Confidential health care for adolescents: reconciling clinical evidence with family values

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ABSTRACT

- Community debate about confidential health care for adolescents was triggered recently by the federal government's proposal to allow parents of teenagers aged 16 years and under access to their children's Health Insurance Commission data without their consent.
- Extensive research evidence highlights the importance of confidentiality in promoting young people's access to health care, particularly for sensitive issues such as mental and sexual health, and substance use.
- Involving parents is important, but evidence for any benefit from mandatory parental involvement is lacking.
- The law recognises the rights of mature minors to make decisions about their medical treatment and to receive confidential health care; however, the doctor must weigh up certain factors to assess maturity and ensure that confidentiality around such treatment will be in the young person's best interests. Evaluation of maturity must take into account characteristics of the young person, gravity of the proposed treatment, family factors, and statutory restrictions.

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The recently proposed Health Legislation Amendment (Parental Access to Information) Bill 2003, which sought to give parents access to their teenager's Health Insurance Commission (HIC) data, triggered community debate about the desirability of adolescents having access to confidential health care.

Based on legal advice, the HIC previously asked adolescents aged 12 years and over for permission before releasing Medicare information to their parents (under this age the information was automatically released). From July 2003, the HIC raised the age to 14 years.[1] The proposed Bill would have raised the age further to 16 years, but the legislation was withdrawn in the face of arguments that it would be detrimental to adolescent health and wellbeing.

Given the recent controversy, it is timely to examine the legal and medical evidence for confidential health care for adolescents.

Current status of confidential health care for adolescents

In just a few decades, we have moved from a legal view of children and adolescents as property items of their parents to one that recognises the growing maturity of adolescents and their capacity to make independent choices and judgements on matters affecting their future.[2] This paradigm shift extends to considering their rights to autonomy and privacy in health care.

In 1986, the landmark case of *Gillick v West Norfolk and Wisbech Area Health Authority* established the legal precedent in Britain that an adolescent under the age of 18 years is capable of giving informed consent when he or she "achieves a sufficient understanding and intelligence to enable him or her to understand fully what is proposed" ("the mature minor principle").[3] This principle was endorsed in Australia in 1992 in *Secretary, Department of Health and Community Services v J W B and S M B (Marion's case)* by the High Court of Australia.[4] The majority of judges acknowledged that this approach did not have the certainty of a fixed-age rule and cautioned that regard for the capacities and rate of development of the individual child was needed.[5]

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Legislation in all states and territories ("Age of Majority Acts", or in NSW "Minors (Property and Contracts) Act") defines a minor as under 18 years; yet, the effect of *Marion's case* was to throw into doubt the assumption that adolescent minors were incompetent to make their own decisions about medical treatment. There are statutory provisions for a person aged 14 years and above in NSW (section 49(2) of the *Minors (Property and Contracts) Act 1970*), and aged 16 years and above in SA (section 6(1) of the *Consent to Medical and Dental Procedures Act 1985*), to consent to their own treatment without undergoing a mature minor assessment. Children over 15 years of age can obtain their own Medicare card,[6] and in any Australian state a doctor may "bulk bill" a consultation with an adolescent using the family Medicare card without advising the parents.

The provision of confidential medical care to adolescents goes hand in glove with acknowledging their right to consent to medical treatment: minors mature enough to consent are medico-legally owed the same duty of confidentiality as adults. For example, the "mature minor" principle has been incorporated in legislation dealing with access to health records (for example, in the Australian Capital Territory, sections 10(6) and 25 of the *Health Records (Privacy and Access) Act 1997*; and in Victoria, section 85 of the *Health Records Act 2001*). Medical, ethical, public policy and legal reasons have been proposed for maintaining confidentiality with young people.[5] In this article, we focus on the health reasons.

Confidentiality, access and effective health care

Health problems which can occur in adolescence include mental disorders, unwanted pregnancies, sexually transmitted infections

1 Confidential prescription of oral contraception to a mature minor

A 15-year-old girl presents alone to a health service after having unprotected sexual intercourse with a 16-year-old boy. After discussing her concerns of unplanned pregnancy with a school nurse, she obtains postcoital contraception over the counter. The girl has been previously sexually active, plans further sexual activity, and wishes to avoid this situation arising again. She is persuaded by the school nurse to speak to her GP about contraceptive options.

After taking a detailed medical and psychosocial history, the GP assesses the girl to be at ongoing risk of unplanned pregnancy and sexually transmitted diseases. The GP discusses a range of contraceptive options, including prescription of the oral contraceptive pill (OCP). Despite encouragement to involve at least one parent, the girl refuses. She is assessed to be a mature minor: the GP believes the girl understands the risks of unprotected sexual intercourse, and the requirements, as well as the risks, of treatment with oral contraception. The OCP is prescribed confidentially. ◆

and substance misuse.[7] For these sensitive issues, prevention or early intervention is desirable. However, adolescents' concerns about confidentiality can be a barrier to their accessing health services.[8-12] When adolescents understand a service is confidential, they are more willing to disclose information about behaviours that entail a health risk, to seek health care and to return for follow-up.[9]

Understandably, parents have an interest in knowing about their children's health problems. However, mandating parental notification about their adolescent's behaviours is unlikely to have a positive effect. In a study of girls aged 12–17 years in the United States,[10] nearly 60% reported that, if their parents were notified, they would stop using all or some sexual health services, or delay testing or treatment for sexually transmitted infections. In other studies, around a third of adolescents reported they would not seek health care for sensitive health concerns if their parents could find out.[11,12] Other research suggests that the overwhelming majority of teenagers wish to obtain health care for some or all of their health concerns without parental knowledge.[13]

Confidentiality is as much a cornerstone of effective clinical relationships between doctors and adolescents as it is in adult health care. Nearly one in 10 US adolescents reported not visiting their health care provider in the previous year — despite wanting to do so — because of fear their parents would find out.[13] The provision of confidential health care was a significant predictor of having discussed substance use with providers in the past 12 months[13] — an indicator of quality health care provision to adolescents.[14]

Assessment of the context for confidentiality

Judgement about whether to maintain confidentiality in consultations with younger adolescents is linked with assessment of maturity; that is, a capacity to understand and appreciate the proposed procedure and the consequences of treatment (as well as possible consequences of not receiving treatment). For simple procedures or when there are clear statutory exceptions to confidentiality, this decision-making is generally straightforward (Box 1).

For more complex or contentious procedures, doctors must balance several factors in making a decision. These include the age, maturity and characteristics of the adolescent, the gravity of the presenting illness and treatment, and family issues.

Characteristics of the adolescent

While the cases of *Gillick* and *Marion* introduced the mature minor principle, the courts did not outline what factors indicated sufficient maturity: this continues to be left to medical judgement.[5] Psychological research into adolescents' decision-making capacities has found that adolescents at least as young as 14 years are capable of making informed decisions.[15] However, cognitive development does not proceed according to chronological age alone. Decision-making capacities vary with the intelligence and social experience of the adolescent. Careful assessment by a doctor of an adolescent's cognitive and emotional understanding of a situation, his or her capacity to weigh-up treatment options and their consequences (positive and negative) is required. Other factors relevant to the judgement of competence include adolescents' ability to express their wishes, make decisions in other areas of their lives, arrange appointments without parents, and live independently.[5]

Doctors must also be able to identify when a teenager cannot be deemed to be a mature minor. Parents of adolescents with intellectual disabilities or conditions affecting their cognitive abilities (eg, severe depression, psychosis or low-weight anorexia nervosa) will often need to be involved in treatment decisions (Box 2). However, even in these situations, if the health issue is not urgent, and parental involvement is against the adolescent's wishes, there may be benefit in not insisting parents be involved immediately (Box 3).

The law does not specifically recognise that adolescents judged to be incompetent to consent to treatment are owed a duty of

2 Negotiating breaking confidentiality in an adolescent with low-weight anorexia nervosa

A 16-year-old girl is brought to a GP by the school psychologist, who is concerned that the girl has been losing weight despite 6 months of counselling focusing on her distorted body image. The girl's parents are not aware that she is having a medical consultation, and she refuses to tell her parents of her condition because she does not want to worry them. They have been preoccupied with one of their sons who has developed a serious heroin addiction and is stealing money from the family.

On examination, the girl has the typical diagnostic features of anorexia nervosa, with the extent of bradycardia and hypotension suggesting severe cardiovascular compromise. She looks very wasted but refuses to be weighed. The question of hospitalisation is discussed with a paediatrician, who confirms that it is necessary and semi-urgent. The girl still does not want her parents to know. However, given the severity of her physical and mental condition, the paediatrician advises that confidentiality cannot be maintained and that the parents need to be involved. The school psychologist is advised to notify the parents that she has taken the girl to see the GP and that the GP has recommended hospitalisation.

The girl does not want to go to hospital immediately, but agrees to meet the paediatrician the following day with her parents. The GP communicates directly with the parents. The girl and her parents meet with the paediatrician the following day, when, after further assessment, the seriousness of her condition is discussed. The girl still refuses admission, although her parents finally persuade her it is in her best interests. ◆

3 Balancing confidentiality with involving parents in an adolescent with early psychosis

A 16-year-old boy in Year 10 is referred to the local GP by the student welfare coordinator who is concerned because the boy confided in him, during a discussion regarding his declining academic performance, that he is hearing voices. The boy is reluctant to seek help and is adamant that his mother not be informed. He is anxious about causing his mother undue worry, as the mother has recently separated from his father and has been diagnosed with bowel cancer. The boy does not want his problems to add a further burden on his mother. His father is no longer in contact with the family.

Despite encouragement, the boy only agrees to consult the GP if he can do so without his mother's knowledge. The GP gains a level of rapport and discusses the nature of confidentiality with him (including the exceptions to confidentiality of risk of suicide, homicide or abuse). The boy describes the voices and their impact on his life. He has been unable to attend school on several days of each week, and has withdrawn from socialising with his friends and from his music group. He is frightened by what is happening to him, but still adamant that his mother not be informed.

The GP makes an assessment of suicide risk and risk to others and judges this to be minimal. The GP compliments the boy for having the courage to seek help for this difficult issue. She explains that this troubling and important symptom does happen to some people and can be treated. The GP outlines the need for further assessment by a specialist service as soon as possible, describes how this service could help, and recommends that the boy involve his mother as he is likely to need her support. The boy agrees to visit the service on his own, but still maintains that his mother is not to be involved.

Concerned that the boy, with this serious psychotic symptom, will disengage from care, the GP arranges for the specialist mental health service to see the boy urgently without his mother's involvement. On phoning the service for a progress report 2 weeks later, the mental health specialist informs the GP that the boy is recovering well. They had also not informed the boy's mother immediately, but the boy became more trusting and willing to involve his mother after three or four visits. ◆

confidentiality. Yet, they may be owed this duty depending on their particular circumstances and whether they are able to form a confidential relationship with the doctor.[16] Guidelines recommend that doctors maintain confidentiality with adolescents unless adolescents consent to disclosure or disclosure is necessary to protect their wellbeing, and, in this case, it is generally best to discuss the disclosure with the adolescent first.[16]

Gravity of the proposed treatment

The mature minor principle was established in relation to the low-risk, non-invasive procedure of prescribing the oral contraceptive pill. The law limits adolescents' capacity for decision-making according to the gravity of the proposed treatment. In more serious situations such as termination of pregnancy, the responsibility lies with the doctor to ensure the adolescent is competent to consent. In some cases, a second opinion may be sought. At all times, careful documentation of the doctor's assessment of maturity is required. It follows that an adolescent assessed as competent to consent to one type of treatment is not necessarily competent to consent to another treatment — a competency assessment must be made for each treatment proposed.

Certain states in Australia have additional clauses that may override the doctor's assessment of a young woman's capacity to consent to termination of pregnancy if she is under 16 years.[17] Doctors are advised to be familiar with the laws in their state concerning mature minors.

In practice, doctors should always encourage adolescents to inform their parents, particularly for complex or contentious procedures, as parents are generally best placed to support their child. However, if, despite encouragement, an adolescent refuses to inform his or her parents, confidential health care can be provided as long as the doctor is satisfied that the adolescent is a mature minor and that the treatment offered is in the adolescent's best interests (Box 4).[18]

In profound or life-altering procedures, such as sterilisation (in a person with intellectual disability) or gender reassignment, not even parents can consent on behalf of their child; the Family Court must decide.[5]

Family factors

Different roles and expectations of adolescents within some ethnic and cultural groups may make it difficult to treat an adolescent without significant parental involvement.[19,20] Indeed, the pull between home and the majority culture can increase health risk behaviours in some young people in minority ethnic groups.[21] While doctors may need to consider different ways of engaging and working with adolescents and families from different cultural groups, adolescents must always be accorded their legal right to confidential health care when they are judged to be mature minors, and there are no legal or ethical exceptions.

Sometimes parents are unable to act in a protective manner (eg, because of substance use or severe mental illness). Here, the decision to maintain confidentiality with the adolescent might seem more straightforward. However, in situations like these where a minor is not deemed mature, involvement of protective services would need to be considered.

Legal and ethical exceptions to confidentiality

There are ethical, statutory and common law exceptions to the duty of confidentiality. Obvious examples are the patient's consent or implied consent (eg, passing on relevant information to a specialist upon referral), and emergency situations with risk of death or serious injury. State and territory statutory exceptions to the duty of confidentiality require doctors to report certain medical information to relevant authorities. Pertinent statutory exceptions for health professionals involve children (variously defined as under the age of 16, 17 or 18 years, depending on the state or territory[22]) in need of protection against neglect or abuse (eg, in Victoria, section 64(1A) and section 63 of the *Children and Young Persons Act 1989*), or those infected with a notifiable disease (eg, in Victoria, section 7, regulation 8 of the *Health (Infectious Diseases) Regulations* 2001). Western Australia is the only state that does not have mandatory reporting legislation.[5] There are also limited legal exceptions to the duty of confidentiality that concur with the ethical exceptions of acting in the patient's or public's best interests. These exceptions may arise when there is a "serious and imminent threat to the life or health" of the individual (eg, suicide) or another person (eg, homicide or transmission of serious infectious disease).[5]

The risk of self-harm is considered an ethical reason to break confidentiality. However, while section 463B of the *Crimes Act 1958*

4 Involving parents in sensitive health concerns

A 16-year-old girl with severe asthma presents to her paediatrician with her mother for a routine appointment. The young woman is seen alone for the first part of the consultation, during which the paediatrician identifies she has a new boyfriend. After discussion about confidentiality, specific questioning reveals she is sexually active, uses condoms for contraception, but would prefer to be taking the oral contraceptive pill (OCP). The paediatrician asks the girl about her mother's views and is told that her mother would also prefer her to be taking the OCP. However, the girl does not want her mother involved. The paediatrician assesses the girl to be a mature minor and there are no contraindications to prescribing the OCP.

The paediatrician explores the likely scenario of her mother finding out about her taking the OCP, and suggests it might be better to be "upfront" with her mother from the start. Despite her mother's apparent support, the girl is adamant she does not want her to be informed. The paediatrician discusses whether it might be better for the girl's GP to prescribe the OCP, but she reports that she doesn't trust her GP as "she is Mum's doctor too". The paediatrician prescribes the OCP confidentially.

At later review, it becomes apparent to the paediatrician that the girl has now shared this information with her mother, after her mother's continued encouragement for her to be on the OCP. The girl is now happy for these issues to be discussed with the paediatrician and GP, acknowledging her earlier embarrassment. Her mother is pleased to have the details discussed and understands her daughter's initial desire for privacy. ◆

(Vic) suggests that doctors are permitted to use reasonable force to prevent suicide, the ambit of this section has not been judicially considered.[5] There is no such legislation in other states, and the common law has not yet addressed the issue. We suggest that public policy reasons would prevent an action against a practitioner for breach of duty ever being brought to court. When adolescents are suicidal, doctors should explain to them the necessity of informing their parents for their own protection, in addition to arranging appropriate psychiatric care.

However, there are multiple perspectives to consider when teenagers engage in very high-risk behaviour that seriously endanger their health. If a 14-year-old boy or girl has unprotected sex with multiple partners, yet appears oblivious of the risks of sexually transmitted infections, pregnancy or emotional harms, for protective reasons, it may become critical to involve the parents or legal guardian. The decision to do so without the explicit permission of the adolescent cannot be undertaken lightly, as, among other negative outcomes, it may seriously undermine future engagement with health professionals.[5] Whether informing the parents will alter any of these behaviours is a separate yet important issue to consider.

Reconciling confidential health care with parental involvement

A caring and supportive relationship with parents is a strongly protective factor in adolescent's lives.[23] Studies of help-seeking consistently show that most adolescents turn first to their parents for health care concerns, particularly younger adolescents.[8,24] Henshaw and Kost found that 60% of unmarried pregnant teenagers involved parents in their decision about termination of pregnancy.[25] However, a third of minors who did not inform their parents had experienced family violence and feared it would recur if the knowledge of pregnancy was shared.[25] Adolescents who are strongly opposed to informing parents about unplanned pregnancy tend to accurately predict their parents' reactions.[26]

In managing adolescent mental and behavioural disorders, the value of parental involvement similarly depends on the relationship between an adolescent and their parents. In the treatment of substance misuse, the more positively family relationships were described by the client before treatment, the more improvement was reported at follow-up.[27] A review of family context and involvement in adolescent presentations to primary care for mental health concerns found that, when parental alcohol misuse problems were present, disclosure of an adolescent's emotional distress triggered anger and disorganisation in families.[28]

Sadly, some adolescents do not have supportive relationships with their parents. In these families, but also more widely, there is little evidence to support the proposition that mandatory parental involvement improves communication between young people and their parents, let alone improves youth health outcomes.[24,29,30]

Future agendas

Given the extent of evidence supporting confidential provision of health care to adolescents, why did this issue raise such heated debate in Australia recently?

Fear about the erosion of traditional family values has been one factor. Families are the bedrock of healthy child development. Effective families are those that attend to the needs, wishes and rights of all members. These rights include developmentally appropriate respect for the autonomy of the individual, which is the same principle that underpins the provision of confidential medical care to an adolescent. If practised well, providing confidential health and promoting family values work to the same ends.

Most parents interviewed by the media during the recent debate on the Health Legislation Amendment (Parental Access to Information) Bill expressed support for adolescents obtaining confidential health care when indicated. The others seemed to be equating parental legal responsibilities for their children with parental rights over their children that now have no legal basis. Hence, it is not family values that are in conflict with providing confidential health care for adolescents but outdated views on parental rights.

Young adolescents do not vote and most politicians are also parents. It is therefore not surprising that there is ready political support for parents' expectations over adolescents' rights. Largely missing from this debate have been adolescents' voices. Without doubt, adolescents support access to confidential health care[8] but struggle within the current environment to have their voices heard. Identifying mechanisms by which adolescents' perspectives can better inform policy development and service provision, as well as contribute to the political debate around these issues, is an absolute priority for politicians and clinicians alike.

The medical profession needs to champion this agenda. Ostensibly, there is widespread support from Australian medical organisations and professional groups for adolescents' access to confidential health care.[16,31,32] However, there is doubt about whether we have adequately incorporated adolescent confidentiality within medical practice, and, equally, whether we have advocated sufficiently within the community around the importance of this issue.[33,34] An audit of knowledge and practice regarding adolescent confidentiality in various medical disciplines is necessary to identify both generic and discipline-specific areas on which to focus undergraduate and postgraduate training.

Clinicians, parents, politicians and adolescents themselves all desire the best health outcomes for adolescents. Emphasising parental rights without considering the clinical evidence runs the risk of poor health outcomes for many adolescents and would represent a retrograde step in promoting adolescent health. It is time to move forward by taking account of the evidence base in providing confidential health care to adolescents, and ensuring that this is translated into government policy, clinical practice and community advocacy. Thus, we will achieve the best possible outcomes for adolescents and their families.

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Competing interests

None identified.

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