

Abstract

Background/Aims: Clinical cancer genetics is an integral part of cancer control and management, yet its development as an essential medical service has been hindered in many low-and-middle-income countries. We report our experiences in developing a clinical cancer genetics service for retinoblastoma in Kenya.

Methods: A genetics task force was created from within the membership of the existing Kenyan National Retinoblastoma Strategy group. The task force engaged in multiple in-person and telephone discussions, delineating experiences, opinions and suggestions for an evidence-based, culturally sensitive retinoblastoma genetics service. Discussions were recorded and thematically categorized to develop a strategy for the design and implementation of a national retinoblastoma clinical genetics service.

Results: Discussion among the retinoblastoma genetics task force supported the development of a comprehensive genetics service that rests on 3 pillars: (1) patient and family counseling, (2) community involvement, and (3) medical education.

Conclusions: A coordinated national retinoblastoma genetics task force led to the creation of a unique and relevant approach to delivering comprehensive and accurate genetic care to Kenyan retinoblastoma patients. The task force aims to stimulate innovative approaches in cancer genetics research, education and knowledge translation, taking advantage of unique opportunities offered in the African context.