CLINICAL ETHICS

Concerns over confidentiality may deter adolescents from consulting their doctors. A qualitative exploration

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J Med Ethics 2006;32:133–137. doi: 10.1136/jme.2004.011262

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Received
18 November 2004
In revised form
15 May 2005
Accepted for publication
17 May 2005

Objectives: Young people who are concerned that consultations may not remain confidential are reluctant to consult their doctors, especially about sensitive issues. This study sought to identify issues and concerns of adolescents, and their parents, in relation to confidentiality and teenagers' personal health information.

Setting: Recruitment was conducted in paediatric dermatology and general surgery outpatient clinics, and on general surgery paediatric wards. Interviews were conducted in subjects' own homes.

Methods: Semistructured interviews were used for this exploratory qualitative study. Interviews were carried out with 11 young women and nine young men aged 14–17. Parents of 18 of the young people were interviewed separately. Transcripts of tape recorded interviews provided the basis for a framework analysis.

Results: Young women were more concerned than young men, and older teenagers more concerned than younger teenagers, about people other than their general practitioner (GP) having access to their health information. Young people with little experience of the healthcare system were less happy than those with greater knowledge of the National Health Service (NHS) for non-medical staff to access their health information. As they grow older, adolescents become increasingly concerned that their health information should remain confidential.

Conclusion: Young people's willingness to be open in consultations could be enhanced by doctors taking time to explain to them that their discussion is completely confidential. Alternatively, if for any reason confidentiality cannot be assured, doctors should explain why.

The 1989 United Nations Convention on the Rights of the Child¹ established rights in which, in every action concerning a child, the best interests of that child should be considered (United Nations,¹ article 3). Article 24 describes children as having rights equal to the rights of an adult in relation to the provision of health care.² Article 12, which relates to children's health, specifies no age at which a child should be deemed to be mentally competent but rules that understanding and wisdom are essential attributes for making their own decisions (United Nations,¹ article 12). The preferences of children who are capable of forming their own views—for example, on their right to privacy—should be given due weight according to their age and maturity.³

Although the UN convention recognises the special role that parents have in bringing up a child (United Nations,¹ article 18), nation states are required to protect the child from interference with privacy (United Nations,¹ article 16). Some adolescents are deterred from seeking healthcare advice because they have concerns about lack of confidentiality in relation to consultations with their doctor. This is especially true when a consultation includes discussion of sensitive issues such as behaviours associated with contraception, health related sexual activities, bullying, depression, or misuse of illegal substances.

Previous research has shown that a high proportion of young people aged 15–16 consult a general practitioner (GP) more than once a year (over 83% of males and 91% of females).⁴ Confidentiality in consultations with their doctors is of prime importance to young people.^{5–7} Some adolescents are reluctant to ask their doctors for advice about sensitive conditions because of anxieties about confidentiality.⁸ Previous research found that although 86% of adolescents would normally seek health care from the family doctor this fell to 57% if the problem was related to pregnancy, HIV, or substance misuse, and 25% would forgo health care if they

had concerns about confidentiality.⁹ Young people unhappy about the possibility of information on sexual health being shared among pharmacists in their small community expressed similar attitudes.¹⁰

Confidentiality is also important because evidence of an association between keeping secrets from parents and the development of adolescent emotional autonomy has been suggested.¹¹

The research described here was part of a larger study to assess public attitudes toward ways in which their health information might be used.¹² A search of medical databases identified no previous research comparing the views of male and female adolescents, and their parents, on the age at which health information should remain confidential between young people and their doctors. The aim of the research was to explore the views of young people and their parents on a young person's right to privacy in relation to health information, and the age at which adolescents should expect confidentiality, in order to help healthcare professionals understand the ways in which adolescents and their parents view these issues.

This paper describes specific differences between male and female adolescents, and their parents, with regard to views on confidentiality in consultations. Reasons for young people's concerns are explored, and suggestions are made for appropriate responses by healthcare services.

METHOD

Design

Qualitative methods enable young people to express themselves more easily than self completion questionnaires with predetermined responses.¹³ Semistructured interviews were therefore selected as the most appropriate method for these

Abbreviations: GP, general practitioner; NHS, National Health Service

exploratory interviews on a topic expected (from pilot interviews) to be unfamiliar to the majority of participants. Young people aged between 14 and 17 years were interviewed using a topic guide. Development of the topic guide was informed partly by findings from previous research on the same project, which showed that adults had little idea of the aims, or the content, of medical records,¹² and partly from the literature, which suggested that the majority of adolescents wish their clinical consultations to remain confidential from parents,^{6, 14} and that secret keeping is linked to developing emotional autonomy.¹¹ After minor changes had been incorporated as a result of initial pilot interviews to reflect the relevance of the discussion to young people, further pilot interviews indicated that the topic guide was appropriate to the aims of the study.

At the end of the interview the young person was asked if they were happy for a parent to be interviewed. Interviews were recorded and transcribed. Analysis of the data was carried out using the framework method,¹⁵ which closely follows the structure of the topics in the interview schedule, at the same time comparing and contrasting the account in each of the transcripts. Approval for the study was obtained from South Sheffield Local Research Ethics Committee.

Recruitment

Adolescents aged 14 to 17 were selected as an age group that typically bridges the transition of most adolescents into sexual relationships. Recruitment of the sample was purposive because this procedure provides a sample that is known to have prior knowledge of the topics under discussion. The sample therefore comprised young people with significant medical records who would be able to give an opinion based on experience of receiving health care in the National Health Service (NHS). The sample included a parent of each of the young people interviewed. Recruitment was via secondary care for ease of contacting a sample of young people with experience of healthcare services. Nursing staff in paediatric dermatology and general surgery outpatient clinics, and general surgery paediatric wards, asked parents of young patients aged 14 to 17 if they would allow a researcher to approach them to describe the study. The researcher then asked parents for permission to approach their children. The researcher explained the aims and requirements of their involvement in the study to the adolescents. Young people who agreed to participate were contacted at a later date and interviewed in their own homes. Informed consent was obtained from adolescents and parents.

Data collection

Great care was taken with the adolescents who, because of their youth, could be vulnerable in an interview situation. Every effort was made to ensure that all respondents felt free to end the interview at any time, and did not feel under pressure to respond to questions they preferred not to address for any reason.

The researchers provided young people and parents with a range of examples of situations in which adolescents might have concerns about privacy. Examples included consultations for contraception; misuse of illegal drugs; bullying; depression, and sexually transmitted infection. Topics were discussed in terms of a third party so that young interviewees did not feel concern that their own lifestyles were under scrutiny. This enabled a fruitful discussion that would not otherwise have been possible, as pilot interviews had demonstrated that young people were unable to visualise imaginary situations associated with sensitive information held in medical records.

Adolescents were also asked for their views on other staff having access to their health information, including a

practice nurse and a receptionist. After the interview each young person was asked if they would be happy for one of their parents to be interviewed.

RESULTS

Nine males (six age 14, one age 15, one age 16, one age 17 years) and 11 females (two age 14, four age 15, four age 16, one age 17 years) were interviewed. Ten were recruited when attending dermatology or surgical outpatient clinics (eight females, two males) and 10 on a general surgery ward (three females, seven males). The sample ranged from young people who had experienced a single acute event within the previous year to those with long term and/or life threatening conditions. The mothers of sixteen and the fathers of two young people (two parents were unavailable) were interviewed. In two cases, the young person and parent were interviewed together, at their request, otherwise parents were interviewed separately from their children.¹

Those interviewed lived in areas with a range of social deprivation, all living in two parent households. All were white British in origin. No parent or young person refused to participate in the study. Interviews ranged in duration from 20 to 45 minutes.

While few young people in the study knew that the NHS collects and stores information about patients, some adolescents, who had experienced ongoing NHS contact over several years, demonstrated awareness of the content of their health record:

how I'm progressing...what kind of pills I'm taking (male inpatient, 1, age 14).

I have a very comprehensive idea of the NHS. Since I was a baby I've been admitted—and to outpatients—in hospital over a hundred times. If it is something serious I go straight to the hospital because they have my history there and can treat me quicker...[medical record holds] full information of what happens to you medically (male inpatient, 2, age 14).

Young people's views on sharing health information

Young people in the study understood the concept of privacy and wanted confidentiality respected appropriate to their growing maturity. Although adolescents in the study were mostly happy for parents to have information about current illnesses many believed that information relating to contraception, sexually transmitted infection, or drug misuse should not be passed on by their doctor. Contraception and sexual behaviour were areas of their lives that they wanted to remain private from parents. Young women were more likely than young men to have thought about contraception and wanted confidentiality to be assured, from age 15 in most cases:

...should be private if it is about contraception from age 15 (female outpatient, 3, age 16).

At age 15 to 16 you're becoming independent...and I don't think it's up to the parent if they are having sex...your doctor's supposed to keep it confidential (female outpatient, 4, age 15).

If I was on the pill I wouldn't want my parents to know, and if anything was wrong with me I wouldn't want my parents to know because they would question me (female outpatient, 5, age 17).

¹ The number following the description of the interviewee, in the quotes from the interviews, is the number assigned to that particular interviewee.

If confidentiality is not assured young people might seek health care elsewhere:

If a young person thinks a parent can see their notes [at age 15] they are just not going to go to their GP but will go somewhere else...everything is supposed to be confidential when you see your doctor so parents shouldn't have access to it...(female outpatient, 6, age 16).

These young patients confirm previous findings that assurances of confidentiality affect their willingness to disclose sensitive information.⁹

Others, in contrast, thought that "Parents have rights too" (female outpatient, 3, age 16).

Several young male inpatients talked about a parent's "right to know", and were the most inclined to allow parental access to their record until age 18:

because it is the legal age (male inpatient, 7, age 16).

Their opinions, however, tended to change as they considered previously unexamined issues. As they grasped the implications of sharing information young men wished to restrict parental access to current health information, and wanted consultations to remain confidential:

but my age group, there's things that's really confidential that you wouldn't want them [parents] to know (male inpatient, 7, age 16).
because they [child] have gone to the doctor in confidence (male inpatient, 8, age 17).

The views of these young male patients suggest a growing awareness of their own autonomy, which has been seen to grow from excluding parents from certain areas of their lives.¹¹

Generally, young men who had frequent contact with the health service expressed trust in their doctor to preserve confidence:

I trust my doctor to keep a confidence (male inpatient, 9, age 14).
I could trust one of the GPs, who is younger than the two older doctors in the practice who have known my family since my mother was a child (male inpatient, 10, age 14).

Young women with similar NHS contact did not, however, share this view:

because every time I go she asks where my mum is, because my mum knows her quite well (female inpatient, 11, age 15),

and:

because people gossip and there are so many blunders in the NHS (female outpatient, 5, age 17).

Their views support research from the US, which found that young women were more likely than young men to have confidential consultations with their doctors,¹³ which may be associated with maturity developing at an earlier age among young women.

Adolescents in the study wanted their doctor to ask them before telling a parent about matters discussed in a

consultation, and to give them the opportunity to tell the parent themselves. In considering families where the relationship between adolescent and a parent was poor, young interviewees thought the young person should have the final say as to whether their GP disclosed a confidence to a parent.

Concerns over "criminalisation"

Some young women thought that, because sex is illegal below the age of 16 in England and Wales, a GP should not criminalise an adolescent by disclosing such information. Younger male interviewees, in contrast, perceived under age sex as an illegal activity that a doctor should report to a parent.

Many adolescents in the study drew a distinction between consultations for contraception, perceived to be a natural behaviour, and drug misuse. Drug misuse was described as a difficult area for doctors wanting to maintain confidentiality for young patients. Typically, young men perceived the use of illegal substances to constitute a serious risk behaviour, which, generally, a doctor should disclose to parents because it is illegal:

...but if it's—for example, drugs, parents should know about it, especially as they would help stop the addiction, up to age 18 (male inpatient, 7, age 16).

Young women, on the other hand, were more inclined to the opinion that:

Parents should not be allowed to discover illegal behaviour (female outpatient, 12, age 16).
drugs should be kept secret because parents wouldn't understand the problem (female inpatient, 13, age 15).

Previous research shows that high school students may not consult their doctor when the problem is related to substance misuse,⁸ and that any assurance of confidentiality should be made explicit. Confidentiality is always conditional, and Ford *et al*¹⁶ found that doctors who emphasised their adherence to confidentiality and explained when and why confidentiality could not be assured, reassured adolescents who consulted about sensitive topics.

The need for flexibility in the doctor's response

Although young people in the study thought their own parents always acted in their children's best interests, some recognised that not all parents are benevolent, and that different relationships and circumstances require different responses. A commonly expressed view was that the doctor should encourage the young person to tell parents about very serious situations.

They wanted a doctor first to tell a young person of an intention to disclose a confidence to parents and, where a relationship between parent and child was difficult, to comply with the young person's wish for confidentiality.

In relation to depression and bullying young people in the study considered that:

Bullying and depression is not something to be ashamed of in a way, is it? (female inpatient, 13, age 15)
maybe the doctor should tell the parents depending how serious it is (female outpatient, 3, age 16).

Parents' views

Parent interviewees were unanimous in their wish to be informed about anything associated with their children's health. Ideas changed and developed as some parents

discussed, and gave some thought to, issues of privacy and their children's medical records. Parents too, with some reluctance, considered that young people's consultations about contraception should be confidential from around the age of 16:

Break off age should be 16, although I'd like it to be higher (mother of patient 3, age 16).

although one mother:

would go to the doctor with [child] if she wanted to go on the pill...parents should have access till age 18. But I might change my mind and say older, because 18 is still young...as long as she is living at home I would like access to her medical record. Twenty one would be a better age (mother of female outpatient, 14, age 16).

Parents acknowledged that relationships between parents and children vary between different families, and thought doctors should take this into account when deciding whether to disclose a young person's confidence. Parents talked about their "right to know" about behaviours such as misuse of illegal drugs by their adolescent children.

Young people's perceptions of sharing information with practice staff

The range of staff who have access to medical records was surprising to adolescents in the sample. Some had assumed that only their doctor had access, and a few were unhappy about practice nurses seeing records. A typical description of several young people's views on information sharing was:

It's ok if it's necessary for the job, but not if it is just out of nosiness (female outpatient, 6, age 16).

Receptionists were seen as staff who had no reason to access medical records. Concern about them disclosing information was widespread, and often associated with personal experience, such as where a receptionist was a friend of the interviewee's mother. Adolescents thought that receptionists were more likely to "gossip" about a patient's medical condition because they had not shown the same commitment to attain training as doctors and nurses:

If you've made the effort to become a doctor or nurse you must be a really good person to do it in the first place (male inpatient, 2, age 14).

and:

It only takes one sentence and it could be out. Receptionists should be made to sign something saying they won't pass on anything (male inpatient, 7, age 16).

Ignorance about rules of confidentiality in general practice was demonstrated by a number of young people who were worried that, typically:

someone just walks in off the street to look at it [medical record] (male inpatient, 10, age 14).

Adolescents recognised conflict between privacy and independence appropriate to their growing maturity, and an ongoing need for parental protection. Nevertheless they

wanted their permission to be sought before parents were given access to their health information. The overall view of young people in the study was that negotiation and discussion with their doctor provided the most satisfactory way of managing this dilemma.

DISCUSSION

Young patients in the study had given little thought to the issue of confidentiality, or the possibility of access to their health information by parents or ancillary staff, before the interviews. On considering the issues, they perceived confidentiality to be of paramount importance and, overall, thought that doctors could be trusted to keep information confidential. Adolescents were clear that information about their sexual behaviour should not be disclosed. Young women were more concerned than young men that privacy regarding consultations with their doctor should be maintained.

At the same time the young people tended to the opinion that it would be reasonable for the doctor to apprise parents of an adolescent's serious health condition. Their preferred course of action was for the doctor to encourage the young person to tell the parents themselves. In families where relationships had broken down, they expected the doctor to maintain confidentiality if the young patient so wished.

Adolescents in the study perceived their own parents as benevolent guardians who always acted in the best interests of their children. Parents (mostly mothers) wanted to know of their teenage children's health problems up to age 21 generally, and beyond in some cases. They accepted, however, that contraceptive advice should be confidential between an adolescent and doctor from around age 16.

The sample consisted of young people with extensive and/or recent contact with the health service who were, therefore, able to base their views on personal experience; and on the complementary views of their parents. The study highlights the usefulness of effective communication between young people and their doctors.

Potentially the young peoples' relatively greater dependence on parents as a result of their medical condition means that the adolescents interviewed may not be typical of young people in general, which may be seen as a weakness. However, the fourth national study (1991–1992) of morbidity statistics from general practice¹⁷ included data on patient contacts with primary care and referrals to secondary care in England and Wales. Unfortunately the published data covers 5–15 and 16–24 age bands rather than the 14–17 group covered in this study. Patient contacts with any doctor in the practice per 10 000 person years at risk were 19 620 in the 5–15 age group and 25 631 in the 16–24 year old group. In comparison, the rate of referrals to secondary care for inpatient, outpatient, accident and emergency care and so forth were as follows: 766 and 700 for males and females, respectively, in the 5–15 age group and 781 and 1352 for males and females, respectively, in the 16–24 age group, per 10 000 person years at risk. Thus the percentage of GP contacts that result in a secondary care contact is relatively small, although the data will be distorted by high consultation rates in younger children in the 5–15 year old group and older women for contraception advice and pregnancy in the 16–24 year old group. In addition, perhaps of greater importance is the percentage of 14–17 year olds who have ever had a secondary care contact, rather than in any one year.

Essentially, as Bryman¹⁸ has described, it is not whether the particular group selected is typical, but whether their experiences are typical of young people in the population at large when they come into contact with the NHS, through consultation with a doctor or other healthcare staff.

Patient views on confidentiality has been described as an under-researched area.¹⁹ Nevertheless, the accounts of young people in the study describing their views on sharing health information reinforce findings from previous studies of adolescents and adults relating to confidentiality of consultations.²⁰ Similarly, the young people expressed concerns relating to confidentiality of health information from external agents,²¹ to explain some of their anxiety around confidentiality.²² The lesser concern of young men compared to young women in allowing access to health information reflects research on adults, which demonstrated that males are significantly happier to allow access to health information than females,¹² and suggests that males have a greater faith in the preservation of confidentiality by healthcare professionals.

While Gillick was concerned that under age sex would be a likely negative outcome of doctors respecting confidentiality of under 16s,²³ this research suggests that young women are unlikely to change their sexual behaviour if they cannot rest assured that their consultations with their doctor are in confidence. Rather, they are likely to seek health care and advice elsewhere. Because keeping secrets from parents promotes the development of adolescent emotional autonomy,¹¹ it should be reassuring that adolescents wish to restrict parental access to their health information.

Implications for future research and practice

The compliance expressed by young men initially may be a function of relative immaturity compared with young women. The young men in the study may also have felt more dependent on parental care as the majority of them had been inpatients. They suffered more serious illness, which is likely to foster feelings of dependence rather than independence, as well as increased trust in their doctors. Research to assess the views of healthy young people with little experience of health service contact might be useful in formulating best practice for encouraging the wider population of adolescents to consult their doctor on health related matters. The views of doctors and other health professionals were not sought in the current study and their opinions on issues relating to adolescents and confidentiality in consultation would complete the picture.

Although few young people in this study had considered the concept of confidentiality in relation to their health information, increasing awareness and maturity appeared to influence the extent of disclosure to their doctors. As described by others, the level of disclosure of health related behaviours¹⁰ by young people increases when doctors discuss issues relating to confidentiality with them.

Explaining to adolescents that consultations are confidential (unless there are particular circumstances in which total confidence cannot be assured) should encourage young people to consult their GP rather than seek advice from an organisation that does not hold their medical history, with the consequent risk of inappropriate treatments.

ACKNOWLEDGEMENTS

We thank the clinical staff who assisted with recruitment, as well as the patients who gave their time. The research was funded by the Department of Health (Information and Communication

Technologies Programme, Department of Health, and the Information Policy Unit, NHS Executive). The views expressed in this paper are those of the authors and not necessarily those of the Department of Health.

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