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Incapacitated Patients' Wellbeing: Surrogate Decision Making

Elizabeth Kaplunov^{a*}, Nigel Harvey^b

* Corresponding author: Elizabeth Kaplunov, e.kaplunov@bath.ac.uk

^aUniversity of Bath, Department for Health, Claverton Down, Bath, BA27AY, UK

^bUniversity College London, Department of Experimental Psychology, Gower Street, London, WC1E 6BT, UK

Abstract

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Patients' wellbeing often depends on making the right decision with regards to their healthcare treatment and other decisions relating to their health care or finances in terms of their end of life. If they are unable to make decisions for themselves, other people have to make those decisions on their behalf. This important task is described in literature as surrogate decision making. We survey and illustrate several important issues that are associated with surrogate decision making and provide an overview of the factors that have been found to affect its accuracy. Selection of a surrogate decision maker has been found to be affected by the beneficiary's nationality, risk attitudes, and personality and by specific qualities of the surrogate. Decision accuracy (as indexed by matching between choices for self or relative) has been found to be affected by factors such as nationality, surrogate qualities, surrogate person choice, risk attitudes and personality.

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1. Introduction

'Good decision making is an essential part of good medicine' according to Chapman (2004). Decision making research can inform and help to improve medical decisions, and medicine is a domain which is useful for studying topics such as biases, expertise, naturalistic decisions and decisions made in circumstances of risk. Decision making on behalf of someone else is very common in medical, such as doctors or family members making decisions for patients.

Surrogate decision making can be defined as a 'useful means through which we can exercise control over decisions that affect our lives when we have lost capacity to make these decisions for

ourselves.’ (Anscombe, 1991; Wrigley, 2014). In the UK, the Mental Capacity Act (2005) provides official guidelines for appointing a surrogate decision-maker and for how surrogate decision making should be carried out. The Act highlights the importance of acting in the best interests of the beneficiary and recommends that the surrogate appointed by the donor should be over 18 years old. It also emphasizes that trust and knowing the surrogate decision maker well are good criteria for choosing a surrogate decision maker who will act in the best interests of the beneficiary when they are no longer capable of making their own healthcare decisions.

2. The accuracy of surrogate decision making

There are inconsistent findings concerning whether surrogates are able to accurately make decisions on behalf of patients. In a study by Silveira, Kim and Langa (2010), it was found that patients aged 60 and over who had announced their healthcare preferences were likely to receive care related to those preferences. Upon the analysis of 3746 surveys in the Health and Retirement Study, it was found that 83.2% of participants, who wanted limited care and 97.1% of those who requested comfort care, received the type of care that they wanted. This suggests that, in most cases, surrogate decision makers do make accurate choices that match the preferences of the patients.

However, other studies have revealed suboptimal surrogate decision making. White, Curtis, Lo and Luce (2006) looked at intensive care unit (ICU) physicians who had to take on the role of surrogate decision makers for 18 patients who were not capable of making their own healthcare decisions. The physicians obtained the opinions of courts or hospital ethics committees for only two patients, asked the opinion of another physician for 10 patients, and acted independently for six patients. The decisions focussed on whether treatment for the patients should be withdrawn. It is noteworthy that, for a third of the decisions to reduce life support, the physicians were likely act on their own accord without seeking other opinions. Although the physicians knew the patients’ illness symptoms and survival prospects, they did not know the patient and were unable to judge what treatment decisions the patient would have preferred. The physician surrogates were potentially biased by their position (being a physician), which led them to base some of the decisions on just their own views. Therefore, it is likely that the physicians did not always act in a way consistent with their patients’ wishes and preferences. However, it was not possible to check what the patients wanted as they did not have advance directive documents and were incapable of announcing their preferences.

In Woo and Prager’s (2009) study, family members made suboptimal decisions on the behalf of a 42-year-old patient on life support. They chose to withdraw life support. However, the patient survived and, when he recovered, said that he would prefer to stay alive even if that meant that he would be disabled. This study highlights how careful surrogates should be when making decisions on behalf of someone else and that it is often possible to make the wrong decision. Thus, research on whether it is possible to make a perfect surrogate decision suggests that, in most cases, it is difficult to do so without a living will that details the beneficiary’s exact preferences. Advice from authorities (such as courts and hospital ethics boards) may also be needed.

3. Factors affecting the accuracy of surrogate decisions

Different factors may affect surrogate decision accuracy, such as the preferences of the surrogate decision maker, nationality of the surrogate and beneficiary, the beneficiary's choice of surrogate, and the risk-taking attitudes, personality and other qualities of surrogate and beneficiary. For example, Marks and Arkes (2008) showed how accuracy was affected by surrogates relying on their own preferences. They attributed this dependence to the use of a projection heuristic (i.e., predicting the patient's preferences on the basis of their own preferences). In their large scale study, predictions of patients' preferences by surrogates for 438 patient-surrogate pairs were examined. It was found that, for 350 cases, the surrogates projected their own wishes instead of accurately predicting the patients' preferences. Therefore, differences between surrogates' and beneficiaries' own preferences impair surrogate decision making. Accuracy of surrogate decision making would be higher if surrogates were more attuned to patients' preferences.

However, Fagerlin, Ditto, Danks, Houts & Smucker (2001) have shown that the projection heuristic produces more accurate surrogate decision making than its opposite (i.e., surrogates recommending for their beneficiaries the opposite of what they would select for themselves). Thus, though the projection heuristic does not perform perfectly, it still provides some guide to the preferences of beneficiaries. It would be useful to look in more detail at how surrogate preferences and patient preferences are matched in order to cast light on how the degree of match between the preferences of surrogates and beneficiaries influences the quality of surrogate decision making.

4. Nationality and ethnic background as factors affecting surrogate accuracy

The degree to which surrogates and beneficiaries are related may affect the accuracy surrogate decision making. Madsen, Tunney, Fieldman, Plotkin, Dunbar, Richardson and McFarland (2007) found that, for participants from European and Oriental backgrounds, the more biologically related a beneficiary was to the surrogate, the more accurate and effortful the surrogate decision making was. In contrast, Ziegler and Tunney (2012) found that British surrogate decision makers made impulsive decisions for more biologically related beneficiaries. Clearly, more research is needed to determine how nationality affects surrogate decision making.

There may be indirect effects of ethnic background on surrogate decision making. Hopp (2000) analysed the Asset and Health Dynamics Among the Oldest Old (AHEAD) survey based on adults aged 70 and over. He found that white (as opposed to African American) participants were more likely to have produced advance directives. Given that people who provide advance directives are more likely to receive the care that they prefer (Silveira et al., 2010), this implies that surrogate decision accuracy can be indirectly affected by ethnic background. Hopp's (2000) study could be extended by studying other ethnic groups and by using features other than ethnicity as a basis for comparison. For example, it would be interesting to compare nationalities or cultural groups that vary in terms of individualism and collectivism as these factors are likely to affect the way in which surrogates relate to beneficiaries (Tower, Kelly, & Richards, 1997; Zha, Walczyk, Griffith-Rose, Tobacyk, & Walczyk, 2006).

5. Choosing a surrogate

In Hopp's (2000) study, the participants were most likely to name family members as their surrogates. However, a meta-analysis (Shalowitz, Garrett-Mayer & Wendler, 2006) has shown that, in a third of decisions, patient-selected family members acting as surrogates were unable to predict the patients' treatment preferences. This implies that beneficiaries may be unable to choose a surrogate who will make best decisions for them and that family members may not be the best surrogate decision makers. However, ICU physicians may not be the best people to act as surrogates either: as White et al., (2006) showed, they tend to make decisions without consulting patient preferences. Clearly, to maximise decision accuracy, it may be better to choose certain people as surrogate decision makers rather than others. However, given our present state of knowledge, we cannot identify who these people are. To date, research has focussed only on physicians, partners, children and grandchildren but has not compared the quality of surrogate decisions made by these people with that of surrogate decisions made by parents, siblings and friends.

6. Risks involved in surrogate decision making

Risk attitudes are likely to have an effect on surrogate decision-making. In the medical domain, differences in risk associated with different courses of action are commonplace and different types of risk have to be taken into account (e.g., mortality risk, risk of severe treatment side effects). Prosser, Kuntz, Bar-Or and Weinstein (2002) showed that patients with multiple sclerosis who were more risk-seeking tended to choose riskier treatments. Specifically, they demonstrated that patients who showed a risk-seeking choice pattern in a lottery scenario were more likely to select a treatment that tended to be more effective but that was also associated with a higher chance of very serious side effects. Studies in other areas have shown that surrogate decision makers are poor at assessing the risk attitude of beneficiaries (Faro & Rottenstreich, 2006; Hsee & Weber, 1997). Hence, it would be very useful to assess whether the risk attitudes of surrogates and patients have an effect on the quality of surrogate decision making in the medical domain.

To test risk attitudes in surrogates and patients, the DOSPERT scale (Blais & Weber, 2006) can be used. This 30-item scale is reliable across different nationalities and is based on ethical, financial, recreational, social, and health/safety risk domains. It measures risk-taking attitudes, the perception of risky situations and the expected benefits of risky situations.

7. Personal qualities of a surrogate

Weller and Tikir (2011) found correlations between DOSPERT and personality, as indexed by the HEXACO scale (Ashton & Lee, 2009). Their finding implies that personality could indirectly influence surrogate decision making. Certain qualities that a surrogate possesses may also directly affect the quality of the decisions that they make. In selecting surrogates, beneficiaries may or may not be able to identify what these qualities are.

A study by Edwards, Brown, Twyman, Christie and Rakow (2011) analysed the qualities that patients look for in surrogates. Three main factors found: esteem regarding general qualities;

perception of specific attributes in relation to the self; concern for others and social norms. These three factors were broken down into further characteristics, such as ‘caring’ for the esteem regarding general qualities factor, ‘knowledge of person’ for the perception of specific attributes in relation to the self factor, and ‘concern for surrogate’ for the concern for others and social norms factor. However, in this study, only 30 undergraduate participants were presented with a hypothetical scenario about losing their capacity to make healthcare decisions for themselves. Use of hypothetical rather than real scenarios and the low number of participants from a very specific background means that the conclusions must be regarded as tentative: they may not generalise to a wider population.

However, the findings of Edwards et al., (2011) do follow the decision standards suggested by Berger, DeRenzo and Schwartz (2008). The standards are patients’ known wishes, substituted judgments and best interests of the patient. These are treated hierarchically consistent with an established convention in medical ethics. First, it is most important to focus on what the patient prefers, then to pay attention to what the surrogate thinks the patient would want and, finally to take account of the patients’ best interests. The fact that the surrogate decision standards are consistent with the Edwards et al., (2011) findings suggests that people are naturally able to judge the qualities of surrogates that lead to improved surrogate decision accuracy. However, to increase generalizability, further research needs to confirm them with more participants drawn from a more culturally diverse background.

8. Conclusion

To summarise, there is research evidence suggesting that decision accuracy of surrogates is affected by nationality, personality, risk-taking attitudes, surrogate qualities, surrogate person choice and surrogate preferences. Surrogate decision making is influenced by ‘the attributes of and the nature of the task, features of the decision maker, and the context in which the decision takes place’ (Smith, Higgs & Ellis, 2008). Given that in a third of cases surrogates are unable to accurately predict patient preferences (Coppolino & Ackerson, 2001), the effects of different factors on surrogate person choice and surrogate decision accuracy need to be assessed.

To this end, some preliminary research was carried out by Kaplunov (2013). Results indicated that Chinese participants tended to choose a sibling as their surrogate whereas Russian and English participants tended to choose their partner. Chinese participants also selected different treatments for themselves and for others, thereby implying that they were less likely to use the projection heuristic. Higher accuracy of surrogate decisions was predicted by a number of factors: being more scared of dying or getting a serious illness; being less likely to take ethical risks; perceiving low risks in recreational and financial situations; having lower expectations of the benefits of taking financial risks. Choice of a parent as preferred surrogate decision maker was predicted by other factors: scoring highly on an Honesty-Humility scale; identifying oneself as ‘brave’ and ‘moral’; being less likely to take health or safety risks; having low expectations of the benefits of taking ethical risks. These findings are provisional and could be usefully extended and generalized in a number of ways.

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