

Educational piece - submission to BMJ Supportive & Palliative Care

Title: The nice thing about doctors is that you can sometimes get a day off school': An action research study to bring lived experiences from children, parents and hospice staff into medical students' preparation for practice

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ABSTRACT

Patient and public involvement in healthcare is important to ensure services meet their needs and priorities. Increasingly patient experiences are being used to educate healthcare professionals. The potential contribution to medical education of children and parents using hospice services has not yet been fully explored.

Objectives

1. To explore perceptions of what medical students must learn to become 'good doctors' among children, parents and staff in a hospice
2. To collaborate with children/parents and staff to develop educational materials based on their lived experiences for medical students
3. To assess feasibility of student-led action research in a children's hospice to develop research skills

Methods

Prospective ethical approval received. Volunteer children (n=7), parents (n=5), and staff (n=6) were recruited from a children's hospice. Data were generated in audio-recorded semi-structured focus groups, individual interviews and/or activity workshops. Participants discussed what newly qualified doctors' needed to care for children with life-limiting conditions. Audio data were transcribed and combined with visual data for thematic analysis. Findings were refined by participant feedback. This paper presents thematic findings and educational material created from the project.

Results

Thematic analysis identified six learning themes: (1) Treat children as individuals; (2) Act as a person before being a doctor; (3) Interpersonal communication; (4) Appreciate the clinical environment; (5) Learn from children, parents and other staff; (6) How to be a doctor as part of a team. The student-researcher successfully developed qualitative research skills, co-producing materials with participants for sharing learning derived from lived experiences.

Conclusions

All participants were willing and able to make valuable contributions and believed that this was a worthwhile use of time and effort. Further work is required to understand how best to integrate the experiences of children in hospices into medical education.

Main text

INTRODUCTION

Patient involvement is important to ensure services meet patient needs and priorities and can result in improved sense of well-being.^{1,2,3} Using patient experiences to educate impacts on medical student attitudes and skill development.^{4,5} Parents and children in general paediatric services are willing to facilitate clinical skills education.^{6,7} Children with life-limiting illnesses need opportunities to ensure professionals are equipped to provide appropriate care but the contributions of children and parents using hospice services together with hospice staff has not been fully explored. Medical students have lower confidence in paediatric palliative care than other specialities⁸ with limited specific teaching.⁹ Despite relative rarity of child mortality from incurable illnesses, understanding care in children's hospices helps students to improve understanding of patient-centred care and enhance communication skills.^{10,11,12,13}

In this paper we explore what children, parents and hospice staff want medical students to learn in preparation for their careers as doctors.

METHODS

Ethical approval was received.

Objectives

To

1. explore perceptions of what medical students must learn to become 'good doctors' among children, parents and staff in a hospice
2. collaborate with children/parents and staff to develop educational materials based on their lived experiences for medical students
3. assess feasibility of student-led action research in a children's hospice to develop research skills

Setting, recruitment and participation (see Table 1)

A medical student (JS) led the study with clinical and academic supervision. The participating hospice provides specialist care and support for children aged 0-19 with shortened life expectancy, and their families. The study was conducted in school holidays to facilitate participation.

Staff recruitment

JS, known to some staff members from non-clinical volunteer work, recruited clinical staff by informal advertising within the hospice and disseminating study information. There were no specific inclusion/exclusion criteria for staff. Written consent was obtained prior to participation.

Child recruitment

An access condition required potential child volunteers to be pre-screened by the clinical director of care and play specialist. These individuals identified all children aged 8-19 who had used hospice services in the last 12 months (n=51). Further inclusion criteria included: verbal communication skills and ability for basic understanding of the study aims: 31 (14 aged 8-12, 17 aged 12-19), were sent study information. Three potential participants could not be contacted with the details supplied by the hospice. A parent or guardian provided written consent (with each child's agreement) prior to workshop participation.

Parent recruitment

JS attended a parent support meeting to advertise the study and invited parents of participating children. Written consent was obtained prior to participation.

Volunteer participants	Workshop attendance	Individual interviews	Focus group
Children (8-12yrs)	3 (2 male, 1 female)		
Children (12-14 yrs)	4 (all female)		
Parents	3 (all female)	2 (both female)	
Staff			6 (all female)

Reasons for non-participation included; time conflict with medical appointments (n=2), away on holiday (n=7), too unwell (n=3), late withdrawal with acute illness (n=2), unknown (n=7).

Data generation

The hospice was considered familiar and safe by participants. Data was generated there via audio-recorded semi-structured focus group (staff), audio-recorded individual interviews (parents) plus two interactive multimedia workshops facilitated with a play specialist. Participants were orientated to the research objectives informally by the first author at the start of each session. Detailed field notes and photographs of children's work were used to capture workshop data as audio-recording was not feasible. A topic guide was used in the focus group/individual interviews to direct discussion to the outlined objectives. In the workshops the play specialist helped JS translate the topic guide into activities to prompt children to talk about their experiences. The focus group lasted for 56 minutes, parent interviews 19 and 42 minutes respectively, and workshops 180 minutes each. JS kept a research diary in which further field notes such as non-verbal cues/body language and participants interactions were recorded during and following each episode of data generation.

Data analysis

Audio data were transcribed and combined with field notes and visual data in a qualitative thematic analysis. All data were mapped into spreadsheets using an initial thematic framework based on topic guide questions. This was expanded iteratively as data analysis proceeded: JS and SY each coding half the data independently, resulting in identification of 10 primary themes. These were compared and discussed with a focus on similarities/differences in researcher coding and between participant groups resulting in consensus on six final themes considered important for medical student learning by all participants.

Production of educational material

A medical student guide, summarising key themes with illustrative verbatim quotations and explanatory notes, was co-produced (see online supplementary file). Three staff suggested refinements that were incorporated. Parents and children provided positive verbal comments on the guide.

RESULTS AND INTERPRETATION OF LEARNING POINTS

All participants drew on lived experiences of helpful and unhelpful interactions with experienced clinicians to describe what medical students needed to learn in preparation for their careers as doctors. Analysis identified themes and principles in the participants' lived experiences to co-produce recommendations for medical student learning. Younger children focused their critique of doctors on two points: how they interacted when a procedure was needed and whether they included the child in discussions. For older children an ongoing relationship with a doctor was particularly important to build trust and respect. Six learning points derived from themes and principles in the lived experiences of participants are presented below. The illustrative quotations come from a range of participants but are only denoted by group to protect anonymity.

Learning point 1: Treat children as individuals

Children emphasised the importance of talking to them (not at them), with a focus on explaining and engaging the child in decision-making:

That they do try their best ... talk to you about something... options of what you can do' (Child)

Parents were less concerned with *what* doctors did than *how* and highlighted the importance of details, such as remembering a name, to engender a sense of their child being an individual:

'We are not a number because that is so important to me... that they remember her name' (Parent)

Demonstrations of humanity, humility and compassion were highly valued with a focus on interpreting whether professionals really saw the child and parent as people not problems.

Parents wanted individualised care, describing better doctors as those who listened and sought to address the problems of the child in front of them rather than discussing usual disease trajectories and patterns. Parents were also emphatic about students needing to experience working with people who have disabilities in order to learn from direct engagement:

'I really do think that people are never the same if they have worked with people who have disabilities or have had people like that in their family's I really think it would be essential to come into a place like this and just experience it and talk to the parents and so on' (Parent)

Learning point 2: Act as a person before being a doctor

Parents wanted primarily a person to connect to when they saw a medical student or doctor:

'Just being a doctor that is your job. It is not who you are, is it? And you need a connection, you need that humanity.' (Parent)

but they also wanted to know who was who:

'A big problem I have is not knowing who is doing what...what they are coming in to do (and) how qualified they are to do it' (Parent)

This theme was more about honesty and transparency than only wanting 'experts'.

Learning point 3: Interpersonal communication

This was the strongest theme across participant groups. Arguably good communication arises out of the first two learning points discussed above and good communication will be facilitated by seeking to learn the points below. In this section we focus, therefore, on data about specific interpersonal communication during consultations.

Children discussed the importance of verbal and non-verbal communication interacting at their 'level', both physically and with appropriate language:

'Doctors are standing over you and you feel intimidated but if they come down [to this child's level – meaning both physically and metaphorically]' (Child)

'All the big words that they use, it was like, can you repeat that again in English please' (Child).

Children wanted honesty from professionals so that they understood what was happening:

'...it would just be better if they told you' (Child)

as long as this was done with compassion:

'They need to choose their words carefully... how they say it because it can be pretty hurtful stuff but they don't mean it' (Child)

Parents valued being involved and having time with doctors.

This was particularly pronounced when parents felt there was no solution to a problem:

'...You appreciate that somebody has taken that time... and say we haven't got the answers - that is fine as long as you don't make me feel like it isn't important.' (Parent)

However, it was noted, particularly by older children, when conversations drifted from child to parents:

'...Some people... actually just talk to the mum instead of... talking to the person who has actually got the condition' (Child)

This was also recognised by staff, who highlighted the importance and challenges of including children in difficult conversations:

'Listening to the child in the first place is the first thing. It is easy to dismiss the child and just talk to the parents' (Staff)

This tension demonstrates why medical students need to learn how to balance a three way consultation between doctor – parent – child.

Learning point 4: Appreciate the clinical environment

For younger children details that might be overlooked in the environment could be significant:

'They [doctors] need a new outfit they do. They scare you with their outfit' (Child)

Staff were concerned about perceptions of hospice and wondered if without direct experience this prevented referrals:

'If the professionals are frightened...about even mentioning the name hospice then you know the parents are going to be aren't they?' (Staff)

However, parents described circumstances immediately prior to seeking help and the subsequent relief that came with the safety of a admissions:

'You can be up for four days and nights until you get to that point where you can't do anymore, and then you go into hospital..., your words are backwards..., you are worried sick about your child'.

(Parent)

Learning point 5: Learn from children, parents and other staff

Parents were pleased with the opportunity created by the study for their children to share experiences:

[child's name] *has been able to come here and tell you her side, so she will go home now thinking, "Well I hope that that has made a difference"* (Parent)

Staff also reflected value from the study, with realisation that much could be learned directly from the children they cared for:

'We often don't listen to children in a learning capacity like that... but it is incredibly powerful, it really is' (Staff)

Parents were concerned about how they might be perceived:

"I'm fine" because you don't want to go into depth but I mean, I'm fed up, erratic, neurotic and emotional' (Parent)

but were keen their experience was used to help both medical students and other parents:

'Because I am further down the journey, I am hoping that if I can get these students right, then new parents who have just come into the system (will) benefit...(and) I can help the next generation' (Parent)

Learning point 6: How to be a doctor as part of a team

Both parents and staff spoke warmly of doctors who worked as part of a team:

'He very much works with us, I always feel that we are an equal part of the team... we are all important to the child's and family's care and you feel that quite strongly' (Staff)

'...if you have professionals who are prepared to fight... there will be people out there who will be able to help you.... I am convinced that we are going to have good outcomes...' (Parent)

Parents perceptions of their part in this team appeared to change over time; with a newly diagnosed child parents relied heavily on doctors:

'...first few times that you go into hospital or have contact with doctors, you do assume that they know best, and you kind of put all your trust in them, so you perhaps don't say things' (Parent)

Over time it became more important for their views to be taken into account and their expertise as carers to be recognised:

'One of the nicest things one of the consultants said to me on the ward or not to me to the staff is that X is nine years of age, she shouldn't have lived this long, will you please listen to the mother'
(Parent)

Staff members described problems that occurred if team-working or trust broke down:

'Last thing you want from the families point of view is for them to be stuck in the middle of people who aren't agreeing about treatment' (Staff)

This was echoed in parents' reports:

'We had confidence broke once and set back massively' (Parent)

'If a child knows that they can come to you, speak to you and it stays within that person. That is a big one' (Parent)

A final important lesson staff wanted to pass on was the need to use the team to assist coping mechanisms:

'Don't just see it as you on a little island and you and nobody else' (Staff)

Production of educational materials

From these themes a guide was produced (see online supplementary file), primarily aimed at medical students a resource to help develop their learning about patient-centred care. It demonstrates one way for lived experiences to be brought into education. The booklet received positive feedback from all participants. The hospice plans to make it available in support of their service development plans. Staff, parents and children had further ideas for educational activities beyond the study resources. Their suggestions (see box 1) illustrate enthusiasm to contribute to medical education but also concerns related to large numbers of students both of which need accounting for in future work.

Box 1: Participant suggestions and concerns regarding further learning opportunities

1. Experience in paediatric palliative care through hospice placements. Although thought the most beneficial teaching method, potential impact on quality of care was a concern from staff.
1. Children- student interactions: appropriate children interviewed with parent/staff consent. Concerns expressed by staff about overburdening children however most parents felt these interactions potentially helpful for their child.
2. Willing parents sharing experiences via individual interviews.
3. Filming family stories– allows more students access to ‘real life experiences’ of children and their families without the logistical problems such as large student numbers. Existing hospice funds suggested to develop multimedia materials.

Option 1 provides greatest direct authentic experience but is also most burdensome for children, parents and hospice staff. Option 4 in comparison integrates easily into education sessions and interactive activities but might not have the same impact as personal interactions.

DISCUSSION

The GMC encourages patient engagement in education.⁵ Lack of palliative care experience may lead to junior doctors being unable to ‘contribute to the care of patients and their families at the end-of-life’.^{14,15,16} Undergraduate curricula increasingly emphasise workplace experience for learning.

Students report notable differences between anticipated and actual interactions with dying patients¹⁷, with experiences affecting future approaches¹⁸. In paediatric palliative care a balance must be struck between direct contact and other means of using patient experiences as learning opportunities.

This action research project covered an important area of medical education and demonstrates the positive results of an action research approach for engaging patients, parents and hospice staff in the development of medical student learning about paediatric palliative care. It portrays children’s, parents and hospice staff views’ about lived experiences of medical care and what they would teach future doctors if the opportunity arose. Six key themes were identified and used to co-develop educational materials that can be used as a teaching aid for both clinicians and undergraduate medical students. The data contained within this material demonstrates the value of experiences and perspectives of children using hospice services for teaching why individualised patient care is so important. The student-researcher leading the project also gained transferable skills in qualitative methodology in addition to greater insights into clinical care. The methods of this project may,

therefore, be of further interest to hospices and medical educators looking to expand research experience of students and trainees.

Strengths and limitations

In the wider field of communication research the views of children have not been adequately represented. This is particularly so for children requiring palliative care services (a relatively under-researched area itself) with respect to what these children can offer to medical students and healthcare professionals with respect to learning from their lived experiences. This action research project sought to address this. We recognise, however, that there remains a need for further research to integrate the views of healthcare professionals (including but not exclusively doctors) and all patients on what is or is not appropriate communication in a doctor-patient relationship. In particular further research is needed to look at problems in practice, and sources of concern arising from 'real life' in order to understand why communication remains such a concern in many areas of healthcare.

The hospice site used for this project had little prior experience of research studies and may have been unduly cautious in screening for potential participants. Although participant numbers were relatively low, analysis suggested theoretical data saturation within this particular hospice was achieved as coding demonstrated recurrence of themes with no new data codes emerging once all groups had been analysed. However, replication studies in other institutions might produce further themes as well as enriching current data. The population of children with a life-limiting condition is small and is further reduced by those who are unable to verbally communicate and are physically able to participate in research studies. The workshop format provided a particularly useful way of engaging children in the project drawing on expertise from a play specialist, but one parent spoke about additional need to engaging children without verbal communication. Additional work is needed to understand the perspectives of fathers who were not represented in the sample.

Implications for practice and further research

Medical undergraduates have relatively little exposure to paediatric palliative care and the guide provides mechanism for sharing patients', parents' and hospice professionals' experience and expertise to a wider cohort of students. Further work is required to understand and develop research and educational collaborations between children's hospices and medical schools. Further research should explore the co-production of educational materials with a view to potentially create multi-media learning resources and test the impact of guides such as the one produced.

CONCLUSIONS

This was a successful action research project that created educational materials for medical students. All participants were able to make valuable contributions and believed this a worthwhile use of time and effort. The student-researcher gained skills in qualitative methodology in addition to insights into clinical care.

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LICENCE FOR PUBLICATION

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CONTRIBUTORS

SY is the guarantor of this paper. She supervised JS during the study which was initially conceived by JS. SY & JS worked collaboratively to design and conduct the study, analyse the findings and produce

the resultant education materials. SY & JS have both contributed to the writing of this paper and approved the final draft.

COMPETING INTERESTS

None declared.

ETHICAL APPROVAL

Prospective ethical approval was received from the University of Keele Medical School Ethics Committee.

FUNDING

An INSPIRE Award from the Academy of Medical Sciences funded JS to conduct this qualitative action study with clinical and academic supervision from SY in collaboration with a children's hospice. INSPIRE is designed to further medical students opportunities in undertaking research, with direct academic and clinical supervision from experts in their respective fields. This provides opportunity for students to learn transferable research skills and gain confidence to continue this throughout their clinical careers.

DATA SHARING STATEMENT

Data sharing was not permitted under the ethical approval of this study. Data has been archived at Keele University but is not publically available due to concerns regarding maintaining of the anonymity of participants.

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APPENDIX 1: Education materials (online only supplementary material)