Addressing the Ethical Challenges for Young Adults, from a Rights-Based Perspective

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Abstract

Healthcare professionals frequently encounter ethical situations in their daily practice while caring for and making decisions with patients and other family members. They may often experience moral uncertainty and dilemmas about the best or right approach to handle ethical concerns. Ethical conflict can sometimes occur particularly when there is a clash of values between individuals, concerning which of the possible options should be chosen: such conflict can be potentially harmful and adversely affect the dynamics within the caring team.

We sought to contribute to the narrative of real-world practice by drawing upon the experience of those delivering direct cancer care. We sought professional's views to present a contemporary perspective on the ethical challenges they encounter while caring for young people with cancer. The narrative that follows has been constructed around the central themes that professionals encounter, which we wove into relevant literature and some personal reflections. The themes include stopping or not stopping when treatment is futile; delaying or avoiding difficult conversations, about cancer, around poor prognosis or end-of-life care; caught between competing obligations between family- and young adult-centred care; patient choice, when faced with treatment options and place of care, access to clinical trials/research and fertility options or when refusing treatment; and tensions between a professional's personal moral compass, expectations attached to their role and conflict with team members.

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We argue here:

1. The need for models of care that are *person-centred* to promote positive and equitable engagement with patients, families and carers, empowering adolescents and young adults in making decisions and enabling them to actively influence their care.
2. The need for an *organisational culture* that has established processes and practices that facilitate and support team discussions about ethical issues and dilemmas that occur in everyday clinical care.
3. The need to create an effective *ethical climate*, where all perspectives are considered, shared decision-making is valued and open dialogue between team members is encouraged.

32.1   Introduction

There is no doubt that life trajectories and biographies are changed as a result of a cancer diagnosis [1, 2]. Stories of lives interrupted and disrupted are evidence of the impact felt, in both the short and long term: the impact being felt 'long after malignant cells have been controlled' [1, p. 279]. The literature suggests that a diagnosis of cancer results in a web of ongoing influences, arising from the disease, treatment and social and personal aftershocks. These influences require negotiation and renegotiation to accommodate the enforced change of personal identity, what some now refer to as 'biographical disruption' [1–4], but has also been referred to as the 'new normal' [5–7], and more recently 'negotiating the present and planning for the future' [8]. The energy and effort invested in creating this 'new normal' include continually visiting a history of a serious illness to make sense of current and possible health and psychosocial consequences and thereby accommodate cancer-related influences on a life course [8]. The 'disruptive force', that is, a cancer diagnosis [9, p. 3], can lead to a portion of a young adult's life 'lived in a state of suspension during treatment and recovery' while at the same time 'their lives were moving forward' [10, p. 383]. A consistent theme throughout the body of evidence about the experiences of young adults with cancer is the impact on daily life and the need to promote a sense of normalcy. Hinds [11] describes normalcy as adolescents looking to the future, of improved or recovered health and how they imagine being able to appear, do and feel like

healthy others. That the patient is first a normal young adult who happens to have a diagnosis of cancer should be the foundation of any model of care we choose to implement [12]: models where creating an environment of flexibility is an essential characteristic, which enables us to deliver developmentally appropriate care [13], irrespective of the place of care, where knowledge of the 'International Charter of Rights for Young People with Cancer' [14] is guiding the principles of care.

This Charter was launched in 2011. It makes explicit nine rights and calls on the international community, 'to recognize that access to quality cancer care is a right, not a privilege, and to improve the services and support that young people diagnosed with cancer receive, regardless of geographical location' [14 p. 49]. Human rights are enshrined in the national constitutions and legislation of most countries. A rights-based approach needs to be underpinned by a values base for practice. A values base must reflect what patients, families and carers are asking for, and according to the PANEL principles (Scottish Human Rights Commission http://www.scottishhumanrights.com/careaboutrights/whatisahumanrightsbasedapproach) [15], this should consist of the following:

- *P*articipation: where everyone has a right to participate in decisions about them.
- *A*ccountability: effective monitoring of human rights standards is in place.
- *N*on-discrimination and equality: where all forms of discrimination are prohibited, prevented and eliminated.

- *E*mpowerment: individuals know their rights.
- *L*egality of rights: the recognition that rights are enforceable.

In essence, when thinking about clinical care, it is about empowering young people to know and claim their rights and increasing the ability and accountability of individuals and institutions who are responsible for respecting, protecting and fulfilling rights. Models of care that promote positive and equitable engagement with patients, families and carers must be a central focus for our rights-based practice [16].

We want to particularly highlight 'right number 6' of the International Charter of Rights for Young People with Cancer, which states: young people have the right to *empowerment in making decisions* supported by full and *detailed explanation* of all treatment options and long-term effects of the disease enabling them to *actively influence their care* (http://www.canteen.org.nz/get-involved/international-charter-of-rights-for--young-people-with-cancer) [17]. It is our intention, to examine further the terms in italics as we advocate for a person-centred approach to all ethical considerations faced by healthcare professionals when working with adolescents and young adults (AYA). Person-centred care aims to ensure a person is an equal partner in their healthcare: the individual and the health system benefit because the individual experiences greater satisfaction with their care and the health system is more cost-effective (Royal College of Nursing [RCN] ttp://www.rcn.org.uk/development/practice/cpd_online_learning/dignity_in_health_care/person-centred_care) [16]. The principles of person-centred care include:

- Treating people as individuals
- Respecting their rights as a person
- Building mutual trust and understanding
- Developing therapeutic relationships

McCormack and McCance [18] describe care processes and prerequisites of person-centred care that leads to better outcomes. These include satisfaction with care, involvement with care, feelings of well-being and creating a therapeutic culture. We argue here, for person, not patient, centred care, informed by a rights-based approach to all aspects of ethical care.

In this chapter, we first describe what we mean by ethical challenges. Our focus will be to present some of the ethical challenges faced by colleagues in the real world of practice and some of the strategies used by them to deal with these. As professionals we are not short of guidance, policies and in many cases 'heavy tomes' that guide us in terms of the practical use of ethics in practice [19–22]. A considerable amount has been written on ethical issues and ethical challenges, and therefore, it is not our intention to duplicate any of those influential and seminal pieces here, more to offer examples that will assist reflection on the reader's own experience. We then conclude, by considering these challenges, and offer our own reflections on the 'right number 6' of the Charter and how a rights-based approach can help us to both avoid and assist when dealing with ethical challenges in the AYA field.

32.2 What Do We Mean by Ethical Challenges?

Healthcare professionals encounter ethical questions in their daily practice and often experience moral uncertainty and dilemmas that accompany critical ethical concerns. Ethical conflict occurs when there is a clash of values between individuals, or within an individual, concerning which of the possible options should be chosen: such conflict can be potentially harmful and have far-reaching consequences [23]. Conflict usually begins as moral disagreements about an issue, the perception of unfairness in dealing with an issue or an emotional response to that situation [24]. Moral disagreements are expected to occur in practice. We work in a complex area of clinical care, often one that is emotionally charged. But when these disagreements progress to ethical conflict, care can become more complicated, and tensions can become high. Ethical conflicts are increasing, for a number of very obvious reasons, including extended life spans, increased technology, the public's ever-increasing expectations of medical care, greater cultural and religious diversity, shifts in healthcare financing and limited resources: where

caring within this context impacts on many factors and can cause ethically challenging situations that can compromise relationships and disrupt teamwork. Vivian-Bryne and Hunt [25 p. 1] argue that 'no action is free of ethical relevance'. They advocate for healthcare professionals to adopt the idea that decision-making is a social meaning-making activity and takes place within context. So, constructing ethics with others can help to maintain relationships and maximise teamwork and reduce ethics-related stress and moral distress [23]. Avoiding raising concerns and avoiding conflict by accommodating differences are described as the least helpful strategies. Organisational structures that support a culture where interdependence and shared decision-making are valued, moral differences are addressed, dialogue is encouraged and all voices of the caring team 'blend in' provide the best environment in which ethical challenges can be addressed [23]. Being on 'the same page', with patients and families, where care goals and treatment goals and their consequences are communicated effectively and in a timely way, ensures patient preferences are considered, and quality of care is maximised. The ethical climate in which ethical challenges occur must not be overlooked [26].

32.3   Why Ask Experts to Tell Us About Their Ethical Concerns and Management Strategies?

Throughout this textbook authors who are experts in their field have drawn extensively on evidence and examples from clinical care to support their writings. Much of this applies to the content of this chapter too. To contribute to the narrative of real-world practice, we have chosen to draw on the experience of those delivering direct cancer care. We have sought professional views to present a contemporary perspective on the challenges that they face, revealing experiences that might best illuminate current ethical issues facing those working with AYA. Our approach was to contact experienced individuals in the field by email to ask if they were able to contribute to this chapter by sharing what they thought were the main ethical challenges they encounter in everyday practice.

32.3.1   Our Approach

We approached individuals who represented different disciplines including medicine, nursing and psychology from countries in Europe, America and Australia. We used personal contact, conference proceedings and published papers to identify individuals working in the field. We received comments back from 12 individuals, from a total of 25 requests sent. The professionals who responded to our request are acknowledged at the end of this chapter. These individuals responded to a list of questions that were based on a questionnaire used by Cecilia Bartholdson and colleagues [27] to explore ethical issues faced by healthcare professionals in children's cancer care in Sweden. We adapted the questions with the permission of Bartholdson and colleagues.

We asked six key questions:

1. Please briefly describe the ethical issues that arise most frequently in your work.
2. Please list here factors that have prevented you from doing what you believe is right/best in relation to ethical issues in clinical care/treatment of patients.
3. Please briefly describe the ethical issues, which, in your experience, lead to the most frequent conflicts with your co-workers.
4. Please mention how you deal with ethical issues that commonly occur in your unit.
5. Have you any suggestions about what you could do to deal with ethical issues?
6. Please briefly describe your experiences of teamwork in dealing with ethical issues in healthcare/treatment of patients.

32.4   What Are Some of the Challenges Professionals in Our Field Face?

The narrative that follows has been constructed around the central reoccurring themes from the returned emails, which we have then woven into relevant literature and some personal reflections. These themes can by no means account for all the ethical challenges healthcare professionals might face nor indeed all that our respondents shared;

they are a perspective on a point in time by a selected group of individuals. But what they serve to do is to highlight the complexity and varied nature of these challenges which when viewed through the lens of ethical principles, we can begin to see how we might use rules to inform our discussions and focus our debate, as well as gathering and understanding the perspectives of all those involved, in order to resolve an ethical challenge.

We have grouped the topics highlighted by colleagues and these include (1) stopping or not stopping when treatment is futile; (2) delaying or avoiding difficult conversations, about cancer, around poor prognosis or end-of-life care; (3) caught between competing obligations between family- and young adult-centred care; (4) patient choice, when faced with treatment options and place of care, access to clinical trials/research and fertility options or when refusing treatment; and (5) tensions between a professional's personal moral compass, expectations attached to their role and conflict with team members. Where relevant we have drawn on their direct words, presented in italics, to really reflect the issues they so willingly shared.

32.5 Stopping or Not Stopping When Treatment Is Futile

With advances in treatment, the expectation is that most AYAs will survive cancer, but this is not the case, and outcomes are not so positive particularly for AYAs as demonstrated by Bleyer's work [28]. The decision to stop treatment is a very difficult one, and often there are conflicting perspectives on how the process should be handled. Our respondents noted that with good survival figures, it has become more difficult to know when to cease active treatment. Indeed, on first entering the environment of healthcare thinking that cancer means death, often their expectations change to think that cure is and in fact is always possible. When it is not possible, *someone must have made a mistake somewhere*, leaving families searching for *new answers*. Frequently all options are considered, and ensur-

ing that *every stone is upturned* can lead to delays or lack of preparation for end-of-life care. Families expect a cure, and adapting to a change in this rule is very challenging for all involved, particularly if there was an expectation of cure from the outset.

Parents may exhort and pressurise healthcare professionals to continue all treatment even if the outcome is futile. This may lead to situations where professionals may continue exhausting all options, even though they may know that survival is unlikely and where quality of life could be affected significantly. Continuation of *pseudo curative treatment versus purely palliative approaches* presents its own challenges, *where clinician comfort, or lack of it, in offering palliative care early enough to allow the AYA and the family to prepare* is compromised. There are problems it would seem, with teams not stopping when treatment is futile, *because the parents are not yet on board*. A number of respondents mentioned differences between paediatric oncologists, haematologists and adult/AYA oncologists, where some are *better at pragmatism* than others. *Even when a clinician recognises that they went on treating for too long, it isn't always possible to say you would do something different next time*. A number of respondents mentioned how important it was that *a patient and their family need to feel that their wishes have been heard*.

The AYA may have strong feelings either way, but if not involved in the decision to stop or to continue with treatment, then their preferences are not heard and their right to participation not upheld, and they are disempowered. Making the decision to stop is a very difficult one for parents, AYA and professionals. Where there are disagreements, then conflict often ensues. Families may look to other countries, search the Internet, seek a second opinion and in general consult widely. Our respondents spoke of some of the challenges that result from this searching for hope, particularly where the AYA has been excluded from any discussion by their parents. Research indicates that open discussion in a supportive trusting environment coupled with information and recommendations can assist in decision-making about continuing care

[29, 30]. A dialogue that begins with the AYA and their family at diagnosis and continues, and where accurate perceptions of the prognosis is gained through such discussions in a trusting relationship, has been show to lead to less disagreements about continuing with cancer-directed treatment [31].

In cases where disagreements cannot be resolved, the Courts may be asked to intervene. In the UK the ability of AYA to refuse treatment before the age of 18 when it is held to be in their best interests is limited – in several cases the Courts have overridden an adolescent refusal of life-saving treatment. While a person aged 16 years and over is presumed to have capacity and their consent must be respected, the law regarding refusal of treatment between the age of 16 and 18 years is ambiguous. In some US states, the mature minor doctrine has permitted teenagers to refuse treatment and die (http://www.thehastingscenter.org/Bioethicsforum/Post.aspx?id=692) [32], but states, where this does not apply, such as in Connecticut situations like that of Cassandra C, who was 17 at the time of discussions, show how overruling the decision of an AYA to refuse treatment presents both ethical and emotional issues http://www.theguardian.com/society/2015/mar/09/teen-battled-cancer-chemo-treament-remission [33]. Cassandra C was clearly able to articulate her views and understood the consequences of her decision, 'Whether I live 17 years or 100 years should not be anyone's choice but mine', she wrote in http://touch.courant.com/#section/-1/article/p2p-82494220/ [34]. 'How long is a person actually supposed to live and why? Who determines that? I care about the quality of my life, not just the quantity'. The issue of competence and the challenges faced when an AYA refuses life-sustaining treatment can be explored further in Ian McEwan's [35] most recent novel, *The Children Act*, or readers can listen to episode 4, series 11, of Radio 4 'Inside the Ethics Committee' on iPlayer http://www.bbc.co.uk/programmes/b0643x61 (these are archived so they can be listened to at any time) [36]. The perspective of the AYA, irrespective of the legal decisional authority in respective countries, is important and supports the need for effective communication, partnership and relationship-based decision-making best described by Hinds et al. [37].

32.6 Delaying or Avoiding Difficult Conversations, About Cancer, Around Poor Prognosis or End-of Life Care

Collusion between parents and healthcare professionals and exclusion of the AYA in discussions at the time of diagnosis, then later when facing end-of-life care, were described by some of our respondents. Open communication with AYA although believed to be a good thing, and enshrined in policy, can still, it would seem, not be taken for granted. The word cancer evokes strong feelings and there remains, despite the best efforts of some healthcare professionals and some organisations, two dominant themes in society: that AYA do not get cancer and that if they do they will die. So it is not surprising that some families, whether for cultural or religious reasons or simply to protect their child, will go to enormous lengths and cause themselves more anxiety and stress by excluding them from any decision-making based on the knowledge that they have cancer. Our respondent's spoke of the challenges this then creates. When parents say that, *they know them best and they won't be able to cope*, healthcare professionals are faced with either further colluding with parents; speaking out and expressing their views and views of the team, based on their experience of what has worked in the past; or placing the AYA central, respecting their rights as an individual and talking direct to the AYA.

The implication of not knowing, as highlighted by many of our respondents, is that AYAs are prevented from being involved in decisions that affect them, and they may be absent from treatment-related/end-of-life care discussions. In the short term, difficulties arise for healthcare professionals in knowing how best to prepare AYA for the journey they are to embark upon. Tensions can arise between professionals and family members, as well as between team members [38]. In the long term, lack of knowledge of what has

happened to them may prevent them from making wise health choices in the future or from being part of decisions about *what happens next*. Receiving clear information and support from the clinical team have been described by AYA as facilitating involvement in decision-making [37].

Mutual pretence and concealing information from AYA are now thought to be unhelpful. There is general agreement that the sharing of cancer-related information leads to improved knowledge and understanding of the illness [39]. Shared information has the potential to enable AYA to feel more in control of their treatment and illness and to participate more fully in their care and decision-making. However information that needs to be communicated is often very complex and can be quite uncertain and emotionally charged, setting the scene for miscommunication [40]. There is clear evidence that young people with cancer desire information about their illness and treatment [39, 41, 42]. Equally challenging is the situation where the AYA excludes their parents/family members from all discussions about their care. Thus a new challenge presents itself in terms of the triad of communication, managing expectations and offering support to all who need it. Some spoke about *parent-free-time* allowing the AYA to be alone and talk to healthcare professionals about what they are feeling and for parents to be able to do the same: together this explicit approach would work towards *creating a trustful and open communication* approach to caring [43].

Participating in end-of-life decisions is life altering for AYA with incurable cancer, their families and their healthcare providers [29, 44]. As Henry Marsh, in his book *Do No Harm*, said: 'the difficulties are all to do with the decision-making' [45]. Parents want to do what's in the best interest of the AYA which may lead parents to try to limit information with the AYA which is not conducive to planning end-of-life care [46]. Tomlinson and colleagues found that hope, increased survival time and child quality of life were more significant in parents' decision-making at end of life compared to professionals who viewed financial considerations as more important [47]. Healthcare professionals often experience difficulty reconciling parents' preferences to withhold distressing

information and the AYA right to information and participation. To respect AYA right to participation, their preferences should be determined and information provided accordingly in a sensitive caring manner. The facilitation of shared decision-making requires active engagement with AYAs and their families, information sharing, clear communication and trusting relationships [48]. We might argue that there is a continuing need for professionals to undergo education and training to enhance their competence particularly with regard to palliative care and end-of-life care [49, 50]. The ability to work more openly, proactively and collaboratively with families, key messages from Coad et al. [51], are useful reminders to all members of the clinical team.

32.7   Caught Between Competing Obligations, Such as Family-Centred Care

Professionals are not working alone and alongside AYA; parents are also essential members of an effective multi-professional team. Thus we talk about a triad when we are referring to partnership working in our field: where partnership is both fluid and dynamic, with role boundaries between all three members of the triad changing over the course of a relationship [41]. Understanding this dyad, young person-parent roles, is essential for professionals to uphold the individuality of each partner and to respect their views and value their input into the multi-professional team. The shifting roles within families make this work more complex. Making a judgement of when discussions need to involve both the parents and the young person is less than straightforward. The need to ascertain values/wishes of the young person and their family is essential; we need to understand the complexities of each family, make no assumptions and be guided by the AYA in terms of how we might define and approach family-centred care for them. Conversations about sexuality and fertility, for example, *drug histories being discussed with minors when parents are present*, all present challenging situations, where there is an obligation to inform AYA about such health matters, irrespective

of how uncomfortable that makes a professional feel or how tricky it might be to orchestrate that meeting to meet different needs [52].

Family-centred care sets the parents at the centre of the child's care, with the young person taking a more passive role [53]. An alternative to family-centred care is however emerging: child-centred care has now been defined as a model where children and their interests need to be at the centre of our thinking and our practice [54]: here we can replace child with AYA in recognition of their agency and right to participate. An important premise in this further clarification of terminology that helps us in our field is the recognition that AYA views are not always the same as their parents or of their health carers, and when given the opportunity, they are able to represent themselves [55]. *Finding the right balance between informing adolescent patients about their disease, its treatment, and prognosis, respecting their need for the truth and a full awareness, while at the same time protecting their feelings and sustaining their hope is very challenging*: what Pavlish et al. [26 p. 595] refer to as 'navigating the intricacies of hope and honesty'. Add into this situation sensitivities regarding family-centred care, in the case of a minor or even a young adult, and the triad of communication can equally present emotional and ethical challenges. There is a danger in 'trying to keep everyone happy', that leads to uncertainty and inaction [23] while recognising still the impact cancer has on the whole family and how they negotiate roles within it [56].

32.8 Patient Choice and Shared Decision-Making, When Faced with Treatment Options and Place of Care, Access to Clinical Trials/Research and Fertility Options or When Refusing Treatment

The empirical literature supports the position that many young people, especially those who are veterans of illness, can produce coherent and rational views relevant to decisions about their care [57]. This literature also reveals that there is no straightforward association between age and competence [58]: except that capability increases as young people grow towards adulthood resulting in increasing autonomy that shifts responsibility from the parent to the young person. Much of the new social studies literature has repeatedly argued to reposition 'children' as competent and rational [59], therefore deserving of the right to make autonomous decisions. Young people's ability and desire to be involved do of course vary. Respecting their differences means supporting them as far as they want to go, trying not to impose on them over-involvement or exclusion in decision-making [58, 60]. We would agree with Dixon-Woods and her colleagues [57] that most decisions in our field are made informally and are negotiated within particular forms of social relations, within which there are either shared decisions or situations where young people and parents defer to one another. Difficulties may arise, however, when young people are receiving their care within an adult setting, *where they tend to deal with the AYA on their own and may not recognise how much the AYA needs a parent with them.*

Patient choice and participating in decisions have been a focus for governments in the UK and elsewhere, with policy documents increasingly focusing on patients being central to decision-making in healthcare, for example, 'Giving people more choice and control over their treatment and services is one of our key priorities in the NHS…' [61]; 'Choice is fundamental to the delivery of a truly patient-centred NHS…' [62]; and 'No decision about me without me' [63]. But where upholding choice conflicts with going against medical advice, then challenges can result. *The young person not wanting chemotherapy because they do not want to lose their hair, and the young person who did not want a nasogastric tube passed because they don't like the look of them* were just a couple of examples that have posed challenges for our respondents. In situations such as these, tensions can be escalated, where members of the healthcare team as well as other family members may have a stake in decisions being made

by AYA [60]. In their review, Davies et al. [64] described several themes, which relate to decision-making in cancer, about whether to enter a clinical trial, around palliative and end-of-life care, fertility issues and risk-taking following completion of therapy. Other than risk-taking, all were mentioned by our respondents and indicate strength of consensus on the everyday decisions made by AYA. Clinical decisions are often complex and context dependent and should be based on best practice and individual patient needs. These are made more complex when many stakeholders are involved and the AYA wants to maintain their independence, but due to the complexities of treatment decision-making, they are forced to rely upon parents and healthcare professionals' support and expertise, thus creating a dependent or interdependent relationship. A young person may also feel pressurised and torn between their own wishes and those of their parents' or healthcare professionals. Hence the burdensome nature of some decision-making strengthens the case for shared decision-making.

Shared decision-making is an emerging strategy that focuses on strengthening the collaboration between clinician and patient, encouraging dialogue and discussion. Involvement in shared decision-making for AYAs means receiving information, being able to voice preferences, having a choice and negotiating and choosing how treatments are administered [65]. In prior research, these approaches to involvement have been reported by young people as being very important for them [66]. Furthermore loss of control can leave adolescents with feelings of inadequacy and anger, a sense of frustration, and potentially lead to non-adherence with treatment [67]. Professionals should adopt an individualised flexible approach so that AYAs can have an active, shared or passive role as and when they prefer [48]. Where potential discrimination may occur when a young person is unable to participate fully, such as in the case of those with cognitive disabilities, then healthcare professionals will need to work even closer with families to understand their preferred approach to communication and shared decision-making.

32.9   Tensions Between a Professional's Personal Moral Compass, Expectations Attached to Their Role and Conflict with Team Members

Practices within our field require multi-professional working, within and across disciplines and also across into other specialities. Thus we may find ourselves working alongside professionals with different values and views to those we uphold, as well as *different philosophies of care*, *paediatric versus adult*. Here again there is the potential for ethical conflict, where *we don't always come up with a unanimous decision*, *but usually one that can be accepted by all*. Probably because decisions are never *black and white……should go with the majority expert opinion*. This indicates the importance of each discipline respecting each other's expertise, listening closely to what others have to say and allowing time for discussion of viewpoints. Viewing an ethical issue through a different disciplinary lens will contribute to a fuller discussion and may raise awareness of different issues that need to be considered within a respectful environment. Inter-professional differences that emerge through different experiences, education, culture, personal values and moral beliefs cannot be avoided and probably align closely with different perspectives of 'in the child's best interest' [27]. Creating the right environment would seem to be key, one that prevents conflicts from occurring or has robust structures in place to manage them, should they occur. Pavlish et al. [23] refer to a 'moral community', the characteristics of which include:

1. Open, respectful team relationships
2. Processes for timely, honest planned communication
3. Accessible, strong, ethics-minded leadership
4. Routine, readily available, system-wide ethics resource
5. Provider awareness and willingness to use ethics resources

The implicit notion of accountability within this moral community is to be welcomed, where

a 'shared commitment to the moral good of high-quality patient-centred care is system-wide' [23 p. 138].

32.10 How Might We Deal with Ethical Challenges?

Many respondents spoke about the strategies they used, such as multi-professional forums, where clinical cases can be discussed and where there is open and frank discussion about clinical decisions, particularly difficult ones. Clinical ethics meetings were also commonplace, where healthcare professionals were able to draw on the expertise of a range of professionals. Some clinical ethics meetings would draw upon the expertise of ethical experts or other personnel, such as the chaplain, that can help provide a fresh or different perspective, particularly if emotions are high and there has not been a resolution of differences of opinions on the best way forward. An *open and allowing climate that permits everyone to raise his/her concerns* was championed by many of our respondents. In contrast, *lots of talk in the lunchroom and during coffee breaks or between colleagues* was thought to give only *a narrow picture of the situation*. Bringing professionals together in a more formalised approach or even in an *ad hoc emergency type meeting* was thought more helpful: *teamwork is more effective than one person trying to sort it out*: where involving the patient, *or at least give them an opportunity to have involvement if they want it*, was more commonplace. We heard about good examples of creative ways for AYA to tell their story and hence have the opportunity for greater involvement in all aspects of their care [68].

Having good team cohesion, respect for different experiences and clear communication were all described as essential factors in clinical ethics meetings. Trust, respect and open communication are essential elements of an effective team and are crucial when a team is faced with an ethical dilemma. Shared communication and an open dialogue were seen by all as the cornerstone of multi-professional working. Multi-professional working is the cornerstone of care delivery, within which professional roles should be clearly defined so that individual roles complement one another [69]. So that, "*it feels difficult to contradict a consultant who has led a discussion*" no longer presents a challenge to team members who *want to do the right thing*: what Pavlish et al. [23 p. 595] refer to as 'weighing risks of speaking up in hierarchal structures'. The importance of open dialogue within the clinical team was emphasised, where professionals from different disciplinary backgrounds can share their understandings of the family situation and contribute their opinions and have those opinions heard and respected in order to reach *inter-professional consensus decisions*.

A review of ethics consultations at St Jude Children's Hospital in the USA revealed religious concerns including refusal of care based on religious beliefs were more common when compared to similar reviews with adults [70]. In addition, consultations were more often prompted by distress arising from disagreements about a treatment plan or from inadequate clinician-family communication. Clinicians in this study frequently consulted on two main issues, when deliberating whether potentially burdensome treatments were truly in the patient's best interest and when deciding how to clarify the goals of care with a family when the prognosis was poor; these same issues were also mentioned by our respondents. A strong professional duty, similar to our respondents, was noted, to advocate for care goals that align most with the clinician's sense of what would be in the child's best interest [70]. Such reviews are helpful in understanding the purpose of ethics consultations, and confirming the reason for consultation depends on one's point of view and may be viewed quite differently by others involved [71]. A typology of case consultations developed by Gillam et al. [72] is helpful in informing our own reflections on what we might seek to take to an ethics consultation and certainly provides a summary on many of the themes examined in this chapter (see Box 32.1).

Box 32.1: Typology of Ethics Case Consultations

1. Parents disagree with recommendations of the treating team.
2. Adolescent/potential mature minor disagrees with recommendations of the treating team.
3. Child is resisting treatment.
4. Parents disagree with one another about treatment or management options.
5. Clinician is uncertain about the appropriateness of offering a particular treatment.
6. Clinicians and parents are both uncertain about the best way to proceed when a variety of options are available.

32.11 Reflections and Concluding Thoughts

Over the past several decades, changes have occurred that have altered the way that healthcare is both perceived and delivered. The availability of new health technologies, the increased consumer demand, cost improvement, cost efficiency, limited resources in healthcare, reconfiguration of services and the improved professional skill and knowledge competencies have all played their part in creating the complex and demanding workplace we work in today. The nature of AYA cancer care will continue to evolve; future challenges of technology, limited resources and service reconfiguration, although not known in detail, can be anticipated. Thus the clinical speciality will evolve and healthcare professionals will continue to specialise and narrow their field of practice to meet these ongoing demands. Ethical situations and conflicts will continue to arise as we are challenged to deliver individualised care in an increasingly complex environment.

It has been suggested that caring in ethically demanding situations can be facilitated through *presence*, *atmosphere*, *self-knowledge* and *time* [73]. Creating an effective ethical climate must include the availability of appropriate 'tools' and resources, such as formal or even informal ethics consultations and training [23]. The centrality of relationships between healthcare professionals was a theme running through the comments of all of our respondents. Specifically mentioned as facilitators to this were trust, mutual respect, open dialogue, professional competence in AYA care and intentional collaborations with AYA and their family members. Barriers were also mentioned, and in addition to the opposite of all the listed facilitators, we draw attention to understanding the shifting roles within families, professional differences within clinical teams and the often ambiguous interpretation of the law regarding those considered a minor (where age varies in different countries). Accommodating expertise of the multi-professional team, parental decisional authority and AYA emerging maturity and competence in decision-making would seem to be the key elements in any model of decision-making in AYA cancer care [74] that could mitigate ethical conflicts.

We all have a responsibility to ensure our own organisations seek ways to both document and improve how we promote the use of ethical principles in our decision-making and to facilitate team-based discussions on ethical dilemmas. Teamwork and recognition of when an impartial expert view might be required are essential, but ultimately we all require openness and the ability to value everyone's contributions to decisions. Young people have the right to *empowerment in making decisions* supported by full and *detailed explanation* of all treatment options and long-term effects of the disease enabling them to *actively influence their care* (http://www.canteen.org.nz/get-involved/international-charter-of-rights-for-young-people-with-cancer) [13]. We hope that with the help of our respondents, we have provided evidence of how we can uphold this right and provide equitable care to young people.

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