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RESEARCH ARTICLE

"We just follow the patients' lead": Healthcare professional perspectives on the involvement of teenagers with cancer in decision making

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Abstract

Purpose: We report on an in-depth interview and participant observation study that uses data from multiple sources to determine how the involvement of teenagers with leukaemia is understood and enacted in healthcare. In this article, we investigate healthcare professionals' (HCP) views of teenagers' involvement in decisions about their care and treatment for leukaemia.

Methods: We conducted participant observation at 98 multi-disciplinary meetings and 95 open-ended, semi-structured interviews and informal conversations with clinical teenage cancer teams at one UK tertiary referral centre. Data were collected over a 9-month period, audio-recorded, transcribed verbatim and analysed using principles of grounded theory.

Results: HCP revealed principles relating to the involvement of teenagers with leukaemia in decision making: (1) do the 'right thing', (2) act on the care and treatment preferences of the teenager and (3) openly disclose information about the teenagers' condition. These principles were prioritised and utilised uniquely in each situation, reliant on three mediating factors: (1) family communication styles, (2) stage of illness and (3) nature of the disease.

Conclusions: Specialist haematology teams are aware of the individual, and shifting and situational preferences of teenagers. They follow the lead which teenagers give them with regard to these preferences. If actual practice with regard to the involvement of teenagers is found to be wanting, this study refutes that this should be ascribed to insensitivity on the part of HCP about teenagers informational and decisional role preferences.

KEYWORDS
adolescents, decision making, haematology

1 | INTRODUCTION

Healthcare professionals (HCP) play a pivotal role in involving teenagers in decisions about their care and treatment.[1,2] Clinical teams work with both teenagers and their families in decision making, communicating information to them, seeking their opinions and incorporating these into treatment plans. Yet, there has been little research on HCP real-time views of involving teenagers, how those views may be affected by time and circumstance and how they are manifest in practice.[3]

In this article, we examine the views of HCP, consultants, registrars/ residents, speciality registrars/ fellows, clinical nurse specialists (CNSs), nurses and allied HCP caring for teenagers aged 13–19 years who were receiving treatment for haematological cancers. In this context, HCP are often dealing with decisions of serious consequence. Sometimes all of the options available have poor outcomes.

Abbreviations: CNS, clinical nurse specialist; HCP, healthcare professionals; IC, Informal conversation; MDT, multi-disciplinary team; TYA, teenage and young adult

We report on the views HCP expressed in interviews, during informal conversations (IC) and in multi-disciplinary team (MDT) meetings over an observational period of 9 months. These data form part of a larger ethnographic study of the role of teenagers with haematological cancers in decision making.[4] We collected data in real time: before, during and after decisions were made for teenagers under the care of the HCP participating in the study. We consider whether views of involvement of HCP were rigid or varied according to context, and take account of the impact of clinical practice on their expressed views.

2 | METHODS

2.1 | Participants

The research was based at a single metropolitan tertiary referral centre in the UK. Data were collected from the multi-disciplinary specialist teenage and young adult (TYA) haematology team. All HCP working as part or in conjunction with the TYA team were eligible and were invited to participate. Ethnographer (ED) provided verbal and written information on the research process to the TYA team through a series of presentations. Consent forms were distributed and returned at MDT meetings. Those who did not wish to consent would have their audio removed from the dataset. Due to the nature of shift work, staff rotation and leave, information provision and recruitment of HCP continued throughout the study. No HCP refused consent.

2.1.1 | Ethical considerations

Permissions were sought and granted as part of the larger study from the UCL ethics committee, NHS ethics committee [Bloomsbury NRES 31-02-2014], the Confidentiality Advisory Group (CAG) and from the Research and Development department at the research site.

2.2 | Research design

2.2.1 | Larger ethnographic study

Our data form part of a larger ethnographic study in which we sought to explore decision making for teenagers aged 14–20 years with newly diagnosed or relapsed acute lymphoblastic or acute myeloid leukaemia, their families and HCP involved in their care.[4] We explored their views in principle and actions in practice.

2.2.2 | Data presented in this paper

ED embedded herself within the clinical team over 9 months, attending psycho-social meetings, day-care meetings and pre-ward round meetings held by the TYA team, and also consultations with teenagers and families.

Data used for this article consisted of observations of MDT meetings (N = 98; 58 HCP), semi-structured interviews with HCP (N = 12; 12 HCP) and IC with HCP (N = 83; 19 HCP). MDT meetings and interviews were audio-recorded and transcribed verbatim. Interviews were open-ended and conducted with a semi-structured guide. IC were audio-recorded and captured in handwritten notes, they lasted between 5 and 30 min and were led by participants in response to situations (meetings, consultations) as they occurred. The primary goal of these conversations was to enable participants to describe the preceding event in their own words, but where necessary the researcher encouraged discussion by using memorised prompts from the interview guide, previous discussions, consultations and meeting outcomes. The combination of observations, interviews and IC produced an account of views of HCP and perceptions of teenagers' involvement across time and setting (see Table 1 for details of data sources and participants' contribution to the dataset).

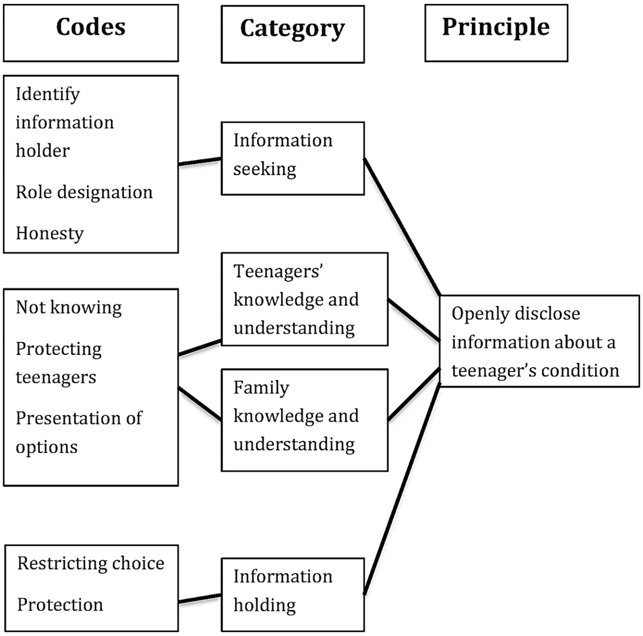

FIGURE 1 Figure depicting an extract of the analysis process for the development of Principle 3

2.3 | Analytic approach

The theoretical perspective of interactionism provided the overarching framework for this research, in which the social world is recognised as a place where meaning is formed through interaction between individuals.[5] Data were coded in two phases. Initially, data were index coded (I-codes) and later analytically coded (A-codes) to identify important concepts within the data. Each transcript was read and, using NVIVO 11, I-codes were applied (ED). I-codes included the diagnosis, the time point in the illness and the decision discussed. 'A-codes' focused on more analytical tagging of the data to develop key ideas that were initially flagged through notes and memos in the field. These codes were refined and categorised as analysis continued (see Figure 1). The team (E.D., L.J. and M.B.L.) met regularly to review coding and analysis, as it occurred to ensure dependability. Ten percent of the complete dataset was reviewed by two members of the team (M.B.L. and L.J.) and disagreements were resolved by consensus. Constant comparison was used to identify similarities, differences and relationships, to refine ideas and to develop new ones. This process identified principles of involvement and mediating factors that influenced how HCP viewed, discussed and reported enacting these principles.

TABLE 1 Overview of participants and their contribution to the dataset

Professional Group	Number of individuals recruited	Number of whom were Interviewed	Number with whom informal conversations were held	Number of whom spoke at MDT meeting
Consultant	6	5	5	6
Junior Doctor	19	0	4	19
Clinical Nurse Specialist	9	4	5	9
Ward Nurse	10	1	3	10
Allied HCP	14	2	2	14
Total	58	12	19	58

Junior doctors include foundation year, speciality trainees and speciality registrars. Allied HCP include psychologists, physiotherapists, dieticians and social workers.

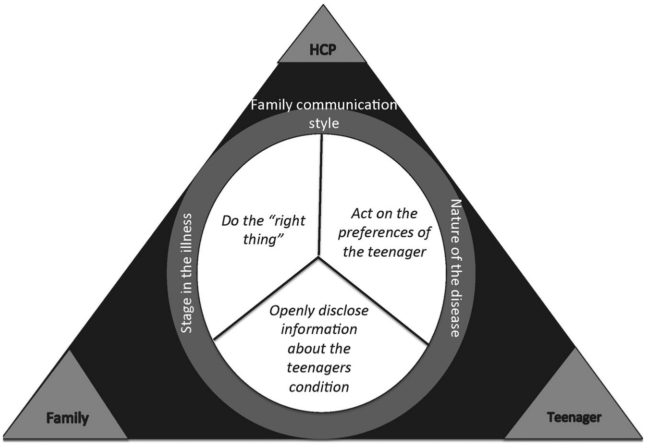

FIGURE 2 Interplay of principles (inner circle) and mediating factors (outer circle)

3 | RESULTS

Fifty-eight HCP were recruited, including six consultants, 19 junior doctors (foundation year, registrar/ resident and specialty registrar /fellow), nine CNSs, 10 ward nurses and 14 allied HCP (psychologists, physiotherapists, dieticians and social workers). HCP specialised in haematology, haemopoietic stem cell transplant or palliative care working principally with patients aged 13–25 years. There were no refusals to consent.

Our analysis revealed three core HCP principles about decision making with teenagers', namely, (1) do the 'right thing', (2) act on the care and treatment preferences of the teenager and (3) openly disclose information about the teenagers' condition, prognosis and treatment. Each of these principles was utilised and prioritised by HCP uniquely in each situation. To do this, HCP relied on mediating factors embedded in the illness of each teenager relating to (1) family communication styles, (2) stage of the illness and (3) nature of the disease (see Figure 2). Exemplar quotes are presented for each principle and factor in Supplementary Table S1.

3.1 | Principles of teenagers involvement

3.1.1 | Do the 'right thing'

HCP spoke explicitly and implicitly about doing the 'right thing' when making decisions about care and treatment. Determination and expression of what the 'right thing' was largely considered the responsibility of the HCP rather than the teenager. Consequently, decisions on the 'right' or most suitable course of action were discussed by HCP in meetings, where teenagers and families were absent. Consistent with this, HCP affirmed that the responsibility for decisions in situations where there is little possibility of long-term cure lies mostly with themselves as clinicians, rather than with the teenagers and their families.

Observations of MDT discussions identified the challenges associated with this approach. HCP recognised that the 'right thing' as determined by clinical assessment did not always align with what the teenager or parents wanted or deemed 'right'. One consultant summarised the challenges this proposed: 'Our job is to do the right thing, not be loved'. Another HCP did acknowledge at interview that when end-of-life issues came to the fore, there might be benefit to involving teenagers and parents, to identify the 'right thing' from the family's perspective.

3.1.2 | Act on the care and treatment preferences of the teenager

A second principle of involvement observed across the dataset was the notion of acting on the care and treatment preferences of the teenager. HCP spoke during interviews of the effort made to 'follow the teenagers' lead'. However, while this principle was advocated for certain decisions (place of care, minor procedures), for others HCP recognised that acting on teenagers' treatment preferences might not be possible, feasible or desirable. This was particularly the case for decisions governed by internationally agreed treatment protocols, or those where there was the likelihood of serious harm, death or suffering (refusal of curative treatment, reduction of chemotherapy dose and escalation of care to intensive care).

MDT discussions highlighted how HCP responses to teenagers' care and treatment preferences varied over time and in the context of different decisions. HCP weighed the feasibility of enacting teenagers' care and treatment preferences against their clinical responsibility to provide what they judged to be the best care.

3.1.3 | Openly disclose information about the teenager's condition, prognosis and treatment

Analysis revealed that open communication was a paramount HCP principle of involving teenagers in decision making about care and treatment. At MDT meetings, HCP regarded information provision as an indication that a teenager had been involved in decision making. However, open communication in their view did not always mean explicit verbalisation of every outcome. Sensitive information was often implied or suggested, not stated directly. One consultant explained that when cure was unlikely, they 'might not actually verbalise "and the outcome is you're going to die"' instead, informing the teenagers of test results and the difficulties moving forward.

HCP recognised the importance of establishing and respecting what the teenager wanted and needed to know at different times across the illness. HCP depended on indications from the teenager to do this. One CNS suggested that if the teenager was not asking the questions, it put them in a 'very difficult situation' particularly with regard to the necessity of obtaining informed consent and relaying prognostic information.

3.2 | Mediating factors affecting prioritisation and utilisation of principles

3.2.1 | Family communication style

HCP articulated the view that each teenager was unique and the approach one took to disclosure would vary. Professionals suggested that teenagers were able to indicate how and when they preferred to receive information and voice preferences regarding their care and treatment. HCP felt they should take the lead on what to disclose from the teenagers themselves. In so doing, they assigned responsibility to the teenager for signalling verbally and non-verbally, their desired degree of involvement in decision making. With experience, HCP learned to pick up cues from teenagers about the level of information they wish to have.

HCP also considered what other family members' communication preferences were. They acknowledged the importance of the family's role, not least due to the reality that it is the family that will be left behind if the teenager dies, with one consultant stating 'You've clearly got to involve the family. They're very important and it's them that are going to grieve'.

Common tensions between age-appropriate growing independence and the necessary dependence of a teenager diagnosed with cancer sometimes led to confusion about the influence of parents and families on teenagers' choices, as one consultant verbalised 'You really don't know what the influences of parents are'.

HCP acknowledged the importance of respecting these family communication styles and allowing parents and teenagers the space to establish their roles in the decision-making process. HCP recognised that the family and teenager were inextricably woven together; attempts to separate the care and treatment preferences of one from the other were not always possible.

3.2.2 | Stage of the illness

HCP noted that the stage of the illness influenced how they felt they were able to enact teenagers' involvement. Professionals suggested that the stage in the illness (diagnosis, first-line disease-directed treatment, relapse, stopping disease-directed treatment, end-of-life) impacted on which principle of involvement they felt able to prioritise in practice. Leukaemia treatment, particularly at diagnosis and relapse, follows strict internationally agreed protocols. HCP acknowledged that this limited teenagers' involvement at these points to listening and understanding, rather than choosing the course of action. During interviews, HCP discussed a possible shift when disease-directed treatment began to fail and suggested that at this point families and teenagers are pulled into the decision-making process, and asked to voice opinions and preferences. However, during MDT meetings and informal discussions, HCP acknowledged that it was difficult to respond to these preferences. In practice, the final authority for such decision making toward end of life lay with HCP and the clinical consensus.

3.2.3 | Nature of the disease

HCP also considered the specific problems associated with haematological cancers. Professionals suggested that due to the systemic nature of the illness, decisions relating to stopping disease-directed treatment were not as clearly demarcated as with solid tumour patients. Consequently, HCP reports and observations of team discussions highlighted uncertainty about the purpose and advantage of pursuing some later stage treatments. HCP reported how the nature of the disease resulted in difficulty in giving teenagers and families' clear and accurate information about different options and their respective outcomes, one nurse stating 'I think it's much harder to sit down and tell someone this is what's going to happen because you just don't know'. This influenced how, when and to what to extent HCP felt able to involve teenagers in decisions about their care and treatment. HCP often sought clinical guidelines and consulted with other professionals to determine whether a certain treatment or trial should be permitted or excluded. During these periods of uncertainty involvement of other professionals was prioritised in reaching a decision, thus limiting the role afforded to teenagers in the process.

4 | DISCUSSION

In this article, we have focused exclusively on HCP principles regarding the involvement of teenagers in decision making. In addition to interviews with HCP about their principles, we used sources of data not previously found in the literature: IC with an embedded ED and verbatim transcripts of MDTs. This triangulated dataset allowed us to hear not only principles explicitly articulated by HCP but also to identify additional principles and factors that would be used in applying these explicit principles to the involvement of teenagers in specific circumstances.

HCP principles, their perception of what constitutes teenagers' involvement and how it should be enacted increase understanding of the process of realising optimal outcomes for teenagers and their families. The effort spent developing written guidance for HCP and providing training in communication reflects a belief that a sound understanding of correct principles is an important part of bringing about involvement of teenagers in decision making.

Previous studies have found that involvement of teenagers is less than optimal and have ascribed this to HCP attitudes and behaviours. Studies suggest that a solution might be more flexible models of care or communication training for HCP to increase awareness of teenagers' and families' preferences.[3,6,7] It is constructive, therefore, to compare the HCP principles we describe with published empirical findings on experiences and preferences of teenagers and families in decision making. This would use available evidence to begin identifying barriers to achieving optimal involvement. This step might locate where in the movement from principles to practice such barriers may lie and in turn what sort of interventions might be needed to enhance shared decision making.

4.1 | HCP principles and previous literature

The terms 'participation' and 'involvement' in medical decision making are understood to encompass a spectrum of activities,[3,6–10] giving and receiving information, expressing an opinion, negotiating with parents and making a choice. Coyne et al. regard shared decision making with children and teenagers as ways in which they can contribute to the decision-making process irrespective of who makes the final decision.[10] These options reflect the experiences of teenagers, parents and HCP.

Both the preferences and roles children and teenagers report are dynamic and situational.[3,6–10] The type and amount of information children and teenagers want, as well as their engagement in consultations, varies over time. Teenagers can variously be keen to make or actively contribute to some decisions and delegate others, or want to know or not be actively engaged.[6] A number of factors can influence these preferences, notably, the stage in the illness trajectory, the teenagers' state of wellness or illness and type of decision under consideration.[9]

It is reported that teenagers do not always state their preferences for information and engagement directly. Gibson et al. report that both younger children and teenagers give non-verbal cues to HCP about whether or not they wished to talk.[11] They also wanted staff to recognise when they were having difficulty asking questions.

4.2 | Alignment of HCP principles, preferences and practices

Our data show that HCP were well aware that the preferences of teenagers changed over time and in the contexts of different decisions; they were sensitive to the fact that teenagers' preferences vary with the nature of information under discussion. They recognised that teenagers would sometimes signal these preferences non-verbally rather than tell HCP what they wanted to talk about and in what detail. HCP tried to avoid overburdening teenagers with unwanted information.

HCP in our study made the distinction between decisions of serious and minimal consequence; these differences are also noted in a number of other studies.[3,6,9,11] They did, when they felt it proper, involve teenagers in discussion about how and when treatments were administered when the choices would not interfere with overall efficacy of treatment. Several studies report that teenagers' and parents' involvement in decisions of minimal consequence is important for sustaining a positive attitude and cooperation.[9]

However, sound principles do not guarantee sound practice. Further research is needed to determine whether any suboptimal involvement of teenagers may be due either to a failure to implement good principles or to external factors that hinder HCP.

These factors can have different sources. Implementation of these principles places demands on HCP to assess a family's communication style and reassess teenagers' preferences at every decision point. This is time consuming and HCP workloads may make this difficult. Some studies suggest that HCP struggle to manage tripartite (HCP, teenagers and families) interaction, which contributes to a diminished role for teenagers.[9,12]

Implementation of principles may be further hampered by conflicts for HCP created by the principles themselves. For example, teenagers' or parental preferences for information may conflict with HCP convictions about the rights of children or with their professional training about what is right for children and teenagers.[13]

The nature of the disease itself and the stage in the illness may also lead to suboptimal involvement of teenagers in several ways.

First, though these HCP applied their principles situationally, one result was constant. When there was an 'optimum curative treatment' available for the patient or a protocol, this was strongly advocated. HCP were aware that in specific cases this might conflict with teenagers' or family preferences. However, they took the position that in these situations clinical judgment must prevail, and teenagers and parents must simply give permission rather than choose between options. Previous studies have observed the same dynamic.[8,10]

Second, when it is important to begin treatment as soon as possible, teenagers and families may feel rushed, lacking sufficient time to work through the impact of the diagnosis.

Third, HCP uncertainty about the course of a teenager's disease could lead to a type of filtering of information by HCP. Professionals in our study reported reservations about how to discuss, with teenagers, uncertainty about the likelihood of success of treatments and trials when the disease had progressed, balancing openness with allowing families to maintain hope.

Any combination of these factors could lead to suboptimal realisation of HCP principles. Such barriers need to be understood before interventions are proposed.

5 | LIMITATIONS

Several factors limit generalisation of our findings. This research was conducted with a dedicated TYA team at a large tertiary referral hospital. The unique population of such a centre may influence HCP reports. Demographic data on HCP were not collected so we cannot assess the potential impact of these on our findings. Not all recruited HCP could be interviewed or engaged in an informal discussion. Some views may have been missed, particularly from registrars/ residents, speciality registrars/ fellows and ward nurses.

Our work focuses specifically on decision making in haematological cancers. Similar research with other disease groups and in illnesses that are not life threatening or life limiting is needed to give a complete picture of how HCP in general view the involvement of teenagers in decision making.

5.1 | Implications for research and practice

HCP views and principles for involvement of teenagers have received little attention. Our research shows that haematology teams are aware of the individual, and shifting and situational preferences of teenagers. If actual practice with regard to the involvement of teenagers is found to be wanting, this study raises questions whether or to what degree this should be ascribed to insensitivity on the part of HCP about teenagers' informational and decisional role preferences. We need to investigate whether the awareness and sensitivity found in this study is shared widely or is an exception. We need to understand what barriers HCP perceive in trying to act upon their principles, institutional, interactional or personal. Such understanding will support the development of training for HCP that is targeted and practical. It could also be used to frame guidance for HCP that is less abstract than what is currently available.[8]

Another crucial step is to study longitudinally and in real time how teenagers and their families view their own involvement in this setting. Further investigation, focusing how these other parties come together in observed encounters to negotiate involvement in practice, will offer a more nuanced picture. It will enable us to incorporate into recommendations for policy and guidance the views and real time experiences of HCP, families and teenagers.

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CONFLICT OF INTEREST

The authors declare that there is no conflict of interest.

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REFERENCES

1. Inglin S, Hornung R, Bergstraesser E. Palliative care for children and adolescents in Switzerland: a needs analysis across three diagnostic groups. *Eur J Pediatr*. 2011;170(8):1031–1038.
2. Matsuoka M, Narama M. Parents' thoughts and perceptions on hearing that their child has incurable cancer. *J Palliat Med*. 2012;15(3):340–346.
3. Ruhe KM, Wangmo T, De Clercq E, et al. Putting patient participation into practice in pediatrics—results from a qualitative study in pediatric oncology. *Eur J Pediatr*. 2016;175(9):1147–1155.
4. Day ER. 2017. Principles and practices for involving teenagers in decision-making about their care and treatment: a prospective participant-observation study to inform policy and practice. Doctoral dissertation. Great Ormond Street Institute of Child Health, UCL.
5. Rock P. The Making of Symbolic Interactionism. Totowa, NJ: Rowman and Littlefield; 1979.
6. Kelly KP, Mowbray C, Pyke-Grimm K, Hinds PS. Identifying a conceptual shift in child and adolescent-reported treatment decision making: "Having a say, as I need at this time". *Pediatr Blood Cancer*. 2016;64:e26262.
7. Weaver MS, Baker JN, Gattuso JS, Gibson DV, Sykes AD, Hinds PS. Adolescents' preferences for treatment decisional involvement during their cancer. *Cancer*. 2015;121(24):4416–4124.
8. Ruhe KM, Badarau DO, Brazzola P, et al. Participation in pediatric oncology: views of child and adolescent patients. *Psycho-oncology*. 2016;25:1036–1042.
9. Coyne I, Gallagher P. Participation in communication and decision-making: children and young people's experiences in a hospital setting. *J Clin Nurs*. 2011;20(15–16):2334–2343.
10. Coyne I, Amory A, Kiernan G, Gibson F. Children's participation in shared decision-making: children, adolescents, parents and healthcare professionals' perspectives and experiences. *Eur J Oncol Nurs*. 2014;18(3):273–280.
11. Gibson F, Aldiss S, Horstman M, Kumpunen S, Richardson A. Children and young people's experiences of cancer care: a qualitative research study using participatory methods. *Int J Nurs Stud*. 2010;47(11):1397–1407.
12. Tates K, Elbers E, Meeuwesen L, Bensing J. Doctor–parent–child relationships: a 'pas de trois'. *Patient Educ Couns*. 2002;48(1):5–14.
13. Worthington R. Standards of healthcare and respecting children's rights. *J R Soc Med*. 2006;99(4):208–210.

SUPPORTING INFORMATION

Additional Supporting Information may be found online in the supporting information tab for this article.

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