic view of autonomy often found in bioethical literature and which is advanced in that literature as the goal of adolescent development. We recognize that even the authors of principlist bioethics now consider the need for a more relational concept of autonomy (19). However, just as the incorporation of evidenced-based research lags well behind the appearance of such research, so too, do frameworks which bring bioethical thinking into practise. It is to such frameworks in the form of institutional and professional guidance that our comments are addressed.

Against this backdrop we offer a summary of empirical findings regarding CYP's views of what constitutes involvement and participation in making decisions about their care and treatment. Crosscutting and reflected in these findings is that, for CYP, involvement and participation in decision-making is not so much about being the final arbiter or decision maker or having the final say, but rather about having their views heard, occupying the role they prefer, and being given the information they want in the way they wish to receive it.

Information preferences

Children desire and value receiving information (28). The amount of information they desire is variable (14). Children, like adults, may want a minimum amount of information or they may come to consultations with notebooks full of internet research (14). This variability exists not just between different children but within the same child at different times and may be affected by where the CYP is in the disease trajectory and by their physical condition (14, 15).

Children also have varying preferences about the type of information they wish to receive. It has been reported, for example, that some children prefer information about the immediate effects of the disease and treatment on their daily lives rather than information about long-term issues such as fertility and overall prognosis (29).

Children have varying preferences about the ways in which they receive information. They may receive it directly, that is as participants in consultations or from their parents, who were present in consultations at which they were not present. Older children are more likely to prefer to attend consultations.

Parents figure into CYPs acquisition and processing of information in a number of ways. Coyne et al. reports that children can want parents to be information filters, both because of their own reluctance to participate in

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questioning and to protect themselves from the content of the news (14). Adolescents also describe 'shared learning' whereby parents help them to understand medical information and care plans. Weaver reports that:

Adolescents described the importance of their parents proactively accessing additional information from the medical team on their behalf via e-mail or telephone calls if a need for clarity arose ... Parental knowledge translated into the adolescent's sense of security in parental insight, which translated into adolescent decisional confidence (30, p. 4421).

CYP who attend consultations together with parents still rely upon parents to be their 'communication brokers' (14). *'Children trusted their parents to share information, and valued their parents' role as interpreters of information, advocates, and communication buffers'* (15, p. 151).

Parents and the filtering of information

In some studies, it was found that parents expressed a desire to control the type of information given to their children. Coyne found a direct relation between the age of the child and parents' desire to filter the information their child received (14). Parents of older children (11, 12, 13, 14, 15, 16) were more comfortable with sharing important information. On the one hand parents endorsed giving information but also wanted to delay or gradually feed it, or only present it when the child really needs to know (14). *'Parents spoke about trying to find a balance with sharing information while also protecting their child from frightening events or procedures that may not happen. They reported interpreting and timing the information sensitively to protect their child's emotional wellbeing'* (14, p. 149). One parent described it as *'enough to answer his question but not so much as to upset him'* (14, p. 149).

Coyne's description of parents and filtering reflects the conflict built into the parental role. Parents are concerned with how information might be presented and want to ensure that it is done in a kind and sensitive manner. Parents assert their expertise in making these judgments, in knowing their children better than others. They need to continue to believe that they are fulfilling their role as 'good parents'.

CYP preferences for their role

Research on CYPs preferred role often distinguishes major from minor decisions. Coyne et al found that CYP preferred a lesser or background role in major decisions such as whether to treat and which treatment overall (28). They did make decisions about how or when treatments took place. Weaver et al reported that adolescents largely preferred shared decision-making roles (30). Their preferred level of involvement was situational.

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When dealing with CYP one cannot make assumptions in a new situation based upon prior assessment of preferences. Several studies emphasize that CYP preferences often change from one situation to the next depending upon factors such as the nature of the decision at hand—major or minor—and the child's illness status (14, 15, 30, 31).

Assessing CYP preferences

It has been reported for adults that direct questions are not always helpful in engaging patients in decision-making (32). Coyne et al. report a similar finding that clinicians relied upon non-verbal cues to assess child's response to information being presented as did Gibson et al. (14, 33). Well-established relationships and good rapport with clinicians are therefore important.

The context of CYP decision-making

Several studies emphasized that decision-making for CYP took place within a relational context. Weaver et al. found that adolescents' decisional roles were embedded into a context of family support and that *'interviews revealed the adolescents' overriding perspective of decisional involvement as an interactive process'* (30, p. 4423).

Similarly, Kelly et al. found that *'Children's preferences assumed the presence and involvement of their parents and doctors'* (15, p. 1). Adolescents generally exhibited trust of and reliance upon others (parents and clinicians).

The impact of the experience

'Adolescents recognize relationships and decisional impact on others as a primary determinant in decision making' (30, p. 4424). This is consistent with a study by Hinds et al. which also found the importance of relationships to adolescents' preferences (34). The authors took this finding as demonstrating that adolescents' choices exhibited maturity rather than dependence. Disease experiences had brought about a more adult perspective than much developmental theory would predict. Findings such as these are important because developmental models are often used or assumed in ethics literature and often in research studies. Recent research in the actual context of illness suggests that because of the unique experiences of seriously ill children their behaviour does not necessarily accord with developmental theories. Patterns which developmental theory identifies as reflecting childlike dependence and submission may be precisely the reverse in the context of serious illness. Adolescents, in exhibiting situational and varied preferences, in preferring shared decision-making and the involvement of others in the process show the behaviours which have been found in adults making decisions.

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Are CYP experiencing suboptimal participation?

It is important to decide whether these empirical findings reflect something normal and positive or something suboptimal. Several authors suggest that an appropriate model for assessing CYPs participation in decision-making is needed. Ruhe et al. write that:

At times patients may prefer to step back in participation and defer responsibility. Such desired non-involvement must be interpreted correctly. A flexible model that avoids a hierarchical perception of different forms of participation may be best suited to represent children's involvement in discussions and decision-making in pediatric oncology (31, p. 1041).

The preferred involvement varied from child to child and within the same child over time (31). Thus, participation is a shifting, non-linear experience. This conceptualization avoids the view that, in changing their mode of involvement, children 'climb down' in their participation.

Kelly et al. call for a more complex position than assuming that increasing information and decision-making authority should be given CYP as they grow older and attain competence.

Our findings suggest that child and adolescent views of their treatment decision-making are more nuanced than this; children should also have a right to choose not to know or not to be engaged at a given time. ... Instead of advocating for their role in treatment decisions, our participants discussed variation in wanting or not wanting information and being part of or not being part of their treatment discussions. These children and adolescents appeared to be more concerned with greater or lesser access to information not treatment choice (15, p. 7).

Clinicians need empirically justified models of involvement and participation for CYP. Models drawn from bioethics and from law lead us to see decision-making as the act of an individual rather than as something in which a number of people can participate in different ways. Both current thinking on shared decision-making and the empirical studies we have just reviewed point in a different direction.

The preferences of CYP mirror those of adults as reported in research. Adults often wish to defer the lead in decision-making to another individual or to make shared decisions in which others participate equally (35).

These ideas challenge an *a priori* notion that power, or the ability to make a decision, is a zero-sum game in which when one participant gains the others must lose. As researchers point out, their findings call out for new models which do not identify all CYP preferences and patterns of behaviour as being either steps up or steps down. What is needed is a conception of maturity not as isolated independence but as being oneself

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in the midst of and alongside other individuals. Adolescents need to achieve this to become functional and successful adults, in work and life.

Clinically, we need to understand how decision-making with CYP can be and should be a genuinely triadic process, and that this can be accomplished without compromising ethical principles. Trying to manage the process of decision-making with young people as alternately dealing with a savvy adolescent and then with deeply involved and concerned parents may lead to frustration for all parties. Empirical studies suggest that adolescents can manage, not only decision-making but also doing so, in an interactive, triadic context.

All of the studies discussed have been carried out in cancer populations. While this is understandable the need for similar explorations with other PPC populations remains. Children with neurological and cognitive impairment present their own challenges. But, we have learned that involvement for children begins with the sharing of information. That is possible over a wide range of ages and capacities. We have also learned that involvement in decision-making does not equate to taking charge, thus widening the scope of what constitutes meaningful participation.

Clinical implications



We have presented decision-making as a process not just within a person's mind but between two and more people. In dealing with serious illness, parents and children have entered a totally new, foreign, and complex world. They must do more than understand this new world. They must form opinions, express preferences, and establish goals. They require the clinician's help to understand, giving information and explanations.

Both clinicians and parents have not just tasks but responsibilities as well. They are both accountable for what they do in a way that people who make decisions for themselves are not. They are aware that their decisions and actions can be scrutinized in light of accepted standards and social norms. They both strive to be competent, as a parent or as a clinician, caring for the child, advocating for their needs, and protecting them from harm. Disagreements are more likely to be resolved constructively if parents' belief that they are fulfilling their role as 'good parents' is not undermined.

Unfortunately, there are times, especially when difficult decisions are at stake, when disagreements arise between parents, clinicians, and the children. Once profound disagreements occur views can become entrenched and resolution difficult and painful. We offer some suggestions of approaches that may help to avoid these situations.

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Trust

Parents and children come to physicians with a problem, which needs to be addressed. They are seeking not just information, but especially treatment, and hopefully to be rid of the problem. The majority of people still come to clinicians with an attitude of respect, socially imbued. They regard, or hope to regard them, not merely as providers of accurate information and care but also as trustworthy. Establishing a relationship based on rapport and trust between the family and clinicians is fundamental to palliative care. It is a cornerstone in the ability to work together throughout the course of the illness, resolving difficult decisions, so as to provide optimal care for the child.

Complexity of information

Formulations and explanations need to be tailored to the situation and to the person for whom they are intended. Clinicians will benefit from getting to know each family and their values and goals, so as to discover what to present and how, for them as individuals. Information may need to be repeated, rephrased, and reformulated in different ways during this process. When patient or parents are struggling to formulate a goal, the clinician may need to probe and perhaps challenge in order to help them reach some clarity.

Establishing a reference point

Clinicians and parents may have different understanding of the situation and so clarifying their views and establishing a shared point of reference is important. But also keep in mind that clinician's and parents' understanding of the child's condition do not always change in step. New symptoms and new clinical investigations can lead to a reassessment of the decision problem. Clinicians need to bring parents along with them carefully. This is especially important when the clinician is relying upon indicators, which are not yet obvious to the parent, because, for example, the child's behaviour and outward appearance have not changed (36).

Reframing loss to gain

In some situations, a parent can be helped by reframing their identification of a choice as a loss. One strategy is to move away from overall labels and instead look concretely at the consequences of a choice and in detail, following the consequences out over time. For example, on the positive side discuss in detail what can be accomplished with the child who is not spending time being treated. Usually that means being out of hospital and at home. Focus on the opportunity and benefits of being with other family members, siblings, and friends. This can offer the chance to 'renew' their relationship with those who care about the ill child. It can be a time for a well sibling to express their concern and affection, which they may not have felt able to do in the past. Family and sibling relations

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are just one example of the specific dimensions in which positive consequences of a choice can be thought through.

Fine-grained, detailed description helps the parent to envision what the choice they are making truly amounts to. This detail replaces broad labels which paint choices as a loss and reframes them in a different way. In discussions of possible outcomes, it is helpful if they are concrete and sufficiently detailed so that the families can envision what their and their child's life and the family's life might be like as the result of a choice. Simplistic and dichotomous labels should be avoided. Discussions of outcomes should pursue consequences over an appropriate distance into the future rather than focusing on the immediate or short-term results of a choice (37).

Conflicting goals

Dual or blended goals are rooted in the dual parental role (23, 38); the palliative care clinician's task is to help parents balance these, not to extinguish one side of this dualism. At the end of life maintaining dual goals can mean affirming the parents' desire to keep hope and search for new treatments even when it is agreed that there is no appropriate disease directed therapy currently available. This helps parents to maintain a trusting relation with the PPC clinician. In turn, it makes it more likely that parents will rely upon clinician's evaluation of appropriate therapy at this point.

Filtering information to the child

Parents sometimes want to filter the information clinicians want to give to their child. This can occur about a wide range of topics, including the prognosis itself. Such requests can be troubling for clinicians.

Clinicians may feel it is important to disclose information because of a belief that respect for autonomy requires full sharing of important information. From this point of view CYP are seen as developing autonomy and are thus owed a full account of their illness. A more pragmatic reason would be that if a young person discovered for him or herself what was being withheld and in so doing discovered the clinician's and parents' lack of openness this could be damaging to trust and their relationships.

From a practical, palliative care point of view respect for the family system should be an important consideration when thinking about overriding strong requests from parents. The family is typically a source of support in all forms for the child. The principles of PPC also support consideration for the family in its own right.

Coyne et al. make a salient observation. They write that it isn't clear that parents' information management affected outcomes negatively. Further, *'health care professional's desire to create an open awareness context [sharing all information] for all families could result in situations where*

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information needs are misjudged with consequent emotional repercussions and potential loss of trust' (14, p. 153).

We take the view that issues about disclosure should not be to tell or not to tell, but look to enhancing communication and, like the entire process, this should be contextualized. Clinicians and parents should focus on what to tell, who should do the telling and when to tell (39).

In summary



Helping families make decisions throughout the trajectory of their child's illness is a vital part of a clinician's role. A spirit of rapport and trust between the clinician and family is the foundation for working together on behalf of the child. Clinicians can help families make decisions by providing information effectively and working alongside the family and child to specifically define the problems they are facing; eliciting their preferences, goals, and values. The clinician, parent and patient all bring their own values and experience to the decision-making process. Each has a perception of their own role and a desire to fulfil what they understand as their responsibility and duty. Through being aware of and acknowledging the importance of each other's roles, and of not undermining them, even when decisions are complex and difficult a mutually agreed approach, in the best interest of the child, can be sought and found.

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