

TEACHING AND LEARNING ETHICS

Whose information is it anyway? Informing a 12-year-old patient of her terminal prognosis

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Objective: To examine students' attitudes and potential behaviour towards informing a 12-year-old patient of her terminal prognosis in a situation in which her parents do not wish her to be told, as they pass through a modern medical curriculum.

Design: A cohort study of students entering Glasgow University's new medical curriculum in October 1996.

Methods: Students' responses obtained before year 1 and at the end of years 1, 3, and 5 to the "childhood leukaemia" vignette of the Ethics in Health Care Survey Instrument (EHCI) were examined quantitatively and qualitatively. Analysis of the students' multichoice answers enabled measurement of the movement towards professional consensus opinion. An analysis of their written justifications for their answers helped to determine whether their reasoning was consistent with professional consensus and enabled measurement of changes in knowledge content and recognition of the values inherent in the vignette. Themes on the students' reasoning behind their decision to tell the patient or not were also identified.

Results: Unlike other vignettes of the EHCI in which autonomy was a main theme, few students chose the consensus answer before year 1 and there was no significant movement towards consensus at any point during the course. In defence of their decision to withhold information, the students expressed strong paternalistic opinions. The patient's age was seen as a barrier to respecting her autonomy.

Conclusions: It is important to identify students' perceptions on entry to medical school. Transformative learning theory may provide the basis for an approach to foster doctors who consider the rights of young people. Small-group teaching is most conducive to this approach. The importance of positive role modelling is also emphasised.

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When children are terminally ill, health professionals can find it difficult to be frank with them about their prognosis. Parents may also request secrecy in order to spare their child from having to cope with distressing information.¹ Evidence would suggest, however, that terminally ill children benefit from talking about their imminent death.^{2–3} Secrecy, bad communication, and a patient's suspicion that important questions are being avoided can contribute to fear and anxiety. Dishonesty undermines trust and can create a barrier between patients and health professionals.¹ Parents may also benefit from talking to their children. Kreicbergs *et al*'s study, which surveyed all parents in Sweden who had lost a child to cancer between 1992 and 1997, showed that 27% of parents who did not talk to their child about death regretted not having done so, whereas none of the parents who discussed death with their child had regrets.⁴ It is recommended that there is open and honest communication between doctors, parents, and children about the prognosis.^{5–12}

When the patient is a minor, competence is seen as a threshold above which they are able to understand their situation and make their own decisions about their health care.^{13–19} Some commentators suggest that from their early years children think and feel deeply about their relationships and experiences and try to make sense of them,^{20–21} and that children as young as 5 years use understanding that adults rely on throughout life.²² Strategic thinking and the ability to plan, however, do not become well established until later childhood or early adolescence.²³ It is assumed in English law that all children under the age of 10 years will not have sufficient competence to refuse to consent to medical treatment.¹³ Psychologists believe that children up to the

age of 12 consider that the locus of control in their lives is external to them, which may result in them being easily swayed into making decisions.¹⁹ Buchanan and Brock²⁴ note that children's development usually increases their ability to be competent. By their criteria this is achieved at around 15 years.^{24–25} Setting such limits, however, has been criticised as arbitrary.^{25–26} In the UK, a recent expert government committee has recommended that the presumption of competence should arise at age 10 or 12 years.²⁷ Cognitive capacity and emotional understanding do not necessarily develop at the same rate and there is huge individual variation in both the time taken to reach particular mental levels and the ultimate levels attained. Accordingly, it is argued that no rule about competence that is based just on chronological age is satisfactory.¹

The University of Glasgow introduced a new learner centred, integrated medical curriculum in 1996, which has medical ethics and law as one of the vertical themes running throughout the 5-year course. The design of the curriculum was influenced by the General Medical Council's recommendations in *Tomorrow's doctors*²⁸ and conforms to the recommendations of the UK consensus statement on the teaching of ethics and law.²⁹ Its introduction provided an opportunity to study longitudinally the effect of a modern medical curriculum on students' potential behaviour on facing ethical dilemmas.

AIM OF THE STUDY

The aim of the study was to examine the effect of a modern medical curriculum on students' attitudes and potential

Abbreviations: EHCI, Ethics in Health Care Survey Instrument

Box 1 Vignette 8: childhood leukaemia

Sunitha is a bright 12-year-old girl whom you have been treating for leukaemia. Her condition is not responding to treatment and you realise that there is nothing more that can be done for her. Her parents are informed of this and they are adamant that Sunitha should not be told. They feel that she has suffered enough through this illness and do not want to spoil the little time remaining by telling her that she is dying.

Your options are:

1. ___ Tell Sunitha.

2. ___ Abide by her parents' decision.

Please state the reasons for your choice:

behaviour towards informing a 12-year-old patient of her terminal prognosis, in a situation where her parents do not wish her to be told.

METHODS

Design and participants

A cohort design was adopted to study a group of 162 medical students from the first intake of the University of Glasgow's new curriculum.

Instrument

The adapted Ethics in Health Care Survey Instrument (EHCI) was used. This consists of 12 case vignettes that include an ethical dimension. Nine of the 12 cases feature consensus problems, which were derived using three standards:

- There was a significant amount of eminent literature on the topic, which had reached consensus over time.
- There was at least one consensus statement by a professional organisation.
- The substance of the particular consensus was ethically consistent with other consensus topics.

The other cases feature "knife-edge problems" about which professional judgements are scarce or divided.

In addition to asking participants to choose one of the pre-set answers to each case vignette, the EHCI also asks them to justify their chosen response.³⁰⁻³³ For the purpose of this study the focus was on the responses to vignette 8 (box 1).

Box 3 Hierarchy of students' action justifications

Level 4

The student, in proposing a course of action, not only demonstrates the ability to identify, classify, and analyse the issue(s) involved, but also demonstrates the ability to consider alternatives when deciding on his or her course of action.

Level 3

The student, in proposing a course of action, demonstrates his or her ability to identify, classify, and analyse one or more of the ethical issue(s) contained in the vignette.

Level 2

The student, in proposing a course of action, demonstrates that he or she is able to recognise and/or identify one or more of the ethical issue(s) contained in the vignette.

Level 1

The student, in proposing a course of action, does not identify the ethical issue(s) contained in the vignette.

Box 2 Responses

Consensus responses

- Category 1: Based on the consensus reasoning of experts in the field of medical ethics, legal requirements on practitioners, or on policies issued by relevant professional institutions.

Subcategories of non-consensus responses

- Category 2: Based on the student's personal values/morality.
- Category 3: Influenced by other non-medical/legal value systems.
- Category 4: Although based on moral argument, not consistent with the profession's normative values.
- Category 5: Indeterminate.

In October 1996, the EHCI was distributed to the 238 students entering the new curriculum. There was no compulsion for students to undertake the questionnaire; their participation was entirely voluntary. They were assured of this and of the confidentiality and anonymity of their responses. A consent form was attached to the instrument. A total of 162 students returned a completed EHCI before commencing year 1, forming the cohort under observation.

Ethics teaching is mainly delivered in the first 3 years of the curriculum as part of the vocational studies course. The content of the vocational studies ethics sessions has already been described.³⁰⁻³² The EHCI was distributed again to the cohort at the end of year 1, the year in which the largest proportion of ethics sessions takes place, and at the end of year 3 after completion of vocational studies.

After year 3, 101 students left the curriculum to undertake an intercalated BSc, of whom 67 were from the cohort. The remaining students entered the predominantly clinical part of the curriculum. Ethics teaching during these clinical years has also previously been described.³² The EHCI was again distributed to cohort students who were in the process of completing year 5, the final year of the medical curriculum. On each occasion the EHCI was presented in the same format and the students were given 3 weeks to return the questionnaire before a reminder was issued.

Box 4 Values recognition hierarchy

Level 4

The student recognises the value system(s) inherent in his or her course of action, the value system(s) of the individuals involved in the decision-making process, and those of wider society.

Level 3

The student recognises both the value(s) inherent in his or her course of action and those of the individual(s) involved in the decision-making process.

Level 2

The student recognises the value(s) inherent in either his or her course of action or those of the individual(s) involved in the decision-making process.

Level 1

There is no recognition of the value(s) inherent in the student's proposed course of action or those of the individual(s) involved in the decision-making process.

Table 1 Kappa coefficients for the agreement between the two researchers on the categorisations and hierarchical classifications of students' written justifications on all survey occasions

	Categorisation as consensus or non-consensus	5-category classification	Action justification hierarchy	Values recognition hierarchy
Kappa coefficient	0.96	0.80	0.70	0.70

Students' choice of pre-set responses to the consensus questions in each questionnaire were tabulated on an Excel spreadsheet. The written responses to each vignette were transcribed and added to the database.

Analysis

The students' multichoice responses to vignette 8 were compared at the four time points, to determine if their views before starting the curriculum were consistent with the consensus judgement of informed professionals and if they changed as they progressed through the course.³³

Students' written justifications of their pre-set answers were classified independently by the researchers (JG, JM). They were initially classified as being either a "professional consensus" or an "other" response, a form of data reduction after Huberman and Miles.³⁴ A "professional consensus" response was considered to be one based on the consensus reasoning of experts in the field of medical ethics, the legal requirements of practitioners, or the policies issued by relevant professional institutions. The "other" response category was subclassified (box 2). These categories were derived from the reflections of the Glasgow researchers (JG, LS, JM) and one of the original developers of the instrument (Ken Kipnis, University of Hawaii), and grounded in responses given by students in both Hawaii and Glasgow.³³

The students' choice of pre-set answers was compared with the categorisation of their written justification of their choice to help to determine whether their thinking was consistent in terms of professional consensus.

Responses judged to be consensus responses were further classified on the hierarchies of students' action justifications

and values recognition (boxes 3 and 4). The hierarchical levels were grounded in previous responses given by Glasgow students and influenced by the consensus aim of medical ethics education. Comparisons of the positions of students' justifications on these hierarchies before and after instruction were used as measures of change occurring with instruction.³⁵⁻³⁷

The reliability of the categorisation/classification process was estimated using the kappa coefficient, which compares the level of agreement between two raters with that which would have been expected by chance alone (table 1). The results indicated acceptable interrater reliability. After independent rating, areas of disagreement between the raters on the categorisations and hierarchical classifications of the written responses were identified and the responses were further examined and discussed until agreement was reached.

The written responses were independently coded again, by JG and JM, to identify themes for students' reasoning behind their decision to enter a relationship with the patient or not. Cross checking of the researchers' themes showed a high level of agreement.

RESULTS

A total of 111 cohort students returned an EHCI at the end of year 1, and 85 at the end of year 3. The final year class contained 107 students, 102 of whom were from the original intake and 79 from the original cohort. Sixty-two cohort students returned the EHCI at the end of year 5; all had provided a multichoice answer to vignette 8. Written responses to vignette 8 at survey points before year 1 and after year 5 were obtained from 57 students on both occasions. Thirty-three students provided written responses on four occasions and a further 11 on three occasions (figures 1 and 2). Students remaining from the original cohort were similar to the whole class in terms of age (cohort mean age 24 years; class 23 years 8 months), gender (cohort male:female 1:2.5; class 1:2), origin overseas (cohort 10%;

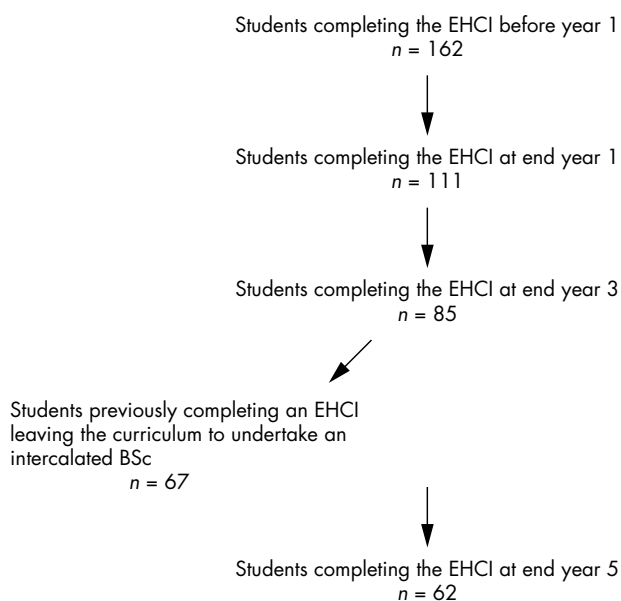


Figure 1 Students completing the EHCI at each survey point (first published in Goldie *et al*, 2004³⁷).

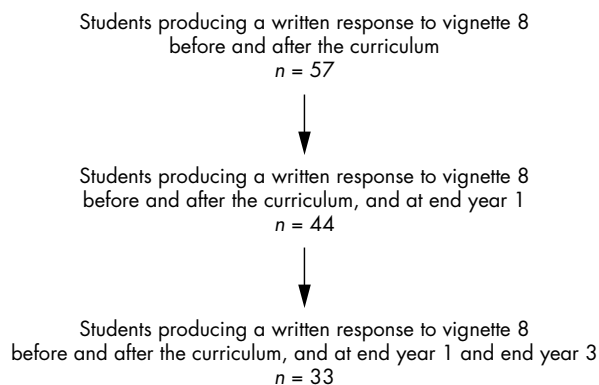


Figure 2 The number of students providing a written response to vignette 8 before and after the curriculum, and at the other survey points.

Table 2 Comparison of the number of consensus written justifications provided by students with the number of consensus multichoice responses chosen for each time point

	Consensus justifications provided: no. (%)	Consensus multichoice response chosen: no. (%)	Agreement (%)
Before year 1 (n = 57)	12 (21)	14 (25)	86
End year 1 (n = 44)	12 (27)	13 (29)	92
End year 3 (n = 33)	8 (24)	10 (30)	80
End year 5 (n = 57)	13 (23)	13 (23)	100

class 9%), and holding a previous degree(s) (cohort 8%; class 8%).

As with the findings of the statistical analysis of students' choice of pre-set answer to vignette 8,³² an analysis of their written justifications showed no significant movement towards consensus at any point in the curriculum. By the end of the curriculum only 23% chose the consensus pre-set answer.

Most of these students justified their position in terms consistent with professional consensus based reasoning (table 2). There was little improvement in students' performance in terms of the position of their written justifications on the hierarchies as they progressed through the curriculum. This was the case in both terms of knowledge content and their abilities to recognise the values inherent in the vignette (table 3).

The reasoning behind responses categorised as non-consensus was most often based on moral argument not consistent with the profession's normative values (table 4).

Students' reasons behind their decision to inform the 12-year-old patient or not, and the frequency of their occurrence at each survey point, are shown in table 5. Often, more than one theme was identified from a response. Where the reasoning behind the decision to tell the patient was aligned with professional consensus thinking, the themes identified most frequently were:

- It is her right to know:

She is an intelligent individual who has a right to know her own state of health and is likely to ask questions, so should be told the truth.

and:

Sunitha is my patient and it is my duty to inform her of what is happening to her. She has a right to know even although it is against the wishes of her parents.

- She is competent:

At 12 years old [she] would understand what you would tell her about dying. If she is bright [as is said] she would ask questions about how long she would live or if she would ever recover—it would be very unfair to keep this information from her.

- The importance of truth telling, honesty, and trust in the doctor–patient relationship:

She probably realises she is dying, children [like Sunitha] are not stupid ... she would lose all faith/trust in me if I lied

Table 3 The hierarchical ratings given by the researchers to written justifications judged to be based on reasoning consistent with professional consensus at each survey point

	Before year 1	End year 1	End year 3	End year 5
Action justification hierarchy				
4	0	0	0	0
3	0	0	0	0
2	11	11	7	11
1	1	1	1	2
Values recognition hierarchy				
4	0	0	0	0
3	2	1	2	3
2	10	9	6	10
1	0	2	0	0

[to her] thus damaging our relationship and harming her care.

- Where students decided to abide by the parents' decision, the most frequent reasoning used was that her parents are in the best position to judge and have her best interests at heart:

Her parents should have the right to decide whether or not their child should be told. They know their child best and only want to protect her and so should be able to do so and let their daughter fully enjoy the time she has left. It is not the doctor's place to make a decision like this.

- The effect on her quality of life was often considered:

A 12-year-old should be allowed to live the rest of her life as happily as possible. Telling her the prognosis will not make any difference and will only make things more difficult for her in the time she has left.

and:

Let Sunitha enjoy the rest of her life. She may not respond well to being told she is dying.

- Other common justifications used were that she was not competent owing to her age and that this is held in law:

Although Sunitha could be deemed competent and thus be able to act autonomously, I feel that, because she is [so] young, her parents' decision should be accepted.

and:

Sunitha's parents are in effect withholding consent to tell her about her condition. They have the right as the parents of a child under 16.

- However, many students, particularly towards the end of the curriculum, felt they were obliged to tell her if she asked directly:

Parents have legal consent over their daughter, but if Sunitha asks about her condition the doctor should not lie and [should] inform the parents of this potential situation.

Table 4 The researchers' categorisation of written justifications judged not to be consistent with consensus reasoning

Multichoice answer	Category	Before year 1: no. (%)	End year 1: no. (%)	End year 3: no. (%)	End year 5: no. (%)
Non-consensus	2: Personal values/morality	15 (35)	11 (35)	9 (39)	11 (26)
	3: Influence of other non-medical/legal value systems	0	0	0	0
	4: Inconsistent with consensus but based on moral argument	27 (63)	19 (62)	14 (61)	30 (70)
	5: Indeterminate	1 (2)	1 (3)	0	2 (4)
Consensus	2: Personal values/morality	2 (100)	1 (100)	2 (100)	0
	3: Influence of other non-medical/legal value systems	0	0	0	0
	4: Inconsistent with consensus but based on moral argument	0	0	0	0
	5: Indeterminate	0	0	0	0

DISCUSSION

Cohort studies are particularly appropriate in research on human growth and development. They provide greater opportunity to observe trends and to distinguish "real" change from chance occurrences.³⁸ This study, like most cohort studies, suffered from sample mortality, in which students undertaking intercalated degrees were a major factor. However, these students were also surveyed at the final survey point, at which time they were completing year 4 of the curriculum. Analysis of the pre-set responses showed that they had a similar performance on vignette 8 to the cohort students completing the curriculum.³²

Cohort studies can also suffer from "control effects". This was a potential source of bias because the same instrument was used on four separate occasions. However, the time interval of 1 year between the first and second stages of the study, 2 years between the second and third stages, and

further 2 years between the third and fourth stages made this less likely. In addition, the students did not receive feedback on the "correct" answer to vignette 8, or on how they performed individually.

The interaction of biological, environmental, and interventional factors can also influence cohort studies. In medical curricula, the longer students are exposed to the hidden curriculum and the process of "moral enculturation", the greater the risk of their ethical development being detrimentally affected.³⁹ However, while this may have played a part in the lack of improvement in performance, the context of vignette 8 is likely to have had a greater influence.

There are six vignettes in the EHCI (1, 2, 4, 5, 6, and 8) in which autonomy is a main issue (see below). Although vignettes 1, 2, 4, and 5 are concerned with the autonomy of adult patients, vignettes 6 and 8 relate to the autonomy of

Table 5 Student's reasoning for and against informing the 12-year-old patient of her prognosis and the frequency of their occurrence at each survey point

Reason given for telling (theme)	Before year 1	End year 1	End year 3	End year 5	Total
Professional consensus based					
It is her right to know	8	7	4	3	22
She is competent	3	6	4	5	18
Importance of honesty/trust	5	1	1	4	11
She is the patient, not the parents	3	0	2	2	7
Doctor's duty to inform her	1	0	1	1	3
Non-professional consensus based					
Negative effect if she finds out/she will work it out	1	3	2	2	8
In her best interests	0	1	1	4	6
But tell parents you are going to inform her	0	2	0	2	4
She can live with the knowledge	1	0	1	1	3
Reasons given for not telling					
Parents know her best	9	13	7	16	45
Enjoy time left/quality of life	15	6	8	6	35
She is not competent	12	8	6	7	33
But if she asks!	5	3	3	13	24
Respect parents' wishes	8	8	2	2	20
Negative effect on parents	7	2	4	6	19
Negative effect on Sunitha	2	2	4	9	17
But convince parents to tell her	2	4	3	3	12
She will work it out	1	2	4	4	11
What good will it do?	4	3	2	2	11
Parents have her best interests at heart	4	3	1	1	9
Parents' right to decide/legal guardians	2	3	0	1	6
I agree with their decision	0	0	0	2	2
As long as they are thinking of Sunitha	0	0	2	0	2
From personal experience	1	0	0	0	1
Miracles can happen	1	0	0	0	1
Arrange counselling for parents	0	0	0	1	1

minors. Vignette 6 is concerned with the autonomy of a 15-year-old patient, vignette 8 with the autonomy of a 12-year-old patient. Before commencing year 1, 84%, 94%, 79%, and 72% of the students chose the consensus pre-set answer for vignettes 1, 2, 4, and 5. Although 53% chose the consensus answer for vignette 6, only 21% chose the consensus for vignette 8. At the end of the course, the high performance achieved before commencement was sustained for vignettes 1, 2, 4, and 5 (86%, 96%, 83%, and 86% respectively). There was a statistically significant improvement for vignette 6 at the end of the course, from 53% to 77%, but little improvement for vignette 8, with only 23% choosing the consensus answer.³²

The topics covered by and the issues involved in the consensus vignettes were as follows (modified from Table 2 of Goldie *et al*³¹):

- Vignette 1: Request for withdrawal of treatment by a competent, paralysed patient who has required a ventilator to keep her alive for 3 years and who has no hope of recovery. The issues involved were:
 - Patient autonomy, competence
 - Withdrawal of treatment
 - Legal precedents
 - Active voluntary euthanasia or passive voluntary euthanasia
 - Beneficence → paternalism
 - Justice (a broad issue re the right to die)
- Vignette 2: Whether to inform a patient with poorly controlled epilepsy, who is opposed to abortion and birth control, about a new medication that carries a 10% risk of severe birth defects. The issues involved were:
 - Patient autonomy, competence
 - Deliberate withholding of treatment
 - Right to know
 - Beneficence, non-maleficence → paternalism
 - Professional guidelines
- Vignette 4: How to respond to a seriously injured patient requiring immediate surgery and blood transfusion, but who, owing to her religion—she is a devout Jehovah's Witness—will not consent to transfusion, thereby greatly reducing her chance of survival. The issues involved were:
 - Patient autonomy versus professional autonomy
 - Respect for others' beliefs
 - Beneficence, non-maleficence → paternalism
 - Rights
 - Truth and trust
 - Duty to treat emergencies
 - Professional guidelines
- Vignette 5: Whether to report an HIV positive prostitute who refuses to refrain from acting in ways that could transmit the virus to her clients. The issues involved were:
 - Patient autonomy
 - Confidentiality
 - Disclosure of information in the interest of others
 - Paternalism and trust ↔ beneficence and non-maleficence
 - Professional guidelines
- Vignette 6: Whether to refer a pregnant 15-year-old Catholic patient for a termination without her parents' consent. The issues involved were:
 - Patient autonomy, competence
 - Confidentiality
 - Disclosure of information
 - Legal precedents
 - Professional guidelines
- Vignette 8: How to respond to the request for information about her prognosis by an intelligent, terminally ill 12-year-old patient with leukaemia whose parents are adamant she should not be informed of her terminal status. The issues involved were:
 - Patient autonomy, competence
 - Legal versus philosophical view of age
 - Information sharing and trust
 - Legal precedents

The improved or sustained high performance at the end of the curriculum for most of the vignettes in which autonomy is a main issue is perhaps not surprising. During year 1, the year with the largest proportion of ethics sessions in the curriculum, there was special reinforcement on autonomy and its prerequisites of patient competence and informed consent. In addition, the concept of autonomy is revisited throughout the curriculum. This emphasis on autonomy reflects conformity with current professional attitudes (such as those described in GMC policy and the UK consensus statement on the teaching of medical ethics) and the law on undergraduate medical education.²⁹ It also reflects current cultural perceptions that partnership or patient centred care is more respectful of the dignity of people as patients.⁴⁰ Students' pre-existing views on adult autonomy, and to a lesser extent the autonomy of a 15-year-old, may reflect these cultural perceptions.

Although there was improvement by the end of the course for the vignette concerning the autonomy of a 15-year-old patient, the curriculum had a minimal effect on the students' pre-existing attitudes towards the autonomy of a 12-year-old girl. This was despite receiving lectures and teaching in large groups on the difference between the philosophical and legal concepts of age and the consequences of the Gillick judgment.⁴¹ The most common justification for not sharing information on her prognosis with Sunitha was that the students believed that the parents' decision to withhold information should be paramount. There were strong paternalistic opinions expressed, such as protecting Sunitha from the consequences of knowing her prognosis. Some students even wished to protect her parents from the consequences of Sunitha knowing her prognosis. Her age would appear to have been a major barrier to respecting her autonomy, with many responses questioning the competence of a 12-year-old, both philosophically and legally. Towards the end of the curriculum, however, more students who stated they would respect the parents' decision indicated they would inform Sunitha if she asked outright for the information. The views expressed may be a reflection on society's views on the autonomy of 12-year-olds.

This article has implications for the future planning of ethics teaching in the University of Glasgow curriculum. The UK consensus statement makes no clear recommendations on the format to be used for ethics teaching.²⁸ In considering how best to foster doctors who will consider the rights of children and young people, we must bear in mind that

students enter medical school with pre-existing perspectives, through which they will view their experiences and from which meaning will emerge. It is important to identify students' perceptions of ethical issues on entry to medical school, and evaluate changes as they progress through the curriculum. Instruments such as EHCI offer the potential to obtain the necessary information.

These meaning perspectives consist of specific values, assumptions, and beliefs, which are often acquired uncritically in the course of childhood through socialisation and acculturation. This occurs most frequently during significant experiences with parents, teachers, and mentors.⁴² These processes have the potential to continue during students' medical education.³⁹ As such they also offer a means of positively influencing students' development because empirical evidence has shown students to be more profoundly affected by role models than by formal coursework.⁴³

Students' meaning perspectives provide them with the criteria for judging or evaluating right and wrong, and what is appropriate or inappropriate.⁴⁴ Values, assumptions, and beliefs can be distorted or invalid, but few people question their basic suppositions about the world or are even aware of them. If students' perceptions are incompatible with their ability to respect the rights of all age groups, is it possible to help them to develop a frame of reference that is more conducive to good practice?

One possible theory for providing the basis for such an approach is transformative learning theory.⁴²⁻⁴⁴ Successful transformative learning questions assumptions, provides support from others in a safe environment, affords challenge, examines alternative perspectives, and gives feedback. New assumptions are tested in the "real" world or in discussion with others.⁴²⁻⁴⁴ Learners' perspectives are potentially transformed into ones that are more "inclusive, differentiating, permeable, critically reflective, and integrative of experience".⁴⁴ Consequentially, the learner is empowered and would be more likely to question a course of action that could compromise the rights of young patients.

Cranton has produced guidelines for transformative educators.⁴⁵ Lectures and teaching of large groups, the format during which the students received direct instruction on many of the relevant issues on the rights of young people, is not conducive to the promotion of transformative learning.⁴⁵ Process evaluation of the first year of vocational studies found that the teaching in small groups process adopted contains many of the conditions conducive to transformative learning—for example, the tutors, who lead the group throughout all vocational studies sessions in the first year, become part of the group and provide challenge to students by adopting a "reformist" perspective. They use various teaching and learning strategies and provide opportunities for rational discourse and critical self-reflection in a "safe" environment. The integration of the curriculum was also found to be important—for example, experiences during early patient contact are used as a challenge and contextualise ethics for students.⁴⁶ There was, however, no direct tuition on the rights of children and young people in this format. We hypothesise that teaching may be more effective if the format of the first year vocational studies teaching in small groups is used. Cranton's guidelines for promoting transformative learning are:

- Promote rational discourse;
- Promote equal participation;
- Encourage decision making;
- Encourage critical self-reflection;
- Consider individual differences among learners;
- Employ various teaching and learning strategies.

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JG conceived and designed the study, collected data, supervised data analysis and wrote the article. JM was involved in the conception and design of the study, its ongoing management, and analysis of data, and contributed to the writing of the article. LS was involved in the conception and design of the study and contributed to the writing of the article.

The Glasgow University Ethics Committee did not wish to consider the study in 1996 when it started. Approval was obtained from the Curriculum Committee at that time.

REFERENCES

- 1 **British Medical Association**. *Consent, rights and choices in health care for children and young people*. 3rd ed. London: BMJ Books, 2003.
- 2 **Nitschke R**, Meyer WH, Sexauer CL, et al. Care of terminally ill children with cancer. *Med Pediatr Oncol* 2000;**34**:268-70.
- 3 **Nitschke R**. Regarding guidelines for assistance to terminally ill children with cancer: report of the SIOP Working Committee on psychosocial issues in pediatric oncology. *Med Pediatr Oncol* 2000;**34**:271-3.
- 4 **Kreicbergs U**, Valdimarsdottir U, Onelov E, et al. Talking about death with children who have severe malignant disease. *N Engl J Med* 2004;**351**:1175-86.
- 5 **Goldman A**, Christie D. Children with cancer talk about their own death with their families. *Pediatr Hematol Oncol* 1993;**10**:223-31.
- 6 **Hilden JM**, Watteron J, Chrastek J. Tell the children. *J Clin Oncol* 2000;**18**:3193-5.
- 7 **Bluebond-Langner M**. *How terminally ill children come to know themselves and their world: the private worlds of dying children*. Princeton, NJ: Princeton University Press, 1978:166-97.
- 8 **Raimbault G**. Children talk about death. *Acta Paediatr Scand* 1981;**70**:179-82.
- 9 **Spinetta JJ**, Swarner JA, Shepesh JP. Effective parental coping following the death of a child from cancer. *J Pediatr Psychol* 1981;**6**:251-63.
- 10 **Massera G**, Spinetta JJ, Jankovic M, et al. Guidelines for assistance to terminally ill children with cancer: a report of the SIOP Working Committee on psychosocial issues in pediatric oncology. *Med Pediatr Oncol* 1999;**32**:44-8.
- 11 **Hilden JM**, Emanuel EJ, Fairclough DL, et al. Attitudes and practices among pediatric oncologists regarding end-of-life care: results of the 1998 American Society of Clinical Oncology survey. *J Clin Oncol* 2001;**19**:205-12.
- 12 **Himelstein BP**, Hilden JM, Boldt AM, et al. Pediatric palliative care. *N Engl J Med* 2004;**350**:1752-62.
- 13 **National Children's Bureau**. *Child health ten years after the Court report: report of the policy and practice review*. London: NCB, 1987.
- 14 **Dworkin G**. *The theory and practice of autonomy*. Cambridge: Cambridge University Press, 1988:85.
- 15 **Holder A**. *Legal issues in pediatrics and adolescent medicine*. New Haven, CT: Yale University Press, 1985:264.
- 16 **Stone GC**. Patient compliance and role of the expert. *J Soc Issues* 1979;**35**:34-59.
- 17 **Alderson P**. *Choosing for the children*. Oxford: Oxford University Press, 1990:107-10.
- 18 **Beauchamp TL**, Childress JF. *Principles of biomedical ethics*. Oxford: Oxford University Press, 1994.
- 19 **Kennedy I**, Grubb A. *Medical law: the text and materials*. London: Butterworths, 1989.
- 20 **Bluebond-Langer M**. *The private worlds of dying children*. Princeton, NJ: Princeton University Press, 1978.
- 21 **Alderson P**. *Children's consent to surgery*. Buckingham: Open University Press, 1993.
- 22 **Gardiner H**. *The unschooled mind*. London: Fontana, 1993.
- 23 **Kail RV**. *Memory development in children*. 3rd ed. San Francisco, CA: Freeman, 1990.
- 24 **Buchanan AE**, Brock W. *Deciding for others: the ethics of surrogate decision making*. Cambridge: Cambridge University Press, 1989.
- 25 **Archard D**. *Children, rights and childhood*. London: Routledge, 1993.
- 26 **Kennedy I**. The doctor, the pill and the 15 year old girl. In: Lockwood M, ed. *Moral dilemmas in modern medicine*. Oxford: Oxford University Press, 1985:37-9.
- 27 **Mental Health Act Review Expert Committee**. *Review of the Mental Health Act 1983: report of the Expert Committee*. London: Department of Health, 1999.
- 28 **Education Committee of the General Medical Council**. *Tomorrow's doctors*. London: GMC, 1993.
- 29 **Consensus Statement**. Teaching medical ethics and law within medical education: a model for the UK core curriculum. *J Med Ethics* 1998;**28**:188-92.
- 30 **Goldie J**, Schwartz L, McConnachie A, et al. Impact of a new course on students' potential behaviour on encountering ethical dilemmas. *Med Educ* 2001;**35**:295-302.
- 31 **Goldie J**, Schwartz L, McConnachie A, et al. The impact of three years' ethics teaching, in an integrated curriculum, on students' proposed behaviour on meeting ethical dilemmas. *Med Educ* 2002;**36**:489-97.

- 32 **Goldie J**, Schwartz L, McConnachie A, *et al.* The impact of a modern medical curriculum on students' proposed behaviour on meeting ethical dilemmas. *Med Educ* 2004;**38**:942–9.
- 33 **Goldie J**, Schwartz, McConnachie A, *et al.* Can students' reasons for choosing set answers to ethical vignettes be reliably rated? Development and testing of a method. *Med Teacher* 2004;**26**:713–8.
- 34 **Huberman AM**, Miles MB. Data management and analysis methods. In: Denzin NK, Lincoln YS, eds. *Handbook of qualitative research*. Thousand Oaks, CA: SAGE, 1994:428–44.
- 35 **Goldie J**, Schwartz L, McConnachie A, *et al.* Students' attitudes and potential behaviour with regard to whistle blowing as they pass through a modern medical curriculum. *Med Educ* 2003;**37**:368–75.
- 36 **Goldie J**, Schwartz L, Morrison J. Students' attitudes and potential behaviour to a competent patient's request for withdrawal of treatment as they pass through a modern medical curriculum. *J Med Ethics* 2004;**30**:371–6.
- 37 **Goldie J**, Schwartz L, Morrison J. Sex and the surgery: students' attitudes and potential behaviour as they pass through a modern medical curriculum. *J Med Ethics* 2004;**30**:480–6.
- 38 **Cohen L**, Manion L, Morrison K. *Research methods in education*. 5th ed. London: Routledge Falmer, 2000.
- 39 **Hafferty FW**, Franks R. The hidden curriculum, ethics teaching and the structure of medical education. *Acad Med* 1994;**64**:861–71.
- 40 Patient–provider partnership in health care [theme issue]. *BMJ* 1999;**319**(7212).
- 41 *Gillick v West Norfolk and Wisbech AHA* (1985) All ER 402.
- 42 **Mezirow J**. *Transformative dimensions of adult learning*. San Francisco, CA: Jossey Bass, 1991.
- 43 **Goldie J**. Review of ethics curricula in undergraduate medical education. *Med Educ* 2000;**34**:108–19.
- 44 **Mezirow J**. Contemporary paradigms of learning. *Adult Education Quarterly* 1996;**46**:158–72.
- 45 **Cranton P**. *Understanding and promoting transformative learning: a guide for educators of adults*. San Francisco, CA: Jossey Bass, 1994.
- 46 **Goldie J**, Schwartz L, Morrison J. A process evaluation of medical ethics education in the first year of a new medical curriculum. *Med Educ* 2000;**34**:468–73.