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"Hey sister! where's my kidney?" : exploring ethics and communication in organ transplantation in Gauteng, South Africa

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2016

http://hdl.handle.net/10539/21425

Etheredge, Harriet Rosanne (2016) Hey sister! where is my kidney? : exploring ethics and communication in organ transplantation in Gauteng, South Africa, University of Witwatersrand, Johannesburg,<http://wiredspace.wits.ac.za/handle/10539/21425>

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Abstract

Introduction

South Africa is characterised by numerous dichotomies and diversities, within which its two-tier healthcare system operates. An under-resourced state sector serves a majority of the population and a resource-intensive private sector serves a small minority. Within the constitutional framework of human rights and distributive justice there are nevertheless expectations of fair and equal access to healthcare services. There is furthermore an expectation of quality care across the health system, in spite of a number of systemic challenges related to staff and equipment shortages, unrealistic working hours and poor working conditions.

Organ transplant is available to different degrees within the South African healthcare sector. Whilst transplant programmes are burgeoning internationally, cadaver transplant numbers in South Africa have decreased over recent years as donor organs have become increasingly scarce. Current research suggests that these challenges to transplant in South Africa arise from aspects of personal and cultural beliefs, illegal transplant practices and resource constraints - which all serve to compromise the ethical implementation of transplant services in the two-tier healthcare system.

The impact of interprofessional communication and transplant professional–patient communication has not been previously researched in South Africa. However, research into other healthcare issues has shown that communication is vital to the ethical provision of healthcare services, especially those which involve patient-centeredness and multidisciplinary interaction. Transplant involves a significant amount of communication within a particularly large network of recipients and their families, cadaver donor families, living donors and a range of transplant professionals. This communication seems a vital part of the transplant process, disseminating information which role-players need in order to promote favourable outcomes. Given the extensive networks involved in the transplant process, communication would seem to be a fertile area for research.

This study aimed to explore communication in organ transplant in Gauteng province, South Africa. It considered both interprofessional communication and communication with

patients as this took place within the hierarchical healthcare system and throughout the transplant process. An ethics of care framework was utilised in order to account for the expectations of care which South Africans confer upon their health system.

Methods

The study took place in the Gauteng province of South Africa across six healthcare institutions. Both the state and the private sector were equally represented. Altogether, thirty in-depth interviews with transplant professionals, two focus groups with transplant coordinators, two interviews with cadaver donor families, and one focus group with living kidney donors, were conducted. Thematic analysis and triangulation of the data utilising Braun and Clarke's (2006) principles revealed three main themes relating to context, communication with patients, and interprofessional communication

Findings

The South African transplant context is complex and multifaceted, shaped by both the patients' expectations of care and the transplant professionals' perceptions of care. These expectations and perceptions are influenced by personal beliefs, suspicions of biomedicine, the media, and resource inequalities which pose challenges to accessing transplant services. The transplant context is characterised by ethical dilemmas relating to distributive justice, as questions about resource distribution and allocation of donor organs are raised.

Transplant communication is influenced by context and varies depending upon role-players in transplant and the different phases of transplant. Demands for care by those hoping to receive an organ had a noticeable influence on transplant professional-potential recipient communication in the pre-transplant phase, a period when emotions of desperation and uncertainty were prominent. By the time recipients had received their organ and entered the more stable post-transplant phase, a relationship of trust developed in which communication was regular and caring roles seemed fulfilled. The opposite trend was evident in communication between transplant professionals and donor families. This was characterised by notions of care in the pre-transplant phase, contrasting with a perception amongst donor families that care was sometimes overlooked in the post-transplant phase - a time often imbued with chronic uncertainty. Even in the pre-transplant phase numerous

ethical issues surrounding autonomy, decision-making and informed consent proved to complicate and challenge transplant communication.

Interprofessional communication was shaped by hierarchical institutional organisation, a lack of continuity of care, and resource constraints, all of which challenged transplant professionals seeking to provide care, and sometimes resulted in aggressive interchanges. The pressure to procure an organ timeously – which could result in patient care and professional respect being somewhat disregarded – could so compromise interprofessional communications that moral distress was created. Furthermore, as a result of miscommunications, an ethical vacuum where the best interests of patients in the transplant process were not, apparently, a foremost consideration, was identified.

Conclusion

Transplant is a highly complex process requiring a number of different communication styles and skills and accompanied by intricate ethical challenges. Although transplant professionals seemed cognisant of the need for careful communication, inequalities, resource scarcity and conflict intervened to create a space for moral distress and uncertainty in which communication was affected, and the provision of care was the casualty.

Appraising results within an ethics of care framework suggests that transplant in Gauteng cannot be considered to be a process fully informed by the imperative of care. The ethics of care proved to be a helpful framework for understanding transplant communication in Gauteng because of the way it accounts for interpersonal relationships - fundamental to the transplant process - whilst also emphasising the importance of resources necessary to provide good care. It was concluded that in the current environment, where there is little legal direction or political buy-in, transplant in Gauteng will be unable to reach its full potential.