

Managing communication with young people who have a potentially life threatening chronic illness: qualitative study of patients and parents

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Abstract

Objectives To examine young people's and parents' accounts of communication about cancer in childhood.

Design Semistructured interviews analysed using the constant comparative method.

Setting Paediatric oncology unit.

Participants 13 families, comprising 19 parents (13 mothers, six fathers) and 13 patients aged 8-17 years, recruited from one paediatric oncology unit. The patients had cancer or brain tumour.

Results Most parents described acting in an executive-like capacity, managing what and how their children were told about their illness, particularly at the time of diagnosis. Their accounts were shaped by concerns to manage their identity as strong and optimistic parents and to protect their child's wellbeing. The patients identified elements of their parents' role that both facilitated and constrained their communication, and while they welcomed their parents' involvement, some expressed unease with the constraining aspects of their parents' role. Some young people described feeling marginalised in consultations and pointed to difficulties they experienced in encounters with some doctors.

Conclusions There are difficulties in managing communication with young people who have a chronic, life threatening illness. Health professionals need to be aware of how the social positioning of young people (relative to adults) and the executive role of parents can contribute to the marginalisation of young people and hamper the development of successful relationships between themselves and young patients.

Introduction

Much attention has focused on the benefits of open communication between adult patients with chronic illnesses and health professionals.¹⁻³ Although the evidence is more limited for young people,⁴ recent guidance from the BMA has supported the principle of informing young patients in all but exceptional circumstances.⁵ However, implementation of this recommendation, particularly for serious illness, is far from straightforward.⁶ Observational studies show that

young people are often relegated to a "non-participant status" in consultations.⁷⁻¹¹ Parents also feel ill equipped to handle discussions with their children about life and death issues and may be reluctant to engage in open communication with them about a potentially life threatening illness.^{12,13} We investigated the views of young people and their parents on the management of communication about their illness and how they perceive the role of their parents in this process.

Participants and methods

We invited patients (aged 8-17 years) attending one English paediatric oncology unit, and their parents, to participate in semistructured interviews about experiences of communication about cancer in young people. Because of the difficulties in this sensitive setting of purposefully selecting participants to meet the requirements of theoretical sampling, our sampling was largely opportunistic.¹⁴ We interviewed 13 of 20 families approached, comprising 19 parents (13 mothers, six fathers) and 13 young people. All the patients (eight males, five females) had cancer and all except one were receiving, or had recently stopped, treatment. The parents' occupations varied, indicating social diversity. One family was of south Asian origin and the remainder were white. Our study was approved by a local research ethics committee.

Reflecting the choice of the patients or the parents, eight of the young people were interviewed alone and five were interviewed with their parents. Prompt guides, based on review of the literature and discussions among the research team, helped to structure the interviews. We tape recorded and transcribed all the interviews, except for a few minutes of one patient's interview at his request. The interviews lasted between 25 and 110 minutes.

All the families except one were interviewed by KW, who kept a reflexive diary to record contextual details of the interviews and her reflections on the research process. Data analysis was based on the constant comparative method, and the parents' and patients' accounts were analysed separately.¹⁵ BY developed the thematic frameworks. Each transcript was repeatedly inspected before applying open codes to describe each unit of meaning. Through comparison across transcripts, the open codes were developed into

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higher order thematic categories to provide a framework for coding the transcripts with QSR NUD*IST software (version 4).¹⁶ BY continually checked and modified the framework categories to ensure an adequate fit with the data, and MDW independently validated the assignment of the data to the categories. A reflexive diary of the analysis was kept.

Results

Setting the tone: the form of disclosure

The period around diagnosis was important in influencing patterns of communication. Parents described assuming an executive-like role during this time, managing what, when, and how their children were told about their illness. This role was tacitly negotiated with them by doctors: the diagnosis was usually disclosed by doctors to parents first, without the patient present. Rarely (two families), the parents and patient were told together. In choosing to disclose to parents first, doctors were acknowledging the authority of the parental role. Subsequent discussions between parents and doctors about how communication with the patient should be managed served to recognise the value of parents' special knowledge of their child's character and to establish the primacy of the parental voice in managing communication with young people.

We were actually asked—um—whether, we should, you know, whether we wanted [son's name] to know what he's got, weren't we? I mean [to son] it's very difficult to hide it from you at your age, but [laughs] we were asked if—if um you know, knowing you whether you [wanted] to know. Parent 10 (son aged 15)

Children expressed a range of views about the form of the disclosure: a few thought it was better to hear the news at the same time as their parents, some thought it was more appropriate for their parents to be told first, and others reported no strong feelings either way:

I like the way they did it, that's good, yeah. Because that way mum knew first—I felt—I felt okay about the way that [the doctor] told me. Patient 10 (male aged 15)

Interviewer: If you chose between them telling you both at the same time, and them telling your mum first, would you prefer one over the other or don't you really mind?

Young person: Telling us both at the same time

Interviewer: Yeah. Why is that?

Young person: It's like my mum keeping a secret from me. Patient 5 (female aged 12)

In contrast, all but two parents who expressed a preference wanted to be given the diagnosis without their child being present, and before the patient was told. These accounts reflected parents' need to manage their identity as strong and optimistic, and their fear of upsetting their child. Parents expressed considerable apprehension about "breaking down" in their child's presence, and thought they would be better able to support their son or daughter if they could first "compose" themselves. The young person's presence when breaking the news could also prevent parents from asking key questions:

But the thing is you can't react because obviously you've got your child with you. So you think, "Oh I've got to be strong for my child," who's trying to be strong for you so ... Well there was certain things that we didn't want to discuss in

front of her, you know, what is the prognosis type thing, in case it was really, really bad ... As soon as she left that was the first thing we asked. Parent 13 (daughter aged 15)

Other parents conveyed their dread of the moment when their child would be told and the difficulties of dealing with their reactions. Although doctors usually urged otherwise, a few parents opted to dilute or delay what their child was told:

But we decided not to say anything to [her], she was only 10 years old and we thought oh no, we, we can't tell her. But we were advised by the doctors um you know Dr Z, that ... she'll see a lot of children with cancer, and she will know about it, so it's best if she's told. And we said yes, we—we do understand but we didn't want to tell her immediately ... we felt so bad at keeping it um from her but we just couldn't tell her ... I really wanted to tell her and then at the same time I was trying to protect her. Parent 12 (daughter aged 14)

The role of parents: communication executives and information boundary setting

Over the course of the illness, some families described adjusting their management of communication away from the "executive" controlling and directive model towards a partnership based model, with the young person and parent roles becoming more equal and communication becoming more open. In other cases, parents described continuing to orchestrate when and what their child was told.

The young people talked in detail about the part that their parents played in communication, describing the overlapping roles that their parents performed within both the executive and partnership models (box). Parents' accounts of their roles were broadly similar to those described by the patients. Both parents and young people described how parents were often involved in setting information boundaries and in censoring or filtering what the young people were told.

Young person: I used to ask a lot of questions about the books mum used to write in ...

Interviewer: What sort of books, were they to write down ...?

Young person: Well, how much treatment I needed and how much, how well I am.

Interviewer: And did your mum explain those things to you? [Pause] You said you asked her, she told you what they were did she?

Young person: Not always ... only once or twice. Patient 7 (male aged 8)

Young people's descriptions of the roles parents performed in communication

Facilitators of communication between health professionals and themselves—for example, the parents' presence in consultations sometimes gave children the confidence to ask questions

Envoys—for example, when the young people briefed their parents to seek information on their behalf

Communication buffers—for example, when the young people used their parents to shield them from the burden of answering questions

Human databases—when parents acted as cataloguers and repositories of information about the illness

Communication brokers—when parents customised, clarified, or reiterated information so that the young people could better assimilate what health professionals had said

I don't think they [staff] spent an awful lot of time explaining to [him] ... I was worried about what they were going to say anyway. So I was better—it felt better because he's been told when I told him, and I was all right with that. Patient 2 (son aged 10)

The young people differed in the extent to which they were satisfied with the executive style of communication. A few, particularly those whose priority was to ensure that their main source of information was someone with whom they had a close and longstanding relationship, seemed to welcome it:

Because the doctors talked to my mum and dad and then I—I really did like my mum and dad talking to me, because it was nice coming from—people I'd known and I can trust. Patient 12 (female aged 14)

However, the accounts of other patients suggested that they thought communication was constrained by their parents. Some referred to the inability or unwillingness of parents to answer their questions; others questioned how the information boundaries had been defined and expressed unease at the perceived disparity between how much information they had been given and what their parents had been told:

But I still didn't feel that they were telling me everything, but they probably did but ... [my parents] were in there for like ages and ages and so they only told me like, not that much, so I don't know what they were being told for ages and ages. Patient 13 (female aged 15)

Young person: They didn't tell you much, they—just told you what—just the minor things, not much, they [health professionals] told mum and dad more, lot more than what they told the child ...

Interviewer: Right and what did you think about that?

Young person: Mmmm—better if they could tell you most things because most people like to know what's wrong. I know I did. Patient 8 (male aged 10)

Clearly, parental involvement in communication, particularly in setting information boundaries, could at times be problematic for young people, particularly if there was discordance between a patient's need to know and a parent's efforts to limit their access to information. But this did not mean that the young people regarded their parents' involvement in communication as inappropriate in principle. Young people's accounts showed how their preferences were fluid and depended on context. Reflecting work with adult patients on awareness contexts, and differing levels of knowledge about life threatening illness, almost all the young people at times embraced, or even actively cultivated, their parents' role as “buffers” to limit their exposure to information¹⁷:

But I felt that what [the doctor] was going to speak to my mum and dad about, I didn't really need to know about it that much. Just something for mum and dad to be concerned about, I didn't really need to know about it so—I thought that was the best thing. Patient 10 (male aged 15)

But when they think it's something which is not really to do with the child, I think they shouldn't actually tell them ... [things] which are just between the doctor and the parents and the nurse. I think they should keep it off the children until they're a little bit older. And they understand a bit more. Patient 7 (male aged 8)

Young people's social positioning, communication, and relationships with health professionals

Prominent in the young people's and parents' accounts were the issues of the young people's social positioning (relative to adults) and questions about their depend-

ency, vulnerability, and competence. Young people were acutely aware of their own position and talked in detail about the importance of age and maturity in mediating what and how young people ought to be told. Importantly, however, their age was not particularly useful in explaining either their own or their parents' accounts of communication. For example, some of the youngest wanted detailed information whereas one of the oldest wanted only “the basics.” There was also variability in the young people's beliefs about the ages at which specific competencies could be expected and the appropriateness of health professionals' use of “child friendly” language and communication techniques. What united all of the accounts, however, was young people's use of their parents as a resource to manage communication. Their ability to use parents in precisely the way they preferred depended, however, on their parents' cooperation.

Young people's dependency on their parents as brokers in the communication process arose because they did not, for the most part, see themselves as having direct access to information through their own interactions with health professionals, particularly doctors. The young people saw themselves as occupying a marginal position in consultations, and some thought that their priorities were of little interest to medicine:

Young person: I probably wouldn't ask what something meant ... just cos I might look stupid ... [I] don't really mind that much about all the facts, I don't want to know that much about all that. I just want to know all the silly things, like ...

Interviewer: Silly things?

Young person: Well, not like important things, like your hair and school and things like that.

Interviewer: And you don't think they're important or ...?

Young person: Well I do but they probably don't because it's not like medical stuff. Patient 13 (female aged 15)

Consultations were largely carried out between parents and professionals, and seemed to leave the young people without a voice:

I think sometimes they talk to both of us, but sometimes they—I find they do just talk to mum and I'm just “hello?” “I'm sitting here” ... especially with the consultants, it's just talking to mum. You know, um “hello?” Patient 11 (male aged 15)

The young people therefore subjected their interactions with health professionals to considerable critical scrutiny, and they were highly conscious of the differences in the status and working practices of different categories of professionals, particularly doctors and nurses. Some did not see “emotional labour” as a duty of doctors, whereas they did see it as something that nurses undertook, and many felt more at ease talking to nurses¹⁸:

The doctors just tell you things but the nurses sit down and explain it and everything. Patient 3 (female, aged 10)

Well I kind of choose who I want to [ask], cause there's like some people who I wouldn't ask and some who I would, who I know will tell me exactly the truth. Cause I wouldn't like—I don't really—some of them I don't think will tell me the truth. I wouldn't ask a doctor, no offence. Patient 13 (female, aged 15)

Discussion

Implementing open communication with young people who are seriously ill is problematic. Parents

have a range of roles in such communication, and professional practices affirm the primacy of parents in decisions about managing this communication. The role of parents has profound implications for how professionals communicate with young people who are seriously ill.

The roles undertaken by parents in our study both facilitated and constrained communication. The young people used their parents to manage the burden of communication but also said how doctor-parent-patient encounters tended to marginalise them. This marginalisation has been reported in observational studies, and it is interesting that the young people themselves commented on this problem.¹⁰ Their non-participant status can conflict with their requirements to make sense of their illness and to have their priorities taken into account. They used their parents as envoys and information brokers. This could, however, leave them uneasy about what had been discussed when they had not been present. However, they also sought at times to be protected from threatening information, and then welcomed the role of their parents as buffers. Parents find the task of managing communication with their children enormously complex, which is influenced by their need to construct a parenting identity that they hope will protect their children's wellbeing and sponsor an optimistic version of reality.^{19 20}

Our study complements recent work that explores the relevance of the social positioning of children and cultural beliefs about childhood in young people's experiences of health care.^{21 22} It also shows that the relation between young people's ages and their preferences for communication is not straightforward, as has also been shown in studies on young people's consent for surgery.²³

Our characterisation of the parents' executive role is supported by both the young people's and the parents' accounts: as well as lending trustworthiness to our conclusions, accessing the accounts of both parties has also highlighted the difficulties that health professionals face in balancing the conflicting priorities of young people and parents. Our study did not address the influence of sex, ethnicity, social class, and the nature of the illness on how communication is managed. Patient's age was not particularly valuable in explaining the management of communication, but this may be due to the limitations of our sampling. Theoretical sampling would help to access families and professionals from a range of different paediatric settings to investigate the circumstances under which parents' executive role constrains or facilitates young people's communication and is concordant or discordant with young people's requirements.

Without undermining the role of parents, professionals must help them to consider how their child's interests might best be served. This means both regulating the young people's access to information and helping parents to overcome their urge to protect by withholding information. The young people in our study clearly wanted their parents to be involved in communication but were not always satisfied with how communication was managed. Differences between young people reflect a range of factors, probably including the degree of congruence between a young person's desire to be involved in communication and

What is already known on this topic

The BMA has supported the principle of open communication with young patients

Young people are sometimes excluded from participating in consultations and parents are reluctant to communicate openly with their seriously ill children

What this study adds

Parents take on an executive-like role, managing what and how their children are told about their illnesses

This role both facilitates and constrains communication with young people

Some young people feel marginalised in consultations—they described unease with this and problems in their relationships with some doctors

the extent to which parents limited their child's access to information. It is clear that professionals need to consider delegating less of the responsibility for communication to parents. They also need to remain alert to the possibility that the needs and preferences of some young people and parents may be discordant, and that their position in this regard is likely to vary during the illness. Perhaps most importantly, professionals need to remain aware of how parents' executive role, and the power relations of professional-parent-child encounters, can be a major obstacle in forging successful relationships between health professionals and young people. These issues will be of crucial importance in implementing the proposed children's national service framework, which has the declared aim of putting children and young people at the centre of care and building services around their needs.

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