

patients are not told that novice doctors are performing treatments, nor are they informed of the risks associated with treatments performed by novice practitioners. A greater happiness (as physical benefit from treatments) is achieved for a larger number of future patients when a novice doctor practices a procedure. To disclose would potentially discourage patient participation and reduce learning, which impacts on future practice and treatment outcomes.<sup>133</sup>

Nurses have been reported to use deception in the case of an asthmatic child<sup>10</sup> and an anxious patient<sup>11</sup> to achieve a therapeutic goal with medication. In both cases, the presence or the true nature of the medication was denied because truthful disclosure would cause the patient to refuse to take the drug, which would fail to maximize the patient's (best) interests in terms of treatment outcomes. Alternatively, consistent with maximizing treatment outcomes, the telling of the truth may be denied in acute and emergency medical situations<sup>109</sup> and because it may cause pain<sup>101</sup> or a response causing death.<sup>104</sup>

*Psychological benefit*

*Preventing harm to others.* In telling the truth, intention is important.<sup>125,134</sup> Discussion of 'bad news' is therefore avoided because it contravenes duties of benevolence and nonmaleficence.<sup>135</sup>

These two action-guiding principles direct another to be deceptive on the grounds that truth disclosure to a patient will cause distress,<sup>112,136</sup> anguish and depression,<sup>97,121</sup> pain<sup>101</sup> and anger,<sup>115</sup> and diminish hope.<sup>63,137,138</sup> Others propose that deception can or has been used to preserve and protect lives and save another's feelings.<sup>139-141</sup> That is, because of these consequences, deception is chosen to avoid harm and promote well-being.<sup>63,142</sup> Therefore 'patients do not want to hear bad news'.<sup>101,112</sup>

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The patient–doctor relationship perceived as ‘legalistic, commercial and contractual rather than something divine or artistic’ demands a different sort of truth.<sup>143</sup> The relationship, recognized as contractual, authorizes the doctor to minimize harm to the patient and to the family by whatever means the doctor deems necessary.<sup>144</sup> Consequently, the ‘paternalistic lie’,<sup>145</sup> withholding information under the guise of therapeutic privilege,<sup>25,109</sup> or even using ‘benevolent deception’,<sup>53</sup> is justifiable. *Preventing harm to self.* Field<sup>146</sup> revealed among nurses in a cancer ward the preference for closed awareness<sup>85</sup> in order to ‘maintain [an] emotional distance from the dying patient’. That is, those nurses who reported the need for distance as a means of self-preservation preferred that only the doctor knew that the patient was dying. Others suggest that lies, deceptions and silences prevail when a family is protecting itself from the fear of death,<sup>147</sup> when a doctor is avoiding legal action<sup>136</sup> or his or her emotional reaction,<sup>138</sup> and when care providers do not want to admit failure of care.<sup>137</sup>

Nurses may utilize deception to calm agitated and wandering patients. In this way, ward work is kept orderly and nurses save time and energy. Additionally, some nurses in Tuckett’s study<sup>10</sup> admitted to denial or falsehoods to cover up mistakes and not disclosing information to patients in wards where the social order (hierarchy) dictated this.

#### *Uncertainty principle*

The uncertainty of a diagnosis or prognosis is offered as a reason for not revealing the truth.<sup>101</sup> This principle suggests that there is no certainty in health care, therefore no

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'absolute truth' to reveal.<sup>148</sup> 'Truth'-telling can never be achieved.<sup>104,106,149</sup> This argument takes a particular view of 'truth' that recognizes it as an absolute or certain knowledge or meaning.

Drickamer and Lachs<sup>25</sup> concede that the absolute truth is 'rarely achieved in medicine' and therefore what is required is an 'open, honest presentation of information as it is *perceived* (italics added) and known'. Nachman makes the point that one must be careful to distinguish the notion of 'truth' as 'the way things really are' (so-called objective truth) from that of 'truth' as 'the way a person believes things to be'.<sup>150</sup> Equally, within the context of the therapeutic relationship of psychoanalysis the claim is made that 'truth... is a matter of definition and varies according to the framework in which it is established'.<sup>151</sup> However, Higgs cautions that care needs to be taken that the epistemological sense of truth as 'an abstract concept, of which we shall always have an imperfect grasp', is not confused with telling the truth 'where intention is all important'.<sup>125</sup>

## Recommendation and conclusion

According to the literature reviewed in this article, most but not necessarily all patients want truthfulness about their health. Additionally, truth-telling practices and preferences emerge as a cultural artefact. Furthermore, over time, practices among nurses and doctors have shifted towards more truthful and honest disclosure about their patients' health.

It is interesting to note that it is the principle of autonomy and the likelihood of

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physical and psychological harm that argue both for and against truth-telling in clinical practice. In addition to these reasons, truth-telling is argued for because it is an intrinsic good, while being argued against on the grounds of the uncertainty principle.

Based on this conclusion, it is recommended that:

- Rather than make assumptions, practitioners ought to rely on therapeutic communication and ask patients and patients' families what informational requirements are preferred.
  - Research should continue into truth-telling in practice, particularly to discover its very nature as a cultural artefact, and other conditions and contexts in which truth-telling may not be preferred.
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#### 4.

##### Telling the truth? Disclosure, therapeutic privilege and intersexuality in children

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##### **Abstract (Summary)**

One possible exception to the notion that disclosure is necessary for capable patients is termed the "therapeutic privilege." It provides a way around the requirement that capable patients ought to have full disclosure in order to be able to fully and voluntarily consent to treatment. At times, information regarding a procedure or regarding the patient's condition is in fact considered to be a potential danger to the patient's well being. With this exception to the disclosure requirement it is thought that doctors can avoid conflict with the most fundamental portion of the Hippocratic Oath: "do no harm."<sup>(1)</sup> In order to protect the patient, some clinicians think it best to withhold or generalize certain disturbing information thought to pose an actual threat to the patient. And some clinicians no doubt feel that there could be nothing more disturbing to a child or an adolescent to discover something anomalous about the nature of their sexual anatomical being. Sex and gender are so central to our culture that these concepts are thought to touch the very core of our social and personal identity.<sup>(2)</sup> And while some sexual differentiation disorders are detected in a child long before there is a question of his/her capacity to consent, others may not be detected until adolescence or beyond.<sup>(3)</sup> Therefore, when a geneticist<sup>(4)</sup> discovers that a child has inherited androgen insensitivity syndrome, for instance, or when a family physician determines that an adolescent has a pseudohermaphroditic condition, the clinician may no doubt be wary of passing along this most sensitive information. The temptation to resort to an exception such as the therapeutic privilege may be overwhelming when considering the fear of harm to the young patient's development and psyche.<sup>(5)</sup> It is precisely the nature and the consequences of that fear that will be developed further here.

Liability for battery could possibly be applicable in the case of a physician's withholding of a diagnosis of intersexuality from a capable child or adolescent. If the child was not found to be capable, consent from a parent or guardian would suffice and there would be no liability for battery. Conversely, if the child were capable, the physician must obtain the child's consent or any touching would constitute a battery. However, the mere withholding of a diagnosis without any further treatment or touching would not constitute battery. Possibly, the instance where the diagnosis was withheld but the treatment itself was otherwise explained and consent was sought would not constitute a battery.<sup>(89)</sup> The most likely instance where the withholding of information would be considered a battery is that of a physician withholding diagnostic information from a competent child and performing a procedure or treatment without consent or explanation. For instance, this might occur if the physician explained that the treatment was "routine," or "for the patient's good." If a physician lies to a patient in order to obtain consent, this is also battery, as fraud vitiates consent.<sup>(90)</sup> Patients, including competent children, must be informed of the nature and consequences of the treatment or its application will amount to battery.

Another cause of tortious liability open in this situation is a negligence action alleging lack of informed consent.(92) Because a physician must give sufficient information to a patient regarding the consequences and material risks of the proposed treatment, any insufficiency in the amount of information proffered may be determined by the court to be insufficient. However, because of the confusion regarding the concepts of capacity and the therapeutic privilege exception, physicians may be tempted not to inform children or adolescents of the information necessary for an autonomous decision. Physicians cannot avoid a discussion of the risks of a procedure or treatment unless they are also invoking the therapeutic privilege for this, as well as for the diagnosis. And of course this would require the same strict analysis as required for the invoking of the privilege regarding the diagnosis. Physicians already uncomfortable with the necessity of disclosing information regarding intersexuality may be tempted to withhold further information about treatment or its risks. This temptation must be avoided if there is to be no fear of a negligence suit.

### **Full Text**

(8848 words)

Sometimes...the best medicine might still be a comforting lie.

- John D. Lantos, "Should We Always Tell Children the Truth?"

In no other realm in medicine do doctors regularly argue for active, nearly wholesale deception.

- Alice Domurat Dreger, "A History of Intersexuality: From the Age of Gonads to the Age of Consent"

### Introduction

Family physicians, pediatricians, and geneticists meet a variety of young patients at various stages of the maturing process. As clinicians are privy to information about their patients that may be disturbing, they develop knowledge about human nature and decide, often along with parents, the appropriate level of information for different children and adolescents. And while it may be possible in a clinical sense to delineate the differing stages of understanding of a particular patient, the law may not always recognize these incremental changes. The law insists with few exceptions that those capable of consenting to treatment deserve the disclosure of appropriate information. This ensures that it is the capable patient and not the physician who is making treatment decisions.

One possible exception to the notion that disclosure is necessary for capable patients is termed the "therapeutic privilege." It provides a way around the requirement that capable patients ought to have full disclosure in order to be able to fully and voluntarily consent to treatment. At times, information regarding a procedure or regarding the patient's condition is in fact considered to be a potential danger to the patient's well being. With this exception to the disclosure requirement it is thought that doctors can avoid conflict with the most fundamental portion of the Hippocratic Oath: "do no harm."(1) In order to protect the patient, some clinicians think it best to withhold or generalize certain disturbing information thought to pose an actual threat to the patient. And some clinicians no doubt feel that there

could be nothing more disturbing to a child or an adolescent to discover something anomalous about the nature of their sexual anatomical being. Sex and gender are so central to our culture that these concepts are thought to touch the very core of our social and personal identity.(2) And while some sexual differentiation disorders are detected in a child long before there is a question of his/her capacity to consent, others may not be detected until adolescence or beyond.(3) Therefore, when a geneticist(4) discovers that a child has inherited androgen insensitivity syndrome, for instance, or when a family physician determines that an adolescent has a pseudohermaphroditic condition, the clinician may no doubt be wary of passing along this most sensitive information. The temptation to resort to an exception such as the therapeutic privilege may be overwhelming when considering the fear of harm to the young patient's development and psyche.(5) It is precisely the nature and the consequences of that fear that will be developed further here.

The suitability of using the therapeutic privilege exception in this area of clinical practice is the subject of this study. While the fear of harm on the part of physicians may be genuine, it is perhaps an unexamined fear. A confusion between capacity to consent and the harm caused by informing children may be operational in this conflict and hence the notion of capacity will be further examined. Finally, the remedies for an unjustified withholding of information will be addressed. But first, in order to lay out the discussion in its proper theoretical framework, the discussion must turn to the reasons for disclosure in the medical context.

#### Informed Consent and the Need for Disclosure

The doctrine of informed consent begins with the notion of autonomy. In discarding the paternalistic approach to decision making,(6) it is now assumed that it ought to be the patient who decides what is done with his/her body and not the doctor. The notion of autonomous decision-making is meant to prevent others from using the individual as a mere means to an end, as Kant's dictum proscribes.(7) Autonomy is meant to encompass the ethical protection of individual interest in making decisions about the body and in preserving in law the fundamental respect of persons. Therefore, individual autonomy is "fundamental to the common law" and is the "basis for disclosure."(8)

In order to pass the mantle of decision-making from the physician to the patient, sufficient information must be disclosed. To say that a patient has consented indicates that she or he has been informed of the basic nature of the procedure and that the patient has assented.(9) If this procedure is then performed as indicated, there can be no liability for battery.(10) However, for this to be an informed consent (and hence not negligence(11)), sufficient information must be provided as to the risks associated with the procedure. Truly informed consent will ensure that the patient's right to autonomous decision-making is enforced.

However, many physicians have resisted this doctrine as being a "myth, a fiction, an unattainable goal, or a snare to entrap physicians."(12) When compiled, the list of complaints levelled against informed consent is long:

It wastes valuable time that could be spent in rendering treatment to the ill, in part because patients do not understand what they are told and in part because they do not want to be informed; it undermines

the trust which patients need to reposit in their doctors if they are to be successfully treated; and it requires disclosure of information about the possibility of the risks of induced treatment or failure of the treatment that may lead to a psychologically self-fulfilling prophecy. In addition, the goal of disclosure of information to patients--that they may make their own choice about treatment--is illusory because disclosure can (and indeed usually will) be made by the physician in such a way as to assure that the patient agrees to the treatment. Also, some patients have their minds made up before they acquire the kind of information that the informed consent doctrine requires that they receive, and the receipt of this information does not change their decision. For other patients, the disclosure of information needlessly frightens them, possibly to the extent that they refuse necessary treatment.(13)

Therefore, rather than viewing informed consent as a means of ensuring that patients are themselves able to decide on their treatment, it has often been viewed as merely a legal requirement -- and an irritating and unproductive requirement at that. However, it is really more a process of negotiation, of education and collaboration,(14) than it is the "lifeless piece of paper"(15) implied by some (ab)using consent forms. The information provided should not be meant as a transparent attempt at "getting" patients to consent, but rather it is there to aid the patient in deciding, not to aid the doctor in persuading.(16)

Not surprisingly, however, given the fact that the distinction between informed consent (the ethical doctrine) and informed consent (the legal requirement) is often blurred or missed altogether. Physicians viewing informed consent as risk management(17) want the law to provide "a clear and predictable legal framework."(18) While the law may sometimes oblige by laying out "minimally acceptable" standards,(19) more often it is unclear where the exact boundaries are drawn around the legal doctrine, and of course, when those boundaries will change to raise the standard:

This dearth of information [about the standard] frustrates medical practitioners, who tend to see the law as a stable system of clear rules that, if followed, will lead to avoidance of liability. The definition of standard encourages this belief: the term refers to a statement of expected behavior that one may follow to avoid litigation and liability. Such a belief, while understandable, is nonetheless a misconception; the law is neither stable nor clear. Today's conduct may conform perfectly to yesterday's judicial decisions, yet still give rise to liability in tomorrow's courts.(20)

Physicians, therefore, must look to the spirit of legal standards and decisions, not merely to their minimal application. Informed consent serves not only to inform patients of the risks and benefits of particular procedures, but it works to create a collaborative partnership between doctors and patients. This, if embraced, can work for the benefit of both parties.(21) However, if it is only grudgingly followed, physicians may be caught explaining today's conduct in tomorrow's court. Or, as is human nature, they may search for legitimate exceptions to the rule that they are not comfortable applying. One such exception is the therapeutic privilege.

#### The Therapeutic Privilege: Its Nature and Its Limitations

The therapeutic privilege is an exception to the general requirement of informed consent. If a physician feels that disclosure of certain information will lead to the harm or suffering of the patient, she or he is

said to be free to withhold this information.(22) Information can be withheld if it is countertherapeutic, dysfunctional, or distorting for the particular patient in question.(23) This doctrine is traced back to the American case of *Canterbury v. Spence*,(24) where it is declared that if information is "menacing" to a patient, it need not be disclosed.(25) The exception is raised where "a direct conflict...arises between the doctor's medico-ethical duty to health and his legal-ethical duty to inform."(26) This is based on the "assumption that the physician cares not only for the patient's physiological health but for his psychological and moral well-being" as well.(27)

While the therapeutic privilege has been termed "an American exception" by one Canadian court,(28) its existence north of the border has nevertheless been alluded to by the Supreme Court of Canada. In *Reibl v. Hughes*, Laskin C.J.C. (as he then was) states that "it may be the case that a particular patient may, because of emotional factors, be unable to cope with facts relevant to recommend surgery or treatment and the doctor may, in such a case, be justified in withholding or generalizing information as to which he would otherwise be required to be more specific."(29) In response to this statement, Maloney J. in *Meyer Estate v. Rogers* has nevertheless declared that the therapeutic privilege has no place in Canadian law. Maloney J. states that because Chief Justice Laskin's comments were obiter, and because of the "hesitancy of Laskin C.J.C.'s tone," "the Supreme Court of Canada has not, in *Reibl*, adopted or even approved the therapeutic privilege exception in Canada."(30) However, even given this strong statement,(31) this does not indicate the death of the exception in Canada.

The following year, the Supreme Court of Canada, in *McInerney v. MacDonald*, again stated that information can be withheld from a patient if it is not in the patient's best interest to receive it.(32) However, the Ontario Court of Appeal has held that the exception does not apply in the case of elective surgery.(33) This limit may not apply in Alberta as the therapeutic privilege exception has been codified in the Health Information Act, which provides:

11(1) A custodian may refuse to disclose health information to an applicant

(a) if the disclosure could reasonably be expected

(i) to result in immediate and grave harm to the applicant's mental or physical health or safety(34)

Therefore, while many commentators have called for its elimination,(35) the therapeutic privilege remains a part of Canadian law.

It is not clear how severe the imagined effect on the patient must be in order to withhold information. The *Canterbury* decision indicates that the impact of the information must be that it would impede rational decision-making. However it is not made clear how being upset would impede rational decision-making,(36) or in what circumstances this would be the case. Dickens suggests that the harm expected must be severe if not actually pathological.(37) Once again, this is not entirely a clarified explanation: were this the only explanation of the privilege, it would leave much up to the discretion of the doctor. van Oosten describes six instances where disclosure is restricted:

a) where disclosure would endanger the patient's life or affect physical or mental health



- b) where disclosure might prevent rational decision making because the information is confusing or frightening
- c) where disclosure causes such anxiety and distress that it might jeopardise the outcome of the intervention
- d) where the patient is moribund and disclosure would be inhuman
- e) where the risks of disclosure are as much as or more serious than that of intervention, or
- f) where disclosure would seriously prejudice third parties.(38)

Excluding the final category, the first five categories explore only the severity or source of harm to the patient. However, without a definition of "serious," even a detailed list such as this one leaves much to the discretion of the physician.

What is certain, however, is that this harm cannot be merely trivial, nor can the "harm" be that a patient may refuse beneficial treatment if informed.(39) The therapeutic privilege must not be invoked because the patient will make an "inappropriate" choice.(40) It is clear both ethically and in Canadian jurisprudence that autonomous individuals are permitted to make "wrong" or "bad" choices for "[i]f there is a single characteristic that symbolizes "autonomy," it is the freedom to make bad, or unreasonable, decisions."(41) If this were not the case, there would be no need for the doctrine of informed consent at all, for the doctor's reasonable medical decisions could be held to stand in for those of the patient, or the patient could merely be handed a list of pre-classified "reasonable" alternatives from which to choose. This scenario would obviously make a mockery of the idea of respect for persons and for bodily integrity.

There is also a concern that the therapeutic privilege exception may be overused because physicians are anxious to avoid dealing with patients who become upset. The notion of clinical distance is taught to medical students, while empathy or understanding may be ignored or actively discouraged because of its effect on clinical distance.(42) Therefore, many physicians may feel, as do many familiar with Western Philosophy's traditional concentration on rationality, that emotions are "bad," or not scientific, or unpredictable.(43) Therefore, physicians may well overestimate the degree to which patients find information troublesome.(44) As well, physicians may have an "ill-perceived conception of psychic injury" that is supposed to follow an upsetting disclosure(45) and may hence equate upset with harm. Finally, because of a lack of appreciation for the useful informational content of emotions, and a lack of training regarding patients' emotional states, some physicians may overlook the positive aspects of disclosure.(46) Because the uninformed patient may actually imagine a situation to be worse than it is,(47) disclosure may ease fears about a procedure. Thus sensitive disclosure of information may actually help a patient from becoming overwhelmed, and may actually prevent psychological harm.(48)

What is not directly addressed in the literature or case law, however, is the issue of whether or not a diagnosis (as opposed to risks of a procedure) can be withheld from a patient because it is feared that its disclosure will cause harm.(49) Physicians may rely on the fact that they need not disclose to children or

adolescents diagnoses about their genetic or biological sexual status because this information would be terribly upsetting to the child. On the one hand, it is arguable that a patient is at least as likely to become upset at this type of information as upon hearing about a proposed treatment. On the other hand, this is precisely the sort of information for which a patient goes to a physician. One would have to imagine a situation where the diagnosis itself would cause harm to the child (for instance in the case of a suicidal child). However, if the physician relies on a pre-existing mental condition to invoke the privilege, she or he confuses the use of the exception with the doctrine of incapacity. This confusion may cause the overuse and misapplication of the exception. To apply the exception to the withholding of a diagnosis, there needs to be a clear indication that the child will be seriously harmed by the provision of the diagnosis itself (not by a pre-existing condition that would lead to a finding of incapacity).(50)

In order to ensure that the therapeutic privilege exception is not misused by overzealous physicians, there are a number of limitations placed on it. The first of these is that the burden of proof (a "heavy" burden(51)) rests on the doctor.(52) The doctor must show that this nondisclosure was in the best interest of the patient.(53) This should be done by balancing the situations described above by van Oosten, as well as by acknowledging that a patient may be as harmed by undermining their self-determination as by disclosing the information in question.(54) As well, if the information is directly solicited by the patient, the therapeutic privilege exception should not ordinarily be advanced.(55) However, if the information would still pose a tremendous threat to the patient, the privilege may still be found to apply. It is arguable but by no means certain that upsetting a treatment regime would be such a harm. In fact, the McInerney case involved a direct request for a patient file which, following the judgment, would not preclude the use of the therapeutic privilege exception. Were the question more specific than a general request for information, however, a court may see this in a different light. Given that the Supreme Court of Canada and many commentators are wary that the exception, if allowed too often, could swallow the disclosure obligation altogether,(56) caution in its application would no doubt be the rule.

Another limitation placed on the exception may well escape the notice of many clinicians. Merely because information disclosed in toto may be upsetting does not preclude all disclosure. Not only must the clinician assess whether or not there may be less upsetting ways of disclosing the information,(57) it may be presented in a way that is more generalized than for the average patient.(58) This may be particularly useful when dealing with children and adolescents. Age-appropriate disclosure may be more difficult or time-consuming but ought to be seriously considered before resort may be had to the therapeutic privilege exception. Urman et al. even suggest that there ought not to be a total withholding of information, but that at least the basic character of the procedure proposed and its inevitable consequences must be disclosed.(59) Again, children may be able to accept simplified explanations of proposed treatments. As well, the upset caused to the patient should abate over time and disclosure and/or treatment should be delayed when possible.(60)

Another limitation placed on the exception is that it may be required (and most certainly would be required in the case of children) that, if the exception were invoked, the disclosure must be made to a close relative (most likely parents or guardians in the case of children and adolescents). This disclosure to a relative first ought to be made in order to assess whether this disclosure would in fact be harmful to

the child, and whether there might be a way to minimize this harm. Therefore parents themselves may be asked to tell children of the genetic or biological sexual abnormality (and any ensuing treatment), in age-appropriate language. Conversely, parents may tell physicians of an easier means of informing the child or may suggest a less upsetting location or time to make this disclosure. If parents are willing to inform children or adolescents in the above manner, there is no real conflict (assuming that the privilege has been properly applied in the first place). Where conflict may arise, however, is when there is no consensus between a physician and parents about disclosure of this information to children or adolescents.

In part, the law has already developed a means of addressing the issue of the proper relationship between children, parents, and physicians in the area of children's capacity to consent. It is to this topic that the discussion will now turn.

### Children's Capacity

Although several provinces have legislated an age or a test for children's capacity,(61) the remainder of the provinces (Alberta included) have left the determination up to common law principles.(62) The law once looked to indicia of maturity in a child in order to determine that an emancipated minor could consent to treatment.(63) The modern formulation of the test, however, is a cognitive one: can this child understand and decide about the treatment and does she or he appreciate the reasonably foreseeable consequences thereof?(64) This is a subjective and functional determination that is made with regard to the child's age, intelligence, and experience.(65) Because this test is subjective, the capacity to consent will vary from child to child and even from procedure to procedure for the child in question.(66) Therefore, a more complex treatment will require the child to have a greater ability to understand.(67)

However, as a decision of the Alberta Court of Appeal has indicated, the ability to understand the treatment need not include an understanding of its ethical or moral background.(68) In that case, it was determined that a child can consent to an abortion if she understands the physical consequences of the procedure.(69) Therefore, simply because a child or adolescent may not understand all of the social ramifications of his/her intersexuality, this does not preclude him or her from consenting to a procedure regarding the physical aspects of this diagnosis, provided that they understand the physical consequences. This reading of the law may make parents and physicians understandably uneasy.(70) However, the advantage of the subjective maturity rule is also its disadvantage: theoretically, the discretion of individual assessment leads both to fair decisions in each case and to uncertainty as to the general application of the rule.(71)

Just as the therapeutic privilege exception cannot be invoked merely because the physician disagrees with a patient's decision, so too is it inappropriate to decide that a child is incapable merely because the child's decision is viewed as "wrong."(72) Children also need the protection from the paternalistic application of medical treatment and hence the acceptance of competent decisions places a limit on paternalism.(73) Conversely, the law must also recognize that the development of maturity (even with adults) is "a moving target."(74) Of course, this statement is even more applicable to adolescents. This

does not mean, however, that physicians must assume that adolescents are incapable, as the Wren case aptly shows. And just as upset does not necessarily translate into harm for the purposes of the therapeutic privilege exception, the emotional changes or instability of adolescence do not necessarily translate into incapacity.

Even given the above, the low common law threshold for children's capacity has not apparently been translated into clinical practice.<sup>(75)</sup> In reality, children are rarely consulted about their care.<sup>(76)</sup> In a study done by Urman, Dickens and Harrison, 14 out of 15 physicians still obtained the consent of parents, unless adolescents attended at a clinic by themselves.<sup>(77)</sup> As well, 10 out of 15 of the physicians stated that disclosure was often more complete to parents than to children.<sup>(78)</sup> This lack of respect or understanding of children's capacity to consent is likely linked either to clinicians' reluctance to accept children's autonomy, or to a fear that borderline cases will result in liability.<sup>(79)</sup> When in doubt, many physicians will involve parents in decision-making about their children. As well, parents are often unwilling to accept the lessening of their authority that accompanies their child's increased maturity,<sup>(80)</sup> and may exert influence over physicians who feel that they owe a duty to parents as well as to their young patients.

When parents are automatically consulted about their capable children, physicians may be breaching the child's right to confidentiality. It must not be forgotten that it is the child not the parent who is the patient and who is owed the duties that can lead to liability. When the child is not capable, the duty is not held by the parent, but is merely exercised by the parent on the child's behalf.<sup>(81)</sup> Therefore, while it may seem a common sense approach to involve parents in such complex and potentially devastating disclosures such as that of a genetic or biological intersexuality, if the child has the capacity to consent on his/her own behalf, automatic disclosure to a parent without a child's consent would in fact breach a child's right to medical confidentiality.

Therefore, the law of capacity calls for a clear decision about whether a patient is capable of consent. There is no halfway point for mature children -- capacity is an all-or-nothing state.<sup>(82)</sup> Physicians must determine whether a child is capable of consenting to treatment decisions regarding the diagnosis at hand. Of course a physician is free to ask a capable child whether she or he would like to have his/her parents informed about the diagnosis, but physicians ought not to assume that parents are automatically owed this information. And as shown above, even a situation as potentially disturbing as that involving intersexuality must not automatically involve disclosure to parents. Capable children must be allowed to make their own healthcare decisions without interference by well-meaning parents or physicians.

And just as the therapeutic privilege exception ought not to become the front for this well-intentioned interference, so too incapacity must not merely be a "policy shortcut."<sup>(83)</sup> If abortion is not out of the reach of capable children, surely information relating to other sensitive topics such as a diagnosis of intersexuality must not be artificially placed out of their reach. Clinicians must understand that, although the provision of this information to children may make parents uncomfortable, this is the right of the capable child under the law as it is now formulated. Discomfort on the part of parents or physicians must not allow for the confusion of pre-existing legal categories. A child is capable if she or he

understands the nature and consequences of a particular treatment. And information regarding that treatment, and certainly regarding the diagnosis itself, must only be withheld if it is reasonably certain to cause serious harm to the child. Though physicians and parents may wish to insert other considerations into these scenarios, neither category should be confused for the other, nor should they be used to circumvent rights given to capable children.

#### Potential Liability for Misuse of the Therapeutic Privilege/Capacity Doctrines

As expounded above, the purpose of informing patients and of obtaining their consent is in order to prevent unwanted interference with the bodily integrity as this would constitute a battery. In order to preserve the right to self-determination, consent must be obtained before any contact occurs.(84)

Absent consent, "any unauthorized physical interference with a person, whether or not that interference causes injury,"(85) is a battery that is actionable under tort law. No special exception is made for medical treatment; all touching, whether direct or indirect,(86) must be consented to, or the person doing the touching is liable for a battery.

Any non-consensual medical touching may be a battery, even if this treatment is in the best interest of the patient. In *Malette*, for example, the patient's life was possibly saved by the blood transfusion given, but this did not prevent the doctor's liability for the tortious act. Consequently, a physician is responsible not only for any injury or damage caused by the treatment, but for all of its direct consequences as well.(87) This may include emotional harm, because, while physical harm is additionally compensable, it is not necessary to show actual physical injury in order to prove a battery. This action is also beneficial to the plaintiff, as the onus rests with the doctor to prove that there was consent to the medical procedure in question.(88)

Liability for battery could possibly be applicable in the case of a physician's withholding of a diagnosis of intersexuality from a capable child or adolescent. If the child was not found to be capable, consent from a parent or guardian would suffice and there would be no liability for battery. Conversely, if the child were capable, the physician must obtain the child's consent or any touching would constitute a battery. However, the mere withholding of a diagnosis without any further treatment or touching would not constitute battery. Possibly, the instance where the diagnosis was withheld but the treatment itself was otherwise explained and consent was sought would not constitute a battery.(89) The most likely instance where the withholding of information would be considered a battery is that of a physician withholding diagnostic information from a competent child and performing a procedure or treatment without consent or explanation. For instance, this might occur if the physician explained that the treatment was "routine," or "for the patient's good." If a physician lies to a patient in order to obtain consent, this is also battery, as fraud vitiates consent.(90) Patients, including competent children, must be informed of the nature and consequences of the treatment or its application will amount to battery.

The only issue that would then remain for the court to decide, if battery were proven, would be the issue of damages. While in *Malette* the plaintiff received an award of \$20,000 even though the treatment was said to have saved her life, this amount may well be deceiving. That case involved the patient's highly believable emotional distress upon receiving a treatment that she was not only strongly

opposed to, but that was in fact contrary to her religious beliefs. The damage to her dignity may well be greater than would occur to the typical plaintiff in her situation. Therefore, while injuries to a plaintiff's emotional being or to his/her dignity are actionable, the ensuing damages may well be minimal.(91) Of course, any physical injury that results from the treatment, even if it is competently administered by the physician, will be compensated in an award for damages.

Another cause of tortious liability open in this situation is a negligence action alleging lack of informed consent.(92) Because a physician must give sufficient information to a patient regarding the consequences and material risks of the proposed treatment, any insufficiency in the amount of information proffered may be determined by the court to be insufficient. However, because of the confusion regarding the concepts of capacity and the therapeutic privilege exception, physicians may be tempted not to inform children or adolescents of the information necessary for an autonomous decision. Physicians cannot avoid a discussion of the risks of a procedure or treatment unless they are also invoking the therapeutic privilege for this, as well as for the diagnosis. And of course this would require the same strict analysis as required for the invoking of the privilege regarding the diagnosis. Physicians already uncomfortable with the necessity of disclosing information regarding intersexuality may be tempted to withhold further information about treatment or its risks. This temptation must be avoided if there is to be no fear of a negligence suit.

As well, it is arguable that consent to a treatment cannot be truly informed if the nature of the diagnosis calling for the procedure is not fully explained. It is conceivable that a patient who does not understand the reason for the treatment cannot consent to it.(93) Or, if this is not the case, it is also arguable that not knowing of a diagnosis means that informed consent is not possible. Physicians have the duty to inform their patients of the alternatives to the treatment being offered,(94) something not possible if the diagnosis or the treatment itself is not explained. Patients not told of their diagnosis of intersexuality cannot get counseling, cannot join peer support groups, and certainly cannot research their conditions further or obtain a second opinion as to treatment.(95)

The disadvantage to a plaintiff arguing a negligence claim is that it is much harder to prove this claim than it is to prove a battery claim. Not only is the onus of proof on the plaintiff as opposed to on the physician, the plaintiff must prove that but for the lack of disclosure, the injury in question would not have occurred. Essentially, this means that the plaintiff must prove that, if they had been fully informed, they would not have consented to the treatment. The standard of proof is a modified objective one: what would the reasonably prudent person in the plaintiff's position and circumstances have done?(96) The injury need not be caused by the item not disclosed.(97) However the injury in a negligence suit must be reasonably foreseeable.(98) Causation is notoriously difficult to prove in negligence suits.(99) This is in part due to the fact that courts will accept as evidence that reasonable patients trust their doctors, and therefore that most patients do as their physicians instruct.(100) There is no indication that the situation of intersexuality would be any different in this regard.(101)

Another disadvantage of a negligence claim is that, unlike a claim for battery, there is no claim without actual injury reasonably foreseeable by the clinician. Such injury need not be physical; psychiatric injury may also be compensated.(102) As well, the injury may be the child's worsening condition or that the

failure to inform prevented the family seeking other treatment or counseling. However, it must be cautioned that a mere loss of a chance to improve the child's health is not actionable: the treatment must be proven on a balance of probabilities to have offered an improvement.(103) In the case of an intersex child, it is arguable that a child's emotional health may worsen if the condition is in some way apparent to the child but is not addressed.(104) It is also arguable that, much as religion was inviolable and sacrosanct in Malette, sexual identity is equally inviolable to a patient, and certainly to an adolescent. Therefore, any unwanted interference with a capable adolescent's biological sexual identity may cause compensable psychological injury. However, the more tenuous the connection between the injury and the clinician's actions, the less foreseeable are the injuries, and the less likely it is that a court will award damages.

Another possible action against a clinician is an action for breach of the duty of confidentiality.(105) Much as patient integrity and autonomy must be encouraged and protected in the realm of medical decision-making, so too do these ideals lead to the need for confidentiality.(106) As well, confidentiality is required to maintain the integrity of the doctor-patient relationship and to encourage the complete honesty and trust of the patient. The Supreme Court of Canada in *McInerney* found that medical confidentiality is almost inviolate: it is absolute unless there is a paramount reason to cause it to be overridden. A properly applied use of the therapeutic privilege or incapacity doctrines would be such a paramount reason (mistaken application of these doctrines would not).

Physicians have a fiduciary obligation to preserve the confidentiality of their patients' health information.(107) Physicians must act with utmost good faith and loyalty toward their patients,(108) and this includes a duty to preserve their confidences. Even a well-meaning breach such as that of the unsolicited inclusion of parents in the decision-making process would be actionable at common law. There may be an action for a breach of fiduciary duty in the case of the disclosure of intersex diagnosis or treatment options.(109)

However, the common law is arguably overwritten following the passage of the new Health Information Act in Alberta.(110) This Act provides that

35(1) A custodian may disclose individually identifying diagnostic, treatment and care information without the consent of the individual who is the subject of the information

...

(b) to a person who is responsible for providing continuing treatment and care to the individual,

(c) to family members of the individual or to another person with whom the individual is believed to have a close personal relationship, if the information is given in general terms and concerns the presence, location, condition, diagnosis, progress and prognosis of the individual on the day on which the information is disclosed and the disclosure is not contrary to the express request of the individual,

(d) where an individual is injured, ill or deceased, so that family members of the individual or another person with whom the individual is believed to have a close personal relationship or a friend of the individual can be contacted, if the disclosure is not contrary to the express request of the individual,

...

(n) if that individual lacks the mental capacity to provide a consent and, in the opinion of the custodian, disclosure is in the best interests of the individual.

Therefore, a physician could disclose information to a parent or guardian of even a capable child without his or her consent, unless this was expressly disallowed by the patient. Under this Act, it would certainly be permitted to "go over a child's head" before the child were given the opportunity to expressly disallow this conduct. Although the interpretation of this provision remains to be seen, this Act may well preclude any true recognition of a capable child's right to medical confidentiality.

### Conclusion

While a capable child may well be owed various legal and ethical duties by the clinicians involved in diagnosing and treating intersex conditions, in the long run, the legal remedies provided for their protection appear ill-suited to the task. Legislation may override duties of caregivers as surely as abuses of capacity and consent doctrines override the autonomy of children and adolescents. Fundamentally, intersex children are often deprived of choice by the medical profession and by parents, both because of a "discomfort" with intersexuality,<sup>(111)</sup> and because of confusion or suspicion of legal doctrines.

Clinicians must be cognizant of the rights of patients not merely because they fear liability repercussions, but because they are willing to work with patients as equals in the decision-making process. Physicians understand more of the physiological workings of the body but they cannot be said to be more competent to make decisions affecting something as fundamental to personhood as a patient's sex. Ultimately, it is the capable patient (whether child or adult) who must make such a decision. Respect for patient autonomy calls for nothing less.

## 5.

### Talking to patients about cancer

Buckman, Robert. *British Medical Journal*. (International Edition). London: Sep 21, 1996. Vol. 313, Iss. 7059, p. 699-700 (2 pp.)

### **P.699**

An extraordinary thing about the medical profession is that it managed to avoid telling the truth to patients for so many centuries. In 1672 the French physician Samuel de Sorbiere considered the idea but thought that it might seriously jeopardise medical practice and concluded that it would not catch on.'



This approach—recognising the need to act but finding excuses not to—is still in evidence today, even though there has been a considerable change over the past 35 years. Two papers in this week's journal remind us that what is comfortable for clinicians is not necessarily what patients want.

In 1961, a landmark paper by Oken showed that 90% of surgeons in the United States would not routinely discuss a diagnosis of cancer with their patients.<sup>2</sup> However, several studies subsequently showed that a growing proportion of cancer patients wanted to know their diagnosis. The proportion of patients wanting to know has varied in different studies, depending on the locale and the sample (Northouse has done an excellent overview<sup>3</sup>, but has often been in excess of 90%.

Medical practice has gradually changed to meet patients' needs, particularly in the United States, and nearly 20 years after the Oken study, Novack et al repeated the survey. They showed that by then, there had been a sea change in clinical attitudes, with more than 90% of American physicians saying that they would tell their patients if they had cancer.<sup>4</sup> In view of this, the crucial question in truth telling should perhaps have moved on from whether to tell patients, to what to tell them—and how. Sadly, this is not yet the case—certainly not in many areas of Europe and in Britain. A survey of European gastroenterologists in 1993 showed that nearly 60% of responders did not routinely tell their patients of a cancer diagnosis if the patient did not ask.<sup>5</sup> A survey of British general practitioners and hospital consultants in the early 1980s showed that 75% and 56% respectively did not routinely tell their patients.<sup>6</sup> By contrast, in the United States (and to a slightly lesser extent in Canada), medicolegal practice has now enshrined the patients' rights to truth, not only in the codes of ethical practice but in case law.

Of course, this has disadvantages; being told the truth (without regard to your own wishes, the manner in which the news is imparted, or the underlying nature of the doctor-patient relationship) can be just as upsetting as being lied to. Centuries of systematic insensitive deception cannot be instantly remedied by a new routine of systematic insensitive truth telling.

It is not hard to understand the main reasons for avoiding sharing bad news with patients. It is unpleasant to be the bearer of bad news and to have to support and assist patients as they absorb and understand the nature of their medical situation. Traditionally, clinicians have found two main justifications for keeping patients in the dark. Firstly, the facts might upset them. This is undoubtedly true, but (legal considerations aside) that line of reasoning has never been acceptable to any other profession in which news might be bad—accountants, bankers, magistrates, stockbrokers, building societies, and so on. Secondly, they presumed that patients don't really want to know.

Two papers in this week's BMJ remove the last vestiges of rationality from both arguments. Meredith et al (p 724) studied 250 patients attending an oncology centre in Scotland; 79% of patients wanted as much information as possible and 96% specifically wanted to know if their illness was cancer.<sup>7</sup> Almost all patients wanted to know the chance of cure and the side effects of treatment. In Benson and Britten's smaller study (p 729), patients reported feeling that they had certain rights to have information about their diagnosis and that they should have a say in who else was told.<sup>8</sup> All patients felt that family members should be told if the patient had given permission, but nearly two thirds felt that if the patient

did not wish the information given the family should not be told, and that information should not be released without consent except in certain circumstances.

Important as these results are, they cannot tell us how to break bad news. Almost all of us still feel some (often much) discomfort during an interview about cancer, and perhaps anxieties about technique are behind most arguments for not telling the truth. Most of us have not been taught how to break bad news sensitively and supportively, and as in all branches of clinical practice we all have a tendency to avoid doing any procedure if we are uncertain of our expertise. Yet over the past decade or so, such expertise has become available to almost anyone who wants to acquire it. There are courses in many medical schools,<sup>9</sup> there are books<sup>10</sup> and videos<sup>11</sup> that describe in detail the practicalities of breaking bad news (including ways of finding out whether the patient wants to know or not), and there are now courses for practising oncologists that use role play and video recordings to show how to learn and improve the techniques.<sup>12</sup> There is even some material available for patients to help them get the best out of communications with the doctor,<sup>13</sup> although we should not need our patients' help in order to help them.

Nowadays there is no excuse for physicians who simply don't want to perform this important part of our job. It needs to be done and it can be done. It has been said that if the breaking of bad news is done badly, patients and their families

#### **p.700**

(or often their lawyers) may never forgive us, but if it is done well they will never forget us. As this week's two papers show, our patients want, expect, and need the truth from us. There are simple, practical techniques that we can learn and use to tell our patients the truth if they want to know, and we no longer have any excuse for avoiding it.

#### **6.**

##### The use of deception in nursing

Teasdale, Kevin, Kent, Gerry. *Journal of Medical Ethics*. London:Apr 1995. Vol. 21, Iss. 2, p. 77 (5 pp.)

#### **Pg. 77**

##### **Abstract (Summary)**

A small-scale study focused on the uses of deception by nurses when attempting to reassure patients. The results suggest that deception can have deleterious effects on trust and the patient-nurse relationship.

##### **Full Text**

(4009 words)

Recent articles in this journal (1-3) have discussed some of the issues relating to deception in clinical encounters. Jackson (1,3) has argued that while lying is almost always morally indefensible, deception can be justified when it does not endanger the trust between a health professional and patient. Bakhurst (2), on the other hand, contends that lying and deception are often morally equivalent, because they infringe a patient's right to autonomy.

Hoffmaster (4) has argued that normative ethics provide a poor model for understanding the everyday ethical decisions made by clinicians since they do not provide a contextual understanding of action. In practice, doctors and nurses often override the rule of veracity in the interests of individual patients in particular situations. Frohock (5) concludes, on the basis of an analysis of treatment decisions in neonatal intensive care units, that the language of harm (the principle of non-maleficence) fits the reality of clinical practice more closely than the language of individual rights.

It seems like that non-disclosure is widespread in patient care. Doctors and nurses frequently see it as part of their professional responsibility to 'titrate' the amount of information they give to patients. This can be justified on empirical grounds since some patients are distressed if they receive more information than they desire (6), but the use of deception is another issue altogether. Deception is much harder to justify and certainly rarely acknowledged in public. Instead, many professionals prefer to use euphemisms such as 'information management' to describe times when they give inaccurate information or withhold accurate information in order to mislead.

It is sometimes argued that such situations should not be described as cases of deception, since the whole truth about a patient's situation can never be known or fully communicated; therefore one can never know whether or not the information which one gives is accurate or not. However, Bok (7) has pointed out that although we can never know the whole truth we still have the option of trying to convey the truth as we understand it. She argues that anything less is a form of deception, stating that: 'The moral question of whether you are Lying or not is not settled by establishing the truth or falsity of what you say. In order to settle this question we must know whether you intend your statement to mislead' (8). Independent support for this viewpoint comes from studies in the philosophy of language which suggest that communication is best described as an inferential process in which one person uses language and non-verbal signs to try to induce another person to infer the intended meaning (9). Thus the key to deception depends less upon the precise coded form of words or other signs employed than upon the intentions of the communicator.

Empirical studies have indicated that deception is used to promote what is perceived as better care for the patient, sometimes through reassurance (for example, maintenance of hope for the future) and sometimes because of organisational needs (for example, time considerations or concern that a patient would become difficult to manage). In a small-scale survey by Schrock (10) of the deceptions used by student nurses, 60 per cent of the deceptive situations were attributed to doctors' orders or ward policy, 20 per cent were carried out in order to promote better patient management (since the nurses

feared that if patients knew the truth they would be unwilling to comply with treatment) and the remainder of deceptions were carried out in order to withhold information about patients'

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illnesses or drug treatments or because truthful explanations would have taken too long.

In a study of midwifery practice, Kirkham (11) observed frequent use of evasive answers to mothers' questions, amounting in many cases to deception. Mothers were allowed very little choice or autonomy during labour, and deceptive strategies were used to maintain medical and midwifery control over the situation. Bond (12) reported similar uses of deception in a cancer ward where the 'social order of the ward' was considered to require non-disclosure of diagnosis. McIntosh (13), identified widespread use of deception by all members of the health care team working on a cancer ward. The team was consistent in its belief that disclosure of diagnosis would destroy patients' hopes of recovery and make their management difficult. McIntosh found that in many instances the patients themselves knew their true diagnosis, but supported the non-disclosure policy of ward staff. Glaser and Strauss (14) noted that nurses caring for patients with cancer were frequently hampered in their communication with patients by uncertainty over what patients already knew about diagnosis or treatment and by what they were allowed to disclose. Melia (15) in the UK found that student nurses faced similar problems, describing this as 'nursing in the dark'.

Although these studies indicate that deception is sometimes used in an attempt to manage situations, there are few indications of its 'success' or its effects on the professional-patient relationship. However, detection rates in real life may be high (16) and the pressures on those using deception increase when the message is an important one and when there are considerable adverse consequences of detection (17). In these circumstances, which are typical of clinical settings, social skills are more likely to break down and the likelihood of discovery to increase (18). The emotional costs of collusion in a deception may be considerable (19) and the need for teamwork in maintaining deception increases the risk of discovery (19). For all these reasons, the use of deception in health care is a relatively high-risk strategy.

The aim of the present study is to provide further empirical data on the use of deception in clinical settings. In a study on the use of reassurance in nursing (20), nurses were asked to describe situations in which they sought to alleviate patients' anxiety or distress. Those situations in which staff reported the use of deception form the database for this report. An analysis of these situations helps to develop a better understanding of the processes involved when nurses actively attempt to mislead a patient.

## **Methods**

### **SUBJECTS**

Ninety-one student and 126 qualified nurses working in medical, surgical, community and psychiatric specialties were asked to complete a critical incident sheet (21) and 55 qualified nurses working in the same specialties were given a semistructured interview. Although no personal details of the staff given

the critical incident sheets were collected for reasons of anonymity, there were 12 male and 39 female nurses in the interview sample, with an average 16 years of nursing experience.

## PROCEDURES

The critical incident sheets asked the staff to describe situations when they (a) nursed a patient who was anxious, worried or distressed, (b) tried to help the patient become calmer, more secure or assured, and (c) were able to find out or observe the effects on the patient of their intervention. The semistructured interviews with the nurses and patients covered the same areas but in more depth. Of the 272 nursing staff approached, 251 (93 per cent) agreed to describe such incidents. The two authors independently assessed the questionnaires and transcripts of interviews for the presence of deception or lying. The first author identified 19 incidents in which nurses used deception in their attempts to alleviate patients' concerns, while the second identified 12 incidents. Full agreement was found for ten incidents, which form the data-base for results described below.

## Results

### DESCRIPTIONS OF INCIDENTS

The 251 nurses indicated that they used a variety of interventions when attempting to help a patients to be calmer, more rested or secure. As shown in Table 1, the most common was the use of prediction (in which staff provided information about what was to happen to the patients), followed by emotional support (touching, providing time to listen), giving the patient some control over events, direct action (making some change in their care procedures) and distraction. Although deception was not given a category in this analysis, most instances involving deception fell under the prediction and distraction categories.

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While the study collected incidents concerning community-based nurses as well as those working in hospital settings, all the incidents involving deception arose from hospital settings. The ten incidents of deception (four per cent of the total sample) involved two types of patients: in six cases the patients were intellectually impaired while the remaining four cases involved patients who were fully competent but who were undergoing diagnostic tests or treatment.

#### (a) Patients with impaired intellectual abilities

Six patients were suffering from confusional states or were mentally handicapped. In four of these incidents the nurses used lies to calm the patients, while in the remaining two they used truthful forms of words which were nevertheless designed to distract the patients from the objective reality of their situation. The aim appeared to be to help the patients 'calm down', at least in the short term, in order to avoid disruption on the ward. One example, with the deception in italics, illustrates the difficulties the nurses were facing at the time of the deception:

'She was pacing the corridor, trying to leave the ward. She was also repeating questions in a distressed way, starting to cry and threatening to hit people with her walking stick if they came too close...I asked her if she would like to come and sit down and talk about the problem. She then repeated her questions about how she could get home. I explained to her that she was in hospital and could not go home today as there was no transport on a Sunday. I also told her that her daughter and son-in-law would be coming to see her later in the day.'

In a second example, the patient had previously reacted poorly to changes in routine, so that the staff anticipated a strongly negative reaction to a planned move to another residence. Here, staff had come up with a 'devious package', in which the patient was deliberately misinformed about the likelihood that he would be required to move:

'The patient in question was living in an old mental handicap hospital. A new community bungalow was due to open in a few months and this patient fulfilled the admission criteria. It was planned that the patient would move when the bungalow opened, but the nurses were reluctant to tell him too far in advance because he had a history of becoming very anxious when under stress, leading to anti-social behaviour and a refusal to eat, with rapid weight loss. The patient became suspicious about the possibility of a move [and] the staff decided to lie to the patient, saying that he would not be going to the new bungalow.'

In these and the other examples in this category, nurses were either reacting to or anticipating distress, and taking steps to minimise or avoid it. As discussed later, such distress was seen as harmful to the patient but, perhaps more importantly, disruptive to the running of the ward.

#### (b) Autonomous adult patients

The remaining four situations involved adults who were competent, but whom nurses believed would suffer if they knew the truth. In such instances, the main objective was usually to reduce individual distress, rather than to minimise disruption. There were three examples of withholding information from patients suffering from cancer, in which the nurses used distraction techniques and gave evasive answers to patients' questions about diagnosis or prognosis. Either the patient's consultant had taken the decision to withhold the information about diagnosis, or the family had requested this, or a nurse had decided not to volunteer an opinion about the patient's prognosis. For example:

'I had a gentleman who had been admitted with cancer of the knee who had come in for various operations to have little bits removed. But all the time we could see that he was deteriorating. There wasn't much hope of a recovery. We'd built up a good relationship and a very good friendship within that. He trusted me. We kept getting the feeling that he wanted to know what was happening, but the consultant in particular was very evasive. Then a friend of his who was a GP came in to see him and told him the truth.'

'The patient was suffering from myeloma, a form of leukaemia. As part of her treatment she needed blood transfusions which she had in the past found particularly painful. The doctors were putting off telling her about her diagnosis due to her anxiety problems and a history of cancer phobia. Cancer was

something she could not cope with. I did say that the doctors were still trying to find the cause of the anaemia but had to treat it by blood transfusions if she was to start feeling more well.'

In addition, there were two instances where information was not given to patients even though nursing staff possessed relevant knowledge:

'A female patient aged 49 years had come into hospital for an operation on her hand. The anaesthetist had explained the operation to her and told her that he had prescribed paracetamol, in case she had any post-operative pain. The patient experienced a great deal of pain when she awoke from the anaesthetic and this led her to believe that the operation must have gone badly. She told me how painful her hand was and I got a doctor to prescribe a stronger pain-killer. I said: "I didn't like to tell you this before, but I had this operation done two years ago and the pain I had for about 48 hours afterwards was awful".'

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'The man's pet had gone to a friend's but they'd put it down because they couldn't handle it. And the patient was with us awaiting placement in a place where they don't take pets. And he was asking about the dog, but we really couldn't tell him that the dog was no longer with us. We were saying "You will get to see him sometime". Really it didn't seem appropriate to tell him. He had a couple of episodes where he got quite agitated and a little bit aggressive, so actually telling him the truth might have made him aggressive. I don't think anyone was against not telling him, we all thought it was for the best. And at handover we would discuss it.'

#### **CONSEQUENCES OF DECEPTION**

Staff were also asked to outline the effects of their attempt to relieve anxiety or distress. For the intellectually impaired patients, the short-term consequences were generally positive, as for the woman pacing the corridors:

'She seemed very happy about this and, after a cup of tea, settled down again, saying thank you to me for helping.'

The mentally handicapped individual grew gradually accustomed to the idea of moving to the bungalow after a few 'visits'. In the case of the gentleman whose dog had been put down, he was moved to a nursing home without being told, so the consequences were unknown.

However, the nurses recognised that there could be longer-term difficulties when the patients were competent and staff had to face the consequences of their behaviour. Sometimes this was because communication patterns between staff are complex in the hospital environment and subject to misunderstandings. In such instances the consequences were not foreseen. In the case of the cancer patient who had been told of his diagnosis by his GP, for example:

'Unfortunately before I went off duty for a weekend I had indicated to one of my members of staff that the patient now knew his condition, knew his diagnosis and that people could be open with him. Because everyone else who had grown particularly attached to him was also finding it difficult that there

was this sort of barrier...and it was almost like everybody was role-acting...playing a part. So I let this member of staff know that this had occurred. Unfortunately this member of staff didn't pass it on to the others. So all weekend he wanted to talk about it but they carried on being evasive. Consequently that added to the patient's distress and added to mine. I think that shattered a lot of trust.'

And in the case of the woman who had an operation on her hand:

'The patient asked me why I did not warn her of [the post-operative pain] and I replied "I didn't want to frighten you, because you thought it wasn't going to hurt very much". The patient reported feeling shocked at this, saying that she would have preferred to have known what to expect.'

#### EXPLANATIONS OF THE NURSES ACTIONS

In some cases the nurses explained the reasons for their actions, but in other cases these must be inferred from the context. Sometimes nurses reported that they were using deception at the request of the patients' families and/or at the request of consultant medical staff. The difficulties of maintaining deception when patients were aware of their worsening physical condition were noted.

In most incidents the nurses explained their actions on grounds of non-maleficence. They used deception to keep the patients from becoming more anxious about their condition, their treatment, or their family. The nurses considered that they were acting positively to benefit their patients by giving them false information which they believed would relieve their anxiety. For the man whose dog had been put down and for the mentally handicapped resident, deception was used to facilitate management because the nurses feared these patients would react aggressively to the truth.

It is not possible to judge from these incidents the full extent to which the nurses engaged in ethical debate before using deception. In two cases (the patient with learning difficulties and the patient whose dog had died) the nurses reported that they discussed the various courses of action open to them before adopting deception. The nurse's reasoning behind her decision to withhold information about post-operative pain appeared unclear. When the patient reported pain, the nurse immediately contacted a doctor to have the patient written up for a stronger analgesic -- yet she took no action before the operation either to alert the patient as to what to expect or to get the doctor to alter his prescription in anticipation. When the nurse admitted her deception after the event to the patient, this undermined the patient's trust in the way her care had been managed.

#### Conclusions

Although the database is limited, a number of tentative conclusions can be reached. First, it should be noted that on only ten occasions was deception used in the sample of 251 incidents, even though the questionnaires were completed anonymously so that there was no 'public' disclosure of deception. While it would be unsound to draw any firm conclusions from this small number of reported incidents as to the actual frequency with which deceptive strategies are used by nurses (the sample is not representative of the nursing profession as a whole and the study itself treated deception as only one among a much



wider array of strategies used to alleviate patients' worries), it appears the use of deception is rare.

Second, the data provide some indication of the reasons for the deceptions. Staff usually perceived themselves as acting under the principles of beneficence or non-maleficence. However, another possibility is that deception was used for organisational reasons, in order to ensure the smooth running of the ward. For example, the nurses who did not disclose the dog's death or the move to the bungalow were concerned about aggressive reactions as well as doing no harm. It seems harder to justify the deception in such instances, although it can be argued that the welfare of other patients was relevant. It is also important that many of the incidents involved patients without full intellectual autonomy, who were less likely than others to uncover the deception.

Third, the results bear on Jackson's (3) contention that deception can be justified in certain circumstances when it does not have an adverse effect on the relationship -- especially the trust -- between patient and professional. These cases illustrate that it is not always possible to foresee the consequences of deception. Even when the nurses were apparently working under the principles of beneficence and non-maleficence, the longer-term consequences were sometimes negative. It was particularly difficult to co-ordinate deception when patients were intellectually unimpaired, and eventual discovery sometimes had an adverse effect on the nurse-patient relationship. Furthermore, both deception and discovery resulted in some distress for the nurses themselves and could lead to what was termed 'playing a part'. Thus it seems unlikely that the consequences of deception can be foreseen with great accuracy. Even though the intention might be innocent, whether a deception will be discovered cannot always be predicted.

Finally, it is useful to note that nurses varied in their willingness to use deception in their dealings with patients. Some nurses in the larger sample reported that they would never seek to mislead patients and would always disclose the truth about a situation if they knew it and believed that the patient was genuinely seeking an honest answer. Other nurses disputed this, believing for example that relatives have the right to direct staff not to disclose information. This is a field where further descriptive study would be of value in order to increase knowledge of the range of situations in which deception is used by nurses and by other health care professionals. The development of a theoretical model which could account for such differences in behaviour would be of great value in understanding the role of deception in practice. Self-reports in the form of critical incidents and interviews with staff and patients are two methods of eliciting this information.