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Palliative care in adolescents

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Abstract

Specialist Palliative Care's involvement in adolescent cancer is relatively new. The challenges are not so much to do with the technicalities of symptom control, but in walking the fine line with patients and families as they wrestle with transitions into an adulthood that will not happen and attempts to pack a lost future into a few months or years whilst coping with arduous and often futile treatments that attempt to buy some more time. The article explores some underlying principles and the model of care that has emerged at this specialist centre for adolescent care.

Keywords: Symptom control; Adolescent Palliative Care; End of Life Care; Terminal Care; Ethics

1. Introduction

Adolescent Medicine and its Palliative Care, in particular, is a new area. There are many technical features in common with adult practice, although the holistic aspects may present unfamiliar problems for those on either side of the clinical and philosophical gap between paediatrics and adult medicine. It should be no surprise that the adolescent in transition tests all the parameters of convention in medicine as much as in their families and society in general.

In the first half of this article, we therefore focus on the issues and challenges that are emerging for us as clinicians and then offer a model of care that we have found to be effective. On specific clinical issues or management, we refer readers to the general texts [1–4]. These detail the pharmacology and therapeutic strategies we use in symptom control in adults and their evidence base. Our defence in doing this is that, come the teenage years, the technicalities of treatment conform as close to the norms of adulthood to be of no practical difference. For example, within reason, basing drug doses on body weight seems to make little difference to symptoms control, and the metabolic quirks that alter drug interactions or pharmacokinetics in childhood have largely disappeared. It is the minefield of transition and holistic care that we explore.

2. General issues and challenges

2.1. Context

2.1.1. The philosophies of palliative and curative care: complement, not conflict

Palliare (lat.) means to cloak or hide and has been coined to indicate, with respect to physical symptoms, that we are interested *prima facie* in their relief rather than in the cure of any underlying pathology. This does not mean that we are ignorant of or disinterested in their pathogenesis and biology: it just isn't our priority. Why should this be, and particularly how can we defend this in the young with so much to lose without sounding overly simplistic or even negligent?

2.2. Meaning versus mechanism: a broadening and integration of biomedicine

Patients presenting with symptoms quite reasonably imagine that they are indicative of a disease in need of diagnosis, treatment and cure: they attend the doctor and s/he obliges with a cycle of investigations, diag-

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nosis, an evaluation of curability and appropriate therapy. These are '*what*' questions that need the reductive approaches at which medicine excels. If this is successful, everyone is happy. On the other hand, if we fail—even partially—or the problem recurs, the bigger and underlying true/primary agenda for the patient and their family emerges: this is the concern of what the symptom *means;* the '*why*' questions (of which 'what' is really a sub-set).

One essential compounder of our problems with the young is that their illnesses are necessarily felt and interpreted not just by them, but by their family also, in which they are likely still to be seen as a child or at the very least a dependent. Therefore, questions like, "why has this happened?" are collective: "why has this happened to 'us' (and what have I or we done to deserve it)?"—in other words, on whom blame might sit-justified or otherwise—are immediate and deeply personal, non-clinical concerns to a whole group [5]. On from this, the fear of implications begins to press in:

- Is there a 'normal' life ahead?
- Will there be long-term consequences?
- Is this curable at all; is it even fatal?

Amongst others, these are the common elements of suffering and to try and see and solve them using medicine alone is a fool's errand. To do so merely stores up a whole load of unnecessary problems and pitfalls for the future patient/clinician relationship [6].

2.2.1. Palliative care as the management of suffering and uncertainty

It is therefore axiomatic in palliative care that pathology is but one element of suffering and that treating diseases alone may never relieve the distress that they have precipitated, catalysed or exposed in the person(s) who have them. This is born out by the literature [7–11].

This is also why 'palliative' is not quite the right word for our practice: on the one hand, we are not concerned explicitly with pathology and are happy to cover over its effects, yet, on the other, we are deeply interested in exposing and exploring the social, emotional and spiritual elements in a patient and their family that lead symptom thresholds to fall and suffering to be expressed as uncontrolled pain, breathlessness, nausea, bowel disturbance and so on. We will come back to this later.

The implications are as follows:

1. It is essential for care to be given by a team operating across disciplines and throughout the cancer journey where there is not just lip service to interdisciplinary practice, but real and present evidence that the imperatives of pathology may not be primary at certain stages of the patient's care.
2. We submit that all cases from the earliest stage must be managed in the light of the clinical uncertainty that most adolescent malignancies bring. It is laudable and virtuous to be positive, aggressive and single-minded in investigating and treating patients, but it is equally remiss and vicious to set patients, families and ourselves up to see disease progression or relapse as failure. The natural causal consequence is for all to seek increasingly futile solutions and a culpable party for what is the march of nature. In such situations, we create a climate of denial and frenetic 'last ditches' that leave us all, when facing an inevitable death, feeling hopeless, helpless and guilty. It is far better that we recognise in the horror and distress of a young person's cancer journey that, unwelcome as death may be, we are willing to face it with the knowledge that the experience can be meaningful, productive and even 'healthy', provided that we manage the process properly [11–15].

In summary, we have touched briefly on some of the broad philosophical issues that palliative care raise, and made the case that the strengths of combining curative and supportive or palliative care are overwhelming. We now turn to the additional challenges that adolescence brings to cancer care.

2.3. The context of adolescence

2.3.1. Normal, but abnormal

Managing transition is the substance of adolescent care. Whilst disability or dying certainly add difficult and painful elements to this storm of change and uncertainty, the evidence suggests, and it has been our experience that, in the exploration of their emergent adulthood and the exit from childhood, young people with cancer are no different from their healthy peers in the issues that they are tackling [10]. Their oscillations between extreme independence and crass juvenility are the same as they attempt to settle to a new equilibrium, except that if death is in prospect, a future adulthood is not. In this respect, though, the tendency we all have to regress when ill is very evident in certain teenagers and, according to their maturity, may produce dissonance and difficulty in communication and coping when they know the facts of their illness cognitively, but lag in their understanding emotionally of the implications. Therefore, the challenge to us as clinicians, on the one hand, is to understand and engage these processes in navigating along a disease journey without undue emphasis being placed on their 'abnormality' [10,16]—in other words, fostering their development into young people—yet, on the other hand, taking account of and recognising that they are deeply abnormal in that they are dying.

2.3.2. *Defining oneself: inclusions and exclusions*

It seems logical and right that a young person's emergent self should be defined, along with their peers, by social and cultural roots that recognise the separation from family (exclusion) and their aspirations for the future as a member of a peer group (inclusion) What is also true is that they should not be defined by their biological state, or the diseases that they have. However, to what extent is integration into peer society possible during or after debilitating disease? For example, does a healthy adolescence and social integration necessitate the individual experiencing all things: is a dying teenager the less for missing drunken nights and the first fumblings of sexual experiments when they are likely only to experience the harms and none of the benefits (such as they may be)? Some would say yes, but we wish to caution that it is not possible to pack a lifetime into a few months or years, and it is for this reason that we emphasise prioritisation later in the paper. However, regardless of one's views, one thing is certain: whilst individuals' futures are by no means settled, the equilibrium is extremely distorted, and there may be precious little time to adjust simultaneously to life in hospital and home with the knock of mortality on the window.

A further difficulty in our experience is the tension that these young people have in existing in several worlds and places at once. For example, there are continual transitions between being a normal teenager with independence and a developing social life, a scholar trying to pass exams or being a sibling, and a regular in-patient life facing, say, chemotherapy and its ravages of side-effects compounded by neutropenias that are expected, but their possible consequences are not.

Before we explore ways of helping and models of care, we need a clear framework of engagement with patients and families.

2.4. *The ethical landscape*

2.4.1. *Some premisses*

Our society believes that all individuals have freedoms and entitlements irrespective of limitations such as age, capacity, disability, etc., and that these 'rights' are to be respected and exercised where possible by the individual or else, if they are incapable, by others on their behalf and in their best interests. For our discussion, the areas of concern are

1. Our patients' emerging autonomy, both potential and actual
2. The duties and responsibilities that this demands of parents and
3. Our rôles *in loco parentis* with respect to their interests.

Naturally, the area of conflict resides in various interpretations of a person's capacity and interest. Where difficulties arise consistently is in refusals and consents, truth-telling (veracity), confidentiality and disclosure. We will deal with these now.

2.4.2. *A word on transition*

It is an *a priori* that children become adults and adults have been children. We have each been through the storm of transition that should make us sympathetic to our patients' needs at this time. Specifically, the move from dependence to interdependence (via the fantasy of independence, one might add), the breaking free from being an object to a subject, the maturation from irresponsibility to responsibility and the changing status from a minor to a peer involves trials and errors, risks and harms. These need to be experienced in some measure by the child *in transit* to teach them responsibilities and give them the capacity to function as an individual (independence) and as a citizen (interdependence). However, illness is inclined to push us all back to dependency and one may see this particularly in the adolescent. For example, it is entirely understandable when a stroppy and assertive new patient transforms rapidly into a fetal child when suffering the side-effects of chemotherapy. It is also relatively easy and probably beneficial for a mother in this situation to handle her teenager back in her arms as a child. However, it is extremely hard for a parent to accommodate the opposite: their child refusing all treatment or appropriate symptom control as a means of denying the immediate problem without considering or, in their opinion, giving due weight to the longer term consequences. Of interest, Donaldson recognised this in the Court of Appeal over a case of 'Gillick Competence' [17][1] in a young woman with Anorexia Nervosa in whom a refusal was overruled. This showed, certainly at that time, the anomaly that patients could be considered in law to be mature enough to consent, but not to refuse [18,19]. However, at a practical, day-to-day level, we are often left clinically to observe or cope with disruptions and inconsistencies in treatment precipitated by such oscillation in 'psychological/emotional capacity'. These may spill into the general ward when such disputes or the symptoms that they exacerbate become very evident and distressing to staff and other patients. Collusion is an easy, short-term, but inappropriate option.

How, then are we to deal with these fluxes in behaviour and our patients' unpredictability? The answer lies in clarity about autonomy, what it really means and its

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[1] Gillick Competence applies: "when [the child] achieves a sufficient understanding and intelligence to enable him or her to understand fully what is proposed [and] sufficient discretion to enable him or her to make a wise choice in his or her own interests; is Contingent upon: [A young person's] maturity and understanding and the nature [seriousness and complexity] of the consent which is requested. . .

importance to the patient as their clearest and most powerful lever of adulthood.

2.4.3. *Autonomy and helplessness*

> Every human being of adult years and sound mind has the right to determines what shall be done with his own body... [20].

Thus runs the classical statement by Justice Cardosa that set consent to treatment in law. Autonomy is therefore, arguably, the cardinal feature of adulthood: it is enshrined in law, and defines the individual by their capacity. Consequently, actions or decisions *in loco parentis* cannot be enforced without delineating capacity, and this is seen equally in law as being in need of evaluation [17]. Naturally for the young person in transition from child to adult their definition of themself finds form in expressing and having control. This is crucial to minimising the loss of hope that helplessness brings. Whilst it may sit uncomfortably, when facing the truth that a young person is dying, there is a strong case to make that observing autonomy, even when it is clearly not a best interest may well be more important than the consequence of say a shorter life. Put another way: is it better for an individual to die in the Spring having had their refusal to treatment respected than to have lived to the summer having been forced to endure more invasive and symptomatically costly therapy? Being clear about this tough balance and giving due respect to the patient turns on one thing: truthfulness.

2.4.4. *Our duty to be truthful*

The clinician/patient relationship depends on honesty trust and respect to work effectively. This is no different for teenagers than anyone else.

A perennial and almost universal tension and difficulty amongst members of the clinical team and with family is truth-telling. This tends to be grounded in three areas of misconception:

1. Being honest about the likelihood of death is in some way ‘prophetic’ and will bring that death closer by removing hope. This has to be flawed unless one assumes that the admission that death is not far off leads all to sit around a bed to wait passively for the end to come.
2. Knowing that treatments have failed and death is inevitable is bad enough, talking about it merely rubs things in and leads to unnecessary distress. Equally, this cannot make sense. To face the truth in the short-term at least allows emotions to be expressed and fantasies and imaginings of what death and dying means and entails to be explored and corrected.
3. Talking about dying gets in the way of living. This cannot be true either. Confronting and dealing with a future spectre of death, by seeing it for what it is and when it may come, gives focus to the time that remains such that specific and particular plans and ideals can be classified as essential or preferable, doable or not and all subsequent interventions and their timings can be tailored to maximise the patients capability and quality of life to achieve specific and desirable goals.

These are the ideals for which we should strive as they are consonant with the truth that life is limited and not the charade that death is optional. This approach necessarily requires difficult conversations and brings us to the other practical elements of autonomy.

2.4.5. *Confidentiality and disclosure*

Autonomy and capacity are of course worked out in two important and practical areas: the permitting or forbidding of actions is the most obvious facet we have just addressed. Permitting and forbidding communication is less spoken of, but equally important. One way of feeling in control is to have information that others don’t (the aphorism that information is power).

Working on the agenda of managing the remainder of a life with a patient is a difficult, but essential, early need to manage their move out of this world. It will usually involve sensitive and private matters that a young person will likely wish to explore or rehearse privately. This confidentiality is deeply important to the young who often see secrets as evidence of their individuality and separation from childhood and being a minor to being a peer with adults. For example, a patient may well wish to talk of their fears that a parent isn’t coping and they may wish to explore or alter plans about treatments or where they wish to die—the probability also is that the parent(s) may feel entitled to forbid such private conversations or at least to restrict their content, which they of course are not. We need to be absolutely clear here: one’s ‘Gillick Competent’ patient has a positive right/entitlement to know or not to know (a patient’s wish *not* to discuss their prognosis etc is just as reasonable an expression of autonomy in the young person as in an adult); their family has *no* right to restrict or control this in English Law.

Young people will inevitably also need to express feelings and fears about death or what may lie beyond, yet feel unable to do this because of the distress that may be caused in the family. For example, patients may have had dreams or ‘near death’ experiences that seem to have spiritual connotations. They may be puzzled or fearful as a result and needing to talk, but they may feel the subject is too sensitive to share in anything other than complete confidence with someone outside of the family. This must be respected and engaged to ensure that death is not accompanied by distress. Early engagement of such matters reduces the likelihood that they will need sedation at the end of life for what is known as 'terminal restlessness'.

In summary for this section, once dying is seen openly as a most likely outcome for a person, the work that needs to be done is substantial and vital to the end of their life going well. Practically, we must ask:

1. What sort of time or quality of life are we likely to be dealing with?
2. How can we maximise this to ensure that a teenager's list of tasks is completed?
3. Have we looked at them properly: for example, what are the real issues they have with family or friend(s) such as a first love in order to have a death in which all the 'Thank Yous', 'Sorries' and 'Goodbyes' have been dealt with properly.

This way death, unwelcome though it is, will be seen as a proper conclusion to a process of healthy, but painful endings and not a tearing away from others with whom an unhealthy bond of unresolved issues leaves unnecessarily raw emotional areas that will complicate the grieving process.

Our duty in palliative care is to ensure as far as possible, that whilst painful, we have ensured that no unresolved agenda remains and that the possible suffering as death approaches is therefore minimised [21]. This puts an edge on palliative care that other clinicians may not have realised was there. Put this way, good and responsible practice *must* give these non-medical elements of care a far higher priority than the vain pursuit of the latest experimental therapeutic idea in some futile attempt to stave off the inevitable. More important still, futile treatments also waste a patient's precious time and energy and are therefore negligent and a dereliction of our duty to care.

2.5. Seeing symptom control as creating a decision space

Aside from keeping someone comfortable, which is also a duty of care, the productive purpose of symptom control must also be to create useable and useful space and opportunity for patients to consider issues, make choices, complete tasks, resolve relationships and reach a place of peace before they die.

1. Effective palliative care is therefore proactive and 'aggressive' in using periods of health to plan and bring some sense of control into an uncertain future.
2. The clarification of issues and planning is done to maximise control within the uncertainty.
3. Having made decisions, this also ensures the best chance of then having the opportunity to enjoy the decisions made.

2.5.1. Using symptoms as signals of the subtexts of communication

Before summarising the broad approach that we take in University College London Hospitals (UCLH), we need briefly to comment on the way symptom thresholds (i.e. the level of pathological stimulus necessary to elicit a reported problem such as pain) may point us to subliminal messages from the patient that private conversations may be necessary.[2] Here are a few examples:

1. Is a patient's symptom saying 'the cancer's getting worse' or 'I'm feeling worse'?

Simply dealing with the pain by changing the analgesia is not going to be enough and may need a specialist to explore the symptom's meaning.

2. Is a patient saying 'I'm feeling better because I am not prepared to recognise that I may be getting worse'?

This needs care and expertise to deal with.

3. Is a patient saying 'If I say I'm better, you won't stop me doing what I want (going home, etc.)'?

Inpatient units and specialist ones, in particular, are vulnerable to seeing that residence is really the only safe place. This is not so. People are designed to live at home. Local services in the right configurations, in the United Kingdom (UK) at least, have all the requisite skills to manage adolescents when supported by local or 'regional' experts and models of shared care are both effective and pragmatic ways to deliver care [22,23]

4. Is a patient saying 'I'm feeling worse because I am not feeling safe'?

5. Finally, many's the time a teenager has needed to look at ways of saying they want to be at home, but they ought to be in hospital for what they see as the family's sake. This will need delicate exploration.

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[2] They can be spotted, incidentally, by looking at the drug chart: is a patient's need for additional analgesia, antiemetic or sedative based on any clinical change in pathology? If not, do not assume that the patient is after the drugs—more likely their symptom threshold has fallen as a result of some additional psychological or spiritual pressure, concern or fear.

3. The UCLH model of palliative care

This final section annotates our approach to managing our dying teenagers based on the principles of the previous sections. They are the ideals to which we aspire, but in reality and in common with our colleagues and readers, we fail in many cases to meet them for many reasons, not least our limited resources. However, we would emphasise at the very beginning that we do not see shared care with primary care or the involvement of adult palliative care services as ways of doing more with less. Quite simply, they have the skills and local relationships necessary to deal with this challenging, but small group of patients and they must be involved.

3.1. *'Breaking the code'*

3.1.1. *Going with a forward flow: communication and decision-making*

1. Treat patients as equals in openness and honesty, and run the gauntlet of potential difficulties with family over refusals, confidentiality and disclosure.

Non-disclosure is a short-term advantage to clinicians and family in that there is an idea that the patient is protected from unnecessary and distressing information. However, this presupposes that the patient is unaware of what is going on. There is no evidence to support this [15]. Conversely, distress will inevitably come from helplessness compounded by shadow-boxing with fears and anxieties that gain size and significance if left to the imagination rather than being tested against evidence and truthful dialogue.

2. Advise and assist patients in making decisions and resist parentalism. Making decisions gives a sense of self. Being considered as an object rather than subject is objectionable to teenagers.
3. Analyse all interventions on an objective assessment of benefits and burdens.
4. Anything goes as long as it has purpose and potential to move the person on in their conclusions.

3.1.2. *Going with the doable: tasks and lost futures*

1. Markers of achievement are most important as consolidators of a sense of self. These may seem silly to the outsider, but the need, for example, to sit exams, have trips and experiences must be honoured as far as possible.
2. The criterion for a task being legitimate is its doability, not its sensibility. Appropriateness is internally defined here and another important marker that autonomy (and therefore the patient's emergent adulthood) is being taken seriously.
3. Anything that fosters socialisation and normality is good.

3.2. *Breaking our perceptions*

1. Truth with colleagues and others is a central plank of good care and should never be compromised.
2. As professionals, we cannot make everything all right. Baggage in a family will accumulate around an ill member and may have nothing at all to do with a patient's cancer or their death.
3. Overcome the mutual views that separate paediatrics from adult care: both groups have valuable things to bring to the child in transition. To keep them in childhood is negligent, but to pass them on to adult practitioners without support and the reassurance that young people are not scary to look after or that there are not the requisite skills around is worse: for adult palliative care teams to say that they don't take teenagers is unacceptable. The interdisciplinary care needed for this group and the packages of care and support needed require us all to work as a team in a focused way for each individual.
4. Work in a team requires the active involvement of all players and their being prepared to debate, disagree and dissent as cases are managed. Many views will get the team closer to what is needed and the tension necessary to achieve the wise way is a sign, not of poor teamwork, but of a strong team [24].
5. Allow crises and emotions, but encourage responsibility in using them to move the patient forward. It is not 'upset' itself that is to be avoided, it is remaining in it.
6. Don't be problem-orientated, be problem-solving.

3.3. *'Breaking taboos': coming to healthy conclusions*

Work with the dying is not easy, especially when we see a lost future and the unfairness of disease, and this is especially poignant in the young. However, the way to make this as healthy as possible for all concerned is to face the reality and engage it with a coherent group of professionals and a strategy. It is bad and negligent practice to hide behind secrecy or futile treatments that waste time, energy and resources and to preside over deaths where all will certainly feel failures.

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