Evolving legal responses to dependence on families in New Zealand and Singapore healthcare

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Abstract
Healthcare decision-making has traditionally focused on individual autonomy, but there is now a change occurring in which the involvement of families is gaining prominence. This appears to stem from an increasing emphasis on relational aspects of autonomy which recognises the individual’s connectedness to their family,[1] and also state reliance upon families to share the burdens and costs of caring for elderly and disabled dependents. Such a reorientation calls for similar legal emphasis on patient autonomy as understood in relational terms, and one that offers more adequate conceptions of independence, confidentiality, and decision-making authority in the light of this change. This paper outlines how two common law jurisdictions, New Zealand and Singapore, have accommodated, or are responding to, these changes.

Introduction
Since the 1970s, healthcare decision-making has focused on individual autonomy, but there is now a change occurring in which the involvement of families in patient decisions is gaining prominence. This appears to stem from an emphasis on relational aspects of autonomy which recognises the individual’s connectedness to their family,[1] and also from growing state reliance upon families to share the burdens and costs of caring for elderly and disabled dependents.[2] Such a reorientation calls for similar legal emphasis on patient autonomy understood in relational terms, and adequate conceptions of independence, decision-making authority and confidentiality in the light of this change. In some societies where familial or communal decision-making have been a part of social tradition, law and ethics have never been couched solely in terms of individual autonomy. However, arguably, emphasis on informed consent and patient rights has grown as physician-patient relationships shift towards a contractual model within many modern healthcare systems.[3] This paper outlines how two societies (New Zealand and Singapore) have accommodated relational understandings of independence, decision-making authority and confidentiality.

Family support and patient autonomy in relational perspective
Recent legal scholarship in the United Kingdom has drawn attention to the exclusionary attitude of English law towards the contributions made by families in patient decisions. This is arguably due to individualistic assumptions about patient autonomy in the law, which focus on individual-centred notions of informed consent and the patient’s best interests.[1,4] Where the law discusses family involvement, its most prevalent concerns are about patient confidentiality and undue influence in the doctor-patient relationship.[1] However, a recent UK study by Gilbar reports that patients are at times unable to make major and risky treatment decisions without the approval and support of their closest family members, knowing that they rely on them for informational, emotional and functional support. In addition, families are involved in decision-making in various ways, including creating a safe place for the patient to make a decision, becoming part of a collaborative team that decides, prompting the patient towards a decision, or making decisions for the patient.[1] This complex picture suggests that families do not tend to make decisions that are either rigidly collectivist or

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excluding individualistic, but instead are involved in ways that reveal important socially- and culturally-inflected values, beliefs and expectations of familial roles and responsibilities.[5]

Within healthcare, patient autonomy is reasonably conceived as relational because most seriously ill patients are often dependent on others. Furthermore, long-term reciprocity and collaborative arrangements with family members or intimates could be vital to patient well-being. Such a configuration of patient autonomy thus presumes various kinds of limits upon an individual’s freedom to opt out of conduct expected within dependent relationships. These limits aim to preserve important relationships that a patient has with others without harming the patient’s autonomy interests.[6]

It is also reasonable to assume relational notions of patient privacy and confidentiality in various care settings. In increasingly collaborative and multidisciplinary patient care settings, patient information must be shared with widening circles of healthcare professionals. Family carers are now often regarded as part of the team that is integral to care that shifts between hospital, community and the home. The inclusion of family carers and those with important roles in the healthcare decision-making process should therefore not be regarded as harmful to the patient’s privacy and confidentiality interests.[7]

While emphasis on relational aspects of healthcare decision-making and information-sharing seems consistent with patient autonomy, it is less clear where the limits lie, and what standards should be adopted. The new emphasis on interdependent care leaves too little guidance on what configurations of decisional authority are possible in varied circumstances. This raises the need to attend to the benefits of relationship while addressing the potential conflicts they can cause: harms to intimates that include health and emotional stresses on carers, and unchecked patterns of exploitation and injustice in the distribution of rights and obligations. Defenders of relational autonomy acknowledge how easily the patient’s rights of self-determination might give way to pragmatic considerations of keeping peace with powerful healthcare professionals and caregivers.[6]

Who then is best placed to protect patients against undue pressure from others and to advocate for the family and caregivers’ interests to be heard?

Finally, cultural patterns of family involvement introduce a stubborn dimension of complexity to information sharing and decision-making in healthcare. Culture may intervene in communication patterns that invoke norms governing appropriate ‘languages’ to convey news of serious illness,[8] or persons who are culturally acceptable conduits of bad news within the family.[9]

Conceptual work on the notion of shared decision-making has identified both its characteristics and importance in light of the legal right to autonomy and informed consent. However, this work has mainly focused on the doctor-patient dyad and not the doctor-patient-family triad.[10] The practical challenges of preserving the balance of the patient’s decisional authority and regard for the interests of intimates are critical matters for contemporary legal and policy implementation. Our commentary on law and professional practice in New Zealand and Singapore offers some ideas on how different cultures and legal frameworks shape boundaries with regard to these questions.

**Legal Responses to Independence, Decision-making Authority and Confidentiality**

**New Zealand**

In New Zealand, the law governing medical decision-making is generally framed in terms of individual rights, reflecting the principles of autonomy and self-determination. For example, sections 10 and 11 of the Bill of Rights Act 1990 give “everyone” the right to refuse medical treatment and the right not to be subject to medical or scientific experimentation. New Zealand also has a Code of Health and Disability Services Consumers’ Rights 1996, which is a statement of patients’ rights and corresponding duties of healthcare providers. It includes the right to respect, the right to have services provided of an appropriate standard, the right to be fully informed, the right to make an informed choice and the right to give informed consent. The Code purports to restate the common
law in plain English, but it has assumed a pivotal role in the doctor-patient relationship by articulating patients’ rights in a definitive manner and providing easy access to a state funded complaints process through which breaches of the Code’s rights can be addressed. The availability of this low level complaints process together with New Zealand’s bar on legal proceedings for personal injury compensation under the Accident Compensation Act 2001 (s.317) explains why questions relating to medical decision-making and informed consent rarely come before the courts.

While the Code is expressed in terms of autonomous rights, it does not preclude relational aspects of autonomy. For example, the right to be treated with respect in Right 1 of the Code includes taking account of the needs, values and beliefs of the patient’s cultural, religious, social and ethnic group. Special mention is made of New Zealand’s indigenous Maori population, because their approach to the human body and medical decision-making differs from that of New Zealanders of European descent. The Maori world view is communal rather than individualistic.[11] It calls for group decision-making, rather than individual decision-making. Health providers in New Zealand must therefore expect Maori patients to discuss choices about medical treatment with the group to which they belong and that in reaching a decision, the interests of the group will have a prominent, possibly even decisive, role. Where tribal affiliations are tenuous, severed or lost, the customary family grouping may only be involved in the patient’s medical decisions if the patient seeks or consents to their participation. Whether medical decision-making is to be based on a dyad or triad relationship will therefore depend on the patient’s connectedness to their customary values and their deference to the family group. A health provider cannot simply assume that all members of a particular culture or religious or ethnic group share the same norms and values. To do so would be disrespectful to patients whose norms and values are different, while compelling them to conform to a value system they do not believe in, or that they think may harm them.

Legal support for family involvement in medical decision-making is not confined to Maori. The duty of respect in Right 1 of the Code applies to all patients, and this provides the avenue through which family involvement is most obviously accommodated. It requires a holistic approach to the patient’s needs that takes account of the patient’s wider relationships. Right 7, which deals with informed consent, appears to focus exclusively on the patient. It stipulates that services may be provided only if the patient makes an informed choice and gives informed consent, except where the law provides otherwise. While this right is expressed in terms of autonomy and self-determination, it is immediately followed by Right 8, which entitles patients to have one or more support persons of their choice present. This Right is an explicit acknowledgement that patients do not exist in isolation and may wish to involve others in their medical decision-making. Right 7 must therefore not be seen as precluding relational autonomy, but rather as giving the patient the choice whether to involve others in the decisionmaking process. A patient’s informed choice is no less that patient’s choice if it was made by involving others. The health provider’s duty is to accommodate the patient’s preferred decision-making process. Where the patient’s expressed preference for a triad relationship is apparent rather than real, the doctor’s duty is to give effect the patient’s actual preference by moving to a dyad relationship. Relational autonomy is thus controlled by and for the benefit of the individual patient, even where the patient is of Maori descent. New Zealand law would not accommodate a collectivist approach to medical decisionmaking that disregarded or overrode the patient’s views and preferences.

The involvement of the family necessarily lowers the bar on patient confidentiality. Without information about the patient’s condition, prognosis and treatment options, the patient’s intimates are not able to assist the patient and advise the healthcare provider. However, as the purpose of confidentiality and privacy is to safeguard sensitive personal information of the individual, these doctrines tend to be patient centred and based on individual autonomy.[8] New Zealand law on patient confidentiality, like English law, imposes a strict duty on health professionals not to disclose patient information without the patient’s consent.[12] While legal proceedings for breach of confidence are rare, disciplinary proceedings for a breach of the Code of Patient Rights or the New
Zealand Medical Association’s Code of Ethics are not uncommon. The latter Code is clearly premised upon individual autonomy and permits disclosure of patient information without patient consent only “in those unusual circumstances when it is clearly in the patient’s best interests or there is an overriding public good”. [13] This limited exception severely constrains health professionals from freely discussing a patient’s condition and treatment with family members.

However, New Zealand’s Health Information Privacy Code 1994 provides more opportunity for family participation. Rule 11 of the Privacy Code regulates the disclosure of health information. Aside from disclosure being authorised by the individual, it also permits disclosure without consent in certain circumstances. The first relevant circumstance is where disclosure is one of the purposes in connection with which the information was obtained. This rule would apply where family members are expected to be involved in the care of the patient. Disclosure is also permitted where it is not desirable or practicable to obtain individual authorisation, and disclosure is to a person nominated by the patient or to the patient’s principal caregiver or a near relative in accordance with recognized professional practice (unless contrary to the express request of the patient). This rule indicates that there may be circumstances where, in the absence of a patient’s express objection, disclosure of patient information to intimates directly concerned with oversight of the patient’s care and welfare is appropriate. While this rule provides some scope for participation by intimates, anecdotal evidence suggests that health providers are slow to rely on this exception to patient autonomy for fear of complaint.

Singapore

Like New Zealand, Singapore inherited the English common law system, but it operates within a multicultural Asian context where the family plays a central—and often dominant—role in the long term care of elderly and terminally ill patients.[8,14] This often manifests itself in collusion between family and physicians to withhold diagnosis and prognosis from patients, and the non-involvement of patients in making important end-of-life treatment and care decisions. The reasons for these are both cultural (rooted in philosophies such as Confucianism) and generic (structural constraints on health care professionals communicating effectively with patients and families).[14,15]

Nevertheless, medical law in Singapore does not simply ride on these social and cultural phenomena. The case law, albeit limited, has firmly recognised the primacy of the patient’s common law right to self-determination.[16] Statutory innovations such as the Advance Medical Directive Act 1995 (AMDA) emplace a transactional, individualistic process that would tend to exclude the involvement of a patient’s family. It precludes anyone who stands to benefit from a patient’s death from acting as the second witness to the AMD (the first must be a medical practitioner). Section 14 of the AMDA also criminalises procurement of an AMD by “unconscionable conduct or undue influence”, with the added, independent penalty of forfeiture of a testamentary or insurance benefit derived from the patient’s personal estate. Finally, patient confidentiality has thus far been emphasised principally as a matter of professional medical ethics, and in particular by s.15(3) AMDA, which requires any communication of patient intent to execute an AMD to a medical practitioner or worker, and all information relating to its execution, to be kept confidential.

Further statutory emphasis on patient autonomy is more recently found in the Mental Capacity Act 2008 (MCA), which is modelled on the UK’s Mental Capacity Act 2005. The MCA’s general principles insist that a patient should not be regarded as lacking capacity unless every practicable step has been taken to help him to make his own decisions. Even when a patient lacks functional capacity, the physician must, in so far as is reasonably practicable, permit and encourage the patient as fully as possible in his medical decisions. In addition, the MCA’s best interest test is likewise focused on the individual’s, rather than the family’s, best interests.[4] In tandem with these legal developments, the
underlying social and cultural attitudes are also arguably evolving. Health care professionals and patients themselves are increasingly supportive of the importance of patient autonomy and involvement in decision-making. [17]

The law, however, does not look at health care financing solely through an individualistic lens. Although individual responsibility and choice is the cornerstone of the market-oriented healthcare system, Confucian ideals of private family responsibility for care also find expression in other Singapore legislation. The Maintenance of Parents Act 1996 imposes a statutory obligation on children to pay maintenance for their parents where it is just and equitable to do so. While maintenance is not awarded for any specific purpose, s.5 of the Act stipulates that reasonable health care costs may be taken into consideration in fixing the amount payable. This is a reflection of the social value of filial piety, which translates into a legal responsibility placed on progeny, in particular, to provide for their parents’ healthcare needs. Similarly, disbursements from the healthcare social safety net, administered under the statutory Medical Endowment Fund (Medifund), are stringently administered and means tested. In determining if Medifund subsidy will be granted, an assessment is made of whether both the patient and his family have difficulty in paying for subsidised healthcare. Thus, it is often practically impossible to insist on an individualistic approach to healthcare decision-making given this de facto allocation of financial responsibility within the Singapore healthcare system.[18]

In view of these potentially conflicting legal requirements that juxtapose patient autonomy and family responsibility, both law and professional practice have had to take explicit account of relational aspects of autonomy as a result. For example, in recommending the enactment of the AMDA, the National Medical Ethics Committee advised that family involvement in the execution of an AMD should be encouraged, notwithstanding its strict formality requirements. Lack of family involvement was likely to create opposition to the implementation of the AMD and obstruct respect for the patient’s autonomy as expressed in the AMD.[15] Thus, the NMEC recommended that the profession should avoid taking a “purely legalistic approach in the implementation of an advance directive...” and make every effort to obtain the family’s support – in effect condoning a relational approach to advance care planning in contrast to that envisaged by the AMDA.[19]

Secondly, the impact of a criminal proscription of undue influence in the AMDA process could be mitigated by legal interpretation of the concept of ‘undue influence’. In the UK, the application of undue influence in the medical decision-making context has been criticised as improperly skewed towards individual autonomy without adequately recognising the important role that family plays in such a process.[1] However, legal interference under the doctrine arguably seeks to protect relational norms in intimate relationships from abuse, rather than simply vindicating some atomistic notion of individual autonomy. In Singapore case law, undue influence doctrine has been observed to take into account cultural values that emphasise the importance of family interests over the individual’s.[20]

Thirdly, medical confidentiality does not seem to be a firm barrier to family involvement if one looks at the realities of medical practice as inferred from professional guidelines and case law.[21] Especially in respect of elderly patients who depend on family financial support, the social expectation is that doctors will consult with family members first before the patient.[8] Family involvement might be squared with respecting patient confidentiality with a more ready inference of patient waiver of confidentiality when, as a matter of social practice, family members often attend consultation together with the patient without any explicit patient objection to this. A patient’s need for family support in financing healthcare further precludes strict observance of patient confidentiality, at least in respect of statutorily recognised next of kin.
Finally, unlike the UK, the MCA 2008 specifically excludes the application of a lasting power of attorney (LPA) from certain medical decisions involving life-sustaining treatment, or any other treatment that a person providing health care reasonably believes is necessary to prevent a serious deterioration in the patient’s condition (s.13(8)). These exclusions significantly restrict patient autonomy prospectively, operate to place discretion ultimately in the hands of the medical profession, and appear to be motivated by a concern to protect the patient from abuse by the donee of a LPA. Ironcally, these restrictions raise the real possibility of greater emphasis being placed on the views and preferences of family members in general, rather than those of the patient – as expressed in her choice of a specified donee of a LPA for medical decisions.[22] In the face of evidential uncertainty concerning the statutory best interests factors, it would not be surprising if a physician tasked with determining best interests accedes to the majority views of the family, particularly where they also accord with his or her professional medical assessment of the situation.[17]

Conclusion

Medical law in New Zealand provides scope for a moderate account of relational considerations in which the patient still has the final say. While the common law and professional guidelines on patient confidentiality are still cast in individualistic terms, the rules in the Privacy Code provide some relaxation to the strict duty of confidentiality. There is therefore some coherence between medical decision-making and disclosure of patient information. In comparison, Singapore law reflects a more ambiguous interaction between apparently conflicting legal norms—patient autonomy and family responsibility. Nevertheless these conflicts may be more apparent than real, if we realise that legal conceptions of autonomy can be more nuanced and open-textured than they appear to be. Autonomy (or self-determination) is an over-loaded concept whose interpretation and influence is evolving and contextual, particularly in the multi-cultural contexts where social values and attitudes are themselves similarly changing. Perhaps the real challenge is not so much overcoming legal impediments to the decision making influence and rights of families, but rather identifying the law’s normative contributions to our understanding of the acceptable boundaries within such intimate relationships, the prevention of abuse, and the proper decision making processes to be used in resolving ethical conflict.

With respect to process, given both the importance and the indeterminacy of cultural and relational factors, Hern et al have proposed a reflexive, negotiated model of interaction to help healthcare professionals deal adequately with this complexity in medical decision-making.[23] This model promotes patient empowerment in healthcare by offering disclosures of diagnosis, prognosis and treatment options to a competent patient at various intervals, while allowing patients to freely decline or delegate these offers to others. The open-endedness of the model offers flexibility to adapt professional interactions with patients and families in accordance with perceptions of a patient’s character, attitudes and patterns of communication within the family and with healthcare providers.

While Hern et al note that there is a ‘western bias’ within their model which centres on the patient (rather than the family), a similar model has also been developed in Japan for advance care planning.[24] This model offers a promising fit with the current, evolving legal and professional responses in both New Zealand and Singapore.[25] notwithstanding legal and cultural variations. What we are likely to see emerge, rather, are differences of emphasis (in the process of negotiation) on the interests of the family, and the degree of acceptability of tacit consent to waivers of confidentiality and diminished participation.[8 at 208]

References
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