



Understanding kidney transplant patients' treatment choices: The interaction of emotion with medical and social influences on risk preferences



Jean Harrington ^{a, b, *}, Myfanwy Morgan ^a

^a King's College London, Division of Health and Social Care Research, Faculty of Life Sciences and Medicine, Addison House, Guy's Campus, London SE1 1UL, United Kingdom

^b National Institute for Health Research (NIHR), Biomedical Research Centre at Guy's and St Thomas' NHS Foundation Trust and King's College London, Tower Wing, Guy's Hospital, Great Maze Pond, London SE1 9RT, United Kingdom

ARTICLE INFO

Article history:

Received 23 June 2015

Received in revised form

15 February 2016

Accepted 16 February 2016

Available online 18 February 2016

Keywords:

United Kingdom

Kidney transplantation

Biomarker

Risk

Emotion

Social influences

'Gift exchange'

Trust

ABSTRACT

Following renal transplantation patients experience on-going immunosuppressant medication to reduce the risk of graft rejection. Over the long term the side effects of immunosuppressive drugs may affect graft survival and significantly increase risks of cancers, stroke and cardiovascular disease. To reduce these risks research is underway to develop a biomarker test to identify those patients who are likely to be 'tolerant' to their graft and therefore able to reduce immunosuppression. Biomarker tests may however incorrectly identify some patients as tolerant, thus jeopardising their graft. Following a quantitative assessment of risk preferences we undertook a qualitative study to investigate the range of influences that shaped the substantial variations found in the level of risk transplant recipients were hypothetically willing to take. In-depth interviews were carried out in the United Kingdom between May 2013 and July 2014 with 24 transplant recipients all of whom had stable kidney graft function. These interviews identified a range of factors that patients take into account when making risk assessments, including familial views, trust and the ritual of 'gift exchange' that permeates the social space of kidney transplantation. Our data support the notion that emotion is not part of a linear process, preceding and separate to reason, but is intertwined with personal understanding and perception of risk and involves a complex interplay between different influences on decision-making. Our data also support Lupton's view that risk judgements are shared and collective rather than located within the individual and suggests that patient choice rather than involving a purely rational weighing of medical benefit is often based on influences that may not accord with the framework nor intention of medical professionals and medical research.

© 2016 Elsevier Ltd. All rights reserved.

1. Introduction

Since the early 1960s sociologists have considered the health hazards associated with the introduction of innovative forms of medical treatments and therapies as constituting a veritable 'risk epidemic' (Schlich and Tröhler 2006:2). This 'manufactured' form of risk, produced by innovative developments in science and technology, has little historical reference arising instead with the

process of modernization and influencing the manner in which we conceptualise and manage risk (Giddens, 1999). Ulrich Beck argues that in the late modern period, with the 'fracturing of monolithic sources of knowledge and identity in contemporary Western culture', reliance on the 'calculability' of risk has been increasingly challenged (1992:71). This is due to the rise of modernity having produced situations of risk for which experts do not have answers. As a consequence many opinions are expressed and the ability to 'calculate' risk, once based on the 'true' knowledge of the expert, dissolves leaving people to 'estimate' the risk. As such the way we come to a decision now involves individual beliefs, behaviours and 'everyday life' and whatever evidence we find most believable (Tulloch and Lupton, 2003; Wasserman and Hinote, 2010). This

* Corresponding author.

E-mail addresses: jean.harrington@kcl.ac.uk (J. Harrington), myfanwy.morgan@kcl.ac.uk (M. Morgan).

means that decision-making is a complex process when faced with biomedical initiatives that bring both the hope of unimaginable advances yet the possibility of often significant negative consequences such as the clinical trial of the immunomodulatory drug TGN1412 during which catastrophic systemic organ failure occurred (Goldacre, 2012). Testing of these new technologies and treatments requires service users to engage with the risk of the unstable and complex framework of scientific claims.

1.1. Framing the concept of risk

Disciplines frame and understand the concept of risk differently. For example the life sciences and medicine apply principles, postulates and calculations to address what is perceived as the *objective* reality of 'risk' whereas psychology views risk as a behavioural and cognitive phenomenon and focuses on judging risky *behaviour* (Zinn, 2015). In contrast anthropologists see risk as a *cultural* phenomenon, including the way in which risk is publicised and moralised (Althaus, 2005) and sociologists emphasise risk-taking as a form of *social action* based on experience and tacit knowledge (Zinn, 2008, 2015). These disciplines also have varying notions of the influence of emotions on decision-making in situations of risk. The psychologist Paul Slovic argues that emotion is important in *guiding* judgement and decision-making, with people drawing on a pool of conscious or unconscious associations that are marked to varying degrees with positive or negative feelings (Slovic et al., 2007). Emotion is thus seen from this perspective as preceding and separate from what is described as reason (Slovic and Västfjäll 2010). Although these perspectives on risk may be relevant to elements of our findings it is Deborah Lupton's argument that 'emotion and risk *interact* in the process configuring each other' that we argue most keenly reflects our findings (Lupton, 2013:641). Lupton regards risk judgements as imbued with emotion, whether this is at the pre-conscious, unconscious or conscious level and depicts emotion and risk as inevitably configured via social and cultural processes (Lupton, 2013:634). Thus although risk may be material, as in a risk to health, it is always interpreted via a social or cultural lens. Lupton describes this in terms of an 'emotion-risk assemblage' that both incorporates notions of affect into the concept and also identifies the ways in which the social and its cultural manifestations shape risk perceptions and decision-making (ibid:636). However, Lupton notes that the relationship between risk and emotion remains under theorised, particularly in the context of health and medicine (ibid:637). Taking up Lupton's conjecture we therefore consider both the place of emotion and social influences on the choices made by kidney transplant patients when faced with a biomarker test.

1.2. Our study

Our empirical study focuses on the process of decision-making in kidney transplant patients in the context of on-going research to develop a biomarker test to identify those patients who can be considered 'operationally tolerant' to their graft and who will therefore not experience rejection in the absence of immunosuppressive drugs (Heidt and Wood, 2012); the term biomarker being defined as 'a characteristic that is objectively measured and evaluated as an indicator of normal biological processes, pathogenic processes, or pharmacologic responses to a therapeutic intervention' (OECD, 2011). It is anticipated that identifying the 'biomarker of tolerance' will improve the present situation where immunosuppressive drugs taken to reduce the risk of kidney graft rejection may in themselves damage the graft and also cause long-term health problems including cancers, stroke and cardiovascular disease (NHS 2015a; Howard et al., 2002). However, biomarker tests are not 100%

accurate with the risk that patients may be *erroneously* identified as tolerant. In these circumstances withdrawal of immunosuppressant medication could lead to the rejection of the graft. In this situation a patient centred approach to the research requires both to weigh the medical benefits of minimizing immunosuppression against the risk of precipitating graft rejection *and* to identify how patients conceptualise, interpret and respond to the risk in the context of their experiences and the priorities of their life world.

The paper forms part of a larger project with the initial stage employing a quantitative approach to identify the level of risk that kidney transplant patients might be willing to take in choosing biomarker led care. In percentage terms this identified hypothetical risk levels ranging from 0% to 50%. The second qualitative phase, reported here, aimed to elicit the variety and interaction of influences on their risk decisions.

2. Method

Participants for the qualitative study were purposively selected from the initial quantitative patient sample to include differences in age, gender, type of transplant and time on dialysis. Ethical approval was obtained for the research following which a research nurse at each of the eight participating hospitals initially contacted patients to establish whether they would be willing to consider taking part in the study. Patients who agreed were sent a letter describing the biomarker research, making clear that the test was not 100% accurate and explaining that the purpose of the study was to identify the level of risk that patients may be willing to take. The first author (JH) then telephoned to discuss the study, answer any questions and for patients who agreed to be involved set a suitable date and time.

Interviews took place in people's homes, cafes or occasionally a meeting room within a Hospital Trust. Informed consent was obtained from all participants following provision of an information sheet and opportunity to ask questions. It was also emphasised to participants that their participation was voluntary and they could withdraw at any stage. Interviews began with participants sharing the 'story' of their renal failure and kidney transplant(s) to elicit the context of their decision-making. The researcher (JH) then explored issues that participant's raised. Other considerations were also probed assisted by a topic guide designed to elicit patients' attitude to risk, including personal priorities - past, present and future - views on the biomarker test and the level of risk they would be prepared to take if the test showed they were 'tolerant' and could hypothetically have their immunosuppressant medication reduced. The interviews took place over 15 months and most lasted 45–60 min. Three interviews were carried out in the presence of a patient's relative - wife, husband or mother - whose voices are brought into our findings. Following 24 interviews it appeared that saturation point had been reached with no new themes emerging.

Analysis occurred concurrently with interviews. Initially the taped interviews were transcribed verbatim and pseudonym(s) assigned. Preliminary coding and thematic analysis were then undertaken and the data entered into the software package NVivo9 to benefit from the automated search and display facilities. Each transcribed interview was then worked through manually to achieve a more complete understanding of the fluid and creative ways that themes emerge (Welsh, 2002).

3. Findings

The participants comprised 24 kidney transplant patients aged between 27 and 68 years from diverse backgrounds (Table 1). No one characteristic appeared to separate those who would take a low risk - expressed as between 0% and 5% - or those willing to take a risk of 20% or more.

Download English Version:

<https://daneshyari.com/en/article/7330333>

Download Persian Version:

<https://daneshyari.com/article/7330333>

[Daneshyari.com](https://daneshyari.com)