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Pediatric heart transplantation (HTx) offers life-saving treatment for young patients with cardiac disease. This innovation extends life; however, it also introduces a complex sequalae that imposes formidable psychosocial challenges for children and their families. Accordingly, parents of children with a HTx must mediate the complex relationships and considerations associated with family life development, health uncertainty, demand for HTx care, and children/adolescents' growing independence. The provision of meaningful and effective education and social support is critical to families' navigation of the complex terrain associated with HTx. To address this need for effective education and support interventions for families, this project has comprised the development and evaluation of curriculum for online parent education and social support, using qualitative approaches.

Participatory methods consist of the involvement of key stakeholders including interdisciplinary HTx team members (cardiac medicine, surgery, nursing, social work, rehabilitation medicine, nutrition, education and research methodology) as well as families affected by pediatric HTx. Input from key informants has been integral to the development and refinement of the resulting curriculum and plan for its implementation. This participatory approach has involved a process akin to "member checking" and data refinement such that the emerging curriculum is increasingly reflective of stakeholder experiences, convictions and priorities. In so doing, an aim of this qualitative inquiry has been to authentically amplify families' and stakeholders' voices. Study findings, implications and recommendations will be discussed.

A Qualitative Longitudinal Approach to Exploring Service User Experiences of Lay-Led Heath Improvement Interventions

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Lay health advisors (LHAs) have been widely used to deliver primary care and health promotion programmes. Although there is some data to support their efficacy, reviews have consistently found insufficient evidence to assess which LHA strategies are likely to be most effective. Furthermore, there is a dearth of research exploring service user views and perceptions. This paper aims to contribute to evidence and theory in relation to lay-led models of working with health deprived communities. By adopting an interpretive, longitudinal approach informed by grounded theory, the intention was to provide insight into the users' experiences and the mechanisms underlying the intervention outcomes. In-depth interviews with service users (n=26) were conducted at 0, 3, 6 and 12 months, and with LHAs and supervisors (n=18) at 0 and 12 months. The interviews were audio-recorded, transcribed verbatim and analysed using the constant comparative method. LHAs were found to employ a holistic, asset-based approach that takes into account the context of a person's life and their access to resources for health. This builds upon the salutogenic theory of health, and is in direct contrast to the paternalistic, deficit model traditionally found in public health medicine. This research is one of few qualitative studies investigating the role of LHAs in the UK. Furthermore, the use of a longitudinal approach is innovative and likely to produce results that have high policy relevance. It represents an important application of a user-focused perspective affording new insights which may also be applied to other complex health interventions.

Assisted reproductive technology within the public health sector in Brazil: qualitative case studies

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In Brazil, access to infertility care, including assisted reproductive technology (ART) procedures is restricted. The objective was to assess the perspective of health professionals and patients with respect to access to ART within the public health network. Based on a quantitative study, following the criteria for purposeful sampling five centers located in different regions of the country were selected for qualitative case studies. Nineteen health professionals based at these centers and 48 patients (men and women) were interviewed. Data were analysed using thematic content analysis. All visited services had implemented ART using resources already available within the institution, and except in one center patients had to pay for the drugs used for the procedures and/or a fee to cover operative costs. For the patients these charges were incompatible with their financial possibilities and required planning and much effort. Health professionals recognized that payment was a limitation of access for low income patients; however, according to their perspective payment was the only possibility of maintaining these services for patients who otherwise would not have access to ART in the private sector. Patients and health professionals referred that waiting time for access to ART procedures varied between three months and six years. Health professionals did not have a clear idea of the difficulties patients encountered to schedule the first appointment. Patients felt very fortunate gaining access to these services. Results uncovered possibilities of organizing ART services within the public health sector and patient's difficulties and limited access to these services.

A theory of adjustment to pediatric multiple sclerosis

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Imagine being diagnosed with a disease that is chronic and incurable, with unpredictable disability and discomfort over a normal life expectancy, that can have physical, emotional, cognitive, social, and financial effects that last a lifetime: Now imagine you are 16 years old