

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

Bridget Young, Mary Dixon-Woods, Kate C Windridge, David Heney



This is an abridged version; the full version is on bmj.com

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. 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

Recent guidance has supported the principle of open communication with young patients in all but exceptional circumstances.¹ However, implementation of this recommendation, particularly for serious illness, is far from straightforward.² We investigated the views of young people 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 sensitive setting, sampling was largely opportunistic. 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.

Reflecting the choice of the patients or the parents, eight of the young people were interviewed alone and five were interviewed with their parents. 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.³ (See bmj.com for details.)

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. Subsequent discussions between parents and doctors about managing communication recognised the parents' special knowledge of their children's character and established the primacy of the parental voice:

We were actually asked—um—whether, we should, you know, whether we wanted [son's name] to know what he's got,

Department of Psychology, University of Hull, Hull HU6 7RX
Bridget Young
lecturer

Department of Epidemiology and Public Health, University of Leicester, Leicester LE1 6TP
Mary Dixon-Woods
senior lecturer

Department of General Practice and Primary Health Care, University of Leicester, Leicester General Hospital, Leicester LE5 4PW
Kate C Windridge
research fellow

Children's Hospital, Leicester Royal Infirmary, Leicester LE1 5WW
David Heney
consultant

Correspondence to: B Young
B.Young@hull.ac.uk

BMJ 2003;326:305-8

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 you know, knowing you whether you [wanted] to know. Patient 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.

In contrast, all but two parents who expressed a preference wanted to be given the diagnosis without their child being present, 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.

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. Patient 12 (daughter aged 14)

The role of parents: communication executives and information boundary setting

Over the course of the illness, some families described developing a partnership based model, with the young person and parent roles becoming more equal and communication more open. In other cases, parents described continuing to orchestrate when and what their child was told.

Parents' accounts of their roles were broadly similar to those described by the patients (box). 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.

The young people differed in the extent to which they were satisfied with the executive style of communication. 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 the perceived disparity between how

much information they and their parents had been given:

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 be problematic for young people. But this did not mean that young people regarded their parents' involvement in communication as inappropriate in principle; their preferences were fluid and depended on context. Almost all at different times embraced, or even actively cultivated, their parents' role as "buffers" to limit their exposure to information⁴:

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 patients' and parents' accounts were questions about young people's dependency, vulnerability, and competence, and the importance of age and maturity. However, the actual age of the young people 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

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 the young people 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

people's beliefs about the ages at which specific competencies could be expected and the appropriateness of health professionals' use of "child friendly" language. What united all of the accounts was the young people's use of parents as a resource to manage communication. Their ability to use parents in precisely the way they preferred depended, however, on their parents' cooperation.

The young people's dependency on their parents arose because they did not, for the most part, see themselves as having direct access to information, particularly from doctors. The young people saw themselves as occupying a marginal position in consultations, and some thought that their priorities were of little interest:

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)

Conversations 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 were highly conscious of the different status of professionals, particularly doctors and nurses. Some did not see "emotional labour" as a duty of doctors, and many felt more at ease talking to nurses⁵:

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

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 described 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.⁶ 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 sometimes leave them uneasy about what had been discussed when they had not been present. However, they also sought at times to be protected from

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

threatening information, and then welcomed the role of their parents as buffers. Parents find the task of managing communication with their children enormously complex, needing to construct a parenting identity that they hope will protect their children's wellbeing and sponsor an optimistic version of reality.^{7,8}

Our characterisation of the parents' executive role is supported by both the young people's and the parents' accounts: these accounts also highlight 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 finding may be due to the limitations of our sampling. Theoretical sampling would help to investigate the parents' executive role further.

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. Professionals therefore 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 these are 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.

We thank the children and parents who participated in this study and Reilín Leonard for interviewing one family.

Contributors: See bmj.com
 Funding: The Ward 27 Children's Cancer Fund.
 Competing interests: None declared.

- 1 British Medical Association. *Consent, rights and choices in health care for children and young people*. London: BMJ Books, 2001.
- 2 Dixon-Woods M, Young B, Heney D. Partnerships with children. *BMJ* 1999;319:778-80.
- 3 Glaser BG, Strauss AL. *The discovery of grounded theory: strategies for qualitative research*. Chicago: Aldine, 1967.

- 4 Timmermans S. Dying of awareness: the theory of awareness contexts revisited. *Soc Health Illn* 1994;16:322-39.
- 5 James N. Emotional labour: skill and work in the social regulation of feelings. *Soc Rev* 1989;37:118-20.
- 6 Tates K, Meeuwesen L. Doctor-parent-child communication. A (re)view of the literature. *Soc Sci Med* 2001;52:839-51.
- 7 Bluebond-Langner M. *The private worlds of dying children*. Princeton: Princeton University Press, 1978.
- 8 Goffman E. *The presentation of the self in everyday life*. New York: Doubleday, 1959.

(Accepted 5 November 2002)



This is an abridged version; the full version is on bmj.com

Risk of prevalent HIV infection associated with incarceration among injecting drug users in Bangkok, Thailand: case-control study

Aumphornpun Buavirat, Kimberly Page-Shafer, G J P van Griensven, J S Mandel, J Evans, J Chuaratanaphong, S Chiamwongpat, R Sacks, A Moss

Health Promotion Division, Health Department, Bangkok Metropolitan Administration City Hall 2 Dindaeng, 7th floor Drainage Building, Mitmaitree Road, Dindaeng, Bangkok 10400, Thailand
 Aumphornpun Buavirat
psychologist
 J Chuaratanaphong
associate professor
 S Chiamwongpat
deputy director

Center for AIDS Prevention Studies, Department of Medicine, University of California San Francisco, 74 New Montgomery, San Francisco, CA 94105, USA
 Kimberly Page Shafer
assistant adjunct professor
 J Evans
statistician

Center for AIDS Prevention Studies, Department of Epidemiology and Biostatistics, University of California
 J S Mandel
research specialist
 R Sacks
research analyst
 continued over

Abstract

Objectives To identify risks for HIV infection related to incarceration among injecting drug users in Bangkok, Thailand.

Design Case-control study of sexual and parenteral exposures occurring before, during, and after the most recent incarceration.

Setting Metropolitan Bangkok.

Participants Non-prison based injecting drug users formerly incarcerated for at least six months in the previous five years, with documented HIV serostatus since their most recent release; 175 HIV positive cases and 172 HIV negative controls from methadone clinics.

Main outcome measure Injection of heroin and methamphetamine, sharing of needles, sexual behaviour, and tattooing before, during, and after incarceration.

Results In the month before detention cases were more likely than controls to have injected methamphetamine and to have borrowed needles. More cases than controls reported using drugs (60% v 45%; $P=0.005$) and sharing needles (50% v 31%; $P<0.01$) in the holding cell before incarceration. Independent risk factors for prevalent HIV infection included injection of methamphetamine before detention (adjusted odds ratio 3.3, 95% confidence interval 1.01 to 10.7), sharing needles in the holding cell (1.9, 1.2 to 3.0), being tattooed while in prison (2.1, 1.3 to 3.4), and borrowing needles after release (2.5, 1.3 to 4.4).

Conclusions Injecting drug users in Bangkok are at significantly increased risk of HIV infection through sharing needles with multiple partners while in holding cells before incarceration. The time spent in holding cells is an important opportunity to provide risk reduction counselling and intervention to reduce the incidence of HIV.

injecting drug users (30-40%).¹ Incarceration has been associated with prevalent and incident HIV infection among injecting drug users,²⁻⁸ but little insight exists as to the timing of transmission (before arrest, while being held at a police station before trial, or during or after incarceration).

We investigated two hypotheses: that the risk of HIV infection is increased before incarceration because of high intensity risk behaviour; and that the risk of HIV infection is increased during the three to eight day holding period, which is likely to coincide with acute opiate withdrawal and increased risk behaviour. To investigate these hypotheses and define more fully the incarceration related risk of HIV infection we examined risk factors occurring before arrest, during the holding period, during incarceration, and immediately after release.

Methods

Participants

From August 2000 to January 2001 we recruited male injecting drug users who had been incarcerated for at least six months during the previous five years from 17 methadone clinics in Bangkok. These clinics serve most injecting drug users who seek treatment. We defined a case as an HIV positive injecting drug user with a medical record documenting a negative HIV test within the five years before the most recent incarceration and HIV positive serostatus since the most recent release. Controls were HIV negative injecting drug users with current documentation. We recruited and interviewed 175 cases and 172 controls.

During structured interviews, we asked participants about demographic characteristics and about injecting and sexual risk behaviours before, during, and immediately after incarceration.

Statistical analysis

We described summary statistics and did bivariate analyses of associations with HIV status for demographic variables, injection drug use, and sexual risk variables. We used multiple logistic regression analysis to identify independent predictors of prevalent HIV infection. We considered variables for inclusion in

Introduction

An estimated one million people in Thailand are infected with HIV, and the prevalence is highest among

BMJ 2003;326:308-10