Back Off, Forge Ahead, or Play the Long Game: The Ethics of Working With Adolescents Who “Aren’t Ready”

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Pediatric psychologists often receive referrals to work with adolescent patients who are not necessarily interested in changing their behavior (e.g., adhering to medication). In these situations, psychologists make decisions about their clinical course of action. Although often not made explicit, these decisions involve important ethical implications. This article presents an example of an ethical decision-making framework and highlights the relevant factors when working with youth who are not interested in changing the behavior for which they have been referred. This article also considers the implications of various courses of action including residual distress for relevant stakeholders. We provide recommendations for making decision-making processes explicit and identify factors that may affect decision-making.

Keywords: ethics, behavior change

Dr. Smith gets a referral from a rheumatologist for Jane, a 16-year-old girl with chronic arthritis who has not been taking her medication. She has recently developed uveitis, an inflammation in the eye; treatment is essential to prevent a possibly irreversible impact on her vision. Jane does not see skipping her medication as a problem even though she verbalizes understanding that the consequences are potentially significant. Before the referral, Jane had multiple visits with health care providers who, along with Jane’s parents, have worked hard to get her to take her medication. They have educated her, lectured her, suggested she set alarms on her phone, and even tried to scare her about the consequences of nonadherence. In the first visit with the psychologist, Jane is sullen and reports that she is only there because her mother made her come. Dr. Smith is skilled in rapport building and uses practices that are consistent with motivational communication, but Jane answers all questions with “I don’t know” and repeatedly asks if she can leave. When asked if she is willing to talk about her health or taking her medication, Jane says “no.”

Although simplified in presentation, cases like Jane’s are familiar for many pediatric psychologists. Nonadherence has been estimated to be approximately 50% within pediatric populations (Rapoff, 2010) and is a challenge across diseases and conditions. Given the role that accurately following prescribed medical interventions can play in the management of disease, nonadherence has been associated with symptom progression, comorbid disease, and mortality (Chisholm-Burns & Spivey, 2012). Nonadherence also has significant implications on health care utilization and society, with an esti-
mated burden of hundreds of billions of dollars per year in the U.S. (DiMatteo, 2004).

The essence of referrals like Jane’s is often “please get patient to do X.” Success in helping patients engage in healthier behavior is common in pediatric psychologists’ work, but most of us have been in the position of assessing a youth who is clearly not “ready” for change or interested in adhering to treatment recommendations. In cases like Jane’s, youth understand the reasons to change and have the knowledge, skills, and social support to do so, but still choose not to engage in healthy behavior. When this choice increases the risks of negative health outcomes, health care providers and parents are often understandably distressed.

There has been little discussion of the ethics of patient readiness in the pediatric psychology literature, despite some discussion in related areas (e.g., eating disorders; see Matusek & Wright, 2010 for an excellent review). In this article we will outline the ethical issues involved in working with youth who are not ready for change and describe ethical considerations in potential clinical courses of action. We use the IDEA: Ethical Decision-Making Framework (Trillium Health Centre, 2010; Figure 1) to illustrate the process of working through this scenario. The IDEA framework is particularly useful because its graphic format makes it accessible for health care providers, clients and families. Part of the benefit of being able to articulate the process of ethical reasoning is that it helps to foster collaboration among stakeholders and demonstrates the way in which various risks and benefits are weighed in the process of generating a treatment recommendation.

We have chosen the IDEA framework for illustrative purposes, recognizing that most organizations have some form of ethics framework and would encourage clinicians to use whichever is most familiar to them. We will use the principles in the Canadian Psychological Association Code of Ethics (CPA, 2000), as relevant within this framework, but again there are other similar sources of principles and values from which we anticipate clinicians will draw (American Psychological Association, 2010). These sources may include organizational mission, vision, and values statements, professional codes of ethics, and individual ethical commitments.

We assume that much of what we describe here is a process that clinicians already implicitly use when providing care. The many “small” decisions that clinicians make every day nonetheless have ethical importance. Truog et al. (2015) term this decision-making “microethics” and define it as “the ethics of everyday clinical practice,” characterized by “the view from inside . . . unique to each situation.” (p. 2). Our goal in this article is to make the process of ethical reasoning in these commonplace situations more explicit, thereby facilitating collaboration and communication among stakeholders. While the important role that context plays means that the particular decision we put forth here may not be extrapolated to other cases, we believe the process of thinking through it can be extrapolated.

IDEA: Ethical Decision-Making Framework

The first part of any ethical decision-making process involves framing the ethical question. In health care, the overarching goal that guides both clinical practice and ethical considerations is to provide the best approach to care (while recognizing that there are a host of factors that affect what is “best” and “possible”). In the abstract, best care seeks to ensure optimal health outcomes while also meeting ethical ideals. The challenge, both clinically and ethically, is to determine what constitutes the best care in any actual case. With respects to our case, the ethical question faced by Dr. Smith is how to best provide care for Jane in both the short- and long-term.

Step 1: Identify the Facts

Using the IDEA framework to answer how to best provide care, the first step involves identifying the relevant facts. In this case, that includes information about Jane’s clinical history, the reason for the referral, the health outcomes associated

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1 Principles and values often serve similar functions in ethical decision-making, but their scopes differ. A value, broadly defined, is something that is important; while principles are more concrete and offer some degree of guidance for how to enact values.

2 Given the limited scope of this article, it is impossible to address all of the relevant facts in Jane’s case. Certainly there are unique clinical and ethical considerations that would be relevant in actual practice.
with continued nonadherence, the evidence regarding likely efficacy of various approaches, the perspectives of various stakeholders, and any relevant legislation or policies. For example, before meeting Jane, Dr. Smith consults with the referring rheumatologist to confirm that Jane has consented to this referral and to learn more about Jane’s treatment history and the medical indications for the recommended treatment plan. Dr. Smith specifically asks about the potential benefits and side effects of the new medication and the time course of impacts on Jane’s vision. The rheumatologist informs Dr. Smith that there is some uncertainty about the time course for risks; some individuals develop relevant complications with cataracts or increased intraocular pressure within a couple of months, and others with ostensibly the same type of problems tolerate poor inflammation control for a year or more.

Dr. Smith also considers the evidence regarding psychological treatment options to address readiness and nonadherence including motiva-
tional interviewing ([MI] for example, Gayes & Steele, 2014), acceptance and commitment therapy ([ACT] for example, Hadlandsmyth, White, Nesin, & Greco, 2013), and family based interventions (e.g., Duncan et al., 2013; Wysocki et al., 2006). Dr. Smith also considers the broader literature on learning principles (e.g., Antonucci & Hayes, 2008), self-efficacy (Stupiansky, Hanna, Slaven, Weaver, & Fortenberry, 2013; Zebracki & Drotar, 2004), and patient–provider interactions (e.g., Croom et al., 2011).

Dr. Smith also takes into account the perspectives of the stakeholders involved, primarily Jane, her parents, and the rheumatologist (see Figure 2). Although Jane cares about being healthy and does not want her vision to be impacted, she has tried several medications in the past that did not work and caused significant side effects. Jane also feels well most of the time, and does not like being made to think of herself as a “sick person.” After repeatedly being told that she needs to take her medication, Jane feels invalidated, disrespected, and patronized by her parents and health care professionals. Jane is taking steps to be more autonomous in other areas of her life and feels she should be in charge of her health care as well. Her “resistance” to medication is possibly tied to her need for autonomy and in that respect, is consistent for her developmental stage. Indeed, as an adolescent, Jane is developmentally primed to seek autonomy and potentially be less sensitive to long-term consequences (Beyers, Goossens, Vansant, & Moors, 2003). With regards to consent for treatment, Dr. Smith also considers relevant legislation. In Dr. Smith’s jurisdiction, there is no explicit age of consent, but instead priority given to respect for dignity.

The principle of respecting the dignity of persons includes respect for autonomy, which is reflected in such practices as informed consent. In Jane’s case, she is aware of the consequences of her behavior and is at a developmental level such that she is able to understand and appreciate the potential benefits and risks of not taking her medication. In this way, she has demonstrated her ability to provide (or withhold) informed consent. The principle of freedom of consent is important here; steps should be taken to avoid Jane being coerced into consenting to take her medication (as is tempting given stakeholders’ urge to protect Jane’s health).

The principle of responsible caring is also central to this tension. Everyone involved, including Dr. Smith, is committed to promoting Jane’s welfare by adhering to the practice of maximizing benefit and minimizing harm. Most obviously, there is the benefit that Jane could receive by taking her medication (e.g., better disease control) and the harm she could suffer by not taking it (e.g., potential visual impairment). The weight of these risks and benefits may also change with time; the stakes get higher as Jane continues to refuse her medication and the chances of visual impairment increase (especially once a few months pass). There are also potential benefits and harms to the patient–health care provider relationship that need to be considered. Jane has a history of feeling disrespected by health care providers and there is the real potential of further damaging her trust. Lack of trust may lead Jane to be less forthcoming in later visits and may increase the likelihood that she refuses potentially beneficial treatments in the future or even stops attending appointments (Polinski et al., 2014).

The need to demonstrate professional integrity in relationships is also pertinent to this case. The rheumatologist or Jane’s parents may be worried if Dr. Smith is not addressing adherence in her work with Jane, and the practice of open and straightforward communication about decision-making is important. The use of an explicit ethics framework is one way to do this, in that it provides an opportunity to illustrate the process of determining how to respond to the central question of how best to provide care for
Jane. It is important that the rationale for Dr. Smith’s course of action is communicated to Jane and all others involved.

Finally, the CPA code directs us to consider the responsibility to society. For example, Dr. Smith’s actions may affect the trust that Jane, her parents, and the rheumatologist have in the profession of psychology. In Jane’s case, resource allocation may also be relevant. Given that Dr. Smith’s time and capacity to see pa-
tients is limited, allocating significant resources to a patient who is not likely to benefit in the immediate future may prevent other patients, who might be ready to engage, from accessing services. That said, as previously mentioned, nonadherence produces a significant financial burden and a potential societal cost (DiMatteo, 2004).

Step 3: Explore the Options

The third step in the framework is identifying various options. The framework prompts us to seek the most ethically justifiable options, considering such things as harms and benefits, laws and policies, and mission, vision, and values. In the following discussion we explore the options by describing their alignment with the principles identified in Step 2 and noting the facts, evidence, and contextual features from Step 1 that might affect the viability or feasibility of these options. This exploration helps us balance the relative harms and benefits and strengths and limitations of each option. In actual practice, we would also need to consider relevant guidance from laws and policies as well as the mission, vision, and values of a particular organization. It is likely that, in this step, there will be more than one option that is ethically justified, and the challenge is in determining which of these options is preferable and in articulating the reasons why. In seeking the best option in terms of ethical justifiability, we aim to incorporate important ethical commitments that are reflected in different ethical principles. In this case, the preferred option is the one that attempts to balance the two key principles of respect for the dignity of persons and responsible. The options presented differ primarily in terms of how these first two principles are emphasized; in all of the options there is consideration of professional integrity in relationship as well as responsibility to society but given the lesser weight of these principles in the CPA Code of Ethics they have less influence in determining the preferred option.

The remainder of this article will focus on this process, as most frameworks come to this point and indicate that a decision needs to be made but do not provide detail about the grounds for making the decision. Although there are many options for Dr. Smith, we outline here three prototypical scenarios to illustrate how prioritizing different principles may lead to different courses of action. These scenarios are admittedly simplified, but are intended to provide an illustration of how an ethics framework can be applied to a case.

Option 1: Prioritizing Responsible Caring

In this option, Dr. Smith prioritizes the principle of responsible caring (potential benefits of medication) over respect for the dignity of persons. Dr. Smith feels that decision-making capacities, particularly considering long-term consequences, in adolescents are not as fully formed as in adults, and so the imperative to respect individual autonomy carries less weight. In Jane’s case, Dr. Smith sees that although Jane cognitively understands that there are risks to nonadherence, she is placing far greater emphasis on the short-term consequences of the medication (e.g., potential side effects). Under this option, Dr. Smith may work with Jane and her parents to develop a behavior modification plan to increase the likelihood that Jane takes her medication. This could include her parents being more involved in medication administration (Duncan et al., 2013) or developing a reinforcement system in which Jane earns privileges for adherence or has consequences for nonadherence (Rapoff, Purviance, & Lindsley, 2005). If Jane is unwilling to participate in sessions, Dr. Smith could work directly with Jane’s parents to develop these plans. In terms of risks, Dr. Smith is aware that Jane has little intrinsic motivation to take her medications (Deci, Koestner, & Ryan, 1999), and may resent the fact that she feels forced to do something that she does not want to do. Implementing a behavior modification plan may negatively impact her relationship with her parents and her health care providers, and may undermine Jane’s self-efficacy for making her own health care decisions. There is also risk of harming the patient–provider relationship between Jane and Dr. Smith because Dr. Smith becomes another health care provider “forcing” Jane to do something she does not want to do. Implementing a behavior modification plan may negatively impact her relationship with her parents and her health care providers, and may undermine Jane’s self-efficacy for making her own health care decisions. There is also risk of harming the patient–provider relationship between Jane and Dr. Smith because Dr. Smith becomes another health care provider “forcing” Jane to do something she does not want to do. This risk has direct implications for the principle of integrity in relationships. It is also possible that Jane may continue to refuse her medications, no matter what rewards and consequences are put in place, and that a behavior modification plan may not be effective. Each time a recommendation does not result in long-
term change, there is a risk of decreased self-efficacy and increased learned helplessness (for parents, psychologist, and patient) and increased likelihood that, when introduced to a similar strategy in the future, patient/parent will respond with “we have tried that and it didn’t work.” Nevertheless, Dr. Smith feels that the potential benefits of medication adherence outweigh these considerations.

**Option 2: Prioritizing Respect for Dignity of Persons**

This option prioritizes the principles of respect for dignity of persons (by respecting Jane’s wishes) over the principles of responsible caring (at least with regards to the long-term benefits of medication administration). In this case, Dr. Smith presents what services she could provide (e.g., motivational interviewing, guidance in developing an adherence plan), but if Jane still indicates she is not interested or is not willing to provide consent for treatment, Dr. Smith discontinues the session and asks Jane to contact her when she is interested in these strategies. In this scenario, Dr. Smith may still consult with the rheumatologist and provide recommendations for supporting behavior change in this context. This option also considers responsibility to society (by using resources efficiently and for their intended purpose), but does not directly address Jane’s medication use, and thus reduces the potential benefits that Jane could experience if she was taking her medication. Further, if not communicated adequately, this option may result in Jane’s parents and the referral source feeling abandoned by Dr. Smith and may reduce trust in psychology by these stakeholders, which is relevant to the principle of integrity in relationships. Dr. Smith, however, has a strong commitment to fostering autonomy and allowing adolescents to have a voice in their own health care decisions.

**Option 3: Balancing Respect for Dignity and Responsible Caring**

In this option, Dr. Smith attempts to balance respect for dignity of persons and responsible caring. Dr. Smith explicitly removes the expectation of medication use in her work with Jane and offers to work on other areas that Jane identifies as priorities. Shifting focus is an important part of this plan of action given Jane’s explicit refusal to discuss her medications. This option may include evidence-based interventions to address Jane’s general coping with her illness or other identified goals including cognitive–behavioral and acceptance-based approaches (Palermo, Eccleston, Lewandowski, Williams, & Morely, 2010; Powers, Jones, & Jones, 2005). This option considers the facts that Jane has a history of negative interactions with health care providers, and provides an opportunity for Jane to develop self-efficacy and behavioral momentum in an area that is important to her. In some cases, work on Jane’s goals may ultimately lay the groundwork for addressing barriers to medication adherence. For example, if Jane identified generalized anxiety as a treatment goal, and learned cognitive–behavioral strategies to manage anxiety, she may later be able to apply these skills to worries about medication side effects. In this option, Dr. Smith can also reassess Jane’s readiness to take her medication and consider motivational interviewing directed toward adherence in the context of their stronger working relationship. In terms of drawbacks, the rheumatologist and Jane’s parents may perceive that Dr. Smith is not addressing the referral issue, especially if Jane does not begin to take her medication after several meetings. In addition, if Jane is willing to work on other goals, meeting regularly means reduced access to services for other patients waiting to be seen by Dr. Smith. Regardless of Dr. Smith’s attempts, it is still possible that Jane chooses not to work on other goals and discontinues treatment altogether. If this was the case, this scenario would look much like Option 2 where Jane is welcomed to come back when she is ready.

**Step 4: Act**

We believe that the third scenario reflects the most appropriate answer to how to best provide care for Jane considering both long- and short-term outcomes, evidence-based treatments, and Dr. Smith’s professional and personal ethical commitments.

Regarding the likelihood that Jane will take her medication, this is possible, but not certain, under Option 1 (behavior modification), less likely under Option 2 (no treatment), and possible in the longer-term, but unlikely in
the short-term under Option 3 (working on Jane’s goals). If, regardless of the option chosen, Jane still refuses to take her medication, Option 3 is the only option that may result in other benefits that can be realized (i.e., meeting Jane’s other treatment goals). So while the outcome in all three options might fall short of the ideal, the best possible outcome from both clinical and ethical perspectives seems most likely in Option 3.

There are a few key issues for Dr. Smith to consider when acting. First, it is important that Dr. Smith works collaboratively with all stakeholders in this decision-making process. If she does not involve everyone in her decision-making and make this process explicit, Jane, her parents, or the rheumatologist may feel that the decision is arbitrary. By using the IDEA framework in a collaborative way, Dr. Smith may be able to facilitate a shared agreement on the treatment course and allay some of the distress associated with the situation. This also addresses Dr. Smith’s commitment to maintaining professional integrity in relationships no matter which option is selected.

That said, collaborating and choosing Option 3 does not eliminate all ethical concerns; there is a real risk of harm from Jane not taking her medication, especially if this course does not change over a few months. Stakeholders may understand that backing away from adherence is the “best” option for right now, but they will likely (and understandably) still worry about the potential for negative consequences and may experience their own distress. Indeed, in the absence of an immediate action plan from Dr. Smith, Jane’s parents and rheumatologist may increase their efforts to convince her to take her medication, which may have the unintended consequence of Jane being even more steadfast in her refusal. It is often difficult to accept that adolescents are sometimes allowed to make “bad” choices, especially for parents. Dr. Smith may need to help Jane’s parents and the rheumatologist cope with their distress around this case, especially if this distress affects their relationships with Jane. Continuing to reinforce the decision-making process may reduce some of this distress, but those involved may still need additional emotional support to manage this situation.

Dr. Smith also needs to be particularly aware of her own reaction to this situation. Working with Jane on other goals is not meant as a way to “trick” Jane into taking her medications, but must genuinely support Jane in building a generalized skill set to manage her life and her health (including potentially, but not necessarily, taking medication). Dr. Smith must remain nonjudgemental to do this work effectively and thus must keep her own distress from affecting her behavior (i.e., by being inauthentic or inadvertently pushing for adherence). If Dr. Smith continues to have difficulty managing her distress, she may also be at higher risk of burnout and other negative consequences (Di Benedetto & Swadling, 2014). Self-reflection, mindfulness, or acceptance-based strategies may be helpful for Dr. Smith in this situation, and she may consider seeking out consultation or supervision if she finds that her distress is affecting her behavior (Brinkborg, Michanek, Hesser, & Berglund, 2011; Goodman & Schorling, 2012).

The final part of acting in the IDEA framework is to continually evaluate and reflect upon the decision once action has been taken. This process recognizes that ethical decision-making is iterative, and the outcome of this situation will influence future decision-making for all involved. Part of this reflection and evaluation will include Jane’s health outcomes, outcomes on relationships among Jane, Dr. Smith, Jane’s parents and the rheumatologist, and any residual distress in this situation.

### Differences That Make a Difference

Our choice of action may have been different had certain characteristics of the situation been different (i.e., different “facts” in Step 1) such that they altered the likelihood of various outcomes and/or the balance between the four ethical principles. For example, if Jane were 6-years-old rather than 16, and less developmentally able to appreciate the consequences of her behavior, we may favor the first option (behavior modification) in the interest of providing immediate benefit. This choice would also be in keeping with the ethical obligation of parents and others to act in children’s best interests (Harrison, 2004). Similarly, if the immediate consequences of Jane’s nonadherence were more severe and imminent (i.e., if cataracts had been identified), we may also lean toward the first option. If Jane’s life were in imminent danger, we may be willing to risk...
harm to our relationship and ignore Jane’s wishes in order to get short-term, life-saving benefit from treatment. At the most extreme end of this option (although not likely in Jane’s case), if Jane’s parents were unable to follow through on a behavior plan to increase adherence, we may choose to impose behavior change in a structured environment (e.g., inpatient admission) or consult with the medical team about the potential reporting of medical neglect. Although controversial, there are recent cases of child protection becoming involved in extreme cases in which parents have not been successful in changing their own or their child’s behavior (e.g., obesity; Murtagh & Ludwig, 2011).

On the other hand, if Jane has a long history of very negative interactions with health care providers and does not provide consent to working with Dr. Smith at all, we may lean toward our second option (i.e., “come back when you are ready”). In this case, we would prioritize demonstrating to Jane that health care providers respect her autonomy and recognize that she can make choices in her care. This reflects an obligation to both foster and respect the developing autonomy of youth as well as an assessment of the low likelihood of any benefit from continued engagement. This option may be particularly important if Jane’s condition requires working closely with health care providers over a prolonged period of time. In this situation, Dr. Smith could continue to support the rheumatologist in a consultant role without seeing Jane.

Lastly, Dr. Smith may also lean toward the second option if she is working within a system in which resources are extremely limited and there are other patients deemed to be at more imminent risk or significantly higher likelihood of benefit, relative to Jane.

Summary and Recommendations

Explicit ethical decision-making is often raised in extreme cases (e.g., refusal of life saving treatment), but we make implicit microethical decisions in clinical practice every day. Ethical choices carry weight; the right choice might not be the easy choice and making what we believe to be the “right decision” will not remove all of the burdens associated with making ethically significant decisions.

As is evident from this discussion, there are no easy answers when it comes to working with youth who are not interested in changing their behavior. Compared with younger children or adults, adolescents present with their own set of challenges. Adolescents differ along the developmental spectrum and vary in their appreciation of long-term consequences, but are generally more susceptible to short-term burdens of treatment than adults. We may lean toward protecting adolescents’ long-term health by pushing for behavior change, but must also respect adolescents’ burgeoning independence and decision-making capacity. Whereas we may place less emphasis on respecting autonomy when working with younger children, underestimating the importance of this principle with adolescents comes with real risks to patient-provider relationships and future care.

In this article, we reference the IDEA framework that can facilitate collaborative ethical decision-making among psychologists, families, and referral sources. Although pediatric psychologists may implicitly use a similar process in their clinical practice, we recommend using a framework such as this one to make decision-making explicit. This framework encourages the succinct outline of relevant contextual features, ethical principles, and options for action. We recommend involving all stakeholders in ethical decision-making processes in an attempt to reach an agreed upon decision. We also acknowledge that even the “best” option may not resolve all distress or ethical issues, and recommend that psychologists are aware of the potential of distress for all involved (including themselves).

Although the case presented here is simplified, our aim was to provide an example that pediatric psychologists can extrapolate to their own work. While this framework may be a novel structure, many of the elements (e.g., medical indications, patient preferences, evidence for psychological treatments, ethical principles) will already be part of pediatric psychologists’ routine practice and thus can be applied in a range of settings (e.g., outpatient treatment, consultation liaison). Additional contextual factors, varying evidence, or differences in medical indications may make cases more complex or lead to different conclusions (e.g., there may be specific barriers to adherence that could be ad-
dressed), but we believe this reasoning process still applies.

In sum, ethical decision-making is part of everyday practice for pediatric psychologists. Making decision-making processes explicit using a framework, such as the one presented here, allows for collaboration among psychologists, patients, their families, and referral sources. Regardless of how well justified, ethical decisions are often not easy and come with real life consequences. By following an explicit process, psychologists are more likely to identify and consider all relevant factors, resulting in the “best” course of action for all involved.

References


